Exercising Power in the Self-Management of COPD: A Narrative Inquiry

A thesis submitted to the University of Dublin in fulfilment of the degree of Doctor in Philosophy

2020

Sarah Delaney
DECLARATION

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Date: 23rd June 2020
SUMMARY

Background and impetus for the study: The initial impetus for this study arose from my experience of people with chronic obstructive pulmonary disease (COPD) as stigmatised, viewed as noncompliant with self-management interventions and hard to reach. Recent policy and practice developments in self-management support and COPD care in Ireland have tended to emphasise compliance with the direction of health care professionals. Little attention has been paid to how people with COPD exercise power to self-manage their illness every day. While international literature has studied power in chronic illness self-management, I could not identify similar work on COPD, either internationally or in Ireland. I came to the conclusion that the exercise of power by people with COPD in their self-management practice was under-researched.

Aim of the study: The overall aim of this study was to develop an in-depth understanding of how people with COPD exercise power in the self-management of their illness. In developing the aim and objectives, I believed that the study would add understanding of how power shapes individuals' everyday self-management practice, thus adding valuable information for policy makers and health care professionals to support the improved design and delivery of self-management support to people with COPD.

Methodology and methods: This study was guided by the work of Foucault on power, knowledge, and agency, applied to a narrative methodology. This was in keeping with the overall aim of the study to examine how people with COPD exercise power in the self-management of their illness. Purposeful sampling was used to recruit 31 participants through the network of local COPD support groups under the auspices of COPD Support Ireland, the national patient representative organisation. Up to three unstructured in-depth interviews were conducted with each participant. The participants could choose to include a family member in one or more of the interviews, and ten family members were thus included in the study. Data were analysed using thematic template analysis.

Findings: This study found that individuals with COPD exercised power by mobilising agency in two main ways. Firstly, they appropriated medical knowledge to suit their own needs, and mobilised knowledge rooted in their bodies (embodied knowledge) and knowledge of complementary and alternative therapies (alternative knowledge) to form the foundation of their self-management practice. This allowed them to resist the idea that medical knowledge is the only legitimate form of knowledge about self-management. Secondly, they engaged in reflexive practices known as “technologies of the self” designed to operate on and transform the self and the body to achieve happiness, well-being and health. As part of this process, they actively integrated medical aspects of self-management with their own personal practices to construct their own approach to self-management.
However, the findings of this study show that the exercise of agency by participants was always constrained and limited by the imposition of power on them. This took the form of scrutinising and disciplining their private lives by health care professionals and in some cases family members. Another strategy of power imposed on participants was to make them responsible for the management of their illness while at the same time holding them accountable for compliance with medical knowledge and expectations and standards of what should constitute “good” self-management. In some circumstances, participants internalised this sense of responsibility and projected this onto others with COPD.

Together, power and agency were interrelated, each shaping and shaped by the other. Participants in this study had to negotiate the shifting boundary between power and agency in their everyday self-management practice. This consisted of negotiating conflicting expectations of compliance, autonomy and self-governance. They had to negotiate the balance between medical knowledge and their own embodied and alternative knowledge. Finally, they negotiated the integration of medical and personal self-management knowledge and practice in order to construct an individualised approach to self-management, always within the constraints of power imposed on them by experts. The exercise of agency in self-management was complex, fluid and multi-dimensional. Self-management thus emerged as a complex concept, adapted and constructed to fit the rhythms of participants’ daily lives.

**Conclusion:** This is the first study that has examined how people with COPD exercise power in the self-management of their illness. The findings offer insight into and contribute knowledge to this topic by showing how a Foucauldian theoretical framework of power, knowledge, and agency can assist in recommending a shift to a model of self-management that is holistic and based on the recognition of the value of COPD patients’ knowledge and agency. The findings thus expand the understanding of self-management as a complex and multi-dimensional concept that is actively negotiated and constructed by people with COPD using considerable skills and resources. This is especially important given the ambiguity that surrounds the information given to people with COPD about their diagnosis. It is also timely with respect to the recent policy and practice developments regarding self-management and COPD care in Ireland. This study supports an overall recommendation that the process of honouring the knowledge, resources and skills of people with COPD should form the heart of self-management support. More specific recommendations are suggested for policy, service provision, education and research to address the implications of these findings.
DEDICATION

To Ruán, with love, always.
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1 Overview of study

1.1 Introduction

This chapter provides an overview of this narrative inquiry into how people with COPD exercise power in the self-management of their illness. I first set out the background and context for this study by describing the nature of COPD, its symptoms, aetiology, prevalence, burden and treatment. I then provide a description of the policy environment for chronic illness and COPD-specific self-management in Ireland. I follow this by describing how I came to focus on this topic and present the research question, aim, and objectives. I then present a preliminary justification for my choice of theoretical framework and methodology before concluding this chapter with a description of the overall structure of the thesis.

1.2 Background and context for the study

1.2.1 Chronic Obstructive Pulmonary Disease (COPD)

COPD is a common but underdiagnosed illness of the lungs and airways. The Global Initiative for Chronic Obstructive Lung Disease (GOLD) describes COPD as a “common preventable and treatable disease that is characterised by persistent respiratory symptoms and airflow limitation, that is due to airway and/or alveolar abnormalities usually caused by significant exposure to noxious particles or gases’ (Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2020, p. 4). It is characterised by breathlessness (dyspnoea), chronic airway obstruction, and chronic cough with sputum production (Russell et al. 2018). These everyday symptoms can be punctuated by exacerbations of respiratory symptoms triggered by bacterial and/or viral infections, environmental pollutants, or other unknown factors (GOLD 2020). Many individuals with COPD have concomitant comorbidities and issues related either to the illness itself (such as cardiac function and gas exchange, skeletal muscle wasting and cachexia) or to the underlying risk factors of smoking, ageing and inactivity (such as cardiovascular disease, heart failure, osteoporosis, diabetes, or metabolic syndrome) (GOLD 2020). COPD is a result of chronic inflammation of the lungs. Although tobacco smoking is a dominant risk factor for the development of COPD in ‘rich nation’ countries such as Ireland, not all smokers develop COPD and not all people with COPD are or were smokers. Up to ten per cent of people with COPD are non-smokers (Health Service Executive 2019a). COPD has been described as overlooked and
receiving inadequate attention (Health Service Executive 2019a). This can be because individuals are not told their diagnosis, or due to nihilism among health care professionals about the illness and its prognosis, or possible prejudice about the illness due to its association with tobacco smoking (Health Service Executive 2019a).

1.2.1.1 Clinical course and life expectancy

COPD is an extremely heterogenous condition and the clinical course differs from one individual to another (Gundry 2019). This means that self-management of the illness is complex and varies from person to person. It is therefore very difficult to accurately determine the course of the illness or its prognosis, but a number of factors are influential such as the degree of airflow limitation, smoking status, chronic hypoxia, low body mass index, severity and frequency of exacerbations, hospital admissions, symptom burden and exercise capacity and comorbidities (National Institute for Health and Care Excellence 2018). The five-year mortality rate for people with COPD typically ranges from 40 per cent to 70 per cent (Nishimura & Tsukino 2000), depending on disease severity, while the two-year mortality rate for people with severe COPD is about 50 per cent (Goodridge 2006).

1.2.1.2 Prevalence

Globally, it is estimated that the number of COPD cases was 384 million in 2010 (Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2020) with a global prevalence of 11.7 per cent and around three million deaths annually. This is expected to rise over the next 40 years. In Ireland, definitive prevalence data are not available. The Respiratory Health of the Nation report (O'Connor et al. 2018) estimates that approximately 500,000 people in Ireland aged 40 years and over could have COPD, of whom over 200,000 have moderate or severe disease and only half are likely to be diagnosed (O'Connor et al. 2018, p. 43).

1.2.1.3 Mortality

Ireland has a high age-standardised death rate for COPD (27.87 per 100,000 inhabitants) compared to other countries in the WHO European region (18 per 100,000) (Health Service Executive 2019a, p. 53). In 2016, the five-year standardised mortality rates for chronic lower respiratory disease in Ireland was 36.10 per 100,000 population (O'Connor et al. 2018, p. 44). It is notable that for the period 2007-2012, deaths from COPD were three times higher in the lower social class compared with the upper social class (Health Service Executive 2019a, p. 54)
1.2.1.4 Treatment and self-management

GOLD (2020) points out that, while chronic, COPD is treatable. Treatment is nonetheless complex and varied, consisting of a mix of pharmacological and non-pharmacological therapeutic regimens. A central element to the treatment of COPD is the requirement for individuals to follow complex treatment regimens, self-monitor symptoms, make lifestyle changes, manage the physical, psychological, and social impacts of the illness, and decide when to consult health care professionals (Bringsvor et al. 2018). Consequently, COPD is an illness that requires extensive and complex self-management (Bringsvor et al. 2018, p. 365). Learning to self-manage in COPD can be a protracted process requiring the mobilisation of considerable resources on the part of the individual with the illness (Russell et al. 2018). This highlights the importance of understanding how individuals with COPD draw on their power to develop their everyday self-management practice.

1.2.2 Self-management background and policy context

The concept of self-management originally emerged from the development of the self-help movements in the 1960s and 1970s and the rise of consumerist approaches to health care (Kendall et al. 2011). There was an implied idea in these movements that individuals were active participants in choosing the direction of their own health care and an advocacy for equal status between health care professionals and individuals with chronic illness (Kendall et al. 2011). However, in the 1980s and 1990s increasing attention was paid in "rich world" nations to the potential of self-management to reduce the impact of chronic illness on health service utilisation and associated costs (Newbould et al. 2006).

The focus on self-management in chronic illness policy and practice in Ireland emerged with the publication of Tackling Chronic Disease: A Policy Framework for the Management of Chronic Diseases (Department of Health and Children 2008) and the Chronic Illness Framework (Health Service Executive 2008). These both aimed to develop policies and clinical practice strategies to address the growing need to prevent and address chronic illness and reduce its associated “burden” (Greaney & Flaherty 2020, p. 3). These policies included reference to self-management in their actions and work streams with a focus on supporting self-help groups, providing educational resources to individuals, and behaviour change. The emphasis was on compliance with the overall requirements of chronic disease management frameworks.
Based on this, the Health Service Executive (HSE) developed a specific integrated care programme for the prevention and management of chronic illness which involved a reorientation of services towards prevention, management and support in primary care (Greaney & Flaherty 2020). An important work stream of this programme was the development of a comprehensive framework for self-management support (Chronic Conditions Working Group 2017). This framework set out a vision of self-management along with specific self-management tasks that were oriented towards the acquisition of disease-related knowledge and monitoring of signs and symptoms, medication management, education and behaviour change, and dealing with the impact of illness on activities of daily living and emotions and relationships. This demonstrated quite a holistic perspective on self-management that positioned the individual as “the leading partner in managing their own life and conditions” (Chronic Conditions Working Group 2017, p. 12). However, in terms of concrete actions and recommendations there was an emphasis on education, behaviour change, self-monitoring, and compliance with the recommendations of health care professionals. An aspect of the Framework for Self-Management Support currently being rolled out is the provision of generic chronic illness self-management education programmes known as the Living Well programme (Health Service Executive 2019b). There is an underlying assumption in this programme that if people know the reasons why and how they should make effective self-management decisions in line with the expectations of health care professionals, then they will do so. However, the Living Well programme also offers participants the chance to share their own knowledge and experiences of self-management with peers and access peer support networks such as self-help groups.

In terms of COPD-specific self-management policy and practice, commencing in 2010, a series of National Clinical Programmes have been rolled out for a range of chronic illnesses, including COPD1. As part of the work of the National Clinical Programme for COPD, an End-to-End COPD Model of Care (Health Service Executive 2019a) was published in December 2019. Self-management is proposed as a core tenet of the management of stable COPD. It is described as a way of assisting individuals with COPD to comply with the “therapeutic, behavioural, and environmental adjustments required to maximise their control over their COPD” (Health Service Executive 2019a, p. 39) in order to reduce the burden of symptoms, increase quality of life, and reduce health service utilisation.

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1 https://www.hse.ie/eng/about/who/cspd/ncps/copd/
Self-management is associated mainly with instruction in various aspects of medication management and interventions regarding behaviour change via structured clinical review delivered by general practitioners. In addition, Respiratory Integrated Care Clinical Nurse Specialists are identified as providing instruction on inhaler use and the formulation of individual self-management plans for patients with poorly controlled illness. Opportunities for self-management intervention are also identified in the provision of pulmonary rehabilitation (PR) and COPD outreach (hospital from home) services. Finally, Section 4.4.4 of the model sets out a recommendation for self-management which focuses on the provision of self-management plans covering when to increase medication, when to start taking steroids or antibiotics, and when to seek urgent medical attention.

Overall it is possible to trace a common focus on medication management, behaviour and lifestyle change, patient education and information provision throughout Irish policy and practice guidance on self-management. However, the policy and practice environment in Ireland still offers opportunities to leverage health care professionals (such as general practitioners and Respiratory Integrated Care Clinical Nurse Specialists) to work with and connect with individuals with COPD in order to understand how they mobilise their own resources to develop individualised approaches to self-management. The timing of this study is therefore key given these recent policy and practice developments relevant to chronic illness and COPD self-management in Ireland.

1.3 The impetus for this inquiry

The initial impetus for this study arose from my experience as a researcher in the field of health services for older people and people with chronic illness with regard to the use and uptake of technological solutions for self-management. In my experience, participation in and adherence to technological self-management interventions was particularly problematic for people with Chronic Obstructive Pulmonary Disease (COPD) but the reasons for this were not clear. This led me to an understanding that COPD was perceived by many of my colleagues in research and clinical practice as a burdensome and stigmatised illness that was heavily associated with tobacco smoking. I had experiences in which COPD was discussed in negative terms by colleagues, whereby individuals with the illness were described as passive, noncompliant with the self-management recommendations of health care professionals, and hard to reach. The illness was
viewed pessimistically by colleagues as chronic and progressive. This led me to examine COPD in a more considered manner.

At the time of these considerations, I was aware of the complexity of treatment and the high demands placed upon individuals with COPD regarding self-management of their illness. I was also aware of the policy and practice developments in COPD management in Ireland outlined above that were increasingly highlighting actions that could be taken to improve care for people with COPD, of which self-management formed an important element. At the same time, I was struck by the lack of clarity about what constitutes COPD self-management and the tendency in the policy literature to equate self-management with medical and behavioural management of the illness. This was especially striking given the expectations placed upon individuals with COPD to engage in self-management, and the reportedly high rates of sub-optimal adherence to formal self-management recommendations and interventions (Schrijver et al. 2020). I became concerned that there was a lack of understanding of how individuals draw on their personal resources and knowledge to self-manage their illness every day. I understood these to be a potential well of power. This was supported by my awareness of literature highlighting the experience of people with chronic illness as a source of power (Garro 1998, Åsbring & Närvänen 2004, Koch et al. 2004, Kendall & Rogers 2007, Lawn et al. 2011, Ellis et al. 2017). However, I found little or no literature that investigated how individuals with COPD exercise power the self-management of their illness in Ireland or internationally.

I was led by these factors to consider how the power exercised by individuals with COPD might shape and inform their self-management practice. I came to the conclusion that the study of the exercise of power by people with COPD in their self-management would contribute to the understanding of researchers, policy makers, and practitioners of the complexities and dynamics of self-management beyond the clinical encounter. It is my belief that undertaking this study contributes to the understanding of how power is exercised by individuals in COPD self-management and how this shapes their everyday self-management practice. I believe that this study adds valuable information for policy makers and health care professionals to facilitate and improve the design and delivery of interventions to support COPD self-management practice.
1.4 Research question, aim and objectives

1.4.1 Research question

Based on these considerations, the research question for the study is:

How do people with COPD exercise power in the self-management of their illness?

1.4.2 Aim and objectives

The aim of the study is to develop an in-depth understanding of how people with Chronic Obstructive Pulmonary Disease (COPD) exercise power in the self-management of their illness and in doing so fulfil the following objectives:

1. To examine how self-management and power are conceptualised in the literature on COPD self-management
2. To develop an understanding of how people with COPD conceptualise self-management
3. To reveal how people with COPD exercise power in the self-management of their illness
4. To inform debate about COPD self-management in the context of Irish policy and national guidelines on the management of COPD.

1.4.3 Defining self-management

Definitions of self-management are varied and confusing and the term is often used interchangeably with other terms such as “self-care”. For the purposes of this study, I have distinguished between self-care as covering the whole span of health from maintaining wellness to preventing illness. I use self-management to refer to activities triggered by illness undertaken to manage the experience of living with COPD every day.

1.5 Selecting a Foucauldian lens to frame the inquiry

The decision to pursue a Foucauldian approach to narrative inquiry to frame the theoretical and methodological foundations of this study was based on careful consideration of the different theories of power and their applicability to the research question, aim and objectives. I explored the work of Lukes, Galbraith, Habermas, and Foucault in particular.

Lukes’ (1974) work on power focused on three levels, which he termed dimensions. The first, termed the “one-dimensional” view of power refers to power which is openly observable in the actions taken by individuals or groups via overt
conflict. The second dimension refers to covert power, in which power is manifested in actions not taken and decisions not made. It is apparent in agenda setting and the suppression of certain topics in political processes. The three-dimensional view of power is not attached to the actions of decisions of individuals or groups but is infiltrated throughout political processes and agendas. This is a latent and sub-conscious form of conflict in which individuals may not be aware of a conflict of interests (Kesting 2005). This is essentially a conflictual model of power defined roughly as “A affects B in a manner that is contrary to B’s interests” (Scott 1994, p. 2). For Lukes, power is a commodity that rests in the hands of certain people or institutions who have power over those who lack power (Skålén et al. 2008). I also considered Galbraith’s perspective on power based on three “rules”: 1) condign power (winning submission through the threat of unpleasant alternatives); 2) compensatory power (winning submission by the offer of reward for doing so); and 3) conditioned power (changing belief via persuasion and education and thus ensuring that individuals view submission as natural, right, or proper) (Wilson 2001, Kesting 2005).

Both Lukes and Galbraith share a view of power as a resource that is commodified and transacted based either on conflict or winning submission. This emphasises the use of power by dominant groups to bend the will and intentionality of subordinates through coercion or persuasion. Such a view of power as a commodity that can be transacted (transferred or withheld in obvious and invisible ways) does not lend itself to my experience of the intricacies of power in chronic illness as exercised in complex and ubiquitous ways, both on individuals with COPD and by individuals with COPD. In addition, there is not much attention given to the social mechanisms of power – how social and cultural forces enable one individual or institution to wield influence over another (Little 2010). For these reasons, I did not adopt these approaches to power in this study.

I also considered critical theory as informed by the work of Jürgen Habermas. Habermas’ critique of power rests in a differentiation of legitimate and illegitimate power, which equates to reason versus force. For Habermas, illegitimate power is the use of force and coercion. Legitimate power, on the other hand, concerns power as based on the consensus achieved by discourse and “communicative action” (Wong 2009) and is fundamentally based on reason. It is through reasoned and rational discourse and instrumental action that the legitimate exercise of power is determined by consensus. This is a view of power that sees it as either illegitimately wielded by force or legitimately exercised through reasoned
consensus (Wong 2009). Power, Habermas argued, should be understood as “the ability to agree upon a common course of action in unconstrained communication” (Habermas 1977, p. 3).

Habermas’ view of power is problematic in two ways. Firstly, he presents a dichotomous view of power as either illegitimate (using force and coercion) or legitimate (using reason and collective consensus). This cannot account for complex interrelations between individuals, institutions and society in which power is exercised simultaneously on and by individuals, as a continuous concept ranging from control through to resistance and personal power. Secondly, in focusing on legitimate power over illegitimate power, Habermas presents a normative ideal of legitimate power that assumes the ability to guarantee freedom of speech and freedom of association, and that the ability to engage in consensus-building is open equally to all citizens, and that participants in consensus-building can be transparent and free from the desires of strategic manipulation (Weng 2014). In short, one must somehow be outside or free from power in order to exercise legitimate power. Habermas’ focus is on power exercised at the level of collectives rather than on individual micro social relations. It is my contention that this is not a useful starting point for theorising power in this study. My professional and research experience of COPD is that individuals are embroiled in networks of power both exercised on them and by them at the level of the everyday. Power surrounds them and inscribes them, informing and shaping actions, interactions and decisions, and displaying “relations of inequality” (Wilson 2001, p. 139). Contra to Habermas’ appeal to reason and liberal ideals of freedom, there is no outside to power relations, both the exercise of power on individuals and by individuals are implicated in a complex and ubiquitous network. This view of power lends itself more to the work of Michel Foucault.

Power in a Foucauldian sense refers to the “ability to create change” (Heller 1996, p. 83). It is a complex concept, a web of relations in which individuals “are always in the position of simultaneously undergoing and exercising power” (Foucault 1980, p. 98). Foucault understood power to be an omnipresent and dynamic network of relations, within every interaction (Wilson 2001, p. 139). In this conceptualisation, power encompasses both the exercise of power on individuals by dominant individuals, groups, or institutions, and the exercise of power by individuals to effect change. This exercise of power by individuals is also known as agency (Miller 2008, Nielsen 2012). I have chosen the work of Foucault because it has contributed significantly to the understanding of power in health and
illness. Conrad and Barker (2010) have pointed out that a Foucauldian examination of health and illness facilitates a critical analysis of the nature of power and knowledge in health care and how biomedical discourse acts to construct dominant knowledge of illness and how it “should” be managed. The work of Foucault is also useful because his understanding of power is subtle, flexible, nuanced and dynamic, which suits the complex interplay of relations between people with chronic illness, health care professionals and policy makers in the process of self-management (Wilson 2001). It is for these reasons that I have chosen to view power, knowledge and agency through a Foucauldian lens and apply this analytic approach to the conceptualisations of self-management identified in the literature.

1.6 Choosing a narrative methodology

Coming to choose narrative inquiry as the methodology to guide this study involved the consideration of which methodology would best answer the research question and fulfil the aim of the study. This involved consideration of alternative qualitative methodologies, namely Critical Discourse Analysis (CDA) and Grounded Theory (GT). CDA is an eclectic and heterogenous body of theory and research that concerns itself with the workings of ideology and power in society; and a specific interest in the way language “contributes to, perpetuates, and reveals these workings” (Breeze 2011, p. 495). Throughout the approaches encompassed within CDA is a concern with the relationship between language (discourse\(^2\)) and power (political struggle, inequality, or dominance) (Breeze 2011, p. 495). The aim of CDA is to uncover power relationships and demonstrate inequities embedded in society (Rogers 2004). CDA differs from other approaches to discourse analysis in its particular interest in power and its underlying assumption that the social relations reflected in language phenomena are part of a larger pattern characterised by unequal power relations (Breeze 2011). There is a strong connection between the work of Foucault and CDA, given Foucault’s view of discourse as defining and producing social practices and knowledge. Foucault’s belief that discourses construct and define what can be said about a particular subject and how arguments can be given legitimacy and truth value is directly relevant to CDA (Lê & Lê 2009). CDA involves an iterative process of micro-

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2 Discourse has been described as language use as social practice (Fairclough 1995), involving ways of combining and integrating language, actions, interactions, ways of thinking, believing, valuing and using various symbols, tools and objects (Gee 2005). It is influenced by Foucault in the sense that discourses involve patterns of belief and habitual action and social practices as well as patterns of language (Johnstone 2008).
analysing texts using varied tools of linguistic, semiotic, and literary analysis, and the “macroanalysis of social formations, institutions and power relations that these texts index and construct” (Luke 2002)

However, CDA has been criticised for being methodologically vague, with a lack of awareness of rigour and a lack of clarity about how the data are actually obtained and subsequently interpreted (Breeze 2011). Critics highlight CDA’s ad hoc approach to analysis, using concepts from different theories without a clear and systematic use of theoretical frameworks and associated methods of data collection and analysis. In addition, CDA is posited on assumptions about the workings of power in society that leads to a focus on exposing ideological manipulation that shapes and “perpetuates power imbalances through discourse” (Breeze 2011, p. 516). This has led to a focus on the repressive aspect of power at the expense of understanding relations of power in their productive aspect (Luke 2002, p. 98). Since my focus is on how individuals with COPD exercise power examining it in its productive as well as repressive sense, this approach was not adopted for this study.

Grounded theory (GT) as a method is an approach to qualitative inquiry designed to construct theory that is grounded in data. It is described by Bryant and Charmaz (2007, p. 1) as a “systematic, inductive, and comparative” approach to inquiry. As a methodology, grounded theory is characterised by interrelated and iterative processes of theoretical sampling, data collection, data analysis and theory development. This process continually contributes to the further development and refinement of the evolving theory. This continues until new data do not contribute any longer to the development of the new theory (theoretical saturation) (Vollstedt & Rezat 2019). GT is best carried out on phenomena which lack a sufficient theoretical foundation (Vollstedt & Rezat 2019). Inherent to GT is the notion of abstraction from data to categories and ultimately to theory. This allows its application over a wide range of empirical areas. As such, theories developed as a result of GT appear to be separated from the data and stripped of context (Glaser 2007). The focus is on organising and relating ideas rather than on presenting the data from which theories arise (Cronin 2009).

It is my contention that power is a well-theorised phenomenon and Foucault provides a comprehensive and useful theoretical framework for exploring power as exercised on and by individuals. Thus, the generation of new theory on power is not the focus of the study, rather it is on mapping and illuminating the exercise of power by individuals with COPD supported by pre-existing Foucauldian theory.
In addition, the abstraction involved in GT can silence the original voices of the researcher and research participants – their narratives and dialogues – in favour of theory generation (Thomas & James 2006). However, in this study I endeavour to foreground the narratives of people who have been positioned in subordinate roles in the hierarchy (Foucault 1980), and to displace the discourses of those in privileged positions of power (Thomas & James 2006). Therefore I did not adopt this methodology for the study.

Ultimately, I came to view the focus of my study as in keeping with a Foucauldian approach to narrative inquiry, as it centres on facilitating vulnerable groups to tell their own stories (Holloway & Freshwater 2007a) contextualised in relations of power. A narrative approach to inquiry fit with my aim of viewing individuals with COPD as both active and socially constructed (Atkinson & Delamont 2006). The narratives of individuals can shed light on their exercise of power in their everyday self-management practice. In keeping with the aim of my study, a narrative methodology has been recognised as a powerful method for uncovering the many, varied, complex and subtle ways that relations of power work their way into narratives of chronic illness (Sarangi & Roberts 1999).

In line with the focus on individuals’ exercise of agency in this study, a Foucauldian approach to narrative inquiry views people’s accounts as sites in which themes of power can be identified (Squire et al. 2013, Tamboukou 2013, Frank 2016) as “counter narratives” to dominant discourses (Tamboukou 2013). It is through these narratives that I can both honour the voices and stories of people with COPD and trace their accounts of exercising power through these stories.

From the very start, I have been an interested party in this inquiry. By identifying the topic and developing the research question, I have declared the topic as important to me and about which I have garnered a body of personal and professional knowledge and experience. This informs the assumptions and beliefs I bring to this inquiry. Rather than attempting to “bracket” this knowledge and experience and these beliefs and assumptions, a narrative inquiry approach involves careful consideration and reflexivity to clarify my positioning as a researcher and as an individual. What is significant about narrative inquiry as a method is that it allows me as a positioned researcher to come together with individuals with COPD to co-construct in dialogue new knowledge about the exercise of power in COPD self-management.
Thus, my focus was to explore, using rich and thick description, how individuals with COPD exercise power when they engage in self-management. Narrative inquiry allowed me to access stories of individuals with COPD as arenas in which power as exercised on individuals and by individuals is expressed. It allowed for the creation of spaces in which I as researcher and individuals with COPD could engage in dialogue and co-construct new knowledge about the topic. Through this, my own knowledge, experience, beliefs and assumptions could be expanded, and, through presenting individuals’ narratives of self-management, new knowledge could be shared with health professionals, policy makers, people with COPD and their families.

1.7 Structure of the thesis

This thesis comprises seven chapters, each of which address the stages of the narrative inquiry as it was undertaken in this study.

Chapter 2 presents a review of the literature related to COPD self-management with the aim of exploring conceptualisations of self-management in the literature. The review presents the contention that two major conceptualisations can be identified: a conceptualisation of self-management as largely biomedical (medicocentric), and a conceptualisation of self-management based on the individualised experiences of people with COPD (experiential). The review then discusses how these two conceptualisations can be mapped to different manifestations of power with reference to the literature on chronic illness self-management and the Foucauldian theoretical framework of the study. A critique of the limitations of medicocentric and experiential conceptualisations in terms of how they understand power in self-management is offered.

Chapter 3 sets out my epistemological, theoretical, and methodological framework for the study. I discuss my epistemological stance of social constructionism, which underpins the entire inquiry. A thorough discussion of how my approach to social constructionism can reveal the workings of power in self-management is presented. This is followed by a discussion of Foucauldian social constructionism and a presentation of Foucault’s conception of power, knowledge, and agency and how this applies to this inquiry. Finally, in this chapter I set out my choice of narrative inquiry as commensurate with Foucauldian social constructionism, and I

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3 I use the term ‘medicocentric’ to describe the norms, values, and mores of biomedicine. Biomedicine looks at health from the point of view of the medical aspects of illness, as opposed to alternative views of health and illness in sociocultural, political, and economic context.
discuss the reasons for my choice of narrative inquiry as my methodology. I explicitly link narrative inquiry to the Foucauldian theoretical framework, and contend that narratives hold strong potential as arenas in which relations of power, knowledge, and agency are manifest. I set out some of the key theoretical positions in narrative inquiry and justify my view of narratives as co-constructed and dialogical. I conclude this chapter with a consideration of how my theoretical and methodological framework shaped and informed the steps of the research process.

Chapter 4 describes how I went about conducting this narrative inquiry. I start by restating the research question, aim, and objectives. I describe the practical steps of sampling and recruitment, data collection, and analysis. In this chapter I refer reflexively to my positioning as a researcher with my pre-existing knowledge, prejudices and assumptions, my experience of interviewing and data analysis. I discuss in detail the steps I took to ensure the quality and rigour of the study and I describe the ethical framework which guided the conduct of the study.

Chapter 5 presents the findings of the analysis according to the Foucauldian framework of power, knowledge, and agency. Data pertaining to the profile of participants, including basic demographic data and COPD-related health status, treatment and care received are presented. Findings are then presented on how power is exercised on participants through surveillance, discipline and responsibilisation. I set out findings which demonstrate how knowledge is used as a vehicle for the exercise of power on participants as well as a vehicle for the exercise of power by participants through the mobilisation of their agency to resist the unquestioning imposition of dominant knowledge. I then present findings which show how participants exercised power by mobilising agency through engaging in certain practices (technologies of the self) with the aim of undergoing transformation in order to achieve health and well-being. I also set out how this agency was still delimited by the imposition of power on participants by health care professionals and other experts. I conclude this chapter by presenting a final narrative by drawing together the themes and sub-themes to show how participants constantly negotiate the boundary between power and agency as they construct their everyday self-management practice.

Chapter 6 critically discusses the key findings in the light of the research and policy literature on chronic illness self-management and in the context of my Foucauldian theoretical framework. In this chapter I discuss how the contextualised findings have highlighted the complex, individualised, and fluid nature of COPD self-
management. I explicate how COPD self-management has emerged as a site where power and agency exist in a dialectical relationship. I discuss my contention that COPD self-management is a set of technologies of the self that manifest both agency and power, and how this is a new finding. My discussion also highlights that the understanding of the exercise of agency as a process of constant negotiation offers a new perspective on COPD self-management, and demonstrates the usefulness of a Foucauldian perspective for shedding light on individuals’ practice of self-management.

Chapter 7, the conclusion of this thesis, discusses the implications of the findings and makes recommendations for policy, practice, education, and research.
2 Literature review

2.1 Introduction

The aim of this study is to explore how people with Chronic Obstructive Pulmonary Disease (COPD) exercise power in the self-management of their illness. Definitions and perspectives on self-management vary according to the different approaches taken by authors in their research on COPD and self-management. These can be linked to distinct understandings of power and how it shapes self-management practice. The aim of this literature review is to explore in detail how self-management is conceptualised in the literature on COPD self-management. This literature review informs the justification for the study, as well as the analysis and discussion of the results of the interviews. This is a narrative review, presented according to the key perspectives and themes arising from the literature. Taking a narrative approach allowed for the integration of theoretical and empirical literature (Coughlan & Cronin 2017). Due to the large number of references in this chapter, and in order to ensure it is easy to read, I have used footnotes for lists of more than three citations.

2.1.1 Search Strategy

2.1.1.1 Search 1: Self-management and COPD

I conducted a search of the literature on self-management and COPD in order to identify the key ways that self-management has been conceptualised in the literature. The search terms used are set out in Table 2.1. In designing my search strategy for the literature review, I used both the terms “self-care” and “self-management” in order to reflect the fact that “self-care” and “self-management” are sometimes used interchangeably with each other, and sometimes distinctly.

I searched the following databases: Medline, CINAHL, PsycINFO, Embase, Web of Science, ASSIA, Open Grey, Proquest dissertations, LENU, OpenAIRE. I also conducted a search of relevant references in identified texts.
I screened titles and abstracts for relevance. I included texts if they had a population of adults aged 18 and over with COPD, and if they reported on self-management. After I screened the titles and abstracts, I reviewed full texts for inclusion. After duplicates and irrelevant articles were removed, I included a total of 60 publications in the analysis.

### 2.1.1.2 Search 2: Power and self-management and COPD

In order to examine how the concept of power was related to perspectives on self-management of COPD, I conducted a second search of the same databases and using the key concepts of power, self-management and COPD. The search terms used are set out in Table 2.2 below.

<table>
<thead>
<tr>
<th>Concept 1*</th>
<th>AND</th>
<th>Concept 2*</th>
<th>AND</th>
<th>Concept 3*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power</td>
<td></td>
<td>Chronic Obstructive Pulmonary Disease</td>
<td>Self-Care</td>
<td></td>
</tr>
<tr>
<td>OR</td>
<td></td>
<td>OR</td>
<td>OR</td>
<td></td>
</tr>
<tr>
<td>Empowerment</td>
<td></td>
<td>Chronic Obstructive Lung Disease</td>
<td>Self-Management</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>OR</td>
<td>OR</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Chronic Obstructive Airway Disease</td>
<td>Self-Monitoring</td>
<td></td>
</tr>
</tbody>
</table>

* a range of synonyms and wild cards were also used as keywords for these concepts

Table 2.2: Search terms used in search 2

As with search 1, I screened the titles and abstracts for relevance and texts were included if they had a population of adults aged 18 and over with COPD, if they reported on self-management/self-care, and if they reported on...
social/psychological concepts of power. I then reviewed the full texts for inclusion. After I removed duplicates and irrelevant articles I found no relevant texts.

2.1.1.3 Search 3: Power and self-management in chronic illness

Due to the lack of results obtained from search 2, I conducted a search for literature that conceptualised issues of power in the context of self-management in chronic illness in general, and in COPD specifically. The search terms used are set out in Table 2.3.

<table>
<thead>
<tr>
<th>Concept 1*</th>
<th>AND</th>
<th>Concept 2*</th>
<th>AND</th>
<th>Concept 3*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power</td>
<td></td>
<td>Chronic illness</td>
<td></td>
<td>Self-Care</td>
</tr>
<tr>
<td>OR</td>
<td></td>
<td></td>
<td></td>
<td>OR</td>
</tr>
<tr>
<td>Empowerment</td>
<td></td>
<td></td>
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<td>Self-Management</td>
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<td></td>
<td></td>
<td>OR</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Self-Monitoring</td>
</tr>
</tbody>
</table>

* a range of synonyms and wild cards were also used as keywords for these concepts

Table 2.3: Search terms used in search 3

I included texts if they had a population of adults aged 18 and over with chronic physical illness, if they reported on self-management and/or self-care, and if they reported on social/psychological concepts of power. After the screening process, I included a total of nine publications.

2.1.2 Characteristics of included texts

The publications included in this review comprised a mix of intervention studies, correlational studies, policy documents, conceptual/discussion papers, qualitative studies, literature reviews, and a quantitative descriptive survey. Table 2.4 presents the numbers of each type of publication included in the review.
<table>
<thead>
<tr>
<th>Type of text</th>
<th>Number included in review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention studies (including systematic reviews)</td>
<td>29</td>
</tr>
<tr>
<td>Qualitative studies</td>
<td>17</td>
</tr>
<tr>
<td>Conceptual papers</td>
<td>8</td>
</tr>
<tr>
<td>Correlational studies</td>
<td>7</td>
</tr>
<tr>
<td>Policy documents</td>
<td>4</td>
</tr>
<tr>
<td>Literature reviews</td>
<td>3</td>
</tr>
<tr>
<td>Quantitative descriptive survey</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 2.4: Type of texts included in the review

Intervention studies were the most common type of study that I identified in the literature search, with 29 of the 69 included texts falling into this category. Intervention studies are designed to test the effectiveness of a particular intervention (for example, a programme designed to enhance self-management of COPD). Intervention studies can include experimental designs such as randomised controlled trials (RCTs), or quasi-experimental designs (such as non-randomised controlled studies, or intervention studies that did not use a control group). I have included quantitative systematic reviews as intervention studies because they summarise the results of intervention studies (normally RCTs) to produce high level evidence as to the effectiveness of an intervention across trials. I have also included non-experimental designs such as observational and cohort studies where these report on the outcomes related to the implementation of an intervention across a sample without randomisation or use of a control group.

Intervention studies that I included in this review comprised most commonly systematic reviews\(^4\), followed closely by randomised controlled trials (RCTs)\(^5\). Two studies were non-randomised controlled trials (Yu et al. 2014, Steurer-Stey et al. 2018). Six studies aimed to assess outcomes related to an intervention but did not use experimental designs. These were a non-randomised prospective


observational design (one study represented by two publications) (Lomundal & Steinsbekk 2007, 2012), a prospective parallel group design (Labrecque et al. 2011), a mixed methods design (Benzo et al. 2013), a longitudinal study (Turner et al. 2014), and a cohort study (Hardinge et al. 2015).

Seven of the research studies included in the literature review were correlational studies. Correlational studies examine whether an increase or decrease in one variable corresponds to an increase or decrease in another variable (Cronin et al. 2015). Six of these were descriptive cross-sectional studies and one was a longitudinal study conducted over two years (Chen et al. 2017b). In addition to these intervention and correlational studies, one study was a quantitative descriptive survey arising out of a prior qualitative study (Cicutto & Brooks 2006).

The search that I conducted for this review identified four relevant Irish policy documents that related to COPD-specific illness management and self-management of chronic illness. These were the National Chronic Disease Management Patient Support Programme for the HSE (Health Service Executive 2006), Tackling Chronic Disease: A Policy Framework for the Management of Chronic Diseases (Department of Health and Children 2008), the National COPD (Respiratory) Strategy 2008 (Health Service Executive et al. 2008), and Living Well with a Chronic Condition: Framework for Self-Management Support (Chronic Conditions Working Group 2017).

The search identified eight conceptual texts for inclusion. Conceptual papers aim to examine concepts or theories that explain or describe the phenomenon of interest (Cronin et al. 2008) and make connections across theories and disciplines in order to provide new insights (Gilson & Goldberg 2015).

I identified seventeen qualitative studies for inclusion in this literature review. Eleven of these were descriptive qualitative studies, three were grounded theory studies (Ehrlich et al. 2010, Cooney et al. 2013, Korpershoek et al. 2016), one was a phenomenological study (Gullick & Stainton 2008), one was a participatory action research project (Koch et al. 2004), and one a qualitative systematic review (Russell et al. 2018). I have included this qualitative systematic review with the

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other qualitative studies because it summarises the results of qualitative studies to produce higher level knowledge of the phenomenon in question.

Finally, I identified three literature reviews for inclusion in this review. Disler et al’s (2012) paper was an integrated review of the literature seeking to define self-management and identify the factors affecting the individual’s experience of living with COPD. Jonsdottir’s (2013) paper was a combination of a synthesis of findings from previously published systematic reviews and an integrated literature review. Hujala et al’s (2014) study consisted of a critical discourse analysis of scientific literature on self-management in chronic illness.

The majority of the publications (25) included in the review were published from 2011 to 2015, followed by 20 publications that were published between 2016 and 2018. The majority of publications were multi-national, reflecting the many systematic reviews included in the review. Of those that originated in specific countries, the bulk of texts were from the United Kingdom, Australia, or Canada.

2.1.3 Structure of literature review

I conducted a thematic analysis (Braun & Clarke 2006) of the included literature. After familiarising myself with the content of the literature, I identified key themes which I then grouped into three main categories. 1) a category consisting of a perspective on self-management as compliance with an “ideal” form and set of practices as defined by health researchers and health care professionals; 2) a perspective that viewed self-management as referring to how people with COPD define and practice self-management independently and on their own terms; and 3) a third category focusing on the conceptualisation of power in each of these perspectives. The structure of the literature review reflects these categories. Appendix 1 contains a summary of the analysis of the literature included in this review.

Section 2.2 examines the first perspective on self-management that emerged from the analysis of the literature, termed the “medicocentric” perspective. Following this, Section 2.3 discusses the second perspective, termed the experiential perspective. Section 2.4 moves on to examine how power was conceptualised in these different perspectives on self-management. Finally, Section 2.5 summarises the findings of the review, draws key conclusions and identifies gaps in the research that my study is designed to address. In addition, throughout these sections, definitions of self-management according to the medicocentric and experiential perspectives are discussed. For the purposes of the review, I
distinguish between self-care as arising independently from and covering the whole span of care from preserving wellness to preventing disease similar to Orem’s (1985) definition of self-care. I use self-management to refer to activities undertaken to manage the experience of living with COPD every day. I include a discussion of the definitional issues surrounding self-management in the conclusion of this literature review.

2.2 The medicocentric perspective on self-management of COPD

This section discusses the first perspective on self-management, that is, a perspective which represents self-management as idealised, standardised and prescribed, and arising from the point of view of health care researchers, professionals and policy makers. Fifty-one texts took this perspective, including 1) intervention studies, 2) correlational studies, 3) qualitative studies, 4) policy documents, 5) conceptual papers, 6) a descriptive survey study (Cicutto & Brooks 2006), and 7) an integrative literature review (Disler et al. 2012).

This section begins by discussing the key concepts included in the formal definitions of self-management presented in the medicocentric perspective, followed by an analysis of the types of measures used in intervention and correlational studies. I discuss the nature of the medicocentric conceptualisation of self-management as identified in the literature. This section concludes with a discussion of the methodological issues related to the publications that took this perspective.

2.2.1 Concepts included in formal definitions of self-management in the medicocentric perspective

My analysis of the formal definitions used in the texts that took a medicocentric perspective on self-management revealed a variety of definitions used across the


In the texts that did provide formal definitions, both the terms “self-care” and “self-management” were used. In the main, no clear distinction was used between these two terms and they were often used interchangeably. However, three texts did distinguish between self-care as arising independently from individuals and covering the whole span of care from preserving wellness to preventing disease, similar to Orem’s (1985) definition of self-care; and self-management as a more biomedical concept covering disease management and treatment and seen as embedded within the concept of self-care (Kaşikçi & Alberto 2007, Bourbeau 2008, Chronic Conditions Working Group 2017). Somewhat confusingly, Disler et al (2012) took the opposite approach, defining self-management as the “skills and behaviours that a person requires to maintain functioning in the context of their lives” (p. 231) and viewing it as an umbrella term that encompasses self-care. Self-care in Disler et al’s paper is then used to refer to specific tasks to manage a chronic illness. This serves to highlight the lack of consensus surrounding the use of the terms “self-care” and “self-management”.

Definitions of self-care/self-management encompassed a range of domains. Many of the authors referred to medical aspects of self-management, including symptom management, self-monitoring, compliance with medical regimens and self-management interventions, and with the recommendations of health care professionals.

Some authors included education of people with COPD in their definitions. Two of the qualitative studies also included the promotion of adequate skills and knowledge for self-management by health professionals to people with COPD.
(Stellefson et al. 2010, Wortz et al. 2012). There was also a focus on behaviour change in many of the definitions.

While the emphasis placed on education and behaviour change revealed a tendency towards a narrow medicocentric definition of self-management, many authors also included social, emotional and functional domains, such as self-esteem, ability to function in social roles, and relationships with others.

### 2.2.2 Measures used in intervention and correlational studies

The type of measures used in intervention and correlational studies reflected the medicocentric concepts used in the formal definitions of self-management. Outcome measures used in intervention studies tended to cluster around 1) health-related quality of life; 2) use of healthcare resources; 3) clinical or physiological measures; and 4) self-efficacy.

The correlational studies examined the relationship between self-management and a range of other variables, some of which went beyond strict biomedical measures to include the social and psychological aspects of self-management. They included measures of self-management or self-care behaviour. Other measures used in the correlational studies clustered around measures of social

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and family support\textsuperscript{24}; 2) self-efficacy\textsuperscript{25}; and 3) clinical measures (Warwick et al. 2010, Park 2017, Bringsvor et al. 2018).

2.2.3 Overall conceptualisations of self-management in the medicocentric perspective

Despite the inclusion of some holistic concepts in formal definitions of self-management across the publications and some of the outcome measures used in intervention and correlational studies, the trend revealed in the analysis of how self-management was conceptualised across the texts was the use of a medicocentric perspective. Emphasis was placed on the treatment of COPD, carrying out disease-specific medical regimens, managing symptoms, and adherence to treatment regimens\textsuperscript{26}. There was a strong focus on education of people with COPD\textsuperscript{27}. Many of the publications that took a medicocentric perspective also emphasised the role of behaviour change\textsuperscript{28}.

According to this medicocentric perspective, self-management was conceptualised as existing in an ideal state of optimum functioning and quality of life. People with COPD were therefore expected to work to attain this ideal state. This is linked to an assumption in the literature that individuals’ knowledge and behaviours need to fit with this ideal state of self-management, and it is health care professionals who define what form ideal self-management should take\textsuperscript{29}.

\textsuperscript{24} (Kaşikçi & Alberto 2007, Kwua-Yun et al. 2012, Chen et al. 2017b, Park 2017)


This notion of an “ideal” form of self-management was reflected in a tendency to assert that people with COPD should comply with the recommendations of health care professionals. Notably, the policy document *Living Well with a Chronic Condition: Framework for Self-management Support* (Chronic Conditions Working Group 2017) went beyond describing ideal self-management to set out the ideal self-manager, who was described as having a very broad and comprehensive array of accomplishments, including possessing appropriate (legitimated) knowledge of their illness, complying with a treatment regimen, engaging in medical management, managing the social, emotional and functional aspects of life with a chronic illness, and engaging in behaviour change where necessary. In this conceptualisation, the required self-management knowledge and skills were defined and held by health professionals who imparted them to people with COPD. This legitimated medicocentric knowledge took precedence over individuals’ own experiential knowledge of living with and managing COPD every day.

However, some studies demonstrated attempts to integrate medicocentric perspectives on self-management with more person-centred approaches. Lomundal and Steinsbakk (2007, 2012) reported on an intervention that was co-designed by people with COPD and health professionals. The intervention consisted of educational sessions, and the content of the last four sessions was decided by participants themselves and consisted of the exchange of participants’ experiences of self-management. Jonsdottir et al. (2015) explicitly took a partnership-based approach to the intervention in their study. This consisted of three strands: 1) participant and family conversations about their experiences of living with and managing COPD; 2) smoking cessation treatment; and 3) group meetings with an education focus. Self-management in this study was therefore

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conceptualised as integrating participants' experiences with behaviour change and education approaches.

Four of the correlational studies also encompassed more person-centred concepts such as empowerment (Kwua-Yun et al. 2012), self-management as self-initiated and self-directed, arising from people with COPD themselves (Kaşikçi & Alberto 2007), and self-management as multi-dimensional and based on factors which cross the personal, medical, psychological, social and system domains (Park 2017, Bringsvor et al. 2018). However, the extent to which these more holistic conceptualisations of self-management can tap into the experiences of people with COPD was constrained by the use of standardised measures of self-management in correlational studies such as the Bristol COPD Knowledge Questionnaire (Kwua-Yun et al. 2012), the COPD Self-Efficacy Scale (Kaşikçi & Alberto 2007, Kwua-Yun et al. 2012, Park 2017), the modified Patient Self-Care Behaviour Scale (Kwua-Yun et al. 2012), the Alberto COPD Self-Care Behaviour Inventory (Kaşikçi & Alberto 2007, Park 2017) and the Health Education Impact Questionnaire (Bringsvor et al. 2018). The authentic voices of people with COPD were not evident in these conceptualisations of self-management.

One conceptual paper (Kaptein et al. 2014) and a literature review (Disler et al. 2012) criticised conceptualisations of self-management that adopt a medicocentric view of “what the [person with COPD] must do” (Kaptein et al. 2014, p. 910) to self-manage. However, both papers still adopted a "top-down" view that people with COPD need to be encouraged to acquire and apply specific skills in self-management, adhering to an idea of “ideal” self-management, defined by health professionals, that patients need to attain.

2.2.4 Methodological issues in the medicocentric approach

The medicocentric perspective was characterised by a predominance of quantitative methods such as intervention and correlational studies. The extent to which intervention and correlational studies could fully conceptualise the experiences of people with COPD of self-management was limited by the rigorous requirements of such methodologies. Intervention studies, especially experimental studies and systematic reviews, benefit from the use of precise and explicit methodologies to draw causal inferences. RCTs, for example, use randomisation and control groups in order to come as close as possible to corroboration of the impact of an intervention on specific outcomes (Polit & Beck 2012, p. 216). Systematic reviews follow a clearly outlined protocol that is
standardised and replicable, in order to maximise the quality, consistency and transparency of the review process (Coughlan & Cronin 2017). However, there are important disadvantages to relying too heavily on experimental studies and systematic reviews, and these need to be taken into account when weighing their contribution to understanding the dynamics at work in self-management of COPD. Experimental designs such as RCTs have been criticised for being too artificial, which is an unavoidable effect of the requirement for randomisation, use of control groups, and strict adherence to protocols. Another artificial aspect of RCTs is the focus on a small number of variables, which has been criticised as being reductionist and “artificially constraining human experience” (Polit & Beck 2012, p. 216).

Quantitative systematic reviews have been criticised by Greenhalgh et al (2018) for relying on superficial, mechanistic processes of exhaustive search, wide exclusion, and pooling of results. They argued that “…the absence of thoughtful, interpretive, critical reflection can render [systematic reviews] hollow, misleading, and potentially harmful” (pp. 3-4). They also highlighted that systematic reviews tend to cluster around certain narrow research questions, to the exclusion of other questions. For example, the quantitative systematic reviews included in this literature review focused on the weight of evidence for or against the benefit of self-management on certain specific outcomes, and did not address the complex and changing nature of self-management and the varied experiences and priorities of people as they manage their COPD every day.

Correlational research, on the other hand, explores the relationship between two or more variables. As such, it benefits from examining a larger number of variables than do most intervention studies. However, their results need to be interpreted with caution, because, in the real world, behaviours, attitudes and characteristics are inter-related in complex ways that may not be picked up by the model used in the study (Polit & Beck 2012, p. 228).

Four of the qualitative studies included in this review32 adopted a medicocentric perspective on self-management as an ideal state that people with COPD should strive to attain. Given that qualitative research is fundamentally concerned with the understanding of human behaviour and experiences from the perspective of the informants, it is striking that these qualitative studies did not conceptualise self-management from the point of view of individuals’ own lived experience. Data

based on qualitative exploration of human experience is powerful and sometimes more compelling than quantitative data (Anderson 2010, p. 2), and adopting a medicocentric “top-down” perspective on self-management in these studies may have missed an opportunity to understand self-management from the individuals’ perspective.

The health policy documents in this literature review did not explore experiences of people with chronic illness in any depth. Health policy documents need to be critically examined, as they are often written from a position of power that legitimates their disregard for certain perspectives and approaches to self-management, such as patients’ experiences of self-management. Health policy documents need to be located within a broader set of social and institutional processes (Crinson 2009, p. 13), including understanding the power dynamics underlying the socio-political forces that have shaped them.

Three of the four conceptual papers in this review also adopted a medicocentric perspective on self-management (Bourbeau 2008, Effing et al. 2016, Korpershoek et al. 2017). One took a more person-centred view, criticising medicocentric conceptualisations of self-management (Kaptein et al. 2014). However, this paper reverted to an assumption that the knowledge, skills, and practices of people with COPD need to be improved to bring them into line with medicocentric expectations and standards of “good” self-management.

Conceptual papers have the advantage of questioning and explicating theories or concepts that might otherwise be taken for granted, such as self-management. Conceptual work, however, lacks the empirical evidence that is needed to corroborate or deny the arguments it sets forth. Both conceptual and empirical research on experiences of self-management are needed to develop and continuously and iteratively improve the understanding of the concept of self-management.

2.3 The experiential perspective on self-management of COPD

This section examines the second perspective on self-management which conceptualised self-management as arising from experiences of living with and managing the illness. Studies that took this perspective were mainly qualitative in design. Four of these were descriptive qualitative studies33, two used grounded

theory designs (Ehrlich et al. 2010, Cooney et al. 2013), one was a phenomenological study (Gullick & Stainton 2008), and one a qualitative systematic review (Russell et al. 2018). An integrative literature review\textsuperscript{34} was also included in this section as it directly critiqued conceptualisations of self-management evident in the literature, with an emphasis on experiences of self-management (Jonsdottir 2013). This section starts with a discussion of the concepts included in formal definitions of self-management, followed by an exploration of the key themes identified in the qualitative studies. I will then discuss the conceptualisation of self-management that emerged from this literature. I conclude with the advantages and disadvantages of using qualitative research to examine experiences of self-management.

\textbf{2.3.1 Concepts included in formal definitions of self-management in the experiential perspective}

Similar to the texts that comprised the medicocentric view, studies that took an experiential perspective provided definitions for both the concepts “self-care” and “self-management”. Four studies did not provide a formal definition of either self-management or self-care\textsuperscript{35}.

With the exception of one study that used the terms “self-care” and “self-management” interchangeably (Cicutto \textit{et al.} 2004), in the main, the experiential literature followed the distinction between self-care as self-directed and self-initiated action to maintain life, health and well-being (Jonsdottir 2013, Apps \textit{et al.} 2014); and self-management as a more disease-specific concept consisting of actions taken to minimise the impact of a chronic illness\textsuperscript{36}. The studies that defined self-management as a disease-specific concept focused on medical management such as medical aspects such as self-monitoring and symptom management (Cicutto \textit{et al.} 2004, Russell \textit{et al.} 2018), compliance with inhaled medication or with the recommendations of health professionals (Cicutto \textit{et al.} 2004, Jonsdottir 2013), and adequate inhalation technique (Cicutto \textit{et al.} 2004). Apps \textit{et al.} (2014) considered self-management to consist of taught activities in their definition, and the concept of behaviour change was evident in the definitions used in two studies (Chen \textit{et al.} 2016, Russell \textit{et al.} 2018).

\textsuperscript{34}An integrative review summarises extant literature and draws conclusions on a given topic. It encompasses primary and secondary research literature as well as theoretical or conceptual literature. The aim is to enhance understanding of a concept or issue, or to create a new perspective or conceptualisation of a topic (Coughlan and Cronin 2017 p. 15)


\textsuperscript{36} (Jonsdottir 2013, Apps \textit{et al.} 2014, Chen \textit{et al.} 2016, Russell \textit{et al.} 2018)
There was some evidence of an idea of person-centredness in two studies. Cicutto et al (2004) included the active participation of the person in the definition they used for COPD-related self-management. Chen et al (2016) described self-management as a “dynamic process in which people with COPD choose the behaviours that suit them and that help them maintain the stability of their health condition” (p. 263) – thus including an element of agency in their definition.

2.3.2 Key themes in patient experiential research on self-management of COPD

The conceptualisation of self-management evident in the qualitative studies on patient experiences of self-management is rooted in and emerged from the data collected in the studies. It is therefore useful to examine the key findings of the studies and show how they link to the overall conceptualisation of self-management evident across the studies. I conducted a thematic analysis (Braun & Clarke 2006) of the findings of the qualitative studies on the self-management experiences of people with COPD. I generated initial codes and then collated these codes into themes which were then grouped into four categories, covering different aspects of experiences of self-management.

2.3.2.1 Category 1: Adjusting to and balancing the demands of living with COPD.

Several authors reported findings related to the struggle to live with the demands imposed by COPD. For example, Cicutto et al (2014) found that living every day with COPD took place in the context of the struggle to survive in the face of deterioration and death. Authors also reported on different strategies that participants used to achieve balance in their lives – a balance between the need to live as normal a life as possible whilst accommodating the exigencies of life with COPD at the same time. These strategies included 1) pacing the body and allowing time to rest\textsuperscript{37}; 2) consciously planning activities to take account of the needs of the body\textsuperscript{38}; and 3) pushing oneself to the limits in order to lead as full a life as possible (Gullick & Stainton 2008, Cooney et al. 2013). Both Gullick and Stainton (2008) and Cooney et al (2013) found that these three strategies were implemented with the aim of finding a balance between pushing to the limits and acknowledging and accommodating these limits. The self-management tasks

\textsuperscript{38} (Cicutto et al. 2004, Gullick & Stainton 2008, Cooney et al. 2013, Apps et al. 2014)
involved in achieving balance were not just physical or medical – they involved managing the social and emotional aspects of COPD as well\textsuperscript{39}.

\subsection*{2.3.2.2 Category 2: Making self-management decisions}

Four studies identified decision-making by people with COPD as a fundamental process in self-management of COPD\textsuperscript{40} – where people with COPD made their own self-management decisions independently and autonomously. Cicutto \textit{et al} (2004) found that participants in their study also engaged in shared or collaborative decision-making – where they made decisions in collaboration with health care professionals, and passive decision-making, in which clinicians made the decisions.

\subsection*{2.3.2.3 Category 3: Learning, experience and knowledge}

A theme that arose across the studies was the finding that the self-management activity of people with COPD was rooted in and born out of personal knowledge gained from the experience of living with and managing COPD\textsuperscript{41}. People with COPD used personal understanding to make sense of a complex array of information and used their experiences of living with COPD to integrate information into personalised knowledge that underpinned their self-management (Ehrlich \textit{et al}. 2010). Four authors reported that participants developed their self-management practice based on the integration of their experiential knowledge and knowledge they received from other sources such as family, friends, and health care professionals\textsuperscript{42}. Three studies described the process of learning to self-manage as based on acquiring expertise and experiential knowledge (Apps \textit{et al}. 2014) through a process of trial-and-error (Ehrlich \textit{et al}. 2010, Cooney \textit{et al}. 2013, Apps \textit{et al}. 2014) and risk-taking (Ehrlich \textit{et al}. 2010).

\subsection*{2.3.2.4 Category 4: Difficulties and barriers to self-management}

The qualitative studies of experiences of people with COPD did not always report a positive picture of experiences of self-management. The studies also reported challenges and barriers to self-management\textsuperscript{43} such as the risk of using avoidant strategies such as restricting oneself and giving in to a shrinking life world and an increasingly limited body (Gullick & Stainton 2008) or hiding from and denying the symptoms of COPD (Cooney \textit{et al}. 2013). Some participants in Cooney \textit{et al}'s

\textsuperscript{40} (Cicutto \textit{et al}. 2004, Chen \textit{et al}. 2008, Apps \textit{et al}. 2014, Chen \textit{et al}. 2016)  
\textsuperscript{43} (Gullick & Stainton 2008, Cooney \textit{et al}. 2013, Apps \textit{et al}. 2014, Russell \textit{et al}. 2018)}
(2013) study described their lives as being out of balance and struggling to maintain control, and others felt dominated by the illness and out of control. Interestingly, Apps et al (2014) reported a contradictory situation whereby people were found to be practising self-management but were unaware that they were doing so, instead describing a lack of confidence in their self-management ability as they did not feel they had enough disease knowledge. Apps et al (2014) argued that patients in their study did not recognise the value of their own experiential knowledge and skills.

2.3.3 Overall conceptualisations of self-management in the experiential perspective

The qualitative studies as well as Jonsdottir’s (2013) conceptual paper set out a conceptualisation of self-management that is different to the medicocentric one that I have described in Section 2.2 of this literature review. Indeed, Jonsdottir (2013) and Russell et al (2018) critiqued predominant conceptualisations of self-management of COPD that represent standardised and prescribed treatment regimens. They differentiated this view from perspectives that take an experiential approach, viewing self-management as person-centred, dynamic and multifaceted.

Only one qualitative study (Cicutto et al. 2004) attempted to integrate a medicocentric perspective with an experiential conceptualisation of self-management. Using a qualitative descriptive approach, they invited participants to share their experiences of self-management, but they did not explicitly explore the link between individuals’ experiences and knowledge of self-management. They conceptualised self-management as both compliance with health professionals’ recommendations about disease management strategies, and as a process arising out of the experiences of living with the disease.

The rest of the publications conceptualised self-management as an autonomous process resting in the hands of individuals themselves, who were active and used agency when engaging in self-management44. This can be described as a “bottom-up” view of self-management – self-management is rooted in and rests with individuals themselves.

The themes identified in the findings of the studies on patient experiences demonstrate that self-management is defined by people with COPD based on their

experience of living with the illness every day\textsuperscript{45}. In this experiential perspective, self-management is conceptualised as fundamentally based on decision-making, either autonomous, collaborative, or passive\textsuperscript{46}, and it is people with COPD who decide what approach to decision-making to take and when (Cicutto \textit{et al.} 2004).

At the heart of the experiential perspective on self-management in COPD is the value placed on the knowledge gained by people with COPD. This is experiential knowledge gained through living with COPD\textsuperscript{47}. The experiential perspective viewed people with COPD as acquiring experiential knowledge and expertise (Russell \textit{et al.} 2018) as a result of learning through trial-and-error and risk-taking (Ehrlich \textit{et al.} 2010, Cooney \textit{et al.} 2013, Apps \textit{et al.} 2014). In this perspective, personal and experiential knowledge was valued and prioritised over biomedical knowledge. Medicocentric knowledge was viewed as another source of knowledge that could be integrated with knowledge from other sources to build self-management as a personal heuristic that belongs to people with COPD rather than to health care professionals or policy makers.

The lived experience of people with COPD was therefore seen as the root and foundation of self-management. This conceptualisation of self-management as located within people with COPD themselves denoted self-management as having personal meaning for them, reflecting personal choice (Jonsdottir 2013) and active agency on the part of people with COPD (Russell \textit{et al.} 2018). However, this agency is not without limits, as demonstrated by the challenges and barriers to self-management identified by the studies that took an experiential perspective.

\textbf{2.3.4 Summary and critique of the experiential perspective}

All but one of the studies focusing on self-management experiences of people with COPD utilised a qualitative study design. This is not surprising, as one of the fundamental characteristics of qualitative research methodologies is that they seek to interpret and understand human experience from the perspective of the person experiencing it (Cronin \textit{et al.} 2015). In general, qualitative research has been criticised for being too heavily dependent on the influence of the researcher and his or her personal biases and subjective interpretation of the data (Anderson 2010). It has also been criticised for its lack of generalisability due to small sample sizes and the subjective nature of the research (Anderson 2010). However, it has

\begin{thebibliography}{99}
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been argued that a great deal of quantitative research that claims to be objective is in fact politically motivated and open to bias (Carter & Hurtado 2007).

It is important to understand the purpose of qualitative research, its aims and what it is trying to achieve if its role and value are to be fully appreciated. Qualitative research strives for rich, in-depth understanding of phenomena (Green & Thorogood 2009). Questions in qualitative work are largely about understanding different perspectives in a holistic manner, and lend themselves well to understanding self-management from the perspective of people with COPD. Subtleties and complexities about self-management in COPD can be discovered that may be missed by quantitative inquiries (Anderson 2010).

2.4 The relationship between power and conceptualisations of self-management

This section discusses the way power is conceptualised in the medicocentric and experiential perspectives on COPD self-management. Additionally, the contribution of the literature on power and self-management in chronic illness in general is explored, using thematic analysis to identify the key concepts related to power. Nine articles that discussed power and self-management of chronic illness in general are included in this section of the literature review. Four of these are conceptual or policy analysis texts\(^48\). Four are qualitative studies (one participatory action research (Koch \textit{et al.} 2004), three qualitative descriptive (Rogers \textit{et al.} 2005, Seear 2009, van de Bovenkamp & Dwarswaard 2017)). One study (Hujala \textit{et al.} 2014) is a critical literature review using critical discourse analysis of scientific articles addressing self-management.

I applied a Foucauldian analytical framework to the key concepts linked to power in self-management that emerged from the literature. This framework consists of three overarching and interrelated concepts of power, knowledge and agency. In this framework, both the power exercised by dominant groups and institutions and the power exercised by individuals (agency) are implicated, each informing the other. Knowledge is a central mediating concept. It is both created by power and is a site for the production and perpetuation of both power and agency. I use this framework to describe and explicate the manifestations of power that I identified in the literature.

2.4.1 Power in the medicocentric perspective on self-management

The medicocentric perspective on self-management of COPD viewed self-management as a concept that was defined by policy makers and health care professionals, not by people with COPD. Power in this perspective was seen as located with policy makers and health care professionals, who exercise it through the assessment and judgement of people with COPD, and who expect people with COPD to comply with the norms and standards of self-management that have been defined by policy makers and health care professionals. The unequal distribution of power evident in this perspective leads to the casting of the person with COPD in a paradoxical situation where the expectation is of a responsible, autonomous, and self-confident individual who is at the same time compliant with the expectations of policy makers and health care professionals (Thorne et al. 2000). The privileged position of policy makers and health professionals is based on their access to legitimated biomedical knowledge that takes precedence over the experiential knowledge of people with COPD.

Even where attempts have been made to integrate a medicocentric with an experiential perspective on self-management, the power to define the content of “ideal” self-management remained in the hands of health professionals and researchers and policy makers. This was either because they designed the content of self-management initiatives, or engaged in the standardisation and measurement of self-management from a medicocentric perspective. Exceptions to this were the work of Lomundal and Steinsbekk (2007, 2012) and Jonsdottir et al (2015) which represented a genuine effort to bring together biomedical and experiential perspectives on self-management. The researchers recognised the power and value of the experiential knowledge of participants as well as the biomedical knowledge of health care professionals. However, even in these studies, limits were necessarily placed on the extent to which the experiences of people with COPD could be prioritised and used to define successful self-management. This is due to the fact that these were intervention studies that used predetermined standardised outcome measures and assessed the success of the intervention on these outcome measures. People with COPD did not have the power to decide what constituted successful self-management.

The literature on power and chronic illness self-management offers useful insight at this point, because it explores in depth the relations of power inherent in the medicocentric perspective on self-management. It also illustrates how unequal relations of power have shaped and formed the view of the role of the individual with chronic illness in the medicocentric conceptualisation of self-management.
Authors critically analysed “top-down” medicocentric perspectives on self-management that were manifest at the levels of policy making and health care professionals. At policy level, authors such as Wilson (2001), Kendall and Rogers (2007) and Kendall et al (2011) have argued that State-sponsored self-management initiatives may provide a veneer of empowerment of individuals, claiming to emphasise the expertise of people with chronic illness, but at the same time locating power firmly in the domains of the State and health care professionals (Kendall & Rogers 2007), who are regarded as the experts. Authors also argued that it is the interpretation of policy makers and health care professionals of what constitutes appropriate self-management that is dominant. For example, Wilson (2001) argued that in the UK’s Expert Patient Programme (EPP)49, the experiences of people with chronic illness were demoted in relation to a dominant medicocentric view of self-management, based on an "enduring assumption that although the patient’s views must be acknowledged, medical knowledge is more valid and reliable than the lay person’s” (Wilson 2001, p. 139). She argued that the EPP imposed a constant surveillance over people with chronic illness, and that people in turn internalised this surveillance, judging themselves by the standards set by experts (p. 139). She stated that the EPP represents an extension of power into the lifestyle and home life of people with chronic illness, and viewed the EPP as a double-edged sword, both liberating and subjugating at the same time (p. 140).

Wilson (2001) also argued that the State’s regulation of citizens, with mechanisms of control and coercion used for motives of cost-containment and productivity, is manifest in State-sponsored self-management initiatives such as the EPP. She argued that such initiatives subtly coerce individuals into self-management in order to prevent deterioration and reduce the demand on resources. Kendall et al (2011) stated that there is an emphasis in self-management policy on cost-cutting and rationalisation of scarce resources, in which the individual is cast as a costly and negative influence on the system that needs to be controlled and modified (p. 90). They argued that power is therefore not located within the individual, but within the health system as it seeks to exercise control over service users. Hujala et al (2014) also described self-management policy initiatives as a hidden use of power in order

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49 The EPP aimed to deliver self-management support to people with chronic illness by developing generic self-management skills, improving people’s confidence and motivation to take more effective control over their lives and illnesses. It was based on the Stanford Chronic Disease Self-Management developed in the USA by Professor Kate Lorig and colleagues (Lorig et al. 1999a, Lorig et al. 1999b, Lorig et al. 2001). The EPP began in 2002 as a large-scale Department of Health (UK) research project. It ran under the auspices of the UK Government from 2002 until 2007, when it was devolved to a Community Interest Company (CIC).
to save healthcare costs and shift the responsibility of care from the State on to the individual person with chronic illness.

This process of shifting responsibility for management of chronic illness from the State to the individual was highlighted by a number of other authors, who pointed out that this happens while at the same time power is retained by policy makers. Kendall and Rogers (2007) argued that this process of “responsibilisation” is linked to a view of the “self” of the individual with chronic illness as lacking or deficient in the properties required to be a whole or fully functioning individual (p. 136). The paradoxical situation described on page 37 re-emerges here in the process of responsibilisation in another form: the individual is expected to be responsible for the illness, but the self is assumed to be deficient and in need of training to become whole. Responsibilisation also carries with it moral value – the individual with chronic illness has a duty to self-manage for the greater social good (Kendall et al. 2011, p. 90). Lawn et al (2011) and van den Bovenkamp and Dwarswaard (2017) argued that this leads to the view that “bad” choices result from the wilfulness of irresponsible people who are held up to blame if they do not live up to the “ideal” of self-management. This obscures the role played by structural distribution of resources and opportunities, and the social context and power relations that determine whether and how people with chronic illness can become active self-managers. Kendall et al (2011) pointed out the risk that this view could form the basis of a punitive system within which only good self-managers have access to rationed health resources.

The critique of power in policy and State-sponsored self-management initiatives therefore argued that the State is simultaneously engaging in a dominant discourse based on ideologies of “freedom” and “choice” (Kendall et al. 2011) while undermining individuals’ agency by imposing norms and expectations upon them of responsibility and dynamism (Hujala et al. 2014). Hujala et al (2014) argued that the active agency of people with chronic illness is harnessed to the goals of managers and policy makers in order to make health care more cost-effective and productive. Kendall et al (2011) stated that this process could serve to accentuate inequalities and marginalise those who manage through different methods.

Authors also critically analysed how power operates in health professionals’ medicocentric conceptualisations of self-management. The practice and discourses of health care professionals are shaped by the wider health policy

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context. It is therefore not surprising that they follow self-management policy in a
tendency to cast the person with chronic illness in a passive role with little agency,
where the focus of power is on compliance with the expectations of health care
professionals. In this view, people with chronic illness are acted upon by health
care professionals who are represented as having agency, although it is important
to recognise that the agency of health professionals is also constrained by power
exercised by the State and health policy makers. Kendall and Rogers (2007)
criticised the legitimacy given to health care professionals who decide what
constitutes a healthy lifestyle and pointed out that precedence was given to health
professionals’ dominant legitimated knowledge in comparison to the marginalised
competing knowledge of people with chronic illness. Kendall et al. (2011) argued
that the unequal distribution of power between health care professionals and
people with chronic illness casts the individual with chronic illness as a “non-
knower”, whose experiential knowledge is undermined in comparison to the
legitimate knowledge of health care professionals. People with chronic illness
become the recipients of dominant biomedical knowledge via education. Rogers
et al. (2005) found that health care professionals exercised power over people with
chronic illness when making judgements about whether they had the ability to self-
manage. This meant that the non-medical aspects of self-management were
marginalised and excluded.

The concept of responsibilisation arises again in this context, in a process where
people are disenfranchised and yet simultaneously held responsible for their own
health. Overall, the value-laden nature of self-management in health professional
discourse was criticised (Lawn et al. 2011), where people who do not opt to self-
manage in accordance with the expectations of health care professionals are
labelled irresponsible. This was viewed by Hujala et al. (2014) as the shifting of
responsibility for self-management on to the individual without an accompanying
transfer of power from professionals to people with chronic illness. They linked
this to the encroachment of power into the private sphere of individuals, their
lifestyle and quality of life (p. 705).

The key criticisms of the medicocentric perspective in the literature on self-
management in chronic illness, therefore, centre on 1) the primacy given to the
medicalised expertise and knowledge of policy makers and health care
professionals at the expense of the wisdom and experiential knowledge of people

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2014, van de Bovenkamp & Dwarswaard 2017)
with chronic illness; 2) the surveillance of people with chronic illness, extending into the private home lives of individuals; 3) the view of individuals with chronic illness as costly and the emphasis on cost-cutting as a motivator for self-management; 4) a drive to shift responsibility for care of chronic illness to the individual without a concomitant transfer of power; and 5) the appropriation of ideologies of “freedom” to impose dominant norms and expectations over individuals. These critiques can be mapped to Foucault’s work on relations of power, which provides a useful framework for analysing and understanding power in the medicocentric conceptualisation of self-management.

Both the early and later work of Foucault can illuminate the understanding of power in this perspective. Foucault’s early work set forth the theory of “disciplinary power”, in which he understands power as operating through the management and shaping of people and their conduct (Moss et al. 2000). Disciplinary power is located throughout society; however, it is distributed more in favour of the State and its institutions, including science and medicine. A key concept of relevance to the medicocentric perspective on self-management is the way in which disciplinary power is maintained through the concept of “normalising judgement” (Foucault 1979), where individuals are compared and judged against a standard of normality imposed, in the case of self-management of chronic illness, by policy makers and health care professionals. Foucault argued that those who fail to meet this standard are at risk of exclusion, improvement, or correction (Miller 2008). In the medicocentric perspective on self-management, it is policy makers and health professionals who exercise normalising judgement by setting the standard of “ideal” self-management and measuring the self-management practices of people with chronic illness against this standard. Medicalised and standardised self-management interventions can be seen as improving or correcting individuals’ self-management practices to bring them in line with “ideal” self-management.

The argument that self-management policy initiatives impose surveillance over people with chronic illness (Wilson 2001) is linked to the concept of “panopticism”, a central element of disciplinary power, in which power is exercised through constant surveillance, and people internalise this and keep themselves under surveillance. According to a medicocentric view this equates to people with chronic illness self-monitoring and self-managing according to the expectations set by policy makers and/or health professionals. The Foucauldian idea of pastoral power can be used to explain how surveillance of people with chronic illness encroaches into their private spheres such as home life (Wilson 2001). Pastoral
power is an extension of disciplinary power which is exercised in organisations whose purpose is to care for and support the individual and society (English 2004). It is a form of power that extends the surveillance of disciplinary power into the most intimate areas of an individual’s life. Forms of knowledge play a central role in the exercise of disciplinary power. Dominant actors establish and maintain power by placing their legitimated knowledge at the centre of discourse, pushing other (subjugated) knowledge to the margins. In the case of policy and health care professional discourses on self-management, dominant biomedical knowledge takes precedence over the subjugated experiential knowledge of individuals with chronic illness.

Other aspects of the medicocentric conceptualisation of self-management correspond to Foucault’s later work on governmentality. Governmentality is a concept that focuses on the way the State and its institutions attempt to produce citizens that are best suited to fulfil the aims of State policy; and the means by which this is achieved through the organised practices of the State and its institutions (and also through those who work in the institutions such as health care professionals). This is achieved through the use of “biopower”, a term coined by Foucault to refer to how the State governs individuals in order to produce responsible citizens who are self-regulating. Wilson’s (2001) analysis of the EPP as a mechanism for control and coercion and at the same time protecting quality of life is a good example of biopower.

The concept of responsibilisation is Foucauldian in origin, linked to governmentality. Foucault argued that governmentalized States actively work to shift responsibility for welfare on to the individual (Miller 2008). Individuals are expected to be willing and able to take responsibility for their own wellbeing, but this should be done in accordance with the expectations and standards set by the State and its agents. This links to the “responsibilisation paradox” that has been discussed earlier in this literature review, in which individuals are expected to simultaneously take responsibility for their care and be compliant with the expectations of policy makers and health care professionals at the same time. According to a Foucauldian analysis, this abdication of responsibility and simultaneous holding on to power is a reflection of the goals of the State and its institutions (and health care professionals) to maintain control over health care while relinquishing the duty of care that once accompanied this role.

Governmentality, biopower, and responsibilisation have been linked to the rise of the neoliberal State in the developed world, and this is manifest in policy and health
care professional discourses, whereby the responsibilisation of individuals is linked to the rationalisation of valuable resources based on the assumption that self-management leads to reduced risk behaviour, improved health, and therefore a reduced use of costly health resources (Kendall et al. 2011, p. 90).

The extent to which people with chronic illness have agency in a Foucauldian analysis of power in the medicocentric conceptualisation of self-management is debatable. Disciplinary power leaves the least room for the agency of the individual. According to Foucault, disciplinary power produced what he termed “docile bodies” (Miller 2008) and the individual with chronic illness is constructed by dominant discourses of “ideal” self-management. The medicocentric conceptualisation of self-management can be seen as a manifestation of disciplinary power that leaves little room for the agency of the individual. Governmentality and responsibilisation appear to allow for more autonomy on the part of people with chronic illness, but in the medicocentric perspective, this may be more of an “appearance of freedom”, a veneer laid over larger systems of power (Miller 2008). However, even in disciplinary power there is room for agency and resistance, which Foucault viewed as a fundamental element of relations of power. Foucault is not so much discounting the agency of the subject as focusing his attention on how sociocultural, political, and historical conditions set boundaries and delineate the limits of agency.

If this were the only perspective to be found in the literature, it could be argued that individuals hold no power in self-management of COPD. However, the fundamental issue with the medicocentric perspective on self-management is that it does not acknowledge the agency and knowledge of people with COPD. This is in sharp contrast to the experiential perspective on self-management, which emphasises the agency of people with COPD.

### 2.4.2 Power in the experiential perspective on self-management

The experiential perspective on self-management of COPD viewed self-management as a dynamic process that arises from the experiences of people with COPD, rather than from policy makers and health care professionals. Power in this perspective was seen as distributed more towards people with COPD, who were seen as autonomous and agentic in the way that they engage in self-management. The literature on experiences of self-management in COPD cast the person with COPD as an expert in his or her own right, who has developed his or her expertise via trial-and-error and risk-taking. People with COPD were seen
as exercising power in this perspective when they define and practice self-management according to their own lived experience, beyond the remit of policy makers and health care professionals.

The experiential perspective on COPD self-management privileged the personal and experiential knowledge of people with COPD. They were viewed as having the power to decide whether and how to integrate biomedical knowledge with their own knowledge, and expertise was seen as resting with people with COPD. Thus, in comparison to the medicocentric perspective, biomedical knowledge was less dominant in shaping the self-management practice of people with COPD. It is integrated with experiential knowledge and knowledge gleaned from other sources, such as friends and family. However, the question of agency in individual experiences of self-management is not without its tensions, and the literature on power and chronic illness self-management also explored the nature and limits of agency and power in this perspective.

The literature on power and self-management in chronic illness also critically assessed the conceptualisation of power in the experiential perspective on self-management. Koch et al (2004) identified a collaborative model of self-management, in which power was viewed as shared between health care professionals and people with chronic illness in a relationship. They viewed power as exercised with people with chronic illness. The extent to which power was truly shared between professionals and individuals with chronic illness remained open to question in this collaborative model, because it was still professionals who defined what self-management should consist of, and who provided education to people with chronic illness on what they defined as “appropriate” self-management. However, they identified other discourses that emphasised the self-agency of people with chronic illness and located power in the hands of individuals who were autonomous and based their self-management on their own agency and ability to act. They also stated that, from this perspective, people with chronic illness exercised power by choosing when and how to seek professional care or to collaborate with health care professionals. Lawn et al (2011) made the point that, beyond the domains of policy and biomedicine, people with chronic illness exercise agency because they are always making choices about how to live their lives and manage their personal care needs. As noted by van de Bovenkamp and Dwarswaard (2017) people with chronic illness use agency to make choices that suit them, even if this goes against the recommendations of health professionals.
Kendall and Rogers (2007) argued that taking an experiential approach allowed for a view of self-management as resistance, either through individuals appropriating technical or biomedical knowledge and applying it in the course of their day-to-day activities or challenging the knowledge base of health care professionals. They argued that experiential views of self-management can represent a form of resistance to the power and authority that is seen as being illegitimately exercised by dominant interest groups (p. 133). Lawn et al (2011) also highlighted the potential for people with chronic illness to resist imposed power. People with chronic illness do this either actively by adjusting the advice given to them by health care professionals to match their situation more realistically, or by omission or nonengagement.

However, the experiential perspective is at risk of presenting too idealistic a picture of the freedom and autonomy of people with chronic illness as they self-manage. It highlighted the agency of people with chronic illness at the expense of recognition of the persistent constraints, expectations, norms and standards of the State and health care professionals. It is important to explore the tensions that exist between agency and autonomy on the one hand, and the exercise of power over people with chronic illness on the other. Kendall and Rogers (2007) argued that people with chronic illness are constantly reflexively evaluating themselves, and that they consider this process as central to their own health and liberation from their symptoms. However, it can be argued that individuals with chronic illness might internalise the norms and expectations of self-management imposed upon them by policy makers and health care professionals and attempt to evaluate themselves according to these expectations, and this may lead some people to undervalue their own experiential knowledge and skills (Apps et al. 2014).

The concept of responsibilisation that was linked to the medico-centric perspective was also discussed by Seear (2009) in relation to the experiential perspective on self-management. She argued that, in relation to people's experiences, responsibilisation can be a double-edged sword. It can empower people, giving them an opportunity to develop their knowledge, expertise, skills and agency in self-management. However, she also pointed out that the process of responsibilisation could represent an extension of social regulation into the private sphere of individuals' lives, exposing them to the risk of being labelled as irresponsible if they do not do everything they can for their health according to the recommendations of health care professionals (p. 195). She located power in this context both with doctors who push for responsibilisation and with people with
chronic illness who develop their knowledge and expertise when they take on responsibility. Seear (2009) linked the concept of responsibilisation to an assumption that individuals have free choice in staying well and avoiding illness\textsuperscript{52}, when in fact autonomy and choice are constrained by contextual factors such as social, economic and political forces.

Kendall et al (2011) similarly critiqued discourses that emphasise self-management as emancipatory. They pointed out that emancipation through self-management may well be possible, but only when individuals are supported to self-manage in the way that they choose (p. 93). In fact, they argued, the dominant discourses of policy and biomedicine actually seek legitimation through appeals to social justice, emancipation and an “ideology of choice” (p. 94). Kendall et al (2011) viewed this as an imposition of freedom, based on an assumption that “free” individuals will choose to become responsible, self-governing citizens. They argued that this is not really freedom, and that such choices are limited by hidden rules about what is deemed to be healthy.

Agency in a Foucauldian analysis of self-management can be expressed in different ways. One way that individuals with chronic illness employ agency is when they develop their own knowledge and expertise, distinct from the knowledge and expertise of health care professionals. Those who use their own experiential knowledge and resist the imposition of dominant biomedical knowledge can be seen to be accessing agency, as are those who appropriate biomedical knowledge and use it in the furtherance of their own self-management goals. In his early work on disciplinary power, Foucault viewed these enactments of agency as forms of resistance to the discursive regimes of disciplinary power imposed upon individuals with chronic illness. He argued that resistance can work in two ways: one way is the re-emergence or adoption of disqualified, subjugated knowledge (Foucault 1980), such as the personal, experiential knowledge of individuals with chronic illness. Subjugated knowledge is that knowledge which is devalued and pushed to the margins by dominant forms of knowledge. In the experiential perspective on self-management, people with chronic illness are seen to mobilise their experiential knowledge, placing it on an equal footing with, or even placing more importance on it, than on biomedical knowledge. The second way that resistance operates is by people employing and reconfiguring already present discursive practices (Nielsen 2012). In this form of resistance, individuals with

\textsuperscript{52} This assumption is known as ‘healthism’ (Petersen 1997).
chronic illness use and rework the dominant biomedical knowledge and discourse, as well as marginalised knowledge and discourses in order to pursue their self-management practices.

In his later work on the care of the self (Foucault 1990), Foucault returned to the question of the agency of the subject in the network of relations of power, focusing on the formation and transformation of the subject. Agency in this phase of his work is expressed through the struggle of the individual to form him or herself as ethical through a process of self-formation and transformation, a process Foucault termed “practices of the self” (Foucault 1990). Individuals have agency in these “practices of the self” when they see themselves as having the potential for transformation, and refuse to be defined in a final, totalising way by policy makers and health care professionals (e.g. as compliant or non-compliant) (Kendall & Rogers 2007). One aspect of “practices of the self” that is of particular relevance for the experiential perspective on self-management is the concept of “technologies of the self”. Foucault defined technologies of the self as techniques that individuals use to “effect by their own means, or with the help of others, a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves, in order to attain a certain state of happiness, purity, wisdom, [or] perfection…” (Foucault 1988b, p. 18). This can be achieved through a state of constant reflexive evaluation and self-imposed disciplinary practices. An example of this can be seen in Kendall and Rogers’ (2007) view of self-management as a practice of iterative self-evaluation. But Foucault did not view technologies of the self as free from the wider network of power relations. Rather, they are undertaken on the basis of the rules, norms, and mores of the wider historical and sociocultural context. Experts play a key role in technologies of the self, as they tell individuals how to conduct themselves.

Overall, then, while the experiential perspective emphasises the agency of self-managers, a Foucauldian perspective views the agency of self-managers as always performed in relation to the practice of power in wider sociocultural and historical context. There is room for resistance and self-transformation in the practice of self-management, but this is always constrained by the standards and expectations set by the State, policy, and biomedicine. Individuals may develop their own self-management practices, but self-management takes place within existing relations of power and is shaped and formed to a certain extent according to these relations of power.
Chapter 4

2.5 Summary and conclusion

The purpose of this literature review was to explore in detail how self-management has been conceptualised in the literature on COPD self-management, and to frame these conceptualisations of self-management by using the lens of power. I identified two important perspectives on self-management of COPD in the literature: a medicocentric perspective that viewed self-management as existing in an ideal state as defined by policy makers and health care professionals; and an experiential perspective that viewed self-management as arising from, and defined by, people with COPD. I then linked these two perspectives to two distinct conceptualisations of power, one which viewed power as resting in the hands of health care professionals and policy makers, and one which viewed people with COPD as having agency in their own hands. I referred to the literature on power and self-management of chronic illness in general (as opposed to COPD-specific) to contextualise and explore the question of power in self-management in more detail. Finally, I applied the work of Foucault to an understanding of these relations of power at work in self-management.

The dominant conceptualisation on self-management in COPD in the literature was a medicocentric perspective that focused on the medical aspects of self-management along with education and behaviour change. Self-management was conceptualised as existing in an ideal state of physical and psychological functioning, and there was an assumption evident in the literature that people need to be educated and motivated to adopt the legitimated knowledge, skills, and behaviours to reach this state. What comprised ideal self-management was defined by health researchers, policy makers, and health care professionals, who are cast as the holders of the legitimate knowledge on self-management in COPD.

My analysis of how power operates in the medicocentric perspective on self-management highlighted how unequal power relations have led to people being subtly coerced into self-management as defined by States, health systems and health professionals. This is manifested in the essentially paradoxical view of self-management that was a recurring theme in this literature review. People with COPD were portrayed as autonomous “experts” who are responsible for managing their illness on the one hand, but on the other are in need of education and training in order to become adequate self-managers who comply with treatment regimens and prescribed self-management practices on the other.
Studies that focused on the experiences of people with COPD of self-management tended to adopt a more holistic, person-centred conceptualisation of self-management. In the main, the perspective on self-management evident in these studies was a person-centred view of self-management as an autonomous and independent process that rests in the hands of people with COPD. This process is shaped by knowledge arising out of experience of living with COPD over time. What comprises self-management is defined by people with COPD, who integrate their own experiential knowledge with information from other sources such as family, friends, and health care professionals.

The experiential perspective on self-management might lead to an optimistic assessment of power as distributed in favour of people with COPD, in which individuals have the agency to practice self-management on their own terms. The literature on COPD self-management and on power and self-management in chronic illness highlighted the agency of individuals and their active resistance to the dominant discourses of the State and of biomedicine. However, some authors pointed out that constraints are still placed on agency by unequal power relations and dominant discourses. This is either through a process of imposing the norms and expectations of policy makers and health care professionals, or through individuals taking on the onus of responsibilisation, or through the imposition of a top-down notion of “freedom” with its subtle rules of what it is to be healthy.

This literature review is novel in that it is the first to identify two competing conceptualisations of self-management in the COPD literature: medicocentric and experiential; and to relate these conceptualisations to differing views on who exercises power in COPD self-management. The polarisation of the literature into medicocentric and experiential conceptualisations in a dichotomous relationship with very little overlap is notable. The dominance of the medicocentric conceptualisation of COPD self-management is striking, reflecting the privileged position of medicocentric discourses in the literature. This may not reflect the everyday experiences of people with COPD as they manage their illness beyond the clinical setting. No studies were found that explicitly focused on how people with COPD exercise power in the management of their illness. While I identified literature on power and self-management in chronic illness self-management, the lack of research on this topic in COPD means it is not clear whether it holds much in common with other chronic illnesses. I will therefore explore how people with COPD exercise power in the self-management of their illness.
3 Philosophical, theoretical and methodological framework

3.1 Introduction

This chapter sets out the philosophical, theoretical and methodological positions that frame my study. I first state my ontological stance of constructionism and how this is linked to an epistemology of social constructionism. After discussing the main characteristics of social constructionism, I discuss how it has been informed by the work of Michel Foucault and relate this to my research question. I then set out my methodology of narrative inquiry, how it links to social constructionism and to a Foucauldian conceptualisation of power. I discuss the key theoretical perspectives within narrative inquiry and the stance I take on these. I finish the chapter by stating how my philosophical, theoretical, and methodological framework inform my approach to the research methods I will use in this study.

3.2 Ontology and epistemology

My initial task in developing the philosophical framework for my study was to examine my ontological position. Ontology is the philosophical study of the nature of being, and my ontological position forms the basis for my understanding of the nature of knowledge (epistemology), my theoretical framework, and the systematic approach I have taken to my research (methodology). A robust methodology is built on the philosophical foundation of a clearly stated ontological stance. Guba (1990, p. 18) defined ontological questions as those that ask: “What is the nature of the ‘knowable’?” Or, “What is the nature of ‘reality’?”.

The ontological foundation for my study is constructionism. Ontological constructionism states that social phenomena are produced through social interaction. Culture and society are taken to be emergent realities that are in a continuous state of construction and reconstruction (Bryman 2016, p. 30). A constructionist ontological position is appropriate for my research question, because it frames self-management as a fundamentally social phenomenon that is produced and accomplished by social actors, which is at the heart of the ontological constructionist position. Constructionism essentially views social reality as an ongoing accomplishment of social actors (Bryman 2016).

A constructionist ontology impacts on my understanding of what constitutes knowledge, or the epistemology of my study. Epistemology is both the study of
knowledge and the criteria for what counts as knowledge (Cronin et al. 2015, p. 2). In research, epistemology focuses on the knowledge-gathering process (Grix 2004, p. 63). If ontological constructionism views social reality as constructed, it follows that knowledge, as a social phenomenon, is a specific, constructed version of social reality, rather than one that can be regarded as definitive (Bryman 2016). Knowledge is therefore viewed as indeterminate and socially constructed. This aligns with an epistemology of social constructionism. The following sections will explain the tenets of social constructionism, and how they have informed and shaped my research approach, theoretical considerations and methodology.

3.2.1 Social constructionism

The origins of social constructionism as an epistemological construct can be traced to the publication of The Social Construction of Reality: A Treatise in the Sociology of Knowledge by Berger and Luckmann in 1966. The basic contention of this book was that reality is socially constructed, and that the self cannot be adequately understood apart from the particular social context in which they were shaped (Berger & Luckmann 1991, p. 68). Berger and Luckmann argued that humans are inextricably intertwined with society in a dialectical relationship.

Berger and Luckmann’s original work was conceived of as emerging from the sociology of knowledge, and so their conceptualisation of social constructionism was bound up with how knowledge in everyday life is socially distributed, that is, possessed differently by different individuals and types of individuals (Berger & Luckmann 1991, p. 60). Citing the example of knowledge in the context of health and illness, they pointed out that one person cannot know everything known to other people in the community. This can result in complex systems of expertise. For example, they argued, an individual may not possess the knowledge to cure themselves of a physical ailment, and, as such, he or she may require not only the advice of experts, but the advice of experts as to which further experts to consult. The main point to be made here is that the relationship between knowledge and society is a dialectical one, that is, knowledge is a social product and knowledge is a factor in social change (Berger & Luckmann 1991, p. 104).

A comprehensive discussion of the nature of social constructionism and its distinguishing properties is provided by Burr (2015), who proposed four key assumptions of social constructionism.

1. A critical stance towards taken-for-granted knowledge
Burr stated that social constructionism critiques knowledge that might otherwise be taken for granted. Social constructionism challenges the idea that we can objectively observe the “true” nature of the world (Burr 2015). This means that the categories we use to describe and understand the world do not necessarily refer to “real” divisions (Burr 2015, p. 13).

2. Historical and cultural specificity
Social constructionism also holds that the concepts and categories that we use in order to understand the world are historically and culturally specific. They are not stable, unchanging, or enduring, but vary according to period of history and across cultures.

3. Knowledge is sustained by social processes
Social constructionism views knowledge as being constructed between people in a society and culture. Everyday social interactions between people create different versions of knowledge (Burr 2015). This means that particular types of knowledge that can be found in any one culture are specific to that culture and are valid according to the cultural context. Researchers in the social constructionist perspective are therefore suspicious of claims that any one form of knowledge or understanding is closer to the “truth” than other ways (Burr 2015, pp. 16-17).

4. Knowledge and social action go together
If knowledge is historically and culturally specific, it follows that events can be socially constructed in a variety of ways, and each different social construction implies a different kind of decision or action from human beings (Burr 2015). This means that power relations are implicated in social constructions because such constructions inform the limits of what is “permissible human behaviour” (Burr 2015, p. 19). Social constructionism denies that our knowledge is a direct perception of reality. Instead, as members of a culture or society we construct our own versions of reality between us. Accepting that knowledge is culturally and historically specific implies that any idea of “truth” or “objectivity” becomes problematic. All knowledge is derived from looking at the world from some perspective or another, and is in the service of some interests rather than others (Burr 2015).

Cruickshank (2012) stated that social constructionists see knowledge as connected to power and believe that hegemonic knowledge claims should be deconstructed. He cited Potter (1996) in arguing that that social constructionists profess a radical scepticism towards all knowledge claims, especially from agents
in authoritative roles, because social norms are taken to be imbued with power. Given this, one of the tasks of social constructionist research is to challenge supposedly objective knowledge claims by exposing them as symptoms of underlying power relations (Cruickshank 2012), and social constructionists seek to foster a sceptical attitude towards knowledge claims.

Social constructionism has been applied to the study of health and illness, with a focus on challenging the precedence given to the knowledge claims of experts such as health professionals over those of people living with illness. Social constructionist perspectives on illness arose out of an opposition to what is commonly termed “biomedicine”. Biomedicine is a term that refers to the idea that the origins and treatment of disease can be solely understood by adopting methods used in the natural sciences. Disease and treatment are understood as being in causal relationships (Burr 2015, pp. 109-110). Social constructionism opposes this view of disease, and Conrad and Barker (2010) stated that a social constructionist approach to illness distinguishes between disease (the biological condition) and illness (the social meaning of the condition), and emphasised that social constructionists focus on how the meaning and experience of illness is shaped by cultural and social systems (Conrad & Barker 2010, p. S67). A social constructionist approach to illness examines how social and cultural meanings impact on how illness is experienced, how it is depicted, the social response to illness, and how individuals manage their illness, and how illness is managed in the social context (Conrad & Barker 2010). Social constructionism views illness as a deeply social matter. It is bound up with how we interpret our illness experience within the social context of assumptions, norms and values. It is also a matter of power relations, in that illness is not only “socially created but is sustained by social practices that often serve the interests of dominant groups in society” (Burr 2015, p. 116).

3.2.1.1 Micro and macro social constructionism

Both Cruickshank (2012) and Burr (2015) have distinguished between two approaches to social constructionist research: micro and macro social constructionism. The main difference between these two approaches is where they place the focus of their research, and how they conceptualise the social structure-versus-agency relationship.
**Micro social constructionism**

Micro social constructionism deals mainly with face-to-face interaction (Cruickshank 2012, Burr 2015). In micro social constructionism, the self is seen as an agent that can transform shared intersubjective values and norms. These values and norms are constructed by language and constitute the identity of the self and its social environment. However, this does not mean that agents can act completely autonomously. Rather, micro social constructionists attempt to strike a balance between subjects who are completely determined by macro-level social discourses on the one hand, and entirely autonomous agents on the other. Micro social constructionists are interested in power, but they conceptualise agents as being able to change the discourses of power in which they are situated (Cruickshank 2012, p. 76). Gergen (1999) took this micro-level perspective, arguing that agency in social constructionism inheres in a dialogical space in which the real is treated as constructed, and where agency is neither “in here” nor “out there” but is realised within the doing of a relationship (Gergen 1999, p. 113).

**Macro social constructionism**

Like the micro form of social constructionism described above, macro social constructionism also understands language as possessing the power to construct, but sees this as intimately interrelated with social structures, social relations and institutionalised practices (Burr 2015). The concept of power therefore lies at the heart of macro social constructionism. Macro social constructionism has been accused of having no notion of the individual agent having any transformative autonomy (Cruickshank 2012). Cruickshank (2012) asserted that macro social constructionists view the individual as being constructed by a discourse that also constructs its social environment, with no aspect of the self being able to transcend its social environment and achieve some form of viewpoint from outside a discourse. However, others have critiqued this view of macro social constructionism, arguing that in fact it is unproductive to position the self and society as polarities, when “in reality we never actually experience ‘society’ divorced from ‘individuals’” (Burr 2015, p. 521). One way forward out of the structure-versus-agency impasse is to view them not as polarities but instead as inextricably intertwined in a dialectic relationship, where both are features of everyday life (Musolf 2003, p. 6). Conceptualising structure and agency as a dialectical process helps us to understand both social relations and practices on the one hand, and the contribution of human agents to social relations and practices on the other. Given that my aim is to explore how people with COPD
exercise power in the self-management of their illness, my approach is aligned with macro social constructionism.

3.2.1.2 Social constructionism and this study

The epistemology of social constructionism informs the current study in a number of ways. Firstly, it is focused on how people with COPD exercise agency and power in self-management. Social constructionism is relevant to my study because it is concerned with bringing to light the exercise of power by people with COPD.

I believe that self-management practices in COPD should be viewed as social constructions, where people with chronic illness are constantly negotiating their experiential knowledge of self-management in relation to other individuals and in relation to the broader social and cultural constructions of “appropriate” self-management. A social constructionist perspective on self-management allows me to view COPD self-management as a practice that has been inscribed upon by the norms and expectations of health professionals, family members, and people living with COPD.

3.2.1.3 Social constructionism and the work of Michel Foucault

Macro social constructionism is influenced by the work of Michel Foucault, focusing on how a power-knowledge relation shapes individuals’ knowledge and behaviour. I have chosen to base my research on the work of Foucault, because he conceptualised power as relational and ubiquitous. Foucault’s work is a useful approach to understanding power in health care. He focused on the way that knowledge, truth and power have come to invest the body in modern society in order to produce particular forms of individuals and social practices. Rather than ask ontological and metaphysical questions of power, Foucault investigated the productive effects of power as it circulates through the practice of people in their daily lives (Jackson & Mazzei 2012). The essential point to understand about Foucault’s conception of power is that it exists as a web-like network of relations. The following quote summarises Foucault’s view on power:

“Power is employed and exercised through a net-like organisation. …Individuals are the vehicles of power, not its points of application.”

(Foucault 1980, p. 98)

This study applies Foucault’s concepts of power as a network of relations to understanding the practice of self-management in COPD. I explore how people
with COPD exercise power in self-management, based on an understanding of power as a network of relations within individuals, their discourses, learning processes, and everyday lives, and between people in social relations (Foucault 1980), acting both to constrain and produce individuals’ experience and practice of self-management.

Social constructionism and Foucault’s analysis of power are intimately interrelated (Moss et al. 2000, Crane 2015) through discourse. Foucault was adamant that we become how we are by way of multiple, sociocultural, and historically particular contingent factors (Nielsen 2012). Foucault (1972) argued that social reality is constructed through the everyday interaction of people, using the language and discourses available in their particular culture. For Foucault, discourse is both written and spoken communication relating to ideas, courses of action, and practices, which collectively produce a particular version of events (Cobb & Farrants 2014, p. 49). So, our ways of naming things and talking about them constitute Foucault’s notion of discourses, and those discourses that exercise a decisive influence on a specific practice are termed “dominant discursive regimes” or “regimes of truth” (Moss et al. 2000). These regimes exercise power over our thought by governing what we see as the truth and how we understand the world. They also exclude alternative ways of understanding and interpreting the world. For Foucault, therefore, language is the effect or product of power, as well as a means for reproducing power. It is important to note here that discourses do not describe or represent “the real”, rather they bring realities into being. Miller (2008, p. 252) provides the example of medical discourse bringing “people into being” as doctors and as patients, ascribing to them certain interests such as health matters, and positioning them in “specific relationships of power”.

Foucault’s analysis of power illustrates how social constructions of individuals with chronic illness and the lived experience of chronic illness are constituted through power relations and dominant discursive regimes. His work also shows how social constructions become embedded into the thinking and practice of health professionals. This process can take place without the awareness of those involved, since power is pervasive and often invisible (Moss et al. 2000, p. 237). Foucault believed that power struggles are actually struggles over “interpretations of constructed social reality” (Miller 2008, p. 269). This means that the extent to which individuals can exercise power over others is due to their position in a discourse, rather than “some ‘property’ they possess, such as social class or occupational status” (Miller 2008, p. 269). The doctor’s power over the patient, for
example, is conceptualised by Foucault not as an effect of occupational status, but instead as “tied to the way doctors can mobilise the privileged discourse of professional medicine in order to enforce their version of the patient’s ‘problem’ in the clinical setting” (Miller 2008, p. 269).

**The relationship between power and knowledge in the work of Foucault**

Central to Foucault’s understanding of power is its relationship to forms of knowledge. He conceived of power as creating knowledge, and knowledge leading to effects of power. But this is not to say that power is equivalent to knowledge. Rather, the relationship between power and knowledge is reciprocal (Jackson & Mazzei 2012). Foucault argued that power and knowledge relations and practices are continuous processes which inscribe themselves on our bodies and inform our actions (Jackson & Mazzei 2012). According to Foucault, knowledge is an activity that produces subjects and informs how they interact with their social and material worlds.

Foucault’s conceptualisation of knowledge exists in an intimate relationship with power, and therefore knowledge runs throughout his work on power. He described dominant, hegemonic knowledge (for example, the knowledge promulgated by biomedicine), which maintains its power through ongoing struggle, via a process of pushing other subjugated “disqualified” knowledge to the margins. Subjugated knowledge consist of ways of knowing and speaking that belong to subordinated groups (Foucault 1980). An example of subjugated knowledge is patients’ experiential knowledge of self-management. However, resistance is always involved in relations of power and is manifest through the re-emergence of subjugated knowledge and the appropriation of dominant forms of knowledge to serve local interests, for example the interests of people living with chronic illness. This is related to an important concept of “cutting” (Jackson & Mazzei 2012). Cutting refers to acts of resistance and struggle, and is manifested through local and specific knowledge, which is opposed by dominant, qualified knowledge such as that held by biomedicine (Foucault 1980).

**Social constructionism and agency in the work of Foucault**

There is a contentious debate about Foucault’s approach to social constructionism, centring on the question of whether individuals are socially constructed “all the way down” — in other words, socially determined. Some scholars (Taylor 1984, Dews 1989, Habermas 1990) have argued that Foucault’s conceptualisation of power strips the subject of any agency or freedom, totally
inscribed by oppressive social and cultural forces (Nielsen 2012). However, as Nielsen (2012) pointed out, Foucault had always emphasised the interrelation of power and resistance and recommended that in order to understand what he meant by productive rather than repressive power relations we should examine the various forms of resistance that occur in particular localised contexts. Another aspect of power relations that needs to be understood is that they are also contingent and open to change, albeit through existing mechanisms and discourses. These discourses, institutions and sociocultural practices are double-sided, both productive and repressive, both oppressing and resisting.

This conflict over how far “down” Foucauldian social constructionism goes and whether his analyses mean “the death of the subject” (Allen 2000, p. 114), or a double-edged practice of determinism, resistance and freedom can be confusing. However, if one takes a chronological view of the development of Foucault’s work, one can see how his understanding of social construction and the subject developed and matured over time. This has led to authors such as Miller (2008) and Nielsen (2012) arguing that in order to get a rounded view of Foucault’s approach to social constructionism and agency, it is necessary to distinguish between his early and later writings, paying careful attention to the shifts of emphasis in his more mature analyses.

Even in his early work on disciplinary power, some scholars of Foucault’s work such as Allen (2007) and Nielsen (2012) have emphasised that although Foucault concentrated in writings such as the Order of Things (Foucault 1973) and Discipline and Punish (Foucault 1979) on the social construction of the subject, his position does not strip agency away from the subject. As discussed earlier, one route to agency in Foucault’s early work is via resistance.

In the middle phase of his work, that focused on governmentality and responsibilisation, Foucault conceived of power as diffuse and fragmented throughout society and the State. Some authors have suggested that this view of power implies a routinely questioning subject who possesses a degree of autonomy. Bunton (1997), for example, cited the example of medical consumers who shop around for different medical knowledge or who challenge doctors’ advice. Others, however, emphasised the limited agency that is available to responsibilised individuals who are subjected to neoliberal programmes of governance and the hidden constraints placed on their ability to make decisions. Miller (2008, pp. 262-263) asserted that the responsibilised actor may be cloaked in an “appearance of freedom” but is nonetheless still an artefact of the larger
apparatus of power of the State. An example of this perspective is provided by Peterson (2003), who pointed to the pressures placed on “consumers” to become experts on their illness in the guise of autonomy.

The final phase of Foucault’s writings is called the ethical or ethicoaesthetic period (Nielsen 2012). Throughout his writings in this phase of his life, Foucault presented an active subject, who engages in self-imposed disciplinary practices (technologies of the self) that allow the individual to reconstruct or transform his or her subjectivity (Nielsen 2012). The subject in this perspective is neither immune to historical and sociocultural forces, nor is he or she a mere effect of these forces, unable to resist social determinism. While Foucault (1988a) remained sceptical of the existence of an entirely autonomous foundational subject, he did envisage a subject that is both constituted through practices of subjection, and at the same time constituted through practices of liberation on the basis of the rules, norms and mores of the historical and sociocultural context. This late phase of Foucault’s work opens up an expanded range of freedom for the subject in terms of relations of power. In relation to dominant discourses, the ethical subject has a certain freedom within limits to reflect on ways it is positioned by such discourses and to consider ways of becoming, of transforming the self (Miller 2008). The emphasis is on self-reflection and self-regulation, what Foucault termed “care of the self” (Foucault 1990). Practices of self-formation can be seen in areas such as body modification, self-help groups (Miller 2008, p. 266) and in the self-management practices of individuals with chronic illness. Of course, the implication is that one regulates oneself within existing relations of power.

It is difficult to neatly summarise Foucault’s conception of agency because the role of the subject is elusive, shifting and changing depending on which phase of his work is in question. At one moment, he can be seen to view social constructionism as determining the subject through-and-through, with little or no room for autonomy, agency or freedom. From another view, he can be positioned as highlighting resistance, subjugated knowledges, and struggle. Miller (2008, p. 265) has cautioned against trying to decide which one of these represents the “right” Foucault. However, it is possible to identify a common thread in Foucault’s conceptualisation of agency, in which agency exists in tension with the constraints of power. Agency is never free from the wider relations of power present in society. Agency is acknowledged to exist in a variety of forms as the subject struggles to relate to and transform the self. But agency, according to Foucault, is always
constrained by dominant discourses; legitimated knowledge, and the surveillance and power exercised by the State and society.

3.3 Narrative inquiry methodology

Narrative inquiry refers to a family of methods for analysing and interpreting texts that follow the form of a story: oral, written, or visual (Riessman 2008, p. 11). Narrative inquiry emerged as part of a realist project in the early twentieth century to objectively obtain and represent events and experiences of different groups of people. This perspective on narrative shifted and developed from the 1960s to the 1980s to embrace interpretivism and social constructionism. The idea that researchers can provide an objective description of narrative has given way to “narrative studies that position the investigator as part of the field, simultaneously mediating and interpreting the ‘other’ in dialogue with the ‘self’” (Riessman 2008, p. 17).

What constitutes a “narrative” is not always clear in narrative inquiry, and indeed some narrative scholars have questioned the need for a definition at all (Tamboukou 2008). In social research, “narrative” refers to a diversity of topics of study, methods of investigation and analysis, and theoretical orientation (Squire et al. 2013). Squire et al. (2013) have described a situation in which narrative scholars have adopted increasingly broad conceptualisations of what constitutes “narrative”. No longer reliant on a concept of temporal sequencing in narratives, state, social, historical, or spatial succession and change are taken as alternative or additional forms of narrative (Squire et al. 2013, p. 13). However, narrative remains defined across these approaches by sequences with a specific order, temporal or otherwise, which takes it beyond description.

3.3.1 Social constructionism and narrative inquiry

Narrative inquiry as a methodology is commensurate with social constructionism in that stories told by research participants can reflect wider social and cultural forces (Chase 2008, Squire et al. 2013). Narratives and stories are fundamentally linked to the sociocultural context and social relations connected to the storyteller (Moen 2006).

A social constructionist approach to narrative inquiry views people as “active, socially constructed beings who lead storied lives” (Sparkes & Smith 2008, p. 296). Social constructionism views narratives as modes of articulating social action
through which human life and our sense of self are constructed, performed and enacted (Sparkes & Smith 2008).

In a social constructionist approach to narrative, the phenomena being studied should be regarded as constituted socially through storytelling. They are made visible through socially and culturally specific narrative resources and formats. Stories are culturally situated and are based on culturally shared conventions about language, ways of telling stories, and ways of hearing stories (Sparkes & Smith 2008). Social constructionism in narrative inquiry therefore focuses on how language, narrative, and subjectivity are socially constructed, and with the power relations at work within narrative.

Studying stories is therefore useful because they can reveal essential aspects of social life. Thus, in taking a narrative approach, I anticipate that the stories of people with COPD could shed light on the socially constructed nature of living with and self-managing COPD. I am interested in how stories can offer us a view of people as both active and socially constructed.

Telling and listening to stories allows people with COPD to make sense of their own lives and experiences (Daiute & Lightfoot 2004). Allowing people with COPD to tell their own stories provides me with an understanding of the social construction of the everyday reality of living with and self-managing COPD and how they exercise power in self-management.

3.3.2 Power and narrative inquiry

Narratives have been treated in social research as modes of resistance to existing structures of power (Squire et al. 2013). Some narrative scholars have looked specifically to the work of Foucault to inform their understanding of power in narrative inquiry (Blumenreich 2001, Harwood 2001, Blumenreich 2004, Tamboukou 2013, Frank 2016). Blumenreich (2001, 2004) used narrative inquiry to explore how power is embedded in the ways that children with HIV think and talk about their lives. She examined how the narratives of children with HIV resisted hegemonic, stereotypical narratives imposed on such children (2001, p. 9).

The relationship between power and knowledge has been investigated using narrative inquiry (Harwood 2001). Harwood (2001) used narrative inquiry to construct stories of individuals whose knowledge has been subjugated and disqualified. She felt that narrative inquiry was a suitable methodology to employ
in this context because doing research that explores subjugated knowledge requires one to pay attention to the individuals who tell stories of such knowledge.

A Foucauldian perspective views narratives as arenas in which discourse and power can emerge (Tamboukou 2013, Frank 2016). Foucauldian narrative scholars have criticised some narrative approaches that view the subject as an autonomous individual capable of negotiating the world in a unique way (Blumenreich 2004). However, this is not to hold that the subject has no agency and is totally determined by discourse through narrative. Narratives can create the conditions of possibility for resistance to arise and agency to emerge. Tamboukou (2013) referred to these as counter-narratives that resist and challenge hegemonic knowledge, ideologies, norms and values. She viewed narratives as a discursive regime in which the self is both categorised, distributed, and manipulated; while at the same time actively turning him or herself into a subject. My position on the agency of the subject in narrative is guided by Foucault’s work on the dialectical relationship between agency and power, in which narratives can reflect the agency of the subject to form and transform itself, while at the same time recognising that this takes place within the constraints of dominant discourse and power and knowledge relations.

Narrative scholars have also used the Foucauldian concepts of technologies of the self and care of the self to examine how narratives can reveal stories of self-governance and of acting to perfect the self (Tamboukou 2013). Frank (1993, 1995, 1996, 1998, 2016), in particular, engaged with Foucault’s work on technologies of the self and care of the self. He believed that first person illness narratives are vehicles for transformation of the self and at the same time disciplining of the self. Frank (1998) came to the conclusion that stories that ill people tell of their experiences are a technology of the self: an act of governing oneself in accordance with knowledge that is perceived as legitimate and self-evident. At the same time, he viewed illness narratives as a care of the self: “a practice of reclaiming a voice that bodily trauma and institutional treatment have caused to be silenced” (Frank 1998, p. 336).

Foucauldian narrative inquiry resists the conventional “resolution” of standard narratives that can be considered as finalising meaning and favouring one single interpretation. Such an approach to narrative views the story told by a person as just one portion of “complex journeys that continue to unfold” (Nespor & Barber 1995, p. 60). Narratives and the meanings ascribed to them are therefore open (Blumenreich 2004). Each person’s story of living with and managing COPD
necessarily changes over time, in different contexts, and in dialogue with different listeners.

In summary, Foucauldian concepts of power, knowledge and agency have been used to explore narratives as sites of power relations (Blumenreich 2001, 2004). In Foucauldian approaches to narrative inquiry, the power relations at play in the emergence and sustaining of particular narratives become the focus of study. Narratives are seen as always emerging in contexts, saturated by power relations (Tamboukou 2013). Holloway and Freshwater (2007a) highlighted the usefulness of the narrative approach in the context of power and resistance. They argued that taking a narrative approach allows people with chronic illness to tell stories of resistance to imposed narratives of health professionals, family and community, and society. Taking a Foucauldian approach to narrative can shed light on the changing nature of people’s experiences of self-management of COPD, and the ongoing negotiation of power between people with COPD and key others in their lives. In this way, the exercise of power in the narratives of self-management told by people with COPD can be revealed.

3.3.3 Key theoretical positions in narrative inquiry

3.3.3.1 Small versus big stories

One distinction in narrative research has the contrast between what is termed “small stories” and “big stories” (Bamberg 2006, Freeman 2006, Georgakopoulou 2007). “Big stories” take as their unit of analysis the content of the autobiographical story, used to analyse identity and often take cognitive perspectives (Phoenix 2013). “Big stories” have often been taken as more or less unmediated and transparent representations of the participants’ lives, experiences and identities. The guiding assumption here is that stories are privileged forms/structures/systems for making sense of the self by bringing together time, space, and personhood into a unitary frame (Bamberg & Georgakopoulou 2008, p. 378).

The precepts of big story research, with its strict definitional criteria of what constitutes narrative, have been challenged by scholars (especially those taking a Foucauldian perspective) who instead analyse narratives as “process” and “force” (Gibson 1996, Squire 2005, Tamboukou 2008). Narrative researchers in general are reappraising assumptions about temporal sequencing, progression, and transformation in narrative time (Squire et al. 2013). They take an approach that is interested in the social actions and functions that narratives perform in the lives
of people: how people actually use stories in everyday, mundane situations. These "small stories" may involve repeated content or themes spread out across interviews (Squire et al. 2013). They do not necessarily fit with traditional definitions of narrative, and generally arise from what participants themselves voice as story (Bamberg & Georgakopoulou 2008). Fleeting moments of narrative orientation in interactions are of interest in a small story approach (Bamberg & Georgakopoulou 2008, p. 382).

Human knowledge is regarded as a plurality of small narratives, local and personal in nature, that are always under construction. There is no single, dominant or static reality but, rather, a number of realities that are constructed in the process of dialogue. Human knowledge as told through these small stories is dependent on an individual's past and present experiences, his or her values, the people the stories are being told to, and when or where they are being told. This approach to narrative inquiry therefore rejects any belief in the possibility of attaining an objective reality or truth (Moen 2006, p. 60). A small story approach holds that story tellers construct the self through small stories, do rhetorical work, put forth arguments, and challenge the views of key others, all in dialogue with interlocuters and audiences both real and projected (Bamberg & Georgakopoulou 2008, p. 393). Small story research therefore regards narratives as constructed via dialogue (Moen 2006, Bamberg & Georgakopoulou 2008). As such, small story research is essentially based on a social constructionist view of narrative. My research focuses on the everyday social practices of self-management and on the social stories of self-management that occur every day in the lives of people with COPD, in keeping with a small story approach.

3.3.3.2 Event-focused, experience-centred, and dialogical understandings of narrative

An important theoretical distinction in narrative inquiry is made between event-focused narrative research, experienced-centred narrative research, and dialogical narrative research. Event-focused research focuses on spoken tales about particular past events that happened to the storyteller and is guided by Labov and Waletzky’s (1967) work on structural analysis. Experience-centred narrative research explores stories that range in length from segments of interview to many hours of life histories (Squire et al. 2013). It is often related to the work of Paul Ricoeur (Ricoeur 1984, 1988, 1991). For many narrative researchers these two approaches can overlap and inform each other. Both event- and experience-centred narrative research assume that there are individual, internal
representations of events, experiences, thoughts, and feelings, that are given external expression through narrative (Squire et al. 2013).

Squire et al (2013) and Riessman (2008) identified a third form of narrative research that focuses on “co-constructed narratives” that develop in conversations between people (Squire et al. 2013, p. 6). This third approach views narratives as constructed between two or more people in dialogue. Researchers in this field are interested in the social patterns and/or functioning of stories, “whether the stories are short, disjointed sequences of conversation or much more extensive broad cultural narratives” (Squire et al. 2013, p. 6). A central feature of the narrative in the dialogic approach is that the narrator engages the listener emotionally, creating a “two-way narrative contract between teller and audience” (Riessman 2008, p. 109). The dialogic view of narrative emphasises contextual issues of society, culture, and relations of power (Riessman 2008, p. 136). The dialogic approach is a powerful method for uncovering the subtle ways relations of inequality and power work their way into a story about living with chronic illness, and this is the approach to narrative I will use in my study.

A consequence of taking a dialogical approach is that participants’ stories are not viewed as distinct descriptions of the lives outside the interview but as acts of engagement with researchers (Mishler 1986). Interviews are co-constructions, by asking questions and merely by being present, the researcher “instigates self-reflections that will lead the respondent not merely to report his or her life but to change that life” (Frank 2005, p. 968).

A dialogical relationship depends on each party being open to the other’s capacity to transform, to become someone other than whoever she or he already is. This view has similarities to the focus in Foucault’s later work on power/knowledge in which he focused on the ongoing transformative capacity of subjects, and his view of the subject as being in a constant state of potentiality and becoming.

I understand that the stories I participate in are co-constructed between the storytellers and me as listener and researcher. I also perceive these stories as inherently dialogical. I believe that viewing narratives as dialogical will help me explore the stories I co-construct with participants to see how the exercise of power in COPD self-management is expressed through these stories.
3.4 Foucault, narrative inquiry, and this study

I view narratives as fundamentally socially constructed, dialogic and co-constructed. They are sites in which power, knowledge, and agency are manifest. Foucault’s conceptualisation of power as complex and ubiquitous, implicated in language and interaction, fits well with my focus on dialogue and co-construction in narrative. Most importantly, this view of narrative in combination with my Foucauldian theoretical framework lends itself to an understanding that narrative holds the potential for the production of new knowledge about COPD self-management. Espousing this perspective on narrative has implications for the research process. It shapes my positioning in the inquiry, my engagement with participants, and how I interpret the narratives.

From the outset, the very act of choosing the topic of my research and posing the question of how people with COPD exercise power in self-management of their illness reveals my pre-existing interest and belief that this topic is important and worthy of study. I come to the inquiry with my life experience and my preconceptions, assumptions and prejudices about the nature of power, the nature of self-management, and the nature of COPD as a lived illness. This influenced me when I engaged with the topic, embarked on the inquiry, and engaged with participants. In a Foucauldian approach to inquiry, the prejudices, privilege and positioning of the researcher have a profound impact on the relations of power throughout the inquiry and fundamentally on the construction of knowledge about the topic. Section 4.5.1.3 of Chapter 4 details how I went about this process of reflexivity. Critical reflexivity and self-reflection are core aspects of a Foucauldian approach to the production of knowledge and therefore it is important for me to bring to light these prejudices and assumptions and to be aware of the knowledge and positioning I bring to the research endeavour. My view of narratives as dialogic and co-constructed reinforces the importance of reflecting on how my positioning influences what participants tell me. I reflect on how they positioned me as the researcher, listener, and co-constructor, and how this influences our dialogue. I remain reflexively aware of the knowledge and understandings the participants and I bring to the research encounter: sometimes shared, sometimes different, but always interacting. My position as a researcher as an individual, along with my prior knowledge, prejudices and assumptions, are explicated in Section 4.3.1 of Chapter 4.
Such reflexivity allows me to remain open to the possibility of undergoing transformation in terms of my pre-existing knowledge and understanding of COPD self-management as the inquiry unfolded. I recognise that the participants in this study also brought their assumptions and knowledge, not only of COPD self-management but of the nature of research, to the inquiry. Therefore, what unfolds during the inquiry is an iterative cycle in which the participants and I shape each other and transform each other, and in this interaction produce knowledge. This understanding of the research process is central to a Foucauldian approach to narrative inquiry.

In considering my engagement with participants in the study, I have to take into account my positioning as a researcher and how I was guided by Foucauldian narrative inquiry. I considered a variety of ways in which I could identify narratives of COPD self-management, such as interviews, photography, journaling, and video. Ultimately, I was guided by three factors. Firstly, I considered the importance placed by Foucault on language as possessing the power to construct and produce knowledge. As discussed earlier in this chapter, in Foucauldian social constructionism, language is intimately related with social structures, relations of power and knowledge. Secondly, I considered my view of narratives as inherently dialogic and co-constructed and sites for the production of knowledge. Finally, in examining the literature on COPD self-management, it became clear that the voices of people with COPD were subjugated by dominant biomedical research on self-management. Taking into account each of these considerations, I decided that focusing on spoken narratives was the best fit with my theoretical and methodological framework. In order to decide what form these spoken narratives should take, I position myself as active, engaged and involved in the construction of narratives and the production of knowledge. This fits well with my view of narratives as dialogic and co-constructed, which lends itself to conducting unstructured face-to-face interviews as my approach to engaging with participants. From a Foucauldian perspective, narrative interviews are not about establishing the “truth” of events, but they are about the co-production of situated knowledge, contingent upon the perspectives of the participants and the dialogic environment of the interview. This is in keeping with a social constructionist epistemology which views knowledge and truth as socially constructed. The knowledge produced in narrative interviews is therefore a product of the relations of power in the interview.
I am mindful that interviews are professional conversations which involve a power asymmetry between the interviewer and interviewee (Brinkmann & Kvale 2015). They are sites in which power constrains the ways in which the participant and I can relate to each other. In keeping with my understanding of power as fundamentally intertwined with knowledge (Foucault 1980), I view interviewing as an active process where I as interviewer and the participants jointly produce knowledge through the interview relationship (Brinkmann & Kvale 2015). I therefore have to create the conditions that would allow for the building of rapport between the participants and me and the creation of genuine and authentic engagement with participants. I need to contribute to the creation of an environment that is conducive to the co-construction of narrative and the production of knowledge. I work to make explicit my own positioning in the inquiry, to be open to participants’ positions, and to maintain an open, reflexive, and questioning stance towards the topic. In doing so, I commit to engaging with participants by being attentive, interested and non-judgemental.

In determining how I would ‘be’ in engaging with participants, I take into account my perspective on interviews as open, contingent, and as occasions for change. I view narrative interviewing as a site for the production of the subject, holding the potential for both the participants and me to undergo transformation within the interview. This fits with Frank’s (1998) view that interviews represent both a care of the self and a technology of the self: a site of transformation through critical reflexivity. Narrative interviewing is therefore always open and never final. It changes over time and in different contexts. I have to be aware of and comfortable with the open and ever-changing nature of narrative interviews. I also have to remain open to the possibility that taking part in the interviews could involve a process of transformation for the participants and for me. In order to capture this, and to allow for the building of a rapport that would facilitate the construction of knowledge, I have come to the conclusion that engaging in more than one interview with each participant is necessary wherever possible.

I follow a “small story” approach to narrative. This approach is informed by my view that the knowledge produced in interviews is dynamic, unfinalisable and contingent upon the personal the social contexts in which they are produced. By taking a “small story” approach, I am guided by what participants tell me as their stories. In keeping with this approach, I focus on narratives at the level of the everyday. I understand that the everyday mundane stories of self-management co-constructed in the interviews will offer me insight into the exercise of power at
work at the micro-level of self-management. This fits with Foucault's emphasis on understanding power exercised at "the level of daily life" (Foucault 1980, p. 59).

My research question asks how individuals exercise power in the self-management of COPD. The concept of power in this question is best described by Foucault's conception of it as a network of intersubjective relations, always moving and circulating among people (Jackson & Mazzei 2012, p. 49). The advantage of this perspective is that it allows me to explore how the actions of people with COPD can be seen as local reactions, responses, struggles and resistances, embedded in relations of power (Jackson & Mazzei 2012, p. 49).

When considering my approach to analysis, I was guided by Foucault's methodological concern with questions such as "If power is exercised, what sort of exercise does it involve? In what does it consist? What is its mechanism?" (Foucault 1980, p. 142). Jackson and Mazzei (2012) stated that a Foucauldian power analysis should locate who exercises power and on whom; map power relations and show power at work.

However, somewhat challenging, Foucault never created a method of analysis or template that would be transferable to my work. He called his methodological approaches "gadgets" and encouraged researchers to use these "gadgets" as "thinking tools", transforming them to suit the purposes of their individual projects (Jackson & Mazzei 2012). Foucault argued that if power is a cluster of relations, then "the only problem is to provide oneself with a grid of analysis which makes possible an analytic of relations of power" (Foucault 1980, p. 199). Therefore, my task is to develop an analytic framework that allows me to bring together my Foucauldian understanding of power and my narrative methodology.

Combining this Foucauldian theoretical framework with a narrative methodology involves identifying themes of power, knowledge, and agency in narratives of self-management in order to map and analyse the exercise of power in everyday practices (Foucault 1980) of COPD self-management. This lends itself to using narrative thematic analysis (Riessman 2008) in order to interpret the narratives I co-construct with participants. Thematic narrative analysis has been applied to questions of power and resistance (Ewick & Silbey 2003), in which a focus on power is combined with an explicit understanding of narratives as "dialogic productions" (Ewick & Silbey 2003, p. 1342). This approach to analysing self-management practices does focus not on their truth value or inherent meaning, but on the ways in which they disrupt or sustain relations of power and advance
knowledge (Jackson & Mazzei 2012, p. 57). The aim is to make visible the power networks that enable certain practices and therefore ensure their significance. Thematic analysis in a power/knowledge reading does not uncover hidden meaning because cultural and material practices are already interpretations. A power/knowledge reading involves “interpretations of interpretations” (Jackson & Mazzei 2012, p. 57). Rather than attempting to uncover meaning, a Foucauldian narrative thematic analysis maps power by locating its manifestations in present practices within current situations (Dreyfus & Rabinow 1982).

The importance placed on language and dialogue in my Foucauldian approach to narrative inquiry meant that I need to play close attention to the audio recordings and the transcripts. By listening to the recordings and reading and re-reading the transcripts, I become familiar with the narratives and they become the basis for my interpretation and identification of themes. Mishler (1986, p. 271) describes transcriptions as “constructions of different worlds, each designed to fit our particular theoretical assumptions” and so I have to be mindful that my approach to transcription is guided by my theoretical framework and view of narrative as dialogical and co-constructed. I am aware that the act of transcription is another level of interpretation. Nonetheless, by including my voice in the transcripts, by paying attention to tone and emphasis when listening to recordings and making transcriptions, and by situating transcripts in context through field notes and reflexivity, I give myself the best opportunity to remain as close as possible to the process of producing narratives when analysing them.

To summarise, my choice of the work of Foucault as the theoretical foundation for this study is based on my view that individuals with COPD are implicated in webs of intricate and ubiquitous power relations that shape and inform their everyday self-management. This is located in my experience that COPD is a stigmatised condition in which the narratives of the individuals with the illness are often obscured by dominant biomedical discourses. Through a Foucauldian approach to narrative inquiry, it is possible to engage actively with individuals with COPD to produce new knowledge about the exercise of power in self-management, all the more so because this has not hitherto been examined using this theoretical and methodological approach.

3.5 Conclusion

This chapter has presented the philosophical, theoretical, and methodological context that forms the framework for my study. My ontological stance of
constructionism underpins my social constructionist epistemology. Social constructionism allows me to view the self-management stories of people with COPD as arenas in which relations of power and knowledge are constructed and manifested. I see self-management as an inherently social practice, inscribed by the norms, values, and assumptions of people with COPD, their partners and families, health care professionals, and the wider sociocultural context.

My social constructionist epistemology, in combination with the focus on power in my research question, led me to examine the contribution of Foucault to understanding power in self-management. I view power as a network of relations between people. I have highlighted the connection between Foucault’s analysis of power and the construction of social reality through interaction between people, and I examined how his work on power, knowledge and agency can be applied to self-management. I concluded that Foucault’s concepts of power, knowledge and agency fit well with my perspective on self-management as fundamentally shaped by the exercise of power within social and cultural contexts.

In order to investigate how power is exercised in COPD self-management, I have decided to use narrative inquiry as my methodology. I chose narrative inquiry because I believe that narratives are fundamentally socially constructed and serve to express the ways in which self-management is constituted socially through story telling. I described how key scholars have used Foucauldian perspectives on power and social constructionism, in that narratives can be seen as arenas where relations of power, knowledge, and agency can emerge. I discussed how narratives can reflect both the agency of people with COPD, and the constraints of power placed on individuals.

This chapter also examined key theoretical positions within narrative inquiry and where I position myself in relation to these. I have taken a theoretical position on narrative that is commensurate with Foucauldian social constructionism. This means using a “small story” approach to narratives and viewing them as dialogical and co-constructed in nature. Finally, I have concluded this chapter with a discussion of how my philosophical, theoretical, and methodological positioning has framed my positioning as researcher, engaging with the participants and my approach to data analysis. The following chapter sets out the methods I used in more detail.
4 Methods

4.1 Introduction

This chapter presents the operationalisation of the study based on the philosophical and theoretical framework presented in Chapter 3. The research question, aim and objectives are presented as is the approach to identifying the sample and accessing and recruiting participants. I discuss how data collection and data analysis were undertaken and how I addressed issues of quality in this narrative inquiry. The ethical framework for the study is delineated. Throughout this chapter, I relate my choice of methods to the chosen narrative methodology and the theoretical focus on a Foucauldian conceptualisation of power. I show how I worked to maintain equality and respect for the participants in the study by attempting to redress the power imbalance between the participants and me. I reflect on my positioning as a researcher and as an individual and how this may have affected my approach to the methods espoused in the study.

4.1.1 Research question, aims and objectives

4.1.1.1 Research question

How do people with COPD exercise power in the self-management of their illness?

4.1.1.2 Aim

To develop an in-depth understanding of how people with Chronic Obstructive Pulmonary Disease (COPD) exercise power in the self-management of their illness.

4.1.1.3 Objectives

1. To examine how self-management and power are conceptualised in the literature on COPD self-management.
2. To develop an understanding of how people with COPD conceptualise self-management.
3. To reveal how people with COPD exercise power in the self-management of their illness.
4. To inform debate about COPD self-management in the context of Irish policy and national guidelines on the management of COPD.
4.2 Sampling and recruitment

4.2.1 Population and sample

The population for this study were adults aged over 18 who had a diagnosis of COPD. The sample was drawn from members of local COPD support groups, under the umbrella non-governmental organisation (NGO), COPD Support Ireland. At the time of recruitment, COPD Support Ireland had an estimated 390 individuals attending ten local support groups across the Republic of Ireland.

4.2.2 Sample strategy

I used a purposeful sampling strategy (Palinkas et al. 2015), a technique widely used in qualitative research for the identification and selection of information-rich cases. Purposeful sampling involves identifying and selecting individuals that are especially knowledgeable about or experienced with a phenomenon of interest (Cresswell & Plano Clark 2011). In addition to knowledge and experience, Palinkas et al (2015) note the importance of availability and willingness to participate, and the ability to communicate experiences and opinions in an articulate, expressive, and reflective manner. Purposeful sampling encompasses a number of designs, however I used criterion sampling, in which all cases that meet predetermined criteria are eligible for selection (Palinkas et al. 2015). Purposeful criterion sampling fit well with my study design and research question as it ensured that I was able to access people who had experience of living with and managing COPD over time. This meant that participants would be able to tell detailed stories of COPD self-management during the interviews. I decided that having experience of living with and managing COPD was my core criterion. I combined this with other criteria to determine eligibility for inclusion in the study. I did not impose any limits on time since diagnosis as I wanted to capture the range of experience of people with COPD from recent diagnosis to more long-standing illness. In practice all participants had received a diagnosis at least a year before the time of the interviews. The final list of inclusion and exclusion criteria was as follows:

4.2.2.1 Inclusion criteria:

- Experience of living with and managing COPD
- Diagnosis of COPD
- Able to communicate in English
- Aged over 18 years
• Able to understand the purpose of the research process and what it entails for the participant
• Able to freely and voluntarily give informed consent to participation

4.2.2.2 Exclusion criteria

• No diagnosis of COPD
• Unable to communicate in English
• Aged 18 and under
• Unable to understand the purpose of the research process and what it entails
• Unwilling or unable to give informed consent

4.2.3 Access and recruitment

My recruitment approach was routed mainly through COPD Support Ireland, who acted as gatekeeper. COPD Support Ireland is an NGO that aims to support people with COPD and their families. It has a network of local support groups across the Republic of Ireland, and also engages in policy and advocacy activities. I sent a letter requesting access to the Executive Director (Appendix 2), and in addition I gave a presentation on my study to the Board of COPD Support Ireland. This was successful and I was given the contact details of the Chairpersons of the ten local COPD support groups across the Republic of Ireland that were active under the remit of COPD Support Ireland at the time (January 2017). I sent recruitment packs to each Chairperson and to the Executive Director for distribution to support group members. The cover letter to Chairpersons is provided in Appendix 3. The recruitment packs consisted of a letter to potential participants (Appendix 4), information leaflets for people with COPD (Appendix 5) and family members (Appendix 6), consent forms for people with COPD (Appendix 7) and family members (Appendix 8), reply slip (Appendix 9), and a freepost addressed envelope. A recruitment pack was also sent to a Respiratory Nurse Specialist (Integrated Care) but no participants were recruited from this route. The study was also advertised in an email newsletter distributed to members by COPD Support Ireland. I was also invited to present my study to local COPD support groups across the Republic of Ireland. People who were interested in taking part in the study could contact me either by returning the reply slip or via the contact details provided in the email newsletter.
Once people with COPD contacted me indicating an interest in participating in the study, I contacted them by phone to explain the study in more detail. I went through the patient information leaflet and described the study, explained what taking part involved, the risks and benefits of taking part, and the steps I had taken to ensure privacy and confidentiality. If the person was still interested in taking part, I arranged a time and date for me to visit them in a location of their own choosing in order to conduct the initial interview. The majority of interviews took place in participants’ own homes. Five people opted to speak with me in a café or hotel. Ten participants opted to include their spouse/partner or adult child in the interview because they felt that their family member played an important role in their self-management of COPD. In these cases, informed consent was also obtained from the family member.

At the time of our meeting, I explained the study in detail, including what taking part entailed. I answered any questions and explained to the participant that I would send a copy of the transcript to them if they wished, and at the end of the study I would send them a summary report of the key findings of my study. I then obtained written consent before starting each interview. Consent was obtained for each interview conducted with a participant.

I acknowledge that by routing my recruitment through COPD support groups, I excluded people with COPD who were not attending these groups, who may be more isolated, vulnerable and marginalised, and who therefore may have had different issues and experiences as a result. The fact that all participants were members of local COPD support groups may have had an impact on their motivation and agency regarding self-management. Snowball sampling was not feasible due to the high numbers of eligible people who replied to the initial invitation to participate. Other means of recruiting (e.g. through primary care or COPD clinics) are also open to bias. Recruiting through primary care is problematic due to under-diagnosis of COPD in the community, the fact that patients are often not told their diagnosis, the risk that health care professionals might “cherry-pick” patients that they deem to be “good” self-managers and the lack of a reliable recruitment pathway. Recruitment via hospital outpatient clinics is problematic because patients attending clinics have more severe illness which would bias the sample in favour of people with moderate-to-severe COPD. In the end, I believe that the recruitment approach used in this study was the best way to access people who were aware of their diagnosis, had varying severity of COPD,
were attending different health care professionals, and had experience of living with and self-managing COPD.

Throughout the recruitment process, I worked to emphasise my awareness of the participants’ own expertise and experience of living with and managing COPD. I was aware of the power and privilege I held as a researcher linked to a high-profile university. I hoped that by being willing to meet the Executive Director, the Board members, and local support group members I could try to share my knowledge and be open to learning from people who had experience of COPD.

4.2.4 Sample size

In deciding upon the appropriate sample size for my study, I originally envisaged a sample size of between 20 and 25, based on the work of Guetterman (2015) who conducted an analysis of sample sizes in narrative inquiry studies in the health sciences. He cited Pinnock et al (2011) who conducted a narrative study of individuals living with COPD, in which the sample size was 21 people with COPD as well as informal and formal caregivers. I did not use the principle of data saturation in order to determine the limits of the sample size. This was because narrative inquiry does not generally rely on data saturation, treating each person’s narrative as unique in its own right (Marshall & Long 2010). My recruitment strategy was more fruitful than I had anticipated. Thirty-three people with COPD contacted me wishing to take part, 31 of whom were eligible for inclusion in the study. This high number of responses could be explained by two factors. Firstly, it is possible that I had tapped into a well of untold stories of people who had not the opportunity to tell their story of managing COPD before. Secondly, my comprehensive recruitment strategy allowed me access to a large group of people with COPD.

Although I did not use data saturation to determine the sample size, I did use an approach to saturation to determine how many interviews to conduct with each participant. I tried to interview every participant at least twice and succeeded in doing so for 26. Five participants were interviewed once only. I then listened to the audio files and read the transcripts of the first and second interviews to determine if I had any questions that would necessitate a third interview (Hawkins & Abrams 2007). I then rang participants and discussed with them whether they wished to take part in a third interview. On this basis I drew up a list of 13 participants who were interviewed a third time.
4.3 Data collection

As explicated in Chapter 3, my positioning in this inquiry in combination with my theoretical and methodological framework of Foucauldian narrative inquiry led me to choose unstructured interviews with people with COPD\(^{53}\) as the best ‘fit’ for the inquiry. My focus on unstructured interviews is commensurate with narrative inquiry methodology. Unstructured interviews allow for maximum flexibility, facilitating the voices and spoken narratives of participants to emerge as freely as possible. They result in stories – some short, some long (Briggs & Mantini-Briggs 2003) – that offer accounts of people’s experiences of self-management. I view open, unstructured interviews as a site where people tell stories about their lives and provide their own local narratives (Brinkmann & Kvale 2015).

4.3.1 Conducting narrative interviews

As set out in Chapter 3, in deciding upon interviews as my method of data collection, I recognised that interviews are sites of both power and knowledge production (Brinkmann & Kvale 2015). In keeping with my social constructionist epistemology, my Foucauldian theoretical framework, and my view of narrative as inherently dialogic in nature, I focussed on the interrelationship between the participants and me and on the social construction of knowledge in co-constructed interviews. This meant that I needed to pay explicit attention to both the practical hows and the substantive whats of interviewing (see Gubrium & Holstein 1997, 2009). Understanding how the narrative process unfolds in the interview is as critical as apprehending what is substantively said. As explicated in Section 3.4 of the previous chapter, I had to engage in reflexivity both prior to conducting interviews and throughout fieldwork to reflect on the role of power and my positioning in the production of the interview knowledge (Brinkmann & Kvale 2015).

Initially, I came to the interviews as a white, middle-class, heterosexual woman from a privileged background. I had previously worked extensively as a researcher in applied research on ageing and chronic illness. At the same time I have chronic health difficulties that have sometimes left me on the margins of life – socially, emotionally, and financially. This has given me personal experience of learning to manage chronic ill-health. I brought to the interviews my prior knowledge of self-management based both on my legitimated academic knowledge and skills in

\(^{53}\) Although I included photographs taken of artefacts shown to me by participants in my data collection and analysis, the main data source for my study was interviews
health research, and my experiential knowledge of living with and managing chronic health difficulties over time. These two forms of knowledge informed the assumptions and preconceptions I held regarding chronic illness self-management – as something that was essentially biomedical and evidence-based. During fieldwork, these assumptions and preconceptions of self-management were fundamentally challenged and deconstructed as I learned from interviewees. My positioning as a middle-class academic researcher from the School of Nursing and Midwifery in a well-known University also affected how participants viewed me. Some participants asked me for clinical advice on their illness and how they should manage it, reflecting their view of me as a holder of dominant medicocentric knowledge.

In order to redress the power/knowledge imbalance in the interviews, I followed Mishler’s (Mishler 1986, p. 131) advice to “yield control to interviewees of the flow and content of the interview,” to be prepared to be surprised, and to “respect the knowledge and experience of interviewees,” so that interviewees felt comfortable in telling their stories. I tried to become open to challenging my assumptions and preconceptions during the interviews. I tried to be aware of my privileged position as the interviewer, and to be as open, empathic, and non-judgemental as possible.

My understanding of narrative interviews as co-constructed dialogues meant that a balance had to be struck between enabling participants to voice their stories of self-managing COPD on the one hand and engaging myself in the process of co-constructing these stories through the use of clarification questions and prompts on the other. In order to find this balance, I used a loose structure based on Jovchelovitch and Bauer’s (2000) phases of the narrative interview (see Table 4.1). However, this structure was flexible and I adapted it depending on individual interviews and their context. I encouraged participants to speak in their own ways, in order to shift power in the interviews as far as possible in favour of the participants (Riessman 2008). Indeed, Jovchelovitch and Bauer (2000) themselves highlight that their narrative interview structure represents the ideal which may only rarely be accomplished. In practice, in line with the experience of Jovchelovitch and Bauer (2000), my interviews went through several iterations of narration and questioning.
Yielding control to interviewees was challenging, as I sometimes found it difficult to know when to intervene and when to sit back and let participants talk freely. I tried to strike a balance between letting participants narrate uninterrupted even if this produced seemingly irrelevant stories, and only intervening when participants had signalled that they had finished narrating with a “coda”, in which the participant verbally or nonverbally signals that they have reached the end of the story. I became more confident about achieving this balance as the interviews progressed.

4.3.1.1 Phase 1: Preparation

The first phase of Jovchelovitch and Bauer’s (2000) narrative interview structure is preparation: exploring the field to gain a preliminary understanding of the topic.
under study and to develop an exmanent\textsuperscript{54} aim and research question. The preparation phase should identify gaps in the research that the study is to address, and to achieve a cogent formulation of the initial central topic (Jovchelovitch & Bauer 2000). In preparation for my interviews, I conducted an extensive review of the research and Irish policy literature on COPD self-management.

This highlighted the lack of focus on patients' own experience and knowledge of COPD self-management and how they exercise power in their everyday self-management practice. This led to the formulation of the initial exmanent aim which was to explore how people with COPD exercise power and control when they negotiate decision-making in relation to self-management of their condition as set out in my ethics application. A subsequent iteration of the research aim drew on Foucault's conceptualisation of power as a network of relations and focused on how people with COPD exercise, are constrained by, and resist power in making everyday decisions about self-management. This was the aim outlined in the cover letters, information leaflets, and consent forms (Appendices 3, 4, 5, 6, 7 and 8). However, in the early stage of fieldwork, it became clear that when people narrate they talk about self-management as a continuous process and way of life that flows throughout their lives over days, weeks, months, and years. I felt that specifically asking participants to talk about power in the interviews was too structured and directive and did not facilitate them to provide narratives of power in COPD self-management. Therefore, the final exmanent research question evolved to read “How do people with COPD exercise power in the self-management of their illness?” This is reflected in the current title of the study: “Exercising Power in the Self-Management of COPD: A Narrative Inquiry”. Based on this, I did not explicitly ask participants to talk about power in the interviews and this is reflected in the generative narrative question set out in Section 4.3.1.2 of this chapter. Rather, I intended to identify and explicate the participants' exercise of power by applying the Foucauldian conceptual framework espoused in this study to the analysis of the participants' narratives. Doing so would allow me to combine the application of prior theory with the identification of themes related to the exercise of power in self-management, based on interviews which were conducted in an open and non-directive manner.

\textsuperscript{54} Exmanent aims and questions as defined by Jovchelovitch and Bauer (2000) are those which reflect the interests of the researcher and his or her formulations and language. Immanent questions are those which arise out of the narrative of the participants, reflecting their accounts of events and the language they used in their narration.
4.3.1.2 Phase 2: Initiation: formulating the initial topic for narration

Once I had developed the initial research question, I then set about developing the interview schedules that would guide my interviews with participants. I developed two schedules: one for the initial interview and one for follow-up interviews.

The initial interview schedule consisted of four sections: (1) introduction; (2) main narration; (3) clarification; (4) conclusion. The follow-up schedule consisted of five sections: (1) introduction; (2) exploration of issues emerging from the previous interview; (3) update on the participant’s situation; (4) clarification; (5) conclusion. Both schedules are provided in Appendices 10 and 11 respectively. I also developed a demographic information sheet that collected information on age, living arrangements, employment status, health status, COPD severity, care and treatment received. This sheet is provided in Appendix 12. Self-rated severity of COPD was also collected using the COPD Assessment Test (CAT). This is provided in Appendix 13. Collecting demographic information allowed me to develop a profile of the participants in order to ‘set the scene’ and contextualise my findings.

A fundamentally important part of the design of the narrative interview schedule was the development of a “generative narrative question” (Riemann & Schütze 1987, p. 353) which was designed to stimulate the interviewee’s main narrative. I made sure to formulate the generative narrative question broadly but at the same time sufficiently specific for the research topic to be clear in the question. In doing so, I followed Jovchelovitch and Bauer’s (2000) recommendation that the central topic should be experiential to participants, ensuring their interest and the production of rich narratives. My generative narrative question was as follows: “I would like you to tell me about your experience of living with COPD, and what you do to manage your COPD every day. Please feel free to give me as much detail as you would like, because everything you say is important to me.”

Follow up interviews broadly followed the same overall structure as the initial interview, without the administering of the demographic interview schedule and with more focus on clarification of themes identified in the initial interview. Four months elapsed between initial and each follow-up interview. This allowed for the development and strengthening of the research relationship and the unfolding of the narrative over time. It also allowed me to capture the impact of the changing

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55 Although in practice I frequently asked for an update on the participant’s situation before exploring issues arising from the previous interview
56 https://www.catestonline.org/hcp-homepage.html
seasons of the year on self-management of COPD, as COPD is an illness that is affected by the time of year (for example, the risk of chest infection rises in winter, and some people with COPD experience breathing problems triggered by high temperatures in the summer).

### 4.3.1.3 Phase 3: Main narration

Following Jovchelovitch and Bauer (2000), I started the interview by introducing myself, explaining what the research was about and what taking part entailed, and answering any questions the participants may have had. Once the participant and I were at ease and ready to start, I administered the demographic information sheet, and I then introduced my generative narrative question. Sometimes the process of administering the demographic information sheet initiated narratives immediately, in which case I waited to introduce my generative narrative question until the participant signalled they had finished these narratives.

Once I asked the generative narrative question, I encouraged participants to tell their story of living with and managing COPD. Once they began to speak, I let them talk uninterrupted, confirming my active listening through nodding, expressive sounds and other vocalisations (such as “mm,” “ah,” and “yeah” or “yes”). I also made encouraging nods and maintained eye contact. Active listening shows empathy and understanding with the participants (Flick 2009, Warnes & Daiches 2011). I waited until the participant had signalled the end of the story, either verbally or by ceasing to speak and indicating nonverbally that they had finished, before moving on to the questioning phase. Aidan, for example, used both verbal and non-verbal cues to indicate when he had come to the end of a narrative sequence. In terms of verbal cues, he used short exclamations and short concluding phrases.

* Aidan: We had the 60th birthday party now for me in January...And, it was...just relations that came around when I was bad. Just thanking them for all they done for Deirdre [his wife] when I was on the life support machine, so. Ah! As I said sure [pause], we got over it.

* Researcher: You did and...it’s just a fantastic place to be in now, isn’t it?

[Aidan interview 1]

Non-verbal cues used by participants included changes in tone of voice and pauses.
So I said, “No that’s it,” I said, “finished.” And since I gave up work, she is a giant of a wife, she’s bringing in coal and I’m sitting there and looking at her and thinking, “Jesus it’s awful that I can’t do it,” but she has to do it for me…it’s just horrible to see that she has to do it all…she’s working keeping this place going. [voice tails off here] [pause].

Researcher: I know, that’s all you can do really, isn’t it?

[Aidan interview 1]

4.3.1.4 Phase 4: Questioning phase

The questioning phase was fundamentally based on my attentive and active listening during the main narration. I focused on the themes and accounts of events that appeared during the main narration, using the language of the participant. I followed Jovchelovitch and Bauer’s (2000) recommendation to avoid asking “why questions” or to seek explanations as this invites justifications and rationalisations. In the questioning phase, I sought further detail about issues participants raised in their narrative (Flick 2009).

In both the main narration and questioning phases, I worked to create a dialogue and interchange between myself and the participants. I sometimes assumed an authoritative voice (for example, when participants asked me questions). I also used an interactive voice at times (creating dialogue between me and the participants, sharing aspects of my own life and experience with illness). Most frequently I assumed what Stokes (2015) termed a supportive voice (affirming participants’ experiences and stories).

4.3.1.5 Phase 5: Concluding talk

Once the questioning phase was over, I made sure that participants had had the opportunity to tell their story by asking whether they had anything they wished to add. Sometimes this generated additional narratives followed by questioning phases. Once both the participant and I were satisfied that there was nothing more to say, I gave the participant the opportunity to ask questions or express concerns. At the end of the interview, after the digital audio recorder was switched off, interesting discussions sometimes took place, throwing light on the narratives in the interview proper. This contextual information was very important for the interpretation of the data. I kept a notebook with me to summarise any key points that emerged and wrote these up as part of my field notes after each interview.
4.3.1.6 Photographs and images

As I conducted the interviews, I soon discovered that participants brought to me various artefacts that illustrated their narratives of managing COPD. These included medications, breathing training devices, alternative therapies such as salt boxes, or artwork created by the participants. I therefore applied to the School of Nursing and Midwifery Research Ethics Committee in April 2017 for permission to take photographs of the artefacts shown to me by participants. I felt that the inclusion of such photographs would enhance and enrich my interpretation and analysis of the narratives. These images were included in my analysis and coded along with interview transcripts. Examples of these are included in Appendix 14.

4.3.2 Interviewing: building rapport and developing the narrative with participants

Interviews lasted between 16 minutes and one hour 24 minutes, with initial interviews lasting longer than follow-up interviews. Thirty-one first round interviews were conducted with participants, followed by 26 second round interviews and 13 final interviews, giving a total of 70 interviews. All interviews were recorded with a digital audio recorder. Before deciding to use the digital audio recorder, I thought about the risk that the recorder might inhibit participants. However, I felt that the benefits of using an audio recorder outweighed this risk. Jovchelovitch and Bauer (2000) recommend audio recording narrative interviews to allow for verbatim transcription\(^57\). I decided to use a small modern digital audio recorder with a built-in powerful microphone that allowed me to keep the recorder in an unobtrusive location. This worked to help the participant and I focus on each other and on the developing narrative.

I made a conscious effort to keep the atmosphere of the interview relaxed and informal. I engaged in informal chat before and after each interview. I let the participants decide where they wanted to talk to me, for example, in the kitchen or the living room of their homes, or in hotels and cafes. This helped me to establish a good rapport with each participant. In addition, as I revisited participants for follow-up interviews, the relationship was strengthened and deepened, allowing for the affirmation of mutual trust and respect.

Both the participants and I experienced the interviews as profoundly moving. As a researcher and a person who has experience of managing chronic illness, I was

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\(^57\) I discuss some of the issues associated with verbatim transcription in Section 3.4 of Chapter 3 and Section 4.4.1 of this chapter.
deeply affected by the intensity and depth of emotion expressed in the interviews – joy, sadness, and determination. I was somewhat unprepared for this, as I started fieldwork with a preconception of COPD self-management as a largely pragmatic and medicocentric enterprise. My own experiences of self-management led me to feel empathy for the participants in the interviews as I could recognise commonality between their stories and mine.

On the whole, participants reacted positively to the interviews, treating them as an opportunity to share their narratives in an open, honest, and candid way. They had not had the opportunity to speak so freely and openly to a researcher before and were willing to share their emotions and experiences during the interviews. This was enhanced by the rapport and trust we built between each other. Although two people became distressed during the interviews, this was a reflection of their ability to speak freely and confidentially to me. I was always careful to remind people that I had a clear and distinct role as a researcher and was unable to intervene in other ways. I had arranged to refer people to a support organisation if needed. At all times I made sure to remain calm and able to contain the emotional impact of the interviews. I worked to support and listen to participants as they opened up to me.

It was often after the interviews, when I was writing reflexive field notes, that I was able to reflect on the full impact of the stories told by participants. I felt drawn into the narratives of participants, experiencing vicariously their emotional lives. Writing field notes both immediately after the interviews and again later on when listening to the sound files and reading transcripts helped me to gain perspective on the reactions of both the participants and me. I was able to trace how my assumptions and prejudices changed during data collection from a medicocentric conceptualisation of self-management to a view of self-management as fluid, dynamic, holistic and individualised.

4.4 Data analysis

Narrative inquiry is associated with a range of approaches to data analysis, based on the theoretical approach one takes to a study. My approach to narratives as dialogical and co-constructed is combined with a theoretical focus on themes of power, knowledge and agency in narratives of COPD self-management. This theoretical approach is most suited to thematic narrative analysis because prior theory is often used to guide narrative thematic analysis, at the same time as searching for novel insights from the data (Riessman 2008). Riessman (2008)
described thematic analysis in narrative inquiry as an approach in which the content of the narratives is the focus of analysis. She cited Nursing and other health disciplines as having adapted the approach to uncover patients' experiences of different aspects of illness.

This is an approach well-suited to narrative inquiry that seeks to combine *a priori* deductive analysis and inductive analysis arising from close reading of interviews. It is a flexible approach that can be applied across a range of theoretical and epistemological perspectives (Braun & Clarke 2006). The decision to select thematic narrative analysis is guided by its flexibility and its fit with my use of *a priori* Foucauldian theory, as well as its suitability as a method for analysing large datasets.

The approach to thematic analysis in this study focused on identifying the key themes related to a Foucauldian conceptualisation of power, knowledge and agency in participants' accounts of COPD self-management. The final outcome of the analysis is a Foucauldian narrative summation of exercising power in COPD self-management based on my interpretation of participants' accounts of self-management that demonstrates the relationship between the concept of power as exercised on participants, and agency as exercised by participants in their self-management practice.

The specific approach to thematic analysis I have taken is template analysis (King 2019a). This involves the development of a coding “template” which summarises themes in a meaningful way. The approach emphasises hierarchical coding, starting with broad themes which encompass successively narrower, more specific ones. Analysis often starts with some *a priori* themes, which are derived from the theoretical approach or literature review. However, these can be modified or dispensed with if they do not prove to be useful or appropriate.

I chose template analysis because it allows for the use of prior theory to guide the analysis, while at the same time it is flexible enough to allow for the generation of new inductive themes and insights from the data. Template analysis does not rely on data reduction and fragmentation. It allows for iterative coding and adaptation. It can be used within a social constructionist epistemology, in combination with an examination of the issues of reflexivity and the nature of the researcher-participant relationship. I used the technique in a flexible way, to consider multiple interpretations of the data, and to avoid closing down to one “best” reading too early (King 2019a).
I adapted King’s (2019b) step-by-step approach to template analysis to suit the specific needs of my study. Box 4.1 below presents the steps I took to template analysis.

1. Transcribe interviews
2. Identify a priori themes
3. Listen to audio files and read through interview transcripts to familiarise myself with the data. Attach field notes as memos to interviews consisting of my reflexive field notes of each interview
4. Carry out an initial thematic coding of the data. Code for a priori themes, adapt a priori themes, and generate new themes. Within these broad themes, code more specific themes and group according to both a priori themes and inductive themes arising from the data
5. On the basis of this initial thematic coding, produce an initial coding template
6. Develop the final template by applying the initial template to all interviews and reviewing and refining the template in an iterative coding process
7. Interpretation of findings – “after coding”

Box 4.1. Step-by-step approach to template analysis adapted from King (2019b)

4.4.1 Step 1: Transcription of interviews

The first step in analysing my interviews was the process of transcribing them. Although contemporary software packages allow for direct coding of audio files (Brinkmann & Kvale 2015), I preferred to have written transcripts. This allowed me to print transcripts and code reports in order to write notes, link segments within interviews, see patterns and contradictions, and get an overview of coding in context. I was guided by Brinkmann and Kvale (2015) in viewing transcription as an initial analytic process which reflected my theoretical perspective.

As there is no one “correct, valid transcription” (Brinkmann & Kvale 2015, p. 213), I followed Brinkmann and Kvale’s recommendation to ask myself “What is a useful transcription for my research purposes?” (2015, p. 213). Based on a view of interviews as co-constructed and dialogical, I used an approach that included the interactional context (i.e. my interjections, comments and questions), the contribution of others present such as spouses and adult children as well as the voices of participants (Riessman 2008). I avoided using extremely detailed or specialised forms of transcription, because it was neither feasible nor necessary for the analysis of large numbers of interviews (Flick 2009, Brinkmann & Kvale 2015). However, I chose to attempt verbatim transcription, preserving frequent
repetitions, and including non-lexical expressions such as “mm”s and “uhuh”s, noting emphasis, tone of voice, and emotional expressions. I preserved pauses, hesitations, and overlaps in the transcripts. I used square brackets for interjection, overlaps, and paralinguistic aspects such as pauses and information about expression of emotion and tone of voice. I also used square brackets to indicate text inserted by me to indicate segments of speech that were unclear, or text that was anonymised by me. I underlined words that were emphasised. Box 4.2 provides an example of transcribed text illustrating some of these transcription conventions.

Declan: When I did stop breathing for that few seconds, it didn’t kick back in again [pause]. And [eh

Researcher: Gosh, scary!]

Declan: It was, because, I mean at that particular time, they – Fiona my wife and my son [name] actually came in and [name] was expecting a baby so they didn’t contact her initially, but Dr [name] in [nearby city] was talking to them about whether they’d switch off the machine at a certain stage and that type of thing, had I asked to be put on, you know, ventilated.

Researcher: Oh my goodness [quietly]

Declan: Sure I didn’t know a thing about it, I was so, it didn’t impact on me! [laugh]

Sarah: Not at the time, but finding that out later must have been [pause].

Declan: It was scary, yeah.

Box 4.2. Example of interview transcription

A full transcription of an interview conducted with Helen and her daughter Ina is provided in Appendix 15. Although I used ID numbers when transcribing interviews, I later converted these to pseudonyms because I felt that these were better at conveying the humanity and uniqueness of each individual. I used a professional transcriber to transcribe 21 of the first-round interviews. A confidentiality agreement was drawn up between me and the professional transcriber.

4.4.2 Step 2. Identifying a priori themes

In template analysis, it is common to identify some themes in advance, which are known as “a priori” themes. These are rooted either in a theoretical framework, or in the research question, or both, that guide which aspects of the phenomena under investigation should be focused on. I derived a set of a priori themes based
on my research question, aim and objectives, integrated with my theoretical focus on Foucauldian conceptualisations of knowledge, power and agency as refined and discussed in my literature review. These *a priori* themes are set out in Table 4.2.

<table>
<thead>
<tr>
<th>Title of theme</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conceptualisations of self-management</td>
<td>This is a broad theme covering how participants in the study conceptualise self-management in their interviews</td>
</tr>
<tr>
<td>Power: Disciplinary power</td>
<td>Power as operating through the management and shaping of people and their conduct</td>
</tr>
<tr>
<td>Power: Biopower</td>
<td>The conjunction of strategies adopted by the State and a diverse range of institutions and agencies to constitute and govern the population, made possible by forms of specialised knowledge and self-governing participants (Raman &amp; Tutton 2010)</td>
</tr>
<tr>
<td>Power: Responsibilisation</td>
<td>The shifting of responsibility for welfare from the State and its institutions to the individual</td>
</tr>
<tr>
<td>Knowledge: Legitimated dominant knowledge (biomedical)</td>
<td>The appearance of dominant biomedical knowledge that acts to disqualify or subjugate other forms of self-management knowledge</td>
</tr>
<tr>
<td>Knowledge: Subjugated disqualified knowledge (patient experiential)</td>
<td>Participants’ own knowledge based on their experience of living with and managing COPD</td>
</tr>
<tr>
<td>Agency: Resistance</td>
<td>Resistance to the constraints of power imposed on people with COPD as self-managers</td>
</tr>
<tr>
<td>Agency: Practices of the self/care of the self</td>
<td>The struggle of the individual to form him or herself as ethical through a process of self-formation and transformation</td>
</tr>
<tr>
<td>Agency: Technologies of the self</td>
<td>Techniques that individuals use to transform themselves in order to attain a certain state of happiness, purity, wisdom, or perfection (within the constraints of the rules, norms, and mores of society)</td>
</tr>
</tbody>
</table>

**Table 4.2. List of *a priori* themes developed at the initiation of template analysis**

However, in developing *a priori* themes, I had to be aware of some of the potential pitfalls associated with their use. Firstly, by focusing on data that fit *a priori* themes, I ran the risk of overlooking material that did not relate to them. Secondly, there was the danger that I would fail to recognise when an *a priori* theme was not the most effective way of characterising the data (King 2019c). I therefore made sure to view *a priori* themes as tentative, just as open to redefinition or removal as any
other theme. I also kept the number of *a priori* themes to a minimum to avoid over-defining the coding template at this early stage. In practice, as I undertook the successive steps in the analytic process, these *a priori* themes were redefined, expanded upon and reorganised.

### 4.4.3 Step 3. Familiarisation with the data and attaching reflexive field notes

After I had developed the *a priori* themes, I familiarised myself with the data by reading the interview transcripts. Where I required further clarification of the contents of the transcripts, I returned to the audio files to check details such as tone, clarity, and emphasis. This process of familiarisation was very important not only for the purposes of thematic coding, but also for triggering reflexive thoughts and considerations, which I incorporated into my field notes. By doing so, I developed and expanded on the field notes I had written at the time of each interview. I used a template developed by Phillippi and Lauderdale (2018) for the structuring and organisation of field notes as set out in Box 4.3.

<table>
<thead>
<tr>
<th>Setting</th>
<th>The location and setting of the interview (e.g., living room of participant’s home)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other people present</td>
<td></td>
</tr>
</tbody>
</table>

**Participants**
- Overall appearance and demeanour
- Baseline nonverbal behaviours
- Interaction between participant and any others in the room

**Interview**
- Participant response to the interview including emotional responses
- Nonverbal behaviours during the interview

**Critical reflection and reflexivity**
- My response to the interview
- My performance as a participant in the narrative and as an interviewer
- The power dynamics at work in the interviews

**Box 4.3. Template for reflexive field notes (Phillippi & Lauderdale 2018)**

At this point, I imported the interview transcripts, field notes, photographs and any additional documents given to me (such as medical history or lists of medications) into NVivo. My decision to use NVivo, a qualitative data analysis software package, was taken after carefully considering its benefits and disadvantages. I engaged in reflexive consideration of the impact of NVivo on my judgements and how it might structure my analysis (Woods *et al.* 2016). I decided to use it to assist
with the analysis because it provided flexibility and thoroughness in handling the data. It allowed for the ability to easily develop and change coding systems, add annotations and memos, and keep track of developing concepts as the research progressed (St John & Johnson 2000). I also valued the role that NVivo played in making the process of coding more explicit, providing a clear audit trail (St John & Johnson 2000). However, I bore in mind the risk that using such software would lead to an over-reliance on coding and retrieval, or would distance me from the data (St John & Johnson 2000). I mitigated these risks by not relying solely on coding as the totality of my analytic process.

I also attached the field notes as memos to the interviews. Content related to the research question in the field notes was coded along with the rest of the data. In addition, I coded field notes for issues of reflexivity that arose throughout the data collection process. Figure 4.1 provides an example of my coding of field notes. The field notes performed a number of functions. They summarised the dynamic, thrust and flow of the narrative of each participant (across each interview conducted with each participant). The field notes helped me to contextualise the interviews in terms of their setting, the demeanour and emotional state of the participants, and in terms of my own emotional and physical status. I was able to track how my initial assumptions about COPD self-management were challenged by hearing the stories of the participants. Importantly, I also wrote in the field notes about the impact on participants of telling their stories to me, and their emotional journey through the research. I also wrote about the relations of power at work in the interviews, which I used to inform my understanding of how the interviews were co-constructed by me, the participants, and others present during the interviews. An example of my field notes is provided in Appendix 16.
Figure 4.1. Example of coding of field notes: Gráinne

4.4.4 Step 4. Initial thematic coding of the data

Once I had familiarised myself with the data (the interview transcripts, photographs, field notes and other documents), I then started an initial thematic coding of the data. I used NVivo to help me with this. Each participant was treated as a case, so I coded each interview successively. For example, if three interviews were conducted with a participant, I coded these three interviews in succession, along with my reflexive field notes and any photographs in order to track the unfolding narrative of self-management over time.

Initially, I created higher-order codes in NVivo for the *a priori* themes. These are referred to as *a priori* codes. I identified the key relevant aspects of the narratives in the interviews that were relevant to my research question. If they related to one of my *a priori* themes, I coded them as such. Figure 4.2 provides an example of coding of raw data to an *a priori* theme.
If they did not clearly relate to an a priori theme, I modified an existing a priori code or created a new code. One example of modifying an a priori code was that of “Subjugated disqualified knowledge (patient experiential)”. This code was originally an a priori code under a parent code named “Knowledge.” It was derived from my theoretical framework and was created to code raw data on participants’ own knowledge of self-management based on their experience of living with COPD. However, as initial coding progressed, I renamed this node “Patient experiential knowledge” and moved it to become a sub-code of the parent code “Patient experiential conceptualisation of self-management” to reflect my interpretation that knowledge should form a theme within the analysis of how patients conceptualise self-management based on their experience of living with COPD. I recorded this modification in the memo attached to this code. Figure 4.3 illustrates this modification.
Figure 4.3. Example of modifying an *a priori* code

An example of a new code created during this initial coding phase was “COPD interconnected ubiquity” which was created to code for participants' accounts of how COPD had infiltrated every aspect of their lives.

Once I had created these broad, higher-order codes I identified more specific codes, according to both the *a priori* and inductive themes. For example, under the code “Disciplinary Power” I created three sub-codes to distinguish between the different forms of disciplinary power I identified in participants' accounts during the initial coding process. The first sub-code was “Disciplinary power exercised by family carer” and was created to code for participants' accounts of disciplinary power exercised over them by family carers. The second sub-code was “Normalising judgement” and was created to code for accounts of measuring and
monitoring of participants’ health by both health professionals and participants according to an ideal standard of health and self-management. The third sub-code created was “Pastoral power” to code for instances where participants gave accounts of the extension of disciplinary power into their private and intimate lives. Figure 4.4 illustrates the creation of these sub-codes. Figures 4.5, 4.6, and 4.7 give examples of how these sub-codes were applied to the raw data. Appendix 17 provides further examples of how raw data were coded.

![Diagram](image)

**Figure 4.4 Example of creating sub-codes in initial coding: Disciplinary power**
Excerpt from Sinéad and Tracey (her daughter) interview 1:

Sinéad: Yeah, because there would be some times now, Tracey, wouldn’t there, and I would say about going to [local COPD support group], ah, Tracey, I don’t feel like going today, yeah, go on, go in.

Tracey: But you would have to though

Sinéad: Yeah, yeah, go on, go

Tracey: She’s like a child at times, you kind of literally have to dress her and put her out the door.

Figure 4.5 Example of coding raw data to Disciplinary power sub-code: Disciplinary power exercised by family carer
Excerpt from Eileen interview 1:

Eileen: Walking – there’s even a walking test, every day you do a walking – you walk for 2½ minutes.

Researcher: Ok

Eileen: And you were, you know, they’d monitor your health when you come in, they monitor it when you leave, they do – what do they do? They do your oxygen levels and all that.

Researcher: Ok

Eileen: Um, you had to wear a little thing, I don’t know if that’s monitoring your oxygen.

Researcher: A wristband thing?

Eileen: [pause] Yeah [pause]. No, no sorry, I didn’t wear it, I held it in my hand, that’s what it was, a thing about that size. And you just hold that while you’re walking, only for that, it was only for the walking. Taking your heart rate. And one day she thought that my heart rate was a bit irregular, so I ended up, she sent me downstairs to, for further examination and anyway I ended up I got another heart scan or something, and the end of it was that it was ok. But they’re just, they’re so vigilant, you know.

Code:

Disciplinary power/
Normalising judgement

Figure 4.6. Example of coding raw data to Disciplinary power sub-code: Normalising judgement
4.4.5 Step 5. Development of the initial template

I completed the initial thematic coding process for the first ten participants in order to produce the initial template. I used King’s (2019d) approach to decide when to produce the initial template, at the point when my preliminary coding was no longer producing many new themes that were distinctly different from previous themes.

I also had to decide how comprehensive the initial template should be. I tried to avoid creating an extremely comprehensive and detailed initial template, as over-coding can lead to reductionism and there is a danger of losing the sense of the narrative as a whole. I also found that NVivo was helpful in this regard, because it made it very easy to rearrange the structure of the template. I tried to focus on the main themes emerging from my preliminary analysis. However, in practice I developed a large number of codes in the initial template, many of which were descriptive codes that covered content related to medicocentric and experiential aspects of self-management. In hindsight, I realised that these codes were not
related to the research question as they did not code content related to the exercise of power in COPD self-management. I addressed this in stage 6 when refining the initial template to produce the final template. The initial template can be found in Appendix 18.

4.4.6 Step 6. Development of the final coding template

Once I had finalised my initial template, I then had to develop it until I felt it provided as good a representation as possible of the themes I had identified in the data. I did this by applying the initial template to the remaining 21 cases. I coded each case and modified the initial template if there was data relevant to the research question which the template did not adequately cover (King 2019e). I made the following types of modifications to the template:

1. Inserting sub-codes – if I identified more specific themes pertaining to material coded under a particular code, I created more specific sub-codes. For example, under the code “Pastoral power,” I created four sub-codes to distinguish the characteristics of pastoral power that I identified in participants’ accounts. These were: “Becoming self-governing,” “Scrutiny and discipline exercised by family carer,” “Scrutiny and discipline of participants’ private lives,” and “Striving to become a good self-manager.” These are illustrated in Figure 4.8. Figures 4.9, 4.10, 4.11, and 4.12 provide examples of raw data coded to each of these sub-codes.

![Figure 4.8. Example of creating sub-codes in developing the final template](image-url)
Excerpt from Declan interview 2:
Declan: COPD-wise, tremendously improved
Researcher: That’s great, isn’t it?
Declan: Say I’m off all the steroids, em, I had arterial afibrillation [sic]
Researcher: Yes, yeah
Declan: I’ve been taken off all the medication for that.
Researcher: Oh have you?
Declan: I had a heart scan done, and she told me that she could see my heart better now than she ever did.
Researcher: Wow.
Declan: Em, and they were putting it all down to really the loss of weight and the change in lifestyle.
Researcher: Right.
Declan: That things have, d’you know, what I’ve done has helped my situation

Code: Pastoral power/ Becoming self-governing

Figure 4.9. Example of coding raw data to Pastoral power sub-code: Becoming self-governing
Excerpt from Helen and Ina interview 2:

Ina: Because in the past, like that I think she’d maybe have tried to suppress it, or there’d have been a little bit of denial, or she wouldn’t want to let me down, but I think we’re better now at kind of saying, “Mmm is that, does that sound like it’s going in the wrong direction?”

Researcher: Mm

Ina: “Do you feel like you need to take action?” And she’d say, “Ah leave it a day,” em, and then I’ll get on her case the following day and say, “Well did” you know, “Are you going, did you go, will I drive you over?” Em, and invariably she drives herself over, you know, but so, we’re, yeah, we’re kind of- we’ve worked a little bit better with that. And then, em, I suppose then kind of stepping back and giving her the space to do what she needs to do.

Code:
Pastoral power/
Scrutiny and discipline exercised by family carer
Excerpt from Eileen interview 2:

Eileen: You have to manage it you know, but, and I put on a few pounds [voice tails off], anyway that’s the first thing that specialist I go to, he said, “How are you?” and then I’ll say how I am, he said, “Well, did you lose any weight?” You know women and weight, but anyway.

Researcher: Jaysus.

Eileen: Hm! [laugh]. They’d like to be losing a couple of pounds, wouldn’t they! But no pounds, no.

Researcher: No.

Eileen: I put on a few pounds, well not a lot. But I have put on say five or six.

Code:
Pastoral power/
Scrutiny and discipline of participants’ private lives

Excerpt from Niamh interview 1:

Niamh: And it’s not that I eat a lot of rubbish. I do eat rubbish, but I eat good food too, you know. I eat the rubbish in between or at night time you know. But, I’m trying to give it up now for the dieting. Because everybody told me, if I lost a bit of weight it would eat the pressure on my lungs.

Code:
Pastoral power/
Striving to become a good self-manager

Figure 4.11. Example of coding raw data to Pastoral power sub-code: Scrutiny and discipline of participants’ private lives

Figure 4.12. Example of coding raw data to Pastoral power sub-code: Striving to become a good self-manager
2. Deleting or merging a code – sometimes it was necessary to delete a code because the material it covered was better included under different codes. For example, the parent code “Conceptualisations of self-management” and all its sub-codes were deleted because they contained largely descriptive material that was not relevant to the research question. Any material relevant to the research question coded here was also included under “Power,” “Knowledge,” “Agency” and their sub-codes. In certain cases, it became clear that a code was not useful or relevant to the research question and I removed it from the template. For example, the code “Doctors differ, patients die” was deleted because it only contained three items of data and these data were not related either to power or to self-management.

3. Changing the scope of a code – I sometimes found that a code was too narrowly or too broadly defined and so I redefined it. An example of this is the definition for the code “Technologies of the self.” It originally read, “Techniques that individuals use to transform themselves in order to attain a certain state of happiness, purity, wisdom, or perfection. This includes the practices of self-reflection and self-monitoring, measuring and evaluating.” But I later expanded this definition to include “abstaining and restricting, disciplining, routines, working on and managing emotions, and relating and revealing troubles to experts – with the aim of achieving personal happiness and health within the constraints of the rules, norms, and mores of society.”

4. Changing a position of a code in the structure. There were cases where I decided that a theme that was initially classified as a higher-order code or a sub-code would be better placed in another position in the coding hierarchy. The codes “Medicocentric knowledge” and “Patient experiential knowledge” were moved from their original positions as sub-codes of “Medicocentric conceptualisation of self-management” and “Patient experiential conceptualisation of self-management” respectively. They were moved to a new parent code “Knowledge” because I identified knowledge as a distinct theme and gave it its own distinct location in the coding hierarchy, reflecting its relevance to the research question.

5. Renaming codes – I sometimes found that the initial name given to a code did not accurately reflect its content, especially if the definition of the code had been changed, and so I renamed it. For example, I renamed the code “Medicocentric knowledge” as “Dominant medicocentric knowledge” to reflect the fact that I identified medicocentric knowledge as a dominant form of knowledge about the clinical aspects of COPD self-management transmitted
by health care professionals to participants with the expectation that they would use this knowledge to become "good" self-managers.

For all these modifications, I created “coding memos” in NVivo attached to each code that tracked my decisions and modifications about each code. I also defined each code very carefully to ensure coding consistency. An example of a coding memo is provided in Figure 4.13, and an example of a code definition is provided in Figure 4.14.

The act of making changes to the template necessitated adjusting the coding of transcripts already coded according to the previous version. This made for an iterative process of coding, modifying the template, and recoding. This process could have gone on indefinitely, because there was no stage at which I could decide with certainty that the process was “finished.” I therefore was guided by the resources available to me and by a law of diminishing returns, whereby I recognised that the changes to the template were becoming increasingly small, yet were not contributing significantly to the overall quality of the analysis (King 2019e). The final template is set out in Table 4.3 below. Examples of how raw data were coded to this template are provided in Appendix 19.

The overarching structure of the final template was designed according to my Foucauldian conceptual framework based on the three overarching a priori themes of power, knowledge, and agency. These three themes formed the higher order categories under each of which related sub-themes were arranged. The final template forms the framework for the presentation of findings in the following chapter.
Figure 4.13. Example of coding memo

Memo:
23/05/2019 This node was originally created and called Knowledge: legitimated dominant knowledge (biomedical). It is an a priori node derived from the literature and the theoretical chapters.
07/06/2019 This needs to be linked to power and resistance
10/06/2019 I have renamed this node FROM 'Legitimated dominant knowledge' TO 'medicocentric knowledge'. I have done this because this is more appropriate at this early stage of coding to cover all biomedical knowledge.
I moved this node from a parent node 'knowledge' to be a child sub-node of 'Medicocentric conceptualisation of self-management' because it seemed counter-intuitive to have a separate knowledge node that was not linked to how self-management is conceptualised by participants
26/11/2019 Move this node FROM 'Conceptualisations/Medicocentric conceptualisations' TO parent node "Knowledge" because I wanted knowledge to stand alone as a category given its importance to the research question.
11/12/2019 Renamed this FROM "Medicocentric knowledge" to "Dominant medicocentric knowledge" to reflect the fact that I view medicocentric as a dominant form of knowledge transmitted by health care professionals to participants with the expectation that participants will use this knowledge to become "good" self-managers. This is in opposition to subjugated knowledge.
Figure 4.14. Example of code definition

**Code:** Alternative knowledge

**Definition:**
This code contains data on instances where participants talk about using alternative therapies in their self-management practice. This could be home or folk remedies, or alternative therapies such as salt or herbal remedies, or alternative medicines not prescribed by health care professionals. This constitutes a local, popular, subjugated disqualified knowledge that is not recognised by health care professionals.
### Table 4.3: The final coding template

<table>
<thead>
<tr>
<th>Parent code</th>
<th>Sub-code level 1</th>
<th>Sub-code level 2</th>
<th>Sub-code level 3</th>
<th>Sub-code level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agency</td>
<td>Care of the self</td>
<td>Technologies of the self</td>
<td>Introspection and self-reflection</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Nurturing well-being and happiness</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Abstaining and restricting</td>
<td>Diet</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Smoking</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Exercise</td>
<td>Standards and expectations of health care professionals</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Setting goals and targets</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Pushing the body</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Individualised exercise regime</td>
</tr>
<tr>
<td>Routine</td>
<td></td>
<td></td>
<td>Routine</td>
<td>Imposition of routine – demands of the illness</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Imposition of routine – demands of the medical therapeutic regimen</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Participants devising routine independently</td>
</tr>
<tr>
<td>Parent code</td>
<td>Sub-code level 1</td>
<td>Sub-code level 2</td>
<td>Sub-code level 3</td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>------------------------------------------------------</td>
<td>--------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Knowledge</td>
<td>Dominant medicocentric knowledge</td>
<td>Transfer of medicocentric knowledge</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Using medicocentric knowledge to inform self-management practice</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Questioning the medicocentric knowledge of health care professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patient expertise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjugated knowledge</td>
<td>Embodied knowledge</td>
<td>Learning</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Resisting therapeutic regimens</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Adjusting therapeutic regimens</td>
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<tr>
<td></td>
<td></td>
<td>Alternative knowledge</td>
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<td></td>
</tr>
<tr>
<td>Sharing knowledge with peers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4.3: The final coding template (continued)
<table>
<thead>
<tr>
<th>Parent code</th>
<th>Sub-code level 1</th>
<th>Sub-code level 2</th>
<th>Sub-code level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power</td>
<td>Disciplinary power</td>
<td>Pastoral power</td>
<td>Becoming self-governing</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Scrutiny and discipline of participants’ private lives</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Scrutiny and discipline exercised by family carers</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Striving to become a “good” self-manager</td>
</tr>
<tr>
<td>Responsibilisation</td>
<td>Health care professionals as vehicles for responsibilisation</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Responsibility as compliance</td>
<td></td>
<td></td>
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<td>Responsibilising other people with COPD</td>
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**Table 4.3: The final coding template (continued)**
4.4.7 Step 7. Interpretation and post-coding analysis

Coding was an important tool to help me produce an interpretation of the data that did as much justice as possible to its richness (King 2019f) and answered the research question. However, I recognised that data analysis is more than coding and continues after coding (Childers 2014) in a process of interpretation and post-coding analysis. St Pierre and Jackson (2014) emphasised that narratives are inseparable from interpretation, and therefore “there are no data without theory that orders and gives classification to the things of the world” (Popkewitz 2004, p. 72). This meant that it was imperative for me to connect participants’ accounts with my theoretical framework.

Coding was helpful in making analysis more manageable and providing a systematic framework for organising themes. It gave me an overview of the key themes in the analysis. However, I also undertook a process of “thinking with theory” (Jackson & Mazzei 2012) by using my Foucauldian conceptual framework based on the themes of power, knowledge and agency in the design and development of my final coding template. The themes identified through my template analysis helped me navigate through the narratives and provided a link between my theoretical framework and my data analysis.

However, once coding was complete I recognised that I needed to go deeper, to reflexively and iteratively “think with theory” in my interpretation and post-coding analysis. Given my use of Foucauldian theory, this phase of my analysis aimed to locate how participants exercised power in their self-management practice. My approach to analysing self-management practices focused on the ways power was exercised on participants, and exercised by participants. I mapped power by locating its manifestations in current self-management practices (Dreyfus & Rabinow 1982). I did this by examining the coded data in much more depth. I printed out reports of the content of codes from NVivo. I highlighted key narratives, wrote annotations and analytic memos to help me think. Examples of annotations and analytic memos are provided in Figures 4.15 and 4.16 respectively. At all times, I went back and forth between the coded data, my Foucauldian conceptual framework, and the whole interviews. This helped me keep in sight the overall narratives and the context of the themes I had generated in the previous phases of my analysis (King 2019f). At this stage of my data analysis, I drew together the themes, and sub-themes and examined them together in order to generate a higher order conceptual narrative of how participants exercised power in the self-management of their illness. Through interpretation and post-coding analysis I
was able to identify that the three concepts of power, knowledge and agency in participants’ narratives of COPD self-management co-existed and were intimately interrelated. I identified a common narrative thread throughout participants’ whole interviews and the themes and sub-themes of constant negotiation of the boundary between power and agency. My final narrative therefore constituted a higher order explication of how people with COPD exercise power in the self-management of their illness.

Figure 4.15. Example of annotation

Excerpt from Aidan interview 1:
Researcher: And em, eh, tell me more about the art though, I’m really fascinated by that. I love what you’re doing, there.
Aidan: I never painted in my life, never. The only thing I painted was walls. And when I started going to [local nursing home] then, there’s a friend of ours, she’s not, what would I say, she’s not a qualified artist. But she's an artist, she paints. And she said to me one day, I was out [unclear] and we were playing cards and she said to me ‘Why don’t you come in and do the art’, and I said ‘Yeah I’ve never painted in me life’ [unclear] ‘Like’ she said ‘Come in and try it’, and I did, and I enjoyed it! And then I, em, I took up then.

Annotation:
09/01/2020 This is an example of an agentic use of technologies of the self - to nurture well-being and happiness for one’s own sake, not restricted to what health care professionals define as COPD self-management. It is a deeper process of relaxation, mindfulness, and transforming the self through creativity and growth - mindful practice of the self.
4.5 Quality in narrative inquiry

The assessment of quality in qualitative research is the topic of much debate (Holloway & Freshwater 2007b, Flick 2009, Holloway & Galvin 2017). Originally qualitative research used to be evaluated in direct comparison with quantitative research to the detriment of the former, which was accused of lacking rigour and validity and therefore legitimacy, and indeed qualitative research in the health services is still accorded lower status than quantitative work (Cronin 2009). This situation has led to debates about how best to evaluate the quality of qualitative research which have centred on three main positions:

1. “Qualitative and quantitative research should be evaluated by the same criteria
2. Qualitative research should be evaluated by criteria that have been specially developed for it.

3. Criteriology (the emphasis on criteria for evaluating qualitative work) should be rejected” (Holloway & Galvin 2017, p. 303).

Proponents have made strong arguments for each position, leading to a proliferation of criteria for evaluating qualitative research and a consequent lack of clarity about what criteria to use for assessing quality in qualitative research (Sparkes & Smith 2013, Holloway & Galvin 2017). As a result, there is no single agreed position or consensus on how to assess and evaluate qualitative research (Onwuegbuzie & Leech 2007, Cronin 2009, Sparkes & Smith 2013, Holloway & Galvin 2017). This confusion surrounding evaluation of quality in qualitative research has particular resonance in narrative inquiry, which has to contend with questions about the nature of “truth” in narrative (Squire et al. 2014) and whether narrative inquiry can be said to be valid and reliable (Holloway & Freshwater 2007b). This is despite the fact that narrative inquiry does not set out to meet such quantitative criteria, as the “stories of participants are unique and the researcher as research instrument also affects the research through his or her specific and individual perspective, background and characteristics” (Holloway & Freshwater 2007b, p. 111).

Holloway and Galvin (2017) have argued that an over-focus on the issues related to quality in qualitative research is linked to a perceived need to defend qualitative inquiry against the criticisms of positivist researchers. Nonetheless, they advocate adopting specific criteria by which to evaluate qualitative research as a useful position in order to be able to adequately demonstrate the credibility of such work. This study is an important, in-depth exploration of how people with COPD exercise power in the self-management of their illness. My aim is to demonstrate its quality and significance to the readership – people with COPD, researchers in both qualitative and quantitative traditions, and health care professionals who wish to be assured that the work is of high quality. For this reason, I have decided to use criteria specifically designed to evaluate the quality of qualitative research. As narrative inquiry is an approach within qualitative research, Holloway and Freshwater (2007b) argued that its quality should be judged by some of the criteria that apply to qualitative research. If narrative inquiry is to be acknowledged as making a “distinctive contribution to the development of knowledge in a discipline” (Dunleavy 2003, p. 27) and be accepted to be of worth, then reference to such criteria is necessary. Elliot et al (1999) acknowledged that even though a list of
criteria may be fundamentally at odds with the spirit of qualitative research, “some form of widely recognised evaluative guidelines for qualitative research are necessary to win wider recognition and acceptability for qualitative approaches” (p. 225).

In considering which set of criteria to use, I bore in mind the need to demonstrate methodological soundness and adequacy (Holloway & Freshwater 2007b). Both Holloway and Freshwater (2007b) and Loh (2013) have advocated using the trustworthiness (Lincoln & Guba 1985) and authenticity (Guba & Lincoln 1989) criteria developed by Lincoln and Guba for the evaluation of quality in qualitative research as a useful approach in narrative inquiry. They argued that although there is some debate as to their usefulness as a yardstick with which to assess and ensure quality (Loh 2013), the work of Lincoln and Guba is very influential and has reconceptualised the quantitative concepts of reliability and validity for qualitative research (Smith 1998, Holloway & Freshwater 2007b).

Loh (2013) advocated Lincoln and Guba’s (1985) trustworthiness criteria for use in narrative inquiry as very influential and recognised across the qualitative research community as an effective and rigorous way of evaluating qualitative research. Loh (2013) explicitly referred to the usefulness of the concepts of trustworthiness and authenticity for qualitative work within a constructionist paradigm. For these reasons, I considered trustworthiness and authenticity as useful criteria to use when ensuring the quality of my narrative inquiry. I describe the process of ensuring trustworthiness and how I adapted the criteria to suit my narrative methodology in Section 4.5.1. I also adopted Guba and Lincoln’s (1989) concept of authenticity. A study is authentic if it can demonstrate the adequacy of the research process, if the ideas of the participants are appropriately presented, and if the outcomes of the study give participants and readers better insight into their own problems (Holloway & Freshwater 2007b).

In Section 4.5.2, I also present some narrative-specific issues that emerge in the discussion of quality in narrative inquiry, specifically the role of “truth” in narratives and the concept of verisimilitude (the quality of seeming to be “true” or real) (Loh 2013).
4.5.1 Ensuring trustworthiness in my narrative inquiry

Lincoln and Guba and others after them developed checklists and very specific criteria by which to assess trustworthiness; however Holloway and Freshwater (2007b) and Loh (2013) caution against unquestioning adherence to long checklists in narrative inquiry. Indeed, in a constructionist epistemology, all knowledge is viewed as constructed, and constructed knowledge is never “perfect” (Loh 2013). This implies that quality criteria and checklists are similarly constructed. I therefore use Lincoln and Guba’s criteria as a guide to aid me in navigating my way to ensuring this study’s quality but have adapted them to suit the needs and circumstances of my narrative inquiry as set out in Table 4.4 below.

<table>
<thead>
<tr>
<th>Trustworthiness criteria</th>
<th>Techniques to achieve criteria</th>
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<tr>
<td>Credibility</td>
<td>Prolonged engagement</td>
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<td>Referential adequacy</td>
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<td>Confirmability</td>
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<td>Thick description</td>
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<td>Reflexivity</td>
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<td>Record of the inquiry process</td>
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Table 4.4: Trustworthiness criteria adapted from Lincoln and Guba (1985)

4.5.1.1 Credibility

Lincoln and Guba (1985) developed the notion of credibility to replace the positivistic concept of internal validity. Credibility is of particular importance in narrative inquiry. It confirms the extent to which the research presents the socially constructed experiences and perceptions of the participants (Holloway & Freshwater 2007b, Holloway & Galvin 2017). In order to establish credibility, I used the techniques of prolonged engagement, peer review, negative case analysis and referential adequacy.
**Prolonged engagement**

Prolonged engagement is a concept originally designed with participant observation in mind and referred to immersion in the research setting for a long period of time. Through such immersion, it is possible to gain insight into the context and setting of the data (Holloway & Galvin 2017). As my narrative inquiry is based on interviews (mainly in participants' homes), it was not possible to immerse myself in the setting. However, I did strive for prolonged engagement by interviewing each participant up to three times over the course of 12 months in order to trace the unfolding of narratives over time.

**Referential adequacy**

Referential adequacy involves the archiving of all data and records pertinent to the study. I retained copies of audio files, transcripts, field notes, as well as my decision diary and reflexive diary entries. Sensitive data are held in an encrypted folder on a password-protected computer. In compliance with the retention policy of Trinity College Dublin, these data and records are retained for five years after the completion of this study.

**4.5.1.2 Transferability**

Transferability is the second criterion identified by Lincoln and Guba (1985) and means that the findings of a qualitative study can be transferred to similar situations or participants (Holloway & Galvin 2017). In narrative inquiry especially, however, the context is crucial if one is to be able to transfer the knowledge and theory from one setting to another (Holloway & Freshwater 2007b). One way of achieving transferability in narrative inquiry is via “processual generalisability” (Stoddard 2004) which focuses on social processes and activities and demonstrates that these are generalisable beyond the specific setting to a variety of other situations. For narrative inquiry this is of particular importance as each individual tells a unique story (Holloway & Freshwater 2007b). Good narrative inquiry describes and illuminates social processes and provides knowledge that can be transferred to other settings and situations (Holloway & Freshwater 2007b).

**Thick description**

The main technique for ensuring transferability is “thick description,” which refers to a “detailed description of the process, context, and people in the research, including the researcher’s conceptual development” (Holloway & Galvin 2017, p. 315). Thick description originated as a tool for ethnographers engaged in
participant observation research (Geertz 1973, Ponterotto 2006) and then was adopted for use by sociologists, psychologists, nurse researchers, and others. According to Ponterotto (2006), thick description refers to the “the researcher’s task of both describing and interpreting observed social action within its particular context” (p. 543). Thick description makes possible “thick interpretation” (Denzin 1989), where the rich descriptions and contextualisation of findings allows for in-depth and meaningful interpretations to be made. This leads the readers to a sense of verisimilitude, where they can “cognitively and emotively ‘place’ themselves within the research context” (Ponterotto 2006, p. 543). However, it can be unclear as to how to apply thick description to interview-based research. Ponterotto (2006) has proposed some ways of using thick description to interview studies, and I have adopted these for use in my study.

1. The policy and practice context.
   In the Introduction to this thesis, I provide a description of the policy and clinical practice context for COPD self-management in Ireland.

2. Participants
   Thick description of my sample involved “describing fully my participants whilst maintaining confidentiality” (Ponterotto 2006, p. 546). I reported relevant demographic and health-related characteristics such as gender, age, living arrangements, COPD severity, comorbidities, treatments received, and personal or practical care received.

3. Data collection
   Following Ponterotto's (2006) recommendations, I recorded and documented the location of the interviews, the length and recording procedures for the interviews, and my own and the participants' reactions to the interviews. This provided a sense of verisimilitude to the reader and made my presentation and discussion of the findings more accessible.

4. Results
   I incorporated thick description of the findings by using illustrative quotes from the interviews and adding relevant information about the emotional state of the participants, as well as contextual information to situate the findings and add richness and depth.
5. Discussion

In my discussion, I interwove my findings from participants’ accounts of power, knowledge and agency with my interpretations of the findings. I discussed these with explicit reference to other research and literature on power, knowledge, and agency in COPD and chronic illness self-management. I thus created a thickly described discussion chapter which provided rich and detailed interpretations for the reader as well as for the participants.

Taken together, this thick description should allow the reader to grasp the findings of this study in their context, and to “discern whether she or he would have come to the same interpretive conclusion” as I did (Ponterotto 2006, p. 546).

4.5.1.3 Dependability

The criterion of dependability evaluates the extent to which a study is consistent and accurate (Holloway & Galvin 2017). Readers should be able to evaluate the adequacy of the analysis by following the decision-making processes of the researcher.

*The audit trail*

Establishing dependability necessitates the development of an audit trail to help readers follow the path of the researcher and how she or he achieved their conclusions (Holloway & Galvin 2017). This is particularly relevant for studies espousing a social constructionist epistemology with its view of knowledge as inherently constructed and dependent upon the stance of the researcher and the participants. This means that the processes by which the researcher gained this knowledge must be made explicit and transparent to others (Holloway & Freshwater 2007b). Establishing an audit trail is also relevant to narrative inquiry, which, as a social science research methodology, needs structure, consistency and coherence. Holloway and Freshwater (2007b) point out that “researchers are accountable for the way they ask questions and the way they report the accounts of the participants. They need to make visible their decision-making processes and show them to be ethical and rigorous” (p. 110). Riessman (2008) also stated that in order to support theoretical claims in narrative inquiry, researchers must ground their claims for trustworthiness by using a carefully documented audit trail. I followed Rodgers and Cowles’ (1993) framework of four types of documentation:
1. Contextual
   I documented the description of the setting and participants as well as the policy and clinical context as part of my “thick description” of the study

2. Methodological
   I detailed my methodological decisions throughout the study, as well as the development of my theoretical framework

3. Analytic
   I kept a dedicated diary for the recording of my decision-making regarding the analysis of my data. This was complemented by my development of a detailed audit trail in NVivo – using memos and annotations to track my coding and analytic decisions throughout analysis.

4. Personal response
   As I described in more detail below, I kept a reflexive diary detailing my experiences of and responses to the research, my assumptions and preconceptions and how these changed over the course of the research, my positioning as researcher and co-constructor of interviews, and my impressions of the emotions and responses of participants to the interviews.

In structuring the written thesis, I have clearly set out the decisions taken at each stage of the research, from the development of the research question, through my epistemological position and chosen methodology, my methods and presentation of findings, to the interpretation and discussion of the findings in the context of the literature, and finally to the implications of the findings for policy and practice.

**Reflexivity**

Another technique to ensure dependability is the practice of reflexivity, a process in which researchers critically reflect on their own preconceptions and monitor their relationships with the participants and their own reactions to participants’ accounts.

According to my social constructionist epistemology, I view research as an enterprise of knowledge production (Guillemin & Gillam 2004). As such, it is an active process that requires scrutiny, reflection, and interrogation of myself as researcher. Being reflexive requires one to accept that the researcher is a central figure who actively constructs the collection, analysis, and interpretation of data. Holloway and Galvin (2017) point out by that adopting a self-critical stance to the research and one’s own role, relationships, and assumptions, the study will become more credible and dependable. In narrative research, reflexivity is
necessary to ensuring the quality of the study (Holloway & Freshwater 2007b). For this study to be considered trustworthy, I needed to uncover my interests and background and how these influenced the research strategies and procedures.

In order to practice reflexivity, I used a number of strategies. I undertook repeated interviews with each participant over a prolonged period of 12 months as recommended by Berger (2013). I discussed my study and my epistemological positioning with my peers and my supervisors. I reviewed my coded transcripts firstly at the initiation of data analysis and then a month after the original thematic analysis. In doing so, I was guided by Berger (2013) who pointed out that allowing some time to pass between initial and subsequent review of coded transcripts offers the opportunity to review the same material through a fresh lens, enabling the identification of biases, assumptions and preconceptions.

I also wrote what Butler-Kisber (2010) has called “identity memos”: these were reflexive diary entries that addressed the questions of who I am, the beliefs that I have that might influence the work, and how I account for my beliefs and assumptions during the study. I recorded these memos using a digital audio recorder and transcribed them. I also wrote reflexive field notes after each interview and added to these later as I read the transcripts. The structure and form of these field notes have been described in Section 4.4.3 of this chapter. I analysed and thematically coded these field notes in NVivo to organise and keep track of my thoughts, feelings, and interactions between the participants and me. I used them to track my experience of interviewing, my changing understanding of self-management, the impact of the research on the participants, my emotional reactions to the interviews, and the delicate balancing of relations of power in the research relationship. In doing this, I aimed to maintain an open and honest account of the reflexive interaction between the participants and me. These reflexive field notes helped me to keep track of my positioning and how I may have influenced the interviews (Butler-Kisber 2010, p. 75), and monitor other contextual or social dimensions that may have impacted on data collection. Because these reflexive field notes were written and expanded upon over time, they follow the development of my reflexive critical thinking.

I kept a decision diary that tracked the key methodological, theoretical, and methods decisions that I made over the course of the study. This was a personal space in which I worked out how to handle methodological and conceptual issues and dilemmas, as well as the changing conceptual and theoretical frameworks of the study (Lawler 2016). My decision diary also tracked my decision-making about
pragmatic and logistical aspects of the research, such as organising fieldwork, deciding to use the services of a professional transcriber, issues related to the General Data Protection Regulation (GDPR), use of resources and so on. During the analysis and interpretation of the data, I continued my reflexive practice. I kept an analytic diary in which I noted key decisions about my analysis and my personal reflections about the analysis.

Throughout this study, I felt that I was on an ongoing reflexive process, constantly asking questions of myself throughout. This involved considering my reasons for conducting the research, my role in the research, the needs of the participants and the importance of the relationships that were developed during fieldwork. As I progressed through fieldwork, the stories told by participants challenged my own preconceived ideas of the role of power in the self-management of COPD. I had to be aware of my own experiences of self-management and find a balance between projecting my own experiences and using them as a useful way of empathising with participants.

4.5.1.4 Confirmability

Confirmability is the final criterion in Lincoln and Guba's (1985) list of trustworthiness criteria. Confirmability allows the reader to assess how the findings and conclusions achieve their aim and are not the result of the researcher's prior assumptions and preconceptions. Confirmability requires a clear audit trail, thick description, reflexivity, peer review, and maintaining a record of the inquiry process. All of these I have undertaken and describe in the previous criteria set out above.

4.5.2 Specific requirements for quality in narrative inquiry

In this section, I discuss two issues that arise with specific regard to quality in narrative inquiry, that is, the nature of truth in narrative and the concept of verisimilitude.

4.5.2.1 Narrative inquiry and the nature of truth

One of the issues in narrative inquiry is that of the nature of “truth” in narratives. It is difficult to assert the veracity of narratives – is the truth being told, or is it the truth as the participants see it? All narratives contain inconsistencies and tensions (Holloway & Galvin 2017). However, in narrative inquiry undertaken from a social constructionist perspective, a narrative is not seen as simply a factual report of events, but instead as “one articulation told from a point of view that seeks to
persuade others to see the events in a similar way” (Riessman 2008, p. 187). As Squire et al (2014) point out, any two people experiencing the same phenomenon will provide different accounts of it. Neither account is false, but each account is and can only ever be partial. They point out that perspectives are always dependent and situated in particular contexts. Knowledge and truth are constructed, and necessarily incomplete. I believe that the narratives of participants are authentic, but necessarily incongruent with historical truth. As Holloway and Freshwater (2007b) assert, both historical and subjective truth are equally authentic. Both are versions of social reality. Indeed, from a Foucauldian perspective, narratives that diverge from established “truths” can indicate “silenced voices and subjugated knowledge” (Riessman 2008, p. 186). According to Foucault, truth cannot be separated from the mechanism of its production. Power produces both truth and knowledge (Tamboukou 2013). They are socially constructed according to the power relations at work behind them and through them. It is my job as a researcher to interrogate what has been accepted as the “truth” of self-management and present and interpret the competing narratives of participants in this study. Denzin (2000) argued that narratives do not establish the truth of experience, rather, they create the very events they reflect upon. When considering questions of validity in narrative research, historical truth is not the relevant issue. It is more important that narrative inquiry is deemed to be trustworthy (Lincoln & Guba 1985) than to reveal some sort of objective “truth” (Stokes 2015).

4.5.2.2 Verisimilitude

It is important for narrative inquiries to meet the criterion of verisimilitude. A study must “ring true,” it must be believable (Loh 2013). The readers of a narrative inquiry report should experience congruence with and recognition of the experiences of the participants (Blumenfeld-Jones 1995). The written report should carry with it a sense of authenticity (Cronin 2009). Verisimilitude is important because it allows others to experience vicariously the situations being portrayed and therefore to be able to “understand the decisions made and emotions felt by participants in the study” (Loh 2013, p. 10). Verisimilitude lends itself to coherence, explanatory power, meaningfulness and importance (Yang 2011). In order to achieve verisimilitude, I engaged in peer review and developed an audit trail (Yang 2011). I also used thick description, documenting the context, setting, my own and participants’ reactions to the interviews, and using illustrative quotes from the interviews in my findings. I strove for clear and expressive writing
enhanced by diagrams where needed. I aimed to stay close to participants’ everyday experiences and avoided misrepresenting them by overemphasising the unusual, graphic, or highly emotive (Cronin 2009).

4.6 Addressing ethical issues in this study

4.6.1 Cultivating an “ethical attitude”

All research conducted on human beings must meet the requirement to be ethical in its approach to and treatment of participants in the research. Obtaining formal ethical approval is a requirement for most research involving humans. Most formal Research Ethics Boards (REBs) base their codes of ethics on the principles of autonomy, beneficence, non-maleficence, and justice. Respect for autonomy relates to issues of voluntary participation, informed consent, confidentiality and anonymity. Beneficence concerns the responsibility to avoid harm to participants, and justice concerns the importance of the benefits and burdens of research being distributed equally (Wiles 2013). In order to ensure that I followed these principles and to comply with the requirements of Trinity College Dublin regarding ethical research, I applied for and received formal ethical approval from the School of Nursing and Midwifery Research Ethics Committee in June 2016 (the approval letter from the ethics committee is provided in Appendix 20 and approval of amendments is provided in Appendix 21). However, I soon realised that ethical considerations and challenges in narrative inquiry extend beyond the stipulations of REBs. I needed to view ethics as a process and way of thinking that permeates throughout the research.

Qualitative researchers and narrative scholars in particular (Smythe & Murray 2000, Josselson 2007) have argued that reliance on principilist codes of ethics alone is not sufficient to ensure ethical practice. A number of alternative holistic ethical frameworks have been proposed such as an ethics of care (Wiklund-Gustin 2010, Wiles 2013, Park et al. 2016), situated research ethics (Guillemin & Heggen 2012), or relational ethics (Clandinin 2016, Park et al. 2016). While these approaches differ slightly in emphasis, they share a focus on the local context in which research is conducted, a focus on everyday ethically significant moments that occur in the conduct of research, and an emphasis on the need for mindful and responsible research practice. Other aspects held in common across these alternative ethical frameworks is the emphasis placed on care and respect for the

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58 Principilist codes of ethics refers to those used by REBs based on the principles of autonomy, beneficence, non-maleficence and justice. They are also termed procedural ethics.
research relationship and the value placed on the concepts of non-judgementalism, compassion, and respect for experiences of suffering and vulnerability (Wiklund-Gustin 2010, Wiles 2013, Clandinin 2016). There is a shared recognition for the relationality and interdependency of the researcher and research participants (Wiles 2013, Clandinin 2016).

I therefore worked to bring together these common aspects to foster what Josselson (2007, p. 537) called an “ethical attitude” towards narrative research. This involved thinking through key ethical issues and deciding how best to honour and protect my participants, in advance of, during, and after fieldwork. At the same time I had to maintain standards for responsible scholarship (Josselson 2007, Park et al. 2016). In concrete terms, my ethical attitude consisted of tackling the following key ethical issues: Risk and harm, exploitation of participants, the research relationship, informed consent, voluntary participation, and privacy, anonymity and confidentiality. In practice, these issues were iterative and interconnected.

![Figure 4.17. Framework for the “ethical attitude” to the research](image)

Cross cutting all of these issues was the requirement for me to be present and attentive to the stories told to me, and also to help participants to convey their
stories without fear of being rejected. I needed to be able to respond flexibly and supportively to ethical issues as they arose during fieldwork (Park et al. 2016).

4.6.2 Risk and harm in narrative inquiry

Narrative research carries with it some specific risks to participants. They may become emotionally distressed while recounting intimate and sensitive details of their lives (Smythe & Murray 2000, Josselson 2007, Wiles 2013). This was particularly relevant in this study, where participants were talking about emotive issues related to chronic illness (Smythe & Murray 2000). As such, I regarded the participants in my study to be a vulnerable population. I was therefore mindful of the potential for participants to become distressed. I had to make my role as a researcher clear and distinct from a more therapeutic or interventionist role (Cronin 2009). At the same time, I needed to respond in a supportive, non-judgemental and empathetic way to the emotions expressed by participants in the interviews. I therefore put in place strategies to manage participant distress and discomfort during fieldwork. I watched out for signs of distress and discomfort on the part of participants during the interviews. If an individual became distressed, I checked to see if he or she wanted me to suspend or terminate the interview. I also made it clear that participants could decline to answer any questions I asked or to discuss specific issues. I had also arranged with the COPD patient support organisation I worked with during recruitment to refer to them participants who asked for further support. Two participants became distressed during the fieldwork. In one case the individual did not wish to stop the interview, nor wished to be referred to the support organisation. In another case I suspended the interview because the participant became distressed about issues unrelated to COPD. This person was already in contact with local mental health services. In most cases, participants expressed emotion but were not unduly distressed during the interviews. However, at all times I made sure that I remained calm, continued to listen, and contained the emotional experience being recounted (Josselson 2007). Indeed, while it was not possible to totally avoid emotional distress during the interviews, participants’ expression of emotion was an indicator that they were comfortable enough with me to “relax [their] controls and defences” (Josselson 2007, p. 543).

A second risk to participants in this study was the strain of undertaking interviews when they were unwell. I was aware that participants might feel obliged to be interviewed having already agreed to participate even if their health was poor (Cronin 2009). To mitigate this risk, I gave participants the opportunity to withdraw, reschedule, or cut interviews short. This was done both at the time of scheduling
the interview and a week in advance of the interview. During interviews, I watched out for signs of fatigue or breathlessness, and encouraged participants to tell me if they needed to pause or stop. I worked at participants' own pace and checked with them whether they needed to take a break.

Another risk that needed to be addressed related to the publication and dissemination of the research once the interviews are completed and analysed. Even though identities are anonymised, participants and others may still recognise themselves and be unhappy with how they are portrayed in research reports (Wiles 2013, p. 59). Participants might make themselves vulnerable in their narratives. I therefore took precautions to protect the reputations of both participants and characters in their stories. Having one’s personal and intimate story reinterpreted and represented according to a social scientific theoretical perspective can be upsetting for participants (Smythe & Murray 2000). As a researcher using narrative inquiry, I face a deep-rooted conflict between acting as a confidant to participants on the one hand, and then writing and publishing my own interpretations of their stories on the other (Smythe & Murray 2000). I made sure that I treated participants’ narratives with the utmost respect and dignity, while still acknowledging my duty to the scholarly community and my ownership of the interpretation of the narratives.

4.6.3 Exploitation of participants in narrative inquiry

Exploitation is another ethical dilemma in narrative inquiry. I was concerned that my participants may feel disregarded, used, or devalued as a result of taking part in the study, after I had finished data collection, especially because I conducted multiple interviews with each person (Wiles 2013). I encouraged participants to provide their personal and sometimes painful stories, but it was I who was the main beneficiary, through reporting on and having the potential to publish the analysis of their narratives.

In order to address these issues, I had to constantly reconcile the benefits to participants of telling their stories with the benefits to me of pursuing my own research agenda. While there was no direct benefit for participants, it is possible that they benefited indirectly by reflecting on their self-management practices, bringing these practices into focus in the context of their everyday lives, which could help them when making self-management decisions in the future. It also became evident during fieldwork that many of the participants had not had the opportunity to speak openly and frankly about their experience of living with and
managing COPD before. They benefited indirectly from my interest in listening to their stories and, through this, they had the chance to consider issues that they had not talked about before. In order to reduce the risk of losing contact with participants after data collection and leaving them feeling used or exploited, I prepared a Plain English summary of the key findings of my study and sent this to participants after completing the write-up of the study.

4.6.4 The research relationship

From the beginning of this study, I have had to contend with balancing my scholarly responsibility as a researcher (Josselson 2007) with respecting the unique nature of the relationship I built with each participant, especially as I interviewed most of the participants at least twice and some three times. In narrative inquiry, the creation of a research relationship is at the heart of fieldwork (Frank 2002, Park et al. 2016). However, Shaw (2008, p. 408) pointed out that ethical issues are raised by the fact that as we encourage people to tell their stories, we become characters in those stories, and therefore change those stories. A complex relationship develops between the biography of the participant and the autobiography of the researcher, and ethical dilemmas can arise out of this – dilemmas to do with balancing the researcher’s need to obtain in-depth narratives against the emotional impact on participants of telling those stories.

I had to be cognisant of the fine ethical balance between building trust between the participants and me, and maintaining sufficient distance to preserve respect for the person. I was mindful of the danger of unwittingly coercing participants into disclosing aspects of their private lives that they might regret later. I had to make sure that participants were sharing their stories willingly and freely, without coercion or manipulation on my part. To achieve this, I was very careful to build rapport based on the values set out by Josselson (2007) of empathy, non-judgementalism, concern, tolerance and emotional responsiveness, while at the same time maintaining clarity about my role as a researcher. Following Josselson’s (2007) recommendation, I approached this explicitly through the information sheet (which I read through at the beginning of each interview) and the informed consent form, and implicitly through approaching each interview from a “human, genuine, empathic and respectful stance” (Josselson 2007, p. 539).

Despite these steps, I was aware that there was always the potential for participants to make private disclosures during interviews as a result of building rapport. Some participants did disclose some very personal issues. I dealt with
this by remaining calm and empathetic, while at the same time making my role as a researcher clear. I offered to provide transcripts of the interviews to these participants to allow them the opportunity to edit the transcript. In these cases I made sure to transcribe the interviews myself rather than use the professional transcriber.

I was acutely aware that the participants in my study were being asked to tell stories about sensitive aspects of their lives, about events that were frightening and/or life changing. As such, I felt that participants would rightly be “exquisitely attuned” to my emotional response (Josselson 2007, p. 546). This meant that I had to be comfortable dealing with complex and often painful emotions. Holloway and Jefferson (2000) have argued that an accepting and sympathetic response to participants’ disclosures may lead to participants finding their experiences less disconcerting or worrisome. I also shared some of my own experiences with participants, in order to encourage a sense of collaboration and to build rapport (Josselson 2007). I judged this carefully, however, to avoid over-sharing and thus embarrassing the participants or derailing their own narratives.

4.6.5 Information and informed consent

Participants in research studies have the right to full and accurate information about the study and what taking part entails. I strove throughout the fieldwork and beyond to give the best information possible and tried to anticipate the risks arising from participating in the research and flag these with participants.

4.6.5.1 Providing information

I treated the provision of information to participants as an ongoing process that started at recruitment and continued throughout the study. I developed a written information sheet which was distributed to all potential participants in recruitment packs. It included information about the aim of the study, what taking part involved, my role as the researcher, the risks and benefits of taking part, the arrangements in place for protecting privacy, confidentiality, and anonymity, and participants’ rights to voluntary participation and withdrawal. This information sheet was designed in line with the guidelines of the School of Nursing and Midwifery Research Ethics Committee and I strove for clarity and conciseness in presenting accessible information that was easy to read. I followed up on this information sheet when contacting individuals who had returned reply slips indicating their interest in taking part in the study. At this point I went through the details of the information about the study and encouraged participants to ask questions and
clarify anything about which they were not sure. This process was repeated when I called to confirm interviews a week before they were scheduled. Finally, I dedicated time at the beginning of each interview to going through the information and answering questions. This was important to determine each participant’s comprehension of the study and to build trust between us. Some participants wished a close family member to join them in one or more of the interviews. In these cases the participants were partly responsible for informing their family member about the research, but I supplemented this by developing a written information sheet for family members and going through the information directly with them at the beginning of each interview. In addition to these procedures, I provided participants with my contact number and encouraged them to contact me any time they wished to ask questions or clarify issues.

4.6.5.2 Process consent

By engaging in this comprehensive approach to information provision, I hoped to facilitate participants’ ability to give informed consent to taking part in the study. However, Wiles (2013) has asserted that it is very difficult to ensure that participants fully understand the implications of taking part in a narrative research study and what, in concrete terms, they are consenting to. This is due to the unstructured, fluid, and dynamic nature of narrative interviews. One way of attempting to address this problem is by using “process consent” (Smythe & Murray 2000, Wiles 2013). In process consent, consent is obtained from participants for each phase of data collection. It is thus particularly suited to research that entails repeated stages of data collection. Consent is viewed as an ongoing process rather than as a one-off *a priori* event. In process consent, consent should be mutually negotiated throughout data collection, as part of the research relationship (Smythe & Murray 2000).

In my approach to process consent, I devised an informed consent form for use in both initial and subsequent interviews. Two copies were signed by participants (both primary participants and family members) and me. This was done at the start of each interview carried out with participants. I retained one copy as documented evidence of informed consent, and participants retained the other. In addition to this I took an ongoing approach to consent, by giving information and checking for verbal consent when confirming scheduled interviews and at the beginning of each interview. I made sure that each participant was aware that they could withdraw their consent at any time up to the completion of data analysis. At all stages of the consent process, I encouraged participants to ask questions and
discuss concerns with me. More generally, I tried to situate the process of obtaining informed consent in the context of an empathetic, open, and genuine approach to the people I was talking to.

4.6.6 Voluntary participation

Participants in research have the right to voluntary participation. This means they should not feel pressured or coerced to take part, and that they have the right to withdraw from the study at any time without penalty. It was therefore incumbent upon me to provide participants with sufficient information to allow them to make a fully informed and free decision about taking part. I set out the right to voluntary participation and withdrawal from the study in the information sheet and reiterated this verbally when in phone contact with participants and at the beginning of interviews. However I was aware of the risk that participants may have felt some pressure from the Chairpersons of their local COPD support groups when they were distributing recruitment packs to group members. I tried to counter this by assuring participants that I would not disclose their decision to participate to Chairpersons or other members. However, I became aware that participants themselves had disclosed their participation to other members of the groups including Chairpersons. While this was beyond my control, it meant that I had to place great emphasis on the voluntary nature of participation and the right to withdraw without reason or penalty.

I also had to ensure that participants did not feel coerced into taking part in subsequent interviews after the initial interview. When I was following up, I made sure to emphasise that further participation was entirely voluntary. Where I could not make contact initially, I tried for a further two times before stopping to make sure that I struck the right balance between giving participants the opportunity to follow up and avoiding pressuring them to continue. In the end, four participants could not be contacted for follow-up interviews.

4.6.7 Privacy and confidentiality

The protection of the privacy and confidentiality of participants and the characters that appear in their stories are central concerns in this study, due partly to the fact that all participants were members of a patient support organisation, and partly to my choice of narrative inquiry as my methodology. Wiles (2013, p. 47) warned that participants who are members of a group may well be able to take an educated guess at people’s identities within a qualitative research report. She recommended that if one is undertaking research with networks of individuals,
“great care needs to be taken to ensure that confidentiality is maintained and that sensitive material is managed in ways that do not jeopardise individuals’ well-being and their relationship with others” (Wiles 2013, p. 48).

In order to ensure confidentiality of participants at the time of recruitment, I enclosed reply slips in the recruitment packs distributed to participants that they could return directly to me without going through a gatekeeper. However, as discussed in Section 4.6.6, some participants had informed other members of their local COPD support group that they had agreed take part in the study. This made it extremely important that I remove any potential identifying information from transcripts and the written report.

I therefore undertook a range of measures to protect the confidentiality of participants. I applied ID numbers to each participant, and pseudonyms were later applied to all participants in the study. I removed the names of organisations, locations, and other settings used in the thesis. Names of health care professionals, experts, family and friends were removed except in the case of family members who participated in interviews – these were assigned a pseudonym. In addition, any additional information that could identify a person, such as unusual personal circumstances or characteristics, was removed.

Personal identities in hard copy form such as reply slips and consent forms were stored in a locked filing cabinet in the School of Nursing and Midwifery. Only I had access to these. Personal identities held in electronic form were held on a password-protected computer in an encrypted folder. All computerised information collected was held in an encrypted folder on a password-protected computer. All data were stored in accordance with the stipulations of the General Data Protection Regulation 2018 and the Health Research Regulations 2018.

However, I realised that I would have to take extra measures to account for the specific risks to anonymity and confidentiality posed by narrative inquiry. Specifically, I offered participants the opportunity to read the transcripts of their interviews. Five participants asked for transcripts of their interviews, but none made any amendments to these. I also obtained specific consent for taking photographs of artefacts shown to me by participants. These photographs were edited to remove identifying information. Permission was sought to include photographs in the thesis and related publications. Information that could reveal the identities of participants and people identified in their stories was excluded from
published material. Throughout the writing of this thesis, I have taken great care to avoid including so much detail that a participant could be recognised.

4.7 Conclusion

This chapter presented the methods I used to conduct this study, derived from my narrative methodology and my Foucauldian theoretical framework. I started by outlining the research question, aim and objectives. I then presented my approach to sampling, access, and recruitment. I went on to discuss my approach to data collection and data analysis. In this way I set out the path I took to come to the narrative of how people with COPD exercise power in the self-management of their illness. I also described the criteria I used to establish the quality of the study and my rationale for selecting this approach. Finally, I set out the ethical framework I used in the study. The next chapter presents the findings of the data analysis which map the exercise of power in self-management in participants’ accounts. The presentation of findings is structured according to my Foucauldian conceptual framework of power, knowledge and agency, and concludes with the presentation of an overarching narrative of how participants exercise power in the self-management of COPD.
5 Presentation of findings

5.1 Introduction

This chapter presents the findings of the analysis of the participants' interviews according to the three overarching and interrelated concepts of power, knowledge and agency. The aim is to identify how participants exercise power in COPD self-management. I begin with a profile of the participants in my study including key demographic information. Following this, I present the findings from the analysis of participants’ interviews according to my Foucauldian conceptual framework based on the key interrelated concepts of power, knowledge and agency that were identified in the data analysis. In this study, ‘power’ refers to the exercise of power on participants by others. ‘Agency’ refers to the exercise of power by participants. The final coding template produced in the data analysis (see Section 4.4.6 of Chapter 4) forms the basis for this conceptual framework and structures the presentation of findings in this chapter. Figure 5.1 presents the relationship between these concepts in my conceptual framework.

![Figure 5.1: Conceptual framework for data analysis](image)

Section 5.2 of this chapter presents the results of the demographic data I collected from each participant in this study. The aim of this is to build a profile of the participants in the study. Data on the number of interviews conducted with each participant, whether they were accompanied during the interview, their gender, age, living arrangements, self-rated COPD severity, their COPD Assessment Test
(CAT) impact level\textsuperscript{59}, comorbidities, clinical treatments received for COPD, and help received for personal and practical care are presented in this section.

Section 5.3 presents participants’ accounts of how power was exercised on their self-management practice. I present findings related to two forms of power identified in participants’ interviews: pastoral power and responsibilisation. Pastoral power refers to the extension of surveillance and discipline into the private and intimate spheres of an individual’s life. Responsibilisation refers to a process of shifting responsibility for the management of COPD from health care professionals to people with COPD. I set out findings which demonstrate the extension of scrutiny and discipline into participants’ private lives. I also provide participants’ accounts that demonstrate how they were expected to take on the responsibility for managing their illness.

Section 5.4 sets out the different types of knowledge identified in participants’ accounts. In this section, I present findings that illustrate how knowledge could either be imposed upon participants, or appropriated and used by them to inform their own self-management practice. I present two forms of knowledge identified in participants’ accounts. The first form of knowledge is dominant medicocentric knowledge of the biomedical aspects of COPD self-management. The second form of knowledge is subjugated knowledge, that is, local knowledge arising from people with COPD. Subjugated knowledge identified in participants’ accounts consisted of embodied knowledge of the body’s reactions to COPD and its treatment and knowledge of alternative treatments and therapies for COPD beyond the remit of biomedicine.

Section 5.5 presents participants’ accounts of how they engaged in reflexive practices of self-management and how they exercised agency while at the same time undergoing the exercise of power on them by health care professionals and other experts. I set out how participants engaged in practices designed to transform themselves in order to attain the goal of wellbeing and health as well as to correct and perfect the self as a “good” self-manager. These practices are known as technologies of the self. I identify five different types of technologies of

\textsuperscript{59} The CAT impact level is an indicator of the impact of COPD on participants’ lives. It is derived from individual CAT scores. A score of 5 or less refers to normal functioning for health non-smokers. A score greater than 5 but less than 10 refers to low impact of COPD. A score of 10 to 20 indicates medium impact of COPD on the functioning of participants. A score of greater than 20 indicates high impact, and a score of greater than 30 indicates very high impact. See the COPD Assessment Test Health Professional User Guide:
the self in participants’ accounts: 1) introspection and self-reflection; 2) nurturing well-being and happiness; 3) abstinence and restriction; 4) exercise; and 5) routine.

In Section 5.6 I draw together the themes and sub-themes identified through my detailed analysis of participants’ accounts in order to present a final narrative of how people with COPD exercise power as agency in their practice of self-management. I discuss how people with COPD exercise agency through resistance to the imposition of power by others through appropriating and mobilising different forms of knowledge, as well as through engaging in self-management “technologies of the self”. I demonstrate the interrelationship between power, knowledge, and agency in narratives of COPD self-management. Finally, I discuss how these interrelated themes represent how participants exercise agency as a process of constant negotiation of the shifting boundary between power and agency in order to construct an individualised self-management heuristic designed to fit their everyday lives.

5.2 Profile of participants.

In total, 31 participants took part in the study. Table 5.1 sets out information on the number of interviews in which they took part, and whether they were accompanied or not during the interviews.

<table>
<thead>
<tr>
<th>Pseudonym of participant</th>
<th>Number of interviews conducted</th>
<th>Accompanied or not – if yes, pseudonym of person accompanying</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eoin</td>
<td>3</td>
<td>No</td>
</tr>
<tr>
<td>Aidan</td>
<td>3</td>
<td>Deirdre (his wife)</td>
</tr>
<tr>
<td>Eileen</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Declan</td>
<td>3</td>
<td>Fiona (his wife)</td>
</tr>
<tr>
<td>Cathal</td>
<td>1</td>
<td>No</td>
</tr>
<tr>
<td>Caitriona</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Betty</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Helen</td>
<td>3</td>
<td>Ina (her daughter)</td>
</tr>
<tr>
<td>George</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Kevin</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Eamon</td>
<td>2</td>
<td>Kathleen (his wife)</td>
</tr>
<tr>
<td>Gráinne</td>
<td>3</td>
<td>No</td>
</tr>
<tr>
<td>Jane</td>
<td>1</td>
<td>No</td>
</tr>
<tr>
<td>Aileen</td>
<td>2</td>
<td>No</td>
</tr>
</tbody>
</table>

Table 5.1: List of participants, number of interviews conducted, and whether participants were accompanied during interviews
<table>
<thead>
<tr>
<th>Pseudonym of participant</th>
<th>Number of interviews conducted</th>
<th>Accompanied or not – if yes, pseudonym of person accompanying</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liam</td>
<td>3</td>
<td>Maeve (his wife)</td>
</tr>
<tr>
<td>Finbarr</td>
<td>1</td>
<td>No</td>
</tr>
<tr>
<td>Jack</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Niamh</td>
<td>3</td>
<td>Mark (her husband)</td>
</tr>
<tr>
<td>Niall</td>
<td>1</td>
<td>No</td>
</tr>
<tr>
<td>Oisin</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Lisa</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Sally</td>
<td>3</td>
<td>No</td>
</tr>
<tr>
<td>Padraig</td>
<td>2</td>
<td>Patricia (his wife)</td>
</tr>
<tr>
<td>Rory</td>
<td>3</td>
<td>No</td>
</tr>
<tr>
<td>Steven</td>
<td>1</td>
<td>No</td>
</tr>
<tr>
<td>Terry</td>
<td>3</td>
<td>Róisín (his wife)</td>
</tr>
<tr>
<td>Ultan</td>
<td>3</td>
<td>No</td>
</tr>
<tr>
<td>Sinéad</td>
<td>2</td>
<td>Tracey (her daughter)</td>
</tr>
<tr>
<td>Alva</td>
<td>3</td>
<td>No</td>
</tr>
<tr>
<td>Bronagh</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Kate</td>
<td>3</td>
<td>Alan (her husband)</td>
</tr>
</tbody>
</table>

**Table 5.1: List of participants, number of interviews conducted, and whether participants were accompanied during interviews (continued)**

Five participants took part in one interview only, for which there were a number of reasons. One person cited family illness as preventing him from taking part in further interviews. Two participants fell ill themselves, and two participants were uncontactable at the time of scheduling second interviews. Thirteen participants took part in two interviews, and a further thirteen took part in three interviews. The decision to schedule the third interview was based on preliminary analysis of the first two interviews to determine whether an additional interview was necessary to complete their narratives of self-management. Ten participants were accompanied by a family member in one or more of their interviews. Eight of these were accompanied by their spouse and two were accompanied by their daughter. Eight people (26%) said they lived alone and 23 people (74%) said they lived with someone else. Seventeen (55%) participants were male and fourteen (45%) were female. \(^60\)

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\(^60\) Percentages have been rounded to the nearest whole number
The average age of participants was 69 years. The most frequent age groups represented in the sample were 61-65 years (20%), 66-70 years (26%) and 71-75 years (32%). However, the youngest participant in the study was Steven who was 48 years old. The oldest participant was Ultan who was 85 years old. Three participants were aged between 81 and 85 years.

Participants were asked to rate the severity of their COPD according to a four-point scale ranging from mild, moderate, severe, to very severe. Most people rated their COPD as moderate (12 participants, 39%). Nine people (29%) rated their COPD as mild, eight (26%) as severe, and two people (6%) rated their COPD as very severe. No participants were smoking at the time of the interviews.
Participants were administered the CAT test to assess the functional impact of COPD on them. Most participants were assessed as having medium (17 participants, 55%) or high (11 participants, 36%) impact COPD. The descriptions of the different impact levels of COPD according to CAT scores are presented in Table 5.2 below.

<table>
<thead>
<tr>
<th>CAT Score</th>
<th>Impact Level</th>
<th>Clinical description of impact level</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 or less</td>
<td>Upper limit of normal for healthy non-smokers</td>
<td>n/a</td>
</tr>
</tbody>
</table>

**Table 5.2: Clinical description of CAT Impact levels**

---

**Figure 5.3: COPD Assessment Test (CAT) Impact level**

![Pie chart showing CAT impact levels]

<table>
<thead>
<tr>
<th>CAT impact level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low impact</td>
</tr>
<tr>
<td>Medium impact</td>
</tr>
<tr>
<td>High impact</td>
</tr>
<tr>
<td>Very high impact</td>
</tr>
</tbody>
</table>

---

<table>
<thead>
<tr>
<th>CAT Score</th>
<th>Impact Level</th>
<th>Clinical description of impact level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 10</td>
<td>Low</td>
<td>Most days are good, but COPD causes a few problems and stops people doing one or two things that they would like to do. They usually cough several days a week and get breathless when playing sports and games and when carrying heavy loads. They have to slow down or stop when walking up hills or if they hurry when walking on level ground. They get exhausted easily.</td>
</tr>
<tr>
<td>10-20</td>
<td>Medium</td>
<td>COPD is one of the most important problems that they have. They have a few good days a week, but cough up sputum on most days and have one or two exacerbations a year. They are breathless on most days and usually wake up with chest tightness or wheeze. They get breathless on bending over and can only walk up a flight of stairs slowly. They either do their housework slowly or have to stop for rests.</td>
</tr>
<tr>
<td>Greater than 20</td>
<td>High</td>
<td>COPD stops them doing most things that they want to do. They are breathless walking around the home and when getting washed or dressed. They may be breathless when they talk. Their cough makes them tired and their chest symptoms disturb their sleep on most nights. They feel that exercise is not safe for them and everything they do seems too much effort. They are afraid and panic and do not feel in control of their chest problem.</td>
</tr>
</tbody>
</table>

*Table 5.2: Clinical description of CAT Impact levels (continued)*
<table>
<thead>
<tr>
<th>CAT Score</th>
<th>Impact Level</th>
<th>Clinical description of impact level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greater than 30</td>
<td>Very high</td>
<td>Their condition stops them doing everything they want to do and they never have any good days. If they can manage to take a bath or shower, it takes them a long time. They cannot go out of the house for shopping or recreation, or do their housework. Often, they cannot go far from their bed or chair. They feel as if they have become an invalid.</td>
</tr>
</tbody>
</table>

Table 5.2: Clinical description of CAT Impact levels (continued)

The majority of participants (n=26, 84%) had other illnesses along with COPD. A very wide range of comorbidities were identified, with many participants reporting two or more comorbidities. The most commonly identified health problems coexisting with COPD were high blood pressure (identified by 7 participants), cancer in remission (5 participants), osteoarthritis (5 participants), mental health difficulties (5 participants), gastro-oesophageal reflux disease (GORD) (4 participants), hiatus hernia (3 participants), kidney disease (3 participants), atrial fibrillation (3 participants), diabetes (3 participants) and heart disease (3 participants).

Figure 5.4: Clinical treatments received for COPD (%)
Figure 5.4 sets out the different treatments received for COPD by participants\textsuperscript{62}. The most common treatment identified by participants was inhaled medication (n=30, 97\%) – this included steroid inhalers and inhaled bronchodilators. Twenty-five participants (81\%) had attended pulmonary rehabilitation (PR). Only two people (6\%) reported receiving oral bronchodilators, but it is possible that other participants were taking them without knowing what the medication was for.

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{Figure5_5.png}
\caption{Sources of help for personal/practical care}
\end{figure}

Sixteen participants (52\%) said they received help with personal or practical care. Of these, eight people (50\%) said they received help from their spouse or partner. Another eight said they received care from their family or friends. Five people (31\%) said they received help from paid carers\textsuperscript{63}. None of the participants worked in paid employment.

\textsuperscript{62} Participants could select more than one option therefore percentages add up to more than 100
\textsuperscript{63} Participants could select more than one option therefore percentages add up to more than 100
5.3 Power

5.3.1 Introduction to power

This section presents participants’ accounts of power as exercised on them by health care professionals and other experts and family members, which shaped and constrained their self-management practice. Using the Foucauldian perspective on power adopted in this study, I identified two main manifestations of power in participants’ accounts of self-management. First, the extension of surveillance and discipline into their private lives: a process known as “pastoral power”. This form of power is an extension of Foucault’s concept of “disciplinary power” and is often exercised via organisations and “pastors” (in the case of self-management, this can mean specialists, experts, health care professionals, and family members) that exist to care for and support individuals in order to exercise a redemptive role in their lives (English 2004). The aim is to encourage and support individuals to care for themselves (Waring & Latif 2018). The second manifestation of power is the transfer of responsibility for managing COPD from health care professionals to participants: a process known as “responsibilisation”. Responsibilisation entails individuals being made responsible for a task which would once have been the duty of another, such as a State agency or professional (Raitakari et al. 2019, p. 266). In responsibilisation, individuals are expected to be willing and able to take responsibility for their own well-being. However this should be done in accordance with the expectations and standards of experts and professionals. In this way, responsibilisation is a technique of power (Lemke 2001).
Section 5.3.2 presents the findings of participants’ accounts of the exercise of pastoral power by health care professionals and family members over them. In this section, I present participants’ accounts of how their everyday lifestyles and activities have become subject to scrutiny and discipline. Section 5.3.3 sets out participants’ accounts of how they are expected and willing to be responsible for the management of their illness.

### 5.3.2 Surveillance and discipline of participants’ lives: pastoral power

According to the participants in this study, pastoral power encompassed accounts of surveillance and discipline being exercised over their everyday lives,
behaviours, and leisure activities. Aspects of participants’ lifestyles that fell under scrutiny and discipline included a strong focus on weight and eating and drinking habits. Such issues appeared to be related to an ideal of “good” self-management in participants’ accounts. Participants reported being asked about their eating and drinking habits and their weight by health professionals and family members. Eileen gave an account of the scrutiny and interrogation of her weight by her specialist.

You have to manage it you know… and I put on a few pounds. Anyway, that’s the first thing that specialist I go to, he said, “How are you?” and then I’ll say how I am, He said, “Well, did you lose any weight?”

[Eileen interview 2]

Terry spoke of the surveillance exercised by others (health care professionals and family members) over his consumption of alcohol. He expressed frustration at this surveillance and attempts to discipline him, describing COPD as a “horrible disease,” restricting his autonomy.

And now [pause] they are at me to stop drinking…It’s not easy [pause] like it’s a horrible disease you know [pause]. It’s a horrible thing to have [pause]. You know [pause] you just can’t do what you want to. I’m watched like a hawk here, Róisín [his wife] watches me like a hawk, you get so much [alcohol] and that’s it, you know?

[Terry interview 1]

Other participants gave accounts that illustrated the exercise of surveillance and discipline that impinged on their leisure activities. Aidan spoke of how he was no longer “allowed” to fly, restricting his ability to take holidays abroad. This was a source of frustration for him.

The only thing is [pause] the thing that I miss most is holidays…I can’t go! I’m not allowed!…I can’t fly any more, and I used to love going to Lanzarote, now, and Deirdre [his wife] now she’s going to a wedding in October in Portugal, my nephew is getting married, I can’t go!

[Aidan interview 1]

Eamon gave an account of his GP’s scrutiny of his attending sports games in his local stadium. His GP advised him to stop attending in order to avoid developing an infection. He had accepted this advice and adapted his behaviour accordingly.
One thing I was doing, and I stopped it, and I missed it, but I just won’t do it again, is…I’m a season ticket holder for [sport]…because again, [my GP] said, “You’re sitting up in the stand, Friday night, frozen.”

[Eamon interview 2]

In a few cases, participants described the scrutiny exercised by family carers on attending doctors or support services. This scrutiny was benevolent in its intention, borne out of love and care and anxiety for the person with COPD. However, it could still be a source of tension between people with COPD and their loved ones. For example, Helen’s daughter, Ina talked about monitoring her mother, taking a “tough love” approach, telling her mother when she should go to the doctor, and monitoring her for signs that she was unwell. Ina said she did this because in the past she felt her mother might have denied the severity of her illness. Ina had struggled to find the balance between intervening in her mother’s life and stepping back and letting her mother make her own decisions.

In the past, like, I think she’d [Helen] maybe tried to suppress it, or there’s have been a little bit of denial, or she wouldn’t want to let me down, but I think we’re better now and kind of saying, “Mum is that, does that sound like it’s going in the wrong direction? Do you feel like you need to take action?” And she’d say, “Leave it a day,” and then I’ll get on her case the following day and say “Well are you going, did you go, will I drive you over?” and invariably she drives herself over, And then, I suppose then kind of stepping back and giving her the space to do what she needs to do.

[Ina interview 2]

On the other hand, Sinéad’s daughter Tracey had taken on a more paternalistic approach, adopting the role of scrutinising her mother’s everyday activities and lifestyle. Both Sinéad and Tracey described Tracey as motivating and pushing Sinéad to engage in her local COPD support group, for example. She used language that constructed her mother as childlike and in need of encouragement and discipline in order to stay engaged with life’s activities.

Sinéad: Yeah, because there would be sometimes now, Tracey, wouldn’t there, and I would say about going to the [local COPD support group] [pause], “Ah Tracey, I don’t feel like going today.”
Tracey: She’s like a child at times [pause] you kind of literally have to dress her and put her out the door.

[Sinéad and Tracey interview 1]

For some participants, the effect of surveillance and discipline of their lives was to motivate them to regulate and govern themselves according to others’ expectations of what constitutes “good” self-management. This was particularly the case when it came to issues of diet and weight. Declan, for instance, described his achievements in improving his health as a result of self-discipline and self-governance over his diet.

COPD-wise, tremendously improved. And they were putting it all down to really the loss of weight and the change in lifestyle. That things have, d’you know, what I’ve done has helped my situation.

[Declan interview 2]

Similarly, Bronagh, over the course of her two interviews, told of her attainment of health through the practice of regulating and governing her diet and weight. Between her first and second interviews she had attended a weight loss organisation and succeeded in losing a significant amount of weight. She experienced a sense of achievement and pride in this regard and attributed her improvement of her COPD at least in part to this weight loss.

Absolutely marvellous. I went to [weight loss organisation], and I lost 16 and-a-half pounds.

[Bronagh interview 2]

However, other participants reacted to the scrutiny of their lifestyle with a certain degree of guilt and anxiety. These people described an ongoing struggle of self-discipline, a struggle to perfect the self as a “good” self-manager. Eileen, for example, blamed herself for putting on weight.

I put on a few pounds, well not a lot. But I have put on say five or six pounds. Yeah, but I know sure it’s my own fault, I’m probably eating too well.

[Eileen interview 2]

Niamh also held herself as culpable regarding what she saw as her less-than-optimal diet and weight. She described herself as eating “rubbish” as well as “good food.”
I do eat rubbish, but I eat good food too, you know. I eat the rubbish in between or at night-time. But [pause] I’m trying to give it up now for the dieting. Because everybody told me [pause] if I lost weight it would ease the pressure on my lungs….I should lose it too [weight], should I not be better?

[Niamh interview 1]

The issue of diet and weight loss was not only identified as a site for the exercise of pastoral power. It was also identified in participants’ accounts as a technology of the self, that is, a way of operating upon the self and the body in order to transform oneself to attain happiness and health. As such, it was identified in participants’ accounts as a site where agency and power co-exist and interact. Diet is therefore discussed in more detail as a practice of abstinence and restriction in Section 5.5.4 of this chapter.

5.3.3 Responsibilisation

Participants’ accounts of self-management contained examples of health care professionals’ expectations that their patients should take responsibility for the management of their illness. Some participants identified pulmonary rehabilitation (PR)\(^{64}\) as an arena in which the facilitators encouraged them to take responsibility for the management of their illness. Eamon, for example, told a story about his experience of PR in which the physiotherapists explicitly assigned responsibility for self-management to the attendees.

\(^{64}\) PR is defined as “an evidence-based multidisciplinary and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities. Integrated into the individualised treatment of the patient, pulmonary rehabilitation is designed to reduce symptoms, optimise functional status, increase participation and reduce health care costs through stabilising or reversing systemic manifestations of the disease. It includes strategies for lifelong management” (Nici et al. 2006). The core components of PR as set out in the Irish Pulmonary Rehabilitation Model of Care include assessment, exercise, education, and self-management support. It should be noted that the Irish Pulmonary Rehabilitation Model of Care stipulates that participants should be “motivated to participate and change lifestyle” as one of their inclusion criteria (National COPD Programme Working Group 2013).
I remember one of the physiotherapists, the last [PR] class we had with them, and she was particularly feisty and great, very encouraging, and she said, “Remember, when you walk out that door, it’s in your hands now and do not forget that.”

[Eamon interview 2]

GPs were also described as encouraging participants to take responsibility for the management of their COPD. Eamon also felt the onus for self-management placed upon him by his GP, who urged him to do as much as he could for himself before attending.

What [GP] said to me, “I can do it, but I don’t want to, it’s not right, to be giving you [antibiotics] and then giving you something else to back it up, eh, steroids…do as much of it as you can yourself.”

[Eamon interview 2]

Gráinne spoke of doctors increasingly handing responsibility to patients, while at the same time resisting being challenged or confronted by their patients.

Doctors have handed it back to the person, to their client, to look after themselves. Do you know, they are kind of handing it back to you. I know some of them don’t like being confronted…or challenged, you know, like the priest.

[Gráinne interview 3]

In their accounts of self-management, participants expressed the view that it was up to them to take responsibility for managing their illness. Oisín stressed the need to take responsibility for managing his illness, for the sake of his adult children. He did not want his children to end up responsible for him. Autonomy, self-governance, and a positive outlook were central to his account of self-management.

I’m a single parent, I don’t want any of those five kids to be responsible for me. In an unnecessary way, if you like…I don’t want them bogged down with my issues…all it’s about is keeping the positivities right, taking responsibility, doing the best you can, holding it back as long as you possibly can.

[Oisín interview 2]
For some participants, taking responsibility for self-management should be done in line with the expectations of their health care professionals. Declan, for example, viewed taking responsibility for self-management as compliance with the recommendations of his doctor. He attributed his improved COPD symptoms as due in part to his adherence to his prescribed treatment regimen.

Yeah and to take the medications, take 'em regularly, you know, do the things that you’re supposed to do, do the breathing exercises….If you, I dunno, maybe it’s because I’m sticking more religiously to everything now, after last year, maybe that’s what’s improved things, I dunno. I know what I have to take and, d’you know, very responsible about taking them every morning and night.

[Declan interview 3]

Participants also gave accounts of health care professionals' views of responsible self-management as compliance with their expectations and standards of “good” self-management. Aidan spoke of the importance his consultant placed on compliance with his expectations of what responsible self-management should look like.

And then if he [consultant] sees you’re doing things right, he’s more time for you…You know, if he says, “You do this,” and you’re doing it, he says to himself, “Right, that man’s listening to me now so I’ll have more time with him.”…’Cause I mean if he said to me, “Do this,” and I’m saying to myself, “I’m not doing that!” You know, he’d have no time for you.

[Aidan interview 3]

Lisa told a story of her consultant who clearly equated responsible self-management with compliance with her own expectations and standards and held Lisa up as an example of “good” self-management when she lost weight.

So I then….went on a diet. [Weight loss organisation]. Lost three stone, walked [loads]… and when she [consultant] saw me the next time, I was her model patient, she told her registrar, “This is my model patient, she’s after losing,” you know, “doing everything I told her.”

[Lisa interview 2]

Sinéad and her daughter Tracey gave an account of Sinéad's respiratory nurse as firmly and explicitly holding her patients responsible for self-managing their COPD, expecting them to govern themselves in line with her own expectations.
Tracey: She’s [respiratory nurse] straight to the point too, there’s no pussyfooting around…She would put a bullet under you as quick as you like, do you know.

Sinéad: If she thought, “Well this one is not getting out for her walking, this one is not doing anything,” she would let you know.

[Sinéad and Tracey interview 1]

In these accounts, health care professionals used the tools of pastoral power, surveillance and discipline, in order to responsibilise participants to make sure that they not only take responsibility for self-management but do so in accordance with health care professionals’ expectations.

The conflicting expectations of taking responsibility for self-management while at the same time being compliant with the expectations of health care professionals meant that the boundary between autonomy and compliance was blurred and indistinct in participants’ accounts of self-management. This gave rise to uncertainty on the part of participants about how to balance being responsible for one’s own self-management versus being compliant. Helen described herself as compliant with her health professionals, but at the same time she talked about self-medicating when she felt it was necessary.

I would be very compliant with health professionals, no problem there…My GP…said, "I'll give you the prescription for the steroids, but don't take them unless you need them."…then I said, “For feck’s sake, I’m going to take them,” I just feel sometimes, I’m over there, and he just thinks I want steroids, and I want anything but, but I want to breathe…more than I hate steroids, you know?

[Helen interview 2]

Helen was emphatic in her assertion of her right to make an independent decision to take steroids. But she also used the word “compliant” to describe her relationship with health professionals. She struggled to negotiate the boundary between responsible, autonomous self-management and compliance.

Uncertainty about this boundary emerged particularly when participants were deciding whether or not to use health services and attend health care professionals. When talking about attending health professionals, participants described a contradiction between the idea that they should be independent and autonomous, reducing their burden and reliance on health professionals, yet at the
same time they should attend health professionals promptly when their experiential knowledge of their bodies indicates that there is a need to. Steven expressed a concern about attending his GP too often or too early. He said that he often chooses to wait until an infection has taken hold because he does not want to waste his doctor’s time by attending too early. He was anxious that he should be a responsible, deserving patient who only uses his doctor’s time when absolutely necessary.

*When I go to the doctor I’m probably about a week and a half too late…Because it’s already there [pause] you would almost feel, if I’m going to the doctor, I want there to be something wrong. I don’t want to be going in with nothing wrong, you know. I don’t want to be going in and saying, eh, I think I’m getting an infection, you know. I would rather the infection be there, and not be wasting his time.*

[Steven interview 1]

In Betty’s case, this contradiction led to conflict with her respiratory consultant. She said she had tried to listen to health care professionals who had told her to present quickly for treatment if she felt ill, resulting in multiple admissions to hospital. However, she found that her respiratory consultant had different expectations of her and publicly confronted her about going to hospital too frequently. This conflict between Betty’s own understanding of responsible self-management and that of her respiratory consultant was very distressing.

*So…I had a bit of a falling out with my own consultant. He began to feel that I was going into the hospital just for the good of my health, that there was much sicker people in and out of hospital than me. But any time I’d ever had a chest infection, I always went to my GP first…I was actually in a public ward when he kind of just let, he just went for me, like, and he was with three or four different people. So talk about feeling vulnerable.*

[Betty interview 1]

The burden of responsibility was not perceived by participants as solely belonging to themselves. Some people looked to their family members to carry some of the responsibility for managing their COPD. Self-management was therefore seen as a joint enterprise, in which people with COPD and their family members shared the responsibility for managing the illness. Declan talked about the confidence he had in Fiona, his wife, who had been trained alongside him in the use of oxygen and how to check his oxygen saturation.
She knows how to operate the oxygen and about every three or four weeks we do a re-run of it...And every so often, we refresh things...about the oxygen, she’d be conscious of checking my oxygen levels maybe if I came back from a bit of a walk, to see what they were.

[Declan interview 1]

In Declan’s account, Fiona had shouldered some of the responsibility for management of his COPD. The process of responsibilisation had started when they were both trained in the use of supplementary oxygen, and as such, was in line with the expectations of the health care professionals who trained them.

In Aidan and Deirdre’s case, Aidan turned to his wife to take the necessary steps to help him when he felt he was deteriorating. Deirdre had taken on the role of the responsible manager of his illness. Indeed, Deirdre gave an account of Aidan’s respiratory consultant explicitly addressing her with the expectation that she would carry the responsibility for managing incipient exacerbations.

Aidan: I tell her [Deirdre] straightaway. She takes the steps then.

Deirdre: And then I get the antibiotics before it goes too far. Even when we went to see [consultant] now there a month ago, I said, “Just in case now he gets a bad one [chest infection], before he sees you again,” because sometimes he does...So he, what he did was he gave us a prescription...and he said, “Hit it hard,” he said, “If you feel he’s getting one.”

[Aidan and Deirdre interview 3]

Deirdre worked as a receptionist in her local GP practice and this may have contributed to her taking on some of the responsibility for managing of Aidan’s illness. It might also explain her focus on managing medication and liaising with health professionals. Similarly, Liam’s daughter was a nurse and had researched COPD in order to understand it better, so as to help her father manage it.

Well I suppose I was lucky, my eldest daughter is a nurse. And she had done a lot of research into COPD when I was diagnosed. You know that she was, you know, made sure that I was using my inhalers properly. And that I was cleaning my nebuliser properly and, you know, that everything was done right, like, which was a great advantage.

[Liam interview 1]
For both Aidan and Liam, responsibilisation of their family members was still done in line with the an ideal form of self-management as defined by health care professionals. They were both happy to hand over responsibility to their family members and trusted them to prioritise their best interests. Betty, on the other hand, talked about her daughter and how she had abdicated responsibility to her at a time when she was quite ill. However, this had lately become a source of tension between them. It had created a co-dependent relationship that Betty was fighting against in a quest to regain autonomy and independence.

But I’ve always had a very good relationship with my daughter but it’s kind of shot to bits at the minute…When I was really quite sick, she sort of took on the role of mother, and me to a certain degree too, I let her. And I wasn’t kind of strong enough to kind of say…I could make these decisions still by myself, but she always did try to baby me.

[Betty interview 1]

Some participants gave accounts in which they projected responsibilisation on to other people with COPD. They expressed annoyance and frustration when they perceived other people with COPD as not managing in line with their expectations of responsibility. Aidan became frustrated with another man who had COPD, who he described in terms that suggested irresponsibility and passivity on the part of the man.

When we were doing exercises, he got bad. Breathing got bad and I says to him, “Have you the oxygen?” “No,” he said. [I said], “Well I’ve mine in the car, do you want to use it?” And he said, “No, no.” He won’t put the oxygen in the car. Now mine never comes out of the car. And…we had a coffee morning and he got bad…his lips went blue. He had no oxygen…And one of the girls had the oxygen, and she said, “I’ll go out for it.”

[Aidan interview 1]

Aidan saw the behaviour of this man as impacting on others, resulting in someone else having to share their oxygen and support him. This was at odds with Aidan’s own expectations of responsibility, autonomy and compliance in self-management. Oisín had expectations of other people with COPD that they should take responsibility for making lifestyle changes that he viewed as central to “good” self-management. He was critical of other people with COPD who he felt would not
stop drinking or smoking. Similarly to Aidan, he was concerned that such people would have a detrimental impact on other people in their lives. He told a story about one man he knew who would not or could not stop smoking and drinking, emphasising his point by using strong language to describe the man as “ignorant,” and “selfish”.

“There’s this guy…he’s choking, and I said, “You need to quit them.” “I’m not giving them up,” he says, “They are the only comfort I have left...He said, “Oh, you know, choices are choices I think.”...But it’s an awful ignorant choice, like, because...smoking has an impact on others again as well, you know. He was one of these guys now, he couldn’t stop smoking or he couldn’t stop drinking, he was never going to. And so he had kind of accepted his situation if you like, and I remember remarking to myself like, “That's a bit selfish.”

[Oisin interview 1]

Kevin also expressed frustration with other people with COPD who did not engage in physical activity, which he viewed as an essential component of “good” self-management.

“They are sat inside their house, wasting away. And a very important thing for COPD, you must be active, you have to do exercise, otherwise...the whole system will...close down. And you try to tell that to people...“I can’t do it,” [they say]. I said, “You can sit in the chair and you can work your hands, you can work your legs...work your head...simple exercises.” But...they just sit in the chair and they just vegetate.

[Kevin interview 1]

These participants had not only negotiated and appropriated responsibilisation for themselves but had projected responsibilisation onto other people with COPD. They expressed frustration with them when they did not self-manage in a way that met with participants’ own expectations of “good” self-management - expectations which in turn were formed and moulded by medicocentric norms and standards.

5.3.4 Power in participants’ accounts of self-management: conclusion

This section presented the findings related to the two manifestations of power identified in the analysis: pastoral power and responsibilisation. In Section 5.3.2, I set out how self-management was described in participants’ accounts as a site
for the encroachment of surveillance and discipline into their private and intimate
lives. Pastoral power was manifested in participants’ reports of their interactions
with health care professionals, and in some cases, family members on how they
should conduct their everyday lives in order to achieve the desired goal of “good”
self-management. Participants’ accounts described health professionals and
family members to be at one and the same time promoting surveillance and
discipline and self-regulation and self-governance. Pastoral power was therefore
exercised both on participants through health professionals and family members
and by participants through self-management.

In Section 5.3.3, I presented participants’ accounts that demonstrated how
responsibility for the management of COPD is borne by them. However, taking
responsibility for the management of the illness was accompanied by expectations
of compliance on the part of health care professionals, who were reported as using
surveillance and discipline to ensure that participants met their expectations of
“good” self-management. Participants’ accounts told of their attempts to negotiate
the indistinct boundary between being autonomous and responsible for the
management of their illness, while at the same time complying with health care
professionals. Participants both appropriated and projected responsibilisation
onto other people with COPD. In this way the process of responsibilisation flowed
from health care professionals to participants, and through them to other people
with COPD.

5.4 Knowledge

5.4.1 Introduction to knowledge

This section of the findings presents participants’ accounts of the different forms
of knowledge which informed and underpinned their self-management practice.

According to Foucault, knowledge is intimately connected with relations of power.
“The exercise of power...creates knowledge and, conversely, knowledge
constantly induces effects of power” (Foucault 1980, p. 52). Knowledge is
manifested in relations of power via dominant, hegemonic knowledge that is
legitimated as being in some way “true.” Dominant knowledge maintains its power
through pushing other subjugated, disqualified, knowledge to the margins.

Medicocentric knowledge was identified as a form of dominant knowledge in
participants' accounts of self-management. “Medicocentric knowledge” is
knowledge of the biomedical aspects of COPD treatment and management.

Medicocentric knowledge is generally legitimated as having more validity and
scientific value than other forms of knowledge, and it is placed high on the hierarchy of knowledge of chronic illness self-management (Fox et al. 2005).

However, knowledge is also manifested in acts of resistance to the constraints of power. Resistance is one way that individuals can exercise their own agency against the constraints of power. One way that knowledge is mobilised in resistance is by local populations (such as ill people) appropriating dominant knowledge (such as medicocentric knowledge) to serve their own interests. Another way of using knowledge to resist power is via the re-emergence of subjugated knowledge. Subjugated knowledge refers to local, popular knowledge that has been disqualified as inadequate and naïve. It is located low down on the hierarchy (Foucault 1980). Two forms of subjugated knowledge were identified in participants’ accounts of self-management: embodied knowledge and alternative knowledge. Embodied knowledge refers to knowledge of the body’s reactions to the exigencies of COPD and its treatment. Alternative knowledge refers to participants’ accounts of knowledge of treatments and therapies for COPD that are not prescribed or endorsed by health care professionals.

Figure 5.7: The forms of knowledge identified in participants’ accounts
Embodied and alternative knowledge are often viewed by health care professionals as less valid than medicocentric knowledge, but participants placed significant importance on them in their self-management practice.

Section 5.4.2 presents the findings of participants' accounts of the role played by medicocentric knowledge in their self-management practice. In this section, I set out how dominant medicocentric knowledge was both transmitted to them by health professionals and at the same time actively appropriated by participants to inform their own self-management practice. Section 5.4.3 presents participants’ accounts of their mobilisation of subjugated knowledge in their self-management practice. Section 5.4.3.1 sets out how participants developed embodied knowledge by tuning into the signs, symptoms, and reactions of their bodies to COPD and its treatment. Section 5.4.3.2 presents participants’ accounts of how alternative knowledge is transmitted from peer-to-peer or via popular media beyond the remit of health care professionals. Section 5.4.4 sets out findings about how knowledge is democratised and disseminated between peers using these fora.

5.4.2 Dominant medicocentric knowledge

Participants’ narratives of self-management included accounts of receiving medicocentric knowledge from health care professionals. Sources of such knowledge identified by participants were pulmonary rehabilitation (PR), individual health care professionals (such as consultants, GPs, respiratory nurses, and dieticians), or in a few cases, family members who worked as health care professionals. PR was one important vehicle for the transmission of medicocentric knowledge to participants. Some participants found the amount of knowledge received to be extensive and sometimes overwhelming. Eileen, for example, described PR as an arena in which large amounts of knowledge were provided, to the extent that she found it hard to take in.

*It was a total and utter crash of education in a sense…I probably didn’t take in half of it.*

[Eileen interview 1]

In participants’ accounts, the aim of transmitting knowledge in PR was to educate participants in the “correct” way to self-manage their illness. This was based on an underlying assumption that people with COPD were not necessarily managing their illness in a way that matched the expectations of health care professionals.
and needed to be corrected. Eoin, for example, told of how PR encompassed advice on the correct way to manage medication.

*Every aspect of life, you’re told about your medication, the reason you’re taking them, and the importance of taking them, and the importance of taking them at a particular time in the day.*

[Eoin interview 1]

Betty spoke of how the facilitators of her PR programme aimed to educate and inform attendees in the right way to manage their lives with COPD with specific regard to managing steroid-induced hunger and attending health care professionals in a timely manner.

*If you were on a high dose of steroids…what to watch out for and to try not to give in to eating a bit more, or if you were, make sure that it’s just rice cakes or things that don’t have a huge amount of calories…*[Doctor] came in [to PR] once, and he was talking about recognising when you’re not feeling well and sometimes people put it off and put it off, and he said, “Sometimes as soon as you feel unwell, you get yourself to the doctor. Because putting it off and putting it off,” he said, “You’re going to be sicker for longer, or you might have to go to hospital.”*

[Betty interview 2]

In addition to PR, participants’ accounts of receiving knowledge from health professionals showed how they viewed professionals as holding legitimate medicocentric knowledge about clinical aspects of COPD. Participants tended to focus on the role health care professionals played in transmitting knowledge that targeted specific clinical issues that they believed were directly relevant to their self-management. Eamon, for instance, gave an account in which he attended an information meeting at which clinicians discussed the disadvantages of using a nebuliser for COPD. He focused on this because it was directly relevant to his self-management practice.

*I was using the nebuliser at the beginning. And I went to a couple of information meetings and the medical people there, both the consultant and the clinical nurse and the senior physiotherapist, all spoke against them [nebulisers] because there were infections in them.*

[Eamon interview 1]
He also discussed how his doctor provided him with targeted specific medical knowledge about the signs of an incipient infection in order to support him to engage in appropriate illness management.

*They [GPs] would say, “Watch the phlegm and note the colour of it. And if it gets dark a lot, you have an infection.”*

[Eamon interview 2]

Medication management was identified in participants’ accounts as an aspect of illness management in which health care professionals were seen as the holders of legitimate medicocentric knowledge to be transmitted to participants. Terry talked about how he used the resources of the clinical staff in the local hospital -to obtain knowledge about his medication.

*If I have a problem, I can just text them up there…should I take these two medicines together…and you get a text back.*

[Terry interview 1]

Sinéad told of how her respiratory nurse corrected her on the proper use of salbutamol65.

*I said to [respiratory] nurse one day, I took it [salbutamol] after walking, and she said, “Well, wouldn't it be wiser now to take it before you started walking.”*

[Sinéad interview 1]

Participants were not simply passive recipients of medicocentric knowledge. They actively engaged with such knowledge and used it to adapt their own self-management practice. For some participants this meant adapting their approach to medication in line with the medicocentric knowledge they had been given. Eamon, for example, had stopped using his nebuliser after attending the information meeting which cautioned against its use.

*So even though I did find it [nebuliser] good, and I still have it there, but I haven’t used it since that evening. There was a [consultant] from [hospital], and the other from the nursing side and they spoke against it.*

[Eamon interview 1]

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65 Salbutamol is a rescue inhaler treatment for the short-term improvement of COPD symptoms
Declan had incorporated the information he was given about appropriate eating habits and used this to adapt his self-management practice accordingly.

\[
And I feel that the loss in weight, when I lie down at night has improved the chest. Because this [indicates stomach] isn’t pushing up into me, and they were explaining that to me as well, in the hospital, the respiratory consultant, that everything pushes up, so the lungs are squeezed, and everything becomes more difficult.
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[Declan interview 1]

Medicocentric knowledge was not necessarily always disempowering or repressive. Aileen found the knowledge she gained about managing breathlessness in PR to be fundamentally important. It helped her to realise that it is possible and even recommended to keep up physical activity in the face of breathlessness. Therefore, she felt more confident about exercising and pushing through the barrier of breathlessness. The knowledge she gained about this was, for her, empowering and agentic.

\[
The pulmonary rehab, when I did that, taught me that exercise is something that you need to do for the conditions to keep the symptoms, to minimise them. And when you are in the throes of breathlessness or wheezing, and you think that you have to stop. But that’s when you have to keep going, not to give up. It really struck a chord. It's actually passing the barrier.
\]

[Aileen interview 1]

Niamh actively sought out such knowledge about potential new treatments for COPD by reading newspapers and talking to other people with COPD about their treatments. The aim was to inform herself and leverage the knowledge she gained to allow her to have direct input into decisions made with her GP about her treatment regimen.

\[
I watch the paper, I buy the [newspaper] every Tuesday. They do a health section in it, and it’s very good. And they let you know what’s coming on the market.
\]

[Niamh interview 1]

I could say going into the class, they’re all using different stuff, and I’d see something that sounded good and I’d come back and I’d say to [the GP], “You know one of the women was using this and it looks [good],” she’d say,
“Ok, we’ll get it for you.” If I hear an inhaler is good for me, I’ll ask the doctor to get it for me.

[Niamh interview 2]

Participants sometimes resisted and questioned the validity and accuracy of the medicocentric knowledge held by health professionals. Some participants had expectations that health care professionals should hold specific expertise and knowledge that the participants would not otherwise have access to: knowledge that was needed to inform their self-management. They expressed annoyance and frustration when these expectations were not met. Eamon questioned the knowledge of his respiratory consultant, especially given the fee he was charged for attending.

I went in [to the consultant]. The first thing was “Ok, that will be €120”. And every time that seemed to be the predominant thing. Then I would go into his room and he was more looking at the colour of my nails and little cosmetic stuff, I would have called it. So I lost confidence in him.

[Eamon interview 1]

Terry similarly felt annoyed and frustrated when he felt that his GP did not have the requisite knowledge regarding his medication regimen. He referred to the knowledge of his wife who worked as a nurse and who questioned his doctor’s prescription.

The last time I went to the doctor, oh he’s a waste of space. He put me on steroids again, two three times a day. And the wife said, “That’s not the way you get steroids at all.”

[Terry interview 1]

Some participants did not believe that their GPs were the appropriate locus of medicocentric knowledge about COPD and its treatment, locating this knowledge with other health care professionals. Niamh did not view her GP as holding sufficient knowledge of COPD, hence her search for knowledge about potential treatments that she brought to her GP.
Now some of the [people] in the [local COPD support group] have various [inhalers]. So when I go to my doctor, next time I am going to ask about them, because they seem to get better benefit than me. But then my doctor is just a GP, so she is going on what information she gets in.

[Niamh interview 1]

In Kate’s experience, pharmacists and nurses were sometimes more knowledgeable about COPD than doctors.

You go to the doctor and he says, “Well, take this one for a month and see how you go.” I just keep going back for repeat prescriptions and he hadn’t changed it and...the pharmacist is actually the best people of all, you can go to them and they show you how to use the inhalers. Well sometimes you don’t need the doctors, sometimes a nurse is all you need, I think sometimes they know more.

[Kate interview 3]

In other cases, participants spoke of developing expertise and knowledge of their medical management of COPD over time. Eoin had learned to recognise when he was developing an infection and self-medicated before attending his doctor. He also read and researched about COPD treatment to enhance his knowledge about the medical management of COPD.

When I find myself going down or getting an infection, I increase them [steroids] myself before I go to the doctor. I used to read up on it as well. I used to spend a lot of time reading, researching on the computer and all that. Proper sites and all, and that’s where I gained information and I always had a habit, when I get a medication, you read the labels, you read the inserts in the boxes as well, you know, the leaflets. I got into a habit of reading, so you knew the side effects.

[Eoin interview 3]

These participants reported that medicocentric knowledge lent them expertise and authority in the eyes of their health care professionals. They referred to earning the trust of their health care professionals by demonstrating that they were able to leverage medicocentric knowledge in a way that accorded with the expectations of professionals.
The respiratory nurse showed me how to use it [inhaler] and she said to me, “Look,” she said, “You know all about it, I don’t have to show you.”

[Aidan interview 2]

My GP gives me a prescription for a strong antibiotic. And I have that with me, he knows that I know when I’m in more serious trouble, and if he’s off over the weekend, he tells me, “You’ll feel it, you’ll know it.” And I do, and I know when I had to start it.

[Declan interview 1]

By developing and using their own medical knowledge of COPD management, these participants were able to exercise a degree of agency in the medical management of their illness. However, such agency was still bound and constrained by the expectations of health care professionals as to what constitutes appropriate self-management.

5.4.3 Subjugated knowledge of self-management

This section presents participants’ accounts of how they mobilised embodied and alternative knowledge in their self-management practice. These forms of knowledge are personal, embodied, local and popular, and are often viewed by health care professionals as holding less validity than medicocentric knowledge. As such, they represent a subjugated body of knowledge.

5.4.3.1 Embodied knowledge

Participants’ accounts revealed embodied knowledge to be personal and subjective. It came from within, as a result of the experience gained from living with COPD over time. Embodied knowledge was mobilised by participants to guide their self-management practice. Eoin spoke of the importance of knowing one’s own body and letting this knowledge guide one in developing a personal approach to self-management.

The way I look at it is, you know your own body. Each client knows their own body, and you have to go by that...You tune into that, you do what suits you.

[Eoin interview 3]

In participants’ accounts, embodied knowledge was used to inform their quest to find balance between pushing themselves to remain as active as possible while at the same time learning to acknowledge the limits placed upon them by COPD and
the need to pace themselves and rest when necessary. Liam described how
tuning into his body allowed him to stop pushing so hard against the limits of his
body. He found a balance between remaining as active as possible and accepting
his limits.

And the other thing I find important is not do overdo it. While you push the
boundaries, you have to know when to pull back as well. It’s knowing when
to stop. I was trying to make the body do three times more than it was able.
By taking stock and going back and doing what I was actually able to do,
rather than what I wanted to do, it just made all the difference.

[Liam interview 3]

According to participants, developing embodied knowledge was based upon
learning about the body: its signs, symptoms, and reactions to COPD and its
treatment. In Eoin’s case, he learned through experimentation and research about
what worked for him.

At the beginning you were just given instructions and you followed
instructions and you struggled, and you gasped but then you started
experimenting yourself, just accidentally, but then I used to read up on it as
well. Trial and error I discovered it.

[Eoin interview 3]

Helen learned through experience to interpret the signs and symptoms of her body
in order to tell whether or not she was developing an infection.

I’ve got quite a lot of phlegm, but I know it’s all upper respiratory, whereas
a few years ago I’d be saying, “Oh God, I’ve an infection”. I can be
coughing up stuff, but my chest still feels clear. So I’m not panicking now,
if I’m coughing something out of my throat that has been accumulating in
my sinuses, I can see the difference.

[Helen interview 3]

For Liam, learning was about the most fundamental aspect of life: learning how to
breathe. This had allowed him to stay as active as possible in his daily life.

And would you believe one of the simplest things that we had to learn to
do was to learn to breathe. Because when you suffer from COPD and you
do anything strenuous you get breathless. And you are inclined to [pant],
which is the worst thing you could be doing. And what I have actually
learned to do is, when I get short of breath, I just force myself to breathe through my nose. But after eight years you are learning to cope with this and I would try and stay as active as I possibly can.

[Liam interview 1]

An important feature of learning about embodied knowledge in some participants’ accounts was how it was mobilised in combination with medicocentric knowledge to prompt participants to take action when necessary. Steven spoke of tuning into his body and learning when to attend the doctor by monitoring its signs and symptoms.

*With the doctor, I go into him, he will give me the steroids or the antibiotics that I need then. So, when I know it’s coming on and you get used to knowing when they [infections] are coming on, you can just feel it on the chest there.*

[Steven interview 1]

Bronagh also described coming to know very specific warning signs of incipient episodes of exacerbation. This knowledge prompted her to use her nebuliser to address the problem.

*I know straightaway when there’s something going to happen because if I’m bad and I can’t breathe, I gets this pain in my head…like little men with hammers, and I know straightaway when I can hear them, boom, boom, boom. I says, “Now right I have to go on the nebuliser”.*

[Bronagh interview 1]

Such mobilisation of embodied knowledge was a way of resisting the idea that medicocentric knowledge alone is valid or solely sufficient for the self-management of COPD.

Some participants were ambivalent about their prescribed COPD medication, based on their experience of their bodies’ reactions to the medication and related side-effects. Eoin, for example, talked about his worries about taking steroids long-term. He was very concerned about the severe side effects that accompany steroids and the toll they had taken on his body. At one stage he had tried ceasing steroids entirely but found he was unable to cope without them. This left him feeling very ambivalent about the side effects of steroids on the one hand, while on the other feeling that he had no option but to take them.
Knowing what I know about them, the side effects, I don’t like it [taking steroids]. However, I do know that I cannot operate without them, I know that now because I tried something without authority [short laugh]. One time I just says, “I’m going to cut these down myself now.” I cut them out altogether, but I very very soon found out that I couldn’t. The breathing was going really bad. And the very minute I went back on them, different person.

[Eoin interview 2]

Niamh said that she did not experience a clear benefit from her inhalers. This, combined with her experience of unpleasant side-effects, led her to forget to take her inhalers as prescribed.

I find the powder inhalers very hard…they stick to your tongue. When you drink something [or] you eat something, it’s like as if you burnt your tongue. I’m supposed to take them at night but actually I forget about them most of the time. And I would probably be an awful lot better if I thought of them. But you see it’s this thing with the tongue that gets me down.

[Niamh interview 1].

I don’t know if they’re any good or not. Because [even when] I’ve forgotten about them, I had a good day. So that’s why I don’t believe they do me any good.

[Niamh interview 2]

This resistance to their medication regimen was a way of questioning a medicocentric reliance on prescribed medication as central to self-management. For other participants, their embodied knowledge gave them the confidence to adjust their prescribed medication regimens to suit their own needs. Liam used his embodied knowledge to adjust his medication regimen.

In the beginning, I was using all the inhalers three times a day, and the nebuliser twice a day. But I gradually cut back as much as ever I could, and now I only use them when I need them. And say an inhaler is supposed to last two months, well I probably get six months out of it. I find to use them when I need them, rather than using them all the time, they’re more effective.

[Liam interview 2]
This was a way of resisting the idea that knowledge of medication rests solely with health care professionals. He was worried about the long-term impact of antibiotics on his body’s ability to fight infection due to the risk of developing antibiotic-resistant infections and directly questioned whether his GP had sufficient knowledge to prescribe appropriate treatment. He privileged his own knowledge and judgement of how to manage his treatment regimen.

*I find the local GP, I wouldn’t say a thing against him, but I don’t think they have a clue with COPD. If you go in and say you are not feeling great, they will examine you, write out an antibiotic and that’s their answer. I find now that when I have a problem, I will crank up the nebuliser a couple of extra times and I find it’s gone, rather than going down the road of an antibiotic.*

[Liam interview 1]

George relied on his embodied knowledge to guide him in his approach to self-management, which was based on setting physical and mental health goals and striving to reach them. He equated self-management with self-improvement, with the aim of reducing his use of medication over time. This led him to adjust his inhaler regimen to suit his own needs and desires, even though he reported that his daughter could tell if he had not taken his inhalers by the re-emergence of COPD symptoms.

*I still take em [inhalers], but I mightn’t be taking them according to the rule book. What I do is keep myself right physically and mentally, and then you top it up with these fellas [inhalers]. Until some morning my daughter’ll come in and she’ll say, “You didn’t take your inhaler last night.” They know from my chest.*

[George interview 2]

Other participants spoke of adjusting their treatment regimens based on their embodied knowledge, but still checking in with their health care professionals to get their endorsement for doing so. Rory, for example, had adjusted his medication regimen to suit his own needs, and validated this approach by referring to the reaction of his respiratory nurse.

*I’m on a 500 dose [of inhaled medication]. I’m supposed to take one in the morning and one in the evening, but I take it twice in the morning which means I’m taking 1000 in the morning, which is a very, very high dose. And when I told the nurse, she was amazed, and I said, “Well I keep forgetting*
to take it in the evening, that’s why I take it twice in the morning.” And she said, “Oh, horses for courses.”

[Rory interview 2]

Eoin spoke of titrating his supplementary oxygen to suit his body’s needs, but this was done with recourse to the approval of his consultant.

Now they tell you that if you’re on two litres of oxygen, you just stay on two litres. However, you know yourself, if it’s not enough for you and you increase it yourself. And that’s what I would do as well, I would be self-managing. My hospital consultant knows that and is quite happy.

[Eoin interview 3]

5.4.3.2 Alternative knowledge

Alternative knowledge was described in participants’ accounts as transmitted between people at local level, in local COPD support groups or in the community. Such knowledge was passed from peer-to-peer, between friends and family, via word-of-mouth or popular media. This could be viewed as a system of knowledge transfer that operated in parallel to but not intersecting with medicocentric knowledge. Declan described how he and his wife were told about the uses of local honey by someone in their community.

Some girl got me on to local honey, we’ve both been taking it. It’s made in [local village] and we’re both sleeping better, we’re both not coughing any time at night.

[Declan interview 3]

Finbarr also described receiving knowledge about a salt therapy device from a man who was attending a computer class with him. Finbarr went on to share this knowledge with a member of his local COPD support group.

I was speaking to a man, I used to do a computer class, and he said to me that I should try a salt pump, so I got one. And I can’t believe the difference. So, there’s another man in the exercises [run by the local COPD support group] and I said it to him, I said about the salt pump.

[Finbarr interview 1]

An important feature of alternative knowledge in participants’ accounts is that it was integrated with medicocentric knowledge by each participant according to his or her own needs. For participants, alternative knowledge was placed in a
dialectical relationship with medicocentric knowledge. This was a relationship in which one was at times privileged over the other, and at other times integrated together. For Jack, alternative knowledge was incorporated along with medicocentric knowledge into his everyday self-management practice. He viewed alternative knowledge as just as valid as medicocentric knowledge. He combined medicocentric knowledge of exercise and medication with alternative knowledge of salt therapy and poitin (a traditional Irish distilled beverage often produced illegally) in his self-management practice.

Researcher: So the main thing you do to manage your COPD is exercises and going to the local group.

Jack: Yeah, and these fellas [inhalers] and the [salt therapy device] there. It’ll be plugged in tonight. And that poitin now, if you did feel a cold coming on, you’d take a right shot of that in the hot water.

[Jack interview 1]

Oisin integrated alternative knowledge of “natural” therapies with medicocentric knowledge. In his case, he gave medicocentric knowledge precedence but still upheld the value of alternative knowledge.

There’s a man [in the local COPD support group] and he did a lot of courses on herbalism and alternative medicines and all of that. And he gave a talk to the group, naming off a whole lot of herbs and things that are quite good for the condition. But the rule of thumb is obey your doctor, but you can experiment with natural products. There’s no harm in it as far as I’m concerned.

[Oisin interview 1]

Alva’s first line of therapy when she got ill was home remedies. It was only when these were not effective that she attended her doctor. In contrast to Oisín, she privileged alternative knowledge but integrated this with medicocentric knowledge when necessary.

Well I’d say it was a bit of the flu and a chest infection, I tried doctoring myself with all the alternative remedies, the ginger, and the lemon and garlic, and the whole works, enough to sink a ship, but then eventually I went to him [GP] and he said, “You need…help,” with me chest.

[Alva interview 3]
In participants’ accounts, alternative knowledge was an inherent source of knowledge for participants to draw on in their personal self-management practice. As such, alternative knowledge was mobilised by participants to empower them to create their own personal self-management practice. The mobilisation of alternative knowledge was a way of resisting the hegemony of medicocentric knowledge in COPD self-management. As a form of subjugated knowledge, participants did not view alternative knowledge as endorsed by health professionals, but this did not prevent them from accessing and mobilising it in their everyday self-management practice. Eamon, for example told a story of obtaining an unlicensed cough medicine from a man who ran a greengrocer’s business. In this case, Eamon went beyond the remit of health care professionals and beyond the reach of the law to obtain a medication that he believed was effective.

*There was a fellow a few doors down [from] where we had the business and he used to have these bottles that he would sell over the counter that somebody used to bring in from the UK. They were legal there, but they weren’t legal here, and we used to get these and it was great, super-duper.*

[Eamon interview 1]

Gráinne explicitly resisted the reliance on medicocentric knowledge for the management of COPD, privileging what she termed “natural” therapies.

*With my COPD group, lots of people who do the exercises, God, they’re on so much medication. It’s unbelievable, they’re on inhalers, some of them are on oxygen. But you know there [are] natural things that can be instead of all these inhalers.*

[Gráinne interview 3]

In Gráinne’s account, her philosophy of holistic and alternative approaches to self-management meant that she resisted adhering to a medication regimen and led her to stop taking COPD medication entirely.

*I’m very healthy. I don’t take my inhalers. Why would you be taking an inhaler for something that’s there and gone? So, I’m on no medication at the moment.*

[Gráinne interview 2]

However, such resistance was largely unspoken with health care professionals. Participants did not discuss their mobilisation of alternative knowledge with their
Finbarr felt that his salt therapy device would not be endorsed by health care professionals, but this did not lessen his enthusiasm for it. He had not told his GP that he was using salt therapy.

**Finbarr:** Most of the medical people won’t subscribe to anything like that. But I couldn’t believe it. And it just happened gradually. I used to cough desperate. Now it’s very rarely I cough at all. I found it marvellous, absolutely.

**Researcher:** And have you told your GP or your health professionals that you are using the salt pipe?

**Finbarr:** No, I haven’t been back to the doctor except to get a prescription for the inhaler.

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### 5.4.4 Sharing knowledge between peers: local support groups

This section presents findings from participants’ accounts about how they shared knowledge with their peers about self-management of COPD. The importance of peers sharing knowledge with each other was emphasised across the interviews. Such knowledge transfer was not restricted to alternative knowledge but encompassed medicocentric and embodied knowledge as well. Local COPD support groups and online resources such as social media platforms were identified as crucial to the sharing of knowledge between people with COPD. This was a way of resisting the idea that knowledge about self-management rests solely with health care professionals. Liam praised his local COPD support group because it provided a forum where members could share their knowledge of managing COPD and learn from others.

**You chat to people who have a similar condition to yourself, and you find out how they manage things, and you’re comparing notes all the time. And hopefully you’re probably helping somebody as well.**

[Liam interview 2]

Sinéad also viewed her local COPD support group as a forum for the transfer of knowledge between peers. She described this process as helping and supporting her to manage.
If you say you have something, they will say, “Why don’t you try – I find such-a-thing good.” These little tips for each other.

[Sinéad interview 1].

Kate described her local COPD support group and its social media platforms as crucial for the sharing of knowledge that informed her self-management practice. She found this to be empowering and agentic for her own self-management practice. It was a source of reassurance and support for her. In this way, the sharing of knowledge represented a democratisation of knowledge, not seen to rest solely in the hands of health care professionals but inhering also in networks of peers.

I find the support group really, really helpful. I said it to the group leader, the fact that they are on the internet, on Facebook, and we have the meetings. I do feel that if I ever needed, if I got some little thing that I didn’t understand or if I was given a medication by the doctor and I was getting some side effect from it, onto the Facebook, or ring [group leader] up and I would get help. Because they have got so much more experience than I have with [COPD].

[Kate interview 1]

5.4.5 The mobilisation and appropriation of knowledge: conclusion

This section presented the findings related to the different forms of knowledge identified in the analysis. These were dominant medicocentric knowledge, and subjugated knowledge consisting of embodied and alternative knowledges. In Section 5.4.2, I set out how participants reported health care professionals as transmitting medicocentric knowledge to them with the expectation that they would use this knowledge to practice “good” self-management. In this way, medicocentric knowledge was a manifestation of the exercise of power on participants, and they had clear expectations of the role that health care professionals should play in transmitting such knowledge. However, participants were not passive recipients of medicocentric knowledge. Their accounts demonstrated how they resisted the exercise of power on them by appropriating this knowledge to suit their needs and using it to develop their own expertise. For participants, medicocentric knowledge had a clear but bounded role to play in their overall practice of self-management.
In Section 5.4.3, I presented participants’ accounts of mobilising subjugated knowledge. Section 5.4.3.1 set out how participants developed embodied knowledge based upon a process of learning through experimentation and expertise. I described how participants mobilised embodied knowledge to prompt them to take specific self-management actions and to resist the imposition of medicocentric knowledge and prescribed therapeutic regimens. However, some participants still cited the approval of health care professionals for their use of embodied knowledge in self-management. In participants’ accounts, therefore, embodied knowledge existed in a dialectical relationship with medicocentric ideas of what constitutes “good” self-management.

Section 5.4.3.2 presented participants’ accounts of accessing and mobilising alternative knowledge of therapies and treatments that lie outside the remit of medicocentric approaches. Participants described alternative knowledge as being transmitted from peer-to-peer or via popular media. It was integrated with medicocentric knowledge to inform their overall approach to self-management. They did not report sharing alternative knowledge with their health care professionals. The mobilisation of such alternative knowledge outside the reach of health care professionals was a form of resistance to the hegemony of medicocentric knowledge.

Section 5.4.4 set out findings about how participants used local COPD support groups and related social media platforms to share knowledge about self-management with other people with COPD. These fora were crucial for the democratisation of knowledge about managing COPD. From this perspective, knowledge, like power, is located in complex relational networks of professionals and peers.

5.5 Agency and power: technologies of the self

5.5.1 Introduction to technologies of the self

This section of the findings presents participants’ accounts of how they negotiate the shifting and nebulous relationship between their own agency and the constraints of power exercised on them by others such as health care professionals. Foucault conceived of agency as existing in a dialectical relationship with relations of power. Individuals are subjected to complex, multiple, shifting relations of power, and at the same time can act agentically, in and through those relations (Allen 2002). As discussed in Section 5.4.1, according to Foucault, agency is exercised as resistance through the appropriation and mobilisation of
knowledge. However, he also conceived of agency as exercised through the process of introspection and transformation known as care of the self (Foucault 1990). Care of the self involves transformation, correction, and purification of the self in order to find salvation and redemption (Foucault 1990). Care of the self is achieved via practices such as introspection, reflexivity, and care of the soul, as well as activities with more tangible outcomes such as giving attention to the health of one’s body and wellbeing (Leontini 2010). These practices are known as technologies of the self. In the context of chronic illness, the ultimate aim of the use of technologies of the self is to exercise care of the self in order to achieve redemption through personal happiness and health (Brodwin 2017).

It is important to understand the relationship between care of the self and technologies of the self. Care of the self is an agentic practice involving the transformation of the self. However, it is performed using technologies of the self which are partly agentic, given their aim of achieving such transformation, but they are also fundamentally shaped by wider relations of power and knowledge (Frank 1998). Together, technologies of the self make up “the self-monitoring and self-managing individual” (Brodwin 2017, p. 78).

Technologies of the self involves a large and complex array of practices. This section presents the different technologies of the self I identified in participants’ accounts of self-management, including introspection and self-reflection; nurturing mental wellbeing and happiness, disciplining the self and the body by abstaining and restricting; exercising; and imposing routines on everyday life (Frank 1998, Leontini 2010). The focus is on technologies of the self rather than on care of the self because it is impossible to separate technologies of the self from care of the self – technologies of the self are the practices that people use to care for themselves.
Sections 5.5.2 and 5.5.3 set out how participants engaged in introspection and self-reflection and nurturing well-being and happiness as a way to use their own agency in order to achieve positive change and care for themselves. Sections 5.5.4, 5.5.5 and 5.5.6 present participants’ accounts of abstinence and restriction, exercise and routine as technologies of the self that are sites for the exercise of power by experts on the one hand, and the exercise of agency by participants on the other. I describe findings that demonstrate the exercise of power via the imposition of expectations and standards of experts and the responsibilisation of
participants in order to produce “good” self-managers. At the same time, I present participants’ accounts that describe the agentic, transformational, and redemptive potential of these technologies of the self.

5.5.2 Introspection and self-reflection

Some participants’ accounts of self-management included the practices of introspection, reflexivity and self-reflection. The practices of introspection, reflexivity and self-reflection identified in participants’ accounts involved them exercising agency in order to transform their relation to themselves in order to come to a new way of living with and accepting COPD. Betty, for example, reflected upon her approach to living with and managing COPD with specific regard to her fight to manage without help. Through a process of introspection, she had come to the conclusion that it was important to transform her outlook on self-reliance in order to come to peace and acceptance of the limits imposed by chronic illness, and to recognise the value of accepting help from others.

I was just fighting people, it was my mess, I need to clean it up myself, but maybe I was just in denial and I now realise I have to be able to ask for help. And it was the asking for help was the hardest thing. So I said, “I have to realise the things I need to ask for help.” I think it did kind of lift me. And I suppose the scales from your eyes fall away.

[Betty interview 2]

Introspection and self-reflection also led her to stop blaming herself for not keeping up with the activities of daily living she had always used to do herself. Such introspection allowed her to view herself in a new, more positive light.

It’s kind of an enlightening moment that makes you feel a bit better. And I know it’s not my fault I’m sick. It’s not laziness that I can’t do it.

[Betty interview 2]

In Oisín’s account, self-management was itself the very practice of introspection and self-reflection. The processes of renunciation of old practices and awakening to new ways of being he described in his account of self-management came about through reflecting on himself, being honest with himself and confronting himself, in order to renounce old unhealthy habits such as smoking.

What I liked about [author] is he challenges you in every aspect of [smoking]. You can lie to yourself but if you read his book correctly you
cannot lie to yourself, you have to be honest. Why would you be lying to yourself anyway at the end of the day?

[Oisin interview 1]

For him, introspection and self-reflection were inherently moral technologies of the self in which he confronted his flaws with clarity and honesty, in order to transform and perfect himself as a good self-manager in his own eyes.

You have to look in the mirror and be honest with yourself and say what you did wrong and what you didn't do wrong. I found it great to be blessed to be able to see my wrongs. You have to address everything.

[Oisin interview 2]

5.5.3 Nurturing mental wellbeing and happiness

Some participants gave accounts of nurturing their mental wellbeing and happiness as an important aspect of their self-management practice. This was done either through hobbies and pastimes, or through working directly on their mental health in order to foster peace, wellbeing and enjoyment in everyday life. Nurturing mental wellbeing and happiness was identified as a way that participants could exercise agency in everyday life with COPD, beyond the limits of medicocentric conceptualisations of COPD self-management. It was a way of facilitating participants to care for themselves through finding happiness and peace, to transform the self into one that is transcendent from the confines of COPD. Aidan, for example, had taken up art as part of his approach to self-management. He had discovered that art was a way of both maintaining mental acuity and finding peace and relaxation.

That keeps the brain going. When you sit down and do a painting, and it’s so relaxing. I’ll sit there now at the table and just paint. Just to have the radio and just paint away. It’s lovely.

[Aidan interview 1]

Aidan found painting at home an effective way of nurturing a sense of mental wellbeing and happiness, but he complemented this with social engagement by attending art classes with a group of women. This provided the opportunity for social interaction and fun.
It’s just very relaxing, it’s lovely, and you have the craic then with the ladies, great craic. Sure I’m the only man in it. So, I enjoy that.

[Aidan interview 2]

Jane had also found art an important way to relax and find peace. Painting reduced her craving for cigarettes and helped her forget about having COPD and smoking.

When I paint I forget everything. It is very relaxing. I think it’s the most relaxing thing, doing any kind of artwork, and I like art. I like to paint. And it does help. Because you go into a place where there is no craving.

[Jane interview 1]

Like Aidan and Jane, Declan also incorporated art into his self-management practice as a way of fostering relaxation and mindfulness.

I also started doing art classes and I do that, especially in the wintertime. It’s therapeutic, your breathing, and there’s a feel-good factor when you’re finished. Your breathing becomes relaxed, everything becomes relaxed.

[Declan interview 1]

Declan had done bowling as a way of having fun and connecting with other people. This was instrumental in lifting his mood at a time when he was struggling with depression and isolation shortly after being diagnosed with COPD.

We met the bowling crowd, I was still on the oxygen 24 hours, but they took no notice of me, the conversations were going on, bit of craic, and it kind of gave me a lift, all of a sudden. I can go away, I can still enjoy myself.

[Declan interview 2]

Oisín placed importance on nurturing a sense of mental wellbeing and happiness in his approach to self-management. Tending to his mental health and cultivating a positive attitude to everyday life was a core element of his self-management practice.

I’m in a better place now than I was 30 years ago. I would have worried an awful lot years ago about different things. All financial issues, they would have caused me a lot of stress and strain years ago. I couldn’t give a shite now, if it’s there [money] it’s there, if it’s not, it’ll have to wait, simple. And I appreciate every day better now.

[Oisín interview 2]
5.5.4 Abstaining and restricting

Another type of technologies of the self that was identified in participants’ accounts of self-management was the practice of abstaining from or restricting behaviours that were deemed to be unhealthy. This was spoken of in particular regard to abstaining from smoking and restricting their diet, which seemed to represent “good” self-management in participants’ accounts. They spoke of how they had exercised agency in their practices of abstinence and restriction. Some participants reported using their agency to recruit health professionals and experts to help them abstain from smoking. This was not a situation where they were passively subject to the prescriptions and knowledge of health care professionals or experts, but where they actively recruited them to bolster their own personal motivation to stop smoking. They made use of expert knowledge to support their abstinence. Finbarr, for example, described recruiting his GP to prescribe varenicline⁶⁶ to help him stop smoking.

*I went to the doctor and I said, “Look, I want to give them up, so he said, “I will keep giving you loads of [varenicline] as long as you want me to.”*

*[Finbarr interview 1]*

Niamh had taken the decision to stop smoking herself but attended a hypnotherapist to help her stop. The hypnotherapist facilitated her in stopping smoking, but the motivation and desire to quit belonged to Niamh herself.

*I went to a hypnotist. And I gave them up very easy. He talks to you about cigarettes and then he says, “Close your eyes, and I will keep talking to you.” And there’s a subliminal tape going in the room. So it was hard, but I will tell you, it worked. He says to me, “Play this tape for a fortnight, every night when you are in bed. And he said, “I guarantee you will give up smoking,” and I did.*

*[Niamh, interview 1]*

The knowledge and skills of experts was thus recruited by participants to bolster their personal motivation to stop smoking. This meant that their abstinence from smoking was at heart a process borne out of personal agency, using and appropriating expert knowledge to support this process.

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⁶⁶ Varenicline is a prescription medication used to treat nicotine addiction
Other participants described the process of abstaining from smoking as a deeply personal process. Jane, for example, described her decision to stop smoking as taken by herself alone.

*But it is a lonely thing. Like me and the dog on the walk that day. It was me on the walk that day that I had to decide. I am going to throw this packet of cigarettes in the bin. And I mean that was a lonely decision made with the utmost strength of thought.*

[Jane interview 1]

Jane had accessed personal agency through a process of introspection and self-reflection to bolster her abstinence from smoking. Some participants spoke of being motivated to quit by experiencing and reflecting on severe illness which had confronted them with the prospect of deterioration and death. They described an intensely personal process of introspection on the implications of these events for their survival and discovered a desire to live and to see the future. Aidan had experienced a life-threatening episode of respiratory failure which necessitated him being placed on a ventilator. This experience prompted him to reflect upon his smoking and reach a personal decision to stop.

*When I got the fright, I gave them up. When I came out of everything and I came home [from hospital], I just said to myself, I said it to no-one [else], “Aidan, my fags are finished.” I just came home after hospital after being told, “You were on a life support machine”. I just said, “Aidan, forget it.” I just gave them up, just quit.*

[Aidan interview 3]

For Helen, quitting smoking was a long journey borne out of recovery from the grief of bereavement and the birth of her grandchildren. This made her reflect on the future and the desire to see them grow.

*Your whole existence is truncated when you lose your partner. And when [grandson] was born, it actually gave me back a future. I mean giving up the cigarettes was such a major thing to do, I mightn’t have done it for myself…I did it for my grandchildren. I said, “I want to see them grow.”*

[Helen interview 1]

Participants gave accounts of abstinence and restriction in which they spoke of how abstaining from smoking or restricting their diet was a transformational and redemptive experience. In this way, abstinence and restriction was a way for
participants to exercise agency through correcting and transforming the self in order to find redemption from ill-health. Some participants spoke of restricting and changing their diet as transformational. Declan described changing his diet as central to his management of COPD, and he viewed this change as transformational for his quality of life and ability to self-manage.

*I must say, for me it’s been life changing. And I think the loss of weight had a big thing to do with it.*

[Declan interview 2]

Oisín found the process of giving up sugar difficult but ultimately an agentic introspective process in which he opened his mind to the possibility of change as part of an ongoing journey of transformation.

*I mean the hardest thing I had was sugar [laugh], I gave up drinking, I gave up smokes, Jesus I thought I’d die giving up the sugar. Now I’m three months without sugar thank God. I mean it’s really about opening your mind to new possibilities and new changes...if you’re not changing every couple of years, you’re stagnating.*

[Oisín interview 2]

Participants also spoke of the redemptive qualities of abstinence and restriction. Declan and his wife Fiona gave an account of restricting and changing their diet as redemption from the inexorable deterioration of Declan’s health, and freedom from the burden of his COPD symptoms.

*Declan: I can walk round town, I have no oxygen, no steroids, I was told recently that I don't really need the Bipap anymore.*

*Fiona: It’s amazing, the loss of weight, what it has done for Declan.*

[Declan and Fiona interview 3]

Declan felt that the transformation he had undergone through restricting his diet had saved him from death.

*My GP even said it to me a couple of weeks ago, “You know, a few years back I’d have been saying to you, ‘I wouldn’t say much about life expectancy’, but I can’t believe it.”*

[Declan interview 1]

Aileen gave an account of how giving up smoking had redeemed her from a life bound and constrained by the exigencies of COPD.
[I was] hanging out the bedroom window in the middle of the night trying to get air. It’s scary. But that’s all behind me, thank God. And I have improved to the extent now where I feel that I can do a lot more than I used to. And at 61 it bodes well. Ok, I know this thing is progressive, but I think if you manage it properly you can keep it, hopefully, it won’t get worse.

[Aileen interview 1]

However, participants also spoke of abstinence and restriction as a site for the exercise of power on them, either by the process of pastoral power, by responsibilisation, or by the imposition of the standards and expectations of others. This was particularly the case when it came to accounts of dieting and weight loss. The exercise of pastoral power on participants with regard to scrutiny of their diet and weight was one way in which abstinence and restriction was subject to power. This has been described earlier in Section 5.3.2. In addition, abstinence and restriction of diet was identified in participants’ accounts as a responsibility that they felt they should take on themselves. Aidan’s account of abstaining from eating sugary foods was an example of how he strove to perfect himself as a responsible self-manager who had taken on the onus of managing his diet.

She’d [Deirdre, his wife] often have small little bars in the fridge, there’s packs of them! And I won’t go near them! I won’t go, because I just say to myself, “Look, I’m watching sugar levels, so I’m not eating them.”

[Aidan interview 2]

The responsibility associated with dieting weighed heavily on Jane. For her, dieting and abstaining from sugary foods was a struggle. She felt it was up to her to “battle” unhealthy eating habits. She saw the struggle to restrict sugary foods as the latest endeavour in an ongoing journey of abstinence and restriction.

Now I have to battle the food. Well I did the drink, then the cigarettes, and now I have to do the food. I am looking at a jar there now, with liquorice all sorts in, and I’m just dying for one.

[Jane interview 1]

Other participants spoke striving to meet the expectations and standards of experts regarding diet and weight loss. Alva, for example, spoke of her struggle to adhere to the expectations and standards of the weight loss organisation she attended. She sometimes rebelled against the expectations of the organisation.
She described attempting to meet these expectations on the one hand and resisting their constraints on the other.

*If I lost weight, it’d be a help, but I am trying, but it’s not easy. The [weight loss organisation], you can eat, but then again, an odd time I do break out, I be bold, you know. I have an old [bar] of chocolate or something like that.*

[Alva interview 2]

### 5.5.5 Exercise

Physical exercise was identified in participants’ accounts as a core element of self-management, as Gráinne described in her account of swimming.

*So I find [swimming] fantastic, and of course it’s helping all these muscles here as well, I just feel that doing all this [exercise] for myself is keeping me very healthy.*

[Gráinne interview 2]

Exercise was described in participants’ accounts as both consisting of formal, standardised and structured exercise regimes designed and delivered by trained professionals or instructors, and also consisting of personal regimes devised by the participants themselves. Participants’ accounts provided examples of the power exercised by professionals and experts to define what constitutes appropriate exercise for management of COPD and to extend their surveillance into the home lives of participants. Terry described how he had been instructed to do certain exercises at home by his health care professionals.

*You have to do your exercises as well, mostly chairobics, mostly things you can do in the chair, but then I have to do what they call wall press-ups, you stand and you push yourself in and out from the wall.*

[Terry interview 3]

Eileen also spoke of being encouraged to do the exercises she had learned through PR at home.

*Lots of simple enough exercises that it is recommended you do on a daily basis [and] at least five days a week walking.*

[Eileen interview 1]

Some participants had targets set for them by health care professionals or experts. Eileen talked about how the professionals delivering exercise in PR set goals and
monitored her progress through the exercise programme. It was expected that she would adhere to the standards and expectations of the professionals delivering the exercise programme in PR.

Throughout the course I felt I was improving from the first day because they give you two-and-a-half minutes and they have a timed watch on. Two and a half minutes to do six or seven different things and they come around, they record your result all the time, of how well you did and if you were breathless and so on. And you kind of got competitive within yourself to try and do better than you did, and they had a record of it so they would tell you if you did better today than you did last week.

[Eileen interview 1]

Eileen found this experience beneficial and motivating. Betty, on the other hand, found the expectations of health care professionals and instructors hard to meet. For her, exercise was based on the knowledge and guidance of experts, and a set of standardised activities that she should follow as part of being a responsible self-manager. This gave rise to an anxiety that she was not meeting these expectations, failing to live up to her responsibility to be a “good” self-manager.

The exercise class on the Thursday, it’s marvellous. The guy who’s done it, he is fantastic. He did special exercises for people with pulmonary problems. But I could be better, you know. When I’m thinking about it, if I’m standing up here, I’ll stand on the spot, march up and down, but I certainly could do more. I did the pulmonary rehab, and my plan was to really kind of be good at it, and do the exercises, and I was good for a while, and then I just [stopped], you know.

[Betty interview 1]

However, exercise was not represented solely as the imposition of power in participants’ accounts. Many participants described integrating formal, structured exercise programmes with their own personal approach to exercise into a unique and individualised exercise regime. Cathal described his own structured exercise plan based on his experience of exercising and keeping fit during his time as a competitive athlete. He described his exercise regime as a strategy he had devised to allow him to live with COPD.

I took it upon myself to start walking. When I get up in the morning, I might do about 20 pushbacks on the door, and then in the afternoon I might do
weights, a few exercises, and if the weather is fine, I’ll go for about a two-mile walk.

[Cathal interview 1]

Oisin, for example, spoke of being motivated by his experience of PR to develop his own exercise routine.

*When I did the pulmonary course then, I did my own little routine. I have my weights, and I sit here and watch TV some nights and I’m just doing this [lifts weight]. I would be working away at things like that. I have others that I wrap on my ankles there and I do a bit of a stretch, and I also do little push ups off the counter. So I have my own little routines.*

[Oisin interview 1]

In their quest to maintain or improve bodily health, some participants spoke of pushing the body to its limits through physical exercise. Exercise was presented as a way of operating on the body in order to reach a state of health and physical wellbeing, to resist deterioration in a quest for redemption from the exigencies of COPD. They spoke of pushing the body in order to resist the limits and progression of COPD. Cathal spoke of his determination not to let COPD beat him and how he focused on pushing the limits of his body.

“Ok,” I said, “How am I going to live with this?” So I decided that it’s not going to beat me. Always push yourself, push yourself, push yourself. Just don’t sit on your ass.

[Cathal interview 1]

Some participants described setting goals and targets for themselves to attain, to demonstrate and bolster their progress in their quest for bodily health and redemption from deterioration. George spoke of exercise as a challenge, setting himself goals to reach in order to push his body to achieve the goal of health. Exercise for George was not just about maintaining health but also about improving his health.
There’s no point in doing exercises unless you set yourself a goal to achieve. Because going in doing the same exercises every week, you dunno whether you’re improving or disimproving. No matter what occupation or problem you have in life, you should set yourself some target to achieve.

[George interview 1]

In some participants’ accounts, they described being driven to push their bodies beyond their limits. They felt driven to exercise aggressively, in some cases injuring themselves in this process. Eoin and Declan were driven by an underlying anxiety at the prospect of deterioration and death to exercise beyond the limits of their bodies. Eoin was driven by the prospect of a lung transplant to try to reach the fitness standards he felt were required for a transplant, not stopping even when he developed a stress fracture in his leg. He described exceeding the standards and expectations of the health care professionals in his exercising.

Exercise would be the big thing for me, cos I do the treadmill, even though it’s painful I still do it. I would do 100 minutes a day on the treadmill. But I know I was doing more before I broke this thing [leg], but just can’t get back into it. But anyways I was advised not to, I’m overdoing it. They were saying that the recommended exercise would be half an hour a day. So I could do two hours, it’s ridiculous according to them. It was as much as I had the transplant in mind. Because your upper body needs to be very fit before they transplant you.

[Eoin interview 2]

Declan was similarly driven to exercise beyond his limits, driven by the urgency of maximising his chances of achieving the best bodily health he could within the limits of COPD, fearing that his lung capacity would deteriorate if he did not exercise. Like Eoin, he developed a stress fracture from over-exercising.

I was trying to build up a little bit of speed [walking], to put pressure on the lungs to function better, I felt that I needed to put them under pressure to try and get ‘em to work again. Whether I was doing the right thing or the wrong thing, but I felt if I didn’t exercise ‘em enough, that they’d never improve a bit. That the capacity would be getting less and less.

[Declan interview 1]
5.5.6 Routine

Routine was also spoken of in participants’ accounts as an important aspect of self-management. Frank (1998) spoke of routine as a technology of the self, imposed upon free practices and constraining them within the delimits of power and knowledge. He viewed medical treatment as a way of imposing routinisation on a patient’s life (Frank 1998). Routine was presented in participants’ accounts as either imposed by the illness itself, imposed by the medication regimen that accompanies COPD, or as an approach to everyday life devised by participants themselves based upon their own agency and experiential knowledge.

A few participants who had severe COPD gave accounts in which they described their daily routine as being dictated by the rigours and demands of COPD. For Eoin, his degree of breathlessness from day to day dictated his daily routine. His morning routine was particularly beholden to the severity of his symptoms.

You can find yourself wakening up breathless or not breathless. However, once you get out of the bed, you end up breathless anyway. And getting dressed is a chore. You always need your nebuliser beside you, so that when you do get dressed you have to use it before you attempt to go anywhere at all. And then you have to make a decision on the day, are you too breathless to even try to shower? Because there are days you just have to forget it. So you go down then and you have your breakfast and you have to have a light breakfast because if you eat too much, your diaphragm is down. So you have to try and just leave enough space so that your diaphragm will work.

[Eoin interview 3]

Other participants described their daily routine as shaped by their medical treatment regimen. These participants structured their days according to their treatment schedule. Participants described a paradoxical situation in which on the one hand sticking to a routine prescribed by health care professionals offered liberation from the effects of COPD, allowing them to maximise quality of life and health; while on the other the imposition of a treatment regimen restricted their agency to live life freely or at least according to a routine of their own choosing.

Niall described how his treatment regimen dictated the rhythms of his daily life, and how he structured his day according to the treatment schedule. He emphasised his reliance on the various COPD treatments that he took each day to allow him to function every day. For Niall, his medication regimen offers quality
of life and a certain degree of relief from symptoms, while at the same time the requirements of the regimen impose their own routine on him and dictate the rhythm of his days.

If I get up in the morning and my chest is blocked with phlegm, I can’t walk because I’m blocked altogether. So I start using the inhalers, and then I would have my breakfast and start the nebuliser. And twice a day I would have to use that. And the oxygen, maybe more.

[Niall interview 1]

Helen placed her medication regimen as the top priority in her daily self-management practice. It underpinned and informed the rhythm of her daily life, and she regarded it as a way of surviving. She described organising and planning her medication as taking quite a bit of effort and she spoke of having to take time each week to plan her medications and prescriptions.

So I have my tea, I take my medication. There’s quite an effort goes into it and then once a week I have to do the whole lot, and then I have to make a list of what I need for the chemist, so I’ve got a reminder, a shopping list on the fridge. So that’s how I stay alive, with the help of these two dispensers and my mobile phone.

[Helen interview 3]

Helen described using medication dispensers and setting an alarm on her mobile phone to help her adhere to her medication regimen. These reminders served as a constant reminder of her illness and were a strategy of power insofar as they imposed a routinisation of her private daily life. They also recruited other family members such as her grandchildren into serving as scrutinisers and prompters to take her medication.

So I’ve my alarm set, which is a great tool. And even the children now, when it goes off, they’ll say, “Gran, your tablets.” So they know as well, they know that the alarm is for me to take my tablets.

[Helen interview 3]

Some participants’ accounts gave examples of how they placed importance on their medication routines but had integrated these into broader personalised self-management routines. They used their agency and experiential knowledge to construct their routines in which medical treatment of COPD played a role but did not impose unduly on them. Although Jack gave a detailed account of his
medication regimen and identified it as an important factor which shaped his daily routine, his account also demonstrated how he resisted the strictures of his regimen by varying his routine and the rota of his inhalers. He devised his own medication routine based on his personal judgement of what would be the most effective.

I vary them a bit. Take one [inhaler] now, and maybe another one, a different one tomorrow. Vary em a bit like that. I thought that was a help more than concentrating on the one.

[Jack interview 2]

Aidan gave an account in which his medical treatment regimen was a constant presence and shaped to a certain extent his daily routine.

When I get up in the morning, I have the oxygen and the Bipap on. And I come out then and take all my medication. And then I take my nebuliser. I might have to take the nebuliser in the afternoon. I usually take it about one o’clock. I don’t have to, but it’s just the routine. I take it at one o’clock and then I take it maybe again around half six. And then I take it around 11 before I go to bed.

[Aidan interview 1]

However, he spoke of his medication routine as part of a broader, weekly routine that he had devised independently. He described how he had developed a routine that was based around activities and social engagement at home, in his local nursing home day centre, and with his local COPD support group. For Aidan, medication was just one aspect of a much broader weekly routine based on activities he enjoyed, rather than a dominant medicocentric routine that dictated the rhythm of his life.

Aidan: I just keep myself active, I love going to [the day centre] on a Tuesday. And then Wednesday we’ve a half day, and we go off somewhere the two of us. I have Thursday mornings then I go to the exercises, I’ve the [day centre] on a Thursday as well. You know, I manage away.

Deirdre: We’re lucky that the oxygen isn’t 24-7, that he can do things for himself. That we can go places.

[Aidan and Deirdre interview 2]
Some participants devised their own routines independently of a medication regimen. In these cases, participants described using their own agency to develop their own regular routines based on their experience of what worked best for them. Gráinne described using her own embodied knowledge and experience to develop a holistic overall routine to manage everyday life, not specific to COPD. In fact, as presented in Section 5.4.3.2, she had explicitly rejected adhering to a medication regimen for her COPD.

I get up in the morning and I either go for a walk or I go swimming. I will come back and have my breakfast. My best energy is before I eat in the morning. I have my cup of coffee and then I set my clock for 15 minutes and I have a rest, and after that I feel I have a bit of energy. I clean out my stove, go out to the garden, go downtown.

[Gráinne interview 1]

In other participants’ accounts, although they described their own independent daily routines, underpinning this was a view of routine as something one should practice in order to perfect the self as a “good” self-manager. The understanding of routine in these participants’ accounts was imbued with internalised self-surveillance and self-discipline. In Padraig’s account, for example, he ascribed moral value to having a daily routine of activity, in order to avoid becoming “lazy”. For Padraig, having a daily routine was based on setting targets of tasks to be accomplished every day in order to remain active and busy. It was equated with “good” self-management.

I get up in the mornings and shower like anyone. And...you had your breakfast. I cleaned out the fire. I cut the grass. I'd sweep all the stonework. You find work to keep yourself going 'cause I'll tell you why. I find that if you sit down on these things, you sort of go into a, I dunno is it a depression, but you get lazy. And if you get lazy, then you'll never move anything. You have to find work to do to make the day go round. You set a target that you have to do.

[Padraig interview 2]

5.5.7 Technologies of the self: conclusion

The findings presented in this section related to the different technologies of the self used in self-management that were identified in participants’ accounts. These were introspection and self-reflection, nurturing mental wellbeing and happiness,
abstaining and restricting, exercise, and routine. In Section 5.5.2 I set out how participants reported engaging in introspection and self-reflection on their life with COPD and its management. The practices of introspection and self-reflection identified in participants’ accounts involved them using their agency to transform how they related to themselves in order to change their way of living with and managing COPD. Their accounts demonstrated how introspection allowed them to draw on their own inner resources to cast their view of themselves in a more positive light as moral individuals who are deserving of help and open to change in the cause of self-management.

In Section 5.5.3, I presented participants’ accounts of actively pursuing activities and practices that nurtured their mental wellbeing and happiness. I identified this practice as a way in which participants could exercise agency over their mental wellbeing and ability to manage their emotional lives with COPD, beyond the narrow confines of medicocentric approaches to self-management. I presented findings from participants’ accounts that demonstrated nurturing emotional wellbeing and happiness as a way of attaining transcendence from the constraints and exigencies of everyday life with COPD.

In Section 5.5.4, I presented the practices of abstention and restriction identified in participants’ accounts. These practices were spoke of with specific regard to diet and smoking. Abstention and restriction were presented as technologies of the self, practices designed to perfect the self as a good self-manager. In participants’ accounts, such practices were agentic in that they held the potential for transformation of the self and the body, reaching the goals of health and quality of life. On the other hand, abstention and restriction were also presented in participants’ accounts as sites for the exercise of power on them. They were practiced according to the norms, expectations and standards of experts. They were also a site for the emergence of responsibilisation of participants, who felt that the onus was on them to become “good” self-managers.

Section 5.5.5 set out participants’ accounts of exercise as an imperative in their self-management practice. In participants’ accounts, exercise was presented as a way of paying attention to the health of the body and of disciplining and pushing the body in order to achieve the aim of health and physical wellbeing. Participants described feeling driven to push and challenge themselves, sometimes beyond the limits of their bodies, in a quest for bodily health and wellbeing. An assumption

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67 The term “experts” is used here to refer to health care professionals and other experts mentioned by participants such as nutritionists and physical fitness experts.
that exercise was beneficial was identified in participants’ accounts of exercise. Participants also described how experts had set their own standards and expectations of what appropriate exercise should consist of. However, participants drew on these assumptions and beliefs, and on the expectations and standards of experts, and integrated these with their own personal and experiential knowledge to develop individualised personal exercise regimens. In this way, exercise is an example of a technology of the self in which the dialectics of power exercised on participants by experts and agency exercised by participants are played out.

In Section 5.5.6, I presented findings related to routine as a central element identified in accounts of self-management. Participants’ accounts of routine revealed it to be at once a practice of power imposed on them through the imposition of medicocentric standards and expectations, in which their freedom was limited by the constraints of the illness, the demands of the treatment regimen, or by their own internalised disciplinary practices. At the same time, routine could also be described as agentic, in that it helped participants to manage their health, to resist the constraints of illness, and to find meaning and enjoyment in life. Participants negotiated the relationship between agency exercised by them and power imposed on them, in many cases resisting and transforming medicocentric routines into personalised routines based on their own experiences of what worked best for them.

In these accounts of technologies of the self, a recurring theme was identified in which participants’ agency existed in a dialectic relationship with the exercise of power on them by the imposition of expectations and standards of experts. Participants were constantly negotiating the boundary between their own agency and the constraints and impositions of power exercised on them. Their own engagement in technologies of the self consisted of accessing their resources and agency to construct their personal heuristic of self-management, while at the same time this was shaped, moulded and constrained by the exercise of power on them. Technologies of the self were employed in participants’ accounts both to transform themselves and to correct and perfect themselves as “good” self-managers in their own eyes and in the eyes of others.
5.6 A Foucauldian narrative of exercising power in the self-management of COPD

The aim of this narrative inquiry was to develop an in-depth understanding through a Foucauldian lens of how people with COPD exercise power in the self-management of their illness. Through analysis of pertinent literature on COPD self-management, co-constructing narratives of living with and managing COPD with participants, detailed textual analysis of participants’ narratives and explication of themes and sub-themes, I presented interrelated themes of power, knowledge and agency that exist in the self-management narratives of participants in this study.

For the participants in this study, exercising power in the self-management of COPD took the form of agency. In keeping with Foucault, agency was manifested through resistance to the imposition of power by dominant groups and institutions on individuals, and through the practice of “technologies of the self” designed to operate on the self and the body with the aim of transforming and redeeming the self.

One way of exercising agency was through the appropriation of dominant knowledge and mobilisation of personal subjugated knowledge. This use of knowledge was framed by Foucault (1980) as resistance to the imposition of power by dominant groups and institutions. In this study, participants resisted the idea that experts are the only legitimate holders of knowledge about self-management and resisted the idea that medicocentric knowledge is the only legitimate form of knowledge about self-management. Instead, participants actively integrated medicocentric knowledge with their own embodied and alternative knowledge in everyday self-management.

Participants appropriated medicocentric knowledge to inform their approach to self-management. This was empowering for participants, giving them added confidence in their ability to self-manage. They also questioned the level of medicocentric knowledge held by experts. They had expectations that experts should hold specific knowledge that they should impart to participants regarding treatment and self-management and that could be used by participants to bolster their self-management. Participants also exercised agency by developing their own medicocentric knowledge and expertise, which helped them self-manage and gave them legitimacy in the eyes of experts.
Medicocentric knowledge was not the only type of knowledge used agentically by participants. They also exercised agency by mobilising their personal and subjective knowledge. This entailed two types of personal knowledge – embodied knowledge and alternative knowledge. Participants exercised agency by mobilising and leveraging embodied knowledge (knowledge of one’s own body, its signs and symptoms of COPD and its reaction to treatment and self-management). They used this embodied knowledge to agentically resist the unquestioning imposition of medicocentric treatment regimens by experts, and to adjust these regimens to suit their bodies according to the knowledge they had developed as a result of experience of living with COPD over time. Participants also exercised agency by using alternative knowledge (knowledge of alternative treatments and therapies not endorsed or prescribed by experts), actively integrating such knowledge with embodied and medicocentric knowledge in their self-management practice. They democratically shared this knowledge between peers. Participants’ use of embodied and alternative knowledge was personal and subjective, and represented a body of subjugated knowledge, accorded less validity than medicocentric knowledge by experts, but viewed as fundamentally important by participants in this study.

A second vehicle for participants’ exercise of agency was through engaging in “technologies of the self”, that is, a set of self-management practices designed to operate on the self and the body in order to achieve happiness, well-being and health. Participants exercised agency through engaging in introspection and self-reflection. They actively used this practice of introspection and self-reflection to help them renounce unhealthy behaviours and engage in new ways of living. They also exercised agency by actively pursuing practices that enhanced their happiness and well-being, their physical health (through abstinence and restriction and exercising), and their daily routines. As with their use of knowledge, participants engaged in such technologies of the self to actively and agentically integrate medicocentric interventions with their own personal practices to construct a unique and individualised approach to self-management.

The ultimate aim of practicing technologies of the self was to transform the self and the body in order to find redemption from the exigencies of COPD. For participants in this study, redemption meant avoiding the worst-case prognosis of COPD by achieving personal happiness and health (as far as possible within the constraints of their illness). Using technologies of the self, transformation for participants meant changing their outlook on living with and managing COPD, in
order to correct and perfect the self as a “good” self-manager. Becoming a “good” self-manager meant mindfully and actively integrating medico-centric and personal practices into an individualised self-management heuristic. It necessitated a delicate balance between agency and the imposition of medico-centric expectations, prescriptions and recommendations by experts.

However, such agency was not totally unfettered. The hegemonic power of experts was always present, imposing upon and delimiting the agency of people with COPD as they practice self-management. From a Foucauldian perspective, dominant power was exercised by experts (and in some cases, by family members) through scrutiny and disciplining of the private lives of people with COPD, and responsibilising them for the management of their illness. The exercise of power on participants by experts was also achieved via the imposition of medico-centric knowledge, expectations and standards by experts about what constitutes “correct” self-management. Participants were subjected by experts to paradoxical expectations of compliance and autonomy. This exercise of power on them was ubiquitous, sometimes obvious and visible, sometimes tacit and subtle.

While the themes of power, knowledge, and technologies of the self in participants’ narratives have been presented separately for the purpose of illustrating the multi-dimensional nature of self-management, they are fundamentally interrelated and interdependent. This is evidenced through the emergence of COPD self-management in the narratives of participants as a site for the interplay of hegemonic power, knowledge, and agency in an enduring dialectic relationship. Foucault (1980, 1988c) viewed agency as always existing in relation to knowledge and the exercise of dominant relations of power. The interrelationship of power, knowledge, and agency in participants’ accounts of self-management therefore reflects his understanding of the relationship between the three concepts.

Together, these interrelated themes represent a narrative of participants exercising agency by constantly negotiating the shifting boundary between power imposed on them by experts and their agency as they engage in self-management. Their agentic negotiation of this boundary was manifested in three ways. Firstly, participants actively negotiated the paradoxical situation they were faced with in which expectations of compliance coexist with expectations of autonomy and self-governance. This was an ongoing process of negotiation in which participants walked a tightrope between being open to the scrutiny of health care professionals and compliance with medico-centric ideals of “correct” self-management on the one hand and becoming autonomous and responsible for the management of the
illness on the other. Secondly, participants exercised agency when they negotiated
the balance between dominant medicocentric knowledge about self-management
versus their own subjugated embodied and alternative knowledge. Finally, people
negotiated their agentic capacity for integrating medicocentric and personal
knowledge and practices in order to construct a unique and individualised
approach to self-management within the delimits and imposition of power by
experts.

For participants in this study, the exercise of agency in self-management was
complex, fluid, and multi-dimensional, and resisted the unquestioning imposition
of medicocentric knowledge and power. Exercising agency was about adapting
and constructing self-management to fit the routines and rhythms of participants’
daily lives. As such, COPD self-management is based on the active negotiation
of power imposed on participants, dominant and subjugated knowledge, and
agency exercised by participants using their experience of living with the illness.

5.7 Conclusion

In this chapter, I have presented the findings of my analysis of participants’
accounts of COPD self-management according to a Foucauldian conceptual
framework based on the three concepts of power, knowledge and agency. I
presented findings which demonstrated how participants’ narratives reveal how
they are both subject to the power imposed by others and at the same time they
are agents of their own self-management practice. I presented findings which
portrayed knowledge as the medium through which power and agency are
exercised. I finished by developing a final narrative of how people with COPD
exercise power through mobilising agency in the self-management of their illness.
In this final narrative, I drew together my findings to demonstrate how people with
COPD exercise agency by actively negotiating the boundary between their agency
and the imposition of power by experts (and sometimes family members). I set
out how this informed their construction of self-management as complex and
dynamic, adapted to suit their individual needs. The next chapter discusses the
findings in the context of the literature on knowledge, agency and power in chronic
illness self-management.
6 Discussion

6.1 Introduction

This chapter discusses my findings in the light of the literature on chronic illness (including COPD) self-management and in the context of my Foucauldian conceptual framework. I conducted a further literature search to facilitate this process. For clarity, the chapter is structured according to my overall Foucauldian narrative of exercising power in COPD self-management (see Section 5.6 of Chapter 5) which brings together the core themes of knowledge, agency and power. While I present the discussion under each of these headings I conclude this chapter by discussing the interrelated nature of each and how people with COPD negotiate the boundary between agency and power. Figure 6.1 illustrates the dialectical relationship between these core themes.

Figure 6.1: Relationship between the three themes of knowledge, agency and power
This additional literature search was conducted using a range of online databases: MEDLINE, CINAHL, PsycInfo, Embase, Web of Science, and ASSIA. I also conducted manual searches of retrieved literature to source further texts. No date limits were applied to these searches. I identified search terms based on the core themes of knowledge, agency, and power. These are presented in the table below.

<table>
<thead>
<tr>
<th>Concept 1</th>
<th>AND</th>
<th>Concept 2</th>
<th>AND</th>
<th>Concept 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td></td>
<td>Chronic illness* OR COPD*</td>
<td></td>
<td>Self-management* OR Self-care*</td>
</tr>
<tr>
<td>Agency</td>
<td></td>
<td>Chronic illness* OR COPD*</td>
<td></td>
<td>Self-management* OR Self-care*</td>
</tr>
<tr>
<td>Technologies of the self</td>
<td></td>
<td>Chronic illness* OR COPD*</td>
<td></td>
<td>Self-management* OR Self-care*</td>
</tr>
<tr>
<td>Power OR empowerment</td>
<td></td>
<td>Chronic illness* OR COPD*</td>
<td></td>
<td>Self-management* OR Self-care*</td>
</tr>
</tbody>
</table>

*a range of synonyms and wild cards were also used as keywords for these concepts

Table 6.1: Search terms used in Discussion literature search

This search yielded two new articles related to COPD and a larger number of studies on other chronic illnesses such as stroke, diabetes, colorectal cancer, chronic pain, inflammatory bowel disease, HIV/AIDS, multiple sclerosis, and cardiovascular disease. This discussion is based on key supporting literature identified as part of the original literature review (Chapter 2) (Thorne et al. 2000, Wilson 2001, Koch et al. 2004, Kendall & Rogers 2007, Seear 2009, Ehrlich et al. 2010, Kendall et al. 2011, Lawn et al. 2011, Apps et al. 2014), key Irish policy and practice documents (Department of Health and Children 2008, Health Service Executive 2008, Health Service Executive et al. 2008, Chronic Conditions Working Group 2017, Health Service Executive 2019a), and the additional literature identified through the search strategy. The literature comprises qualitative research studies, theoretical and discussion papers, and policy and practice documents located in the disciplines of health policy, medicine, nursing, psychology and sociology.

Section 6.2 discusses how the different types of knowledge identified in participants’ accounts and in Irish policy can be mapped to a Foucauldian
understanding of the relationship between knowledge, power and agency and how this compares to the findings of the literature on knowledge and chronic illness self-management.

Section 6.3 examines how the representation of agency in participants' accounts compared to representations in the literature on chronic illness self-management. It discusses the role played by the Foucauldian concept of technologies of the self in agency, and discusses the complex issue of the balance between agency and power in technologies of the self.

Section 6.4 discusses the manifestations of power exercised on people that sets limits on their agency and how this is evidenced in participants' accounts and in Irish policy. The relationship of these manifestations of power to Foucault's conceptualisation of power is discussed in relation to the literature.

The final section (Section 6.5) discusses the interrelationship of these three concepts and how individuals negotiate the boundary between agency and power in their everyday self-management practice.

6.2 Knowledge

Knowledge was identified in participants' accounts as fundamental to self-management. It acted both as a vehicle for the imposition of power by experts on participants, and as a route for agency exercised by participants in their approach to self-management. This reflects the iterative and dialectical relationship between power and agency identified in this study. Participants gave accounts in which medicocentric knowledge was transmitted to them by experts with the expectation that they should use this legitimated, dominant knowledge to practice "good" self-management. In Irish policy and clinical guidelines, this view of the role of medicocentric knowledge in self-management is evident, in which self-management is seen as dependent on acquiring the "right" knowledge about the illness, its signs and symptoms, and appropriate treatment and self-management strategies (Chronic Conditions Working Group 2017, Health Service Executive 2019a). Notably, this expectation was also identified by Ellis et al (2017), in their descriptive qualitative study conducted in the UK to explore how people with chronic illness (n=97), family carers (n=35), health care professionals (n=20) and NHS commissioners (n=22) conceptualised self-management. They found that medicocentric knowledge about chronic illness was seen by health care professionals, NHS commissioners and people with chronic illness as the valid knowledge that should be utilised to enact behaviour expected of a "good" self-
manager, and that failure to do so means that a patient is not self-managing (p. 30).

In the current study, there was an assumption that participants needed to be educated in the “correct” way to self-manage. This is reflected in policy and practice guidelines which have also focused on educating individuals in self-management via the clinical encounter or formal education interventions (Department of Health and Children 2008, Health Service Executive et al. 2008, Chronic Conditions Working Group 2017). Whether medicocentric knowledge is transmitted via formal education interventions or in the clinical encounter, Ellis et al (2017) argued that there is an assumption that people with chronic illness are not knowledgeable enough about self-management and need to be educated in the “right” medicocentric knowledge in order to self-manage.

The policy and practice context and the findings of Ellis et al’s (2017) study demonstrate how medicocentric knowledge is afforded a privileged position in health care discourses of self-management. This is further corroborated by Fletcher et al (2019) who conducted a qualitative secondary analysis of interview and focus group data from a qualitative research study of self-management (n=46) and used a Foucauldian lens to analyse relations of power in stroke self-management. They also identified a view of self-management that linked it to a specialist body of knowledge which affords health care professionals and policy makers privilege and legitimacy over individuals. This process of privileging medicocentric knowledge can be mapped to Foucault’s (1980) understanding of how power is exercised through the leveraging of medicocentric knowledge as dominant and legitimated. This occurs at the expense of other forms of knowledge drawn on by individuals with chronic illness, marginalising and undermining their legitimacy.

Participants in the current study viewed medicocentric knowledge as useful in targeting specific issues that they saw as directly relevant to their ability to self-manage. In this way, they saw health care professionals as the legitimate holders of medicocentric knowledge, but viewed this knowledge as only one type of knowledge, among a range of others, they drew on to self-manage. This is in contrast to Kendall et al (2011), who conducted a critical review of multiple sources of data collected from 2004 to 2008 inclusive. The data sources included all Australian State and national government policy documents pertaining to self-management as well as those derived from large healthcare organisations; and interviews and focus groups with health practitioners, self-management course
leaders, and health ‘consumers’ (the sample size was not provided in this article). They found that participants in their studies held the view that health care professional knowledge was the most valuable form of knowledge, and that self-management fell within the domain of health professionals. This could be due to the fact that the data drawn on by Kendall et al (2011) consisted of interviews with individuals who were participating in trials of formal self-management interventions, which lent self-management a structured clinical focus rather than a focus on everyday informal practice. It is difficult to ascertain the strength of their argument because the sample profile and size for the studies they included in their review is not provided.

Even when participants in the current study received medicocentric knowledge, they exercised agency by engaging with it, using it to inform and shape their self-management practice. They also appropriated it and took ownership of it. They were not passive recipients of medicocentric knowledge, rather, they actively sought it out and incorporated it into their own approach to self-management. Such knowledge was obtained from a variety of sources such as PR, health care professionals, information meetings, reading newspapers or talking to other people with COPD. Other studies such as Hegdal’s (2013) grounded theory study of individuals’ experiences of bodily knowledge and actions that contribute to well-being in chronic illness (n=56) and Johansson et al’s (2015) qualitative phenomenological study of the experiences of individuals learning to live with diabetes (n=12) also found that individuals with chronic illness accessed medicocentric knowledge from these sources and from technical literature, and used it to support their learning to live with and manage chronic illness.

In addition to receiving and utilising medicocentric knowledge from external sources, some participants in the current study had developed their own medical skills and expertise by living with and managing their COPD over time. The significance of this finding is supported by Koch et al (2004), in their multi-method (in-depth interviews and participatory action research groups) qualitative study that aimed to explore the impact of asthma on older people (n=24). They found that participants in their study were experts on their own illnesses, possessing medical knowledge of the management of their illness and using this to monitor changes to medical approaches to illness management. Wilson (2007) conducted a grounded theory study to investigate perceptions and the promotion of patient expertise in the UK (n=163). She also found that people with chronic illness can access clinical knowledge that in the past would only have been available to health
care professionals. In some cases individuals' knowledge can outstrip that of professionals, whose professional knowledge is actually “restricted and impoverished by an absence of knowledge derived from living with the condition” (Wilson 2007, p. 209).

Participants in the current study kept up to date with new clinical treatments for COPD and some brought this knowledge to their health care professionals to inform their treatment plan. In their critical appraisal of national self-care policy initiatives in the UK and Australia, Kendall and Rogers (2007) referred to this process as “lay re-skilling” (Giddens 1991), in which technical knowledge is “reacquired or reappropriated by lay people and routinely applied in the course of their day-to-day activities” (Kendall & Rogers 2007, p. 132). This appropriation of medicocentric knowledge by people with chronic illness equates to a Foucauldian understanding of resistance, in which people aagentically appropriate dominant knowledge for their own purposes and resist the idea that health care professionals and other experts are the only holders of medicocentric knowledge.

For participants in this study, medicocentric knowledge was not the only form of knowledge they drew on to inform their self-management practice. They also accessed a rich body of knowledge that developed as a result of the experience of living with COPD over time. This experiential knowledge has been identified by other authors as the foundation for chronic illness self-management (Paterson 2001, Thorne et al. 2003). These authors found that experiential knowledge was the bedrock upon which self-management is based, and as such forms a source of power for people managing chronic illness, even if this is not always acknowledged as credible by health care professionals (Paterson 2001). In a paper that presented several findings of a grounded theory study of 22 expert self-managers with long-standing type 1 diabetes, Paterson (2001) found that people with chronic illness develop “experiential insights which can be considered as authoritative knowledge and a source of personal power” (p. 575). This knowledge is what individuals consider “legitimate in making self-care decisions and what they mainly weigh in deciding how to manage their illness, even if it contradicts the advice of practitioners” (Paterson 2001, p. 575). Thorne et al (2003), in their qualitative secondary analysis of data from two studies of expertise in self-management decision-making (n=43), also emphasised the practical and authoritative knowledge that people with chronic illness can develop by living with the illness over time, and highlighted that people with chronic illness come to rely
heavily on a knowledge and skill base founded on personal experience with the illness when engaging with self-management.

Notably, in the current study, I found that participants spoke of such experiential knowledge as essentially rooted in the body. The experience they developed over time was about tuning into and listening to their bodies. This “embodied knowledge” (Heggdal 2013) formed the core of their self-management. This finding is supported by other studies that explored the role of embodied knowledge in chronic illness self-management. In the context of COPD, Ehrlich et al (2010) conducted a grounded theory study that aimed to report how people with COPD gather, interpret and apply health affecting information (n=9). They linked the “intimate experiential knowledge and personal theory about the meaning of symptoms” (p. 265) to a process of listening to the body to determine whether and how to take action and to inform self-management. Listening to the body allowed individuals to enact self-management in a useful and personally relevant way, even if this did not coincide with health care professionals’ knowledge and expectations of self-management. This supports the importance of the finding of the current study that the experiential knowledge of participants was in essence embodied knowledge. Subsequent work by Heggdal (2013) and Johansson et al (2015) found that individuals regarded their own bodies as the most valuable source of knowledge for self-management, and that experiencing and reflecting on their bodies’ reactions allowed them to find out what worked for them regarding self-management. As with my study, participants in these studies tuned into their bodies, learned their bodies' tolerance levels, and learned how to interpret bodily signs, symptoms and reactions. Over time, this embodied knowledge was refined, integrated, and expanded, to form the fundamental basis for self-management. This highlights the significance of the finding of the current study that embodied knowledge was mobilised by participants over time to shape and construct their personal approach to self-management. The body became a rich information source which could empower them to self-manage their illness on their own terms, a finding supported by Chen et al (2017a) in their online qualitative study of how people with chronic illness tune into and manage the flow of information from their bodies (n=9).

Participants in the current study described developing embodied knowledge through a process of learning. Studies by Johansson et al (2015) and Chen et al (2017a) have emphasised how people with chronic illness learn individualised approaches to self-management through considerable experimentation and
monitoring of the body's responses. In Johansson et al's (2015) study, they described individuals as learning to self-manage by integrating knowledge about the changes in the body caused by the illness. Interestingly, they linked this learning process to a perceived onus on the part of individuals that they must take responsibility for the management of their illness – a sense of responsibility that participants in the current study also felt. For Johansson et al (2015), learning was inherent to the development of embodied knowledge. Learning meant incorporating the illness and its treatment into daily life and flexibly adjusting to the changes in the body's needs. Chen et al (2017a) also found that learning the body's language and rhythms and tuning into and working with the body were key to effective self-management. They described such learning as a “conversation” with the body, viewing it as a rich and ever-changing source of information. For some participants in the current study, such learning took place via experimentation and trial-and-error as a way of learning about the body and its reactions to the exigencies of COPD and its treatment. Confirming the importance of this finding, this was also found to be the case by a number of authors studying COPD self-management (Ehrlich et al. 2010, Apps et al. 2014, Clari et al. 2017). Ehrlich et al (2010) found that trial-and-error was the main process used for integrating and testing new information and changing health behaviours. Apps et al (2014), in their qualitative descriptive study of the self-care experiences of individuals with COPD in primary care (n=15), also found that participants engaged in trial-and-error to try out different ways of managing symptoms in order to build their confidence in their knowledge of self-management. Clari et al (2017) conducted a qualitative systematic review of literature on self-care behaviours and strategies used by people with COPD (14 included papers covering a total of 262 participants). They reported that individuals adopted strategies without formal instruction from health care professionals. These strategies were learned on a trial-and-error basis and were used to inform effective self-management.

Embodied knowledge in the accounts of participants in the current study sometimes led them to resist their prescribed COPD medication because of negative side-effects of the medication on the body. They mobilised their embodied knowledge to inform adjustments to their regimen to suit the needs and daily rhythms of their bodies. In this way, they resisted the idea that medication was the core of self-management and that health professionals were the only holders of knowledge of medication regimens. This finding is corroborated by Thorne et al (2003), who found that most people in their study had changed the
“amount and timing of prescribed medication because the regimen interfered with how they preferred to live their lives” (p. 1346). They reported that people with chronic illness adjusted routines, dosages, and health care professional recommendations according to an “individualised and finely-tuned sense of what matters in life” (p. 1350).

Embodied knowledge as articulated by participants in this study can be viewed as an example of Foucault’s (1980) concept of subjugated knowledge. It is local, personal, and experiential. It is a way of knowing that belongs to individuals rather than to health care professionals or policy makers. Embodied knowledge is not always recognised as credible by health care professionals, who may delegitimise the knowledge of people with COPD and ally themselves with medicocentric knowledge (Paterson 2001, p. 577). However, this did not deter participants in the current study from developing and drawing on embodied knowledge as a core component of self-management. While embodied knowledge may be pushed to the margins in policy and health care professional discourses, the current study found participants actively leveraged it to inform their individualised approaches to self-management. This provides a good example of agency as exercised via resistance in the Foucauldian sense, whereby participants mobilise their embodied knowledge to resist the hegemony of medicocentric knowledge, and to resist the idea that medicocentric knowledge alone is valid or sufficient for self-management. This reflects Foucault's positioning of the body as a site for the interplay of power and agency (Crossley 1996).

Embodied knowledge was not the only form of subjugated knowledge mobilised by participants in this study to inform COPD self-management. They also drew on knowledge of non-medical complementary and alternative therapies that were not necessarily endorsed by health care professionals – a body of knowledge that is referred to in this study as “alternative knowledge”. Alternative knowledge was integrated with both medicocentric and embodied knowledge to construct participants’ individualised self-management practice. This finding is notable in that it is supported by Thorne et al (2002) who conducted qualitative secondary analysis of a dataset comprised of 63 individual interviews, 42 think aloud recordings, and three focus groups involving a total of 21 Canadian people with chronic illness in order to explore the rationale for decisions to use complementary and alternative medicine. They found that individuals in their study did not view complementary and alternative medicine as fundamentally opposed to
conventional medicine but recognised each as offering different possibilities for achieving the best level of health possible.

The current findings demonstrated how alternative knowledge was shared across a network of peers in their COPD support groups and people in their social networks, via word-of-mouth, or in popular media. This network operated in parallel to more official information channels such as PR or clinical encounters but did not overlap with them. The current study and the work conducted by Thorne et al (2002) suggest that this parallel network was the most important source of alternative knowledge. However, while Thorne et al (2002) found that individuals in their study strove to engage in ongoing dialogue with their conventional health care practitioners about their use of complementary and alternative medicine, participants in the current study did not report sharing their alternative knowledge with their health care professionals. It is difficult to identify a definitive reason for this difference because Thorne et al (2002) did not describe the nature of the sample in their original study in detail, nor did they provide a reference to the original study. However, they indicated that the attitudes of their participants' health care professionals influenced their ability and willingness to talk about their use of complementary and alternative medicine. Participants in the current study may have been reluctant to discuss their use of complementary and alternative medicine with their health care professionals because they anticipated negative or dismissive reactions to their use of such therapies.

Even though they felt that health care professionals would not endorse their use of alternative medicine, participants in this study were not deterred from drawing upon it to inform self-management. Warren et al (2013), in their grounded theory study of complementary and alternative medicine use among Australian people with type 2 diabetes and/or cardiovascular disease (n=69), described the use of complementary and alternative medicine as a form of productive resistance – a way of establishing autonomy in chronic illness. Notably, participants in the current study mobilised alternative knowledge in a quest to improve their health, and a way of resisting the unquestioned imposition of medicocentric knowledge. Complementary and alternative medicine was a system of knowledge that was subversive, local, and popular. It was not endorsed or discussed by conventional health care professionals. As such, it fits with Foucault's (1980) description of the mobilisation of subjugated knowledge as a form of resistance to the power of dominant medicocentric discourses of self-management. Together, embodied and alternative knowledge can be viewed as subjugated knowledge that participants in
this study mobilised agentically to construct their personal self-management practice.

This constant negotiation of dominant versus subjugated knowledge was reflected in participants’ integration of the different forms of knowledge they had access to: medicocentric, embodied, and alternative. The import of this finding has been confirmed by a number of other authors who have also described how people with chronic illness integrate different types of knowledge to create a rich personalised knowledge base to support their practice of self-management (Ehrlich et al. 2010, Heggdal 2013, Warren et al. 2013, Storni 2015). Storni (2015) in particular, in her ethnomethodological study of patient expertise in chronic illness self-care (n.=21), argued against the opposition of medicocentric knowledge contra to the “lay” knowledge of people with chronic illness, and found the two to be intertwined. She argued that individuals actively “integrate, appropriate, contextualise and compromise” medical knowledge with personal knowledge of the illness (p. 1444). In the current study, participants not only integrated but agentically negotiated the emphasis given to different forms of knowledge according to their needs and priorities at different times. However, in the current study, embodied knowledge was the foundation that guided participants in this negotiation. It is notable that this agentic negotiation and integration of multiple sources of knowledge by people with chronic illness is not alluded to in Irish policy and clinical practice guidelines. Instead the focus appears to be on a unidirectional flow of knowledge from health care professionals to individuals with little recognition of the knowledge that they may already hold regarding self-management.

6.3 Agency

One way that participants in this study exercised agency was via the mobilisation and appropriation of knowledge, as discussed in the previous section. However, participants also gave accounts of exercising agency in other ways to resist the reduction of their self-management practice to medical management. The exercise of agency in participants’ accounts is supported by many other authors in the field of chronic illness self-management (Tang & Anderson 1999, Kendall & Rogers 2007, Lawn et al. 2011, Moore et al. 2015, Ellis et al. 2017). In a key early study, Tang and Anderson (1999) examined the interplay of power and agency in narratives of self-management of chronic illness in a secondary analysis of two qualitative critical interpretive studies (n=24) of women’s experiences of living with diabetes. They argued that the women in their study did not surrender their bodies
to the health care system but resisted the role of patient imposed on them by reclaiming agency in their daily management of illness. Kendall and Rogers (2007) traced the emergence of agentic self-managers who viewed themselves as autonomous and reflexive, challenging older ideas of passive patients who unquestioningly followed the advice of their health care professionals. They viewed individuals’ agency in self-management as representing a form of resistance to the power and authority exercised by dominant groups such as health care professionals and policy makers.

Lawn et al (2011) published a discussion paper examining the conceptualisations of responsibility and self-management in Australian State initiatives. They argued that self-management by people with chronic illness is carried out largely beyond the domains of biomedicine. They stated that people with chronic illness exercise agency as they continually make choices about how to live their lives and manage their personal care needs, not necessarily in line with medicocentric expectations and ideals of self-management.

Moore et al (2015), in their descriptive qualitative study drawing on elements of grounded theory (n=21) identified a group of highly engaged self-managers who exercised “full” agency with a high degree of stability and routinised patterns of behaviour. However, they also argued that these individuals provided medicalised narratives of self-management which merged with professional discourses. On the contrary, Ellis et al (2017) equated the “good” self-manager with the ability to act agentically, and to make informed decisions, but not always what health care professionals would recognise as compliant decisions.

This exercise of agency is reflected in the current study by participants’ accounts of engaging in a range of reflexive practices that reflect a holistic view of self-management that accorded with their changing sense of self and the realities of their daily lives, even if this did not coincide with the recommendations of their health care professionals. What was important in these practices was how they mobilised their agency to develop unique approaches to self-management which they integrated with medicocentric interventions to construct self-management as a personal heuristic.

Together, these reflexive practices were designed to enable participants to care for the self in order to achieve happiness, well-being, and the best health possible within the limits of their illness. These reflexive practices constitute a set of “technologies of the self”, which Foucault viewed as operations on the self and the
body in order to enact care for the self. Foucault (1988b) posited that in modern
times, care of the self has come to be equated with constant ongoing care for the
health of the body and the self, becoming “the doctor of oneself” (p. 31) and an
“accomplished counsellor of one’s health” (Moore et al. 2015, p. 1255). In this
context, participants exercised agency by engaging in technologies of the self.

In participants’ accounts, they described using introspection and self-reflection
agentically in order to undergo a process of transformation. Relatively few authors
have examined chronic illness self-management through the lens of technologies of
the self, and none were found in the context of COPD self-management.
However, those that were identified also pointed to the important role that
introspection and reflexivity played in technologies of the self. Fox et al. (2005),
conducted a qualitative study using virtual participant observation and in-depth
online interviews (n=12) with women members of an online forum for users of a
weight-loss drug. They aimed to examine how the women shared information to
become expert in their condition and its management and found that users of the
forum were introspective and reflexive about their condition, and engaged in “a
reflexive project” (p. 1307) constituting a technology of the self. Similarly, Kendall
and Rogers (2007) viewed the growth of reflexive consumers of health care as
having a greater tendency to engage in technologies of the self, that is, to enter a
state of “constant reflexive evaluation” (p. 132).

Leading from this process of introspection and self-reflection in participants’
accounts were more concrete practices designed to nurture health and well-being.
This encompassed engaging in creative activities such as art, nurturing mental
health, looking after the physical health of the body, and establishing daily routines.
This is supported by Powell and Biggs (2004) who published a theoretical paper
that applied a Foucauldian theoretical framework to a critical appraisal of ageing.
While this paper did not discuss self-management, many of its arguments bear
relevance to the issues faced by people with chronic illness when they engage in
care of the self. They identified the maintenance of bodily and mental health in
later life as a manifestation of technologies of the self. They saw exercise, diet
and routine as key ways of shaping the older body and mind. Notably, in the
current study, practices of abstinence and restriction and physical exercise were
operations performed on the body and mind to shape and transform the self in a
quest for health and redemption from the exigencies of COPD. Powell and Biggs
(2004) saw this as a discourse which closely associates the construction of a
healthy lifestyle with positive self-identity. This is echoed in the finding that
participants engaged in technologies of the self as both an agentic and a moral enterprise with the aim of enhancing their self-identities as "good" self-managers.

The potential for transformation identified in participants' accounts of technologies of the self is agentic, in that it allowed participants to mobilise their agency to enter new ways of being and becoming to reach the goals of health and quality of life. For Foucault (1988b) this process of transformation is central to the care of the self and is achieved via technologies of the self. For the participants in this study, transformation meant a profound change in their values, beliefs and self-management practices. The importance of transformation as an element of self-management is supported by authors who examined the concept in the context of living with and managing chronic illness (Paterson et al. 1999, Kralik et al. 2010, Danholt 2013). Paterson et al (1999) conducted a qualitative study based on grounded theory with 22 Canadian people with type 1 diabetes using a modified think aloud technique, formal interviews and focus group interviews. They identified transformation as a core aspect of living with diabetes, resulting in significant changes to the participants' values, beliefs, assumptions and practices in living with diabetes. As with the participants in the current study, the process of transformation in Paterson et al's (1999) study involved reflection on the self and its experiences of living with diabetes, in which health was conceptualised as self-enhancement, transcendence, and balance. Similarly, Kralik et al (2010), in their qualitative participatory action research study based on longitudinal emails as data (n=42), found that people living with chronic illness described the process of self-care as transformational in terms of self-identity. They argued that self-care was “entwined with a sense of ‘being’ and ‘becoming’” (Kralik et al. 2010, p. 200). Danholt (2013) conducted an ethnography to investigate the day-to-day practices of managing diabetes, using observation and qualitative interviews (n=8). He found that participants were engaged in an ongoing process of transformation of the self, with a persistent and enduring process of forming and reforming the self anew.

This is in line with Foucault's view that transformation via technologies of the self is never final or total, but always ongoing. Participants in the current study similarly gave accounts of technologies of the self in which they described an ongoing process of change. Paterson et al (1999) also found that transformation in their participants’ accounts was never final. Kendall and Rogers (2007) saw this potential for ongoing transformation and refusal of individuals to be defined in a finalising way as inherently agentic.
Although participants in the current study gave accounts which illustrated the agentic aspect of technologies of the self, their accounts also revealed the imposition of power that bound and constrained them. Foucault (1988b) viewed technologies of the self as always shaped and performed in accordance with the standards and expectations of the wider sociocultural context, and in this study by health care professionals and other experts. In this study, technologies of the self were not only agentic, but constrained by the expectations and standards of biomedicine, open to scrutiny, discipline, and responsibilisation. This tension between the agency of participants and the power imposed upon them as they self-manage ran throughout the findings of the study and is reflected in the literature on technologies of the self in chronic illness. Some authors emphasise the interrelationship between agency and power in technologies of the self (Powell & Biggs 2004, Naue 2008), whereas others focus on technologies of the self as solely practices of power (Fox et al. 2005, Moore et al. 2015). Fox et al (2005) stated that participants in their study faced a paradoxical situation in which engagement with peers on an online forum appeared as a “radical, democratising process” (p. 1305), giving the patient control over their options for weight management. However, they argued that participants were (intentionally or unintentionally) accepting and perpetuating a constraining biomedical perspective that a “faulty body” could be “treated” (p. 1305). According to the authors, participants in their study had adopted and espoused dominant sociocultural norms of acceptable weight and biomedical views of overweight as an illness. In this regard, Fox et al (2005) argued that self-management and the development of patient expertise constitutes a technology of the self, emphasising it as a site of power, “a disciplining of the body in relation to dominant systems of thought” (p. 1307). Moore et al (2015) asserted that technologies of the self in coronary heart disease self-management are to be understood as a form of self-discipline, self-control, and personal subjection (p. 1255). They viewed technologies of the self as a form of self-regulation performed by an “altered, coerced individual” (p. 1255), consisting essentially of self-surveillance and lifestyle change, health behaviour and risk management.

Participants in my study did provide examples of technologies as sites of power, for example in the cases of practices of abstinence and restriction, exercise, and routine, in order to perfect the self as a “good” self-manager. Concepts such as happiness, health, and “good” self-management were defined by society and biomedicine in terms of Neoliberal ideals of well-being, responsibility, autonomy
and compliance. However, power was neither final nor totalising in participants’ accounts of technologies of the self in this study. Whereas Fox et al (2005) and Moore et al (2015) both link technologies of the self to the perpetuation of a medical model of self-management, participants in the current study engaged in technologies of the self that encompassed a more holistic view of self-management as nurturing and caring for the self in psychological and creative ways, and undergoing a transformation of the self beyond the confines of biomedicine.

Possible reasons for this divergence in findings regarding agency and power in technologies of the self include the nature of the sample in Fox et al’s (2005) study. The sample was drawn from members of an online forum for users of a weight-loss drug. This could have resulted in a bias towards people who had already chosen to use a medical treatment for overweight and thus were more likely to subscribe to a medicocentric view of overweight and its management. In addition, the topic of the forum was centred around the use of the medication and its side-effects which may have meant that non-medical aspects of self-management and technologies of the self were under-represented in participants’ online discourse. In Moore et al’s (2015) study, participants were classified into “engaged” and “burdened” self-managers. Technologies of the self were associated exclusively with “engaged” self-managers, which they viewed as highly medicalised in their approach to self-management. In the current study, participants were not classified in this manner and each narrative was treated as unique and individual. I therefore avoided imposing a classification system on such a complex, fluid, and dynamic concept as self-management. This may explain why the technologies of the self identified in participants’ accounts in this study encompassed a more holistic set of practices than described in Moore et al’s (2015) study and included aspects of agency as well as strategies of power.

Participants in my study gave account of technologies of the self in which agency was represented in a dialectic with power, and in which they constantly negotiated the balance between the two. Technologies of the self are therefore a site where both agency and power are interwoven to shape COPD self-management. This important finding is supported by Naue (2008) in her paper discussing the impact of the concept of self-care on people with Alzheimer’s disease. She argued that technologies of the self comprise both agentic action and the imposition of power. Individuals enact agency through technologies of the self, but this takes place within the borders of interpretation by dominant groups of essential concepts (such
as “good” self-management). Powell and Biggs (2004) viewed technologies of the self as agentic in that they allow individuals to transform themselves through self-management, and to accept or reject certain truth claims of biomedicine based on their own experience. They argued against viewing agency and power in technologies of the self as opposing each other. Rather, they believed they should be viewed as intertwined and interacting. They highlighted Foucault’s (1993) emphasis on the importance of exploring the relationship of both agency and power in technologies of the self by identifying examples of where the two meet and intermingle. In the following section, I discuss how the agentic practices identified in participants’ accounts are circumscribed by the imposition of power.

6.4 Power

The findings of this study supported by the literature on power and self-management of chronic illness support a Foucauldian conceptualisation of power as exercised on people with COPD via the imposition of standards and expectations of experts, surveillance, discipline, and responsibilisation. Wilson’s (2001) theoretical discussion paper examining the Expert Patient Programme in the UK discussed the contribution that a Foucauldian perspective on power can bring to understandings of self-management, allowing for an understanding both of power as exercised on people with chronic illness and power as exercised by people as they actively attempt to negotiate the balance between power and agency.

The accounts of participants in the current study presented how power is exercised on them by key stakeholders in their lives as they navigate the complexities of self-management. The findings of identified a persistent tendency for health care professionals and other experts to attempt to assert a privileged position over participants’ self-management practice, assuming the power to identify what “good” self-management consists of. Notably, this is supported by a number of studies that have examined the relations of power underpinning chronic illness self-management. Tang and Anderson (1999) found that biomedicine had been positioned as “science,” and therefore positioned in a hegemonic relationship to other discourses of self-management. In this way, Tang and Anderson argued that “expert” knowledge was valued over the experience of the women in their study, and that self-management is therefore constructed within a hierarchy of power relations. Subsequent work by other authors also strengthen the importance of this finding by identifying a tendency to cast the person with chronic
illness in a subjugated role compared to health professionals, policy makers, and other “experts”. These authors critically analysed the imposition of power as reinforcing expectations of compliance with what is judged by “experts” to be ideal self-management (Koch et al. 2004, Kendall & Rogers 2007, Kendall et al. 2011).

These studies support my finding that health care professionals and other experts exercised power through imposing expectations of compliance and medicocentric standardisation of self-management that people with COPD should strive to meet, for example, with regard to ideals of diet and weight, taking medications, or exercising. This focus on compliance reported by the participants in my study was related to a conceptualisation of self-management as existing in an ideal state – an ideal that participants strove to attain. This was a theme that was also identified in Irish policy on chronic illness self-management. Although some documents refer to the active participation and empowerment of people with chronic illness (Department of Health and Children 2008, Health Service Executive 2008, Health Service Executive et al. 2008), in the main, and particularly in more recent documents (Chronic Conditions Working Group 2017, Health Service Executive 2019a) the focus of self-management policy is on patient education, behaviour change, and medical self-management action plans. This betrays an assumption that “ideal” self-management rests within the domain of health care professionals and policy makers, undermining the agency of people with chronic illness.

Ellis et al (2017) linked this idealisation of self-management to the notion of the “good” self-manager who engages in positive self-management strategies, such as adopting healthy lifestyles and taking regular exercise. They argued that this positions individuals as either being “good” or “bad” self-managers, according to the standards and expectations of health care professionals. Significantly, this idea of “good” self-management was identified throughout my findings as participants strove to correct and perfect themselves according to the norms and standards set by experts.

Both the literature and the findings show how health care professionals attempt to exert such dominance through the imposition of their own standards and expectations, and manifest this through the scrutiny and discipline of individuals’ private everyday lives. This study found that scrutiny and discipline was a pervasive feature in participants’ accounts of self-management. This extension of scrutiny and discipline into individuals’ private lives equates to the Foucauldian concept of pastoral power. Very little literature could be found that examined this in detail, however, as discussed in Chapter 2, one study (Wilson 2001) is of note
because it used pastoral power as a concept to illuminate how the most intimate areas of a person’s life fall under the gaze of the health system in the context of self-management. Wilson (2001) argued that State-sponsored self-management initiatives constitute a form of pastoral power, where the lifestyle habits and way of life of a person with chronic illness become the focus of scrutiny of the health system and health professionals that work within it. In another study, Fox et al. (2005) criticised the exercise of pastoral power in State-sponsored self-management initiatives, where the patient is both positioned as being informed and engaged, while at the same time left open to scrutiny and discipline. This paradoxical exercise of pastoral power was also evident in Irish chronic illness and COPD management policy (Health Service Executive 2008, Health Service Executive et al. 2008) in which the need for an engaged and informed population is set against the need to educate, scrutinise and discipline individuals in terms of their lifestyles and behaviour beyond the medical encounter.

Significantly, I found a similar contradiction in participants’ accounts. In this way, pastoral power was utilised as a technique for the responsibilisation of people with COPD by health care professionals and individuals with COPD themselves. The findings of the analysis of participants’ accounts in the current study explicated how pastoral power was manifested in their interactions with key stakeholders such as health care professionals and in some cases family members, as well as in their own self-management practice.

In keeping with the findings of this study, a number of studies examined the process of responsibilisation in depth. As discussed in Chapters 2 and 3, responsibilisation is a Foucauldian concept, rooted in his work on governmentality. It is a “technique for directing human behaviour” (Rose et al. 2006, p. 1). The emphasis on the intertwined ideals of autonomy and surveillance reveals responsibilisation to be a strategy of power (Raitakari et al. 2019).

Authors have highlighted the process of shifting responsibility for the management of chronic illness from the State to the individual, while at the same time retaining the power to determine “good” self-management (Kendall & Rogers 2007, Kendall et al. 2011, Lawn et al. 2011, van de Bovenkamp & Dwarswaard 2017). Van den Bovenkamp and Dwarswaard (2017), in their qualitative study exploring how patient self-management is shaped in everyday practice (n=20), argued that this leads to individuals being held responsible for their own self-management while at the same time being expected to comply with a medicocentric ideal of self-management.
This process was also identified in the practice of health care professionals by Seear (2009) who conducted a qualitative study of the experiences of 20 Australian women living with endometriosis, using semi-structured interviews in order to examine how women become experts in their own care. She adopted Novas and Rose’s (2000, p. 489) term “proto-professionals” to describe how health care professionals constructed women with endometriosis as responsible for their own healing and health in line with the expectations and standards of professionals. Seear’s findings highlight the important finding in this study that such processes of responsibilisation represent the extension of power into the private domain of individuals. The process of responsibilisation is described by authors as embedded in the socio-political context of Neoliberalism, which places emphasis on individual responsibilities over rights (Horton 2007, Seear 2009). Interestingly, in the literature, responsibilisation was linked to a sense of morality, of being a “good” self-manager, which was also found to be the case in this study. In keeping with the findings of the literature review (Chapter 2), Kendall et al (2011), Lawn et al (2011) and van de Bovenkamp and Dwarswaard (2017) pointed to the moral value ascribed to responsibilisation. This corroborates my finding that some participants viewed taking responsibility for self-management as a moral obligation to do what was right for themselves and for their families. This was particularly evident in participants’ frustration with peers who they felt were not taking responsibility for their own health. Ellis et al (2017) found that to take responsibility for self-management is to fulfil a moral obligation not only to oneself, but to one’s family, peers, and to society, by reducing one’s dependency on the State. They found such discourses of responsibilisation not only in accounts of health care professionals and policy makers, but also in accounts of individuals and caregivers.

In this study, participants had to negotiate the expectations of responsibility and autonomy placed upon them to reduce their dependency upon health professionals, against the expectation that they should attend health professionals promptly. Significantly, Ellis et al (2017) also found a contradiction between health care professionals’ ideas of responsibility and appropriate use of health care services and individuals’ ideas of “good” self-management as seeking help from health care services early to prevent complications. This “responsibilisation paradox” was highlighted by many authors (Wilson 2001, Fox et al. 2005, Ellis et al. 2017, van de Bovenkamp & Dwarswaard 2017) as pervasive throughout self-management policy and clinical practice. It was also
identified in Irish chronic illness and COPD management policy and practice guidance. For example, in the 2008 National Respiratory Strategy (Health Service Executive et al. 2008), the need to empower individuals to actively manage their condition is set out alongside the need to ensure patient education and compliance with medical treatment. Similarly, in the Framework for Self-Management Support (Chronic Conditions Working Group 2017), the ideal self-manager is presented as informed and engaged, confident and autonomous, and at the same time compliant with an agreed care plan with health care professionals and educated in the “right” knowledge for self-management. The Health Service Executive’s (2019b) End-to-End COPD Model of Care also presents an aim of building confidence in self-management skills against a stated need to ensure compliance with the “therapeutic, behavioural and environmental adjustments required to maximise patients’ control over their COPD” (p. 39).

Thorne et al (2000) conducted a secondary qualitative analysis of the experiences of 35 individuals with long-standing chronic illness and examined their reports of interactions with health care professionals. They found evidence of a general disbelief on the part of professionals in individuals’ ability to make “good” self-management decisions autonomously, running alongside an expectation that individuals should become autonomous and active self-managers. They found that when participants in their study attempted to modify their adherence to prescribed regimens in order to live as well as possible, their efforts were typically met with considerable resistance by health care professionals. In line with these findings, participants in the current study adjusted treatment regimens and had recourse to alternative therapies not recommended by health care professionals. They did not always tell their health care professionals about self-management practices that were not in line with professionals’ recommendations. This was also found to be the case by Thorne et al (2000), where participants “pretended” compliance with professionals when their knowledge and skills led to a self-management decision that differed from the recommendations of their health care professionals.

6.5 Negotiation and integration

The constraints of power described in the previous section set limits on the agency of participants in this study as they practiced self-management but did not dictate their self-management to point that their agency was negated. Power may have been exercised on participants in different ways, but this power was not absolute.
Participants in this study constantly negotiated the balance between the exercise of power on them, and the exercise of power by them as agency. This dialectic and iterative relationship between power and agency identified in participants' accounts is supported by the number of authors who described both power and agency simultaneously in their analysis of chronic illness self-management (Tang & Anderson 1999, Koch et al. 2004, Kendall & Rogers 2007, Wilson 2007, Naue 2008, Lawn et al. 2011, Moore et al. 2015, Ellis et al. 2017, Fletcher et al. 2019). In particular, Wilson (2007) found that the individuals in her study were very aware of the power of dominant discourses in self-management but had learned how to navigate the competing medicocentric and personal perspectives on self-management. However, she argued that this came at a cost to themselves, for example tension in their relationships with health care professionals, the shifting of responsibility from health care professionals, or the extension of surveillance into the private domains of individuals. In the current study, participants reported tension and uncertainty when their own approach to managing COPD were not in line with the expectations of their health care professionals, and when they were perceived as failing to live up to the expectations of responsibility placed upon them. Nevertheless, this did not appear to stop participants from quietly and consistently constructing their own unique and individualised self-management practice based on their appropriation and mobilisation of knowledge and the development of personal self-management practices over time. Ellis et al (2017) explicitly explored how participants in their study negotiated the boundary between power exercised on them and their agency. They found that everyday experiences of living with chronic illness were about balancing medicocentric expectations of compliance against making self-management decisions influenced by lifestyle and social well-being and sometimes prioritised these over complying with medical advice. They located patient agency in a context in which individuals negotiate making decisions that were compliant and those that were noncompliant but influenced by a sense of self, the demands and rhythms of everyday life, and meaningful participation in social life. Ellis et al's (2017) study support the findings of the current study that participants actively negotiate their agency with the constraints of power. This negotiation is at the core of Foucault's (1993) recommendation that the nexus between agency and power, the point at which the two meet and interact, should be the focus of scholarly inquiry.

This negotiation of agency and power identified in the current study resulted in individuals actively integrating medicocentric and experiential practices into an
individualised and unique approach to self-management. The complex, dynamic and individualised nature of self-management described in the findings and in the literature supports an experiential conceptualisation of self-management as discussed in the literature review (Chapter 2). In constructing self-management as a complex, dynamic construct integrating medico-centric and experiential aspects of self-management, participants in the current study did not follow a distinction between “self-care” (as self-directed and self-initiated action to maintain life, health and well-being) and “self-management” (as disease-specific activity to minimise the impact of a chronic illness). Rather, self-management encompassed all of these activities and arose from the participants themselves. This supports my use of the term self-management to refer to activities undertaken to manage the holistic experience of living with COPD every day according to the perspective of individuals with COPD

Participants’ exercise of agency was necessarily fluid and responsive to the demands of COPD, their changing sense of self, their daily lives, and expectations placed upon them. This required them to maintain equilibrium between the demands of medico-centric conceptualisations and their own experiential understanding of self-management. COPD self-management therefore draws upon agency while at the same time it is shaped and constrained by existing relations of power.

6.6 Conclusion

The discussion of the findings of this study in the light of previous research has highlighted how people with COPD exercise agency in self-management in fluid and dynamic ways, always intertwined with the constraints of power. Agency was found to be exercised through the appropriation and mobilisation of knowledge in its different forms: medico-centric, embodied and alternative. Previous research supports the finding that using such knowledge was central to individuals constructing an individualised and heuristic practice of self-management that integrated medico-centric and personal experiential aspects. Together, my findings and the literature support the contention that knowledge is a vehicle for the exercise of agency when taking the perspective of individuals’ personal everyday self-management practice.

The literature also supports my finding that self-management constitutes a set of technologies of the self, consisting of a range of reflexive practices designed to achieve health, well-being, and transformation. Previous research supported the
importance of transformation for individuals practicing self-management. In this sense, self-management is about more than medical management but is a holistic concept encompassing emotional, social, physical and spiritual transformation of life with COPD. There was disagreement in the literature as to the extent to which technologies of the self in self-management allow for the exercise of agency. However, there were caveats attached to both studies that advocated a view of technologies of the self as solely strategies of power. Ultimately, I contend that technologies of the self in COPD self-management are sites of both agency and power. This finding is new to the study of COPD, but supported by previous work in the fields of Alzheimer’s disease and ageing.

However, there was strong evidence to support the finding that power is ubiquitous and interwoven with both the use of knowledge and exercise of agency via technologies of the self. My finding that power can be linked to Foucauldian concepts of pastoral power and responsibilisation were corroborated by the literature. Essentially, the exercise of agency is bound and delimited by these constraints of power. In relation to this, my findings and the literature combine to shed light on how individuals negotiate the boundary between agency and power in everyday self-management. This offers a new perspective on reconciling and uniting the concepts of agency and power in COPD self-management.

This is the first study that has applied a Foucauldian framework that unites the three concepts of knowledge, agency and power to the study of COPD self-management. This framework is particularly suited to the complex, holistic, and ubiquitous nature of self-management. Relations of power and agency in accounts of COPD self-management fit with Foucault’s understanding of the concepts, as omnipresent and operating at the micro-level of social relations, as well as in policy and clinical practice. Together, my findings and the literature support the applicability and relevance of a Foucauldian conceptual framework to understanding the experiences of people with COPD as they self-manage.

The following chapter concludes this thesis by discussing the implications of the study and makes recommendations in the context of recent developments in policy and practice regarding chronic illness and COPD management in Ireland.
7 Conclusion, implications and recommendations

7.1 Introduction

The final chapter of this thesis discusses the implications of the findings regarding the exercise of power through the mobilisation of agency in COPD self-management. Leading from this, recommendations for policy, service provision, education, and research are presented. These recommendations should be read in the light of the context and setting of the study, the challenges encountered, and the steps taken to ensure its quality and rigour as set out in Chapter 4. The study’s novel contributions to the knowledge base are discussed. The chapter concludes with a discussion of the limitations of the study.

7.2 Summary of findings

The findings of the study show that people with COPD exercise agency in a number of ways, demonstrating their skills and resourcefulness in practicing self-management. They resist the imposition of power by leveraging and mobilising medicocentric, embodied, and alternative knowledge. In doing so they resist the idea that only health care professionals and other experts have access to legitimate knowledge for self-management. They view all these types of knowledge as fundamentally important to provide them with a basis for constructing their own self-management practice. Exercising agency is also achieved by engaging in technologies of the self – practices designed to operate on the self and the body in order to achieve happiness and health. In engaging in these technologies of the self, individuals with COPD undergo a transformation in their outlook on life with COPD and who they are as people living with and managing the illness. However, this agency is constrained by the imposition of power by others – health care professionals, other experts, and sometimes family members. This delimits the boundaries of their agency. They are subject to surveillance and discipline and are held responsible for the management of their illness while still expected to comply with the knowledge, expectations and standards of health care professionals and other experts. This leads to an important finding of this study: that people with COPD are in a process of constant negotiation of the boundary between power and agency. This reflects Foucault’s understanding of power, knowledge and agency as existing in a continuous, iterative and dialectic relationship. The process of negotiation results in individuals actively integrating medicocentric and experiential aspects of self-management.
7.3 Implications of the study

This is the first study in Ireland and internationally that has examined how people with COPD exercise power in the self-management of their illness. Although narrative inquiry does not aim to achieve generalisability of findings to other settings, I contend that this study has processual generalisability (Stoddard 2004). The discussion (Chapter 6) demonstrates how the findings of this study compare with research conducted on other chronic illnesses. The study also demonstrates analytic generalisability (Sandelowski 2004), in which deep understanding has been created which can contribute to wider knowledge (Braun & Clarke 2013). The research approach adopted in this study enriches and deepens the knowledge of power in self-management by shedding light on how individuals with COPD exercise power through mobilising agency in their self-management practice. This adds a valuable insight and contribution to the literature on COPD self-management. In addition, the detailed, step-by-step description of how I went about analysing the data using thematic template analysis offers the opportunity to share with other researchers my experience of combining a Foucauldian theoretical framework with narrative thematic analysis to produce new knowledge about COPD self-management.

The findings of this study offer insight and contribute to the knowledge on this topic by showing how the medicocentric and experiential conceptualisations of self-management identified in the literature review can be brought together to explicate a united and holistic understanding of the exercise of power in COPD self-management. The findings also show how a Foucauldian perspective on power, knowledge, and agency can contribute to the knowledge base by shifting the focus from a one-dimensional medicocentric view of self-management to a more holistic perspective based on both medicocentric and experiential aspects integrated into a complex and multi-dimensional concept. The Foucauldian final narrative of the dialectical relationship between power, knowledge and agency reveals the shifting boundary between power and agency in COPD self-management, and how participants in this study showed considerable resources and skill in negotiating this boundary when they self-manage. However, this can be a burdensome process. These findings demonstrate the need for an acknowledgement in COPD self-management policy, practice and research of the complex interweaving of medicocentric and experiential aspects of self-management by people with COPD, as well as an acknowledgement of the skilled work that people with COPD put into their everyday self-management practice.
However, the research and policy literature on COPD self-management shows the dominance of a medicocentric conceptualisation of COPD self-management as education, behaviour and lifestyle changes, and compliance with the direction of health care professionals and other experts. There is less focus on how people with COPD self-manage beyond the remit of the clinical encounter. It is also concerning that there are many people in Ireland who have COPD and yet are undiagnosed. Many people are not told that they have COPD by their health care professionals. COPD in general tends to be an overlooked illness (Health Service Executive 2019a). This undermines the ability to obtain a clear picture of the prevalence of COPD and the needs for self-management support of people with COPD. It hinders the building of a comprehensive approach to self-management support. In addition the lack of information provided to people with COPD undermines their ability to access the resources they need to self-manage. A perceived lack of knowledge on the part of primary health care professionals can lead to a reductionist view of self-management as medicocentric management and can act as a barrier to open and effective communication between health care professionals and people with COPD.

The recent policy and practice developments in Ireland such as the Framework for Self-Management Support (Chronic Conditions Working Group 2017) and the End-to-End COPD Model of Care (Health Service Executive 2019a) offer an opportunity to bring COPD into focus as a complex chronic illness that demands significant self-management input from individuals. The Framework for Self-Management Support recommends embracing a person-centred, empowering approach to chronic illness self-management in which the individual is the “leading partner in managing their own life and conditions” (Chronic Conditions Working Group 2017, p. 12). The End-to-End Model of Care proposed a significant increase in resource, the development of new integrated care pathways, the appointment of integrated care nurses and physiotherapists and the resourcing of multi-disciplinary teams, all of which enhances the opportunity to improve and expand holistic self-management support to people with COPD. However, when it comes to concrete actions to support patient self-management in COPD, both these documents demonstrate a tendency to reduce self-management to action plans (appropriate action to be taken in the case of an exacerbation), COPD-specific education and training, behaviour change, and compliance with health care professionals’ recommendations.
It is therefore my contention that the process of honouring and leveraging the considerable resources of people with COPD to self-manage should form the heart of person-centred self-management support. If the power of professionals and experts is left unaddressed, people with COPD run the risk of being left in a paradoxical situation created by conflicting expectations of autonomy, responsibility and compliance. The important role that professionals play in recognising individuals’ own knowledge and agency in practicing self-management must be highlighted. The significance of individuals’ profound exercise of agency in self-management may be overlooked if too much focus is placed on a reductionist medicocentric conceptualisation of self-management. The agency of people with COPD and their ongoing negotiation and construction of self-management as a unique and individualised practice needs to be recognised by health services. So too does an understanding of COPD self-management as holistic, complex, multi-dimensional and personal and socially constructed. Only then will people with COPD be adequately supported to self-manage. If interactions with health care professionals and other experts focus on clinical assessment, direction, and compliance, medicocentric perspectives on self-management will continue to dominate and people with COPD may well quietly go about their own approach to self-management without communicating their knowledge and skills to their health care professionals. This would result in a missed opportunity to place the individual at the heart of care and decision-making. It would also result in a failure to honour and utilise individuals’ self-management knowledge and skills to inform and enrich not only the individual’s practice, but that of other people with COPD, and the development of self-management knowledge on the part of health care professionals.

This study has been completed at a serendipitous point in Irish policy and practice on COPD self-management. The increased focus on COPD is an opportunity to recognise and incorporate the sophisticated self-management knowledge and skills of individuals with COPD. In order to operationalise this understanding the following sections set out recommendations for policy and practice, education, and research.

7.4 Recommendations for policy, service provision, education and research

7.4.1 Policy recommendations

7.4.1.1 Co-design of policy and strategy
The ongoing implementation of the Framework for Self-Management Support published (Chronic Conditions Working Group 2017) should incorporate the knowledge and agency of people with COPD into the co-production of implementation actions. This can be achieved by collaborating with people with COPD through service user panels and engaging with patient representative organisations.

Service user panels are representative, consultative bodies of health service users, in this instance, people with COPD. They are typically used by statutory agencies to identify policy priorities and to consult service users on specific issues. Service users who agree to participate are invited to a rolling programme of research, consultation and co-production of policy, strategy, and service delivery planning68. Samples of people with COPD can be recruited from the service user panel to engage in more intensive policy co-production such as action planning which is designed to produce grassroots knowledge to feed into policy design and implementation. Service user panels should be resourced and funded by the HSE and utilised by the National Lead for Self-Management Support, the National Oversight Group for Self-Management Support, and the National Self-Management Support Programme Team to engage in co-production of self-management support policy implementation.

Patient representative organisations are a valuable route to understanding the perspective of people with COPD and family carers on a national level. These organisations should be co-opted on to self-management policy implementation bodies such as the National Oversight Group and the National Self-Management Support Programme Team.

7.4.1.2 Incorporate engagement with people with COPD into implementation actions

The lead actors in the implementation of the Framework for Self-Management Support (e.g. the National Lead for Self-Management Support, the National Oversight Group for Self-Management Support, and the National Self-Management Support Programme Team) should target their engagement with people with COPD via service user panels and patient representative organisations in order to utilise their knowledge and agency in the following key implementation actions:

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68 https://www.involve.org.uk/resources/methods/citizens-panel
• Meaningfully position people with COPD as “active partners in their health care” (Chronic Conditions Working Group 2017, p. 7)
• Identify patients’ and carers’ needs, priorities and preferences for self-management support
• Develop partnerships with patient representative organisations to support self-management. This can be achieved by inviting patient representative organisations onto policy and strategy working groups and treating their input as equal to that of policy makers, health care professionals and clinical leads

7.4.1.3 Value the knowledge and agency of people with COPD in self-management policy

Cross-cutting these specific actions is the need for lead actors in the implementation of the Framework for Self-Management Support to use the learning from engagement with service user panels and patient representative organisations to:

• Understand COPD self-management from the point of view of people with COPD as holistic, dynamic, nuanced and multi-dimensional
• Promote the value of COPD patients’ knowledge and agency in self-management by sharing learning from engagement with people with COPD with implementation partners (people with COPD, statutory agencies, service planners and managers, community and voluntary organisations, and health care professionals)

7.4.2 Service provision recommendations

7.4.2.1 Co-production Partnerships

The Self-management Support Co-ordinators that are planned to be appointed in all Community Healthcare Organisation (CHO) 69 areas should support the integration of the knowledge, experience and agency of people with COPD into self-management support service provision planning and delivery. This can be achieved by recruiting and resourcing people with COPD to take part in the design, development and implementation of COPD self-management support using a Co-production approach. Co-production refers to a way of working where service providers and users work together to achieve a collective outcome. It is recommended that a self-management Co-production Partnership be set up in

69 CHOs are HSE-run organisations which cover services provided outside of the acute hospital system including primary care, social care, mental health, and health and wellbeing services. See https://healthservice.hse.ie/healthcare-delivery/.
CHO areas, managed by Self-management Support Co-ordinators and funded by the HSE workstream for the *Framework for Self-Management Support* (Chronic Conditions Working Group 2017) and integrated with the local delivery of the *End-to-End COPD Model of Care* (Health Service Executive 2019a). Integration with the Model of Care is facilitated by including key health care professionals (Respiratory Integrated Care Clinical Nurse Specialists, general practitioners, and members of the COPD Outreach Team) in the partnership. It is therefore recommended that Self-Management Support Co-ordinators should identify and invite partners in the CHO area to participate in the networks. These should include:

- People with COPD and their family carers (via the Service User Panels recommended in section 7.4.1.1)
- Representatives of local COPD support groups (via COPD Support Ireland – the national patient representative organisation)
- Service managers and planners
- Health care professionals (including Respiratory Integrated Care Clinical Nurse Specialists, general practitioners, and members of the COPD Outreach Team)
- A Co-production co-ordinator should be appointed to moderate, facilitate, and manage the partnership.

Key tasks of the Co-production Partnership should include:[70]:

- Supporting people with COPD and their carers to contribute to the design and development of self-management support service provision in the context of the *End-to-End COPD Model of Care*
- Resourcing and supporting people with COPD and their carers to:
  - Contribute to partnership meetings
  - Lead peer mentoring support sessions
  - Deliver self-management training
  - Inform the implementation of the *Framework for Self-Management Support* in their CHO area.

[70] http://www.lgowit.org/
A useful way to initiate Co-production Partnerships is to collaborate with international well-established Co-production organisations such as the Scottish Co-production Network\(^{71}\) to provide training and information on Co-production.

### 7.4.2.2 Personal Outcomes Approach

In order to support people with COPD to make their own informed choices about how and when to draw on self-management support, health care professionals need to respect the needs, desires, and priorities of people with COPD. One way of doing this is by using a Personal Outcomes Approach (Curtice & Greig 2020). This consists of a structured conversation that explores what matters to the person and elicits their own knowledge and agency in self-management. It consists of three stages: engagement, recording information and using information to make decisions (see Box 7.1)

<table>
<thead>
<tr>
<th><strong>Engagement</strong></th>
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<tbody>
<tr>
<td>Engaging with people with COPD about</td>
</tr>
<tr>
<td>• What is important to them in life</td>
</tr>
<tr>
<td>• Why these things are important</td>
</tr>
<tr>
<td>• How to go about achieving these things</td>
</tr>
<tr>
<td>• Who will be involved (the person, their carers, family and community and services</td>
</tr>
<tr>
<td>• When and where</td>
</tr>
<tr>
<td>• The extent to which these personal outcomes are being achieved – facilitators and barriers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Recording this information</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualitatively in the language used by the person with COPD</td>
</tr>
<tr>
<td>Summarised using personal outcomes scales</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Using this information</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Using the information recorded in decision making about treatment, care, and self-management support</td>
</tr>
</tbody>
</table>

**Box 7.1. The stages of a Personal Outcomes Approach (Personal Outcomes Collaboration)\(^{72}\)**

The Personal Outcomes Collaboration website\(^{73}\) has collected training materials and resources on this approach for health care professionals and service users.

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\(^{71}\) [http://coproductionscotland.org.uk/](http://coproductionscotland.org.uk/)

\(^{72}\) [https://personaloutcomescollaboration.org/](https://personaloutcomescollaboration.org/)

\(^{73}\) [https://personaloutcomescollaboration.org/](https://personaloutcomescollaboration.org/)
7.4.3 Education and training (health professional) recommendations

7.4.3.1 Training in public and patient participation in self-management support

A training module in public and patient participation in self-management support including specific training on co-production and the Personal Outcomes Approach should be designed for inclusion into the education and training of Self-Management Support Co-ordinators and health care professionals. This should be developed and managed by the National SMS Programme Team in partnership with the Integrated Care Programme for the Prevention and Management of Chronic Disease (ICPCD), further and higher education institutions, the Irish College of General Practitioners, the Making Every Contact Count Team (MECC), Self-Management Support Co-ordinators, and other national training bodies for health care professional groups. This training module should be delivered at the following levels:

1. Inclusion into the standard curriculum for chronic disease prevention and management at undergraduate level
2. Post-graduate training in self-management support for health care professionals

An example of such training and education in public and patient participation in health care is that provided by the UK-based Social Care Institute of Excellence74.

7.4.4 Education and training (individual level) recommendations

7.4.4.1 Delivering training in public and patient participation in health care

Training in public and patient participation in health care should be offered to people with COPD who wish to participate in the design and delivery of self-management support, either via service user panels or co-production. This should include general skills needed for public and patient participation covering:

- Communication, negotiation and assertiveness skills
- Presentation skills
- Committee process

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74 www.scie.org.uk/training/co-production/introduction
• The COPD self-management support context (policy, organisation and delivery of service)
• Auditing and evaluating services
• Networking skills (adapted from Delaney et al 2003).

Training should also be provided on skills specific to Co-production including
• Choosing a topic or issue relevant to COPD self-management support services
• Mapping stakeholders and assessing their needs
• Designing and evaluating a service solution to the topic or issue identified (adapted from Kendall 2019).

Funding for this training should be provided by the HSE workstream for the Framework for Self-Management Support.

7.4.4.2 Adapting and expanding the Living Well Programme to include the priorities and expertise of people with COPD

The Living Well programme currently being rolled out in Ireland as part of the Framework for Self-Management Support should be adapted to incorporate a Personal Outcomes Approach from the very start. It should engage with people with COPD to elicit their needs and priorities for self-management support and their pre-existing expertise and knowledge of COPD self-management. This Personal Outcomes Approach should underpin the design and delivery of future Living Well programmes. Specific workshops should be added to the programme dedicated to:

1. Mapping the needs and priorities of people with COPD for self-management support
2. Inviting people with COPD to share their knowledge and experience of self-management with their peers.

This adaptation of the Living Well programme should be overseen by CHO Self-Management Support Co-ordinators and hospital group self-management support leads.

7.4.4.3 Implementing a Personal Outcomes Approach in COPD self-management education

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75 The Living Well Programme is a free group programme delivered over six workshops (one 2½ hour workshop per week for six weeks) based on the Stanford Chronic Disease Self-Management Programme (CDSMP) (Health Service Executive 2019a).
As part of routine clinical practice, COPD-specific self-management education delivered by health care professionals should take a Personal Outcomes Approach that is centred on the knowledge, experience and priorities of people with COPD, and integrates this into a personalised approach to self-management.

7.4.4.4 Integrating peer self-management knowledge in Pulmonary Rehabilitation

COPD-specific patient education as included in Pulmonary Rehabilitation (PR) should take a Personal Outcomes Approach and include the opportunity for sharing self-management knowledge and experience between peers. Patient representatives should be invited to present their knowledge and experience of self-management as part of the educational component of PR.

7.4.5 Research recommendations

Given the dearth of literature exploring power in COPD self-management, and the fact that participants in this study were all members of local COPD support groups, a study incorporating national primary and secondary care centres should be undertaken. This would help gain a more comprehensive analysis of the exercise of power in COPD self-management. The Foucauldian framework of power, knowledge, and agency should be used in this wider study to ensure consistency.

Additional research should be undertaken in order to further elucidate how individuals’ negotiation of power and agency in COPD self-management affects their decision making and how this compares to other chronic illnesses. The knowledge arising from this research should be used to inform the future design of self-management interventions to maximise their potential benefit.

Research should be conducted which applies this Foucauldian framework to self-management of other chronic illnesses. This would expand the evidence base and establish whether experiences of exercising power in self-management are consistent across different chronic illnesses.

A study that examines the role of transformation in COPD self-management should be conducted. This would update and expand on the topic in self-management in general, and in COPD in particular.

Research should be conducted into how knowledge of COPD self-management is shared between peers, family members and social networks. This would add to an understanding of the process of sharing knowledge and how this informs individualised COPD self-management practice.
In order to honour the knowledge and agency of people with COPD, a participatory health research study should be conducted on COPD self-management. In participatory health research, people with COPD are involved and participate in all stages of the research process, from the formulation of the precise research question, the aim and objectives, the development of the research design, the selection of appropriate methods, implementing the research, interpreting the results and disseminating the findings. The entire research process should be a partnership between key stakeholders, i.e. researchers, people with COPD, carers, health care professionals and policy makers (International Collaboration for Participatory Health Research 2013). This approach aims to address power inequalities, views people with COPD as “experts by experience” (Care Quality Commission 2020), and democratises the research process. Because the topic, design, and methods are decided in collaboration with people with COPD, participatory health research has the potential to identify and focus on the issues in COPD self-management that are of most relevance and importance to people living with COPD and their carers.

The principles of public and patient participation in research (PPI) should be espoused across all these research activities. PPI has been described as “occurring when individuals meaningfully and actively collaborate in the governance, priority-setting and conduct of research, as well as in summarising, distributing, sharing and applying its resulting knowledge” (HRCI & Trinity College Dublin 2020, p. 9). In practice, this means that people with COPD and their carers should be involved in governance and oversight of research (via steering groups and advisory groups, for example), setting priorities and topics for research, reviewing grant proposals, designing research proposals and strategies, collecting and analysing data, contributing to write-up of research, disseminating the findings and applying knowledge arising from the research (Medical Research Charities Group 2018). In order to achieve this, training should be provided to researchers and to people with COPD and their carers. Research involvement networks should be set up to share information and opportunities for PPI with people with COPD and carers (Medical Research Charities Group 2018). Currently, there are five PPI Ignite programmes active in Irish universities which can build capacity for researchers to engage in high quality PPI in health research. There is also a new National PPI Network to further support researchers and individuals who wish to engage in PPI\(^76\).

\(^{76}\) research.ie/funding/national-ppi-network
7.5 Contribution to knowledge

The aim of this study was to explore how people with COPD exercise power in the self-management of their illness. Through applying a Foucauldian framework of power, knowledge and agency, this has informed the development of a final narrative of exercising power that has illuminated a previously little-known area of COPD self-management by giving people with COPD the opportunity to voice narratives of living with and managing COPD in which the exercise of power can be identified. This reveals not only how power is exercised on and by participants, but also how they actively negotiate the boundary between power and agency in everyday self-management of the illness. This was represented in a Foucauldian narrative which constitutes a new contribution to the body of knowledge on COPD self-management.

This study also contributes to the understanding of how knowledge is leveraged by people with COPD by viewing embodied and alternative knowledge as a body of subjugated knowledge that is used to resist the imposition of medicocentric power and at the same time is used as the foundation for the development of a personal and individualised approach to self-management. This understanding of subjugated knowledge is a new contribution to the field of COPD self-management.

The study also contributes to the understanding of COPD self-management by examining it as a set of “technologies of the self” designed to achieve transformation of the self and the body. While other studies have referred to self-management as representing technologies of the self, this has not been applied to COPD self-management and it is under-represented in chronic illness self-management. The finding that technologies of the self are sites in which both agency and power are evident in a dialectical relationship is new to the study of self-management in chronic illness in general and COPD in particular. Additionally, while the role of transformation has been the subject of research into living with chronic illness, its contribution to the understanding of COPD self-management is new.

The use of a Foucauldian framework in this inquiry led to an understanding of how participants integrated medicocentric and experiential aspects of self-management into a complex, holistic, multi-dimensional conceptualisation of self-management. This adds to the argument that research and policy on chronic
illness should uphold a person-centred model that recognises the agentic process of constructing self-management that individuals engage in every day.

A valuable contribution is also made by this study to the body of knowledge on chronic illness self-management by focusing on people with COPD, and illness that is often stigmatised and overlooked. It demonstrates the utility of applying a Foucauldian framework to narratives of COPD self-management. While elements of Foucault’s work on power have been applied to chronic illness self-management, this is the first study that unites the three concepts of power, knowledge, and agency in an overarching conceptual framework applied to narratives of self-management.

This study contributes to the methodological knowledge of undertaking a Foucauldian approach to narrative inquiry. In Chapters 3 and 4, I explicated how I went about translating Foucault’s theoretical work on power and knowledge to narrative inquiry. I described how this affected my positioning as a researcher, data collection, data analysis and interpretation. I have described in detail a systematic approach for applying prior Foucauldian theory to thematic analysis of narratives using template analysis. In doing so I have provided a new insight into how thematic template analysis allows for the translation of a Foucauldian theoretical framework to narrative inquiry. By describing how I went about thematic template analysis step-by-step, I have the opportunity to share what I have learned about this approach with other researchers.

Finally, the use of a narrative approach to analyse power demonstrates the value of viewing narratives as dialogical and co-constructed. Through dialogue I was able to engage with participants in unstructured interviews to co-construct and produce new knowledge. This demonstrates how authentic reflexive engagement with participants provides a route for them to contribute narratives of power and agency in self-management. This strengthens the argument that viewing narratives as sites in which power is intertwined with narratives of the “stuff” of everyday life. This contributes to the understanding of how undertaking a narrative approach to inquiry is commensurate with a Foucauldian analysis of power.

### 7.6 Limitations of the study

While I have discussed the strengths and contribution of this study, some limitations were also identified. Similar to other qualitative studies undertaken in the social constructionist paradigm, the narratives co-constructed in this study were contingent and unfinalized. Both Foucault and narrative scholars emphasise...
how the narratives are never total or final. The knowledge produced in narrative interviews therefore represent just one part of an ongoing story that will continue and change beyond the interview encounter. Thus, the knowledge produced in the interviews conducted for this study does not account for the totality of their experience of COPD self-management.

As indicated in Chapters 3 and 4, I had an unavoidable impact on how the interviews unfolded. Especially in the early stages of interviewing, my struggles to yield control of the interviews may have meant that I guided and intervened too much, thus unconsciously directing the flow of the interviews. I tried to address this through critical self-reflection and journaling, but it is still commensurate with the very nature of narrative interviewing that the nature of my presence and the way I used clarification questions and prompts, in addition to my initial struggle to know when to intervene and when to step back, had an impact on the co-construction of the narratives.

The perspective I have taken on narrative interviews as dialogic and co-constructed produced knowledge that is contingent upon many factors. These include the knowledge, prejudices and assumptions of self-management brought by the participants and me to the interviews, my positioning as a researcher and that of the participants, and the rapport we built together. My approach to analysis and interpretation of themes also impacts my final narrative of exercising power in COPD self-management. These factors cannot be replicated, and it is likely that different researchers and participants would bring different influences, assumptions and knowledge to bear upon the research question. Thus, while this study demonstrates rigour and quality as a qualitative inquiry, the conclusions and implications of the study have to remain tentative.

Another limitation is related to the fact that Foucault never set out a methodological approach to applying his theoretical work on power to research. Narrative scholars working with Foucault have therefore adopted a variety of approaches to research methods, (Blumenreich 2001, Harwood 2001, Blumenreich 2004, Tamboukou 2013) but a clear systematic methodology remains elusive. I therefore produced an analytic framework based on template analysis to bring together my Foucauldian theoretical framework with narrative inquiry. In doing so, the methodological decisions made within this study are influenced by my interpretation of Foucault’s theoretical concepts and how best to incorporate these into a narrative inquiry in order to answer the research question. Without detailed guidance from other Foucauldian narrative inquiries, there is the potential that I
may not have adequately transformed Foucault’s methodological “gadgets” into thinking tools to develop my “grid of analysis” (Foucault 1980, p. 199).

There were also limitations of the study regarding the sample and how participants were recruited to the study. As discussed in Chapter 4, recruitment was routed through the network of local COPD support groups under the auspices of COPD Support Ireland, the national patient representative organisation for COPD. This strategy yielded far more people who wished to take part than I had anticipated. Because I sent out invitations to participate to all local support groups at once, I was ethically bound to include all those who returned reply slips and were eligible to take part in the study. Not to do so would have silenced the very voices I was trying to honour. This large dataset (ultimately a total of 70 transcripts) constrained the choices I had available to me about data collection and analysis. Ultimately, I had to choose an approach that was commensurate with my Foucauldian theoretical framework and at the same time honoured the voices of all the participants in the study. This guided my selection of unstructured narrative interviews and thematic template analysis. However, in hindsight, staggering the recruitment process by inviting one person at a time to participate would have given me more control over the recruitment and ultimate sample size.

Finally, my decision to recruit via COPD Support Ireland meant that all participants were active members of their local COPD support group. This probably had an impact on their motivation and agency to self-manage. This recruitment approach precluded me from reaching more isolated, vulnerable, and marginalised people who struggle to self-manage. It may be that the sample comprised participants who were better resourced to self-manage than the general population of people with COPD.

7.7 Conclusion

The final chapter of this thesis drew together the implications of the findings of the study and set out the recommendations and the contribution of this study to the existing body of knowledge on COPD and chronic illness self-management. In hearing the voices and co-constructing the narratives of participants, I have explicated how participants exercised power by mobilising agency in complex and dynamic ways, always in a dialectical relationship with the constraints of power imposed upon them. Overall, the findings provide preliminary evidence of the process of constant negotiation that participants engage in to navigate the boundary between power and agency, according to a conceptualisation of self-
management that is complex, holistic, dynamic and individualised. This study gives voice to people living with an illness that is stigmatised and often overlooked, and in which the bulk of the policy and research literature eclipses their personal experience of negotiating power and agency in their self-management practice. It is hoped that the recommendations of this study will be considered and incorporated into the current policy and practice developments in self-management support and COPD care in Ireland.
8 References


Berger R. (2013) Now I see it, now I don't: researcher’s position and reflexivity in qualitative research. *Qualitative Research* **15**(2), 219-234


Lawler D. (2016) Reflexivity in qualitative data analysis. Trinity College Dublin, Dublin


Smith R. (1998) It doesn't count because it's subjective! (Re)conceptualising the role as 'validity' embraces subjectivity. AARE Annual Conference, Adelaide.


Appendices
### Appendix 1: Summary of included texts in the literature review

#### Intervention studies

<table>
<thead>
<tr>
<th>Authors</th>
<th>Aim</th>
<th>Type of study (e.g. intervention study, correlational study, patient experiences study, other (specify))</th>
<th>Study design (Qual, quant, specify exact)</th>
<th>Formal definition of self-care and/or self-care/self-management</th>
<th>Conceptualisation of self-care/self-management</th>
<th>Outcome measures</th>
<th>Type of results reported and rationale for results (e.g. summary of results, then explanation for these results (compliance/adherence, the need for further education, knowledge/agency/taking action etc))</th>
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<tbody>
<tr>
<td>(Gallefoss &amp; Bakke 2002)</td>
<td>To examine the effect of patient education and self-management on patients with COPD on medication utilization, the necessity for GP visits, patient satisfaction and to perform cost-benefit and cost-effectiveness analyses.</td>
<td>Intervention study</td>
<td>Quantitative randomised controlled trial, cost-benefit and cost-effectiveness, 1 year follow up</td>
<td>None provided</td>
<td>Medico-centric Focus on medical management Focus on cost-reduction Focus on compliance Focus on education and information provision Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and</td>
<td>• Medication was coded to defined daily dosages (DDD) • Rescue medication • Dispensed medication (monthly print outs from pharmacy computer records) • Number of GP-visits (self-report at monthly intervals) • Absenteeism from work (self-report at monthly intervals) • Days in hospital (self-report and hospital records)</td>
<td>Quantitative results reported on the impact of the intervention on outcome measures. Reported reduction in direct, indirect and total costs in intervention group compared to control. Explanation of results: Authors attributed results to effects of: • Avoiding GP visits, avoiding absenteeism from work, reduced hospitalisations • Educational component of the self-management education</td>
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</table>
practices of people with COPD need to be enhanced to meet this ideal.

‘Top down’ approach

- Patient satisfaction with health professionals (questionnaire)
- Costs based on utilisation of care and unit costs. Patient co-payments included in costs.
- Direct costs = costs borne by the health care system, community and family.
- Indirect costs = productivity loss and time costs borne by the individual, family, society or by the employer.

intervention was reported as being of key importance in explaining effects.

- Patient satisfaction was used to explain the positive effects – a good doctor-patient relationship was seen as likely to encourage doctor-patient relationship leading to positive attitudes and experiences of successful self-management.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Aim</th>
<th>Type of study (e.g. intervention study, correlational study, patient experiences study, other (specify))</th>
<th>Study design (Qual, quant, specify exact)</th>
<th>Formal definition of self-care and/or self-care/self-management</th>
<th>Conceptualisation of self-care/self-management</th>
<th>Outcome measures</th>
<th>Type of results reported and rationale for results (e.g. summary of results, then explanation for these results (compliance/adherence, the need for further education, knowledge/agency/taking action etc))</th>
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<tbody>
<tr>
<td>(Bourbeau 2003)</td>
<td>To present a comprehensive and critical evaluation of the international literature with respect to the benefits of disease-specific self-management programmes on health status and health resources in patients with advanced COPD.</td>
<td>Intervention study</td>
<td>Systematic review (best evidence synthesis)</td>
<td>Self-management or self-care refers to: (i) engaging in activities that promote health, build physiologic reserves, and prevent adverse sequelae, (ii) interacting with health care providers and adhering to recommended treatment protocols; (iii) monitoring both physical and emotional status and making appropriate management decisions on the basis of the results of self-monitoring; and (iv) managing the effects of the illness on the patient's self-esteem, ability to function in important roles, and relationships with others (Von Korff et al, 1997).</td>
<td>Medicocentric Focus on medical management Focus on compliance Focus on education Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal ‘Top down’ approach</td>
<td>Health-related quality of life (health locus of control, Sickness Impact Profile, St George’s Respiratory Questionnaire (SGRQ), General Health Questionnaire (GHQ), Hospital Anxiety and Depression scale (HADS), quality of wellbeing, State-Trait Anxiety Inventory, depression, health state questionnaire) Health resources (hospital admissions, duration of hospitalisation,</td>
<td>Quantitative results reported focused on the impact of the intervention on the outcome measures. Of the ten studies evaluated, four were able to demonstrate an improvement in health status. Two of the six studies that assessed the use of health resources were able to demonstrate a reduction in physician visits (acute). Only one was able to demonstrate a reduction in emergency room visits and hospital admissions. Explanation of findings: The author felt that these findings were explained by degree to which education was included in the interventions. Argued that</td>
</tr>
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physician visits, use of other health providers, emergency room visits

• Other (patient knowledge of COPD and COPD medication, use of medication, patient satisfaction, dyspnoea, 6 Minute Walking Test (6MWT), Borg scale, need for rescue medication, lung function, incidence of acute exacerbation)

self-management education is the way to improve patients’ capacity to undertake activities of daily living (ADLs), adopt a healthier lifestyle, comply with medication regimens, and to recognise and take action re: exacerbations.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Aim</th>
<th>Type of study (e.g. intervention study, correlational study, patient experiences study, other (specify))</th>
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</tr>
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<tbody>
<tr>
<td>Bourbeau et al. 2003</td>
<td>To evaluate the impact of a self-management programme on the use of hospital services and health status</td>
<td>Intervention study</td>
<td>Parallel group, multi-centre randomised clinical trial 1-year follow-up</td>
<td>Self-management is a term applied to any formalised patient education programme aimed at teaching skills needed to carry out medical regimens specific to the disease, guide health behaviour change, and provide emotional support for patients to control their disease and lead functional lives. This continuum of self-management training and support services can go from self-help approaches to more intensive case management</td>
<td>Medicocentric Focus on medical management Focus on education Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal ‘Top down’ approach</td>
<td>Lung function (spirometry) Exercise capacity (6-minute walking test - 6MWT) Acute exacerbations Hospital admissions Emergency department visits Physician visits Health-related quality of life (SGRQ)</td>
<td>Quantitative results reported on the impact of the intervention on outcomes such as physical health status, health-related quality of life, and health service utilisation. Patients in the intervention group showed a positive impact of the intervention on hospital admissions, emergency department visits, unscheduled physician visits, and health-related quality of life. Explanation of findings: The authors could not identify which component of the intervention lead to these benefits. They suggested that the attention and communication provided to</td>
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patients in the intervention group by trained care professionals may have led to these benefits and to the observed benefits on non-COPD-related hospital admissions.

Results did not report on the patients' experiences of the intervention or their compliance with the self-management training they had received. No reporting of patients' own self-management skills and practices beyond that which was provided in the education programme.
<table>
<thead>
<tr>
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<th>Explanation of findings:</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Monnikhof et al. 2003)</td>
<td>To assess the effects of a comprehensive self-management intervention on health-related quality of life (HRQoL), symptoms and walking distance in patients with stable moderately severe chronic obstructive pulmonary disease (COPD).</td>
<td>Intervention study</td>
<td>Quantitative randomised controlled trial (1 year follow up)</td>
<td>Self-management is a term applied to any formalised patient education programme aimed at teaching skills to optimally control the disease, behaviour change, and coping with the disease.</td>
<td>Medicocentric Focus on education Focus on physical fitness training Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal Assumption that patients’ lack the correct knowledge re: self-management Assumption that patients need to change their</td>
<td>• Health-related QoL (SGRQ). • Exacerbations • Walking distance (6MWT) • COPD symptoms (diary-keeping by patients) • Self-confidence re: COPD (1 item self-report)</td>
<td>Quantitative results reporting on the impact of the intervention on the outcome measures. The authors did not find a positive effect of a comprehensive self-management programme on HRQoL, walking distance, symptoms and exacerbation frequency in COPD patients.</td>
<td>The authors put forward a number of possible reasons for their findings: 1. The COPD treatment of patients was optimised before the trial, so that confounders such as smoking cessation and optimisation of</td>
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<td>2. Self-selection bias may have played a part, i.e., those patients who agreed to take part may have already been highly motivated. Patients gave consent to participate in an investigation that was going to last for three years, and at time of randomisation for the self-management trial, they were already participants for ten months.</td>
<td>2. Self-selection bias may have played a part, i.e., those patients who agreed to take part may have already been highly motivated. Patients gave consent to participate in an investigation that was going to last for three years, and at time of randomisation for the self-management trial, they were already participants for ten months.</td>
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<td>3. The HRQoL of patients was already high at baseline, and so there may not have been much room for improvement.</td>
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<td>4. The HRQoL of control patients did not decline over time as would have been expected, perhaps because of the Hawthorne effect (e.g., because they received more attention than would otherwise be the case).</td>
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<td>5. Early self-treatment of exacerbations by the patients may have influenced their HRQoL, particularly in the intervention group.</td>
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patient in the intervention group might prevent further deterioration of the condition and self-treatment might increase disease-specific self-confidence and self-determination of the patient.

6. The SGRQ and 6MWT may not be sensitive enough to pick up relevant self-management specific changes.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Aim</th>
<th>Type of study (e.g. intervention study, correlational study, patient experiences study, other (specify))</th>
<th>Study design (Qual, quant, specify exact)</th>
<th>Formal definition of self-care and/or self-care/self-management</th>
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<th>Outcome measures</th>
<th>Type of results reported and rationale for results (e.g. summary of results, then explanation for these results (compliance/adherence, the need for further education, knowledge/agency/taking action etc))</th>
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<tbody>
<tr>
<td>(Gadoury et al. 2005)</td>
<td>To assess the long-term impact on hospitalisation of a self-management programme for chronic obstructive pulmonary disease (COPD) patients.</td>
<td>Intervention study</td>
<td>Quantitative multicentre, randomised clinical trial conducted over 1 year with 2 year follow up</td>
<td>None provided</td>
<td>Mediocentric&lt;br&gt; Focus on cost reduction&lt;br&gt; Focus on education&lt;br&gt; Health professionals prescribe defined set of knowledge and skills&lt;br&gt; Self-management as an ideal set of knowledge, skills and practices&lt;br&gt; Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal&lt;br&gt; Assumption that patients lack the correct knowledge re: self-management&lt;br&gt; Top down approach</td>
<td>All cause hospital admissions&lt;br&gt; All-cause emergency visits</td>
<td>Quantitative results reported on the impact of the intervention on outcomes – hospital admissions, emergency room visits, and predicting factors of hospitalisation. At 2 years, there was a statistically significant and clinically relevant reduction in all-cause hospitalisations of 26.9% and in all-cause emergency visits of 21.1% in the intervention group as compared to the standard-care group. After adjustment for the self-management intervention effect, the predictive factors for reduced hospitalisations included younger age, sex (female), higher education, increased health status and exercise capacity.</td>
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</table>
Explanation of findings:

The authors did not discuss the possible explanations for these results, beyond identifying the predictive factors for reduced hospitalisations.

There was brief reporting of the rate of patient compliance with the intervention (reported that all but 1 patient complied with the seven-eight weeks of the programme, but they did not go into detail as to what compliance meant and how it was measured.)
<table>
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<tr>
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<tr>
<td>(Lomundal &amp; Steinsbekk 2007)</td>
<td>To describe the outcomes during and one year after the end of a one year (46 hours) self-management program and during and after a two-year pulmonary rehabilitation program including education in patients with COPD.</td>
<td>Intervention study</td>
<td>Quantitative</td>
<td>None provided</td>
<td>Integration between medicocentric and patient experiences</td>
<td>Primary outcomes:</td>
<td>Quantitative results reporting on the impact of the intervention. General findings = Patients with COPD participating in the one-year self-management program (SMG) had an improvement in quality of life and no deterioration in exercise tolerance from the start to one year after the end of the program.</td>
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<td>Open prospective observational outcome studies 2 year follow up</td>
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<td>People with COPD worked with health professionals to design the content of the self-management programme educational sessions, and the content of the last four sessions was decided by participants and focused on the exchange of experiences about how to manage (dyspnoea mainly). Focus on patient education Focus on patient experiences But outcome measures were pre-set and standardised biomedical measures – medical focus</td>
<td>Secondary outcomes:</td>
<td>Explanation of findings: The authors explained their results as due to:</td>
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<td>Focus on patient education Focus on patient experiences But outcome measures were pre-set and standardised biomedical measures – medical focus</td>
<td>Primary outcomes:</td>
<td>The comprehensive nature of the program (46 sessions over 1 year)</td>
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<td>• health-related quality of life (SGRQ) • Exercise tolerance (6MWT) Secondary outcomes:</td>
<td>Secondary outcomes:</td>
<td>The significant exercise component in the programme.</td>
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<td>• Perceived exertion (Borg scale) • Dyspnoea (Breathing Problems Questionnaire short version)</td>
<td>Secondary outcomes:</td>
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<td>• Self-efficacy (COPD Self-Efficacy scale) • FVC FEV1 • Arterial O2 saturation • Number of hospitalisations</td>
<td>Secondary outcomes:</td>
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**Primary outcomes:**
- health-related quality of life (SGRQ)
- Exercise tolerance (6MWT)

**Secondary outcomes:**
- Perceived exertion (Borg scale)
- Dyspnoea (Breathing Problems Questionnaire short version)
- Self-efficacy (COPD Self-Efficacy scale)
- FVC FEV1
- Arterial O2 saturation
- Number of hospitalisations
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<th>Days spent in hospital due to exacerbation-related hospitalisations</th>
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<td>The cooperation between experienced COPD patients and clinicians</td>
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<td>The high rate of compliance of patients</td>
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<td>The range of measures of physical, psychological health status.</td>
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<tr>
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<td>Kheirabadi et al. 2008</td>
<td>To assess whether psycho-educational plans (self-management and behaviour modification) administered in primary care have beneficial effects on symptoms of patients with COPD.</td>
<td>Intervention study</td>
<td>Quantitative prospective, unblinded, randomized controlled trial Three-month follow-up</td>
<td>Self-management can be described as a set of skilled behaviours and refers to the various tasks that a person carries out for management of their condition</td>
<td>Medicocentric Focus on medical management Focus on education Focus on behaviour change Assumption that the knowledge, skills and practices of people with COPD need to be enhanced 'Top down' approach</td>
<td>• Clinical status (Clinical COPD Questionnaire (CCQ))</td>
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low sample size (n=42, 21 in each group).

They suggested that the focus on psychosocial domains in the intervention had more of an effect on patients’ mental states including anxiety and depression. They reported high compliance with the intervention and explained this as due to the intensive support and training offered to participants.

The experiences of patients, their own knowledge, their experience of living with COPD, their own approach to managing, these were not reported on.
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<tr>
<td>Labrecque et al. 2011</td>
<td>To assess the effects of a self-management program on health-related quality of life (HRQoL) and morbidity commonly associated with chronic obstructive pulmonary disease (COPD).</td>
<td>Intervention study</td>
<td>Quantitative Non-randomised, Parallel group, prospective study 12-month follow up</td>
<td>Self-management is also a term applied to educational programs aimed at the teaching skills needed to perform medical regimens specific to the disease, guide health behaviour change, and provide Emotional support for patients to control their disease and lead more functional lives.</td>
<td>Medicocentric Focus on medical management Focus on education Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal ‘Top down’ approach</td>
<td>Primary = Health-related QOL (SGRQ) Secondary = • Patient’s knowledge of COPD (COPD Knowledge Questionnaire) • Hospitalisations • Emergency department visits • COPD exacerbations</td>
<td>Quantitative results showed a significant positive impact of the intervention on HRQoL, hospitalisations and emergency room visits. Explanation of findings: Results were explained by the education programme increasing patients’ confidence in their ability to self-manage and engage in ADLs. Patient compliance was not reported on.</td>
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<tr>
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<td>(Bentsen et al. 2012)</td>
<td>To evaluate the benefits of self-management interventions on the quality of life of patients with chronic obstructive pulmonary disease.</td>
<td>Intervention study</td>
<td>Quantitative systematic review (but used content analysis)</td>
<td>'Self-management' is defined, according to Barlow et al (2002), as the individual's ability to manage his/her symptoms, treatment, physical and psychosocial consequences and lifestyle changes when living with a chronic condition.</td>
<td>Medicocentric</td>
<td>Overall QoL, Health-related QL, Dyspnoea (as measured by BORG dyspnoea scale or Visual Analogue Scale (VAS)), Burden of symptoms (SGRQ/Nottingham Health Profile Questionnaire (NHPQ)), Patient activity (SGRQ/6MWT), Physical condition (6MWT), Physical and psychosocial activity (SGRQ), Total health status (SGRQ/NHPQ)</td>
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<td>Quantitative narrative findings</td>
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**Explanation of findings:**

The authors claimed to report on quality of life, but the results really describe physical and psychosocial health status. Only one study evaluated the impact on overall QoL and it found no significant benefit.
No rationale provided. The authors did point to the need for further research in order to fully understand how COPD self-management interventions might impact on the symptoms, QoL, and burden of COPD.
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<td>(Lomundal &amp; Steinsbekk 2012)</td>
<td>Investigate long-term effects four years after the end of a one-year self-management program (SMP) with 30 hours of education and 16 hours of physical activity in patients with chronic obstructive pulmonary disease (COPD).</td>
<td>Intervention study</td>
<td>Quantitative Prospective observational outcome study Four year follow up</td>
<td>None provided</td>
<td>Integration between medicocentric and patient experiences People with COPD worked with health professionals to design the content of the self-management programme educational sessions, and the content of the last four sessions was decided by participants and focused on the exchange of experiences about how to manage (dyspnoea mainly). Focus on patient education Focus on patient experiences But outcome measures were pre-set and standardised biomedical</td>
<td>Primary outcomes = • Health-related quality of life (SGRQ) • Exercise tolerance (6MWT) Secondary outcomes = • Perceived exertion (Borg scale) • Dyspnoea (Breathing Problems Questionnaire short version) • Self-efficacy (COPD Self-Efficacy scale) • FVC FEV1 • Arterial O2 saturation • Number of hospitalisations • Days spent in hospital due to</td>
<td>Quantitative results reporting on the long-term effects of the intervention at four years post-intervention. The authors found that patients with COPD who took part in a 1-year self-management program had maintained their pre-intervention level of health-related quality of life and exercise capacity four years after the completion of the program. <strong>Explanation of findings:</strong> The rationale for these results cited by the authors included: The high rate of compliance with the programme, and the high rate of continued physical exercise post-intervention.</td>
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<td>Measures – medical focus</td>
<td>Exacerbation-related hospitalisation</td>
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<td>Continuation of exercise during follow-up time</td>
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Representatives from voluntary organisations and from private practice physiotherapists gave presentations to the participants during the intervention, which may have made it easier to contact and join other groups (social support).

The focus on positive attitudes and the emphasis on self-efficacy re: exercise. The use of action plans to detect and treat exacerbations early.

Participants learned how to cope with dyspnoea may have raised their general level of physical activity.

Participants could contribute to the content of some of the sessions, choosing what was important for them to discuss (rather than being solely guided by health professionals as to content of all sessions) as well as being able to discuss important issues both with health care professionals and with other participants – could have led to a sense
of support and increased self-efficacy
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<tr>
<td>(Taylor et al. 2012)</td>
<td>To explore the feasibility, effectiveness and cost effectiveness of a novel, layperson-led, theoretically driven COPD self-management support programme. [page e687]</td>
<td>Intervention study</td>
<td>Quantitative pilot randomised controlled trial (six month follow up)</td>
<td>Self-management has been defined as 'the tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions' (Adams et al 2004) [page e687]</td>
<td>Medicocentric Focus on costs Focus on self-efficacy Focus on education Participants encouraged to set goals Participation in course delivery encouraged Participants encouraged to join patient support organisations Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be</td>
<td>• Health-related quality of life (SGRQ, EQ-5D) • Anxiety and depression (Hospital Anxiety and Depression Scale HADS) • Self-efficacy (Stanford self-efficacy scales) • Self-management behaviour for exercise and communicating with physicians (Stanford self-management behaviour scales) • Self-rated health (one-item self-rated health measure) • COPD-related healthcare use (telephone consultations)</td>
<td>Quantitative results of the impact of the intervention were reported tentatively, as this was a pilot RCT and statistical significance could not be ascertained. At two months' follow-up, little difference could be seen between those in the intervention and control arms of the study, but by six months greater differences had emerged in favour of the intervention group in both self-reported exercise levels and HRQoL. Changes in scores for self-efficacy to manage the disease and to communicate with doctors tended to be very small; less than one-third or one-tenth of a standard deviation (SD), favouring control and intervention respectively. Economic analyses suggested that with</td>
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enhanced to meet this ideal.

specialist nurse visits, GP surgery and home visits, out-of-hours consultations, rapid response team visits, emergency department attendance, hospital admissions, outpatient visits, and COPD-related medication)

- Burden of comorbidity (Cumulative Illness Rating Scale)
- Unit costs of resources used were obtained from national reference cost databases (applied to individual healthcare records to estimate mean and median costs per patient for the intervention and control groups)

thresholds of £20,000 per quality-adjusted life-year gained, the intervention was likely to be cost-effective.

Explanation of findings:
The authors explained their results by theorising that self-management skills gained on the course, such as goal setting and action planning, develop with practice over time.

The authors noted that uptake and attendance at sessions was relatively low: Only one-quarter of patients with moderate to severe COPD identified from primary care disease registers expressed an interest in participating in the study, and 35% of those offered the self-management courses failed to attend any sessions. The authors said that this might be due to the intervention not being integrated into primary or secondary care and participation in the course was not specifically recommended or endorsed by healthcare professionals.
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<tr>
<td>(Benzo et al. 2013)</td>
<td>This article describes the development, training required, pilot testing, and delivery of the motivational interviewing-based, self-management intervention, with results addressing intervention feasibility, patient acceptability, retention, and patients’ opinion of the intervention and their working alliance with the interventionists.</td>
<td>Intervention design and implementation study with evaluation component</td>
<td>Mixed methods</td>
<td>None provided</td>
<td>Medicocentric</td>
<td>Focus on medical management</td>
<td>Quantitative evaluation of impact of intervention on impact of COPD. The CRQ results showed a positive trend in all domains and a statistically significant change in the domain of emotions: Quantitative evaluation of the working alliance between patients and interventionists (interventionists = pulmonary rehabilitation professionals, respiratory therapists, nurses). The WAI-SR results revealed positive perceptions of the patient/interventionist relationship.</td>
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<tr>
<td>'Top down' approach</td>
<td>Behaviour changes resulting from the program.</td>
<td>perceived benefits, rather than on experiences of their own self-management practices. Qualitative results reported focused on satisfaction with the programme, self-management behaviour change, enhanced knowledge of COPD and how to manage it, perceived impact on physical activity, and perceived value of relationship with interventionist. <strong>Explanation of findings:</strong> The authors highlighted the personalised approach to this intervention as a key factor in enhancing the satisfaction and acceptability of the intervention on the part of patients. They pointed to the high level of retention of patients in the intervention (adherence). They also felt that the combination of action plans and motivational interviewing were of central importance in explaining the results.</td>
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| (Mitchell et al. 2014) | To evaluate the effectiveness of the Self-Management Programme of Activity, Coping and Education (SPACE) FOR COPD intervention in primary care. | Intervention study | Single-centre, investigator-blinded, randomised controlled trial six week and six-month follow-up | None provided | Medicocentric  
Focus on medical management  
Focus on education and skills acquisition  
Focus on behaviour change  
Health professionals prescribe defined set of knowledge and skills  
Self-management as an ideal set of knowledge, skills and practices  
Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal  
‘Top-down’ approach | Primary outcome =  
• Change in the CRQ-SR dyspnoea domain from baseline to six months  
Secondary outcomes =  
• Fatigue, emotion and mastery domains of the CRQ-SR,  
• The Bristol COPD Knowledge Questionnaire (BCKQ),  
• The Hospital Anxiety and Depression Scale (HADS)  
• The incremental shuttle walk test (ISWT) | Quantitative results reported on the effectiveness of the intervention on the outcomes at six weeks and six months follow up. At six weeks, there were significant differences between groups in CRQ-SR dyspnoea, fatigue and emotion scores, exercise performance, anxiety, and disease knowledge. At six months, there was no between-group difference in change in CRQ-SR dyspnoea. Exercise performance, anxiety and smoking status were significantly different between groups at six months, in favour of the intervention. |
• The endurance shuttle walk test (ESWT)
• The Pulmonary Rehabilitation Adapted Index of Self-Efficacy (PRAISE)
• Self-reported smoking status.

Explanation of findings:
The rationale given for these results was the lack of ongoing sustained support given to patients, which the authors felt might explain the initial positive impact on effectiveness, followed by no effect at six months. Other explanations for the study’s negative findings might be that aspects of the intervention were not comprehensive enough to sustain prolonged change. The authors suggested that the lack of any kind of group support, supervised exercise training and healthcare professional-led education may have limited the effectiveness of this intervention for maintaining outcomes.
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<tr>
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<th>Type of results reported and rationale for results (e.g. summary of results, then explanation for these results (compliance/adherence, the need for further education, knowledge/agency/taking action etc))</th>
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| (Turner et al. 2014) | To see whether attending a COPD self-management programme (SMP) improved patients with COPD activation, health status, quality of life, psychological distress and self-management ability. | Intervention study                                                                               | Quantitative longitudinal evaluation of an SMP for patients with COPD that took place in a real-world health care setting and so did not include a randomized control group. | None provided                                       | Mediocentric Focus on self-efficacy Focus on education Focus on behaviour change Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal | Primary outcome measure =  
• Patient activation (Patient Activation Measure (PAM)) 
Secondary outcome measures =  
• Health status (EQ-5D)  
• Health related quality of life (Euro Qol Visual Analogue Scale (EQ VAS), Chronic Respiratory Questionnaire Self-Report (CRQ-SR))  
• Anxiety and depression (HADS)  
• Self-management ability (Health Education Impact Questionnaire (hei-Q)) | Quantitative results indicated that patient activation significantly improved six months after the SMP. There were also significant improvements in COPD mastery and significant improvements in a range of self-management abilities (self-monitoring and insight, constructive attitude shift, skills and technique acquisition). No impact was observed on health related Qol or health status. No impact was observed on anxiety and depression.  
Explanation of findings:  
The authors identified weekly goal setting, action planning, feedback and... |
follow-up as a possible reason for the positive results. However, patients were not asked directly for their own experiences of the self-management programme, nor were they viewed as possibly having their own skills and mastery independently of the SMP.

The SMP completion rate (attended >five sessions) among the 206 patients with COPD who completed baseline questionnaires was 69%. The authors theorised that this high completion rate was possibly due to patients being referred by a known clinician, who also co-delivered the SMP.

The authors suggested that the lack of impact on HRQoL may be due to worsening health over time, but they could not be conclusive due to the lack of a control group in their study. They also felt that it was possible that course content on dealing with negative emotions in the SMP was potentially not in-
depth enough to have an impact
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| (Yu et al. 2014) | To explore the effects of self-management education on the quality of life of patients living with chronic obstructive pulmonary disease (COPD). | Intervention study                                                                                 | Quantitative non-randomized controlled trial (6-month follow up) | Self-management refers to strategies by which patients can make therapeutic, behavioural and environmental adjustments built on health-related knowledge and skills from healthcare providers to improve their ability to care for themselves (Bourbeau 2004) | Medicocentric  
Focus on medical management  
Focus on compliance  
Focus on education  
Self-management as an ideal set of knowledge, skills and practices  
Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal  
‘Top down’ approach | • Health-related quality of life (SGRQ) | Quantitative results reported that statistically significant differences in favour of the intervention were observed between the intervention and control groups at three months based on SGRQ impact domain scores. In addition, statistically significant differences were also observed between groups at six months based on SGRQ symptom, impact, activity domain and total scores.  
Explanation of findings:  
The authors explained the results as due to the encouragement given to patients to integrate the knowledge and skills they gained from the |
intervention into their everyday lives. They argued that self-management education provided the patients with the knowledge to face the disease, devise proper strategies and prevent the worsening of symptoms.
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| (Zwerink et al. 2014) | 1. To evaluate whether self-management interventions in COPD lead to improved health outcomes. 2. To evaluate whether self-management interventions in COPD lead to reduced healthcare utilisation. | Intervention study | Quantitative systematic review and meta-analysis | Self-management training aims to help patients acquire and practise the skills they need to carry out disease-specific medical regimens, to guide changes in health behaviour and to provide emotional support to enable patients to adjust their roles for optimal function and control of their disease. Essential patient skills for successful self-management include problem solving, decision making, resource utilisation, forming a partnership between patient and healthcare provider, taking action and self-tailoring. Self-management interventions were defined as structured interventions | Medicocentric  Focus on medical management  Focus on behaviour change  Health professionals prescribe defined set of knowledge and skills  Self-management as an ideal set of knowledge, skills and practices  Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal  'Top down' approach | Primary outcomes  • Health-related quality of life (HRQoL) scores.  • Number of hospital admissions.  Secondary outcomes  • Hospitalisation days.  • Number of exacerbations requiring emergency department visits.  • Use of (other) healthcare facilities.  • Number of exacerbations requiring a course of oral corticosteroids or antibiotics. | Quantitative results reported on the impact of the intervention on primary and secondary outcome measures. Self-management interventions in patients with COPD were associated with improved health-related quality of life as measured by the SGRQ, a reduction in respiratory-related and all cause hospital admissions, and improvement in dyspnoea as measured by the (m)MRC. No statistically significant differences were found in other outcome parameters.  

Explanations of findings: The authors point to the interventions in the included studies focus on... |
for individuals with COPD aimed at improvement of health behaviours and self-management skills.

- Use of rescue medication.
- Symptom scores.
- Anxiety and depression.
- Self-efficacy.
- Days lost from work.
- Lung function.
- Exercise capacity.

COPD self-management skills that aim to stimulate ‘proper’ patient behaviours and actions. They also point to the focus on recognition and responding to potential exacerbations, including the use of action plans, as another reason.
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<th>Type of results reported and rationale for results (e.g. summary of results, then explanation for these results (compliance/adherence, the need for further education, knowledge/agency/taking action etc))</th>
<th>Explanation of findings:</th>
</tr>
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</table>
| (Hardinge et al. 2015) | To report findings from a six-month, clinical, cohort study of COPD patients' use of a mobile telehealth based (mHealth) application and how individually determined alerts in oxygen saturation levels, pulse rate and symptoms scores related to patient self-initiated treatment for exacerbations | Intervention study | Quantitative six-month cohort study | None provided | Medicocentric  
Focus on medical management  
Focus on education  
Focus on compliance  
Health professionals prescribe defined set of knowledge and skills  
'Top down' approach | • Use of mHealth system alerts and their relationship to events | Quantitative results reported on patient use of and compliance with the requirements of the telehealth mobile application. Results also reported on the number and type of alerts generated by the system and their relationship to exacerbation events.  
Patients identified no difficulties in using the mHealth application and used all functions available. 40% of exacerbations had an alert signal during the three days prior to a patient starting medication. The researchers reported that compliance with the system was high. | |
The researchers pointed to the ease-of-use and flexibility of the system to adapt to the daily routines of patients as one reason for these results. They also cited the use of videos instructing on different aspects of self-management (e.g. inhaler) technique as instrumental in reinforcing self-management strategies.
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<td>(Jonsdottir et al. 2015)</td>
<td>To evaluate the effectiveness of a six-month, partnership-based self-management programme for patients with mild and moderate chronic obstructive pulmonary disease.</td>
<td>Intervention study</td>
<td>Quantitative pragmatic randomized control design. Six-month follow up</td>
<td>None provided</td>
<td>Integration between medicocentric and patient experiences</td>
<td>• Smoking status (point prevalence abstinence) measured in exhaled breathing by a carbon monoxide monitor where the cut-off point for abstinence was considered ≤6.</td>
<td>Quantitative results reporting on the impact of the intervention on the outcome measures. Patients who participated in the partnership-based self-management programme perceived less intrusiveness of the disease and its treatment than patients in the control group. Patients in the experimental group did not have better health-related quality of life, less anxiety or depression, increased physical activity, fewer exacerbations or better smoking status than patients in the control group. Patients in both groups found participation in the research useful and important. The authors found that scores on the subscales of symptoms,</td>
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<td>• Anxiety and depression (HADS)</td>
<td>Anxiety and walking became significantly worse in both groups and the number of exacerbations increased over the period.</td>
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<td>• Self-reported physical activity (International Physical Activity Questionnaire short version)</td>
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<td>• International Physical Activity Questionnaire short version (IPAQ))</td>
<td>Explanation for findings: Rather than indicating a worsening of conditions these findings might indicate intervention effects, i.e. that participants had become more aware of their body, their capacity and what the future with the disease might bring for them. The authors also suggested that the reason for the lack of impact of the intervention on the health outcomes was due to the time spent with each patient and the length of treatment time being insufficient.</td>
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| (Jordan et al. 2015) | To undertake (1) a systematic review of the evidence for the effectiveness of self-management (SM) interventions commencing within six weeks of hospital discharge for an exacerbation for COPD (review 1); (2) a systematic review of the qualitative evidence about patient satisfaction, acceptance and barriers to SM interventions (review 2); (3) a systematic review of the cost-effectiveness of SM interventions (review 3) | Intervention study                                                                 | Quantitative and qualitative systematic reviews  
Cost-effectiveness analysis and economic modelling | 'Self-management' has been defined as the ability of a patient to deal with all that a chronic disease entails, including symptoms, treatment, physical and social consequences and lifestyle changes. Self-management support involves collaboration between the health-care professional and the patient so that the patient acquires and demonstrates the knowledge and skills required to manage his/her medical regimens, change their health behaviour, improve control of their disease and improve their well-being. | Medicocentric  
Focus on medical management  
Focus on compliance  
Focus on behaviour change  
Focus on education  
Focus on self-efficacy  
Health professionals prescribe defined set of knowledge and skills  
Assumption that the knowledge, skills and practices of people with COPD need to be enhanced | Hospital admissions  
All-cause mortality  
Emergency department visits  
GP visits  
Health-related QoL  
Exercise capacity  
Lung function  
Anxiety and depression  
Exacerbations  
Dyspnoea  
Disease knowledge  
Behaviour change  
Self-efficacy  
Patient satisfaction with the intervention  
Economic outcomes (QALY gains, costs of interventions) | Quantitative results reporting on the impact of the interventions in the included studies on the primary outcome measures decided upon for the systematic reviews. Review 4 also reported results on the particular components of self-management interventions that had impact on the outcomes. The reviews of the effectiveness of SM interventions immediately post admission for an exacerbation revealed modest potential benefits to HRQoL with no other statistically significant effects, but with most other outcomes (excluding mortality) favouring the SM arm. There were no good qualitative papers reporting patient experience of these interventions. |
SM support interventions within six weeks of hospital discharge for an exacerbation of COPD (review 3); (4) a cost-effectiveness analysis and economic model of post-exacerbation SM support compared with usual care (UC) (economic model); and (5) a wider systematic review of the evidence of the effectiveness of SM support, including interventions (such as pulmonary rehabilitation) in which there are significant components of SM, to identify which components are the most important in reducing exacerbations, hospital admissions/readmissions and health service utilisation (hospital admissions and readmissions, duration of admissions, ED visits, days lost from work, drug utilisation and cost-effectiveness).

- Health service utilisation (hospital admissions and readmissions, duration of admissions, ED visits, days lost from work, drug utilisation and cost-effectiveness).

Explanation for findings: The authors found that many of the included trials were small and methodologically inadequate, and the heterogeneous nature of the interventions makes comparisons hard and conclusions difficult to draw. They also pointed to...
<p>| improving quality of life (review 4). | the almost total lack of qualitative research on patient experiences of self-management interventions and lack of cost-effectiveness evaluations of self-management interventions. Patient compliance not reported on. |</p>
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<td>Majothi et al. 2015</td>
<td>To assess the clinical effectiveness of interventions to support self-management among patients with COPD who have recently been discharged from hospital following an acute exacerbation [page 854]</td>
<td>Intervention</td>
<td>Quantitative systematic review and meta-analysis</td>
<td>Self-management is defined as the “ability of a patient to deal with all that a chronic disease entails, including symptoms, treatment, physical and social consequences and lifestyle changes” (Barlow et al 2002)</td>
<td>Medicocentric Focus on medical management Focus on education Focus on behaviour change ‘Top-down’ approach</td>
<td>Primary outcomes = • Mortality (all cause) • Hospital admissions (all cause) • Emergency department visits • GP consultations Secondary outcomes = • Health related quality of life • Anxiety and depression • Exercise capacity • Dyspnoea and lung function</td>
<td>Quantitative meta-analysis results on the clinical effectiveness of the included studies. The authors found no apparent evidence of an effect of self-management interventions on all-cause mortality. There was no clear evidence of an effect on all-cause hospital admissions. Self-management support delivered shortly after an acute exacerbation shows an apparent benefit to patients’ HRQoL, although this may be overestimated due to high loss-to-follow-up. The authors concluded that the evidence is not currently adequate to support self-management</td>
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interventions for COPD patients recently after hospital discharge.

Explanation of findings:
The main rationale for this lack of effect is the paucity of evidence and methodological weaknesses of many of the available studies, and the heterogeneous interventions which makes comparisons hard and conclusions difficult to draw. The authors also noted that patients may be too ill immediately after an exacerbation to take up the more rigorous aspects of a given self-management intervention until they are more stable.
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<td>(Cannon et al. 2016)</td>
<td>To analyse the outcome of self-management randomised control trials and their impact upon chronic obstructive pulmonary disease patients’ health outcomes using meta-analysis approach</td>
<td>Intervention study</td>
<td>Quantitative systematic review and meta-analysis</td>
<td>Self-management as a concept itself is not defined, but the authors do provide a definition of self-management programmes as follows: Self-management programs for COPD patients are defined as approaches which encourage individuals to make behavioural changes which enhance the social, emotional, and physical aspects of their health; with the primary outcomes of improving both functioning and quality of life (Cameron-Tucker et al 2014).</td>
<td>Mediocentric Focus on education Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal</td>
<td>• Number of respiratory related hospital admissions • Quality of life (SGRQ) • Self-efficacy (COPD Self-efficacy Scale) • Exercise capacity (6MWT) • Anxiety and Depression (HADS)</td>
<td>Quantitative results measuring the impact of self-management education programmes on hospital admissions, quality of life, self-efficacy, exercise capacity and anxiety and depression. The pooled effects revealed that self-management interventions significantly improved all aspects of COPD patients’ health related quality of life. They found that self-management interventions improved some aspects of self-efficacy: primarily, reductions in their feelings of helplessness. Other aspects that showed improvement included breathlessness following physical exertion, nutrition and breathing techniques. It was also found that...</td>
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<td>COPD patients who undertook self-management experienced significant improvements in their exercise capacity.</td>
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<td>No improvement was found in number of hospital admissions, levels of anxiety and depression, and other aspects of their self-efficacy such as feelings of anger and stress, and the impact from changes in the surrounding weather and environment.</td>
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**Explanation for findings**

The authors identified COPD education as the component as the most influential component on health-related quality of life, exercise capacity. The authors rationalised this by arguing that providing COPD education increases patient confidence and competence, which empowers patients to self-manage.
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</table>
| (Johnson-Warrington et al. 2016) | To investigate if a Self-management Program of Activity, Coping, and Education for COPD (SPACE for COPD) employed upon hospital discharge would reduce readmission rates at 3 months, compared with usual care | Intervention study | Quantitative prospective, two-centre, single-blinded randomized controlled trial with a 3-month follow-up period | None provided | Medicocentric | Focus on education  
Focus on physical exercise  
Focus on behaviour change  
Health professionals prescribe defined set of knowledge and skills  
Assumption that the knowledge, skills and practices of people with COPD need to be enhanced | Primary prespecified outcome measure =  
- Respiratory-related hospital readmission at 3 months.  
Secondary outcome measures =  
- Chronic Respiratory Questionnaire – self reported (CRQ-SR),  
- Hospital Anxiety and Depression Score,  
- Bristol COPD Knowledge Questionnaire,  
- Incremental Shuttle Walk Test (ISWT),  
- Endurance Shuttle Walking Test (ESWT), |

Quantitative results measured the impact of the intervention on respiratory hospital readmissions, health care utilisation, mortality, and on the secondary outcome measures.  
No differences were found in readmission rates or mortality at 3 months between the groups. Ten control patients were readmitted within 30 days compared to five patients in the intervention group (P<0.05). Both groups significantly improved their exercise tolerance and Chronic Respiratory Questionnaire (CRQ-SR) results, with between-group differences approaching statistical significance for CRQ-dyspnoea and CRQ-motion, in favour of the
• Pulmonary Rehabilitation Adapted Index of Self-Efficacy,
• “Ready for Home” survey.

intervention. The “Ready for Home” survey revealed that patients receiving the intervention reported feeling better able to arrange their life to cope with COPD, knew when to seek help about feeling unwell, and more often took their medications as prescribed, compared to usual care (P<0.05).

Results on patient knowledge of COPD were reported via the Bristol COPD Knowledge questionnaire, wherein disease-specific knowledge increased from baseline for those who received the intervention (P<0.05) but not for usual care.

Explanation of results:
The authors suggested that introducing a self-management program to unwell patients who may have impaired cognition might have contributed to the limited effects of the intervention (the target group for recruitment was individuals admitted to
hospital for acute exacerbation with COPD).

Another possibility suggested was that all patients received specialist usual care follow-up which may have already been optimum care for their needs.
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<td>(Jolly et al. 2016)</td>
<td>To identify the most effective components of interventions to facilitate self-management of health care behaviours for patients with COPD.</td>
<td>Intervention study</td>
<td>Quantitative systematic review (and meta-analysis)</td>
<td>“Self-management” has been defined as “the ability of a patient to deal with all that a chronic disease entails, including symptoms, treatment, physical and social consequences and lifestyle changes”. (Barakat et al 2008) [page 305] For the purposes of this review, Self-management interventions were defined as those which involve collaboration between health care professional and patient, so the patient acquires and demonstrates knowledge and skills required to manage their medical regimens, change their health behaviour, improve control of their disease,</td>
<td>Medico-centric Focus on cost reduction Focus on behaviour change Health professionals prescribe defined set of knowledge and skills</td>
<td>• Hospital admissions • HRQoL measured by the St George’s Respiratory Questionnaire (SGRQ) and Chronic Respiratory Disease Questionnaire (CRQ) total scores</td>
<td>Quantitative results reporting on the impact of the interventions included in the review on the primary and secondary outcome measures. Few interventions reduced hospital admissions, with only one analysis of one trial having a significant effect. Many different interventions improved HRQoL, particularly in the shorter term. It was unfortunately not possible to describe a package of effective elements, although exercise and dyspnoea management seem important. [Explanation of findings: The authors attributed the reason for the improvement]</td>
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and improve their well-being.

In HRQoL, to a reduction in dyspnoea and distress from dyspnoea as a result of exercise and breathing techniques, reduced fatigue, improved mental health from increased physical activity, an altered perception about limitations in daily activities, and an increased confidence in management of their condition. These may also lead to increased confidence in taking part in social activities. It should be noted that this effect is only for trials with up to 3 months follow-up. Not enough studies reported longer follow-up for the researchers to find evidence of an effect over a longer time.
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<td>(Baker &amp; Fatoye 2017)</td>
<td>To evaluate the clinical and cost-effectiveness of nurse-led self-management for patients with COPD in primary care</td>
<td>Intervention study</td>
<td>Systematic review (narrative summary method to describe review findings)</td>
<td>Self-management = the individual’s ability to manage the symptoms, treatment, physical, psychological, and psychosocial consequences and lifestyle changes inherent in living with a chronic condition (Barlow et al 2002, p. 178)</td>
<td>Medicocentric&lt;br&gt;Focus on medical management&lt;br&gt;Focus on compliance&lt;br&gt;Focus on education and provision of information&lt;br&gt;Self-management as an ideal set of knowledge, skills and practices&lt;br&gt;Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal</td>
<td>Intervention effects on:&lt;br&gt;- Generic quality of life&lt;br&gt;- COPD-specific quality of life&lt;br&gt;- Physical health status&lt;br&gt;- Mortality&lt;br&gt;- Psychological health status&lt;br&gt;- Use of medication&lt;br&gt;- Knowledge of COPD and medication&lt;br&gt;- Psychosocial factors (self-efficacy, social support, social participation, daily functioning)&lt;br&gt;- Self-management behaviours (smoking behaviour, physical activity, exacerbation management)&lt;br&gt;- Use of health care resources (Hospital admissions)</td>
<td>The results indicated that nurse-led self-management programmes may be associated with reductions in anxiety and unscheduled physician visits and increases in self-efficacy, but definitive conclusions could not be reached. Few studies addressed economic outcomes and the diverse perspectives, time frames and settings made comparisons difficult. Evidence on cost-effectiveness was inconclusive.</td>
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All-cause emergency department visits
Scheduled/unscheduled GP visits
Costs (direct and indirect costs, costs of intervention)
Patient satisfaction (with the intervention/with health professionals)

The authors pointed to the low participation rates in the included studies as an issue and recommended the need for more qualitative studies to explore patients’ needs and views of self-management. They felt that quantitative studies may not be able to study this.

Overall, the authors struggled to find a reason for their inconclusive results.

The studies included in this review had a number of methodological problems as discussed above: heterogeneous programmes and outcome measures, poorly described interventions and usual care, short follow up periods, a failure to fully describe the professional background of nurses delivering interventions and outcomes measures that did not match the content or aim of the intervention.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Aim</th>
<th>Type of study</th>
<th>Study design</th>
<th>Formal definition of self-care and/or self-care/self-management</th>
<th>Conceptualisation of self-care/self-management</th>
<th>Outcome measures</th>
<th>Type of results reported and rationale for results (e.g. summary of results, then explanation for these results (compliance/adherence, the need for further education, knowledge/agency/taking action etc))</th>
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<tr>
<td>(Murphy et al. 2017)</td>
<td>To determine the clinical effectiveness of self-management (SM) interventions for adults with COPD</td>
<td>Intervention study</td>
<td>Quantitative</td>
<td>SM is defined in general as ‘the systematic provision of education and supportive interventions by health care staff to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support’. (Adams et al 2004) [page 277]</td>
<td>Medicocentric&lt;br&gt;Focus on medical management&lt;br&gt;Focus on education&lt;br&gt;Focus on behaviour change&lt;br&gt;Health professionals prescribe defined set of knowledge and skills&lt;br&gt;Self-management as an ideal set of knowledge, skills and practices&lt;br&gt;Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal</td>
<td>• Health related QoL&lt;br&gt;• Hospitalisation&lt;br&gt;• Emergency department visits&lt;br&gt;• Mortality</td>
<td>Quantitative narrative reporting of results according to the outcomes listed here. The authors found that six out of 11 systematic reviews reporting on HRQoL showed improvement. But the strongest evidence here was for PR, which is essentially different to SM. Seven out of eight reviews reported positive results on hospitalisation and three out of five reporting improvements for ED visits. No impact on mortality. No discussion of compliance. <strong>Explanation of findings:</strong> No rationale provided for results</td>
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goals of motivating, engaging and supporting the patients to positively adapt their health behaviour(s) and develop skills to better manage their disease' (Effing et al 2016) [page 277]
<table>
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| (Newham et al. 2017) | To summarize the current evidence base on the effectiveness of self-management interventions (SMIs) for improving health-related quality of life (HRQoL) in people with COPD. | Intervention study                                                                                   | Quantitative systematic ‘overview of reviews’ Narrative synthesis + meta-analysis | None provided                                                                                           | Medicocentric  
Focus on behaviour change  
Health professionals prescribe defined set of knowledge and skills  
Self-management as an ideal set of knowledge, skills and practices  
Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal | • Health-related QoL (SGRQ/Chronic Respiratory Disease Questionnaire (CRQ), Clinical COPD Questionnaire (CCQ), or Sickness Impact Profile (SIP)) | Quantitative results showed SMIs were significantly more effective than usual care in improving HRQoL and reducing the number of ED visits in patients with COPD.  
SMIs that specifically target mental health concerns alongside symptom management were significantly more effective in improving HRQoL and reducing ED visits than SMIs that focus on symptom management alone.  
Explanation of findings:  
The authors explained this with reference to the high prevalence of comorbid anxiety and depression in... |
COPD, and the vicious circle that can develop where anxiety leads to breathlessness which leads to deteriorating respiratory health which increases anxiety.

Authors also hypothesised that mental health interventions may have an effect on self-efficacy. They also suggested that such interventions may improve mood, which may lead to better motivation to engage in other health behaviours such as physical activity, medication adherence, improved nutrition.

What is clear, however, is that the authors still point to a medicocentric view of optimum self-management and view the reasons for the results from a biomedical perspective and do not take on board the perspective and knowledge of the patients themselves. They refer to potential for patients to have poor health literacy and the potential to have poor cognitive processing of the most suitable course of
action at times of heightened anxiety.
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<tr>
<td>(Ng &amp; Smith 2017)</td>
<td>To evaluate the effectiveness of a specifically designed self-management education programme (SMEP) on levels of self-efficacy in Chinese patients with COPD.</td>
<td>Intervention study</td>
<td>Mixed method, exploratory randomized controlled trial (a separate exploratory study of a complex intervention to address all the components and outcome measures, rather than being as part of the overall evaluation package.)</td>
<td>None provided. Medicocentric Focus on education Health professionals prescribe defined set of knowledge and skills</td>
<td>• Self-efficacy (COPD self-efficacy scale)</td>
<td>Quantitative results focused on the effect of the intervention on self-efficacy and reported that patients in the experimental group showed greater improvement in general self-efficacy and three specific dimensions of self-efficacy (i.e., intense emotional arousal, physical exertion and weather/environment). The qualitative results concentrated on how patients had experienced the self-management programme, whether it had had an effect on their self-efficacy, and in what ways were the effects felt by participants. Three themes emerged during the focus group analysis that expressed their perceived self-efficacy in managing</td>
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<td>COPD after the program:</td>
<td>1) greater disease control, 2) improved psychosocial well-being and 3) perceived incapability and individuality.</td>
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<td>Explanation for findings:</td>
<td>none provided</td>
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<tr>
<td>(Wang et al. 2017)</td>
<td>To update a previously published systematic review on the effectiveness of self-management education (SME) as compared with standard methods of care in health outcomes for COPD patients</td>
<td>Intervention study</td>
<td>Quantitative systematic review</td>
<td>No formal definition given of self-management itself, but “self-management education” defined as: SME is a commonly utilized behaviour change technique (BCT) for patients with chronic illnesses; it focuses on the enhancement of patients’ problem-solving techniques. SME usually consists of three domains, as follows: “medical or behavioural management”, “role management,” and “emotional management”</td>
<td>Medicocentric Focus on medical management Focus on education Focus on behaviour change Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal ‘Top-down’ approach</td>
<td>• Health related QoL (SGRQ/Chronic Respiratory Disease Questionnaire (CRQ)) • COPD-related hospital admission rate • COPD-related emergency department visits • Smoking status • Pulmonary function (FVC/FEV1) • Emotional status (HADS) • Breathlessness • COPD (or self-management) knowledge • Nutritional status (BMI) • Mortality</td>
<td>Quantitative meta-analysis showed better quality of life among COPD patients receiving SME. Significant reductions in COPD-related hospital admissions and emergency department visits were identified in the SME group. The authors proposed that SME may positively affect the reduction of COPD patients’ emotional distress. No significant reduction in smoking rate and mortality rate was observed between groups. No clear evidence supports the improvement of pulmonary functions, dyspnoea, and nutritional status in COPD patients with the use of SME.</td>
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</table>
Explanation of findings:
The authors pointed to the fact that the self-management education interventions in the included studies usually covered symptom management and psychosocial support for COPD patients, and this, combined with the aim of such interventions to enhance disease-specific knowledge, self-efficacy, and self-management skills, may have contributed to the positive impact observed.
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<td>(Steurer-Stey et al. 2018)</td>
<td>To assess the effect of the Living Well with COPD (LWWCOPD) intervention on behavioural changes and disease-specific HRQoL in patients receiving primary care for COPD, compared to a control group of patients with COPD from a Dutch and Swiss primary care cohort</td>
<td>Intervention study</td>
<td>Prospectively planned, non-randomised controlled study (2 year follow up)</td>
<td>None provided, however the authors stated that the intervention was based on the Living Well with COPD self-management programme.</td>
<td>Medicocentric Focus on education Focus on self-efficacy Focus on compliance Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal</td>
<td>Primary outcome measure = Health related QoL (Chronic Respiratory Questionnaire (CRQ)) Secondary outcome measures = 1. rate of moderate to severe exacerbations over a maximum of two years 2. Smoking cessation rate 3. Self-efficacy (Self-Efficacy for Managing Chronic Disease Scale)</td>
<td>Quantitative analysis of the impact of the intervention on the listed outcomes found that the LWWCOPD intervention in a primary care setting improved HRQoL to a clinically relevant extent and reduced COPD exacerbations. Explanation of findings: The authors attributed these findings to the fact that the care team, based on the primary care setting, comprised a respiratory physiotherapist, pulmonologist and trained practice assistants. This team structure carried the advantages of care continuity, familiarity and communication compared...</td>
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Another key element to success was regular contact, which empowered patients and promoted safety. The authors also argued that effectiveness of adequate self-management on health outcomes arises from improved self-efficacy, mastery and integration of self-management skills on a day-to-day basis. The authors reported high adherence to the programme, but did not elaborate on the reasons for this/patient perceptions etc.
### Correlational studies

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<tr>
<td>(Kaşıkçı &amp; Alberto 2007)</td>
<td>To examine the relationship of family support, perceived self-efficacy and self-care behaviour in Turkish patients with COPD.</td>
<td>Correlational study</td>
<td>Quantitative descriptive correlational design</td>
<td>1. Self-care can be described as a set of skilled behaviours and refers to the various tasks that a person carries out for management of their condition. Teaching self-care/management skills is not enough to bring about change in behaviour; the patient should learn to integrate these skills in his everyday life. 2. The term self-care or self-management denotes any self-initiated, self-directed action of engaging in</td>
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<td>The main focus of the results of this paper was the statistical relationship between self-care behaviour, self-efficacy and perceived family support. The focus was not on compliance per se, but obviously scoring patients against an ideal measure (the Alberto COPD self-care behaviour inventory) implies a greater or lesser degree of appropriate self-management.</td>
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activities of daily living and other activities to preserve physical, emotional and social wellness (Orem 1985). [page 1470]

3. Worth (1997) defined self-management related to COPD as the active participation of the patient in the treatment of the disease based on sufficient coping behaviour, compliance with inhaled medication, attention to changes in the severity of the disease and adequate inhalation technique. As treatment is a long-term process, patients have to use strategies to manage their illness. [page 1470]
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<tr>
<td>(Warwick et al. 2010)</td>
<td>To describe self-management and symptom monitoring among community-dwelling older adults with COPD of moderate severity and to identify the influence of self-efficacy and sense of coherence (SOC), amongst other predictors, on self-management and symptom monitoring</td>
<td>Correlational study</td>
<td>Quantitative prospective, descriptive survey.</td>
<td>No formal definition of self-management is provided, but the following description of what self-management entails is provided: The key feature of chronic illness self-management is that the individual understands his/her illness and is involved in the management of his/her care on an ongoing basis. Optimal self-management depends critically on the attainment of several generic and disease-specific skills.</td>
<td>Mediocentric Focus on medical management Focus on self-efficacy Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices</td>
<td>• Clinical and demographical data were collected from participants' medical records. • Generic self-management for chronic illness (Partners in Health Scale) • Symptom monitoring (Symptom monitoring checklist) • Self-efficacy (Self-Efficacy for Managing Chronic Disease Scale) • Sense of coherence (Attitude to Life Questionnaire)</td>
<td>Quantitative results reported that the average participant had a moderate sense of coherence (SOC) score, moderately high self-efficacy for managing the chronic illness and reported good to very good levels of self-management of the COPD Symptom monitoring was not ideal and inconsistent across symptoms. The predictors of self-management were self-efficacy, SOC and hospitalization within the six months prior to the commencement of the study, with the final model accounting for 34% of the variance in self-management. A significant amount remains unexplained, most likely from variables not measured in the study. The significant independent predictors of symptom monitoring were illness severity and marital status.</td>
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status, which explained 35% of the variance in symptom monitoring.
Again, differences in scores on symptom monitoring can be explained to some extent by these two predictors, but 65% of the variance remains unexplained. When other variables were held constant, participants with more severe COPD and those who were married reported higher levels of symptom monitoring.

**Explanation of findings:**
The authors rationalised their findings by pointing to the fact that the majority of patients in this study were receiving support services which have been shown to improve disease management, thus explaining the high self-management scores, but not explaining the low symptom monitoring rate. Having a more severe illness was predictive of better symptom monitoring. It is likely that when symptoms are more prominent or intrusive, motivation to engage in symptom monitoring may be stronger. The finding that having a spouse was predictive of higher levels of symptoms monitoring was explained by the authors as potentially due to spouses’
motivation to provide support because of the impact on them of deterioration in QoL of patients. The authors also felt that collectively, self-efficacy and sense of coherence contributed to self-management because both are health promoting factors which contribute to better coping with life challenges.
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<tr>
<td>Kwua-Yun et al. 2012</td>
<td>To investigate relationships between self-management and the caregiver burden, and the influence of family caregivers’ caring behaviour on COPD patients’ self-care behaviour</td>
<td>Correlational study</td>
<td>Quantitative correlational cross-sectional study</td>
<td>Self-care behaviour is a term that describes the skills needed by patients to adhere to COPD treatment regimens and change their health-related behaviour in order to manage their symptoms and lead functional lives. Self-care behaviour requires education about the disease and its management, and psychological empowerment of the patients to participate fully in their own self-care.</td>
<td>Medicocentric Focus on medical management Focus on self-efficacy Focus on education Focus on behaviour change Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal Assumption that patients need to be empowered to • Disease-related knowledge (Bristol COPD Knowledge Questionnaire) • Disease Characteristics of COPD (COPD questionnaire) • Ability to perform activities of daily living (Barthel) • Health belief (COPD Health Belief scale) • Self-efficacy (Modified COPD Self-Efficacy scale) • Self-care behaviours (modified Patient Self-Care Behaviour Scale) • Family caregiver caring behaviour (Family caregiver)</td>
<td>Quantitative results focused on the correlations between family caregiving and patient self-care/self-management. Findings indicate that rigorous caregiving is associated with less self-reliance among COPD patients and also that increasing COPD patients’ self-care behaviour may reduce the caregiver burden on relatives who provide day-to-day caregiving. Positive correlation between the duration of family caregivers’ care and patients’ self-care behaviour may indicate that, with enough time, the relationships between familial caregiver and patient become more supportive of self-care behaviour, or that the transition to appropriate self-care behaviour is delayed by familial caregivers’ tendency to over-care for the COPD patient.</td>
<td>Explanations for findings:</td>
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<tr>
<td>participate in self-management</td>
<td>caring behaviour scale</td>
<td>The authors explain their results by reference to patients' need for further education, enhancement of self-efficacy and reduction of reliance on family caregivers. They also explain their results by referring to family carers' tendency to over-care, and family caregivers' need for education and training.</td>
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<td>Caregiver Reaction Assessment (Caregiver Reaction Assessment scale)</td>
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| (Chen et al. 2017) | To determine the association between structural and functional social support and self-care behaviours in adults with COPD | Correlational study | Longitudinal Mixed-effects and logistic regression | No formal definition provided, but self-care behaviours were defined as physical activity, smoking status, participating in pulmonary rehabilitation, receiving vaccinations, and adhering to inhaler or nebulizer medication | Medicocentric Focus on medical management Focus on self-efficacy Focus on compliance Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices | • Structural social support (cohabitation, partner status, number of close friends and relatives, presence of family/friend caregiver) • Functional social support (Medical Outcomes Social Support Scale) • Self-care behaviours (Physical activity – Stepwatch 3 Activity Monitor/Cigarette smoking in the past week/participation in Pulmonary Rehabilitation/Influenza and or pneumonia vaccination in the last year/Adherence to inhaler or nebuliser medication regimen | Quantitative results presented the relationship between structural and functional social support and self-care behaviours. Results reported that structural social support (living with others) had a strong association with physical activity, associated with a clinically meaningful increase compared to living alone. There were small associations between functional social support and smoking behaviour and vaccination. There were no associations found between either type of social support and adherence to medication regimens.
Explanation of findings:
The authors hypothesised that living with others may be one of many important factors that contribute to maintaining patients' daily physical activities through greater opportunities for reciprocal social interactions.
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| (Khan et al. 2017) | To describe self-management behaviour and support among COPD patients and explore behaviour associated with having a self-management plan | Descriptive and correlational study | Quantitative cross-sectional Descriptive correlational | None provided                                           | Medicocentric                                                                 | - Self-management behaviour  
- Knowledge of COPD (Bristol COPD knowledge questionnaire (BCKQ)),  
- COPD exacerbation knowledge, receipt of self-management plans and advice from healthcare professionals. These were questionnaire items on the Birmingham COPD Cohort Study – further information not available | Quantitative statistics reporting the frequencies of the key outcome measures, and then reporting on the relationship between self-management behaviour and receipt of a self-management plan.  
Less than half of respondents reported having an agreed self-management plan; including patients reporting a recent exacerbation.  
Similarly, despite 62.9% reporting severe dyspnoea and, therefore, having the potential to benefit from pulmonary rehabilitation, <7% were referred to the service.  
The authors found that results indicated various patient benefits associated |
with receiving a self-management plan, including increased medication adherence, greater disease knowledge, increased attendance of training courses and support groups, and improved quality of life. The authors noted a discrepancy between patients’ ‘poor’ knowledge regarding use and benefit of inhaled medications, and the high proportion of patients who reported satisfaction with the level of information provided about their medication. The authors suggested that this showed that while patients may think they have a good level of knowledge, they actually do not.
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<td>(Park 2017)</td>
<td>To describe the level of self-care among Koreans with COPD and to examine factors associated with self-care behaviour, including symptoms and symptom clusters</td>
<td>Correlational study</td>
<td>Quantitative cross-sectional and descriptive</td>
<td>Self-care defined as &quot;behaviours to promote health, prevent illness, and treat and cope with health problems&quot;</td>
<td>Medicocentric&lt;br&gt;Health professionals prescribe defined set of knowledge and skills&lt;br&gt;Self-management as an ideal set of knowledge, skills and practices</td>
<td>• Demographic and clinical characteristics&lt;br&gt;• Physical functioning and general health perception (Medical Outcome Study 36-item)&lt;br&gt;• Self-Efficacy (COPD Self-Efficacy Scale)&lt;br&gt;• Dyspnoea (Visual Analog Scale and Modified Medical Research Council Scale)&lt;br&gt;• Anxiety and depression (Profile of Mood States-Short Form)&lt;br&gt;• Social support (subscale of the MOS Social Support Survey)&lt;br&gt;• Self-care behaviour (Alberto Chronic</td>
<td>Quantitative results reported on the relationship between self-care behaviour and the other measures listed. The researcher reported that the level of self-care behaviour in Koreans with exacerbated COPD was poor. Education level, comorbidities, emergency department visits during the past year, general health perception, and education on exacerbation and symptom management explained a significant amount of the total variance in self-care behaviour. Explanation of findings:&lt;br&gt;Results were explained with explicit reference to</td>
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<p>| Obstructive Pulmonary Disease Self-Care Behaviour Inventory | patient compliance with what is determined to be good self-care behaviour according to the Alberto COPD Self-care Behaviour Inventory), citing low levels of engagement in self-care behaviours. The researcher concluded that participants in the study required more education in order to practice 'good' self-care for COPD. |</p>
<table>
<thead>
<tr>
<th>Authors</th>
<th>Aim</th>
<th>Type of study (e.g. intervention study, correlational study, patient experiences study, other (specify))</th>
<th>Study design (Qual, quant, specify exact)</th>
<th>Formal definition of self-care and/or self-care/self-management</th>
<th>Conceptualisation of self-care/self-management</th>
<th>Measures</th>
<th>Type of results reported and rationale for results (e.g. summary of results, then explanation for these results (compliance/adherence, the need for further education, knowledge/agency/taking action etc))</th>
</tr>
</thead>
</table>
| (Bringsvor et al. 2018) | To examine the relationships of sociodemographic and clinical characteristics and symptom burden with different self-management domains in persons with COPD. | Correlational study                                                                                  | Quantitative cross-sectional              | Self-management is a multidimensional construct that consists of various domains. Eight independent domains describing self-management have been identified in the widely used Health Education Impact Questionnaire (heiQ): 1) positive and active engagement in life; 2) health-directed activities; 3) skill and technique acquisition; 4) constructive attitudes and approaches; 5) self-monitoring and insight; 6) health services navigation; 7) social integration and support; and 8) emotional distress. | Holistic perspective on self-management  
Self-management as a multi-dimensional construct  
Health professionals prescribe defined set of knowledge and skills  
Self-management as an ideal set of knowledge, skills and practices | • Sociodemographic and clinical characteristics (age, sex, education, cohabitation, comorbidity, pack years smoking, use of inhaled corticosteroids, participation in organised physical training, previous participation in pulmonary rehabilitation)  
• Lung function (spirometry)  
• Symptom burden (COPD Assessment Test)  
• Self-management domains (Health Education Impact Questionnaire (heiQ)) | Quantitative results reporting on relationship between the domains of self-management as measured by the heiQ and symptom burden and sociodemographic and clinical characteristics. The most notable finding was the strong and consistent association between higher symptom burden and worse scores in all the self-management domains except for self-monitoring and insight. The participants with higher symptom burden reported lower positive and active engagement in life and lower social integration and support.  
Explanation for findings: |
The authors suggest that one possible explanation for these findings is the “vicious COPD circle,” in which COPD-related pathophysiological changes and respiratory symptoms result in reduced physical activity and social engagement in life.

Rationale for the findings tended to focus on characteristics of the COPD patient such as high symptom burden, skills and technique acquisition, the ability to navigate health services, presence of constructive attitudes, presence of comorbidities.
### Quantitative descriptive survey

<table>
<thead>
<tr>
<th>Authors</th>
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<th>Measures</th>
<th>Type of results reported and rationale for results (e.g. summary of results, then explanation for these results (compliance/adherence, the need for further education, knowledge/agency/taking action etc))</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Cicuttto &amp; Brooks 2006)</td>
<td>To identify, from the perspective of individuals living with COPD, their management approaches</td>
<td>Other (descriptive)</td>
<td>Quantitative descriptive mailed survey</td>
<td>Self-care implies monitoring symptoms, implementing treatment regimens, maintaining a healthy lifestyle, and coping with and managing the impact of illness on daily functioning, emotions and relationships.</td>
<td>Medicocentric Holistic perspective on self-management Focus on compliance Focus on self-efficacy Health professionals prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal</td>
<td>• Self-management activities (breathing exercises, exercises (walking, etc.), strengthening exercises, inhaled short-acting bronchodilators, inhaled long-acting bronchodilators, inhaled corticosteroids, inhaled combination, (long-acting β agonists and corticosteroid) therapy, oxygen, flu shots, follow-up visits with a doctor and other health professionals, and the use of Quantitative descriptive statistics were reported on self-management approaches used by patients according to the variables set out in the questionnaire. The researchers found that most individuals with COPD use a combination of self-care strategies to manage their condition that include an annual influenza vaccination, inhaled short- and long-acting bronchodilators, inhaled corticosteroids, follow-up medical appointments, and breathing exercises. Several barriers and enablers to self-care existed. The most common motivators were a desire to feel better, a fear of getting...</td>
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</table>
- Level of helpfulness was determined through use of a five-point Likert scale.
- Level of confidence or self-efficacy
- Risk of depression (Center for Epidemiologic Studies Depression Scale (CES-D))
- Level of involvement in management decisions
- Perceptions of the quality of interactions with health care team
- Demographic and respiratory health-related information.

Respondents relied on their self-determination and personal discipline to manage COPD. Common barriers identified included a lack of knowledge, not having the activity recommended by a health care professional, a low energy level or inability to perform the activity, changes in normal routine, and mood. A considerable proportion of respondents had scores suggestive of depression (44%). Participants preferred some level of shared care in managing COPD.

This study did not set out to assess compliance with a predetermined standard of self-management, but to describe the self-care activities that patients were undertaking themselves. There is reference to self-determination, but this seems to actually refer to 'will power' or being determined to change, not to self-determination in the context of personal
autonomy, power, and the freedom to choose.
### Policy documents

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<thead>
<tr>
<th>Authors</th>
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<th>Outcome measures</th>
<th>Type of results reported and rationale for results (e.g. summary of results, then explanation for these results (compliance/adherence, the need for further education, knowledge/agency/taking action etc))</th>
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</thead>
<tbody>
<tr>
<td>(Health Service Executive 2006)</td>
<td>To research and develop a national chronic disease management patient support programme for HSE.</td>
<td>Other (policy document)</td>
<td>Mixture of different approaches including: (1) Secondary analysis of epidemiological and research data (2) A survey of current Irish programmes of care for chronic illness (diabetes, heart failure, coronary heart disease and COPD) (3) A literature review of best practice in chronic disease management programmes. (4) Site visits to chronic disease</td>
<td>None provided</td>
<td>Mediocentric&lt;br&gt;- Focus on medical management&lt;br&gt;- Focus on compliance&lt;br&gt;- Focus on education&lt;br&gt;- Self-management as an ideal set of knowledge, skills and practices&lt;br&gt;- Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal</td>
<td>n/a</td>
<td>n/a</td>
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<td></td>
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<td>management programmes in the UK and USA. (5) Information and consultation conference (6) Feasibility testing of the programme via stakeholder interviews with key experts in the Irish healthcare system</td>
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<td>(Department of Health and Children 2008)</td>
<td>(i) To promote and to improve the health of the population and reduce the risk factors that contribute to the development of chronic diseases and (ii) to promote structured and integrated care in the appropriate setting that improves outcomes and quality of life for patients with chronic conditions.</td>
<td>Other (policy document)</td>
<td>n/a</td>
<td>none provided</td>
<td>Medicocentric</td>
<td>n/a</td>
<td>n/a</td>
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<tr>
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<tr>
<td>(Health Service Executive et al. 2008)</td>
<td>To:</td>
<td>Review scientific literature scientific on prevention and management of COPD</td>
<td>Mixture of methods encompassing:</td>
<td>None provided</td>
<td>Medicocentric</td>
<td>n/a</td>
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<td></td>
<td></td>
<td>Review the epidemiology of COPD in Ireland</td>
<td>• International best practice guidelines, risk factors and Irish burden of illness data were identified.</td>
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<td>Focus on medical management</td>
<td>n/a</td>
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<td></td>
<td></td>
<td>Outline the COPD services and initiatives available in Ireland</td>
<td>• Extensive written consultation took place with key groups and organisations.</td>
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<td>Focus on compliance</td>
<td>n/a</td>
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<td></td>
<td></td>
<td>Consult with relevant stakeholders</td>
<td>• Focus group work was undertaken with a patient support group.</td>
<td></td>
<td>Focus on education and information provision</td>
<td>n/a</td>
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<td></td>
<td></td>
<td>Make recommendations for the management of people with COPD and its services, having regard to current best practice</td>
<td>• Information was gathered</td>
<td></td>
<td>Health professionals/policy makers prescribe defined set of knowledge and skills</td>
<td>n/a</td>
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<td></td>
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<td>Self-management as an ideal set of knowledge, skills and practices</td>
<td>n/a</td>
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<td>Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal</td>
<td>n/a</td>
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<td>‘Top-down’ approach</td>
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<tr>
<td>1. Make recommendations on the development and implementation of an integrated approach to improve respiratory health and the care of people with COPD.</td>
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<td>2. Research was commissioned on prescribing patterns for COPD in Ireland.</td>
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<tr>
<td>Authors (Chronic Conditions Working Group 2017)</td>
<td>Aim</td>
<td>Type of study (e.g. intervention study, correlational study, patient experiences study, other (specify))</td>
<td>Study design (Qual, quant, specify exact)</td>
<td>Formal definition of self-care and/or self-care/self-management</td>
<td>Conceptualisation of self-care/self-management</td>
<td>Outcome measures</td>
<td>Type of results reported and rationale for results (e.g. summary of results, then explanation for these results (compliance/adherence, the need for further education, knowledge/agency/taking action etc))</td>
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<tr>
<td>To: • Provide an overview of self-management support • Provide recommendations on how self-management support for four major chronic conditions – chronic obstructive pulmonary disease (COPD), asthma, diabetes and cardiovascular disease - should be implemented in the Irish health system • Inform a plan for the implementation of</td>
<td>Other (policy document)</td>
<td>Mix of Health Technology Assessment (HTA), literature and policy review, survey of existing self-management support provision in Ireland, review of other evidence on provision in Ireland Consultations with the Patients’ Consultative Forum, national consultation via focus groups with health care professionals, patients and representatives of patient organisations, interviews with</td>
<td>Self-care is defined as the actions people take to care for themselves, their children and their families to stay fit and well. This includes: staying fit and healthy, both physically and mentally; taking action to prevent illness and accidents; correct use of medicines; treatment of minor, self-limiting illnesses and better care of long-term conditions. Self-care is understood to include the self-management of chronic conditions Self-management is defined as the tasks that individuals must undertake to live with one or more chronic</td>
<td>Medico-centric Focus on medical management Focus on compliance Focus on education and information provision Focus on behaviour change Health professionals/policy makers prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal</td>
<td>n/a</td>
<td>n/a</td>
<td></td>
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<tr>
<td><strong>the self-management support framework</strong>&lt;br&gt;• Guide prioritisation of investment in self-management support initiatives according to the evidence base.</td>
<td><strong>HSE senior management and representatives of the ICGP and Department of Health</strong>&lt;br&gt;conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their condition. Self-management support is defined as the systematic provision of education and supportive interventions, to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support.</td>
<td>&quot;Top-down&quot; approach</td>
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</table>
### Conceptual/discussion papers

#### Medicocentric conceptual/discussion papers

<table>
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<tr>
<th>Authors</th>
<th>Aim</th>
<th>Type of study (e.g. intervention study, correlational study, patient experiences study, other (specify))</th>
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<tbody>
<tr>
<td>(Bourbeau 2008)</td>
<td>To provide an overview of the model of self-management, an essential component of disease management. The behavioural and cognitive processes in self-management are covered and examples specific to COPD provided.</td>
<td>Other (conceptual)</td>
<td>n/a</td>
<td>The Expert Panel Approach (National Health Service, 2001) uses the term self-management to refer to a &quot;formalized patient education program aimed at providing the patient with the information and skills necessary to manage their condition within the parameters of the medical regimen.&quot; [page 328]</td>
<td>Medicocentric Focus on medical management Focus on behaviour change Focus on self-efficacy Health professionals/policy makers prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be</td>
<td>n/a</td>
<td>n/a</td>
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</table>
enhanced to meet this ideal
‘Top-down’ approach
<table>
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<tr>
<th>Authors</th>
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<th>Type of study (e.g. intervention study, correlational study, patient experiences study, other (specify))</th>
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</table>
| (Effing et al. 2016) | To obtain consensus regarding the conceptual definition of a COPD self-management intervention by engaging an international panel of COPD self-management experts using Delphi technique features and an additional group meeting. | Other (Definitional/conceptual study)                                                            | Delphi study                             | A COPD self-management intervention is structured but personalised and often multi-component, with goals of motivating, engaging and supporting the patients to positively adapt their health behaviour(s) and develop skills to better manage their disease. The ultimate goals of self-management are: a) optimising and preserving physical health; b) reducing symptoms and functional impairments in daily life and increasing emotional well-being, social well-being and quality of life; and c) establishing effective alliances with healthcare professionals, family, friends and community. | Medicocentric  
Focus on medical management  
Focus on behaviour change  
Health professionals/policy makers prescribe defined set of knowledge and skills  
Self-management as an ideal set of knowledge, skills and practices  
Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal  
"Top-down" approach | n/a | The result of this study was the final definition of COPD self-management intervention agreed on by participants in the Delphi study |
“The process requires iterative interactions between patients and healthcare professionals who are competent in delivering self-management interventions. These patient-centred interactions focus on: 1) identifying needs, health beliefs and enhancing intrinsic motivations; 2) eliciting personalised goals; 3) formulating appropriate strategies (e.g. exacerbation management) to achieve these goals; and if required 4) evaluating and re-adjusting strategies. Behaviour change techniques are used to elicit patient motivation, confidence and competence. Literacy sensitive approaches are used to enhance comprehensibility.”
<table>
<thead>
<tr>
<th>Authors</th>
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<th>Type of study</th>
<th>Study design</th>
<th>Formal definition of self-care and/or self-care/self-management</th>
<th>Conceptualisation of self-care/self-management</th>
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</table>
| (Korpershoek et al. 2017) | To reach expert consensus on the most relevant set of self-management behaviours that can be targeted and influenced to maximize reduction of exacerbation impact. [page 2735] | Other (Delphi)                       | Mixed method Delphi study                                       | Self-management = an individual’s ability to detect and manage symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition.               | Medicocentric   
Focus on medical management   
Focus on compliance   
Focus on education and information provision   
Focus on behaviour change   
Health professionals/policy makers prescribe defined set of knowledge and skills   
Self-management as an ideal set of knowledge, skills and practices   
Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal   
‘Top-down’ approach | n/a                                                                                                                                                                                                 | Quantitative results were reported on consensus of experts as to the most relevant and feasible self-management behaviours that can be targeted and influenced prior to, during and after a COPD exacerbation. Consensus within the expert panel was reached on a set of 17 self-management behaviours that were perceived both relevant and feasible to target and influence. According to our study results, self-management should focus on adherence to pharmacotherapy, influenza vaccination, physical activity/exercise, avoiding stimuli, smoking cessation, early detection of symptom deterioration, medical treatment of exacerbations, managing |
stress and anxiety, and awareness for recurrent exacerbations.

**Explanation of findings:**
The authors explained that the selection and agreement on these specific self-management behaviours may be explained by the study’s explicit focus on targeting the impact of COPD exacerbations. Behaviours were also selected by experts based on the perceived relevance (link between the behaviour and exacerbation impact and relevant available evidence), room for improvement and feasibility to influence such behaviours. Qualitative results on commentary about the degree of consensus across experts, and individual experts’ commentary on proposed domains of the model were reported in tabular format.
<table>
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<tr>
<td>Kaptein et al. 2014</td>
<td>To analyse treatment strategies regarding self-management in patients with COPD, review the methods applied in encouraging self-management behaviours, the efficacy and outcomes of self-management programs on quality of life (QOL) and behavioural outcomes, and discuss how self-management may be incorporated into regular medical care for people with COPD.</td>
<td>Other (conceptual/review)</td>
<td>n/a</td>
<td>Self-management is to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. ... [the] ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life.</td>
<td>Medicocentric Critique of medicocentric conceptualisation of self-management BUT Assumption that the knowledge, skills and practices of people with COPD need to be enhanced.</td>
<td>n/a</td>
<td>n/a</td>
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<td>Study design (Qual, quant, specify exact)</td>
<td>Definition of self-management</td>
<td>Conceptualisation of self-management</td>
<td>Conceptualisation of power</td>
<td>Type of results reported and rationale for results (e.g. summary of results, then explanation for these results (compliance/adherence, the need for further education, knowledge/agency/taking action etc))</td>
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<td>(Wilson 2001)</td>
<td>To conduct a policy analysis of the UK Expert Patient Programme (EPP)</td>
<td>Other (policy analysis/conceptual)</td>
<td>Policy analysis</td>
<td>Not provided</td>
<td>Experiential perspective</td>
<td>Critique of medicocentric view of power</td>
<td>n/a</td>
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<td>Patient-centred conceptualisation</td>
<td>• Power as resting in the hands of health care professionals and policy makers</td>
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<td>Focus on self-management as an individual response in social and historical context</td>
<td>• Dominance of health care professionals and policy makers' knowledge and interpretation of self-management over patient experiences</td>
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<td>Focus on patients' own expertise</td>
<td>• Foucauldian concepts of disciplinary power (panopticism/constant surveillance, biopower, pastoral power)</td>
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<td>Critique of State self-management policy</td>
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<td>Critique of self-efficacy</td>
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<td>Critique of medicocentric perspective</td>
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<td>Conceptualisation of power</td>
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<td>(Kendall &amp; Rogers 2007)</td>
<td>To critically appraise the principles and use of the chronic disease self-management programme (CDSMP) as a national self-care policy initiative</td>
<td>Conceptual/policy analysis</td>
<td>Policy analysis</td>
<td>Self-care has been defined as a set of behaviours and actions undertaken to enhance health, prevent disease, evaluate symptoms and restore health. (Dean, 1981). The authors critique this definition because they feel it does not take into account the interests and values associated with self-care in a broader social context. Self-management refers to a sense of coherence that individuals are able to maintain in the face of their condition and the notion of a self-management</td>
<td>Experiential perspective</td>
<td>Critique of medicocentric view of power</td>
<td>Power rests with the professional/policy maker Agency of the patient is undermined Legitimacy and precedence given to health professionals’ knowledge and definition of “appropriate” self-management at the expense of patients’ experiential knowledge Foucauldian concept of ‘responsibilisation’ and the ‘responsibilisation paradox’ Power as social oppression, discrimination and exclusion</td>
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<td>Analysis of experiential view of power</td>
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<td>Power rests with the persona with chronic illness or self-help groups</td>
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<td>Individuals appropriate and use biomedical knowledge for their own ends</td>
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<td>Individuals’ resistance to biomedicine and related policy</td>
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<td>Foucauldian concepts of ‘practices of the self’, ‘technologies of the self’.</td>
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| (Kendall et al. 2011) | To explore the assumptions that underpin common usage of the term self-management among policy makers, professionals and consumers. | Discussion/conceptual                                                                          | Review and secondary thematic analysis of multiple sources of data collected over the five years prior to the publication of the article. | The authors did not set forth an explicit definition of self-management, rather the whole study is dedicated to discerning conceptual trends in multiple definitions of self-management. | Experiential perspective  
Critique of medicocentric perspective  
Focus on self-management as an individual response in social and historical context  
The authors identified 4 main conceptualisations of self-management evident in the data.  
1. Self-management as cost-cutting mechanism:  
2. Self-management as the domain of health professional experts:  
3. Self-management as emancipation discourses.  
4. The authors recommend an ecological model of self-management | Critique of medicocentric view of power  
Power rests with the health system and health care professionals—exercises control over service users  
Patient = costly and negative influence on the health system  
Health professionals = holders of the ‘right’ wisdom and knowledge  
Individual patient = passive and in need of education – ‘non-knower’  
Patient agency is undermined  
Foucauldian concepts of governmentality and responsibilisation and the responsibilisation paradox | n/a |
Analysis of experiential view:
Experiential perspective has the potential to offer patients more power, liberation, voice and equity. Power rests with individuals as a network of relations intertwined with the individual's world in sociocultural context. But this limited by the dominance of medicocentric perspective.
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| (Lawn et al. 2011) | To examine the concept of self-management and responsibility from a range of standpoints, focusing on the Australian context | Discussion/conceptual            | n/a                | Self-management as involving a range of ‘attitudes, behaviours and skills’ and suggest that the following are key features of successful self-management for chronic conditions: (1) Having knowledge of the condition and/or its management (2) Adopting a self-management care plan agreed and negotiated in partnership with health professionals, significant others and/or carers and other supporters (3) Actively sharing in decision-making with health professionals, significant others and/or carers and | Experiential perspective  
Focus on self-management as an individual and family response in social and historical context  
Focus on learning and experience  
Focus on ‘self-managers’ as consumers of health care  
Focus on the rights of patients to manage their health in the way that they choose  
Conceptualisation of self-management as a process  
Critique of medico-centric perspective  
Critique of ‘top-down’ state self-management policy | Critique of medico-centric view of power  
Criticism of the focus on individuals with chronic illness as ‘self-regulating subjects’  
Criticism of the focus on individuals as engaging in ‘responsible behaviour’ without sharing of power  
Criticism that the medico-centric perspective ignores the distribution of resources  
Foucauldian concepts of governmentality and responsibilisation | n/a |

Analysis of experiential view:  
People with chronic illness are always making choices about how to live their lives and manage their personal care needs.
other supporters (4)
Monitoring and managing signs and symptoms of the condition (5)
Managing the impact of the condition on physical, emotional, occupational and social functioning (6)
Adopting lifestyles that address risk factors and promote health by focusing on prevention and early intervention (7) Having access to, and confidence in the ability to use support services.

Focus on patient resistance to imposed power - either actively by adjusting the 'advice' given to them to match their situation more realistically, or by omission or nonengagement.
Self-management is not so much the ceding of power by health authorities and professionals, but the establishment of new and different forms of control.
Foucauldian concept of resistance via appropriation or non-use of dominant knowledge
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| (Disler et al. 2012) | To define self-management, identify the determinants which influence the individual’s ability to cope and adjust to living with chronic obstructive pulmonary disease in the community, and identify implications for clinical practice and research. | Other (literature review) | Integrative review | Self-management refers to the skills and behaviours that a person requires to maintain functioning in the context of their lives. In chronic disease, these skills and behaviours are used to maintain physical and emotional functioning and reduce the impact of a patient’s condition on their daily lives. There is lack of consensus around the term self-management. Self-management is viewed, in this review, as an umbrella term which encompasses the elements of self-care and disease management. Self-care refers to the | Medicocentric Critique of medicocentric conceptualisations of self-management. Focus on self-management as a process in which patients are active participants BUT Focus on medical management Focus on education and skills acquisition Focus on behaviour change Health professionals prescribe defined set of knowledge and skills | n/a | The authors found that self-management is less well characterised in chronic obstructive pulmonary disease compared with other chronic conditions. A conceptual model was derived from the findings of the integrative review to illustrate the elements that impact on ability to self-manage. These included:  
- Physical determinants (dyspnoea, functional impairment, energy conservation)  
- Psychological determinants (illness perception, anxiety, depression, hope, self-efficacy, sense of control) |
| Specific tasks that people carry out on a day to day basis in order to manage their condition. Self-management additionally implies those behaviours and skills used by individuals to maintain emotional, social and physical functioning in the context of their lives with chronic illness. | Self-management as an ideal set of knowledge, skills and practices. | • Social determinants (social isolation, loss of social role, social support, health literacy, socioeconomic status)  
• Existential determinants (meaning of life, spirituality)  
• Provider determinants (access to resources, relationships with providers) |
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<tr>
<td>(Jonsdottir 2013)</td>
<td>To synthesise a summary of findings from previously published systematic reviews on self-management programmes for people with COPD and findings of an integrated review that was conducted on studies published after the publication of these systematic reviews.</td>
<td>Other (conceptual) Literature review</td>
<td>Synthesis of findings from previously published systematic reviews and an integrated review that was performed on papers published between January 2007–June 2012</td>
<td>Self-management is embedded within the notion of self-care. Self-care refers generally to activities that individuals, families, and communities undertake with the intention of protecting and enhancing health and preventing disease. This notion has a reference to day-to-day activities that people do more or less intentionally to preserve and enhance their well-being. As a part of daily life, self-care is located within the experience of all people and does not need to involve health professionals. Self-management, however, indicates actions to minimise the impact of a chronic</td>
<td>Experiential perspective Criticises medicocentric conceptualisations of self-management - standardised and prescribed treatment regimens, and actions taken by individuals to monitor and manage symptoms in order to adhere to treatment protocols. Contrasts these with conceptualisations that take an experiential approach and illuminate self-management as person-centred; a process of learning and exploring with each individual to find out what works within the context of his/her life as a whole. Self-management is considered to have a personal meaning for</td>
<td>Jonsdottir reported the kinds of outcome measures typically espoused in intervention studies. These included: • Clinical/physiological (e.g. lung function and disease severity), • Functional (e.g. exacerbations of a disease, pain), • Cognitive (e.g. knowledge, self-efficacy, psychological health), • Healthcare resource use (e.g. hospitalisations, emergency room visits, visits to general practitioners) • Healthcare cost.</td>
<td>Narrative discussion of the results of systematic reviews. Noted the lack of evidence as to the effectiveness of self-management interventions in COPD. Noted the lack of emphasis on the theoretical background or the conceptual approach of self-management programmes, and the prominence of health-professional-centred approaches, although she noted more of a trend in more recent studies towards patient-centredness. Author critiqued the dominance of behaviour change approaches, and the tendency to standardise and prescribe self-management for patients as counter to the</td>
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Patients carry out self-management activities prescribed or recommended by healthcare professionals (HCPs); they are expected to become capable managers of their health conditions and be engaged and active in using and accepting self-management support from HCPs.

- Behavioural outcomes (e.g. exercise, diet)
- Health-related quality of life (HRQL).

Management of the illness is viewed as a part of living life in its entirety, each individual. It reflects personal choice, is dynamic and multifaceted.
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<td>Hujala et al. 2014</td>
<td>To illustrate how the social reality of multimorbidity, faced by patients and other actors, is discursively constructed in scientific articles addressing the development of care related to multiple chronic conditions</td>
<td>Other (Literature review)</td>
<td>Critical discourse analysis of texts (scientific articles)</td>
<td>None provided</td>
<td>The authors do not put forward their own conceptualisation of self-management, rather, they examined how self-management was conceptualised in discourses in the literature. Self-management is conceptualised in a normative manner – that is, it is an ideal to which patients should aspire based on dynamic concepts of goal setting, personal targets, effective strategies, problem-solving. This conceptualisation is somewhat 'top down', as what is defined as good self-management is decided by health researchers/health professionals. But there is some room made for the right of patients to express their own preferences and opinions. There is an expectation though, that these preferences and opinions should be moulded to fit the shape of 'ideal' self-management.</td>
<td>Critique of medicocentric view of power</td>
<td>Power rests with policy makers and health care professionals. Criticism of encroachment of self-management discourse into private sphere of individuals. Criticism of trend towards responsibilisation of people with chronic illness without transfer of power. Patient agency undermined by norms and expectations placed upon them. Hidden use of power to save health care costs and responsibilisation of patients. Foucauldian concepts of responsibilisation and the responsibilisation paradox, biopower and pastoral power</td>
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co-worker, who participates as an equal actor in the relationship. This highlights a tendency towards shared agency of key actors.

4. Patients as self-managers: characterized by dynamic, business-like vocabulary, often with normative connotations aiming at effective performance: self-management, goal setting, personal targets, self-management strategies, problem solving. This individual discourse on patients as self-managers challenges the patient to be responsible for her/his health. Those who are not able to manage themselves, are not “fully capable”, thus minimizing their agency.
### Qualitative studies

#### Qualitative medicocentric studies

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<tr>
<td>Stellefson et al. 2010</td>
<td>To assess the self-management learning needs, experiences and perspectives of COPD patients who were treated at a Certified Federal Rural Health Clinic in order to inform the development of a COPD self-management DVD.</td>
<td>Other (descriptive)</td>
<td>Qualitative descriptive</td>
<td>COPD self-management refers to engaging in activities that promote adequate inhalation technique, building physiologic reserves, preventing adverse health outcomes, complying with recommended treatment protocols, monitoring respiratory and emotional status and making appropriate management decisions on the basis of this self-monitoring, and managing the effects of illness on</td>
<td>Medicocentric</td>
<td>n/a</td>
<td>Qualitative findings reported that self-management practices varied according to how long the person had had the diagnosis for. People who had recently been diagnosed reported fewer self-management behaviours and much less knowledge about self-management than those who had been diagnosed for longer. Among those who reported undertaking self-management, the self-management behaviours identified were limited to taking prescribed medications and reducing movement and activity (planning and pacing). However, the authors felt that the participants did not realize the importance of practicing other COPD self-management skills and</td>
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behaviours. Patients reported a lack of knowledge and skill development related to alternative rehabilitative activities such as controlled breathing and coughing, stress reduction, smoking cessation, nutrition, and paced walking/activity. The authors attributed this to the fact that the participants had never been exposed to any seminars or informational resources which showed them how to perform these skills.

What is notable is that the findings did not explore in depth the participants’ own definitions of self-management beyond the planning and pacing activities reported by participants.
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| Sheridan et al. 2011  | To explore, in a specific New Zealand context, whether individuals with moderate to very severe COPD experience helplessness, how they interpret this, and the consequences for their self-management including the services they access. | Other descriptive (exact approach not specified, probably descriptive) | None provided | Mediocentric  
Focus on medical management  
Focus on compliance  
Focus on education and information provision  
Health professionals/policy makers prescribe defined set of knowledge and skills  
Self-management as an ideal set of knowledge, skills and practices  
Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal  
‘Top-down’ approach | n/a | Qualitative results reported a pervasive sense of helplessness and poor self-management. The authors found two distinct approaches that co-exist with, and may support these attitudes and behaviours, 1) self-blame (in a small, mostly European group, of participants; and 2) Religious faith (in a mostly Pacific Islander group) centred around God, Church and family.  
In both groups self-management was found to be ‘poor’, centred on short-term symptom management, linked to poor knowledge/information about the illness.  
Explanation of findings:  
The authors came up with two reasons that might explain these findings. |
1) Both groups had a sense of helplessness – group 1 based on a fatalistic sense of self-blame and guilt and low expectations of care, group 2 resigned to living with COPD and managing symptoms in the short-term, viewing their own health as less important than religion and family. The authors postulated that this helplessness could undermine a sense of control that is essential to improving HRQoL.

2) Clinician attitudes towards COPD – blaming patients for having inflicted it on themselves because they smoked – the authors viewed as crucial in influencing patient attitudes towards an illness and its management. This could reinforce the self-blame that participants in group 1 reported and, combined with a lack of social support further undermine their motivation to engage in self-management.

3) The lack of information reported by participants may also undermine self-management, and the authors recommended facilitating access to effective education and information, especially about the long-term requirements of living with and managing COPD.
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<td>(Mousing &amp; Lomborg 2012)</td>
<td>To explore how group patient education influences the self-care of patients with chronic obstructive pulmonary disease [page 19]</td>
<td>Patient experiences</td>
<td>Qualitative descriptive</td>
<td>Self-care is defined as the patients’ own resources and ability to live a healthy life in agreement with their own preferences and wishes</td>
<td>Integration of medicocentric and patient experiences</td>
<td>n/a</td>
<td>Qualitative results reporting on the experiences of patients 3 months after attending a group patient education. Patients reported that their knowledge of chronic obstructive pulmonary disease had increased, that they had acquired tools to handle their symptoms, and that the social aspect of patient education had motivated them to utilize their new habits after finishing the course. The data indicate that patients need a period of adjustment (a &quot;ripening period&quot;): It took time for patients to integrate new habits and competencies into everyday life. Talking to health care professionals focused the patients'...</td>
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attention on their newly acquired skills.

Explanation of findings:
The authors explained their results to a certain extent by referring to the researcher effect: The Hawthorne effect

Notably, the patients found that taking part in research interviews increased their awareness of the effects of the patient education programme. The interviewer functioned as a mediator, encouraging the participants to tell their personal stories and consequently contributing to their realization of the effects of attending the programme.

The authors suggested that this might mean that talking to health care professionals might lead to increased self-reflection and reflexivity on the part of patients. The authors therefore recommended that health care professionals introduce a 3-month post-training dialogue intervention may be important for patients
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<td>Wortz et al. 2012</td>
<td>To learn about patients’ concerns, fears, learning needs, barriers, facilitators, goals, and expectations concerning self-management of COPD and to guide delivery of cognitive-behavioural intervention as part of self-management support.</td>
<td>Other (descriptive)</td>
<td>Qualitative descriptive</td>
<td>Self-management support defined as ‘the systematic provision of education and supportive interventions by healthcare staff to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support’. The goals of self-management are behaviour changes to promote improved functioning and quality of life. The goal of self-management support is to ‘change patients’ behaviour by increasing the patients’ self-efficacy and knowledge’</td>
<td>Medicocentric Focus on education and information provision Focus on behaviour change Focus on self-efficacy Health professionals/policy makers prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal ‘Top-down’ approach.</td>
<td>n/a</td>
<td>This study did not explore patient experiences of self-management. Rather it explored their fears, needs and expectations of self-management. Three main themes (loss, fear, and desire for improved care). Patients reported the loss of ability to participate in pleasurable and necessary activities of daily living and the desire to recover at least some of their functioning. They expressed problems with social isolation and uncertainty about their prognosis, as well as the hope to improve. In addition, fearful experiences associated with uncontrolled breathlessness and a wish for greater understanding and knowledge about treatment were major concerns.</td>
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Explanation of findings:
The authors suggested that findings might be interpreted as reflecting the patients' desire and motivation to overcome losses and fears and to access better information and care.
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<td>Korpershoek et al. 2016</td>
<td>To identify and explain the underlying process of exacerbation-related self-management behaviour.</td>
<td>Other (qualitative grounded theory)</td>
<td>Qualitative grounded theory</td>
<td>None provided</td>
<td>Medicocentric Focus on medical management Health professionals/policy makers prescribe defined set of knowledge and skills Self-management as an ideal set of knowledge, skills and practices Assumption that the knowledge, skills and practices of people with COPD need to be enhanced to meet this ideal 'Top-down' approach</td>
<td>n/a</td>
<td>Qualitative results reported that identified several patterns in exacerbation-related behaviour based on two important self-management skills: recognition of an exacerbation and performance of self-management actions. With regard to recognition, three different patterns in patients were identified and detailed in our conceptual model: 1) early recognition, 2) late recognition and 3) difficulties with recognition. Subsequently, these patients showed different types of self-management actions, which were subdivided into “absence of self-management actions”, “self-management actions to reduce symptoms”, and “contacting a health care...”</td>
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professional (HCP). In general, patients who recognised an exacerbation early were more likely to undertake self-management actions to reduce symptoms and, if necessary, to contact a HCP in a timely manner. This became less likely for patients who recognised exacerbations late or not at all.

Explanation of findings:

The authors explained the different approaches to exacerbation-related self-management by referring to the personal beliefs of patients, their perceptions regarding the seriousness of the illness, their knowledge of exacerbations, and their prior experiences of exacerbations, and link this to the Health Belief Mode
### Qualitative studies of patient experiences of self-management

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<td>(Cicutt et al. 2004)</td>
<td>To understand the day-to-day self-care activities of people living with COPD that takes into account their meaning of the activities. [page 169]</td>
<td>Patient experiences</td>
<td>Qualitative descriptive (focus groups)</td>
<td>The terms self-care or self-management denote any self-initiated, self-directed action of engaging in activities of daily living and other activities to preserve physical, emotional and social wellness. Self-management related to COPD is defined as the active participation of the patient in the treatment of the disease based on sufficient coping behaviour, compliance with inhaled medication, attention to changes in the severity of the disease, and adequate inhalation technique.</td>
<td>Integration of biomedical and patient experiential approach, with more emphasis on patient experiences. Focus on compliance with health professionals’ recommendations. Focus on self-management as based on experience of living with COPD</td>
<td>n/a</td>
<td>Qualitative findings were reported based around living with COPD and trying to self-care in the following domains: Living everyday with COPD takes place in the context of survival – description of the struggle to survive in the face of deterioration and death. Self-care – adjusting physically: adjusting emotionally. In the current study, the authors observed that three models of decision-making were used by individuals (1. Patients making decisions independently (active), 2. shared or collaborative decision</td>
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Clinicians making (in collaboration with health professionals),
3. Clinicians making decisions (passive)). The authors noted that
depending on the treatment activity, they would use
differing models of decision-making. Patients felt comfortable using an
independent active role in adjusting their recommended exercise
regime but felt that the adjustment of oral medications was
something different that required a shared model or reliance on the clinician for
decision-making, experiential knowledge. Similarly, agency and
taking action were not discussed. Patients’
descriptions of balancing the requirements of
disease management with living life showed a tension,
a resistance to all-encompassing demands of self-management, but on
the whole the paper did not report a high degree of
agency on the part of patients.
<table>
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<tr>
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<th>Outcome measures</th>
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</thead>
<tbody>
<tr>
<td>Chen et al. 2008</td>
<td>The aim of this study was to explore the self-management behaviours of patients with COPD as a means to understand how patients manage their disease. [page 597]</td>
<td>Patient experiences</td>
<td>Qualitative descriptive</td>
<td>None provided</td>
<td>Experiential perspective Self-management is understood from the patients' perspective, as an integration of patients' own experiences and health professional knowledge and guidance. Self-management in this conceptualisation is located in the hands of patients themselves. Bottom-up conceptualisation of self-management.</td>
<td>n/a</td>
<td>Qualitative results reported based around patient experiences of living with and managing COPD. Participants choose the self-management behaviours that best suited them on the basis of integration of their experiential knowledge and professional guidance. Participants were the main decision makers about their own self-management. They assessed the situation and took appropriate action (agency) based on their past disease management experience. Only if this did not work did they change their approach.</td>
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</table>
Patients with chronic obstructive pulmonary disease chose suitable self-management behaviours, based on experience, wisdom and professional guidance.
<table>
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<tr>
<td>Gullick &amp; Stainton 2008</td>
<td>To explore the experience of the person who lives within a body with emphysema – a form of COPD. [page 606]</td>
<td>Patient experiences</td>
<td>Qualitative – Heideggerian phenomenology Existential philosophy of Merleau-Ponty</td>
<td>None provided</td>
<td>Experiential perspective Self-management conceptualised as ‘conscious body management’ – a process arising from patients themselves and their own responses to the exigencies of COPD in the body. ‘Bottom-up’ approach. Self-management is conceptualised as resting in the hands of patients, their own lived experience.</td>
<td>n/a</td>
<td>Qualitative results focused on the strategies people with COPD used to manage their lives and the illness, and practice self-care, within the context of a shrinking world and an increasingly limited body. Themes that arose included (1) pacing the body and catching breath, (2) consciously planning for the needs of the body, (3) forcing the body, (4) pushing to limits balanced against knowing their limits, (5) consciously managing the body’s environment, these body management strategies arose from patients themselves and the results focus on the competing strategies of active, agentic, body management versus an avoidant strategy of...</td>
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</table>
succumbing to a shrinking life world and body. Agency and taking action were evident in some of the active strategies, but also the idea of striving for balance between pushing and pacing.
<table>
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<tr>
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<tr>
<td>(Ehrlich et al. 2010)</td>
<td>To report how people with chronic obstructive pulmonary disease (COPD) gather, interpret and apply health affecting information</td>
<td>Patient experiences</td>
<td>Qualitative grounded theory</td>
<td>None provided. Self-management was not the direct focus of this study, although it provided the context for the study</td>
<td>Experiential perspective</td>
<td>Self-management conceptualised as arising from the patients themselves and their personal experiences and understanding – ‘bottom up’ approach. Self-management is conceptualised as resting in the hands of patients, their own lived experience, and it is they that define what self-management is and how to engage in it.</td>
<td>n/a</td>
</tr>
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</table>
interpret that information). (2) the goal-oriented health behaviours that arose from the process of ‘Listening to my body’. Integration of intrinsic (personal information from within) and extrinsic information (family, friends, health professionals, via trial and error and risk-taking and, notably, via a critical event that provided an impetus for change.

The authors concluded that people with chronic disease use personal understanding to make sense of a complex array of information and then use trial and error and risk-taking behaviours before integrating information into the personalised knowledge that underpins how they actually look after their bodies.
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</table>
| (Cooney et al. 2013) | To understand the meaning of chronic obstructive pulmonary disease (COPD) for people and their response to this disease | Patient experiences                                                                           | Qualitative grounded theory            | None provided.                                               | Experiential perspective                       | n/a             | Qualitative results reported on:  
• Hiding from COPD  
• Hiding the symptoms of COPD  
• Hiding or denying the symptoms of COPD  
• Battling: struggling to lead a normal life despite COPD  
• Experiencing limitations in desired activities/everyday life  
• Self-management: planning and pacing  
• Learning what to do through trial and error  
The authors developed a theory of co-existing with COPD to explain their results. They used the term ‘controlled co-existers’ to describe participants who described themselves as successful in coexisting with COPD.  |
with COPD, in incorporating COPD into their lives while continuing to live their life to the optimum. In contrast, ‘uncontrolled co-existers’ felt dominated by their disease and out of control. This could be modified by, for example, learning skills and techniques for managing symptoms. ‘Strained co-existence’ lies in between and reflects when the balance is not quite right, that is, the person is somewhat dominated by the disease. This may be transitional, for example, during an acute exacerbation of COPD.
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| Apps et al. 2014 | To understand the self-care experiences of patients with COPD who are primarily managed in primary care, and to examine the challenges of engaging in such behaviours | Patient experiences of self-management                                                                | Qual descriptive + thematic analysis     | Self-care = a function that individuals must perform to maintain life, health and well-being. Self-management = a range of behaviours and skills necessary for disease management. Self-management considered as taught activities, whereas self-care = a function that occurs more automatically. | Experiential perspective Self-care is conceptualised and defined by patients themselves – 'bottom up'. Independently initiated behaviours that evolve automatically based on experience and trial and error Self-care based on experiential knowledge of living with COPD | n/a              | Findings can be summarised as coalescing around  
  - Experiential knowledge (and perceived lack of knowledge)  
  - Planning and pacing  
  - Experimentation  
  - Decision making, action and agency  
  - Development of expertise  
  - Adaptation and learning  
  - Social and family support The authors highlighted that patients appeared to be unaware that they were performing self-management behaviours and instead described a lack of confidence about managing their symptoms |
as they did not feel confident about their current level of disease knowledge [page 261].

Explanation of findings:
The authors explained their findings with reference to both self-initiated and independent self-management activities and to those self-management activities that require support from health professionals. Findings were linked to the experiential knowledge of patients versus patients’ perceived lack of disease knowledge indicating a lack of recognition of their own resources and skills.
<table>
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<tr>
<td>Chen et al. (2016)</td>
<td>To explore the process of self-management and relevant factors of influence from the perspective of patients with COPD as a means to understand their daily lives. A further aim was to provide a foundation for the development of effective self-management programs to enhance quality of life in this population.</td>
<td>Patient experiences</td>
<td>Qualitative descriptive</td>
<td>Disease self-management = a process by which patients with COPD acquire the skills and behaviours to manage their condition. It is a dynamic process in which patients with COPD choose the behaviours that suit them and that help them maintain the stability of their health condition. In self-management, patients change their health behaviours, and healthcare providers offer emotional support to enable patients to control their disease. Self-management aims to guide changes in health behaviour,</td>
<td>Experiential perspective Self-management is viewed from the perspective of patients’ experiential knowledge, ‘wisdom’ and self-regulation, above and beyond instruction provided by health professionals. Their personal experience of the illness and their bodies formed the conceptualisation of self-management. Self-management rests in the hands of the patients and evolves independently of health professionals based on experience of living with COPD symptoms. Bottom up conceptualisation of self-management</td>
<td>n/a</td>
<td>Qualitative results reported on self-management from the perspective of patients’ own experiences and knowledge as follows: Self-management is something that must be conducted independently by participants, should avoid relying on health professionals Patients practice self-management independently, based on their experiential knowledge of their bodies and of the illness Control of the self and self-regulation are fundamental to self-management. Patients themselves are the decision makers (agency). They take advice given to them by</td>
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</table>
health professionals and integrate it with their own experiential knowledge.

Participants chose the healthcare behaviours that best suited them. The most common expectations of these behaviours were that they help prevent the emergence or exacerbation of lung disease symptoms and facilitate the maintenance of stable physical functions. [page 266].

Experience of illness (in general, not restricted to experience of COPD), psychological health status, knowledge of COPD and its treatment, and social support were reported as playing an important role in patients' own self-management.
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<tr>
<td>(Russell et al. 2018)</td>
<td>To provide an in-depth insight into the barriers and facilitators to self-management from the perspectives of COPD patients and practitioners involved in the care of COPD patients</td>
<td>Patient experiences</td>
<td>Qualitative systematic review</td>
<td>Self-management relates to “an individual’s ability to detect and manage symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition” (Barlow et al 2002).</td>
<td>Experiential perspective] Self-management is seen as in the hands of patients, what patients say they do and think about managing their COPD. Viewing self-management as interwoven with the ‘life worlds’ of patients, shaped by personal experiences. Conceptualisation of self-management linked to idea of patients becoming experts over time. Patients hold self-management knowledge, a knowledge gained through trial and error and learning over time what works and what does not. With a n/a</td>
<td>Qualitative findings suggested that living with COPD is a complex, individual experience and thus the ability and capability of people with COPD to engage in successful self-management is dependent on their own personal life context, attitudes, beliefs, emotional responses, socio-cultural resources, and time living with the condition. Notwithstanding the conceptualisation of self-management as something that arises from patients, the author still found that some patients lacked knowledge, motivation and agency for self-management, whereas others exhibited more agency despite a perceived...</td>
<td></td>
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<tr>
<td>link to an idea of active agency on the part of patients. ‘Bottom up’ view of self-management as arising from patients themselves, independently of health care professionals</td>
<td>lack of knowledge and information about COPD. The twin ideas of knowledge and agency were identified as factors that positively and negatively influence self-management.</td>
<td></td>
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</table>
Aim

To present the
findings of a
recent research
project in which
the authors
explored selfmanagement
with older
people who
were
diagnosed with
asthma.

Authors

(Koch et al.
2004)

Patient
experiences

(e.g.
intervention
study,
correlational
study, patient
experiences
study, other
(specify))

Type of study

Focus on the creation of
order, discipline, and control
in everyday life with chronic
illness.

Focus on self-management
as integrated into everyday
life.

Emphasis on learning from
experience.

Self-management as personcentred experiential
conceptualisation.

Participatory
action
research

Conceptualisation of selfmanagement

Experiential perspective

Definition of selfmanagement

Qualitative

(Qual,
quant,
specify
exact)

Study
design

Qualitative studies on power, self-management, and chronic illness

2.

1.

398

The medical model: where
self-management consisted of
adherence to prescribed
medications and following
orders from health care
professionals. Patients
placed trust in medical
knowledge and management,
indeed they were expected to,
because patients were not
invited to take part in asthma
management.
Collaborative model of asthma
management which used a
combination of biomedical and
experiential terms to describe
asthma. Self-management
was conceptualised as a
partnership between health
care professionals and

Three models of self-management
were identified based on the
interviews.

Critique of medicocentric
In the medicocentric or
medical model of selfmanagement identified in
this study, power was seen
to rest in the hands of
health professionals, who
managed the disease
process rather than the
patient. In this model the
person was objectified as
‘the patient’, who was cast
into a passive role with little
agency and where the
focus of power was on
compliance with the
dominant health care
professionals. Expertise
and agency of patients
largely dismissed. Power
expressed as medical
management done TO
patients.

Type of results reported and
rationale for results (e.g.
summary of results, then
explanation for these results
(compliance/adherence, the
need for further education,
knowledge/agency/taking action
etc))

Conceptualisation of
power


Critique of integration of medicocentric and patient experiences – collaborative or partnership

In the collaborative model of self-management, power was viewed as being shared between health care professionals and patients in a relationship. The patient was seen as more of a ‘client’ than ‘patient’. Power expressed as self-management done with patients. But collaborative model still relies on a view of self-management as defined by professionals who provide education. Expectation is that patients should self-manage appropriately in accordance with the recommendations of health professionals.

Analysis of patient experiences – self agency

The third self-agency model of self-management located power in the hands of patients who were autonomous and based patients, and went beyond a narrow, medicalised conception of self-management to one which embraced more holistic perspective such as practical tips for managing activities of daily living.

3. Self-agency model: this model of self-management covered participants who had identified their own responses to illness. They planned and managed their own daily routines in order to create and maintain order in their lives. They had developed their own alternative lifestyle habits. The person became self-determining. Patients exercised power and control by choosing when and how to seek professional care. These people were experts on their own conditions and responses to illness because their life experiences had informed them about managing the self.
their self-management on
their own agency and ability
to act. Self-agency and
self-determination central to
this understanding of power
in this model. This is very
much linked to a patient
experiential
conceptualisation of self-
management, not the
medicocentric
conceptualisation. Power
expressed as self-
management done by
patients.
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<td>Rogers et al. 2005</td>
<td>To illuminate the quantitative findings of a randomized controlled trial (RCT) of a self-management program for people with inflammatory bowel disease (IBD)</td>
<td>Patient and consultant experiences</td>
<td>Qualitative descriptive</td>
<td>None provided</td>
<td>Experiential perspective</td>
<td>Critique of medicocentric</td>
<td>Qualitative findings reported that in a few cases, patients had actively shared decisions about the type of medication they were on. Such patients tended to be those already experienced in managing their condition. The way in which information was given and negotiated affected the willingness and ability to engage in decision making with the practitioner. Patients expected they would be given time to discuss issues of concern about their treatment and medication with their consultant. Yet, a number of respondents reported individual key concerns being left unattended to. Self-management was interpreted narrowly as referring to compliance with medical instructions. As far as the consultants were concerned, self-management equated with compliance with medication in</td>
</tr>
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</table>
consequences of having IBD.

The consultants generally made decisions about medical treatment; there was little evidence that patients introduced their own ideas about self-management. In particular, patients' experiential self-management strategies were marginalized. There was little evidence that these strategies were shared with consultants in the same way as medication management.

Most consultants still held to a core belief that patients needed guidance on medical treatment and that doctors were there to give instructions, to tell patients what to do.

The question of making a judgment about suitability of patients for self-management was seen as the sole responsibility of the consultant and was felt to require the medical experience and skills which patients were assumed not to possess.
<table>
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<tr>
<td>(Seear 2009)</td>
<td>To explore the experiences of twenty Australian women living with the chronic and incurable gynaecological condition endometriosis. The author examines how women become experts in their own care and the ramifications of these processes for women.</td>
<td>Patient experiences</td>
<td>Qualitative descriptive</td>
<td>None provided</td>
<td>Experiential perspective Self-management conceptualised as work that women engaged in to inform themselves and develop their knowledge – in this case ‘technical’ knowledge. Self-management was based on patients’ own knowledge that they gained through support groups, internet research, self-help literature, consisting of technical knowledge of traditional and complementary therapies. This was combined to form the basis for their self-management practice.</td>
<td>Analysis of power through the concept of responsibilisation and the expectation that patients become experts. Responsibilisation as simultaneously empowering and constraining agency Criticism of the lack of attention paid to contextual factors Foucauldian concept of responsibilisation and the ‘responsibilisation paradox’</td>
<td>Considerable work is involved in the self-management of endometriosis. Some women were prompted to become experts in the management of their own condition by medical professionals: to take their own share of the responsibility for getting themselves better. Women joined support groups, began research on the Internet and read self-help literature. Women acquired technical knowledge of the condition, drug therapies, aetiological hypotheses, natural therapies and management options. Many of them became involved in strategies of self-management on the basis of information they had acquired through support groups and self-help literature. The process of self-management and development of expertise has positive dimensions for women, such as feeling empowered;</td>
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facilitating slowing down and taking better care of oneself; the process of acquiring knowledge and the resulting emphasis upon self-care led to women's heightened awareness of their own bodies and increased sense of responsibility towards themselves; developing a greater understanding of the body; They had a sense they were in control of their lives and could transfer the skills they acquired and the confidence they developed into other areas of their lives.

The process of self-management and development of expertise has negative dimensions, the quantity, quality, and contradictory nature of the information women found on how to manage endometriosis combined with the drive towards women becoming responsible made it very difficult for them to negotiate.
<table>
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| (van de Bovenkamp & Dwarswaard 2017) | To explore the way patient self-management is shaped in practice, including the implications of the difficulties encountered. | Patient experiences | Qualitative descriptive | None provided. The authors point out that self-management is a contested concept with the extent and focus of patient involvement in their care differing among definitions. This may be why they did not provide a formal definition of self-management. | Experiential perspective  
Criticism of medicocentric conceptualisation  
Focus on self-management as shaped by patients in social and personal context.  
Bottom-up approach to self-management.  
Self-management is conceptualised as dynamic – shifting between various degrees of agency and passivity according to factors such as the stage of the illness, whether or not there is an exacerbation, and the degree of agency the patient wishes to take on.  
Self-management therefore is a normative issue, depending on the norms and values patients adhere to, those of health care professionals, and the norms and values of health care policy. | Several tensions in the way power is distributed in the network of relations surrounding self-management:  
1. Tension between self-management as a positive force for patient autonomy and choice; and self-management as part of a neoliberal agenda to shift responsibility for care onto citizens in order to reduce public spending. Foucauldian concept of responsibilisation.  
2. Tension between growth and spread of self-management and power remaining with health care professionals.  
3. Tension about who defines what self-management is and how they define it. Definitions range from medicocentric self-management is shaped in practice and is influenced by a number of intertwined factors:  
Self-management is shaped by personal and social dynamics which are partly outside the patient's domain of influence.  
Self-management is very much shaped by patients' ideas of the good life.  
Patients wanting to make autonomous choices can clash with professionals who expect patients to follow their orders, while passive patients do not feel at ease with professionals eager to activate them. |
Criticisms of medicocentric definitions that grant power to professionals. The authors support experiential definitions which are more holistic and focus on overall quality of life, causing patients to make choices that suit them but that may go against the recommendations of health professionals. In this instance patients use power and agency to self-determine their self-management.
Appendix 2: Letter to Executive Director of COPD Support Ireland requesting access to local COPD Support Groups

Executive Director
COPD Support Ireland

RE: Research into every day decision-making in the self-management of COPD

10th February 2017

Dear [name],

I am writing in connection with the research we have been collaborating together on, entitled ‘Every day decision-making in the self-management of COPD’. The aim of the study is to explore how people with COPD negotiate decision-making in relation to self-management of their illness. I hope to gain valuable insights into how people use power and control when they make every day decisions about managing their COPD. I anticipate that the findings of the research will help to identify how self-management practices can better align to the lived experience of individuals with COPD. Ultimately, I hope to inform the design of self-management programmes towards person-centred approaches based on equality and a recognition of the decision-making power of individuals with COPD.

Although self-management has become increasingly recognised as important in the treatment of COPD, many people do not follow all the recommendations given for successful self-management. Little research has been done to find out why people with COPD make the decisions they do to self-manage their illness.

The results of the research will be published in academic journals, and a summary report of the key findings of the study will be produced, targeting people with COPD, key non-governmental organisations, and the HSE. It will also be written up as a PhD thesis.

The research will consist of in-depth interviews with individuals with COPD. The key themes that will be explored include:

1. The experience of living with COPD
2. How people with COPD define and practice self-management
3. How individuals use power and control when making every day self-management decisions

With the permission of the individual with COPD, their main carer/family member (if available) will be invited to take part in one interview along with the individual with COPD. This research project is being undertaken as part of my PhD study with the School of Nursing and Midwifery, Trinity College Dublin. I would be very grateful if you could assist me in recruiting participants for this study. This would consist of sending recruitment information packs to the Chairpersons of the support groups of COPD Support Ireland and Respiratory Integrated Care Nurses currently in post, as well as publicising the study on the website of COPD Support Ireland. I would be happy to meet with you at a time and place of your convenience to discuss the study and recruitment arrangements in more detail.

Yours sincerely,
Sarah Delaney
PhD candidate
School of Nursing and Midwifery
Trinity College Dublin
Email: xxx
Telephone: xxx
Appendix 3: Cover letter to Chairpersons of local COPD support groups

Date

Dear [name of Chairperson]

I am writing to invite you to inform you about a study being undertaken by the School of Nursing and Midwifery, Trinity College Dublin, and to request your assistance with informing people about the study with a view to inviting them to participate. The study aims to explore how people with COPD exercise, are constrained by, and resist power in making everyday decisions about the self-management of COPD. I enclose an information leaflet, which I invite you to read carefully. I also enclose a set of information packs, which I request that you distribute to the members of your COPD support group. The information packs contain a cover letter, information leaflet, reply slip, stamped addressed envelope, and consent form.

I am undertaking this research as part of my PhD study with the School of Nursing and Midwifery, Trinity College Dublin. I am interested in this topic because little research has been done to find out why people with COPD make the decisions they do to self-manage their illness. I hope that the research will help to place people with COPD at the centre of self-management practices and programmes and increase the recognition of the decision-making power of people with COPD.

The results of the research will be published in academic journals, and a report will be produced for people with COPD and key organisations such as COPD Support Ireland and the HSE. It will also be written up as a PhD thesis.

I greatly appreciate any assistance you can provide in informing people with COPD about this research. I am happy to attend one of your meetings to explain the research in more detail, if you wish. You can contact me at the details provided at the bottom of this letter.

Yours sincerely

Sarah Delaney
PhD candidate
School of Nursing and Midwifery
Trinity College Dublin
Email: xxx
Telephone: xxx
Appendix 4: Cover letter to potential participants

Dear Sir/Madam

I am writing to invite you to participate in a study being undertaken by the School of Nursing and Midwifery, Trinity College Dublin. The aim of the study is to explore how people with COPD exercise, are constrained by, and resist power in making everyday decisions about the self-management of COPD.

I enclose an information leaflet, which I invite you to read carefully. It contains information about the nature and purpose of the study and what taking part involves. You will also find a consent form included with this letter. If you decide that you want to take part in the study, I will ask you to sign the consent form when we meet. Before you sign the consent form, I will discuss the research with you and answer any questions you may have. **Please do not sign this form before we meet.** The research will consist of up to three interviews with you over the course of eight months. With your permission, I will also invite your main carer or family member, if available, to take part in one interview along with you. If you agree, I would like to take photographs of any items you bring me that are related to your experience of COPD. Interviews will be transcribed, and if you wish, I can send you copies of your transcripts so that you can read them.

I am undertaking this research as part of my PhD study with the School of Nursing and Midwifery, Trinity College Dublin. I am interested in this topic because little research has been done to find out why people with COPD make the decisions they do to self-manage their illness. I hope that the research will help to place people with COPD at the centre of self-management practices and programmes and increase the recognition of the power of people with COPD.

The results of the research will be published in academic journals, and a summary report of the key findings will be produced for people with COPD and key organisations such as COPD Support Ireland and the HSE. It will also be written up as a PhD thesis.

Should you wish to discuss taking part in the study, please complete the reply slip included with this letter and return it as soon as possible, using the stamped addressed envelope provided. I will then contact you to discuss your participation and answer any questions you may have. Your participation is entirely voluntary; you do not have to take part if you do not want to. If you do agree to take part, you can change your mind and withdraw from the research. If you do not want to take part in this study, I will not contact you about it again.

Yours sincerely
Sarah Delaney
PhD candidate
School of Nursing and Midwifery
Trinity College Dublin
Email: xxx
Telephone: xxx
Appendix 5: Participant information leaflet

Title of study: Power as a mediating force in every day decision-making in the self-management of COPD

Name of researcher: Ms Sarah Delaney, School of Nursing and Midwifery, Trinity College Dublin

1. INTRODUCTION

You are invited to take part in this study because of your experience of living with and managing COPD. COPD is a disease of the airways that makes it hard to breathe. Self-management is an important part of the treatment of COPD. However, many people find it difficult to follow all of the recommendations made by their health care professionals. This research sets out to find out more about how people with COPD make self-management decisions. This leaflet is designed to give you more information about the study to help you decide whether or not you want to take part.

2. DESCRIPTION OF STUDY

The aim of the study is to explore how people with COPD exercise, are constrained by, and resist power in making everyday decisions about the self-management of COPD. At the end of this research, information will have been gathered on the experiences of people living with COPD, how they manage their illness and how they use their power and sense of control when making every day self-management decisions. Findings from the research will help to place people with COPD at the centre of approaches to self-management.

The research will involve in-depth interviews with people with COPD. Each person will be interviewed up to three times over the course of six to eight months. Interviews will usually take place in your home, or at a location of your choosing.

The results of the research will be published in academic journals and a summary report of the key findings of the study will be produced for people with COPD and key organisations such as COPD Support Ireland and the HSE. The study will also be written up as a PhD thesis.

3. PROCEDURES: WHAT DOES TAKING PART IN THE STUDY INVOLVE?

Interviews with you

I would like to talk to you to find out about your experience of living with and managing COPD. I would like to speak to you on three occasions. This will allow you time to tell your story and how it changes over the time you are involved in the research. It will also allow you to reflect on each meeting. Each interview should last about an hour. The interview will be carried out at your own pace, and you can take breaks when you need to. If you take part in the first or second interviews, but opt out of subsequent interviews, I would like to use data from the interviews you did take part in (with your permission) in my analysis.
Each interview will be audio recorded. I will use this so that I do not have to take notes and I can concentrate on what you are telling me. I will transcribe the interviews, and you can request a copy of the transcribed interview if you wish.

If you wish to show me items that you feel are important to your experience of living with and managing COPD, I would like to take photographs of these. Any information that could identify participants will be excluded from the photographs. Photographs will be taken using a dedicated digital camera and stored in an encrypted folder on a password-protected computer.

Quotations from the transcribed interviews will be used in publications based on the research, however no identifying information will be included in these. Data from the research will be stored for five years after the completion of the study and may be used in future studies, with your permission.

**Interview with a close family member**

**ONLY IF YOU ARE WILLING** I would like to invite a member of your family, or your main carer (if available) to take part in ONE interview but where you would also be there. This is because I also want to see what their views are. This family member will be the person identified by you. I will ask you when we meet for the first time if you are willing to do this. If you do not want to I will not ask you again.

**Who can take part?**

You can take part in the study if:

- You have a diagnosis of COPD
- You can understand the purpose of the research and what taking part involves
- You are over 18 years of age
- You can speak English
- You willingly volunteer to take part and can consent to take part.

**4. BENEFITS**

There are no direct benefits to you from participating in this research. However, you may benefit indirectly by being offered the opportunity to reflect on how you manage your illness every day. You may gain more understanding of why you make the decisions you do in terms of managing your COPD, which could benefit you when making self-management decisions in the future.

**5. RISKS**

The potential risk to you as a participant is low, however there are some issues you should keep in mind. You may become upset during the interview. If this happens, you can stop the interview until you feel ready to continue, or you can end the interview. If you wish you may resume the interview at another time of your choosing. You do not have to give me any information that you do not wish to. You may experience some inconvenience in terms of taking time out of your day to take part in an interview, and being interviewed on three separate occasions. I will try to reduce any inconvenience by organising interviews according to your own preferences for time, date and location. If you have severe COPD, you may find it difficult to talk for long periods of time due to feeling
breathless. If this is the case, I will work with you at your own pace, and I will regularly check with you to make sure you feel able to continue.

6. EXCLUSION FROM PARTICIPATION

You cannot participate in the study if any of the following are true:

- You are not able to speak English
- You are aged 18 or under
- You are unable to understand the purpose of the research and what taking part means for you
- You are unable or unwilling to give consent.

7. CONFIDENTIALITY

Your identity will remain confidential and an identity number will be used instead. Your name and any other information that could identify you will not appear in any report, article or publication. Your identity will not be given to anyone outside the research team. The research team consists of Professor Patricia Cronin, Professor Geralyn Hynes and Ms Sarah Delaney, in the School of Nursing and Midwifery, Trinity College Dublin. All information will be kept confidential. Any computer-based information will be stored on password-protected computers that only I can access. Hard copies of information will be stored in a locked filing cabinet and only I can access it.

However, you should note that I will be obliged to break confidentiality in the following situations:

- You request to be referred to health and support organisations for further help
- You reveal information that is criminal in nature, or has child protection implications. In this case the relevant agencies would need to be informed (i.e. the Gardaí or the HSE).

8. COMPENSATION

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails the rights of those who take part in the study. There is no payment for taking part in the study.

9. VOLUNTARY PARTICIPATION

You are free to decide whether or not to participate in this study. If you decide to volunteer to participate in this study, you can withdraw at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not give up any benefits that you had before entering the study.

10. STOPPING THE STUDY

You should note that the researcher may withdraw your participation from the study at any time without your consent.

11. PERMISSION

This study has been granted ethical approval by the Research Ethics Committee of the School of Nursing and Midwifery, Trinity College Dublin.
12. FURTHER INFORMATION

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Ms Sarah Delaney, at the School of Nursing and Midwifery, Trinity College Dublin, by telephone at xxx or by email to xxx.

If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

THANK YOU FOR READING THIS LEAFLET
Appendix 6: Family member information leaflet

Participant information leaflet (main carer/family member)

Title of study: Power as a mediating force in every day decision-making in the self-management of COPD

Name of researcher: Ms Sarah Delaney, School of Nursing and Midwifery, Trinity College Dublin

13. INTRODUCTION

You are invited to take part in this study because of your experience of living with someone who has COPD. COPD is a disease of the airways that makes it hard to breathe. Self-management is an important part of the treatment of COPD. However, many people find it difficult to follow all of the recommendations made by their health care professionals. This research sets out to find out more about how people with COPD make self-management decisions. This leaflet is designed to give you more information about the study to help you decide whether or not you want to take part.

14. DESCRIPTION OF STUDY

The aim of the study is to explore how people with COPD exercise, are constrained by, and resist power in making everyday decisions about the self-management of COPD. At the end of this research, information will have been gathered on the experiences of people living with COPD, how they manage their illness and how they use their power and sense of control when making every day self-management decisions. Findings from the research will help to place people with COPD at the centre of approaches to self-management.

This part of the study is about exploring your experiences of living with or caring for a family member who has COPD and discussing your perspective on managing the illness. The research will involve one in-depth interview with you and the person you care for. Interviews will usually take place in your home, or at a location of your choosing.

The results of the research will be published in academic journals and a summary report of the key findings of the study will be produced for people with COPD and key organisations such as COPD Support Ireland and the HSE. The study will also be written up as a PhD thesis.

15. PROCEDURES: WHAT DOES TAKING PART IN THE STUDY INVOLVES?

In order to take part in the study, your family member who is already part of the study has agreed that I can approach you. You must be over 18 years of age and be caring for your family member who has COPD. As the study is about managing COPD every day it is important that you are willing to talk about your experiences and feel able to do so.

I would like to talk to you to find out about your experience of caring for someone with COPD and of helping them manage their COPD. The information gathered in the study will be based on an interview at which the person with COPD will also
be present. The timing of the interview will be negotiated with you, and the interview should last about an hour.

The interview will be audio recorded. I will use this so that I do not have to take notes and I can concentrate on what you are telling me. I will transcribe the interview, and you can request a copy of the transcribed interview if you wish.

Quotations from the transcribed interviews will be used in publications based on the research, however no identifying information will be included in these. Data from the research will be stored for five years after the completion of the study and may be used in future studies, with your permission.

**Who can take part?**

You can take part in the study if:

- You are the main carer/nominated family member identified by the person with COPD
- You can understand the purpose of the research and what taking part involves
- You are over 18 years of age
- You can speak English
- You willingly volunteer to take part and can consent to take part.

**16. BENEFITS**

There are no direct benefits to you from participating in this research. However, you may benefit indirectly by being offered the opportunity to reflect on your experiences of helping the person with COPD manage their illness every day. It is hoped that the knowledge gained from the study will help identify more targeted interventions to support the self-management of COPD.

**17. RISKS**

The potential risk to you as a participant is low, however there are some issues you should keep in mind. You may become upset during the interview. If this happens, you can stop the interview until you feel ready to continue, or you can end the interview. If you wish you may resume the interview at another time of your choosing. You do not have to give me any information that you do not wish to. I realise that at times you or your family member may not agree about some aspects of your experiences. In order to avoid any upset or distress, we will meet beforehand to agree how we will deal with any sensitive topics. You may experience some inconvenience in terms of taking time out of your day to take part in an interview. I will try to reduce any inconvenience by organising interviews according to your own preferences for time, date and location.

**18. EXCLUSION FROM PARTICIPATION**

You cannot participate in the study if any of the following are true:

- You are not able to speak English
- You are aged 18 or under
- You are unable to understand the purpose of the research and what taking part means for you
- You are unable or unwilling to give consent.
19. CONFIDENTIALITY

Your identity will remain confidential and an identity number will be used instead. Your name and any other information that could identify you will not appear in any report, article or publication. Your identity will not be given to anyone outside the research team. The research team consists of Professor Patricia Cronin, Professor Geralyn Hynes and Ms Sarah Delaney, in the School of Nursing and Midwifery, Trinity College Dublin. All information will be kept confidential. Any computer-based information will be stored on password-protected computers that only I can access. Hard copies of information will be stored in a locked filing cabinet and only I can access it.

However, you should note that I will be obliged to break confidentiality in the following situations:

- You request to be referred to health and support organisations for further help
- You reveal information that is criminal in nature or has child protection implications. In this case the relevant agencies would need to be informed (i.e. the Gardai or the HSE).

20. COMPENSATION

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails the rights of those who take part in the study. There is no payment for taking part in the study.

21. VOLUNTARY PARTICIPATION

You are free to decide whether or not to participate in this study. If you decide to volunteer to participate in this study, you can withdraw at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not give up any benefits that you had before entering the study.

22. STOPPING THE STUDY

You should note that the researcher may withdraw your participation from the study at any time without your consent.

23. PERMISSION

This study has been granted ethical approval by the Research Ethics Committee of the School of Nursing and Midwifery, Trinity College Dublin.

24. FURTHER INFORMATION

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Ms Sarah Delaney, at the School of Nursing and Midwifery, Trinity College Dublin, by telephone at xxx or by email to xxx.

If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

THANK YOU FOR READING THIS LEAFLET
Appendix 7: Participant consent form

PROJECT TITLE: Power as a mediating force in every day decision-making in the self-management of COPD

PRINCIPAL INVESTIGATOR: Ms Sarah Delaney, PhD student, School of Nursing and Midwifery, Trinity College Dublin. Phone: xxx. Email: xxx

Study background: The aim of the study is to explore how people with COPD exercise, are constrained by, and resist power in making everyday decisions about the self-management of COPD. At the end of this research, information will have been gathered on the experiences of people living with COPD, how they manage their illness and how they use their power and sense of control when making everyday self-management decisions.

You will be interviewed up to three times over the course of six to eight months. With your permission, your main carer or close family member (if available) will be invited to take part in one interview along with you. If you have any items related to your experience of living with and managing COPD that you wish to show me, I will ask your permission to take photographs of these.

The results of the research will be published in academic journals and a summary report of key findings will be produced for people with COPD and key organisations such as COPD Support Ireland and the HSE. The study will also be written up as a PhD thesis.

Your identity will remain confidential and an identity number will be used instead. Your name and any other information that could identify you will not appear in any report, article or publication. Your identity will not be given to anyone outside the research team. All information will be kept confidential.

PLEASE READ THE FOLLOWING AND TICK THE BOXES IF YOU AGREE:

I have read the information sheet and this consent form □

I have had the opportunity to ask questions and have them answered □

I understand what is involved if I take part in the project □

I consent to information from initial interviews being used in the analysis if I opt out of subsequent interviews □

I consent to photographs being taken of any items I wish to show to the researcher □

I consent to my main carer/close family member being invited to take part in an interview with me □

I understand that I can withdraw at any time from the study without penalty □
I understand that the researcher can withdraw me from the study without my consent

I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential

I consent to the use of anonymised quotations from the interviews in publications arising from the research

I understand that data from the research will be stored for five years after the completion of the study and I consent to the publication of the results of this research

I understand that I can have access to my interview transcript if I wish

DECLARATION

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

PARTICIPANT’S NAME:
______________________________________________________________

CONTACT DETAILS:
______________________________________________________________

PARTICIPANT’S SIGNATURE:
______________________________________________________________

Date: ____________________

Statement of the investigator’s responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that might be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR’S SIGNATURE:
______________________________________________________________

Date: ____________________
Appendix 8: Family member consent form

PROJECT TITLE: Power as a mediating force in every day decision-making in the self-management of COPD

PRINCIPAL INVESTIGATOR: Ms Sarah Delaney, PhD student, School of Nursing and Midwifery, Trinity College Dublin. Phone: xxx. Email: xxx

Study background: The aim of the study is to explore how people with COPD exercise, are constrained by, and resist power in making everyday decisions about the self-management of COPD. At the end of this research, information will have been gathered on the experiences of people living with COPD, how they manage their illness and how they use their power and sense of control when making every day self-management decisions.

Your family member/the person you care for with COPD who is already part of the study, has agreed that I can approach you. If you agree, you will be interviewed on one occasion in the presence of your family member/person you care for. I wish to talk to you about your experiences of helping the person with COPD manage their condition every day.

The results of the research will be published in academic journals and a summary report of key findings will be produced for people with COPD and key organisations such as COPD Support Ireland and the HSE. The study will also be written up as a PhD thesis.

Your identity will remain confidential and an identity number will be used instead. Your name and any other information that could identify you will not appear in any report, article or publication. Your identity will not be given to anyone outside the research team. All information will be kept confidential.

PLEASE READ THE FOLLOWING AND TICK THE BOXES IF YOU AGREE:

- I have read the information sheet and this consent form
- I have had the opportunity to ask questions and have them answered
- I understand what is involved if I take part in the project
- I understand that I will be interviewed in the presence of the person with COPD
- I understand that I can withdraw at any time from the study without penalty
- I understand that the researcher can withdraw me from the study without my consent
- I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential
I consent to the use of anonymised quotations from the interviews in publications arising from the research

I understand that data from the research will be stored for five years after the completion of the study and I consent to the publication of the results of this research

I understand that I can have access to my interview transcript if I wish

DECLARATION

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

PARTICIPANT’S NAME:

______________________________________________________________

CONTACT DETAILS:

______________________________________________________________

PARTICIPANT’S SIGNATURE:

______________________________________________________________

Date: ______________________

Statement of the investigator’s responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that might be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR’S SIGNATURE:

______________________________________________________________

Date: ______________________
Appendix 9: Reply slip

Reply slip

Your name: ____________________________________________________________________________________________

I wish to be contacted to discuss participation in the study entitled: *Power as a mediating force in every day decision-making in the self-management of COPD*

I can be contacted at the following telephone number: _______________. Alternatively, I can be contacted at the following email address:
________________________________________________________________________________________

________________________________________________________________________________________

I understand that discussing participation with the researcher does not mean that I am consenting to participate in the research.

Signature: ____________________________________________________________________________________________

When you have filled out this reply slip, please place it in the enclosed stamped addressed envelope provided and post it back to the researcher, Ms Sarah Delaney.
Appendix 10: Initial interview schedule

First interview

Section A: Introduction

- Introductions
- Read through participant information leaflet
- Questions and answers
- Informed consent
- Pro-forma patient characteristics

Section B: Main narration

[Researcher] I would like you to tell me about your experience of living with COPD, and what you do to manage your COPD every day. Please feel free to give me as much detail as you would like, because everything you say is important to me.

Uninterrupted narration

Section C: Clarification

This section seeks clarification on key points raised in the main narration. It is important to avoid ‘why’ questions at this stage; therefore questions will simply seek more detail on the main narration, phrased in terms of ‘could you tell me more about x’, and ‘what happened when x occurred’.

Section D: Conclusion

[Researcher] Do you have anything you wish to add to what you have told me?

[Researcher] Do you have any questions or concerns you wish to discuss?

At this point, the researcher may refer the participant to sources of help and support if requested

End interview.
Appendix 11: Follow up interview schedule

Section A: Introduction

- Introductions
- Read through participant information leaflet
- Questions and answers
- Informed consent

Section B: Exploration of issues emerging in previous interview

This section consists of exploratory questions based on the key issues that arose from the previous interview.

[Researcher] I would like to start by exploring some of what we discussed in more depth…

Section C: Update of participant’s situation

[Researcher] I would like you to tell me how things have been going for you since we last spoke. Have you changed anything about how you manage your COPD every day?

Uninterrupted narration

Section D: Clarification

Clarification on key points in the narration in Section C.

Section E: Conclusion

[Researcher] Do you have anything you wish to add to what you have told me?
[Researcher] Do you have any questions or concerns you wish to discuss?

At this point, the researcher may refer the participant to sources of help and support if requested

End interview.
Appendix 12: Demographic information sheet

Participant background information sheet

Participant ID Number: ____________

Introduction

This short questionnaire is designed to gather information about you. I will keep your information private and confidential.

Section A: Demographic information

1. Could you tell me what age you are? ________________

2. Do you

   Live alone □  Live with someone else □

3. Are you currently working in paid employment?

   Yes □ [go to question 4]

   No □ [go to question 5]

4. Has your health condition(s) impacted on your working hours?

   Yes □  No □  Slightly □

Section B: Your health

5. How severe would you say your COPD is?

   Mild □

   Moderate □

   Severe □

   Very severe □

6. Do you have any other health conditions as well as COPD?

   Yes □  No □
If ‘yes’, state additional health conditions in the box below:

Section C: Care and treatment received

7. Do you receive help with personal/or practical care tasks?
   Yes ☐ [go to question 9] No ☐ [go to question 10]

8. Do you receive care from [tick all that apply]?
   Spouse/partner ☐
   Other family/friends ☐
   Formal/paid carers ☐
   Other, please state: _____________________________________________

9. What treatments do you receive (or have you received in the past) for your COPD [tick all that apply]?
   Antibiotics ☐
   Steroids ☐
   Inhalers ☐
   Nebulisers ☐
   Oxygen supplementation ☐
   Pulmonary rehabilitation ☐
   Other, please state: _____________________________________________
   Don’t know ☐
10. If you receive treatments for other health conditions, could you tell me what these are?

Thank you very much for answering these questions
Appendix 13: COPD Assessment Test

How is your COPD? Take the COPD Assessment Test™ (CAT)

This questionnaire will help you and your healthcare professional measure the impact COPD (Chronic Obstructive Pulmonary Disease) is having on your wellbeing and daily life. Your answers, and test score, can be used by you and your healthcare professional to help improve the management of your COPD and get the greatest benefit from treatment.

For each item below, place a mark (X) in the box that best describes you currently. Be sure to only select one response for each question.

**Example:** I am very happy 0 2 3 4 5 I am very sad

<table>
<thead>
<tr>
<th>Statement</th>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I never cough</td>
<td>0 1 2 3 4 5</td>
<td>I cough all the time</td>
</tr>
<tr>
<td>I have no phlegm (mucus) in my chest at all</td>
<td>0 1 2 3 4 5</td>
<td>My chest is completely full of phlegm (mucus)</td>
</tr>
<tr>
<td>My chest does not feel tight at all</td>
<td>0 1 2 3 4 5</td>
<td>My chest feels very tight</td>
</tr>
<tr>
<td>When I walk up a hill or one flight of stairs I am not breathless</td>
<td>0 1 2 3 4 5</td>
<td>When I walk up a hill or one flight of stairs I am very breathless</td>
</tr>
<tr>
<td>I am not limited doing any activities at home</td>
<td>0 1 2 3 4 5</td>
<td>I am very limited doing activities at home</td>
</tr>
<tr>
<td>I am confident leaving my home despite my lung condition</td>
<td>0 1 2 3 4 5</td>
<td>I am not at all confident leaving my home because of my lung condition</td>
</tr>
<tr>
<td>I sleep soundly</td>
<td>0 1 2 3 4 5</td>
<td>I don't sleep soundly because of my lung condition</td>
</tr>
<tr>
<td>I have lots of energy</td>
<td>0 1 2 3 4 5</td>
<td>I have no energy at all</td>
</tr>
</tbody>
</table>

COPD Assessment Test and the CAT logo is a trade mark of the GlaxoSmithKline group of companies. © 2006 GlaxoSmithKline group of companies. All rights reserved. Last Updated: February 24, 2012
Appendix 14: Examples of photographs of self-management artefacts

Jack: Salt therapy device
Niamh: Inhaled medication
Appendix 15: Example of interview transcript

Sarah Delaney with Helen and Ina (her daughter) interview 2
23rd August 2017

Sarah: Brilliant, so you were saying there, that em, eh, you had a reflection based on reading the transcript

Helen: Yes, yeah, I've been, like in the last month I've had two lots of antibiotics
Sarah: Oh really
Helen: And steroids so I was kind of feeling a bit oppressed by it, now quite a few of the group have been not well over the summer, you might have met some, so you'll know. The great weather wasn't great for us, you know?
Sarah: Mm
Helen: The very great heat wasn't great, anyway, reading the transcript [pause], having been just a little bit downhearted, I realised that, like my default response if anybody asks me how I am, 'I'm grand' and then I start thinking 'Well actually, I'm not' but I have this, it's a habit, it's a, a, an optimism
Sarah: Mm
Helen: That's part of my personality, I suppose
Sarah: Mm
Helen: That everything is fine, and then I look for the bad things, it's not everything's bad and I look for the good things.
Sarah: Yeah, yeah, yeah
Helen: So I actually felt, you know, and you're trying to get reflected back what it is like to have this disease, I suppose. And I felt it was a little bit upbeat. Now, it wasn't that I was lying
Sarah: Mm
Helen: But, because of the way I go,
Sarah: Mm
Helen: Em, it didn't actually reflect the downside of having this condition
Sarah: Ah, ok
Helen: Is what I thought
Sarah: Ok, yeah, yeah

Helen: Em, and I just felt that I mean, again, it's not that I wasn't truthful, but, maybe it was just a little bit misleading?

Sarah: Ok

Helen: And I don't know. Like 'tis only you can judge that. [cough]

Sarah: Well, I'm guided

Helen: [cough]

Sarah: Em, by what you-I'm guided by what you say,

Helen: Yeah

Sarah: Em, I mean, and then when I go back and I, I start analysing the transcripts, it's, it is the words that you say, that I'm guided by.

Helen: Yes

Sarah: So, em, eh, if you, what you express to me is what I take from it

Helen: Exactly, and it is perfectly true.

Sarah: Yeah.

Helen: But maybe it didn't express all of it, that's what I felt when I was

Sarah: So what are the bits that you think that you'd like to add to it?

Helen: Em, [pause] that it is quite a challenge [quietly]

Sarah: Mm

Helen: You know and like you were talking about, you know, the em, the resistance to power

Sarah: Mm

Helen: Em, I would be very compliant with the health professionals, no problem there

Sarah: Mm

Helen: I would take their word, trust them, do what they ask. Em, I wouldn't be as compliant with my own needs as with theirs, in that I would still try to convince myself or convince others that, you know, I'm not that bad really, or I'll just have another antibiotic and a steroid, a dose of steroids, and I'll be fine then

Sarah: Yeah
Helen: Em, and it was just reading, that's why I felt it was slightly misleading

Sarah: Right

Helen: You know, em, and it's possibly to do with one's own denial

Sarah: That's, yeah

Helen: You know, em, which I think, like I just thought that that was significant in, d'you know, acceptance of, well age, irrespective of illness, but also illness and limitations

Sarah: Mm, mm

Helen: So I just felt that that transcript was somebody who was going through in a blasé fashion, saying 'I'm still grand, I'm still grand' and actually, when you look at it, there are days that are very challenging.

Sarah: Mm

Helen: And that was just my insight into reading the transcripts

Sarah: No that's really interesting

Helen: And it was very interesting for me to see it.

Sarah: Yeah

Helen: Because I know, and when, 'tis a pity Ina isn't here, already, because I think she would agree with that hugely, and I haven't had a chance to speak to her now since I read the transcript. Em, that she would more say, you know, if I've had a few bad days and then I say, 'Look I'm grand again', and she said 'Mum, you've got to give yourself more time.'

Sarah: Mm

Helen: So she'd be more conscious of that

Sarah: Yeah

Helen: So, whereas it's not resisting power, it's actually resisting, I resist my condition

Sarah: Yes

Helen: So I just thought that was an interesting insight

Sarah: Yeah, that's really, that is really interesting, isn't it? Em, and I wonder is that the case for lots of people, I don't know, you know, I have to, have a dig around and see.
Helen: Yeah, and there was, like, we met for lunch, there last week.
Sarah: You and your daughter?
Helen: No, no, no
Sarah: Oh the group?
Helen: Me and the - us crowd of deadbeats, we had lunch in [pub] and it is really nice, and there was one girl there who, girl, woman, who hasn't been there for a while and it was lovely to see her because we weren't even sure if we'd see her again, do you know?
Sarah: Oh right, ok
Helen: Em, [name] is her name, I don't want to know whether you see her or not, but she wouldn't have been, you know, it would have been hard for her to give interviews I'd say, anyway she's a really, really nice lady and she was there, her daughter and daughter-in-law brought her, so it was lovely to see her.
Sarah: Ah that's lovely, yeah
Helen: But we were chatting away anyway, and I suddenly realised that, I spoke quite a bit in this about the group, and you know, how wonderful it is and how we understand each other, like that's the one place you can actually be totally honest
S; Mm
Helen: You know, somebody will say 'I kind of found Thursday [?hard]' I said 'I know yeah, I couldn't, I just actually, you know had to abandon, and d'you know, not do what I needed to do because I couldn't get into the car it was too hot', d'you know? So within the group you're actually more honest
Sarah: Mm
Helen: Than you are outside the group and I just noticed that
Sarah: So when you were talking to me, em, do you think that em, you kind of automatically went into this upbeat, eh
Helen: Em, well it's not-not because I was talking to you.
Sarah: Mm
Helen: It is my default
Sarah: Oh yeah, ok
Helen: You know. It's, not, no, I wasn't trying to give you a wrong impression, because it,

Sarah: Oh no, that's not what I meant, no no

Helen: Yeah, no-no-no but it

Sarah: No, no, I meant, you know, sometimes when you're speaking to a, you know, subconsciously, I'm not even talking about consciously, you automatically...

Helen: Yeah, but this is it, but no more you than anybody else

Sarah: Yes, yeah, yeah

Helen: You, yeah, yeah

Sarah: That's what I mean, yeah

Helen: You default, you subconsciously default into everything is fine

Sarah: Yeah

Helen: And, because you're, like I do think, it's not that you're trying to fool people, you're actually trying to fool yourself

Sarah: You are, yeah

Helen: You know, it's-it's em, it's not wanting to show weakness

Sarah: Yeah

Helen: Wanting to be able to do what you always did

Sarah: Yeah

Helen: You know, em, like, I would never say to the grandchildren I can't run after you now, you know, like I used to, but Ina would. 'You just can't play that game with gran-gran anymore.' D'you know. Em, 'you can do other stuff with her.' D'you know, I just thought 'twas interesting, and [pause] yes it made me realise that, even to myself I deny, it's not a question of fooling people cos

Sarah: No, no

Helen: I deny to myself, em, the limitations and the challenges involved in this.

Sarah: Yeah

Helen: Em, [pause]

Sarah: And I wonder is that almost a self-protective thing, because you have to get up every day, you have to face
Helen: Yeah, well, [exhales], I - [bb what to do] it's [pause] it's a kind of a refusal to capitulate, you know, do not go

Sarah: Yeah, yeah

Helen: Do not go quietly, gently into that good night, do you know. I think it's that as well, you know, because there's always a question in your mind, 'Would I be feeling this tired, just because I'm 68, or is it, is it all down to the...

Sarah: COPD

Helen: The COPD. Em, obviously 'tis, it has to be a bit of both, em, my brother is the older sibling, there are five of us, and I'm number two, em, and recently, like I always thought that I'd probably be the first one to check out because of the COPD, not that I dwell on it, but you know, it might be likely, and then his blood pressure spiked in the last month

Sarah: Oh no!

Helen: Outrageously out of control so we were ringing him, 'Are you alright, have you got it checked, are you on the medication' and em, and it was interesting because his daughter is a pharmacist, so he said, I said, 'Did you get your blood pressure checked recently?' And he said, 'I'm going over to [name] now, she's going to do it'

Sarah: Mm

Helen: 'And sure then if 'tis normal I can go on the pints again tonight.' And I thought

Sarah: Oeuuuh

Helen: Yeah

Sarah: Jasus

Helen: This is more part of it, you know, you don't let these things stop you in your tracks, you just kind of stop at the barrier, jump over it or walk around it, and then carry on as if you were still 16

Sarah: [laugh]

Helen: And he's doing exactly the same!

Sarah: Right, right, right, yeah, yeah, yeah, yeah

Helen: Like I had another episode of atrial fibrillation since I saw you last
Sarah: Oh did you? Yeah

Helen: Yeah, em, again it was reverted I didn't have to be shocked, em, and the trigger seems to be, like a bad infection, you know

Sarah: Oh ok

Helen: Yeah, so like that seems to be a trigger, so now they've tried me on medication and they're quite happy. I'm fine now, I even have an app on my phone to check my heart rate and it's grand

Sarah: Oh very good

Helen: But like you don't need the app. Because you know it.

Sarah: Right yeah

Helen: And em, it was just, I was here feeling very funny one night, and I thought, 'That's a bit fast.' And I was doing my yoga breathing trying to pull it down, and it didn't pull down, and then I went to the app and 'twas 130.

Sarah: Ohhh

Helen: Yeah, you know, but. But they told me inside people go in there with 180 heart [unclear]

Sarah: Jasus

Helen: And I said, 'Are they still alive?' 'Yeah they are it's amazing what we can' But it's obviously, it's the fear of the clotting, you see, with the

S: Yeah,
    yeah

Helen: The rapid heartbeat, and

Sarah: Yeah

Helen: So they [unclear] irregularity, so em, so yeah, that happened, but

Sarah: So and you've been, you said you had a few infections

Helen: Yeah, and like I'm still on the antibiotic

Sarah: Right

Helen: Em, and like I've been tired when, having the house full of paint, and painters, I mean it's grand, I'm delighted with it, em, like this would be the end now, I'm delighted, by the end of the summer, it'll be done, you know, the windows are
done, the outside of the house is done, the inside of the house is done, I can kind of make a few Dundee cakes and [laugh]

Sarah: [laugh] You're all set up for the [unclear]

Helen: Exactly, yeah

Sarah: And em, and you were saying, do you think, cos you, do you know why you got the infections, do you think it was the hot weather? Or just...stuff was going around

Helen: I, there was stuff going around, and the hot weather certainly doesn't help, em, I do think, I definitely do think being tired and not giving yourself a break, and I have been actually very busy

Sarah: Mm

Helen: And again, like that's another thing that I don't, I don't say 'I can't do that now' Because I'm still in this forward thrust of, you know, get over the infection and then carry on with normal life. I suppose that's one of the hardest challenges to kind of come down, do you know? [voice gets quieter here]

Sarah: Yeah, and I wonder is it like em, is it like a finding the balance between activity and relaxation and

Helen: It is, absolutely, yeah

Sarah: Ok

Helen: Absolutely. It is, it is, finding the balance, em, [pause] and then in my head, like, I realise exercise is really good, [pause]

Sarah: Mhm

Helen: But then when you're really knackered, you shouldn't be doing exercise, so when is exercise good and when is exercise actually counterproductive, you know?

Sarah: Yeah, yeah

Helen: Em

Sarah: That's not easy to work out is it?

Helen: No it's not, because, especially when you think, 'I should be exercising therefore not exercising equals laziness' and it's not always. Like I went down to walk around the [park] one day with my sister, and I just had to sit down at the second bench, you know, and I said 'You go on, you go around, and I'll be here
when you get back', and then after about five minutes I kind of again just re-you know, got my breathing back, also had adjusted to the change of temperature cos quite often if I go out, the sudden change of temperature will, you know, and I find that, you know

Sarah: Mm

Helen: Either from hot to very cold, or cold to very hot, em, so then I actually walked around kind of half the other side of the [park] and met her and came back with her

Sarah: Oh ok yeah

Helen: So and then another day, I think I, yes I told you about this before that I went up to the garage and, you know, like the last time, I went up to the garage and when I was coming down, I had to ring my sister

Sarah: Yes, yes, yes

Helen: And I was kinda pretending, well I was on the phone, but, you know, like I found it hard to get home.

Sarah: Mm

Helen: So I didn't risk it, I had my MOT again, or my NCT, and, I got my sister to collect me, I just had it arranged in advance, I wasn't going to do that to myself anymore, d'you know? Em, and then Sunday, town is very, very difficult, you know, like I would park in [location] and then usually, like I always need something in [shop], I always need a book or something. So getting from [location] across the road into [shop], back again to the car, you know, that's fine, but walking the length of [name of street] would be a challenge sometimes, and other times it's not.

Sarah: Mm

Helen: You know, so it just depends on the conditions, it depends on the amount of oxygen going in

Sarah: Yeah, yeah, yeah, and how things have been. And how many years is it since you were diagnosed, then?

Helen: Em, we reckon, and again, now 'twas only recent that, about 2009, even though I had problems before that, em, it was, I was in Germany with my daughter and her family, and the doctor said 'COPD', so , you know, so that put a name on it, em,

Sarah: Mm, but it had been grumbling around, and
I: Yes, constant infections

Sarah: Yes I remember you saying that, yeah

Helen: Before that, then kind of you know, I'd bronchitis, smoker's cough, you know, all this kind of thing.

[pause]

Sarah: I'm just putting the phone on silent there, em, so, eh, so has-having read the transcript and stuff and having had the kind of few infections, and stuff, have you changed anything about how manage your COPD every day, do you think?

Helen: Em, [pause] I have actually got a lady to come in

Sarah: Oh have you?

Helen: I have. Now, em, it, like it's every fortnight. Eh [cough] excuse me now, I'm doing the coughing, so

Sarah: That's fine, don't mind,

Helen: [cough] Em, I'm like somebody in the old days, it used to be called the consumption [laugh]

Sarah: Oh yeah, yeah, yeah

Helen: Em, [pause] once a fortnight I get somebody in to clean the house, now [00:15:11:22] I had them in two weeks running because there was an awful lot of, you know, dirt, because of the, em,

Sarah: The work

Helen: Of the, the painting, and that, but, and then when like he started in the attic room this morning, so my daughter helped me, you know, just move stuff or whatever, I helped her move stuff, she did most of the heavy lifting, em, and so I'm, not doing that, I'm not forcing myself to do that anymore.

Sarah: Right.

Helen: And that again is, you know like, when you're able to do things yourself, you did it, and you did it now and, you know, one of the frustrations of having a husband who was going to do it is that it never got done, d'you know, tis easier to do it yourself type of thing, yeah

Sarah: I have one of those at home

Helen: Mhm, I know yeah
Sarah: A lovely man, a lovely man
Helen: They mean the best
Sarah: Oh yeah
Helen: They mean the best yeah
Sarah: Oh yeah, yeah
Helen: Yeah
Sarah: But god help you if you
Helen: And you'd be better off not asking, because once you've asked him, then it
sounds like sour grapes if you go and do it yourself, so you're better off to say, 'I
better do that now before I ask him and cause myself trouble'
Sarah: Yeah, yeah, yeah
Helen: But em, yeah, so, that's another one of the challenges, you know, I want to
do, like, this needs to be pruned back, em, there's a thing needs to be planted
which I won't dream of doing, so I've to wait until somebody actually comes and
digs the sod for me
Sarah: Right
Helen: Em, and you just, like, you just have to learn to have patience with yourself
and the bits and pieces of your life
Sarah: Mm
Helen: So definitely, and again, like until you can't do it, you're going to keep trying.
Sarah: Mm
Helen: And this is, this, I think this is the, we're always so used to doing the needful,
whether tis actually needful or not but what we perceive as the needful, doing it,
getting it done, moving on
Sarah: Mm
Helen: And that's all part of the challenge of accepting that maybe sometimes there
are things that have to be left,
Sarah: Yeah, yeah
Helen: You know, em,
Helen: And

Sarah: So that's kind of a shift in thinking isn't it?

Helen: It is a shift in thinking, yeah, it's a shift in thinking, and it's a shift in managing your day-to-day life, you know?

Sarah: Yeah

Helen: And that should be out in a box of electrics to give, to bring over to the recycling. It's just there. It won't do me any harm, usually, they'd all be out in the shed where they should be, and you know, and you just kind of calm down [whisper], you know, yeah

Sarah: Yeah, yeah

Helen: Yeah, there's no room for OCD with COPD

Sarah: [laugh]

Helen: [laugh]

Sarah: No, no, you just don't have the energy for OCD

Helen: No you don't, no you don't have the energy, yeah and it takes a fierce amount of

Sarah: Yeah, because, yeah, OCD is a very time-consuming condition

Helen: It is very very

Sarah: Em, ok so that's really interesting, I'm fascinated that em, the - the transcript had that kind of impact on you

Helen: Absolutely, it did yeah

Sarah: That's really interesting. Because, em, I rarely get the opportunity, often - most, a lot of the times I'm doing research, it's just one-off interviews and I don't come back

Helen: Yes, yes, yeah

Sarah: So I have sent plenty of people transcripts in the past, but I've never had the opportunity

Helen: Yes, yes

Sarah: To see

Helen: Yeah
Sarah: What that's like for you,
Helen: Yeah, yeah
Sarah: D'you know what I mean?
Helen: And it, like, it's a very useful insight for me, as well as maybe for your research, do you know
Sarah: Yes, absolutely, I'm delighted. Yeah it's great, em, because a lot of the times with this kind of research, I'm not coming to offer, I can't offer you a kind of a clinical intervention
Helen: Yes, yeah or a solution
Sarah: Or a direct benefit, so I'm, you know, obviously, em, eternally grateful to everybody who takes part, but that's interesting to see the benefit of actually reading a transcript
Helen: Exactly, yeah.
Sarah: Em, now, I was just gonna em, there were two things I wanted to kind of follow up with you, and then I had a few things just for your daughter.
Helen: Mhm
Sarah: Em, you mentioned in the transcript, em, kind of things around stigma and embarrassment, or, you know, the kinda, way, COPD is perceived and how that might affect you, and I was just wondering, em, you know, maybe going back to when you were first diagnosed, or?
Helen: Yes, again, it's like not going gently into the good night, it's not, yeah, showing weakness?
Sarah: Ok
Helen: You know?
Sarah: Yeah
Helen: Em, I mean number one having a weakness, but bad enough to have it, but then to show it, and to, capitulate, d'you know, to em, to not be able to fight the good fight
Sarah: Yes, yeah, yeah
Helen: Just wondering if that's Ina if [00:20:02:10] you'll excuse me
Sarah: Sure
[goes to check if Ina is coming]

Helen: She'll be here in ten, is that ok for you?
Sarah: Ten minutes, perfect

Helen: Yeah, grand perfect. Right, that's grand, em, yes, em, I suppose there were-apart altogether from decrepitude and weakness right
Sarah: Mm
Helen: You know, getting to be not as capable and in control, in contro-you know control has a part in it as well
Sarah: Mm
Helen: Em, there's also because of what it was and because I came to it as a smoker, there's that kind of shame
Sarah: Mmm, oh yeah, ok, yeah
Helen: You know, that I did this to myself
Sarah: Yeah
Helen: Em, that, I mean I've well forgiven myself, because I understand the addiction, em, but even the painter was saying about some client of his who was, he's an ex-smoker himself, but this lady, em, she was very worried about her husband, and he was still smoking, and he said, I used to be trying to get him off them, and I said, 'But don't you realise as an ex-smoker yourself, you have to have your time'
Sarah: Mm
Helen: Your time comes, like the number of times we've all done it, like you and I have been through it, how are you doing by the way?
Sarah: [makes positive gesture]
Helen: Great, brilliant, that is just great
Sarah: The sugar, is, has, the sugar intake has gone up, but as you say, I'm gonna live with that for the
Helen: Absolutely yeah
Sarah: And I'll tackle that next year
Helen: Yeah, it's the
Sarah: Yeah, but the s
Helen: Ah it's the lesser of two evils
Sarah: It's absolutely, em, but I'm delighted, yeah
Helen: Do you feel that freedom?
Sarah: Yes, that freedom from addiction
Helen: I actually couldn't believe that freedom
Sarah: It is amazing, it's so liberating
Helen: Yeah, but I would never nag somebody because
Sarah: Just, just
Helen: Well, it's-it's counterproductive anyway, it's absolutely useless to do it, and you're only annoying yourself and you're annoying them.
Sarah: Yeah
Helen: You know, em, so, I'm delighted now that you're doing well
Sarah: Yes, seven months now
Helen: Yeah, that's great
Sarah: Yeah
Helen: That's great, and the time will come like me, you won't know how long it is
Sarah: No I know yeah, yeah
Helen: That'll happen, I mean I used to know it in the days at one stage
Sarah: [laugh]
Helen: But em, yeah, no it's em, so there's that, like there's the feeling, ok, I know my medication is quite expensive, em, I got a medical card because of my condition, so I only pay the €2.50. Em, I know, I'm costing the State, and I suppose there's a certain amount of guilt about that, d'you know I did this to myself, but, maybe I could have, you know, like, on the other hand I could have something else that was not my fault at all, and d'you know there are lots of people who smoke and don't get caught, I was just unlucky, I was one of the unlucky ones who ended up this way, rather than another way, em
Sarah: Yeah
Helen: So yeah, when you say kind of stigma, em, [pause] it's it is a bit like, I remember when I spent years with reading glasses and distance glasses and they were on and off, and all then I couldn't stand it anymore, I was sitting on the wrong one and I had the wrong one on me, you know, em, was wondering why I wasn't driving the car properly, I'd my reading glasses on and all this, and one day, I just said, 'Right, ok, it's varifocals, let's get on with it.' And I did it, and, now I am slightly, irritated by my friends who can never find their glasses and say, 'Will you read that for me?'

Sarah: [laugh]

Helen: 'Jesus Christ like why don't you hang it around your neck?' 'Oh I couldn't do that!' Anyway. Em, I was at a meeting one night, and I put up my hand, and the guy in the podium said, 'The lady down there with the glasses' and I said, 'Oh shit, I'm now a lady with the glasses.'

Sarah: Oh dear

Helen: You know, and it's like that, you know, the woman with the glasses, the woman with the white hair, you know, the-em, the person with COPD, d'you know?

Sarah: Yeah, yeah, yeah

Helen: So, you know, and em, and I mean there are several of our crowd, like the woman with the oxygen, the fella, you know, with the walker

Sarah: Yeah

Helen: Em, anything that marks you out as different I suppose we don't want to

Sarah: Yeah, we don't want to

Helen: To have to do

Sarah: Yeah

Helen: But I can tell you, like now, one thing that I've started to do. When I stop at the supermarket just to run in for the milk which is always at the back wall

Sarah: Yeah

Helen: Em, instead of rushing down to get the milk, and by the time I'm up at the cash desk kind of gasping, I actually go into the supermarket, take my trolley, even if tis only one thing I want. Walk down leisurely, walk back, and I-that's one thing I've

Sarah: Ok
Helen: I've discovered. And I do that for myself now.

Sarah: Learning kind of, is it kind of learning [00:25:01:09]

Sarah: Kinda learn to pace yourself or something?

Helen: Learning to pace yourself, learning to take all the help you can get, whether tis, you know, I would still park in a normal space

Sarah: Mm

Helen: Unless I need it, and then I went to a funeral the other day now, and I was late, and everything was jammers, but there were two places in the wheelchair thing, and I just used it because I'm entitled, and so things like that

Sarah: Mm

Helen: You know like before I would have said 'I'm not going to park there.'

Sarah: Oh yeah, yeah, yeah

Helen: There was a very interesting thing happened actually, this is just funny, but I thought it was a scream. My older brother, he had, he had trouble with his heel, and 'twas actually em, oh, oh Lord what is it? Uric acid in the

Sarah: Gout?

Helen: Gout. He had an episode of uric acid which was really really painful, and he was here one day, and very - struggling to get home, but he did drive home. Em, and I said, 'I've crutches upstairs', since my knee was gammy, and I never gave them back because if you give them back to the [...] Health Board they'll throw them away.

Sarah: Mm

Helen: So I keep them for emergencies

Sarah: Mm

Helen: Em, and he said 'No, I'm fine' but a couple of days later he said 'Would you ever let me have the crutches?' and I said 'Of course I'll drop them down to you,' so, he lives in [location] dropped down the crutches anyway, had a cup of tea, and his partner was there. So he was saying, again, like that now, 'if my blood pressure gets down I'll have the jar on Friday night. All I'm worried about now is that I'll be able to get onto the plane in em, we're going to Alicante, or, somewhere, Lanzarote, in three weeks' time'. So I said 'but why don't you do what I do and get Airport Assist? It's brilliant!' So he said, 'What's that?' and I was explaining and
then his partner, who's a bit younger than him, said 'Out of the question [name of brother].' So em [laugh]

Sarah: What?

Helen: She said, 'Out of the question!' Now she is eh, an Aer Lingus em, hostess

Sarah: Oh right, ok

Helen: So em, I said, 'Why?' She said 'You'd ruin my credibility'

Sarah: Oh!

Helen: I'm too young to be going round with somebody who needs a wheelchair. Now he was breaking his ass laughing, of course, if it was absolutely necessary, but he wouldn't want to do it anyway. I just thought 'twas so funny, 'Yeah tis bad for your credibility, so you can hobble on to the plane!'

Sarah: Yeah, you hobble, suffer away there

Helen: Exactly. But like, 'I couldn't be, I couldn't have my colleagues know that that my fella has to has, needs a wheelchair!' [laugh] I just thought, 'The cheek of you!'

Sarah: Jasus!

Helen: That's my big brother you're talking about!

Sarah: Yeah, yeah, yeah

Helen: It was just so funny!

Sarah: Aw my goodness, it's funny

Helen: But he was fine, he was fine

Sarah: It's amazing em, that kind of sense of

Helen: That perception

Sarah: Yeah, yeah. And I suppose with COPD, em, there are public signs of it as well. That make it

Helen: Yeah. And the other, like the other public sign, and I might have said this to you before, as well, is that if you meet me on a good day. You'd, and I would be absolutely fine, and even finer because, as I say, my default is to say, 'I'm great!' you know, and I would be. And I'd feel great, em, and I'd forget very quickly that it had taken me a long time to get on the road that morning, you know, the slow start is definitely increasing.
Sarah: Mm

Helen: Em, but, then you might ring me. Three days later and ask me to do something with you

Sarah: Mhm

Helen: And I'd say I can't, or you might even have rung me first and said 'Can you-will you [unclear]?' and I said 'D'you know, I'm not feeling that great, and then three days later you meet me and I'd be fine and you're kind of worrying that somebody's saying, like, 'What kind of...'

Sarah: Yeah, I know what you mean

Helen: You know, 'Is she just telling lies?' D'you know?

Sarah: Yeah, no, I get you, yeah

Helen: D'you know that, em,

Sarah: That fluctuating

Helen: D'you need another

Sarah: No, no, I'm fine thanks

Helen: Like you're good when you're good and you're bad when you're bad.

Sarah: Yeah

Helen: Yes, and that fluctuation, can, be, I'm sure it's - it can be confusing, d'you know? Em, I've said to my sister at, with whom I was having a cup of tea when I should have been over here for you,

Sarah: [laugh]

Helen: But you see, I-I went to her house just to give him a chance to have his lunch, and you know not be in his face when he wants a break as well [quietly]

Sarah: Mm

Helen: He wants to make his phone calls or whatever, em, so I was actually just hiding across the road [whispers], because my sister just lives across the road, and I was saying 'tis such a pity she didn't ring me when he told me, d'you know

Sarah: Oh yeah, yeah

Helen: So, em, anyway, look it doesn't matter if you're ok timewise

Sarah: Yeah
Helen: But em, so, jakers what was I saying?

Sarah: Ah, fluctuations. Eh, so one day, saying to somebody

Helen: Oh no-ah yeah, I was over with my sister and I was telling her about meeting you, and I was saying 'I was reading the transcript, and I realised that I'm kind of upbeat a lot of the time.' She said, 'You are yeah', em, we'd a family barbeque on Saturday. But now, that's definitely a change. That I would have said to them, you know, when we're kind of planning and plotting and, you know, the three sisters, like the three witches kind of doing this, and, allocating the jobs and all, and, like I said at the start of the week, I said, 'I don't know what way I'll be'. But I had made the Dundee cake, I had made the jelly, I had gone shopping when I was able, you know, and it was grand, so we'd, all the shopping in, and then I said 'I can't anticipate what I'm going to be like on Saturday, but you know the one thing I can do actually, if I'm not able to kind of help with the serving, or d'you know, kind of do that, or em, I actually can stand at the sink and do the initial, you know the initial clean off'

Sarah: Yeah

Helen: So I said, 'Look I'll be able to do the clean up anyway, I mightn't be able to,' like I wouldn't be the bar man. I wouldn't be going back and forth now, offering drinks and that sort of thing because it would be too much up and down the steps into the garden and,

Sarah: Oh yeah, yeah

Helen: D'you know it would be too much

Sarah: Yeah

Helen: Em, but I can stand at the sink no problem with a pair of rubber gloves and I can

Sarah: And your sisters understood that did they?

Helen: But they do of course, they do of course, but like that I think it took them a while to realise, maybe I felt it worse when this started, and this would be going back several years, that I felt maybe they thought I wasn't pulling my weight. And it took a while for me to be able to admit to them that what I was doing was as much as I could do.

Sarah: Mm

Helen: And of course they understood that
Sarah: Mhm

Helen: But this again is kind of the capitulation, d'you know? And I was actually em, we were talking about [name], our second sister, em, she is up to there with grandchildren at the moment, we both think that she's being taken advantage of, that there is just no understanding at all that she is, what she is, she's younger than me, but I mean she's in her mid-sixties

Sarah: Mm

Helen: Em, and she's always been a brilliant mother and she's a wonderful grandmother, but they're actually, you know, they're asking too much of her now, really, and she's not saying 'No'. So we were kind of, we w-you know, I was talking about that in the context of, like, [sister 1], is always just fine to do it, as is [sister 2], and mine is more serious because when I really can't do it I just can't do it, so, you know, like [sister 1] will keep on going and I'm a bit worried about her because she is about to have an eye operation and I really do think she needs to be rested, d'you know, and we agreed, Mammy, who in retrospect had COPD

Sarah: I remember you saying that, yeah,

Helen: But she always had, and we never understood it, and I'm suffering the consequences now, but, Mammy took the path of least resistance. Like it is in me to fight on

Sarah: Mm

Helen: And maybe because, you know, Mammy just, we couldn't get her to even walk to the gate. D'you know, when we were trying to keep her active.

Sarah: Mm

Helen: Em, she just felt a little bit down and went to the couch, but then she would have had psychiatric medication as well, so like she didn't have, you know, she would have been a depressive type of personality, whereas I certainly wasn't, d'you know, em

Sarah: And if you have depression, I mean

Helen: Oh you don't need COPD on top of it, yeah

Helen: So she wasn't able to help herself

Sarah: Mm
Helen: So but I think that that was, 'Well I'm not going to end up like my mother on the couch.'

Sarah: Oh yeah, I get ya, I get ya, yeah

Helen: Do you know and that this is a kind of a psychological thing as well, you know. That you kind of are 'I'm not going to give in, in that way.'

Sarah: Mm

Helen: So that's part of it, and I think we all have it, but, em, Ina would kind of know what I am capable of and what I endeavour to do and when one doesn't equal the other she would be pulling me back

Sarah: Mmm

Helen: You know, em, whereas I'd be pushing myself, but she wouldn't have had, she wouldn't have had a mother who gave in at the first hurdle.

Sarah: Mm

Helen: So she doesn't have to, you know, she's, well she does too much anyway, but we all see it in other people. You know, em, she's absolutely running around like a whirling dervish

Sarah: Oh does she work?

Helen: With the kids. She does. She does, she works in [university] em, and she's in the music department so it's not all nine to five, you know, it's like rent-a-crowd, like night-time, during the summer she was [cough] her husband was in Germany, clearing out his mum's house cos she died in October and that was very sad, like the three siblings were there, and [name] was up doing a concert in [university], so Helen: So she was up three weekends in a row, and he was in Germany for those three weekends, I had the children, you know, it was mental, it was absolutely manic. Em, it wasn't easy [unclear] exhausted, and that I'm mixing up my times of appointments,

Sarah: Absolutely, yeah

Helen: But em, but like, yeah, like and I know that she felt guilty about that, you know, em and he wasn't able to do the German trip except those weeks, because he had to fit in with his two siblings

Sarah: Mm
Helen: Who had other stuff going on, em, they needed to be together because 'twas they're so sad about their mum, you know, she was a lovely, lovely granny, em, lovely woman, and then they're, like they're tidying up and disposing of their whole lives, do you know, so it's not

Sarah: Aw

Helen: Like his older, his brother was 60 now, em, they went back then in August and had the 60th celebrations, so that [name] was up to there with work and commitment, and actual performance, d'you know, whatever about working in the background, when you have to be up performing so it's just a nightmare. Anyway, we survived it.

Sarah: And em, yeah, you got through it, but no wonder you're tired.

Helen: Mm

Sarah: And the other thing I was gonna ask about then, was em, your relationships with your health professionals

Helen: Mhm

Sarah: Like, how would you say, thinking of consultant, GP, nurses, how would you characterise your relationship with them? Would you say it's a good relationship?

Helen: Oh yes it is yeah, it is, I'd like they're, particularly I spoke to you before about the pulmonary nurse

Sarah: Oh yeah, yeah

Helen: Who had her little baby girl!

Sarah: Ah yeah

Helen: She's just wonderful! Em, yeah, she is just an extraordinary person. She has a very great empathy, em, and the physio is the same, like she, the physio there, like a two-man band, em, she has the ear to the consultants because the consultants know, they respect her ability to kind of judge the clients and that, and the consultants are very good, you know, I mean they, they're trying, they try different things, it's still kind of experimental, you know, like they're fully behind the exercise programmes, they're reckoning, you know, they're hoping to prove I think is in, [university].

Sarah: [university], yeah,
Helen: They're doing a kind of an exercise versus inhaler kind of research thing I think?

Sarah: Ah oh wow I'll have to have a look at that.

Helen: Yeah, em, yeah, em, if I have it wrong I can correct it, but I do know, because 'twas I had a physio, I was at a physio because of a physical thing in my neck

Sarah: Mhm

Helen: And em, of course once he heard my breathing, and he kind of was talking about the posture and breathing for the COPD, he was kind of a holistic guy, he wasn't only going to fix my [unclear]

Sarah: Right, right, right

Helen: Em, but he said that the is it the chartered physiotherapist or something, that there's some, there's some research being done

Sarah: There's your doorbell

Helen: Yeah, that's Ina now, em, there's some research being done and because they reckon that exercise is so important, that they, you know, that it actually in some ways can take over from inhalers

Sarah: Oh very good

Helen: You know and replacing exercise with medication or medication with exercises, [goes to open door]

[greetings daughter and grandchildren]

[grandchildren come to say hello to me]

Helen: So em, so,

Sarah: Hi!

Ina: Sarah, isn't it?

Sarah: Yeah

Ina: [name] is my name

Sarah: Nice to meet you [name], how are you?

Ina: Are the girls set up out the back?
Helen: They're-they're beginning to play because you see since the last time they were there, em, the carpet came out and everything so

Ina: Ah

Helen: So they have to - now you're keeping an eye. You might actually be more comfortable here, would you?

Ina: I don't mind

Sarah: I'm fine now

Helen: Yeah, you're fine, ok yeah. So were we in the middle of something just when the door rang?

Sarah: Oh yeah, just how you find your

Helen: The health professionals

Sarah: Yes, yeah, yeah

Helen: Oh yes, and the study, they're very good, like sometimes they're kind of saying, they're a bit stumped, and they'll say, 'We'll try this now and let me see how you get on.' So, it's like a collaborative thing

Sarah: Mm, mm

Helen: You know

Sarah: Oh that's great

Helen: Yeah. They're, em, they will listen to you. My GP, I can understand that he, you know, doctors don't like you having steroids too much, or antibiotics too much, and when I went over to him last week he just said, 'Look I'm going to give you the antibiotics.' Now I was pretty stuck, wasn't I, I was very, very tight, and em, he said 'I'll give you the prescription for the steroids, but don't take them unless you need them.'

Sarah: Mm

Helen: And I came home, and I hadn't filled the prescription, but I always have one set of, they're inside

Sarah: Ah ok

Helen: In case, you know, if I go away, I bring them with me, just in case, em, and then I said 'For feck's sake [whisper], I'm going to take them,' like, as somebody said to me, ok, the steroids are bad for your bones, but like what's the point of
having bones if you can't breathe? So you have to, and I just feel sometimes, I'm over there, and I feel, he just thinks I want steroids, and I want anything but, but I want to breathe

Sarah: Mm

Helen: More than I hate steroids. You know?

Sarah: Mm

Helen: So that's the only thing I find, like it's almost as if they disapprove of you taking your steroids?

Sarah: Ah, steroids, bone of contention

Helen: Yeah, yeah. There's just one more thing before you talk to Ina. You had asked me, you know, what things I have been doing or what

Sarah: Mm

Helen: Em, what changes I made. When I went with my sister to see the [gallery]

Sarah: Mm

Helen: Because of the state of [city] at the moment with all the roadworks

Sarah: The [public transport] works, yeah

Helen: We were kind of saying where could we park, you know and I just said 'Look, taxi to the door, and taxi back to the door.' Because, and I said, 'It's non-negotiable, I'm paying for the taxi.' She said, 'But sure I can park.' I said 'I want all my energy to go in to see [artist]. I do not want to arrive at the door of...'

Sarah: Panting, yeah

Helen: Panting, and then having to go up the stairs, which you know you do have to go up the stairs

Sarah: Mm

Helen: And I just said 'No,' So like, it's changes like that, it's just, just get the taxi

Sarah: Mm

Helen: You know? It's- you know by the time you've put the petrol in the car, paid for the car park, and more than anything paid for the stress

Sarah: Mm, of trying to get there

Helen: Of trying to get there
Sarah: Yeah

Helen: So that was one huge change, did I tell you I did that? Yeah, that just taxi to the door, and we walked out, through the [gallery], into a taxi and straight home

Sarah: Fantastic

Helen: So that was, em,

Sarah: Ok that's fantastic

Helen: Yeah

Sarah: That's brilliant, em, and, em, thanks a million, fascinating, just really, really interesting

Helen: Yeah

Sarah: And it's em, great, em, I take it you want, you'd like me to send you the transcript?

Helen: I'd love it again, yeah, because I found reading that transcript was very interesting, Ina, I never told you that. Will I make you a cup of tea? While you're having a chat? Sarah, would you be ready for a cup of tea?

Sarah: I won't, no, I'm em, I've had

Helen: You've had

Sarah: Many coffees today

I and Ina: [laugh]

Ina: You've maxed out.

Sarah: I have maxed out, yeah I have to sleep tonight, and em, I em, I've given up, off cigarettes seven months,

Ina: Oh good for you! Congratulations

Sarah: But you metabolise caffeine differently once you're off

Helen: Yeah, ok

Sarah: You're actually more sensitive to caffeine than you were before, so I have to, I used to drink coffee with impunity and now I have to just keep a very close eye

Helen + Ina: Yeah

Helen: And have you done the decaf at all yet?
Sarah: Em, no, I eh, I can't quite bring myself to do that

Helen: I know, I don't blame you one bit. I've actually, I have the, because since my fibrillation I use decaf tea, because tea was my constant 24-7, and I actually do, I find it grand, I don't even notice the difference, except the headaches at the start

Sarah: Yes

Helen: And the GP just said, 'Look, take a caffeinated tea in the morning, and eventually you mightn't even need it.' So first one is caffeinated, and then

Sarah: And then

Helen: And then I'm on the decaf for the rest of the day

Sarah: Oh great!

Helen: And it works

Sarah: That's interesting

Helen: It works fine, yeah

Sarah: Yeah

Helen: Because, like, I used to get, and I don't suffer from headaches, I used to just get hammered

Sarah: And the caffeine headache, oh!

Helen: Yeah, the no-caffeine headache, yeah, exactly, so I'm kind of adjusting, and he said maybe one of the days you won't need it, but

Sarah: Yeah

Helen: I still do it, just the one

Sarah: Just the one

Helen: Yeah

Sarah: That's a good idea

Helen: Well, one teabag, two cups of tea [laugh]

Sarah: Ok, [laugh]

Helen: I use the teapot you see, so I can have

Sarah: Oh yeah,
Helen: I'll have the two cups of tea. Right, I'll give you [addressing Ina] a cupán [unclear]

Sarah goes through information sheet and consent form with Ina. Ina signs consent form

Sarah: Em, so basically then, em, [name], all I'm really here is for basically you to tell me your personal story of em, you know, your mum's em, COPD and how that impacts on you, and the kind of things that you try and do to support her, and that kind of stuff.

Ina: Yep, em, yeah, I mean, well you probably have gotten a sense from her that she's very much, em, you know, she's very proactive in her own management of her condition, em, very much, em, in control I would say of what she needs to do, em, and how to manage things, like I think, as time has gone on, em, things have stabilised in terms of how she might kind of, em, well first of all what she does on an ongoing basis, so she probably told you that she goes to this weekly rehab meeting.

Sarah: Yes, yeah

Ina: Em, which I think has been really important for her, em, definitely physically, but also just in terms of kind of support, and socially, and feeling like, em, she has a bit of a peer group

Sarah: Mhm

Ina: Because nobody in her direct family or circle of friends would have the same experience with the condition, em, so I think that's important, and, I suppose I'd be removed from that, like I've never met any of the people in that circle, but to me anyway, it just seems like it's important to know that there are people that she can have access to who really understand

Sarah: Mm

Ina: Because like the rest of us, I think, can't really em, fully get what it must be like when her chest is very bad

Sarah: Mm

Ina: How limiting that must be

Sarah: Mm

Ina: Em, part of that of course is because she tends to manage it very well herself, em, and maybe even not fully reveal to us maybe when she's really struggling, if
she is, so like that now, em, I do think that she will often have kind of soldiered on a bit

Sarah: Mhm

Ina: Maybe when she shouldn't have

Sarah: Right

Ina: So what she was describing there about the steroids, like I've definitely observed that, em, in the past, maybe even a year ago or two years ago, I think mum would have been far more em, likely to go with the doctor's instructions to the strict letter of you know, 'He told me not to start the steroids until I need them', now she knows she needs them.

Sarah: Right, right, right

Ina: She really is the best judge of that

Sarah: Ok

Ina: And, like, I- I know the issues with the steroids, but I've seen over the years the times where she's tried to hold out, and not take the steroids because intellectually she knows she shouldn't, and because the doctor would have said 'Leave it go as long as you can', whereas in fact that's often gotten her into a worse condition

Sarah: Right, yeah, yeah

Ina: So I think that's a kind of a shift more recently where she is the person who's best placed

Sarah: Yes

Ina: And she has more confidence I think in herself to know, 'I'm under pressure, I can let this go 48 hours, and then need a second antibiotic at the end of it, or I can just call it now myself, take the steroids and do what I need to do.'

Sarah: Ok

Ina: Em, so I went off on a little bit of a tangent there

Sarah: No, that's fascinating! That's really good, yeah

Ina: Em,

Sarah: And then, thinking just in terms of your own experience

Ina: Mm
Sarah: As a daughter, you know

Ina: Mhm

Sarah: How has the COPD impacted on you, do you think?

Ina: Em, well, [pause] it's hard I suppose to kind of separate out, em, how it's impacted on me, eh, from how it's impacted on mum.

Ina: D'you know, like, of course, you know, if she's sick or struggling, or em, yeah, kind of having a hard time, then em, obviously, all my concern is for her.

Sarah: Yeah

Ina: Em, so, and like over time, it definitely would, I suppose kind of seeing mum learn to manage it

Sarah: Yes

Ina: Better and in a different way

Sarah: Mm

Ina: Like, how it's impacted me, I suppose like, it's always a worry.

Sarah: Mm

Ina: Em, and we've definitely all been on a kind of a - and I'm gonna have to use the word, I'm afraid! A journey!

Sarah: [laugh]

Ina: We've all been in a process of kind of, I suppose, first of all discovering what it is, and what it means exactly for mum's lifestyle

Sarah: Mm

Ina: Em, and, really just kind of squaring up to that and accepting it, I think,

Sarah: Mm

Ina: So, and I think mum has definitely come to a good place of understanding

Sarah: Mm

Ina: For me, along that, through that process, em, I'm relying really on her to give me the information about how she is, where she's at with it, you know, her own levels of acceptance, em, like I, I'd take my cues from mum

Sarah: Mm
Ina: First and foremost, having said that, over time, like there have certainly been situations where I kinda felt that I could see her struggling

Sarah: Mm

Ina: Before she was ready to kind of face up to it herself or admit it, maybe, to me. So that is kind of tied up in how involved mum is with my family and my kids.

Sarah: Yeah

Ina: So she's such an active granny, and she plays a huge role in helping me [loud noise in the background] childcare, and, em, she's a really big part of my kids' lives

Sarah: Mm

Ina: So, and that's been true for years, and over those years like we've put huge demands on her, like you know, there's a whole load of stuff we just couldn't do without gran-gran. Em, and that puts physical pressure on her and it puts also, I think, emotional pressure because I know that if she feels she's getting sick, I think she feels a bit of a burden then that, 'Oh if I can't, if I can't have the kids next Thursday, what's Ina going to do?'

Sarah: Mm

Ina: Em, so we've had to, and I think this is still ongoing, like, we've had to try to find a way where I can make mum feel, 'You need to be able to step out' like you know, you need to not feel that, you know, my entire child care and working set-up is dependent on you,

Sarah: Mm

Ina: being in the full-in the fullness of your health. Because she's always going to have [pause] times where her chest just won't allow her to, and also, you know, she's - not ancient by any means, but you know, she's just getting older

Sarah: Mm

Ina: And her energies need to be conserved for the other parts of her life

Sarah: Yeah, yeah

Ina: That we don't take over. So, em, that is something that's kind of been evolving over time

Sarah: Ok

Ina: And initially I think when, well certainly, when none of us really knew, I think, what was involved it was kind of, a lot of it was bound up I think in, em, stopping
smoking and struggling with that, and then having these awful chest infections repeatedly, and kind of the story of 'Oh well, I'll be fine after this one, that'll be the end of it.'

Sarah: Mm

Ina: Em, coming to the realisation that, no, this is chronic

Sarah: Mm

Ina: So this is going to be ongoing, we don't get rid of this, but we manage it

Sarah: Yeah

Ina: Em, that, that has kind of em, helped, me, to first of all kind of monitor her

Sarah: Mhm

Ina: Em, because she is inclined to just battle on, and

Sarah: Ok

Ina: Kind of ignore the signs, I think, and I can say that to her, like, you know, em, it's easier to say it when she's not in the room obviously, but I can certainly say it to her, like, 'Really? Really? Are you really going to wait until Monday morning to go to the doctor?'

[Ina's phone rings]

Ina: Or are you going to just accept that [breaks off to deal with ringing phone]

Ina: So sorry

Sarah: That's fine

Ina: No I think I've just answered it [pause] call ended. Em, so that

Sarah: You'd be able to say to her, you know, are you sure this is something you should be doing, or

Ina: Yeah

Sarah: Ok

[other phone rings]

Ina: I mean, and I feel like, I have felt guilty, and you know she knows this as well, em,

Ina: And I felt really guilty about feeling like I had to take a bit of a tough love approach, like kind of saying 'Are you mad?' Like, 'You can't do that, you just, with
the way you're feeling now, or I think you're breathless, I think you're panting.' Em, 'It sounds to me like that's heading towards'

Sarah: Mm

Ina: You know, so, em, I mean that's another thing that I'd have learned over time, and I'm not saying that I'm kind of, fool-proof with it, but, I've gotten better at kind of just being able to gauge

Sarah: right

Ina: When she's coughing if it kind of sounds like it's a little bit more than what she would usually do, or if it seems like it might be heading towards a

Sarah: An infection, or

Ina: Yeah

Sarah: Something, ok.

Ina: And then I think we've both got better at actually being able to talk about it

Sarah: Ok

Ina: So,

Sarah: Oh fantastic

Ina: Because in the past, like that I think she'd maybe have tried to suppress it, or there'd have been a little bit of denial, or she wouldn't want to let me down, but I think we're better now at kind of saying, 'Mmm is that, does that sound like it's going in the wrong direction?'

Sarah: Mm

Ina: 'Do you feel like you need to take action?' And she'd say, 'Ah leave it a day,' em, and then I'll get on her case the following day and say, 'Well did', you know, are you going, did you go, will I drive you over?' Em, and invariably she drives herself over, you know, but, so we're, yeah, we're kind of we've worked a little bit better with that. And then, em I suppose then kind of stepping back and giving her the space to do what she needs to do

[child interrupts]

Ina: Em, so yeah, and then, yeah, I suppose kind of helping mum to be ok with her limits and yeah maybe to kind of accept that there are things that she can't do

Sarah: Yeah
Ina: Em,
Sarah: And that's been a journey, as you say.
Ina: Definitely
Sarah: Ok
Ina: Yeah, it's definitely, and I think it's kind of, ongoing in some ways, because, like, em, I'm not always entirely sure, still, that she will fully reveal to me exactly how much she's struggling
Sarah: Oh right ok, yeah, yeah, yeah
Ina: So I'll know that she's on an antibiotic maybe, and I'll know that she's em, you know maybe caught, or particularly low, em, but like I say, it's kind of hard for me to imagine, like if, for example, she can't walk across the road to her sister's house
Sarah: Mm
Ina: I mean I think that's got to mean that you're pretty badly caught
Sarah: Mhm
Ina: You know?
Sarah: Mm
Ina: So I just wonder, em, I suppose what I don't know is where that's going,
Sarah: Mm
Ina: Like is that, em, is that a deterioration, already, is that something that, you know, should I be encouraging her, say, 'You've got to walk over to [interviewee's sister's] house, you can't be driving', you know,
Sarah: Mm
Ina: Or should I be pushing that, or em, yeah, so,
Sarah: Yeah, that's
Ina: I think that's ongoing
Sarah: Yeah, yeah, yeah and that would be, you know it's interesting now is that that would have been something I've come across in a few interviews that I've done
Ina: Ok
Sarah: That that is a constant learning process, adjusting, adjusting, adjusting
Ina: Mm
Sarah: And trying to find the balance, the sweet spot between pushing yourself too hard, and not pushing yourself enough and that's very, everybody is negotiating that. Everybody I've spoken to is trying to negotiate that.

Ina: And I've nothing to base it on.

Sarah: Yeah

Ina: D'you know, other than grilling mum herself about how she's feeling, what the doctor will have told her.

Sarah: Mm

Ina: And then it's just observation and I dunno, like, is a person, so sorry this is going to be horrible for your transcription.

Sarah: Oh listen, I'm an expert in transcription so don't you-don't worry at all.

Ina: Mouthful of biscuit! Like, is somebody of 68, so is somebody of 68 years of age with all of mum's em, statistics. Is it normal for them?

Sarah: Mm

Ina: To be performing to this level

Sarah: Mm

Ina: And having so and so many flare-ups a year, I mean I just, I have no clue

Sarah: Mm

Ina: So, tricky. And I wonder then, am I neglecting something? Like that because she's so autonomous, and in control of her stuff and em, like, apart from what's wrong, otherwise very lucky with her health. You know and very engaged and active and

Ina: and active and all that kind of thing. Very hands-on. I wonder sometimes, em, you know and if that's not today, or this year, how far along is it, that em, like will I know when the next step happens for example

Sarah: Mm, mm

Ina: Like you know, people that she goes to rehab with, have oxygen all the time

Sarah: Mm

Ina: Should-do I need to be looking out for that and kind of making sure that, she can't walk to her sister's, ever again. Could she be so badly stuck for oxygen that-is this something that we need to consider?
Sarah: Mm

Ina: And if so, how do I have the conversation, when do I ask about it?

Sarah: Mm

Ina: Like will I be way off the charts inappropriate if I do?

Sarah: Yeah, I know it's-yeah, yeah, it's kind of a bit of a morass, isn't it? Yeah

Ina: It's a total mystery, em, and I don't want to kind of leave her em, I don't want to leave her unsupported in that either, you know, so like I wonder if she's having a bad episode for example, and she's thinking 'Ssshhh, sugar, like, it's-em, it's really hard to breathe even with the least physical exertion.'

Sarah: Mhm

Ina: Em, I want her to be able to have that conversation with me

Sarah: Mm

Ina: And not feel like she has to protect me from that reality

Sarah: Yes, yeah, yeah.

Ina: Cos I think, I don't know if it's a mother-daughter thing, or certainly because she's always been the person to manage and look after everybody else, em, in my mind that might be a little bit, em, difficult for her to do

Sarah: Yeah, yeah

Ina: So on the other hand, I don't want to be in her face, kind of saying '[unclear]

Sarah: No

Ina: You know, blah-blah-blah, one thing I've noticed, I don't know if this is em, relevant, at all really, but my younger brother, is a physiotherapist. Now, and em, I find she talks to him in a certain way

Sarah: Oh!

Ina: about her

Sarah: That's interesting, yeah

Ina: She can kind of em, and she always finds him great, and he is great, em, you know to give advice and he kinda knows the anatomy of what she's talking about and that kind of thing. So, well he lives in England, so you know we don't, em, kind of have heart-to-hearts all that often, but, like maybe two years ago, last summer maybe, when he was home I was able to say to him 'Look,' like 'What's
your assessment?' Cos you see he wouldn't be here to see the day to day, but he'd have the chats with her on the phone and like that I think she might open up to him a little bit more

Sarah: Mm

Ina: On a purely kind of physiological basis

Sarah: Mm

Ina: Em, and it was he who said to me that like, well you know, if she is doing this a lot, like the pphh, pphh [query – is she doing pursed lip breathing?] that it, he was able to describe it physiologically, that you know she's trying to create a certain effect in the lungs which helps somehow

Sarah: Mm

Ina: Em, and I can't remember was it he who said to me that you know, he said mum could be kind of functioning on about 50% like you know, she could be down to one lung, and that was kind of what brought it home to me

Sarah: Ok

Ina: I thought, oh my god! Cos we'd never talked about it in those terms

Sarah: Mm

Ina: And I've never been at an appointment with her to, you know, and even if I was I wouldn't go over her head to a specialist to kind of say you know, tell me,

Sarah: Yeah

Ina: Em, so,

Sarah: So it's kind of a-eh you're operating, kinda, in a bit of a, black box thing, you're not-you don't have the information that would help you

Ina: Yeah

Sarah: To make an assessment, yeah, yeah

Ina: Yeah, kind of, feeling our way around it, and then because it is a little bit unpredictable, how she's going to be

Sarah: Mhm

Ina: You know, in, kind of, two or three-month blocks

Sarah: Mm
Ina: She's had times where it has just been constant, em and she was totally worn down and kind of, excuse me, a bit demoralised and defeated by the constant cycle of antibiotics, em, but then, she's also had phases where it's been much better than that, and, em, the gaps between antibiotics have increased and then I think she's been psychologically a bit better able to deal with, 'Ok, look, this is just another one, I know what I have to do, I take my steroids, and I take my antibiotics'

Sarah: Mm

Ina: Not going to go to rehab, or not gonna mind the kids, and

Sarah: Yeah

Ina: She knows what she has to do

Sarah: Yeah

Ina: Em, so, and, I think she, like in terms of her relationship, with us, you know there's the one brother in England, who I think she can have more of a medical discussion with, em, but who kind of comes in and out a little bit, and then I'm here always, obviously. Em, and then we've another brother who's in Sweden, who again she wouldn't have, you know,

Sarah: Yeah, yeah, yeah

Ina: [unclear] with, em, so I suppose, I kind of see it as well a little bit in the family context, too, you know, em,

Sarah: You're the one who's, you're the one who's kind of here, present

Ina: Exactly. Yeah. The day-to-day. Yeah

Ina: Yep. Em

Sarah: Ok

Ina: Em, so yeah, so like, in terms I suppose of how, I still don't think I've really kind of answered your question

Sarah: No you have, you have, but you know it's, no, no, you have, like, there's a lot going on and, yeah, you're kind of learning as you go along

Ina: Yeah, yeah, but I suppose like, I don't feel personally em, impacted, other than like it's mum who's impacted

Sarah: Mm
Ina: D'you know, and, em, and I think some of that might come from a little of her own tendency to buffer

Sarah: Mm

Ina: I think, I don't know, my brothers might see this totally differently, em, like I don't feel like a victim in any of this I suppose is what I'm trying to say

Sarah: No, no, no, yeah, yeah, absolutely, yeah

Ina: But certainly like, for the mechanics of our lives and the logistics of our lives and, you know, for how much she'd like to be involved with the grandkids and all of that, then yeah, absolutely like it has, it has, em, dictated and limited certain things. Probably sooner than would otherwise

Sarah: Yeah, yeah

Ina: For somebody her age, you know

Sarah: Yeah

Ina: Em, em, so yeah and I suppose the only other thing to say really is that, like, I think maybe there is a kind of an emerging, a slowly emerging awareness of the condition at all.

Sarah: Mm

Ina: And I think that does have an impact as well, that if you kind of feel that you're isolated and nobody else has what you have, and you have no community or no kind of fellow sufferers, em, that's not the nicest place to be. Whereas if now there is more research being done, and more supports in place, em,

Sarah: More awareness, I mean, I was em [pause], I-I got into this topic because I worked for years in health services for older people, researching. And em, obviously you're gonna look at chronic illness, if you're looking at ageing, the two tend to go hand-in-hand, and em, but COPD kept cropping up as this kind of em, over to one side, you know, and kind of, not really - it is researched but there are huge gaps in the research.

Ina: Mm, mm

Sarah: And em, the silence of the people with it, d'you know what I mean? Em, so the voice was always a clinical voice and not necessarily em, lived experience.

Ina: Yeah
Sarah: And eh, so, and when I was doing my smoking cessation course, the nurse, cos she knew what I was doing for my PhD and she showed me this HSE video, em, well it was a health board video, so it was that old, it was made in the 1990s. And it was hilarious as a piece of social history,

Ina: I can imagine!

Sarah: God! I didn't think it was that long ago! My God it was crazy

Ina: I know, the nineties

Sarah: And they were smoking in the office, and they were - you know - totally crazy, but they had the specialists on, you know, two consultants, and they spoke about heart disease and they spoke about lung cancer, they never mentioned COPD.

Ina: Mhm

Sarah: So em, hopefully things are shifting now

Ina: And how long is it in existence as a kind of a diagnostic term?

Sarah: Oh my goodness,

Ina: I wonder that as well, because I remember like sitting at the laptop with mum, after she'd had yet another chest-she was still smoking at the time. And kind of going 'Oh! Well,' you know, google, we're all, you know Google diagnosticians, em, so it comes up, you know, you click, and you kinda go, 'Oh hang on, listen to this, right, it means, if it's this, well that's you, if it's this, that's you too, this sounds like you,' and kind of going through the checklist going, 'This is a thing!'

Sarah: Mm

Ina: This is a thing, we hadn't heard of it, you know, the emphysema bronchitis all the

Sarah: Bronchiectasis and all that kind of thing, yeah

Ina: Em

Sarah: D'you know I'll have to have a look at that. I don't know how long the diagnostic term 'COPD' has been in existence. I mean, and it's so, it's so murky, because, the journey that a lot of people go on, is they will present to their GP, and they'll first be told they have bronchitis, and then they'll be told they have chronic bronchitis, and then they might say 'Well you have emphysema'

Ina: Mm
Sarah: And you know, only, it takes a long time before somebody says that this is COPD.

Ina: Mm

Sarah: Em, but I don't know about the evolution of the term. I'll have to have, d'you know that's a very good point. I'll have to have a look at that.

Ina: Like, similar, like as I was thinking about it, that was exactly, kind of, what I was going through my own checklist that I, you know, I always knew what bronchitis was, my brother had it as a baby, you know I remember people talking about people having emphysema, all distinct individual, issues we'll say.

Sarah: Putting it all together [loud noise] [unclear]

Ina: It wasn't until we were doing that, our Dr Google

Sarah: Yeah, yeah, yeah

Ina: I had any awareness at all, em,

[Helen is on the phone talking in the background]

Sarah: I'll have to do a bit of digging around, it's been around for a while

Ina: Yeah

Sarah: But it's - it's used differently in different countries, I mean, even trying to estimate the global prevalence is very difficult

Ina: Of course, yeah

Sarah: Em but it looks like, the latest estimate for Ireland is 440,000 people

Ina: Ok! Wow!

Sarah: With COPD. Of which, 200,000 don't know that they have it.

Ina: Yep, but I believe that, actually, I believe that people don't know they have it, because even like you know if you say to somebody, 'Oh my god, he's got lung cancer' or 'he's got, eh-it was heart disease' or something, people have an association, I think if even like in the general popular mind

Sarah: Yeah, yeah

Ina: You kind of know what to do, with a lot of categories of illness.

Sarah: Yeah
Ina: Whereas, you know, if I'm explaining to, you know, friends or whatever, like, you know that mum's having another flare-up of her COPD, you have to explain what it is

Sarah: Mm

Ina: Still, so, em, it totally matches my experience with it, of finding out what it was, and kind of then figuring out that it's applicable in mum's case, to then realising that it doesn't really have a foothold in people's consciousness. So you won't get health programmes, I suppose, or campaigns, or fundraising, for the same that you would on, what is it, national kidney day or [unclear]

Sarah: Yeah, yeah, yeah

Ina: Em, having said that, she is so delighted with her rehab people, and the nurses

Sarah: I know, she was saying, yeah

Ina: She loves them and she's em, very lucky in that regard. And she's got, you know, huge respect for her consultants and all that kind of thing, so, em,

Sarah: It's great. It's great.

Ina: Yep

Sarah: Well listen, I think that's everything from my end of things, thanks a million for chatting to me. It was really, really useful, yeah, really useful

Ina: And the best of luck with, em,
Appendix 16: Example of field notes

Helen’s interviews

Setting

The first interview took place in the kitchen/dining area of the participant’s home. The home was situated in a suburban area of a city, with a park and a lake nearby, where the participant said she went for walks when she felt up to it. The area seemed well-settled and comfortable. The kitchen/dining area was homely. I felt very comfortable. We sat on either side of a table in the space. There were photos of family around the area. The participant was alone during this interview. Her husband had died a good while ago.

The second interview took place in the sunroom of the participant’s home. This was a bright room with large windows facing out to the back garden. It was a nice day in the late summer.

The third interview took place in the kitchen/dining area of the participant’s home.

Participants

In the first interview, the participant was neatly but casually dressed. She seemed slightly anxious about the interview. It was obvious that she had read the information carefully and thoroughly, and wanted clarification about the purpose of the study, especially about the role of ‘power’ in the research. I provided clarification, while emphasising that the participant should feel free to tell her story in any way she saw fit. She struck me as a determined woman, who had survived bereavement and was determined to live as well as possible with COPD. She seemed to be a very reflective and thoughtful person.

In the second interview, the participant seemed more settled than in the first interview. I had sent her the transcript of the first interview, and she had read this carefully and had thought deeply about it. She had also asked me to interview her daughter after the first interview, so this second interview was split between the participant and her daughter. I had emailed an information sheet to the daughter prior to this interview and obtained informed consent before interviewing her. The participant and her daughter and grandchildren appeared to have a very close relationship.

In the third interview, the participant was in good form and open and willing to talk. By this time we had developed a good rapport and this was evident in her body
Interview

The first interview didn’t explore self-management in-depth. However, some pertinent issues arose. When I asked her to tell her story in terms of COPD, she started with a short story about her diagnosis with COPD in 2009 and how things developed from then. Interestingly she talked about feeling guilty about getting COPD because she had been a smoker. So, she felt responsible in some way for getting COPD. She talked about the progression of her COPD and her repeated attempts to give up smoking.

At this point, however, she segued into talking about the death of her husband in 2002 as a defining point in her life. She described live coming to a kind of a halt for her when her husband died: her existence being ‘truncated’. This seemed to be a defining moment, more important a trauma than the diagnosis of COPD. She talked about the birth of her grandchild years later as the impetus, the motivator, the trigger, to pick up the traces of life again and move forward. Why did she talk about this at this early point in the interview? What is the relationship between the death of her husband, the birth of her grandson, in the context of diagnosis of COPD and smoking? Well, it seems that the birth of her grandchildren provided the motivation for her to finally give up smoking and start engaging in self-management/self-care. Giving up smoking was difficult, a real struggle for her, and so it loomed large in her talk. It was a story of struggle, failure, and ultimate success.

Being diagnosed with COPD was a gradual process, as she continued to smoke and they introduced inhalers and medication bit by bit, gradually. But eventually a point came when she had to accept having COPD and this came with a psychological cost, because she did not want to be defined by COPD. This was very important for her. She struggled to accept that she had COPD and to separate the condition from the self. She engaged in a power struggle – her ‘self’ and her identity versus the constraints and defining power of COPD. She felt quite alone for a while, and alone in needing medication. For example, finding out that friends of hers were also on medication gave her a sense of relief and an ability to talk about how she felt about having COPD.

She didn’t really talk about whether and how she has come to accept having COPD, but she moved on to talk about and praise pulmonary rehabilitation.
Pulmonary rehabilitation loomed large in her talk about living with COPD, how useful it was, the education and information sessions and the exercises. She described this as empowering. Attending pulmonary rehabilitation seemed to have changed her mindset – shifting to accepting that she is older, has a chronic illness, and is entitled to help and support – from pulmonary rehabilitation, from patient support groups, and from the State. This she felt was an expression of power, ‘taking the power into your own hands and managing stuff’. She also used the example of feeling free and able to use ‘airport assist’ when flying. Like other participants, she emphasised the importance of the local COPD support group. She felt it helped overcome this feeling of being defined by COPD, and reduced her isolation. She took inspiration from the other members of the group who were pushing on with their lives despite their COPD. This gave her a sense of perspective interacting with other people whose COPD might be more severe than her own. This was very important to her. She had formed a friendship with another woman who was a member of the group and they motivated each other to keep attending the group. She described the local COPD support group as a little community. Regarding self-management, it was difficult to put my finger on what she was saying about self-management. She talked a little about routine, medication, etc. She also briefly touched on the need for her to pace herself, plan out activities and rest periods, recognising that if she pushes one day, she may need to rest the second day. One important thing was her acceptance of using a medication dispenser box – she had resisted using this because it was linked in her mind to ageing, older people, dependence. But once she accepted this, she felt it was beneficial. Acceptance seems to be a large aspect of this interview. Also she accepted someone to come into the house to help with heavy housework. But we come back to the social as the most important factors in her experience of living with COPD. The following interviews might reveal more about self-management as she had time to think about her story.

The second interview was really interesting, because the participant had read the transcript of the first interview and had experienced new insights into herself and her coping style as a result. This is a good example of how participating in the research affects and changes the participant’s point of view. The participant felt that the first interview reflected her tendency to err on the optimistic side, to tell people, including me, that she is grand, when in fact she may be struggling more than she admits. She calls this a habit, this optimism and eliding of the negative. This habit of glossing over the negative she describes as a habit she has in many
of her interactions with others, and even with herself, she denies to herself the limitations imposed by COPD. Interestingly, she feels able to be more honest about how she is managing when she is with her COPD support group because others are going through the same thing. This denial of the limitations she links with resistance, with fighting the illness, ‘refusal to capitulate’, refusal to give in.

She also spoke more directly about her relationship with health professionals, describing herself as largely compliant with health professionals, trusting them, and taking them at their word. But as the interview progressed there was some evidence that this is not necessarily total compliance – her GP had given her a prescription for steroids but asked her not to use them unless absolutely necessary. But she felt that there was pressure on her not to take them, that ‘they’ (health care professionals) disapprove of her taking them. However, she felt a need to take them perhaps more frequently than health care professionals. She based this on her experience of the body in breathlessness. So there was tension between her self-management decision to take steroids and the perceived attitude of health care professionals about when and how often to take steroids.

The participant spoke about the challenges in finding the balance between exercising and pushing the body, and resting and pacing activities. She found this difficult, and so did her daughter when I spoke to her. There was a lot of uncertainty about when to push and when to relax and pace. Pushing, pacing, balance, finding equilibrium – she described this as learning to have patience with oneself and learning to accept the limits constraints of COPD, while finding room for activities within those limits. What is interesting is that self-management was not spoken about in terms of concrete and discrete actions or tasks, but as an all-encompassing attitude to life – staying active, fighting for normality, taking medication, pushing and pacing, based on experience of living with COPD and the body over time.

She briefly mentioned the shame involved in having inflicted COPD upon herself. Importantly, she links this with ‘costing the State’ because she has a medical card and therefore her healthcare is subsidised by the HSE. Is this an expression of guilt linked to responsibilisation and neoliberalist concerns?

Overall the participant had a sense of independence and autonomy that she felt is compromised by COPD. In reaction to this she talked a lot about fighting – fighting the illness and the limits it places upon her, fighting the realities of life with COPD, fighting for independence and normality. But she also talked about balance and
acceptance of the illness and how she had to find a balance between fighting and acceptance. She linked this to her experience of her mother who she felt had COPD and had 'given in' to depression and inactivity.

I then interviewed the participant’s daughter in this interview. She talked about the participant’s proactivity in managing her life and her condition. She echoed the participant’s praise of the COPD support group and pulmonary rehab. She felt this was important as she cannot really understand the participant’s experience of living with COPD. The daughter said she had noticed that participant’s approach to self-management had changed over time, from an early style of compliance with health care professionals to a more recent style of knowing when she needs to take medication herself, not necessarily in line with the recommendations of health care professionals. The daughter referred to the fact that participant has more confidence in herself to know what to do and when if she is not feeling well. She also echoed the participant’s self-assessment of not revealing when she is struggling, of over-emphasising the ‘I'm grand’ side of things. She talked about her own lack of knowledge of COPD and how that made it hard for her to know how far to place demands upon her mother as an active grandmother. She expressed some frustration and not knowing enough about how COPD was impacting on her mother, how far to encourage her to stay active versus encouraging her to relax and take it easy. Interestingly, the daughter talked about monitoring her mother, about taking a ‘tough love’ approach, about telling her mother when she should go to the doctor, gauging when her mother is really unwell. But she felt that this had moved from a point earlier on in the illness when her mother might have denied the severity of her symptoms to a point where mother and daughter collaborate more together on deciding whether and when to go to the doctor or to take medication. She wanted to support her mother to be ok with her limits. But even still she is sometimes unsure whether her mother always reveals the extent to which she is struggling.

This third interview was the shortest but perhaps the most important of the three. In this interview the participant talked in the most detail about self-management of COPD. It is as though the three interviews have followed a narrative path through the upset and confusion surrounding her initial diagnosis and coming to terms with having COPD, through a period of learning and acquiring experiential knowledge, to a place of acceptance and agency/knowledge regarding self-management. Interestingly, the participant also said that she felt that her doctor has come to trust her in her self-management over time. In the second interview she described the
taking of steroids as being a point of conflict with her doctor, but now her GP is more trusting of her use of steroids. Participant felt that her doctor now believes her when she says she takes them when necessary, and trusts her judgement about whether when to take medication for an exacerbation.

Acceptance and coming to terms with living with COPD was key to the participant’s self-management. Across the interviews she talked about this, for example, her decision to use a medication dispenser was a big leap for her, because she associated it with age and dependence, but she had come to terms with it and had decided to use it because the array of medications she had to take required a lot of time consuming organisation that could be saved by using a dispenser. This is part of her self-management journey. Accepting the impact of her COPD had worked paradoxically to liberate her to self-manage more proactively. I took a photo of the medication dispenser because it was an important symbolic object that represented the liberation of acceptance.

Another process she described was her coming to ‘trust’ herself. This is very important. Over time, she talked about coming to know herself and her body and signs of exacerbation. For example, she had learned to tell the difference between upper respiratory symptoms that are relatively benign, versus a deep-seated chest infection. She also described being more confident in finding the balance between activity and rest, between pushing and pacing. She went through her self-management routine, again this was a broad conceptualisation of self-management which was stitched into and woven around everyday life. Medication, shopping, exercises, walking, local support group, Slimming World and diet. Keeping life full and active within limits. The support group was an integral part of her self-management, for the exercises but more for the social connection with others who shared her experience.

**Critical reflection and reflexivity**

The first interview didn’t manage to explore self-management in depth. I felt that we were skirting around the issue, or staying superficial about certain things, although I couldn’t put my finger on precisely what was preventing a more in-depth discussion. The participant seemed a little wary and uncertain, and wanted clarification at the beginning of the interview as to the role of ‘power’ in the research question. She seemed anxious to ‘get it right’, to do the interview ‘correctly’. While I felt we developed a rapport, it wasn’t as open an interview as I had had with others. I was slightly on edge during this interview. I tried to develop rapport by
disclosing my own experience of giving up smoking because this was obviously of importance to the participant and I wanted to let her know she was not alone in her experience of quitting smoking. But there was a distance about the participant that I couldn’t bridge. I think she had carefully prepared for the interview. It was not as spontaneous and free as others. I try to support the conversation by frequent expressive sounds, words and phrases to show the participant that I’m listening and engaged and interested. I tried to show ‘unconditional positive regard’ to support the participant in telling her story to me.

In the second interview, I felt that the participant opened up a lot more. What was interesting was the effect that reading the transcript of the first interview had had on the participant. She developed deeper insight into her coping style and her default habit of talking about living with COPD with optimism and positivity. This time, she felt more able to discuss the challenging aspects of living with and managing COPD. Her disarming honesty and forthrightness touched me and I felt we went deeper into her story during this interview. I felt that our rapport was stronger than in the first interview and this meant that I stepped back more in this interview and let her tell her story with less intervention from me. I was also fascinated by the experience of interviewing both the participant and her daughter separately in this interview. This forced me to negotiate my relationship with the participant and her daughter. In my mind, I was aligned with the participant and so tried to stay as neutral as possible with the daughter. I wanted to balance developing a rapport with the daughter against my obligation to respect the participant as my key informant. I didn’t want to betray her trust. I feel that I managed to achieve a satisfactory balance between these two interviewees. This task was made easier by the love and trust that obviously existed between mother and daughter.

The third and final interview was the strongest in terms of the rapport built between the participant and me. She seemed to have turned a corner in her self-management and her experience of living with COPD. The key message I am taking away from this interview is ‘acceptance’ or ‘coming to terms’ with having COPD which led to her feeling free and liberated in her ability to make self-management decisions. Anyway, in this final interview I specifically asked her to talk to me about her everyday self-management, and it was in this interview that she began to speak specifically about self-management. I feel that the three interviews have been an occasion of reflection for her, which may well have impacted not only on her views and thoughts about self-management, but her self-
management practice. I asked her to take me through a typical day in terms of self-management, but actually she talks partly about her daily routine, and partly about overarching self-management concerns. I also asked about managing medications, which reveals my tendency to think in medicocentric terms myself about self-management, rather than leaving it up to the participant to decide what self-management consists of herself. But this question yielded valuable insights into the symbolic role that using a medication dispenser played for this participant’s conceptualisation of her sense of self and identity. So it was worth probing this area with her. As with the other interviews, I use lots of expressive language and supportive words to encourage her to keep talking to me and to let her know that I am listening and interested in what she has to say.
Appendix 17: Example of initial coding of raw data

Example of coding raw data to Power sub-code: Responsibilisation

Excerpt from Aidan interview 1
Reference 3 - 7.66% Coverage

Aidan: The thing is with him, Sarah, is he doesn’t [pause] he doesn’t want to accept what he has

Sarah: Augh, yeah, ok, yeah

Aidan: He was in [local town] there now, and he was bad, em, with the breathing problems, and I said to him there, I said. Oh yeah, he knew nothing about having the portable oxygen, the one you pull behind you, you know. They were giving me, you know these small bottles you put up on your back.

Sarah: Mm

Aidan: But they only last 4 hours, whereas this thing, it keeps you going, you can bring it in the car, plug it into the cigarette machine, in the car and it works.
And he knew nothing about that, so he got one of them. So then I said to him one day, he got, so above when we were doing exercises, he got bad. Breathing got bad and I says to him. I says, eh, ‘Have you the oxygen?’ ‘No,’ he said. ‘Well I’ve mine in the car, do you want to use it?’ And he said ‘No, no.’ He won’t put the oxygen into the car. Now mine’s in the car 24-mine never comes out of the car. It’s behind my seat the whole time. No matter where I go, it’s there. If I’m going for a walk, I take it, I come back, I put it back into the car. It’s never in here. And, he won’t bring it in the car. And he was above in [local town], eh, 3 weeks ago […] we had a coffee morning, and he got bad, now when he got bad, his lips went blue. He had no oxygen.

S: No oxygen.

Code: Power/Responsibilisation
Example of coding raw data to Agency sub-code: Practices of self and care of the self

Excerpt from Declan interview 1

Reference 5 – 1.46% Coverage
Declan: D'you know what I also started doing, eh, Sarah, was eh, art classes.
Sarah: Oh yeah! Lovely!
Declan: And I've I bought a lot of the gear and I do a share of that, especially in the winter time. When you can't be out, and 2-3 hours go so quickly
Sarah: That must be lovely, actually.
Declan: And, I dunno, it's therapeutic, your breathing,
Sarah: yeah, and it's bringing all your attention into that
Declan: Into that, and there's a feel-good factor when you're finished
Sarah: Yeah, it's like-
Declan: do some nice ones, but again, you're relaxed. Your breathing becomes relaxed, everything becomes relaxed
Sarah: It's almost like a kind of mindfulness, isn't it?
Declan: It is, very much so, and it, now I went to various mindfulness programmes, and I've my book there and I often go through it. D'you know again to keep the maintenance side of things, it's like the COPD, maintenance is a huge part of it

Reference 6 - 2.30% Coverage
Declan: Well I suppose tis different, different grades of it, I mean I [...] my GP even said it to me there, a couple of weeks ago, he said 'you know a few years back I'd have been saying to you, 'I wouldn't say much about life expectancy' but he said 'I can't believe'
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### Conceptualisations of Self-Management

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### Appendix 18: Initial coding template continued

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Appendix 18: Initial coding template continued

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Appendix 18: Initial coding template continued
Appendix 19: Example of NVivo coding of raw data according to final template:

Extract from Helen interview 3 (interview text and NVivo coding stripes)
Extract from Eoin interview 3 (interview text and NVivo coding stripes)
Appendix 20: Approval letter from School of Nursing and Midwifery Research Ethics Committee

Sarah Delaney  
School of Nursing and Midwifery  
Trinity College Dublin  

23rd June 2016

Study title:  
Every day decision-making in the self-management of COPD

Dear Sarah,

I am pleased to inform you that your study has been granted ethical approval from the School of Nursing and Midwifery Research Ethics Committee. You can now proceed with your study.

Yours sincerely,

Chair of School of Nursing and Midwifery Research Ethics Committee
Appendix 21: Approval of amendments to ethics application

Amendment 1: 19th September 2016

Chair, School of Nursing and Midwifery Research Ethics Committee

School of Nursing and Midwifery

Trinity College Dublin

RE: Every day decision-making in the self-management of COPD

19th September 2016

Dear [redacted]

I am writing with regard to the PhD study entitled ‘Every day decision making in the self-management of COPD’. This study was granted ethical approval on the 23rd of June 2016.

I am requesting permission to make two amendments to the study:

1. I would like to carry out interviews with the main carers/family members of the individuals with COPD, if available. Permission will be sought from the participants with COPD before approaching main carers/family members. The relevant cover letters, participant information leaflets, and consent forms have been amended accordingly and are attached to this letter.

2. In Appendix 1: Pro-forma patient characteristics; I would like to change from using the MRC Breathless Scale to the COPD Assessment Test (CAT). The CAT is sent as a separate pdf file attached to my cover email.

I would be very grateful if you could let me know whether these changes are acceptable

Yours sincerely

Sarah Delaney
Amendments to ethics application - Everyday decision making in the self management of COPD

Hi Sarah,

Apologies for the delay in responding to you.

You request for approval to these amendments has been granted by the deputy Chair of the SNMREC.

Kind regards,

From: Delaney Sarah
Sent: 20 September 2016 12:23
To: sometoc
Subject: Amendments to ethics application - Everyday decision making in the self management of COPD

Dear Sir/Madam

[Quoted text hidden]
Amendment 2: 4th January 2017

Chair, School of Nursing and Midwifery Research Ethics Committee
School of Nursing and Midwifery
Trinity College Dublin

RE: Every day decision-making in the self-management of COPD

4th January 2017

Dear [redacted]

I am writing with regard to the PhD study entitled ‘Every day decision making in the self-management of COPD’. This study was granted ethical approval on the 23rd of June 2016.

I am requesting permission to make one amendment to the study: I would like to adapt the recruitment strategy to include recruitment via Integrated Care Nurses working with people with COPD. Integrated Care Nurses are Clinical Nurse Specialists working with patients with respiratory health needs. It is proposed that the Executive Director of COPD Support Ireland will make initial contact with Respiratory Integrated Care Nurses to provide initial information about the study and request their permission to distribute information packs to patients with COPD in their caseload. Once permission has been obtained, the Executive Director of COPD Support Ireland will provide recruitment packs to the Integrated Care Nurses for distribution to patients. Integrated Care Nurses have a care relationship with their patients. It is emphasised in the letter to Integrated Care Nurses that patient participation in the study is entirely confidential and voluntary. Integrated Care Nurses will not know whether an individual has decided to take part or not.

The cover letter to Integrated Care Nurses, and the amended cover letter to the Executive Director of COPD Support Ireland, is attached to this letter. I also attach the amended recruitment strategy as specified on the SNMREC application form.
I would be very grateful if you could let me know whether this change is acceptable

Yours sincerely

Sarah Delaney
Amendment 3: 18th April 2017

Chair, School of Nursing and Midwifery Research Ethics Committee
School of Nursing and Midwifery
Trinity College Dublin

RE: Every day decision-making in the self-management of COPD

18th April 2017

Dear Sir/Madam

I am writing with regard to the PhD study entitled ‘Every day decision making in the self-management of COPD’. This study was granted ethical approval on the 23rd of June 2016.

I am requesting permission to make one amendment to the study, to allow me to take photographs of the artefacts and accessories that participants with COPD bring to show me during interviews. These photographs would be driven by the participants actively bringing me artefacts of living with and managing COPD. Images form an important part of narrative research and can powerfully illustrate narratives of chronic illness.

Participants will be asked permission before any photographs are taken. Any information that could identify participants will be excluded from the photographs. Photographs will be taken using a dedicated digital camera and stored in an encrypted folder on a password-protected computer.

Information sheets and consent forms will be adapted to reflect this change and participants who have already agreed to take part will be alerted to the possibility of taking photographs.

I would be very grateful if you could let me know whether this change is acceptable

Yours sincerely

Sarah Delaney
Dear Sarah,

Your request for an amendment has been noted and approved.

Can you please email me a copy of the adapted PIL, letter to participants and consent form when the changes are made (for our own records).

Kind regards,