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Quality of life and anti-dementia drugs

An exploration of the experiences of people living with dementia and their care-partners

By

Ana M. Diaz-Ponce

A Thesis submitted to the
School of Social Work and Social Policy
Trinity College Dublin
in fulfilment of the requirement of the
Degree of Doctor of Philosophy

April 2014
DECLARATION

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Ana M. Diaz-Ponce

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SUMMARY

Dementia is a chronic, progressive, incurable disease that has a major impact on the quality of life of people diagnosed and their families. Some anti-dementia medications exist (cholinesterase inhibitors and memantine) that can alleviate the symptoms of the disease, nevertheless the efficacy and value of these drugs remains highly controversial. A key unresolved debate in the research literature relates to the clinical significance of the benefits reported in clinical trials, and most importantly whether such improvements represent meaningful changes to the quality of life of people living with dementia (PLWD). Despite much research being undertaken on this topic, the views, expectations and experiences of the consumers of these drugs have been rarely sought. When their views have been considered, there has been a tendency to rely on scales and on proxy informants and to evaluate a range of outcomes pre-defined by the researchers. To address this gap in the literature, this thesis adopts a qualitative approach to explore the ways in which PLWD and their care-partners (CPs), think and talk about their quality of life, their expectations and experiences with anti-dementia medication and the impact that the drugs have on their quality of life. In addition, this thesis explores the usefulness of taking a social constructionist lens, in comparison to the more conventional use of quantitative scales, to investigate quality of life and medication issues.

METHODOLOGY

A total of 14 PLWD and 14 CPs participated in the study. Participants were interviewed at the time they were diagnosed and prescribed the anti-dementia drug and six months later. All participants were community dwelling; had mild or moderate stage dementia and were recruited from the same memory clinic situated in Ireland. Data were collected through in-depth interviews and using a dementia-specific quality of life scale (QoL-AD).

FINDINGS

Quality of life and dementia

The quality of life domains identified in this study are similar to the domains reported in previous international studies. These included: family and friends, keeping busy, being independent, feeling well in oneself, and remaining healthy. Participants' understandings and evaluations of their current quality of life were mediated by (1) biographical preferences and current expectations of what was normal and acceptable at this stage of their lives for each domain; (2) how the person with dementia was perceived and treated by others; and (3) their understandings and images of dementia. These three factors seemed more relevant to the participants' understandings and evaluations of quality of
life than the experienced dementia symptoms. Comparison of findings using the QoL-AD and the qualitative data showed the usefulness of both approaches. Nevertheless, the normative approach failed to shed light on the complexities, tensions and ambivalences found in the private voices of the participants.

*Lived experience of using anti-dementia drugs and quality of life*

Findings showed the tensions arising between the participants' perceptions of their current good lives and their fears of future deterioration. Drug treatment represented some hope for stopping the progression of dementia and holding onto their current lives. When participants were first prescribed the drug, most were uncertain about how the drugs could benefit them; their main concern related to potential adverse effects. After six months, more than half of the dyads reported benefits and believed the drug had helped them to experience a greater sense of normality and continuity with their former identities and lives. Participants with dementia were able to give very concrete examples of how in their view the drugs had benefited them. Examples of such benefits rarely concurred with more normative indicators of drug efficacy. Participants' evaluations of drug benefits and of their impact on their quality of life were extremely complex and often dominated by feelings of uncertainty and hope. Most participants who did not experience benefits continued to take the drug treatment. The participants' understandings and subjective evaluations of quality of life at follow-up seemed to be also influenced by their adjustment to the diagnosis and to deficits experienced. In cases where further deterioration due to dementia had occurred, the QoL-AD failed to detect this relevant aspect of quality of life in dementia.

**CONCLUSIONS AND IMPLICATIONS**

In evaluating the efficacy of any intervention in dementia care, this thesis argues that the subjective understandings and evaluations of PLWD and their CPs should be taken into account. An important implication arising from this thesis concerns how to involve PLWD in a meaningful way in the decision-making and evaluation of these drugs. Individualised services and methodologies should be put in place to facilitate this involvement. Other implications arising from the thesis relate to the use of more creative approaches in research that integrate both, quantitative and qualitative approaches in order to capture a more in-depth understanding of the lives and experiences of PLWD. In the light of findings emerging from this thesis some recommendations are also made on ways by which the QoL-AD might, in the future, be further strengthened.
ACKNOWLEDGEMENTS

I would like to first of all, thank my supervisor, Dr. Suzanne Cahill for her guidance, support and intellectual stimulation throughout the way of completing this thesis. I have been extremely lucky to have a supervisor who cared so much about my work and my person, and who has been always keen to help and to spend time to discuss with me every concern. Her expertise, motivation and passion about dementia research have been an inspiration.

I would also like to thank each of the individual people who very generously accepted the invitation to participate in this study. I am very grateful that they willingly shared their time, experiences, opinions and concerns with me. Without them this thesis would not have been possible. I sincerely thank the Director of the MIRA Memory clinic, Professor Lawlor, for giving access to the sample; and the staff in the memory clinic who assisted me with the recruitment, in particular the Senior Medical Social Worker, Matthew Gibbs. Thank you also Dr. Robert Coen and Irene Bruce for you valuable words at the beginning of this thesis. I would like to extent my gratitude to the staff in the DSIDC who have supported me in many different ways in this journey.

I would also like to express my sincere appreciation to Professor Virpi Timonen who several years ago believed in me and encouraged me to get involved in research.

I thank my colleagues and fellow students in the LiD and SPARC for their encouragement and friendship. Their dear, support and advice have been invaluable. Special thanks go to Dr. Maria Pierce for her help, understanding and for taking me through the complexities and nuances of social constructionism. She is a very generous person and a wonderful researcher. Heartfelt thanks to Dr. Marita O’Brien, who has supported, encouraged and cheered me up when most needed. She read many chapters of this thesis and always gave useful and timely feedback. She is a great professional and a marvelous and caring friend. Her hospitality has made my trips to Dublin unforgettable. I sincerely thank Dr. Martha Doyle, Dr. Sarah Donnelly and Janet Convery who at different points in time made extremely valuable and constructive suggestions. Thanks are also due to Caroline Forsyth, Vanessa Moore and Colette Garry for their help with the administrative work at TCD and for always being so resourceful. Finally thanks to my colleagues Dr. Emer Begley, Dr. Claire O’Regan, Treena Parsons, Andrea Bobersky, Dr. Ciara O’Dwyer, Dr. Edurne Garcia and Minerva Rivas, for their wonderful friendships.
They have made working from Luxembourg less lonely, and feeling each time I was in Dublin, as being back home. I feel extremely lucky to have worked with such inspirational people.

I gratefully acknowledge the financial support for my research of The Atlantic Philanthropies.

I would like to conclude these acknowledgements by thanking my wonderful family, my husband Manuel for his endless love, companionship and support these years, and my two little Princes, Manolo aged 5, and Pablo, 4. I have found in their charming smiles and unconditional love the greatest motivation to complete this thesis to the best of my abilities.
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CHAPTER ONE: INTRODUCTION AND BACKGROUND

1.1 INTRODUCTION

Dementia is a chronic, progressive, long lasting syndrome which has a profound impact on individuals, families and societies (Wimo et al., 2011). Since the 90's cholinesterase inhibitors and memantine (heretofore referred to as anti-dementia drugs) have become the mainstay of pharmacological treatment of Alzheimer's disease, the most common dementia sub-type (O'Shea, 2007). Despite only modest improvements being reported in randomized controlled trials (O'Brien and Burns, 2010), many people diagnosed with Alzheimer's disease are prescribed one of these drugs in the hope that the drug will, at least in the short term, address some of their cognitive deficits.

The cost-effectiveness of the anti-dementia drugs and their significance from the perspective of people with dementia and caregivers remains a controversial subject (Post, 2001; Farlow, Miller and Pejovic, 2008; O'Brien and Burns, 2010; Smith et al., 2011). It is argued that research into the efficacy of these drugs has been largely “governed by the requirements of statutory authorities” rather than aiming to capture the full impact of the drugs on the day-to-day lives of its users (Traynor and Dewing, 2002:4). Outcome areas have mainly been decided, designed and measured by professionals leaving little opportunity for people living with dementia and their families to voice opinions about the outcomes that are meaningful and relevant to them. Indeed, despite great efforts to evaluate the efficacy of these drugs, there is a dearth of research looking at what people with dementia and caregivers most value about these treatments and about their personal experiences of taking anti-dementia medication (Howard and Rockwood, 1995; Traynor and Dewing, 2002; Traynor, Pritchard and Dewin, 2004).

In the absence of better treatments, quality of life has become an overarching principle of care and there is increasing interest in understanding how both, pharmacological and psychosocial interventions, may impact on the quality of life of the people using these drugs (Cooper et al., 2012 and 2013; Woods et al., 2012). It is suggested that any
intervention should promote the quality of life of people living with dementia and that quality of life outcomes may help to ensure that an intervention does not leave "the person feeling less positively about themselves" (Woods et al., 2006:220).

It is not surprising therefore, that research about quality of life in dementia has flourished in recent decades (Droes et al., 2006). A number of quality of life scales have been validated and are now regularly used to evaluate the quality of life of people with dementia (Ettema et al., 2005; Traynor, Pritchard and Dewin, 2004; Schölzel-Dorenbos et al., 2007). Quality of life research using these scales has produced valid and relevant findings. Most notably it has provided relevant information about factors that might predict or determine quality of life in dementia (Woods, 2012). Nevertheless, most of these scales are reductionist, in that they attempt to explain extremely complex phenomena in simple terms so much so that findings can become dissociated from the phenomena. The assumptions that many of these scales make about quality of life for individuals living with dementia, contrast with the growing body of literature about the heterogeneity of experiences of living with dementia. In particular, scales fail to give recognition to the importance of different life courses and personal biographies and the relationship these have with an individual's experience of dementia (Bond and Corner, 2006). There is little cross fertilization of ideas between the quantitative and qualitative approaches, and as far as I am aware, little attempt to compare and contrast the strengths and weaknesses of the two approaches and use identifiable divergences to advance the debate further on quality of life in dementia.

This thesis attempts to address these lacunae in the literature by adopting a social constructionist approach to explore the manner in which older people who have recently been diagnosed with dementia and prescribed a drug to treat it, think and talk about the quality of their lives, their expectations and experiences with anti-dementia drugs and the impact that these drugs have on their quality of life. In addition, this thesis explores the usefulness of taking a social constructionist lens to examine and understand quality of life in comparison with the more traditional quantitative approach. To this end, along with the social constructionist qualitative inquiry adopted in the study, a quality of life scale (the QoL-AD) is used and findings derived from each approach will be juxtaposed and critically discussed in the thesis.

1 Alzheimer's disease or mixed dementia.
2 Further information about dementia specific quality of life scales, the selection of this particular scale, and the rationale behind the approach taken in this thesis are provided in chapter two and four of this thesis.
The specific research questions that this thesis attempts to address are:

- How do, people recently diagnosed with dementia and their care-partners, think and talk about the quality of life of the person living with dementia?
- What understandings and meanings do these people attach to the quality of life of the person living with dementia?
- What challenge, if any, does having dementia pose to their understandings of quality of life?
- What are their understandings and expectations of using a drug to treat dementia? How do participants expect the drugs will affect their quality of life?
- What are their experiences of using these drugs? How do participants talk about the benefits of the drugs?
- How, in their view, does taking a drug to treat dementia affect quality of life?
- Is there any difference in quality of life appraisal over time between those who believe the drug works and those who were of the view it failed?
- How do data collected using a normative and a micro social constructionist approach differ?
- What are the main strengths and the limitations of using each approach?

Before moving on to critically reviewing the specific literature on quality of life and anti-dementia medication (explored in chapters two and three) this introductory chapter provides further relevant background information on the study. In the section to follow, the main ways in which dementia has been conceptualized in the scholarly literature are reviewed (dementia frameworks). Following this, the principles underpinning social constructionism and the particular approach taken in the current study are introduced.

1.2 OVERVIEW OF DEMENTIA FRAMEWORKS

This section outlines some of the most relevant perspectives on dementia in the academic literature and the ongoing shift away from an understanding of dementia as being exclusively a medical condition. This is important as different approaches to understanding dementia lead to different ways of looking at quality of life and medication use (Bond, 1999; Downs, Small, and Froggatt, 2006).
1.2.1 The bio-medical understanding of dementia

Most of our knowledge about dementia comes from how the illness is understood medically (Innes, 2009). From a medical perspective, dementia can be defined as a chronic disease. It is used as an umbrella term for several degenerative brain conditions including Alzheimer’s disease (62% of all dementia cases), vascular dementia (27% of all cases), and more rare conditions such as Lewy body dementia and Korsakoff’s syndrome (Knapp et al., 2007). No single cause has been attributed to the development of Alzheimer’s disease or vascular dementia and it is thought that a combination of factors may contribute (Alzheimer’s Society, 2010). After a diagnosis of dementia, people usually live for 7-12 years (UK National Dementia Strategy, 2009). All these degenerative brain conditions involve a progressive and most often irreversible decline in mental functioning. This is often accompanied by some deterioration in emotional control, social behaviour and motivation (O’Shea, 2007).

The course of the illness and specific symptoms vary depending on the subtype and the area of the brain that is affected (Cahill, O’Shea and Pierce, 2012). Generally, early symptoms are related to short-term memory difficulties. Other common symptoms include disorientation, thinking and learning difficulties, problems performing familiar tasks, difficulties using language appropriately and sometimes mood and personality change. As the person progresses to an intermediate stage, his/her ability to perform basic activities of daily living becomes more impaired. People with severe dementia become totally dependent on others for almost all activities of daily living and both short and long-term memory become very impaired or completely lost. Nevertheless, as O’Shea (2007:6) suggests, considerable variation in symptoms can occur during the course of the illness:

which means that not everybody with the disease necessarily progresses neatly from one stage to the next. The uniqueness of the disease must, therefore be acknowledged, in that no two individuals with dementia are likely to be affected in precisely the same way.

(O’Shea, 2007:6)

From this perspective great efforts have been made to find a cure or treatment for dementia. Current available drugs offer a degree of relief and benefit to some people. A central aspect of the research and practice guidelines relating to these drugs focuses on cost-efficacy criteria. Within this research other social and emotional costs and benefits
associated with the drugs tend to be absent. The views of people diagnosed with dementia and their expectations, concerns, experiences and the significance of these drugs to their lives have not been given as much attention.

This bio-medical understanding of dementia can be extremely useful for anyone affected by dementia and their relatives and for the development of drug treatments. Nevertheless, important limitations have been identified in this approach (Bond, 1992; Kitwood, 1997; Innes, 2009). The bio-medical approach can become a problem when the sole focus is on pathology, aetiology, the symptoms, pharmacological treatments, prognosis and the ultimate search for a cure. In other words, if the focus remains on the disease/illness there is a danger that the priorities, values and experiences of the person living with dementia may get lost. An exclusive focus on the bio-medical aspects of the condition can then have a negative impact on the person who is quite clearly more than a diseased or atrophied brain. Moreover, this approach tends to emphasise the negative aspects of the illness and the loss of "normality" experienced by people with dementia (Bond, 1999). Individuals diagnosed with dementia are described as "victims" or "sufferers" of an illness that is beyond hope (Oliver, 1986 as cited by Bond, 1999). Dementia is portrayed as a daunting condition that imposes great burden on primary caregivers and families in general. Socially, dementia is considered a major public health problem - an "upcoming epidemic" - that poses huge economic costs to health and social care systems (Behuniak, 2011; Van Gorp and Vercruysse, 2012). Finally, it is argued that in this approach, dementia and the symptoms and behaviours associated to it, are often defined as "medical problems". Thus, the medical profession is given authority and power over the condition and its treatment (Innes, 2009).

The bio-medical understanding of dementia has important implications on how traditionally the topics relevant to this thesis (quality of life and drug treatments) have been understood and approached. Examples include the focus on symptoms and functioning, and the common belief that a decline in function will inexorably result in a decline of quality of life (Bond, 1999; Bowling et al. 2003). Another example can be found in the dominance of health professionals’ values and understandings in the selection of quality of life domains or of medication benefits (Traynor and Dewing, 2002).
1.2.2 The psychosocial approach

A progressive shift in the understanding of dementia away from the bio-medical perspective towards a more psychosocial and holistic approach has brought attention to the interplay between neuropathological and psychosocial factors. The focus accordingly has moved away from the diseased brain to the “social and psychological adjustment by people with dementia and their informal caregivers to the condition” (Bond, 1999:564). This body of work highlights how, comparatively speaking, little attention had been paid to the subjective experiences of individuals diagnosed with this illness.

In this approach, the work of Kitwood and colleagues, on personhood and person-centred care, has been very influential (Bond, 1999). Building on Kitwood’s theory, proponents of this approach place a focus on the person rather than on the illness and on how the wellbeing of PLWD can be promoted. Over the last number of years many efforts have been made to try to better understand what it means to live with dementia (Steeman et al., 2006 and 2013; Phinney, 2008). Coping and identity, and more recently awareness (Caddel and Clare, 2010), are some of the key issues that have been explored by scholars adopting a psychosocial approach.

Steeman and colleagues (2006) and, subsequently, Phinney (2008) have extensively reviewed the extant literature on the lived experience of dementia. Steeman et al. (2006) frame the experience of living with early dementia as a transitional process that starts with the acknowledgement that “something is wrong” and progresses to the integration of dementia in the daily life of the individual. Common features of living with mild dementia include the experience of uncertainty and the importance of autonomy, meaningfulness, and security. They posited that memory decline could affect many domains of life, mainly through the multiple experiences of loss. They claim that particularly relevant are the loss of control over reality and over life; loss of meaningful activities, loss of meaningful relationships and intimacy; and loss of self-esteem and of sense of self. Steeman et al. (2006) further showed that along with negative feelings and fears, people with dementia also experience positive feelings, indeed negative and positive feelings often occur simultaneously.

Kitwood defines personhood as “a position or social relationship that is bestowed on one human being by others, in the context of relationship and social being” (Kitwood, 1997, p. 8).
Phinney (2008) reviewed the impact of dementia on how people with dementia feel about themselves. In her work some of the strategies that people with dementia used to cope with negative feelings were highlighted. These include avoiding challenging situations, being active, minimizing difficulties, and keeping a positive outlook. Other scholars have claimed that maintaining normalcy and sense of continuity with life can also be important to cope with the illness (Van Dijkhuizen, Clare and Pearce, 2006). Some people with dementia may downplay the significance of the disease or refer to it as normal ageing. Normalcy and continuity with life is also found in those who find ways of maintaining their everyday routines or household chores (Phinney, Chaudhury and O’Connor, 2007). Clare (as cited by Van Dijkhuizen, Clare and Pearce, 2006:74) claims that most often people with dementia combine strategies that involve continuity with prior identity (self maintaining strategies) and strategies that help the person to integrate the changes produced by the illness (self adjusting strategies).

Moreover, the work of Kitwood made a call on the moral concern for “others” in dementia care (Dewing, 2007). His work on personhood highlights that human beings are interdependent and interconnected (Woods, 2001:S13). Since then, many other scholars have referred to the person with dementia as a social being and have investigated the relationship between how people diagnosed with dementia are perceived and treated by others and their experiences of dementia (Kitwood, 1997; Sabat, 2001). For example, Steeman and colleagues (2007 and 2013) contended that the threat of living with dementia stems not only from the cognitive loss, “but foremost from being accused, restricted, ignored, or patronized by others” (Steeman et al., 2006:735). They argued that “being valued” is central to the experience of living with dementia. They posited that this experience of being valued shifts as dementia progresses from being valued for what you do (performance-related values) toward being valued for who you are (existential values) (Steeman et al., 2013).

In summary, this psychosocial approach is relevant to quality of life as it highlights that other factors, beyond pathology, affect the way in which people live with dementia. It suggests that whilst dementia may be a daunting experience, living well with dementia is attainable in spite of various impairments. This approach has evidenced that people with dementia use different strategies to cope with the negative feelings produced by dementia. Most often people with dementia combine strategies that help them to maintain a sense of continuity with previous identity and strategies that help them to integrate the
changes produced by the illness. In addition, this psychological approach has revealed that beyond functioning and abilities, "being valued" remains a core element for individuals with dementia. Thus, there is an acknowledgement of the relevance of how others treat and perceive the person with dementia.

1.2.3 The social and citizenship approaches

The sociological perspective explores the role of social and cultural factors to better understand dementia in society. Using this social lens, dementia has been considered as part of normal ageing (Gubrium, 1986; Holstein, 2000) or as socially constructed (Bond, 1992; Harding and Palfrey, 1997; Lyman, 2000; Innes, 2009.). This approach has contributed to discussions that aim to deconstruct traditional understandings of dementia as merely a medical condition (Innes, 2009).

This body of literature has shown that living with dementia is far from being a homogeneous experience. It has been argued that deficits and disabilities produced by dementia may carry different significance to people depending on their age or lifestyle. Barlett and O’Connor (2010) illustrate the relevance of age and argue that interpretations of dementia may differ according to whether an individual is diagnosed in early or later life and according to his/her individual priorities and lifestyles (Barlett and O’Connor, 2010:71). This highlights the uniqueness of the lived experiences of dementia as well as the fact that people’s responses and understandings of dementia may be grounded in life course experiences.

Sabat’s (2001) work has expanded the debate about dementia as a socially embedded phenomenon. Using social constructionist theory, Sabat showed how selfhood is constructed in interaction with others. He differentiated between three selves; self 1, 2 and 3. Self 1 refers to the personal identity. Self 2 consists of the person’s attributes but also includes how others perceive these attributes. It is contended that, if in social interactions the person’s more negative attributes are dominant, the relationships between the people living with dementia and “healthy” others will be affected in a negative way (Sabat et al., 2011). Finally, the self 3, refers to the multiple “social personae” that an individual constructs in interaction with others. Sabat and colleagues provide examples of such personae: “a romantic spouse; a loyal friend or a loving devoted parent” (Sabat et al., 2011:289). Sabat and colleagues (2011) highlight the difference between seeing and treating the person as a “demented patient” or as an individual with dementia but an
individual who has a life to live and who wants to keep “a biographical continuity between life before and after a diagnosis of dementia” (2011:288).

Nolan and colleagues (2004) have advanced the relational model with the concept of relational reciprocity. They argued that whilst the psychosocial approach recognises the relevance of others, it fails to acknowledge the fact that the person living with dementia has agency (Barlett and O’Connor, 2010). In contrast, Nolan et al.’s (2004) relational model emphasises the importance of looking at the relationships between and among family members and people living with dementia. People living with dementia are expected “to retain status as an active partner in the dementia experience” (Barlett and O’Connor, 2010:25). This is a bi-directional approach where the person is influenced but also can influence and contribute, and makes explicit that people living with dementia have power and can influence their relationships (Barlett and O’Connor, 2010).

This social science research, and particularly the citizenship model, claims that the experience of living with dementia is grounded in the socio-cultural context in which the person lives. This includes the social location of the person within a social group (e.g. gender, class or economic position) but also how societal discourses may shape the understandings of people with dementia of the importance of, for example, cognitive functioning (Barlett and O’Connor, 2010).

Using the former perspective (social location of the person), Hulkó (2009) challenged the assumption that dementia is universally experienced as negative and, cautioned us to consider the bias and problems which may arise by treating dementia unequivocally as a problem (Hulkó, 2009). Hulkó (2007) placed the experience of living with dementia on a continuum. In her study some participants claimed that living with dementia was “not a big deal”, others identified it as a “nuisance”, and others experienced it as “hellish”. She pointed out that the social location of the person might help to better understand his/her lived experience of dementia. In her work she found that people with more marginalized social contexts (in terms of race, gender, class and ethnicity) experienced dementia as less problematic than those in more privileged situations. The diverse social positions that people living with dementia occupy can, thus, enhance or have an adverse impact on their experiences of dementia.
In relation to the latter approach (societal discourses) Van Gorp and Vercruysse (2012) identified some of the dominant underlying cultural frames for understanding dementia in the media. They identified six negative dominant frames. These frames perpetuate the negative connotations and stigma associated with the illness. They also identified and proposed six alternative more balanced ways of looking at dementia (counter-frames). The counter-frames included: the unity of body and mind (instead of dualism); carpe diem (instead of focusing on deterioration and illness progression) and each in turn (instead of role reversal or burden).

In summary, this section has explored some of the competing ways in which dementia is conceptualised in the scholarly literature. Traditionally dementia has been conceptualised as a disease. Such a conceptualization has been extremely useful in furthering our understanding of the neuropathology associated with the disease and is critical in the quest for a cure against dementia. Main concerns within this medical framework relate to the functional and cognitive impairment and the burden that dementia places on families and societies (Innes, 2009). A weakness of this approach is that the unique needs and experiences of the individual living with dementia may be overlooked. In this framework the understanding of dementia is largely negative. Stigmatising images of the disease are invoked, for example dementia is described as: “the living death”, “never ending funeral” or the condition as the “mind robber” (Behuniak, 2011; Van Gorp and Vercruysse, 2012). The psychosocial and social frameworks offer an alternative perspective within which to view dementia. These frameworks, without denying the existence and relevance of neuropathology, offer a broader and more complex scope for conceptualising and understanding the experience of dementia and the impact that living with dementia may have on the quality of life of these people.

The research guiding this thesis is informed by the social approach to dementia. Of particular relevance is the emphasis this framework places on individuals’ and societies’ interpretations of dementia. It underscores how the experience of living with dementia is more than merely the disabilities and impairments produced by the disease. This framework recognises that many of the problems experienced by the person are “socio-environmental and not biomedical” (Bond, 1999). It highlights the influence of

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4 They reviewed news and media content concerning dementia. It included newspapers, books, audiovisual material and public health care brochures.
interpersonal relationships as an essential factor for understanding the dementia experience, and particularly how some of the deterioration that a person can experience is caused not by the condition itself but by how the person is treated by others (Sabat and Harre, 1992; Sabat, 2001; Woods, 2001; Nolan et al., 2004; Steeman et al., 2013 among others). In addition, there is an acknowledgement of relationships and interactions as bidirectional. This means that the individual living with dementia is influenced, but also influences interpersonal and social relationships (Nolan et al., 2004). In this thesis the relational aspects of the individual’s life and how relationships are managed, maintained, re-created and sustained whilst living with dementia are given great consideration. Concepts of particular relevance are: relational reciprocity, interconnectedness and agency.

Furthermore, the social framework has illustrated the great heterogeneity and complexities surrounding the ways in which individuals experience dementia. This more holistic approach provides an individualised and contextualised understanding of dementia as part of the life course of the individual. Using this framework, the focus is therefore on the subjective and complex experiences of the condition rather than on disease progression (Bond and Corner, 2001). Embracing this approach to dementia has an important impact on how quality of life is understood. Following this approach quality of life is “not solely determined by neuropathology but also by the personal histories, interaction with others and by how people are perceived within their social context” (O’Connor et al., 2007 as cited by Barlett and O’Connor, 2010:19).

Whilst the citizenship framework has not been fully exploited in this thesis, some of its principles have been very useful and are used in this thesis. Particularly relevant to this thesis has been its emphasis on regarding the experiences of people with dementia as grounded in the broader socio-cultural context where they live (Barlett and O’Connor 2010).

1.3 OVERVIEW OF SOCIAL CONSTRUCTIONISM.

An approach that fits well with the complexity and diversity of the experiences of living with dementia is social constructionism (Bond and Corner, 2004; Barlett and O’Connor, 2010). The next section outlines the main principles underpinning the social constructionist approach and the theoretical perspective selected for this thesis.
The term social constructionism has been found in the social sciences since the 1960s. It emerged within the cultural and intellectual movement of postmodernism (Holstein and Gubrium, 2008) and originated as an attempt to come to terms with the nature of reality (Andrews, 2012). Social constructionism is often contrasted with positivism, a paradigm that assumes that facts can be gathered by disinterested and neutral observation, and that is concerned with uncovering the truth and presenting the empirical evidence (Henning, Resburg and Smith, 2004). In contrast, social constructionists are concerned with the process by which social reality is “put together and assigned meaning” (Holstein and Gubrium, 2008). From a social constructionist approach there is no one ultimate truth or reality, but multiple valid views. These two paradigms are often considered to compete to produce knowledge.

Berger and Luckmann’s book “The social construction of reality” published in 1966 is regarded as one of the most influential works in the development of social constructionism (Holstein and Gubrium, 2008; Burr, 2003). Nevertheless social constructionism has been influenced by other intellectual movements, such as ethnomethodology, social studies of science, feminism, post-structuralism, narrative philosophy and psychology, post-foundational philosophy and post-positivist philosophy of science (Stam, 2001:294). Whilst social constructionism is far from being a homogeneous paradigm, Gergen (1985) and Burr (1995, 2003) have outlined four main premises underpinning and bringing together the social constructionist approach. These are briefly outlined in the next section of this chapter.

1.3.1 Premises underpinning social constructionism

Social constructionism is underpinned by four main tenets (Gergen, 1985; Burr 1995, 2003):

A critical stance toward taken-for-granted knowledge

This first tenent of social constructionism invites the researcher to be critical of the notion of reality as an objective and unbiased truth, as something that is just “out there” waiting to be discovered and with the right instruments, knowable. Rather, social constructionism challenges the conventional understandings of this reality. The main focus is on the processes by which these understandings come to be seen as true by people.
Historical and cultural specificity

The second premise suggests that “all ways of understanding are historically and culturally relative” (Burr, 2003:4). The ways in which people understand and represent the world are historically and culturally situated, that is, they depend on the particular social and economic arrangements prevailing in a particular time and space (Burr, 2003). Worldviews are then multiple and can change over time.

Link between knowledge and social processes

The third principle proposes that the construction of knowledge is an interactive process. The way in which people describe and explain the social world is the outcome of relationships. Realities are constantly constructed and re-constructed by individuals within the context of their everyday interactions. What is thought as “true” is what has been negotiated, accepted and shared as such in social interactions. There are then competing interpretations of the world, and in these negotiations of truth, certain interpretations are privileged over others.

Social constructionism places great emphasis on how language is used to construct reality (Andrews, 2012) and language is central to the making, maintaining and contesting of meanings as it provides the basis for all our thought. Language is also considered “the medium which provides much of the raw material for our activity” (Cromby and Nightingale, 1999:4).

Link between knowledge and social action

The last premise contends that knowledge and social action go together. This means that the construction of knowledge has social consequences as with a particular version of reality some forms of action become integrated, whilst other patterns of social action are excluded and seen as unthinkable or unacceptable. As Burr (2003) suggests, the social construction of the world is bound up with power relationships because they have implications for what is or is not permissible to do.

In summary, these four premises suggest that many of the things that we may take for granted as given, fixed or objective “are created and perpetuated by human beings who share meanings through being members of the same society or culture” (Burr, 2003:45).
There are different approaches to conducting social constructionist research. Holstein and Gubrium refer to it as a mosaic that “belongs to everyone and to no one” (2008:4). The differences arise in relation to the scope of the inquiry (for example micro or macro approaches); the strategies and techniques employed during the inquiry (e.g. ethnographic, discourse analysis or grounded theory methods) or in the particular topic addressed (e.g. social construction of the body, of emotions or of medical knowledge) (Holstein and Gubrium, 2008).

Drawing on Holstein and Gubrium (2008), the approach adopted for this thesis can be described as “micro” social constructionism. This approach places great emphasis on micro level practices and daily interaction and is interested in talk, situated interactions and local cultures. This micro approach differs from macro social constructionist approaches that focus on the way particular public discourses have emerged and have become taken for granted. For example, an approach based on the political economy of ageing emphasizes the broad implications of structural forces and processes that contribute to constructions of old age and ageing as well as to social policy (Walker, 1981; Estes, 2001).

Another important difference is in what is termed as strong or as weak social constructionism. Strong social constructionism claims that all of reality is socially constructed. For example, a disease, like dementia is regarded as a social construct that has been arrived at by consensus. The neuropathology of the disease is not relevant from this perspective. In contrast, weak social constructionism admits that some objects are “ontologically subjective but epistemologically objective” (Searle, 1995). This means the recognition of the existence of objective facts, such as in this case, the neuropathology and symptoms of dementia but also that these facts become relevant or valuable, because human beings have agreed upon particular meanings. An example provided to illustrate this is that a five euro note exists as a piece of paper, but the value and meaning of the note depends on what as a society we have agreed on, e.g. what money is for or why having money is relevant (Searle, 1995).

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5 Walker (1981) illustrates how political economy of ageing, in contrast to other traditional approaches that have been interested in “dependency” as biological differences or as individual adjustment to aging, concentrates in the social construction of “dependency”, in the structural relationships between young and older people or between different groups of older people (Walker 1981).
For this thesis I have taken the weak approach. Taking a strong approach would have implied that dementia is only a social construct and hence, thinking about treatments or cure would have seemed irrelevant. Whilst I agree that the singular quest for a cure can provide a dehumanizing image of dementia, I believe that ignoring the significance that preventing, curing or treating the disease may have for these people and their families is not prudent. A weak position fits well with the dementia frameworks embraced in this thesis. Thus, without denying pathology and symptoms, the belief is that the understandings of dementia are shaped by “social interactions, shared cultural traditions and shifting frameworks of knowledge” (Conrad and Barker, 2010:70). This logic and debate similarly applies to many other concepts such as dependency that will be discussed in the thesis. Consequently, the position I have taken is that I believe that facts exist (for example that a woman has memory problems). My interest, however, lies in the individual subjective perception of the phenomenon, the meaning and values that the individual attaches to it, and on how the manner in which a person talks about such phenomenon may differ from the way another individual talks about it or from how it has been conceptualised on the scales.

In summary, whilst positivism is concerned with objectively quantifying, predicting or measuring issues around quality of life and medication use, a social constructionist approach highlights relativity, diversity and multiples positions and voices (Hutchings et al., 2010a). Inspired by the work of Bond and Corner (2004, 2006) and following a constructionist lens, in this thesis the topics of quality of life and medication use are regarded as subjective personal experiences. The thesis involves an understanding of people living with dementia as actively managing their lives, in other words as agents acting upon, negotiating and developing their own quality of life and medication experiences (Hendry and McVittie, 2004). This standpoint recognises the significance of individual values and life experiences. It gives recognition to the diverse biographies and lives of individuals living with dementia. Furthermore, it recognises that experiences are constantly constructed and reconstructed by people over their life course.

1.4 PERSONAL MOTIVATION AND USE OF TERMS

My interest in dementia arose originally as a result of my work experience and many years of practice as a social worker with older people with dementia. My more recent involvement in dementia research, particularly the completion, in 2008, of a Master’s
dissertation on quality of life of people with cognitive problems living in long-term care, further ignited my interest in this subject area. This thesis builds on these past experiences and work, on my reflections after practice, and feedback received following the publication of papers on quality of life and presenting some of this work at conferences, seminars and workshops. It led me to question the dominance of positivist approaches and the bio-medical understanding with respect to both quality of life and anti-dementia drugs.

The works of Jaber Gubrium (1986, 1993) and John Bond and Lynne Corner (2006, 2008) have been particularly inspiring and have greatly influenced my thinking and belief that the issues of dementia, quality of life and medication use could be explored from an alternative theoretical perspective. As I progressed in my reading, I become more aware that social constructionism offered me a vantage point to explore the topic in a manner that sharply contrasted with the more conventional approach. In addition, I believed that by using and critically comparing both approaches (conventional and social constructionism) I could make the voice of people living with dementia more easily heard.

Use of terms
Fischer and Forester (as cited by Naue and Kroll, 2009) have suggested that language does not “simply mirror or picture the world but instead profoundly shapes our view of it in the first place” (2009:294). They emphasise that the way we talk and the words we use are not neutral but reflect attitudes, values and power relationships (Naue and Kroll, 2009). In this thesis, I gave much consideration to which terms to use to refer to the participants that had been diagnosed with dementia and to their relatives.

In referring to the participants that had a diagnosis of dementia, I immediately rejected the term “patient” as this word suggests people as “passive recipients of (medical) advice” (Naue and Kroll, 2009). Also, as this is a term commonly used in and associated with medical contexts. In the Oxford dictionary, for example, the definition of patient is “a person receiving or registered to receive medical treatment”. Other words rejected were “demented” since that denotes a pejorative and negative connotation; and “suffering from dementia” since that seemed to imply that dementia is always accompanied by suffering and affliction. The common term “people with dementia” seemed also problematic as the diagnostic label (“dementia”) becomes an adjective that describes the
person. As dementia can have very negative connotations, this may restrict the way in which the person is perceived (Sabat et al., 2011). The term chosen for this thesis is "people/participants living with dementia" (PLWD). This appears to be the term preferred by PLWD themselves (Sabat et al., 2011) and has previously been used in dementia research. It has no negative connotations, as the focus is not on the diagnosis but on the individual who is living a life and who among other things has been diagnosed with dementia.

Consideration was also given to the term used to refer to their relatives. The word family or informal "caregiver" has been used widely. Nevertheless this term suggests a unidirectional relationship between the PLWD and their families, where the PLWD is viewed as the individual receiving help and the carer as the provider of help or as the one taking care. This image was not consistent with my own understandings of PLWD as active agents and as people that could contribute and affect others; or of care relationships which are often characterized by interdependence and reciprocity. The term "care-partner" was chosen to convey that the PLWD can receive but also can provide and reciprocate care to others.

When drawing on the work of other scholars, the terms that they adopt are retained. Therefore sometimes throughout the thesis, other terms (for example caregiver or people with dementia) will appear.

In summary, this introductory chapter has provided the foundation for understanding the topics that are addressed in this thesis and how they are approached. It has outlined the pointers that I found in the literature which motivated me to undertake this thesis in this particular way and my own personal motivation for undertaking and writing this dissertation. The final part of this chapter now provides information on the layout of the chapters contained in this thesis.

1.5 STRUCTURE OF THE THESIS

This thesis is organised into eight chapters.

Chapter two explores the relevant international literature on quality of life in general and on quality of life in dementia specifically. It discusses the main and ongoing debates
around the term quality of life and quality of life in older people. Two main approaches to investigating quality of life in dementia are critically reviewed (normative and interpretivist) and some of the assumptions underpinning each of these frameworks and their limitations are identified and critically discussed.

Chapter three reviews the medical and social science literature on the topic of anti-dementia medication. In this Chapter the main characteristics of these drugs, the debates about their efficacy and cost, and the main difficulties encountered in clinical practice are discussed. The limited available research involving PLWD and their families is also presented.

Chapter four presents the research design and methodology adopted to undertake the research. The chapter shows how a follow-up qualitative design was employed and dyads (people diagnosed with dementia and their care partners) were interviewed at two points in time. The research questions that this thesis sets out to address are articulated. The ethics, design and sample recruitment process and the interview schedules and the quality of life scale (QoL-AD) used in this research, are discussed. The manner in which the data was analysed is outlined.

The research findings are presented in chapters five, six and seven. Chapter five presents data on quality of life at the time of the first interview. This chapter is based on the analysis of data derived from the quality of life scale and the analysis of qualitative interviews. Findings about the main domains of quality of life as identified by the participants are presented; also comparisons are made between the findings obtained with the scale and those derived from the qualitative interviews.

Chapter six moves the focus of discussion to the participants' understandings and ways of thinking about the anti-dementia drug they had been prescribed. It explores how participants constructed their expectations about the drugs and identifies and presents their expectations. It also outlines the implications of such expected benefits for their quality of life.

Chapter seven looks at the follow-up data. It explores the manner in which participants talked about dementia and quality of life, and the participants' experiences and benefits of using the drug over time.
Chapter eight, the conclusion, reflects on the key findings of the thesis including the merits and demerits of using two different methodological approaches to help gain a better understanding of quality of life of persons with dementia. The main implications arising from the research for theory, policy, practice and future research are also discussed.
CHAPTER TWO: DEFINITIONS AND APPROACHES TO QUALITY OF LIFE

2.1 INTRODUCTION

This chapter critically reviews the literature on quality of life in general, and the literature that focuses more specifically on the quality of life of community-dwelling older people living with dementia. It begins by introducing the current interest on quality of life issues and the conceptual development of the term quality of life. Following this, the chapter identifies and reviews two approaches to understanding and investigating quality of life, with a focus on the implications that these have had for our understanding of quality of life for older people and for people living with dementia. These approaches can be divided into an objective approach to quality of life and an interpretive approach where quality of life is viewed as a subjective individual experience. The main ontological and epistemological assumptions underpinning each of these approaches and their methodological implications are outlined. Based on the literature the chapter points out the strengths, limitations and key findings on quality of life for older people and of those with dementia using each approach. The chapter concludes by summarising the gaps identified in the literature and outlining how this literature has helped to inform the conceptual framework of the thesis.

2.2 CURRENCY AND INTEREST IN THE TOPIC ‘QUALITY OF LIFE’

The term quality of life is not new. It dates back to Plato and Aristotle and their work about the “good life” and “living well” (Smith, 2000). The term itself relates to the wellbeing of both societies and individuals. The notion of quality of life has attracted renewed interest since the mid 20th century (Taillefer et al., 2003). Currently, the term is of interest across several disciplines including Economics, Sociology, Political Science, Psychology, Philosophy and Medical Sciences (Bowling, 2001; Rapley, 2003). Issues relating to quality of life have been embraced by governments and public sector agencies worldwide.

6 The literature search strategy used in this chapter can be seen in Appendix A.
The currency of the term can be attributed to a number of factors that reflect a desire to better understand what constitutes a good society and, at an individual level, how the life of the person can be improved. Initial interest in quality of life in the 1960s developed in a climate of economic affluence and was triggered by an attempt to understand how economic growth could impact on human wellbeing. In a health context, a relevant factor that has contributed to the increasing interest in quality of life is the shift in the medical professions' focus towards a broader and more holistic understanding of the welfare of the whole patient (Farquhar, 1995). Also, it was observed that medical advances have added years to life but not necessarily quality to life (Smith, 2000). Over the years, interest in the concept of quality of life has become more specific, and the concept is also used in relation to particular groups such as older people and people living with dementia. The premise is that what is important to people, and the meaning that people attach to the things that matter to them, may differ depending on their age (Puts et al., 2007) or health status (Logsdon et al., 2002).

In the context of global ageing, the topic of quality of life in older people has become a major topic of research interest (Ettema et al., 2005). Current estimates suggest that there are some 36 million people living with dementia worldwide, of those around 7 million live in Europe and roughly 47,000 within Ireland (Cahill, O'Shea and Pierce, 2012). Global ageing means that, in the absence of a cure, prevalence rates will continue to rise (Van der Flier and Scheltens, 2005).

One important reason behind the increasing attention given to quality of life issues of older people and people living with dementia is the potential the topic may have to reduce public expenditure (Bowling et al., 2003). The burgeoning of interest in the topic has been attributed to the increasing availability of pharmacological and psychosocial therapies and interventions for dementia. From a health economics perspective, quality of life assessment is one way of appraising treatment outcomes and cost and can be used to inform “health economic decisions and debate about the allocation of scarce resources” (Selai and Trimble, 1999:101). In addition, quality of life outcomes may help to demonstrate the effectiveness of treatments and interventions by identifying areas of improvement not assessed by standard cognitive or functioning tests. This may provide further information about whether an intervention has made an important difference to an individual’s life (Logsdon and Albert, 1999).
A second reason for the burgeoning interest in this topic relates to the emergence of more positive perspectives on healthy ageing. For example, Bowling and colleagues (2003) have argued that future public policy may shift from dependency issues to policies that empower older people and enable them to maintain an active contribution to society. In the context of dementia a broad dissemination of the term quality of life focuses attention to positive states and personhood rather than to deficits and pathology (Ready and Ott, 2003).

2.3 CONCEPTUAL DEVELOPMENT OF THE CONSTRUCT QUALITY OF LIFE

Despite this growing interest in the topic of 'quality of life' and the large body of academic work that has been published on the subject, no consensus has been reached to date on a definition for quality of life. It is a difficult concept to define and measure and there is no consistency about what it means. Some experts have claimed that in fact quality of life cannot be defined, suggesting that quality of life should, in fact, move in the direction of "hearing people's life stories" (Keith, 2001 as cited by Lefort and Fraser, 2002:236). Several factors make the concept difficult to define and measure, namely: the subjectivity of the term ("different people value different things", George and Baron, 1980), the absence of a gold standard measure, the dynamic nature of the term (perceptions of quality of life may vary over time) and the difficulty in discerning between what variables constitute quality of life, what variables contribute to or influence quality of life and what variables act as mediators to the effects of adverse effects and circumstances (Ready and Ott, 2003; Taillefer et al., 2003; Bowling et al., 2003).

It is not surprising that for these reasons, published research studies often fail to provide a definition of the term or explicitly state what they purport to measure. This has added further confusion to the operationalization of the term (Taillefer et al., 2003). It is suggested that a clear-cut definition of quality of life is needed as to date quality of life has been used as an "umbrella" concept where almost everything could be considered to be part of it (Feinstein, 1987). For example, for several decades, quality of life has been used in many different ways, often as a proxy for health, the ability to function or psychological well-being. This means that the concept of quality of life can often "mask differences in conceptualization and in what is being measured" (Bowling, 2001).
2.3.1 Conceptual approaches to quality of life

Veenhoven (2001) suggests that the term "quality of life" is a broad concept that covers different meanings. She argues that the term is often used to denote the quality of the political, economic and cultural environment (living conditions of a nation/society). This meaning of the term has been largely used in sociological studies. It involves the measurement of national indicators such as material affluence, security, freedom, social equality, cultural climate (education, information, religion and values), social climate (tolerance, membership of voluntary organizations, peacefulness), modernity and the social position of the individual in society (gender, income, occupation, social participation). In addition, quality of life is also used to denote how well people cope. This approach is mostly used in therapeutic professions and equates quality of life with physical ability or mental propensities. The main elements here relate to health, ability, personality, life goals, lifestyle and convictions. Finally, quality of life is also used to refer to "enjoyment of life". As Veenhoven (2001:68) summarises it "the good life is then a life one likes". Quality of life is, in the eye of the beholder and what is worth considering is how individuals feel or perceive their life experiences. Consequently, this meaning of quality of life can only be appraised by the individual him/herself; and it is referred to as subjective quality of life. Concepts such as happiness, life satisfaction and subjective wellbeing are often used interchangeably with this conceptualization of quality of life.

Another approach used in the conceptualization of quality of life is linking it to human needs. From this perspective quality of life can be defined as the satisfactory fulfilment of these needs (Brown et al., 2004). This conceptualization is often based on the original work of Maslow (1970) and his hierarchy of human needs – basic needs, safety, belonging and love, esteem and self-actualization. Different types of needs have been used to conceptualise and measure quality of life. As an example, Bowling and colleagues pointed out that most scales to measure the quality of life of people with mental health problems are based on satisfaction of basic needs and global wellbeing. However other approaches to quality of life in terms of needs, have included resource needs such as shared time, available space and status; the fulfilment of higher needs such as control, autonomy, or self-satisfaction; or the personal evaluation of his/her objective circumstances and access to information, advice or services (Brown et al., 2004). This approach to understanding quality of life in terms of needs has also been taken in dementia research (Miranda Castillo et al., 2010, 2013).
A different way to conceptualise quality of life was provided by Calman (1984). He defined it as the difference or gap between expectations and hopes of the individual and current experience. A good quality of life is a life where “the hopes of an individual are matched and fulfilled by experience” (Calman, 1984:125). He posits that the contrary is also true, a dissonance between the expectations and experience would result in a poor quality of life. This model is based on social expectations and comparisons with others (Bowling, 2003). One important challenge in this approach relates to “shift response” or adaptation (Carr, Gibson and Robinson, 2001). Carr et al. (2001) maintain that quality of life is closely related to individual expectations (discrepancy between expectations and experience), but they pointed out that people’s expectations may change over time (accommodation / adaptation to change) and thus the evaluation of quality of life will constantly change over time.

2.3.2 Quality of life definitions and domains

Quality of life definitions tend to highlight the multidimensionality of the concept (Bowling, 2003). This suggests that whilst quality of life refers to the life of an individual as a whole, a range of different dimensions or life domains exist that can be used to describe the relevant components an individual should include in their day-to-day existence to experience an optimal quality of life. Svensson (1993:185) (as cited by Gubrium, 1993) describes these domains as “qualities” in life, and they are defined as “the specific areas a person perceives to be vital to the ability to enjoy life and to feel that it has meaning”. These are qualities that have high meaning to the individual. Most scholars define the construct quality of life as multi-dimensional and suggest that these domains are interactive and not mutually exclusive (Bowling, 2003). Nevertheless there is no consensus about the definition or number of domains which the concept encompasses, or if all domains equally contribute to quality of life.

Felce (1995), Hagerty et al. (2001) and Schalock (2004) conducted major reviews in an attempt to comprehensively document all domains of quality of life. Overlapping domains in these three major reviews include 1) material wellbeing and living environment, 2) health, including physical and psychological wellbeing, 3) interpersonal relationships and social connection with family and friends, 4) social inclusion/wellbeing and feeling part of the community, and 5) productive activity and work. Other dimensions are spirituality, independence and self determination, safety and rights. Most quality of
life definitions take this multi-dimensional approach. The WHO's definition of quality of life is a good example of this as this definition highlights the broad nature of the term, as well as the complex relationships between the domains relevant to quality of life, the individual's own values and the living environment where the person lives:

An individual's perception of his/her position in life in the context of the culture and value system in which he/she lives and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment.

(WHO Quality of Life Group, 1995:28)

To reflect life experiences, some scholars have argued that quality of life definitions should reflect positive and negative domains. Others highlight the dynamic nature of the construct and the influence of personal values reflecting the relevance of, satisfaction with, or expectations that the individual has about the domain. The quality of life definition put forward by Felce and Perry (1995:58) reflects most of these aspects:

An overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values.

(Felce and Perry, 1995:58)

Felce and Perry contend that three elements, namely objective life conditions, subjective wellbeing and personal values are constantly interacting and are capable of change independently as a result of external influences including social, economic and political variables.

2.3.3 Health related quality of life

As stated in the previous section, quality of life conceptualization and definitions generally aim to encompass all aspects of an individuals' life. However, in health service research, a narrower way of looking at quality of life, labelled as Health Related Quality of Life (HRQoL) has been developed. HRQoL refers to the aspects of quality of life relevant to an individual's health, and those aspects of life thus directly affected by
changes in health and expected to improve with appropriate medical intervention (Spilker and Revicki, 1996).

Drawing on this particular conceptualization, it is noted that disease-specific approaches to understanding quality of life are designed to be relevant to particular interventions, certain sub-populations or patient groups that are disease-specific, for example dementia. Disease-specific quality of life measurements include domains that are important to the particular disease under investigation. Thus, they facilitate an understanding of the impact that this disease may have on the individual’s quality of life. Whilst this makes it more difficult to generalise results or compare results across different diseases or with general populations, Schoezel-Dorenbos (2010) argues that these disease-specific scales are more responsive than generic ones to any change arising due to the course of the illness or in response to treatment.

One of the main assumptions underlying the HRQoL and disease specific orientations is that as health declines with age, HRQoL also declines. Although the WHO’s definition of health draws attention to a comprehensive understanding of health, including bio-psycho-social wellbeing, focussing on HRQoL has often led researchers to examine aspects of quality of life affected predominantly by the disease, thereby addressing negative issues which mostly relate to limitations and impairment (Jonker et al., 2004).

2.4 APPROACHES TO QUALITY OF LIFE

As stated in the introduction of this chapter, quality of life is a topic that is of interest to multiple disciplines including Medicine, Psychology, Sociology, Economics or Politics among many others. This highlights the complexities of the quality of life investigation and the multiple perspectives and forms that a quality of life inquiry can take. The concept of quality of life is conceptualised, defined and used in different ways pending the aims and context in which quality of life is used, but also on the conceptual and scientific orientation of the investigator (Logsdon and Albert, 1999; Bond and Corner, 2004). The latter refers to the user’s understandings of the term, his / her epistemology and position and agenda in the social and political structure (Bowling, 2003).

The next section presents two interrelated and often converging issues of content: the debate about the nature of quality of life as objective, subjective or as a combination of
both; and two of the paradigms that have informed the approaches to understand quality of life. These two approaches (the normative or positivist approach and the interpretivist or humanistic approach) follow distinctive ways of collecting information about quality of life and each approach can produce different types of understandings about quality of life. Whilst these paradigms have often been regarded as competing or as mutually exclusive ways of producing valid knowledge, an interest in this thesis is to identify and compare the potential convergences between both and use potential divergences as a source of discussion that could bring additional insights to the topic. In short, this thesis is concerned with trying to advance the debate on quality of life further rather than arguing which type of approach or knowledge is more valid or true.

2.4.1 The normative approach to quality of life

This approach implies that quality of life can be described, defined and measured objectively. This way of approaching quality of life is particularly useful for producing knowledge about large groups of people, and for making generalizations and comparing quality of life across a range of settings and across different groups. It is also a useful approach for making predictions or for conducting causal analysis (cause and effect).

Most of the initial work on quality of life was based on the premise that quality of life was an objective concept. The assumption was that researchers could identify a number of areas that would be relevant to most people and such areas could be measured and evaluated. Consequently, an important aim was the development of scales to measure quality of life (Bond, 1999). Challenges arising from this approach relate to determining which domains should be included in these scales and quality of life levels. Important questions are: who decides which domains should be included; whose values these domains represent and how quality of life levels (good, fair or poor quality of life) are determined (Bond and Corner, 2004).

Most scales report on psychometric properties including validity, reliability or responsiveness to change. However, it has been argued that scales largely represent the views and values of the people who have developed them and reflect the ways of understanding the world embedded in the dominant theories of the time (Bond and Corner, 2004). For example by and large the initial conceptualization and measurement of quality of life in older people stemmed from experts’ views as opposed to lay people’s or older people’s views (Bowling, 2001). Consequently, quality of life scales for older
people may represent the views and values of young, middle class professionals (Bond and Corner, 2004) as well as theoretical perspectives of what was understood as successful ageing at a particular point in time, for example, freedom from disease and disability, functioning or engagement (Rowe and Kahn, 1998). These perspectives place most emphasis on functional capacity and forward a perspective that everyone aspires to an optimal level of functioning (Bowling et al., 2003). Consequently those impaired or who have a disability are assumed to have an inferior quality of life. Another example of this can be seen in theories of quality of life in older people based on activity theory where people with a higher level of activity were regarded as enjoying a better quality of life. In relation to the completion of the scale, a purely objective approach to quality of life is defended in instances where the researcher is the only one responsible conducting the assessment. For example, the objective evaluation of an individual’s functioning in health.

In the 1970s, the salience of the subjective nature of quality of life gained relevance as it was argued that objective indicators of quality of life could be perceived differently by different people (Ettema et al., 2005). For example it was noted that people suffering from an illness do not necessarily report a poorer quality of life than their healthy counterparts (Evans, 1991 as cited by Hendry and McVittie, 2004). It was therefore contended that adverse external circumstances may not be reflected in individual experience (“disability paradox”). Also, whilst these approaches (quality of life as greater level of functioning, activity or wealth) can be supported by the behaviours of some people, they are “too simplistic to account for the complexities of the modern world” (Bond and Corner, 2004:78) and they do not reflect important features such as the role of the environment or other psychosocial factors (Bond and Corner, 2004).

This has led to a trend towards progressively involving older people in the development and in the later completion of quality of life scales. It has led to attempting to take into account what older people themselves have to say about their own lives and the quality of these lives. The work of Farquhar (1994) and Bowling (1995) and Gabriel and Bowling (2004) provide some examples of research studies that have included older peoples’ views about their quality of life. Farquhar’s work showed that family relationships, health, material circumstances, activities and social contact were relevant to older people.
Bowling and colleagues, using findings from a survey as well as from qualitative work, explored what quality of life meant to older people in England and Scotland. They developed a conceptual framework about quality of life and argued that the main building blocks of quality of life in older age are (Bowling 1995 and 2011): (1) psychological factors: people’s standards of social comparison and expectations in life, sense of optimism rather than a tendency to think the worst, looking forward to things, acceptance and other coping strategies; (2) having good social relationships with children, family, friends and neighbours; (3) social capital: living in a good home, living in a neighbourhood with good community facilities and services, including transport, feeling safe in one’s neighbourhood, (4) health, mobility and physical functioning; (5) engaging and participating in social, voluntary, or other leisure activities, and feeling supported; (6) having adequate income; and (7) maintaining independence and control over one’s life. Also their work has showed that subjective ratings of such domains better explain the variance in quality of life ratings than objective economic or socio-demographic indicators (Bowling et al., 2003).

Similarly, there has been a trend toward giving the person whose quality of life is being assessed the opportunity to complete the scale. This is often described as taking into account the subjectivity of the person. Whilst researchers might purport to achieve this in most cases, subjectivity here is very limited, as the person has no opportunity for deciding which domains are relevant to his/her quality of life. Indeed in most scales, the individual evaluates a number of predetermined domains and it is the researcher and not the individual who has decided on such domains. The subjectivity of the account of the individual is then reduced to pigeonholing responses (Bond and Corner, 2006). An exception to this can be seen in the Schedule for the Evaluation of Individual Quality of Life (SEIQOL, O’Boyle et al., 1990). This scale is based on Calman’s approach (1984) to quality of life. In the SEIQOL, individuals are asked to nominate the areas of life that are most important to them, to rate their level of satisfaction with each, and to indicate the relative importance of each to their overall quality of life. Thus, the resulting scale is uniquely relevant to that individual. Whilst this is a well-established scale and it has been widely used to assess the quality of life of older people, the use of this scale in dementia is limited. A study that used the SEIQOL in a sample of 20 people with dementia showed that the majority of participants had a poor understanding of the domain rating concept, and only six individuals who were less cognitively impaired could complete the scale (Coen et al., 1993).
Another challenge arises when the capacity of the individual, whose quality of life is being measured, to complete the scale is questioned, as is so often the case in dementia. Due to dementia-related impairments in research on dementia, it was traditionally presumed that the accounts of the person with dementia were not reliable. For this reason the views of the person's informal or formal caregiver (proxies) were pursued instead. Over the last decade, evidence has shown that many PLWD can give valid and meaningful information about the quality of their lives and that in fact, the views of PLWD and those of their caregivers often diverge. This debate will be further addressed in section 2.5.1.

In the debate about the objective or subjective nature of quality of life, the value of combining both objective as well as subjective components, to better understand quality of life has gained increasing popularity in recent years. By exclusively relying on subjective evaluations of quality of life a concern has been that this,

may not provide an adequate safeguard for the best interests of vulnerable and disadvantaged people. Expressions of satisfaction may simply reflect the intractability of conditions commonly experienced by those with limited skills, autonomy, and attachment to the mainstream society and its economy.

(Felce and Perry, 1995:57)

One example of the combination of subjective and objective components can be found in the framework proposed by Lawton (1991, 1994). His work is considered to be one of the most systematic approaches to conceptualizing quality of life in older adults and presumed to account for all areas of life, for every aspect of behaviour, environment and experience (Ettema et al., 2005). Lawton defined quality of life as “the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person–environment system of an individual in time past, current and anticipated” (1991:6). He classified quality of life in a quadripartite division including objective and subjective dimensions: psychological well being, behavioural competence, perceived quality of life and objective environment (Lawton, 1994). He suggested that the assessment of behavioural competence may include activities of daily living (external – normative evaluation), cognitive performance (neuropsychological testing) and social behaviour (using scales of pathological behaviour). The environment might be assessed either by physical means –the amount of space in the bedroom, presence of amenities, physical safety, privacy, or by experts’ ratings of the “homelike quality of a care area”. Finally the
two subjective dimensions (well being and perceived quality of life) refer to the persons own evaluations of the many facets of their environment and mental health (Lawton, 1994: 138-139). Lawton model presents “psychological well being” as the subjective individual evaluation of the person’s overall quality of life and is consequently proposed as the ultimate outcome of the model (Lawton, 1991).

In summary, this section has identified the main features of the normative approach to understanding quality or life. A key premise underpinning this approach is the view that quality of life can be objectively accessed and thus predicted, controlled and measured. The debate has advanced from one which exclusively considered quality of life of older people as objective to the progressive incorporation of some level of subjectivity into the term. Today many scholars would agree that quality of life of older people is a combination of both objective and subjective components. Whilst the involvement of older people in the development and, particularly, in the completion of the scale, is often claimed to represent a subjective evaluation of quality of life, this remains in essence a normative (post-positivist) approach to quality of life (Ettema et al., 2005; Bond and Corner, 2006). In short in these approaches, quality of life remains as an objective construct that is seen “through the eyes” of the individual who interprets the world (subjectivity).

The following section will introduce how this normative approach has influenced and dominated the conceptualizations of quality of life in dementia. For this reason from here on, I will refer to this as the “conventional approach to quality of life” to differentiate it from the interpretivist approach.

2.4.1.1 Normative conceptualization of quality of life in dementia

A common feature across conventional approaches developed to conceptualise quality of life in dementia, is that most scholars have based their conceptualization on Lawton’s seminal work (Ready and Ott, 2003; Ettema et al., 2005; Moyle et al., 2011). A major concern in the area has been to develop a framework for quality of life in dementia with a view towards finding a way to effectively evaluate it for this group. Between 1999 and 2007, at least seven different disease-specific quality of life scales have been developed and validated for use with people with dementia living in the community. The next

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[^7]: This figure only includes published work in English. It does not include other scales that are exclusively used in long term care (for example, DCM dementia care mapping, the QUALIDEM developed by Ettema and colleagues, or scales that are specific for severe dementia such as the QUALID).
section outlines the main frameworks and subsequent scales derived from such frameworks relating to quality of life in dementia. The section also highlights the main assumptions underpinning each of the frameworks and scales.

**Rabins, Kasper and Black, 1999. University of Johns Hopkins, USA**

Rabins and colleagues used the concept of HRQoL to conceptualise and measure quality of life in dementia, thus focussing on aspects of life that are directly influenced by health. The development of their conceptual framework was based on the existing literature about generic and disease specific HRQoL, pre-existing instruments measuring wellbeing and distress in dementia, and qualitative research involving panels of health care professionals, family caregivers and national experts in the field of dementia.

With the exception of three main areas, most of the domains included in their framework paralleled the domains identified in existing literature on scales. Firstly, specific items for each of the included domains were tailored to dementia in their scale and thus reflected “the ranges of scores possible among these individuals, rather than higher level that would be expected in non-affected individuals” (1999:39). Another important difference is that they deliberately did not include any domain related to cognitive and/or physical functioning. They argued that whilst cognition and functioning are obviously important factors that can affect quality of life, they are closely aligned with disease progression and therefore it would be risky to associate and assume a decline in functioning on these domains with a decline in quality of life. A final difference between the Rabins et al. (1999) scale and the existing HRQoL literature was that, at the time, most of such measures focussed on limitations and disabilities, whilst the approach used by Rabins and colleagues also included positive behaviours that caregivers and care providers considered relevant for quality of life of PLWD (e.g. enjoyment, interaction).

Another relevant feature of their approach is that PLWD were not included as informants for the conceptual development of their framework nor were they considered for the completion of the quality of life scale. Whilst in later writings they have acknowledged that some people with a mild and moderate dementia can be valid sources of information (Rabins et al., 2010), they argued that a proxy approach is the best methodological approach for measuring quality of life in dementia. This, in their view, facilitates the

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8 Frameworks are presented in chronological order.

9 Such areas were commonly included in other (non dementia) HRQoL instruments (such as the SF-16).
inclusion in research of all people living with dementia, regardless of their impairment. They argued that using proxies is a way of promoting the underlying assumption that “each person with dementia has personhood no matter how severe the illness” (Rabins et al., 1999:46). In keeping with the evidence that support the belief that PLWD and proxies are more likely to agree in concrete and observable aspects of HRQoL than in subjective elements (Weyerer and Schaufele, 2003; Ettema et al., 2005) and to increase the reliability of their scale, Rabins et al. (1999) scale focuses on issues that can be observed behaviourally by proxies.

The five domains included in their framework are (Black and Rabins, 2009):

1. Social interaction - how the person with dementia relates to family members, friends, neighbours or professional caregivers in some observable way through gestures, talking or facial expression
2. Awareness of self - this refers to an awareness of his/her own special personal identity and of major relationships in the family, in friendships, work or community
3. Feelings and mood - this refers to signs that can be seen or heard by others of how a person often feels. These may be spoken statements, expressions or physical gestures
4. Enjoyment of activities - this refers to participation and enjoyment in daily life, such as in leisure and recreational activities or hobbies.
5. Response to surroundings - this deals with how a person respond to his/her living environment and other places, in some observable way through physical gestures, talking or facial expressions

Building on this conceptualization of quality of life, Rabins et al. (1999) developed the Alzheimer's Disease Related Quality of Life Scale (ADRQL). The original ADRQL consisted of 47 items with positively and negatively worded items included in each domain. It was later shortened and published as a 40-item version with improved measurement properties. The ADRQL is administered using a standardized, structured interview. The respondent is either a formal or informal caregiver with extensive and recent knowledge of the behaviours and daily activities of the individual with dementia. The caregiver is asked to identify recently observed behaviours that reflect various aspects of the person’s HRQoL. It takes approximately 10 to 15 minutes to complete.
In summary, the main assumptions informing Rabins and colleagues conceptualization of quality of life in dementia are that quality of life in dementia should be framed as being health-related; that whilst cognition and functioning are relevant factors they should not be included in the measurement of quality of life; that quality of life is multidimensional and should include negative and positive domains, and that these domains are similar to those found in general populations but should be operationalized appropriately for PLWD and described as “observed behaviours” and completed by proxy informants. The domains included in the scale are: social interaction, awareness of self, feelings and mood, enjoyment of activities and response to surroundings. The scale can be applied to all stages of dementia but it is always completed by a proxy.

A positive aspect of this framework and scale is that quality of life in dementia is not exclusively represented in negative terms. Nevertheless, important issues and limitations arise in relation to the absence of the views and understanding of people with dementia in their conceptualization of quality of life, scale development, and in the completion of the scale. This illustrates the important role that researchers and carers can play in defining what type of behaviours may be more or less appropriate and acceptable in a definition of quality of life in dementia.

Brod, Stewart, Sands and Walton, 1999. Goldman Institute of Aging, USA

Brod and colleagues (1999) were among the first researchers to incorporate the voice of PLWD when attempting to conceptualise quality of life in dementia (Thorgrimsen, Selwood and Spector, 2003). They used three focus groups consisting of caregivers, health care providers and people with dementia to develop their framework. Although only 6 individuals with dementia participated in these focus groups, their work was novel as prior to then, evidence was only ever based on literature or on perceptions of caregivers (Jonker et al., 2004).

Brod and colleagues (1999) conceptualised quality of life in dementia as a complex, multidimensional and health related construct. They believed that the unique characteristics of dementia entailed differences in the importance and in the definition of the quality of life domains and subdomains. In fact, from their qualitative investigation, Brod and colleagues concluded that traditional domains such as physical functioning, activities, mobility, social interaction and bodily wellbeing relevant to the quality of life of older people in general were also relevant to those with dementia. However, the
definition of each of these domains was “shaped by the presence of the dementia”. Brod and her colleagues found two additional new domains relevant to people with dementia namely aesthetics -“experience of appreciation and pleasure obtained from sensory awareness” - and interaction capacity -“communication difficulties as well as difficulties in social interactions”- (Brod et al., 1999:29).

In addition, Brod and colleagues (1999) believed that a disease specific approach to quality of life facilitated the evaluation of the effects of therapies and interventions and increased the likelihood of capturing change over time (Brod et al., 1999:25). Nevertheless, whilst their approach highlighted the impact of dementia on quality of life, they also stressed that other forces including health, welfare/finances and religion, contributed to quality of life and that “dementia does not by definition strip an individual of these influences” (1999:32).

They claimed that a comprehensive evaluation of quality of life in dementia should include both objective and subjective domains, nevertheless they argued that the subjective experience of quality of life is the “true” aspect and defended objective elements as determinants of quality of life (Sloan et al., 2005; Jonker et al., 2004). Thus, the focus of their work was on developing the more subjective aspect of quality of life and its evaluation. The subjective and individual experiences of quality of life should take into account feeling states and mood and in their words, the “values, needs, and adaptabilities of individuals to various circumstances” (Brod et al., 1999:34). They claim that individuals with mild and moderate dementia can provide reliable and important information about their quality of life and thus, the perceptions of people with dementia should be considered the “gold standard” by which to measure their quality of life.

The rationale put forward for involving PLWD in measuring their quality of life was based on the evidence that there is disagreement between PLWD and caregivers’ perceptions of quality of life and this cannot be entirely attributed to cognitive impairment. They pointed out that a lack of awareness of deficits (a reason often forwarded to exclude the views of people with dementia in quality of life research) is conceptually distinct from the awareness of feeling states. Finally, they purport that issues such as questionnaire formatting and its administration (clarity, simplicity, brevity) could have a great influence on the ability of PLWD to report on their own conditions.
Brod et al. (1999) scale, entitled the Dementia Quality of Life Instrument (DQOL), is the only tool ever published that is exclusively completed by the PLWD. The DQoL is a 29-item scale comprising five subscales: negative affect, positive affect, self-esteem, sense of aesthetics and feelings of belonging. It takes approximately 10 minutes to complete:

1. Negative affect: frequency by which the person feels depressed, worried, frustrated, sad, angry, lonely, embarrassed, afraid, nervous, anxious, irritated
2. Positive affect: frequency by which the person feels happy, cheerful, laughs, makes jokes, is content, hopeful
3. Self-esteem: frequency by which the person feels confident, satisfied with self, accomplished something, makes own decisions
4. Sense of aesthetics: extent of enjoyment derived from listening to sounds of nature, watching animals/birds, looking at colourful things, listening to music
5. Feelings of belonging: frequency by which the person feels lovable, useful and liked

In summary, the Brod et al. (1999) framework of quality of life in dementia states that quality of life is multidimensional and disease specific. It recognises the contribution that other factors unrelated to dementia may have to quality of life. The framework also stresses that quality of life is a highly subjective and individual construct, and regards objective indicators as determinants rather than as part of its definition. In their view, the subjective aspects of quality of life should be assessed directly through interviews conducted with the PLWD using the instrument outlined above.

A strength of Brod and colleagues’ approach is the inclusion, although limited, of PLWD in its development and the core role that PLWD play in completing the scale. They also recognise that social factors beyond dementia can be relevant to quality of life. Nevertheless, their scale limits its focus to the feeling states of PLWD and does not take into account aspects of life such as family, friends or activity, topics that often emerge when talking with PLWD. Another limitation is that the scale can only be used with PLWD who have a mild and moderate stage of dementia (MMSE score of 12 or above).

Logsdon, Gibbons, McCurry and Teri, 1999 and 2002. University of Washington, USA

Logsdon and her colleagues developed another dementia specific scale entitled the Quality of Life in Alzheimer’s disease (QoL-AD). Mirroring Lawton’s (1994) work, their
framework incorporated domains such as behavioural competence, psychological status, interpersonal environment and subjective quality of life but also the domain called "physical functioning" (mobility). The latter was not included originally in Lawton's model. Logsdon and colleagues (1999) claimed that quality of life should be conceptualised as a dynamic construct as what is relevant to quality of life may change as dementia progresses. Moreover, they posited that factors that influence quality of life “may differ for both patients and caregivers at different stages of patient cognitive impairment” (1999:51). Also, they hypothesised that a decline in behaviours and skills may influence perceptions of quality of life. However, they argue that once individual adjusts to such decline, such decline may no longer be as important to quality of life.

Their investigations showed that caregivers' ratings of quality of life do not substitute PLWD ratings. They showed that caregiver's observation of the PLWD mood and the carer's own psychological status, were critical components in the evaluation of the quality of life of the person with dementia. Thus, caregivers' views may not correspond with the views of the PLWD.

Logsdon and colleagues' scale (1999, 2002), QoL-AD, was reviewed by people with Alzheimer's disease, caregivers, cognitively intact older adults and experts in Geriatrics and Gerontology. Based on their feedback a new item was added to the scale and another item was modified. The scale is made up of 13 items and an overall scored is obtained by adding scores from the 13 items. Scores range from 13 to 52 with higher scores indicating a higher quality of life. A composite score can be obtained by multiplying the scores of PLWD by two, adding the caregiver score, and dividing this by two. In this way, the ratings of PLWD are given priority over caregivers' ratings.

The QoL-AD was initially validated with people with mild and moderate dementia. However, further research has shown that it can be also applied to those in the severe stages. The QoL-AD is often described as the broader tool of quality of life in dementia. Participants are asked to rate their physical health, energy level, mood, memory, relationships with family, spouse and friends, self as a whole, ability to do chores, ability to do things for fun, financial situation and life in general. They are asked "how do you feel about “your relationship with your family”, would you say it is poor, fair, good or excellent?". Edelman et al. (2005) later developed a revised 15-item version of the scale. In this version, Edelman and colleagues re-phrased some of the existing items (for
example, ability to do chores was re-phrased as ability to keep busy) and introduced some new items (for example, ability to take care of oneself; ability to make choices in one’s life). This new version was intended for use in long-term care.

In summary, Logsdon and colleagues (1999, 2002) conceptualization of quality of life in dementia mirrored Lawton’s approach and included a broad understanding of quality of life. An important contribution is their suggestion that quality of life in dementia should acknowledge the dynamic nature of the construct as priorities and needs of the PLWD and of their caregivers may change as dementia progresses. They stressed the impact that adjustments of PLWD and caregivers to deficits may have on their evaluations of quality of life. Their work showed the challenges and limitations involved in using proxy informants.

Their scale has been used extensively in research studies around the world. Whilst they did not involve lay people in the initial development of their framework, some PLWD, caregivers and Geriatricians were involved in reviewing the scale. A strength of this scale is its emphasis on how quality of life is a dynamic concept. A criticism on the other hand is that it mostly links such change to dementia progression rather than to other factors such as the person’s life course or life context. The QoL-AD scale is very broad and reflects many social elements that may impact on quality of life such as relationships or finances. Nevertheless, it is noteworthy that three items on the scale are based on evaluation of abilities and functioning: ability to do chores, ability to do things for fun and memory.

Selai, Trimble, Rossor and Harvey, 2001. University College London, UK

Selai and colleagues (2001) instrument was based on a scale used to measure quality of life in patients with epilepsy and neurological disorders. Based on a comprehensive literature review they defined five main areas relevant to quality of life, namely: physical functioning; emotional states; social and family life; economic status; and cognitive abilities. Adding to this, they believed that the importance of each area varies from individual to individual, and suggested that quality of life in dementia is determined by the gap between the individual’s expectations and life situation. Finally, they argued that quality of life is a comparative phenomenon and thus, in order to evaluate it, the individual must make comparisons with others and with their own previous experiences.

10 This was not included in the scale.
These principles underpinning their framework importantly differ from previous approaches to quality of life in dementia.

Accordingly, and in line with these principles, the scale developed by them (QOLAS) collects information about what is important for the quality of life of the person with dementia within five predetermined domains, the ways in which dementia is affecting these quality of life domains, and how much of a problem this is to the person. The QOLAS is completed by the PLWD and caregiver.

It is interesting that this approach takes into account the extent to which dementia deficits are considered to be a problem to the PLWD. Nevertheless a fundamental limitation of this scale is that whilst the views of PLWD are considered, their views are constrained within predetermined domains of quality of life. It is taken for granted that these five domains represent what matters most to the person completing the scale.

Ready, Ott, Grace and Fernandez, 2002. Brown Alpert Medical School, USA

Ready et al. (2002) developed the Cornell Brown Scale for quality of life (CBS-Quality of life), a scale which was adapted from the Cornell Brown Scale for depression (CBS-D). The assumption underpinning this scale is that a high quality of life is typically indicated by the presence of positive affect, satisfaction, self-esteem and the absence of negative affect. Ready and colleagues (2002) selected the CBS-D as the basis from which to develop the CBS-Quality of life based on the assumption that negative mood and experiences reflect a poor quality of life. To measure positive aspects of quality of life, the items of the original CBS-D were broadened to include assessment of positive emotions, experiences, and satisfaction. Thus, as measured by the CBS, high quality of life is indicated not only by an absence of negative experiences, but by the presence of positive emotional experiences. Each item is phrased in a positive and negative pole (for example, happiness – sadness), and includes mood, ideational and behavioural disturbance, physical signs and sleeping patterns. The scale differs from existing scales in that the information is rated by a clinician, rather than by a caregiver, after an interview based on symptoms and signs experienced during the week prior to the interview.

This framework also looks at quality of life from observable behaviours. An important limitation of the scale is that items are scored as part of a two-way continuum, for example one item reflects sadness vs. happiness. This does not recognise the complexity
of feelings nor take into account the fact that often people can report what may be regarded as contradictory feelings at the same time. Also, it defines as positive elements such as speed (quickness in movements, speed in communication), weight satisfaction and sleeping patterns (falling asleep easily), reflecting values commonly held among younger populations.

Smith, Lamping, Banerjee et al. 2005 and 2007, King’s College London, UK

Another example of involving people with dementia in research can be seen in the work of Smith et al. (2005 and 2007). They argued that there was a need to develop a scale that “keeps the perspective of the PLWD central in all stages of questionnaire development and evaluation” (2005:1). Consequently, to develop their conceptual framework they carried out 19 individual interviews with community dwelling PLWD (including those with mild, moderate and severe cognitive impairment) and 20 interviews with family caregivers. This was the first time that the views of a large number of PLWD on the development of a quality of life scale in dementia were elicited. In addition, they reviewed the current literature in dementia, HRQoL and available scales. This conceptual framework guided the scale development (DEMQOL).

Their framework included five conceptual domains, namely (1) daily activities, (2) health and wellbeing, (3) cognitive functioning, (4) social relationships and (5) self concept. Whilst most of their findings concurred with generic models of HRQoL, similar to Brod et al. (1999), they advocate that some of the domains that emerged in their work (the domain “self concept” and the sub-domain “embarrassment”) are unique to dementia and are not well represented in generic models of HRQoL. Two initial components mentioned by PLWD as relevant to their quality of life (keeping busy and fearfulness) were not retained in the scale as the evidence supporting these was insufficient. Conversely they included other components such as going to the toilet, or memory for people’s names, which although not mentioned by PLWD, were supported by “other literature, clinical expertise or reported by caregivers” (2005:891).

Their work confirmed earlier findings that PLWD and caregivers perceive quality of life differently. They showed that PLWD report on the “here and now”, tend to be positive and reflect an acceptance of their limitations. In contrast, caregivers seemed to focus on how things had changed and overall on more negative issues such as the limitations and challenges related to caring. Consequently, they proposed that quality of life should take
into account these differences in perspectives. For this reason, they suggested using two
different scales - one for PLWD and the other for caregivers – DEMQOL and DEMQOL proxy. These two versions give different but complementary perspectives on quality of
life. Whilst their framework and quality of life scale can be applied to all stages of
dementia, the patient DEMQOL can only be used in PLWD in mild or moderate stages,
and they suggest using the proxy version in severe dementia.

The DEMQOL scale consists of 28 items\(^1\) answered on a 4-point Likert scale and
administered by an interviewer using response cards. The total score ranges between 28
and 112, with higher scores indicative of better HRQL. To avoid respondents reporting
on functional ability rather than feelings, the questions about memory and everyday life
are worded as “how worried have you been about ...?”. Factor analyses carried out during
the development phase of the scale and in a more recent work (Mulhern et al., 2013)
suggested a 5-factor solution of the scale: cognition, positive emotion, negative emotion,
social relationships and loneliness.

DEMQOL - Proxy contains 31 items also scored 1 to 4 (score range 31 to 124) and is
interviewer administered using response cards. Caregivers are asked to describe how the
PLWD felt over the week preceding the interview and if possible to give the answer that
the PLWD would give. The proxy measure has been validated across the full range of
dementia severity. Factor analysis in the proxy scale suggested a 5-factor solution:
cognition, positive emotion, negative emotion, daily activities and appearance.

An important contribution of Smith and colleagues work (2005) is their effort to
incorporate the subjectivity of the PLWD in the scale. This was done in three main ways:
firstly, by involving large numbers of PLWD in different stages of dementia in the initial
development of the framework. Secondly, rather than asking about abilities or
functioning, the scale rates how worried the person is about his/her memory or other
cognitive impairments. Accordingly, whilst including the cognitive deterioration as part
of the scale, they did not take the traditional functional approach (for example, in the
QoL-AD the person is asked how he/she feels about memory, is it poor, fair, good or
excellent, and here the tendency is to evaluate their memory functioning). Thirdly, when
the views of caregivers are taken as a proxy for the quality of life of the person with
dementia, the caregiver is asked to rate each item as they think the person would do. This

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\(^{1}\) All items refer to the individual's experience in the last week.
is an important difference to all other scales where the convention has been to ask caregivers about their own views on, and evaluations of, each item.

Nevertheless, an important tension in their work is the contradiction between their initial intention to keep the person living with dementia at the centre stage, and their later favouring in the scale the views and priorities of experts and caregivers over those of the PLWD (Byrne-Davis et al., 2006). For example relevant elements to PLWD that were highlighted in the interviews, such as keeping busy and embarrassment, were not included in their scale. Also, of note, is the negative phrasing given to a number of the items on the scale12.

Trigg, Skevington and Jones, 2007. University of Bath, UK

Trigg and colleagues (2007) claimed that quality of life is a subjective construct and maintained that the perspective of the PLWD should remain central. Accordingly, they argue that its conceptualization should go beyond observable aspects that merely reflect health states, functional capacity or performance. An important difference between their scale and previous frameworks and scales is that, to better reflect subjectivity, they argued that scales should examine individual's satisfaction with each domain rather than the degree of performance. A person may be satisfied with a life domain in spite of poor functioning, due to adjustment or coping, or the domain may not be perceived as important to the individual.

Another important difference with regard to previous work is that whilst recognising the relevance of health and the impact of dementia on quality of life, they suggest that quality of life models should differentiate between the causal variables (such as symptoms or deficits) that affect quality of life and outcome variables that reflect quality of life (2007:790). Not making this differentiation might result in an erroneous assumption that a worsening of the symptoms of dementia entails a poorer quality of life. Finally, similar to previous frameworks, they claim that an understanding of quality of life that focuses exclusively on loss and disability is faulty. The conceptualization of quality of life should also include positive constructs (such as self worth and life satisfaction) that reflect positive life experiences.

12 Examples include - how worried have you been about ... not having enough company, not being able to help other people and not playing a useful part in things?
Their conceptual framework of quality of life in dementia was developed based on in-depth interviews with 45 people with mild and moderate dementia, "reflecting the recurrent themes in the interview data" (2007b:3). They propose an evaluation of nine areas of life (1) health, (2) social interaction, (3) function, (4) mobility, (5) being occupied, (6) energy, (7) sleep, (8) psychological and (9) environment. Their scale, Bath Assessment of Subjective Quality of Life in Dementia – BASQUID, includes 14 items. This scale does not provide a comprehensive profile of quality of life, rather "it assesses a subset of quality of life items that appear to be useful in discriminating between individuals with dementia and in exploring changes in quality of life over time in response to disease change or interventions" (2007:795).

The BASQUID scale assesses 1) the person’s level of satisfaction with his/her: health, ability to look after him/herself, level of energy, enthusiasm, the way the person usually spends his/her days, level of independence, personal relationships, ability to talk to other people; 2) the extent to which the person is able to: move around in local community, do activities that he/she wants, do things that he/she enjoys; and 3) the extent to which the person: feels he/she has a choice, feels useful and feels happy.

Similar to Smith et al. (2005), the work of Trigg et al. (2007) reflects the great efforts in the quality of life inquiry to represent the subjectivity of the construct. The latter was made by involving very large numbers of PLWD and also in their scale by looking at satisfaction, which may reflect personal values. Nevertheless whilst satisfaction reflects personal values it does not reflect the priorities of the individual. In addition, in terms of the domains examined, the BASQUID is a very broad quality of life scale which centres on the things that may be relevant to the everyday lives of PLWD (for example, looking after oneself, how the person spends his/her time, relationships, or activities and things the person enjoys). Nevertheless some items are phrased in a very abstract and open way. Three examples are: satisfaction with his/her level of independence or the extent to which the person feels he/she has a choice.

2.5.2 Which quality of life scale in dementia best represents quality of life?

Over the last decade, different groups of experts have reviewed these scales and have compared them in terms of validity or applicability. The overall conclusion is that no single scale on quality of life can adequately capture the broad canvas of quality of life (Sloan et al., 2005).
Among the revised scales the DQOL and the QOL-AD are the most widely used and the ones that most often have been compared against each other in terms of their completion rates, internal reliability or assessment of QOL (Thorgrimsen et al., 2003; Sloan et al., 2005; Selwood et al., 2005; Moyle et al., 2010). In 2003 Thorgrimsen et al. (2003) conducted an important study looking at, among other things, the content validity of the QoL-AD scale. They conducted focus groups involving PLWD and caregivers. Participants were invited to talk about quality of life and to assess whether items of the scale were in their view relevant and whether any important aspect of quality of life was not covered in the QOL-AD scale. Overall it was concluded the QoL-AD had good content validity. However, this study indicates that some PLWD would have hoped that the scale could have included items on what the person perceives as important or needs for his/her life to be worthwhile (Thorgrimsen et al., 2003). In addition, the DQOL and QoL-AD scales have been found to significantly and positively correlate with each other, suggesting that these two scales, whilst looking at different domains, broadly measure the same construct when used with the same sample (Thorgrimsen et al., 2003; Moyle et al., 2010).

Whilst there is some consensus that no scale can claim superiority (Sloan et al., 2005; Moniz Cook et al., 2008), often the QoL-AD has been reported as the measure of choice. Reasons for its superiority include the fact that it is short and easy to complete, has been used in people with mild to severe dementia, has been used widely and has been translated and validated in several different languages (Selwood et al., 2005; Moniz Cook et al., 2008; Moyle et al., 2010). Nonetheless, some researchers such as Schozoel Dorenbos and colleagues (2007), suggest that the applicability of the scales should be based on factors such as the severity of dementia of the individuals, the care-type/setting, and the specific quality of life domains the research or intervention focuses on.

2.4.1.2 Factors predicting quality of life in dementia

Banerjee and colleagues have recently shown that little is known about the factors that determine quality of life in dementia (Banerjee et al., 2009). A main issue is the contradictory findings about the topic. The only two findings that have been consistently reported are that PLWD tend to evaluate their quality of life in positive terms, and more positively than do their formal and informal caregivers. This finding is the same through all studies and holds true regardless of the scale used to assess quality of life.

13 Thorgrimsen et al. (2003:23) define content validity as the extent to which “an instrument appears to be measuring what it purports to be measuring”.

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Another relevant finding is the caregivers' inclination to identify poor physical functioning and impaired cognition as detrimental to the quality of life of the person with dementia (Logsdon et al., 2002; Banerjee et al., 2009). Nevertheless, when self-report is used, PLWD themselves do not associate their level of cognition or functioning with their quality of life. Whilst the hypothesis in the past has often been that this disagreement was due to limited awareness of PLWD of their poor functioning, research conducted by Ready et al. (2006) found that discrepancies between the PLWD and caregiver persist in PLWD with good insight and/or mild cognitive impairment. In addition, the idea that quality of life and cognition are not associated in dementia is also supported with evidence from longitudinal studies showing that the quality of life of PLWD over time (1 to 2 years) either does not change at all or varies very little over time (Lykestos et al., 2003; Selwood, Thorgrimsen and Orrell, 2005; Missoten et al., 2007, Heggie et al., 2012). Mood (depression, anxiety) seems to be the only factor consistently associated with quality of life and with quality of life change over time in dementia (Banerjee et al., 2009, Hoe et al., 2009, Heggie et al., 2012). These findings can lead us to conjecture that the subjective experience of living with dementia may be more relevant to quality of life than the objective symptoms (Hoe et al., 2009). 14

Studies investigating insight and anosognosia in dementia have yielded discordant findings. In contrast with previous evidence (Vogel et al., 2006), recent studies suggest that impairment of insight or lower awareness of memory function may be associated with better quality of life in people with moderate dementia (Hurt et al., 2010; Trigg et al., 2011).

The relationship with the caregiver is another important factor impacting on quality of life in dementia (Menne, Judge and Whitlatch, 2009; Woods, 2012). PLWD who are more involved in making decisions about their day-to-day activities and those who have less negative relationships with their caregivers may enjoy a better quality of life (Menne et al., 2009).

The common view that community-dwelling individuals enjoy a better quality of life than those living in long-term care was recently challenged (Missoten et al., 2009). In this

14 The Quality of Life scales used in the studies described in this section are: Selwood et al., 2005; Vogel et al., 2006; Woods et al., 2006; Hoe et al., 2009; Menne et al., 2009; and Heggie et al., 2012 - used the QoL-AD scale; Lykestos et al., 2003; and Missoten et al., 2007 - used the ADRQL; Ready et al., 2006 - DQoL; Hurt et al., 2010 - DEMQOL and Trigg et al., 2011 – BASQID. Banerjee et al., 2009 and Woods, 2012 are reviews of the literature.
research, the authors claimed that people with severe to moderate dementia living in an institution had a better quality of life than people living at home. It should be noted, however, that this study used a proxy scale for measuring quality of life (ADRQL) and thus such views may not be representative of the individual's understandings of quality of life.

2.4.1.3 Pharmacological and psychosocial interventions

There is a growing interest in understanding how pharmacological and psychosocial interventions may impact on quality of life (Cooper et al., 2012 and 2013; Woods et al., 2012). Research evaluating the effectiveness of psychosocial interventions has shown the complex relationship which exists between cognition and quality of life. Although, as outlined above, there is consistent evidence suggesting a lack of association between quality of life ratings and cognitive function ratings, quantitative research has shown that cognitive stimulation programs aimed at improving cognitive function (as for example Cognitive Stimulation Therapy), can improve the quality of life of PLWD – as measured by the QoL-AD scale (Woods et al., 2006). This suggests that: “whilst quality of life in dementia appears to be independent of level of cognitive function, interventions aimed at improving cognitive function can, nonetheless, have a direct effect on quality of life”. (Woods et al., 2006:219). It is interesting to note that in this study (Woods et al., 2006), deterioration in cognition in the control group was not associated with a decline in quality of life. In their work, quality of life improvements were related to energy level, memory, relationship with spouse and ability to do chores. Moreover better quality of life was related to a reduction in symptoms of depression and an improvement of communication (Woods et al., 2006).

Cooper and colleagues (2012 and 2013) have conducted two systematic reviews about quality of life, one looking at psychosocial interventions (2012) and the other one at pharmacological interventions (2013). In the review of psychosocial interventions, they included 20 research studies. Of these, almost half, had used the QoL-AD as a tool to evaluate quality of life. They concluded that interventions that promote family coping strategies (with or without activity intervention for the person with dementia) can improve quality of life of people with dementia living at home (Cooper et al., 2012). In contrast, they could not find consistent evidence that pharmacological treatments could improve the quality of life of PLWD. It has to be noted that in this review they included 15 articles, nevertheless, only a small minority of these studies (four) included the type of
drugs that are of interest to this study (cholinesterase inhibitors or memantine). In these four studies that included anti-dementia drugs, Cooper and colleagues noted that a scale of unknown validity and reliability was used to measure quality of life, therefore their results about quality of life were of poor quality.

2.4.1.4 Conclusion

This section has argued that the quality of life of particular groups, including older people and people living with dementia, may need a unique approach as quality of life issues for these populations may be dependent on age or health conditions. The seven scales critically reviewed in this chapter reflect, by and large, a consensus that disease specific scales are more suitable to measure the quality of life of PLWD than generic scales. Nevertheless, an important conclusion emerging from this literature review is the very complex relationship that exists between cognition and quality of life for individuals living with dementia, and the many unresolved issues about how dementia, and in particular its cognitive and functional symptoms and deficits, may impact on the quality of life of the individual. These scales have advanced in many ways the current knowledge about quality of life in dementia, and seem to be easy to administer and not overly time intensive. The use of such scales has facilitated the comparison of large groups of PLWD and helped to identify relevant determinants of quality of life and changes brought about by interventions.

A common trend in frameworks and scales presented in this section is the effort to reflect positive aspects of quality of life in dementia (e.g. enjoyment) rather than exclusively focusing on impairment or disability. Important differences were nevertheless found in relation to how and what aspects of dementia should be included in the scales. For instance, Rabins et al. (1999) suggested that the type of scores and activities included in the scale should be tailored to the capacity of the PLWD whereas others, such as Brod et al. (1999) and Smith et al. (2005), highlighted that there are specific domains of interest to PLWD. It is noteworthy that the relevant domains included in these scales vary considerably (Scholzel-Dorenbos et al., 2007); confirming the lack of agreement about what domains best represent quality of life in dementia (Bond, 1999). In almost all

\[15\] Remaining studies included other pharmacological interventions, including: ginkgo biloba, anti-inflammatory drugs, nutritional supplement, tarenflurbil, antipsychotics, antidepressants and testosterone
dementia specific quality of life measurements, “affect”\textsuperscript{16} has been found to be an essential domain (Ettema \textit{et al.}, 2005; Scholzel-Dorenbos \textit{et al.}, 2007). In addition, most scales contain at least one of the following domains: (1) self-esteem, (2) activities, (3) enjoyment and (4) social interaction (Ettema \textit{et al.}, 2005).

A difference found between scales is that some have included symptoms of dementia (memory loss) as part of the scale (eg. Logsdon \textit{et al.}, 1999; Smith \textit{et al.}, 2005) but others have taken these symptoms and the impairment that dementia generates as causal variables and argued these should not be included in the scale (Rabins \textit{et al.}, 1999; Brod \textit{et al.}, 1999; Trigg \textit{et al.}, 2007a and b).

Another relevant issue that the analysis of the dementia specific quality of life scales has raised, relates to the debate around the subjective-objective nature of quality of life and about whose views the scales represent. A trend that can be observed in the scales presented in this chapter is a progressive shift towards including some level of subjectivity in the scales. Similar to what was described in relation to the older population, in dementia, this has taken two forms: the inclusion of PLWD and caregivers’ views on the development of the frameworks informing the scale, and the progressive involvement of PLWD in the scale completion. Attempts have also been made to obtain a higher level of subjectivity by including questions about how worried or satisfied the person is, rather than evaluating level of functioning in items.

Nevertheless, I would argue that the scales reviewed above on quality of life in dementia as a whole are more often a reflection of the researcher assumptions, previous literature and of the views and values held by caregivers and not by PLWD. Also, in relation to the completion of the scale there is a trend towards giving the PLWD the opportunity to have a say about his/her quality of life. Nevertheless, with the exception of one scale (Selai \textit{et al.}, 2001) no other scale presented above, allows the PLWD the opportunity to talk about other issues that may matter to him/her or to say to what extent the domain is relevant to him/her. This is an important finding from this literature and one is given further attention in this thesis.

\textsuperscript{16} For example, the DQoL, CBS QoL, DEMQoL and BASQUID look at the presence of positive or negative affect (e.g. the person feels happy, cheerful, enjoying life, sad, lonely, etc.), and other scales, such as the QoLAD and ADQRL look at the person’s mood (e.g. how do you feel about your mood?).
Exploring the issue from an alternative perspective, the final part of this chapter now turns to explore the interpretivist or humanistic approach to quality of life, particularly as it relates to quality of life in older people and in dementia.

2.4.2 The subjective approach to quality of life

A very different approach to understanding quality of life is exemplified by those who believe that quality of life is a subjective lived experience to which every individual attaches different meaning (Hendry and McVittie, 2004). The main assumption underpinning this approach is that the meaning of quality of life is known to individuals' and the only way to access this, is through the individual subjective accounts. In short, this implies that only the individual is able to determine what really matters to him or her and that the individual is the person who establishes what is optimal. This approach to quality of life validates the individual experience or perception of how good his/her life is. However, measurement or comparison between individuals within this approach is either a great challenge or impossible.

The understanding of quality of life as exclusively a subjective experience fits well with the aims of many qualitative research traditions. For example, in attempting to understand the subjective meanings that older people give to quality of life researchers have used phenomenology, since the main interest of phenomenology is on the “meaning of the lived experiences” (Creswell, 2007: 125), and on how individuals make sense of their world. Thus, in contrast with the positivist approach that focuses on the “object” (here quality of life), phenomenological approaches focus on how the person experiences quality of life from a “first person” point of view (Pietersma, 2000). Accordingly, quality of life depends on the individuals’ interpretations and perceptions of what is relevant to their lives (Bowling, 1995).

Adopting a phenomenological approach, Hendry and McVittie (2004) interviewed a sample of ten older people to examine quality of life experiences and the extent to which these views were represented in measurement scales. An important finding of this study is that older people present their experiences as interlinked and in a holistic way. They do not “segment their lives into components parts” (or domains) as scales often suggest. Also, they showed that older people’s personal experiences and interpretations of the quality of life domains are very complex and difficult to be represented in a unilinear scale. For example, some older people may experience ambivalent feelings about some
quality of life domains (e.g. home can bring both feelings of security and loneliness). Adding to this, they argue that some scales assume in an unproblematic manner the positive impact of some domains on quality of life, and that these assumptions do not always correspond with older people’s experiences. They also showed that quality of life is not a passive experience, but it is experienced by older people as something that they can manage and control. They argued that quality of life is highly personal and showed how participants differentiated between their public and private accounts about quality of life, questioning which of these views is reflected when quality of life is approached using scales. Based on these findings they suggested that quality of life is a holistic, multifaceted, complex, and equivocal experience. In their view, measurement instruments can never elicit the full range of subjective experiences of quality of life, thus they conclude that scales provide only part of a greater overall picture.

Other scholars (Bergland and Narum, 2007; Hambleton, Keeling and McKenzie, 2008) using phenomenology have similarly highlighted the holistic and relative nature of the quality of life experiences of older people. How older people experience the current quality of their lives is greatly influenced by positive and negative events over the life course (Bergland and Narum, 2007). Also, this holism relates to the relevance of a sense of continuity with life and to the capacity of older people to adapt to and accept the changes that ageing involves and their current situation (Bergland and Narum, 2007). Continuity with life, feelings of empowerment and the ability to grasp meaning in their lives seem to be cornerstones of the quality of life experience of older people (Bergland and Narum, 2007).

Another relevant approach to this subjective understanding of quality of life is found in social constructionism. This, as stated and briefly described in the introductory chapter, is the theoretical perspective adopted in the thesis. Of particular relevance here is Bond and Corner’s work (2004) about quality of life in older people using a social constructionist standpoint. They define quality of life as a subjective state that is strongly influenced by the individuals’ life course experiences, their current circumstances as well as by the wider social world, that is, the contexts in which people live and establish their identities.

17 Public accounts are the accounts participants assume the interviewer wants to hear or which are constructed with the public accounts of others. Contrarily, the private accounts reflect personal circumstances rather than traditional stereotypes, and comprise complex narrative reconstructions of relationships, events and experience (Corner, 1999 as cited by Bond and Corner, 2004:64).
A central assumption of the social constructionist approach is that quality of life is a relative concept. This relativity implies taking into consideration personal and cultural values and, thus, an acknowledgement that multiple realities exist. As stated by Bond and Corner the quality of life of individuals “is relative to the historical, economic and social context in which they are situated and will be influenced by individual life experience” (2006:9). Thus, the relative importance of different quality of life domains changes throughout the life course and according to the context of time and space. This translates into differences in the definition of quality of life between people based on the life course, needs, socio-economic status or context. The consideration of different times and spaces explains the diversity of perspectives and meanings of quality of life (Bond and Corner 2006). For instance, it is claimed that the understandings of quality of life of the younger and older population, or of older people with or without disabilities, or of people living in different cultures, will vary.

Whilst the positivist approach regarded quality of life as an objective and measurable reality, for social constructionists quality of life exists in the form of “multiple realities constructed and reconstructed by individual older people within the context of their different lives and histories” (Bond and Corner, 2004:101). An important conclusion which highlights the difference between this standpoint and positivism, is that “no unequivocal explanation of quality of life will ever be possible” (2004:102).

The relevance of the context and of personal biographies has also been put forward by Gubrium and Lynott (1983). They argue that biographical approaches are necessary to better understand quality of life and the significance of the domains of life that may be relevant to individuals or groups. Individuals are a product of “ongoing biographical work”, assigning meaning to actions and experience over time (Gubrium and Holstein 2006). From these standpoints, quality of life should be conceptualised in a time-oriented frame and interpreted against a background of lived experiences.

Another relevant difference between this approach and positivism is that whilst positivists argue that researchers can define and describe the quality of life of others, (e.g. of older people), social constructionists claim that only older people themselves can describe their lived experience of being an older person. Bond and Corner (2004) argue that when
investigating quality of life, social constructionism would seek to explore what different aspects of life mean for the individual, the relative value that such aspects have to the individual and how the context (time and space) impacts on the quality of life of the individual.

Based on this social constructionist perspective, quality of life becomes a "political act" as it raises the question of what and whose values should govern the way we view and conceptualize quality of life. The approach recognizes the fact that the choice of particular value systems empowers some individuals, whilst disempowering others. One example which illustrates this, can be drawn by applying activity theory to wellbeing and quality of life. By emphasizing activities and being busy as part of a positive quality of life, this approach makes inactivity problematic and this has a very negative impact on some older people who may for different reasons remain inactive (Katz, 2000) but who may be happy to do so.

In keeping with these outlined assumptions, social constructionists and phenomenologists not only do not approach quality of life using scales, but also, give greater consideration to how to facilitate the active participation of individuals in interviews and how to uncover the private accounts of the participants. These private views of the world and of their quality of life, as Hendry and McVittie (2004) suggest, may not be accessed when using scales.

In summary, the last section of this chapter has critically reviewed understandings of quality of life as a subjective experience. It has outlined some of the most relevant features and assumptions of two relevant qualitative approaches, phenomenology and social constructionism and has pointed out how these differ from the positivist approach to quality of life. Whilst these approaches (phenomenology and social constructionism) differ in many ways, a main point of agreement, and in stark contrast with positivism, is that quality of life issues are subjective to each individual and only the individual knows what matters most to him/her. Also, these approaches are not interested in evaluation or measurement but in knowing about the individual experience, in understanding how individuals make sense of their quality of life and in the meaning that individuals attach to what matters to them. Quality of life experiences from these standpoints are therefore grounded in the individual's past experiences, present lifestyle and expectations for the future.
One important and challenging dilemma arising from these positions, is that a unique, definite quality of life explanation becomes impossible. In fact, both approaches assume that experiences are multiple, and that there may be as many understandings of quality of life as individuals. Thus generalizations, comparisons or predictions about quality of life may not be achievable. This can be regarded as an important limitation of these approaches. Another limitation is that methodologically these approaches are very time consuming and resource intensive. It could be argued that is not only the researcher’s resources that are at play, but also, interpretivist approaches require interviewing the individual several times and in great depth about sensitive and intimate issues in relation to their lives. In contrast some scales may take only five to ten minutes to complete.

2.4.2.1 Interpretivist conceptualization of quality of life in dementia

Whilst the lived experience of dementia, as it relates to identity, awareness and coping, has been extensively researched using phenomenological and social constructionist approaches; the topic of quality of life has been less often investigated from these standpoints. Some exceptions, however, include the works of Katsuno (2005), Fukushima et al. (2005), Droes et al. (2006), Byrne-Davis, Bennett and Wilcock (2006), and Robertson (2013). Of these five studies, only the last uses a biographical approach and narrative methods, the remainder were qualitative studies which used thematic analysis or grounded theory techniques for the analysis.

An important finding of the subjective approach to quality of life in dementia is that often dementia specific issues do not seem to play an important role in the experiences of PLWD of quality of life; rather PLWD discuss many other aspects of life including relationships, financial stability and the quality of their physical environment (Byrne-Davis et al., 2006). This is in keeping with other scholars (Barlett and O'Connor, 2010) who have also suggested that dementia may not be the most significant issue in these older people's lives. This finding challenges very seriously the predominance of domains such as functioning and cognition in many quality of life scales in dementia (Robertson, 2013) and resonates with the definitions of quality of life articulated by Gubrium and Holstein (2006), who have highlighted the relevance of life-course understandings of quality of life.

Similar to what has been discussed in the previous section, these qualitative studies have also shown that the way in which PLWD talk about the quality of their lives is more complex than what is reflected in the scales. PLWD talk about relevant aspects of their
lives not included in the quality of life scales. For example, sense of autonomy and control, security and privacy, self determination and freedom, spirituality and giving meaning to life seem to be crucial to PLWD but these domains have a very low impact in conceptual models and scales (Droes et al., 2006). In addition, Droes and colleagues found important differences in what was relevant to people living at home versus those living in long-term care (Droes et al., 2006). These differences might arise due to the different contexts and living situations of these people.

These studies have also highlighted the relevance of restoring and maintaining a sense of living an ordinary life (Byrne Davis et al., 2006, Fukushima et al., 2005 and Robertson, 2013). The work of Ettema et al. (2005) and of Byrne-Davis et al. (2006) emphasised the role of adjustment and adaptation to the limitations that the disease could bring to the individual’s everyday life. It is suggested that PLWD can adjust to changes and then experience their quality of life in positive terms. This approach suggests that, the experience of their everyday lives as similar as possible to what the individual expects or wishes, is core to the achievement of a positive quality of life. The work of Fukushima et al. (2005) further supports that PLWD hope to “maintain an ordinary life” that includes peacefulness, living healthy and helping each other. Their work also alluded to the confusion that dementia can introduce to the everyday lives of PLWD and their caregivers. Nevertheless, in contrast with Byrne-Davis et al. (2006), in this study, PLWD and carers “acceptance of their diagnosis of dementia” was the main element that had contributed to restore a state of balance and of quality of life. This acceptance was facilitated by the attendance at a day care centre. On the other hand, Robertson study (2013) showed that a sense of coherence and continuity with life were cornerstones in the experience of quality of life in dementia. In her view, the evaluation of a good quality of life “depends upon whether PLWD can make sense of their experiences in ways that enable them to continue to be represented as ordinary within their social context” (2013:14).

These studies (Byrne Davis et al., 2006; Fukushima et al., 2005; Robertson, 2013) illustrate in different ways the relevance of maintaining or regaining a sense of living an ordinary and acceptable life to quality of life in dementia. Maintaining ‘an ordinary’ life can be enhanced by a sense of continuity with previous events in the life. It can also be enhanced by internal or external processes that facilitate acceptance of, coping with, and adjustment to dementia. These concepts of maintaining/regaining a normal life after
diagnosis are useful and will be returned to later in the findings and conclusion chapters of this thesis.

The complexities of the lived experience of quality of life in dementia have been further illustrated in the work of Katsuno (2005). His work showed that myths continue to be rife in society about dementia such as that people with dementia are ‘crazy’ or ‘out of their mind’. Such negative assumptions can lead cognitively intact people to maintain their social distance and serve to increase the stigma surrounding dementia. Katsuno’s (2005) work revealed that negative public attitudes about dementia, and fears of social isolation, loss of friends or more generally, of stigma, were highly relevant to quality of life in dementia.

In similar vein, Banerjee et al.’s work (2010), based on data collected in open groups carried out at six consecutive Alzheimer’s Disease International (ADI) Conferences (1999-2005) and involving professionals, PLWD and caregivers attending the conference, suggested that quality of life in dementia should include individual domains and also societal domains. In the societal domains, among other aspects they highlighted the relevance of public attitudes and social understandings of dementia.

The key findings from three further studies will be presented briefly in the final part of this chapter. These studies did not primarily aim to investigate quality of life issues, nevertheless relevant implications to the topic are found in their findings. These studies are Phinney, Chaudhury and O’Connor (2007) study about the meaning of activities in dementia, Wolverson et al. (2009) study about hope in mild dementia and Caddel and Clare (2011) study about identity.

These three studies highlight the hope of PLWD for continuing to live a good and meaningful life for as long as possible (“keep living well” in Wolverson et al., 2009; “life is pretty much the same” in Caddel and Clare, 2011). Phinney and colleagues (2007) study illustrates how, through doing activities based on the person’s past experience and familiarity, PLWD can sustain a sense of continuity despite the changes resulting from dementia. Activities facilitate experiences of pleasure and enjoyment, make PLWD feel they still belong in the world, and help them to retain a sense of autonomy and identity. These studies also highlight the tensions found between this sense of continuity and the relevant changes that dementia may cause to these people’s lives. Caddel and Clare
(2011) found that PLWD can report feelings of continuity and of change at the same time. Their work focussed on the ways in which PLWD adapt to changes. Similarly, the work of Wolverson et al. (2009) reveals how the positive coping of PLWD together with keeping healthy and maintaining relationships are relevant to quality of life in dementia.

2.4.2.2 Conclusion
The previous section has critically reviewed the subjective approach to quality of life in dementia, and has showed how published studies following this approach are limited and methodologically diverse. The main finding from these studies relates to the complexity found in how PLWD understand and talk about quality of life. Another important finding is that not all PLWD raise the issue of dementia when talking about quality of life issues and that the quality of life experience may go beyond the person, and, as suggested by some, may be related to stigma among other social factors. Another relevant finding include the fact that similar to findings on quality of life of older people, their everyday lives and a sense of continuity with their lives may be core aspects of the quality of life experiences of PLWD. There seems to be different ways by which PLWD achieve this continuity, including activities or interests connected to their biographies. Also, the literature highlights the tension between continuity and change and how PLWD deal with change through positive coping strategies and by accepting dementia.

2.5 IDENTIFIED GAPS AND APPROACH TAKEN FOR THE THESIS
This review and critique of the literature on quality of life in dementia has shown the substantive amount of research that has been devoted to conceptualising and operationalizing quality of life in dementia. It has been argued that the quantitative measurement of quality of life has dominated efforts to understand quality of life in dementia. The chapter has shown the trend towards including the views of PLWD and their caregivers in this normative approach. Nevertheless, it has been argued that within this approach the subjective understandings of quality of life are not fully addressed. The chapter has also reviewed an alternative approach to quality of life (interpretivist) and has shown that the amount of research using this perspective is limited. This approach to the subjective experiences of quality of life has mostly focussed on the individual and his/her experiences and efforts to keep their everyday life and a sense of continuity with the past in spite of dementia.
The chapter has also shown how, to date, there has been little attempt to compare and contrast the strengths and limitations of the two approaches and use identifiable divergences to advance the debate further on quality of life in dementia. Two of the central aims of this thesis are to investigate the subjective experiences of quality of life from the first person point of view including the meanings and significance that domains have to PLWD and their caregivers, and to compare and contrast the type of knowledge that this subjective approach generates compared with the traditional understanding of quality of life. To achieve this second aim, quality of life information will be collected using both of these methodologies (a dementia specific quality of life scale and a qualitative interview).

The critique of this literature has also assisted me in the choice of scale used to represent the conventional approach to quality of life in dementia. I have chosen the QoL-AD to do this for several reasons. The QoL-AD gives the opportunity to PLWD and their caregivers to complete the scale; also it is one of the most comprehensive scales, including social aspects such as finances and social relationships. The scale can be applicable to PLWD living in the community (and this thesis is about people living in the community) and has been validated for all stages of dementia. Also, as this thesis will use a follow-up design, the QoL-AD has been used longitudinally and is sensitive to change over time. Another important reason for using this scale is that many scholars have agreed in that it is short and easy to complete, and that it is the scale most widely used in dementia research, arguably then reflecting a typical approach to quality of life in dementia from a quantitative perspective.

This Chapter has explored quality of life conceptualization issues as they apply to older people and older PLWD. The next chapter will move the focus of attention away from the measurement and understanding of quality of life to the use of anti-dementia medication - a pharmacological treatment that aims to alleviate some of the symptoms of dementia. Quality of life is important in the context of these pharmacological treatments as currently, there is a view that provided that dementia has no cure, any intervention should promote or maintain the quality of life of these people. Quality of life outcomes may help to ensure that the intervention does not leave “the person feeling less positively about themselves” (Woods et al., 2006:220).
CHAPTER THREE: THE PHARMACOLOGICAL TREATMENT OF DEMENTIA

3.1 INTRODUCTION

Chapter two looked at the topic of quality of life generally, and explored the concept of quality of life as it relates to people living with dementia. The chapter showed the different approaches commonly used in the conceptualization and operationalization of quality of life and highlighted the differences in understanding quality of life of PLWD using a normative or an interpretivist approach. The chapter also discussed the topic of quality of life over time and outlined how psychosocial and pharmacological interventions aim to improve the quality of life of these people. It outlined some of the limited available information about the efficacy of these interventions to improve quality of life. This chapter moves attention away from the topic of quality of life, to focus on pharmacological interventions used to treat some of the symptoms of dementia. Drawing upon literature from Medicine and the Social Sciences, it seeks to provide a review of the international literature in the area of pharmacological treatments for dementia.

The chapter is divided into six main sections. Sections 3.2 and 3.3 focus on the medical literature drawing on evidence from clinical trials. In these sections, the licensed drug treatments currently being used for the treatment of dementia are discussed. In particular, the expected goals of these drug treatments, the available evidence about their efficacy and some of the main drawbacks of this scientific evidence are outlined. Section 3.4 looks at the long-term use of anti-dementia drug treatments and discusses the main challenges encountered in clinical settings when prescribing and making decisions about continuation or discontinuation of such treatments. The chapter then moves on to explore the Social Science literature on the subjective experiences of using anti-dementia treatments. A case is made for including PLWD and caregivers' views in this traditionally medically dominated area. Based on the literature the section explores what PLWD and caregivers value about anti-dementia drug treatments, their expectations and reported benefits of using these drug treatments. Factors and dilemmas influencing PLWD and caregivers' starting, continuing or discontinuing drug treatments are
discussed. Section 3.6 summarises and discusses three relevant and competing spheres (scientific, clinical setting and consumer experiences) where knowledge about these drug treatments is constructed, and it identifies tensions and common goals. The chapter concludes by summarising gaps and limitations evident in the existing literature on this research area.

3.2 PHARMACOLOGICAL TREATMENTS FOR DEMENTIA.

Dementia remains an incurable condition and its management requires both pharmacological and non-pharmacological interventions (Farlow, Miller and Pejovic, 2008). Over the last few decades the relevance of psychosocial (non-pharmacological) interventions in dementia has been increasingly recognised and the efficacy of such interventions is well documented (Cooper et al., 2012). This chapter, however, will focus exclusively on pharmacological interventions namely cholinesterase inhibitors (ChEIs) and memantine to treat dementia. Other medications, such as anti-psychotic treatments, used to alleviate the behavioural and psychological symptoms of dementia, are not addressed in this review.

3.2.1 Pharmacological strategies

Since the late 1960s, biochemical investigation of the brains of individuals with Alzheimer’s disease (AD) has sustained the hope that a clearly defined neurochemical abnormality could be identified and could provide the basis for the development of therapeutic interventions (Francis et al., 1999). Whilst to date this remains a challenge, a number of drugs have been approved to “counteract the pathological consequences of neurotransmitter alterations associated with the disease” (Alvarez, Linares and Mashlia, 2012) and to treat dementia. Tacrine was the first drug approved for the treatment of AD but it is no longer actively marketed due to its role in increasing the risk of cardiovascular and hepatotoxicity side effects associated with taking the drug (Tasman et al., 2011).

Current available licensed pharmacological treatments include three second generation\(^{18}\) cholinesterase inhibitors (ChEIs) - donepezil, rivastigmine and galantamine- and the N-methyl-D-aspartate receptor antagonist (memantine). Other pharmacological therapies,

\(^{18}\) A first generation drug is the first one to show the desired activity, in this case tacrine. Second generation ChEIs demonstrate a similar benefit but have lesser side effects than tacrine.
including Vitamin B12 and folate, oestrogens, anti-inflammatory drugs and statins have also been investigated as treatments for dementia. These therapies are not recommended for routine use as there is insufficient evidence to support their efficacy (Singh and O'Brien, 2009).

ChEls are therefore the mainstay of treatment for mild to moderate forms of AD (Overshott and Burns, 2005; Lleo, Greenberg and Growdon, 2006; Farlow, Miller and Pejovic, 2008) and some evidence suggests they may be effective for the treatment of other type of dementias such as Lewy Body dementia, dementia related to Parkinson's disease and Vascular Dementia. Generally ChEls inhibit acetylcholine and enhance the cholinergic neurotransmission in affected cerebral areas (Farlow and Cummings, 2007). In addition, rivastigmine inhibits butyrycholinesterase and galantamine modulates activity at nicotinic receptors. The clinical significance of these additional mechanisms of actions is not clear (Farlow and Cummings 2007).

Memantine is the approved agent for the treatment of moderate to severe AD. Brain cells damaged by AD release glutamate (a neurotransmitter) in excess amounts and sustained elevation of glutamate causes further cell degeneration in the brain. Memantine selectively blocks the effects associated with the excessive release of glutamate. It can be prescribed on its own or in combination with ChEls (Lee et al., 2011). Nevertheless, to date, there is no evidence that the combined use of memantine and donepezil can add further benefits to patients with moderate and severe AD (Howald et al., 2012).

3.2.2 Tolerability and safety

Each of the anti-dementia drug treatments is available in oral form and rivastigmine is also available in a transdermal patch. The formulation and dose of each treatment are detailed below (National Institute for Health and Clinical Excellence, NICE, 2011).

- Donepezil tablets should be administered once daily normally at bedtime. It is given initially at 5 mg and after one month can be increased to 10 mg
- Galantamine is available as tablets, oral solution or slow release capsules\(^\text{19}\) and should be taken once or twice daily depending on the formulation. Capsules are given initially at 8 mg once daily, and can be increased to 16 mg after 4 weeks of treatment. Tablets and liquid preparation are given twice daily

\(^{19}\) Slow or extended release refers to a solid dosage form which releases a drug in such a manner to allow a reduction in dosing frequency as compared to that drug presented as a conventional dosage form (immediate release).
- Rivastigmine is available as capsules, oral solution or patches. The initial dose is 1.5 mg twice daily and can be increased at intervals of at least 2 weeks up to a maximum of 6 mg twice daily. The patch is started initially at 2.6 mg patch per day, and can be increased to 9.5 mg patch per day.

- Memantine is available as tablets and oral drops and should be taken once daily. Memantine is initially given at 5 mg once daily and then increased in steps of 5 mg at weekly intervals to a maximum of 20 mg daily.

There is evidence that overall the three ChEIs and memantine are safe and quite well tolerated by the majority of people (NICE, 2011). Main adverse effects of ChEIs are nausea, vomiting, diarrhoea, anorexia, abdominal pain, headache, dizziness, tremor, weight loss and fatigue (Overshott and Burns, 2005a). Where these side effects occur they are generally of mild intensity and transient (Takeda et al., 2002). Rates of adverse events are greater with higher doses of ChEIs when compared with lower doses. Slow rate of titration and taking the medication with food can limit some of the adverse affects (Overshott and Burns, 2005a). Common undesirable effects of memantine are dizziness, headache, constipation, somnolence and hypertension (NICE, 2011).

### 3.3 EFFECTIVENESS OF THE DRUGS

#### 3.3.1 Main goals of anti-dementia drugs

The main goals of anti-dementia drug treatments include symptomatic treatment and the slowing of disease progression (Holden and Kelly, 2002; Katona et al., 2007).

**Symptomatic treatment**

From a regulatory perspective, the improvement of symptoms should be primarily assessed in cognition, activities of daily living (ADLs) and overall clinical response. Secondary benefits may include a reduction in neuro-psychiatric and behavioural symptoms (European Medicines Agency, EMEA, 2008). In addition, some experts have suggested that delaying the person’s placement in a Nursing Home, reducing health care costs (Geldmacher et al., 2003; Hatoum et al., 2009) and benefits to caregivers e.g.

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20 Titration means to slowly add a new ingredient and refers to the dosing approaches or schedules of a drug. Slow titration involves starting the drug therapy with a dose that usually is too low to provide benefit in order to allow the system to adjust and minimize side effects.

21 The regulatory perspective refers to the European Medicines Agency - this is the Agency responsible for the scientific evaluation of medicines developed by pharmaceutical companies for use in the European Union. Such perspective is relevant as before a drug can be prescribed, it has to be licensed by the EMA, who scrutinise the relevant data, and if satisfied that the new medicine is effective and safe, issue a license. Here it specifically refers to the guidelines for AD and dementia medication that this Agency published in 2008.
burden relief, improvement in time use, psychological well-being (Lingler, Martire and Schulz, 2005) should be also considered as meaningful and measurable benefits. The assessment of quality of life as an outcome of the pharmacological treatments for AD is at present not mandatory from a regulatory perspective (Broich, 2007; EMEA, 2008). However, it has been increasingly argued that any intervention, including pharmacological, should aim to improve the general quality of life of the people with this disease and their caregivers (Selwood, Thogrimsen and Orrell, 2005; Overshott and Burns, 2005b; Katona et al., 2007) and that quality of life should be measured as a relevant endpoint in clinical trials (Scholzel-Dorenbos et al., 2007).

**Slowing of disease progression (disease modifying effects)**

A debate remains about whether anti-dementia drugs can effectively bring about a change in a fundamental aspect of the progressive neuropathology of AD. An approach to demonstrate the modifying effect of these drug therapies is to show that, in addition to a sustained long-term symptomatic effect, a key feature of the underlying disease process has been altered based on biological markers (O'Brien and Burns, 2010; EMEA, 2008). The most commonly proposed features are the proteins associated with the defining lesions of the disease: Tau and B-Amyloid (Kaye, 2000).

### 3.3.2. Current available evidence: clinical and cost-effectiveness

The next section reviews some of the available evidence about the outcomes and efficacy of these drugs. By and large this evidence is obtained from Randomised Clinical Trials (RCTs) and meta-analysis of RCTs. Although these are considered the most rigorous ways of determining the effectiveness of a drug, their use is limited by ethical concerns and cannot occur over prolonged periods of time. Evidence about the continued efficacy, safety and tolerability of a drug is most often based on non-randomised studies such as open label studies and population studies, or on clinicians’ impressions gained through clinical practice.

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22 RCTs are studies in which people are allocated at random to receive one of several clinical interventions, one of such interventions is the standard of comparison or control. The control may be a standard practice, a placebo or no intervention.
23 A statistical technique for combining the findings from two or more RCTs.
24 A type of study in which both the health provider and the patient are aware of the drug treatment being given.
25 A study of a group of individuals taken from general population that share a health condition.
Clinical effectiveness of ChEIs

At present it is largely agreed that anti-dementia drugs only provide symptomatic relief, as they cannot modify dementia and thus truly slow down its progression (Farlow, Miller and Pejovic, 2008). Evidence from clinical trials demonstrate that the three ChEIs treatments at the recommended dose offer statistically significant, albeit clinically modest, benefits for cognitive, functional (ADLs) and global outcomes. The latter relate to the clinician’s impression of change based on global change scales that assess multiple aspects of the individual’s performance in cognitive, behavioural, and functional domains (Birks, 2006, NICE 2011). Benefits of treatment can be defined as improvement\(^{26}\), stabilization or as a slower decline of symptoms.\(^{27}\)

To date there is no consistent evidence from clinical trials and systematic reviews that anti-dementia drugs can improve quality of life (Takeda et al., 2002; NICE, 2011; Cooper et al., 2013). The challenges involved in evaluating quality of life of PLWD as described in chapter two, and the fact that it is only relatively recently that specific scales to evaluate quality of life in dementia have been developed, are reasons often given to explain the poor quality of the available evidence on this topic in clinical trials (NICE, 2011; Cooper et al., 2013). Nevertheless, evidence from clinical practice suggests that these treatments may help the individual to maintain mood, to cope and interact better with others, and may have benefits on functional outcomes (not included in the standardized scales used in trials). These include, for example, improved involvement in some domestic activities and the maintenance of aspects of personal identity (NICE 2011; Rockwood et al., 2004). In addition, it has been suggested that anti-dementia drugs can improve attention and motivation, may reduce apathy, mood and agitation, and may improve social interaction and involvement in domestic activities (Rockwood et al., 2004). This evidence from clinical practice suggests an effect on quality of life that has not been detected in trials (NICE, 2011).

On the other hand, “treatment failure” is typically defined as an unsatisfactory response within the first year of treatment (Massaud et al., 2010; Gauthier et al., 2003). This “unsatisfactory response” has been operationalized in different ways. In some clinical studies it has been operationalized as a decline after one year of treatment of at least two

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\(^{26}\) For example, ChEIs have been shown to produce improvements in cognitive function, on average -2.7 points in the mid-range of the 70 point Alzheimer’s disease Assessment Scale – Cognitive sub-scale (Birks, 2006).

\(^{27}\) Slower deterioration in patients taking these drugs versus the projected course on placebo (Massoud et al., 2010).
points on the MMSE. Other studies also include decline of functional autonomy. In clinical practice the judgment of the clinician remains paramount in determining response to treatment (Massoud et al., 2010).

To date, no real difference in the clinical effectiveness of the three cholinesterase inhibitors has been proven (Overshott and Burns, 2005) and it is noteworthy that ChEI treatments do not work for all individuals. Approximately one third of treated individuals get better, one third do not deteriorate further and in one third the treatment makes no difference (Overshott and Burns, 2005). There is no available evidence to predict for which patients the medication will work but there is some evidence to indicate that approximately half of the individuals experiencing lack of efficacy with one ChEI can gain benefit from switching to another ChEI (Overshott and Burns, 2005; O’Brian and Burns, 2010).

Clinical effectiveness of memantine
The efficacy of memantine for treating moderate to severe dementia has also been evaluated in several clinical trials. Overall memantine is associated with statistically significant global improvement, as well as improvement of cognitive, functional and behavioural symptoms in individuals with moderate to severe AD. Memantine also appears to have an effect on agitation, aggression and psychotic symptoms and may have the potential to reduce the need for antipsychotic medication. Memantine is likely to have an effect on the quality of life of individuals with severe dementia because they are more likely to experience behavioural symptoms (NICE 2011).

Cost-effectiveness of ChEIs and memantine
Anti-dementia drugs do not cure the condition and do not work for everyone; taking these drugs may, at best, result in temporary and modest improvement in symptoms or delay decline in cognitive function (Birks, 2006). Whilst many experts defend the value of these drugs, others have argued that their cost outweighs their benefits.

Economic analyses that could help decision makers compare the value and benefits of alternative interventions and facilitate resource allocation have been developed over the last years. Cost effectiveness analyses “compare the cost of drugs or programmes that have a common health outcome and quantify cost per health outcome” (e.g. cost per time of institutionalization avoided) (Wu et al., 2003). Cost-utility is a special type of cost
effectiveness analysis and it estimates the ratio between the cost of a health-related intervention and the benefit it produces. Instead of monetary terms, the benefits are expressed in terms of utilities, such as quantity and quality of life (quality-adjusted life years - QALYs).

In the UK the National Health Service (NHS) employs these types of analysis to inform their decisions about efficacy and cost. The most recent evaluation of anti-dementia drugs undertaken by the NICE in 2011, concluded that there are cost savings associated with the three ChEIs and memantine compared to best supportive care (that is, without treatment with any ChEIs or memantine). For moderate dementia, memantine was found not to be cost effective compared with the ChEIs. (NICE 2011, Bond et al., 2012). Accordingly, in the UK, ChEIs are recommended for people with mild and moderate dementia and memantine for those with severe dementia. NICE guidelines recommend that memantine only be used for people with moderate dementia who are intolerant or have contra-indications to AChEIs. (NICE 2011). The 2011 NICE report reversed previous NICE recommendations (2006) that restricted the use of these drugs because of lack of evidence to support their cost effectiveness in mild dementia. ChEIs were previously recommended exclusively for the management of moderate AD and this policy was very controversial.

3.3.3. Interpreting the evidence

The relevance and validity of the available evidence about the efficacy and benefits of anti-dementia drugs has been criticised. Some scholars claim that the methodological quality of most clinical trials is poor and consequently the validity of the results is very questionable (Kaduszkiewicz et al., 2005; Roda, Morgan and Walker, 2009). Accordingly, it is argued that the results of these individual clinical trials, as well as of systematic reviews and meta-analysis using these “flawed” trials are questionable (Kaduszkiewicz et al., 2005).

For instance, it has been pointed out that the clinical trials have been largely drug-industry-sponsored. Evidence suggests that research funded by drug companies is biased to favour the sponsor’s product, showing that industry-sponsored studies are four times more likely to show favourable results than studies funded by other sources (Lexchin et al., 2003). In addition, in the case of anti-dementia drug trials, research has shown that vendor-supported trials tend to use a promotional rhetoric language when reporting the
results of drug trials (Gilstad and Finucane, 2008). For instance, Gilstad and Finucane (2008) showed that whilst the results of vendor-supported trials and those of trials independent of the pharmacological industry can be quite similar, the results are reported in a very different way. Vendor-supported trials tend to stress the drugs "efficacy or effectiveness", whilst independent trials describe the same drug’s effects as small or absent and often emphasise the need for better treatments (Gilstad and Finucane, 2008).

The tendency in these trials to recruit subjects that are young, healthy and free from complex health problems has also been subject to criticism (Gille et al., 2004). This is another important drawback because it raises questions about the applicability of the results to the wider population of older people and in particular to the more frail individuals (Holden and Kelly, 2002).

Another point of controversy is the small and below the threshold for clinical significance difference found between placebo and treatment groups (Kaduszkiewicz et al., 2005; Courtney et al., 2004). This means that differences found between treated and untreated individuals may be statistically significant, but may still be too small to be of any practical value. Because of the high cost of the drugs and the small effect that these drugs have on PLWD, it has been suggested that other interventions such as social care services should be prioritised in public budgets (Logan, 2005).

For some experts, the relevance and validity of the outcome areas chosen such as cognition or functioning to assess the efficacy of the drugs is also a concern. Moreira (2009) draws attention to the links between the controversies around the definition of dementia and the processes of construction of its therapeutic approaches. Historically cognition has been regarded as the core symptom of dementia and the primary goal of anti-dementia drug treatments has been to treat cognitive decline (Graham, 2010). It is argued that over the last decades there has been a shift away from considering cognition as the central domain to broaden the definition and treatment of dementia to include other non-cognitive symptoms such as function, behaviour and more recently quality of life (Leibing, 2009a and b). As a result, these are no longer seen as peripheral symptoms/outcomes of an intervention but as primary goals of any treatment.

Some experts (Graham, 2008; Leibing, 2009a; Moreira, 2009) claim that whilst this re-thinking of dementia and of its therapeutic focus may have had a positive effect on
personhood and person centred care, it has also greatly benefited the pharmaceutical industry. In a context where the efficacy and value of anti-dementia drugs had been questioned, this reformulation of dementia has contributed to the finding of new grounds on which to revise and redefine the utility of such drugs (Graham, 2008; Leibing, 2009a; Moreira, 2009). Accordingly, the type of outcomes and benefits that anti-dementia drugs can claim have been considerably broadened evolving from a focus on cognitive symptoms to a broader focus on other domains including functional, behavioural and quality of life benefits (Moreira, 2009; Leibing, 2009a). As an example Leibing shows that, whilst Tacrine was only meant to improve memory, newer drugs are linked to improvements in activities of daily living, behavioural and psychological problems or quality of life. Likewise, others (Leibing, 2006; Moser, 2008) have pointed out that current marketing efforts of the pharmaceutical industry tend to downplay the cognitive benefits of the drugs and focus on their power for delaying institutionalization or decreasing caregiver burden. These experts argue that these new outcomes are generally broader and more difficult to measure and primarily benefit the interest of the pharmacological industry that keep selling expensive drugs which are of little benefit to the consumer.

Whilst some have criticised the broadening of outcomes being measured, others have welcomed the inclusion of non-cognitive benefits in the belief that they are more meaningful to patients. They advocate that such non-cognitive benefits should be legitimately included in the evaluation of the efficacy of anti-dementia drugs. To illustrate this point, Traynor and Dewing (2002) argued that the choice of outcomes in RCTs has been largely “governed by the requirements of statutory authorities” (2002:4) rather than aiming to capture the full impact of such drugs on the day-to-day lives of its users, and that outcome areas have mainly been decided, designed and measured by professionals leaving little opportunity for PLWD and their carers to voice their opinions about those outcomes that are meaningful and relevant to them.

Another point of controversy is the relevance and sensitivity of the scales used in clinical trials to detect the impact of drugs (Rockwood et al., 2004). Rockwood et al. (2004) claim that whilst these are largely standard psychometric tools, they may “not necessarily capture effects that might be most relevant to patients, their caregivers and treating physicians” (2004:956). They developed a tool (Goal Attainment Scaling, GAS) to evaluate the efficacy of anti-dementia drugs in an individualised manner. In the GAS,
PLWD and/or their caregivers are asked to set their own goals for medication, which are then reviewed in regular check-ups with their clinician. Individual proposed goals of treatment can be similar to those identified in the literature such as cognition, functioning, behaviour or they may nominate other reasonable goals such as social interaction or leisure activities. Rockwood et al. (2002) have shown that this tool (GAS) can be more efficient in detecting benefits from drugs than traditional scales used in clinical trials. They concluded that the regular re-assessment of treatments goals with a clinician can help PLWD and their caregivers better understand the benefits of the drug and “not be unduly influenced by a single memorable event or by incidents that are not representative but whose saliency is raised by having happened recently” (2002:505).

Some scholars have raised ethical concerns about how the benefits from anti-dementia drug treatments could paradoxically have a negative impact upon the wellbeing and quality of life of PLWD (Post, 2001). Specifically, it is argued that these drugs may extend the earlier stages of the disease or prolong morbidity and this could result in a longer period of suffering and distress for the PLWD and/or caregiver. In addition, unrealistic hopes about the benefits of the drugs could cause anxiety, frustration, or depression in PLWD and caregivers, since benefits are transient and the disease will inevitably progress at some point (Post, 2001). Huizing et al. (2006), in a small scale qualitative study, showed nevertheless that caregivers did not share these concerns raised in the academic literature and that overall they viewed any delay in cognitive decline as positive. Yet this debate is interesting as it calls attention to the responsibility of researchers and clinicians to ensure that interventions that aim to improve cognitive functioning do, in addition to this, have a positive impact on quality of life and wellbeing (Woods, 2006).

3.4 CLINICAL PRACTICE

In clinical practice, the prescription of anti-dementia drugs is made by a clinical specialist as soon as the diagnosis is made. This is done as (uncontrolled) evidence suggests that an early, persistent and continuous treatment can maximize the benefits of these drugs on cognition and functioning (Singh and O’Brien, 2009).

28 Uncontrolled evidence refers to evidence that has been found in non-randomised studies. Whilst such studies can help to understand adverse effects and long-term use of therapies, this type of evidence has to be used with caution as such studies may be at a high risk of bias (Higgins and Green, 2011).
As the three ChEIs seem to have similar efficacy, choice is mostly based on tolerability, ease of use (American College of Physicians) or cost (NICE, 2011). Across Europe, donepezil seems to be, by and large, the most commonly used ChEI (NICE, 2009; Pariente et al., 2008). Similarly in Ireland, a recent national study examining the use and prescription patterns of anti-dementia drugs from 2006 to 2010 (Brewer et al., 2013), showed that during this period 24,238 individuals had initiated treatment with an anti-dementia medication, and that donepezil and memantine were the most frequently prescribed anti-dementia drugs (65.1% and 19.1%, respectively). The predominant use of donepezil is not surprising as it was the first second generation ChEI marketed in most European countries (Pariente et al., 2008) and until recently was the only drug with a once a day dose.

Whilst ChEIs and memantine are the current drug treatments for AD, the evidence about their use and benefits in the long term is scarce (Lleo et al., 2006). Most published clinical trials have assessed the efficacy of the drug over three, six or 12 months (Takeda et al., 2006; Rodda, Morgan and Walker, 2009; Howard et al., 2012), with a consequent lack of evidence for continuing treatment beyond this time frame (Seltzer, 2007). A number of open-label studies have assessed the long-term efficacy of cholinesterase inhibitors (Geldmacher, 2003; Farlow and Lilly, 2005; Burns, Gautier and Perdomo, 2007) by and large suggesting that cognitive levels of ChEI-treated individuals remain higher than those predicted for a hypothetical placebo group for periods of up to four to five years (Winblad and Jelic, 2004; Seltzer, 2007). This is in keeping with the views of caregivers and patient experts that claim that the benefits of taking these drug treatments may last up to four years (NICE, 2011).

Nevertheless, concerns have been raised regarding the adverse effects associated with long-term use of anti-dementia treatments. Population-based studies have shown a rare but increased risk of cardiac complications (syncope, bradycardia, permanent pacemaker insertion) and hip fracture in older adults with dementia who are taking cholinesterase inhibitors (Gill at al., 2009; Park-Wyllie et al., 2009).

Kurz and Lautenschlager (2010) suggest a “drug-free interval of several weeks” as a possible way to determine if a treated individual still benefits from a drug treatment. Nevertheless, this approach has not been widely applied and the effects of discontinuing
medications are not well documented to date. There are mixed results about the effects of discontinuation; whilst some small scale studies suggest that discontinuation can be done safely and with little negative effects for the individual (Howard et al., 2012), other studies have reported a rapid worsening of the condition after discontinuation (Herrmann et al., 2011).

International guidelines and recommendations about the continuation or discontinuation of treatment in the long term are overall vague (Gardette et al., 2010; Herrmann et al., 2011). The guidelines for the treatment of AD of the College of Physicians, and those of the American Academy of Family Physicians (2007), suggest that decisions about continuation should be individualised. In these guidelines, reasons for discontinuation include tolerability, cost and lack of efficacy. However, it is also acknowledged in the guidelines that efficacy may be challenging to assess. The French Consensus Statement and the Canadian guideline (as cited in Herrmann et al., 2011) on severe dementia concurred that drug treatments should be continued as long as clinical benefit persists or until benefits can no longer be demonstrated. In the UK, it is suggested that “treatment should be continued only when it is considered to be having a worthwhile effect on cognitive, global, functional or behavioural symptoms” (NICE guidelines, 2011:67). This worthwhile effect should be determined by a specialist team and be based on regular cognitive, global, functional and behavioural assessments of the PLWD as well as on carers’ views on the condition over time. Interestingly no reference is made to the importance of the viewpoint of the individual swallowing the drug on a daily basis. In Ireland there are no specific guidelines about the prescription or continuation of these drug treatments and prescribing doctors at memory clinics often discharge patients back to their GPs for on-going care and review.

In experimental contexts, up to a quarter of individuals seem to discontinue the treatment, most often due to adverse effects. The rate of withdrawal of PLWD from drug treatments in clinical settings is not well documented. Some studies indicate that the drop-out rate in clinical practice is higher than in clinical trials. For example, Umegaki et al. (2008) showed that in Japan 53% of people had discontinued the drug after two years while in Ireland around 40% discontinued within a four-year period. Nevertheless, other research studies have reported a high rate of individuals treated in the long term; for example, in the study by Gardette et al., 2010, only 12.7% of the sample of PLWD discontinued treatment after two years. These studies indicate that, in clinical practice, the main
reasons for drug treatment discontinuation are institutionalization, hospitalization or change of doctor and the worsening of the condition; and to a lesser extent, lack of effectiveness of the medication and the presence of side effects (Gardette et al., 2010; Umegaki et al., 2008).

3.5 THE VIEWS OF PLWD AND CAREGIVERS

Despite considerable efforts being made over recent years to evaluate the efficacy of anti-dementia medication, very little is known about what PLWD and caregivers most value about these treatments and about their personal experiences in taking anti-dementia medication (Howard & Rockwood 1995, Traynor and Dewing, 2002; Traynor, Pritchard, and Dewin, 2004). Due to their cognitive deficits, the capacity of PLWD to reliably report on their experiences has often been questioned and traditionally PLWD have been silenced and excluded from research. With increasing advocacy work going on in the area of dementia, and the recognition of the rights of people living with dementia, some of the earlier held presumptions about the lack of capacity and insight of PLWD are now being questioned (Wilkinson, 2002). To date several studies using qualitative methodologies have confirmed that PLWD can be engaged in research and are well able to contribute and voice their opinions (Train et al., 2005; Jonas-Simpson and Mitchell, 2005; Steeman et al., 2006; Droes et al., 2006).

In clinical research, RCTs have traditionally been recognised as the gold standard and the benefits of using RCTs by way of creating scientific knowledge have been largely demonstrated. However “to rely solely upon this method restricts the areas that are open to research and narrows access to useful knowledge” (Gibson et al., 2004:422). By eliciting the voices and experiences of PLWD about the use and efficacy of these drugs, qualitative approaches can widen and complement the current knowledge and help to generate new ideas and concepts (Gibson et al., 2004).

A number of studies have elicited the views of caregivers’, clinicians’ and PLWD about anti-dementia drugs. These studies have investigated a broad number of topics and are methodologically diverse. However, with the exception of two recent studies (Hutchings et al., 2010a and b; and Smith et al. 2011), most of the literature provides a fragmented picture of the topic. These two studies (Hutchings et al., 2010a and b; and Smith et al. 2011) are of great relevance to this thesis as they represent the first attempts, as far as I am aware, to investigate people’s experiences of being prescribed and using anti-
dementia drugs in a holistic manner. In addition, it has to be noted that most studies have elicited the views of caregivers rather than the views of PLWD. There is a paucity of research exploring the views, experiences and concerns of PLWD.

3.5.1 Starting the drug treatment

An important area of investigation relates to the willingness of caregivers and in some cases PLWD to try or pay for a new (hypothetical) treatment for dementia. These studies have elicited important information on attitudes and preferences for treatment (Oremus and Torride, 2008). Findings suggest that side effects (Karlawish et al., 2001; Wu et al., 2003; Lindstrom et al., 2006) and cost (Konig and Wettstein, 2004; Werner et al., 2002) are core issues for caregivers and PLWD. These may influence their attitudes to and may inform their decisions about whether or not to accept drug treatment. The literature shows that although some PLWD may question the use of high-cost drugs (Lindstrom et al., 2005) most caregivers and PLWD are willing to pay for a drug to treat dementia (Konig and Wettstein, 2004).

The literature suggests that most caregivers hold positive attitudes toward new dementia drugs (Karlawish et al., 2003; Huizing et al., 2006; Oremus and Tarride, 2008). When the drugs do not involve potential risks for the person with dementia, most caregivers would be willing to have their relative use them. In the case of potential risks, the caregiver’s subjective appraisal of the current quality of life of the person with dementia and other factors, such as dementia severity and caregivers’ characteristics (age and education), may importantly influence their willingness to have their relatives try a new dementia drug. Where more positive evaluations of the PLWD quality of life arise, findings show a higher likelihood of risk taking and of trying new drugs that could slow the progression of the condition (Karlawish et al., 2001 and 2005).

In addition, caregivers and PLWD seem more willing to try and pay for a new medication when the expected outcome for the PLWD is positive or is perceived as valuable (Karlawish et al., 2000; Konig and Zweifel, 2004). Survival, maintaining current functioning and delaying nursing home placement are some of the most popular outcomes for using a hypothetical drug for dementia. Oremus and Tarride (2008) noted that PLWD and caregivers’ attitudes to drug benefits suggest the presence of “mutual altruism” among them: caregivers tend to attach greater value to PLWD-related benefits, whilst PLWD tend to place greater value on not being a burden to their caregivers.
Two factors that may play an important role in the initiation of anti-dementia drugs are the caregivers’ and clinicians’ perceptions of treatment availability and effectiveness; and of resource capacity (Hutchings et al., 2010b). Higher public awareness and information about the existence of anti-dementia treatments through the media, internet and the pharmacological industry’s marketing, seemed to impact on treatment initiation. This may have mobilised caregivers to pursue diagnosis and pharmacological treatment for their loved ones. On the other hand, ageist attitudes and health professionals’ negative perceptions of the effectiveness of these treatments can act as barriers to accessing and initiating anti-dementia treatments (Hutchings et al., 2010b). The second factor, “resource capacity”, refers to clinicians’ workload and caregivers’ availability to ensure compliance with treatment. The views of PLWD about reasons for initiating drug treatment may be difficult to explore due to their difficulties in remembering discussions about the treatment (Hutchings et al., 2010b).

A key concern emerging from the literature relates to the limited involvement of the individual living with dementia in decision-making of drug treatment (Hirschman et al., 2004 and 2005; Hutchings et al., 2010a). Generally, the findings suggest that the influence of PLWD on decision-making is minimal and that PLWD largely rely on their caregiver to make decisions about treatment (Karlawish et al., 2001 and 2002; Hutchings et al., 2010a and b). This is in contrast with their wishes to be involved in decisions about any treatment that could affect their lives (Hirschman et al., 2005).

The level of involvement of PLWD in decision-making about anti-dementia medication seems to be mediated by the caregiver’s assessment of the capacity of the person with dementia to consent and his/her impression of the level of insight of the person with dementia about the condition (Karlawish et al., 2001; Hirschman et al., 2004; Karlawish, 2008). The lack of involvement of the PLWD in the medication treatment process may be disempowering for the PLWD who may be often left out of these processes. In addition, such practices can have macro structural implications such as contributing to unequal access to available treatments (Hutchings et al., 2010b). If treatment seeking mostly depends on caregivers, those PLWD with no informal caregivers or advocates who could promote the prescription of treatment and ensure compliance with treatment, and PLWD perceived by their caregivers as having severe dementia and/or a poor quality of life, may
be left with fewer chances of starting medication (Karlawish et al., 2001, Hirschman et al., 2004).

3.5.2 Expectations

Between 2005 and 2010, five relevant research studies have looked at lay people's expectations about anti-dementia medication. These studies differ a little from the current thesis insofar as the majority of participants in these studies had been on the drugs for very long periods (up to seven years) and were interviewed retrospectively about their initial expectations.

The findings suggest that caregivers' main expectation may be related to the stabilization of the condition (Lindstrom et al., 2006; Andersen et al., 2008; Smith et al., 2011). Three main aspects of stabilization have been highlighted, namely maintaining the person's current functioning level (Traynor and Dewing, 2002; Lindstrom et al., 2005; Andersen et al., 2008; Smith et al., 2011), retaining abilities that would help the person to perform activities that he/she enjoyed (Traynor and Dewing, 2002; Smith et al., 2011) and maintaining the ability of the person with dementia to relate to their loved ones (Lindstrom et al., 2006). Caregivers also expected the anti-dementia treatment to slow down the decline of the disease and make it more gradual (Lindstrom et al., 2006; Hutchings et al., 2010a; Smith et al., 2011). To a lesser extent caregivers expected the medication would restore, enhance or improve lost capacities. Some caregivers referred specifically to their expectations about memory improvement. (Lindstrom et al., 2006; Andersen et al., 2008; Smith et al., 2011). Expectations about improving quality of life were made in some research studies (Lindstrom et al., 2006; Hutchings et al., 2010a, Smith et al., 2011).

Like their caregivers, PLWD expected the anti-dementia drug treatment would help them to maintain their abilities and to slow down the progression of their deterioration. These studies also suggest that PLWD were more optimistic than their caregivers about the potential that drugs had to improve and restore lost capacities. One of these studies showed that PLWD hoped that in the long term, the treatment would help them to restore a sense of normalcy in their lives (Hutchings et al., 2010).

Most of these studies concluded that the PLWD and caregivers' expectations went beyond existing evidence of what the drugs could actually do. Claims about the need for
better and more accurate information about the drug treatment given to PLWD and their caregivers were made in many of these studies. Also some studies warned about the negative effect that high expectations could have in the long term if PLWD and caregivers' anticipated benefits were not realised.

3.5.3 Continuation with treatment and benefits

Caregivers play a key role in ensuring adherence to treatment and on taking decisions about drug treatment continuation (Hutchings et al., 2010b; Smith et al., 2011). Some studies suggest that caregivers' decisions about continuation of anti-dementia treatments may be primarily based on a subjective risk - benefit assessment of the drug (Lindstrom et al., 2006; Huizing et al., 2006; Oremus et al., 2007). These studies suggested that caregivers prefer the PLWD to continue treatment if in their view the therapeutic benefit of the drug outweighs any experienced harm from it (Oremus et al., 2007). For example, there is some indication that side effects, such as weight loss and loss of appetite, that are perceived as less severe seem to be well accepted by caregivers, but most caregivers would be reluctant to accept other adverse effects (Oremus et al., 2007).

Different approaches have been used to investigate the benefits of drugs from the point of view of the caregivers and of PLWD. These include: the completion by caregivers of scales indicating their impression of the benefits of taking an anti-dementia drug (Shua Haim et al., 1997); focus groups involving PLWD, caregivers and clinicians (Post et al., 2001); surveys asking people using the drugs and their carers to report if the drugs worked for them and if so how (Alzheimer’s Society UK, 2004); and interviews with caregivers (Huitzing et al., 2006, Smith et al., 2011) or with PLWD and caregivers (Hutchings et al., 2010a).

Findings from this literature suggest that PLWD may more easily recognise the benefits of medication than their caregivers (Hutchings et al., 2010a). PLWD have reported benefits to cognition, such as being less forgetful (Alzheimer’s Society 2004; Hutchings et al., 2010a), feeling more confident about their cognitive capacities (Post et al., 2001), and having greater clarity of mind and alertness (Post et al., 2001; Alzheimer Society, 2002 and 2004; Hutchings et al., 2010a). They have also cited other improvements including improved mood (e.g. optimism, confidence, feeling brighter, happier) and better functioning (Post et al., 2001; Alzheimer Society 2002 and 2004; Hutchings et al., 2010a). In addition, PLWD have reported that the medication was working if they felt...
they were not getting worse. An important conclusion is that the experienced benefits of taking drugs may contribute to the PLWD remaining in the community rather than moving into an institution, maintaining their independence and personhood (“mind”) and being more socially active (Alzheimer Society, 2004; Hutchings et al., 2010a).

Findings on perceived benefits as reported by caregivers are more ambiguous. In the Alzheimer’s Society (UK) survey, 73% of the respondents felt that medication worked or had worked for the PLWD. Many other studies, however, could not find such clear evidence of concrete benefits. In the area of cognition and functioning, results from the current studies are equivocal. Some studies have reported benefits related to an improvement in memory, orientation, clarity of mind, verbal skills, alertness and attention (Shua Haim et al., 1997; Post et al., 2001; Alzheimer’s Society, 2004; Hutchings et al., 2010a), whilst others report little improvement in cognition (Smith et al., 2011; Huizing et al., 2006) or functioning (Hutching et al., 2010b; Smith et al., 2011). Behavioural and psychological benefits of the drug treatments have been more often recognised by caregivers. Smith and colleagues (2011) suggested that this was the only area where caregivers could clearly identify benefits. In their sample, a high proportion of study participants felt the PLWD was calmer, more amenable, and less anxious as a result of drug treatment. Other caregivers have also reported optimism and the PLWD being happier and brighter. Halting and slowing down the progression of the condition are the outcomes most frequently reported by caregivers.

Some studies have also highlighted the ambivalence found in the PLWD and caregivers’ evaluations of drug treatment (Hutchings et al., 2010a; Smith et al., 2011). Factors contributing to ambivalence include the absence of a standard to compare, the ongoing and fluid deterioration that characterises dementia (“good and bad days”) and the hypothetical scenario of what would have happened if the person had not been treated. Smith and colleagues (2011) pointed out the difficulties in teasing out how positive care practices, rather than the drug itself, could be contributing to reported improvements.

In addition, some of this literature shows that caregivers evaluate the benefits of drug treatments in the context of the care relationship (Smith et al., 2011); in some cases, drug treatment outcomes are perceived as facilitating the care relationship in aspects such as intimacy, hope and enabling carers to cope better (Hutchings et al., 2010; Smith et al., 2011). Other caregivers experience a negative impact from drug treatment as, at times,
ensuring compliance with medication regime may add burden to care (Huizing et al., 2006; Hutchings et al., 2010). In addition, increased awareness may make caring for the PLWD more difficult, for example the PLWD may complain more often about being bored, may want to take more decisions, or may want to drive (Post et al., 2001).

The studies conducted over the last years show that in addition to the evaluation of risk and benefits, caregivers’ decision making about the continuation of a drug treatment is influenced by the uncertainty of what would have happened in a non-medicated scenario, fears of discontinuing the medication (especially fears of rapid decline), and trust in the prescribing physicians (Hutchings et al., 2010b; Smith et al., 2011). Even when caregivers’ appraisals indicate that the drug treatment may not work, most of them seem to prefer to keep their relatives on treatment (Smith et al., 2011).

3.5.4 Discontinuation of treatment

When experts have been consulted about the criteria for drug discontinuation, there is some consensus about the need to consider the PLWD and caregiver preferences and the presence of troubling side effects (Herrmann et al., 2011). Whilst this may seem straightforward, one study showed that PLWD and caregivers do not necessarily hold similar views about their preferences for stopping the medication (Lindstrom et al., 2006). Most of the PLWD in their sample felt the medication would be always worthwhile, whilst the majority of the caregivers felt that there would come a point where medication should be stopped (Lindstrom et al., 2006). Lindstrom and colleagues argued that this may be due to difficulties experienced by PLWD in hypothesising about and planning for their future and they stressed the inclination of PLWD to “live each day at a time”. Also, although caregivers may be aware of the need to discontinue the antideementia medication at some point, this may represent for some caregivers a way “of giving up” and loss of hope (Huitzing et al., 2006).

A rapid decline or an overall worsening in the mental and /or physical health of the PLWD seems to be the most common reason reported by caregivers, clinicians and experts for stopping the use of medication in absence of (bothersome) adverse effects. However, defining rapid and overall decline is a challenging endeavor (Herrman et al., 2011).
3.6 COMPETING SPHERES IDENTIFIED IN THE LITERATURE

In summary, the international body of literature on drug treatment and dementia reviewed in this chapter shows that there are at least three competing spheres operating simultaneously in the area of anti-dementia medication research. The first sphere is dominated by experimental or "scientific" knowledge. In this sphere knowledge is generated by clinical trials, systematic or meta-analysis and open label studies. Key stakeholders are the pharmaceutical industry, regulatory bodies, physicians involved in research and health policy makers. The main issues are related to proving "statistically significant" benefits and the extent to which these treatments are cost-effective. The language used often makes reference to regulation requirements, evidence, statistics, profits and value for money.

The second sphere is related to clinical practice. This sphere involves health professionals facing decisions in their daily practices about drug prescription. Here the questions that may arise concern issues such as how long these drugs should be prescribed to patients, what information should be shared with patients and to whom should clinicians talk about the drugs. In this sphere the scientific knowledge available from experimental trials and other studies is combined with professional experience, impressions and judgements about the drugs and also with the clinicians' workloads and drug availability. Main concerns relate to ethical issues, daily practices and potential side effects. Practice concerns are often linked to the vague guidelines available about these drug treatments and the heterogeneity of the personal, family and health circumstances of their patients. Key stakeholders in this sphere are health professionals involved in diagnosing, prescribing and following-up drug treatments. The language relates to clinical improvements, to evidence that is clinically meaningful, to side effects, to ethics and to a lesser extent financial issues.

A third sphere relates to the personal lived experiences of the "real" consumers of these drug treatments – mainly PLWD and their caregivers. This sphere also includes interest groups such as Alzheimer’s Associations and patient experts that represent and advocate on behalf of PLWD and their relatives. Main issues defining this sphere are the multiple and complex experiences of living with or caring for someone with dementia, the risks and side effects of the drugs, ensuring compliance with treatments and living a good life for as long as possible. The language is more often related to present hopes and fears, to
maintaining the personhood and past values of the PLWD, and to uncertainties about the future. This third sphere has been largely ignored when conducting some of the most significantly funded research studies on drugs. Also, as this chapter has shown, the views and experiences of PLWD are severely under-represented.

These three identified spheres are contextualised in a global space that represents how dementia and its therapeutic interventions are understood, conceptualised and framed. These three spheres are interconnected and at times compete. Nonetheless despite the inherent tensions and contradictions, it could be argued that the overarching theme which connects these three spheres is the common goal of trying to facilitate the best life possible for PLWD and their caregivers (See Figure 3.1).

Figure 3.1: Interconnected spheres relating to anti-dementia medication
This chapter has illustrated the growing interest and use of quality of life as a primary or secondary outcome measure in anti-dementia drug treatment clinical trials. The objective has been to ensure that the benefits of the drugs do not leave “people feeling less positively about themselves” (Woods et al., 2006:220) and that in addition to their potential effect on cognition, these drugs have a positive effect on the wellbeing and quality of life of PLWD. Current evidence from RCTs about how these drugs could impact on quality of life is not conclusive, partly due to the inherent difficulties in the measurement of quality of life for PLWD and also, as it is only recently that validated specific tools have been included in clinical trials. Whilst the evidence remains inconclusive, it seems that some clinicians have observed some benefits of anti-dementia drugs that are not traditionally measured in clinical trials that could have an important impact on the quality of life of PLWD. However, many other clinicians remain sceptical about the potential of drugs to improve the lives of PLWD and suggest that other (psychosocial) interventions should be promoted instead.

The literature suggests that PLWD and their caregivers value drug treatment and find it meaningful and beneficial in terms of facilitating the person with dementia to stay at home, to maintain his/her independence and personhood, and to be more socially active. They are willing to start a treatment that could alleviate and slow down the symptoms of dementia; and overall their hopes and expectations about anti-dementia drugs are higher (or different) from what might be concluded from the research. However, research studies exploring the benefits that taking the anti-dementia drugs may have for the lives of PLWD are very limited, and of those, the views of family caregivers have largely been prioritised over the views of PLWD themselves.

3.7 CONCLUSION

The literature addressed in this chapter shows that the topic of drug use specifically to treat dementia has attracted the attention of scientists, practitioners and consumer groups. Based on the extant literature, the chapter has argued that anti-dementia drugs (either ChEIs or memantine) have a small but demonstrable benefit for some (but not all) individuals living with dementia and can provide some symptomatic relief (cognition, function, global outcomes and to a lesser extent behaviour). However, their capacity to prevent or modify the progression of the disease still remains unclear (Farlow, Miller and Pejovic, 2008). Defining the efficacy or failure of treatment is not straightforward. Efficacy has been defined as improvement or stabilization of symptoms, but also as a
slower decline of dementia. Whilst this seems achievable in clinical trials, in real life evaluating such benefits remains a great challenge, as there is no information as to how the individual would have progressed in a non-treated scenario. Likewise the definition of treatment failure remains a grey area (Gauthier et al., 2003), and it is often operationalized as a decline in cognitive tests (such as the MMSE), and/or deterioration of functioning or behaviour, and such evaluations are based on scales and on the judgements of treating clinicians who are encouraged to take into consideration the caregivers’ views.

The reviewed literature also raises concerns about whether anti-dementia drugs are cost effective. Cited in this chapter is the most recent UK NICE evaluation that describes ChEIs as cost-effective treatments for mild and moderate dementia, and memantine as cost effective for the treatment of severe dementia compared to best supportive care.

The benefits of the long-term use of anti-dementia medication are still controversial and there is no clear international consensus about when and why drug treatment in clinical settings should be discontinued. The chapter highlights the lack of clinical guidelines about the use of these drug treatments in Ireland.

Finally the chapter has also reviewed the Social Science literature pertaining to drug therapies for PLWD. The paucity of studies undertaken to date which included the views of PLWD about drug use has been shown. The chapter argues for the need to include the views of PLWD and their caregivers in this traditionally medicalized area of research and has reported on a growing body of research exploring caregivers and to a lesser extent the expectations of PLWD and the experienced benefits of taking these drug treatments. The chapter has highlighted the fact that until very recently, the Social Science literature has provided only a limited and fragmented exploration of this area. The views and experiences of PLWD about the use of these treatments have been largely under-represented. This constitutes a major gap in the literature and one which this thesis will help to narrow.

Findings from the Social Science literature indicate that caregivers value medication for treating dementia and feel it is worthwhile. The literature shows that decision-making about the initiation and continuation of drug treatments may be based on caregivers’ rational evaluation of the risks, monetary cost and perceived benefits of drug treatment.
along with sentiments such as hope, uncertainties about the future, fears and trust. However little is known about the relevance and meaning that such elements (risk, cost, benefits, sentiments) may have for PLWD, or whether other factors may be more significant to them.

The literature reviewed in this chapter has shown that caregivers and PLWD expect that drug treatments might help to maintain functioning, slow down or improve the condition. The review of the literature has identified the benefits that PLWD and caregivers report after drug use. However, it has also shown that most of these studies, whilst listing benefits, have not explored the meanings that PLWD and caregivers confer to such benefits and the significance that such benefits may have for their quality of life. Again this thesis will generate new information about this aspect of anti-dementia drug treatment.

A perusal of the Medical and Social Science literature on drugs has shown that there are at least three competing and interlinked spheres in discourses about drug treatments. The first is the sphere of the pharmaceutical industry, regulatory bodies and policy makers that seeks to determine the efficacy of the drugs and if and when drugs are cost effective. The second sphere relates to practices in clinical settings whilst diagnosing dementia, prescribing and making decisions about long term use of such treatments. The third sphere is occupied by the individuals with dementia who are taking the drugs, and their caregivers. Emerging issues in this sphere relate to hopes, fears and uncertainty. The literature argues that a broader understanding of dementia may have led to a greater focus within each of the spheres over quality of life issues. Accordingly, whilst these spheres may have some competing interests and agendas, the chapter argues that they share the common goal of promoting the best possible quality of life for PLWD and caregivers. Quality of life in this context remains largely unexplored and is a major focus of the thesis.

Identified gaps in the literature
At the time of starting this thesis and after conducting the first literature search, I became aware that very few studies had been reported on in the literature involving the participation of PLWD. Where lay peoples’ views were sought about drugs and dementia they tended to be predominantly the views of family members and ironically not the views of the person swallowing the tablet daily. Another deficit noted in this literature
was that whilst some studies had explored family members’ views about particular issues relating to the drugs, their cost, willingness to pay and perceived outcomes, none had looked at the overall experience of drug commencement, drug impact including side effects, and drug continuation from the perspective of dyads. In these studies, often the lay persons’ views were compared with scientific evidence and no effort was made to actually document the way the people living with dementia and their caregivers together perceived the drug was impacting on their lives. Based on the literature review an open invitation existed to delve into this new area previously unexplored. There was an opportunity to gain new and original insights into how older people framed having dementia, what their individual experiences were of taking drugs to treat dementia and how they experienced life after being diagnosed with dementia whilst taking this medication. Chapters five and six will report findings on these topics but before presenting such findings, the next chapter will describe in detail the methodology used in this thesis.
CHAPTER FOUR: RESEARCH METHOD

4.1 INTRODUCTION

Chapter two critically reviewed the international literature on quality of life and quality of life in the context of older people with dementia. Based on a review of a different body of literature, chapter three provided insights into the mainstream drug treatments currently prescribed after the onset dementia and discussed the debates and controversies in this literature about the extent to which drug treatments may or may not benefit peoples’ lives and quality of life. These two bodies of literature (quality of life and anti-dementia drugs and their potential benefits) have also helped to shape the research questions explored in this thesis and have informed the overall design of this study. This chapter now shifts the focus of discussion away from the literature to the research methodology employed in the study. The chapter is divided into four main sections. The first introduces the reader to the broad aims and objectives of the study and to the ethical implications of the approach taken. The second presents an overview of the research design used in this study and describes how participants were recruited to the research, their profile, and from whom, where and when the data was collected (the follow-up design) and the approach used for data analysis. Following this, an overview of how the researcher dealt with evaluating the quality of the research is provided.

4.2 RESEARCH QUESTIONS

This thesis is concerned with issues relating to quality of life and use of anti-dementia drugs in dementia. To address this topic and in keeping with the principles underpinning the dementia frameworks informing this thesis, I believed that people living with dementia themselves and their relatives are best positioned to discuss their experiences and to evaluate their quality of life. This was also consistent with my understanding of quality of life as a subjective experience. Thus, a group of 14 PLWD recently diagnosed with dementia and prescribed an anti-dementia drug at a memory clinic in a metropolitan hospital in Ireland, and their family care-partners (dyads) were invited to participate in this study.
The questions this thesis sets out to explore include:

- How do, people recently diagnosed with dementia and their primary care-partners, think and talk about the quality of life of the person living with dementia?
- What understandings and meanings do these people attach to the quality of life of the person living with dementia?
- What challenge, if any, does having dementia pose to their understandings of quality of life?
- What are their understandings and expectations of using a drug to treat dementia? How do participants expect the drugs will affect their quality of life?
- What are their experiences of using these drugs? How do participants talk about the benefits of the drugs?
- How, in their view, does taking a drug to treat dementia affect quality of life?
- Is there any difference in quality of life appraisal over time between those who believe the drug works and those who were of the view it failed?
- How do data collected using a normative and a micro social constructionist approach differ?
- What are the main strengths and the limitations of using each approach?

4.3 RESEARCH METHODS

Since the thesis is concerned with getting to the heart of several complex questions the approach taken was in essence qualitative. A qualitative approach is best positioned to explore this phenomenon in depth, and to present individual differences and the potential complexity of the subject under study. Qualitative research is exploratory in nature and permits a description of life “from the inside out” from the point of view of subjects (Sarantakos, 2005). Also a qualitative approach “supports a way of looking at research that honours an inductive style, a focus on individual meaning, and the importance of rendering the complexity of a situation” (Creswell, 2009: 4).

In addition, a dementia-specific quality of life scale (QoL-AD) has been chosen to represent the traditional way in which quality of life in dementia has been investigated (for further information see chapter two, section 2.5).

Throughout the thesis, findings and conclusions drawn from the subjective approach to quality of life will be juxtaposed and critically compared with data on quality of life
obtained from administering Common findings of both approaches will be identified, and where divergences arise, they will be used to further discuss and expand understanding of the topic.

4.4 ETHICS AND FIELDWORK

This thesis has involved a sample of people living with dementia and their carepartners, and using a social constructionist approach, has explored the ways in which they think and talk about the quality of their lives and their experiences with anti-dementia medication. It has also collected data about quality of life using a scale and PLWD themselves were given the opportunity to assess it. In the approach taken in this thesis then the voices, experiences and evaluations of PLWD and their relatives have been central. Methodological approaches that facilitate research with, rather than on people are considered good practice in health research. Nevertheless, this methodological approach in dementia research can be fraught with challenges since one main challenge lies in the ethics of the study.

Ethics in dementia research are in part similar to the ethics of any other social research that involves human beings, and includes gaining ethical approval from the relevant research and ethics committee/s, ensuring that no participant is involved in the study against his/her will and ensuring that participants are not exposed to undue harm. These ethics have particular meaning and application in dementia research due to the cognitive problems those experiencing the illness have and due to some of the challenges involved in gaining consent from those who may lack capacity or those who may have communication problems. These are issues that through the development and different stages of the thesis I have carefully reflected about.

An important issue at the early stage was the extent to which the topic chosen was relevant to these people and their lives, and how could this research benefit them. At this time I had planned to also include in this thesis the views of the Health Service Professionals involved in the memory clinic, but as I progressed on my work I realised that this could distract my attention from what to me was the real focus of this thesis (PLWD and their CPs) and I decided not to involve them. Also, the relevance of the topic, and the implications for practice, research and policy development are discussed in chapters one to eight of the thesis.
Another relevant issue at the early stage of the study, was gaining approval from relevant ethical Committees. Other ethical considerations and implications of this research will be discussed later in this chapter (see sections 4.4.6 and 4.4.7). In addition, ethical considerations at the end of the research are also relevant, for example participants were asked if they would like to receive a summary of main findings once the thesis was completed and they were assured that their wishes would be respected. Efforts will be made to disseminate the findings in relevant forums such as international conferences and relevant scientific journals. The next section now describes the relevant steps taken since the study was first designed to the collection of the data.

4.4.1 Ethical Approval

To gain approval for conducting this study, two different ethical committees were approached. The first was at Trinity College Dublin and the second at the Hospital (St James’s) where the sample was recruited.

Ethical approval from the Trinity College was obtained in December 2009. Once this approval was obtained the Mercers Institute for Successful Ageing (MISA) memory clinic in St. James’s Hospital was approached as a potential site to access the sample. This memory clinic was envisaged as the ideal site for recruitment as memory clinics are primarily concerned with the diagnosis and treatment of memory problems (Lindesay, Marudkar, Van Diepen and Wilcock, 2008) and thus, could facilitate recruitment and enable me to interview participants as close as practicable28, to the time of diagnosis and the commencement of the drug treatment.

This memory clinic is one of the 14 memory clinics in Ireland (Cahill et al., 2008). It is a national clinic that offers diagnostic, treatment and information services to people experiencing memory or cognitive problems (Cahill et al., 2008). The clinic does not routinely offer follow-up services and the overall policy there is, following assessment, diagnosis and disclosure, to discharge patients back to the care of their General Practitioners (GPs). It was chosen for its national scope and because it was a convenient site for the researcher due to the academic links already established between this hospital where the clinic is based (St. James’s) and Trinity College Dublin30.

28 Within the first four weeks of treatment.
30 St James’s is a teaching hospital attached to Trinity College Dublin.
A number of meetings were held with relevant staff members of the memory clinic (including Medical Registrars, Research Nurse, Neuro-Psychologist and Medical Social Worker) who were given information about the study. At these meetings, the aims and objectives of the study and the intended research design, including the type of questions that would be asked, were discussed. The information sheets for PLWD and for CPs were also developed and discussed with staff.

The main concerns of staff raised at these meetings centered around the potential harm for their “patients” and also for the researcher during the encounters. To prevent or reduce the possibility of any harm, the issue of how PLWD and their families would be approached and how consent would be obtained in the study were given careful thought and discussed in depth with the staff of the memory clinic. Specific strategies to promote patient well-being were agreed with the staff of the memory clinic and adopted both during and after the interview (see section 4.4.6). In addition, in cases where the PLWD lived alone, a decision was taken to talk with their relatives after the interview in order to ensure the person had no adverse reactions. Also, it was agreed that if a participant was severely depressed and not treated for this, with the permission from the dyad, the local GP would be contacted. Finally the comments and suggestions of the staff members about safety issues for the researcher were also taken on board. Such included having my mobile phone switched on during interviews and informing a colleague about the location and time of each interview.

Final agreement was obtained in January 2010 for sample recruitment to take place at this memory clinic. In addition, approval was granted that with the permission of the person living with dementia their MMSE scores would be accessed from his/her medical record. Following this, the second ethical approval for the study was sought and gained in March 2010 from hospital’s research ethics committee.

4.4.2 Sample recruitment

Recruitment of the sample was undertaken over a six month period between December 201031 and June 2011 with the assistance of the clinic’s Senior Medical Social Worker (SW). The approach to sampling was purposive. In contrast with probability or random sampling, where the generalizability of the results is a priority, the power of this non-

31 The gap between the ethics approval from Hospital at the end of March 2010 and the beginning of the recruitment in December 2010 was due to my maternity leave.
probability purposive sampling lies in intentionally selecting participants who can provide a rich diversity of experience about the relevant matters under study, yielding insight and in-depth understandings instead of empirical generalizations (Patton, 2002). These multiple and diverse perspectives can enhance the understandings of complex phenomena (Malterud, 2001).

Therefore the intention was to recruit a sample with diverse characteristics including: different stages of dementia, different ages, gender and educational attainment, and PLWD and CPs with different types and qualities of relationship. I expected that a diverse group of participants could potentially help to uncover differences in the PLWD way of thinking about quality of life, in their experiences of the impact of living with dementia on quality of life and in how these people talked and felt about the medication prescribed.

**Inclusion Criteria**

Relevant initial inclusion criteria for sample recruitment were discussed with the SW of the memory clinic. These inclusion criteria were that the person must:

1. Have a clinical diagnosis of dementia
2. Be about to start one of the four anti-dementia drugs available
3. Live in the community
4. Have some level of awareness of their cognitive problems and ideally of the use of medication for dementia
5. Have a family CP co-habiting or in regular contact

Since the recruitment process began, considerable effort was made to ensure that a sample of PLWD would be obtained with a diversity of characteristics which would be relevant for the study topics (Kuzel, 1992). For this, a table was designed into which the characteristics of the dyads were inputted and updated as new participants were recruited.

Diversity regarding cognitive impairment (mild or moderate), age, educational attainment, and type of relationship with CP (spouses, adult children, sibling) were achieved with the help of the Social Worker. Gender needed to be specifically targeted as after nine interviews the researcher noted that curiously most participants with dementia

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32 Diversity in the prescribed drug treatment (three types of ChEI) was not pursued as relevant studies have consistently shown similar benefits in the three ChEIs drugs.
were male. Other criteria that could have been relevant to quality of life such as the quality of the relationship between the PLWD and CP, or the perception of CPs of burden could not be ascertained in advance of the interview and this made it difficult to ensure diversity in this area.

After half of the interviews had been conducted I observed that most dyads expressed rather positive attitudes to dementia and had taken the news of their diagnosis relatively well. This was of some concern to me as I believed that these peoples’ attitudes to dementia could have a relevant impact on the way they talked about quality of life. Discussion of this matter with the Social Worker revealed a potential conflict between study’s objectives and the memory clinic obligation to protect their patients’ vulnerability and wellbeing. It transpired from this discussion that a type of bias had crept into sampling insofar as this gatekeeper thought it inappropriate to approach dyads if in his view, the PLWD or CP once diagnosed, reacted with symptoms that could suggest distress. The closeness in time of the research interview to the disclosure of the diagnosis to participants was a key consideration informing this decision. Similar issues relating to the gatekeepers role in recruiting a sample have been discussed by Hellstron and colleagues (2007) who pointed out that gatekeepers may actively exclude certain individuals from participation and the methodological and ethical issues that this can raise. In their case Hellstron et al. (2007) noted that all couples taking part in their study about living with dementia had a happy and positive marital relationship. This fact has to be considered and will be acknowledged in the limitations of the findings and conclusion drawn from this research.

My position on the matter was that the individual’s right to be asked and to decide (when capable) about study participation was his or her prerogative and should be respected. This point of view was further discussed with the SW and he was also reassured about the researcher’s profile, a professionally qualified social worker with many years of experience in dementia services. Further discussion and negotiation with the Social Worker resulted in a change in an agreement being reached that from here on, those individuals displaying mild or moderate distress on the day their diagnosis would, along with others, be approached and given an opportunity to consider participation in the study. The final sample (14 dyads) included two participants who were moderately distressed at diagnosis and disclosure but despite this agreed to participate in the study.
4.4.3 Recruitment procedure

Between December 2010 and June 2011 potential candidates satisfying the study’s inclusion criteria were identified, approached and informed about the study by the SW of the memory clinic. Two out of 17 dyads approached by the Social Worker declined the invitation to participate. PLWD and CPs who were willing to participate were provided with a copy of the Information Letter (see Appendix B). The Social Worker sought permission from them for the researcher to contact them.

Contact details including the name, telephone number and address details of both members of the dyad were provided to the researcher and dyads were contacted by phone in the days following their meeting with the SW. When dyads were firstly contacted, in most cases, it was the CP who answered the phone. In one case, where the PLWD was initially contacted, she preferred that arrangements were made with her husband.

During the first call I introduced myself to the CP, explained the aims of the research and what participation in the study would entail. After this preliminary introduction, the CP was encouraged by me to discuss this information with the PLWD and I sought permission to contact them again in the following days to know their decision regarding their study participation. Only one dyad decided not to take part in this study. The reason given was that they were going on holidays. All 14 remaining dyads were willing to participate and the baseline interview with the researcher was arranged at a time and location convenient to them. Most interviews (13 participants with dementia and 11 care-partners) were conducted in the dyad’s home. One PLWD and two CPs chose to be interviewed in Trinity College Dublin. One CP who lived apart from the PLWD had her interviews conducted in a quiet cafe in the vicinity of the house of the person living with dementia. In four dyads the interview was conducted jointly, and the remaining separately (see section 4.4.7 for further information).

4.4.4 Qualitative data collection instruments

In-depth interviews were used as I believed this was the most suitable research method to access the participants’ private views and experiences. Interviews were preferred over other available qualitative tools such as focus groups, due to the closeness in time of interviews to diagnosis and the concern that participants may be inhibited from sharing
inner feelings and thoughts with others in a group. This type of face-to-face interview has been extensively used and is well established in dementia research.

**Interview guide**

Previous approaches used in qualitative and quantitative research in dementia care were drawn on to construct the interview guide (Alzheimer Society, 2004; Jonas-Simpson and Mitchell, 2005; Droes et al., 2006; Andersen et al., 2008). See Appendix D for interview guides used in this thesis.

The two interview guides developed were similar in format and covered the same broad topics. PLWD were invited to talk about their experiences and views about quality of life and medication use. Care-partners were asked to report their perceptions and own opinions about the topic (Ready, Ott & Grace, 2006). The care-partners own quality of life or expectations of medication for their own quality of life were not pursued. Nevertheless, during the interview CPs sometimes elicited their own views and perspectives and often contextualised their discussions by way of talking about the daily difficulties they were experiencing whilst caring for the relative with dementia. Whilst information about the perceptions and views of CPs were not actively pursued, I listened, recorded and incorporated these views and concerns into analysis when appropriate.

The baseline interview guide explored five topics of direct relevance to the research questions: (1) awareness and understandings of dementia; (2) biographical information; (3) current daily life experiences; (4) quality of life understandings, meanings and significance of each issue of interest; and (5) experiences with the anti-dementia drugs. The guide and the type of questions used can be seen in Appendix D. These questions were used in a flexible and conversational manner.

The participants' level of awareness of dementia and the words and phrases they used when talking about it were probed before starting the interview. The participant was invited to talk about his/her current memory functioning and to explain in his/her own words the outcome of their assessment in the memory clinic. The same term the PLWD or CP used to refer to the condition (e.g. memory problems, memory loss problem, dementia, Alzheimer's disease) was used during the interview. This approach has been successfully used in previous research that involved PLWD. Also the PLWD was asked if he/she was taking any medication for his/her memory. PLWD who could not remember
or who seemed unaware of the use of the anti-dementia drug (4 PLWD) did not complete this part of the interview. This was in order not to distress PLWD by asking them questions about a medication they did not recall or did not know they were taking.

The interview finished by inviting the participant to add any other comment about quality of life or medication use not addressed during the interview. It also briefly explored how the person felt having completed the interview. No participant wished to add any comment or felt there was any unexplored yet relevant topic. All participants reported feeling comfortable and many stressed the fact they had enjoyed the interview and viewed it as an opportunity for talking openly about things that mattered to them. However, three participants also reported feeling anxious prior to starting the interview as they feared not being able to respond adequately to the questions. One PLWD confided that whilst feeling overall relaxed and comfortable during the interview it was sometimes difficult to “put his experiences and feelings into words”.

The follow-up interview was undertaken six months after the medication started. It started with a brief summary of the analysis of the baseline interview, which reflected my own interpretations of the main topics and issues that had been elicited by the person at baseline. This gave me an opportunity to clarify and verify my own understandings and interpretations of each baseline interview with the individual.

The type of topics explored and questions used in the follow-up interview can be seen in Appendix D. Like the baseline interviews, the approach used reflected a flexible and conversational format. This interview concluded by asking the participant to talk about any issue or concern that had not been explored during the interview.

4.4.5 Quantitative data collection instruments

The chosen scale for this thesis, as detailed in chapter two, was the QoL-AD. A copy of the scale can be seen in Appendix C. The QOL-AD is an internationally validated 13-item scale (range 13 to 52, with higher scores indicating a better quality of life). This is the most widely used tool applied in dementia research to assess quality of life and has been previously used in longitudinal studies. In this scale, both the PLWD and the CP are

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33 Permission was given to the researcher to use this tool in this research by Prof. Logsdon who developed the tool.
given the opportunity to complete the scale. In this thesis, both the PLWD and the CP were invited to complete the QoL-AD at baseline (within four weeks of diagnosis and drug commencement) and at follow-up approximately six months later. All but one participant (PLWD dyad 7, Gary) completed the QoL-AD test at baseline and at follow-up.

As no standardised cut-off points for the QoL-AD scale have been published for use in differentiating between quality of life ratings, for the purposes of this thesis, I developed my own cut-off points to be used as a tool to visualise the ratings of quality of life of PLWD and of CPs. This is used in chapter five and scores are presented in a Figure (see Figure 5.1 in chapter five). In the figure, PLWD and CPs scores lie in a continuum ranging from poor to excellent quality of life. Cut off points suggested in this Figure (13, 26, 39 and 52) have been calculated following the logic that if a participant scored all items of the scale as poor (poor =1) the global score would be 13, if all items are scored as fair (fair = 2) global score would be 26, and so on.

In addition, socio-demographic information was collected on the age of both members of the dyad, their marital status, and the relationship between PLWD and CP. Information was also documented about the clinical diagnosis of each PLWD and the type and dose of the anti-dementia medication prescribed. The CP was requested to complete this information at baseline. In addition, and with explicit consent from dyads, the last MMSE\textsuperscript{34} score of the PLWD available from the memory clinic was obtained from medical records as in all cases this test had been conducted in the clinic during their recent assessment. In this research study, MMSE scores were used purely for sampling variation criteria purposes and for assisting me in the consent process. They were not used as a means for looking at efficacy of the drugs, which was never the intention of this thesis. Hence, this test was not conducted at follow-up.

\textsuperscript{34} The Mini Mental State Examination (MMSE) is a widely used and internationally validated screening test for cognitive impairment in older adults. It scores 0 to 30. Different cut off points can be used depending on the purpose of the study, when the intention is to classify the severity of CI such as in this thesis, Folstein et al. (2001) recommended the following classification: normal cognitive function = 27-30, mild CI = 21-26, moderate CI= 11-20, severe CI = 0-10.
4.4.6 Preparing the interview: Challenges in interviewing PLWD

The onset of dementia can pose several communication challenges and barriers for PLWD. To optimise participants’ voices and responses, it is said that qualitative researchers should attempt to ensure that communication with participants is effective (Beuscher and Grando, 2009). For example, to overcome communication challenges and facilitate meaningful communication, the researcher’s attitude toward the PLWD during the interview should be caring and respectful. Also, it is important that the researcher is knowledgeable and understands the communication difficulties that a PLWD may experience and anticipates strategies to overcome such challenges.

Several recommendations from the international literature were taken into account in this study. Firstly, the vocabulary used was kept simple and jargon free. The interview questions were designed in an easy to understand manner and probes and prompts were anticipated to further elicit and help to elaborate participants’ views when necessary. Other strategies used to optimise communication included (Beuscher and Grando, 2009): (1) allowing ample time to respond, (2) offering re-assurance to participants if they felt distressed finding a word or communicating an idea, (3) refraining from contradicting participants’ statements or quizzing them about further details they could not remember, (4) validating the meaningfulness and relevance to the study of their own experiences and reports. Also, during the interviews there were several times where the PLWD or the CP laughed or joked and this may have contributed to make the interviews more relaxed and enjoyable.

Format and duration of the interview

In keeping with the relationship-centred approach to dementia (see chapter one, section 1.2.3) and consistent with active interviewing techniques, all the interviews were flexible in format and took the form of a “dialogue” (Hulko, 2009) rather than following a more structured question and answer format. Whilst a semi-structured guide had been devised in advance and all main topics were explored in each interview, nonetheless, the researcher remained flexible and the phrasing and order of the questions were altered or replaced when necessary (Hansen, 2006).

The length of the interviews was also given consideration as previous literature suggests that older participants may tire easily (Murphy et al., 2007). In addition and in the
context of dementia, attention span can became a challenge. It was intended that each interview with PLWD would last approximately one hour. To balance data collection needs and participants' well-being, it was decided that, with explicit consent from the PLWD and care-partner, the last MMSE score available from the memory clinic would be accessed.

4.4.7 Procedure: relevant considerations during the interview

Before starting the interview: Negotiating consent with participants
As stated by the King’s College & South London and Maudsley NHS Trust (2010), all research participants should be given sufficient information about a study, in a format they understand, in order for them to exercise their right to make an informed decision whether or not to participate in a research study.

Indeed PLWD have been described as a vulnerable group mainly because of their “compromised decision making abilities” (Beuscher and Grando 2009). Although a diagnosis of dementia does not preclude competence to provide consent for research participation, this has largely been regarded as one of the most challenging issues in research in this area and can be an important barrier when involving this population in research. Two relevant concerns relate to whether PLWD have capacity to consent and how the capacity assessment should be made. As a result, research has extensively relied on proxy consent (typically a family member) as a substitute for PLWD consent. This proxy decision-making process, however, has raised concerns as it cannot be guaranteed that these decisions always accurately reflect the attitudes and values of the person with dementia (Fisk, Beattie and Donnelly, 2007; Karlawish et al., 2000; Connell et al., 2001).

In this thesis, to facilitate PLWD involvement and informed consent, a concise and straightforward version of the Information Letter and Consent form were devised for the PLWD (see Appendix B and D). Also, prior to starting the interview, the researcher explained in simple English the main features of the study and emphasised what was expected from the person should they decided to participate.

Each participant had ample opportunity to ask questions about the study. A number of important points were discussed with every participant, such as the voluntary nature of participation, the right to refuse to answer any question if they should so wish and to stop the interview at any moment for any reason or withdraw completely from the research.
All participants were reminded that either their co-operation with the research or their decision not to partake, would not affect their medical or social care or treatment in any way.

An important issue around consent in dementia is how and who should assess the capacity of the PLWD to consent. In dementia research, it has been agreed, that the level of protection of the individual should be proportional to the risk involved in participation, with least protection required in minimal risk studies. In this latter case, the Alzheimer Association’s (2004) Guideline suggests that an informal assessment of capacity made by the researcher is sufficient. The qualitative nature of the study suggested the study entailed minimal risk and no anticipated potential harm for the individual. I decided that in the cases of PLWD with a moderate cognitive impairment (as per MMSE) the CP would be invited to stay with the person with dementia whilst consent was being sought. This approach has been used before in conducting research in dementia for ensuring an adequate level of protection to the person.

Whilst consent as described above was formally sought and all participants gave written consent (see a copy of the consent form in Appendix E), in dementia research consent is better understood as an ongoing process rather than as a formal procedure at the beginning of the interview. This approach to consent is aligned with personhood and facilitates the inclusion of PLWD in research regardless of their degree of impairment (Hulko and Stern 2009), and can be regarded as “an improvement over traditional informed consent protocols” (2009:74). According to this, in addition to the initial written consent, consent was revisited during the interview and the researcher paid special attention to the participants’ verbal and non-verbal communication (Dewing, 2007; Slaughter, et al. 2007).

Another important dilemma and decision which needed to be made was about conducting separate or joint interviews. Separate interviews were the best option to address the research goals since I believed that participants might feel less inhibited and more ready to speak their own minds in an honest way. All PLWD and CPs were asked for their own preferences and it transpired that four couples (Harry, Gary, Ruth and Orla) preferred a joint interview and all the remaining couples preferred a separate interview. In most cases the decision about a separate interview was made by the CP and later some stated this had facilitated their honesty and meant that they felt they did not distress the PLWD. Joint
interviews can pose several methodological challenges to the researcher. Nevertheless joint interviews also have advantages as they can help in establishing rapport with participants and can create an atmosphere of confidence and may reveal relevant non-verbal information such as the nature of relationships and interactions between participants (Arksey, 1996). In addition, in dementia research joint interviews are now claimed as a way of protecting the individual with dementia, as the individual may feel safer and more comfortable during the encounter (Pesonen et al., 2011).

Relevant issues during the interview: Creating a safe context

Considerable attention was given to the way the interview was conducted, and I tried at all times to put the participant at ease and to make sure the person felt comfortable and relaxed during the interview. The conversational and flexible format of the interview and my own professional experience as a Social Worker with much exposure in dementia care may have facilitated this. In addition, I tried to ensure that all participants had some level of power during the encounter about the content of the interview, and all the stories relevant to the person were listened to with attention and validated. As an example of this, one participant living with dementia was describing an anecdote about his work life and then reflected his concern about “wasting” my time as he felt this was not relevant to the study. I reassured him about the relevance and worthiness of any story that he wanted to share with me or felt important.

I was also extremely vigilant to signs of fatigue or distress when posing questions. Participants were invited to take a break should he/she feel tired, nevertheless participants were very keen to talk and no participant wanted to stop the interview or take a break. It was felt that the dialogue format was particularly suitable as participants were free to raise topics and concerns of interest to them. Some participants explicitly talked about feeling tired when their memory was tested in the Clinic, but not in a context where they were asked to speak their minds.

Sensitive issues were explored with caution. In the case of PLWD, I used the same word that the participant used to refer to dementia. In the interviews of CPs, some felt emotional when elaborating on questions about the future. When this happened, the issue was not further explored, unless the person wished otherwise.
All PLWD and CP were assured of confidentiality. Pseudonyms were used for each participant in the 14 dyads. Protecting participants' identity and ensuring confidentiality is a taken for granted assumption when doing social science research. Nevertheless, some scholars have questioned this assumption that confidentiality is desirable for all study participants (Crow and Willes, 2008) and have argued that disclosure of the real names of participants can be perceived not as a breach of confidentiality but as a “wanted” and “empowering” experience for the individual. This raises the issue that PLWD may well deserve to be asked their opinions and decisions about confidentiality to be respected. I believed, however, that the identities of participants should be anonymised in this thesis.

Relevant considerations at the end of the interview

Concluding the interview is another important point to create a safe context and previous research indicates that it is “important to leave the person with dementia with a sense of achievement and to find a positive subject on which to conclude” (Hellstrom et al., 2007:612).

On average interviews lasted around one hour and 15 minutes, and the longest interview (with a CP) lasted one hour and 40 minutes. After each interview, I spent time with the person in social conversation. Many dyads invited me to have coffee or tea once the interview was concluded and it was an opportunity to engage in small talk. During this time, I was many times asked about my personal life, nationality and reasons for living in Dublin. Relevant details about my personal life were disclosed as appropriate with the intention to balance the information disclosed and shared by both parties.

In the two cases where the PLWD lived alone, particular care was taken to conclude the interview on a positive note and to ensure wellbeing. In these two cases, prior to the interview, it was agreed that the CP would call in the house of the PLWD after the interview. The wellbeing of the PLWD was later confirmed by telephone to me.

Regarding the follow-up interview and in contrast to other studies, most PLWD remembered their previous participation in the study. Five out of 12 PLWD reported they had been looking forward to the follow-up meeting, and three of them claimed they would had liked to meet again in the future. Such wishes can raise ethical concerns, as although I made all efforts to explain the nature and characteristics of the study (a PhD
thesis, involving one baseline and one follow-up study), in some cases PLWD and CP may have preferred an ongoing relationship and an opportunity to be followed up by a health professional. This was particularly relevant given the context of these peoples' lives – having been recently diagnosed with a greatly feared disease and being discharged from the memory clinic with no further regular follow-up.

At the end of the follow-up interview all participants were asked about their desire to receive a summary of the findings of the study once the thesis would be completed. All dyads were interested and I agreed to send participants a summary of the findings at a later stage.

4.5 SAMPLE PROFILE

The sample consisted of 14 dyads at baseline and 12 at follow-up since at follow-up two dyads declined the invitation for second interview\(^35\).

4.5.1 Profile of PLWD

Socio-demographic key characteristics

Table 4.1 reports on the socio-demographic characteristics, and on cognitive and health status of the sample of PLWD. The table also shows the anti-dementia medication they were prescribed. Names of PLWD in the table have been anonymised. It shows that PLWD were mostly males (8) and their ages ranged from 61 to 87 years (five participants were in their 60s, four in their 70s and five in their 80s). Most PLWD (11) had worked outside the home and were now retired. Three female participants defined themselves as homemakers. Around two-thirds of the PLWD had primary education and the remainder had secondary or tertiary education.

As can be seen in Table 4.1, most PLWD (10) were married and lived with their spouses or in one case with a non-married partner. Four participants were widowed, of whom two lived alone but were supervised by adult children or sibling. In the other two cases, adult children (in both cases sons) had moved into the house of the PLWD.

\(^35\) In one case, the dyad had initially agreed to participate in the follow-up interview, but declined the invitation on the day the interview was scheduled, as the person with dementia did not want to be involved in another conversation regarding her memory problems. In the other case the reason given was they were at the time refurbishing their house and the timing was not suitable to them. In addition, both dyads stated nothing significant had happened since the first interview and they had nothing relevant to add.
Health status

Ten participants had a clinical diagnosis of Alzheimer’s disease and four had mixed dementia (Vascular and Alzheimer’s disease). Their overall mean MMSE score of the sample was 20.3, reflecting overall a moderate dementia. However, seven of the 14 MMSE scores reflected a mild cognitive impairment (mean score was 23.3), and the remaining MMSE scores reflected a moderate cognitive impairment (mean MMSE score was 17.3). Table 4.1 provides individual MMSE scores for each participant\(^{16}\). The most commonly prescribed anti-dementia drug was donepezil and only three people were prescribed memantine. Only one participant had discontinued using drug treatment at follow-up and in this unusual case the drug in question was memantine.

At baseline, four participants reported experiencing restricted mobility, of whom three were severely limited in independent walking but none was at that point in time wheelchair dependent. At follow-up, the mobility problems of two of these PLWD had considerably worsened and one of these two people was now using a wheelchair and the other reported experiencing very severe pain due to arthritis.

Table 4.1: Profile of PLWD

<table>
<thead>
<tr>
<th>Dyad</th>
<th>Age</th>
<th>Marital status</th>
<th>Working situation</th>
<th>Lives with</th>
<th>MMSE score</th>
<th>Diagnosis</th>
<th>Drug</th>
<th>Mobility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harry</td>
<td>75</td>
<td>Married</td>
<td>Retired</td>
<td>Spouse</td>
<td>23</td>
<td>Alzheimer's disease</td>
<td>Donepezil</td>
<td>Independent</td>
</tr>
<tr>
<td>Eoin</td>
<td>64</td>
<td>Widowed</td>
<td>Retired</td>
<td>Alone</td>
<td>25</td>
<td>Alzheimer's disease</td>
<td>Donepezil</td>
<td>Independent</td>
</tr>
<tr>
<td>Paul</td>
<td>87</td>
<td>Married</td>
<td>Retired</td>
<td>Spouse</td>
<td>19</td>
<td>Mixed dementia</td>
<td>Memantine</td>
<td>Independent</td>
</tr>
<tr>
<td>Angela</td>
<td>68</td>
<td>Widowed</td>
<td>Retired</td>
<td>Alone</td>
<td>20</td>
<td>Alzheimer's disease</td>
<td>Donepezil</td>
<td>Independent</td>
</tr>
<tr>
<td>Peter</td>
<td>72</td>
<td>Married</td>
<td>Retired</td>
<td>Spouse</td>
<td>22</td>
<td>Alzheimer's disease</td>
<td>Donepezil</td>
<td>Independent</td>
</tr>
<tr>
<td>Gordon</td>
<td>81</td>
<td>Married</td>
<td>Retired</td>
<td>Spouse</td>
<td>13</td>
<td>Mixed dementia</td>
<td>Memantine</td>
<td>Independent</td>
</tr>
<tr>
<td>Gary</td>
<td>80</td>
<td>Married</td>
<td>Retired</td>
<td>Spouse</td>
<td>16</td>
<td>Alzheimer's disease</td>
<td>Donepezil</td>
<td>Independent</td>
</tr>
<tr>
<td>Ruth</td>
<td>75</td>
<td>Married</td>
<td>Home maker</td>
<td>Spouse</td>
<td>16</td>
<td>Alzheimer's disease</td>
<td>Donepezil</td>
<td>Independent</td>
</tr>
<tr>
<td>Richard</td>
<td>82</td>
<td>Widowed</td>
<td>Retired</td>
<td>Son</td>
<td>16</td>
<td>Alzheimer's disease</td>
<td>Memantine</td>
<td>Independent</td>
</tr>
<tr>
<td>Colette</td>
<td>61</td>
<td>Married</td>
<td>Home maker</td>
<td>Spouse</td>
<td>24</td>
<td>Alzheimer's disease</td>
<td>Donepezil</td>
<td>Independent</td>
</tr>
<tr>
<td>Dora</td>
<td>85</td>
<td>Widowed</td>
<td>Home maker</td>
<td>Son</td>
<td>17</td>
<td>Mixed dementia</td>
<td>Donepezil</td>
<td>Needs help</td>
</tr>
<tr>
<td>David</td>
<td>78</td>
<td>Married</td>
<td>Retired</td>
<td>Spouse</td>
<td>17</td>
<td>Mixed dementia</td>
<td>Donepezil</td>
<td>Needs help</td>
</tr>
<tr>
<td>Claire</td>
<td>69</td>
<td>Married</td>
<td>Retired</td>
<td>Spouse</td>
<td>23</td>
<td>Alzheimer's disease</td>
<td>Donepezil</td>
<td>Needs help</td>
</tr>
<tr>
<td>Orla</td>
<td>65</td>
<td>Cohabiting</td>
<td>Retired</td>
<td>Partner</td>
<td>24</td>
<td>Alzheimer's disease</td>
<td>Donepezil</td>
<td>Independent</td>
</tr>
</tbody>
</table>

4.5.2 Profile of CPs

Table 4.2 reports on the socio-demographic characteristics of the 14 CPs. It shows that nine CPs were female and five were male. Their ages ranged from 31 to 80 years. The

\(^{16}\) MMSE scores were obtained from the Memory Clinic and were the last available score.
two youngest CPs were single. All of the non-spouses CP (n=4) were working at the time of the interview. Almost two thirds of CP had secondary or tertiary level education.

Table 4.2 Profile of CPs

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Education</th>
<th>Relationship with PLWD</th>
<th>Working situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary</td>
<td>72</td>
<td>Primary</td>
<td>Wife</td>
<td>Home maker</td>
</tr>
<tr>
<td>Esther</td>
<td>68</td>
<td>Tertiary</td>
<td>Sister</td>
<td>Working</td>
</tr>
<tr>
<td>Jenni</td>
<td>73</td>
<td>Secondary</td>
<td>Wife</td>
<td>Home maker</td>
</tr>
<tr>
<td>Dianne</td>
<td>42</td>
<td>Tertiary</td>
<td>Daughter</td>
<td>Working</td>
</tr>
<tr>
<td>Hiliary</td>
<td>73</td>
<td>Secondary</td>
<td>Wife</td>
<td>Home maker</td>
</tr>
<tr>
<td>Lisa</td>
<td>75</td>
<td>Primary</td>
<td>Wife</td>
<td>Home maker</td>
</tr>
<tr>
<td>Janet</td>
<td>80</td>
<td>Primary</td>
<td>Wife</td>
<td>Home maker</td>
</tr>
<tr>
<td>Laura</td>
<td>40</td>
<td>Secondary</td>
<td>Daughter</td>
<td>Working</td>
</tr>
<tr>
<td>Adam</td>
<td>31</td>
<td>Tertiary</td>
<td>Son</td>
<td>Working</td>
</tr>
<tr>
<td>Connor</td>
<td>68</td>
<td>Primary</td>
<td>Husband</td>
<td>Retired</td>
</tr>
<tr>
<td>Kevin</td>
<td>61</td>
<td>Secondary</td>
<td>Son</td>
<td>Retired</td>
</tr>
<tr>
<td>Maeve</td>
<td>70</td>
<td>Secondary</td>
<td>Wife</td>
<td>Retired</td>
</tr>
<tr>
<td>Daniel</td>
<td>67</td>
<td>Secondary</td>
<td>Husband</td>
<td>Retired</td>
</tr>
<tr>
<td>Matthew</td>
<td>63</td>
<td>Tertiary</td>
<td>Partner</td>
<td>Retired</td>
</tr>
</tbody>
</table>

4.6. DATA ANALYSIS

All interviews were audio recorded with participants’ consent and transcribed verbatim (see transcript of a baseline interview with a participant living with dementia in Appendix F). An approach to data analysis consistent with social constructionism was used. This approach was based on Charmaz’s (2001, 2006) constructionist grounded theory, and facilitated listening to the multiple voices and experiences of participants in order to focus on participants’ own constructions and diverse interpretations of their experiences.

The interview transcripts were subjected to constructivist grounded-theory (GT) inspired coding. However, other features of the GT methodology (theoretical sampling) were not used (Willig; 2008; Langdridge & Hagger Johnson, 2009). The strategies and techniques employed in the analysis were primarily based on those described by Charmaz (2006), including: line-by-line analysis, constant comparison and focused analysis. During the analysis, as recommended by Charmaz, I used as much as possible gerunds\(^{37}\) to code for

\(^{37}\) Charmaz advises researchers to code in gerunds (the noun forms of verbs) as in her view this way of coding encourages the researcher to code for processes, actions and meanings rather than for topics or themes.
action and “in-vivo” codes. The latter refers to the practice of labelling codes using the participants’ own words.

Data analysis started after the first four baseline interviews were conducted and transcribed. These four interviews were read and re-read several times to facilitate familiarization with the data and also to have a comprehensive understanding of the stories and experiences of each participant. Then, a line-by-line open analysis was performed. Line-by-line analysis can be described as a way of “fracturing the data”. It facilitates a deep immersion in the data and entails examining each line of data and naming, defining, or labelling actions or events that occur in it or that are represented by it. This coding invites the researcher to examine the words used by the participants to describe their experiences and the feelings, meanings and assumptions they attach to these experiences. Thus it provides an insider’s view. An example of this type of analysis can be seen in Appendix G.

Following the line-by-line analysis, a focused analysis was performed. This second type of analysis was used for all interviews. For the baseline interviews, data about quality of life and about experiences with medication were analysed independently. Charmaz (2006) identifies focused coding as being the second major phase in the coding process. In focused analysis the researcher has to choose the most telling codes to sort, synthesize and represent the participants’ voice. This analysis showed the main components (domains) that formed the participants’ understandings of quality of life and looked at the multiple representations that each domain had for participants. It also looked at participants’ experiences of challenges and changes with a particular but not exclusive focus on their experiences of dementia. Early experiences of being prescribed a drug to treat dementia were analysed with a focus on how participants talked about the drugs and about their expectations, and how, in their view, taking the medication could impact on their quality of life.

At this stage of the analysis I found the constant comparison technique particularly useful. This technique is used during analysis, looking for similarities and differences between incidents in each participant and among participants. For example, I examined closely the type of language, behaviours and feelings used when referring to one of the

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38 This decision was made due to the high complexity of the data relating to quality of life, also as this facilitated a better understanding of the multiple meanings that participants attached to their quality of life and to the impact of dementia on their quality of life.
most relevant categories; being busy. By using this technique the different meanings, feelings and ways of being and keeping active in the sample were compared. This was done by examining the language participants used (eg. remain active, having something to do, doing my little things, filling my days); comparing how activities were referred to in the past and at present in each interview; looking and comparing how participants felt whilst doing these activities; identifying the different type of activities participants reported they were able to do or they could no longer do, and looking at the different contexts where activities occurred or failed to happen. In addition, the meanings, concerns and ways of talking about activities as referred by PLWD and CP were contrasted. An unusual or deviant case was identified (dyad 10, David and Maeve) and other participants’ narratives where activities had a relevant role were compared against this story. Lastly, individual participants’ experiences at baseline and at follow-up were compared and relevant elements that facilitated or hindered activity and elements that connected activity and quality of life were identified.

The comparison technique was also used in contrasting data obtained with the QoL-AD scale and the participants’ subjective experiences. The assumptions behind the scale for each domain of quality of life and the participants’ own understandings and meanings were contrasted. Also the individual PLWD and CP scores on the scale were contrasted with their subjective views. Any relevant comments made by participants whilst completing the scales was transcribed and used as additional data.

At the last stage of analysis the core categories that helped to illustrate all participants’ experiences about quality of life were identified. Three main core categories stood out: the individual experiences grounded in the biographical and constructed values and preferences for each domain; the relational aspects including how the PLWD is perceived and treated by others; and the dyad’s understandings and images of dementia. The main core categories in this analysis of the medication were: trust, hope and keeping current lives for as long as possible.

Analysis of the follow-up data made understandings more complex. Quality of life data arising from follow-up data was analysed using the same frame developed at baseline. This analysis required a constant contrasting of baseline and follow-up data, in an iterative process where I was coming back and forward to the dyads’ baseline and follow-up interviews. Three main topics required this constant comparison: their understandings
of dementia, their way of talking about the medication and their views now on quality of
life.

4.7 RIGOUR

A main issue in qualitative research is how to evaluate the quality of the study. Whilst in
quantitative research validity and reliability are the main means of establishing rigour, a
consensus exists that their use is not appropriate in qualitative studies (Aguinaldo 2003).
Qualitative researchers have conceptualized the idea of rigour in multiple ways. Charmaz,
for example (2006) suggests that research can be evaluated by four criteria: credibility,
resonance, originality and usefulness. These criteria relate to the rigour used in the
analysis of the data; that the research findings reveal new coherent insights; and that
findings can contribute to policy and practice development.

Charmaz (2006) suggests different questions that researchers should consider when
evaluating qualitative research. Examples of these include,

- Credibility: Has your research achieved intimate familiarity with the topic?; Are
  there strong logical links between the gathered data and your argument and
  analysis?
- Originality: Do your categories offer new insight?; What is the social and
  theoretical significance of this work?
- Resonance: Have you revealed both luminal and unstable taken-for-granted
  meanings?; Do your findings make sense to your participants?
- Usefulness: Does your analysis offer interpretations that people can use in their
  everyday worlds?

These are questions that have guided the research methodology and analysis and
questions that I have on several occasions during my journey through this thesis returned
to and reflected upon.

4.7.1 Credibility and resonance

Different strategies have helped to enhance the credibility and resonance of the findings.
One important strategy was participant checks. In every follow-up interview, as
mentioned, I provided a summary of my conclusions and interpretations of the baseline
interview to the participant and the participant had the opportunity to comment on findings. Also, this second interview afforded the researcher the opportunity for clarifying or asking for further details when necessary. A second way of enhancing credibility was by documenting in detail how that analysis was performed and, also as through the writing of the thesis I have openly discussed challenges, decisions and difficulties encountered. Another important strategy was the use of a quality of life scale and qualitative interviews. This was not done to triangulate data but to explore the dominant taken for granted meanings and other alternative meanings that could emerge after the onset of dementia.

4.7.2 Originality and usefulness

This thesis offers new insights into quality of life issues and also into the relationships between quality of life and anti-dementia issues. The contributions that this thesis can make to current knowledge and implications for practice will be further discussed in the concluding chapter.

4.8 CONCLUSION

This chapter has described the general methodology used in this thesis. It has articulated the key research questions the thesis hopes to answer by using a social constructionist lens. These research questions were based on my prior work and research experiences and they were particularly motivated by the review and critique of the literature I undertook (chapter two and three). The latter helped me reach the conclusion that most research studies investigating quality of life and anti-dementia medication have been informed by a positivist approach and have a main focus on measurement rather than on understanding the PLWD and caregivers' priorities and concerns about quality of life (Hutchings et al., 2010b). The research questions in this thesis are based on the realization that research about anti-dementia drugs has been extensively dominated by health service professionals, clinical trials and standardized scales with the latter providing the main source of evidence (Traynor and Dewing, 2002; Hutchings et al., 2010).

The research questions and the particular design and philosophical position taken in this thesis importantly contrast with the traditional approaches observed and critiqued in the literature review. This thesis looks at the ways PLWD think and talk about what gives
quality to their lives and how their individual subjective experiences of living with dementia, in this particular point in time and context of their lives, may have impacted on their understandings of quality of life. The thesis is also concerned with how interactions with others and with the wider society may shape the experiences of quality of life. The thesis also critically compares these meanings and experiences with the results that are obtained using a quality of life scale.

This thesis does not try to determine the clinical effectiveness of the anti-dementia drugs, or evaluate their cost-effectiveness nor the extent to which PLWD experiences with the drugs are real, demonstrable or measurable. Instead, it attempts to highlight ways of thinking about the drugs as experienced by PLWD and their CP and the significance that taking these drugs could have for the quality of their lives. In this approach there is an acknowledgement of diversity and subjectivity of the experiences.

The chapter has explored the ethics of conducting research into this sensitive area and has shown the challenges and multiple implications of involving PLWD in research. It has shown how the study has complied with all the required recommendations about doing social research in this area, such as gaining ethical approval from the relevant ethics committees, ensuring voluntary participation, obtaining written consent and ensuring confidentiality and anonymity. Nevertheless, it has been argued that an on-going process approach to ethics seems more appropriate in dementia. The latter includes issues such as an on-going evaluation of the person's willingness to answer particular questions or talk about specific topics or events, prioritizing the wellbeing and values of PLWD over any research interest and a constant reflexive attitude on the part of the researcher.

The chapter has also provided information on the inclusion criteria used for recruiting the sample; how the sample was recruited as well as how the data was collected and analysed. It has shown that whilst it was intended to interview a diverse sample of people, such diversity was ultimately limited for reasons outside the researcher's control. Therefore the sample is somewhat biased and reflects a group of people relatively privileged in terms of their positive relationships and security. Another relevant issue discussed in the chapter is the flexible and tailored approach to data collection, and the systematic, rigorous and reflexive way in which the data was analysed using techniques derived from Grounded Theory methodology.
The findings from this study will be presented in the next three chapters. Chapter five reports data on the meaning that dementia and quality of life have for people recently diagnosed and for their CPs. Five main domains of quality of life are identified. Much thought has been given to identifying the best way to present these findings. A decision was taken to present results from the quality of life scale and those from the qualitative approach alternately in order to compare and contrast such data. The decision to present the findings using scale first was taken as this represents the conventional approach to quality of life in dementia. Following this, the findings from the qualitative approach are presented and used to substantiate the normative findings. Main differences and advantages of taking each approach are critically discussed.

The finding chapters six and seven focus on participants' experiences with the anti-dementia drugs and on the impact that the drugs had on the quality of life of PLWD. In chapter six, the participants' ways of thinking about the drug they were prescribed, their expectations about the medication and what taking these drugs represented to their lives are explored. Following on from this, chapter seven presents data from the interview that took place six months later and explores changes in how participants talked about dementia, quality of life and medication. Comparisons between the findings obtained from the analysis of the quantitative and qualitative data are also provided following the same approach as that used in chapter five.
CHAPTER FIVE: "THE DAY-TO-DAY KIND OF THING". PARTICIPANTS UNDERSTANDINGS OF QUALITY OF LIFE

5.1 INTRODUCTION

This chapter reports findings on quality of life based on the analysis of interviews with 14 people living with dementia (PLWD) and their care-partners (CPs). It also sets the scene for chapter seven where findings on quality of life as they relate to the use of anti-dementia medication will be presented. This chapter presents data on the participants’ overall ratings and understandings of quality of life at the time they were first diagnosed and after being prescribed an anti-dementia drug. It looks at the ways in which these people talk about the things that matter most to them and the impact that living with dementia had on the quality of their lives. In order to do this, quality of life is examined using two different approaches.

The first approach follows the conventional normative method used to measure quality of life in dementia. Each participant was asked to complete a dementia-specific quality of life scale (QoL-AD). Both groups completed this with regard to the quality of life of PLWD. The second approach draws on a social constructionist methodology and each participant was invited to talk openly and in-depth about their quality of life. Bond and Corner (2004) have approached quality of life in older people using social constructionism, but to my knowledge this is the first time that this approach has been used to explore quality of life issues of a group of older people recently diagnosed with dementia. Also this is the first time that these two co-existing approaches to quality of life - normative and interpretivist - are critically explored and compared in dementia.

The type of diagnosis, drug prescribed and further details about the participants’ profile can be found in chapter four, Table 4.1. Relevant information about quality of life and validated scales in dementia can be found in chapter two. The generic word “participant” in chapter five and six is used to include both the PLWD and CP. It has to be noted that other studies have used scales along with qualitative methods (for example Thorgrimsen et al. 2003; Cahill et al. 2004; Katsuno, 2005) but these studies looked at the content validity of the scale, or the easiness or appropriateness of the questions used in the scale.
This chapter is divided into two parts. The first reports on participants' general understandings of dementia and of quality of life and their ratings of the latter. The second focuses on five particular quality of life domains as identified by participants during the in-depth discussions namely: family and relationships, being busy, remaining independent, feeling well about themselves and being healthy. Both parts of the chapter follow a similar structure: each section begins with findings obtained using the conventional positivist approach (findings based on the scale), and this is followed by a presentation of the findings emerging from the subjective approach to quality of life (qualitative interviews). Finally, each section concludes with a brief summary of the findings and a discussion of the implications of using each approach.

5.2 DEMENTIA

5.2.1 Participants' diagnosis and dementia severity

The 14 participants had been assessed and diagnosed with Alzheimer's disease or mixed dementia in the weeks preceding the interview. All participants had been invited to attend a feedback meeting in the memory clinic where the assessment was undertaken. At this meeting diagnosis and pharmacological treatment options were discussed with the PLWD and their families. With the exception of one woman who refused to attend the meeting (Ruth, PLWD), a full diagnosis was disclosed to all other participants. In addition, the 14 participants were prescribed an anti-dementia drug (ten donepezil and four memantine). According to medical charts at this point in time, half had a mild cognitive impairment (N=7) and the other half were moderately impaired (N=7). This classification was based on the participants' most recent MMSE assessment undertaken at the memory clinic. Interestingly, participants with mild cognitive impairment tended to be younger than those with a moderate impairment (six out the seven PLWD with mild cognitive impairment were 75 or younger, and six out of seven PLWD with moderate cognitive impairment were over 75).

5.2.2 Participants' understandings of dementia

By and large, participants talked openly about their cognitive problems and provided detailed examples of symptoms and feelings during the interviews. Despite this, only four PLWD referred to their difficulties as “dementia” or “Alzheimer’s disease”. The most
recurrer: the way of referring to dementia was as "memory loss problems" or as their brains not working well.

Participants talked about dementia as incurable and most made references to the progressive nature of the condition and their future deterioration due to dementia. In many interviews, however, it was not unusual to find contradictions. A typical example was a PLWD who at one point in the interview talked about concerns relating to deterioration, whilst at other times his comments suggested that the condition could be indefinitely maintained at its current stage.

Referring to dementia as a progressive disease was relevant as most participants talked about dementia with reference to the severe stage of the condition. Several positioned themselves as being "at the beginning" of the journey ("I am not too bad") or in a pre-dementia state (a mild cognitive impairment that could convert to dementia in the future). Others, whilst acknowledging their poor memory, referred to the many abilities and skills they still retained. Overall then, PLWD felt their condition was still mild or manageable.

Participants tended to equate "real dementia" with "when you have it bad" (Claire PLWD) or "when you lose it altogether" (Orla PLWD). Examples were given of people who they believed really had dementia and these included people who failed to recognise close family members or did not remember their own name or the names of spouse or children; people who failed to recall immediate significant events such as the visit of a sibling; people who displayed challenging behaviours such as aggression, behaviours that placed them or others at risk such as leaving the house or turning on the gas at night or people who were incontinent and needed to be fed. Dementia was also referred to as "wasting away", "acting out of character", "inhuman, like the living death". Such images of severe dementia provided by participants reflected a sense of loss of control of mind and body. Four of the participants Orla (PLWD), Maeve (CP), Angela (PLWD) and Colette (PLWD) stated that severe dementia was an undignified state in which life was no longer of any worth: "if you lose your memory for goodness sake you are the walking dead" (Orla PLWD).

References to dementia were also linked to negative imagery of dementia in society and crystallised into fears of how others would treat them if the diagnosis was disclosed and concerns of becoming a burden to their families. It would appear that framing their
condition as a “memory loss problem” was easier, less stigmatizing and more acceptable to most participants than talking about Alzheimer’s disease or dementia. This was very well articulated by one of the CP when he commented,

I don’t use the word Alzheimer’s at all because that is the end of the journey. And when you tell somebody you have Alzheimer’s they think that you are at the end of the journey, but we are at the start of the journey and we don’t know how long that journey is, it could be 10, 12 years ... (...) Orla has a memory loss problem. Because when you tell people that they just see you in a different light. They see you with Alzheimer’s. And memory loss, it’s a different thing altogether. That’s – that’s – that’s a – word that should be banned in this country. It just conjures up all sorts of things. Matthew CP.

In summary, in the weeks preceding the first interview for this thesis, participants had been given a diagnosis of dementia. MMSE scores suggested that, at this point in time, half of the sample presented a mild and, the other half, a moderate cognitive impairment. Participants’ qualitative accounts reflected the complexities of their understandings of dementia. Most participants perceived (or talked about) themselves as having memory loss problems rather than as having Alzheimer’s disease or dementia. Their current mild condition and the manageability of their current symptoms contrasted with their concerns about the future and about what, to most, was “real” dementia. Dementia was described using negative terms often linked to the complete loss of the person and to the stereotypes about dementia often held by society.

5.3 QUALITY OF LIFE RATINGS AND UNDERSTANDINGS

5.3.1 Quality of life ratings

As discussed in the methodology chapter, the quality of life scale chosen for use in this thesis is the QoL-AD\textsuperscript{43} (Logsdon \textit{et al.}, 2001). Table 5.1 reports on the total QoL-AD\textsuperscript{44} scores for each individual from two perspectives: that of the PLWD and the CPs. The table also shows mean QoL-AD scores from both perspectives.

\textsuperscript{43} This is the most widely used dementia quality of life scale, more detailed explanation and rationale for using this scale in this thesis can be found in chapters two and four.

\textsuperscript{44} QoL-AD scores are obtained by summing the scores across the 13 items included in the scale: physical health, energy, mood, living arrangements, memory, family relationships, relationship with spouse, relationship with friends, self as a whole, ability to do chores, ability to do things for fun, finances and life. Each item is rated on a 4-point scale, 1 being poor and 4 excellent. The maximum score that can be obtained is 52 and the minimum is 13, higher scores indicate higher quality of life.
The QoL-AD scores of PLWD ranged from 29 to 47, with a mean score of 39.1. These scores are in accordance with international studies using samples of similar characteristics (Vogel et al., 2008) but higher than others, typically using samples with large number of people in long-term care (Selwood et al., 2005; Woods et al., 2006; Hoe et al., 2007). In keeping with the literature (Banerjee et al., 2009), as a group, the scores of CPs tended to be lower than the scores of PLWD: scores range from 25 to 47, mean score 35.8. The same trend was observed in individual scores.

Table 5.1: Comparison of QoL-AD total scores head-to-head

<table>
<thead>
<tr>
<th>Dyad</th>
<th>PLWD</th>
<th>CP</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Harry</td>
<td>Mary</td>
</tr>
<tr>
<td>2</td>
<td>Eoin</td>
<td>Emer</td>
</tr>
<tr>
<td>3</td>
<td>Paul</td>
<td>Jenni</td>
</tr>
<tr>
<td>4</td>
<td>Angela</td>
<td>Dianne</td>
</tr>
<tr>
<td>5</td>
<td>Peter</td>
<td>Hilary</td>
</tr>
<tr>
<td>6</td>
<td>Gordon</td>
<td>Lisa</td>
</tr>
<tr>
<td>7</td>
<td>Gary</td>
<td>Janet</td>
</tr>
<tr>
<td>8</td>
<td>Ruth</td>
<td>Laura</td>
</tr>
<tr>
<td>9</td>
<td>Richard</td>
<td>Adam</td>
</tr>
<tr>
<td>10</td>
<td>Colette</td>
<td>Conner</td>
</tr>
<tr>
<td>11</td>
<td>Dora</td>
<td>Kevin</td>
</tr>
<tr>
<td>12</td>
<td>David</td>
<td>Maeve</td>
</tr>
<tr>
<td>13</td>
<td>Claire</td>
<td>Daniel</td>
</tr>
<tr>
<td>14</td>
<td>Orla</td>
<td>Matthew</td>
</tr>
</tbody>
</table>

Mean PLWD score = 39.1; Mean CP score = 35.8

The scores presented in Figure 5.1 show that PLWD most often rated their quality of life as either good or excellent (around 55%), whilst CPs were more likely to rate the PLWD quality of life as fair to good (71%). Only one participant (a CP) rated the quality of life of the person living with dementia as poor to fair.

Figure 5.1: Baseline QoL-AD scores continuum as per PLWD and CPs

**Note that one participant (person living with dementia dyad seven) did not complete the QoL-AD scale.**

**See chapter four (section 4.4.5) for a discussion of how cut-off points in this Figure were calculated.**
5.3.2 Living a good and ordinary life

Participants talked about their quality of life in terms of living and enjoying a good life. The latter was described as an ordinary and normal life, made up of domestic chores, day-to-day routines and social interaction. It involved diverse everyday activities such as running errands, paying bills, shopping, doing the household chores, watching a favorite TV show, going to Mass, and doing and enjoying hobbies and activities relevant to them.

This ordinary and good life reflected the personal values and preferences of PLWD over the life course. For example for one CP, a good life was one where her mother living with dementia (a woman who was always proud of herself as a homemaker) could continue to undertake chores and everyday routines as usual,

If she [PLWD] has to do something strange you know – out of the usual then she may get a little bit uptight, but the general housework, the washing machine the whole thing you know is no problem. Laura CP.

Nevertheless participants’ accounts showed how understandings of a normal and good life had changed as they aged. Often participants compared their current simple and relatively undemanding lives with their former busy earlier lives. Their accounts showed that what was considered normal and acceptable now at this stage of their lives differed from what they would have thought of as normal earlier in their lives,

When we were younger it was different, it was a different life ... Life now it has to be different you can’t sort of stay at the same level all the time. Peter PLWD.

The main change is that I was working, lets say 5 years ago, and life was completely different, I mean ... now I don’t work I have a very easy life, very easy, I mean you know, this memory loss has no effect now. So the biggest change is the retirement (...) now you enjoy your life, no stress, no worries, we [herself and partner] get up in the morning and we can do whatever we like (...) I don’t have the same level of stress. Orla PLWD.

Understandings of a normal and acceptable life were also linked to participants’ expectations and experiences of aging. The latter made reference to positive and negative experiences. Typically for several, positive experiences related to being grandparents and being retired. Negative experiences included chronic health conditions (arthritis, vascular
problems, colostomy) and significant losses including deaths of significant others and widowhood,

It [my quality of life] is a bit down now, on account of [name of husband] being gone. (…) So what it is important for me now? well it would be to have [name of husband] back, but that’s impossible. Dora PLWD.

These experiences posed challenges and brought about changes to the participants’ lives. The notion of PLWD as ageing individuals gave some participants a sense that these challenges and changes were acceptable at their age. This was a very salient theme in the interviews with the five PLWD who were in their eighties. On the contrary, these changes seemed more difficult to accept to others, or at times participants showed ambivalent feelings. For example, most PLWD referred to retirement as a positive change in their lives as they had more free time, had a less stressful life or in the climate of economical recession and unemployment they had a secure monthly income. At the same time many greatly missed their jobs and the interactions they had with their colleagues or other people at the time.

In summary, this section has shown the context and the understandings of what was a normal and good life to participants. This included being able to do ordinary, everyday things that were perceived as normal for their age, preferences and stage in life, whilst at the same time, being able to deal with and accept any decline in health and functioning and other significant losses experienced. Changes that were perceived as not acceptable for their age or lifestyle importantly challenged what participants perceived as a good life.

5.3.3 Living with dementia and quality of life

A change of particular relevance to this thesis was their recent diagnosis of dementia. Many participants referred to the process and difficulties for coming to terms with the diagnosis, and their accounts were often ambivalent. For example, it was not unusual that participants at some point of the interview suggested that dementia was not challenging their lives, and at others their accounts showed they were upset or sad.

Often PLWD talked about attempting to manage the impact of dementia on their lives by adopting a positive outlook and attitudes. Typically PLWD referred to being a positive person, making the most of each day and living their lives to the fullest. Adam (a CP)
when referring to his father summed this up well when he said,

I think he [PLWD] does have a very positive outlook on everything. There is very little news you could tell him that would upset him, because he was always very positive, even with really bad news he tends to sort of, you know, not really let it affect him too much from what he shows anyway. Adam CP.

Some, whilst acknowledging their memory problems, attempted to focus on and appreciated other things, including the family and remaining abilities they still had,

I mean, I forget things and all that sort of stuff. But I mean I’m still quite capable for (...) Like, I don’t have a problem with, you know, doing things or even going down getting the messages for here or stuff like that. Orla PLWD.

Another common approach was not to dwell on deficits and loss, in participants’ own words they “let things go”. Many claimed they did not allow the dementia to get the better of them or take over their lives. This was in their views a way of preventing feelings of depression and sadness,

Like this thing of the memory it kind of concerns me but I don’t let it worry me, I deliberately don’t let it, because if I did, it would take me over. Gordon PLWD.

In addition to current deficits due to dementia, the prospect of future decline was for many participants a great challenge. Several participants lived with much uncertainty which mostly referred to the duration and extent of the disease and pace of deterioration,

Yeah, I mean, I have days when I’m really down when I think about it, you know ... where, do you know ... is this it?. How long will it be before I lose my memory? And you know, these things go through my head. And it’s – it’s a huge thing. I mean because I’m – I’ve got fears that I could end up like my mother. (...) If I could stay the way I am even. I, well, I mean, I’m –it’s okay, you know. Orla PLWD.

At the hospital, the doctor said to me, it could be – we don’t know. That’s what they said. We have to wait and see. It could be 8 years, you know. It could 8 be years and you’ll be all right, or whatever. Colette PLWD.

To these participants, “living in the present” looked like the best alternative to face uncertainty. Many referred to “living each day at a time” and “crossing this bridge when
"I'll get there". This reflected these people's desire to maintain their current lives and highlighted the relevance that the present had for them. In addition, many participants actively avoided thinking, talking or planning about the future as it was daunting and painful,

Well I do [have concerns about quality of life] I fear about the future but I am good at burying my head in the sand and not thinking about it, I've learnt to think about today and that's it. I don't think about the future. Hilary CP.

In summary, this section has shown that QoL-AD mean scores of PLWD and their CPs suggested that their quality of life was good or excellent. On the other hand, whilst their subjective accounts also reflected the participants' good lives, these accounts provided a richer and more complex understanding of quality of life. Two main themes emerged from the analysis of the baseline interviews (see Figure 5.2).

The first was that these individuals were continuing to enjoy what they considered an ordinary, normal and good life despite having to face several challenges and changes sometimes but not always, dementia-related including widowhood, and other chronic health problems. An important way of facing these changes was framing them in the context of ageing and by using coping strategies such as positive attitudes, living in the here and now and not dwelling on things. This understanding of good life and coping well goes some way to explaining what these people meant when they scored their quality of life as high in the QoL-AD scale.

The second theme emerged from discussions about dementia and in particular about negative images of severe dementia. This reflected the contradictions and tensions these people experienced between holding on to their current good lives and current coping and their prospects of future decline (see Figure 5.2). Their stories here included elements of uncertainty, fears, concerns and at times clear efforts to explicitly ignore the implications of having been diagnosed with dementia. By positioning themselves at the beginning of their journey into dementia and by living in the present, it could be argued that participants attempted to distance themselves from what in their view was real dementia.
Participants’ stories could then be summarized as a struggle to maintain their present lives and selves, minimize the impact of changes and avoid the future. As will be shown in the chapter to follow, these views were tightly interwoven with their understandings, expectations and hopes about the anti-dementia medication they had been prescribed.

5.4 QUALITY OF LIFE DOMAINS

The experiences that participants believed gave quality to their lives were well articulated by participants during the in-depth interviews and for the most part resonate with those domains identified by Logsdon and colleagues in the QoL-AD. Five main areas that contributed to their good lives (domains) were identified by participants, namely: 1) their family and friends, 2) being busy, 3) being independent, 4) feeling well about themselves and 5) feeling healthy. Most of these five areas are also addressed in the QoL-AD\textsuperscript{47} scale and in such cases findings from the scale are presented along with the qualitative accounts.

5.4.1 Family and friends

Family

Two items in the QoL-AD scale capture the significance of the family for quality of life in dementia; the first relates to the relationship of PLWD with family members and the second evaluates their relationship with his/her spouse (or in the absence of spouse of a significant other)\textsuperscript{48}. Table 5.2 shows frequencies of responses from PLWD and CPs given to these two items. For clarity, frequencies have been collapsed into two response categories: poor-fair and good-excellent.

\textsuperscript{47} Note that the QOL-AD items, as for example “finances”, that were not raised by PLWD or CPs during the interviews are not explored in this thesis.

\textsuperscript{48} If the individual is single, widowed or divorced, the question refers to the closest relationship the person has – in this sample the person that was unanimously chosen by PLWD and by CP in non-married dyads was the CP.
Table 5.2: Frequencies of PLWD and CPs responses to QoL-AD items: relationship with family and relationship with spouse (marriage)

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<th>Poor to fair</th>
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<td>PLWD</td>
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<td>Family</td>
<td>1</td>
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<td>Marriage</td>
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The data in the table shows that all participants rated their family life and marriage to be either good or excellent and none used scores suggesting a poor or fair relationship in any of these items. In addition, data shows a high level of agreement between both groups. Based on these scores, it can be argued that participants in this sample appeared to enjoy very positive relationships with their families and with their spouses or significant others.

Similar conclusions can be drawn from qualitative data collected. Participants gave several examples to illustrate the good relationships they had with their families and referred to family and family life as the most important aspect of their quality of life. The next section illustrates this through the rich qualitative data. It shows what for these people was meant by a good family / couple relationships, the key features of these relationships and how these contributed to their quality of life.

Participants’ understandings of good families

Participants’ accounts suggested that for them a good family was one that was close, got on well, spent time together, undertook activities together, and never fell apart.

> We're a close-knit family. Although some of the children are in America some of them are France, but oh yes, we would be very close. Paul PLWD.

> You could say that's where my life is around, the family and the grandchildren. Harry PLWD.

Married couples referred at length to the many years and good times they had shared together. The significance of having shared a life together and bringing up a family, generated a sense of intimacy, where PLWD felt loved and befriended, and shared responsibilities and activities. It was still important now, as a couple, to feel in love and

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49 Note that one PLWD did not complete the QoL-AD at baseline (N=13)
particularly to get on well and share time and activities together. Paul and Gordon’s comments were echoed by several others,

My wife obviously the fact that I still love her but you know—and, yeah, that’s really important, and that we do get on very well together (…) I do like this, that we do still get on so well and do things together, like we still go to the Opera and things like that. Paul PLWD.

Like we may have differences but we never have rows or, we don’t agree on everything but we get around things. Gordon PLWD.

Likewise, their accounts showed the relevance to them, of regular visits and contact with adult children and grand-children: “this table is never cleared, there is always someone [from the family] coming” (Harry PLWD); “My son lives in Germany, he phones me every Thursday and we talk half an hour” (Gordon PLWD). These were, for most, cherished and enjoyable times.

Key features of family relationships: reciprocity and trust

Relationships in the family were by and large described as reciprocal. Here reciprocity referred to dynamic relationships between individuals, where giving and receiving was part of normal living. This sense of reciprocity had developed through the participants’ lives and was part of lifelong relationships. Many references, for example, were made to the PLWD as being a good parent and/or spouse, and several talked with pride about how they had raised their children, and about family life and routines in the past.

Analysis of the interviews showed the participants’ trust in and reliance on family members. This included reliance on any support required by the PLWD but most importantly the continuous concern that families, and particularly the CP, had for the PLWD wellbeing (“being there for me”).

My family, the main one is my sister and my nephew [name of godson]. (...) Their concern, their help, their dear, especially with [name of godson]. If I phone him he is here, you know, like that. If there is anything wrong I just phone him and he is here. Eoin PLWD.
Concern also extended over to future care needs and CPs referred to this as constantly "keeping an eye" or "watching out". Some referred to the on-going help, support and concern as something the PLWD had earned and deserved,

When I had the stroke he [PLWD] brought breakfast every morning, he brought everything for me, he was always there. (...) I am not turning my back now and say ... hello you don’t count on me anymore. You don’t do that when you got your 50, 51 years together, you just don’t do that. Maeve CP.

Nevertheless the majority talked about currently facing difficulties together and "helping each other".

We live with one another that way (...) that’s how we live... that’s the way we approach it, we have to help each other. Matthew CP.

Moreover, PLWD accounts showed that whilst they understood, that they themselves were receiving support they also realized that they were contributing to their families in different ways. Concrete examples of this reciprocity were found in the couples’ everyday lives and housework. For instance, several PLWD stated they were doing “their share” in the house or sharing the chores. It was also evident in the help and support many PLWD themselves provided to their adult children or grandchildren. This included the PLWD availability for adult children at any time and their helping them in different ways. Examples here included child minding, (babysitting), sewing or ironing for them, looking after their homes when they were on holidays and their constant concern for their grandchildren wishing to see them do well, making grandchildren feel at home, or buying things for them when they visited.

One thing I would really like to show is how available we are for the children. One day, the son, Kevin, rang up, can you collect the children in the school? Harry PLWD.

You're looking after them (grandchildren) all the time, even in your own mind. Gary PLWD.

My eldest daughter is 17 and a half and my youngest is 3, so she [PLWD] loves spending time with the grandkids, she would pop over to [name of supermarket] and buy pyjamas for them or you know anything. Dianne CP.
Relevance of good family relationships to quality of life

The relevance of a good family to quality of life was demonstrated in different ways. Firstly, when the family “was around” most PLWD were happy and felt unconditionally loved,

They [grandchildren] come, they cheer me up (...). It’s lovely to see them day after day (...) they sort of light it when they come in to see you, they run and give a big kiss (...) The children come in here, they throw their arms, they love you.

Dora PLWD.

In addition, opportunities to contribute to their nuclear and extended family made PLWD feel valued and bestowed on them a sense of worthiness, being part of and involved in their families. One CP summarized it, as being “equals” in the relationships. Finally, trust in family members gave most PLWD “peace of mind”. It was often stated they had “nothing to worry about” as they believed their families would support them whenever necessary. In a similar vein, some CPs referred to being a “safety net” for the PLWD.

In summary the qualitative data illustrates the way PLWD looked upon their families and how for them good families were those who were close, looked after and cared for each other, got on well and spent time together and undertook activities collectively. Family relationships were grounded in participants’ past biographies, they continued to unfold now in the context of the everyday lives, and also related to PLWD future needs. Reciprocal and trusting relationships where the PLWD felt safe and could also contribute and remain involved, seemed to be key features of good relationships.

5.4.1.1 Living with dementia and family relationships

The previous section has shown the complex ways in which PLWD and CPs thought and spoke about the family. By exploring the many ways in which family and spouses were significant to PLWD it has also emphasized the good relationships shared. Nevertheless interviews also reflected some difficulties families were facing after the onset of dementia. Whilst most participants talked about the significance of family visits and regular contact and described it as cherished times, some PLWD referred to the difficulties encountered dealing with visits that involved a number of family members all visiting at the same time, or with grandchildren’s visits, as such events triggered changes to routines or the peacefulness of the household,

But now she [PLWD] can’t cope, that’s the difference, that’s the change, before everyone was here and now she can only take them in small... that’s only a few months, it’s too much on her, you know what I mean, she can’t handle it, you see
much than she loves them (...) But the kids know, they have noticed, so they
don’t come all together. Connor CP.

Living with dementia could also challenge their understandings of and desires to
contribute to their families. For example, Angela (PLWD) used to on a weekly basis, visit
her daughters who lived 30 miles away and during these visits she used to help her
daughters with their children and with households chores. Now because of her dementia,
she preferred that her daughters and families visited her in her apartment. She said,

The only thing that has changed, is that I used to go down nearly every weekend
to see [name of two daughters] (...) I felt if I was due now that I had to bring
down loads of things for the children, because I love doing that. Then this [dementia] may have been started, and one day I brought them bread, you
imagine bringing bread from Dublin! but that’s the kind of thing that I was doing,
I felt like … they [grandchildren] probably though that it was silly, nonsense (...) I
felt that it was time to step back, and for them to come to me rather than me …
now they all come to me. Angela PLWD.

Significant activities where this woman felt she could contribute to her family and what
she perceived as her duty as a grandmother (bringing gifts to the children and spending
time with them) seemed to be affected by her experiences of living with dementia. What
was at stake here was not her dementia per se, but how the family would perceive her and
how they would react to any unusual behavior. The resultant way of resolving this
challenge (staying at home and having her daughters visit her) represented an important
change to what she had thought of as her role in the family: her “stepping back” and
having her daughters take over. Analysis of the interview data showed her ambivalence
about this change. On the one hand, she described her participation in this family time in
a more passive way, but seemed to have accepted the change,

[Name of daughter] and the whole lot of children were here yesterday; and they
brought in stuff and they did the dinner, I had just to sit down at the table and it
was lovely seeing them. Angela PLWD.

On the other hand, during the interview, the difficulties she experienced accepting help
and the feeling of being a burden to her family were often brought up. To her, a mother
should give rather than receive help and her changed behaviour now meant for her a type
of role reversal,
I am “the Mother” and they [daughters] are mine, you know what I mean, and it is difficult for me then to accept I need help from them, like is the mother that does that, like not the daughters done to the mother (...) I have two lovely daughters and they’d do anything for me, but I don’t want to be a burden. Angela PLWD.

Similar findings on role changes, burden and supports within relationships were found in other dyads where the CP was an adult child or sibling.

Another woman, (single) but in a long-term relationship talked about her concerns over sustaining her relationship because of dementia. She had not shared her initial memory concerns with her partner and had tried to conceal from him the appointment she had at the memory clinic. Her accounts reflected great concern about how her partner might react to her memory loss problems now and in the future. She feared in fact that he might leave her as she believed dementia might challenge their relationship as a couple and the couple's current and future lifestyle:

I would’ve been afraid of his [partner] reaction to all of this [dementia] obviously. (...) I think that would be something that you would think about [that her partner could abandon her]. I sort of feel well I am not going to be able to keep up with him [husband] now, and all that kind of stuff. You know, and then if he gets fed up. Orla PLWD.

These changes and challenges were particularly significant for this couple, as they had both recently retired, and enjoyed a rich and active social life. They had also planned long trips overseas. Whilst her partner felt they could find ways to adjust this lifestyle to accommodate her mild cognitive difficulties, she (the PLWD) did not feel this was acceptable as it marked an important change for her, of what she had thought and planned for her life,

Well I’m finding it difficult, you know, at the moment. (...) It is like having a plan that is not going to be your plan anymore, or a future that you thought it was going to be your future and you are a couple and you have things worked out and now it is different, you know. Orla PLWD.

Like with this dyad, for some other spouses (CPs) dementia posed significant challenges to what for them being a married couple represented. An important change was the fact
that they could no longer count on their spouses living with dementia to share decisions, socialize or talk about everyday life concerns. This was framed as a rupture of the intimate and reciprocal couple relationship. One wife summarized it when she said she felt like a “living widow”.

Accounts of some CPs illustrated how moderate dementia could affect the way in which PLWD who had previously shown interest and concern for their grand-children’s lives and affairs. For example short-term memory difficulties made it difficult for one man to make sense and remember his granddaughter’s impending plans,

> We were up with (name of daughter) last week, and the eldest girl, she’s going off somewhere. Well, he asked the poor child so many times where she was going, what she was doing. “When are you going back to school?” And she got a little job in the hotel for the summer, and he had grasped that it was a hotel. He can’t – he keeps asking where is it she’s going. Lisa CP.

In another case, a CP explained how her grandson now greatly missed the concern and interest that the PLWD had always shown in the family. She said he would love to see this aspect of her personality returned,

> My grandson said, nanny, I used to give out because granddad, I would come in and he would ask me 20 questions, what are you doing? Anything and you know, he said, now I wish he would do it. Maeve CP.

These changes reported by CPs were regarded as markers of the progression of the disease.

Finally, it is somewhat remarkable that in spite of their good and loving relationships, most families did not talk openly about dementia, or about their expectations or concerns in an attempt to protect each other. In attempting not to worry their relatives often PLWD hid their symptoms and emotions,

> Like my daughters would be ringing and saying Mum are you ok? And I said I am great, and I was probably sitting here on the other end of the table crying, but because I didn’t want to worry them, I wasn’t really open. Angela PLWD.

On the other hand some CPs were unsure of the extent to which their relatives understood their diagnosis. They felt that raising the topic about dementia with them would be either
too painful or useless. Their concerns typically centered around feelings of depression, awareness and distress,

I don’t think he registered that he has Alzheimer’s (...) now the doctors gave me a leaflet and she said for us to read it but I read it myself and I don’t know whether to give it to him to read. I don’t know whether he would even take it in or whether he will remember or whether it will upset him and I don’t know if it would be good for him or bad for him. Lisa CP.

To summarize, this section has shown how living with dementia could, at times, challenge what these people thought of as normal roles (being a good mother, spouse, grandmother) and of what to them were good and normal family relationships. Whilst reciprocity was an important feature of the family relationships, participants’ accounts showed that living with dementia could challenge the ways in which some PLWD contributed to the family and family lives. This included from the PLWD perspective letting their families take over or not feeling they could contribute to the couple’s life in an equal way, and from the CPs the feeling that moderate dementia could change the ways in which PLWD had kept interested and involved in the couple’s and family’s lives. The qualitative data also suggest that, whilst trust seemed to be an important feature in families, families often tried to protect each other by not talking openly about their feelings and concerns, as the latter might cause distress to others. Accordingly some struggled alone and failed to discuss the impact that living with dementia had or could have on family life.

Friendship
The QoL-AD has an item on friendships where the PLWD is asked to rate on a Likert scale his/her relationships with friends\(^50\). Table 5.3 shows how PLWD and CPs rated this item.

Table 5.3: Frequencies of PLWD and CPs responses to item Relationship with friends

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<td>PLWD</td>
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<td>Friends</td>
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\(^{50}\) If the person states he/she has no friends, the person is asked to rate his relationships with a person he/she enjoys being with besides the family – in absence of such relationships the person is asked to rate how does he/she feel about having no friends.
Scores in this table show that the majority of these people (10 PLWD and 10 CPs) felt the PLWD had a good or excellent relationship with their friends. Almost one third of the participants assessed their relationships with friends as poor to fair.

The qualitative data demonstrated that friendships were a significant part of many PLWD identities and lives. Many PLWD referred to close friends and life-long relationships: these were people who they met regularly and in whom they confided. Friends were part of their biographies and were perceived as significant people who knew each other well, and had regular and meaningful contact:

Well, I don’t see them daily, but they ring me almost everyday - and we are like that from when we went to school, and we have been friends since then. (...) they are all very good, and we have been a long time together (...) and we meet every Thursday night up in the Club (...) I enjoy it so much, and like we have a great night up there. Angela PLWD.

Friends had also a key role to play in taking PLWD out of the house, and facilitating opportunities for entertainment and fun. This was particularly relevant in the cases of widows, as in such dyads the PLWD normally spent long hours alone. Having someone to call in, or take the person out of the house, contributed to alleviating feelings of loneliness and isolation,

Sometimes I know he [PLWD] gets a little bit lonely, he’s at a loose end here. Adam CP.

5.4.1.2 Living with dementia and friendships
Whilst friendships made up a significant element of quality of life, at the initial interview, most PLWD had not shared news of their diagnosis with their friends since they claimed they had either not had the time or opportunity to do so. Many also confided that they felt embarrassed or lacked confidence when meeting their friends. The main issues disclosed here surrounded being able to hold a conversation, word-finding difficulties, and fears of repeating the same comments over a conversation.

PLWD also referred to general fears relating to the stigma of dementia, to being considered a sick person and treated differently, or being left out if their friends noticed their symptoms or knew their diagnosis: "It would spread like wild fire"(Orla PLWD), "I kept saying I am not well, because I thought that this was a stigma you know, that if they..."
(friends) knew I could probably be left out “ (Angela PLWD). PLWD often dealt with this by avoiding or minimizing their social contacts.

5.4.1.3 Conclusion
The QoL-AD scale emphasizes the relevance that the family, spouses and friends have to PLWD, and focuses on the individual’s (PLWD and CPs) assessment of their relationships as a key domain of quality of life. Findings from the QoL-AD scale have shown the positive and strong relationships that PLWD had with their families, spouses and friends. The scale also revealed how PLWD and CPs mostly concurred on the quality of these relationships. An important benefit of the QoL-AD scale is its capacity to provide a concise snapshot picture of the quality of the relationships that PLWD had with significant people.

In this thesis, these quantitative findings were further substantiated by rich qualitative data where the relevance to participants of families and friends and in particular, of their relationships with these people was confirmed. The analysis of the qualitative data has also shown that PLWD and CPs held multiple discourses about the family and that their relationships with families and friends were complex. Relationships with families and friends were strongly connected to PLWD biographies, and the values and meaning that PLWD attached to these relationships marked them out as qualitatively different from other social contacts. Reciprocity and trust were key features of these relationships. There was much reference to still being able to do things for each other (helping each other), but also to their current relationship as a way of paying back to the PLWD (each in turn).

This finding strongly resonates with a counterframe for dementia identified by Van Gorp and Vercruysse (2012), and suggests that exclusively framing these relationships in a discourse of burden or reverse roles, (topics that for years dominated the literature about families and dementia), does not reflect the complexity of these relationships. Whilst much of the literature has highlighted the family in terms of instrumental care and care burden, participants’ accounts here emphasized the significance of the family as providing peace of mind, security, intimacy and feelings of safety.

Findings also illustrate some ambivalence in these relationships. PLWD and CPs stressed the good and positive relationships they had with their families and friends. At the same time interviews also revealed the significant challenges some participants faced in the context of dementia. Such challenges included concerns about how the PLWD would be
perceived by significant others, to how dementia impacted on role expectations, or about stigma and the implications for their families of current and future deterioration. The section has also highlighted the significance that PLWD and their CPs attached to such changes in the relationships. For some participants changes represented a way of stepping back and leaving their families to take over, whilst others referred to changes as markers of deterioration and loss.

In summary both the QoLAD scale and qualitative data highlight the overall positive relationships these people involved in this study had with their families. Nevertheless, the scale is not conducive to investigating the complexities, tensions and ambivalence surrounding family relationships, issues which emerged in these participants’ qualitative accounts. An important limitation of the scale therefore rests in its reductionist approach to relationships. This limitation was also brought out by participants. One participant for example (Orla PLWD) had difficulties rating her relationships with friends based on the scale. She noted that throughout her life and also now the relationship with her friends was excellent, but that over the last weeks “Well I have kind of dropped out of it. I haven’t been seeing people” – This posed a dilemma for her as to how to best reflect this in the scale.

5.4.2 Keeping oneself busy and active

The scale (QoL-AD) focuses on two particular types of activities relevant to PLWD, namely doing household chores and doing things for fun. In both cases the ability of the person to undertake such activities is the facet that the scale looks at.

Table 5.4: Frequencies of PLWD and CPs responses to items “ability to do chores” and “to do things for fun”

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<td>PLWD</td>
<td>CP</td>
<td>PLWD</td>
<td>CP</td>
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<tr>
<td>Chores</td>
<td>6</td>
<td>9</td>
<td>7</td>
<td>5</td>
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<tr>
<td>Fun</td>
<td>9</td>
<td>10</td>
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Table 5.4 shows that almost half of the PLWD rated their ability to do chores as poor to fair and roughly two-thirds rated their ability to do things for fun as fair to poor. This finding was even more evident on CPs ratings where nearly two thirds scored these two

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51 This item “household chores” may have also been influenced by the male preponderance in the sample, as older Irish men’s role in the domestic sphere is often very limited.
items as fair to poor. It is worth noting that in the previous section (relationships) both groups were more positive in their assessments, also that in their assessments of relationships PLWD and CPs tended to be more similar, whereas here, data suggests greater disagreements, with CPs tending to score these items more poorly.

In the qualitative interviews participants talked at length about activities. PLWD and CPs referred to “having things to do” and to “being busy” or “being active”. This section explores the ways in which PLWD talked about being busy, how being busy contributed to their lives and the main facilitators for keeping busy.

**What was an acceptable level of activity to participants?**

The type of activities that PLWD and CPs referred to when talking about being busy included: daily routines, with particular reference to household chores (making beds, ironing, cooking, shopping, running errands, preparing dinner, going for the newspaper.). Often these activities were referred to as “my little things”. In addition, most PLWD talked about leisure activities and hobbies. These included activities done alone, such as gardening, reading, swimming, walking, cycling, doing sudokus and crosswords; or activities involving others, such as bowling, table tennis, visiting friends, having coffee in town and playing cards. Lastly some talked about activities that involved helping others (volunteering, helping friends, neighbours or family members, Mass collection). In summary, therefore, being busy meant that PLWD had a structure and daily rhythm and being occupied also provided opportunities for meeting and engaging with others in diverse ways and contexts.

These activities differed from what being busy had meant to participants in the past where they referred at times to demanding jobs and parallel responsibilities;

> I was in the [name of Bank] as an agricultural consultant (...) and I’d go out and advise farmers and I’d know what they were doing and if they were looking for money they would send me out to assess the situation and make sure the money was safe and what they needed. You know, I had to go through the whole thing. That was no problem. Paul PLWD.

Many talked about and framed activities in the context of what was considered acceptable for a person of that age, and also according to the PLWD personal previous values and preferences,
I mean, there’s a man who’s actually over 90, he lives up there in [name of place]. He gets his golf, his hobbies, and he has a very good quality of life. Whereas Paul doesn’t, you see, Paul never had friends. He never got involved in sports. Because he was farming, his whole focus was on that. Jenni CP.

Married dyads talked about acceptable levels of activity in accordance with previous and current lifestyle and social life. This included travelling together and going on holidays, having dinner at restaurants, and going to the theatre.

Whilst ways in which PLWD kept busy and what was an acceptable level of activity could differ, all agreed that inactivity or “doing nothing” was something unnatural, unacceptable and reflected a poor life. Many participants provided examples of people just “sitting” and spending days “watching TV” to illustrate life of no quality, as a CP summarised “this is no life”. Similarly, Colette (PLWD) viewed doing nothing as being “dead”. Some PLWD made reference to the great efforts that they made to keep themselves occupied as much as they could,

I could not be sitting there, just doing nothing. As my daughter said “get out of the house ma, don’t be sitting in the house or you’ll be dead”. Colette PLWD.

I would hate to be sitting down all day, I never do, like if I am here I go out and I cut the grass or I do something, always do something. Richard PLWD.

**What did being busy represent to participants?**

In contrast to sitting around or doing nothing, being busy for these people meant feeling alive, happy, having fun and being independent and involved with their immediate social worlds,

I like the bowling, its a lot of fun. Peter PLWD.

He likes helping out in anything that is needed, in the garden or in the house. (...) Being busy, this is what he likes, when he is busy he is happy, he is a different person if there are things that he can do. Lisa CP.

I wouldn’t stay on [at home] a night just to see the telly. That’s why I tell to myself I have to keep going, I have to get out and meet people. Richard PLWD.
By engaging with others, PLWD often felt recognised and valued. A good example of this was provided by Richard, who talked about one of his many hobbies being “singing along”. He mentioned how every week he prepared a different song to sing in front of the people who were important to him. This was a place and an activity where he felt valued,

Well what I really like is the singing, sing along, to go there and sing, the place is full, full of different people, is a place beside the Church, and I know everyone in there (...) I like singing there (...) one night somebody asked me to sing. There’s a man there. He said, “Richard, will you sing a song for us?” (...) and at the end everyone was clapping (...) I sing every Wednesday now. Richard PLWD.

Some other PLWD similarly felt valued and validated in activities where they helped others. For example as stated before many were helping their families in diverse ways, also a PLWD was helping an older neighbour do the shopping, and others were volunteering in Church (cleaning, Mass collection and counting the money),

We [PLWD and husband] do voluntary work, we clean the church, I mop the floor and he helps as well, and that’s once a week, just voluntary. Ruth PLWD

Finally being busy was one way of keeping healthy. For instance, all PLWD talked about going for walks as part of their daily routines and many felt this improved their health status,

I walk everywhere (...) And I’m healthy that way. I go every day for a walk for an hour to an hour and a half. Colette PLWD.

I did have a heart attack. So that is keeping me going, walking everyday day, walking exceptionally - the doctor, say do you walk? and I said, I do walk, yes of course. Paul PLWD.

Likewise, three PLWD, Orla, Colette and Eoin talked about keeping their minds stimulated by reading books, the newspaper or doing Sudokus and crosswords. Activities and keeping occupied could help PLWD forget about current problems,

I enjoy it, I sit there and just work on it [woodwork], you have to be all into the thing, your mind is on it (...) When you are active, you just forget about everything else, you just don’t think about this [points his head]. Peter PLWD.
In short, PLWD wanted to keep busy as this represented individuals who had fun, were happy, socially engaged, valued and healthy.

**How did being busy contribute to quality of life?**

Being active and having things to do also gave everyday life a sense of normality. On the one hand, most PLWD felt that being active was something good in itself and something that was part of peoples' lives, being busy made PLWD feel they had a normal and ordinary life. On the other hand, many participants strove to maintain the activities that connected them to their former lives prior to the onset of dementia. One CP (Hilary) for instance, remarked about the efforts she made to keep taking holidays or having dinner in a restaurant with her husband for as long as possible. These were things they as a couple had shared for years. In some way, maintaining this normality and continuity represented a way of counteracting the many changes and challenges posed by dementia,

> We are going to do everything that we always did, we are going to go on holidays, we are going to go out for meals, we are going to do everything that we always did nothing is going to change. Hilary CP.

The concept of being busy was often linked to that of being able and talked about in the same context: "Doing the things that I like, that I can do what I want to do". Such instances illustrate the multiple connections between being active, independence and health. These were domains of quality of life that in many cases appeared to go hand-in-hand in the participants’ accounts;

> I would say it [quality of life] is probably very good because he is able to do all of those things [that are important to him]. May CP.

> Once she can continue to do her daily tasks, to get to town and get her pension, and the day-to-day routines she will be grand. Laura CP.

Many participants referred to other factors that contributed to their being active. Several talked about the weather and how a warm day afforded opportunities for doing things outdoors. Another factor that contributed to being active was the availability of appropriate public facilities where PLWD felt comfortable. Harry (PLWD) referred to the local swimming pool as a non-threatening place: "nobody would ask you anything, you just go and swim". For others the local pub or activities organised in the Parish were friendly spaces where they and their relatives felt the PLWD was safe both physically and
socially. In addition, driving, using the bike, being able to use the public transport or walking were key issues for remaining active and for quality of life,

As soon as the weather fixes up and he [PLWD] is outdoor bowling that’s great, he goes down and … that’s why it’s important for him to drive because he can drive to the bowling club. Hilary CP.

CPs were also shown to have an important role in promoting activities and maintaining the person busy;

I have to keep her [PLWD] active right, so now and again I get her to do the dinner. (…) And if she doesn’t do it, I do it, or whatever you know. Kevin CP.

In summary, there was an implicit understanding that to be active a number of conditions had to be met. These included mobility, health and a positive psycho-social environment.

5.4.2.1 Keeping busy whilst living with dementia
The accounts of some participants suggested that dementia had not brought relevant changes to their lifestyle and, specifically, to the ways they kept busy and active. This was observed in the accounts of participants with restricted mobility and suffering from pain, and of the oldest participants. Often the oldest participants’ accounts suggested they were living a quiet and undemanding life “Well we have an easy life, just get up in the mornings and do your own bits and pieces” (Gary, PLWD). In addition, accounts of the participants suffering from pain or with mobility problems evidenced that these health conditions had already significantly limited the activities in which they could be involved. Claire’s reduced mobility and pain for example, prevented her from going shopping: “I love to go over to that side (of town), and look at some of the clothes or shoes, or whatever, but I don’t because it kills me to walk around”. Dora could no longer attend Mass due to her very poor mobility, and this was something that she greatly missed and interestingly for these few participants these problems were more significant for their quality of life than was the dementia.

Yet many accounts of PLWD revealed the impact of living with dementia in this domain. Living with dementia could challenge the activities that conformed their daily lives, routines and the things they found enjoyable. One PLWD for example, reported she was no longer doing many of the things she normally enjoyed in order to avoid her friends or others noticing her memory problems. She talked about this as having dropped out from her former life. Staying at home and withdrawing provided strong images of ways in
which some PLWD tried to exercise control over their situation and of the significance that this had on their lives,

I sort of “went into myself” with it [dementia]. I kind of just “dropped out”. I’m a shopper. And I never went into the shops for I don’t know how long. I wasn’t doing the things that I like to do. (…) I just didn’t want to meet people. Orla PLWD.

In other cases, care-partners referred to the impact of lack of motivation and concentration on the everyday life of the person living with dementia. For example, Hilary said: “Peter couldn’t even settle to watch a TV program, I think he went to bed at night time because he was bored, he couldn’t think on anything to do” (Hilary CP).

Examples were also provided of how some PLWD no longer enjoyed activities, or felt unsettled when meeting people. Concerns and fears about how the person was perceived during social interactions that many activities entailed, were recurrent,

Everyone stops her on the street and talks to her and she is embarrassed meeting people … you know?, she has changed a lot, where before she would be open to talk all day, now she just hates that, before she went with her friends and she did all the talking but now she goes but doesn’t talk, she still goes (…) but she is only quiet whilst before … you know. Connor CP.

In summary, being busy and active was significant to PLWD and most talked about their daily activities and routines as important ways of keeping busy. Living with dementia could challenge these activities and routines in different ways, including in terms of deficits but also due to the concerns and fears about how PLWD would be perceived whilst interacting with others. Some PLWD dropped out and others whilst still involved, could not enjoy activities or behaved in a different way. This reflected a significant change to their understandings of a good and active life, and of their everyday lives before dementia.

Moreover, some accounts showed how living with dementia could challenge the sense of continuity and interest in relevant things and activities of PLWD. These were situations that had been very meaningful to the person and where they had felt valued. Harry, for example, had stopped attending his annual professional meetings and Paul had stopped
attending the horticultural society meetings. In the past, these activities had been important for them as they connected them back to their former work roles.

We have a thing every year to go to a Church meeting down here for prayer [retirement police force group]. I should be down there doing that, but I don't bother (...) I worked with them years ago and oh such a fellow, such a fellow. And when I meet them, maybe working for years with them and I can't remember the name. Harry PLWD.

Now, he was interested in gardening so he did join The Royal Horticultural Society of Ireland and that was great (...) but then, he's given that up and he just decided... he didn't want to go to these things, and this was kind of his life before. This was a big change to him. May CP.

Another CP, talked about her concerns over her husband feeling stigmatised or getting hurt when doing activities that had been significant for him in the past, and which he still wanted to do,

He [PLWD] is going to do some work with the election, he's been a supervisor and he's done that for years and years (...) and I hate him to go and make a mess of it and then be upset, you know that's all I care about. Hilary CP.

In summary, some PLWD had discontinued or had difficulties in remaining involved in activities that reflected past job-related interests or hobbies. Whilst for some, such as Harry, these activities seemed now not as significant as they had been in the past and they were comfortable and felt ready to let go, for others, withdrawing represented a significant loss. Or as in the case of Peter (Hilary's husband), the activity was so relevant that he preferred to expose himself to some risks rather than withdraw.

In one unusual case (Dyad 12- David and Maeve) the PLWD had withdrawn from almost every activity he had done in the past. After retiring this man had spent his time working in his workshop, and dedicated much of his time to taking care of the repairs the house needed. Now his life was reduced to “just sitting in this chair and watching TV”. Living with dementia had progressively challenged what his wife considered to be a normal life. Since the onset of dementia David had changed from being active and able to do several things in the house on his own, to being asked by his daughter to do things, to now doing nothing outside of watching TV. This to her was “no quality of life,”
He [PLWD] could be sitting all day long, all day. And it is very hard because he was such an active man, he could do anything, he could do electricity, he could do plumbing, he could do ... carpentry was his main thing (...) Four years ago, he did that full decking outside the patio, just 4 years ago and he was 72, and last year, my daughter asked him to build a chicken coop, just to keep him occupied, and he did it and that was last year, but this year is absolutely nothing, no interest outside the telly (...) When you can’t get up and go out on your own that’s no quality of life. Maeve CP.

During the interview, David talked with great ambivalence about his quality of life. On the one hand, he defined his current life as fair and highlighted the pleasure he got out of watching his favourite shows on TV. On the other hand, he stated: “well I have nothing to do (...) my life is empty”; this reflected his difficulties in making sense of what to him may have been an acceptable level of activity.

This case illustrates how apathy and lack of initiative, symptoms typical of dementia, may greatly conflict with the dominant discourse of successful ageing as synonymous with ageing actively, and with the sense of normality that being occupied in everyday things may give to PLWD.

5.4.2.2 Conclusion
The QoLAD scale prioritises two particular type of activities, chores and fun. Both of these activities can be part of the everyday lives of people with dementia, and in this sense illustrate activities that are meaningful to participants. Nevertheless, activities on the scale are only framed in terms of abilities to perform household chores or do things for fun, aspects of this domain that whilst important, were rarely brought up by the PLWD during the in-depth interviews. This is consistent with other literature that has shown how PLWD themselves do not associate functioning with quality of life (Banerjee et al., 2009). Also, ability per se did not reflect in any way how the person would actually perform the activity, as often other factors such as stigma, lack of confidence, perception of risk or issues not related to dementia (such as mobility and environmental factors) could preclude the PLWD from doing the activity.

The qualitative findings in this section have shown that, in keeping with mainstream understandings of ageing successfully, most PLWD in this sample derived benefits from
feeling busy and keeping active and they did this, through everyday tasks, daily relationships and routines. Doing everyday things provided participants with a feeling of living a normal and healthy life. This predominant image of active ageing and normality was challenged in one case, through the narrative of David and Maeve. Here the dyad’s struggle to make sense of David’s current state of inactivity reflected great ambivalence. This was an exceptional case in the sample.

Findings also show that the particular ways in which these PLWD kept themselves active differed greatly. As other scholars have argued (Bond and Corner, 2004; Phinney, Chaudhury and O’Connor, 2007), many participants showed much concern over being busy and active. However participants’ discourses were at times ambiguous. On the one hand, whilst being active, busy and doing things was meaningful to PLWD as this reflected being healthy, valued, ordinary, independent, involved and connected to others persons (Phinney, Chaudhury and O’Connor, 2007), on the other hand, activities often entailed meeting others, and several claimed they lacked confidence, had fears and experienced embarrassment when others might notice their dementia. It was this, the latter that had a very significant impact on their quality of lives and it restricted some from doing the things they enjoyed or meant that they could not enjoy them as much as before. Living with dementia also implied that some PLWD distanced themselves from the things that in the past had been very significant for them.

In summary, living with dementia could pose a challenge to what these people thought of as a good and active life in three main ways: reducing their involvement in the everyday activities they enjoyed or the enjoyment they got from activities and social life; distancing PLWD from activities that were part of their biographies and values; and limiting their lives to doing nothing or “watching TV”. Similar themes have been previously raised in the literature (Phinney, Chaudhury and O’Connor, 2007; Caddell and Clare 2011), but it is important to note, that the significance and the impact that these changes had on the quality of life of PLWD were not homogeneous. A main concern related to what to participants was a good and acceptable active life and how withdrawing from interests distanced (or not) the PLWD from their past normal lives.

To conclude, I would argue that the items on the scale in this domain do not clearly capture the PLWD and CPs understanding, ambiguities and the complexities of what being busy and active meant and represented to participants. Moreover, if activities are
framed exclusively in terms of "abilities" to undertake same, the PLWD and his or her deterioration are positioned as key determinants, neglecting other relevant factors which may affect activities such as relationships, environmental factors, mobility and the impact of the decision making of CPs on risk-taking and autonomy.

5.4.3 Being independent

Independence is not reflected in any item of the QoLAD scale. Thus, in this section, only data arising from the qualitative interviews will be presented.

Prior to exploring participants' views about independence, it needs to be acknowledged that ten out of the 14 dyads in this thesis explicitly referred to "independence" in the interviews. Whilst qualitative approaches do not focus on figures and numbers, in the light of the very limited attention that independence has received in quality of life frameworks and scales, I believed it is relevant to highlight that this was not an issue that only interested a minority but in fact was talked about by almost all.

The significance and understandings of independence differed greatly among participants. For some, independence related mainly to remaining physically independent with no restricted mobility. Here several spoke about "being able to move around" or more specifically walk, cycle, take the public bus or drive. It gave participants the freedom to go out, where and when they wanted to.

Being able to move around, being independent. Ruth PLWD.

[The bicycle] is his own little bit of freedom you know. Lisa CP.

Others discussed independence in the context of PLWD being autonomous in their daily functioning or more specifically, their ability to do things without the help of others: "on his/her own". This was used as opposed to "depending on others" for accomplishing certain things (e.g. cooking or taking medication),

Well I suppose is just being independent, being able to get to town and do your own bits and pieces. Ruth PLWD.

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52 As it was shown in chapter two, the revised version of the QoL-AD scale (Edelman et al. 2005) included two items that made reference to independence (ability to take care of oneself and ability to make choices in one's life), but to date this revised scale has not been widely used, and it was originally devised to be used in residential care.
If he loosens his independence, if he could not go for his walk on his own or could not stay here [at home] without me, that would be big. May CP.

Finally, three PLWD (Eoin, Peter and Angela) talked about independence in the context of having control over things considered significant to them. This was linked to decision making about areas relevant to the individual such as finances, stopping driving or selling their cars. It also was related to having control over looking after themselves and “running” their own lives,

My independence, taking care of myself, of my life. Eoin PLWD.

For most participants independence was relevant as it was connected to the psychological wellbeing and self-esteem of PLWD, and probably to some extent, whilst not explicitly mentioned, to their dignity,

[What it is important to him now is] being independent, maybe someday we will have to stop [going on the bike] but at the moment I feel is good for him to do something himself and I wouldn’t like to say no, I go with you [to Mass]. Lisa CP.

Like if she’s getting the dinner, and she wants to think about what’s next, or what to get, I let her think about it herself for a while. If it affects her, I will say let me get it. But I think this is good for her, that she feels that she can do things on her own, that she is independent. Kevin CP.

5.4.3.1 Living with dementia and independence
In the context of living with dementia, participants also talked about being independent as a potential risk. For example, taking medication and managing their own finances were important areas where independence and perception of risk and safety were closely connected. In some cases, concern for the safety of PLWD meant that CPs took the person’s sense of independence away. This was well illustrated by Angela (PLWD) and Eoin (PLWD),

I haven’t got the tablets [at home], cause what was happening to me, I was taking them when I shouldn’t been taking, and the chap in the Chemist there, we now him for years, my daughter told him “Don’t give my mum the tablets” cause one night, well I have taken all my tablets and I said oh God what tablets did I take
today? and I took them again and it was a completely different tablets that I should have taken, and I was into a panic, really panicky what have I done? And I was up all night just drinking water, water, water, to have it all out of my system. (...) I was frantic here crying ... just couldn’t sleep you know. And I said that will never ever happen again. Angela PLWD.

The fact that ... when I had control of my own my money, seemingly I used to lose it, I gave it away and forgot it. Now my sister looks after that. Eoin PLWD.

These excerpts highlight what seemed to be a common pattern for many people in the sample: having to withdraw from doing otherwise normal things and thus limiting their independence. This was not easy for some PLWD, who wanted to hold onto their independence and autonomy including everyday things like choosing their own clothes,

If I said to him: “I am leaving now that for you to wear”, he would throw it and get something else, he didn’t want to be told to do things. Lisa CP.

Other PLWD articulated this as “depending on others”. For some PLWD this was an important change to their lives and was experienced as having an adverse impact on the quality of their lives,

Before I was totally independent. Now they allow me so much and I have to come from everything. I don’t have full independence. [Later in the interview] (...) That is the one part that would bring it [quality of life] down from being very good now. Because I’m depending on her. Eoin PLWD.

In these examples the main issue at stake was how some PLWD felt that the control they were now exercising over different decisions was insufficient for them. But there were contradictions and complexities in people’s perceptions and understanding of what being independent meant. Eoin, for example, believed he was no longer fully independent (as he was before) and he missed this, yet dependency meant him seeing more of his relatives and he was grateful to his family for helping him to organise his life. It is noteworthy that independence intersected with the relationships of PLWD with others, and that here independence unfolded into multiple concerns, his own feeling of no longer being in control of his finances and life and the concern of how this could impact on the life of his sister,
That [his independence] I miss a bit but it doesn’t matter ... my sister is there. And if I need something they get that for me. (...) Before I was in touch with them [family] but they wouldn’t be... they wouldn’t come to visit as often. Now my sister has to come and help, everything has to be organized for me. But I don’t want to be a burden. Eoin PLWD.

Some CPs also talked about the tensions they confronted trying to balance independence and safety needs of the PLWD. Lisa (CP) seemed to have prioritized her husband’s independence over her own concerns and those of her neighbours when she said,

I don’t want to stop him doing the bicycle, but neighbours had said to me “Oh you should be watching Gordon [PLWD] on the bike” and I’d be terrified turning corners or whatever, but it is something I don’t want to take from him (...) because I think that’s taking his last little bit of independence. Lisa CP.

Her narrative also shows the complex and sensitive nature of these decisions and the great emotional weight that these entailed. Other CPs referred to this in a very similar way.

So far, the section has reported on ways in which independence and safety issues could conflict, and how this could impact on quality of life. Nevertheless, it is noteworthy that “depending on others” did not appear to be a negative issue for all PLWD. For instance, Angela felt that organising relevant support for her gave her more control over her life rather than the reverse. She said,

I feel that I am back in the world again that is the way now that I cope, like Dianne would give me a call everyday and she would ask how are you? Grand, grand, and she may say don’t forget today you have to do this or this. Angela PLWD.

In a different way, some participants (Orla PLWD) and (Maeve and Mary, CPs) talked about depending on others as not being a new phenomenon but rather being a characteristic of the relationship between the PLWD and the CPs in the past or part of people’s personality and that these PLWD did not resent being dependent,

I feel if he [partner] – if he can do it for me, why do I have to ... he saves me from having to ... I mean a lot of it is laziness I mean, when we’re away we had the brochures when we were on this tour. And I kept asking him questions. You know, I could have the brochure myself and read it. But why would I read this
when he’s going to read it – you know what I mean? But I’ve just been like that all my life. Orla PLWD.

5.4.3.2 Conclusion

The significance that being independent had for participants in this thesis contrasts sharply with the poor representation that the concept of “independence” has had in most measurement scales on quality of life in dementia. Findings about independence were embedded in the interviews with many of the participants involved in this thesis. PLWD and CPs talked about the different ways in which they wanted to remain independent and this provided them with feelings of freedom, wellbeing and sense of control over themselves and everyday lives. Nevertheless, participants’ accounts also showed the ways in which independence and perception of safety could compete in the context of living with dementia.

The findings have illustrated the ways in which independence intersected with other significant areas of life for people in this sample, such as relationships with others, especially families. Firstly, as feelings of independence were connected with the ways these people and their families related, thus reflecting how PLWD could greatly differ in their understandings of the role that family now played in helping to organize their everyday lives. Secondly, as findings also suggest that the way in which PLWD were perceived by CPs had a great impact of how levels of independence were negotiated in the dyad.

5.4.4. Feeling well about: psychological wellbeing

Two items on the QoL-AD refer to psychological wellbeing: “mood” and how the participant “feels about him/herself as a whole”. Table 5.5 reports frequencies as rated by PLWD and CPs on both items.

Table 5.5: Frequencies of PLWD and CPs responses to items “mood” and “the self as a whole”

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<th>Good to excellent</th>
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<td>PLWD</td>
<td>CP</td>
</tr>
<tr>
<td>Mood</td>
<td>4</td>
<td>2</td>
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<tr>
<td>Feeling about Self</td>
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Whilst PLWD and CPs rated the “self as a whole” quite similarly, CPs ratings of the PLWD mood were slightly more positive than PLWD own ratings (12 CPs vs. 9 PLWD good to excellent). This may reflect the difficulties in evaluating such a subjective domain of quality of life. Also as shown in the previous section, dyads often failed to talk openly about dementia and about their feelings, it is not surprising then, that their respective appraisal of mood might be a little different.

During the qualitative interviews, PLWD and CPs also referred to positive psychological wellbeing as an important component of quality of life. The following dialogue from one interview of a participant living with dementia illustrates the complexities and multiple connections that were part of this domain,

PLWD: To feel well in yourself, you know, it’s good; to know that you do feel well and that you are mobile and everything in my little flat is fine and that within yourself, the confidence. To be able to go out everyday that’s very important to me; that makes me feel well.

Interviewer: What do you mean by “feel well”?

PLWD: To feel well to me is to ... that you haven’t got aches or pains or well I don’t really have worries because like I have my daughters and I manage with my pension, you know what I mean, and just the whole ... I am looking for a special word like “coming out”... maybe it would be confidence, to have it back. Angela PLWD.

In short, psychological wellbeing was often related to positive feelings and, as illustrated in this quote, it was connected to many other areas of quality of life, for instance physical health (aches, pain), mobility, and independence (for moving around, also living at home). Feeling well was also equated with not being worried or having concerns, and feeling safe and financially secure (family relationships and pension). All these factors seemed to contribute to the overall feeling that the person was living a good life and that this in turn promoted a personal feeling of wellbeing in terms of achievement or success and in leading what was perceived as a good life. Interestingly, in this quote the PLWD stressed “confidence” as something particularly important for feeling well.

Many other participants also made references to their satisfaction with current or past lives. PLWD often talked about being happy and/or content with their lives. References
to feeling lucky when compared to other people they knew and feeling proud of what they had achieved in life were recurrent positive feelings reported in these interviews.

Several felt grateful for being alive and enjoying a good and healthy life. Dora’s (PLWD) words were reiterated by many others when she said: “I want to live as long as I can (...) I am lucky that I don’t have that awful pain (...) every morning I think, thank God I am alive still”.

Hope was also important to participants. It centered around maintaining current health so they could live at home comfortably for as long as possible,

Well if I keep going the way I am at the moment, I hope … well I am 68 now, if I last another few years the way I am now, and I feel so well, I’ll be happy, just here in my small flat – so that’s my hope. That keeps me going. Angela PLWD.

In summary, psychological wellbeing referred to positive psychological states including confidence, contentment with previous and current life, feeling physically and psychologically safe and secure, and feeling lucky, grateful and hopeful.

5.4.4.1 Living with dementia and the self

“Confidence”, or its absence, played a very important part on how PLWD felt about themselves. Other negative recurrent feelings were embarrassment, frustration, anxiety and episodes of distress. Whilst some PLWD described positive ways of coping with such feelings, in terms of not dwelling on negative emotions and focusing on the positive, in other cases negative emotions seemed to impact on self images. Some PLWD explicitly referred to their low self-esteem or more generally to their “not feeling well about him/herself”.

The stories of Angela (PLWD), Colette (PLWD) and of Orla (PLWD) illustrate the struggle that dementia can pose to the self and each of their stories summarized how dementia could be experienced as a lack of continuation with the person they used to be. Orla for instance, talked at length about herself as a “shopper”, a “good mixer” and someone who enjoyed having fun and being out and about. However since being diagnosed with dementia things had changed,
My self-esteem is quite low. And – and I am kind of “weepy.” (…) It is about not feeling good with your own self. Like that … you don’t like what you see. Orla PLWD.

Similarly some CPs also provided examples of how at times they could no longer recognize their relative in the person they were caring for. Challenges and difficulties surfaced many times in the context of everyday care. PLWD were described as not as caring as they used to be, their sense of humour was no longer the same, or they tended to get “narky at times” or were "giving out" constantly. Lisa (CP) explained,

He was very aggressive; he got very aggressive before the tablets. Just verbally, like very annoyed and giving out and I couldn’t understand it- he wasn’t himself, he was aggressive. Lisa CP.

Psychological wellbeing was threatened when the PLWD did not feel well about him/herself or when CPs felt the PLWD was behaving in a way that did not correspond with how the person had behaved in the past. For these people, this represented a lack of continuation with the person they used to be.

5.4.4.2 Conclusion

QoL-AD scores indicated that one third of the PLWD felt fair or poorly about their self and their moods. Feeling well about oneself and about one’s life was something relevant to PLWD but understandings of feeling well were complex as often PLWD associated feeling well with many other areas of quality of life including health, independence, safety, relationship with others and to satisfaction with current and past achievements and lives. Feeling well therefore related to positive feelings about current and past lives including contentment, confidence, feeling safe and hopeful and grateful. In contrast, this domain was threatened when PLWD or CPs experienced a discontinuity with previous life or sense of identity.

In summary, these two items on the QoL-AD scale seemed to reflect well the main concerns that surfaced in the qualitative interviews.
5.4.5. Feeling healthy

Three items on the QoL-AD make references to health: physical health, energy and memory.

Table 5.6: Frequencies of responses to items “physical health”, “energy” and “memory”

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<th>Item</th>
<th>Poor to fair</th>
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<td>PLWD CP</td>
<td>PLWD CP</td>
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<td>2 7</td>
<td>11 7</td>
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<tr>
<td>Energy</td>
<td>8 7</td>
<td>5 7</td>
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<tr>
<td>Memory</td>
<td>9 13</td>
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Table 5.6 shows that most PLWD (n=11) felt their physical health was good to very good. Nevertheless, their own evaluations of their energy and their memory were quite negative. CPs evaluations of health were slightly more negative than PLWD own evaluations. Again, in the ratings of CPs, memory stood out as being the one item on the scale with most negative appraisal.

In the qualitative interviews, the topic of health was often raised with respect to what was reasonable for the participants’ age and given their health condition. Many PLWD were suffering from other chronic conditions but perceived themselves as healthy if and when medical advice and appropriate treatment had been sought. Understandings of health were also influenced by the participants’ biological age. In summary, PLWD by and large talked about their health in relative terms and most defined themselves as healthy in spite of suffering from other chronic conditions. The words of Paul illustrate these points well.

My health is very important. But I’m lucky, I did have a dicky heart and that sort of thing but I’m taking the tablets. But yeah I do think that I am [healthy]. I’m not boasting but I think for my age I am healthy. Paul PLWD.

Two main concepts stood out in the participants’ understandings of health: suffering from pain or aches and/or losing mobility. Many defined “health” as such: “That I have no pains or aches” (Angela PLWD); “As long as I can walk” (Paul PLWD). Lack of mobility was a daunting prospect that could importantly reduce their quality of life. Some participants who were pain free and remained quite mobile also feared what the future

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53 Memory was the only item on the scale where nobody with dementia claimed their memory was very good.
might bring. In one case, a PLWD preferred to tolerate discomfort and reduced mobility rather than taking the risk of surgery. His CP said,

[ Talking about Peter’s knee problem ] They can’t operate, they’re afraid to operate, because the operation they have in mind, they’re afraid, it’s not always successful. So straight away, he could end up in a wheelchair, so I just said no, no way. At least now he’s able to get around. Hilary CP.

Claire (PLWD) and Dora (PLWD) had very limited mobility. In particular their stories highlight how pain, suffering and lack of mobility rather than dementia per se, can noticeably erode quality of life;

The thing that upsets me is the legs pain. I can’t walk too far, and I have arthritis in the lower spine you see (…) I don’t go upstairs too much because that kills my legs. I go up and make the bed but [Name of husband] does all the hoovering, all … he does everything. I do as much as I can in the kitchen. (…) And I love shopping, going to town. Now they have to leave me outside the shops that I am going into, and then come back there that’s the way it is. Claire PLWD.

In here once again the qualitative findings on health reflect a dynamic interplay between health, activities, and independence and how each in turn impact on quality of life.

In addition, mobility was significant to participants as it could impact on the PLWD possibilities to stay at home. Some female CPs raised concerns about whether they might still be able to look after the PLWD should their relative’s mobility worsen. Maeve (CP) illustrates this well,

I am grand now, as far as he is mobile, it’s good, if he loses his mobility I couldn’t care for him because I couldn’t mobilise him, I can’t, I haven’t the strenght you know (…) because if he can’t walk, what am I going to do? What am I going to do then? Maeve CP.

5.4.5.1 Conclusion

In summary, health was experienced and evaluated according to what these PLWD found reasonable to expect for their age and medical condition. Health was often discussed in the context of physical health (mobility and pain), two areas that could limit their lives seriously. Intense pain or reduced mobility posed a relevant challenge for what participants thought of and what they experienced as a good life.
Interestingly, analysis showed that memory was the item where QoL-AD scores and qualitative data differed most strongly. For example, interview data pertaining to the three PLWD (Paul, David, Richard) who rated their memory as being most impaired (fair to poor) suggested that poor memory was not a major problem for them and it had little impact on their daily lives. In contrast, other PLWD who rated their memory as good, in their qualitative accounts, talked about problems associated with memory loss such as stigma, lack of confidence and withdrawing from activities. Whilst memory problems may have been important for some PLWD, accounts reveal that it was not just memory or how they perceived their memory to function but also feelings, including fears and the subjective impact of memory problems which had a greater impact on their quality of life.

5.5 DISCUSSION OF THE CHAPTER AND CONCLUSIONS

In line with the literature, using a conventional approach to investigate quality of life, findings have shown that PLWD overall enjoyed a good quality of life and they themselves evaluated their quality of life more positively than CPs did. Scrutiny of quantitative data yielded through the responses of PLWD and CPs to individual QoL-AD items show that relationships with family and friends received by far the most positive ratings for both groups on the scale. More than two thirds of PLWD rated their memory as being only poor or fair which suggests good insight on the part of these participants into their limitations. Also several rated their ability to do things for fun and their energy as poor. On the other hand, CPs poorest rating was by far memory, followed by ability to do chores and things for fun, health and energy.

These findings were enriched and expanded upon by the qualitative data. Findings have helped to uncover what these people meant by a good quality of life, and in line with previous scholarly work (Fukushima et al., 2005; Robertson 2013) findings have highlighted the significance for many of what was perceived as a normal and ordinary life to understandings of quality of life.

The findings suggest that PLWD wanted to maintain a life where they perceived themselves as happy; active, involved and socially engaged; supported but also making valuable contributions to their families and friends; and where they could remain independent and healthy. These domains of quality of life are akin to the ones found in other studies on quality of life in older people and quality of life in dementia (Farquhar
Nevertheless findings from this thesis reveal the diversity of experiences and the complexity of the discourses that PLWD may hold when talking about these domains. Thus, the chapter has expanded on the quality of life literature in dementia by exploring the participants’ complex and diverse ways of thinking about what to them constitutes good family relationships and friendships and what for them was an acceptable level of activity, independence and of physical and psychological wellbeing. The findings support the view that quality of life is a highly individual, dynamic and multi-faceted subjective concept.

Findings also reflect the type of contextual understanding of quality of life advocated by Bond and Corner (2004) and Gubrium and Holstein (2006). The qualitative data suggested that participants’ understandings of quality of life were grounded in their biographical experiences and in their perceptions of their current stage in the life-course. In keeping with the works of these scholars mentioned above, findings have shown that participants’ understandings of what it takes to age successfully and what they considered as normal and acceptable for their age and condition, impacted on how these people gave meaning to their current everyday life experiences.

This chapter has explored how PLWD tried to maintain their good lives in the face of adversity and change (Wolverson et al., 2010; Caddell and Clare 2011). It has revealed the types of challenges that living with dementia posed to what participants thought of and what they experienced as a good life. Living with dementia could, for example, challenge the dynamics and relationships that PLWD had developed over time with families and friends, and could represent a threat to continuing to live an independent and active life. The findings show how often these challenges brought about changes in these individuals’ everyday lives and interactions. The impact that living with dementia had on the quality of life of PLWD related then more to how manageable or otherwise unacceptable such challenges and changes were for the PLWD and the CPs. This finding is partly in keeping with those reported by Ettema et al. (2005) and Byrne-Davis et al. (2006) who discuss the role that coping and adjustment have in quality of life in dementia. I will return to and expand about this in chapter eight, conclusion.

Similar to Bond and Corner (2004), findings from this chapter show that how PLWD are perceived and treated by others, could have a great impact on their quality of life. An
important challenge to how these people felt and behaved related to what they believe other people would think of their deficits and impairments. For this reason, some actively avoided or minimized their social contact with others. Fears of being stigmatized or treated differently by others were recurrent themes in this chapter. This is in keeping with the work of other scholars who have framed dementia as being more than cognitive and functional deficits and have explored the lived experience of dementia in a broader way (Sabat 2001; Katsuno 2005; Sabat et al., 2011; Steeman et al., 2013). This is an important finding as whilst most quality of life scales (see review of scales in Chapter two) include some items that look at relationships or interactions with others; none consider how the individual with the illness is perceived by others and none consider how stigma and negative social attitudes can significantly impact on quality of life. These findings therefore force us to move away from conceptualizing quality of life as exclusively focusing on the individual and his/her abilities and functioning, to incorporating into its conceptualization how other people perceive and treat the PLWD. This fits well with current understanding dementia as introduced in chapter one.

The chapter has also shown the way in which dementia is framed by PLWD and CPs can impact on quality of life. It was argued that most PLWD and CPs held a very negative image of dementia and that they had strong concerns about its negative perceptions. For many the PLWD future was worthless and dementia would devalue them as humans. The impact that negative ways of understanding dementia (in western societies) has for individuals has been recently explored by Van Gorp and Vercruysse (2012) (see chapter one for further detail). Three dominant negative frames and two positive counter-frames that Van Gorp and Vercruysse (2012) identified in the media were also found in this thesis. In the negative frames PLWD are presented as losing their identity and humanity, care is framed in terms of reverse role and burden, and much attention is given to deterioration and advanced stages. These three frames were echoed in the accounts of some participants of this thesis. Findings emphasize the participants’ uncertainties about the progression of the disease and suggested a strong feeling that the type of life that they could live, if they had severe dementia, was of little value. This importantly impacted on their current quality of life, and reinforced their desire not to deteriorate further. At the same time, participants of this thesis seemed to deal with these concerns by living each day at a time, making the most of their current lives and by actively avoiding thinking and planning for their future. This is similar to the positive counter frame “carpe diem” (Van Gorp and Vercruysse, 2012). Likewise the way in which participants talked about
relationships also reflected negative and positive frames, this included understandings of care as a burden and also as part of life long reciprocity and trust (positive counter frame “each in turn”). This ambivalent use of frames might be reflective of these people’s understandings of dementia based on information in the media and dominant negative public attitudes to dementia, and their own more positive experiences.

So far, these findings have pointed to three different levels relevant to quality of life in this study: the individual level, the relational level and the macro level. A graphic representation of this is provided in the next Figure (Figure 5.3)

Figure 5.3: Representation of levels relevant to quality of life in dementia

This proposed model on Figure 5.3 shares similarities with the model of quality of life suggested by Banerjee et al. (2011) (see chapter two, section 2.6.1 for further detail). As the model suggested by Banerjee and colleagues (2011), it reflects micro and societal elements in the conceptualization of quality of life in dementia. However, the model I am proposing emphasizes the relational factors, in particular how PLWD are perceived and treated by others, something that Banerjee’s model did not include. This is in keeping with the significant influence that other scholars, such as Nolan et al. (2004), have given to relationships in dementia. Whilst the way others treat and perceive the PLWD seemed
to importantly contribute to their quality of life, this is not to say that PLWD are just passive agents, receiving help or suffering from stigma. An important conclusion of this thesis and in line with findings of Barlett and O’Connor (2010) is that of recognising PLWD as individuals with agency. This places the focus of attention in the bi-directional relationships between PLWD and their families. It has become clear that the help, support and love of their families are critical aspects of the PLWD quality of life. Nevertheless, findings have evidenced that PLWD need to equally contribute, help and look after their families.

Finally, the chapter also compared in great detail the type of data on quality of life obtained using both quantitative and qualitative approaches. Findings have shown both the value and indeed the limitations of using scales to investigate quality of life in dementia. The main value of the scale lies in its power to provide a clear and concise snapshot picture of items that seemed relevant to these people. The main demerit lies in its reductionism. The qualitative findings emphasized the complexity, ambiguity and overlapping of domains and demonstrated well the ripple effect different behaviours had. For example, the findings showed the complex and multiple connections between family relationships, emerging needs, independence and wellbeing. Whilst families contributed to peace of mind as they supported and helped PLWD in remaining at home and feeling safe, at the same time this was also interpreted as a lack of full independence and could impact negatively on quality of life. This shows how some domains could have both positive and negative implications for quality of life. This finding is in accordance with the work of Hendry and Mcvittie (2004) whose study, on quality of life of older people, showed the difficulties involved in capturing these complexities on a scale. Also similarly to Hendry and Mcvittie, findings emerging from this thesis lead to questions being raised about the extent to which a scale can reflect the private accounts of PLWD and CPs. This was particularly relevant on items looking at relationships with others, where the scale only reflected positive evaluations, whereas interviews showed the complexities, contradictions and challenges experienced within relationships.

In addition, and as some scholars have suggested (Rabins et al., 1999; Trigg et al., 2007b) including in the scale factors that are related to the progression of dementia (as in here, activities is regarded in terms of abilities, or memory) could hamper the power of the tool to portray how these people experienced and evaluated their quality of life. A final limitation of this scale is that it does not represent independence, something that this
thesis and previous studies (Droes et al 2006) have highlighted as very relevant to these people’s lives.

In summary, this chapter has shown the usefulness of looking at quality of life in dementia using a social constructionist approach. The approach can provide a rich understanding of the dynamic nature of quality of life where the complexities, ambiguities and multiple views of participants are best represented. By inviting PLWD themselves to talk about the meanings and values of often taken for granted knowledge, this lens also helps to question how well the participants’ private accounts are reflected in the scales. Limitations of this approach have, nevertheless, to be acknowledged. Findings of this thesis reflect the experiences of living with dementia and quality of life of quite a privileged group of people. For instance, all participants enjoyed strong relationships with their families, had relevant social support and none had important financial issues. Findings then represent the participants’ experiences from a particular social location. It may be argued that the experiences, hopes and concerns of people living with dementia who might not enjoy the same level of family and social support, or who may have significant financial constraints may be quite different. In addition participants had been assessed in a well resourced memory clinic, had been given the opportunity to attend a feedback meeting with their families and their diagnosis had been explained in a gentle manner by dementia trained professionals. This may not be the reality of many other PLWD in Ireland (Cahill, O’Shea and Pierce, 2012) and this may also have impacted on their views about the topics explored in this thesis.

This chapter has provided the evaluations and the complex understandings of quality of life of a group of people recently diagnosed with dementia. All these PLWD were prescribed a medication to treat dementia (anti-dementia drug) at the time their diagnosed was made. The unresolved debates and challenges about the efficacy of the drugs and about their cost have been extensively investigated (see chapter three of this thesis). Nevertheless, the experiences of PLWD and their CPs with such drugs, what these drugs mean to them, how they expect these drugs would impact on their quality of lives and their actual experiences of this, remain largely unexplored. The next two chapters set out to address this gap in the literature.
CHAPTER SIX: “I HAVE A GOOD LIFE, I JUST WANT TO KEEP IT”. EXPECTATIONS AND SIGNIFICANCE OF MEDICATION FOR QUALITY OF LIFE

6.1 INTRODUCTION

Chapter five explored understandings of quality of life among 14 individuals recently diagnosed with Alzheimer’s disease or mixed dementia and their CPs. It showed that these people were leading what they considered to be a good, ordinary and normal life commensurate with their age and stage in life. Main components of this good life included: enjoying good, meaningful and reciprocal relationships with family and friends; keeping themselves busy, active and independent in their everyday lives; feeling positive about themselves and lives, and feeling they had a good physical health.

The chapter showed that living with dementia could pose several challenges to what these participants thought of and what they experienced as a good and normal life. In addition to the functional deficits and impairments, living with dementia challenged their images of themselves and how they were perceived by and how they related with significant others. The perceptions of these changes by the PLWD as acceptable and manageable or otherwise (difficult and unacceptable), provided an understanding of the type of impact that living with dementia had on their quality of life. Their current lifestyles and the use of strategies and positive attitudes seemed to have helped some of these people to integrate dementia into their lives.

The previous chapter therefore provides a useful background for the next two chapters (chapter six and seven) which focus on participants’ experiences of taking a drug for dementia (ChEIs or memantine) prescribed by doctors at the memory clinic and on which they very recently commenced.

54 Detailed information about the participant’s profile and drug they were prescribed can be seen in Chapter four, sections 4.5.1 and 4.5.2.
55 ChEIs and memantine – generally referred to as anti-dementia drugs - are the mainstay of treatment of Alzheimer’s disease and are routinely prescribed by Consultant Old Age Psychiatrists, General Practitioners
As described in the methodology chapter dyads was interviewed twice. The first interview was conducted within the first four weeks of being told their diagnosis and when the anti-dementia medication was prescribed. During this interview medication issues were not addressed with four of the fourteen PLWD.

This current chapter reports the findings from the baseline interviews about medication and expectations. It begins with a discussion of participants' perceptions of the anti-dementia drug they had been prescribed. Following this, the participants' understandings of drug efficacy and their initial expectations are explored. Also, the section looks at the significance of drug efficacy for their quality of life. The chapter concludes with a discussion of the findings in the light of the extant international literature.

6.2 PARTICIPANTS' PERCEPTION OF DRUGS

Two major themes dominated participants' accounts about the drug treatment. The first theme referred to medication as something positive that was part of the participants' everyday lives. In this theme participants' trust in the doctors prescribing the medication, and their overall positive experiences with medication were very salient. A second theme concerned the challenges and concerns that starting a new drug treatment could pose to their lives. These two themes were intertwined in participants' interviews and will now be discussed.

6.2.1 Trusting prescribing doctors

Overall participants talked about the memory clinic's assessment as a thorough process, and about doctors as good and caring professionals whom they trusted. The phrase “in good hands” summarises the way that most participants referred to their doctors,

I wasn’t given just like you know, they don’t just give you a few tablets like that. They went through a lot to get the right medication. Angela PLWD.

I have no concerns, no. I trust the people who gave them. Lisa CP.

and Geriatricians in Ireland. These drugs primarily address symptoms of dementia such as cognition, functioning and behavior. Nevertheless there has been an increasing debate about whether and, to which extent, these drugs also have an impact on quality of life. For a detailed discussion of this matter, see chapter three. From here I will refer to such drugs generally as anti-dementia drugs.

Four participants: Angela, Peter, Carmel and Gordon, had already been taking the medication between 3 to 4 weeks at baseline, the remaining PLWD had been taking medication from 1 to 10 days.

As explained in the chapter four, section 4.4.4, for ethical reasons participants who were unaware or unsure of medication use were not interviewed about the drugs. This was the case of four participants at baseline: Dora - donepezil, David - donepezil, Richard - memantine and John - donepezil.
Indeed, most believed that prescribing doctors had the knowledge to make the best decision about their medical treatment. Thus, by and large, participants neither felt that they had any role to play nor needed to be involved in the decision-making about medication, with respect to either starting or stopping. This type of response was typical across dyads in this thesis. For a good number “swallowing the medication” was the only thing they thought was expected of them. Most talked about an “on-going prescription” and as taking the drug “as directed”. Their role in medication seemed to be confined to knowing when to take the drug and what the dosage was,

I just take it [tablet]. I don’t even need to know I just take it and that’s it [laughter] (...) You know some people read up on medication. What does it do? What it doesn’t do? We were just given by the doctor. I don’t even know the name of what I take, I take it and that’s the end of it. Carmel PLWD.

Only one CP thought about the medication differently. This CP would have welcomed more involvement and to have a better understanding of why her mother had been prescribed this particular medication. Greater involvement for this daughter represented a way of providing the best possible care to her mother,

I just want the very best for my mother, I just wanted to understand things (...) but when I asked him about ... how do you decide, I asked him, to put her on Aricept?, how do you come up with that decision and not something else?, he never answered. So it’s Aricept now. Dianne CP.

6.2.2 Positive previous experiences with and attitudes to drug treatments

All PLWD were already taking medication for other illnesses and thought of taking medication as part of their daily routines. For PLWD taking a drug was easy: “you just swallow it (tablet), and that’s all you need ... this is all you have to do” Angela PLWD; useful:“up to now any medication he has been put on has been worthwhile” – Esther, sister; and a private act since no participant had told their friends or acquaintances they were prescribed memory tablets.

This contrasted with their views about services or using other type of interventions such as day care or meals-on-wheels service. These interviews exemplified their views on the
struggles they could face when using such services as opposed to the "simplicity" of taking medication. At this stage, using specialist dementia/older peoples' services whilst helpful could portray participants in negative ways. For example, in participants' own words using such services might mean that they would be seen as elderly, demented or less capable. Also it could remind them of the progression of the condition.

Angela's (PLWD) example illustrates how refusing a meals-on-wheels service could make participants feel capable and still young: "up in the Hospital one of the girls asked - do you want to have your meal on wheels? and I said God no! I can make the food for myself (...) I am still happy to do it, and I said No! It would make me feel that I am very old, that I have to get somebody to come with my lunch, oh no! I am still able to do that" (Angela PLWD).

Moreover whilst taking the medication was a private act, in a sense that nobody else had to know about it, attending a day care centre in contrast could be stigmatising, as others would become aware of the illness and the individual might have to spend time in the company of others with much more severe dementia,

She [social worker] said “I am attached to a Day Centre” and I knew instantly of course it was an Alzheimer’s Day Care Centre (...) and she said to Eoin “a bus will collect you” and so when I went downstairs letting her out I said to her, the bus will have “Alzheimer Society” written across it? (...) I had the feeling on the pit of my stomach this was not right, it’s too early all together. I felt he is not ready for this, he won’t be happy that everyone here could see him on that bus (...). Also because I think he would feel depressed, thinking you know, will I end like that? Esther CP.

6.2.3 Drugs and everyday life

Participants’ accounts also showed the type of challenges and concerns that a new medication could pose. Here, experiencing side effects was the main concern reported by PLWD. Their concerns related to how taking the drug could affect the person and their everyday functioning. Some examples included,

It [drug] may make me feel different in some way. Gordon PLWD.
She thought that she’d be doped up on some medication and she would be sitting in a chair all day. Dianne CP.
Well it is [side effects] important yeah … [because] you may not be able to do your things. Peter PLWD.

Moreover, some PLWD talked about how experiencing side effects could interfere in their interactions with others,

I think it would be quite embarrassing, I’d be mortified if I was like vomiting or the stomach was you know … unsettled, if you are meeting someone or if you are, like doing something, and you feel like your tummy … it is not nice to be around someone like that. Colette PLWD.

Most PLWD referred to the fact that if they were to experience side effect this would be the main reason why they might discontinue the drug treatment. Thus, side effects also represented the end of the participants’ hope of taking a drug that could stop their deterioration. As one PLWD summed up: “It would blow my bubble”.

In contrast to PLWD, CPs concerns centered mainly around managing the medication and ensuring compliance. This was critical as not taking the drug as prescribed could involve safety issues, but also that the PLWD would not benefit from the drug treatment: “That’s critical for the medication - to get it right” (Esther CP). This was commonly framed in terms of adding a new responsibility to the care role they had and it was not unusual that CPs referred to tensions and disagreements arising. The latter usually occurred with respect to the autonomy of the person living with dementia on the one hand, and the responsibility of the CP to ensure this new medication was correctly taken, on the other,

He won’t take it on the day that’s on the sheet of tablets. He’ll just take them willy-nilly. And I say, “If you took them by the day, you’d only have to look at it.” But he wouldn’t, no (...) he does it his way, but some days he doesn’t take them (tablets), that’s why I’ve to watch him. Lisa CP.

New medication routines could, as this CP suggests (Dianne, CP), have an important impact on the lives of the PLWD living alone: “if she [PLWD] sees that medication is running low in the box, she forgets I am coming in and she panics”.

In summary, most participants talked about starting the drug treatment as something that was part of their relationships with their prescribing doctors, people they trusted. With the
exception of one participant, the majority felt that taking the drug as directed was what they were expected to do as good patients. Medication was something that was part of these participants’ daily routines and for some taking the drug was more straightforward and acceptable than other more visible service interventions. Nevertheless their accounts showed how medication and side effects could pose concerns for PLWD and taking the medication could create challenges for the day-to-day care practices and routines. It could impact on PLWD, on the CP, on the relationships between them, and on their everyday lives.

In line with findings from other international studies on anti-dementia medication, all participants in this study were prepared to use the drug since they expected that: “if it makes me better” (Gordon PLWD). Most expected not to experience adverse effects as they claimed they had a healthy lifestyle or were in good health. Hope that the medication would help them in some way, a belief that the likelihood of experiencing side effects was small, and their trust in the medical profession were all relevant issues that PLWD and their CP thought about when initiating the medication treatment.

6.3 UNDERSTANDINGS OF DRUG EFFICACY AND EXPECTATIONS

6.3.1 Drug efficacy

In the absence of a cure, for many participants the efficacy of the anti-dementia drug was limited: “no magic bullets” (Orla PLWD); “it is not a magic pill that is going to fix the memory” (Carol CP); “it is not a miracle cure” (Harry PLWD). Accounts showed that some expected more effective treatments to be soon available.

A second important theme in relation to the efficacy of the drug treatment related to the participants’ uncertainty. Several PLWD referred to the unspecific and the limited ways in which benefits had been discussed with them at the memory clinic where an emphasis tended to be on the side effects,

They never said like “if it works”… it was more if it has an adverse effect on you – and they never went beyond that. Orla PLWD.

They said you won’t see the difference, he told us that, oh you won’t see it, you may not see the difference. Connor CP.
Consequently, talking about the benefits of taking the drug was hypothetical or what they hoped,

If it stops it from getting worse that would be great but I don’t know if that’s what it does, I don’t know. Orla PLWD.

Another source of uncertainty centred around how could they assess the outcomes of the drug or how might they know if they were experiencing benefits,

I suppose it may stop my memory getting any worse. But then, how can I judge that? ... You know I can’t judge that. Eoin PLWD.

A third theme concerned efficacy in relation to the severity of dementia. Here, for some, the stage of dementia was what was significant and depending on its stage, this would facilitate or hinder the drug from working. In the latter, the idea of “being too late” or “being too advanced” was recurrent,

If I were truthful I would say it will not work. That is the way I think but you know, I then I leave it and say well you never know give it a chance. I think it is too late. But anyway I keep hoping for it. Jenni CP.

Nevertheless, as the above quote indicates, even those who thought the likelihood of their relative benefitting would be slim still had hopes. Participant’s desire to try anything that could prevent the PLWD from getting worse was very salient. Almost all participants referred to the drug treatment as an on-going prescription, where experiencing side effects rather than benefits was the main reason behind decision making about continuing or stopping the drug.

In summary, mirroring the debate that surrounds the efficacy of drug treatments at a policy and clinical level, most participants talked about the anti-dementia with much uncertainty, yet most had hope about the drug. Participants’ accounts showed three main areas of uncertainty: (1) what outcomes could they expect?, (2) how could they evaluate efficacy?, and (3) was it too late for their relative to benefit from taking the drug?
6.3.2 Participants’ expectations

6.3.2.1 “Maintaining where he is now as opposed to getting worst”

Participants’ main expectation related to the power of the drug to stop, maintain or stabilise the condition. This seemed significant for most participants, particularly with the prospect of future deterioration. Maintenance was often linked to the view that the person was still capable and/or able to function well. Here the focus was on the condition and the belief that either symptoms were mild or were not troubling the person,

I am not too bad, so if I stood as I am now, it would be fine. Claire PLWD

If I could stay the way I am. I forget things but I am quite capable. Orla PLWD.

I think it is supposed to stop the memory getting worst. Anyway it [memory] doesn’t bother me. Peter PLWD.

In addition, maintenance was discussed in the context of the dyads’ overall coping situation. Here, it is upon the dyad’s good coping, rather than symptoms, that participants’ discourses focussed,

To stay as we are for as long as possible, at this present moment on time, so we can cope and she can cope with the way things are at the minute. Dianne CP

Consequently, in both cases participants referred to maintenance or stabilization of symptoms as an acceptable and valuable benefit from these drugs. In contrast, some participants’ accounts showed that the changes and challenges that dementia was currently posing to their lives were too hard to live with. In this context, maintenance or stabilization of symptoms did not seem as valuable,

Interviewer: What would make your quality of life bad?

Colette: If I was left like this. Colette PLWD.

6.3.2.2 “I hope …” ;“It would be nice if …”: Improving

Whilst expectations mostly revolved around maintaining and stopping deterioration, comments about improvements were also raised by some. In these instances, it was typical that whilst the question posed referred to current expectations, responses reflected on “ideal” benefits (Thompson and Sunol 1995)\(^{58}\). Some examples of this are: “I hope

\(^{58}\) Predicted expectation is what an individual thinks will occur as a result of a health intervention, whilst ideal expectations refer to what an individual wants, hopes or desire to occur (Thompson and Sunol, 1995)
that it will make it better for me” (Angela PLWD); “I pray for it to work, that there will be some kind of improvement” (Colette PLWD); “It would be like a miracle if it works and he gets better” (Maeve CP).

This may reflect the struggles between what these people thought was realistic to expect or had been told would be likely to happen and their desire and hope for finding a way of getting better. In some cases hope was fuelled by what these people had seen on TV shows or what they had been told by other people about the medication,

It was great to have that [positive information about drug] before I went there [memory clinic], because I knew that this medication was working for her [someone she knew] (...) so I had an idea of how it was. Because [name of doctor in memory clinic] told me that these tablets, he more or less said that it could suit one and it wouldn’t suit another, like it may not work you know. Everyday in my prayers I say please God let it work for me. Angela PLWD.

It was not unusual to find contradictions within the interviews, between expectations about the very limited benefits of the drug (not getting better) and their own desires and hopes of improving,

If I stay as I am now I would be happy (...) I think it’ll be stopping rather than getting better. I don’t see getting better (...) [Later in the interview] I was hoping that it [anti-dementia drug] would help in my confidence. I lost all confidence (...) just not writing in the diary or need other people to remind me. You know it would be to sit down and be confident, taking care of myself. Eoin PLWD.

The above quote highlights the main areas (confidence and independence) where Eoin hoped for improvement. For Eoin, these areas represented the most important changes he had to confront after the onset of dementia (see chapter five, p. 148 for further detail). The excerpt illustrates how stabilising his condition was perceived as good, probably as for him it meant holding onto his current life rather than being faced with new challenges and deterioration. Conversely, the end of the quote suggests that he believed that improving his confidence and memory was a way of regaining what in his view was an acceptable level of independence and in summary, what he identified as his life as it used to be.
Another area where some participants hoped the drug might benefit them was in communication and social interaction. As an example, Colette and her husband talked about her word-finding difficulties. Colette (PLWD) described herself as a bubbly and outgoing person, and until she was diagnosed with dementia, she had enjoyed a good social life with her husband (see chapter five for further detail). She now felt embarrassed when meeting others and was coping by avoiding seeing and talking to people. For this dyad, this change in personality was profound as was the change noticed in how she interacted with others. Referring to the drug she said: "All I pray for is that it will make me better. That my speech will get better" (Colette PLWD). Her husband further expanded about this,

She has changed a lot, where before she would be open to talk all day, she talked for Ireland, but now she just hates that you know, before she went with her friends and she did all the talking but now she goes but doesn’t talk (...) it is just the speech. The speaking is more important to her than the memory you know that embarrasses her, she gets panicky (...) [with regards to medication] I hope something to do with the speech, they [doctors] said about her memory as well but her memory is not that bad. They said it would at least maintain it but I hope it will get better. That’s my hope that she will feel more confident, and will be able to … I don’t know, to talk to people as before. Connor CP.

For another participant (Harry PLWD), his hopes in the drug were that it might help him remember people’s names better and more readily. The latter was compromising the quality of his relationships. For example, as showed in chapter five, he had stopped attending the annual professional meeting of the Police force as he could not remember the names of his colleagues. He said,

It would be nice to be able to remember the names of people I meet, that would be nice yeah. Harry PLWD.

The last type of hope that participants talked about was related to care. These hopes were typically raised by the CP and related to symptoms or behaviours that in the literature are generally described as characteristic of moderate stages of dementia. For instance May hoped that her husband would not be asking the same question over and over, or that he would remember things "my hope would be that some memory would stay – not as bad as it is now. That will be my hope (...) So what it means is that he might just not keep asking the same question over and over again. He might remember things. He just might."
Similarly another wife hoped her husband “would listen and give more thought to what he says, that he would remember what he promised he would do”. Another wife referred to her husband’s apathy and felt if the medication helped him recover initiative and interest in things that would be a very meaningful benefit to them. Another son referred to his father’s lack of concentration and poor short-term retention. It is noteworthy that all these examples related to the caring relationships, and how dementia was posing challenges that seemed to have affected both the PLWD and the CP. These improvements, it was believed, would facilitate the relationships with the PLWD and would make caring more tolerable for the CPs,

I do hope that it will help him maintain some concentration. If it even helps with some short-term retention, because sometimes I find difficult I have to really sit him down and tell him, look, I’m going to tell you something and I really need you to concentrate on this (...) So if it helps him focus a little bit better, a little bit more sort of short-term retention that would be fantastic. (...) Because I find it frustrating, it frustrates me, you know, and then we end up getting a little bit sort of tension and stuff. Adam CP.

6.3.2.3 “After three weeks something kicked in”: Early experiences
Three participants59 (Angela, Gordon and Peter) talked about early experiences rather than expectations. Gordon (PLWD) gave a very vivid account of the changes he had noticed since starting the drug,

I think there is an improvement, I feel more at ease. I find that since I went on the Ebixa [memantine] I am less inclined to worry, things do bother me at times but not as much. And that’s a great improvement for me, I don’t feel anxious if things go wrong. Like nothing happened over the first week or two and then after three weeks something kicked in, I suppose when I got a certain amount into my system you know ... I certainly feel much better since I got it, since it kicked. (...) Well I don’t know it’s just that I do feel this is an improvement, I am brighter since I started, so I expect that I will be like that if I take it. Gordon PLWD.

59 At the time of the first interview, these three participants had used the medication during three to four weeks, whereas remaining participants were interviewed within seven to 10 days of having started the medication.
For him, the power of the drug meant he felt more at ease, less anxious and worried and brighter. This to him represented an “improvement” of his condition and was valuable as these improvements made him feel better and helped him to confront his daily life. This was something he hoped to maintain: “I will be like that if I take it”. For his wife, the main change she noticed related to his mood swings being less obvious and for her this was important as it impacted on the care relationship.

Likewise both Angela (PLWD) and her daughter felt she had gained confidence and was more upbeat since starting the medication. This was significant for her daughter as it meant that her mother had regained part of her former personality,

Really this week it is like if part of her personality is back, is like part of her … like she’s got such a great sense of humour and it’s just different things like she sounds in better form – so that hopefully she will keep improving like this.

Dianne CP.

In a similar vein Peter (PLWD) and his wife talked about having noticed some improvements, it seemed he was starting to be more interested and involved in things.

In summary, exploration of the participants’ expectations at the beginning of the drug treatment suggest that maintaining and being stabilised as opposed to further deterioration or to recovering completely was the main expectation most participants had. The section shows that PLWD and CP talked about maintenance in different ways: it related to the perception of the PLWD as being capable and doing well; to the perception of symptoms as being not so bothersome; and to the perception of the dyad coping and managing the current situation well. In this context maintenance was a valuable benefit arising from taking the drug.

Findings also reflect the complex struggles that participants experienced between their realistic expectations and their hopes and desires for future improvement. How they talked about expected improvements was clearly linked to findings on how living with dementia was challenging important domains of their quality of life. Interestingly, these were not always related to memory loss but to other areas such as independence, social relationships and activities, the way they felt about themselves and the behaviours and symptoms that PLWD and CP found difficult to cope with.
6.4 EXPECTED BENEFITS AND QUALITY OF LIFE

6.4.1 Implications for quality of life of “stopping/maintaining”

Expectations about maintenance or stabilization of the condition highlighted the participants’ sense of stability (balance) and their confidence in the ways they had developed for dealing and coping with dementia at the time. “Maintenance” was valuable to participants as it allowed them to keep living and enjoying the good, normal and ordinary life. As Colette (PLWD) summed it up: “I have a great life I just want to keep it”. This life, was a life in which PLWD could stay at home with their families and friends and where they could keep busy and enjoy some independence and autonomy. Moreover, “maintenance” reflected participants’ expectations about the power of the drug to control their condition and allowed them “buy time” against the progression of the illness,

If I could stay like this, that’s fine. Angela PLWD.

If it [drug] gives me another six or eight years before I get worse. Colette PLWD.

If mum could stay at this level for even another year or 18 months, it would just be such a gift. Dianne CP.

As chapter five has shown, the progression of dementia to its severe stages was a key concern for many and was an issue once again discussed in relation to medication. If the medication did not work, some expected they would probably just “get worse and worse and worse” and others feared a sudden and rapid deterioration: “I don’t know whether she will get full-blown” (Daniel CP). As mentioned in chapter five, images of severe dementia reflected loss, a life lacking in meaning and being a burden. In a few cases, this challenged the worthiness of being alive. Deterioration was linked to the need for new care arrangements and for many this meant institutional care,

I just told myself this has to work because I need it to work (...) if it doesn’t? … that would be really bad - I would be a wreck in one of those John of Gods places or anything like that. I would rather top myself off first. Angela PLWD.

In addition, failed treatment and further deterioration raised concerns about the ability of CPs to carry on with care. Some CPs had particular concerns regarding handling potential
challenging behaviours or as mentioned earlier not being sufficiently physically fit to manage their relatives’ physical care if needed:

Like even if I could maintain him like that, the way he is now, I am ok, I am good. But if he got to the stage where he couldn’t walk ... or he needed help, I wouldn’t be able to lift him anyway, or I wouldn’t be able. Maeve CP.

Finally, in some cases “maintenance” fostered participants’ hopes for a future medication that could possibly cure the disease. This prospect of a future cure made, for some, thinking about the severe stages of dementia more acceptable,

At the end of the day they [doctors] are working on tablets for this thing for the last years and years, and tried to come up with something, so I feel when it comes around to that time [when Aricept will no longer have benefits for her], that there would probably be something else on the market, I would say so because they are working on it all the time, it’s something that they are working on you know, full blast because they could come up with something for this, you know, so now I don’t think about the future. Orla PLWD.

6.4.2 Implications for quality of life of “improving”

Whilst the significance of maintenance for quality of life was linked to the participants’ current sense of stability and fears about the severe stages of dementia; hopes for improvement were ways of combating what participants perceived as the most troublesome or unacceptable changes and challenges that dementia was posing. The prospect of improving reflected their hopes of regaining some of their former lives. As an example, one CP (Maeve) talked about her marriage and her feelings about the “couple”.

She felt lonely now that there was no conversation between herself and her husband and nobody with whom to discuss household day-to-day issues. The type of improvement she hoped for would involve a renewed relationship with her husband more in keeping with what she experienced in the past as a good/normal relationship for a married couple,

It would be like the sleeping beauty if he woke up – it would be wonderful if we could have some conversation, if he had an interest in things, it would be like the way we used to be. Maeve CP.
6.5 DISCUSSION OF CHAPTER AND CONCLUSIONS

This chapter has explored the ways in which 14 dyads of PLWD and their CPs, talked about anti-dementia drugs at the beginning of the course of the treatment, their expectations of how the drug would work and the significance and implications that taking these drugs could have for their quality of life. In summary, the findings illustrate that anti-dementia drugs represented for these people a way of controlling the disease, thus maintaining their current situation and coping as opposed to experiencing further deterioration. In addition, anti-dementia drug treatment provided participants with hope for the future and for further improvement. These improvements were connected to the specific challenges dementia posed for these participants and to what they thought of and experienced as good relationships with family and others, and to acceptable levels of independence and being busy. Improving then could help them to reconcile their living with dementia and their understandings of what was a good and normal life. Findings show how whilst initially, narratives about the anti-dementia drugs seemed to be very positive, further exploration revealed their hopes, ambiguities, uncertainties and diverse concerns and challenges. These findings will now be discussed in the light of extant literature on drugs treatments and dementia.

In line with Hutching et al.'s research (2010), findings from this thesis have highlighted the limited involvement that PLWD and CP had in decision-making about the drugs. Opportunities that participants were given for further involvement in medication decision making were limited. However, some of the data suggests that the majority of the sample were not dissatisfied with their level of involvement and rather most argued that doctors knew best and they felt in good hands. As Smith et al. (2011) suggest, this may be a reflection of participants’ trust in science and medicine, and it may reflect the deference afforded to the medical profession in dementia care.

Indeed, a common challenge for clinicians prescribing these drugs relates to how best to communicate their ambiguous, inconclusive and controversial findings to their patients in order not to create unrealistic hopes (Post, 2001; Farlow, Miller and Pejovic, 2008). It is recommended that the goals of treatment should be cautiously discussed with families. Farlow and colleagues (2008) specifically suggested that clinicians should remark that “treatments are rarely seen as an improvement in symptoms, but rather as an extension of patient independence” (2008:416), and to refer to treatment goals as delaying the onset of more severe symptoms or long-term care placement. Findings of this thesis suggest that
This was probably the way most participants in this study were told about the drugs. It seems that benefits were described as being subtle, uncertain and difficult to detect and discussions tended to focus more on side effects than on benefits. Findings of this study raise the concern over the extent to which this way of communicating treatments goals and potential benefits was beneficial to participants, and suggest that it may have added confusion and ambiguity, since participants did not know what to expect or how to act now or in the future. In addition, this ambiguity helped to sustain an implicit assumption that these drug treatments were beneficial \textit{per se} or may have fuelled the hope that they would be beneficial in the long term. This is particularly significant in the context where these people were not followed up by specialist services. This issue will be returned to in the concluding chapter of this thesis.

Hutchings \textit{et al.} (2010) study identified two factors contributing to the initiation of anti-dementia drug treatment, namely: perceptions of availability and effectiveness of the drug treatment and resource capacity. The findings presented in this chapter support the importance of these factors, particularly in relation to the significance of the availability and willingness of a CP who will ensure compliance. The way in which PLWD and their CPs understand anti-dementia medication is another important factor contributing to drug initiation, specifically the participants’ perception of the drug treatments as part of their everyday lives, and of being easy to take and private.

This section has also shown, that for some PLWD, taking drugs could be easier than using specialised services or interventions. This is important as some international studies have suggested that benefits of ChEis may be questionable as similar benefits could be obtained with non-pharmacological interventions (see Smith \textit{et al.}, 2011). Stigma and having to spend time with other people in more severe stages of dementia were concerns that PLWD and their CP talked about and that made taking the drug a preferable option. Accordingly, findings from this thesis suggest that for some PLWD taking a drug, particularly at early stages, can be more acceptable and less stigmatizing than other service interventions.

But findings also show that taking these drugs could contribute to stigma if side effects became apparent to others. These concerns about the impact of the drugs on PLWD and in their relationships with others have rarely been addressed in the extant literature. Moreover, in keeping with Huizing \textit{et al.} (2006) and Hutchings \textit{et al.} (2010a), findings
from this thesis also illustrate that at the start of treatment taking a new drug can place further responsibilities on care-partners and may for reasons of safety and compliance cause further tension and friction in family relationships.

In summary, findings reflect the complex ways in which participants talked about the drugs, and how in their discourses the present (side effects, difficulties for managing medication) and the future (fears of deterioration, not progressing) needs were often competing.

The finding that PLWD and their CP expected the drug to maintain or improve their condition is not new and is in line with findings reported in the international literature (Lindstrom et al. 2005; Anderson et al. 2008; Hutchings et al. 2010; Smith et al. 2011). Nevertheless, a new finding from this thesis is that participants’ understandings of maintenance were heterogeneous; maintenance was significant to PLWD and their CPs when individuals perceived themselves as being capable and doing well, when the changes and challenges that living with dementia were posing were perceived as manageable and when PLWD and CPs felt that both parties were coping well. Maintenance is an important benefit for most PLWD and reflected on the one hand, their desire to continue leading their lives and on the other hand, of not progressing into more advanced stages of dementia. Maintenance gave participants a sense of control over the condition, and some confidence that they could still live and enjoy what they experienced as a good life. It offered hope for improvement and for a future cure.

Smith and colleagues (2011) argue that caregivers’ appraisals of the anti-dementia drug benefits are embedded in deep concerns and hopes for their relatives and, in particular, about issues of identity and loss of self. This thesis suggests that such concerns and hopes were present in the accounts of both, CPs and PLWD, and played an important role at the beginning of the drug treatments. Concerns and hopes related to the severe stages of dementia and to issues about loss and identity, care arrangements and the ability of CPs to look after their relative at home.

In summary, this chapter has explored the participants’ understanding and expectations of the anti-dementia drug, and the significance that taking the drug had for their quality of life at the time they had started to use it. The next chapter will discuss their experiences with the drug overtime.
CHAPTER SEVEN: "TO ME NOW LIFE IS NORMAL ENOUGH". DRUGS AND QUALITY OF LIFE OVER TIME

7.1 INTRODUCTION

Chapters five and six of this thesis presented findings pertaining to the first interview and were based on interviews with 14 dyads consisting of a PLWD and a CP. In chapter five participants' understandings of dementia and of quality of life whilst living with dementia were explored. Their evaluations of their quality of life at this point in time were also provided. Chapter six explored participants' understandings and expectations of drug effectiveness within the first few weeks after these drugs were prescribed, and how they expected drugs could affect the quality of their lives.

This current chapter presents findings from follow-up interviews with 12 of the 14 dyads. It reports data on participants' experiences of the anti-dementia medication six months after they were first prescribed and explores the manner in which these 12 dyads talked about three main topics: (1) participants' understanding of dementia and their experiences with the drug treatment after six months of use, (2) evaluation and experiences of quality of life over these six months period, and their views about (3) the contribution drugs had to their quality of life. During this second interview, the section about medication experiences could not be completed in four interviews of PLWD.

7.2 UNDERSTANDINGS OF DEMENTIA AT FOLLOW-UP

At the time of this second interview, 11 PLWD were still taking the anti-dementia medication and planned to continue using the drug in the future and one person (Paul - dyad 3) had stopped the medication having used it for three months. As stated the medication experiences were not explored with four of the 12 PLWD at follow-up,

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60 Two out the fourteen initial dyads did not participate in the follow-up study – for greater details see chapter four, section 4.5
61 As explained in the chapter four, section 4.4.4 for ethical reasons participants who were unaware or unsure of medication use were not interviewed about the drugs. Four participants did not complete the medication questions at follow-up: Dora - donepezil, David - donepezil, Richard - memantine and Gordon – memantine.
nevertheless all participants were interviewed about their experiences of living with dementia and of quality of life overtime.

The following section explores the participants’ experiences over the six months period, in particular, how participants talked about dementia and about the impact that the drugs had had on their dementia (experienced benefits).

7.2.1 Experiences of improvement: feeling better

The accounts of seven of the 12 dyads (Eoin, Angela, Peter, Gordon, Colette, Claire and Orla) can be summarised as now feeling better than before. As Eoin (PLWD) described it: “I can do things that I could not before and I feel more confident”. The type of improvements that these participants referred to are shown in Table 7.1. In addition, the table provides further details on the improvements as they relate to each of the dyads.

<table>
<thead>
<tr>
<th>Cognition, orientation, speech and functioning</th>
<th>Source of report</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better overall memory</td>
<td>Reported by PLWD and CP</td>
</tr>
<tr>
<td>Remembers things he did not before</td>
<td>Reported by PLWD and CP</td>
</tr>
<tr>
<td>Remembers prayers</td>
<td>Reported by PLWD</td>
</tr>
<tr>
<td>Writing post cards</td>
<td>Reported by PLWD</td>
</tr>
<tr>
<td>Better concentration and more focussed</td>
<td>Reported by PLWD</td>
</tr>
<tr>
<td>Reading better</td>
<td>Reported by PLWD</td>
</tr>
<tr>
<td>Able to finish a puzzle</td>
<td>Reported by PLWD</td>
</tr>
<tr>
<td>Follows TV shows</td>
<td>Reported by CP</td>
</tr>
<tr>
<td>Remembers how to go to town</td>
<td>Reported by PLWD</td>
</tr>
<tr>
<td>Able to find his way whilst driving</td>
<td>Reported by PLWD and CP</td>
</tr>
<tr>
<td>Able to take the bus independently</td>
<td>Reported by PLWD and CP</td>
</tr>
<tr>
<td>Improvements in speech: word finding, less stuck for words</td>
<td>Reported by PLWD</td>
</tr>
<tr>
<td>Better in conversations: easier to communicate what he wants to say, clearer thinking.</td>
<td>Reported by PLWD and CP</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mood and behaviour</th>
<th>Source of report</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feels more confident</td>
<td>Reported by PLWD and CP</td>
</tr>
<tr>
<td>Willing to do things, to get involved in things, looks forward to things</td>
<td>Reported by PLWD and CP</td>
</tr>
</tbody>
</table>

62 Whilst Gordon (PLWD) was not aware of the use of medication at follow-up, he was able to talk about his dementia and about how he felt now in comparison with baseline.
Has more energy
Feels positive, brighter, sense of humour, making jokes
Has fewer meltdowns; is more relaxed, less anxious
Less aggressive

Reported by PLWD
Reported by PLWD and CP
Reported by PLWD and CP
Reported by CP

<table>
<thead>
<tr>
<th>Reported improvements by dyads</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eoin (PLWD): confidence, mood, memory, conversation, energy, and willingness to do things. Esther (CP): confidence, mood and willingness to do things.</td>
</tr>
<tr>
<td>Angela (PLWD): confidence, mood, taking the bus and conversation. Dianne (CP): mood and reduction of anxiety and of melt downs.</td>
</tr>
<tr>
<td>Peter (PLWD): confidence, mood, memory, initiative and orientation (knowing his way whilst driving car). Hilary (CP): same and also concentration.</td>
</tr>
<tr>
<td>Gordon (PLWD) and Lisa (CP): mood and reduction of anxiety.</td>
</tr>
<tr>
<td>Colette (PLWD): PLWD: confidence, speech (word finding), mood, willingness to do things, concentration (puzzles, reading) and orientation (going to town). Connor (CP): confidence, mood and willingness to do things.</td>
</tr>
<tr>
<td>Claire (PLWD): memory (writing and prayers), felt more focussed (knowing what he wanted), speech (word finding) and better mood. Daniel (CP): mood and speech.</td>
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</table>

A common pattern found in analysing the data from these seven dyads interviews was how they talked about the positive role that the anti-dementia drug played in improvements; but, at the same time, most could not tell exactly how it had happened nor ascertain the extent to which drugs had contributed;

I don’t know! I can’t understand it myself what has happened. I just started feeling better and more confident. Colette PLWD.

I really can’t answer that, I should need to go for couple of months out of the medication and see... for being able to answer that, to see the difference whether I would still progress or I would maintain or whether I would regress, you know, I suppose the medication has helped, it has to be yeah. Eoin PLWD.

By and large, PLWD talked about experiencing improvements in cognition (memory, concentration, orientation or speech), in mood (confidence) and in initiative (will for doing something) simultaneously. For example, one woman who reported she could now do jigsaw puzzles, believed her improved concentration had allowed her to achieve this, whilst at the same she highlighted how greater confidence and determination also helped.
This merger of cognitive improvements, confidence/mood and initiative was typical of the examples given by participants,

I used to do puzzles and I am back to that, you know I did the puzzles for years, and then when this started [memory problems] I didn’t bother, I could not concentrate on it, I found it too hard. But now [name of daughter] brought in a puzzle and I said Jesus Christ, I can’t believe it and then, here I was I couldn’t get it done as I used to at the start, but I felt my concentration was good and I well, I tried and tried and, I was in the bed one night and said, I am doing this - so anyway I got it! I couldn’t believe it. Colette PLWD.

Indeed participants could not tease out whether improved skills made them more confident, or conversely whether increased confidence improved their skills, or whether these improvements operated independently and augmented each other. Kathleen was now taking the bus independently, something she did not do before starting the medication. She could not tell whether this was because of her improved orientation, confidence, mood or if it were all of these factors together. Similar accounts were found in those who talked about improvements in their communication. Some talked about fewer word-finding difficulties, others felt they could think more clearly and this helped in their communication, but at the same time, all reported feeling more confident and less worried when meeting people in social events,

Like I feel six months ago I would have been all the time – “how can I put it”? I was not able to answer to questions, I didn’t want to get involved in a conversation (...) Now I am not afraid to express myself which I was before, you know well it was not that I was not able to express myself but it was when I was with someone else ... but this is the same thing, the same consequences as I wasn’t talking to people I didn’t want to meet people. Eoin PLWD.

Participants also spoke about improvements with ambiguity. This meant that whilst they noticed some improvements, they also mentioned noticing situations where the person had either not improved or had disimproved. This was a recurrent topic among both PLWD and CPs,

That’s a very tricky question! my memory probably has ... [improved] it probably has ... like I can ... how can I answer that? I can remember things I could not remember a year ago, I don’t use the Diary as much anymore, it’s there but I
don’t rely as much, I don’t really. But then in other things.. like I don’t cook, I still have my frozen food, so I wouldn’t be doing this for instance. Eoin PLWD.

I noticed first of all that her sense of humor had come back. She seems to be mentally stronger (...) I don’t know if I would’ve noticed anything huge about her memory. But she definitely seems more upbeat. She is not getting as anxious. (...) She’s still very independent. But there are quite pronounced things that she doesn’t do anymore. She doesn’t cook anymore at all. She’ll only cook something like breakfast things. Dianne CP.

Moreover many noted that even where there were significant improvements, a return to the level of functioning experienced before the onset of dementia had not occurred. Orla for example, referred to feeling more confident than before, yet her previously confidence levels weren’t reached again,

Still my confidence’s taken a bit of a batch alright, there is no doubt about that. I sort of notice that even when I am in company you know that I can feel that my confidence level has dropped a bit you know. Orla PLWD.

These examples show the complexities surrounding the manner in which PLWD and CPs thought and talked about improvements and about the benefits of taking anti-dementia drugs. On the one hand they referred to them in a very positive way and believed they had had an important impact on their lives, but on the other hand their accounts also reflected ambiguity and uncertainty. In fact, improvements and changes happened in a complex way, were often interconnected and occurred in the normal course of dementia progression. This could be challenging for PLWD and for CPs and family members to understand,

Like my sister would say: “Don’t tell Mom because she can’t handle the worry.” My husband lost his job. (...) But she [PLWD] will worry about it one week. And then she’s really strong giving advice the following week. It’s such a paradox. It wrecks my head. Dianne CP.

A second way by which participants talked about their improvement was in terms of their experiences of living with and coping with dementia. For instance, some PLWD referred to the negative expectations and fears they had at the time of diagnosis,
Initially I kind of thought Oh my God I am going to be like Mum, and I remember Mum repeating herself and all that and I just thought Oh I am going to be like that, I am going to be told that I need to be looked after and I am going to be a burden on everyone’s lives and all this. Eoin PLWD.

Experiencing improvements and less deterioration than what was originally expected made living with dementia more acceptable. As this woman stated, having dementia did not preclude them from enjoying their lives,

Well, I used to think that it was the memory, but I mean I am doing great and I can do what I have to do and all like that, you know that to me was phenomenal, that’s the word I can use. Angela PLWD.

At this follow-up interview, some CPs accounts reflected a more positive image of their relatives compared with the first interview. This more positive image was not always related to an improvement in cognition but to the absence of (expected) challenging behaviors and a reduction in anxiety (of “meltdowns”). These were key factors and seemed to reflect the understandings of CPs of what to them was an acceptable way of behaving,

If somebody’d ask me how is your brother, has he got Alzheimer’s?, no, I don’t think so, he just has memory problems (...) because his memory is definitely affected, he needs to be reminded about things but I don’t see other mannerisms and things like repeating same questions over and over, and over, walking up and down, picking on things putting them down, or taking them away ... as I’ve seen other people with Alzheimer’s do, you know, he doesn’t do that. Esther CP.

This section has shown the way in which seven of the twelve dyads at follow-up talked about the improvements they experienced since the time they had been diagnosed and had commenced the drug treatment. A main issue arising in the data is about the complexities of these people’s discourses. Participants talked about feeling better in different ways. It meant experiencing improvements in some cognitive or functional areas but also many times there was acknowledgement of other areas that had disimproved, had not changed, or where participants felt the improvement was not back to the pre-dementia level. Improvements in confidence and mood pervaded the interviews of all these people, along with other range of improvements. In addition, some participants referred to their having
less negative images of dementia and the person was now functioning in a more acceptable manner than previously expected.

7.2.2. Experiences of deterioration

The accounts of the remaining five dyads (Harry, Paul, Richard, Dora and David) reflected a downward trajectory of decline. In these instances, typically participants could not identify significant improvements and the overall impression was that the PLWD was: "getting worst, he is deteriorating day by day" (Maeve CP). These five CPs and two PLWD\textsuperscript{63} believed the drug had not worked for them. Still some wondered whether the drug might have limited the pace of deterioration or slowed it down,

I certainly know that dad is not the same – he’s definitely degraded in the time that he’s been on it [drug] but I don’t know if the medication has helped to limit the degrading? Adam CP.

She’s definitely taken a bit of a down turn in relation to before. So I can’t say the medication has been helping to keep it from dropping more, I can’t really say. Kevin CP.

My memory isn’t better, no. But it could be worse. That’s the thing, I think it could be worse, but I don’t know. Paul PLWD.

Deterioration mainly related to new cognitive deficits including short term memory loss, and attention and communication difficulties. This was the main way in which both PLWD and CPs talked about decline,

My memory is poor – is getting worst I think. David PLWD.

My memory is bad, very bad now. Paul PLWD.

His short term memory is really bad now (...) I find that even communicating now; you have to sort of try to get his attention to even explain something. (...) and him himself trying to remember things, he wants to get the information out, but he just can’t find the words to get them out. Adam CP.

\textsuperscript{63} The other three PLWD were not aware of drug use at follow-up and their views about the effectiveness of drugs were not pursued.
Also, this cognitive deterioration meant that the PLWD behaved in a way that clearly differed from what CPs considered to be normal behaviour,

He can put something on the table and then turn around and turn back and pick it up and wonder, what is this? and that stuff, what it’s for? Adam CP.

He went outside to the garden, I think, to do something. And then he came back in and he was going around like a mad thing. And I said what is wrong with you? He says I don’t know what I’m supposed to be doing. Jenni CP.

These CPs now had to devote more time to caring tasks, even sometimes during the night, What’s happening now is she’s been getting up in the middle of the night. She gets up, dresses herself, and she could be sitting there all night unless I hear her, I sleep with the doors open now all the time. Kevin CP.

Two of these five dyads however talked about decline in a more fluid manner: as having good and bad days. A good day was when the person could remember or function well, and a bad day was perceived as “a hit and miss effort” (Angela CP). During the follow-up interview these two dyads switched from discussions about stabilization to that of deterioration,

I think things are at a standstill. (...) The short-term memory is coming and going. (...) Some days are very good now, other days it’s a hit and miss effort. Mary CP.

In summary, six months after their diagnosis and after being prescribed a treatment for dementia, seven of the 12 dyads talked about having experienced benefits from using the drug and about feeling they were better than before (improvement). Narratives here related to their evaluation of improvements noticed in abilities and functioning across different spheres often interconnected, but also to their experiences of living with dementia including images of dementia that were remarkably less negative than the images they held at baseline. Nevertheless, improvements were contextualised in the course of dementia and often co-existed with other deficits. Overall in these examples the way of functioning and behaving of the person living with dementia was closer to what for PLWD and CPs was acceptable.

Five dyads in contrast, believed the PLWD had not benefitted from the drug and they were at follow-up getting worse. Deterioration here referred to the emergence of several
new and significant deficits, most often, but not exclusively, relating to cognition. Deterioration was also referred to as behaving in unusual ways and as an increasing need for care and supervision. These deficits and behaviours distanced these participants from normality.

7.3 EXPERIENCES WITH THE DRUG AND EVERYDAY LIFE

Regardless of their perceptions of improvement or decline, 11 of the 12 PLWD were at follow-up taking the drug and planned to continue it. Three themes were particularly salient in the accounts of these 11 dyads. The first related to compliance with the doctor prescription. For most satisfaction and continuation were not significant concepts as these were drugs participants had assumed they had to take for the rest of their lives: "The thing is that I am on prescriptions. I'll take it until I am told otherwise" (Peter PLWD); "We are not questioning it, just taking it" (Richard PLWD). As at baseline, participants' accounts evidenced their acceptance of doctors' authority. A second theme related to benefits. This included the benefits that some had already experienced and that were helping to improve their everyday lives, the possibility that the drug was doing something albeit not apparent for the PLWD, and also the hope that the drug could still work in the future. A third important theme was that the drugs were not disturbing the participants' everyday lives. The effect here was twofold and included the absence of adverse effects from the drug and secondly that taking the drug was not adversely affecting the care relationship (typically that the PLWD was not confronting or fighting against the drug),

In the beginning I had to watch it, because he wasn't taking it [drug]. And he'd say to me, "I took the tablets." And when I'd go up, I knew the number, and there'd be an odd number. But I have them now, and he agrees with me now. He's got into the routine and he knows now. Lisa CP.

Whilst only one PLWD had stopped the drug in this study, and hence any conclusion has to be interpreted with great caution, the accounts of this CP were very vivid and can illustrate the daily concerns and difficulties of other CPs outside of this study,

There was one evening he [PLWD] was at it [preparing the medication dispenser], and he must have gotten cheesed off with it. (...) And so I came in and some of them [tablets] were on the floor, they were scattered on the floor. So when he was ensconced looking at the news, I came in and sorted the whole lot out. (...) And very often, he would forget to take them (...) And sometimes I say Paul, did you take your tablet? "I don't know". And then sometimes I will see
he puts them out here in a spoon on the table and he'll take them and then five minutes later he'll say I wonder did I take my tablets (...) But if I try to help him … he wouldn’t let me. He’d go mad. He’d say leave me alone (...) I haven’t the energy to remind him. I don’t have the energy to keep on yapping off. Jenni CP.

The account of this CP suggests that decision of stopping the drug was based on the lack of evidence of benefits but most importantly, on the increasing tensions and stress created in attempts to ensure compliance.

Having presented the qualitative data on the participants’ experience of using these drugs, the chapter now moves on to explore participants’ accounts of quality of life during this second interview and of the role medication played in contributing to their quality of life from the perspective of these participants.

Quality of life at follow-up was explored in a similar way to baseline, i.e. using both a normative and a social constructionist approach. Findings from both approaches are presented in turn. As this thesis is concerned with exploring quality of life issues as they relate to the use of anti-dementia medication, in the sections to follow the findings from the group of seven dyads who reported drug benefits and findings of the group who did not (five PLWD) are explored and presented independently.

7.4 QUALITY OF LIFE OVER TIME

Table 7.2 shows the type of drug the person was using, the PLWD age, baseline MMSE\(^{64}\) score and the QoL-AD scores at baseline and follow-up. In the table individual scores are presented in relation to the two groups, those seven who experienced benefits from using the drug and the five people who reported they experienced no benefit.

\(^{64}\) For information about MMSE test see chapter four, section 4.4.5.
Table 7.2: Prescribed drug; PLWD age and MMSE score at baseline; and PLWD and CP QoL AD scores at baseline and follow-up

<table>
<thead>
<tr>
<th>N=12</th>
<th>PLWD</th>
<th>QoL-PLWD Scores</th>
<th>QoL-CP Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug</td>
<td>Age</td>
<td>MMSE-B</td>
<td>QoL AD-B</td>
</tr>
<tr>
<td>Dyads who experienced benefits</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dyad 2</td>
<td>D</td>
<td>64</td>
<td>25</td>
</tr>
<tr>
<td>Dyad 4</td>
<td>D</td>
<td>68</td>
<td>20</td>
</tr>
<tr>
<td>Dyad 5</td>
<td>D</td>
<td>72</td>
<td>22</td>
</tr>
<tr>
<td>Dyad 6</td>
<td>M</td>
<td>81</td>
<td>22</td>
</tr>
<tr>
<td>Dyad 10</td>
<td>D</td>
<td>61</td>
<td>24</td>
</tr>
<tr>
<td>Dyad 13</td>
<td>D</td>
<td>69</td>
<td>23</td>
</tr>
<tr>
<td>Dyad 14</td>
<td>D</td>
<td>65</td>
<td>24</td>
</tr>
<tr>
<td>Mean</td>
<td>68.6</td>
<td>22.9</td>
<td>38.4</td>
</tr>
<tr>
<td>Dyads who experienced no benefits</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dyad 1</td>
<td>D</td>
<td>75</td>
<td>23</td>
</tr>
<tr>
<td>Dyad 3</td>
<td>M</td>
<td>87</td>
<td>19</td>
</tr>
<tr>
<td>Dyad 9</td>
<td>M</td>
<td>82</td>
<td>16</td>
</tr>
<tr>
<td>Dyad 11</td>
<td>D</td>
<td>85</td>
<td>17</td>
</tr>
<tr>
<td>Dyad 12</td>
<td>D</td>
<td>78</td>
<td>17</td>
</tr>
<tr>
<td>Mean</td>
<td>81.4</td>
<td>18.4</td>
<td>39</td>
</tr>
</tbody>
</table>

Drugs: D= Donepezil; M= Memantine
B= Baseline; F= Follow-up

Although these results need to be interpreted cautiously due to the small numbers involved, it is interesting that in the group that experienced benefits, PLWD and CPs mean QoL-AD follow-up scores were higher than their baseline scores (PLWD 38.4 vs. 42.5; CP 35.5 vs. 39.1). People in this group, tended to be younger and their cognitive impairment was milder than participants in the other group.65

In contrast to the other group, the QoLAD mean score of PLWD remained fairly similar to baseline scores (PLWD 39.1 vs 38.6), whereas the mean QoLAD score reported by CPs had notably dropped (CP 35.2 vs. 31.6). This trend, where the QoL AD scores of those reporting benefits from the drug were higher than at baseline; the scores of PLWD who did not benefit were maintained, and the scores of CPs of the latter had considerably dropped, can be observed in both group and individual ratings66.

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65 Small number of participants on this study did not allow to investigate this matter further but this may be an interesting hypothesis to test in future research about the efficacy of these drugs.
66 Only one person from each group failed to follow this pattern.
It is also worthy of comment that for the group who claimed they experienced no drug benefits, whilst the QoLAD scores of PLWD did not indicate improvement, scores remained relatively high: 38.8, so overall this group seemed to still enjoy a good quality of life.

Important differences arise when comparing follow-up scores among groups and of particular note is the fact that mean scores of PLWD are moderately higher in the group of those who benefited from the drug (42.5 vs. 38.6 respectively). This difference is more obvious between the CPs groups at follow-up, (no benefits 31.6 vs versus benefits 39.1).

In summary, QoLAD scores of PLWD and of CP suggest that the quality of life of the group that experienced benefits from the drug had improved. In contrast, the quality of life of those who did not experience benefits from the drug treatment had either remained the same or decreased. The latter group were much older and overall had a more moderate CI at the time they had started the drug treatment. Mean scores show that the score differences in terms of the QoL-AD rating between the groups tended to diverge more compared with baseline. Due to the very small number of participants involved in this study no attempt was made to conduct further statistical analysis on the QoLAD and even frequency results and measures of central tendency need to be interpreted with great caution.

In keeping with the way baseline data on quality of life was presented in the last chapter, the section to follow reports quality of life follow-up findings for each of the five domains which emerged during the qualitative interviews at baseline and which form for the most part the key domains identified by Logsdon et al. (2001). The same structure used to report on quality of life in chapter five is followed here: in each of the five domains (family and friends, being active, remaining independent, feeling well and feeling healthy) QoL-AD frequencies are presented first, and then the qualitative accounts are explored. Data is presented in accordance with the two sub-groups identified, those who believed the drugs had worked, and those who could see no benefits from taking them.
7.4.1 Dyads that experienced drug benefits

7.4.1.1 Family and friends

Table 7.3 shows the frequencies given in response to the item asked at follow-up about family spouses and friends. All of the seven participants rated their relationships with families, spouses and friends as good or excellent and, like at baseline, no participant rated any of the three relationships as poor or fair.

Table 7.3: Frequencies of PLWD and CP responses to items relationship with family, spouse and friends

<table>
<thead>
<tr>
<th></th>
<th>Poor to fair</th>
<th>Good to excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PLWD</td>
<td>CP</td>
</tr>
<tr>
<td>Family</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Spouse</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Friends</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Participants’ accounts highlighted the changes in the way PLWD were now perceived and treated by their families. For example, Angela (PLWD) referred to her daughter’s pride in her achievements: “Like Dianne and I were talking and she said to me, well, Mom, I have to say to you, I’m very proud of you.” Similarly Eoin felt he was now more confident and able to do things, but most importantly he felt his family trusted him more in doing things, was less inclined to monitor him, and gave him more opportunities to function independently,

I feel more confident in myself and I feel, others, like my sister as well have more confidence on what I can or can’t do (...) I am not being checked as much, there is more confidence in me to do things. Eoin PLWD.

More positive perceptions of the PLWD often provided them with further opportunities for contributing or giving help and seemed to facilitate better relationships, that were arguably more in tune with understandings of reciprocal relationships than were discussed at the first interview. Eoin described two events where his family had invited him to help and become involved. The first involved helping his sister to paint her house, and the second involved helping with funeral arrangements of a nephew who had passed away. He believed that six months earlier he would have been “left out” of both events because of his “situation”. Involvement made him feel he could contribute to his family and this stood out in stark contrast to six months earlier when he was the one who needed help and often felt a burden.
Eoin: It was a huge shock [sudden decease of a young nephew] – [name of Godson] asked could I give a hand with flowers and stuff

Interviewer: How did you feel about this?

Eoin: I felt good about it, the fact that I was able to do it was good. Six months ago I wouldn’t have been asked. In my situation, I’d have been kept from all this.

Interviewer: And is that important to you?

Eoin: Of course you want to be able to help the family, to be there for them as they had been for me. Eoin PLWD.

For several of the dyads as well, the caregiver-carerecipient relationship was perceived as being more equitable, balanced and reciprocal compared with the relationship at baseline, She [PLWD] is great with advice. And she’s always there to listen. She’ll ring me at home if something is going on. She’ll say - How are things? How is [name of husband]? - So it’s not that it is only one-way. Dianne CP.

Similarly, Colette (PLWD) talked about the couple now planning and doing things together, whereas at baseline she lacked motivation and had to be dragged out of the house by her husband to carry on with her life: ‘as a couple we still do all we want, we go to the places we like, we live everyday to the fullest’.

Another example of change for married couples was provided by one wife (Hilary) who explained how her husband was now more appreciative of the help and support she gave him and their relationships had now become more intimate and rewarding.

The other day, he [PLWD] said: "Oh, I don't know what I'd do without you. Do you want, do you need anything on the way home?" and I said "No, go straight home." And he [PLWD] said "Whatever you like, I'll drive over to the shop and I'll get you some flowers." You know, like, ... like he really appreciates ... he is, is great. Hilary CP.

Lisa (CP) referred to her husband as being less aggressive and calmer now, something that “it may look small, but this is very important to us”. The significance of this benefit was that he could stay at home, rather than having to go into long-term care, as Lisa felt that she would not have been able to look after him if the aggression had continued. Furthermore, in the context of a marriage they defined as excellent “we get on great, we have been married for a good number of years now, we never fight, we don't argue.”
(Gordon PLWD); it was clear how difficult it was for Lisa to understand her husband’s behaviour particularly his continuous argumentative manner. Thus, for her, her husband’s calmer and more agreeable attitude, made their relationship, whilst markedly different from the relationship they shared before, more acceptable,

Before the tablets he was very aggressive, he got very aggressive before, just verbally, very annoyed and giving out and I couldn’t understand it you know he wasn’t himself, he was aggressive (...) but since the tablets he is calmer, he is more relax, he doesn’t argue about things. Lisa CP.

**Friendships**

An important change since baseline was that some PLWD had by now disclosed their diagnosis to their friends. Analysis of interviews suggest that improved communication skills and their having more confidence now had helped in their decisions to be more open with friends,

Because now, I don’t feel as stuck [for words], I can be talking for hours [with her friends], and sometimes I still may not find the word, but it is not happening as often. Claire PLWD.

Nevertheless, a greater acceptance of their diagnosis also seemed to have played an important role in these decisions;

And I told people, I told them and it was fine, initially I didn’t want to tell anybody but then I did you know, I thought sort of what’s the point in not telling, people are not that worried about you anyway, everybody has their own stuff so it is not that important to them, it is important to me, but is not important to them because they probably have some thing else, something or the other, they all have their own stuff. Orla PLWD.

Participants’ improvements in communication and disclosing their diagnosis to their friends seemed to have contributed to the re-establishment of PLWD regular contact with friends,

I mean the thing is that I am ok you know I am ok and I feel I can sit down with them and chat with people. I meet people for lunch or, like this morning I had coffee with two of my friends. Orla PLWD.
In short, in keeping with the complexity of the family and friendships shown in chapter five, these findings illustrate the many different ways in which improvements could facilitate more positive relationships, and how such relationships were now more similar to what participants thought of a good relationships. The findings show that whilst some changes and improvements were attributed to the drug treatment, other factors, including greater acceptance of the diagnosis and seeing the dementia in a different light, may also have contributed.

7.4.1.2 Being busy and active
This domain refers to the participants’ desire to keep as busy and active as possible. Table 7.4 shows the frequencies of these seven dyads in relation to the ability to do chores and to do things for fun of the person with dementia at follow-up. It shows that these PLWD rated their abilities to do things for fun very positively, but their ability to undertake chores was rated slightly worse. Similarly CP tended to score the PLWD ability to do chores more negatively than for doing things for fun.

Table 7.4: Frequencies of PLWD and CPs responses to items ability to do chores and ability to do things for fun.

<table>
<thead>
<tr>
<th></th>
<th>Poor to fair</th>
<th>Good to excellent</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>PLWD</td>
<td>CP</td>
</tr>
<tr>
<td>Chores</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Fun</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

At follow-up, a change identified by most related to their greater involvement in activities and their willingness to do things previously given up or avoided. This finding was common across these participants. The significance of these changes for their quality of life was elaborated in three different but interlinked ways: (1) PLWD spending their time in a more meaningful way, (2) making their lives more normal or more in keeping with their age and (3) providing a sense of continuity with the life led before the onset of dementia. Several examples were provided.

Spending time in more meaningful and enjoyable ways
Whilst baseline data showed that outings and activities that involved socialising were a challenge for some participants, follow-up data showed significant changes with regard to these. Eoin for example, who at the time of first interview said he avoided any social events, now felt relaxed, more confident and was more willing to be involved in activities that entailed interacting with other people. He gave helpful examples including
going to the opera and spending weekends with his family in the countryside. These were
times and activities that he enjoyed and that provided opportunities for socialising,

I am just back from [name of place in countryside] I’ve been there a couple of
days there with my nephew, and it was lovely yeah, that was my holidays. It was
great, and then I was lucky the weather was very nice, so it was nice and we
could get out and being out and you know…. It was a lovely change. (...) In
[name of place in countryside] now I was quite relaxed and I was Ok with being
with people, I was mixing grand. Eoin PLWD.

Likewise Colette (PLWD) who some six months earlier just sat passively and did not talk
when on outings, now went dancing, enjoyed her days out and looked forward to these
activities.

Claire (PLWD) provided a powerful example of how she could now remember the words
of prayers and was more involved in Mass – this is something that in Mass, everybody
else was doing but she could not do before,

We always go to Mass (...) and you know when you’re at Mass and the Priest is
saying a prayer or something? Everyone there … they start saying it out loud but
I tried and couldn’t do it. I couldn’t do it. Now I’m back. So that’s how good
now I am. Claire PLWD.

Making life more normal and more in keeping with age

Peter (PLWD) was now at follow-up back to playing solitaire, doing woodwork and was
now better able to follow TV shows- all activities that he enjoyed and that kept him
occupied daily, but which he found difficult to do six months earlier. His wife explained
that six months earlier he was going to bed early as he could not find anything to do or
concentrate on. She summarised the implications of these changes when talking about the
six months period, when she said: “he likes to be busy, and I think he's been really busy”.
In short regaining these everyday activities had given to their lives a sense of normality,

As far as I'm concerned, to me now life is normal enough. Hilary CP.

Whilst for Eoin, the main issue seemed to be around how he was now enjoying more the
things he used to do. For his sister (the CP), it was evident that the way Eoin now
interacted with people was more acceptable for her and in her view more normal. In
short in her view, his life was now more in keeping with a life of someone of his age.
He went for a little walk round and he came around the pier and he just looked at what was going on, and the locals are very friendly down there, they know us so they chatted to him and that was great (...) My husband and myself we like opera (...) so we brought him (to the opera) and I thought he may want to go home or go for a cigarette and not come back in or whatever, but he loved it. (...) So I am trying to involve him a bit more, you know with going out, like he has a life like any other person of his age, 62, I would like to see that. Esther CP.

Continuity with previous life

Some participants, like Orla (PLWD) and Angela (PLWD) talked more generally about getting back to their former lives now. This meant doing the type of things they used to do before the dementia onset and which they had given up. Resuming these activities gave a sense of normality and of continuity to their lives,

I am back to my normal life. I meet people I know all the time, like I had lunch with these two girls today, you know, like I meet them all the time, you know, sort of, and I have lunch or maybe even after a meeting we go for cup of coffee and that sort of thing, so I mean, I enjoy that, I do enjoy that. Orla PLWD.

Peter (PLWD) provided another example of how resuming activities provided some continuity with previous life which involved some level of involvement in the local branch of a political party. This was significant for Peter who had always been politically active. Some time earlier he had withdrawn from this as he did not feel able to do it but being involved again positioned him more successfully and more in keeping with the person he used to be (Peter now “saving” the party from falling apart). His wife (CP) commented,

But he was secretary of [political party] and the local branch of [political party]. (...) He had given all that up himself. He just knew he wasn't able for it. And a few months ago, they rang him up and said the branch was falling apart, nobody was taking it over. And he's back there doing it all again. I'm delighted for him (...) and the fact that he was confident enough to say yes, because he gave that up himself. Hilary CP.

Moreover some participants talked about how they had had time to reflect over their lives and the improvements noted were not only due to the medication but also to their own determination to make the most of their lives and to come to terms with their diagnosis,
I was going out but I was sitting there [in the Pub], I was really like..., like a baby... all frightened, but I had to pull myself together and said stop this (...). So yeah the medication suits me but also I think myself ... I have done a lot of thinking. Colette PLWD.

I suppose I just came to terms with it [diagnosis], that I have this [Alzheimer’s disease] and this is the way it is, and ... I rather keep going and you know make the best for life. Orla PLWD.

Claire’s (PLWD) account here is interesting since it shows that although her language skills including word-finding difficulties had improved, her reduced mobility and increased pain were very negatively impacting on her life. She could now do a lot less on her own and there were many things she could no longer share with her husband. Her husband (CP) explained,

That’s the real job actually, she can talk to people and to everyone coming here, she can talk and she could talk the whole day (...) but it would be great if she could walk down the town or come with me for a walk with the dog things like that, that to me would be good quality of life. (...) To be able to get up everyday and to do whatever you want to do, whatever you need to do. Daniel CP.

In another case the PLWD (Eoin) whilst now doing more, provided an example of a situation in which he felt he had more energy and felt more “vibrant” but this feeling did not always correspond with opportunities afforded to him. He commented,

I have more energy than I used to, but there is not that much really to use it on, let’s put it that way. I feel more get up and go, I feel more vibrant but the vibrancy is none, it isn’t there, you know I haven’t been … there is no many opportunities to do. Eoin PLWD.

Finally, improvements in the PLWD activity level could at times have paradoxical consequences. For example Hilary (CP) felt her husband was now more aware of when he was left out of social situations. Six months earlier his lack of awareness might have protected him from feeling overlooked but now he noticed this and was disappointed. She said,

He’s funny, you know. He’s like a child. They have leagues [bowling], and you can be picked for a team. (...) But anyway, he said to me the
other day, "I haven't had any matches this year at all. (...) I don't know why they don't ask me, because I'm a good bowler." Six months ago it wouldn't have occurred to him. Hilary CP.

7.4.1.3 Independence

Independence was another relevant domain of quality of life for participants which emerged during the follow-up in-depth interviews\(^{67}\). Peter (PLWD) and Angela's (PLWD) narratives for example reflected the greater sense of independence they now enjoyed (being able to drive or to take public transport). Better cognitive functioning and confidence in driving contributed to PLWD doing more things on their own and enjoying more independence,

> Being able to drive, that was huge (...) He was always a brilliant driver. And it was only this business of not being able to find the way. That kind of unnerved him. (...) Now, he's more decisive, he goes out on his own, he drives anywhere, he can remember where he's going. I mean, he's great, he really is great. (...) he's abled, he's independent to a certain extent which he wasn't before. Hilary CP.

Another example of PLWD being independent related to wanting to be involved and make decisions about their everyday life. For example, both at baseline and at follow-up, Eoin talked about his care arrangements and highlighted that anything he needed was arranged for him. Nevertheless a core difference at follow-up was that he now felt more involved and that he had a role in making decisions about and in planning his care:

> "Anything I need is arranged and I am involved". This involvement reflected his improved ability to do things "that anything is not done for me, that I still do things, that I can do things", but also in that Eoin felt he now wanted to have a say about "what I can or I can't do", and that other people, like his sister, trusted him more and gave him more opportunities to do things.

> The fact that I am taking more care of myself, in the past I wouldn't have been bothered (...) My family used to play a major role which I think is becoming less. They phone me and remind me and check that I've done it, which I don't mind (...) and that I think has improved in the last months. Eoin PLWD.

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\(^{67}\) As shown in the last chapter independence is not an item on the QoL-AD therefore only qualitative data are available here.
Another example of Eoin’s increased independence could be seen in his making individual choices when grocery shopping. These two examples illustrate how he felt he had greater control over his day-to-day life and that he was in his own words “running his life”.

I go with Esther every week for shopping and I am more confident when I go with her yeah, taking what I want to take, and I do more suggestions that I think I used to. Eoin PLWD.

For his sister this was another way of distancing Eoin from what for her was a behaviour typical of dementia;

He looks in the supermarket and he picks things, whereas before he would walk around after me and he’d let me ... I’d say, would you like this? “Ah that’s alright, whatever you think”. So now that’s a difference. He is more confident about I would like to pick this and not this or whatever (...) I think it makes him feel more normal. Esther CP.

It seemed that whilst at baseline dementia had clearly challenged how Eoin thought about and experienced independence and the help he received from his sister (whilst necessary it was perceived as a threat to his quality of life) now he had found a way of managing his care that was more in keeping with his understanding of an acceptable level of independence. The latter had involved his increased engagement and involvement in decision making regarding his own care and life.

Whilst this domain reflected changes for the better which improved day-to-day living for several participants, the improvements were limited as they still needed help in other contexts,

But like my sister ... she still makes sure I have food, she makes sure that all is ok, she controls that my medication... that I am taking the medication, there are several things that she looks after. Eoin PLWD.

Similar views about acquiring greater independence but still needing support were found in the narratives of Peter and Angela. When Angela (PLWD) spent a weekend in a hotel with friends she often lacked confidence and felt disorientated, and in this context she needed more assistance. Peter (PLWD) needed help in some contexts such as with medical appointments whereas before he could manage independently.
In addition, mobility and pain could threaten the independence of some participants,

Because she can go to the supermarket and she knows what she wants, she know
where it is, but she can’t ... she cant walk at all (...) I have to take her or someone
has to bring her to the supermarket or the shops anywhere she wants to go, she
can’t, she needs someone to take her. Daniel CP.

7.1.1.4 Psychological wellbeing
Table 7.4 shows how all but one of the participants (PLWD and their CP) rated their
mood and self at follow-up very positively.

Table 7.4 Frequencies of PLWD and CP responses to items “mood” and the “self as a
whole”

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<td>Mood</td>
<td>PLWD</td>
<td>CP</td>
</tr>
<tr>
<td>Mood</td>
<td>0</td>
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</tr>
<tr>
<td>Self</td>
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In discussions, two main themes reflected the changes arising in this domain, namely
their belief that they were back to “the person they used to be”, and their now
experiencing a greater sense of agency.

“The person I used to be”
As argued in chapter five, for some participants, living with dementia had an important
impact on how they felt about themselves or how others perceived them. At baseline
some talked about not feeling well in themselves, not feeling confident or about relevant
changes to core elements in their identities: “When that [memory problems] happened, I
was a different person. I did not want to go out I was hiding from people, you know, that
was all” (Colette PLWD). In contrast with how they described themselves at baseline, at
follow-up, all seven participants talked about how they now felt more confident, positive,
relaxed, outgoing and able: “I feel so well in myself. I feel more positive and
relaxed. (...) this (drug) has made me more or less a whole person again” (Angela
PLWD). These positive images were more in keeping with what these participants
considered good psychological wellbeing or in her own words “a whole person”.

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Changes in the self could translate into aspects of their physical self, such as taking pride in one’s appearance: “Like I have plenty of jewellery, necklaces and stuff and I am back to wearing them”. Colette PLWD.

PLWD were perceived as being more like the person they were before the onset of dementia: “She is now like she always was, looking forward to things” (Connor CP). Talking about how the person used to be, referred to aspects of the individual’s life such as activities and to personality,

She seems to be mentally stronger and more like her old self. Her sense of humour. She definitely seemed more upbeat (...) It’s like her old self. It’s like her personality started showing through again, very much so. Dianne CP.

This quote shows changes in how the PLWD was perceived by her daughter as mentally stronger, with better sense of humour, able to make jokes and in good form. This in the view of her daughter better reflects the way her mother used to be.

**Sense of agency**

Feeling better about oneself was at times reflected in the PLWD sense of agency. Some examples from participants illustrate how they felt stronger, more decisive or more able to make decisions. Angela talked with pride about her decision to give up smoking, something she had tried before without success. She now felt confident and believed she could manage to do this. She stated that over recent months she felt more assertive and confident in herself. She summarised it saying that she felt “if you want something you have to go for it, it is not just about moaning and complaining” (Angela PLWD). This type of attitude whilst not related to dementia symptoms was very significant as this participant felt that her confidence and feeling better had facilitated such decisions.

Another example was provided by Colette who, when she talked, stressed the first person singular “I”. She compared herself to six months earlier when she had to be taken out of the house as she did not want to meet other people. Now she felt more confident and she “herself” wanted to do things,

And I am now back to all that, and there’s a big difference in that you know “I” want to go to town, I always did but it was because [name of CP] forced me, I always liked going to the shops and then for a cup of tea, definitely, I have never stayed in the house, but I feel now that “I” want to do it (...) So now I am happy
I can do what I want, so I feel back to my own self, definitely. Colette PLWD.

The change for Colette was doing things because she wanted to and looking forward to doing these things. The quote also illustrates the significance of everyday life and routines and how she felt she was now taking control of these things that were core elements of her prior life (going out with her husband, going shopping, socialising).

Despite such positive findings at follow-up, some participants noted that improvements whilst important failed to bring the person back to their pre-dementia level. A good example was provided by Hilary (CP) who talked about her husband being “90% of the person he used to be”, meaning that the he had greatly improved his abilities but that still he needed sometimes help or acted in a way that was not as he did before.

7.4.1.5 Feeling healthy

Table 7.5 presents the frequencies of PLWD and CP responses to physical health, energy and memory. These findings show that the QoLAD ratings on memory are remarkably more negative than for each of the other items. About half of PLWD and CP rated memory as being fair to poor. The ratings on memory and the ability to do chores (Table 7.4) are the poorest among all scale items both from the perspectives of PLWD and CP.

Table 7.5 Frequencies of PLWD and CP responses to items “physical health”, “energy” and “memory”

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<td>PLWD CP</td>
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<td>Health</td>
<td>1 1</td>
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<tr>
<td>Energy</td>
<td>1 1</td>
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<td>Memory</td>
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In relation to physical health, many PLWD felt they enjoyed better health and had more energy and as Eoin summarised some were more “up and go”. As at baseline, no participant referred to his/her memory per se when talking about their quality of life.

In summary, this section shows that the seven PLWD who could identify benefits derived from the drugs reported experiencing, as per the QoL-AD, better quality of life compared with baseline. In examining the different domains, it became evident that scores on items relating to the participants’ relationships with others, feelings about the self and doing
things for fun were very positive with almost all participants rating these domains as good or very good at follow-up. Nevertheless, at follow-up, scores on ability to do chores and scores on memory were generally less positive. Poor ratings on these domains were even more noticeable in CP ratings, where more often these items were negatively scored and evaluated as being either poor or fair.

In the qualitative approach, a main theme that emerged at follow-up was about a greater sense of normality and continuity with previous lives. Many had resumed activities and felt their lifestyles were more in tune with what they considered a normal life for their age and values. A second theme related to their relationships with others; how these people seemed to feel more able and willing to take control of their lives, and how families and CPs seemed to regard them less as someone with dementia but more like a normal human being. Nevertheless the qualitative accounts show that some people believed that these positive changes had not taken the person back to the pre-dementia level, and interestingly in one case for the dyad, it was mobility and pain, and not dementia, which had had a greater impact on quality of life.

7.4.2 Dyads who did not experience drug benefits

Having presented follow-up quality of life data on the group who believed the anti-dementia drugs worked for them, the next section explores the quality of life of the remaining participants who claimed drugs had not worked.

Table 7.6 shows data on frequencies of responses to the QoL-AD items relating to relationships, activities, wellbeing and health. It is interesting to note that once again the most positive ratings are in the relationships these people had with their spouses, families and with respect to their mood. On the other hand, most dyads scored poorly the items related to chores and memory. CPs also scored the item “ability to do thing for fun” poorly.

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68 As stated in section 7.1, three out of the five PLWD did not remember the use of the medication.
69 As stated earlier four of these five PLWD continued to take the drug.
Table 7.6: Frequencies of PLWD and CP responses to items “relationship with family”, “spouse” and “friends,” “ability to do chores” and “things for fun”, “mood”, “self”, “health”, “energy” and “memory”

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<td>PLWD</td>
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<td>Family</td>
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<td>Spouse</td>
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<td>Friends</td>
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<td>Chores</td>
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<tr>
<td>Fun</td>
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<tr>
<td>Mood</td>
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<td>Energy</td>
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<tr>
<td>Memory</td>
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Like at baseline, follow-up interviews highlighted the significance of spouses, family and of being busy to these people’s quality of life. Families were reported as being understanding and their acceptance of the PLWD was critical to their feeling involved and remaining part of family life. PLWD often felt they were treated with respect and were included,

When they [family] are in, they will be all talking about the same things or ... and nobody is whispering or ... everybody is outspoken, yeah so even if the memory is not that good, you are not altogether shut out. Dora PLWD.

Now I wouldn’t remember when I saw some of them [adult children] last. But when they come I would say, when were you here last? and they would tell me, they kind of accept it. Which is lucky for me. And I know that if I said to them, what’s this you said? They would always tell me, they accept it, no problem with it. Paul PLWD.

Being busy was still very relevant to these PLWD and this was in their view central to keep their good quality of life : “My entire life is getting down to the Club and doing the bowling or the table tennis” (Richard PLWD). As at baseline, understandings of being busy mostly related to being able to carry on with their lives, and the little things that although to some might be unimportant filled their everydays with routines,

You just sort of carry on … keep doing the things you have to do. Harry PLWD.
I am able to carry on with my life (...) It’s just small little things to do, to keep you kind of busy, but nothing important really, no pressures (...) Like I walk every day, … the newspaper, that’s one – it’s an excuse to go outside everyday.

Paul PLWD.

However, being busy and getting on with normal everyday routines could now pose further problems for these people because of memory problems,

My memory is not that great. I do miss sometimes … like when I have to go to the table tennis or the bowling – like if there’s bowling I go down [to the Club].

Like on Saturdays it’s at ten but I think the Wednesday’s one is at half ten and the other one starts at three maybe. And some days I am like is it today at 10 or half 10? I am going down and check. PLWD Richard.

Accounts showed that most PLWD were able to find ways of combating these difficulties.

One of these people (David), had since baseline, started attending a Day Centre and the latter had provided this man with a new lease of life. For David, going to the Day Centre was something he looked forward to and made the days in which he went to the centre “special”. This sharply contrasted with how this dyad talked at baseline about David having an empty life and one of just sitting and watching the TV (Maeve CP). Whilst accounts in the first interview with this dyad suggested that David had “lost” his life, their account now was much more positive and seemed to be more attuned with what they thought of a normal and good life.\(^{70}\)

I like going to the [Day] Centre. Being out of the house. (...) Going on the bus. I like that. David PLWD.

I love him going to the Centre because he loves it, he gets out on the bus and you see him happy, having something to look forward to, that to me makes a whole difference in his life. (...) He has lost his life, that’s what I think. So that’s why I love that Centre, because the days he goes, he seems happy, is getting some kind of life back to him. Maeve CP.

\(^{70}\) This CP believed the anti-dementia drug had not worked for the person living with dementia as, in her opinion, the condition (dementia) had noticeably progressed over the six months period. The person with dementia (David) was not interviewed about medication due to his lack of awareness.
Remaining independent was still very important to many of these PLWD. Understandings of independence involved doing things on their own but now most often with the supervision of or help from the CP. This was particularly salient in the context of taking medication, a task none of these people could now do independently,

He is still doing things (...) Before he was able to fill out the pill dispenser himself; now I’ve started to do that for him (...) And sometimes he’ll come in here with a cup of tea and sit down, and I’ll ask him: Did you take your tablets? - “I think so.” - I’ll go and check- and they’ll be gone, so I can only assume that he’s taken them. Richard PLWD.

A dominant theme in the accounts of CPs concerned the PLWD being now more dependent on them. This meant the CPs often having responsibility for many more care duties compared with at baseline,

I mean, she couldn’t fend for herself now, I’m here all the time. Kevin CP.

I think I’m finding that I’m doing a little bit more for him now. I think the fact that I’m here is sort of a safety net for him as well. He knows that if he has a problem or something he can talk to me about it and stuff like that. Adam CP.

This group of PLWD summarised their psychological wellbeing at follow-up as their looking forward to the next day and their desire to live for as long as possible. On the other hand, CPs referred to how the more noticeable memory loss problems made the PLWD, at times, more anxious, cross or “touchy” with things. This was an important change from baseline,

There could be events like a party or a birthday party something like that, the invite would be sitting there and we’d have organized someone to come and pick her up and take her and we would have told her that (...) but she would still be – as soon as she sees the invite, it’s, “Oh, I have to organize something for this”. It’s like everything gets her worried and concerned. Kevin CP.

He doesn’t really know how to look after it (bills) anymore and stuff like that would make him a little bit anxious. Mary CP.

In summary, the mean QoL-AD score of PLWD suggests that their quality of life at follow-up was fairly similar to that experienced at baseline. In contrast, the mean score of
CPs suggested an important deterioration in quality of life. From the more micro analysis (frequencies of responses to each domain) it would appear that this sub-group scored negatively overall but particularly on items relating to activities (abilities) and memory, and to a lesser extent on relationships with friends and psychological wellbeing.

Qualitative accounts likewise reflect the increasing difficulties and dependency of this group of PLWD, but paradoxically their belief that they still enjoyed a good life. Their desire to “carry on” and of being accepted by those who were significant to them was very salient. Whilst accounts suggested that some domains could have deteriorated, all PLWD seemed to hold onto something that still made their lives worthwhile. For example, in Richard’s case his busy social agenda (activities and social interaction) was very important to him; for Paul, his daily routines and the independence that going for walks alone and buying the newspaper on his own afforded him; in Dora’s and Harry’s cases their families and the time they spent with them, and for David attending a day centre.

It is noteworthy that the accounts of CPs reflected a recurrent and very salient theme about future deterioration and a concern about the future quality of life of PLWD if decline continued. Such deterioration reflected the progressive deterioration associated with dementia but also that their lives would be further distanced from what to them was normal and acceptable. It was with respect to this second theme that the anti-dementia drugs played a very relevant role, fuelling their hope that their symptoms of dementia could be still maintained at their current level,

Well, if his memory keeps getting worse, his quality of life is going to automatically get worse. And I think because he’s going to get more frustrated, or if he can’t go to his walk. This is not a life. Jenni CP.

If it gets to a stage when he is forgetting his social agenda, social calendar, if he was forgetting to go then, that would be obviously – that would limit what he could do because I can’t bring him all the time (...) It would be more difficult for him then because it would start breaking up his routine. Adam CP.

To summarise this section, the data show that some noticeable differences in quality of life domains and scores were found. The quality of life of the group who believed that the drugs had worked had overall improved, whilst in contrast, the quality of life those who
believed the drugs had not worked remained the same or in fact in some cases had deteriorated.

Qualitative follow-up data has helped to uncover further what was going on these 12 peoples’ lives six months after they commenced taking the anti-dementia drugs. The most common and recurring theme in some participants’ accounts was normality, resuming life and a greater sense of agency in their lives and in their relationships with others. In contrast, other accounts suggest that the most salient theme related to being able to carry on with their lives, feeling accepted by others and a strong desire to be alive and looking forward to the next day. The data therefore suggest that understandings of quality of life are very complex and extremely difficult to elucidate using quantitative approaches such as quality of life scales.

7.5 ROLE OF MEDICATION IN QUALITY OF LIFE

Overall drug treatment was only one of a number of factors identified as helping PLWD achieve a better quality of life over this initial six months period and the dyads were unable to identify the exact contribution of particular factors to enhancing quality of life. Most felt that it was a combination of many elements that had facilitated their quality of life improvement.

For example, some participants referred to the complexity of a person’s life where many other things apart from taking drugs were going on,

I have not get any worse and I got better since you were here - it could be anything, I mean we are on this diet for six or seven weeks and I’ve lost a good bit of weight, one stone, I’ve got the cholesterol down, so something else is happening there, I have a healthier life now, so I can not just say yeah Aricept is great, it’s done a great job because there are so many things that have changed and could be helping, you see. Orla PLWD.

In addition, as stated in previous sections several PLWD referred to a greater acceptance of dementia and often their accounts reflected a more positive attitude towards their experiences of dementia compared to at baseline. This greater acceptance of their diagnosis of dementia, and better knowledge about it, were discussed as important contributors to improvements in quality of life. It was also referred to as “overcoming the grieving period” (Orla PLWD). PLWD accounts showed how greater acceptance was
related to greater sense of agency over their condition and their lives and to their actively seeking more things to do and to look forward to. Interviews revealed that many PLWD claimed they themselves had been active agents of their change and of what happened to them.

The dyads who felt they had not benefitted from taking the drug often talked about the drug in terms of doing “no harm”, as in their view the PLWD had not experienced any adverse side effects. Some few mentioned how the drug could had limited the deterioration. Their accounts were greatly straddled with hope and the belief that the drug could in the future do something for their relatives with dementia. This was relevant as most talked about the impact that further deterioration would have on quality of life of the PLWD,

I can’t say it [drug] has helped. (...) But it could be worse. (...) it would be great if you know, if we could hit some sort of a plateau to maintain as opposed to further deterioration ... that would be good. Adam CP.

Both groups referred to other factors not associated with the drug treatment that also contributed to their better quality of life. These included: (1) a good family network and friendships and arrangements that allowed the person to live independently, (2) a healthier life style and better routine with which the PLWD felt comfortable, (3) the weather, (4) compliance with all medication they were prescribed including anti-dementia or other medication.

7.6 PARTICIPANTS DISCOURSES ABOUT BENEFITS, IMPROVEMENT AND QUALITY OF LIFE

An important finding from the follow-up interviews and data collected after six months, is the great complexity found in the participants’ ways of talking about drug efficacy. Four different but overlapping (and often difficult to disentangle) concepts can be identified in the participants’ accounts namely, benefits, improvements, changes and value of change. The relationship between benefits (of the drugs) and improvements (in their condition) was extremely complex, and PLWD found it difficult to disentangle the impact and influence of each. Their accounts suggest that the concept of improvement was complex and was influenced by different factors. Drug treatment was one important factor but other factors were also equally salient including societal attitudes and
acceptance. The findings show that improvements noted were not straightforward, as they often co-existed with disimprovements. Improvements occurred in the context of the natural progression of the disease and most importantly the progression of participants' own lives.

Another significant and related concept is how these people experienced change. This relates to the impact that benefits and improvements have on these peoples' everyday lives. Not all benefits or improvements meant change (e.g. a person may feel his attention has improved, he may feel he could cook, but for different reasons, he may not cook). In this way, changes seemed to be limited and only applied to certain areas. Finally, reflecting on the value for these people of any change experienced is also useful. This refers to the significance or value the PLWD attached to a change and its relative value. For instance, an improvement could have been very noticeable as (e.g. fewer word-finding difficulties) but the value of the improvement may have been extremely limited as this person may no longer be able to socialise due to other health/mobility problems. On the contrary, the improvement may be regarded as limited (less aggressive) but to the person, in this case the CP, this may be extremely significant (their loved one can stay at home). The value assigned to these respective changes or improvements seems to be what these participants considered, when they talked about quality of life improvements.

A second relevant finding emerging in this chapter relates to the heterogeneous and multiple discourses found about quality of life in dementia. These discourses include continuity with life and the person as he/she used to be (normality, agency); adapting to more simple undemanding ways of living (carrying on, being alive), and fears of a future which might represent a total discontinuation with previous normal lives. What was important in these discourses was the extent to which the person felt the issues confronted were an acceptable way of living for his/her age and circumstances. Discourses converged in the relevance of being accepted, valued and respected by others and of the PLWD accepting dementia and wanting to make the most of their lives.

7.7 DISCUSSION OF CHAPTER AND CONCLUSIONS

Based on quantitative and qualitative approaches, this chapter has explored the ways in which participants thought about and discussed the medication they had been prescribed to treat dementia six months after they had been diagnosed. It also has looked at quality of life and dementia issues as they relate to the use of anti-dementia medication.
Findings suggest that the trust participants had in their doctors, their positive attitudes to medication and their strong desire to hold onto their current lives were relevant to the commencement, construction of early expectations and to their hopes during the course of the drug treatment. This thesis raises some fundamental questions such as: are decisions made by PLWD and their relatives about anti-dementia drugs based on rational risk-benefit evaluations (Lindstrom et al., 2006; Oremus et al., 2007; Hutchings et al., 2010a), or are they mostly grounded in hope and concerns about what life would look like if a more severe dementia developed? (Smith et al., 2011).

In keeping with many others (Shua Haim, 1997; Post et al., 2001; Alzheimer's Society, 2004; Hutchings et al., 2010a), many of the dyads participating in this research could easily identify direct benefits from the drugs. In line with findings of Hutchings et al. (2010a), it is argued that many of the PLWD themselves could more easily identify benefits of drug use than their CP. This finding has important implications for practice and policy development and will be returned to in the concluding chapter.

Findings demonstrate the complexities surrounding the way in which these participants talked about drug efficacy. Participants talked with uncertainty, ambiguity and hope about the drugs benefits (or lack of them). Benefits occurred in the context of the progression of dementia and other age-related health problems, and in the context and complexities of their own lives. It is important to take this into account when trying to understand how these people make sense of the drugs. Findings suggest that people living with dementia found it more meaningful to talk about changes experienced over the six months rather than about concrete benefits they could categorically say were exclusively associated with drug use (typically about how they felt better or had resumed their lives rather than about whether their memory or functioning had improved). As Dewing (2002) suggest, PLWD and their relatives seemed more concerned by the changes in areas of life that were important to them than about “ticking boxes” of scales that aim to measure the expected outcomes of the drugs. This is an important difference between what drugs represent to these people and the agendas of the pharmaceutical industry, regulatory bodies and some health professionals conducting clinical trials that most often have as a central focus a desire to measure the economic benefit of drugs or their impact on cognitive and behavioural functioning. Moreover it suggests that quality of life,
particularly using a qualitative approach, can be a useful approach for understanding how PLWD and their CP think and make sense of the efficacy of the drugs.

Using the QoL-AD scale, findings from this thesis suggest that people who benefited from the drug experienced positive relationships with spouses, families and friends, enjoyed good mood, and good psychological well-being (self as a whole) and could do things for fun. This is in part similar to the benefits that Woods et al. (2006) reported using the same scale from a cognitive program, as they reported improvements in their participants' relationships, activities and depression. Nevertheless in their study, improvements in memory and in the participants' abilities to perform chores were more prominent than findings emerging from this thesis. These people's accounts similarly suggested that the drugs were importantly contributing to their lives and interactions with others.

The QoL-AD ratings suggest that for some PLWD, quality of life had been maintained or had not improved over time. These ratings were most often, but not exclusively found in PLWD who had reported treatment failure. QoL-AD ratings of their memory, their abilities to do chores and things for fun were particularly poor for this group. Whilst the ratings of PLWD on quality of life were still high, the ratings of their CPs had importantly dropped and were significantly different from the ratings of the CPs of the group who benefited from the drug.

The findings of the qualitative inquiry showed more vividly the different ways in which participants talked about quality of life. Discourses about quality of life over time were diverse and sometimes could overlap. One main discourse was in terms of the participants' sense of continuity with their lives: maintaining a life as normal and as similar as possible to the lives they had led before the onset of dementia. This theme of continuity and normality is supported by previous studies that have also shown the relevance of establishing continuity across the life course in dementia (Menne et al., 2002; Fukushima et al., 2005; Robertson, 2013). Findings have highlighted the PLWD everyday lives and their struggles to maintain a sense of coherence and continuity with previous life. Moreover, in line with the literature (Phinney, Chaudhury and O'Connor, 2007), it seemed that returning back to previous significant activities and roles in their families was integral to fostering this feeling of coherence and continuity. There was a suggestion that coping and better acceptance of dementia could be relevant to regain a
sense of continuity and normality with life. Findings suggest that anti-dementia medication along with other factors, may have helped these people to regain this sense of normalcy in their lives.

A second but different discourse about quality of life relates to participants being able to carry on with their daily lives with the help and support of families, looking forward to the next day and to their strong desire for being alive. In this way of talking about quality of life, normalcy was not found in the past but in how the person had learnt to accept as acceptable and worthwhile this different life.

Finally, a third discourse referred to fears of a complete separation from a normal life that severe dementia could entail. This reflects the significance of experiencing continuity and discontinuity in dementia (Caddell and Clare 2011). Findings showed the connections between discontinuity and social images of severe dementia. As argued earlier, this may make more explicit the separation between the lives of those who have dementia and the lives of those who do not (Naue and Kroll, 2009).

The role that the medication had on quality of life has been explored in this study. In line with the work of Smith et al. (2011), findings suggest that other factors along with the medication may impact on the participants' experiences of quality of life improvement. Whilst Smith et al. (2011) specifically referred to the role caregivers' positive care practices had in promoting quality of life; this thesis has highlighted the role that more positive attitudes to dementia, greater acceptance of the diagnosis and in one instance, day care attendance had on quality of life improvement. Although this is only one case, it is particularly interesting since at baseline findings showed some participants' reluctance to use specialized services because of stigma. This illustrates how these people's values and preferences may evolve and the value of an ongoing assessment of the dyads' situation, complex needs and of their quality of life understandings.

The last three findings chapters (chapters five, six and seven) have presented data emerging from this thesis and in these chapters, findings have been discussed against the backdrop of the international literature reviewed and critiqued in chapters two and three. The final chapter of this thesis now draws together the main conclusions arising from this work. It provides reflections on the methodological and ethical issues emerging and the
implications of these. It makes some recommendations for theory, practice, policy development and future research in this area.
CHAPTER EIGHT: THESIS CONCLUSIONS

8.1 INTRODUCTION

This chapter provides an overall conclusion to this thesis which has taken a micro social constructionist approach to explore the manner in which older people recently diagnosed with dementia and prescribed dementia drug medication to treat it, think and talk about their quality of life, their expectations and experiences of the anti-dementia medication and the impact that the latter has on their quality of life.

This chapter is divided into three parts. The first section discusses three main areas of interest as conventionally approached in the literature and the findings emerging from the approach taken in this thesis. Following this, a reflection on the implications of the approach taken in this thesis is provided and the limitations of the study are discussed. The third and last section of this chapter outlines some relevant implications emerging from the thesis for practice, policy and theory development.

8.2 THE ADVANTAGES OF JUXTAPOSING THE NORMATIVE AND THE SOCIAL CONSTRUCTIONIST APPROACHES.

The underlying principles, assumptions and concepts of two important and co-existing traditions of knowledge, positivism and interpretivism have, throughout this thesis, been analytically discussed and contrasted. Attention has been given to how quality of life and medication issues in dementia have heretofore been approached and understood and to how relevant findings have been presented. The argument has been made that the normative approach has conventionally and predominantly informed the investigation of both topics, quality of life and medication in dementia. Three main areas that were of particular interest in the normative research (as shown in chapters two and three of the thesis) will now be revisited and discussed in light of the findings of this thesis. These are:
1) The impact of disease progression and severity of dementia on quality of life, in other words, how symptoms of dementia and impairments can interfere with the daily functioning of PLWD and with the way they relate with others.

2) Measuring and evaluating quality of life. There is within an understanding that quality of life can be measured and therefore that some people may have a better quality of life than others. Also, that quality of life can “neatly” improve or decline due to diverse type of interventions.

3) The statistical and clinical significance of the benefits that a person may experience as a result of taking the drug, and the debate about the cost-effectiveness of the anti-dementia drugs.

8.2.1 Disease progression, symptoms and quality of life.

The literature reviewed for this thesis showed that the impact of dementia on quality of life remains unclear. Symptoms of dementia and impairments associated with it can importantly interfere with the daily functioning of PLWD and with the way they relate to others. Yet, the exact role of cognition on quality of life is not straightforward and remains inconclusive (Woods et al., 2006; Banerjee et al., 2009). Several studies have reported the lack of association between quality of life and memory ratings, typically as measured by the MMSE test (Thorgrimsen et al. 2003; Selwood et al., 2005; Banerjee et al. 2009). The literature reviewed showed that PLWD consistently evaluate their quality of life positively. Whilst initial interest in the literature was on lack of awareness about symptoms and how this might explain the reported good quality of life in spite of dementia (Ready et al. 2006), there is now more interest on how PLWD may adjust to deficits and to decline.

Different models of psychological adjustment have been proposed and used in the context of chronic diseases (De Ridder et al., 2008), but particularly relevant to dementia are the models of cognitive adaptation and the stress and coping model. The former highlights illness acceptance and perceptions of control over illness. The latter focuses on the strategies used by “patients” to deal with adaptive tasks imposed by disease (De Ridder et
Drawing on the stress-coping model, Ettema and colleagues (2005) suggested that quality of life assessments in dementia should include the adaptation of the PLWD "to the perceived consequences of the dementia" (2005:366). The assumption behind this is that once the person has adjusted and found ways of coping with the symptoms or deficits produced by dementia, he/she may report a positive quality of life (Logsdon et al., 2002; Ettema et al., 2005). In a similar vein, Byrne-Davis and colleagues (2006) claimed that a person with dementia might evaluate his/her quality of life positively "as a result of changed internal evaluations" (Byrne-Davis et al. 2006). On the other hand, Fukushima et al. (2005) posited that the individual's adaptation to the diagnosis of dementia is crucial to quality of life (cognitive adaptation). The latter suggests that positive attitudes and understandings of dementia might help PLWD to evaluate their quality of life in positive terms. In summary, in these approaches the focus seems to be on how the person adjusts using internal or external strategies to diagnosis, to deficits or to consequences of such deficits.

In keeping with this literature, findings from this thesis have shown that positive attitudes and outlook, acceptance and positive images of dementia, and a sense of control over the disease, positively impacted on the quality of life of participants. Findings add another dimension to our knowledge about the experience of PLWD; whilst adjustment theory refers to the individual and to how well or how poorly the individual adapts and seeks to continue with his life despite illness, findings from this thesis have shown how social understandings of and attitudes about growing older and dementia, as well as how these are internalised by PLWD and their families, can also have an important impact on quality of life. Through the approach taken in this thesis broader issues emerge including: how concepts such as being active or independent are defined and operationalized in society, whose values and interests these definitions represent, and how these might impact on the person's understandings of what constitutes a good or acceptable life. As Conrad and Barker (2010) proposed, without denying the symptoms and deficits of dementia, this thesis has paid attention to the multiple meanings and significance that being diagnosed with dementia had for participants and how the context (time and space),

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71 Dementia causes important changes in the lives of PLWD. Depending on the perceived meaning or personal appraisal of changes, the PLWD tries to cope with them and regain a balance. Successful coping leads to a better quality of life (Ettema et al. 2005:361).

72 For example, if a person is unable to do an activity due to his/her dementia, following the work of Ettema et al. (2005), the focus of attention would be on how the person might find a way to cope with that, for example a less challenging activity. On the other hand Byrne-Davis et al. (2006) specifically focused on how the person might change his/her internal evaluation of the activity. They posited that a person can "adjust to anything using internal processes alone" (as opposed to external interventions).
and participants’ own experiences and interactions with others, helped to shape and re-shape their understandings and evaluations of quality of life.

Other psychological theories that also resonate with the findings of this thesis are continuity theory and the life course perspective. The findings point toward the importance of looking at quality of life as part of lifelong processes (Bond, 1999; Gubrium and Holstein, 2006; Barlett and O’Connor, 2010; Sabat et al., 2011; Robertson, 2013). This thesis confirms that PLWD are a highly heterogeneous group, with diverse and complex life-course experiences. The findings reflect how PLWD made sense of their quality of life based on previous values and preferences and on their current expectations and understanding of what was normal or acceptable at this point in time in their lives according to their age, lifestyle and health conditions. Living an ordinary and normal life gave participants a sense of continuity and coherence with their lives (Fukushima et al., 2005; Robertson 2013). Participants’ discourses also highlighted concerns about the discontinuity with their understandings of normality that the progression of dementia, and particularly advanced dementia, represented (Caddell and Clare, 2011). A sense of continuity and coherence was achieved through being involved in meaningful activities (Phinney, Chaudhury and O’Connor, 2007), through maintaining significant relationships with others, and through acting with agency and exerting power over their own lives.

This represents an important divergence from how quality of life has previously been understood in normative approaches where symptoms and decline are often per se seen to be negatively affecting quality of life.

8.2.2 Measuring and evaluating quality of life

An assumption underpinning the normative approach is that quality of life can be measured and represented as a single true reality. This involves a judgement that some PLWD have a better quality of life than others, and assumptions that improvement or decline of quality of life can be interpreted unproblematically.

In keeping with the international literature, findings from this study have confirmed the usefulness of using the QoL-AD scale to measure quality of life in dementia. Almost all participants were able to answer the questions posed on the scale, and the scale was found short and easy to complete. Also, follow-up findings showed that the scale reflected quite
accurately the improvements felt by participants. Nevertheless, the micro social constructionist approach adopted in this thesis has shown that PLWD held multiple and diverse discourses about their quality of life. The participants’ ways of thinking about quality of life were heterogeneous and often their accounts reflected ambivalence, contradictions and the overlapping of quality of life domains.

I would argue that whilst the normative approach is useful, in this thesis it was found to have limitations and to be reductionist. The findings suggest that the scale used in this research (QoL-AD) attempted to explain extremely complex phenomena such as family, friendships, or activities in very simple terms, so much so that the findings could become dissociated from the phenomena being studied.

As an example, a person living with dementia could have a good relationship with his/her spouse or with the CP, yet evidence from this thesis demonstrated that at times, dementia posed important challenges to what people felt was their role (e.g. as spouse) or to what being a good couple or togetherness represented. Moreover, the qualitative findings have shown how some aspects of life that were relevant to participants often competed with each other (for example independence, security, and relationships with the CP). PLWD could feel that they had very good social relationships with their family, and feel safe and grateful for that, but at the same time, the same relationships may have had an adverse impact on what, for that person, constituted an acceptable level of independence.

The idea of looking at quality of life improvement in an unequivocal way was challenged in this thesis. Both qualitative and quantitative follow-up data about quality of life showed that some PLWD felt the quality of their lives was better six months after first taking anti-dementia drugs. Nevertheless, their rich narratives showed that the way some participants talked about quality of life improvement was extremely complex. For example, they saw improvement in some areas but not in others. In addition the improvement in quality of life was relative as some people could feel in better mood, have energy and interest in things or experience greater abilities but may not always have had the opportunities to make use of them. The extent to which quality of life had improved was also relative to the value that the change had to the person. What some might see as a very small or even trivial change had, for other participants, great value.
PLWD most often talked about quality of life improvement as multi-factorial with multiple issues affecting their quality of life apart from dementia and the drugs. Measuring and deciding what makes a life better or worse seemed from this perspective a great challenge. Nevertheless, hearing these complexities and attempting to unravel them may help to better understand quality of life issues, how PLWD make sense of benefits derived from interventions and their quality of life over time.

8.2.3 The significance of drug benefits

Most studies looking at benefits and efficacy of the anti-dementia drugs have used standardised cognitive and functional scales to measure outcomes. The main question explored in these studies is whether the drugs can produce results that are statistically significant when compared with a control group. The debate is also around the statistical versus the clinical significance of these results. This thesis has shown the usefulness of looking much more in depth at the broad concept of quality of life to better understand the impact of anti-dementia drugs on the lives of people to whom such drugs are prescribed. It has looked at the significance of the experienced benefits (whether true or otherwise) of drug treatment on people’s lives.

It has been shown that PLWD and their CPs can cogently talk about their experiences of taking the drugs, but they do so without necessarily referring to their memory or abilities. Indeed, this thesis has shown the complexities involved in attempting to “isolate” the impact that dementia drugs had on cognition or functioning. It was not always possible to identify in an unequivocal way, what were the “real” outcomes of using anti-dementia drugs. Participants’ complex accounts included their experiences with the drugs but also with many other circumstances of their lives and relationships. It could be argued that benefits and improvements reported in this thesis could in fact be a reflection of a placebo effect or of the participants wanting to please the researcher by providing favorable answers. Nevertheless, this study was not concerned with evaluating the efficacy of the drugs but rather with representing and eliciting the voice of PLWD and their relatives and hearing about the lived experiences of taking the medication, the ways in which they talked about these drugs and the type of benefits these drugs represented to their lives (Bond and Corner, 2004).

The findings have successfully shown how PLWD felt and behaved immediately following their diagnosis and six months after first being prescribed the drugs. Findings
show that several participants believed the drugs had improved their quality of life. Participants were not concerned about whether their MMSE scores were now higher or lower but rather with feeling better about themselves and their lives. This is an important difference compared with how the efficacy and outcomes of using the drugs are usually measured and conceptualised in the literature. Findings suggest that the anti-dementia drugs may benefit PLWD and their CPs by creating further opportunities to experience biographical continuity and coherence with their lives. That said, it must be kept in mind that drugs were not the only factor contributing to this, and drugs should be contextualised and understood against the backdrop of the complexities of lives of the people taking them.

**Economic cost of drugs**

An important concern in the literature and of particular relevance to governments, policy makers and the pharmaceutical industry is the topic of the financial cost of these drugs. This has typically been framed as drug cost-effectiveness, and much research has concentrated on attempting to estimate if benefits derived from drugs are worthwhile considering the cost of financing them. At a macro level, drug use can be regarded as potentially cost saving; the person may, as a result of medication, be able to remain at home for longer and thus delay a move into more expensive hospital or institutional care.

The accounts of PLWD and CPs in contrast revealed other types of costs which were largely social and emotional. Findings have shown the impact that using the drugs could have on the everyday lives of PLWD and their CPs. The accounts of PLWD often reflected their concerns about side effects and the emotional cost that drugs could have for them. Likewise, the drugs could create difficulties and tensions in the relationship between PLWD and their CPs or could be perceived by CPs as an extra task in their caregiving role.

Follow-up data indicated that difficulties in managing medication over time could influence decisions around the continuation or discontinuation of drug treatment. Although this finding has to be interpreted with great caution as only one person in the sample discontinued drug treatment, the accounts of the remaining participants supported this supposition. Whilst at baseline, CPs referred to drug management as an extra task in caring and as something considered by some to be challenging, follow-up data showed
that manageability and good adherence to prescribed drug treatment influenced participants' decisions about drug continuation even in the absence of benefits.

The benefits of the drugs were often contextualised in terms of improved relationships between PLWD and their CP. Consistent with the existing literature, the findings from this thesis showed the power anti-dementia drugs had to provide some benefits “by serving as a focal point for enhanced interactions between caregivers and treated relatives” (Smith et al., 2011:406). In harmony with Sabat’s principles (2001), the findings showed how improvements in quality of life were related to changes in how others perceived the PLWD. Such changes were positive and using Sabat’s words, they focused on the most positive attributes of the person rather than on their cognitive decline. This afforded people greater opportunities to live what to them was considered a normal and good life. This can be interpreted as a benefit and an important outcome of using anti-dementia drugs that has been overlooked in the literature.

Thus, overall, findings pointed to both the negative and positive “costs” that taking the drugs could entail. These included emotional and also direct costs (care) that are often overlooked in the discussions about these drugs.

In chapter three (Figure 3.1) three competing spheres were identified in the literature on anti-dementia drugs. The first included the pharmaceutical industry, regulatory bodies and policy makers. The second related to practices in clinical settings whilst diagnosing dementia, prescribing and making decisions about long-term use of the treatments. The third force referred to the consumers, the individuals living with dementia who are taking the drugs and their families. The chapter argued that whilst the quality of life of PLWD seemed, for different reasons, relevant to all spheres, the perspectives of each were most often considered separately. This thesis highlights the relevance of bringing together all of these different perspectives to achieve a better understanding of what is a complex phenomenon. The findings showed how the concerns, understandings, expectations of PLWD and CP and the ways of talking about the benefits and usefulness of drugs can importantly differ from those of the pharmaceutical industry, policy makers or clinicians. The suggestion from this thesis is that the concerns, views and hopes of PLWD should be heard and kept at centre stage when attempts are made to calculate the costs and benefits of anti-dementia drug treatments.
8.3 METHODOLOGICAL REFLECTIONS AND LIMITATIONS OF THE STUDY

As outlined in the methodology chapter, this study has used a micro social constructionist approach to look at quality of life issues, and has drawn on relational theories of dementia that focus on the PLWD as an active agent in relationships with others. As suggested by Bartlett and O’Connor (2010:11), careful attention has been paid to the language used by me throughout the thesis. I have attempted at all stages to use words that denote a positive and equitable way of thinking.

The lens used in this thesis has been particularly useful to exploring the everyday lives and interactions of study participants. It has enabled me to give PLWD a voice and has allowed me uncover their ways of thinking, their concerns, wishes, fears, values and the meaningfulness of the things that were part of their lives. This lens was also useful in enabling me to explore how participants made sense of their dementia and what drug treatments represented for their current and future lives. It has paid attention to some macro factors such as shared understandings of being older and of living with dementia, and the type of lives that are considered acceptable for them. Nevertheless other approaches could have enriched the findings of this thesis.

For example, the citizenship framework could also have been useful in helping to guide the thesis’s conceptualization and in helping to make sense of the data. Despite having made efforts in this work to regard PLWD as part of interdependent relationships, often in this thesis, participants are presented as people in need of care and supervision. Concepts such as disease progression, disability and impairments have had a more central focus on this study than what I initially envisaged. This may be partly explained by the way the sample was recruited (a memory clinic) and by the closeness of the interview to the time the diagnosis had been disclosed to participants. In retrospect, taking the citizenship framework further could have helped me to position these people as full citizens with rights and also responsibilities rather than as part of a care relationship where the disease was more central (Barlett and O’Connor 2010). In addition, it could be argued that the micro approach used has overlooked other important macro factors that could be extremely relevant to quality of life. These include the social location of the person, ethnicity, gender, or socioeconomic positions (Hulko 2007, 2009) and organizational practices and policies (Barlett and O’Connor 2010).
LIMITATIONS OF THE STUDY
Resources including financial and timeframe constraints have impacted on and limited the scope of the study. As shown, only a small sample of PLWD and their CPs limited to one memory clinic in Ireland was recruited. Also other relevant stakeholders’ views such as clinicians, pharmaceutical industry and Alzheimer’s organizations, and the views of people who have not had the benefit of acquiring a diagnosis or been offered medications have not been considered. As mentioned earlier this was something that I have at the onset of the thesis considered, nevertheless the decision I made was to focus on the voices of PLWD and their CPs. The results of this thesis therefore pertain to a select group of people and need to be interpreted cautiously.

Another important limitation of the study lies on what some might perceive as a biased sample as the researcher had a relatively limited access to participants who showed concern or distress after disclosing diagnosis. Findings of this thesis reflect the experiences of living with dementia and quality of life of quite a privileged group of people. For instance, all participants enjoyed strong relationships with their families, had relevant social support and none had important financial issues. Findings then represent the participants’ experiences from a particular social location. It may be argued that the experiences, hopes and concerns of people living with dementia who might not enjoy the same level of family and social support, or who may have significant financial constraints may be quite different. In addition participants had been assessed in a well resourced memory clinic, had been given the opportunity to attend a feedback meeting with their families, and their diagnosis had been explained in a gentle manner by dementia trained professionals. This may not be the reality of many other PLWD in Ireland (Cahill, O’Shea and Pierce, 2012) and this may also have impacted on their views about the topics explored in this thesis. In retrospect an approach that allowed the researcher to spend more time in the memory clinic during the time of data collection and to be more closely involved in recruitment process would have been beneficial.

The very limited number of participants in the quantitative findings is another relevant limitation in the interpretation and use of these findings. Like in all qualitative studies, results from this study are not generalizable and findings must be interpreted cautiously and with due consideration given to the context where the study was developed and located within.
8.4. POLICY, PRACTICE, THEORY AND RESEARCH IMPLICATIONS

8.4.1 Policy and practice implications

The majority of PLWD involved in this thesis were well able to elaborate their views and to report in-depth on their experiences of the medication prescribed. Indeed, PLWD themselves could more readily talk about the benefits and impact of drugs on their quality of life than their relatives could do (Hutchings et al., 2010a). This is an important finding as to date, research studies have tended to rely heavily on caregivers’ views and opinions about drug treatment and not on the opinion of the people most affected by the drugs, the consumers. This has also very important implications for policy and for clinical practice. For example, the last NICE guidelines in the UK included caregivers’ opinion as an important factor to consider in the context of continuing or discontinuing the drugs. However, no reference in these guidelines was made to the experience and opinion of PLWD about the drugs. In line with the findings of Hutchings and colleagues (2010a), this thesis confirms that many PLWD with mild and moderate dementia can very cogently talk about their quality of life, the benefits of the drugs and their impact on their quality of life. This finding suggests that future guidelines might consider including the opinions of PLWD whenever possible and appropriate in the evaluation of drug benefits.

Most scholars would agree now that “patients” should be involved and participate in their medical care but PLWD are rarely included in discussions about their own care or treatment. Participants’ capacity and desire to talk about the drugs contrasted with their limited involvement in decision making at the memory clinic. This resonates with findings of previous literature (Andersen et al., 2008; Hutchings et al., 2010a and b).

Previous scholarly work has shown the low level and scope of information about drugs that is made available to PLWD and CPs (Smith et al., 2011; Andersen et al., 2008). In the light of the many complexities and ambiguities that surrounded participants’ ways of thinking about the drug they were taking, the level of trust older people tend to have in their prescribing doctors (Hall et al., 2002), and the dominant and often exclusive discourse around drugs as part of medical care, providing information to these people may not be enough. I would argue that meaningful involvement of PLWD in decision making about drug treatments that may affect their lives in different ways is desirable and

73 See chapter three, section 3.4, for further detail.
that in order to achieve this, an approach that involves more than giving accurate information may be necessary. It may require other more complex approaches that “move beyond seeing the individual person as a passive care recipient” (Barlett and O’Connor, 2010:4). For example, participants in this study were discharged from the memory clinic once they were diagnosed and prescribed medication and were essentially referred back to their GPs for follow-up and prescription renewal. Most PLWD felt their opinions and concerns about the drugs were not relevant. Yet their narratives at times reflected uncertainties, concerns and a distinct lack of knowledge about what to expect regarding the prognosis for the future.

A recommendation emerging from this thesis is that individualized services should become available to PLWD and their relatives to support them in decision making about drug treatment. Such services might provide assistance and support regarding the different important decisions about the drugs that often affect their lives (Traynor and Dewing, 2002; Rockwood et al., 2002). This type of service would elicit the opinions of PLWD who have insight and capacity and take them into account when decisions about drug treatment are being made. For example, when decisions about whether to start the drug are being made, their views should be taken into consideration. Also, when decisions about what type of available medication format (e.g. tables, solution, patches) might best suit their lifestyles and needs, or other relevant decisions about the continuation or switching of drugs, are being made, their views should be considered. This service would mean that the person’s on-going concerns, hopes and difficulties could be identified and better addressed. It could also support PLWD to participate in the on-going evaluations of drug efficacy; as this thesis has shown, PLWD may be confronted with multiple challenges when attempting to evaluate the efficacy and worthiness of taking the drugs.

In this context, the model proposed by Rockwood et al. (2002) using the Goal Attainment Scaling (GAS) to evaluate the efficacy of anti-dementia drugs in an individualised manner could be useful (see chapter three, section 3.3.3). In the GAS, PLWD and their CPs are asked to set their own goals for medication, which are then reviewed in regular check-ups with a clinician. This on-going follow-up, and the setting of treatment goals which are meaningful to the person, may be more significant to PLWD and CPs than just being provided with initial information about the drugs. Considering the usefulness demonstrated in this thesis of using quality of life as a context to better understand the
impact of drugs on people’s lives, I would argue that regular and ongoing discussions and concurrent decisions should be based on quality of life issues rather than on setting goals for medications.

Finally, I would argue that PLWD and their relatives should be allowed to choose between a range of different interventions, and if over time they are convinced that the anti-dementia drugs do not work, alternative services and interventions should be available to them. It seems, that for the sample, pharmacological and non-pharmacological interventions (such as reminiscence, cognitive stimulation therapy, aromatherapy or other alternative therapies) were poorly integrated and for the most part, the respective approaches inhabit parallel but separate worlds.

A key unresolved challenge lies in how to involve PLWD who are unaware or unsure about drug use. How best can researchers include these people in scientific studies and practice? Where people lacked insight about the anti-dementia drug use, the approach adopted by me in this thesis was to instead attempt to elicit their views about other issues, mainly about their experience of living with dementia and their perspectives on quality of life over time. This has helped to ensure that the voice of this group was heard in this study. In retrospect, whilst I made all attempts to ensure their views would be elicited, I could probably have used other strategies to further facilitate their communication. The “talking mats” for instance is a tool that has been proven to help people living with dementia to express themselves more efficiently (Murphy et al., 2010).

8.4.2. Implications for theory

Findings from this thesis also have important implications for theory. The conventional approach to investigating quality of life has been often framed in terms of causes and consequences (Taillefer et al., 2003; Trigg et al., 2007) but this approach clearly does not reflect study participants’ own ways of thinking about quality of life. It seems that an

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74 As discussed in chapter four, in this study PLWD who denied or were unsure if they were taking a medication for their memory were not asked about the drugs, this was not grounded on the validity of their accounts but in my fears of causing them any distress. The wellbeing of participants was at all times prioritized over the study needs.

75 The Talking Mats is a low-tech communication framework that has been developed at the University of Stirling (UK). It provides a method of helping people to organise their thoughts and express their views using visual symbols, a simple scale and a mat for presentation. Research has shown that Talking Mats can help people with dementia to communicate more effectively (Murphy et al., 2010).
approach rooted in the reality of their everyday lives and one looking at changes, responses to change and the acceptability of changes would be more relevant to the participants' understanding than the more traditional cause and consequences framework most often used in quantitative studies.

The findings of this thesis have demonstrated that the life course approach can be a useful perspective for looking at and gaining a better understanding of dementia, anti-dementia drug treatments and the quality of life of PLWD. As it has been illustrated through this thesis, participants found it difficult to talk about their current quality of life without placing it in the context of their overall life and how things were before and how they expected it to be at this time in their life. To my knowledge this is the first time that a life course perspective has been brought to bear on anti-dementia drugs, dementia and quality of life. This has important implications for theory as this suggests that quality of life domains *per se* are not as relevant as the life-long significance that the specific domain has to PLWD, as well as, the expectations the person has about what can be considered as good or normal. This places quality of life as part of "on-going histories" (Robertson 2013) rather than as a snapshot picture of domains. Moreover, in this thesis, there was clear indication that some areas that have been traditionally excluded from scales such as independence, sense of normalcy or stigma were significant for several participants. The findings have shown that being able to function in a way that was more in keeping with the person wishes gave the person a feeling of normalcy and of independence. This is not the first study making this claim (Droes *et al.*, 2006; Byrne-Davis *et al.* 2006) but to date these still have had little impact on the scales in use.

Quality of life frameworks and scales in dementia have rarely taken into consideration the implications of considering PLWD as social beings although in most scales, there is an acknowledgement of the positive benefits to quality of life of maintaining social relationships. As an example, in the QoL-AD scale there are items rating the PLWD relationships with his/her family, spouse and friends. But how the PLWD is treated and perceived by others, the impact of being labelled with an illness that can stigmatize and at the extreme ostracise the individual and the extent to which PLWD are afforded opportunities to act with agency have often been overlooked. Similarly, the impact of the social context on the PLWD quality of life is often reduced to measuring the adequacy and appropriateness of where the person is living, but public attitudes, stigma associated with dementia and expectations about growing older or having dementia are generally not
addressed. Overlooking such vital components to our very existence, can recast PLWD as being ultimately and solely responsible for their own quality of life (e.g. how active the person is; how well he/she functions/copes/adapts to dementia, and so on).

In summary, the findings of this thesis have important implications for theory and contribute to a more comprehensive understanding of quality of life and medication use in dementia.

8.4.2.1 Recommendations regarding the QoL-AD scale in the light of findings
Findings of this study, have confirmed the usefulness and value of using the QoL-AD scale in dementia research. However in using the scale, the study has identified some relevant shortcomings. The fact that PLWD themselves can complete the scale is a very positive aspect of this scale, nevertheless an important shortcoming is that the person is not allowed to identify the domains that are relevant to his/her life and is invited, instead, to evaluate pre-conceived domains. In addition, the domains are evaluated in terms of functioning and other aspects such as the value the domain has to the person, his/her degree of satisfaction with it, or adjustment or changes in relation to the individual’s expectations with such domain are overlooked. This is relevant as findings show that, as important as the particular domains, is the understanding of such domains on people’s ongoing life-stories and in the context in which their lives develop. In short, this shows that ratings on the scale do not take into account the person’s different interpretations and frames of reference. This could be improved using an idiographic approach to quality of life (e.g. SEIQOL\textsuperscript{76}). An idiographic approach could provide a way to gain better understanding of the meaning that the person attaches to different domains, and to take this into account in the evaluation of effects associated with disease and treatment. The main challenge remains then, on how to validate these more complex idiographic approaches to dementia, particularly in moderate and advanced stages, as research has shown that the use of such scale (SEIQOL) in dementia is limited (Coen et al., 1993).

Finally, another important shortcoming of the QoL-AD scale is that it does not address important areas of life such as independence, agency, normalcy, public attitudes and stigma, findings which this thesis and other previous studies have suggested are very significant to people living dementia (Droes \textit{et al.}, 2006; Katsuno 2005, Byrne Davis \textit{et al.} 2006; Robertson 2013). These areas fit well with current understanding of PLWD as

\textsuperscript{76} See chapter two, section 2.4.1, for further information about the SEIQOL.
active agents of their lives and as people having rights and responsibilities. The modified version of the QoL-AD (Edelman *et al.*, 2005), that was developed for looking at quality of life of people with dementia living in institutional care, incorporates some of these items (see chapter two, section 2.5.1 for further detail). This modified version of the QoL-AD scale has been validated, nevertheless, its use for community-dwelling individuals is still scarce.

In summary, findings from this thesis have shown that quality of life is a useful perspective for looking at the experiences of PLWD with medication and to the meaning and significance that taking these drugs have on the lives of PLWD. An important recommendation, in the light of the findings of this thesis is that, along with scales, qualitative approaches should be used when looking at and evaluating the efficacy and benefits of anti-dementia drugs, and the expectations and understandings of efficacy of people living with dementia and their families taken on board. This, as claimed by Barlett and O’Connor (2010:96), would replace the traditional notion of a “hierarchy of evidence”, where RCT and experimental studies are regarded as the “best source of evidence”. Instead, quantitative and qualitative approaches should be equally valued as part of a “continuum of evidence”. Also, findings from this study have helped to identify some important shortcomings of the most widely used quality of life scale in dementia (QoL-AD). Recommendations have also been forwarded on how it could be improved to be more reflective of the aspects of life that really mattered to the people living with dementia in this study.

8.4.3. Implications for research

This thesis could have been conducted in many other alternate ways in order to address the key research questions. Future research is now needed to investigate the understandings of quality of life after diagnosis and over time amongst a more diverse sample including for example PLWD not using ChEIs, or indeed a sample who were using some other psycho-social interventions.

Reflecting back over the approach taken, another relevant question is the extent to which the perspectives of CPs were necessary given the very rich and unique insights gained from most of the PLWD narratives. As the findings showed, many PLWD themselves provided very insightful and comprehensive accounts of quality of life and of medication experiences. There were, however, a few PLWD who were either not aware or could not
remember if they were using the drugs and in these cases, the views of CP supplemented the perspectives of PLWD. Also, taking into account the views of CPs helped to provide context which contributed to a better understanding of the views of PLWD. I believe that seeking out their views augmented and did not supplant the perspectives of PLWD. During all stages of the thesis I attempted to keep the perspective of the PLWD at the forefront. For example, in conducting the interviews, I always attempted to interview the PLWD first and I always analysed the PLWD interviews first and in advance of the CPs.

8.4.3.1 Scope for future research

Findings of this thesis have shown both the merits and demerits of using quantitative and qualitative approaches when investigating quality of life issues in dementia. Findings have also shown the complexities, yet the value, of exploring quality of life in the context of anti-dementia medication use. Further cross-sectional research, is now needed which would draw on larger samples of people living with dementia in order to consider the advantages of using both approaches together.

Future longitudinal research is also needed to investigate the way in which people living with dementia and their care-partners talk about the benefits of the drugs and the impact the drugs have on their quality of life. A question worth investigating, and not fully explored in this thesis, is what factors are likely to contribute to drug discontinuation and how, stopping drugs may affect quality of life of people with dementia. Findings of this thesis suggest that care-partners often perceived administering and checking compliance to the medication regime as an extra challenge and duty in caregiving. There was some preliminary indication that these challenges experienced by care-partners may play an important role in decision-making regarding the drugs continuation or discontinuation, arguably even more than experienced benefits. This, along with other potentially relevant factors contributing to drug discontinuation, should be explored in larger samples.

An important limitation of the approach that I used in this study, is that it was not possible to discern if the improvements experienced by the participants were due to the drugs or to other factors. A quantitative approach using much larger samples would have been better positioned to address and tease out what caused improvement or disimprovements. This may be also an important topic to be addressed in future research.

Finally, another interesting finding not fully explored in this study, and fruitful for future research is the question of how factors such as age and mildness of dementia and
presence or absence of a primary CP may contribute to effectiveness of the drugs or to a more positive experience of benefits.

8.5 CONCLUDING REMARKS

Dementia is a chronic and progressive illness that affects some 47,000 Irish citizens. This thesis has illustrated the ongoing debate and some of the controversies surrounding the pharmaceutical treatment of dementia. Whilst there is a significant body of evidence showing that anti-dementia drugs (cholinesterase inhibitors and memantine) may alleviate some of the negative effects of dementia on cognition, functioning and behaviour, a key unanswered question in the literature is whether these statistically significant improvements translate into clinical significance, and most importantly whether these improvements represent a meaningful change to the quality of life of people living with dementia. Despite a huge amount of research being undertaken on this topic, the views, expectations and experiences of the consumers of these drugs (people with dementia) have been rarely sought. This thesis has addressed this important gap in the literature by exploring the experiences of people living with dementia and their care-partners about living with dementia, quality of life and anti-dementia drug use.

The findings of this thesis have confirmed the usefulness of using quality of life to look at the meaningfulness of the drugs for people with dementia and their relatives. Findings showed that participants overall wanted to hold on to their current lives, and how in this context, the medication represented a hope for not progressing to what was perceived as real dementia, something considered by most as devastating. Whilst representing an important hope for these people, this thesis has shown the limited involvement and knowledge about the drugs that participants had at the time of starting to use them; most could not articulate their expectations as they did not know what was reasonable to expect. Experiences with the drug were diverse and overall positive. More than half of the sample reported benefits, and felt this had positively impacted on their quality of life. Nevertheless their quality of life improvement was also linked to other factors most notably a better acceptance of dementia. Benefits of the anti-dementia drugs and quality of life improvements were not described in terms of improved cognition or functioning, but rather as gaining a greater sense of normality, empowerment and feeling closer to what the person expected and considered a good life.
Important implications for practice and policy arise from this thesis. One important implication is the need for individualised services that can help PLWD and CPs to be meaningfully involved in decision making about drug initiation and discontinuation. Other implications relate to the use of new approaches in research that integrate both, the use of quantitative scales but also more qualitative approaches such as in-depth interviews which elicit the voices and experiences of PLWD. Finally, this thesis has provided recommendations on how to improve the most widely used quality of life scale in dementia to better address the concerns and values of PLWD and their CPs.
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Cahill, S., Gibb, M., Bruce, I., and Headon, M. (2008) “I was worried coming in because I don't really know why it was arranged”: The subjective experience of new patients and their primary caregivers attending a memory clinic. *Dementia, 7* (2), 175-187.


Traynor, V., and Dewing, J. (2002). *Drugs for Dementia*. Project Stage Two. “To identify user and carer-defined outcomes that can be used to evaluate the effectiveness of drugs for dementia”. Alzheimer’s Society and RCN Gerontological Nursing Programme, RCN Institute.


APPENDIX A: QUALITY OF LIFE

LITERATURE SEARCH STRATEGY

In chapter two, three different but interrelated bodies of literature were considered: firstly literature which focuses on the concept quality of life generally, secondly, literature which focuses on quality of life as it pertains to older people and thirdly, literature which focuses on quality of life in the context of dementia.

The decision to include literature about quality of life in older people was motivated by two observations: firstly, whilst not all people living with dementia are old, the expectation was that most participants in the current study would be aged over 60 years. Secondly the literature on older people has informed much of the work on quality of life for people with dementia. For example, most scales in dementia have drawn on Lawton’s seminal work on quality of life in older people. Nevertheless, it has to be noted that the literature in this area is extensive, and that only an introductory summary of some relevant studies in the area are provided.

The main focus of the search is on the quality of life of older people living with dementia. The scope of the search was limited to people with mild or moderate dementia living in the community, as I expected this would reflect the profile of the participants in the study. I believed that the concerns and understandings about quality of life for people with dementia in long-term care would differ substantially from those living at home. Abstracts of articles that exclusively related to advanced dementia or to quality of life in long-term care or quality of care were reviewed only in a few exceptional cases.

The literature search on quality of life for PLWD was undertaken using the following strategies:

1. A literature search of electronic databases: Pubmed, Medline, the Cumulative Index to Nursing and Allied Health Literature (CINHAL), PsychINFO, JSTOR and Cochrane databases. Search terms included free text words and combinations of the following terms: quality of life, health related quality of life, wellbeing, dementia, Alzheimer’s disease, cognitive impairment, measurement, scale, qualitative, phenomenology, social constructionism, determinants, factors, improvement, longitudinal.
2. A review of indexes to theses written on the topic of quality of life and dementia.

3. Hand-searching through bibliographies of key articles and books.

4. Books authored or edited by well known academics with expertise in dementia and/or quality of life were also reviewed.

5. Online hand search of relevant Journals: Dementia, Aging and Mental Health, Ageing and Society, Quality of Life Research, Health and Quality of Life Outcomes.

6. Focused search on Google Scholar of each of the dementia specific scales and of potential studies using phenomenology or social constructionist approaches.
What is this study about?

My name is Ana Diaz, I am a Social Worker and I am currently doing a PhD in Trinity College Dublin under the Supervision of Dr. Suzanne Cahill. The main purpose of this study is to learn more about the quality of life of people with memory problems and about their opinions and experiences of using (name of drug).

What will my participation in this Study means?

- If you agree to take participate in the study I will be interviewing you twice. The first interview will be close to the time when you start using this medication and the second interview will be six months later. Each interview will last about 1-2 hours.

- In the first interview I will asked you to talk about your quality of life, in other words what is important to you and what make you feel happy at the moment about, and about your views on the use of the medication and what, if anything, you expect from using this medication. After this, I will ask
you to complete two short questionnaires, one will be about your memory and another about your quality of life.

- In the second interview (in six month time), we will be talking about your experience using this medication and how do you feel this medication is affecting your life and the things that are important to you. Your will be also asked to complete the quality of life tests

- There are no right or wrong answers; what is important for this study is your personal opinion and experience.

- Finally, with your permission I will ask the Senior Social Worker in the Memory Clinic in St. James’s Hospital to access some data (your diagnosis and your score in a memory test you completed as part of your assessment in the Clinic) contained in your medical file and he will disclose this information to me

**Do I have to take part in this Study?**

Your decision to partake in this Study is entirely voluntary and you do not have to take part. If you decide not to participate in the Study your decision will not affect your medical care or treatment in MIRA, St James in any way. If you choose to participate in this Study you are free to stop the interview at any time, or to decide that you do not want to respond a particular question without giving any reason.

**Is there any risk for me if I decide to participate?**

The interviews will not harm you in any way. If you feel tired during any of the interviews we can stop and take a break if you wish. If you choose not to answer certain questions asked then this will not be a problem.

**Are there any advantages likely to be gained from Study participation?**

There are no expected direct benefits to you for participation; however you may find the interviews to be enjoyable and pleasurable, as it will give you the
opportunity to share your experiences and opinions. By participating in this research, you may also benefit others by helping people to better understand what people with memory problems mostly expect from these drugs and how those are affecting their lives.

_How will the information be used?_

Your name will remain completely anonymous and the results of the interview will be only used for the purposes of the study. The interview will be tape-recorded with your permission, but your name or any other identifiable material will be removed and will not appear in any publication. I will not disclose the information that you may give to me during the interview to your relative, clinician or any other person without your consent.

*Please take time to consider whether you want to take part in this research or not.* If you have any questions about the study, I am very willing to discuss and explain any part of the study with you further at (number) or (mobile number).

*Many thanks in advance for your time and consideration,*

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Ana Diaz  
PhD Student  
School of Social Work and Social Policy  
Trinity College Dublin
INFORMATION SHEET - Care-partners

INFORMATION SHEET
Living with Dementia Program
School of Social Work and Social Policy
Trinity College Dublin

Research project: “An exploration of the experiences of people with memory problems and their families of using medication for their memory and of the impact that these drugs have on quality of life”

You are being invited to take part in a research study on memory problems, quality of life and the use of anti-dementia medication. The study is being conducted by Ms. Ana Diaz and is being supervised by Dr. Susanne Cahill from the Living with Dementia Program, School of Social Work and Social Policy at Trinity College Dublin (TCD). The study results will be used to write up a Ph.D. Thesis in TCD. The researcher (Ms. Ana Diaz) is a Qualified Social Worker and has a wealth of professional experience in working with older people with dementia and their families. This study has received ethical approval from Trinity College Dublin and from the St. James and AMNCH Research Ethics Committee.

What is this study about?
The main purpose of the study is to gain a better understanding of quality of life of people with memory problems and of the perceptions, expectations and experiences, they and their families have of using (name of drug).

Your opinion and those of your relative are extremely relevant to this study. In particular, I am very interested to learn about your experiences of your relative
using this medication, your hopes about the anti-dementia drug and what outcomes this medication have for your relative or for both of you. Finally I would like to know whether, in your opinion, this anti-dementia medication is having any particular effect on your relative’s quality of life.

**If you decide to participate, what your participation in this study involves?**

This is a follow-up study, meaning that you and your relative will be invited to participate in a separate interview with the researcher at two different points of time. The first interview, will take place close to the time when your relative starts using this medication and the second, 6 months after this. In each time each interview will last about 1-2 hours

a) **The interviews with YOU**

You will be interviewed about your relative’s quality of life, your views and expectations about the drug and your own views on what this medication may be important for your relative at the moment. Also, I will ask you to complete a standardized test about quality of life, and a socio-demographic questionnaire.

In the second interview, you will be asked to complete the quality of life test and I will have a conversation with you about your experiences of the drug and how in your opinion the drug is impacting upon your relative’s life.

b) **The interview with YOUR RELATIVE**

Before starting the interviews with your relative I will determine whether he/she is aware of using any medication for his/her memory by asking a few simple questions. To protect your relative well-being, if he/she is not aware of taking the medication, he/she will not be asked about the medication and only your views will be collected on this topic.
In the first interview with your relative, I will ask him/her about what is important for his/her life now, and about the use of the medication, what he/she expects from using it and why is important to him/her at the moment. After this, I will ask your relative to complete a quality of life questionnaire.

In the second interview, I will talk with your relative about his/her experience using this drug and will ask him/her how he/she believes the use of this medication have impacted on any of these things that he/she most value. He/she will be also asked to complete the quality of life questionnaire.

All the interviews will be conducted in a place of your choice and will, with your and your relative’s permission, be tape-recorded.

In addition to the interview, the researcher will need to access some of the health data contained in your relative’s hospital chart in the Memory Clinic in St. James Hospital. This data are related to your relative’s diagnosis, and his/her score in one memory test he/she completed during his/her assessment. Your permission along with your relative’s will be sought to access this information. No other data from your relative’s hospital chart will be accessed.

**Do I have to take part?**

Your decision to be in this research is completely voluntary. In addition to your consent, your relative will be informed and asked separately about his/her own participation. Your relative will be only interviewed if he/she is willing to participate. You and your relative may refuse to answer any questions and may withdraw from the study at any time for any reason. Refusal to take part in or withdrawing from this study will not affect your relative’s medical service in the Memory Clinic in St James in any way.
Is there any risk for me or my relative if I decide to participate?

The interview should not harm you or your relative in any way and will be stopped if you or your relative shows any signs of distress during the interview.

What advantages can be gained by me from Study participation?

There are no foreseeable direct benefits to you for participation; however you and your relative may find the interviews enjoyable and pleasurable, as it will give you the opportunity to share your experiences and opinions with a professionally trained Social Worker and nonjudgmental interviewer. By participating in this research, you may also help others by contributing to a better understanding what people with memory problems mostly expect from anti-dementia drugs and how those are affecting their lives.

How will the information be used?

The results of the interview will be only used for the purposes of the study and your and your relative’s name will at all times remain completely anonymous. In this context, several steps will be taken to protect your identity and anonymity. While the interviews will be tape-recorded, the tapes will be destroyed once they have been typed up. The typed interviews will not record your name, and any identifying information from the interview will be removed.

Please take time to consider whether you want to take part in this research or not. I am very willing to discuss and explain any part of the study with you further at (phone numbers) or contact me by e-mail (email).

Many thanks in advance for your time and consideration,

---------------------------------------------
Ana Diaz -PhD Student
Living with Dementia Program
School of Social Work and Social Policy
Trinity College Dublin
# APPENDIX C: QOL-AD SCALE

**QOL-AD Scale - LOGSDON ET AL. 2002**

Used in this study with permission of Dr. Logsdon

<table>
<thead>
<tr>
<th>Quality of Life: AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviewer administer according to standard instructions. Circle responses.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1. Physical health.</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Energy.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>3. Mood.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>4. Living situation.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>5. Memory.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>6. Family.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>7. Marriage.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>8. Friends.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>9. Self as a whole.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>10. Ability to do chores around the house.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>11. Ability to do things for fun.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>12. Money.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>13. Life as a whole.</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
</tbody>
</table>

Comments:__________________________________________

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APPENDIX D: INTERVIEW GUIDES

INTERVIEW GUIDE PLWD BASELINE

Before starting the interview the information sheet will be read to participants, who will be asked if they have any query about the study. Written consent and consent to record the interview will then be sought.

MEMORY PROBLEMS
- At present, do you have any concern about your memory?
- Can you tell me a bit more about your memory

QUALITY OF LIFE
- Can you tell me a little bit about yourself?
- What life is like for you at present? How do you spend your days?

Can you tell me about your quality of life at present?

Prompts
- Can you describe what the term quality of life means to you?
- How is the quality of your life at present?
- What makes your QoL (good/bad/fair)? How could your QoL be improved?
- What would make your QoL worst?
- Do you have any concern about your QoL now and in the future?
- Can you tell me how experiencing (memory problems/dementia - use same word used by person) is impacting, if in anyway, in your quality of life?

Specific Subjective Domains of QOL
Can you tell me what are the most important areas of quality of life now, the things that you feel are important for having a good life?

PROMPS FOR EACH OF THE AREAS
Could you tell me briefly about (area) at the moment?
What do you mean by (area)?
How (why) is this important to you?
Can you tell me how your (memory problems/dementia/AD) is affecting this area? Has anything changed in this area since you have memory problems/dementia?

USE OF DRUGS
- Has a specialist ever prescribed any medication to you for your memory?
- Are you taking any medication/tablets for your memory at the moment?

Can you tell me about the medication you have been recently prescribed for your memory?
Prompts

1. Tell me why do you think you have been given this medication?
2. How do you feel about taking this medication?
3. How long do you think you will be taking this medication?
4. Do you have any concern about this medication? Is there anything that worries you about taking this drug?
5. What do you expect the drug will do for you?
   - How important are these to you?
   - Why are they important to you?
6. Can you imagine any reason why you may need to stop taking this medication?
7. Can you foresee any other advantages to you of taking this medication?
8. Can you foresee any other disadvantages to you of taking this medication?

Is there anything else about your quality of life or about the use of medication that you feel has not been discussed in the interview or that you want to add?

How did you feel during the interview?
Did you feel any of the questions was too difficult to answer?
Is there any question you feel should be changed or added?
INTERVIEW GUIDE PLWD FOLLOW-UP

Summary of baseline interview and brief discussion of main conclusions and ideas discussed.

Can you tell me what has happened since we met last? Can you tell me how do you feel compared to six months ago?
Can you tell me about how your (memory problems, dementia ... use same word used in baseline interview) is now? How is life like for you now?

Can you tell me about your experience during these 6 months with the drug treatment?

Can you tell me any problems, difficulties or side effects related to the treatment?
  - Can you give me an example of this?
  - How did you deal with this? How did you feel about this?

Are you still taking the drug? If not- can you tell me what happened to decide to discontinue?
If yes, can you tell me what do you think the drug has done for you?
  - Do you think the drug has been useful in any way?
  - Do you think you have experienced any benefits?
  - Can you give me an example of this?
  - How is this important for you?
  - How do you feel about this?

Overall how do you feel about the drug treatment now?
Do you have any concern/fears in relation to the use of this medication now or in the future? (If any specific problem/concern was raised at baseline also refer to it)

Are you satisfied with the use of the drug? Can you elaborate about this?

Are you willing to continue with the drug treatment? Can you tell me why do you want to continue in the treatment?

Is there anything else about this medication that you feel has not been discussed in the interview or that you want to add?

Quality of life
Can you tell me about your quality of life at present?
We talked 6 months ago about (list domains raised at baseline) how do you feel at the moment about these areas? Is there anything else that may be important?
The first area you mentioned six months ago, was X. Is this still important for you?
  - Could you tell me briefly about X at the moment?
  - Can you tell me what has happened over these 6 months in this area?
  - Do you have any concern about X at present?

Is there anything else about your quality of life that you feel has not been discussed in the interview or that you want to add?
CARE-PARTNERS' INTERVIEW GUIDE BASELINE

Interviews refer to the PLWD quality of life and expectations of how memory drug may benefit the PLWD.

MEMORY PROBLEMS
- Can you tell me about the recent assessment and diagnosis of your relative at the memory clinic? Can you tell me in your own words what do you think is happening to your relative? How do you feel about this?

QUALITY OF LIFE
- Can you tell me a little bit about your relative?
- What life is like for him at present? How does he spend his days?

Can you tell me about your relative quality of life at present?
Prompts
- How is the quality of your relative’s life at present?
- What makes his/her QoL (good/bad/fair)? How could his QoL be improved?
- What would make his QoL worst?
- Do you have any concern about his/her QoL now and in the future?
- Can you tell me how experiencing (memory problems/ dementia – use same word used by person) is impacting, if in anyway, in his/her quality of life?

Specific Subjective Domains of QOL
Can you tell me what are the most important areas of your relative’s quality of life now, the things that you feel are important for your relative to have a good life?

PROMPS FOR EACH OF THE AREAS
Could you tell me briefly about (area) at the moment?
What do you mean by X?
How (why) is X important to him?
Can you tell me how his (memory problems/ dementia? AD) is affecting this area? Has anything changed in this area since he has memory problems/ dementia?

USE OF DRUGS
Can you tell me about the medication your relative has been recently prescribed for his memory?

Prompts
- Tell me why do you think hyour relative was given this medication?
- How do you feel about this medication? How does your relative feel about it?
- How long do you think your relative will be taking this medication?
- Do you have any concern about this medication? Is there anything that worries you about the drug?
- What do you expect the drug will do for your relative?
  o How important is (X) to him/her?
  o Why is (x) important?
- Can you imagine any reason why your relative may need to stop taking this medication?
- Can you foresee any other advantages to your relative of taking this medication?
- Can you foresee any other disadvantages to your relative of taking this medication?

Is there anything else about your relative's quality of life or about the use of medication that you feel has not been discussed in the interview or that you want to add?

How did you feel during the interview?
Did you feel any of the questions was too difficult to answer?
Is there any question you feel should be changed or added?
CARE-PARTNERS’ INTERVIEW GUIDE FOLLOW-UP

Summary of baseline interview and brief discussion of it
Can you tell me what has happened since we met last?
Can you tell me how do you think (name of PLWD) is compared to six months ago?
Can you tell me about (name of PLWD)’s (memory problems, dementia ... use same word used in baseline interview) now? How is life like for your relative now?
Can you tell me about his/her experience during these 6 months with the drug treatment?
Is your relative now taking the drug? If not taking the drug – can you tell me what has happened?
Can you tell me what do you think the drug has done for your relative?
  - Do you think the drug has been useful in any way?
  - Do you think your relative has experienced any benefits?
  - Can you give me an example of this?
  - How is this important for your relative?
Can you tell me any problems, difficulties or side effects related to the treatment?
  - Can you give me an example of this?
  - What this mean to your relative?
  - How did your relative deal with this?
Do you have any concern/fears in relation to the use of this medication now or in the future? (If any specific problem/concern was raised at baseline also refer to it)
Overall how do you feel about the drug treatment now? Are you willing to continue with the drug treatment? Can you tell me why do you want your relative to continue in the treatment?
Are you and your relative satisfied with the use of the drugs?
Is there anything else about this medication that you feel has not been discussed in the interview or that you want to add?

Quality of life
Can you tell me about the quality of life of your relative at present?
We talked 6 months ago about (list domains raised at baseline) how do you feel at the moment about these areas? Is there anything else that may be important for your relative now?
The first area you mentioned six months ago, was X. Is this still important for your relative?
  - Could you tell me briefly about X at the moment?
  - Can you tell me what has happened over these 6 months in this area?
  - Do you have any concern about X at present?
Is there anything else about your relative’s quality of life that you feel has not been discussed in the interview or that you want to add?
APPENDIX E: CONSENT FORMS

PERSON LIVING WITH DEMENTIA CONSENT FORM

CONSENT FORM

Living with Dementia Program
School of Social Work and Social Policy
Trinity College Dublin

Research project: “An exploration of the experiences of people with memory problems and their families of using medication for their memory and of the impact that these drugs have on their quality of life”

Please circle yes or no as appropriate

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes</th>
<th>No</th>
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<tr>
<td>I confirm that I have read and understand the information sheet for the above study</td>
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<tr>
<td>I have had the opportunity to ask the researcher any remaining questions to my satisfaction</td>
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<td>I know enough about the study now to participate in it</td>
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<tr>
<td>I am aware that becoming involved in this study will not effect my medical care or treatments in the MIRA Memory Clinic in St James now or in the future</td>
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<tr>
<td>I understand that my name will not be associated with anything I say or do during the interview</td>
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<td>I was informed that I can refuse to answer any questions asked</td>
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<td>I understand that I can stop the interview at any stage</td>
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<tr>
<td>I was informed and I consent for the researcher to access some health information (my diagnosis, other relevant illnesses and drugs I have been prescribed for my memory) contained in my</td>
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medical file in the (name of Memory Clinic) |  
---|---
I am aware that this study is being carried out by Trinity College Dublin and that the results will be used to write up a PhD Thesis | Yes | No

|  
---|---
I understand that I will be interviewed twice (now and in 6 months time) and I consent for the researcher to contact me and/or my relative in 6 month time | Yes | No

By signing this form I consent to take part in this research.

Date: ________________  
Participant Name: ____________________ (Please print)

Participant Signature: ____________________  
Researcher Signature: __________
CARE-PARTNER'S CONSENT FORM

CONSENT FORM

Living with Dementia Program
School of Social Work and Social Policy
Trinity College Dublin

Research project: “An exploration of the experiences of people with memory problems and their families of using medication for their memory and of the impact that these drugs have on quality of life”

I have read the Information Sheet about the proposed study as detailed above to be conducted by Ana Diaz of the School of Social Work and Social Policy, Living with Dementia Program at Trinity College Dublin, under the supervision of Dr. Suzanne Cahill. I have been given a copy of the Information Letter and Consent Form, which I have now read and understand fully.

I have also had an opportunity to ask any questions relating to this study, to receive satisfactory answers to my questions, and to require additional details needed.

I understand the purpose of the study and I agree to take part in it. I also agree that my family member can participate if he/she is willing to. I understand that taking part involves answering questions in two separate interviews; the first at the beginning of the use of the anti-dementia medication and the second six months later. I am aware that the researcher will contact me again in 6 months time with the purpose of arranging the second interview with me and my relative. As well I am aware that the researcher will access some health data (i.e. clinical diagnosis, memory test score) from my relative history in MIRA Memory Clinic, St James Hospital.

I am aware that the interview with me will be audio-taped to ensure an accurate recording of my responses.

I was informed that my participation in this study is voluntary and that I may withdraw consent at any time by advising the researcher.
I am aware that the Study has been reviewed by, and has received ethics clearance through Trinity College Dublin and through the St. James and AMNCH Research Ethics Committee.

Participant Name: ________________________________ (Please print)

Participant Signature: ________________________________

Date: ________________________________
APPENDIX F: FULL TRANSCRIPT OF BASELINE INTERVIEW

INTERVIEW WITH EOIN (Participant 2)

Interviewer: These are my contact details, and a copy of the information sheet.

Eoin: That’s okay.

Interviewer: You can keep this, all I explained to you, all details about my research are in there.

Eoin: Yeah.

Interviewer: So I leave that for you here.

Eoin: Good.

Interviewer: So are you happy then to participate (Eoin: Sure) Excellent, Eoin do you have, at present, any concern about your memory?

Eoin: A little bit. Yes.

Interviewer: A little bit. Can you tell me about your memory?

Eoin: Well, at the moment, I’m depending a lot on my sister, Miriam, to look after all my money and all that kind of things, and she has been doing that now for me for a while and that’s just grand. I have no problem in there. But since then, I seem to be forgetting, not immediate things. Long term things I can remember, no problem, it’s just immediate things. And to make sure that I keep appointments I have to write everything down.

Interviewer: Okay. And how are you coping with this?

Eoin: Okay I think now.

Interviewer: What do you mean by now?

Eoin: Well, until I started getting a diary and writing things.

Interviewer: Okay. So you have your strategy here.

Eoin: Yeah, yeah, yeah. I have methods, I put notes up in the door. Like you know...shopping, what I need for shopping and things like this. I keep a diary on the door and a diary here.
Interviewer: Okay. And is that important to you?

Eoin: Well I forget appointments, just general things. It’s not... it’s actually hard to say one thing, you know. It’s just day-to-day things.

Interviewer: And have you been recently then in St. James’s in the memory clinic?

Eoin: I haven’t been there now for awhile.

Interviewer: Okay.

Eoin: It’s about six months...nine months, I’d say, since I’ve been there.

Interviewer: Okay. Okay. And what happened there?

Eoin: I just have to go down and go to the clinic and attend meetings with other people, at the patients and we would go different things.

Interviewer: Okay. What happened?

Eoin: they said it was okay for me to finish.

Interviewer: Okay.

Eoin: I did okay. And they said that they had done as much as they could.

Interviewer: Okay. So did they prescribe any medication?

Eoin: They and my own doctor, Dr. X had me on medication. They prescribed a mix of medications. Now, for medications, I don’t know. I just get my pills and I take them.

Interviewer: You take all of them?

Eoin: Yeah. My sister looks after all that.

Interviewer: Okay. Are any of these pills for your memory?

Eoin: Oh, yes.

Interviewer: Okay.

Eoin: Yes.

Interviewer: And...
Eoin: All, I think. But no, no, no, no, no, no. No, that’s wrong. Some are for vitamins.

Interviewer: Okay. And this one is specific for your memory.

Eoin: Yeah for the memory.

Interviewer: Together, they prescribed for you. Okay, excellent. So then...and my first question is quite open can...and can you tell me a little bit about yourself?

Eoin: I was born in 1946, which means I’m 64.

Interviewer: Good.

Eoin: I worked in a hotel in catering business most of my life, all of my life.

Interviewer: Okay.

Eoin: I retired about a year ago, just over a year ago.

Interviewer: You retired a year ago.

Eoin: Yeah. I took early retirement because of my memory.

Interviewer: Can you tell me a bit more about this Eoin?

Eoin: I used to be very good at doing figures and accountancy and that kind of thing, which mainly didn’t work. I used to work up in (name of place). I worked for them for about 16 or 18 years, I’m not sure. I’d say 16 years.

Interviewer: Yeah.

Eoin: And I finished there last year

Interviewer: Okay. Okay, and that was because?…

Eoin: Yeah, I wasn’t able to do my figure work as good as I used to and, you know, general ... just small things.

Interviewer: Okay. So you decided you take early retirement?

Eoin: Yeah, well the doctor... I asked him would it be okay to do it. I felt I wasn’t doing my job out there as well as I could so I asked the doctor would it be okay to take early retirement and he said yes ... I would have retired eventually, this year maybe so it was ok . That’s all. I’d have gone on retirement at 65 anyway ... (laughs)
Interviewer: Can you tell me a bit more about this, was it difficult?

Eoin: It was. Yeah, because I loved my work and I loved the company and, you know, it was my social life as well as my work life. Like, I worked always in the evening time. I usually went to work at five o’clock and come home at two or three in the morning.

Interviewer: Okay.

Eoin: So the social life was there as well.

Interviewer: And you’re still in touch with them?

Eoin: Yeah, they come and some of the staff comes down to see me. Yeah.

Interviewer: Yeah. Anything else you want to tell my about yourself?

Eoin: Well, I lived with (name of partner) for 38 years and he died two years ago. Was it two years or three years ago? So this … it just started after that.

Interviewer: Okay.

Eoin: My memory … It started after that because I noticed it about 2 or 3 years ago. This memory thing started after (name of partner) died

Interviewer: Okay. Excellent. What life is like for you at present?

Eoin: I think is grant. Is grand. I’m quite happy. As I’ve said my sister does…well we do the shopping together, she comes and we go shopping once or twice a week. And for food, she would cook some stuff. She cooks most of my meals and I may cook one or two meals. That’s all.

Interviewer: Okay. And she comes...

Eoin: She and her son, (name) my nephew, my godson as well. They come in and they check on me a couple of times a week

Interviewer: Okay. How do you feel about this?

Eoin: Oh it is ok, yeah, like my life has kind of changed, obviously yeah. It’s just I’m retired, so (laughs) - So it’s part of retiring. It’s part of getting old.

Interviewer: Okay. And how are your days now? How do you spend your days?

Eoin: My days?

Interviewer: How is a normal day for you?
Eoin: I’m very interested in doing sudokus, like crosswords. So normally I’d do
the paper...cook my meal, read the paper, watch the telly. That’s it.

Interviewer: Okay.

Eoin: I go for walks sometimes, and I go very late to bed (laughs) As I was used
to.

Interviewer: you have done this all your life, right?

Eoin: Yes, and this is very difficult to change. Thought the people in the clinic
did suggest I try and change but I can’t. Forty years is hard to change. (pause) and
ten the rest of the day I’m here. Watching telly or doing my sudokus, the
crossword. And then my dinner is at midnight.

Interviewer: Okay.

Eoin: Yeah, because I used to do that at work. I used to always eat when I came
back from work

Interviewer: Okay.

Eoin: At work, I used to eat a little bit not a lot this is how I spend my days
(pause) the telly is good company, I have it on I don’t normally watch it. It’s nice
in the background. But sometimes I watch the news if I want to know about
something. Like the mine disaster in Chile, I watched, yeah. Otherwise, no, it’s
just background, noise

Interviewer: Ok, now Eoin, we are going to talk about your quality of life. Can
you tell me about your quality of life at present?

Eoin: It is grand yeah.

Interviewer: Can you describe what the term quality of life means to you?

Eoin: For me, as long as I can exist comfortable with myself and I don’t cause
too much trouble or problems on the other person.

Interviewer: Okay.

Eoin: I’m okay.

Eoin: Would this definition have been the same some years ago?

Eoin: It is to a degree because 10 years ago I would have gone out and socialized.
But now... Then socializing may would have been important. But now, I don’t
and I don’t care.
Interviewer: Okay. Can you tell me what are the most important areas of quality of life now, the things that you feel are important for having a good life?

Eoin: For me, myself, that would be...that’s my health.

Interviewer: Your health?

Eoin: My health and my happiness.

Interviewer: What do you mean by health?

Eoin: That I am not in any pain or you know that I can walk, that I can think, that I can...well, (he laughs) on the thinking side we leave that and you know that I can do what I want to do.

Interviewer: Okay. Okay. And how do you think your health is at the moment?

Eoin: I think it is quite good except for this, my forgetfulness.

Interviewer: For the memory.

Eoin: Except for the memory it’s good. But anyway I think we are doing everything we can, we are trying new drugs we are trying everything.

Interviewer: Everything.

Eoin: My mother had suffered from this as well so it is hereditary, although hers was much worse than I was, than mine is.

Interviewer: Your mother had...

Eoin: Had this as well, yeah.

Interviewer: the memory thing?

Eoin: Yeah. Yeah.

Interviewer: Okay.

Eoin: I think she suffered from it for a couple of years.

Interviewer: Were you expecting this, then?

Eoin: I wasn’t expecting but when it came I wasn’t surprised. When they told me I wasn’t too surprised.
Interviewer: In the memory clinic in St James?

Eoin: Yeah

Interviewer: Okay.

Eoin: I was hoping not but I wasn't too surprised when they told me. And the only difficulty now is in it because I don't want to be burden on other people.

Interviewer: Okay. I see.

Eoin: And I am slightly and that I don't like it

Interviewer: Okay. Now, you said health is the first thing for you, which would be the second thing important for you?

Eoin: Happiness, I suppose.

Interviewer: Happiness.

Eoin: Yeah. Content. Which I am, quite content.

Interviewer: And how could your happiness be improved?

Eoin: If I had my memory, if I was confident, if my confidence was back, I would be grand.

Interviewer: what do you mean?

Eoin: Because of my memory, my confidence is not great. Like my confidence in cooking, my confidence in...because sometimes I cook and I fall asleep and forget.

Interviewer: Okay.

Eoin: Once it has happened where I fell asleep and burned my food.

Interviewer: And that ....

Eoin: That concerns me. It does, a bit, yeah. So that's why my sister does most of the cooking now.

Interviewer: Okay. And is there any other thing where you feel concerned or worry about?

Eoin: Well the fact that ... When I had control of my own my money, seemingly I used to lose it, I give it away and forget it
Interviewer: Okay.

Eoin: It doesn't... but, before I was totally independent now they allow me such much and I have to come from everything. I don't have full independence. That I miss a bit but it doesn't matter. (silence) My sister is there. And if I need something they get that for me.

Interviewer: So your independence is something important, is that what you mean

Eoin: Yes, very much. And also that I have my family.

Interviewer: How is your family important to you?

Eoin: They're here with me most of the time.

Interviewer: your family?

Eoin: Well, yes, that's my sister and my nephew. They're my main family.

Interviewer: Okay.

Eoin: I have a brother and I have a sister who lives in (name of city) who would phone me once a week or so.

Interviewer: Okay.

Eoin: Which is good, she used to only phone me once a year at Christmas time to get her Christmas present (laughs) So now that's an improvement, now she phones once a week And I have a brother in Canada.

Interviewer: Okay. How do you get on with him?

Eoin: Okay, yeah. But my family, the main one is my sister.

Interviewer: Miriam.

Eoin: Miriam, yup.

Interviewer: Okay.

Eoin: And Ronan.

Interviewer: Okay.

Eoin: They are my day-to-day, yeah.

Interviewer: The day-to-day.
Eoin: Yeah. Yeah. They are always there ... Yup. I could not ask for anymore.

Interviewer: What do you appreciate most from them?

Eoin: Their concern, their help, their dear, especially with Ronan. If I phone Ronan he is here, you know, like that. If there is anything wrong I just phone him and he is here. Or else I can phone him just to say hello, what are you doing, that kind of things. My sister, I only phone...well, she phones me everyday. And she's more of the cooking and my pills and all that kind of things But with Ronan is more for the chat, socializing, chats. I mean, he helps out, any thing I need he will do it. And usually we like, you know when he phones me we talk about soccer, football, you know, sports.

Interviewer: Okay. Okay. Excellent. Is there something else for you important now?

Eoin: No, well smoking, I like smoking

Interviewer: Is that a big thing for you?

Eoin: I've always smoked.

Interviewer: You always smoked. A

Eoin: All my life, yeah. I smoked about 20 to 40 a day.

Interviewer: Okay. And do you have any concern with the smoking?

Eoin: That's all I have left, so no.

Interviewer: what do you mean?

Eoin: this is the only... well that nobody tells me what to do, I can smoke when I like, as much as I like (laughs)

Interviewer: Okay. Okay. Okay. Anything from your memory having an impact on the smoking?

Eoin: Nope. No.

Interviewer: Excellent. Have your memory problem had any impact in your relationship with your family, like your sister or your godson?

Eoin: Only the fact that they have to care for me more.

Interviewer: Okay. And before
Eoin: I was totally independent.

Interviewer: Okay.

Eoin: I was totally independent. I was in touch with them but they wouldn’t be... they wouldn’t come to visit as often.

Interviewer: Okay. So that’s the change?

Eoin: That’s a change, yeah.

Interviewer: How do you feel about this?

Eoin: It bothers me, yeah. I don’t like to be a burden on them. But they are quite happy, yes. Yeah, there’s no problem.

Interviewer: And you talk to them about this

Eoin: I talk to them...sorry. I talk to them not about that, no, not about the relationship. This is a concern I have myself, but I have not talked to them about this, no

Interviewer: Okay. And is there any other person, I think you mentioned last Friday, when we first met there was someone coming to visit you?


Interviewer: Chris. Is that a friend of yours or...

Eoin: No. He was given to me by the health board.

Interviewer: Oh, okay

Eoin: And he takes me out for walks.

Interviewer: you enjoy it?

Eoin: It’s grand. It’s good. He’s a nice man and we get on well.

Interviewer: Do you have things in common?

Eoin: Not really but we’re trying. We’re trying to getting there.

Interviewer: Okay. Do you have any hobbies?

Eoin: I used to play golf and I used to... I went drinking (laughs). And well, but I don’t now, I don’t now. Outside the crossword and sudokus no.
Interviewer: When did you stop the golf?

Eoin: Oh, I suppose...I used to golf a lot when I was young man. I was good at this but I...the catering business... You don’t get time. With my work I did not have the time.

Interviewer: and now.

Eoin: I like walking, I do more walking

Interviewer: Okay. And you still go for walks everyday or...

Eoin: Two or three times a week. Two or three times a week, yeah.

Interviewer: Okay.

Eoin: At least two, sometimes three.

Interviewer: Okay. And is that kind of nearby here?

Eoin: Around here. Yeah, rounds. Different areas maybe I go this way once, that once, trying everywhere

Interviewer: Would you take the bus and go to town or something?

Eoin: No, no.

Interviewer: No. Would you feel confident to do that?

Eoin: If I had someone with me, there’d be no problem.

Interviewer: Okay, excellent.

Eoin: If I’m on my own, I might be a bit nervous.

Interviewer: Okay.

Eoin: I could do it but I’d be nervous.

Interview: You would feel nervous?

Eoin: yeah, if I don’t know it well, I may get lost. I wouldn’t like this, you know. But If I had someone with me that’s ok then

Interviewer: Okay. Eoin, overall how is the quality of your life at present?
Eoin: It I good. Between good and very good.

Interviewer: Between good and very good.

Eoin: Yeah.

Interviewer: And how was it 10 years ago?

Eoin: Good. Very good.

Interviewer: Very good.

Eoin: Well now my sister has to come and help, that is the one part that would bring it down from being very good now

Interviewer: Okay.

Eoin: Because I’m depending on her.

Interviewer: Okay.

Eoin: Depending on family. Everything has to be organized for me … It’s okay. But I don’t want to be a burden.

Interviewer: what do you mean by a burden?

Eoin: That they have to come and do meals, stuff like this. I feel I am a burden to them

Interviewer: Okay. Okay. And is she, if she has to go into a trip or something, how will you manage with that?

Eoin: Well then, Ronan will help me or someone will help. They don’t go together.

Interviewer: Oh, okay.

Eoin: Well, sometimes I go with them, sometimes I don’t.

Interviewer: And how do you foresee your future, Eoin? You ever thought about it?

Eoin: uhhh No.

Interviewer: Ok

Eoin: Since this happened I live day-to-day.
Interviewer: Okay. Which means for you living day-to-day?

Eoin: I only think of tomorrow and what I have to do.

Interviewer: Okay.

Eoin: And I write everything in my diary. Tomorrow will be tomorrow. Can't think any think further than tomorrow, you know what do I have to do tomorrow, to be able to do the things that I have to do, this is what matters now

Interviewer: Okay, excellent. Now, I want to ask you about the medication you were telling me, the one for your memory, not the others. Just the one for your memory. So as far as you know, what was happening that caused you to be given this medication?

Eoin: What's it called? I forgot the name. I forgot the disease that I have.

Interviewer: It's fine.

Eoin: I know, I can remember the name is called disease, but can remember the name of it.

Interviewer: It's fine. Can you tell me about this medication you have been prescribed for your memory?

Eoin: People in the St. James, in the clinic, they gave out a list of the properties of each tablet or what it contained and all those kind of things but I didn't really...I was nervous. I didn't really concentrate on it because my sister looks after all that. I know how to take the tablets and when to take them and all that. But they told also what's in each tablets but ... I didn't concentrate on it. No

Interviewer: Okay. I remember when I came on Friday, you were joking, "Maybe in six months I wouldn't be taking the medication."

Eoin: Right. Right. But I think I will be taking the medication.

Interviewer: Were you given any choice about taking or not taking the medication? Was there a choice or...

Eoin: No. No choice.

Interviewer: And how do you feel about taking this medication?

Eoin: I don't mind. As long it help, if it's worthwhile ... I'd give it a go and see. Yeah.
Interviewer: Okay, excellent. And how did you react when they told you this disease you have and this is the medication you have to take?

Eoin: I suspected it myself to start with ... so it was no surprise.

Interviewer: Okay. And then?

Eoin: And when they told me, I was a bit disappointed, I think. I'm trying to remember now. But it all came up gradually.

Interviewer: Okay.

Eoin: And I was part of this.

Interviewer: Okay.

Eoin: And it didn't really matter that much you know what I mean?

Interviewer: Okay. Okay.

Eoin: It was coming gradually so it was on top of me.

Interviewer: Okay.

Eoin: So it was there and I had to do with it and that was it.

Interviewer: Had you ever heard about this medication before?

Eoin: No, my mum, she had no medication. This medication is quite new, yeah.

Interviewer: What do you expect the drug will do for you?

Eoin: I think it may probably help a little bit, yeah.

Interviewer: How do you think this medication can help you?

Eoin: I don't really know

Interviewer: No. Okay.

Eoin: I have ideas but I'm guessing.

Interviewer: Okay. And what are your ideas then?

Eoin: Well, it may help my memory, to improve.

Interviewer: What do you expect for the drug?
Eoin: If it stops my memory getting any worse.

Interviewer: Okay.

Eoin: But then, how can I judge that?

Interviewer: Okay.

Eoin: You know I can’t judge that (pause) And I think it’ll be stopping rather than getting better. I don’t see getting better.

Interviewer: Okay.

Eoin: And well, I’m only going by what happened, in the past with my mother, you know. And as long as it doesn’t get any worse, I’d be quite happy.

Interviewer: Okay. Okay. So for you it would be to kind of maintaining.

Eoin: Yeah. If I stay as I am now, I’m happy, and well, I don’t know really. But it does help people.

Interviewer: Okay. Can you give me an example of how could it help?

Eoin: Well if I had the confidence, probably I’d be trying to do things again.

Interviewer: Okay. What kind of things?

Eoin: My independence, taking care of myself, of my life

Interviewer: How long have you been on the medication now Eoin?

Eoin: I’m on only a couple of months.

Interviewer: that is the one called Aricept.

Eoin: Yeah, the one I take at night.

Interviewer: And have you noticed anything since you started?

Eoin: no, not really.

Interviewer: Okay, And do you know how long would you be taking this tablet?

Eoin: I don’t know. The doctors may have told Miriam but they didn’t tell me.

Interviewer: Okay. How do you feel about this?

Eoin: I’m happy. I do what they tell me (laughs)
Interviewer: And can you imagine any reason why you might decide to stop taking the medication?

Eoin: Oh, if the doctor tells me this is the only reason. If not, I'll keep taking.

Interviewer: Okay. So whatever the doctor tells you?

Eoin: I do.

Interviewer: Excellent. And how likely do you think it is the medication will have a good effect on you?

Eoin: I can't judge that. I don't know.

Interviewer: Okay.

Eoin: You need to ask other people that.

Interviewer: Who do you think should I ask about this?

Eoin: My doctor, maybe Miriam

Interviewer: Okay. Did the doctor tell you about the benefits of taking this drug?

Eoin: I think...no, I'm not sure. They did not talk rally about benefits. I think that it only works for some people. It does not the same for every person.

Interviewer: And you know why...

Eoin: It's just too new. They don't know. It's very new

Interviewer: So do you think you will see any benefits?

Eoin: It's too early to say. I don't know. Yeah.

Interviewer: It's too early to say. Okay.

Eoin: It's only been a couple of weeks, so.

Interviewer: Do you know when this medication is supposed to be effective?

Eoin: Yeah. I suppose it is probably now. But for instance, I haven't been noticing any effect, for me to notice. I suppose it won't be my memory back but it may stop it going. As long as it stabilizes then it'd be okay.

Interviewer: And which are the main things that you will like to maintain?
Eoin: It’s just at the confidence on my memory.

Interviewer: Okay.

Eoin: I lost all confidence.

Interviewer: What does it mean for you to have the confidence back,?

Eoin: It’s just that I won’t have to write everything down, that I would be confident...

Interviewer: Okay. Does this bother you?

Eoin: It doesn’t bother me...but it bothers me the fact that I have to write it down to be sure I remember it. If I could I’d prefer not to write it down. You know ... Bang!! It’s ok and I’ll get to remember that.

Interviewer: Okay. And is there any other thing?

Eoin: Not really, no. Just not writing in the diary or need other people to remind me. You know it would be to sit down and be confident, taking care of myself

Interviewer: Okay. You were telling me before that in your quality of life health and happiness or contentment are very important to you. Will this pill help in anyway with these two things?

Eoin: It might help my confidence.

Interviewer: Okay.

Eoin: Yeah.

Interviewer: And that will be related with your happiness?

Eoin: Well, if I have confidence I’ll be happy. Yeah.

Interviewer: Okay. Okay. And would the pill, the tablet, help you with anything with your family?

Eoin: No.

Interviewer: That will be the same.

Eoin: I think nothing can help in there, it’s perfect, it’s not perfect but it’s 90% it is very good. It’s very good, so no pill could help there

Interviewer: do you have any concern or any fear about this tablet?
Eoin: I don’t … no. No, because I’m only on for a few weeks so I’m confident in them.

Interviewer: Okay.

Eoin: I had no fear of taking it. There’s no harm.

Interviewer: Did the doctor mention any side effects?

Eoin: Well, I’m afraid it might have some side effect, all right, but that’s… I am not worry I don’t know, they spoke more to Miriam about that than to me.

Interviewer: Okay. Do you know roughly how much the tablets costs?

Eoin: I haven’t a clue. I have the medical card.

Interviewer: The medical card, all right.

Eoin: Yes.

Interviewer: And if you have to pay for them?

Eoin: You need to talk to Miriam. I don’t know.

Interviewer: Okay. Would you… like I said, I’m thinking like if you have the money and you have to pay for them, I think they are 100 euros or I don’t know how much or something like it, would you pay for them?

Eoin: well if it helps, yes.

Interviewer: Okay. What do you mean by if it helps?

Eoin: To start with, of course I would, to see if they were any good.

Interviewer: Okay.

Eoin: If I had been on them for six months and I found no improvements, then I might stop.

Interviewer: And by improvement, you mean?

Eoin: If I could not … if I could not see any help from my memory or whatever.

Interviewer: Okay. So what do you think in six month’s time you’ll be telling me?
Eoin: That I am as good as I am now. I will be very happy if by six months I am like I am now. That I’m not getting any worse because I said I remember my mother that she got worse and worse and worse.

Interviewer: Okay, which is your main concern with getting worst?

Eoin: That I will be a handicap for my sister and I don’t want

Interviewer: Okay. I see.

Eoin: I don’t want to give burden on them. Touch wood, it will stay as it is. Now is just forgetting a few things, is not bad. And I’m lucky that like everything like the fire, the place is safe … my fire is electric. It’s guarded so I can’t do any damage there if I leave it on. Everything around me is safe, so.

Interviewer: And who did organize all this?

Eoin: I did myself.

Interviewer: You did,

Eoin: This was when I bought the place, yeah.Yup. I didn’t know this was happening then. But then now I am happy I did it this way, I did it really because at the time when I worked at night and I come home at two in the morning or three in the morning. I couldn’t be safe in a fire. I just wanted the fire to plug in.

Interviewer: Okay.

Eoin: And sit down at, you know. It was a great time then…

Interviewer: You mean your work?

Eoin: Yes, my work …

Interviewer: How was it?

Eoin: Oh, it was everything, it was my life. I loved it

Interviewer: Okay. And how is retirement, besides your memory problem, how was retirement for you?

Eoin: A bit lost at time.

Interviewer: Okay.

Eoin: No things to do. Of course I’m happy now it was at the start

Interviewer: Was it more difficult at the beginning
Eoin: Yeah, yeah, yeah.

Interviewer: How did you cope with that at the beginning?

Eoin: I don’t really know to be quite honest. It just happened and I had to and that was it. Now, I don’t mind, yup. And that was time ago now

Interviewer: Okay. Okay. And have you seen this, the positive side of being retired?

Eoin: Oh, yeah. Yeah, I am happy to be retired. I am happy not going and working up to 3 or 4 in the morning; driving up and down … Although I could nearly do it in my sleep.

Interviewer: If in any friend of yours would be prescribed this medication, would you recommend this tablet to them?

Eoin: I think so, yes. I’d warn them about the side effects, which I didn’t suffer from, okay, first. And then I would say, “Well, try it because, you know.” It may do some good.

Interviewer: Have you told…apart from your sister and your godson, have told any other person about your disease and the tablets?

Eoin: No.

Interviewer: No.

Eoin: No.

Interviewer: No. I mean, have you for example ever talked to Chris him about this?

Eoin: I haven’t talked to him about it but I’m sure he knows from the health board. I presume he was told before he came out.

So this was the end of the main interview. And now, if you’re okay, we can complete the tests.

Eoin: Yeah.

Interviewer: It may take a couple, like another five or 10 minutes.

Eoin: That’s okay.

Interviewer: So first is just a yes or no question, okay?
Eoin: Okay.

Interviewer: Are you satisfied with your life?

Eoin: Yes.

Interviewer: Yes. Do you feel that your life is empty? It’s yes or no.

Eoin: No I suppose. No.

Interviewer: Are you afraid that something bad is going to happen to you?

Eoin: No.

Interviewer: No. Do you feel happy most of the time?

Eoin: Yes.

Interviewer: Yes. Okay. Then, you can say now poor, fair, good or excellent. I want to ask about, how do you feel over the last weeks your physical health has been? Poor, fair, good or excellent.

Eoin: Okay.

Interviewer: That’s fair or good?

Eoin: Good.

Interviewer: Good. And your energy?

Eoin: Fair.

Interviewer: Fair.

Eoin: No, it’s good. Good.

Interviewer: Your mood?

Eoin: Fair to good. It’s good.

Interviewer: Good. Your living situation?

Eoin: Grand.

Interviewer: That means excellent?

Interviewer: Your memory? Poor, fair, good, excellent.

Eoin: Good, I think.

Interviewer: Good.

Eoin: Put a question mark...Just in case.

Interviewer: Your family...

Eoin: I suffer from memory, so why are you asking me about memory?

Interviewer: You never...I mean, you can really take things for granted with these things.

Eoin: It is Okay, fair

Interviewer: Your family?

Eoin: Excellent, yeah.

Interviewer: And your friends?

Eoin: Don’t have any so I don’t know.

Interviewer: Would you consider Chris as a friend?

Eoin: Good question. He’s a friend once he comes in here.

Interviewer: Okay.

Eoin: But I don’t think he would come in if he didn’t have to come. But there’s one girl from work that comes to visit me regularly from there.

Interviewer: Okay. But is she a friend then?

Eoin: Oh, yeah.

Interviewer: So your relationship with her would you say it is Poor, fair, good, excellent

Eoin: It’s good. She comes and tells me about other people in work

Interviewer: ok, do you visit her too?

Eoin: No. Well my sister took my car so I have no car.

Interviewer: Okay. Can you tell me a bit more about this Eoin
Eoin: Well I was finished with it, I didn’t need it everyday.

Interviewer: Okay.

Eoin: It was just lying there. So she needed the car to go to work so I gave it to her.

Interviewer: And this was?

Eoin: My sister in Howth, (name)

Interviewer: And when did that happen?

Eoin: As soon as I retired.

Interviewer: Okay. And how did you feel about it?

Eoin: I wasn’t happy, no. It happened too quick because I told her that it would be okay for her to take the car but I thought it may take two or three weeks, not the same day. She took it as I finished work, bang, gone (pause) Look if I had the car, I wouldn’t be driving everyday, no but maybe maybe once a month. I don’t know. I wouldn’t go out to journeys if I had the car, if you know what I mean.

Interviewer: Okay, you miss it?

Eoin: Not really, no. It’s just it is back there (points his head) If I had the car I probably would never drive, but the fact is that I don’t have my car. It’s needed there... she needs it. And if I need to go up ... somewhere I can ask my godson to drive me.

Interviewer: Okay.

Eoin: But I was supposed to be going up to (place where he used to work). I’ve asked him last week would it be ok if we go to say hello to everyone. Yeah. So hopefully we will be going sometime, haven’t fixed a date yet.

Interviewer: Okay, we are back to the test now, “Your self as a whole” do you think thing is poor, fair, good or excellent.

Eoin: Fair.

Interviewer: Fair. Why fair?

Eoin: Because no matter how good things are, you want them to be better.

Interviewer: Okay. And how could you be better?
Eoin: I don’t know (laughs)

Interviewer: Okay. Your ability to do chores around the house.

Eoin: Chores. Okay.

Interviewer: Okay, is that poor, fair, good or excellent?

Eoin: Fair. Like I do some of the laundry, some of the cooking, some of the washing up and cleaning. Like the maintenance, daily maintenance and stuff like that. And then the cleaning lady, she comes every week and does the clean, the good clean that kind of thing.

Interviewer: Okay. And how would you rate your ability to do things for fun? Poor, fair, good or excellent?

Eoin: That’s...no, I don’t know because I haven’t done anything for fun for a long time.

Interviewer: I see

Eoin: Well, I suppose to my crossword and my sudokus that’s for fun, that’s a fun.

Interviewer: Okay.

Eoin: So it’s good.

Interviewer: It’s good. What does fun mean for you?

Eoin: (laughs) I don’t know. Going for a couple of drinks, having a chat.

Interviewer: Okay. And you haven’t been...you have mentioned before, you haven’t been for a drink ...

Eoin: Years, yeah. Over a year.

Interviewer: What happened?

Eoin: The doctor just stopped it, because the tables he suggested I gave up to drink, it can interfere with the medicine. So I decided to give it up.

Interviewer: How do you feel about this?

Eoin: Well I suppose I still could pop in the pub and have a...soft drink.

Interviewer: Okay.
Eoin: But not like I used to.

Interviewer: And this is not fun.

Eoin: No. Having a Coke and everyone looking at you... what's wrong with this fella there ...

Interviewer: And what does this mean to your life?

Eoin: When I was working... yeah I used to have a drink. In the Pub... here. Just next door, locally

Interviewer: The next door. And you haven't been there?

Eoin: I haven't been there for a year. Once or twice, but not...

Interviewer: Not often.

Eoin: Yeah. When someone comes to visit, I go there. At the beginning I found it hard. Now, I don't mind. It was hard because ... socially more than anything. You know, because socially, I'm very quiet.

Interviewer: Okay.

Eoin: Unless I have a drink. And when I drink, I can talk easier.

Interviewer: Okay. So it's kind of...

Eoin: Yeah, loosens... it loosens my tongue (laughs). But then now, no I don't get involved as much now as I used to

Interviewer: you mean?

Eoin: I don't meet people as much as I used to, I am here most of the time so I don't need it.

Interviewer: Then the next thing is money. Poor, fair, good or excellent?

Eoin: What, ... money?

Interviewer: Yeah.

Eoin: Good, I suppose. Good.

Interviewer: Good. And then the last one is, how would you rate your life as a whole, and that is poor, fair, good or excellent?
Eoin: Good, I suppose, yeah. I can't say it is very good because I'm afraid that I can't remember something... an appointment, I am afraid that I can't, you know... this is holding me back a little bit

Interviewer: Eoin, this was the last question of the test. Now is there anything you want to talk in relation to your quality of life or to the medication?

Eoin: No, I don't think we missed anything important.

Interviewer: Okay.

Eoin: No I don't think you missed anything important, I just trying to think if is there something else that you could add ... If it is, it'd be petty, so no, I don't think so... I think you covered everything. I can't see anything else, ok?

Interviewer: Now before finishing. I would like to hear about how being in this interview, how did you feel during this interview. So how did you feel about responding to my questions?

Eoin: Before you came I was a little nervous.

Interviewer: Okay.

Eoin: Just a little.

Interviewer: Okay.

Eoin: During, no problem.

Interviewer: What were you expecting then?

Eoin: I didn't know. It just worried me a little bit. That you could ask something that I did not know, that I could not reply

Interviewer: Ok But then, once we started ...

Eoin: There's no problem.

Interviewer: There was no problem.

Eoin: Yeah.

Interviewer: Did you feel, like, some of the questions were too intimate?

Eoin: No.

Interviewer: No.
Eoin: I was grand, no problem. No problem there at all.

Interviewer: You were fine. And how did you feel about talking about your memory?

Eoin: I didn’t mind.

Interviewer: And how did you find talking about and the things that are important to you, about the quality of your life?

Eoin: No problem.

Interviewer: No problem. Excellent. And did you find any of the questions difficult to respond?

Eoin: Generally, I didn’t find it hard to respond. To put into words, yes

Interviewer: Okay. How did you find the tests? Were any of them difficult?

Eoin: To be accurate, yes.

Interviewer: Okay.

Eoin: You know what I mean, I didn’t find it hard to answer question, but to be exact, yes.

Interviewer: Okay. Okay. Did you feel uncomfortable by answering?

Eoin: No, no, no.

Interviewer: No. Do you have any suggestion for the next interview?

Eoin: No. you are asking a dumb person (laughs)

Interviewer: Or is there anything you think I’m missing

Eoin: No, I don’t think we missed anything important.

I spent another 15 minutes with Eoin, and we engaged in a social conversation
APPENDIX G: EXAMPLE OF OPEN CODING

EXTRACT FROM BASELINE INTERVIEW WITH PAUL (PARTICIPANT 3, PLWD). Open coding in brackets, black

Interviewer: Paul, at present, do you have any concern about your memory?

Interviewee: Do I have...?

Interviewer: Any concern about your memory at present?

Interviewee: Oh yes. It...it is annoying me (impact of memory)...it is...I hate it (feelings about dementia)

Interviewer: Can you tell me a bit more about your memory, why do you find it annoying?

Interviewee: Because, I can't ... No. I looked at the paper this morning and I cannot tell you the day or the date (example of experienced cognitive problem)

Interviewer: Okay.

Interviewee: It's terrible, yes it is very annoying (impact of dementia, feelings). Really it is.

Interviewer: When did it start?

Interviewee: When did it start? Well over ... it is going now for a good number of years (locating the illness, when dementia started)

Interviewer: Okay.

Interviewee: Yes. I am on some type of tablets for it too... (taking medication)

Interviewer: To help your memory?

Interviewee: Yes. But they don't (evaluating the efficacy of drugs). Of course, I could be worse ("I could be worse" in vivo coding) if I did not take the tablet (uncertainty, unknown scenario)

Interviewer: What do you mean you could be worse?

Interviewee: It could be well...I do remember my name and (wife)'s name and the children's names... (remaining skills, things that are important to him) But you know.... it could be worse I suppose. Couldn't it? (Uncertainty, unknown scenario)

Interviewer: Okay.

Interviewee: Yeah! Yeah! Because there are things that I do remember (remaining skills, relative impact of dementia)

Interviewer: Can you tell me a bit more about these things that you do remember?

Interviewee: That is a good question. Oh. Yeah! I would remember where I live, (orientation, remaining skills that are relevant to him) of course if I went down for the paper, I'd no problem coming back (orientating in familiar places, remaining skills that are relevant to daily life) because I am used to it (value of routines, coping). You know...
Interviewer: Okay, and is that something important to you?

Interviewee: Yes! Exactly! Because I go down every morning... for the paper, and I would not be happy if I could not do that (relevance of remaining skills for quality of life). I like going down every morning (things he enjoys, quality of life). And I am sure it...I am sure it could be worse (in vivo coding) I can remember my name you know... (remember name) but I did look at the paper and I saw... I saw the date. I cannot tell you now the date or the day (orientation in time, examples of cognitive problems).

Interviewer: And is that important for you?

Interviewee: It annoys me. (Feelings) It does, it has an effect you know (feelings about dementia, dementia matters to me) it is terribly annoying (feeling annoyed) because if somebody asked me (how social life is affected by dementia) if I had to give the date I'd have to look at the paper for the day and the date (Coping with cognitive problems). Like today, I think it might be Tuesday but I might could be wrong (uncertainty, impact of dementia in life) and I did see the date perhaps I got the paper and I saw I am honest I still... cannot remember (examples of experienced problems). That sort of thing you know, and people's names now (examples of experienced problems). Are you Ana?

Interviewer: Yes.

Interviewee: Because I saw it just there a while ago (pointing the information sheet) I will forget Anna now the name (example of cognitive problem) but I would remember the face. The name would be out (can't remember names). I would remember like I am looking at you now. I would remember you... but not the name Ana no... (cognitive problems and social life) And it annoys me (feelings about dementia) But you know, I am so used to it now (in vivo coding) and (wife name) might say something, she says, remember I told you something and I say now what is it? Like that but... (interaction with spouse, examples of lost skills) it can be annoying (feelings annoyed). But (name of wife) knows me now (getting used to dementia, adjusting, coping as a couple) and well it may be annoying for her I suppose as well (burden?), but she knows me and we are fine (adjusting to dementia, impact of dementia on marriage, expectations on wife).

Interviewer: And how is this affecting your life, if in any way?

Interviewee: Well, to be honest, I cannot really remember...how long I have it. (locating dementia in time) It seems it's certainly not getting better (evaluating the progression of dementia) and I am on tablets (evaluating the memory medication). But it could be worse (in vivo code) if I did not take the memory tablets (usefulness of medication, uncertainty, resignation).

Interviewer: Okay.

Interviewee: The tables...kind of give me some hope... (medication as hope) that is right, that I won't get much worst (expectations, severe, real dementia) Yes. But it can be very annoying (feeling annoyed) as you can imagine that.

Relevant themes observed in the open coding

- Understandings of dementia, examples of cognitive problems, and coping with problems.
- Impact of dementia on daily life, marriage and social life (faces but not names).
- Mixed feelings about dementia – it is terrible, annoying but I am still coping well because: I can still do things that are important to me and my wife understands what is happening to me.
- The future "It could be worse", severe dementia – not remembering the name of wife or of significant people, not being able to do things that are important to him.
- Uncertainty about medication, unknown scenario. Medication and hope, not progressing.

In vivo codes "It/I could be worse"; "I am so used to it now".