

Positioning Human Rights of Older People in Long-term Care in Ireland- a Foucauldian Critical Discourse Analysis

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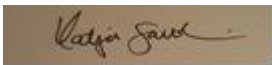
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Summary

Background:

Human rights have been positioned as basic principles which apply to everyone. However, there are frequent reports of human rights breaches when older people access long-term care (LTC), with heightened debate during the COVID-19 pandemic. Fundamental rights, such as liberty, security, dignity, and autonomy, are impacted when older people enter LTC facilities (Cahill, 2018), and because of the intensified vulnerability of older people in this setting, they may face isolation and discrimination. When age-related issues in society become increasingly prominent, addressing them should be a priority. While various scandals and Health Information and Quality Authority (HIQA) reports have identified concerns, there is scant research which explores the concept and experience of human rights in LTC. Consequently, this study provides a unique understanding and illuminates the context of the human rights of older people in the LTC in Ireland using Foucauldian critical discourse analysis (FCDA).

Aims and Objectives:

The aims of the study are:

- To examine how residents, family members, and staff discursively construct older people's human rights in long-term care.
- To investigate knowledge of and language used by residents, family members and staff in relation to human rights of older people in long-term care in Ireland.

The objectives of the study are:

- To use an archaeological approach to examine the history of the present in relation to older people's human rights in long-term care.
- To identify how the human rights of older people in long-term care are facilitated, constrained, limited, or illuminated within discourse formations.
- To present the discourse and power-knowledge nexus to recognise differences in views and attitudes of older people's human rights between various participant groups.
- To make recommendations based on the findings of the study.

Methodological Approach:

Using FCDA, this study applied a qualitative design using semi-structured interviews with older people (residents), family members, and staff at four LTC facilities in Ireland. Ethical approval was granted by the Health Science Faculty Ethics Committee of Trinity College Dublin. Data were collected through individual semi-structured interviews (n=37) and a focus group (n=6). All interviews were audio-recorded, and transcription was undertaken by the researcher. Transcribed interview data and reflection notes were analysed using a 6-step FCDA framework developed by psychologist Carla Willig (2013).

Findings:

Forty-three individuals participated in the study: 17 older people, 11 family members, and 15 staff members. The findings demonstrated that the discursive positioning of human rights of older people in LTC in Ireland was based on three main discourses: protection, conditional rights, and governance. Discourses that emerged were interlinked and driven by ageism and paternalistic practices. In these practices, the decision-making of the older person was often limited, and for the older person, the human rights are limited or restricted. Power lies within the institution and is mediated by staff, which impacts the (non) ability of older people in LTC to claim their rights.

Conclusions:

FCDA provided a unique way to investigate the intricacies of power-knowledge-discourse about how the human rights of older people were positioned in the LTC. Older people in LTC are positioned as 'others' (othering) (Rohleder in Teo, 2014), constituting a marginalised group that has lost their voice. A proxy voice was provided by family members who positioned themselves as advocates. Despite poor knowledge of human rights among staff, they unknowingly play an influential role in shaping the discourse surrounding human rights of older people in LTC. Through their daily interactions and decision-making processes, staff wield disciplinary power and are an extension of the governmentality apparatus. This disciplinary power, as analysed through the Foucauldian framework, underscores the extent to which they can shape knowledge production in this context.

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“To deny people their human rights is to challenge their very humanity”

-Nelson Mandela

Abbreviations

ADI	Alzheimer's Disease International
ADMA	Assisted Decision Making Act (2015)
AdoN	Assistant Director of Nursing
CNM	Clinical Nurse Manager
CoE	Council of Europe
CRPD	Convention on the Rights of Persons with Disabilities
DoH	Department of Health (Ireland)
DoN	Director of Nursing
DSS	Decision Support Services
ECHR	European Convention of Human Rights
ENNHRI	European Network of National Human Rights Institutions
ESRI	Economic and Social Research Institute
EU	European Union
FCDA	Foucauldian Critical Discourse Analysis
FREDA	Fairness Respect Equality Dignity Autonomy
GDS	Geriatric Depression Scale
GP	General Practitioner
HCA	HealthCare Assistant
HCW	Healthcare worker
HIQA	Health Information and Quality Authority
HPSC	Health Protection and Surveillance Centre
HRBA	Human Rights Based Approach
HSE	Health Service Executive
IHREC	Irish Human Rights and Equality Commission
INPEA	International network for the prevention of elder abuse
IPC	Infection Prevention and Control
LTC	Long-term care
LTCFs	Long-term care facilities
MIPAA	Madrid International Plan of Action on Ageing

MMSE	Mini-Mental State Examination
NGO	Non-Government Organisation
NHI	Nursing Homes Ireland
NICPOP	National Integrated Care Programme for Older Persons
NPHE	National Public Health Emergency Team
OECD	Organisation for Economic Cooperation and Development
OEWGA	Open Ended Working Group on Ageing
OT	Occupational Therapist
PCC	Person centred care
PIC	Person in Charge
PPE	Personal Protective Equipment
QQI	Quality and Qualifications Ireland
UN	United Nations
UNCHR	Universal Declaration of Human Rights
WHO	World Health Organization

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CHAPTER ONE

Introduction

1.1 Introduction

Human rights represent a forceful paradigm underpinning arguments and topics related to individuals' inequalities and restrictions on freedom in many areas of society. Since the Universal Declaration of Human Rights (UNCHR) (UN, 1948), there has been an increased focus on societies' responsibilities concerning broad civil and political issues. While rights are not a new social phenomenon (Phelan & Rickard-Clarke in Phelan, 2020), the articulation of the UNCHR (1948) was prompted by the atrocities that occurred during the two World Wars and represented the first universal commitment to the self-determination and individuality of human beings (Moyn, 2010). Despite this focus since the mid-twentieth century, the rights of one group, older people, have generally received scant attention. Yet, in more recent discourses and reflecting an ageing population, both globally and in Ireland, this is slowly changing (Saha, 2022). As the United Nations (UN, 2023) predicts that in the year 2050, people over 60 years old will outnumber children the world over, Western societies, such as Ireland, are progressively concerned with ensuring the dignity and well-being of older people. While this has been a welcome advance, there is limited focus on human rights in long-term care (LTC) settings. However, instances of elder abuse, cases of neglect, and inadequacies in healthcare have raised challenges regarding how to safeguard the fundamental rights of older people, particularly in LTC facilities. Moreover, these concerns have become more acute during the COVID-19 pandemic (Anand et al., 2022; Ayalon et al., 2020).

This study focuses on the human rights of older people in LTC in Ireland using Foucauldian Critical Discourse Analysis (FCDA). Studying human rights of older people in LTC is crucial as it delves into an increasingly significant societal issue and critically examines how the language of rights related to older people is constructed within this setting. This introductory chapter introduces the topic by providing a brief background, motivation for the study, theoretical framework, and reasoning behind why the FCDA approach was introduced early as a lens to critically analyse the literature as well as the method to guide data analysis.

1.2 Background

There is an agreed upon universal social acceptance that human rights apply to all people. However, there are continuous reports of human rights breaches in different contexts in Western societies (Moyn, 2018), including when older people access LTC. Fundamental rights, such as liberty (freedom), security, dignity, and autonomy, are impacted when older people enter LTC facilities (Cahill, 2018), and because of the intensified vulnerability of older people in residential facilities, they may face isolation and discrimination. When age-related issues in society become progressively more prominent, addressing these issues and promoting the human rights of older people should constitute a societal priority. Consequently, there is a heightened demand for a specific UN Convention on Older People's Rights (INPEA, 2010). Despite this demand, international discussions have yet to reach a consensus. Regardless of whether a new convention is needed, there has been increased recognition of the need for advocacy for and action on the human rights of older people, with an emphasis on transparency and autonomy both internationally and in Ireland (Sage Advocacy, 2023a). This lobby stems from the realisation that while human rights apply to everyone, negative attitudes and regular discrimination towards older people (ageism) occur in contemporary society (Doron & Apter, 2010). Deeply rooted ageism may marginalise rights when allocating resources and collecting data that influence health policies (Macnicol, 2010).

While human rights related to older people has garnered increasing attention (Browne, 2016; INPEA et al., 2010; Martin et al., 2015), there is scant focus in relation to the context of LTC. There have been some related publications which consider the application of a human rights framework (ENNHRI, 2017) or develop a conceptual model (Ibrahim et al., 2020), however, the intersectionality of data from older residents, staff and families is absent. Acknowledging this gap in knowledge, this PhD study provides empirical findings that can be used in the discussion of the human rights of older people in LTC.

1.2.1 Researcher's own background

Motivation to conduct research to obtain a PhD stem from a personal incentive into an area of research that has defined my nursing career. My own journey in LTC for older people was an important motivation for conducting this study. Prior to completing my bachelor's degree in nursing in Sweden in 2006, I worked as a healthcare assistant at a large LTC facility for older people. While working in this setting, I was allocated to a dementia unit where my own

personal drive and enthusiasm was to provide good care to the most vulnerable in society, while not jeopardise their individual integrity.

Since qualifying as a nurse with a bachelor degree at Karolinska Institute, Stockholm, I have continued to work within the LTC for older people and this continued when I moved to Ireland in 2008. Through my various positions, I observed changes in standards and regulations, such as Health and Information Quality Authority (HIQA, 2016) related to the LTC of older people in Ireland. Moreover, these standards and regulations have been an important driver in the quality of care provided and part of my own drive to be a healthcare professional in care delivery in a way that encompasses rights and self-determination. I obtained my MSc in gerontological nursing from Trinity College Dublin, School of Nursing and Midwifery in 2016 with a thesis titled 'Nurses' experiences of advance care planning in long-term care'. Another driving force behind the motivation to conduct this research is my own experience of relatives' writing living wills (in Nordic countries), which successfully demonstrated how such documents provide agency to the older person.

Although standards have improved, my own experience with the older person's choice, decision-making, and rights is that these standards have not always been translated into practice. This has fuelled my interest in researching the rights of those living in LTC in Ireland, and this interest has led to the research questions. Professional experience and progression have seen many changes in practice in both Ireland and Sweden, reinforcing the belief that self-determination and empowerment of older adults are key to providing quality care and are crucial responsibilities of healthcare professionals.

1.3 Theoretical framework

Broadly explained, I am interested in how older people (residents), staff, and family members understand and experience human rights in LTC facilities. In investigating this understanding and experience through an analysis of language, my focus is on the qualitative paradigm. Because language constructs ideas, and ideas impact behaviour, early on, my focus was on discourse analysis. Therefore, at an early stage in this thesis, it is important to understand the epistemological framework that will be used in every aspect of the thesis. The methodological approach I have taken for this thesis is underpinned by the epistemological assumptions of knowledge creation and guided by the phenomena investigated in a rational analytical method (Denzin & Lincoln, 2011).

When considering the philosophical and theoretical framework for the research questions and the aim of the study, the emphasis was on the knowledge socially constructed by residents, staff, and family members regarding the rights of older people in the LTC in Ireland. Exploring that knowledge and reviewing philosophical and methodological approaches led me to Michel Foucault's discourse analysis approach (Foucault, 1972). Discourse analysis is research into language and the use of language, whether written, spoken, vocal, or expressed in other forms (Hall in Wetherell et al., 2008). While there are many traditions within discourse analysis, such as critical discourse analysis and discursive psychology, discourse analysis is used as an umbrella term (Morgan, 2010). The goal of discourse analysis is to create an understanding of the language used to enact identities and activities. Compared to phenomenology, where the goal is to describe the lived phenomenon, or grounded theory, where the goal is to create an explanatory theory for social behaviour, discourse is suited to the study's aim and research question as it aims to critically describe what is shared by participants regarding the rights of older people in LTC in Ireland (Starks & Brown Trinidad, 2007).

1.3.1 Research questions, aim and objectives

There are official guidelines for positioning the human rights of older people (HIQA, 2019; WHO, 2015a), but as the following chapters will reveal, the experience of rights of older people in LTC is not known, explored, or generally discussed sufficiently in Ireland. Moreover, this study emphasises knowledge and 'taken for granted truths' regarding what is known about the rights of older people in LTC in Ireland. The study aims are:

- To examine how residents, family members, and staff discursively construct older people's human rights in long-term care.
- To investigate knowledge of and language used by residents, family members and staff in relation to human rights of older people in long-term care in Ireland.

The following research questions were then developed:

- How are the human rights of older people in long-term care discursively constructed by residents, family members, and staff in Ireland?
- How are these discourses used by residents, family members and staff in long-term care in Ireland?
- What enablers or constraints are present in the relationships between the discourses constructed and power-knowledge and how have these been socially constructed? What are the consequences of such constructions?

The objectives of the study are:

- To use an archaeological approach to examine the history of the present in relation to older people's human rights in long-term care.
- To identify how the human rights of older people in long-term care are facilitated, constrained, limited, or illuminated within discourse formations.
- To present the discourse and power-knowledge nexus to recognise differences in views and attitudes of older people's human rights between various participant groups.
- To make recommendations based on the findings of the study.

Research questions, aims, and objectives reflect the theoretical framework in which knowledge production is at its core. As this study takes a critical approach to the discourse analysis, the core in epistemology and methodology was the work of Michel Foucault.

1.3.2 Michel Foucault and Critical Discourse Analysis

Michel Foucault's discourse analysis argued that it is in the everyday speaking, thinking, and behaviour that we reflect the formation of discourse (Alèx & Hammarström, 2008; Foucault, 1972). Foucault's methodology is better understood when explained in the context that it was initially presented. Michel Foucault (1924-1984), was a French historian and philosopher who worked and studied poststructuralism. Poststructuralists argue that meaning is not a predetermined element; instead, it is contingent on various social, historical, and linguistic factors (Khan & MacEachen, 2021). This approach emphasises the importance of considering both the concept and its surrounding context, which include a system of knowledge that generates the concept (Choat, 2010). Furthermore, poststructuralism is closely related to phenomenology and stems from fundamental philosophical questions such as the notion that meaning is derived from the subject's perception (Danaher et al., 2000; Harcourt, 2007). Foucault's research and work emerged in the 1960s and the 1970s, and he remained an active researcher until his death in 1984. Considered one of the great modern philosophers, Foucault admitted being inspired by Nietzsche's ideas and influenced by the work of Heidegger, one of the founding fathers of phenomenology (O'Farrell, 2005; Sluga in Gutting, 2005). Foucault's main work was within history, and as a literary critic, he analysed historical text, but the ideas Foucault produced have been widely used, particularly within social policy, media studies, psychology, and healthcare research (Gutting, 2005). Part of Foucault's philosophical thinking was the rejection of labels and categories attributed to his thinking, and therefore, he refused to categorise his theory in a certain discipline (Raffnsøe et al., 2016).

Foucault's (1970) discourse analysis offered a way of examining how the world is socially constructed, but importantly, also takes a postmodern approach, which critically examines power relationships, rejecting the meta-narratives of taken for granted 'truths'. Two of

Foucault's primary methodological tools were used in this study: archaeology and genealogy (Foucault, 1972, 1977, 1978). Archaeology offers a way to examine how taken-for-granted assumptions constitute a system of conceptual possibilities that underpin the generation of knowledge within a given topic and timeframe. Therefore, it is a critical epistemological approach, using historiography, to trace the knowledge of the human rights of older people in the LTC. Using Foucault's approach means that philosophical endeavours commence at the point of the literature on the topic. Accordingly, to explain the literature and explore relevant concepts for this study, chapter two presents the premises of Foucault's archaeology which guided the literature review. Archeology is concerned with the history of the present and the contributing discourses. The literature review is presented in chapters three–five. Genealogy, Foucault's second methodological tool, underpins the examination of the study data, which focuses on the microphysics of power, and will be further explained in chapter six as part of the research design as it underpins the data analysis phase of this study.

1.3.3 Reflexivity

The study followed a deep personal passion, and it was impossible to create precise divisions between my academic activity, preferred theories, and professional and personal life. This study is the result of those blurred lines or fractured subjectivities (Peckover et al., 2009; Phelan, 2010) between the different divisions, and does have an impact on the reasons why the study was conducted. Being self-critical and maintaining the process of internal dialogue are significant in conducting a study of this magnitude. This has made reflexivity part of the research process from my early engagement with the topic. Following quote from Berger (2015) encapsulates how reflexivity is part of this thesis.

The worldview and background of the researcher affects the way in which he or she constructs the world, uses language, poses questions, and chooses the lens for filtering the information gathered from participants and making meaning of it, and thus may shape the findings and conclusions of the study. (Berger, 2015, p. 220)

Reflexivity is a fundamental aspect that permeates the entire research process, and it is crucial to describe the steps taken in this thesis with transparency (Olmos-Vega et al., 2023). For instance, when discussing the sample selection criteria in the methods section, it was important to provide a rationale that is not only based on the research aim but also on the researcher's positionality. Constant reflection on the researcher's bias is crucial throughout the study, and reflexivity provided an active opportunity to acknowledge the bias. Reflexivity

impacts all aspects of the research process, including the theoretical and philosophical framework used to analyse data (Palaganas et al., 2017).

My role as a nurse within the LTC sector for older people and my experiences provided me with knowledge in the study area before conducting the study. Alèx and Hammarström (2008) pointed out that for knowledge creation, reflexivity is key to being cognisant of the knowledge process. Buetow (2019) warns that experienced nurses may want research to provide the result that they have experienced and believe strong reflexivity progress brings alertness to one's own unconscious bias. All aspects of my own person require awareness in this research process: professional qualification (nurse), political and social belief systems, my immigration status (being non-Irish), sexual orientation, linguistic tradition (English is not my native language), and my own emotional response, not only to the participants' interviews but also to the overall emotional well-being throughout my PhD journey. Throughout the chapters, reflexivity is referred to, particularly in chapters Seven, Eight and Nine (findings). Chapter Ten (discussion) includes a detailed account of my own experiences during the PhD progress and how these experiences may have impacted the study. Therefore, it is crucial to be aware of the researcher's stance on using reflexivity as part of the methodological framework.

1.4 COVID-19 pandemic

Detailing the path of COVID-19 pandemic is important as it impacted the context of participants' discourses as well as the data collection phase of the study. On the 11th of March 2020 the World Health Organisation (WHO, 2020a) declared COVID-19 (SARS-CoV-2) a public health emergency of international concern. COVID-19 impacted countries worldwide, not only within healthcare, but also had social, economic, and general impacts in most societies. In Ireland, the 1st case of COVID-19 was detected on 29th of February and by the end of March 2020, cases had been confirmed in all counties (HSE-HSPC, 2022). The Department of Health in Ireland established the National Public Health Emergency Team (NPHE) for COVID-19 in January 2020, in response to the newly discovered SARS-CoV-2 virus in Wuhan, China (DoH, 2020). NPHE would have a central role in Ireland's COVID-19 pandemic response by managing the health sector and its response to the pandemic. Their role was to provide guidance, direction, and recommendations on how to prevent the spread of the virus. The team acted as the main public health advisory team to the Department of Health in Ireland (DoH, 2020). NPHE was dismantled in February 2022, when most COVID-19 restrictions in the public were gone (Lehane, 2022).

One of the NPHET's first main recommendations in March 2020 was the closure of schools and colleges, childcare facilities, cultural venues, and restrictions on gatherings which ultimately led to the cancellation of scheduled St. Patrick's Day parades later that month. Further heightened restrictions were announced at the end of March 2020, when the then Taoiseach, Leo Varadkar TD announced a strict 'Stay at Home' order (DoH, 2020). This order included the closure of all non-essential retail stores, and movement was limited to exercise within a 2 km radius or for essential shopping. Only those considered essential workers, such as healthcare workers, were permitted to move beyond these limits. These measures remained in place until May, 2020. The first wave of the COVID-19 pandemic was managed by a prolonged national lockdown in Ireland, which was one of the longest in Europe (Kelly et al., 2022; OECD, 2020a). The second wave in Ireland occurred in October 2020, followed by the third in January and February 2021. By now the deployment of a national vaccination programme was in place, with the priority of residents and staff in LTC facilities (Kelly et al., 2022). A range of restrictions, from visiting restrictions and restricted movement to strict infection prevention and control (IPC), including isolation, immediately impacted LTC facilities. Undoubtedly, older people are more susceptible to viruses such as SARS-COV-2 and protection measures were fundamental to public health guidance (HSPC, 2020). The COVID-19 pandemic became the main priority for LTC facilities both in Ireland and globally. In the beginning of May 2023, the WHO (2023) declared COVID-19 over as a public health emergency, but was cautionary about how the virus would continue to impact health as part of seasonal respiratory illness. By 30th April 2023, nearly seven million people worldwide had died of COVID-19 (WHO, 2023).

In Ireland, by January 2024, there have been a total of 1,725,026 confirmed cases of Covid-19 and 9358 deaths from or with the disease in the Republic of Ireland, with older people aged 65 and over accounting for almost 90 percent of those deaths (DoH, 2024; HSPC, 2024). This study did not seek to explore the COVID-19 pandemic; however undoubtedly, public health restrictions and the overall impact of COVID-19 on not only older people in LTC but also on study progression were significant. The personal journey of completing a PhD at the Trinity College Dublin School of Nursing and Midwifery started in March 2020 and coincided with the first public health restrictions as part of the COVID-19 strategy in Ireland. This led to a range of events, both on a personal level and on the PhD journey that requires consideration. This is reflected upon as well as included in each literature chapter, and there is a section on how the COVID-19 pandemic affected not only the study but also older people, LTC facilities in

Ireland, and the human rights of older people. Interviews took place from November 2021 to November 2022, and the topic of COVID-19 was often brought up prior to asking questions about the pandemic. Therefore, COVID-19 is part of the study context and cannot be ignored because of its significance in the LTC sector during the past four years.

1.5 Structure of the thesis

This thesis is structured according to how FCDA impacts both knowledge production and subject positions through the power-knowledge nexus in the discourse on the human rights of older people in LTC. Although researchers (Dewey, 2020; Petersen, 2012; Powell, 2009) have pointed out that Foucault himself did not present a set approach. This thesis is divided into eleven chapters. To understand the aims and research questions of the study, this chapter presents the background of the study as well as the researcher's motivation for conducting the study. It then explains why the theoretical framework of discourse analysis was selected. The second chapter considers the first methodological tool of Michel Foucault (1972), archaeology, which is used through a review of the literature in Chapters Three to Five. The literature review focuses separately on three areas of discourse: older people, LTC, and the human rights of older people. Chapter Six continues the methodological description by explaining how Foucault's (1977) second tool of genealogy is used, and provides the practical steps used in conducting the data collection phase with residents, family members, and staff. Chapters Seven to Nine present the findings, with Chapter Seven describing subject positioning. Chapter Eight details the findings in relation to understanding the discourse of human rights, and Chapter Nine introduces the dominant discourses found in relation to the human rights of older people in the LTC. Chapter Ten discusses the discourses and their implications in practice, as well as returning to reflect, using reflexivity, on overall PhD progress. The final Chapter Eleven, derives conclusions, identifies strengths and limitations, and articulates recommendations for policy and practice, including what would be beneficial for future research in the area.

CHAPTER TWO

Archaeology

2.1 Introduction

Within the theoretical framework of Foucauldian Critical Discourse Analysis (FCDA), two main tools have been developed; archaeology and genealogy. Archaeology is the study of human activity through historical materials. As it concerns itself with knowledge production, it is used as a lens to interrogate the literature on the concepts of older people (Chapter Three), long-term care (LTC) in Ireland (Chapter Four) and human rights of older people (Chapter Five). This chapter presents Foucault's epistemological assumptions related to knowledge production and the methodological tool of Foucault's archaeology (Foucault, 1972). Foucault's (1977) second methodological tool, genealogy, is presented in Chapter Six, as it is concerned with analysis of the data extracted from the interviews. Foucault (1972) developed archaeology as a way of tracing the history of the present and genealogy followed, which deepened the analysis of taken for granted 'truths' by introducing power-knowledge relationship.

By choosing FCDA there is a requirement to introduce the theory early on as analysis starts with archaeological review of the literature. In the production of ideas as part of discourses, Foucault (1972) focused on how society created these ideas and presented buildings blocks to be used as a methodology in positioning of discourses. The main discourse in this study is the rights of older people in LTC, and to examine the discourse around this, there is a need to look at each concept (older people, LTC and human rights of older people), separately. The literature review provides relevant discourses in how we understand each concept, while the study data provides a deeper understanding of the rights of older people in LTC, putting archaeology to work through genealogy (Fox, 1998). Figure 1 illustrate the two stages; archaeology and genealogy of FCDA analysis.

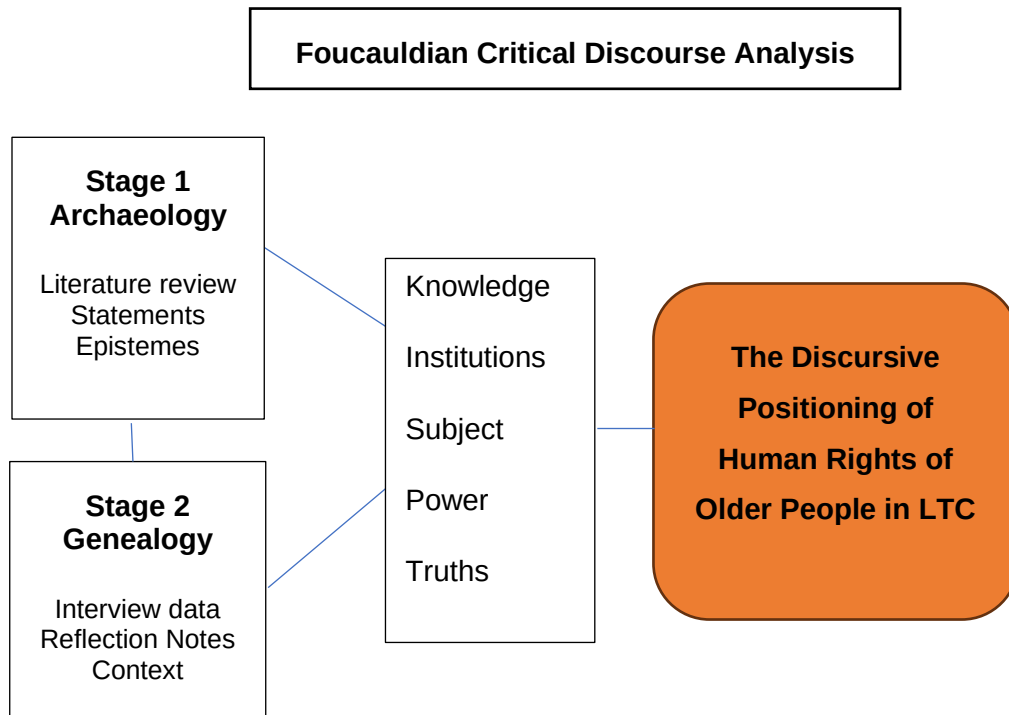


Figure 1: FCDA two stages of analysis

Combining FCDA tools of archaeology and genealogy offers a robust approach to understanding how knowledge and power are constructed, maintained, and transformed over time. Archaeology involves a methodological approach to studying the history of the present. (Garland, 2014). It aims to uncover the rules and structures that govern the production of knowledge in specific periods without focusing on the intentions of individuals or continuity. Genealogy, on the other hand, focuses on the contingencies by tracing the emergence and transformation of power relations and practices (Foucault, 1978; Oksala, 2008).

By combining archaeology and genealogy in FCDA, the strengths of both methods underpin an understanding of the complex interplay of knowledge and power. These methodological tools are integrated by first using archaeological methods to map out the discourse formations and epistemes of a particular period (O'Farrell, 2005). This provides a structured understanding of the rules and limits of discourse. This is then followed with a genealogical analysis to trace the trajectories of these discourses, uncovering the power relations, conflicts, and contingencies that have shaped their development (Foucault, 1972; 1978; 1986; Oksala, 2008).

The FCDA takes a sceptical approach to knowledge generation; it opposes the neutral generation of 'what we know to be true' and engages in a deeper analysis than individual subjects by revealing systems of thought and knowledge that individual subjects may not be aware of (Evans et al., 2022). This is what creates the critical part of the analysis. FCDA can show how the rights of older people in LTC are shaped by processes that affect those rights, while the analysis questions the basis of the consideration that it is a functioning discourse (Foucault, 1978; Springer & Clinton, 2015). Using Foucault's tools in this study demands the awareness that there is more than one discourse operating regarding the rights of older people, yet there is a dominant powerful discourse that becomes the uncontested 'truth' (Foucault, 1972; Oksala, 2008).

Archaeological analysis tools such as knowledge production, statements, epistemes, institutions and subjects are described to provide the foundation for the literature review in chapters three to five.

2.2 Archaeology of Knowledge

Presented in detail in Foucault's (1972) *Archaeology of Knowledge*, archaeology is a process of working through various statements and texts to disclose the discourse formations that construct knowledge within society (Foucault, 1970, 1972). In his two previous books, *Madness and Civilization* (1965) and *The Order of Things* (1970), Foucault introduced the theory behind discourse formations. Yet, he continued to develop and deepen the methodological use of his tools, even after the publication of *Archaeology of Knowledge* (1972). Subsequently, this constant development makes Foucault's theoretical framework behind the formation of the discourse complex (Garrity, 2010). The classical view of archaeology is to pay attention to the discontinuities between cultural formations, creating a historiography in which the aim is to assign a cultural item-traditionally a building, a statue, or object-to the age to which it belongs (O'Farrell, 2005). This involves working out a periodisation of the past, and Foucault follows the traditional view of archaeology so far that he divided the past into distinct periods, all of which had their own intellectual order referred to as epistemes (Foucault, 1972), which are defined further in the chapter. However, archaeological terminology can be misleading, as traditional archaeology assigns a cultural item to the age to which it belongs. This is where the use of the term archaeology can be confusing, as it differs from the traditional view. Although Foucault studied history from an archaeological perspective, his methodological tools refer to the classification and archive way

of examining a concept (O'Farrell, 2005). Consequently, the description of knowledge emergence is non-teleological; that is, it does not represent progress wherein one set of knowledge is inherently better than previous forms, but simply looks at the production of knowledge within the episteme. The formation of discourses at a certain point in history reflects events that have produced knowledge of that society in time.

Archaeology can be referred to as a mapping process, by which one digs and searches for a specific concept to uncover hidden 'truths' (Foucault, 1972). Foucault (1985) was clear that discourse creates the illusion of 'truth' however the discourse is neither true nor false, it is the product of the knowledge constructed within the episteme and powerful voices that serve to validate and sustain 'truth'. These hidden 'truths' are what form the discourse takes and the accepted knowledge it creates. Part of this archaeological method is to uncover where a discourse has emerged from, who is involved in the formation of the discourse, where and how it is applicable. The method includes where statements are in relation to each other within a discourse and all the possible connections that might exist between them. Foucault defines archaeology as detailed below.

Archaeology tries to define not the thoughts, representations, images, themes, preoccupations that are concealed or revealed in discourses; but those discourses themselves, those discourses as practices obeying certain rules. It does not treat discourse as document, as a sign of something else, as an element that ought to be transparent, but whose unfortunate opacity must often be pierced if one is to reach at last the depth of the essential in the place in which it is held in reserve; it is concerned with discourse in its own volume, as a monument. It is not an interpretative discipline: it does not seek another, better-hidden discourse. It refuses to be 'allegorical' (Foucault, 1972, p. 138-139)

Although Foucault's own research was embedded in history, the archaeological methodology used is not historical. History is a way of establishing the present but not a way of explaining the present as an emerging from the past. Foucault's methodology includes looking for contingencies instead of causes (Kendall & Wickham, 1999) which is a way of looking at history as never ending. For instance, Foucault (1984) highlighted this within the punishment system and maintained that the one contingency is the idea of imprisonment (to be punished for a crime). This has been the same for different historical times, yet, how it has been implemented has changed.

All these elements are encompassed by what Foucault (1970, 1978) called in French *dispositif*, translated to the apparatus, although Kessler (2007) argues that it is not an exact translation. Apparatus refers to a network of all (heterogeneous) elements, such as practices, institutions, and discourse. All these elements in the apparatus produce and regulate the power-knowledge nexus and subject position. This is a clear example of what the literature review in the following chapters attempts to do: by reviewing statements and establishing which elements that expressed these statements, the subject of this study (older people) in LTC (context) and their human rights (object) are delimited, designated, named, and established. The *dispositif* of Foucault (1977) is a critical element of social reality within discourse, as it determines what is considered real and taken for granted. Additionally, it influences not only what can be imagined and anticipated but also what can be hoped for and acted upon to bring about a desired outcome, making it a significant aspect in shaping our understanding and actions (Raffnsøe et al., 2016).

As Foucault moved away from discourse being solely related to language, his theoretical progression, referred to discourse as bodies of knowledge (McHoul & Grace, 2015; Morgan, 2010). Foucault (1977) states that discursive practices “are characterised by a delimitation of a field of objects, the definition of a legitimate perspective for the agent of knowledge, and the fixing of norms for the elaboration of concepts and theories” (Foucault, 1977, p. 199). Foucault (1972) maintained that thoughts set in a particular context affect actions and thinking in that context. Therefore, context is crucial and the literature review provides contemporary context for the discourse formation (Raffnsøe et al., 2016, 2018).

A fundamental principle behind the method of archaeology is the principle of order, in which Foucault (1970) acknowledges that there are any number of different ways of ordering experience and knowledge regarding a concept and that alternative orders are always possible. In the search for constructions of the discursive concepts, the search is guided by both explicit as well as implicit references (Willig, 2013). The same discursive concept can be constructed differently and create sub discourses within the discourse. Foucault’s methodological tools can be used anywhere where there is meaning. Archaeology, as a methodological framework, is to be seen as a toolbox. A set of tools that will order concepts that are relevant and to find contingencies in the crucial context. Figure 2 shows the researcher’s interpretation of archaeological literature review and demonstrates the four main elements as the tools used in the theoretical framework as proposed by Foucault (1972).

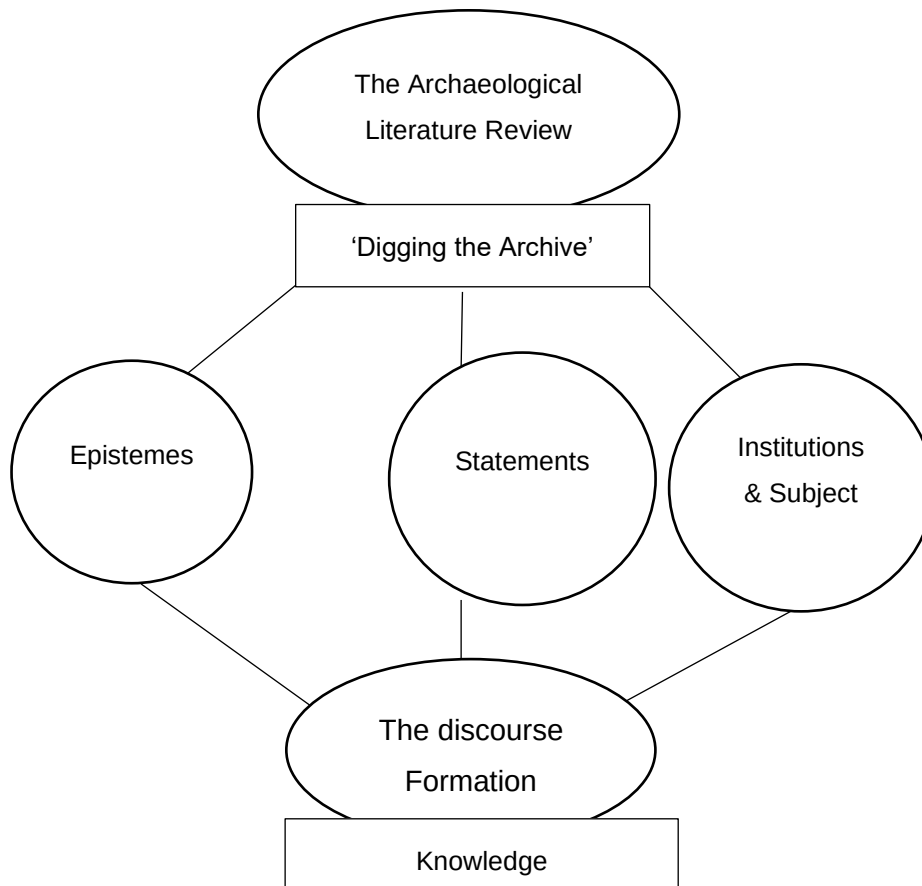


Figure 2: Researcher's interpretation of framework for conduction archaeological review

There are the four main elements that Foucault refers to and are used in the literature review in the *knowledge* production of the discourse formation of older people, LTC and human rights of older people; statements, subjects, institutions and epistemes. In searching the taken for granted truths within the history of the present related to the relevant topics, four steps guided the literature review:

- Analyse and review *statements* by classifying and ordering the statement between one statement and other statements, keeping in mind what is not said or visible compared to what is said. This classification and order are seen as the rules of the statements, how are they used.
- To highlight *subjects* that are identified in the statements and personified within the discourse. For example, for this thesis, the subject is older people, particularly the

older person in LTC. Yet, staff, family members, researcher and/or stakeholders also forms the subject in the discourse and are therefore crucial.

- To examine the *authority or institution* that constitutes the statement and knowledge of the discourse. The authority or institution also provides limitations in which the discourse exists and determines where and how discourses are acted upon.
- To highlight that a different discourse will arise at a different time, and inherent in this, *epistemes* will be revealed. That will not diminish the previous discourse but is also not a contingent of the previous discourse. A form of specification is a way of describing the relationship between epistemes and different discourses.

(Foucault, 1972; Hall in Wetherell et al., 2008; Kendall & Wickham, 1999; O'Farrell, 2005; Willig, 2013).

The archaeological method seeks to determine the discourse by answering questions such as; who is speaking/writing? From what institution is the speaker/writer pronounced? What are the connections between the statements within the discourse? All these questions are asked within the epistemic frame (Foucault, 1972; Webb, 2012). Archaeology is the methodology to understand what makes knowledge possible under the rules and orders of that episteme (Foucault, 1972). Hence, the archaeology of knowledge is formed.

2.2.1 Knowledge

Knowledge within discourse is made up of perspectives, ideas, narratives, commentaries rules, categories, laws, terms, explanations and definitions produced and applied through institutions, disciplines and authorities (Danaher et al., 2000). Particularly, disciplines were a way for Foucault to refer to the idea that certain skills as well as some knowledge is required to belong to a context (Schirato, 2013). Disciplines of healthcare, education or history were examples where some form of skills or/and some knowledge was required in order to legitimize the domain. Knowledge is composed by both the say able and the visible and different forms of knowledge exists in a society, however, Foucault (1972, 1977) argued that power relations withing the discourse determine what constitutes main knowledge (Kendall & Wickham, 1999). This power-knowledge nexus is detailed further in Chapter Six under genealogy.

Foucault (1972) focused on contingencies and how emerging discourses are not predetermined but instead contingent on historical, cultural, and social contexts. In other

words, what is considered 'true' in one context may not hold in another, yet contingencies may be robust and create dominant discourses. Therefore, FCDA allows for questioning these dominant contingent narratives that form the discourses. The focus on contingencies is significant as FCDA does not seek relations of cause and effect, which for historical researchers have been a key focus, to attribute a cause for events occurring (Mills, 2004; Oksala, 2008). The concept of contingency has a historical and philosophical approach, revealing that certain fundamental aspects of the present reality have been shaped by specific historical circumstances, but that they could also have been widely different (Koopman, 2011). Contingencies also answer questions about practice and how the apparatus (through the power-knowledge nexus) impacts the discourse (Koopman, 2011).

Foucault maintained that one of the most significant forces shaping our experiences is language and saw discourses as windows that allowed humans to make sense and see things (Foucault, 1972). However, Foucault also recognised it is much more than the language we use and different from other discourse analysis approaches, he links language to behaviour. Within Foucault's philosophical and historical thinking, he argued for a particular way of generating knowledge which integrates context (Danaher et al., 2000). To establish the knowledge production through literature review the four elements of statements, subjects, institutions and epistemes are analysed.

2.2.2 Order of statements

Statements are meant to explicate and demonstrate how and why, at a practical level, discourse performs its work across different cultural fields and times. Moreover, the statement is a point of intersection and translation: it is the place where different discourses (say from and across a group of very different fields such as medicine, sociology, economics and sport) are integrated together and rendered continuous, both in syntagmatic and paradigmatic sense (Kendall & Wickham, 1999). Discourse is never consistent of only one statement, one text, one action, or one source, as it also takes into consideration what is not said or stated. Instead, it is a system of the formation of objects, modes of statements, concepts, and strategies for a particular discourse. In other words, the archive is not as much a collection of written works as a set of rules or norms constraining what can be said or written (Danaher et al., 2000; Foucault, 1972). Following quote illustrates how statements provide an order for the discourse formation.

It can be said that the mapping of discursive formations, independently of other principles of possible unification, reveals the specific level of the statement; but it can also be said that the description of statements and of the way in which the enunciative level is organized leads to the individualization of the discursive formations. The two approaches are equally justifiable and reversible. The analysis of the statement and that of the formation are established correlatively. When the time finally comes to found a theory, it will have to define a deductive order. (Foucault, 1972, p. 116)

The archaeological focus is to examine the relationships between statements belonging to certain domains of knowledge with the limits of that field being always in question. It is not to seek the underlying meaning of statements or assess their truth, but to listen to such statements in relation to others that are purportedly about the same thing or within the same region of inquiry, creating the rules of the discourse (Foucault, 1972). Statements create an order of systems which for Foucault, relate to each other creating dominant discourses (Danaher et al., 2000). It is crucial to establish that statements take on different forms and are not seen as evolution but just knowledge at that particular time.

2.2.3 Subjects

The issue of subjects within Foucault's discourse theory was developed throughout his academic career. It is an area within theoretical thinking that continued to be developed until his death. In his book *The Subject and Power* (1982), he deepens the subject thinking in relation to discourse and linked subject with power. As a post structuralist, Foucault (1972) sees subjects as social constructions and presented multitude ways of looking at subject-object dichotomy (O'Farrell, 2005). Two distinctive meanings emerge from Foucault's (1970, 1972) thinking in relation to the subject. First, it connotes the thinking, feeling, conscious being possessing subjectivity, as is understood in philosophy and Foucault pointed out that assumptions that are still relevant today such as freedom, democracy, truth, medicine, and science can be traced all the way to Aristotle's and Plato's philosophy (Danaher et al., 2000; O'Farrell, 2005). Secondly, the subject as a person, is something directed to; "I was subject of an investigation" is an example where the 'subject' would mean the process of directing actions, thoughts and feelings (Schirato, 2013). The implication of this in the literature review is to consider the actions, words and thoughts that are constructed around the subject and how that impacts the formation of discourse. It is important to point out that in FCDA an episteme produces knowledge, not the subject. Subjects may produce texts, statements and be part of institutions, but they are operating within the limits of the episteme, the discourse

formation and regime of truth, which means that the subject is produced within the discourse. The subject is always within the discourse as it is subjected to the discourse (Hall in Wetherell, 2008).

2.2.4 Institutions

Foucault (1972) referred at times to institutions as disciplines, at times as authorities and mostly used the language of institutions to explain how a concept such as madness may be owned by institutions. His own example of what he meant with institutions comes from *Madness and Civilization* (1965), where he argued how the definition of madness may change within epistemes, but that it was contingent on the medical institution to dictate what was included in the madness discourse. Examples of institutions are medicine, psychiatry, education, and the practitioners within these disciplines. Practitioners in these institutions become 'the expert' within a distinct body of knowledge, and their final verdict is relied upon in court, medical diagnosis and in acceptance of what is madness. There is a further link with medical gaze and normalization (see Chapter Six). In the following quote from the *Archaeology of Knowledge* (Foucault, 1972) in relation to how madness discourse emerged, institutions are described.

We must also describe the authorities of delimitation: in the nineteenth century, medicine (as an institution possessing its own rules, as a group of individuals constituting the medical profession, as a body of knowledge and practice, as an authority recognized by public opinion, the law, and the government) became the major authority in society that delimited, designate, named, and established madness as an object [...]. (Foucault, 1972, p.41-42)

2.2.5 Episteme

One of the key tools to understanding Foucault archaeological work is the concept of episteme (Scott, 2017). Foucault defines the episteme as "the totality of relations that can be discovered, for a given period, between the sciences when one analyses them at a level of discursive rationalities" (Foucault, 1970, p.191). Foucault researched mainly three periods as part of his research and referred often to these three periods in time- the Renaissance, the Classical Age and the Modern Age- which he referred to as epistemes. Epistemes are periods of history in which specific worldviews and discourses are organised around. Archaeology is the process of working through the episteme to highlight the discourse formations and events that characterised that period (Foucault, 1972). Epistemes can be linked with 'truth', a set of

conditions that constitute the knowledge at that timepoint in history. Truth is also not superior authenticity; it exists with the discourse and changes with the episteme. Therefore, in FCDA the games of 'truth' and rules form the discourse (Calvert-Minor, 2010; Mills, 2004).

With the tool of episteme, there is a period established in the formation and analysis of discourses. One example is the different epistemes of human rights, as the classical ancient Greek episteme of human rights are explored but knowledge generated at that time and place suggested that human rights were only relevant for privileged males and did not include women or men of lower class (for example slaves) (Golder, 2015). Similar examples are found in context of age and LTC. Foucault (1970, 1972) also emphasised that there cannot be judgement on the knowledge produced at certain time as it is a production of that episteme (time and place). However, he did offer a significant understanding in how power and systems create knowledge and how these are related to each other (Danaher et al., 2000).

2.3 Foucauldian Critical Discourse analysis and Nursing Research

Critical theory methodologies, such as FCDA, have distinctive features that are suitable for nursing research, particularly when questioning structures around vulnerable or socially marginalised populations by identifying the elements of the apparatus (Paradis-Gagné & Pariseau-Legault, 2022). As this study is within the gerontological nursing paradigm and older people, a vulnerable population, the FCDA suits the aim of identifying the discursive positioning of rights. Foucault's critical analysis of text and language makes it relevant for nursing research, as language reflects behaviour, including that of nurses (Springer & Clinton, 2015).

Foucault has had an undeniable impact on social science research, and through his own research, he highlighted marginalised themes, such as sexuality, psychiatry, and prison services (Raffnsøe & Beaulieu, 2018). Within the field of gerontology, FCDA has gained importance through the work of social gerontologists, Jason Powell (2012) and Simon Biggs (Biggs et al., 2020). Both have explored how knowledge within gerontology is produced (Biggs & Powell, 2001; Biggs et al. 2020). Powell and Biggs research, both jointly and separately have been focused on the medical gaze to understanding the 'ageing body' (Powell, 2009), the governmentality and social policy on ageing population (Powell & Biggs, 2003) and how elder abuse is managed (Biggs & Haapala, 2013). Similarly, within nursing, FCDA has been helpful in determining how nursing discourse has formed. Springer and Clinton (2015) argued

that FCDA is an efficient tool for nurses to critically question the historical and philosophical role of nurses and their relationship with nursing. Perron et al. (2005), using FCDA, explored the role of nurses and the use of bio-power (detailed in Chapter Six) in everyday nursing by questioning nurses' professional autonomy in healthcare. Therefore, the use of FCDA in the topic of human rights in LTC facilities and within the paradigm of gerontological nursing allows for critical questioning of how the discourse has emerged and the analysis of what those discourses mean in practice.

As described by Foucault, the discourse informs the activities and shapes the practices in a set of ways within that discourse. By analysing the formation of discourse relevant to the study (old age, LTC, and rights of older people), one can determine the set of knowledge that dictates the practice in LTC. In healthcare, knowledge is fundamental, and the power-knowledge-discourse impact is overtly evident when people avail of healthcare services. As Foucault (1972) brings in unacknowledged assumptions and hidden statements (as much about what is not said as it is about what is said), his methodological framework provides an insightful analysis of knowledge by providing a robust, critical, systematic approach towards language. Using a Foucauldian approach in gerontological nursing research is an innovative way to unravel and problematise knowledge systems that are created around ageing and subjects within the discourse (Powell & Biggs, 2003).

2.4 Conclusion

The purpose of this chapter was to provide an understanding of the methodological framework of FCDA by outlining the first, archaeology, of the two-stage analysis. Chapter Two is complimentary to Chapter Six, as the FCDA, as applied in this thesis, consists of two stages: archaeology and genealogy. Archaeology is the analysis of knowledge production and literature (text), with the aim of establishing current dominant discourses by examining the history of the present. Historical analysis is not seen as a progress between different epistemes. Instead, the analysis focuses on the contingencies and strong dominant discourses that define the object of the literature review. This chapter has provided the underlying theory of archaeology on which the following three chapters' literature review is based. Using the archaeological tools of statements, order, archive, subject, epistemes, institutions, and production of knowledge, the concepts vital for this study were reviewed by analysing relevant texts. The following three chapters will provide the results of the analysis in literature in relation to old age, long-term care and human rights of older people.

CHAPTER THREE

Older people

3.1 Introduction

Chapter Two detailed the archaeological tools underpinning the analysis of literature, which comprises three chapters. As the study was concerned with three main discourses intersecting with the aim of the study, the literature review focuses on these discourses; older people, LTC, and human rights. This chapter presents the discourse formed in relation to older people (ageing) and provides key formations that constitute the ‘truths’ of old age- being an older person. As discussed in the previous chapter, a literature review based on FCDA has a different aim than a traditional literature review such as a narrative or systematic review. Looking at these concepts through Foucault’s (1972) archaeological tools, statements, epistemes and institutions, social and historical constructions of the discourse of older people are presented. Chapter three starts with details of how literature was searched, followed by the topics that emerged from the review.

3.2 Literature search strategy and terminology

Language and text are key in discourse analysis therefore the search for literature (text) is also a key feature in the archaeological method of tracing discourse formations. All types of empirical studies were considered. The search also included policies and procedures and position statements regarding older people and ageing with an extra focus on Irish and European context. Furthermore, sources of text included in the review are legislation, regulations and standards, books and publications (non-fictional) published in English. Table 1 summarises the search inclusion and exclusion parameters for literature review of older people.

Table 1: Inclusion and exclusion search criteria in literature review of older people

Time Frame	Although Foucauldian digging into archives would not set a limiting scope for text, the limitation on search was 2000-2024 (January).
Databases	CINAHL, PubMed, MEDLINE, Google Scholar
Language	Publication limited to English, or translated to English. This excludes text in researcher's own mother language (Swedish and Finnish).
Participants	Older people (aged >65 years).
Type of text/Publication	Peer-reviewed studies, reports from international organisations, government departments (Ireland) and reports from professional associations
Setting	Older people as a population group. Exclusion of older people in specific additional population groups for example older people in rural communities or migrant older people.
Context	Older people as a population group in society and its impact from a micro, meso and macro perspective.
Key search words (used in different combinations with BOOLEAN terms)	Older people, ageing, ageing population, history of ageing, social construction, discourse.

Databases CINAHL, MEDLINE, PubMed and Google Scholar were searched using key terms such as 'older people', 'older adults', 'ageing' and 'old age'. However, the use of one of those terms on their own, for example 'older people' generated large amount (over half a million) results which was not beneficial for the review. Therefore, the search was limited by adding search terms such as 'social construct', 'discourse', 'theories', and 'ageing population'. Appendix 1 is a flowchart of the screening process of literature. As part of the Foucauldian historical digging of the archive, a time frame on the search is not recommended, however necessary due to pragmatic reasons (2000 to January 2024). From FCDA perspective it is important to be aware of key literature beyond the time frame, for example theories that are still relevant such as the disengagement theory by Cumming and Henry (1961). From 2020 onwards, articles relating to older people and the COVID-19 pandemic emerged; this is reflected in section 3.7. A key focus in the literature review was to establish the dominant discourse formations for older people in general, which meant excluding discourse formations for older people with additional population characteristics, for example female older people or

older people from the LGBTQIA+¹ community. The main conceptions determining the discourse of older people are shown in an illustration, figure 3. Through the archaeological analysis of the literature, these main areas are identified as persistent thoughts that define the scope of ageing discourse, often in quite contradictory ways.

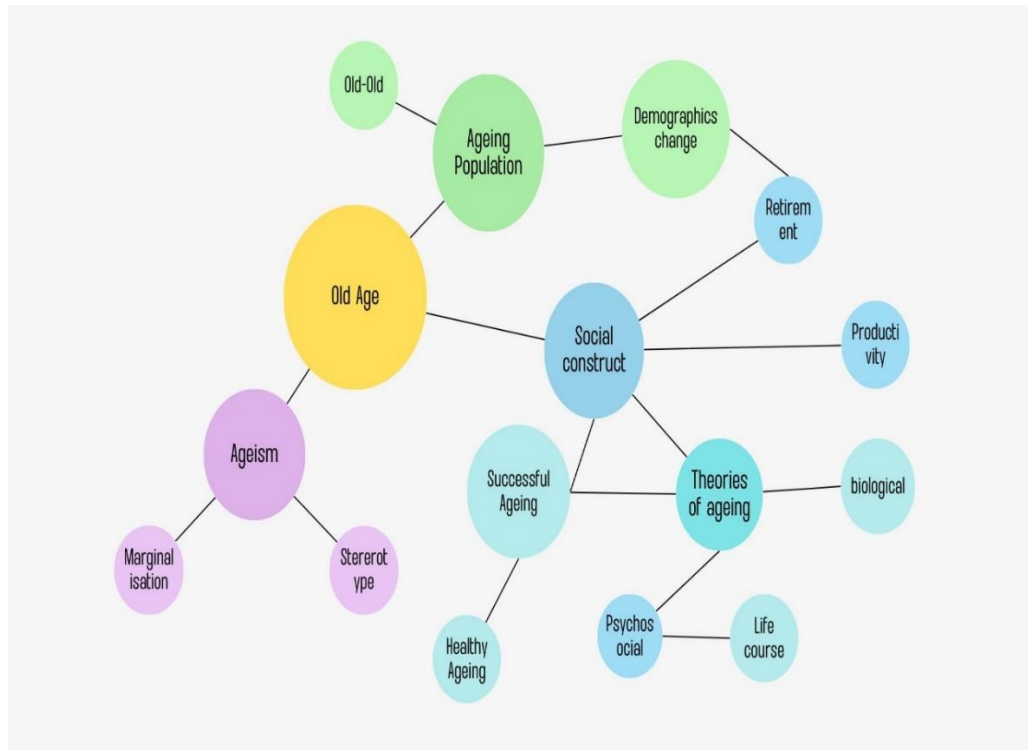


Figure 3: Illustration of headings derived from literature review of older people

By reviewing the text in the publications, the following headings have emerged; social construction of old age, the ageing population, theories in ageing and ageism. Ageism is revealed as a fundamental part of the formation of discourse of old age and examples of ageism can be found in the construction of old age, the narrative around the ageing population and in theories that attempt to define and understand ageing. This chapter considers these

¹ LGBTQIA+= lesbian, gay, bisexual, transgender, queer and/or questioning, intersex, asexual/aromantic/agender.

issues, concluding with a critical review on COVID-19 and older people, which emerged from 2020 due to the significant impact the pandemic had on the older population.

3.3 Social construction of old age

Ageing is universal, yet it is not uniform or simple. How old age is constructed is complex, however theories of old age have provided ways of understanding the ageing process (Moody & Sasser, 2020). The science concerned with ageing is gerontology and in comparison, to other scientific sciences, it is considered a fairly 'young' science and was first used in the beginning of the 20th century (Victor, 2013). Thus, ageing is not only a biological process as Gergen (2001) explains that the concept of old age is a social construction. Old age is given a particular meaning, depending upon the social and historical context. The social construction of old age occurs at all levels² in society; the macro-level (state and economy), the micro level (the individual and their relationships) and the meso-level (the organisations that operate between the micro and macro levels) (Estes et al., 2003). None of these levels are independent of each other. The construction is not only relevant at a societal level, but it affects people's view of old age and their own individual ageing. The life course is affected by decisions that are everyday in the context of resources, priorities and needs at these different levels (Estes et al., 2003). Social theories have attempted to explain and examine gerontological concepts and apply them to the social construct of ageing. It is not the single element of chronological age that will construct old age in society, but the collective structures of codes, language, words, and generic rules that will form the discourse (Green, 2017).

Although old age has existed since the wise old (men) in Ancient Greek, as a social construction, it is a relatively new phenomenon in human cognizance (Binstock et al., 2011). From the late Middle Ages until the 19th century, old age was mainly measured by life stages, such as marriage or ability to work, and not necessarily yearly anniversaries. In this episteme, old age was evidenced in the affluent upper class, those who could keep track of their birthdays and life course (Binstock et al., 2011). Among these upper-class societies, retirement and pensions were referred to usually by lining advanced age to leisure activity. For the rest of society, characterised as being in the lower classes, old age was marked by

² Throughout this thesis micro-, meso- and macro-levels will be referred to as discourses are operational at all levels.

poverty, inability to work, and the need for assistance. Accordingly, there were very few accounts of retirement at those time periods for majority of workers (Katz et al., 2004). By the end of 19th century, industrialisation had been fully integrated into society as part of employment and productivity. The focus on older employees and their contribution in organisations as well as society became more of an interest (Binstock et al., 2011).

Retirement has emerged as significant in the discourse of older people by defining older people as separate from other adult populations. Otto von Bismarck in Prussia (later Germany) is recognised as introducing the first national pension programme in a country. In 1881, Bismarck launched a mandatory pension programme for those over the age 65 (Fenge & Scheubel, 2017). The launch of pensions was a contingency motivated by attaining workers' loyalty as the attraction of socialism gained momentum. This was a crude form of social support and the initial creation of the welfare state. Crucial to understanding the context is that the average life expectancy in the world in year 1900 was 31 years of age; in Europe, it was slightly higher at 47 years of age (EuroStat, 2020). As aspirational as the national pension system implemented by Bismarck was, it only benefited a few; often wealthy and upper-class employees such as public servants (Fenge & Scheubel, 2017). However, the idea was motivational, and the programme quickly gained popularity in countries such as Austria, Denmark, and Sweden (Binstock et al., 2011). These social security programmes, with a focus on pensions and looking after the old and ill, grew in the United Kingdom (UK) and the United States of America (USA) in the 1920s and the 1930s (Powell & Steel, 2005). Concurrently in Ireland, in 1937, Ireland's constitution was articulated and principles of safeguarding and looking after those who are 'infirm' and 'aged' were included, referring to them as weaker sections of the community (Bunreacht na hEireann 1937; 45.4.1). Pensions and retirement have continued to have an important meaning in societies' understanding of old age as a major part of the social protection system (Phillips et al., 2010). This development has been important in the discourses of old age as it defined old age by productivity, that is, how valuable a person is in terms of their productivity within a society and if not productive, classed as 'infirm'. These formations in the discourses of older people are significant, and due to their dominance (Powell & Steel, 2005), they have had an impact on the construction of old age, both in Ireland and most Western countries.

Thus, after the two World Wars, pensions became a common social protection system in most European countries and the USA. Through the systematic allocation of pensions, the concept of retirement was formed during the 20th century (Walker, 2010). In addition, retirement has

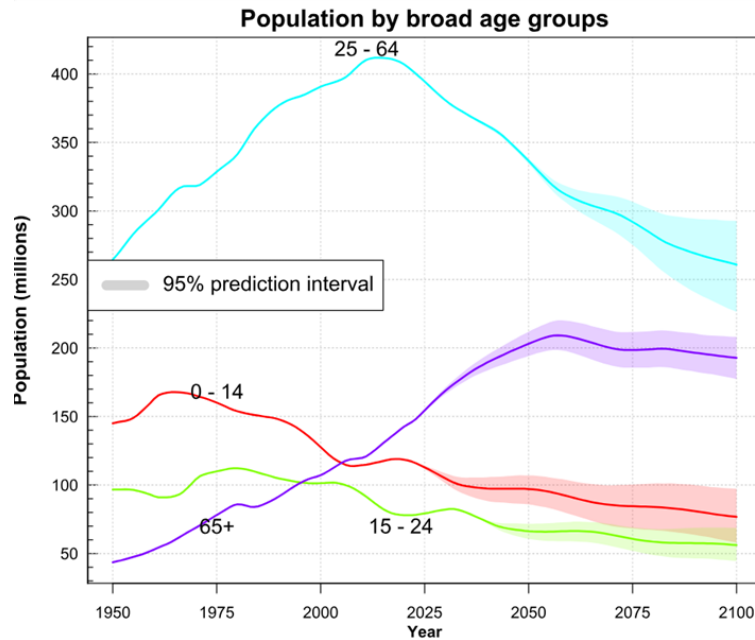
become a distinct period in the life course, and together with improvement in life expectancy, it is considered a long period of time (Phillips et al., 2010). While pensions and retirement were a reality only for the privileged few at the beginning of the 20th century, they were a common reality for the majority by the end of the 20th century in the Western world. Thus, different discourses are emerging in 21st century as the current pension systems are changing through the allocation of funding and changes in the pension age (Kasek et al., 2008). It is noticeable when reviewing the literature on ageing in the 21st century that headings such as 'who will pay' (Heller, 2003) and 'challenges of ageing' (Torp, 2015) are common reflections of a pension system that is not equipped for meeting needs due to aged population growth. The economic impact of ageing population growth (see the next section 3.4) has led to an increase in the pension age. Instead of discourse on ageing populations as a public health success (Beard & Bloom, 2015), they are framed as a challenge. This use of language as the ageing population grows reveals the discourse of seeing old age as a 'burden', a common reference by society as well individual older people in regard to old age (Biggs & Powell, 2001; Lueddeke, 2016; Phelan, 2018). This knowledge within the discourses of old age can be constructed as 'truths' or facts. If no competing discourses emerge (or are constrained) to create new knowledge that challenges these original ideas, these truths are assimilated as part of the social construction of old age discourse. As Foucault (1972) highlights, our everyday behaviour, including perceptions, beliefs, and fears, is formed by these constructions of old age.

3.4 The ageing population

As mentioned above, the 20th century marked significant changes in population shifts, and the terminology of ageing population emerged (Harwood et al., 2004). The 20th century saw unparalleled population growth in most industrialised countries, some more than others. For example, Japan, Italy, and Sweden saw exceptional growth from the 1950s onwards (Bengtsson and Scott, 2010). Initially, this trend was welcomed and not labelled as problematic as it coincided with economic growth (Bengtsson & Scott, 2010). Yet the demographic shift to ageing populations is a trend that has continued and continues well into the 21st century (UN, 2015). There is a distinction between individual and population ageing, and although interlinked, an ageing population has a greater societal impact which has contributed to the changes in country demographics (Moody & Sasser, 2020). An ageing population is, in social, historical, and anthropological terms, a new phenomenon that has

reshaped the demographic and socioeconomic landscapes of most countries (Bloom & Luca, 2016; Lowry, 2022).

The term ageing population is widely used and encompasses several different factors in different contexts. The most elementary explanation of an ageing population is that there are proportionally fewer younger people and more older people within the population (OECD, 2019a). Other ways of characterising the ageing population are by examining the birth rate versus death rate or by reviewing dependency ratios. Dependency ratios look at the age-population ratio of those not in the labour force compared to those in the labour force (the productive part includes those aged 15 to 64). One important dependency ratio is the old-age dependency ratio: those aged over 65 years compared with the working population 15-64 years of age (Eurostat, 2020). In Europe in 2010, there were about four people of working age (ages 15–64) for each person of retirement age and above (ages 65+); however, in 2050, the ratio is expected to be less than two to one (Eurostat, 2020). This dependency ratio is not only driven by an increase in longevity, but also by a falling fertility rate, which fundamentally alters the subsequent age structure of a population, and if sustained, leads to increasing median ages and an ageing demographic. Europe is the continent with the largest population aged 60 years or over and has the highest old-age dependency ratio (Eurostat, 2020; UN, 2023). Figure 4 illustrates this in a population graph for Europe in relation to four major age groups. As can be observed, the age group 65 years and older has already surpassed those under the age of 15 (indicated by the cross section of the two graphs aged 65+ and aged 0-14) which means that the predictions of an increasing ageing population are being realised, and not merely estimations.



World Population Prospects 2022: Europe (UN DESA, 2022)

Figure 4: Population graph for Europe by age groups from 1945 to 2100

This change in population structure contributes to the complexity in the discourse of old age, and the core statement formatting the discourse of an ageing population is statistics. The UN (2023) predicts that by 2050, the number of people aged 65 years and older will be 1.6 billion. This trend is also referred to as rapid ageing and occurs in all parts of the world, with Europe and Northern America having the highest share of older people. However, parts of Africa and Asia will experience the fastest growth in the number of older people over the next three decades (WHO, 2015b; UN, 2023). These statistical transitions have enforced the discourse of old age as a problem and a crisis that has emerged with worst-case scenarios presented as part of governmental policies (Marier, 2021). Housing and access to societal resources change when an ageing population might require different services than a younger population (senior housing, quick and efficient access to healthcare) (Vlachantoni, 2019). The ageing population has a discourse of crisis and burden, focusing on issues such as the collapse of pension schemes, exhaustion of healthcare systems, and an increased demand for long-term care. This is viewed as a destabilising current and potentially future resource, leading to raised fiscal demands within finite financial budgets (Van Dyk, 2014).

3.4.1 The 'old-old'

Life expectancy is increasing in all age groups, but there is a significant increase in people aged 85 years and older, at times referred to as old-old or the fourth age. Due to the increased longevity of older people, the categorisation of old age has shifted to reflect an extended life course. The categorisations are young-old (those aged 55-65), old (aged 65-85) and old-old (those aged 85 and over) (Escourrou et al., 2022). The older age group (85 years and over) is growing at a faster pace than any other age segment of the European Union's (EU) population and is projected to more than double by 2080 (Eurostat, 2020). The UN (2015) states that in 2070, Europe will continue to have the highest old-age dependency ratio, mainly because of the increase in those who are considered old-old (UN, 2023). For some countries, such as Italy and Sweden, the estimated survival improvements in the old-old category will be a major factor in continuing ageing population trends (UN, 2023).

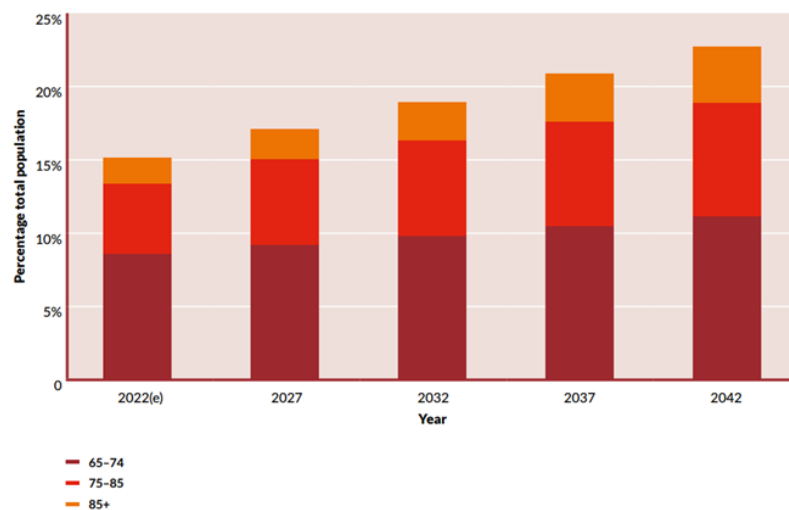
The population is living longer and healthier, and even as this is seen as a success in public health (Bloom et al., 2015), it continues to have implications at a societal level, particularly in governmental policies. One of the solutions to the changing dependency ratios (such as the number of people working compared to those who are not) is the increasing cutoff of retirement age (Axelrad & Mahoney, 2017), reinforcing retirement as a strong contingency in the ageing discourse. State pension ages are rising in many countries, and the majority of European countries plan to review their retirement age as part of their social security policies (OECD, 2023). Included in one of the many European countries that will increase pension age is Ireland, where in 2028 the pension age will increase to 68 years of age; currently, the pension age is 66 years of age (Department of Finance, 2021). The increased pension age is a consequence of an ageing population, where political discourse is concerned with the increasing burden on pension systems, resulting in legislative change. This is an example of how the episteme has changed, from pensions and retirement as a motivational financial goal from the beginning of the 20th century to causing social and financial problems in the 21st century. Although some resistance against this legislative change is visible, for example, widespread protests were seen in France in 2023 when the government planned to raise the retirement age from 62 to 64 (Crowley, 2023).

Although there are no doubt challenges ahead with an ageing population, such as higher healthcare cost and loss in tax revenues (when working population decreases), older people have been unfairly labelled as an age group with the catastrophe status or "silver tsunami"

(Greenlee, 2020) , producing a negative crisis language as older peoples access to resources (Van Dyk, 2014). Once again, ageing is met with a ‘burden’ in the construction of related discourses. Other domains also reflect negative stereotypes for older people such as employment (Abuladze & Perek-Białas, 2018; Stypińska & Nikander, 2018), and the legal system (Doron et al., 2018).

3.4.2 Ageing Population in Ireland

In Ireland, the demographic trend is similar to global ageing, however, compared to many other EU countries, Ireland has had a high birthrate and a lower percentage of older people (Privalko et al., 2019). Yet, this is changing as the most recent census in 2022 shows that Ireland is catching up with its European neighbours with regards to the ageing population. Eurostat (2020) statistics and reports from the DoH (2022) indicate that Ireland has the fastest growing ageing population in Europe. This growth is estimated to continue, as seen in figure 5.



Source: DoH (2022), based on CSO (2022) statistic.

Figure 5: Older Age Groups Population 2022 and Projected Population 2027–2042 in Ireland

This growth can be illustrated by the number of retired people, and a significant change was seen in the Census 2022 in Ireland. Compared to the census in 2016, the number of retired people increased by 21 percent (to nearly 658,000) (CSO, 2022), and the number of older people grew (22 percent increase compared to the 2016 census) (CSO, 2016; 2022). This

trend is set to continue, as the number of people aged 65 years and over is expected to double in the next two decades, with significant increases in the old-old group (i.e.) those aged 85 years and over (DoH, 2022).

Both universally and in Ireland, there is a general lack of positive discourse examples of an ageing population when discussing related policies. More recent emerging discourses attempts to change the negative narrative. For example, UNECE (2021) pointed out that the ageing population is a strong consumer group and, as part of their increasing numbers, also impacts political decision-making. An example of the strength that the older population can have in policymaking is the nationwide referendum regarding abolishment of compulsory military service held in Austria in 2013. The young voters were in majority favour of the abolishment; however, two-thirds of the older voters favoured compulsory military service. In the end, older voters (who practically will not be affected by compulsory military service) decided on the military service of younger voters (Hess et al., 2016). Equally, in Ireland in October 2008, the government experienced a politically unforeseen backlash by older people marching to the Oireachtas to protest against changes in the medical card scheme (Irish Times, 2008). This led to a political turnaround on planned amendments, and represented resistance to traditional (political) power. These factors must be considered when deciding on policies (UNECE, 2021)

The dominant discourse emerging is that of old people seen as a group of people that after retirement is of ill health ('infirm') and continuous 'burden' on society. Organisations such as the UN and the WHO see the need to change the narrative of how older people are perceived in society. Based on the Madrid International Plan of Action on Ageing (MIPAA) (UN, 2002), the WHO Global Strategy on ageing and Health (WHO, 2016), and The UN Decade of Healthy Ageing (2020 to 2030), the WHO (2021) laid down ten concrete actions to be achieved based on the principle "leaving no one behind, ensuring that people of all ages in all segments of society can reach their potential and lead a life of dignity in fulfilment of their human rights." (WHO, 2021, p.3). This reflects the recognition of the marginalisation that older people may experience as a result of societal positioning.

3.5 Theories of old age

Since the nineteenth century, with increased longevity, theories of ageing have emerged. The key discourse formations of the ageing theories are presented in this section. Presenting

theories of ageing is useful as they create meaning within the disciplines that are influential in forming the discursive positioning of old age. Subsequently, theories form part of the knowledge that stems from institutions and authorities and provide statements relevant to discourse formation (Foucault, 1972). Ageing theories tend to be derived from the intellectual domains (disciplines) of biology, sociology, psychology, and spirituality (Victor, 2013). Broadly, they ask, 'why do we age?' and 'How do we age?'.

Two main categories of ageing theories are presented in this section. The first theories to be presented are biological, as chronological age standards are recognised as crude indicators of the ageing process. These are often celebrated in Western society through birthdays, as ageing pivots on many intrinsic and extrinsic factors, leading to heterogeneity in experience and morbidity (Beltrán-Sánchez et al., 2022; Johfre & Saperstein, 2023). Biological ageing theories are relevant, as they draw on declining intrinsic capacity, which underpins admission to LTC, and indicate aspects of physical decline which can highlight ageist assumptions. Social and life course theories are key to this study, as they describe the society, relationships within that society, and behaviours that determine those relationships (Giddens, 2000). Additionally, the theory of successful ageing is presented, as it has been influential in the development of policies around ageing.

3.5.1 Biological theories

A large emphasis has been placed on biological research on ageing to understand the ageing body and its mechanical processes (Kirkwood, 2008). This represents a dominant understanding within healthcare, but also within public perceptions, and biological models are characterised by an inevitable loss and decline (da Costa et al., 2016). Biological models centre on an individual's in-built biological process, 'the biological clock', and different theories are used to explain these processes (da Costa et al., 2016; Strulik, 2023). These theories mainly focus on physiological loss and abilities. Biological theories often ask why we age and how we age by looking at multiple biological factors (Jin, 2010; American Federation for Aging Research (AFAR), 2016). One of the key biological theories is the wear and tear theory, which simply assumes that cells in the body, such as machinery, wear out. Another main theory in biological knowledge is linked with genetics, which theorises that the life span of a body's cells is genetically determined (Pathath, 2017).

Biological theories have been the main source of knowledge as they are concerned with the evolution of humans, a topic often high on research agendas (Kyriazis, 2020). Therefore, it is imperative to recognise and include the biological model, as it is a leading dominant discourse in old age, particularly in healthcare. Here, ageing is seen as being determined by an in-built biological process within an inevitable loss of health and decline (AFAR, 2016). Subsequently, biomedical models are highlighted as part of their 'truth' statements in the formation of the discourse on old age. The importance of biological models within the discourse on old age is demonstrated in the perceptions of older people within society. They are commonly reinforced in everyday life. For example, societies' obsession with youthfulness (Åberg et al., 2020) is perpetuated in areas such as the popularity of cosmetic surgery, covert messages in film and media, and other covert ageist expressions. Thus, ageing can be dichotomous of ageing and anti-ageing (Madden & Cloyes, 2012). While ageing is no doubt a biological process, it is also influenced by social, economic, and cultural factors. Because of these different processes and factors, there is no simple definition of old age (Victor, 2013).

3.5.2 Social and life course theories

Social theories linked to gerontological research evolved in the 1950s when expectations and roles regarding ageing were explored (Powell, 2012). Liang and Luo (2012) argue that no social theory stands on its own, and instead of being theories opposing, most theories complement each other. Traditional views of old age have consisted of the construction of ageing as a process of economic, social, and physical decline (Biggs & Powell, 2001). However, with population ageing, there has been a move from decline models to more life-span developmental models, where the focus is on adaptation and health (Charles & Carstensen, 2010). Neugarten (1973) explained that there is no single universal pattern of social, biological, or psychological theory because the experience of ageing differs in many ways and the person's role in society is both complex and individual.

In the 1950s and post-World War II, the focus was on functionalistic theories that explained development from birth to death, and this was the dominant approach to ageing; those who were older had a biological loss and therefore were not productive members of society (Elder & Johnson, 2018). These theories influenced policy and society at the time when it was believed that both physical and social development ended during adolescence. One such significant theory was Erikson's (1982) developmental theory. Erikson's (1982) theory based on psychosocial development, focuses mainly on stages in childhood, adolescence and young

adulthood and referred to old age as a time of reflection of the previous stages. Erikson's theory gained wide acknowledgement and was referred to in public policy decision-making at the time (Palmore et al., 2005). As Foucault's methodology suggests, Erikson's theory was the 'truth' in the episteme it was produced (Palmore et al., 2005). The final stage of psychosocial ageing, stage eight, was presented as a period of ego integrity or despair. Those over 65 years old could reflect on a successful life marked by peacefulness, accomplishment, and fulfilment. Alternatively, the person could experience regret characterised by stagnation, reflection, and a lack of productivity (Erikson, 1982). This created a divide in old age, although Erikson (1982) noted that individuals could experience a balance between both positions as they made sense of their lives (Lane & Munday in Zeigler-Hill et al., 2017). A critique of Erikson's development theory was his lack of comprehensive development in the adult life stage. There was more focus on the childhood and adolescent stages of this theory, and Erikson referred to the later stages as reflection and contemplation (Pelaez et al., 2008).

In contrast to Erikson, Neugarten (1973) continued the development of theories looking at life courses by emphasising two perspectives on ageing. The first perspective on ageing focuses on the norms that are expected to be part of the life course, referred to as social clocks. Norms, such as finishing school, marriage, and having children, are standard behaviours in society with regard to people's ageing process. Language such as "she is too old to wear that" or "the ship has sailed for him" are examples of how society has created norms in relation to age. The second perspective, Neugarten (1973), proposes that the individual adapts to those norms, more precisely coping with and accepting their ageing. Neugarten (1977) was one of the first to point out that when longevity increases, new norms and understandings are introduced. For example, turning 70 years of age or even 80 years today is distinct from what it was experienced 50 or 100 years ago, and new norms of what is considered "old" are created (Neugarten, 1977). Neugarten (1977) also proposed a new classification of age groupings; the "young old" (55–75), those who may be retired but still relatively healthy and active, and then the "old-old" (defined as those over the age of 75 by Neugarten (1977)), those who might need support to function as fully as possible.

Two other prominent theories of ageing were introduced around the same period: the activity theory by Havighurst (1961) and disengagement theory by Cumming and Henry (1961). Both theories focus solely on the functional role of older people in society and still influence social policy. Although the two theories, on the surface appear to oppose each other's ideas, they are complementary rather than contrasting (Asiamah, 2017). Havighurst (1961) developed

the activity theory which argues that as one ages, the individual encounters problems or performance tasks associated with ageing and whether a person accomplishes these problems or performances will establish that person's role in society (Havighurst, 1968). The theory assumes that positive ageing is centred on the older person needing to be as healthy and physically active as possible to maintain social engagement and productivity (Teles & Ribero in Gu & Dupre, 2019). In contrast, the disengagement theory by Cumming and Henry (1961) stated that ageing is inevitable and that a person's abilities, including the ability to socialise, will reduce over time. The implication is that the older person will lose ties with others in society and become physically inactive and lonely compared to younger generations (Cumming & Henry, 1961). Disengagement theory considers the changing needs of older people in relation to society. Crewdson (2016) highlights that both theories are supported in empirical studies, confirming the idea that they are complementary and not opposing. It is more likely that a single theory is too basic to explain old age in society, as many factors such as socioeconomic, cultural, and demographic factors are significant. However, research has found that physical activity and loneliness are two major challenges for the ageing population, confirming the importance of both activity theory and disengagement theory but recognising that achieving social and physical activity is not easy (Arslantas et al., 2015; Bernard, 2013). Similar to successful ageing, which is presented further in the chapter, theories can create standards of ageing that are not achievable by everyone, thus exemplifying a divide in practice.

As life expectancy continues to rise and population structures continue to change, old-age categories are not simple to define. This is the development of more recent theories referred to as the third and fourth ages. These theories question previous theories of singular old age grouping by emphasising variability, diversity, and individual differences within age groups (Gilleard & Higgs, 2010). The third age typically refers to the period of active retirement, similar to Neugarten's (1973) categorisation (approximately 55-75 years), in which individuals may be free from the demands of work and family responsibilities. It is considered a time for personal fulfilment, learning, and leisure. The fourth age, on the other hand, denotes a stage of increasing frailty and dependency due to old age, aligning with the old-old (aged 85 years and over) in population health statistics. The boundary between the third and fourth age is not clear (Lloyd, 2015), and the stages correspond with the evolving needs and experiences of individuals as they progress through later life. There are also inconsistencies in the definitions of third and fourth age, as Kydd et al. (2020) found in their extensive literature review of third

and fourth age definitions. They concluded that there is a need for consensus in the further categorisation of old age, as the population is set to increase and societal demands may change (Kydd et al., 2020). Someone aged 65 years might be classified in the 'old age' group in data collection, such as census data, but on an individual level does not identify him/herself as old (Vauclair et al., 2016). As life expectancy continues to rise, it is likely to reflect the readjustment of middle-age understandings rather than old age. This aligns with the ageing population phenomena and biological models of ageing, where life span continues to increase, thus creating new norms in the ageing population.

3.5.3 Successful Ageing

Pickard (2009) argues that the discourse on dependency and function in society was dominant until the 1980s and was structured by the dominant discourse of mandatory retirement, followed by meagre pensions, resulting in older people being dependent on younger family members. This is notable in the theories reviewed, which highlight changes in the older person's role in society (mostly negative changes). In the 1980s, the rise in the number of people living longer together with improved health, and enabled some advances in economic prosperity (Philips et al., 2010) led to a shift in the discourse of ageing. This shift included a discourse of successful ageing which is underpinned by conceptual frameworks of how some older people (both from a sociological as well as biological perspective) age well and others do not (Carstensen et al., 2006).

Successful ageing refers to several different concepts such as 'healthy ageing', 'ageing well', 'positive ageing' or 'active ageing' (Dillaway & Byrnes, 2009; Katz & Calasanti, 2015), but the theme running through these theories is adaption to the process of growing old and the methods which old people use to adapt (Tate et al., 2003; Torres, 2003). Successful ageing can be traced to the work of Rowe and Kahn (1998), who coined the term and argued that those with a low probability of disease and disability together with a high functional level of cognition as well as active life, both physically and socially, will age successfully (Rowe & Kahn, 1998). Rowe and Kahn (1998) observed that successful ageing is an ongoing process and that a person can be successful at different times in their lives, and the responsibility of an older person is to always work towards successful ageing. The successful ageing theory can be seen as an extension of the active theory proposed by Havighurst (1961) (Timonen, 2016) and has become one of the main reference theories within the field of gerontology, fundamentally impacting the discourse of ageing (Bülow & Söderqvist, 2014).

Despite the increased focus on the discourse of successful ageing in the past two decades, no overall universal definition of successful ageing has been proposed (Bowling & Dieppe, 2007). One of the main critiques of the discourse on successful ageing is the conceptualisation that an older person needs to be successful (Dillaway & Byrnes, 2009). The determinants for an older person to be successful include low body mass index (BMI), normal blood pressure, active social life, and well-being through intergenerational relationships (Rowe & Kahn, 1998). Yet, these parameters are specific and may be biased towards certain groups in society. The idea of successful ageing also stereotypes those who are not successful as a burden in society and discriminates against older people with chronic conditions (Fraser et al., 2016). Successful ageing theory has also been criticised because of its narrow view (often referred to as the heteronormative and neoliberal views) of the individual. It does not consider inequalities due to gender, sexuality, social economic status, and health status (for example, disability that may be present prior to ageing) and a range of characteristics that exclude an individual from successful ageing (Fabbre, 2015; Jones, 2022; Marshall, 2018). Successful ageing is also subjective, and older people may consider themselves to have aged successfully even when established models and theories do not consider the experience of successful ageing (Bowling & Dieppe, 2007). Teater and Chonody (2020) argued this in a scoping review of successful ageing: how older people themselves did not describe successful ageing in the same way as the theory would indicate. Consequently, more recent theories of successful ageing include subjective meanings of successful ageing as well as individual quality of life (Martinson & Berridge, 2015). These theories emphasise the subjective inclusion of how older people themselves would like to define ageing.

Despite the criticism, successful ageing has gained wide recognition among policymakers and organisations, using the term ‘healthy’ or ‘active ageing’. The World Health Organization (WHO, 2017) introduced their commitment to healthy ageing and emphasised the need for strategies to promote active and healthy ageing. Yet, WHO (2017) also recognised that ageism and age-related barriers need to be addressed for active ageing to have potential and launched five strategic objectives to foster “functional ability across the life course and where older people experience equal rights and opportunities and can live lives free from age-based discrimination” (WHO, 2017, p. 6). Similar to the WHO (2017), Ireland’s Department of Health (2013) published The National Positive Ageing Strategy, in which goals and requirements for positive ageing were established. Successful ageing, whether referred to as healthy or active ageing, has become a strong discourse in policy planning for older people. In a qualitative

study, Calasanti (2016) found that the term successful ageing created tension for older people. Calasanti (2016) also linked successful ageing (although participants wanted to achieve the same) closely with ageism and even suggested that the ambition of successful ageing increased ageism.

Using a Foucauldian lens in the discourse formation of ageing theories points to complexity in the attempt to describe ageing with one theory. Biological theories have significance in explaining the chronological effect of time on a person; however, ageing is also explained by social theories and has an impact on an older person's ageing. One theory alone does not seem to capture the complexities of ageing. Successful ageing, which has gained noticeable acceptance in policy development, requires one to be successful in ageing. Current contingencies of old age still suggest the older person should be productive to be successful, whether that productivity comes in a different form than employment, like continued activity (Dahany et al., 2014) or health status, being a successful older person. While societies change, some theories, even if they were developed decades ago, can still have influence. Because theories inform practice, it is important to assess their validity (Michie et al., 2005), yet also to accept that they represent points of truth in a given time and emerging through powerful and "legitimized" discourses. Foucault (1984) highlighted that knowledge within a discourse can be challenged; in this case, old age structures and categories challenge disciplines' knowledge of what is considered old. A universal definition of the process of ageing has not been agreed upon or accepted, and what society perceives as old and young differs due to cultural and national perceptions (Lamb, 2014) as well as demographic and sociological transformations. However, these theories shape society and have a powerful influence on policy decisions. This means that the contingencies in the epistemes are productive older persons, despite changing the parameters for retirement and what is considered old (Foucault, 1985). The binary assumption of Foucault and fellow postmodernist researchers is that there are opposites in the structure of formations: healthy and unhealthy ageing. If an older person does not seem to be 'successful' there is the discourse of burden and being the passive, thus the older person has no 'meaning' within society. This would point to systematic ageism in society.

3.6 Ageism

In the review of literature including 'old age', 'age' and 'older people', a concept that emerges is that of ageism. Ageism emerged in the literature as a defined concept but paradoxically is

also persistently present in unconscious descriptions of older people by stereotypical labelling and taking for granted truths about older people for example frailty as part of ageing or the perpetuation of fear of ageing (Weir, 2023). Ageism has also been linked to the death terror management theory, where one's own mortality is confronted when in contact with older people (Greenberg et al., 2017; Draper et al., 2024). Ageism, like theories of old age, can be defined through different perspectives; however, due to the significant implications and challenges of an ageing population, it is important to understand ageism in relation to this study. In the context of old age, it is crucial to understand how ageism is expressed, experienced, and perceived in society as well as how it affects policymaking. Ageism was first coined by Butler (1969) to describe prejudice and discrimination towards older people. Butler (1969) compared ageism to other forms of prejudice (racism and sexism), and described ageism as a process of systematic stereotyping. Ageism involves the assumption of age stereotypes, prejudice, and discrimination, and centres on the stigmatisation of an individual based on their belonging to a particular age group (Bratt et al., 2018). Butler (1969) described ageism as a collective term used to explain a) prejudice (how we feel about different age groups), b) stereotypes and beliefs, and c) behaviour towards an age group. Such perceptions of older people can impact their quality of life (Kim et al., 2021). All these three are created at different micro, meso, and macro levels.

At the micro level, one can see how we as individuals perceive ageism and the social psychology that drives this perception. Ageism is intertwined in society and internalised at a very early age. Research has shown that internal self-perceived ageism is widespread and has consequences for how older people perceive their positions in society (Okun & Ayalon, 2023; Horst, 2019; Levy, 2022). At the meso level, ageism is manifested through procedures and policies that provide rules for the institution to function. For example, if a company has a policy of not hiring anyone over the age of 50 (official or unofficial policy) or a mandatory retirement policy of 65 years regardless of state level pension age (Jecker, 2023). Equally, at the meso level, ageism can be experienced in the healthcare system (Ben-Harush et al., 2016; Nemiroff, 2022). There are examples of ageism at a macro level; one could argue that a successful ageing policy (as presented in the previous section) may be ageist, as it dictates how ageing should look (Butler, 1969; Calasanti & King, 2021; Palmore, 2001). Ageism at the macro level has many dimensions, such as economic status, health, employment, environment, and social participation, which can vary culturally (Kim et al., 2021). Ageism has systematically marginalised older people as 'them', those we do not belong to, yet age in itself

is universal and all will belong to that population. Angus and Reeve (2006) pointed out that ageism is widespread, yet generally accepted, and in many instances ignored. In a global report on ageism, WHO (2021b) pointed out that ageism is widespread in institutions, legislation, and policies that damage health and deny people's human rights. In a systematic review of ageism's impact on health, Chang et al. (2020) identified that ageism leads to severe health outcomes, consequently affecting quality of life.

Ageism is a strong factor in the discourse formation of old age and considering that ageism has the potential to impact every person, it has been poorly studied (Robbins, 2015). Ayalon (2014) argues that, in Europe, perceived ageism is more prevalent than perceived gender and ethnicity-based discrimination. However, there are difficulties in assessing and collecting data in relation to discrimination studies, which leads to challenges in comparison between findings. As social theories of ageing highlighted, age is often set by norms and stereotypes and there are arguments that age has become an oppressive device used to "slot" people into fixed, stereotypes roles (Cruikshank, 2013). As noted in the previous sections of this chapter, the discourse around old age has been predominantly that of 'challenge' and a form of 'burden' and even when ageing is spoken about in positive terms, the older person needs to be successful in their ageing in order to be productive members of society. Policy programmes created to promote positive ageing are usually based on stereotypes (implicit or explicit) held by policy makers; stereotypes such as older people are in poor health, isolated, or inadequate workers (Palmore et al., 2005). These are examples of deep-rooted systematic ageism that influences the discourse on age and is part of the driving force behind policy development. Phelan (2008) argued that ageism influences how human and citizenship rights are articulated and formulated for older people through policy decisions. This is why ageism is part of the discourse on ageing and has a multitude of implications. Equally, as ageism is pervasive in society, it can be internalised by older people (Levy, 2022) and perpetuated by families (Gordon & Gonzales, 2022).

3.6.1 Ageism in healthcare

As ageism is systematic in Western societies, healthcare is not immune. Many patients in healthcare are older people, yet Macnicol (2010) pointed out that professional healthcare providers may apply an aged-based stereotype to an individual older patient. The Health Service Executive (HSE) Quality Improvement Division and Age-Friendly Ireland conducted a report in 2015, where the aim was to listen to the voices of older people. The report showed

that two of the ten themes were poor communication between healthcare staff and patients, and another theme was lack of respect and compassion for older people as well as fragmented care. This points to a healthcare system that devalues older person, and this impacts the treatment and experience of older person in need of care.

Lytle and Levy (2019) pointed out that there is a great need for strategies to reduce ageism in healthcare as well as the whole society through targeted educational and media campaigns. Raising knowledge regarding ageism can have an effect on attitudes towards working with older people. Low expectations about what healthcare and interventions can achieve for older people can result in ageist planning. This thinking can become self-fulfilling, as the expectations of older people's abilities are low, often resulting in inappropriate and infantilizing behaviour from healthcare professionals (Ben-Harush et al., 2016). Individual health is also impacted by ageist thinking. For instance, Villiers-Tuthill et al. (2016) examined linkages between tobacco and alcohol use with ageing self-perceptions in Irish older people. Findings indicate that older people did not think there was any point in quitting as they were 'too old' illustrating the internal ageist thinking (Villiers-Tuthill et al., 2016). Ageism at the macro level can be seen in healthcare systems, as discussion often leads to a financial 'burden' in relation to healthcare for older people. Terms such as 'bed blocker' or 'oldies holding up healthcare' are examples of how language reflects how deeply entrenched attitudes are (Applewhite, 2019). Equally ageism is evident in areas such as limiting rehabilitation (Najem et al., 2018), non-referrals (Wyman et al., 2018) and screening test limits (Gram et al., 2023; Smith et al., 2023).

Several reports from Irish Non-Governmental Organisations (NGOs) have pointed out widespread ageism within the health and social services in Ireland (Community Foundation Ireland, 2023; Gibney et al., 2018; The National Council on Ageing and Older People, 2005). These reports highlight indirect discrimination such as barriers to access to services, inadequate transportation, excessive waiting in emergency and outpatient departments, and underfunded community services. These barriers are widespread and frequent and are taken for granted by older people. When systems lack services (such as home care) for older people, this is a sign of systematic age discrimination (Community Foundation Ireland, 2023). Similarly, the Age Platform Europe (2021) found in their report that age discrimination is present in healthcare systems and policies in Europe, seen in the form of access and age limits on diagnostic screening tests. These reports highlight the widespread ageism in

healthcare systems around Europe, yet very few policies or recent legal changes reflect this systematic discrimination (Previtali et al., 2022; Swift et al., 2022).

Discourse around ageing is constantly changing; however, stereotypes and prejudice still affect knowledge production (Madden & Cloyes, 2012). By conceptualising the stereotypical views of older people, prejudices, attitudes, actions, and societal marginalisation are evident as a driving force in policy and regulating standards. Deeply rooted ageism may marginalise rights when allocating resources and collecting data that influence health policies (Macnicol, 2010). For instance, the Alzheimer Society of Ireland (ASI, 2013) stressed that older people are often seen as recipients of care rather than rights holders. Likewise, many of the older people may see themselves as a burden rather than an autonomous individual, and this perception is particularly acute for people living with dementia (ASI, 2013). With increased longevity and demographic changes in global populations, older people should have opportunities to grow and create social relationships. By contrast, older people still find themselves marginalised which in turn diminishes their capacity to contribute and thrive (Achenbaum, 2015).

Ageist views also exclude older people from crucial research that determines the policies and recommendations concerning them. Research needs to include older people as active participants to give change a chance to happen realistically (Angus & Reeve, 2006). Research has frequently prioritised younger populations, perpetuating an endless cycle in which the unique challenges of older people are not fully addressed (Elder & Johnson, 2018; Watts, 2012). As with the lack of comprehensive data on ageing populations, policies are not suitable, and instead reinforce stereotypes and misconceptions about older people. Additionally, the underrepresentation of older adults in research can lead to inadequate healthcare practices and social policies that do not effectively address the diverse needs of this demographic. A call for a more inclusive research approach involving older people in study design and implementation has been made (James & Buffel, 2022; Littlechild et al., 2015; WHO, 2021b). Therefore, it was key for this empirical study to include the older person in LTC to foster an inclusive mindset and to obtain a comprehensive understanding of the rights of older people in LTC.

3.7 COVID-19 and its impact on older people

As previous sections indicate, the discourse formation of the older person has multiple dimensions; older people are required to be successful and productive or otherwise they are seen as a 'burden' on the social, economic, and healthcare sectors. COVID-19 did not alter these discourse formations but served to magnify them. Evidence demonstrates that there is an increased risk of severe illness and complications from COVID-19 for older people, and the virus disproportionately affected older people, leading to higher mortality rates among this demographic (Silva et al., 2021; Tay & Harwood, 2020; Wang et al., 2020). During the COVID-19 pandemic, particularly during the spring of 2020, knowledge of the infection was poor. Yet, knowledge production was rapid and society responded quickly to the pandemic; the biggest example was the rollout of the vaccine programme at the beginning of 2021 (DoH, 2021).

The COVID-19 pandemic has had a profound impact on individuals across all age groups; however, older people have been particularly vulnerable to its physical, emotional, and societal effects. The pandemic highlighted and exacerbated existing challenges faced by older people, bringing particularly ageism to the forefront of public discourse (Brooke & Jackson, 2020; McDarby et al., 2022; WHO, 2020b). Ayalon et al. (2021) suggested that during the COVID-19 pandemic a "parallel outbreak of ageism" (p.1) was evident. This was seen in the initial public health regulations implemented in Ireland (as well as in other countries). They were discriminatory as they were a direct result of a person being 'old'. For example, all people over the age of 70 in Ireland were told in the spring of 2020 to 'cocoon'. The term 'cocooning' referred to staying at home and avoiding all social interactions (DoH, 2020; HPSC, 2020), translating to a form of self-isolation due to age. This advice was based on the view of older people as a vulnerable frail group and in need of protection. Consequently, statutory advice was underpinned by a blanket approach for all older people, thus making them a homogenous group bereft of making informed decisions based on the facts of COVID-19's virulence and characteristics (Fletcher, 2021; Swift & Chasteen, 2021). Other examples of ageist measures were the clear disregard for older people in the population, such as not including the deaths of older people living in LTC facilities in data gathering (Frazer, 2020; McDarby et al., 2022). Other instances of age-based discrimination in healthcare settings, where older individuals were deprioritised in the distribution of medical resources, such as ventilators or intensive care unit beds (Jecker 2022; Rueda, 2021).

During the pandemic, there was also noticeable conflict in practice. For example, research before COVID-19 has shown that loneliness and physical activity constitute a challenge for older people, which in many ways should be a priority to address (Gardiner et al., 2018; Prohaska et al., 2020; WHO, 2019). Yet, during COVID-19 these challenges worsened. Heid et al. (2021) found in their survey in USA that public health restrictions mostly constrained social interactions (key component against loneliness) and decreased physical activity for older people. Equally, in LTC, loneliness and social isolation increased (Rodríguez-Blázquez et al., 2023; Simard & Volicer, 2020). Although some protective public health measures may have been warranted, the stringent protective measures of lockdowns, social distancing, and isolation have affected older people's emotional well-being (Dunford & Brooke, 2022; Hopf et al., 2021; Tomaz et al., 2021). Societal attitudes toward older people have played a role in perpetuating ageism during the pandemic (Frasier et al., 2020; Ehni & Wahl, 2020). In a social constructivist review of Irish media coverage of older people during COVID-19, Beasley and Timonen (2023) found that despite the older person becoming the 'face of COVID-19', the portrayal of an older person as a burden rendered them even further voiceless. Additionally, the authors concluded that their results were similar to those seen in research before COVID-19, where older people were portrayed as passive care recipients (Beasley & Timonen, 2023). Consequently, negative stereotypes, ageism and older people's position as 'other', were all more visible during COVID-19 pandemic and further placed the older person in a separate subject position from the rest of the population.

3.8 Conclusion

This chapter used archaeological tools to dig into the literature to establish the formation of statements that are part of the discourse on old age. No doubt the complexity of old age, whether on individual level, organisational level or societal level, is apparent in the literature. The social construction of old age has historically moved from a social welfare basis framed as the dependent poor old person to a more productive, active, and hence successful old person, providing parameters that are to be achieved. Yet, the discourse surrounding older people continues to be strongly influenced by economic factors, such as retirement policies and pension systems. Essentially, societal expectations regarding productivity and contributions to the workforce can impact how older individuals are perceived, positioned, and valued. Chronological age has, with medical interventions, living standards and general improvement, increased life expectancy. Despite the great success of longevity, the discourse of older people continues to differ from that of the rest of the population. An older person must

age successfully to be seen as a productive individual in society. If not successful, the older person is seen as a burden, and this is supported by the language used and framing this as a problem. Successful ageing has been adopted by a range of influential institutions such as the WHO and the DoH in Ireland, which makes successful ageing part of dominant knowledge and taken for granted 'truths'. Consequently, by analysing statements within the diversity of the literature, strong discourses of older people as a separate population group emerged, a group that is seen as 'burden'. The term 'burden' is often found in the discourse of older people, to such as degree that older people themselves see them as 'burden' through internalised ageism. Language plays a crucial role in shaping the discourse around ageing, and terms that are negative contribute to the stigmatisation. In contrast, positive and inclusive language can challenge stereotypes and promote a more nuanced understanding of the ageing process.

The final section focused on the COVID-19 pandemic. As this research was conducted during the pandemic, it was necessary to consider how this impacted the discourse formation of older people. It was evident that COVID-19 highlighted and extended previous discourse formations. The ageist practices were strengthened and blatant, particularly in the discourse of protection of the older person. In conclusion, the discourse of older people and the social construction of old age are complex issues shaped by cultural, political (policy), economic, and historical factors driven by ageism and stereotypes. The discourse formation constructs older people as separate from the rest of the population. With the dominant subject position of the older person in mind, the next chapter reviews how LTC, as an apparatus in care provision, is discursively formed.

CHAPTER FOUR

Long-term care

4.1 Introduction

While the previous chapter focused on the discourse construction of older people (subject), this chapter examines LTC (context) for older people. Subsequently, within an archeological approach, this chapter unpacks the discourse formations of LTC in general, but specifically those within the Irish context. A review of the LTC context provided discourses that make certain subject positions possible, which may constrain or support ways of being, feeling, and seeing a phenomenon (Foucault, 1972; Pickard, 2009). Using FCDA and digging into epistemological statements, key characteristics in the discourse of LTC for older people are found: the need for LTC, LTC systems and their place in the provision of care, person-centred care, and final characteristics of legislation, regulation, and policy within LTC, particularly in Ireland.

The emergence of LTC for older people has been contingent on poor laws since the late nineteenth and early twentieth centuries, followed by increasing regulations in the latter part of the twentieth century (i.e. HIQA). More recently, care has, at least in theory, moved towards more personalised care. It is evident that at the core of any LTC provision is an older person in need of care (Gillick, 2017; National Academies of Sciences, Engineering, and Medicine, 2022), yet other factors such as family involvement and availability of resources influence LTC for older people. This chapter provides the institutional context in which the older person (detailed in Chapter Three) exercises their human rights, which is reviewed in the next chapter. The chapter concludes with how COVID-19 impacted discourse formations within the LTC sector.

4.2 Literature search strategy and terminology

Chapter Two provided the framework for archaeological analysis of the literature and, as stated, the literature review is also concerned with context and statements in language and its application. Similar to the search in the 'old age' review, a literature search based on the broad topic of LTC generated copious publications. Therefore, search limitations were implemented, focusing on LTCFs (nursing homes). Terms used to describe LTCFs can be 'nursing homes', 'assisted living', 'residential care facilities', 'aged care', 'care homes', and

'retirement homes'. This vast terminology highlights the extensive and varied provisions of LTC. Journal articles in English and those published within the last 15 years (2008-January 2024) were included to reflect the current discourses on the topic. By 2020, the literature was influenced by the COVID-19 pandemic. Table 2 summarises the inclusion and exclusion criteria for the LTC literature search.

Table 2: Explanatory inclusion and exclusion criteria in literature review of LTC

Time Frame	Although Foucauldian digging into archives would not set a limiting scope for text, the limitation on search was 2008-2023 but using snowball effect digging into discursive epistemes before 2008 in the context of Ireland.
Databases	CINAHL, PubMed, Medline, Google Scholar
Geographical Context	Focus is on LTC in Europe and particularly in Ireland.
Language	Publication limited to English, or translated to English. This excludes text in researcher's own mother language (Swedish and Finnish).
Participants	The focus is on Older Person (>65 years of age) in formal LTC and how provision of care is organised to them. This can then include studies with staff as they represent professional position in organisations.
Type of text/Publication	Peer-reviewed studies, reports from international organisations, government departments (Ireland) and reports from professional associations (for example organisations such as Sage Advocacy or Nursing Homes Ireland (NHI))
Setting	LTC facilities are included where formal care provided by healthcare professional in structured manner. Excluded are palliative care (hospices), hospital and primary care, rehabilitation including addiction rehabilitation facilities. Excluded as well any facility that are not purposely for older people such as intellectual disability centres or child care centres.
Key search words (used in different combinations)	Long-term care, care homes, aged care, LTC facilities, residential care facilities, nursing homes, institutional care, older people, structure of LTC, social construction, discourse.

Four databases (CINAHL, MEDLINE, PubMed and Google Scholar) were searched, and a key focus was how long-term care facilities (LTCFs) structured the general provision of care. Journals were identified based on studies within the LTC (both qualitative and quantitative). These include those underpinned by approaches, such as concept analysis, systematic

reviews, and case studies. Non-fiction books detailing these topics are included. As part of the FCDA, it was important to identify formal discourses regarding LTC; however, for pragmatic reasons, this was limited to Irish policies, standards, regulations, and legal texts as well as reports from significant groups or public bodies related to LTC for older people. This included grey literature in the form of publications, policies, and reports from the WHO, Organisation for Economic Co-operation and Development (OECD), UN, and the Central Statistics Office (CSO) in Ireland, the Department of Health in Ireland (DoH), legislative publications such as the Health Act (2007), and key policies from Health Service Executive (HSE) and HIQA. This enabled a review of the legitimised discourses of LTC for older people in Ireland. Key articles were identified using a snowball approach in the literature review. Appendix 2 provides a screening flowchart showing the rationale behind the articles.

Figure 6 illustrates the four main discourses of LTC: 1) why LTC is required for older people and as part of the older person's need to access regular systematic healthcare, 2) LTC systems, 3) what person-centredness means in LTC in Ireland, and 4) the final segment of legislation and policy of LTC in Ireland.

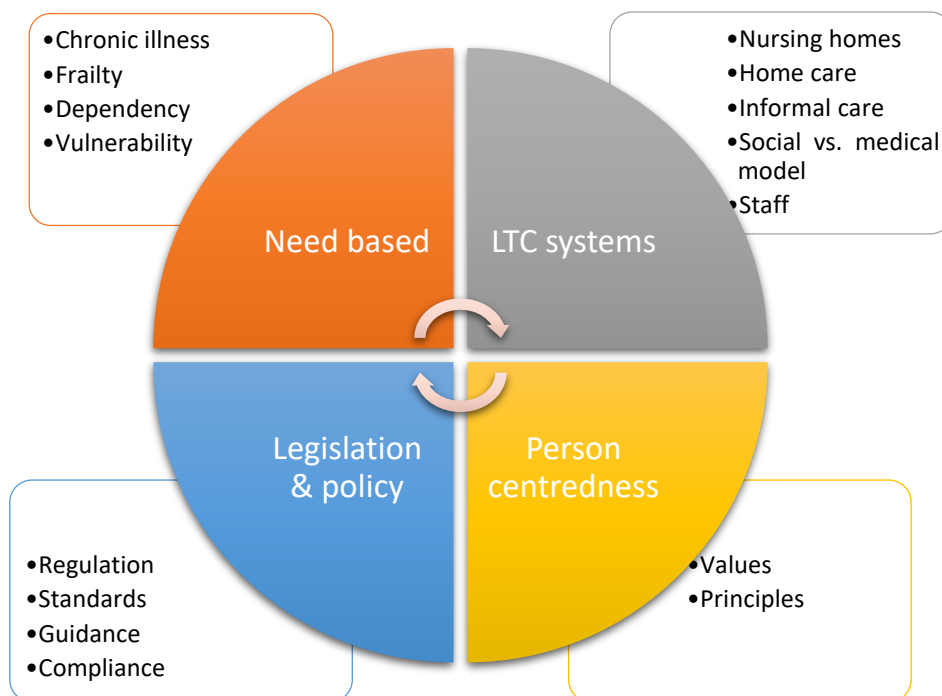


Figure 6: Illustration of discourse formation on LTC for older people

4.3 The need for long-term care

As seen in Chapter Three, one of the greatest achievements of the 20th century was increased longevity. Consequently, in most countries, one of the challenges for the 21st century is to ensure that this longevity can be experienced in the context of good health and high quality of life (WHO, 2017). In 1948, the World Health Organization (WHO, 1948 p.1) defined health as “a state of physical, mental, and social well-being and not merely the absence of disease and infirmity”. The longevity, combined with chronic illness, is discussed in the following section in the discourse formation of the need for LTC. The discourse is significant as it reveals the dependency continuum and the complexity of providing care to older people, as both physical and psychological changes may need to be met. In this context, Huber et al. (2011) pointed out that the WHO’s definition of health has lost its purpose and is unsuitable for an ageing population. They suggested that the definition moves towards adaptability and self-management with regard to health (Huber et al., 2011). As noted in the previous chapter, the ageing population in Ireland will significantly increase, and although good health is expected for most older people (CSO, 2022; O’Shea et al., 2017), chronic conditions are more common with increasing age. When people age, their health tends to become more complex, and there is an increased likelihood of having not just one but several chronic diseases. This, in conjunction with the ageing population, causes complexity in healthcare (Vetrano et al., 2018; Kane, 2010). Chronic illness has impacted and influenced ongoing discussions on how LTC is planned and provided in Ireland (O’Shea et al., 2017; Wren et al., 2017).

Consequently, one of the distinctions to be made regarding the health of older people is that age appears to be a factor but not a deciding factor. As Beard et al. (2016) emphasised, chronological age is an inefficient measurement of health, as a 60-year-old can have a chronic condition requiring LTC, while an 80-year-old may be considered healthy and independent of any care. The absence of chronic illness is a key characteristic of successful ageing, as outlined in the discourse formations in Chapter Three (Rowe & Kahn, 1998). WHO’s (2017) vision of healthy ageing involves the prevention and promotion of strategies to combat chronic illnesses in older people. However, this discourse conflicts with the needs of older people for LTC, where chronic illness is the main reason for admission to residential setting (Tobis et al., 2021). An older person who becomes a candidate for LTC (whether in a facility or at home) has a reduced capacity to perform the tasks or activities required to live independently. Often, such requirements increase to the extent that the interventions are required from formal

services to assist the individual and/or their informal carers (i.e. family) (Ausserhofer et al., 2016; Vetrano et al., 2018).

Understanding the need for LTC and how it is linked to dependency is significant in the subject position of older persons in the discourse. Older people in LTCFs depend on the care delivered, and there is a tacit surrendering of independence as part of the adaptation to LTC (DeLong et al., 2019; Weicht, 2010). This loss of independence is linked to self-worth and self-determination, which are significant in the discourse on rights. Those in need of LTC depend on assistance with daily activities for a long period (Colombo et al., 2011). These services are often referred to as assistance with basic activities of daily living (ADLs), such as dressing, bathing, toileting, transferring, and nutrition. ADLs are considered fundamental and are included in the formal assessments in LTCFs to determine dependency levels (Aspell et al., 2019), indicating the expert gaze of who requires what care. In addition, LTC integrates care specific to clinical needs and illness trajectories, such as caring for older people with various morbidities and comorbidities, including dementia, respiratory or cardiac illnesses, or various neurological disorders (Hockley et al., 2017).

Therefore, the main reason for admission to LTC facilities is the need for support, which is generally not based on choice (AARP, 2021), and is often taken in the context of crisis following an acute health event (Konietzny et al., 2018). Family members emerged as having a significant role in the decision for admission to LTCFs and the decision is often marked by prolonged anxiety and agony over care delivery (Davidson et al., 2019; O'Neill et al., 2020). In a recent study by Phelan et al. (in press), many of the focus group participants described their admission to a LTC facility as not being their choice. Despite the intention of policies such as 'healthy ageing' in Ireland and the rights of ageing in place, the need for care is often acute, and the choice of staying in place (at home) is not an option which consequently means that the right to choose is diminished (Sage Advocacy, 2020; Walker & Paliadelis, 2016). Several studies have also highlighted how admission to LTC facilities translates into an automatic loss of autonomy (O'Neill et al., 2022; Paque et al., 2018; van Loon et al., 2021). In addition, admission to LTCFs means a new identity for the older person and a huge change in their lives. O'Neill et al. (2022) found in their Irish study residents' experiences of moving into LTC facilities that although the older person felt that they needed to make the best out of the situation, they were also dependent on the facilities' structures and procedures for care. Older people are required to adapt to their new surroundings which means a loss of identity and belonging (O'Neill et al., 2022; Walker & Paliadelis, 2016). Paddock et al. (2019)

conducted a qualitative study of residents in care homes and found that their transition to an LTC facility affected their identities. The findings pointed to several challenges, such as the LTC facility's environment and resource constraints, that impacted the identity of residents. This is central to this study, as identity is intricately connected to rights articulation (i.e. autonomy and decision-making) which is further explored in Chapter Five.

4.3.1 Assessment of the need for LTC: Frailty and Vulnerable Discourse

To determine whether an older person requires LTC, it is necessary for a healthcare professional to conduct an assessment. Healthcare professionals and policymakers use numerous assessments to determine care needs and to allocate resources. These assessments grant the medical expert the power to dictate the desired behaviours of the older person in need of LTC. The primary determinant for admission to LTCFs is an assessment of the older person's need for continuous nursing care which may be attributed to chronic illness, debilitating conditions, such as dementia, or inability to receive adequate care at home (Sverdrup et al., 2018). A variety of assessments are available, all of which form an integral part of the expert function within the discourse (HSE, 2016a; NHSS, 2009).

One of the assessments that has gained significant impact as part of discourse formation is the frailty assessment (Romero-Ortuno & Soraghan, 2014). Several validated frailty assessment tools have been developed, such as the Rockwood Clinical Frailty Scale and Edmonton Frail Scale (HSE, 2016a; Rockwood et al., 2005; Rolfson et al., 2006); however, there is no single definition of frailty (Martin & O'Halloran, 2020). These assessment tools are used for an overall gerontological assessment and represent medical gaze in the power-knowledge-discourse expressed in normalising judgements (Danaher et al., 2000; Foucault, 1977). For example, within Ireland's National Clinical Programmes for Older People, frailty is a major focus of comprehensive geriatric assessments (HSE, 2016a). The frailty assessment objective is to obtain a baseline score on which treatment and care are based. However, as guidance from the National Health Service (NHS, 2014) in UK points out, it is vital that frailty is not seen as a problem or burden within the care system. As burden is a common discourse when referring to older people and they have been referred to as 'bed blockers', additionally labelling the older person as a problem when there are frailty-related issues may delay discharge from the acute sector (Walthal, 2019). This review objective was not to evaluate these assessments but to show how they are used in the context of LTC for older people and how they influence everyday language with regard to older people and provide 'legitimate

truths'. By using assessments, often referred to as an evidence-based assessments of care needs (Boltz et al., 2020), the actions of healthcare professionals are legitimised.

Frailty has increasingly become a prominent feature of the health assessment of older people in need of LTC, providing a lens within which to view the decline in the ageing body (Green, 2017). Healthcare professionals in reference to older people in LTCFs often refer to them as frailest in society (Chadborn et al., 2019; Vetrano et al., 2018). Sarvimäki and Stenbock-Hult (2016) pointed out that frailty is often intertwined with and indistinguishable from vulnerability; another descriptive characteristic used for older people in need of LTC. Similarly, Bajotto et al. (2017) found that vulnerability was synonymous with frailty in their study of vulnerable older people in Brazil. The formation of vulnerability in older people as part of their need for LTC is a construct with a multi-dynamic context, in which they are at risk of health problems and inadequate economic, social, and/or psychological resources (Sherwood-Johnson et al., 2022).

Another common reason for formal LTC is cognitive impairment or dementia³. Although not all residents in LTCFs have dementia, the World Alzheimer's report showed that among the residents in LTCFs, those with dementia are overrepresented (ADI, 2023). Various studies have estimated between 60 percent and 90 percent of older people in LTCFs have some form of cognitive impairment or dementia diagnosis (ADI, 2023; Mukamel et al., 2023; Nordin et al., 2017). Pierse et al. (2019) estimated in their Irish prevalence study that 72 percent of all residents in LTCFs have some form of dementia. This is significant in the LTC discourse, as it points to the characteristics of residents in a LTC facility and the consequences when applying the rights in the context of capacity. Yet, current care systems are seen as inadequate for people living with dementia, where best practice points to small numbers in care facilities as opposed to the larger cohorts as in current care (Cahill et al., 2012; O'Shea et al., 2019). Older persons with a high level of dependency in combination with cognitive impairment due to dementia make them exceptionally frail (Cadigan et al., 2012), and by being

³ Dementia is used as the umbrella term for a range of conditions. Most common dementia diagnosis is Alzheimer disease, yet there are over 200 different diagnosis that are classed as dementia (ASI, 2024).

in LTCFs those residents may, both physically and metaphorically, have lost their voice (AGE Platform Europe, 2021).

The discourse formation of needing LTC is based on frailty, dependence, and vulnerability, normalised through healthcare professionals' assessments of the older person, indicating the further marginalisation of the older person in LTCFs. As there is clearly a need for LTC, the next section explores the construction of LTC systems and, specifically, what characterises the LTC system in Ireland.

Table 3: Definitions, characteristics and comparison of LTC systems

International:

How LTC for older people is developed and organised across the world differs greatly. A general; definition of Long-Term Care (LTC) is following: “a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care. The daily living activities for which help is needed may be the self-care activities that a person must perform every day (activities of daily living, or ADLs, such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions) or may be related to independent living (instrumental activities of daily living, or IADLs, such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone)” (Social Protection Committee and European Commission, 2014, p. 11)

A range of LTC services exist. Most common is informal LTC provided by family member(s).

Formal LTC care can be referred to as nursing homes, assisted living, aged care, residential care homes, care homes, LTC facilities, residential care facilities.

Despite the differences of LTC systems around the world, one common feature is the expenditure on LTC, including the divided expenditure on public and private sector of LTC.

Majority of formal LTC workforce is comprised of women (between 80-90%).

In the EU27, about 6.3 million people work in LTC, which is 3.2% of the EU’s entire workforce.

There is also a divide between countries whether LTC is social care or part of the acute and medical healthcare.

Ireland

Formal LTC sector in Ireland is predominantly referred to as Nursing Homes. HIQA (2022) estimated that around 32 000 people live in LTC facilities in Ireland.

	Voluntary <i>HSE – funded bodies under Sections 38 and 39 of the Health Act 2004</i>	Private <i>One provider can have more than one facility, a trend in recent years of group corporate ownership</i>	Public <i>Health Service Executive (HSE)</i>
Number of Beds 2019	1,123 (4%)	24,981 78%	5,864 18%
Number of Centres 2019	20	443	122
Number of Beds 2020	978 3%	25,517 80%	5596 17%
Number of Centres 2020	17	443	113
Number of Beds 2021	946 3%	25,574 80%	5,322 17%
Number of Centres 2021	17	439	111
Number of Beds 2022	921 3%	25686 81%	5067 16%
Number of Centres 2022	17	429	111

Sources: Eurofound, (2020); HIQA (2020; 2023); NHI (2020); OECD, (2015); WHO, (2022)

4.4 The long-term care system

It is evident from the discourses of ageing and frailty that there is a need for formal LTC both internationally and in Ireland. The provision of care builds on the contingency of dependency and its management; however, how the provision of care is systematically organised can differ significantly between countries, sometimes even within a country (Eurofound, 2020). Table 3 provides general definitions and descriptions of the LTC system both internationally and in Ireland. This section provides further knowledge on the systematic provision of formal LTC, particularly in Ireland, by examining the key characteristics of the LTC systems that define discourse formation. As seen in table 3, and through the search of literature on LTC for older people, it becomes apparent that the definition of LTC is not linear. It can take many forms, and no universal or simple definition exists (OECD, 2020). This range of variance in definitions of LTC points early on to a discourse formation of complexity and that LTC can be provided, and should be provided, through diverse and inclusive care (WHO, 2016a). As part of the healthy ageing commitment from the WHO, the World Health Assembly (WHO, 2016a), in which 194 countries participated in May 2016, it was agreed that every country should have an integrated LTC system specifically for older people. However, a few participating countries have these systems in place, and it was also acknowledged that health services are generally designed to treat acute one-off conditions and lack coordination in providing care services beyond the acute sector (WHO, 2016a). This reflects a devalued focus on care outside the acute sector, a care sector which often affects those with chronic illnesses. As noted in Chapter Three, when a country has a growing population of older people (>65 years of age), LTC provisions require transformations to align with the changes in those populations (Matthews et al., 2016). However, the LTC sector has not received the same attention as acute care, and LTCFs worldwide have been marked by long-standing structural deficits, underinvestment, a lack of qualified staff, and a lack of diversity in services (Estabrooks, 2021; OECD, 2020; WHO, 2016a).

The majority of LTCF in Western countries were historically modelled in the hospital setting, being architecturally reproduced as a clinical, medically focused space with long corridors, nursing stations in positions of observation, ward-like multiple occupancy rooms, and large communal areas (de Boer et al., 2018). Environmental structures are part of the function of surveillance (Foucault, 1977); nursing surveillance to maintain older persons' care needs aligns with the institutional rules of LTCFs. LTCFs have been referred to as 'home from home'

(Kenkmann et al., 2017; Moore & Ryan, 2017). In the past 15 years, there has been a cultural change towards more care where the resident of LTC is in the centre (person-centred care), and the restructuring of architecture has focused on creating home-like environments (Kane & Cutler, 2015). Kenkmann et al. (2017) pointed out that the space has a conflict with two main functions; one that of 'home' of the resident and second the staff's workplace. These two functions must be organised differently and can have an impact on the space. Understanding the environment is significant, as it impacts residents' sense of belonging and ability to perform activities (Johansson et al., 2022). The use of the term 'beds' to illustrate the older person in LTCFs indicates that a bed is their home. Yet, there is no reference to their space being an apartment or studio, meaning that the bed (which can be in a shared room) is the 'home' of the older person. Simultaneously, they negotiate space with the staff and their ability to work (Nettleton et al., 2018). The transformation to a home-like environment stems from the discourse changing from a medical model to a social care model with increasing visibility and discourse of person-centred care (Donnelly & MacEntee, 2016; Kane, 2015).

In both disability services and care for the older person services, there is a distinction between the medical model and the social care model. The debate is whether LTC is referred to as social care or falls under generalised healthcare (Zùniga et al., 2015). The social model emphasises personal care and aligns with person-centred care with holistic ethos, while the medical model focuses on the treatment and provision of medical care (Haegele & Hodge, 2016). At the macrolevel, the distinction has been represented by how to financially structure care provision, and in that sense LTC is often referred to as social care (Humphries et al., 2016). In recent years, the emphasis has shifted away from the distinction between social and medical models in the context of LTC for older persons. Instead, discussions have centred on the provision of integrated care, led by the WHO (2019b) publication of a model of Integrated Care for Older People (ICOPE) which aligns with the healthy ageing policy. However, implementing integrated frameworks for older people is not without challenges, as Bajeux et al. (2021) highlighted in their French review of ICOPE. They identified deficiencies in the execution of comprehensive programs for older people, which led to increased fragmentation of their care (Bajeux et al., 2021). Additionally, a systematic review of integrated care by Briggs et al. (2018) revealed that there were insufficient integration strategies at both the meso- and macro-levels, with these gaps encompassing both knowledge and strategy deficits. What seems to be a contingency irrespective of whether LTC for older people is labelled as social care, medical model or introduce in an integrated care framework, is that LTC for older

people continues to be fragmented, under resourced, and contradictory to the text of governmental policies, not prioritised (Browne, 2016; Mosca et al., 2017; Ranci & Pavolini, 2015).

4.4.1 Long-term care in Ireland

Archaeological digging into the literature on LTC in Ireland reveals how LTC for older people has been viewed, and how the LTC system in Ireland is produced. To fully distinguish the LTC sector in Ireland through the FCDA, an epistemological approach is required. In the Irish LTC context, this means that the episteme prior to 2005 is different from the post-2005 (establishment of HIQA), and, as per Foucault (1972), different epistemes do not mean better or worse; the contingencies between epistemes are part of the formations of the discourse. This also illustrates that the FCDA literature review requires flexibility in the search timeline.

From a historical context, the provision of care (formal) for the older person in Ireland was primarily focused on institutional care for the most impoverished. In the nineteenth century, some provisions for the poor were provided, but this was not standardised. Moreover, families were responsible for caring for older people (Gillick, 2018). A contingency of extreme poverty was, in 1838, the Poor Law (Ireland), which established workhouses or country homes which were places where the destitute went (Irish Legal Blog, 2024). Over time, specialised institutions have been developed to provide LTC for older people, those with mental health challenges, and people with disabilities (Gillick, 2018). Following second world war post-war development, 'nursing homes' or 'long stay hospitals' were established, often run by religious orders and voluntary organisations. Formal assistance and support for older people living in their own homes became available much later, and there was a general assumption that care and support would be informal with the help of the family (Timonen & Doyle, 2008). This was constant until the end of the 1980s when there was a movement to reform Irish LTCFs (Mercille, 2017). In the 1990s, Irish LTC beds were predominantly provided by Health Boards (precession to the HSE) in the form of public beds and with few privately owned facilities (Mercille, 2017). In 1998, the Irish government established tax relief for private providers, pursuing a neoliberalist approach to LTC for older people (O'Halloran, 2005; Mercille, 2017). Over time, the dominance of the public sector in the provision of LTCFs has reduced, particularly during the COVID-19 pandemic (ERSI, 2024).

In the 2000s, there was a significant epistemological shift in Ireland's LTC sector (Mercille, 2017). In 2005, Raidió Teilifís Éireann (RTE, 2005), the Irish national television broadcaster, aired an exposé of systematic abuse and poor care practices in an LTC facility in Dublin, named the Leas Cross scandal⁴. This led to public and political concerns, and provided a catalyst for the formation of the Health Information and Quality Authority (HIQA) in 2007, with the first care regulations and standards (HIQA, 2009) for older persons residing in LTC. New standards and requirements created particular requirements related to buildings and structures. This furthered the neoliberalist agenda as rather than investing in meeting these standards in public facilities, there was further incentive to establish private LTCFs through, for example, tax relief and support in building costs (Mercille, 2017). However, O'Shea et al. (2017) pointed out that there has been a narrow view on formal LTC in Ireland, associated mostly with 'nursing homes', with few other options available. The 'scandal' discourse is significant part of the Irish LTC discourse and despite legislation changes, more recent scandals have been reported in Ireland, such as the Brandon and Emily report⁵ (National Independent Review Panel & HSE, 2021; 2023).

These shifts in provision led to a significant transformation in the distribution of LTC beds in Ireland, with the majority being public beds in the 1990s to privately provided beds (HSE, 2012). Consequently, with a reduction of public beds and a rising demand, the majority of LTC beds are currently provided by private facilities, albeit with a significant number of beds being financially supported via the publicly funded 'Fair Deal' scheme (NHI, 2020). Nursing Home Support Scheme, referred to as 'Fair Deal Scheme', is currently the only statutory scheme in place for LTC for older people in Ireland (O'Shea, 2017) and it does not extend beyond LTC facilities. An estimated 80 percent of all LTC residents avail the NHSS system (NHI, 2017). There are also reports of financial differences in the weekly contribution negotiated between the LTC facility and the National Treatment Purchase Fund (NTPF), which is run by the Irish

⁴ The Leas Cross scandal erupted in Ireland when the nursing home with this name, located near Swords in Dublin, closed several weeks after a 2005 Prime Time television report revealed sub-standard living conditions there.

⁵ The Brandon report refers to serious sexual incidents committed by a resident in a public residential care facility for adults with disabilities between 2006 and 2016. The Emily report refers to a resident reporting rape committed by a staff member, revealing physical or sexual abuse in relation to 21 past or current residents. Both reports highlight serious systematic failures in safeguarding vulnerable residents.

State. The Nursing Homes Ireland (NHI) association, which represents the majority of all private facilities in Ireland (80 percent of all private and voluntary facilities), has pointed out these financial discrepancies, noticeable between private and public facilities. They argue that public facilities have received 50 percent more than private facilities in weekly contributions from NTPF (NHI, 2020).

As seen in Table 3, at the beginning of this section of general information on LTCFs in Ireland, there are currently three types of LTCFs providers in Ireland, with private providers being the largest group of care providers accounting for 80 percent of all LTC beds (HIQA, 2023; NHI, 2020). In recent years, it has been noted that an increasing number of LTCFs are large (over 100 beds) and operated by the same providers, which are increasingly international corporations (HIQA, 2019; Wren et al., 2017; ERSI, 2024), indicating that the same entity (either a person or company) runs multiple facilities. It is also observed that the provision of care by sole suppliers is reducing as the ERSI (2024) notes the growth of large corporate providers. Fourteen corporates now provide 38 percent of LTC beds (ERSI, 2024). While the literature review did not seek to include editorials, for the Irish context, an editorial in the Irish Times (10th of January, 2024) provided a good description of the different objectives of the LTC sector. The editorial identified objectives such as state-high care quality, corporate profits to return to lenders in private equity, economic and international climates, market control, difficulties if these entities withdrawn, and challenges in care provision in rural areas. These changes marked a temporal shift from benevolence to profit. In addition, by 2023, smaller LTCFs were closing down, citing increased costs as a factor (NHI, 2023). Wren et al. (2017) and HIQA (2023) emphasise that if the trend of a small number of owners operating an increasing number of centres was to continue in Ireland, policy-makers would need to be mindful of the country's dependence on private LTCFs to cater for an increasingly ageing and dependent population — and specifically Ireland's potential dependence on a smaller pool of large-scale providers. There is some European evidence that staff working in small-scale LTCFs have higher job satisfaction, lower work demands, more time with residents, less burnout, and improved teamwork than facilities with a large number of beds (Adams et al., 2017; Vermeerbergen et al., 2017; Willemse et al., 2014). Yet, similar data do not exist when reviewing texts of LTCFs in Ireland. Although HIQA (2016) publish individual inspection reports for each facility in Ireland, there appears to be a lack of data comparing public, private, and voluntary facilities. No current independent Irish systematic study comparing private LTCFs with public facilities in relation to care provision and its quality was found (Mercille,

2017). The ERSI (2024) report emphasised how lack of data makes it difficult to analyse care provision in LTCFs in Ireland and suggests a centralised data set.

In contrast to this overreliance on LTCFs, the Department of Health in Ireland has declared that older people should be supported to live at home and in their communities for as long as possible (DoH, 2012; HIQA, 2021). In addition, through a strategy of integrated care similar to WHO's strategy, the National Integrated Care Programme for Older Persons (NICPOP) was set up as a framework to design and deliver integrated care for older people across local communities and hospitals with the objective of the older person to stay at home as long as possible (NICPOP, 2012; DoH, 2014). However, to date, there has been no reform or restructuring of the LTC sector, and there continues to be no statutory obligation for Ireland to provide home care, despite various calls to do so (Citizens Assembly, 2017; Sage Advocacy, 2020). There are plans to establish a Commission on Care for Older People in 2024 to "examine provision of health and social care services and supports for older people and make recommendations to the government" (DoH, 2023, p.1). The discourse on the overall structure of the Irish LTC sector for older people provides insight into the contingencies of how institutions function. Foucault (1972) highlighted that all elements within an institution create language and norms. It is seen in terminology and statements where the LTC is reduced to the term 'bed' and yet policy statements from governmental institutions promote individual choice. In practice, a choice that does not exist (Sage Advocacy, 2023a). There is no doubt that formalised LTC has a fundamental role in the care continuum; however, Hainstock et al. (2017) emphasised that there is continuous evidence that the LTC sector is disintegrated, unsystematic, and unequal in access and funding. The way LTCFs are structured in terms of access, finance, support, and variances between public and private providers shows that there is a conflict between the provision of LTC from a structural societal perspective and the provision of care from a policy- and person-centred care perspective (ESRI, 2024; Murphy & O'Sullivan, 2021). This clash could be significant when applying a human rights approach in LTC facilities.

4.4.2 Staff as part of the LTC facility

The main subject position for this study is older people; however, staff are a key component of the LTC facility and, therefore, an inherent part of the discourse. Their positions in LTCFs reveal the structures of LTCFs and the power relationships that may exist. With LTCFs as institutions, they have routine procedures. This maps to an organisation's management of

resources, as the practices need to be practical and efficient. Yet, LTC is about people and older people, where safety, a sense of self, and quality of life are empowered for meaningful living. These two aims within facilities are, at times, in conflict with each other in terms of resource efficiency, and older people as individual persons rather than collectives (Pirhonen & Pietilä, 2015). In the discourse on LTC, this balance or a possible lack of balance is an important quality issue in since it affects the structure, delivery, and experience of LTC for both staff and residents. Foucault (1970) refers to this as 'order of things' and in addition to the formal policies and protocols, there are social practices and systems within organisations which may not be explicit, but are ingrained, produced and reproduced. While LTCFs promote and support person-centred care at its core, the system in which an organisation exists (all of the elements of an organisation, such as cultural, governance, etc.) has its own explicit rules and systems. The institution of LTCFs for older people has a set of rules and norms, some of which are public and regulatory (standards and policies), whereas other rules and norms are within the institution itself. The facility is where residents, staff, and family members meet and create relationships between constructions within the discourse (Danaher et al., 2000; Foucault, 1972).

Thus, the staff at LTCFs play a significant role in residents' everyday lives. Not only does staff support and assist the older person in their ADLs, but staff also have the opportunity to promote social connections. By creating social relationships, staff are in a vital position to support residents' decision-making and autonomy (Sixsmith et al., 2017; Saeteren et al., 2016). Knowing the resident is also important in providing person-centred care, as detailed in the next section. However, if staff members, often seen as a collective homogenous group, are devalued and unsupported, the institutional rules that govern LTC facilities reflect their ability to support older people (Banks, 2018). Facilities need to be diverse in their skill mix to meet the various needs of older people. As seen in the discourse on the need for LTC, a range of complex care needs may exist for older people, which requires mixed and highly skilled staff (Spilsbury et al., 2011). Internationally, the LTC sector is hindered by high staff turnover, low-level support, low investment, and poor organisation of work (McGilton et al., 2012; Mukamel et al., 2023). Staff working in LTCFs for older people are often poorly prepared because of the complexity of the care needs of the older person (Hockley et al., 2017). Challenges within LTCFs in terms of skilled staff are also related to having an adequate number of staff. The Organization for Economic Co-operation and Development (OECD) (Muir, 2017) highlighted that staff shortages within LTCFs, as well as other healthcare sectors,

intensify as the demand for nurses continues to increase, as well as a shortage of skilled healthcare assistants and nurses' aids, which is already visible in many European countries (Koopmans et al., 2018). However, nurses play a vital role in maintaining individual personhood through their leadership and evidence-based knowledge to promote individualised healthcare interventions in LTC (Sullivan & Willis, 2018).

The LTC workforce, both in the EU and Ireland, is dependent on foreign workers, and 7.9 percent of the EU's LTC workforce is made up of foreign workers, compared to 4.8 percent in general healthcare. Ireland is at the top end of the EU countries, with an estimated 19 percent of the Irish LTC workforce being foreign workers in 2020 (Eurofound, 2020). Once again, there is a lack of data on staff working in LTCFs in Ireland, and currently, there is no Irish national mandatory staffing ratio for LTC sector (DoH, 2019a). Nurses working in LTCFs need to be registered with the Nursing and Midwifery Board Ireland (NMBI); however, the majority of direct personal care is provided by healthcare assistants (HCAs) under the supervision of registered nurses. HIQA (2016) expects each LTC facility in Ireland to have at least one registered nurse on duty at all times, and the number of staff members is inspected in relation to the residents' needs and the size of the facility (both in terms of layout and number of beds). Currently, there is no legal regulatory requirement for a recognised training program for HCAs, although HIQA (2016) recommends HCAs to be educated at level 5 on the National Framework of Qualification. The lack of data to make comparisons and conclusions of how staff characteristics may impact the everyday life of older people in LTCFs underscores that it has not been a priority. Hockley et al. (2017) pointed out that care homes in UK have a broken image and majority of the facilities need significant quality improvement, and this creates barriers to recruitment. As there are diverse needs within the population of residents in LTC, there is a strong argument for the need for expertise in gerontological nursing care (Hockley et al., 2017; Phelan & McCormack, 2013). Moreover, Sullivan and Willis (2018) stressed that nurses in LTC have an ultimate stance to change the model of care from a survival and maintenance focus to one focused on thriving and a form of quality-of-life experience. Despite the focus on social care in LTCFs, the care provided is specialised and adapted to the complex needs of those admitted (Zúñiga et al., 2015).

4.5 Person centeredness in LTC

Person-centred care has become embedded in the European LTC discourse (Rosengren et al., 2021) and is a fundamental focus in health services and LTC regulation in Ireland (HSE,

2016b; HIQA, 2016). The term person centredness can be traced back to the mid-twentieth century. For example, Carl Rogers (1957) presented client-centred therapy as an unconditional acceptance of a person's negative and positive feelings and experiences. Through further development specific to healthcare, Tom Kitwood (1997) examined the context of dementia care with the concept of personhood, and argued that person-centred care was founded on a relationship with others that gives value to the person. McCormack (2004) further developed a person-centered care approach within nursing with core principles of being in relation, being in place and being with self. This approach has been further developed to include prerequisites for nurses' skills, as well as organisational factors influencing the delivery of person-centred care (McCormack & McCance, 2017).

Person-centered care is grounded in human rights principles, and the two approaches to care (person-centred care and human rights approaches to care which is detailed in Chapter Five, section 5.5) are not competitive (HIQA, 2019). On the contrary, they complement each other, and if person-centred care is fully implemented as the theory intended, then person-centred care is human rights-based care. A major component of person-centred care is self-determination, which is also central to human rights. Self-determination is to be seen as a "process in which a person has control, legal and ethical rights, knowledge and the ability to make a decision of their own free choice" (Ekelund et al., 2014 p. 121). Person-centred care places the person (patient, client, resident) central to the care management (Josefowitz & Myran, 2005). The person-centred approach is supported by the WHO (2021), with the aim of making healthcare more humanistic by grounding it in fundamental principles of human rights, such as dignity, equality, participation, empowerment, access, and fairness, as well as fostering a collaborative relationship between healthcare providers and patients. Figure 7 (from McCormack & McCance (2017) on their person-centered framework) demonstrates the language around person-centered care and it can be observed how closely it aligns with the language used in human rights principles (see Chapter Five, section 5.4).

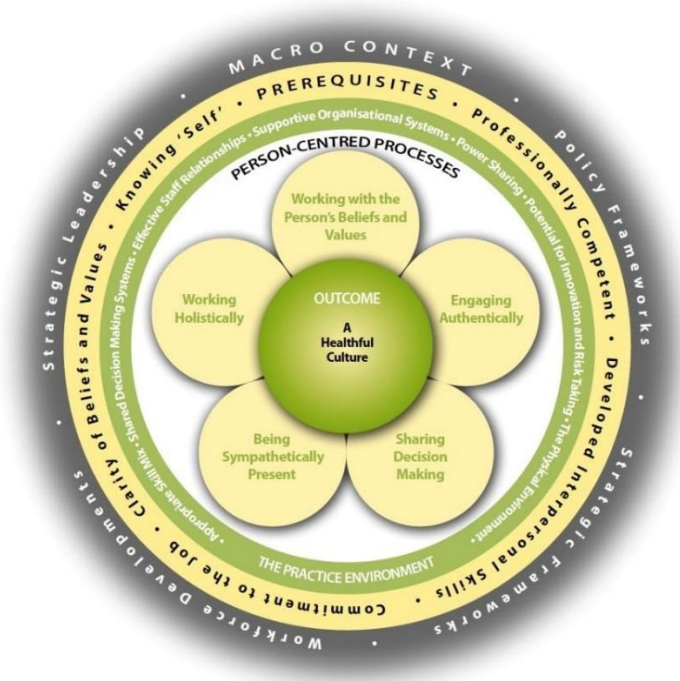


Figure 7: Person-centred nursing framework (McCormack and McCance, 2017)

Since the early 2000s, person-centred care and the associated cultural change have aligned with the shift from a task-oriented medical model in LTCFs towards social care models in which dementia has been given a more holistic view than medical (Kitwood, 1997; Jönson & Harnett, 2016; Shakespeare et al., 2019). The right to have choices, wishes, and requests respected is inscribed in the guidance documents (HIQA, 2016) governing care and services for both younger and older people. Personhood in care for older people has been theorised through concepts such as personalisation and person-centred care, an approach juxtaposed to task-oriented care, common in institutional care (Kitwood, 1997; McCormack & McCance, 2017). While the construct of ‘patient’ can be associated with the medical model, the construct of ‘person’ is linked with a life story. Indeed, Ekelund et al. (2014) identify fundamental differences in terms with patient-centred care focusing on function and person-centred care focusing on meaning. Kitwood (1997) also noted that being a person can be associated with rational thinking, and when a person suffers from dementia, their ability to think rationally diminishes. This can lead others to compromise personhood and assume a paternalistic approach to care that is task-based rather than based on person-centred relationships. McCormack & McCance’s (2017, p3) description illustrates this: “[...], the older person with

dementia is not seen as a 'person' and therefore is not afforded the same standards as another person, enforcing the concept of 'otherness', or not quite like us".

Brooker and Latham (2016) argued that despite PCC becoming central in LTCFs policies and written into mission statements, job descriptions and protocols, the lived experience of those living in residential facilities, particularly those living with dementia, can be anything rather than person centred care. Several studies have confirmed this argument and shown that providing person-centred care is met with a range of challenges (Backman et al., 2024; Byrne et al., 2023; Nolte et al., 2020; Vassbø et al., 2019). Person-centred care is a multilayer concept, as McCormack and McCance (2017) theorised, which impacts several different levels in healthcare organisations. For example, factors such as organizational support and job satisfaction influence staff's provision of person-centred care (Vassbø et al., 2019). Additionally, Røen et al. (2017) conducted a study surveying over 1000 staff from 45 LTC facilities to provide person-centred care and examined a wide range of factors. The most crucial factor in providing person-centred care was job satisfaction (Røen et al., 2017). Other studies have found that routine practices such as rigid schedules, limited time for activities, constrained bedtimes, and few opportunities for flexibility hinder the provision of personalised care (Güney et al., 2021; Schenell et al., 2019). This points to the institutional rules that dictate discourse formation.

There is a close relationship between PCC and human rights approach to care and they can even appear complementary as HIQA (2019) states in their guidance document on human rights approach to care. However, there are several complexities and potential conflicts that can arise if attempting to integrate these frameworks, and raises question of how personhood is viewed (Tieu et al. 2022). While personcentred care focuses on the individual older person needs, preferences and values human rights approach is grounded in international human rights standards with focus on legal and ethical obligations to uphold rights (Phelan & Richard-Clarke in Phelan, 2020). The conflict arises when for example respecting an older person's autonomy in PCC can conflict with the human rights principle of protection. Additionally, a person with advanced dementia have lost sovereign autonomy which can make PCC difficult, the human rights principles still indicate a right to health and life. Balancing PCC and the individual needs with the systemic rights of HRBA requires addressing not only immediate individual care but also structural problems (Australian Commission on Safety and Quality in Healthcare, 2019; Phelan et al., 2020; WHO, 2020).

4.6 Legislation, regulation and policy in LTC

As already observed in the previous sections, institutions, whether government, authorities, or healthcare organisations, are important knowledge producers within the discourse. Foucault (1972) explains, as part of archeological assumptions, that it is as important to highlight who is talking as well as what is being said within a statement as part of discourse formation. This section considers at strategies that are put in place through legislation, regulation, and policy in LTC in the Irish context. Legislation and the regulating system provide rules for the conditions for existence in discourse (Krarup, 2021).

The discourse formation of legislation, regulation, and policy in LTC is important to present, as it has a fundamental impact on the language used and subsequently how LTCFs in Ireland complies and operates. Although legal text is generalised, with different wording than ordinary language, it provides normative power in discourse (Green, 2017). As stated in this chapter, there are various variations in how LTC systems are not only defined, but also structured and financed. These variations extend to how care provisions to those in LTCFs are legislated and regulated, which in turn can have an impact on the quality of care (Easton et al., 2017; Matthews et al., 2016). LTCFs in Ireland operate under a range of legislation, the most significant of which is the Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013). Following the previously mentioned scandal of RTE's (2005) undercover broadcast, the Health Information and Quality Authority (HIQA) was established as part of the new regulative legislation. HIQA is responsible for the registration and inspection of all private, voluntary, and public LTC facilities in Ireland, as well as other healthcare such as hospitals and disability services. HIQA (2016) publishes a set of standards based on the regulations that each facility is inspected against, and publishes their reports to the public. Lloyd et al. (2014) pointed out that scandals play an important mechanism in policy changes and can accelerate regulative policies in LTC sector, thus HIQA was established as a contingency of the Leas Cross exposé by RTE in 2005.

Pre-2009, LTCFs in Ireland were inspected by the HSE but there was no regulating document instructing on how to provide the care (HSE, 2006) and in many cases, the HSE was conducting inspections on their own LTC services. Another challenge was the lack of legislative support to apply punitive sanctions for facilities that were of concern. The change in regulative practices was fundamental in Ireland, and the LTC for older people standards

and regulations published in 2009 (revised in 2016) enabled the commencement of regulatory inspections (HIQA, 2009, 2016). These standards created a new discursive space and referenced legislative and evidence practices in other European countries to drive the care in LTCFs in Ireland forward (HIQA, 2009, 2016). Power and Lavelle (2011) believe that the launch of HIQA in 2007 has had a pivotal impact on the change of care ethos in LTC, with a shift towards person-centred care and quality-driven leadership. For LTCFs, regulation standards are divided into eight themes (see figure 8), namely; person-centred care and support, effective care and support, safe care and support, better health and well-being, use of information, use of resources, workforce, and the final theme is governance and management (HIQA, 2016). The standards focus on the rights and diversity of each resident and HIQA's role is to ensure that these standards are not only evidenced, but also actively promoted (HIQA, 2016). As HIQA's regulatory scope expanded, it also launched guidance on a human rights-based approach in social care services in 2019; this is presented in chapter Five section 5.5 under discourse of human rights based approach in healthcare.



Figure 8: HIQA's eight themes as per National Standards for residential care centres for older people (HIQA, 2016)

Including HIQA standards in the review of power-knowledge discourse is crucial, as HIQA plays a significant role in the development of regulatory language within the context of LTCFs in Ireland. For example, the progress of person-centred care in LTC in Ireland was an

epistemological change in the provision of care within LTC. It followed the international trend of standards changing towards a culture where the resident is in the centre of care (Kane, 2010).

HIQA uses regulatory practice via announced or unannounced inspections, and in this ways LTCFs are required to demonstrate that they comply with the standards. Figure 9 exemplifies language used by HIQA (2023) in an inspection report of a LTC facility, publicly available on the HIQA website. Compliance is a common reference for the HIQA standards and reflects the normalising practices expected through a regulatory gaze.

Regulation Title	Judgment
Capacity and capability	
Regulation 15: Staffing	Compliant
Regulation 16: Training and staff development	Compliant
Regulation 22: Insurance	Compliant
Regulation 23: Governance and management	Substantially compliant
Regulation 31: Notification of incidents	Not compliant
Regulation 34: Complaints procedure	Compliant
Regulation 33: Notification of procedures and arrangements for periods when person in charge is absent from the designated centre	Compliant
Quality and safety	
Regulation 10: Communication difficulties	Compliant
Regulation 11: Visits	Compliant
Regulation 5: Individual assessment and care plan	Compliant
Regulation 6: Health care	Compliant
Regulation 7: Managing behaviour that is challenging	Compliant
Regulation 8: Protection	Compliant
Regulation 9: Residents' rights	Substantially compliant

Figure 9: Example of language used in inspection reports published by HIQA (2023)

HIQA inspection outcomes can be divided into three categories: fully compliant, substantially compliant, and not compliant towards the regulating standards. Compliance is referred to as conformity with regulations as per legal acts, mainly the Health Act (2007). The LTC facility has a named provider as per the Health Act (2007), and through the provider, a nominated Director of Nursing (DoN) who is responsible for the operationalization of care in the facility. Providers, in conjunction with the DoN, are responsible for the facility's compliance with the standard. This is significant in terms of power relationships within the context of LTCFs; the provider and DoN, together with the inspection team/inspector from HIQA, are key players in

maintaining and inspecting the regulation of compliance in a facility. Therefore, the standards and regulations produced by HIQA (2016) and stated in the Health Act (2007) are legitimised documents that provide knowledge within the discourse of regulation. HIQA's (2016) standards and the regulations draw on the Health Act (2007) to promote and encourage individual residents' care needs, yet in the inspections, the language becomes specialised and clinical referring to compliance. In addition, there are no definitions or practical guidance on how to operate these standards; they are to be seen as the goal of care, and each facility is tasked with creating centre-specific policies on how to operate (HIQA, 2016).

Foucault (1977) terms this as a dividing practice in which, on the one hand, the LTC facility is encouraged to maintain itself (create centre-specific policies); on the other hand, there is categorisation, objectification, and clear structural goal (achieving full compliance) that drives the care in LTC (HIQA, 2016). The main reason for a regulating body, such as HIQA, is continuous quality improvement and the minimum standards required for that quality to be continuous. This itself represents a powerful discourse in the current episteme and is immersed in 'truths' related to quality care standards and risk assessment. O'Dwyer (2015) found in a review of European regulation of LTC facilities, three different models. The first model, common in Northern European countries, follows a self-regulation model associated with high level of quality of care. Many countries, including Ireland, operate on the second model referred to as command-and-control regulatory approach, which was associated with a moderate standard of quality of care. The third model was seen in Mediterranean and Eastern European countries with a limited regulation, thus resulting in a lower standard of care quality (O'Dwyer, 2015). In an international review of regulators, Poldrugovac et al. (2023) highlighted that as the LTC sectors are set up differently, regulation can differ between countries. They pointed out that countries that are required by law to have quality management systems in place (as in Nordic countries), LTCFs have structural supports for quality of care. Poldrugovac et al. (2023) also pointed out that regulators need to navigate complex interactions with providers.

In Ireland, HIQA has also been viewed as a mix of deterrence and compliance model, where deterrence is punitive and adversarial, and the other model is compliant with prevention and encourages resources to make improvements (HIQA, 2016; Walshe, 2001). The blend of the two models gives HIQA an opportunity to react when there is an incident, while simultaneously maintaining cooperation and support for compliance (Walshe, 2001). As Poldrugovac et al. (2023) highlighted the complex relationship between LTC providers and regulation, this is

evident in Ireland by HIQA's mandated reporting to the Department of Health who also oversee the HSE and thus the funding of nursing home support schemes as well as the operating provider for public LTC beds (Lombard & O'Nolan, 2019). HIQA standards (2009; 2016) highlight that the care provided should be person-centred, and they provided a catalyst in the implementation of person-centred care in LTCFs in Ireland. As Broderick and Coffey (2013) point out, person-centred care theories are a key feature in the care of older people. In a study on person-centred care in LTC in Ireland, Kelly et al. (2019) emphasised that person-centred care is a concept with several definitions and found three dimensions of person-centred care: hospitality, safety, and everydayness. In addition, it is notable that HIQA (2016) does not provide a definition of person-centred care, and it has been up to the LTCFs themselves to determine what constitutes person-centred care. Prior to establishment of HIQA, policy planning around LTC in Ireland was ad hoc, and there was no national common needs assessment of LTC (OECD, 2011). Policy development is required as healthcare is notoriously known to be a high policy driven sector, yet policy development is often complex and is assumed to be associated with quality research and governmental policies (Quaglio et al., 2016). However, policymakers at all levels are likely to be influenced by different knowledge sources and can be under pressure from a range of interest associations. Furthermore, the regulation of LTCFs has been associated with risk (Cunnigham et al., 2020) and led to an increasing focus on additional policies and procedures underpinned by risk aversion, which is a fundamental aspect of public health approaches. Risk, itself, is based on normalising practices (Foucault, 1978) where concern focuses on people, organisations or other phenomena which present outliers to expected measures such as standards of care.

Despite policies ultimately influencing older residents in LTCFs, the views of older people are seldom sought (Eley, 2016), however, in line with HIQA inspections and the expansion of the patient experience settings (HIQA, 2022), older residents' voices are being encouraged. In November 2022, The National Care Experience Programme⁶ published results from a nationwide survey of residents' experiences of living in LTCFs. It was part of the response from COVID-19 expert panel recommendations (see section 4.7). Overall, the survey found that most residents had a good experience in their LTC facility, yet areas where poorer

⁶ The National Care Experience Programme is a joint initiative by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health in Ireland.

experience was found was in having a staff member to talk to and being involved in decisions about the care (National Nursing Home Survey, 2022). It was the first time a survey of this magnitude (national) was conducted with the residents of LTCFs in Ireland.

4.7 COVID-19 and Long-term care for older people

COVID-19 constituted a significant challenge to the LTC sector both globally and in Ireland and brought unprecedented challenges to LTCFs, with outbreaks and disproportionately high fatality rates (Comas-Herrera et al., 2020; UN, 2020). Reports of abandoned facilities, overcrowded morgues and staff having no access to personal protective equipment (PPE) were common challenges within a large number western countries (OECD, 2021; UN, 2020), particularly in the first year (2020). What exacerbated these challenges for LTC settings in most countries was the clear exclusion of the LTC sector in the planning and management of COVID-19 at the macro level (Kelleher & Twomey, 2020; Rocard et al., 2021). This was especially evident in Ireland as many of the LTC facilities were outside the HSE governance framework. This exclusion had an impact on resource allocation, such as PPE and COVID-19 testing, as well as staff allocation (e.g. when staff were not able to work due to COVID-19, there was no access for replacement) (Giri et al., 2021; McGarry et al., 2020; White et al., 2022).

Early on in the pandemic, it was stressed that older people living in LTCFs would have a higher risk of complications from COVID-19 infection (NPHET, 2020; WHO, 2020b). The higher risk was due to the older person co-morbidity, subsequently rendering the older person further in the vulnerable position (Andrew et al., 2020). It was also pointed out that LTCFs would have a high level of transmission once COVID-19 entered the building. Several organisational and structural factors, such as sharing communal areas, facilities, air conditioning, and personal intimate care provided in an institutional setting with many residents, are risk factors to consider (Cangiano et al., 2020). Prior to COVID-19 activities, such as free movement of visitors and encouragement of resident activity within the community would have increased the risk of transmission. As mentioned in chapter three there were also reports indicating that deaths in LTC facilities were not counted in mortality figures, an ageist stereotype enforced by the view of 'they are about to die anyway' (Peisah et al., 2020).

Several studies of the impact of COVID-19 on staff working in LTC have been produced both internationally and in Ireland (Brady et al., 2022; Navarro Prados et al., 2022; Phelan et al., 2022; Sarabia-Cobo et al., 2021; Savolainen & Ahern, 2022; White et al., 2021). Burnout, anxiety, increased stress levels, and the impact of COVID-19 on the psychosocial well-being of staff have been reported. As staff is a fundamental part of the formal LTC, COVID-19 impact on staff highlights how care provision for older residents may be influenced. Reports on care change during COVID-19 from social connection to more clinical infection prevention have impacted person-centred care practices (Byrne et al., 2023; Hanna et al., 2022; Savolainen & Ahern, 2022; Sweeney et al., 2022). The older person in the LTC facility was further objectified into the dependent individual, and personhood was lost (Ó Néill, 2023).

Ireland was no exception to the challenges described and by May 2020; 60 percent of all COVID-19 deaths occurred among residents of LTCFs (DoH, 2020). Ireland's disproportionate deaths in LTC led to specific Oireachtas hearings about this setting as part of a larger COVID-19 review, in relation to the management in which accounts were given by HIQA, NHI, and the HSE (Oireachtas, 2020). Due to the events of the spring of 2020 and the fact that older people living in LTC facilities are more vulnerable to COVID-19 infection and severe outcomes (NPHET, 2020; WHO, 2020b), the Department of Health in Ireland appointed an expert panel in May 2020 (DoH, 2020). The Nursing Homes Expert Panel examined the complex issues surrounding the management of COVID-19 among the vulnerable population of older people in LTC facilities (DoH, 2020). The Panel produced a report in which they criticised the initial efforts in 2020 for not protecting the most vulnerable and found significant failures in the planning and management of COVID-19 in the LTC sector in Ireland (Kelleher & Twomey, 2020). The report outlined 15 different themed recommendations which the sector was to implement within a 12-to 18-month timeframe. By 2022, a fourth and final progress report was produced, in which some progress was made. Where some recommendations such as improved communication (Theme 13) have been implemented, more strategic recommendations such as integrated care (Theme 15) were still not completed (Kelleher & Twomey, 2022).

Some key characteristics were amplified during the COVID-19 challenge, including the issue of how this could happen, as all reports prior to the first case of COVID-19 in Ireland highlighted the impact it had on older people. Prior to the first case in Ireland, the invisibility of the LTC sector in planning and subsequent responses became obvious. Discourses of public health were exclusively on acute care and ventilator supply accompanied by the battle cry of

‘flatten the curve’ (Motorniak et al., 2023). This eclipsed self-evident risk areas, such as congregated settings, particularly LTCFs. Once the crisis became evident, as the number of infection clusters increased and reports of the incredible trials facilities encountered, the invisible LTC sector became increasingly visible through media and official reports (NHI, 2020; RTE, 2020). Interviews with family members, staff, and management were reported; few interviews with residents themselves were noted, those who were mostly affected by the challenges (RTE, 2020). The invisibility of private and voluntary LTCFs in public health preparations is even more evident. Facilities were divided into different information flows; public LTCFs received information from the HSE, while it was noted that there was a delay in information to private or voluntary facilities. The inequality between centres was noticeable as some facilities were affected by COVID-19 to the brink of closure, while other centres were not affected to a large degree or had no outbreaks (Loubert, 2021). It is noted that during the COVID-19 years, one in five private nursing homes, with under 30 beds, closed equating to the removal of 700 beds in the sector (ERSI, 2024).

As detailed in section 4.4.1, prior to the pandemic LTC sector in Ireland was marked by fragmentation and lack of coherence between stakeholders, facilities and the acute healthsector with private providers often excluded from planning and resources (Phelan et al., 2022). COVID-19 was a crisis that highlighted that existent fragmented sector and underlined the vulnerable position an older person dependent on LTC is in. As seen in previous ‘crises’ and ‘scandals’ such as the Leas Cross, LTCFs were relatively invisible until the scandal becomes public. As Kelleher & Twomey (2020) pointed out Ireland’s LTC sector is detached from general healthcare and is often overlooked in planning. This reflects the status afforded to the sector and its residents and was visible during the COVID-19 pandemic, for example, private providers are the main providers of institutional care in the care of older people and are seldom invited to the planning of care at the governmental level (Kelleher & Twomey, 2020; NHI, 2020).

4.8 Conclusion

This chapter provided insight into the context of the LTC, specifically focusing on Ireland. By examining the ensemble of discourses related to LTC in Ireland, four dominant intersecting discourses allocating ‘truths’ of the sector were identified. First, the older person’s need to access LTC; second, the system within which LTC is provided; third, the discourse formation of person-centredness; and fourth, the legislation and standards upon which LTC acts.

By needing LTC, the older person, by “legitimate” assessment is labelled frail or/and vulnerable, further positioning the older person in a separate group from the rest of the population. Frailty, vulnerability, and often the diagnosis of dementia are factors for older people seeking LTC in institutions. LTC in Ireland is synonymous with nursing homes, and the contradictory policies and legislation that have been implemented in Ireland means that there is no statutory right to LTC other than in residential facilities. Other options, such as home care and assisted living, although they exist and are provided for, are limited in how to access the same. This would indicate a lack of choice early in the continuum of care, where policies at the governmental level (macro) encourage ageing in place, yet practical provision is lacking. The frailest of older people living in LTC facilities is predominantly not a resident by neutral choice but because of the need for staff that provide specialised care under strict regulations and guidance. Person-centred care has become a common care ethos within LTCFs, aligning with holistic care based on relationships and knowing the person. Despite the implementation and acceptance of person-centred care in LTCFs, there are barriers to its practical implementation. The LTC facility itself operates under standards and regulations and is scrutinised for quality of care. The demand for specialised LTC is high, yet LTC facilities are often understaffed, lack staff with gerontological training, and have a poor skill mix. While HIQA, as an authority, produces guiding documents and encourages a human rights approach in LTCFs in Ireland, practical inspections are broken down to domains of compliance equating to quality. Yet, achieving compliance may be the focus of LTCFs, not necessarily providing high-quality person-centred care to the older person. COVID 19 did not provide any new insights; on the contrary COVID-19 was able to highlight existing structures within the LTC sector, stimulating the (re) problematisation of this sector and providing further evidence of how fragmented the sector is. LTC and older people living in residential facilities were not prioritised, once more highlighting the ageist views in society. While this chapter provided the context of LTC in Ireland, next chapter presents the different key factors in determining the construct of human rights of older people in LTC.

CHAPTER FIVE

Human rights of older people

5.1 Introduction

The archaeological investigation into text continues with the examination of discourse formation of the human rights of older people, with a specific focus on the context of LTCFs. This chapter builds on the statements and discursive positions presented in the previous two chapters and follows a similar archaeological literature review. Similar to the review of old age and LTC, the human rights of older people take a broad definition of literature review, where the aim is to conduct a historical digging to establish discourse formations. Chapter Three illustrated the view of the older person (subject), Chapter Four presented the institutional rules and statements that define the LTC sector (context) Subsequently, this Chapter examines the human rights (object) constructed in the literature for older persons in need of LTC.

5.2 Literature search strategy and terminology

The search for literature and subsequently text to analyse followed the similar strategy used in Chapters Three and Four yet with the attention shifting to human rights of older people. Using 'human rights' search word on its own produced a large amount of literature, which indicated that there was a need to the narrow search down. While there has been a focus on the human rights of older people in LTCFs before 2020 (although mostly editorials), COVID-19 demonstrated an increase in publications. Literature was searched up until January 2024, and no limitation was added on the lower timeframe. It was noticeable that most relevant journals and reports were produced from 2005 onwards, indicating how the topic has emerged in the last two decades. Table 4 illustrates the inclusion and exclusion criteria used in the search. As aligned Foucauldian standpoint, it is key not to narrow search criteria excessively in order to reveal dominant discourse formations. However, pragmatic solutions are required in time-sensitive research.

Table 4: Inclusion and exclusion criteria in literature review of human rights and older people

Time Frame	All relevant text until January 2024.
Databases	CINAHL, PubMed, MEDLINE, Google Scholar
Geographical Context	International, but with attention to Europe and Ireland.
Language	English
Participants	Older People in focus, but legal text of human rights included to show its application on older people
Type of text/Publication	Peer-reviewed studies, reports from international organisations, government departments (Ireland), legislation and reports from professional associations. Position papers on rights of older people included. Book chapters included. Opinion and editorials excluded unless they are based on projects or studies.
Setting	Older people in need of LTC, in facilities. Mainly in Ireland, however any text that may have an impact in Irish context included (for example European legislation).
Context	Human rights of older people in LTC facilities.
Key search words (used in different combinations)	Rights, human rights, older people, autonomy, freedom, equality, dignity, self-determination, long-term care, citizenship, social construct, discourse, history of human rights of older people. (Boolean terms used)

The electronic databases CINAHL, PubMed, MEDLINE, and Google Scholar were searched using a range of terms, which were further narrowed down using MeSH and Boolean terms (AND/OR). Other search words that represent human rights principles, such as autonomy, freedom, and equality, were trialed with mixed results. As with previous chapters; policies, legislation, and reports from interest groups were included in the literature review, as they are part of discourse formation. The text sample was narrowed down by initially reading the title followed by the abstract. Appendix 3 presents a flowchart of the literature screening process. Articles, reports, and journals were excluded if the main emphasis was not on human rights or if the context of the journal was not specific to either older people or LTC. Studies that addressed a single principle of human rights (e.g. autonomy or dignity) were included if the principle was the focus of the study (Heggstad et al., 2015; Tuominen et al., 2016; Rehnsfeldt et al., 2022). However, studies that addressed for example dignity in the context of specific care provision, such as dignity in incontinence wear (Ostaszkievicz et al., 2018), were not included. No empirical study was found that addressed human rights as a comprehensive

concept in the context of older people in LTC and had included older people in the study (that is not to say such studies exist). Following the literature review, this chapter presents how human rights have been produced in different epistemes and their significance in the discourse on older people's human rights. This is followed by current progress in human rights legislation. The main principles of human rights are presented to show their impact on older people, specifically in LTC. This chapter also presents how the human rights-based approach (HRBA) has emerged in the context of care delivery. Chapter Five will conclude with how COVID-19 has impacted the rights of older people in LTC.

5.3 Human rights: A history of the present

As Foucault (1972) states, to construct a discourse, one needs to first order and structure the initial context of the topic. Therefore, the initial process involved an exploration of what are human rights and how different epistemes resulted in different distinctive features within knowledge and 'truths' (Danaher et al., 2000). By assuming an archeological stance, various discourse formations are revealed in the history of human rights and the rights of older people in LTC. Figure 10 summarise the significant milestones in those epistemes that have influenced how the human rights of older people have evolved from an Irish perspective.

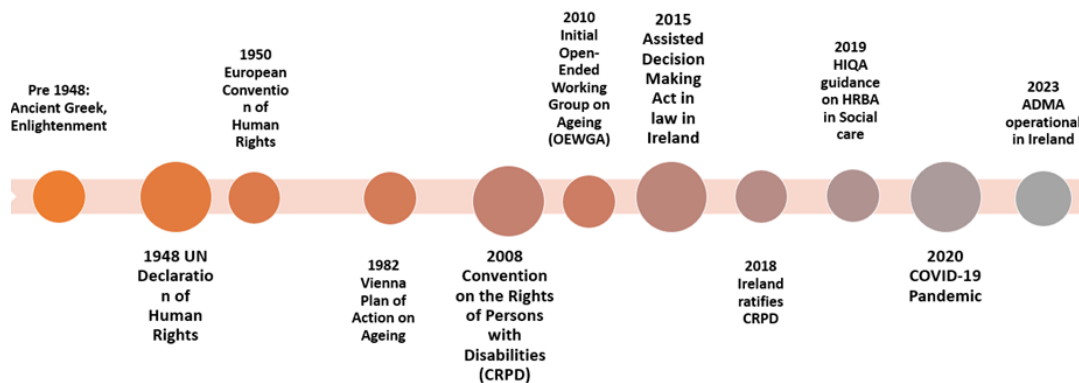


Figure 10: Illustration of milestones in history of human rights (global and Ireland)

As a post-modernist researcher, Foucault studied sociological events, and rights were a concept he included in his research. Foucault (1977, 1978) refers to the inclusion and exclusion paradigm as a societal creation and the binary opposite of who is included in the

description of a discourse, but also of who is not. This is an important assumption to consider when examining the literature related to human rights, particularly the rights of older people and LTC. Several examples of the inclusion-exclusion binary relationship are apparent in the human rights discourse, and as older people, by definition, are self-evident human beings, they should enjoy human rights. However, based on the subject position of older people as vulnerable and dependent on care (as described in Chapter Three and Four), this is not always the case.

Rights for mankind are not a modern concept; philosophers in ancient Greek argued that all human beings are equal by nature and that the foundations for humans to live together are liberty, equality, and justice (Kaur, 2014). Human rights are often historically subject to a person's status in society and could subsequently render other individuals vulnerable to the exercise of power. Constructed 'truths' regarding rights could depend on ethnicity or gender; this elitist perspective represents a dividing practice. For example, the Romans claimed different rights to different levels of citizenship (there was a three-tier citizen level for Romans), and slaves in this period had no rights (Ishay, 2008). Similarly, historical documents that have asserted forms of human rights, such as the English Bill of Rights (1689), French Declaration on the Rights of Man and Citizen (1789), and US Constitution and Bill of Rights (1791), excluded women and people of colour. The declarations were only relevant to certain social, religious, economic, and political groups and were a reflection of the society in which they were produced. Yet the principles in these documents, particularly the right to self-determination and freedom (for the chosen people), are core even in modern documents (Moyn, 2018), disclosing contingencies between epistemes. On a societal level, within previous epistemes, only certain individuals (free men) had rights, and this discourse was sustained until the end of the 19th century and beginning of the 20th century. The suffragette movement at the start of the 20th century saw the start of a new episteme which evidenced lobbying for women's rights (Hoffman, 2016). Most European countries provided women with the right to vote in the early 20th century, and in Ireland, women received the right vote in 1918 (Ryan & Ward, 2018). After the two world wars, particularly the horrific lack of consideration for human rights during the Second World War, the acknowledgment of human rights as a priority became an international concern (Moyn, 2012). This represents a contingency of what could emerge within the post-World War II discourses with the UN Declaration of Human Rights (1948).

Founded in 1945, the UN has become the international representation of nations and a champion of universal human rights with the specific purpose of promoting human rights, improving living standards and social progress, developing positive relations among states, and maintaining peace and security (UN, 2006). Within these discourse formations, the UN engaged with 58 countries after World War II, and human beings were given a subject position of equality with the publication of the Declaration of Human Rights (UNCHR) (UN, 1948). This was significant, delineating 30 articles relating to individual rights, which, although not legally binding, many countries have supported the principles within their own state legislation (Odello & Cavandoli, 2012). Moreover, as rights-based approaches have increased in scope, charters have guided and developed human rights further among other the Convention on the Rights of the Child (UN, 1989) and the Convention on the Elimination of All Forms of Discrimination against Women (UN, 1979). It is the UNCHR (UN, 1948) that has received the most attention, with it being signed by 192 countries and marked a new beginning for the development of modern human rights.

5.3.1 Human rights legislation and progress since 1948

The discourse formation of human rights before 1948 is significant as it points to the exclusion of certain populations in the human rights discourse. With the UNCHR (UN, 1948), a new episteme formed in the discourse on human rights. With the Second World War ending in 1945, the political landscape in the world, but specifically in Europe, was determined for collaboration and unity, which led to the creation of the Council of Europe (CoE) and later the European Union (EU) (Merrills & Robertson, 2022). Being newly established, the CoE in 1950 drafted the European Convention on Human Rights (ECHR) which came into force in 1953 (CoE, 1950). It stimulated a mandate within Europe to protect and promote human rights, and throughout the years, the charter has been part of the development of new policies and guidance regarding human rights (Merrills & Robertson, 2022, ECHR, 2022). It is referred to as a living instrument which indicate there has been a number of amendments since 1950 (ECHR, 2022). The Convention also established the European Court of Human Rights, located in Strasbourg, France, which provides an opportunity for anyone who feels violated in their human rights by a state party to appeal cases. Because of the European Court of Human Rights, the European Convention is regarded as successful (and therefore constructed as legitimate) because it has an effective supervision and control system in its implementation (Spanier et al., 2013).

These European developments were of significance to Ireland; as part of the EU since 1973⁷, European legislation is applicable in the Irish context. However, even if Ireland is to translate EU international law related to the ECHR, it can only be given effect to Irish law through the Acts of Oireachtas or where a treaty right is already provided for under the Irish Constitution (Bunreacht na hÉireann, 1937). Through the Irish Constitution (Bunreacht na hÉireann, 1937), the European Convention of Human Rights Acts 2003 and 2014, and the EU Charter of Fundamental Rights (ECHR, 2022), Ireland upholds the human rights of the ECHR (IHREC, 2020). Martin et al. (2015) stressed that the CoE and EU have vital roles in the future of ageing in Europe and in the protection of older persons' rights. Through its participation in the international human rights framework, Ireland has undertaken efforts to ensure that its constitution, laws, policies, budgets, and practices reflect these legal obligations and achieve, rather than undermine, the minimum standards to which it has agreed.

In the 1980s, a focus on those who had disabilities was raised, and separately, older peoples' positions in society were discussed by UN in 1982 in the first World Assembly on Ageing in which Vienna International Plan of Action on Ageing was adopted (UN, 1982). This focus on recognising marginalized groups lack of human rights led to the UN drafting the Convention on the Rights of Persons with Disabilities (CRPD) in 2006 which was signed into force in 2008. The rationale for a separate rights-based instruments was that generic conventions and declarations of human rights exemplified a diving practice, as they did not address the special requirements of individuals with disabilities; thus, it became necessary to develop a more comprehensive and inclusive approach (Kanter, 2014). Language in CRPD is modern, reflecting a 21st century approach to human rights with responsibilities outlined by states who ratify the Convention (Waddington, 2007). Terms such as participation, legal capacity, and articles that define member states' obligation to implement CRPD articles made the convention more detailed than previous ones (UN, 2007; IHREC, 2018). However, in a policy paper from the Alzheimer Society Ireland (2013) and supported by reports from Sage Advocacy (2015; 2023a), it was stated that in the Irish legislation, the lack of acknowledgement of rights of older people was noticeable and needed to be addressed. One example was in the timeframe of how Ireland ratified the UN Declaration of rights for those

⁷ Ireland joined European Economic Community (ECC) on 1st of January 1973. ECC would later on become European Union (EU).

with disabilities (CRPD, 2007). Although Ireland signed the CRPD in 2007, it was not ratified until 2018, marking Ireland as the last EU country to do so. One of the reasons for the delay was to systematically ensure that the CRPD could be upheld by Irish's law and systems (IHREC, 2018). Delay is a noticeable characteristic of the discourse of rights in Ireland for vulnerable groups, such as older people, as there is an observable lag in both signing rights-based legislation for at-risk groups and implementing their provisions (ASI, 2013; Sage Advocacy, 2023b). Another noticeable example is the Assisted Decision-Making Act (2015) (ADMA), which was signed into law on 30th of December 2015 and provides for the abolition of the existing Ward of Court regime, introducing a new Decision Support Service within the Mental Health Commission to support vulnerable people in decision-making. It took until April 2023, almost eight years, for full implementation (Sage Advocacy, 2023b).

Despite the principles enshrined in the Declaration on Human Rights (UN, 1948) and the CRPD (UN, 2007), HelpAge International (2012) in the UK argues that the CRPD is insufficient to protect the rights of older people. The CRPD focuses on persons with disabilities which do not incorporate ageing issues; however, in debates on the necessity of a distinct rights convention for older people, there is a counterargument that the CRPD is adequate if used to its full potential (Morrison-Dayana, 2023). However, this requires acknowledgement of older people being defined as people with disabilities (Kane, 2010). Subsequently, in recent years there has been a demand for a specific Convention for Older People similar to that developed for people with disabilities as there are challenges that older people face, such as ageism, that are not addressed by the CRPD (Georgantzi, 2020). The demographic change, social construction of old age, and regulations in LTC, together with deep-rooted ageism (as presented in the previous chapters), have increased the discussion and demand for a specific charter of human rights for older people (Boyle, 2008; Kohli et al., 2020; Zhang, 2022). Although the UNCHR include all people, as seen in the previous chapters, older people in the LTC are marginalised through the label of vulnerable and dependent, placed in a separate group than the rest of the population. There seems to be a general view that, despite the vulnerability of older people, parts of human rights articles are implicitly not always seen as relevant in relation to older people. Unlike other vulnerable minority groups such as children, women, and those with disabilities, older people continue to lack a specific binding treaty designed solely to their rights (Mock, 2020). Acknowledging these challenges, advances in the rights of older people are apparent (Mock, 2020). For instance, in 1982, the UN launched the Vienna International Plan of Action on Ageing, followed by the UN Principles for Older

Persons (1991), the Madrid International Plan of Action on Ageing in 2002 (UN, 2002), and the decision to start an open-ended working group on ageing (OEWGA, UN, 2010). These non-binding instruments aim to advance and protect the human rights of older persons. It is hoped that a Convention on the Rights for Older People will be in development (Cahill, 2018; UN, 2010). One of OEWGA's purposes is "for the purpose of strengthening the protection of the human rights of older persons" (UN, 2010, GA Res. 65/182, para. 28). The Convention provides the most fundamental protection against abuse at the international level (Mock, 2020).

Older people in Ireland, including those living in LTCFs, are protected in law by the Bunreacht na hÉireann (1937), which includes the rights to equality before the law, freedom of expression, and freedom of religion (articles 40 to 43 Bunreacht na hÉireann, 1937). However, it has been acknowledged that the rights of older people are not fully protected in the Irish constitution (ASI, 2013) and correspond with the discussion of a specific UN convention on older people's rights. There is a plethora of reports and policy documents related to older people's human rights in the LTC in Ireland (Sage Advocacy, 2020; ASI, 2013). However, they are generally, similar to the description of reports of ageism in Chapter Three, publications from NGOs and interest groups. Apart from the ADMA (2015), no direct legal or governmental policy has been implemented that influences older people's rights in the LTC. Voluntary organisations such as Sage Advocacy (2020) and the Alzheimer Society in Ireland (ASI, 2013) have repeatedly argued that the lack of real alternatives (see Chapter Four, section 4.4.1) in the care of older people in Ireland is a breach of human rights. Equally, no direct study was found which involved a focus on LTC residents and their human rights in Ireland and, significantly, included older persons as a participant group. This exemplifies Foucault's (1974) 'order of things' ideas and the binary assumptions of who is included in the human rights discourse. Due to older persons' dependency status, they are not equal in the practical implementation of rights, and thus do not enjoy the same level of rights.

5.4 Human Rights Principles in the context of older people in LTC

Tracing and digging into human rights show that there are core principles within human rights theory that are to be applied, in theory, to all humans. However, the interpretation and definitions of principles can differ depending on the context and paradigms (differences between law, social, and healthcare paradigms). This section presents these principles in the context of older people in LTC from a care perspective. Although principles are separate

concepts with their own definitions, they share common issues, particularly when applied in the context of older people in LTC. Human rights approaches underpin the quality of life in LTCFs. For example, factors such as autonomy, choice, control, and participation are key (Murphy and Welford, 2012), whereas Baer et al. (2016) emphasise that each human right is inter-reliant and symbiotic with other rights. In reviewing documents, particularly the UNCHR (UN, 1948), the ECHR (2022), and the CRPD (UN, 2007), there are some key underpinning ethical values. These values are autonomy, self-determination, decision-making, freedom, and equality, based on older persons' citizenship and participation (Flynn, 2011; Mock, 2020; Yates-Bolton, 2010). Although several rights are listed in conventions and charters, the following principles are of interest in the formation of discourse on the rights of older people in LTC and capture the vital underpinning of human rights. Figure 11 illustrates these main principles, and how they are interlinked, often overlapping in definition and application.

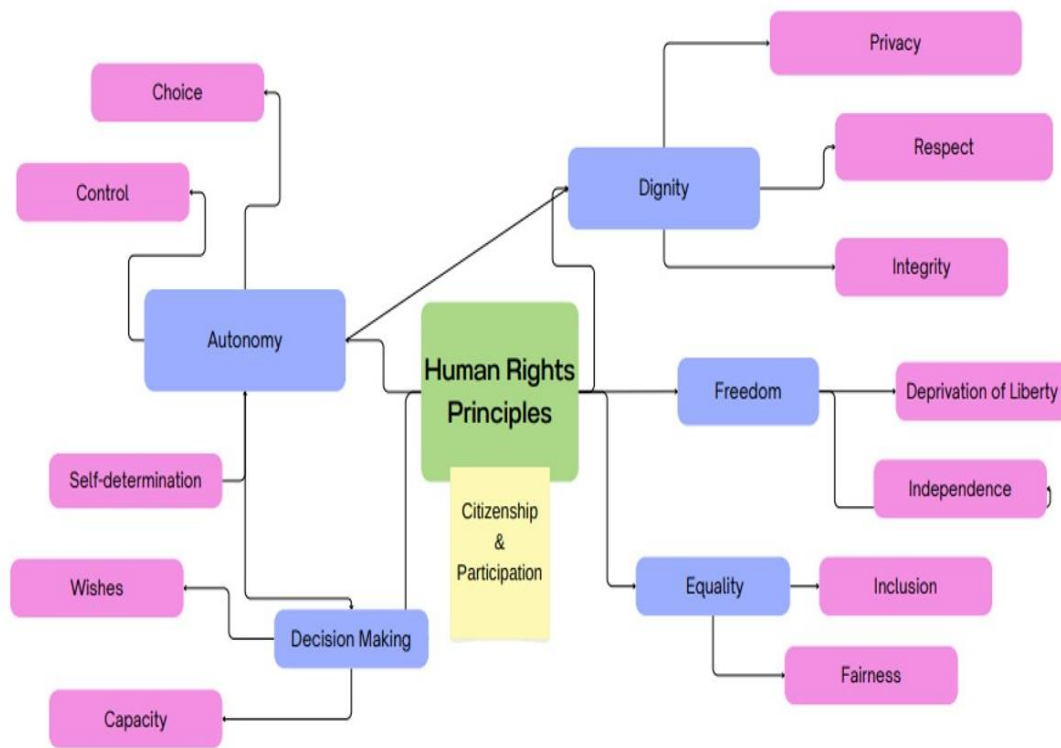


Figure 11: Illustration of Human Rights Principles

5.4.1 Citizenship and Participation

Citizenship refers to the legal status typically tied to a nation state. In this analysis, it is referred to as the social construct that defines an individual's citizenship and how it is part of participation. Participation is closely linked with citizenship, which is about belonging to communities and social structures, as well as having a sense of social inclusion (Kelly & Innes, 2013). Citizenship as social construct of belonging, promotes the idea that all individuals, regardless of their background, deserve equal rights and dignity within the communities to which they belong (Ursin & Lotherington, 2018). Citizen rights, while overlapping with human rights, define the relationship between an individual and state. Early conceptualisations of citizenship can be traced to the work of Theodore Marshall (1950), who delineated three domains of citizen rights: social (including shelter, healthcare, and food), political (such as the right to vote), and civil rights (rights to own property, freedom of speech). Marshall (1950) provided a framework on how states should perceive rights in order to provide support in these domains. Citizenship and participation can be seen as contingencies from the inclusion and exclusion discourse within human rights. It is also linked to personhood, as detailed in the section 4.5 on person-centred care in Chapter Four. Flynn and Arstein-Kerslake (2014) argued that similar to women being denied full personhood until the 20th century, the same conditioning is applied to those with cognitive impairments. Thus, these ideas are founded on the balance of being productive members of the state (aligning with Chapter Three and being a productive members of society) and citizens' ability to be part of the social system (Kelly & Innes, 2013). This is in agreement with the potential underlying assumption that older persons in LTC are no longer active citizens of society due to dependence on care (as also described in Chapter Four) and therefore are "othered" and do not have the same level of citizenship and, consequently, rights (Baldwin & Greason, 2016; Kelly & Innes, 2013; Ursin & Lotherington, 2018). Similarly, when an older person living with dementia loses their ability to engage in rational thinking, their citizenship and rights are diminished (Phelan & Patrick-Clarke in Phelan, 2020).

More recently, there has been a shift towards active citizenship with a focus on participation (Eggers, 2023). Again, this can be linked to the idea of successful ageing. In the archaeological review of the literature concerning rights, many statements refer to the right of participation and enablement to be involved. For example, in the CRPD (Articles 29 and 30), there is a fundamental principle of participation, in which the right to information and the right to participate in political and social activities are explicit. Studies beyond the domain of older

persons in LTC have some relevance. Although set within the context of the intellectual disability population of Ireland, McCausland et al.'s (2018) study is one of the few on the rights of and citizenship for older adults with intellectual disabilities. When exploring choice-making, advocacy, and political participation, the authors found low rates in participants' exercise of these civil rights. In particular political participation was low, and older people with intellectual disabilities required support to participate politically as equal citizens (McCausland et al., 2018). In addition, HIQA (2016) emphasises the right to participate in their standards for LTCFs by stating that "residents are actively involved in determining the services they receive and are empowered to exercise their human and individual rights [...]" (HIQA 2016, p. 18). This can be viewed through FCDA in legitimising the simultaneous management of the state's resources as well as involvement in the lives of its citizens (Foucault, 1979). The expected standards are met by citizens and require two apparatuses: a body of knowledge (i.e. older people, dementia), and a mode of administration (government, healthcare professionals, legal people, etc.). When framing rights, a number of concepts are relevant-these are autonomy, dignity, decision making and equality.

5.4.2 Autonomy

Autonomy is one of the overarching principles derived from the discourse on human rights. Through its Greek origins, autonomy refers to self-rule or self-governance (auto = self, nomos = rule or governance). Autonomy as per the CRPD is integral for the individual and "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons" (UN, 2007, p.5). Additionally, respect for autonomy has become an important ethical principle in healthcare (Beauchamp & Childress, 2019). The autonomy concept is based on the choice, control, and independence to make decisions, and it is closely interlinked with dignity, self-determination, and decision-making, illustrating the interlinkage between human rights principles. For example, if an older resident in an LTC lacks autonomy, her/his dignity is also rendered hazardous (Heggestad et al., 2015). Autonomy and its meaning for older people in LTC are under-researched (Kydd & Fulford, 2020), although more recently, researchers are attempting to see the link between provision of care in LTC and autonomy, particularly what barriers and challenges exist in autonomy in LTCFs (Durocher et al., 2015; Evans et al., 2018; Sherwin & Winsby, 2011; Tuominen et al., 2016). Studies have found that autonomy for older people in LTC is connected to how staff and family members support older residents in their decision-making, choices, and wishes (Bollig et al., 2016; Hillcoat-Nallétamby & Ogg, 2014; Walker & Paliadelis, 2016). However, comparable to

person-centred care, organisational factors such as care routines, staffing, and time constraints in providing ADLs led to fewer choices and less control over everyday life, resulting in a loss of autonomy (Donnelly & MacEntee, 2016; Taverna et al., 2014; Tuominen et al., 2016). In the context of older people and LTC, the more recent term used is relational autonomy. Relational autonomy recognises that not everyone has equal opportunities to make autonomous decisions (Durocher et al., 2015). Relationships, social, cultural, economic, contextual, situational, political, and medical elements have a relational effect on a person's ability to make decisions. As noted in Chapter Four, the older person in LTC is often a person with cognitive impairment, chronic illness, and considered frail and vulnerable; all components that would hinder autonomous decision-making (Durocher et al., 2015; Sherwin & Winsby, 2011).

Autonomy is also closely linked to self-determination, even occasionally in healthcare given the same definition (Ryan & Deci, 2017). They differ in their application but share attributes, as self-determination is a key part of autonomy. Self-determination can be described using the self-determination theory proposed by Ryan and Deci (2017), which shows how human motivation is key in self-determination. Ryan and Deci (2017) proposed that this motivation can be either autonomous or controlled which makes the theory highly applicable to healthcare, specifically LTC which is a controlled environment. They also proposed that basic needs must be satisfied for people to grow and maintain integrity. These needs are competence, autonomy, and relatedness (Ryan & Deci, 2017). Similar to decision-making, as presented in the next section, a term that appears in relation to self-determination and autonomy is that of 'best interest'. It is often linked with the older person's ability to make decisions; 'best interest' refers to when a person decides for another person (Tuckett, 2006), often a healthcare professional or family member. This is also the term used in the Mental Capacity Act (2005), in England and Wales. However, there is often an inconsistency between the healthcare professional's (or indeed the family member's) idea of 'best interest' and the actual interest of the older person themselves, resulting in paternalistic practices and a lack of self-determination (Fernández-Ballesteros et al., 2020; Tuckett, 2006).

Self-determination seems to be influenced by LTC facilities' stance towards risk and safety (Davis et al., 2021). In many Irish LTC facilities, this is referred to as risk management or safeguarding of residents (HIQA, 2016). This is a crucial formation of statements in the discourse of the human rights of older people in LTC: the dichotomy between care

professionals' duty to keep the older person safe while maintaining and supporting their autonomy despite any risk the autonomous choice creates (Browne, 2016). This formation is essential not only in the autonomy part of human rights but also in the discussion regarding capacity of older people in LTC (see section 5.3.4 below). Bailey et al. (2017) conducted a qualitative study with Australian residents in LTC focusing on food choices and risk. The authors observed that residents wanted to take the risk in relation to eating certain foods and linked it with their right to make choices, even if it constituted a high risk. Autonomy and self-determination have also been linked to capacity, which is further detailed in Section 5.4.4. Welford et al. (2012) found in their literature review regarding autonomy a strong relationship between autonomy and capacity where many of the reviewed authors defined capacity as "an integral ingredient to autonomy" (Welford et al., 2012 p. 67). This finding has implications in the LTC for older people, in which, as described in chapter four, the majority of the residents (estimated at 72 percent of all residents in LTC (Pierse et al., 2019)) have some form of cognitive impairment.

5.4.3 Dignity

The concept of dignity is similar to that of autonomy, a core attribute of rights. For example, the first article of the UNCHR states that "All human beings are born free and equal in dignity and rights" (UN, 1948, p.1). Although the ECHR does not explicitly mention dignity, it underpins most of the articles, as dignity is considered the support, respect, and promotion of self-respect and the notion of human dignity (Curtice & Exworthy, 2010). Similarly, the CRPD (UN, 2007) does not mention dignity, but Article 17 refers to the protection of a person's integrity, which is a characteristic of dignity (Høy et al., 2016). Dignity generated a fair number of results in the literature search; however, they were studies within the care providing context, such as dignity in continence care (Ostaszkievicz et al., 2018) or dignity at the end-of-life care (Holmberg & Godsken, 2022). Although they may not be specific to this study and the human rights discourse, these studies highlight the role of staff in supporting older people's dignity in LTCFs (Hall, 2009; Ostaszkievicz et al., 2018). Upon examining the concept of dignity in the context of older people in LTCFs, it becomes evident that dignity is multifaceted and complex (Nåden et al., 2013; Rehnsfeldt et al., 2022; Tadd et al., 2010). Dignity appears to correlate with the older person's integrity, being self, and part of the relationships created within LTCFs (Høy et al., 2016; Rehnsfeldt et al., 2022; Tranvåg et al., 2015), similar to person-centred care.

In an empirical exploration of older Europeans' experiences of dignity, Tadd et al. (2010) concluded that dignity is a multidimensional concept which is easier to construct by its absence than its presence. As Foucault (1972) maintained, discourse is constructed as much by what is not stated than by what is stated in the construction of knowledge within a discourse. Both dignity and autonomy can be relational, meaning that they are dependent on staff and how other residents in LTC facilities are perceived (Heggstad et al., 2015). Dignity can be related to how the LTC facility organised the care provision, once again highlighting the impact of the facility as an institution in the discourse of human rights.

5.4.4 Decision-Making

The key elements under the human rights principle for older people are legal capacity and the ability to make decisions. Capacity is closely interlinked with autonomy, and for older people with any kind of cognitive impairment, such as dementia, capacity is a frequent topic in the literature as well as policy reports of older people (Boyle, 2008; Donnelly, 2019; Welford et al., 2012; Sage Advocacy, 2023a). Capacity is, in simple terms, the ability to make decisions, and has been used in terms of being equal to competence and ability (Katona et al., 2009). There is unanimity that capacity is not a single concept; instead, it is in the context of specific decisions, tasks, or fields (O'Neill & Peisah, 2019). Everyone over the age of 18 is assumed to have capacity (regardless of illness), and there is an obligation to support decision-making under Article 12 of the CRPD Convention which Ireland ratified in 2018 (UN, 2007).

Traditionally, capacity has been viewed from a status approach: once a person is diagnosed with a condition such as dementia, it is assumed that there is a lack of capacity (Cahill, 2018). However, this view is not congruent with a human rights approach, nor does it promote the individual's will, preferences, values, and beliefs which are fundamental in a person-centred care approach. Flynn and Arstein-Kerslake (2014) pointed out that a system such as Victorian guardianship treats individuals as objects instead of subjects with individual decision-making rights. Foucault (1972) refers to subjectivity of a discourse; in this context, it can be evidenced as positioning the older person's identity as the product of the discourse and institutional practices within the discourse, again this reinforces the older person in LTC as a passive and 'other'. This can also be internalised in that is how the older person views him/herself, and hence will not voice their rights within the discourse, as they assume this is taken for granted subject position (Danaher et al., 2000).

This view of capacity changed legally in Ireland with the introduction of the Assisted Decision-Making Act (ADMA) in 2015. Previously, the Lunacy Regulation (Ireland) Act (Irish Statute Book, 1871), took a broad status approach to capacity; once capacity was in doubt, that judgement remained in all situations. Within the ADMA (2015), there is a shift in legal capacity towards a functional approach, where capacity is deemed present unless proved otherwise and assessment is performed to determine whether, at a specific time and related to a specific decision, the older person comprehends the significance and consequences of the decision and is able to communicate a decision. This shift requires a transition of health and social care that affects both service users and healthcare professionals, as there is an onus to promote autonomy and maintain individual decision-making. Consequently, in relation to healthcare, the professional has an obligation to break the information down to understandable parts and ensure that every effort is made to enhance understanding (Donnelly, 2016). The legislation takes on a modern approach to capacity and decision-making. Compared to legislation in England and Wales (Mental Capacity Act 2005 (MCA)), the ADMA (2015) does not make any reference to the term 'best interest, instead of focusing on the will and preferences of the person. Led through Decision Support Services (DSS, 2023), the legislation follows a three-tier framework. The ADMA (2015) provides assisted decision-making initially as Decision-Making Assistance, followed by a Co-Decision-Maker, and the final tier is a Circuit court-appointed Decision-Making Representative. The Act also includes amendments to the Power of Attorney and provides a legislative framework for Advance Healthcare Directives (AHDs) that set out clear guidelines to allow a person to make a legally binding refusal of treatment and to make treatment requests. A directive-maker may also appoint someone to act as their Designated Healthcare Representative and give this person authority to consent to and refuse treatment, with reference to AHD (DSS, 2023). Donnelly (2016) argues that the ADMA (2015) capacity approach, together with legislation of ADHs, provides some control to the person who may lack capacity in the future. Thus, through legislative rights decision-making and autonomy can be supported.

Yet, a number of factors have impinged on this approach as a standard within care. Despite becoming law in December 2015, the ADMA (2015) took until April 2023 to be fully operational. It was delayed because of amendments that were procedural and technical to support the courts in the judicial process (Flynn, 2020). This was compounded by Ireland's delay in ratifying the CRPD. Delays in translation to reality can mean that the human rights of older people are not understood and consequently, not upheld in Ireland. This is particularly

the case for those who require assistance in decision-making, for example, older people with dementia. However, being operational only since April 2023, the full impact on older people's decision-making is yet to be determined. While ADMA (2015) provides a structure around who can make decisions if a resident in LTC cannot, until now, there has been a reliance on 'next of kin' (usually a family member) to make decisions. The term 'next of kin' has no legal entity (Donnelly, 2016). Yet, through the use of 'next of kin', family members have emerged as a strong proxy for decision-making in LTCFs (Giertz et al., 2019).

5.4.5 Freedom

The literature review revealed that part of the human rights principles is the idea of free will and the ability to be free to make choices, as well as freedom of movement. Freedom of movement is a fundamental right and part of the ECHR (Articles 10-11 ECHR, 2022) and the UNCHR (1948). Few studies have examined the freedom of older people in LTC (Caspari et al., 2018). Liberty equals freedom and refers to a state of being unrestricted and unencumbered by the limitations or constraints imposed by others (Jones & Fowles, 2023). Despite this being a fundamental principle, the literature review established that there seems to be a greater focus on the lack of freedom among older people in LTC. This connection leads to the binary concept of deprivation of liberty discourse in relation to the freedom principle for older people in LTC facilities. Thus, freedom for older people in LTC was constructed due to the binary concept of deprivation of liberty, a term that has emerged in recent years related to LTC (Series, 2022). Deprivation of liberty is described as when a person is deprived of liberty without consent or outside the legal framework (i.e. prisons or police legal sanctions) (Sage Advocacy, 2023b). HIQA (2016) standard (Standard 3.5) stipulate the requirement for LTC related to the implementation of a restraint-free environment, and highlight key areas where restraint should not be used, such as a control mechanism. HIQA (2016) also considers deprivation of liberty as the use of restrictive procedures that limit an older person's movement, activity, or function. These restrictive procedures have an effect on the older person's ability to acquire positive reinforcement and result in loss to the older person in the form of object loss or sense of loss in dignity and self (HIQA, 2016; DoH, 2010).

Caspari et al. (2018) conducted a hermeneutic study into the freedom of residents in LTC facility in Norway and found that personal autonomy is based on making decisions and this affected their sense of freedom or lack of same. If the resident had made the decision to move into the nursing home, including choosing the actual living space (in their study referred to as

flat), it provided a sense of freedom and satisfaction. However, for the older person in LTC, there was a tension between the inner sense of freedom and the actualisation of that freedom. Wanting to go out, closing one's own door, and moving around on their own were not actualised in the nursing home environment (Caspari et al., 2018).

Restrictive procedures include not only physical restraint, such as mechanical devices restricting a person's freedom of movement, but also chemical restraint (the use of medication to control behaviour) and environmental restraint. Environmental restraint restricts an older person in a LTCF from accessing their environment either by limiting their movement to leave or enter parts of the facility (DoH, 2010; Hofmann et al., 2015). However, these standards set out by HIQA (2016), are not supported by legislation in Ireland (Sage Advocacy, 2023b). There is limited evidence that countries that have adopted legislation on restraints in LTCFs have lower prevalence of restraints. For example, Germany, with legislation in restraint procedures, has a prevalence of approximately 27 percent of restraints in LTCFs compared to Spain, where legislation is lacking and has a prevalence of 87 percent (Leahy-Warren et al., 2018). Ireland, despite standards and national policies, has yet to implement any legislation regarding restraints, although there is a Deprivation of the Liberty Safeguards (similar exist in England and Wales, termed Deprivation of Liberty Safeguards and are part of the Mental Capacity Act 2005) bill in process by the Department of Health which had a public consultation in 2019 (DoH, 2019). Leahy Warren et al. (2018), in a study of staff's perception of restraints in Irish LTCFs, noted the main reason for opting to use physical restraint was a safety measure, particularly related to prevention of falls. This reflects that autonomy can rest on a balance of risk, which appears to be a common approach in LTC as a way of justifying the procedures used (Bailey et al., 2017). Despite this, a systematic review of restraints in LTCFs (Hofmann & Hahn, 2014) concluded that there are more adverse effects from physical restraints than benefits. The use of restraints also has significant consequences, causing psychological and physical pain, fear, and humiliation (Hofmann & Hahn, 2014). Therefore, there is a universal agreement that restraint use must be extremely limited. There is a lack of comparable data on restraint practices in LTCFs in Ireland, although HIQA (2023) conducts thematic inspections of restrictive practices and collects quarterly notifications from facilities in relation to restraints used. Data from quarterly notifications are not openly available. This contradiction between freedom as a human right and LTC facilities' aim to minimise risk are in constant conflict (Heggestadt et al., 2015), as the institution attempts to control the environment. This literature review highlights that older people appear to lose their freedom as part of their

admission to LTC, and limitations are not only applied to freedom but also to autonomy and decision-making (Heggestad et al., 2015; Øye & Jacobsen, 2020).

5.4.6 Equality

Although equality is a central principle in human rights, there is scant literature related to it within the context of LTC. Equality is an established principle in human rights discourse. For example, the first article of UN Declaration of Human Rights (1948): “all humans beings are born free and equal in rights and dignity” (Article 1, UDHR 1948). Flynn (2011) states that everyone is equal before the law and identifies several CRPD articles such as the right to life (Article 10 in CRPD) and Article 5 (equality and non-discrimination in CRPD). In Ireland, the Equality Act (2004) has explicit nine grounds for discrimination of which age is one of them. Equality is closely linked with ageism, which is described in chapter three and equality is mainly described by the examples of existing marginalisation (HelpAge International, 2012). In this regard, ageism, as a manifestation of unequal treatment, is evident in healthcare decisions, as it could represent the sole reason for denying care (Rosen, 2023). As Sage Advocacy (2018) in Ireland reported in a submission as part of review by the UN Committee Against Torture, accessibility to appropriate care for an older person living in an LTC facility is limited and that the move to an LTC facility meant a loss of some of the community services. This evidence of inequality related to setting, such as access to medical services available in the community, may be lacking unless such services are individually paid for in residential care (Sage Advocacy, 2020). Research findings have also identified challenges such as organisational obstacles and staff views, and similar challenges have been found in other research on human rights principles in LTC facilities (Caspari et al., 2018; Tuominen et al., 2016). Lack of equality and increased exclusion can result in a sense of loneliness, which Drageset et al. (2015) reported as a common feeling among older people, even in LTCFs. This renders the older person in LTC further invisible.

In conclusion to this section on human rights principles, all of these key principles are important contributing discourse formations in rights’ discourses of older people in LTC. However, as evidenced in this chapter, human rights for older people in LTC appear to be eclipsed to a large extent, and there is a dividing practice in operation. The institutional rules of LTC, which staff follow in the provision of care, determine which actions and behaviours are acceptable. If they are not within the norm, they are determined as deviant or ‘abnormal’. This creates a rationale for dividing practices. In the context of LTC, there is a set of rules for

the two different groups in this case the older people in LTC and 'normal' people (Danaher et al., 2000; Peters & Besley, 2014). Using FCDA to human rights, older residents are placed in a particular subject position, resulting in compromised independence, equality, freedom, and participation in order to benefit from care in the LTC. These represent the 'games of truth' related to human rights for older people in LTC, as the older person tacitly accepts this situation and does not assume or, in many cases, expect that the rights will be upheld (Danaher et al., 2000). Accordingly, there may be a considerable gap between the articulation of human rights principles in human rights frameworks, policies, and legal instruments and the actual implementation of the same in the care of older people (Biggs & Haapala, 2013).

5.5 Human Rights Based Approach in healthcare

In recent years, there has been a focus on how healthcare can in general, but particularly related to social care, promote human rights, and how to adopt a human rights-based approach (HRBA) to healthcare (Curtice & Exworthy, 2010; HIQA, 2019). Although several policy documents regarding a human rights approach have been produced both internationally and in Ireland (ASI, 2013; HIQA, 2016), few have had practical applications of human rights in the delivery of care in LTC facilities (Butchard & Kinderman, 2019). Through the work done by the Department of Health in the UK and the activation of the Human Rights Act (1998), the UK has taken a proactive approach to putting operational tools in place for HRBA care. This was the result of several reports indicating a lack of dignity in the care in the older person in the UK (Curtice & Exworthy, 2010). Similarly, the Scottish Human Rights Commission (2018) has produced education training and resources for organisations to use in the implementation of HRBA.

HRBA can be seen as the application of human rights to all aspects of healthcare, from policy and research to practice and monitoring (Patel, 2019). Like person centred approaches, it is a framework that places the vulnerable person in the centre, and those who apply HRBA critically assess the authority and power in the interest of empowering the vulnerable person. As power is part of knowledge production within healthcare, HRBA provides a framework in which practices can be questioned by asking who has power (Patel, 2019). HRBA provides a shift in discourse formations and acknowledges the balance between power and control, where HRBA can provide agency to older persons in LTC and be supported in exercising their rights. HRBA has become an approach used by many organisations. In 2015, the WHO (2015b) launched the Participation, Accountability, Non-discrimination, Empowerment, and

Legal (PANEL) framework and advocated by the Scottish Human Rights Commission (2018). Jönson and Harnett (2016) introduced a framework for older people in LTC facilities based on the Scandinavian normalising theory for those with disabilities, with the aim of normalising living conditions instead of normalising the older person to adjust their care needs. The HRBA framework relevant for this study and the one that has been promoted by both the NICE guidelines (Butchard & Kinderman, 2019) and the Irish regulating body HIQA (2019) to be used in social care settings is the HRBA framework of the FREDAs principles.

5.5.1 FREDAs Principles

Curtice and Exworthy (2010) produced a framework of FREDAs principles as part of their work on Mental Health and Human rights in the UK. FREDAs refers to fairness, respect, equality, dignity, and autonomy. Initially started as an acronym of FRED, autonomy was added to promote self-determination and, more recently, identity was added, making the acronym FREIDA (Butchard & Curtice, 2019). In a guidance document named 'Human Rights-Based Approach to Care and Support in Health and Social Care Settings', HIQA (2019) highlighted how FREDAs can be used in Ireland. Language had already been changed in the standards and regulations document produced in 2016, which focused on rights of the resident to be upheld and supported. Figure 12 illustrates the five principles, as explained in detail in the HIQA (2019) guidance document.



Figure 12: FREDAs Principles as illustrated by HIQA (2019)

In this guidance document, HIQA (2019) referred to how the FREDAs principles and how care can be provided to align with human rights articles. The guidance aims to apply human rights to practice and how healthcare users' rights are upheld while in a vulnerable situation of

receiving care (Curtice & Exworthy, 2010). Apart from the HIQA (2019) guidance document, there is an absence of policies or standards regarding HRBA in LTC for older persons in Ireland. The FREDAs guidelines follow the bottom-up approach in human rights, compared to the top-down approach which requires knowledge about the law surrounding human rights. The bottom-up approach provides an opportunity for staff members to support vulnerable persons in exercising their rights without having extensive knowledge of the legalities (Curtice & Exworthy, 2010). As the HIQA (2019) guidance is relatively recent, how facilities have adopted an HRBA in LTCFs in Ireland has not yet been evaluated. However, this publication and its FREDA principles are relevant to this study as they form part of the interview guide, with the addition of freedom as an alternative to F in FREDA⁸.

5.6 COVID-19 and human rights of older people in long-term care

Chapter three and four describe the impact of COVID-19 on older person and LTCFs as an unprecedented global challenge. Unsurprisingly, in the context of the human rights of older people in residential facilities, COVID-19 also showed discourses that seemed to emerge as part of COVID-19 but had already been present. As detailed in this archaeological review of the literature, there are systematic breaches of human rights and ageist policies in the context of LTC for older people. These discourse formations have predated the COVID-19 pandemic. However, the COVID-19 pandemic has magnified these issues. For example, both the UN (2020b) and Age Platform Europe (2020) claimed in Spring 2020 that there was an immediate threat to the human rights of older adults during the COVID-19 pandemic. The Irish Human Rights and Equality Commission (IHREC) concurred with these claims, arguing that marginalised groups such as older people in LTC, disabled, and minority groups were at a disadvantage during COVID-19 pandemic (IHREC, 2020b).

Age Platform Europe (2020) urged for special measures in sharing information, inclusion, and access to services, as well as measures to ensure protection from discrimination and abuse. Access to relevant and accurate information has become a crucial feature in the fight against COVID-19, but early on it was noted that older people in LTCFs were not included in information provision (Lloyd-Sherlock et al., 2020). In emerging policies and planning for

⁸ Researcher added Freedom in questions although not part of FREDA principles to see if there was an understanding of the human rights principle freedom.

COVID-19, there was a lack of inclusivity and older people were not represented or misrepresented (Formosa, 2021; Fraser et al., 2020). The nursing home expert panel report (presented in Chapter Four), pointed out in their expert review of the management of COVID-19 in LTCFs in Ireland how the LTC sector was left out of the initial planning and management of COVID-19 (Kelleher & Twomey, 2020).

Key human principles that were noticeably breached during COVID-19 were the right to life, freedom (liberty), and security (Anand et al., 2022). Bilková (2022) pointed out that these breaches and gaps in upholding these rights were already present for older people, COVID-19 deepened the gap. Ageist blanket policies as described in Chapter Three, such as no access to healthcare due to age can be seen as infringement of the right to life, one of the key rights in UN declaration of human rights (Anand et al., 2022). The restrictions implemented by LTCFs, such as strict IPC, reduced movement, and full isolation in own rooms, further reduce the limited freedom for older persons in the facility. The justification of COVID-19 stems from the powerful discourse of public health, specifically related to protection of risk. These blatant breaches in rights during COVID-19 have increased calls for specific conventions for older people, as their rights were systematically not upheld, particularly in the LTC (Dark & Quinn, 2023; Penhale, 2023).

5.7 Conclusion

This chapter concludes the literature review. The three chapters comprising the literature review have enabled an archaeological exploration of discourses related to older people, LTC and human rights and older people. In this chapter, the UNCHR in 1948 is watershed in equal rights supported by a large number of countries globally. However, in recent decades, it has been recognised that marginalised groups do not have the same opportunities to exercise their human rights. This development has called for a specific convention of human rights for older people, similar to the CRPD for people with disabilities. All the human principles mentioned in this chapter; autonomy, dignity, equality, freedom, and decision making, are interlinked and built on the person's citizenship and participation in society which is also connected to the discourse of personhood. As residents in LTC facilities are frail, dependent, and vulnerable, their status as citizens is not equal to that of the rest of the population. Rights as applied to 'normal' people in society appear different as dividing practices mean that once an older person enters LTC, they lose a part of their rights. The 'games of truth' related to human rights implicitly change. Situations such as choices, freedom, restraint, and deprivation

of liberty can occur as accepted 'norms', and actions are justified by the rationale of risk management and paternalism.

As evidenced in various publications related to the COVID-19 pandemic, these issues have gained some visibility 'under the radar', yet they could be countered by public health discourses. However, it was apparent that autonomy, free will, and choice disappeared during the pandemic, and older people in LTC were all isolated for long periods, did not have access to healthcare, and no choice was given. Human rights-based approach frameworks, such as the FREDIA principles, can aid in making human rights practical in the LTC setting; however, they are fairly new in their introduction and similar to person-centred care encounter the challenges of organisational and institutional rules in the implementation.

The comprehensive literature review conducted for the three concepts presented indicates the complexity of the topic. The literature review concludes stage one of the FCDA by providing an archaeological lens on discourse formations in statements and text. Findings demonstrated the subject position an older person as separate from the rest of the population and often constituted as a 'burden'. This is the case in older people needing LTC; the older person, due to the high need for care, becomes even further marginalised. Chapter Four presented a complex discourse formation in relation to LTC, in which the lack of choice and clear definitions of care provisions were common. Added to the human rights principles in this chapter, there are clear obstacles in upholding the rights of older people in the LTC. The next chapter provides the methodological steps taken in conducting stage two of the FCDA; genealogy and interviews with older people, family members, and staff.

CHAPTER SIX

Methodology

6.1 Introduction

Chapter Six commences where Chapter Two concluded, by delving into the theoretical framework of the FCDA stage two analysis, depicted in fFigure 1 in Chapter Two. While stage one, the archaeological analysis, was conducted by reviewing the literature, Chapter Six begins by further exploring the epistemological and theoretical underpinnings of FCDA by outlining genealogy. The Chapter includes a recap of the research aims, questions, and objectives to provide a context for the study's progression from archaeological analysis. Subsequently, the chapter describes the process of the stage two analysis, which involves examining the power-knowledge nexus, the various power sources, and how the subject is positioned in the genealogy analysis. This section also presents the use of reflexivity as a secondary theoretical methodology. The practical aspects of the research design are then outlined, including steps such as accessing LTCFs, adhering to ethical standards, selecting a sample, and collecting and analysing the data while maintaining trustworthiness to achieve rigour and validity.

6.2 Rationale for research design

As described in the Introduction Chapter, the origin of this study stems from my own interest in the rights-based approach within LTCFs. As presented in previous chapters, there is scant empirical literature on the rights of older people in LTCFs, and even within the identified studies, few have included older people residing in facilities. Consequently, this study sought to determine how knowledge of these rights is constructed by residents, family members, and staff in LTCFs in Ireland.

6.2.1 Research aims, objectives and questions

Willig (2013) explains that FCDA aims and objectives have a more multilayered approach than traditional discourse analysis, which analyses the use of language. FCDA explores the use of language, as well as how subjects use language to construct their view of the world (society) and draw on taken for granted 'truths'. In this context, my interest emerged in questioning these constructs and determining how the discourses presented themselves in the current

LTC milieu. The following aims, initially presented in Chapter One, for the study were then developed.

- To examine how residents, family members, and staff discursively construct older people's human rights in long-term care.
- To investigate knowledge of and language used by residents, family members and staff in relation to human rights of older people in long-term care in Ireland.

Formulating a research question within FCDA discourse translates to an examination of not only what is being said but also who, where, and when it is being said are as important. These methodological principles were central in generating the research questions (Harper in Slade & Priebe, 2006; Willig, 2013). The following research questions were then formulated.

- How are the human rights of older people in long-term care discursively constructed by residents, family members, and staff in Ireland?
- How are these discourses used by residents, family members and staff in Ireland?
- What enablers or constraints are present in the relationships between the discourses constructed and power-knowledge and how have these been socially constructed? What are the consequences of such constructions?

With the following objectives of the study determined.

- To use an archaeological approach to examine the history of the present in relation to older people's human rights in long-term care.
- To identify how the human rights of older people in long-term care are facilitated, constrained, limited, or illuminated within discourse formations.
- To present the discourse and power-knowledge nexus to recognise differences in views and attitudes of older people's human rights between various participant groups.
- To make recommendations based on the findings of the study.

6.3 Genealogy

The archeological approach provided a tool to trace the historical accounts of discourse formations and led to a deep dive into the topic of older people, LTC, and human rights through the literature review. Archaeology is a description of patterns and an analysis of how statements have been found or replaced. Genealogy continues this work by deepening the analysis by exploring power relations and being aware of the subject in the discourse (Mills, 2004).

One way to understand these approaches is to divide Foucault's theories into three stages. The first stage, presented in Chapter Two, is historical digging in the form of archaeology,

which was introduced in the 1960s. This was followed by the second stage in the 1970s, when he introduced genealogy in 1970s with books such as *Discipline and Punish* (1977) and *The History of Sexuality, Vol. 1: The will to knowledge* (1978). These two books, together with *Archaeology of Knowledge* (1972), are considered significant for understanding Foucault's theories. His third stage is related to ethics and the reflection of self in discourse, and represents concepts that are not as widely developed as archaeology and genealogy (Oksala, 2008). The term genealogy does not have a unilateral definition, and is connected to the writings of Nietzsche, whose work Foucault studied (Mills, 2004; Sluga in Gutting, 2005). Genealogy questions the way we think about ourselves and others within the discourse, and critically analyses why we think in this way (Kendall & Wickham, 1999). Genealogy deals with the connections and relationships between 'truth', knowledge, and power. Within these relationships, there is also resistance, which is part of these connections. By revealing the 'truth', genealogy can identify the consequences of the dominant discourse on the human rights of older people in LTC.

6.3.1 Power-Knowledge Nexus

As presented in Chapter Two, knowledge is a key principle in Foucault's theory, and includes a range of ideas, narrative categories, rules, terms, and definitions (Danaher et al., 2000). Knowledge, as seen in archaeological analysis, is embedded in institutions, and genealogy deepens it by examining the power structures that exist as part of the production of knowledge. Knowledge within the FCDA is socially constructed and daily social interactions sustain this construction. Dominant discourse emerges through a power relationship within a social construction. Traditionally, when thinking of power, it has been a commodity to be fought over, or a characteristic that a person has or does not have (Cisney & Morar, 2020). However, when introducing power, as seen in FCDA, a non-hierarchical network of relations has a different meaning. Foucault (1977) emphasised the role of power in the production of knowledge. Power is not to be seen as an entity of its own, but a form of production. The relationship between power and knowledge is complex and multifaceted, and various actors wield power differently. In each discourse, there is a dominant discourse that is considered the 'truth', and this discourse exerts its power through the exclusion or constraint of other perspectives. As a result, certain knowledge is privileged within the discourse (Foucault, 1972, 1978; Mohammed et al., 2021). Through power, one can determine the genealogy of older people's human rights and how they are part of the knowledge apparatus (Patton, 2017). Power is a productive force within discourse that allows subjects to make sense of the discourse. 'Truth' and knowledge

through the subject of self are all constructed through the exercise of power (Foucault, 1985). Certain forms of knowledge, such as scientific knowledge, gain dominance in society and become a 'truth' that is taken for granted. For Foucault, power is a verb flowing in institutions, and not a noun to be owned (Mills, 2004).

Power must be analysed as something which circulates, or rather as something which only functions in the form of a chain. It is never localised here or there, never in anybody's hands, never appropriated as a commodity or piece of wealth. Power is employed and exercised through a net-like organization. And not only do individuals circulate between its threads, they are always in the position of simultaneously undergoing and exercising this power. They are not only its inert or consenting target; they are always also the elements of its articulation. In other words, individuals are the vehicles of power, not its points of application. (Foucault cited in Gordon, 1980, p. 98)

Foucault described his theories about power in several different journals, lectures, and interviews, but it was in his publication *The History of Sexuality vol. 1* (1978), where he conceptualised power and gave examples of how it acts within the apparatus. Although *The History of Sexuality* (1978) deals with the historical development of sexuality in society, the book highlights how social construction has emerged in contemporary society (Danaher et al., 2000; Foucault, 1985; Oksala, 2008). Foucault (1978) describes the key forms of power; governmentality, biopower, and disciplinary power. They operate through power relations at different levels, such as within institutions and through the subject.

6.3.2 Governmentality, Biopower and Disciplinary power

As with many other Foucault's concepts, governmentality continued to develop until his death in 1984, and as with other of his concepts, Foucault (1977) was cautious of not labelling governmentality as a theory (Hutchinson & O'Malley, 2018). Instead, governmentality is seen as a modality of power that works through a range of elements including institutions, policies, authorities, and procedures. Governmentality incorporates biopower and the subject position within the discourse, which means that governmentality is more than practice of governance; it also includes self-governance. One of the concepts that illustrates power is that of biopower, which Foucault introduced in *Discipline and Punish* (1977) and the *History of Sexuality* Volumes (1978, 1985, 1986). As a basic explanation, biopower is power over life. Biopower encompasses various aspects of life including demographic factors, health concerns, and education. This can be influenced from two perspectives: at an individual or at a population level (Perron et al., 2005). Structures, relations, compositions and practices are exposed by

biopower, which also shapes and constitute the subjects. However, it is a masked power not visible or thought about as the power is embodied in everyday life (Cisney & Morar, 2020).

Governmentality and biopower are surveillance functions. In particular, in *Discipline and Punish* (1977), Foucault theorised surveillance as part of the power apparatus and used Bentham's Panopticon⁹ as an example of how institutions are set up for individuals (such as prisoners, patients, residents, and students) to be observed from a central location. Foucault (1977) explained that constant surveillance alters the behaviour and thinking of those being observed. With modern technologies, surveillance has extended beyond architectural panopticons, although it still exists (Mortenson et al., 2016). Surveillance often involves evaluating behaviour, a concept he developed in *The Birth of the Clinic* as a medical gaze (Foucault, 2003). The aim is to objectify individuals based on their symptoms and within the body of biomedical knowledge. As part of the surveillance process, individuals may modify their activities by adopting socially accepted practices and behaviours. This self-discipline results in the production of 'docile bodies', as described by Foucault (1977). Docile bodies exhibit a high degree of conformity, regulation, and submission to authority, reflecting the impact of social, political, and institutional influences on shaping behaviour and identity within a discourse (Perron et al., 2005). Part of this shaping is disciplinary power, which is another form of power that exists in the power-knowledge nexus and is part of the governmentality and biopower apparatus. For example, the practical element of the Panopticon provided the prisoners with a 'new' form of disciplinary power; there was not an element of violence or punishment yet the disciplinary power of surveillance rendered the prisoners in a state of 'docile'. This disciplinary power can be seen in education, the medical field, and most institutions where the aim is to construct subject formation with discourse (Foucault, 1978; Oksala, 2008).

⁹ Jeremy Bentham, an 18th-century English philosopher, devised the Panopticon, a prison control system. Derived from the Greek "panoptes" meaning "all-seeing," it enables a single guard to observe all inmates without their knowledge. Though physically challenging, the uncertainty of being watched compels prisoners to self-regulate. The design, featuring a central inspection house within a rotunda, was envisioned for various institutions. While equally applicable to hospitals and schools, Bentham primarily focused on perfecting the panopticon for prisons, making the term commonly associated with this concept (Fiddler, 2022).

6.3.3 Subject

The subject in discourse was initially presented in Chapter Two; however, as with a large part of Foucault's theories, the subject continued to develop (Oksala, 2008; Powell, 2009). Archaeological analysis defines the subject within a discourse, whereas genealogical analysis deepens the analysis and positions the subject in the discourse construct (Foucault, 1977). For example, through genealogy, Foucault (1977) demonstrated how mentally ill people and delinquents are constructed in discourse formations. By exclusion, their subject position becomes normal and is accepted as the 'truth' in the discourse. Foucault was critical of the traditional view of the subject as an individual who is fully endowed with consciousness and independent autonomous self (Hall in Wetherell, 2008), rather, the subject is the 'result' of the discourse formations.

Foucault further explains his views on the subject in lectures and individual writings, and he is clear to make a point that his research focus was not power but how people are made subjects. Yet, Foucault (in Faubion, 2020) details how power is used to objectify the subject by "dividing practices" (Foucault cited in Faubion, 2020, p. 326). This implies that the subject is divided from others, for example, as in 'the mad one' or sick versus the healthy one. The subject is not only in a position of production and significance but also in a position with complex power relations. Power and its relational impact allow the subject to adapt to the existing power interactions. Foucault referred to this as technologies of self, which is a form of self-governance (Foucault, 1977). An example from Foucault's research is how prisoners in the panopticon model started to self-govern by acting as if they were watched, although they did not know whether they were watched (Foucault, 1977). In healthcare, self-monitoring and adapting to health behaviours are ways of self-governing (Lupton, 2013). Technologies of the self are closely linked to surveillance, and through these interactions create 'docile bodies'.

6.3.4 Resistance

Foucault (1978) stated "where there is power, there is resistance" (Foucault, 1978, p. 95). This is an important part of the theoretical framework, as power is not seen as a stagnant possessive entity that represses a group of people. Instead, it is an operational entity in the system at all levels and in all relationships (Mortenson et al., 2016). Resistance exists in these power practices and is similar to power; it is not in a fixed position. By introducing resistance, Foucault (1978) does not believe that power is a negative concept; he merely recognises that

not all power relationships are the same. Resistance can, like power, be challenging to recognise as it occurs in micro-interactions, such as refusal of medication, non-cooperation, or refusal to accept diagnosis (Lupton, 2013). All subjects can resist within the discourse, including those with expert positions such as healthcare professionals (Mayes, 2015).

6.3.5 Critique of Foucault

Foucault's methodology has been influential not only in social sciences and humanities but also in geography, media studies, psychology, and organisational studies (Koopman, 2011). Foucault's methodology, while influential, has also faced significant criticism, and researchers have attempted to divide Foucault's work into phases, according to the books he published (Fendler, 2010). However, Foucault rejected classifications and did not want to label his methodological framework (Oksala, 2008). This has led to different interpretations of Foucault's methodological work and the main critique of the lack of clarity.

During Foucault's lifetime he was publicly criticised by his contemporary intellectual thinkers within sociology such as the American Professor Noam Chomsky, the German philosopher Jürgen Habermas and the French Sociologist Pierre Bourdieu. Each had different perspectives on their critique, although their commentaries generally focused on how Foucault viewed power (Barry, 2021; Christensen, 2023; Verovšek, 2022). Chomsky (1987) argued that Foucault's analyses of power dynamics neglected a consideration of the underlying human capacities, motivations, and universals. Thus, Chomsky positioned that understanding human nature is crucial for developing effective strategies for social change and liberation (Barry, 2021). Habermas (1990) criticized Foucault for neglecting the role of communicative action and rational discourse in shaping social relations and argued that Foucault's understanding of power lacks a normative framework, leading to a pessimistic view of social change and emancipation (Verovšek, 2022). Bourdieu (1989) argued that Foucault neglected the subtler forms of power that operate through symbolic systems such as language, culture, and ideology (Christensen, 2023; Cronin, 1996). Despite these arguments against Foucault's theories, all of them engaged in extensive philosophical debate with Foucault, sometimes publicly (Chomsky & Foucault, 2015). The criticism has fueled ongoing critique of how Foucault oversimplified power and reducing individuals to passive subjects of power rather than agents capable of resistance and agency. For instance, Borg (2015) argues that Foucault's neglect of agency and subjectivity undermines the potential for social change and

political action. Moreover, Powell (2012) identified that resistance is a key part of Foucault's treatise, yet he did not deepen the idea of how resistance can be (Powell, 2012).

Despite the extensive use of FCDA in feminist research (Allen, 2018; McNay, 2013; Sawicki, 2020), Foucault has been criticised for overlooking feminism and women's perspectives in his theories (McLaughlin, 2003). As Foucault (1978, 1985, 1986) produced three books on the history of sexuality (Vol. 1, 1978 and Vol. 2, 1985, Vol. 3, 1986), there is a significant lack of reference to the female perspective (Powell, 2012). Additionally, Foucault's emphasis on individual agency and resistance may not fully capture the complexities of feministic struggles against oppressive systems (Bannerji, 2020; Macias, 2015). Feminist researchers argue that, while individuals can resist power, they are often constrained by intersecting systems of oppression, such as sexism, racism, and classism, which shape their experiences and opportunities for resistance (Bagshaw, 2019). Moreover, some feminists criticise Foucault for not adequately addressing the experiences and perspectives of women in his analyses, thereby marginalising their voices and contributions to struggles for liberation (Taylor, 2019). One of the main critiques is from the American professor of gender studies, Judith Butler, who references the lack of normative dimension in Foucault's theory, leading to limitations in the social construction of women according to FCDA (Butler, 1993; Dudrick, 2005). Butler (2002) further developed her own ideas within critical theory, focusing on providing body agency which was inspired by Foucault's genealogy. A key aspect of Foucault's influence on Butler is his concept of power as productive, operating through language, norms, and social institutions, to shape subject positions and identities. Butler (2002) extended this notion by exploring how gender, as a social construct, is enacted and perpetuated through everyday practices and performance. She argues that gender is not an inherent or stable identity but rather a repetitive performance that is both constrained and enabled by power structures (Butler, 2014; Powell, 2012).

Overall, despite this critique, Foucault's contribution to critical theory cannot be denied (Marshall, 2001; Wandel, 2001), as it challenges social constructs, but it is not without its flaws and limitations, prompting ongoing debate and criticism within academic circles. Yet, Foucault never claimed to have a theoretical framework to solve all problems (Oksala, 2008; Powell, 2012). Another critical argument is that his methodological approach lacks empirical evidence and relies heavily on theoretical speculation, thus leading to potentially spurious interpretations. However, the forty decades of influence in a range of research domains would maintain that, despite Foucault himself not producing a range of empirical evidence, others

have used his methodological framework successfully (Koopman, 2011; Macias, 2015; Raffnsøe et al., 2019). Taylor (2019) argues that part of Foucault's analysis is that the analyst may adopt their own methodological process which is imbedded by theory of Foucault but guided by the research topic, question and specific focus. Foucault never clearly gave one main direction to his theoretical thinking, as he was driven by paradoxical endeavours and contradictions (Veyne, 2013). As Foucault intentionally left a clear methodological process (which he termed "tools") for the researcher to interpret on his/her own, his discourse analysis approach can be criticised for lacking rigour and validity (Hansen & Triantafillou, 2022; Neto, 2018). However, Foucault responded to the criticism of his methodological tools in interviews.

I do not have a methodology that I apply in the same way to different domains. On the contrary, I would say that I try to isolate a single field of objects, a domain of objects, by using the instruments I can find or that I forge as I am actually doing my research, but without privileging the problem of methodology in any way. (Foucault, cited in Fontana and Bertani, 2003, p. 287-288)

6.4 Reflexivity

From the onset, another important part of the theoretical framework for this study is reflexivity. Reflexivity has many different definitions depending on its use, and has been used for over a century in different fields of research (Dodgson, 2019). The reflexivity definition of Berger (2015) was used in this study, as presented in Chapter One. Berger (2015) argued that reflexivity plays a key role in knowledge creation, as it highlights subjectivity and links it with the sense of self. Reflexivity has become a core characteristic of qualitative research as it allows the researcher to acknowledge that their background may impact the findings (Creswell, 2009). However, it is not to be seen as a fixed position; instead, as Bright et al. (2023) argue, it is to be seen as "the process of academic self-formation which is continuous and dynamic – a process of constant self-creation" (Bright et al., 2023 p.1). Reflexivity, as applied in this study, is just that, a dynamic process that has, by questioning my own bias, allowed me to become a researcher. My role as a researcher requires a level of scrutiny and transparency on how I, as a novice researcher, come to the conclusions of the construction of the knowledge.

Furthermore, tools of reflexivity are used in this study to create validity for the process. In discourse analysis, as a researcher and qualified gerontological nurse, I am part of and subject to the discourse and therefore need to be aware of my own positioning (Starks &

Brown Trinidad, 2007). I can easily create connections that may not exist. Apophenia (a precondition to see connections or meaningful patterns between unrelated or random things) and bias are common risks for qualitative nurse researchers, who may see patterns in behaviour that do not exist (Buetow, 2019). Flynn and Lynam (2020) pointed out that there is an appeal for researchers to look for causality, which is not the aim of FCDA (which looks for contingencies). Therefore, being conscious of one's own bias is a crucial element in qualitative research (Berger, 2015). Using a Foucauldian lens also has an impact on the approach to reflexivity. Foucault argues that we should be sceptical of knowledge as "truth". Kendall and Wickham (1997) suggest this is akin to pyrrhonism scepticism which argues you can never be sure of anything, including the fact that you can never be sure of anything. Therefore, as with Foucault's caution on taken for granted "truths", findings from this study also attract a sceptical approach in relation to their truth status.

From a FCDA perspective, reflexivity also provides an opportunity to highlight the power relationship between the participants and researcher. Dodgson (2019) explains that the researcher has expert knowledge of the study and therefore automatically has a level of power-knowledge that the participants does not have. Reflexivity is a tool to raise awareness for me as a researcher of that power relationship. Creswell (2009) proposes that the researcher's approach to data collection and analysis relates to their epistemological and ontological stance, which shows that my role as a female gerontological nurse background is already determined in the selection of the topic. My consideration of reflexivity concludes in the discussion chapter.

6.5 Research Design

When considering the research question, the main focus was inductive exploration lending itself toward a particular critical ontological position of discursive practices as a human activity within a system of rules that direct the production, operation and regulation of those discursive practices (Fox, 1998). Therefore, the epistemological approach was within the qualitative paradigm. Qualitative research methodology has become a dominant research technique in nursing (Miller, 2010), and several different paradigms guide that research, such as ethnography, grounded theory, and phenomenology. The choice of analysis with FCDA provides a critical investigation of how knowledge is produced, disseminated, and shapes our understanding of how LTCFs operate in the context of older people's human rights. Therefore, the qualitative paradigm and FCDA suited this study, as it provided crucial knowledge of

complex phenomena within LTC (Khankeh et al., 2015) asking how and why rather than what. Challenges in conducting qualitative research have been well documented (Khankeh et al., 2015; Renjith et al., 2021; Sandelowski, 2015), and the following section provides details of the steps taken in the study and presents some of the challenges encountered.

6.6 Setting

To provide a vital context, it is important to understand the setting of the data collection; the LTCFs. First, my own gerontological background in the LTC sector provided me with an understanding of how the facilities operate on a daily basis. Second, my initial interaction with potential LTC facilities to gain support in conducting the study provided me with insights into how the sector engaged with research. Finally, by conducting archaeological analysis, there was increased knowledge of the standards, regulations, and mandates that govern the sector.

6.6.1 LTC settings

Prior to applying for ethical approval to conduct the study, access to suitable LTCFs was required. The focus was on locating potential facilities that were interested in supporting and contributing to the study by being facilities where recruitment of participants would take place. Several facilities were contacted directly to establish an interest in acting as recruitment sites with a low level of success. Contact with potential sites occurred in early 2021 (February-May 2021), and at this time, LTCFs continued to be overwhelmed by responding to the demands of the COVID-19 pandemic. The initial search for potential LTCFs was challenging, and Jenkins et al. (2016) found similar obstacles (pre COVID-19) when conducting research in care homes in the UK, describing this as a paradox. On the one hand, LTCFs participating in research assist in quality of care and standards, while obstacles for conducting research within these settings discourage research.

Owing to the low level of responses from LTCFs, the researcher used professional contacts who worked in LTCFs to establish potential recruitment sites. A letter of invitation to participate was sent to these potential sites (Appendix 4). This was followed by meeting the Directors of Nursing (DoNs) at three potential recruitment sites, all of which confirmed participation. The DoN in each facility provided a letter of support (Appendix 5-7) to act as a recruitment site, which supported the ethics application. None of the sites required separate ethical approval as they did not have individual ethical boards. Table 5 provides an overview of the LTCFs. Initially, three facilities were included as participant recruitment sites, but due to a lengthy

COVID-19 outbreak, accessing and attending the second LTC facility (LTCF2) became challenging. Subsequently, a fourth facility (LTCF4) was then added, particularly as the recruitment of family members halted. LTCF4 was only used for the recruitment of family members, this is detailed further under section 6.11.2 in this chapter.

Table 5: Overview of LTC facilities supporting recruitment of participants

LTC RECRUITMENT SITE	LTCF1	LTCF2	LTCF3	LTCF4
PROVIDER TYPE	Private	Private	Public	Voluntary
NUMBER OF REGISTERED BEDS*	141	92	45	134
LOCATION	Co. Kildare	Co. Louth	Co. Dublin	Co. Dublin
TIME PERIOD FOR RECRUITMENT	November 2021	December 2021	January 2022	October 2022
TIME PERIOD COMPLETION OF INTERVIEWS	End of November 2021- January 2022	No access due to COVID-19 outbreak	January-April 2022	Focus Group November 2022
*AS PER HIQA REGISTRATION AT THE TIME OF THE RECRUITMENT				

6.7 Ethical Approval

Ethical approval was sought after gaining access and support from DoNs to conduct the study at the LTCFs and before commencing any recruitment of potential participants. Ethical approval was obtained from the Research Ethics Committee at the Trinity College Dublin Health Science Faculty in August 2021 (Appendix 8). Through a rigorous ethical process, a data protection impact assessment (DPIA) was conducted to establish that the study met the expectations of GDPR legislation. However, research ethics are much more than receiving ethical approval; it is the conduct of the researcher throughout the study (Lach, 2019). Apart from the four key principles presented by Beauchamp and Childress (2019) regarding medical ethics (autonomy, non-maleficence, beneficence, and justice), there are several other values that a researcher must consider in the process. These range from confidentiality and honesty to transparency and upholding of the law and standards (Pietilä et al., 2020). Furthermore, Lach (2019) observed that research often occurs when the researcher is on his/her own, relying on the integrity and conduct of the individual nurse researcher.

One of the main ethical challenges encountered, which needed to be addressed in the ethical application, was the process of obtaining consent. The dilemma is two-tiered, in that the described access to the LTC facility represents the first level of consent. Although the participating LTCFs did not have an ethical approval committee, they all required any research project to be reviewed by the senior management. Hagerty Lingler et al. (2009) explain that this initial first-tier consent can be as challenging as the individual consent as it is often non-structured. The second ethical dilemma was the process of obtaining consent from individual participants. All participants received the Participant Information Leaflet (PIL) and were encouraged to ask questions before beginning the interviews. Appendices 9 (residents), 10 (family members), and 11 (staff) contain the invitation letter, participation information leaflet, and consent form for each participation group. All participants returned a signed copy of their consent form before participation and the interview date was set. Explicit consent was obtained from all the participants. Participants were informed early on through the information leaflet that there was no personal benefit but that they may enjoy talking about their lives and experiences regarding the rights of older people in LTC facilities. Beneficence makes a greater contribution to the knowledge of the discursive positioning of rights in LTC. No harm to the participants was a key principle throughout the process and was significant, as the interview topic could evoke feelings, memories, and opinions. The researcher had an obligation to plan for any harm that could occur as well as to monitor and assess potential risks to the participants.

The second ethical dilemma, considering consent, is also driven by the vulnerability of the residents of the LTC facility due to their physical/cognitive status. Any research conducted requires rigorous ethical considerations, but this becomes more significant due to the in-depth nature of interviews with vulnerable participants, such as the residents of LTCFs. Vulnerability within research participants follows a similar construction as within society (this is touched upon in chapters three to five), which is dependent on a power relation between the marginalised, in this case older people, and non-marginalised (family members, staff, and researcher). Consideration of this group of participants required protocols to be in place to safeguard their vulnerability. Vulnerability is multi-faceted, where the institutions that provide care protect vulnerable older people from getting upset unnecessary within research. The informed consent process must address this vulnerability (Hall et al., 2009).

The DoN in each facility played a role in recruitment (see 6.10) and assisted in the assessment of functional capacity. Residents of LTCFs are not referred to as patients, yet facilities operate

in many ways within the medical model of patients' and doctors/nurses' power relationships. Øye et al.'s (2016) case study on ethical considerations in healthcare found that patients' main reason for participating was healthcare professionals' guidance. This illustrates the balance of wanting the participants to decide on their own to participate, yet being dependent on gatekeepers and other key personnel in the promotion of the study. This is a consideration of the vulnerability of participants, particularly if they agree to participate because of the influence of the healthcare professional, for example, DoN, rather than by their own choice. None of the participants participated under the influence or diligence of others, but one cannot ignore the role of institutional influence in wanting to please or acquiesce to staff in participating. Although staff and family members are not considered vulnerable participants (adults and not in a care-receiving position), awareness of the impact of the topic on participants was required.

All potential participating residents received PIL and consent forms, and although the consent form was provided to the researcher prior to the interview, there were some discrepancies in whether the participating residents remembered the content of the PIL and consent forms. The consent form was adapted for the residents to include pictures; however, the PIL was too detailed to remember all details. Thus, as researcher, I spent time at the beginning of the interview detailing the study objective. Similar observations of the process of obtaining consent were reported by Hall et al. (2009) and Bettie et al. (2019). It was key for the researcher to use the principles of autonomy and self-determination; if these were clear in the residents wishes to participate, explicit consent was considered to be received (Seedsman, 2019). By using the human rights approach to the study there is a critical requirement to include the older people living LTC facility as the study is about them. This requires support for older people to make decisions while participating in the study without any undue pressure to participate. The LTCFs that supported the recruitment of participants saw the benefit of research outweighing any risks that may occur due to research within institutions. It is important that older people in LTCFs are included in research despite the challenges in recruitment and informed consent as it benefits their care (Nocivelli, 2023).

6.8 Sampling

In general, sampling in qualitative research has been a source of discussion, and lacks clarity and consensus (Vasileiou et al., 2018). Similarly, sampling within discourse analysis has not been seen to have clear guidance or rules regarding how many people are considered a sufficient sample. Convenience sampling was used based on the participants' interest in

participating in the research, which is a common sampling method in qualitative research (Brodaty et al., 2014). Yet, in the motivation to participate, there may also be a bias that the researcher must be aware of (Stratton, 2021). Sampling is part of achieving saturation, a common aim in qualitative data collection and refers to the point in data collection where few or no new themes appear (Lincoln & Guba, 1985; Sandelowski, 2015; Weller et al., 2018). Weller et al. (2018) highlight that saturation has become a frequent topic in qualitative research as a measurement of rigour and validity, yet there are few clear guidelines on how to accomplish saturation. Fusch and Ness (2015) describe this perplexity as problematic for research, especially for novice researchers, as they argue that data saturation and research designs are not 'one-size-fits-all' methods. In this study, saturation was defined as the point at which new interviews were found to add little to the discourse formations that emerged from the analysis (Mortenson et al., 2016). As an achievable goal, the number of participants in each participant group was aimed at 15 individual participants. This is not a specific number provided by any research design guidance; however, as Weller et al. (2018) point out in their statistical study of achieving saturation in qualitative interviews, even small samples of 10 participants were able to produce most of the occurring themes and small sample sizes are typical in discourse analysis (Phelan, 2010).

6.9 Eligibility Criteria

The participants did not have to be in a dyad relationship; that is, the staff members did not have to look after the resident who participated and the family members did not have to have a relationship with the participating resident. Only by chance was there one dyad relationship between a family member and a resident among the participants; however, no significant difference in description was found due to this dyad relationship. This enabled a general reflection on the discourses of the rights of older peoples rather than on issues related to a single resident. The inclusion and exclusion criteria are detailed in Table 6.

Table 6: Inclusion and exclusion criteria for participation in the study

	Inclusion criteria	Exclusion criteria
Older people	Be a resident in the long-term care facility for at least four months Be 65 years or older Be able to give informed consent using a functional capacity approach.	Under 65 years of age. Not able to give informed consent. No verbal communication
Staff	Be a staff nurse or healthcare assistant and have worked at least 6 months in the long-term care facility. Be involved in providing direct care to residents.	Management, ancillary staff (kitchen, housekeeping, maintenance, administrators), MDT (multi-disciplinary team), such as physiotherapist.
Family member	Be a spouse, partner, child, nephew/niece of a resident in the long-term care facility Named representative for a resident	Friends, not named family members according to the resident.

All participating residents were required to be 65 years or older with no upper limit on age. They also have to be resident in the facility for at least four months to ensure that they have experience of being resident and may be able to associate human rights principles in the context of LTCFs. Staff were required to have worked for at least six months at the facility, also to reflect experience and the ability to associate human rights principles in practice. Staff included were healthcare assistants (HCAs) and staff nurses (registered nurses) who provided direct care to residents. Family members participating could be any named representative of the resident, or those who the resident had determined to be a family member. It could be a spouse, partner, child, or nephew/niece of a resident in the LTC facility.

6.9.2 Exclusion Criteria

Residents who were unable to provide consent for research participation because of conditions such as severe dementia or other cognitive impairments were not included in this study. The decision to exclude this group based on impairment was ethically challenging due to the topic of human rights and the principle of inclusion. In addition, LTCFs in Ireland have residents under the age of 65 years, and this group was excluded from the study. Participants who could not communicate verbally or appropriately in English were excluded from the study. This again impacted mostly residents who may have lost their verbal communication.

Staff that were management, ancillary staff (kitchen, housekeeping, or maintenance), administrators, or other multidisciplinary healthcare professionals, such as physiotherapists, were excluded. Nurse managers, and particularly the DoNs, assisted in the study in the capacity of providing access and as part of the assessment of who could participate in the study (i.e give consent through a functional approach) and thus were excluded. Exclusion also included those who visited the LTC facility as a resident's friend or acquaintance, or had no familiar relationship with a resident, such as a volunteer.

6.10 Recruitment of Potential Participants

One of the most time-consuming parts of qualitative research, and subsequently, in this study, is the recruitment of participants. As Marks et al. (2017) point out, this requires a detailed recruitment strategy for effective data collection. Despite the ageing population and a clear need to conduct research in the area of older people, specifically in LTCFs, there remain challenges and barriers to conducting research in this area (Maas et al., 2002; Namageyo-Funa et al., 2014; Tilden et al., 2013). Some of these challenges have been mentioned such as access, obtaining informed consent and retention in the recruitment (Tilden et al., 2013). This study's recruitment was dependent on key steps, such as access and dependency on DoN and gatekeepers. It was further challenged by COVID-19 pandemic restrictions with regard to access to recruitment sites.

6.10.1 Participant Recruitment

The LTCFs and particularly DoNs were key in the recruitment of all participants. The DoN in many ways acted as a gatekeeper, as the DoN provided access and support in facilitating the study, although there was a separate gatekeeper assisting in the recruitment. A gatekeeper was appointed in each facility and received a detailed letter (Appendix 12). With the assistance of the DoN, I met with each gatekeeper (an administrator, nurse educator, and activity staff member) to explain the process and distribute the study information. The gatekeeper also received the poster (Appendix 13) to display or distribute in the LTC facility. All this is assisted by the DoN at each recruitment site. They play a key role in the study through their position and being part of the initial screening to identify potential suitable participants. Thus, they have a significant part in the study completion. Despite not being participants, the DoNs' institutional knowledge is part of the study, and as Foucault (1972) stated institutional knowledge is part of the discourse. Potential resident participants were reviewed by the DoNs to have functional capacity (as per the ADMA, 2015) to participate, but this review was conducted before the

potential participant contacted the researcher. Functional capacity, is used as a screening of potential participants ability to make informed decisions, as it is contextual, situational, and time-based (ADMA, 2015). As the researcher, I did not access any medical, nursing, or social assessment, documentation or diagnosis. If I had any sense of a participant not understanding the scope of the study, the interview did not go ahead or was stopped. This was the case with two potential resident participants who wanted to participate (and had signed the consent form), yet lacked an understanding of what the study involved. No questions regarding medical diagnoses were asked during the interviews. For staff members, the gatekeeper informed potential staff participants of the study and provided them with information packs (Appendix 11) which the researcher followed up on. Staff interviews were held in the LTC facility the staff members worked in, which participants said they preferred for easy access.

The participant group that provided the most challenges in recruiting was family members. Recruitment challenges such as poor planning, timing of recruitment (COVID-19 restrictions were still ongoing at the end of 2021 and beginning of 2022), loss of interest from participants, and communication were all noted in the recruitment of family members. Recruitment was mainly driven by posters and same gatekeepers as for residents and staff. However, COVID-19 regulations limited visits to all LTCFs, which could account for another barrier to the recruitment of family members. Apart from COVID-19, this study met challenges that are all well documented in qualitative research (De Chesnay, 2014; Holloway & Galvin, 2017; Tremblay et al., 2021). Five family members were interviewed individually using Microsoft Teams (online) in January 2022. However, due to continued difficulties in recruitment, the decision to conduct a focus group was made in August 2022. Support was received from a fourth LTC facility (Appendix 14). This was followed by an ethical amendment, which was approved in October 2022 (Appendix 15). The fourth facility also appointed a gatekeeper (Appendix 16 for gatekeeper's invitation letter) that assisted in the recruitment of participants. A new poster was developed and used in recruitment (Appendix 17). Invitation to participate in a focus group (Appendix 18) was developed, and Appendix 10 PIL and consent form for family members used. Six family members participated in this focus group.

6.11 Data Collection and Management

A structured data management plan, was developed which enabled the accumulation of information in various forms and locations within the systems used. The following section describes the management plan, which used Microsoft Excel and SPSS to keep track of data

collected. Each participant was assigned a key code to align with their participant group and this allowed for pseudo anonymisation. Table 7 provides example of the key codes and meaning.

Table 7: Example of participants' key code

Key code	Meaning
S1R1	S-Facility R-resident
S1F1 S4FG1	S-Facility F-Family Member FG-Focus Group
NS1S1	N-Nurse S-Facility S-Staff
HS3S5	H-Healthcare Assistant S-Facility S-Staff

After each participant received a key code, their private details were held in an encrypted file on a password-protected computer. The written consent forms (hard copies) were kept in a locked secure cabinet at Trinity College Dublin, School of Nursing and Midwifery. Audio recordings were only accessible to the researcher, and destroyed once the transcription was checked and completed. The supervisor had access to transcription for verification during the analysis process. However, the transcripts were pseudo-anonymised and did not contain any personal details. In line with the Trinity College Dublin's Good Research Practice Policy (Trinity College Dublin, 2021), anonymised data will be stored for a minimum period of seven years after completion of the study. Personal details and key to codes are deleted after study is finished.

Statistical data about participants, such as age, contact details, and length of stay in the long-term care facility, were stored in an Excel spreadsheet and a quantitative data analysis software program (SPSS®) was used to generate conceptual information. All files were password-protected and saved in the TCD's secured cloud database. The interview data used a qualitative data analysis program (Nvivo®) to manage the vast content. Figure 13 gives an overview of the data collection, management and subsequent analysis process.

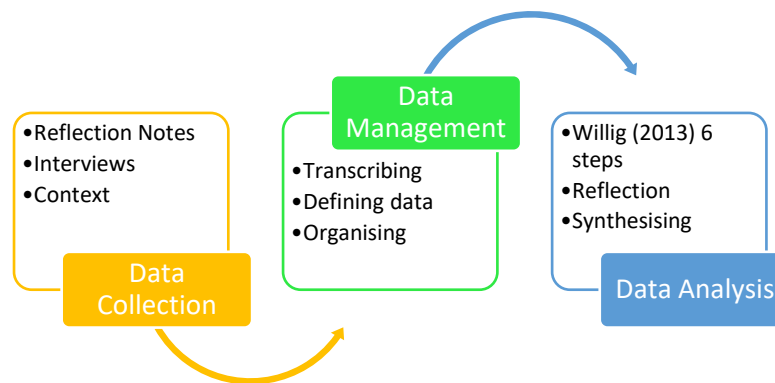


Figure 13: Illustration of data collection, management and analysis

6.11.1 Individual Interviews

Semi-structured interviews are considered time-consuming (Adams, 2015), yet represent one of the most common qualitative methods. They are particularly useful for collecting in-depth, open-ended data and flexibly exploring experiences (DeJonckheere & Vaughn, 2019; Samsi & Manthorpe, 2020). Their use in research is seen to enable probing of complex issues (Wilson, 2014) balanced with standardizing points of conversation through the use of a topic guide (Magaldi & Berler in Zeigler-Hill et al., 2020). Moreover, this form of data collection is advantageous for use with older people (Millwood & Health, 2000). While FCDA can be applied to a multiplicity of qualitative data sources, the semi-structured interview served to explore experiences and provided rich data to meet the research aims.

All interviews with residents and staff members took place in the supporting LTCFs. The DoN usually allocated a private room to be used. The interviews were conducted in these private rooms unless residents indicated a preference for their bedrooms. Some residents did require assistance to attend the allocated private room which required a carer to provide said assistance. The interview location does have a significance in the interaction between interviewer and participant and adds a layer of meaning. Elwood & Martin (2000) argue that the interview location can provide data beyond the interview text and as the interviews with residents and staff were held in the LTCFs; this became an important aspect of the interview. In FCDA it is significant to be aware of context, which include surrounding environment. The location of interviews with residents and staff in the LTC facility meant that the interview site

may not be considered neutral and all those micro interactions that occurred in the space could affect the information that was provided (Eldwood & Martin, 2000). It was important to be attune to these interactions. Before commencing the interviews, the purpose of the study was explained and a reaffirmation of consent was obtained. Semi-structured interviews were conducted for residents and staff. Access to LTCFs was possible in December 2021 and January 2022 as part of the researcher being vaccinated and conducting antigen tests prior to visiting sites. These were all part of the procedure prior to conducting the interviews with staff and residents.

For family members, there was a combination of individual interviews (n=5) and a focus group (n=6) due to the above-mentioned challenges in recruitment. As there were restrictions as part of COVID-19 response by the Irish Department of Health, all of the individual interviews with family members were conducted online through Microsoft Teams during January 2022. Conducting qualitative research using virtual platforms has also risen in popularity in recent years (Flynn et al., 2018) with a need for further innovation in data collection in time of COVID-19 (Roberts et al., 2021; Keen et al., 2022). However, disadvantages include the potential for technological problems and the change in rapport and engagement (Self, 2021).

An interview (topic) guide¹⁰ was developed for each participant group (appendix 19 to 22). The interview guide started with asking demographic details such as which age group and gender the participant identified with. Residents of LTC facilities were also asked how long they had been in the facility, while staff were also asked of length of employment at the facility and experience in care of the older person. Family members were additionally to age and gender asked of connection to the resident. Demographic details of participants (for the semi-structured interviews and focus group) is a key step in describing the participants (Adeoye-Olatunde & Olenik, 2021). The details asked differed depending on participant group and these can be viewed in appendices 19-22. The archaeological analysis of literature (Chapters Three to Five) provided some guidance in developing the questions. Although there were some divergences present in the three different topic guides, there are similarities regarding what area of human rights the questions apply to. The topic guide acted as a prompt, and the

¹⁰ In the interviews, the term nursing homes was used instead for LTC facilities, as this is a common reference.

questions were not always asked in a specific order, but guided by the direction of the participants' narratives.

Discussions often led to additional follow-up questions for the participants to clarify or provide examples. Some questions appeared to be easier to understand and others required modification and further explanation depending on participants' understanding of the question. Prior to asking questions, general questions about their lives or work were asked to establish a rapport. Some participants did become emotional during interviews, as their experiences were explored. This related to residents and family members who described emotional experiences. Despite the emotional impact, no participant wanted to stop the interview and further adverse effects were not noted from participating in the interview. Several participants did thank the researcher for the opportunity to talk about their experiences. This may have indicated a discursive silence in their opportunity to previously navigate these experiences.

6.11.2 Focus group

Due to challenges in recruitment of family members, most likely exacerbated by visiting restrictions, a decision to conduct a focus group with family members was made. The ethical amendment was submitted in September 2022 with amendment approved by the Trinity College Dublin Faculty of Health Sciences Ethics Board in October 2022 (Appendix 15). This meant that an additional fourth site was added as a recruitment site and added as part of LTCFs (LTCF4). Focus groups enable the efficient collection of meaning and similar to semi-structured interviews, allow exploration and elaboration of experiences (Kreuger & Casey, 2000). Ideally, focus groups should have 6-8 participants (Gill et al., 2008). Focus groups are useful to elicit a variety of perspectives and, like semi-structured interviews, are suitable to use in FCDA. Recruitment for the focus group commenced in October with the help of a gatekeeper (Appendix 21) who approached family members. 11 potential participants were approached with 6 participating in one focus group. The focus group interview was held in November 2022 and lasted 1.5 hours and although questions were similar to individual interviews some modifications were required to adapt to the group interview (Appendix 22). As in individual interviews, demographic questions were asked and participants in focus group were reminded that there was no pressure to share unless they wanted to. Instead of individual questions, questions were made more general and towards encouraging discussion. There was also the addition of group dynamics to consider. While the change from individual interviews to focus group suited this study and felt like a natural step when

recruitment halted, it was important to be aware of the different structure in focus group compared to individual interview. The individual interview allowed me to be in tune with the participants and allowed me to adapt the conversation to the participant (Heath et al., 2018), this type of interview suited particularly the participating older person. On the contrary, in a focus group of six people it is not possible to be in tune with all, however I made conscious effort to address all participants. For this study, the focus group of six people was beneficial as there was balanced discussion and provided large amount of text and statements to be used for analysis.

6.11.3 Journal notes- reflexivity

Journal notes as part of the reflexivity framework, became an important source of data and were critical to knowledge generation (Holmes, 2020). It provided validation in data collection and structured ways to adhere to the procedural norms. Reflexivity notes provided an opportunity to reflect on what interview contexts and which questions were most effective. It also provided a guide to verbal nuances, from both researcher and participant, that may have impacted the interview process (Berger, 2015). Before and after each interview, notes were made of observations, sensations, and how the interview went. The journal notes observed context, body language, and hesitations that may not been noticeable in the interview transcript. By going through journal notes, I was mindful to explore any bias or reaction from me which may have been an unconscious way to determine the results. Noting down thoughts during transcription process provided another contextual layer for the analysis. For me, the researcher, reflexivity also allowed me to reflect on the interviews and participants' contributions. Moreover, I considered my own research positionality reflexivity provided an understanding of my positioning in relation power-knowledge-discourse inherent in the subject positioning (older people) in the study. This enabled an account of "the situated and embodied nature of knowledge" (Subramani, 2019, p. 2).

6.12 Data Analysis

Firstly, demographic data regarding each individual participant were entered in Excel. SPSS was then used to analyse the demographics data using descriptive statistics. Data collection and analysis were conducted concurrently by the researcher until the last interview was transcribed and then a final overview analysis of all interviews was conducted. The data not only consisted of a vast number of transcripts, which were all transcribed by me, but also reflection notes that considered the context in which the data were collected. Once

transcribed, each interview was read while listening to the sound file, and during that simultaneous task, verification of the transcriptions' accuracy was performed. In addition, any discrepancies that may have arisen were dealt with, and the task provided an overall interpretation of the interview data. Although not specific to FCDA, some researchers within general discourse analysis argue that transcribing should not be outsourced and should be conducted by the researcher. Details such as hesitations, pauses, and silences can be crucial in understanding statements within a discourse (Edwards in Schiffrin et al., 2005; Kosmal & Crible, 2022; Sulzer, 2022).

As mentioned in Chapter Two, Foucault's methodologies can be seen as a toolbox from which the researcher can use for analysing data within the study (O'Farrell, 2005). Oksala (2008) describes this use of the toolbox as one of the controversies around Foucault's methodologies, for not being clear enough about steps to be taken within research. Therefore, practical steps for FCDA, produced by Carla Willig (2013), were used to interrogate the data. Willig (2013), whose research is within psychology, developed a six-stage text-based analysis to create a structure for discursive positioning. The stages enable an exploration of the constructions of the discourse that is revealed by what is said, by whom it said, and where (context) it is said (Willig, 2013). The six steps were applied to each separate participation group's data, and after completing each participant group, a review of preliminary findings was completed to see if there were any differences. Willig's (2013) steps in the FCDA followed the ontological position of critical realism. It is this realism that allows social construction by identifying what enables and constrains it. The application of the steps is delineated in table 8.

Table 8: Willig (2013) steps in Foucauldian critical discourse analysis

Step	Willig's description of step	Application
1	<i>Discursive Constructions</i>	The discursive object of the study is human rights of older people. The first step is to highlight how the three participant groups reference the rights of older people, or observe if there is a lack of reference about the topic. All references about human rights of older people in LTC were identified. This step seeks to locate those fundamental statements in the text.
2	<i>Discourses</i>	The second step involved analysis of the comparison differences in the references identified from step 1. This is a crucial step as three separate participant groups are included in the study.
3	<i>Action Orientation</i>	The third step of analysis involved a closer examination of the discursive contexts within which the different constructions of the object are being deployed. This step sought to answer what function the discursive statements have.
4	<i>Positionings</i>	This step searched the findings for meaning, not only for subjects but meaning of the objects. How they positioned themselves within the discourse and network of relations with each other in the context of human rights was examined.
5	<i>Practice</i>	The fifth step in the analysis concerned the relationship between statements, knowledge and practical action. It was a significant step in analysis as non-verbal practices form part of the discourse and could be in contraction to what has been said in the statements. This can produce an imbalance of what can be said versus what can be done. An example is how staff in long-term care facilities justify making decisions for older people when they lack capacity. Or when an older person has dementia-that diagnosis could be used as part of all decision-making.
6	<i>Subjectivity</i>	The final step proposed by Willig (2013) was the construction of social reality in relation to human rights of older person in long-term care. The person places him/herself in a 'truth' that is the way of seeing the world. An example from the study could be that older people perceive themselves as 'outsiders' or not requiring same rights as others because the discourse has positioned the person in a particular way within the discourse 'believe' this positioning to be true.

The first step is labelled discursive constructions and it functions to deepen the understanding of the object that is being studied, in this case, the object being human rights of older people in LTC. As the discursive constructions are divided at times into three areas; rights, older people and LTC, these are the objects that are analysed. Data was initially analysed by finding how these objects are described in the text (transcripts) (if they are described at all). As Willig (2013) points out, it is not about finding the object words, for this study the three object words are rights, old people and LTC, but also the unspoken reference to an object. This deepens the construction of the discourse. The three participant groups' interview data were separately

analysed to find all implicit and explicit references to the human rights of older people in LTC. This step can be compared to thematic analysis as proposed by Braun & Clarke (2012) as finding codes and themes, however, within discourse analysis codes are conceptualised. Instead, it can be referred to as finding statements that represent shared meaning within discursive constructions. This step is significant and it was important that researcher transcribed the interview data instead of relying on a professional service, as it is as much about finding what is not said or if there are hesitations to any statements.

The second step involved looking at the different ways of referring to the subject both within the participant group and differences between the three participant groups. As three participant groups have been selected for the study (residents, staff, and family members of residents in LTCFs), these represent the main stakeholder groups' interests in the context of the research aims. They are powerful interest groups within the discourse and although other interest groups exist these three groups influence how the discourse is constructed at the micro-level of everyday experience. The day-to-day routines and interactions between these groups sustain the knowledge that is constructed within the discourse. However, it is also important to note that there are other groups that influence the dominant thinking within the discourse such as regulators (legislative and standards), medical and socio-political groups (Willig, 2013). While these groups did not form part of the genealogical analysis, they were considered in the archeological exploration in the literature chapters.

The third step involved paying close attention to the function of each discourse and finding the action concerning the discourse and how action give the discourse a function. The fourth step focused on allocating the subject within the discourse and positioning the subject. The main subject in this study was older people in LTCFs (resident) and discourses both enabled and constrained particular ways of being. This included the subject positioning of the resident by staff and family members. The fifth step involved exploring the possibilities that were offered within the discursive constructions. The lack of possibilities or silences were also key. For example, if older people are told they have rights and yet there are barriers within the LTC facility in how they can utilise those rights, these observations are important to determine and reflect critical realism. This step revealed the initial consequences of possibilities within the discursive constructions. The final step was the construction of the discourse(s) and how it affected the subject within the discourse, in other words, the older person residing in LTC. The final step considered the composite of data from all three participant groups, to elicit those

'hidden truths' that were expressed and determine the consequences of these truths in relation to human rights of older people.

6.13 Rigour

One of the most discussed areas within qualitative studies such as this one is the validity of results to obtain rigour and validity (Burnard et al., 2008). The goal of obtaining validity, similar to quantitative research, is according to Sandelowski (2015) not a sustainable goal and qualitative research should look for its own standards of validity. Acknowledging the uniqueness of qualitative research, other criteria have been proposed to achieve rigour. Criteria such as the importance of fit (research question and aim to fit with methodology), integration of theory, coherence, documentation, sensitivity to negotiated realities and transferability (Dyar, 2022; Henwood, 2008; Rolfe, 2006). One way of achieving this is through reflexivity and Koch & Harrington (1998) argued that reflexivity is a key tool throughout the research process. Validity and reliability of the demographic data is demonstrated by summarizing the descriptive data and providing descriptions of data qualities such as the sample frequency and central tendencies (Lawrence, 2015; Mishra et al., 2019).

Discourse analysis needs to apply rigour to address issues related to transparency and credibility and this can be supported in demonstrating the frame of discursive approach, detailing the audit trail, detailing the analytic pathway and process of interpretation and careful description of the findings and conclusions (Greckhamer, & Cilesiz, 2014). The epistemological and theoretical framework of FCDA provides challenges in validity as there can be differences in application. As seen in the critique of Foucault (section 6.3.5) one of the shortcomings of FCDA, has been that individuals are seen to be positioned largely as passive users of discourse in the face of all prevailing discourses, with limited agency (Budds et al., 2014). Adding to the challenge is the researcher's own epistemological stance that affects the interpretation from the onset. Critical discourse analysis, as used in this analysis, already assumes there are structures and power relationships that shape the construction of discourse and hence have an impact on the knowledge creation (Greckhamer & Cilesiz, 2014). Add to this the reluctance of Foucault to label research protocols (Mills, 2004) or his death at the age of 57 years which some claim left his methodological tools unfinished (Danaher et al., 2000). These are the challenges that are present when attempting to create transparency to achieve rigour in this study. Subsequently, to provide transparent to the approach of FCDA is not easy, as Foucault (1970) himself pointed out that scientific discourse and its supposed objectivity

have gained hierarchical importance over social science. To illuminate rigorous transparency, I have provided steps in how I worked with the data. However, as Korobov (2020) argues in an editorial regarding discourse analysis rigour, the work around discursive data is often conducted “back-stage”, which means that it is challenging to show all the analysis directions that occur. This aligns with the idea that researcher is part of the discourse and often may be challenging to maintain objectivity.

Discourse analysis can be enhanced by Potter and Wetherell’s (1987) idea of fruitfulness, which refers to the ability of an analytical approach to generate rich, insightful, and novel interpretations of data. The method includes opening up a new and meaningful understanding of the deep, nuanced accounts of how language functions in social interactions. The fruitfulness of this study started with the chosen framework. By choosing FCDA, the tools of archaeology and genealogy enabled to dig deeper into the analysis. The archaeological literature review provided open-ended interview questions to provide rich and detailed answers, ensuring that the data collection was fruitful. Genealogical analysis allowed the researcher to uncover subject position and power-knowledge relationships and establish dominant discourses, revealing deeprooted assumptions through the interview text. Reflection provided the researcher with an opportunity to assess the fruitfulness of the process. Fruitfulness refers to when discourse analysis has reached its goal, making sense of new discourses and the formulation of innovative explanations, thus enhancing the trustworthiness of the findings (Harper, 2006; Wortham & Reyes, 2020). Thus, using FCDA was specifically fruitful, as it not only captured the surface issues of the human rights of older people but also the deeper, complex dynamics that exist.

Rigour was then achieved by adherence to key steps such as maintain detailed interview protocol and by using Willig (2013) steps in analysis and reflexivity as a secondary data source. The detailed interview guide ensured that questions were formulated to unveil power relations and discursive practices. In FCDA, the researcher needs to be attuned to the nuances of language and power, acknowledging that discourse is a site of struggle and negotiation. Using Willig’s (2013) steps in data analysis contributed to validity in the analysis stage as practical steps were applied and delineated in uncovering the discourse formation. Within the epistemological underpinning of critical realism, a way to assess the reliability of research is the use of triangulation (Madill et al., 2020). In this study, triangulation refers to the use of different data sources (interview and focus group text and reflective notes), and a second analysis conducted by researcher’s supervisor which validated findings. Reflexivity

also provides the researcher an opportunity to reflect on his/her own positionality and potential biases, ensuring a nuanced interpretation of the data. Validity is thus contingent upon the researcher's ability to interpret interview data within the broader socio-political context, recognising how power operates through language. This makes reflexivity notes important. Qualitative interviews contributed to validity by providing rich, context-specific data that allowed for an in-depth exploration of discourse formations. The participants were asked whether they wanted to read their interview transcript. No resident participant availed of the option, three staff members availed of the option and one of the individual family members wanted to read the transcription. But none of those who availed of the option came back with changes or comments.

Transferability is another issue for qualitative researcher and this study is significant to one period of time (conducted during COVID-19), in specific LTC settings (facilities in urban Dublin locations). As it is contextual, transferability frameworks do not reflect FCDA, but findings may echo discourse formations in other LTCFs and may provide insights into how to approach the topic of human rights of older people in LTC. Lincoln & Guba (1985) used the term trustworthiness which encapsulates the aforementioned principles of transparency, credibility, validity and transferability. The core in achieving trustworthiness and rigour is the reflective journal and being transparent of the steps in the research process.

6.14 Conclusion

This chapter presents the steps taken in the conduct of the study and commenced with an explanation of how Foucault's second tool of analysis; genealogy is theorized. FCDA concepts of power-knowledge nexus, governmentality, biopower, disciplinary power and resistance are explained to provide an understanding of the analysis approach. Thus, as a methodological tool, genealogy deepens the analysis of archaeology by investigating the power-knowledge-discourse relationships.

Contributing to the richness and rigour of the study, the process and practice of reflexivity were considered. Attention to reflexivity began in chapter one and will continue in the discussion chapter as a vital part of acknowledging the role and impact of the researcher in the study. As subjectivity and subject positioning is core to FCDA, the researcher must be mindful of self and being part of the episteme's power-knowledge -discourse which produce taken for granted 'truths'. Data were collected through 37 individual interviews and one focus

group (n=6). All interviews were recorded and transcription conducted by the researcher. Transcribed interview data and reflection notes were analysed using a 6-step framework developed by psychologist Carla Willig. These steps allowed for analysis to be structured and contributed to the rigour in the research process. The process of ethics approval, recruitment and the conduct of the data collection and analysis was delineated. Moreover, the issues of collecting data in COVID-19 was considered particularly as public health restrictions limited access and therefore was a contributing factor in the data collection challenges and the need to reformulate the data collection approach. The chapter also provided the context of general standards of rigour in qualitative research and within the methodological approach used. The careful consideration of rigour contributes to the study audit trail and the confidence in the process and findings. Following on from a focus on the research design, the next three chapters present the findings from the analysis of the data.

CHAPTER SEVEN

Demographics and Subject Position of Older Person in LTC

7.1 Introduction

The findings of this study are presented in the three following chapters. The chapters present these findings within the intricacy of three participant groups' discourses on the topic of human rights for older people in LTC settings. Findings follow the three main research questions as initially presented in chapter One (section 1.3.1). Three data sources were used: semi-structured individual interviews, focus group, and reflective notes, and the following three chapters present the findings of genealogical analysis, the stage two of the critical discourse analysis. In Chapter Two section 2.1, figure 1 illustrated the two main stages of the research analysis: archaeology and genealogy. The first stage commenced with a history of the present which applied an archaeological lens to the literature and current day knowledge of human rights, older people and LTC. Foucault's (1978) second methodological tool, genealogy, was used to interrogate the data and examine the contingencies within taken-for-granted 'truths'. Figure 14 provides an overview of how the findings of stage two genealogical analysis are presented.

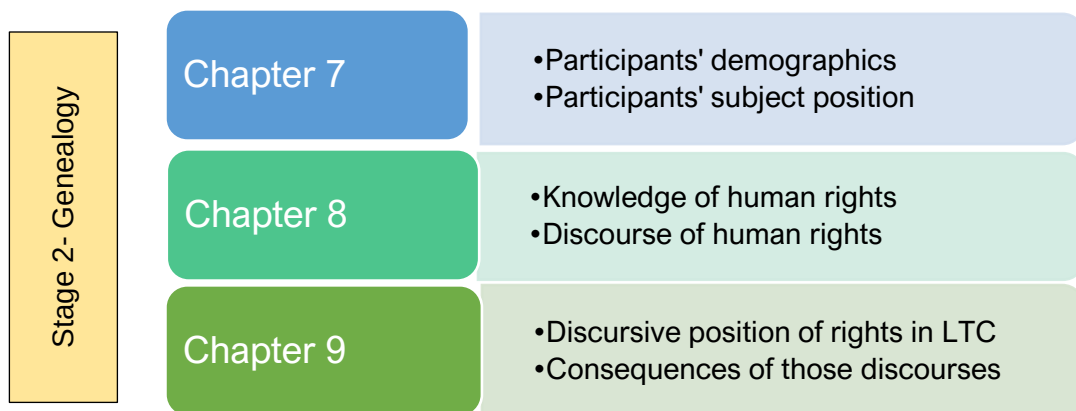


Figure 14: Overview of the findings from the stage two of genealogy analysis

This chapter, Chapter Seven, is the first of two chapters that present the findings related to the first research question. Chapter Seven commences with a review of the participants'

demographic details to contextualise the participant groups. This provides a foundation for understanding the application of a Foucauldian genealogical lens in terms of 'who is speaking'. Using a genealogical approach has the advantage of not simply analysing the transcriptions of discourses within the participants' interviews; it enables a deep examination of the construction of the discourse, examining orientations, subject positions, practices, and subjectivities (Willig, 2013). Consequently, Chapter Seven, following the demographic descriptions, presents the findings in relation to the subject position in the discourse, particularly the action orientation subject positions presented in the narratives.

Chapter Eight continues the interrogation of the first research question examining findings related to how the participants' discourse legitimises the understanding of human rights for older persons living in LTCFs, addressing the practice step within Willig's (2013) analytic pathway of the discourse. Chapter Eight also includes an initial analysis of the second research question; how discourses are used in practice. Chapter Nine continues the presentation of the development of the relationship between discourse, subjectivities and further examines the consequences for participants taking up particular subject positions within complex power-knowledge relationships. Furthermore, Chapter Nine ties together findings from the genealogical analysis with archaeological analysis and presents the three main discourses that are key in participants' constructions of the rights of older people in LTC. Chapter Nine focuses on what are the consequences of these discourses.

Quotes from transcribed interviews are provided to illustrate the findings. The quotes are verbatim and have the [...] to indicate when there is something said that is either incoherent or irrelevant to the quote. If ... appear without brackets, it is an indication of hesitation or a short pause. Longer pauses and silences are indicated by [pause] or [silence]. The interviewer's response or question is often included in the quote to provide context or probing. As the topic at times was difficult to grasp (this is presented in chapter Eight), probing was key to the interviews.

7.2 Demographic details of participants

Although demographic data are not used as part of discourse analysis, which focuses on the text (Willig, 2013), the knowledge of participants' demographic data provides context and comprehension for subject positioning. As there were three different participant groups, the demographic data also provided insights into the characteristics and potential differences

between the participants. In particular, demographics assisted in revealing a particular identity, and together with statements, locate the subject positioning of self for the three participant groups.

A total of 43 people participated in the study. As described in Chapter Six, under data management, each participant was assigned a key code. The keycode makes a distinction between the three participant groups. Data were collected through 37 individual semi-structured interviews and one focus group with six family members. All individual interviews were conducted between November 2021 and April 2022; the focus group was held in November 2022. Residents and staff were individually interviewed at the LTC facility to which they belonged. Individual family members were interviewed online using Microsoft Teams, and a focus group was conducted in person. Of the 43 participants, 20 were recruited from a private LTC facility, 17 from a public facility, and six (family members) from a voluntary facility. For all interviews, including the focus group, there were COVID-19 restrictions in place for the LTCFs. This affected the interviews in various ways, such as conducting interviews, challenges during interviews, and conversations about COVID-19 and residents' rights. Therefore, the reflective journal became an important part of the data collection process as it provided context, observations on the 'unsaid' and provided the opportunity for the researcher to uncover bias.

Four LTCFs were involved in recruiting participants. Table 9 describes the four facilities with the type of provider and number of beds registered for each facility to show their characteristics. The number of beds refers to beds registered with HIQA, and this number was recorded at the time of the interviews (November 2021 to November 2022). Due to a persistent COVID-19 outbreak at the second LTC facility (LTCF2), the recruitment of residents and staff to participate was not possible. Only one family member was recruited and interviewed through this facility. LTCF number four was then only used to recruit family members after recruitment was exhausted in other facilities.

Table 9: Participating LTC facilities

LTC RECRUITMENT SITE	LTCF1	LTCF2	LTCF3	LTCF4	TOTAL
PROVIDER TYPE	Private	Private	Public	Voluntary	
NUMBER OF REGISTERED BEDS	141	92	45	134	
NO. OF RESIDENTS PARTICIPATING	7	0	10	*	17
NO. OF FAMILY MEMBERS PARTICIPATING	4	1	0	6	11
NO. OF STAFF PARTICIPATING	7	0	8	*	15
TOTAL	18	1	18	6	43

* Facility was only used to recruit family members

Generally, there were no significant differences in the demographics between participants from private, public, or voluntary facilities; some, staff demographics differed between private and public facilities. However, there was no indication that this difference affected the discourse on the rights of older people. Those identifying as female were overrepresented among all participant groups; this was unsurprising, as by tradition, staff working in LTCFs are predominantly female (Eurofound, 2020). As the female voice is overrepresented, it must be considered in the discourse formation.

7.2.1 Residents

All residents' data were collected via in-person, semi-structured interviews. Interviews with the residents (n=17) were conducted between November 2021 and January 2022. Two additional residents were interested in participating and had received the PIL and consent form; however, on discussing the study with the participants, I, as the researcher, concluded that they could not consent to the study, because the potential participants did not fully understand what participation entailed. This is an illustration of my own (as a researcher) subject position and part of the power-knowledge relationship, further explained under section 7.3.1. Table 10 presents the demographic details of the participating residents.

Table 10: Participating residents' demographic details

Demographic Details	No.	N=17
Gender		
Male	6	35%
Female	11	65%
Age		
65-70	2	11.8%
71-75	1	5.9%
76-80	3	17.6%
81-85	4	23.5%
86-90	5	29.4%
91-95	2	11.8%
Average Length of stay in LTC facility (in years)	2.42 years	
Longest stay	8.5 years	
Shortest stay	6 weeks	
Average length of interview (in minutes)	20.31 min	
Longest Interview	40.22 min	
Shortest Interview	09.42 min	

As demonstrated in above table, 11 of the 17 residents were female, and the majority (64.7 percent) of the residents participating were over 80 years of age. The average length of stay for residents in the LTCFs was 2.42 years, with the longest length of stay of 8.5 years and the shortest of six weeks¹¹. The interview length varied, with the shortest being less than 10 minutes and the longest being approximately 40 minutes. This was noted in journal entries after each interview. The interview guide in Appendix 14 was used, but as the interviews were semi-structured, questions were asked in a conversational order.

7.2.2 Family Members

Interviews with family members were divided into five individual semi-structured interviews and one focus group. The five individual interviews with family members were conducted in January 2022 using Microsoft Teams and the focus group with six family members was held

¹¹ One resident was included as participant despite not fitting the inclusion criteria of four months in the LTC facility. This is due to the resident being well acquainted with the facility as her husband had been a resident for over a year and she visited daily until she moved into the facility.

in November 2022. Demographic details for participating family members are presented in table 11.

Table 11: Participating family members' demographic details

<u>Demographic details: family members</u>		N=11
<u>Gender</u>		
Male	0	
Female	11	100%
<u>Age</u>		
51-55	4	36.5%
56-60	3	27.5%
61-65	2	18%
66-70	0	
71-75	1	9%
81-85	1	9%
<u>Relation to resident</u>		
Child (daughter)	8	73%
Sibling (sister)	2	18%
Spouse (wife)	1	9%
Average Length of Interview (n=5)	51.64 min	
Longest	64.21 min	
Shortest	39.58 min	
Focus group	92 min	

All participating family members were female, and eight of the 11 participants had a daughter-parent relationship. This gender dominance may have contributed to descriptions about family dynamics and gender roles in the provision of care. The majority (64 percent) of the participating family members were between 50 and 60 years of age, and many of their occupational status were revealed in the interview conversation. Some examples of these roles included assistant principal, special-needs teachers, and administrators at third-level institutions. All participating family members visited the facility regularly (if allowed as part of public health restrictions) and were informed of their family member's care needs. A key characteristic of the interviews with family members was the duration. The shortest individual interview lasted approximately 40 minutes, and all other interviews lasted over one hour, with the focus group lasting 1.5 hours. The consequences of lengthy interviews included large amounts of data and time spent conducting interviews, as well as transcribing and analysing data. Family members were significantly more emotional during the interviews, which may account for the length of the interviews and the tacit impact of COVID-19. As the five individual interviews were conducted using Microsoft Teams (online), it is acknowledged that the

communication dynamics differed. For example, context and body language were key features that could have been affected.

7.2.3 Staff

Staff interviews (n=15) were conducted between January and April 2022. Two facilities¹² were included in the recruitment process and 15 individual interviews were conducted. Nine staff nurses and six healthcare assistants were included in the study. The experience of staff members varied; however, the overall average length of employment in the LTC sector was 7.76 years (Table 12). Among the nine staff nurses who participated, three described themselves as senior staff nurses with additional duties such as supervision and auditing. Of all the participating staff, 73.5 percent (n = 11) were over 30 years of age.

Table 12: Participating Staff Demographic details

Demographic details: Staff		N=15
Gender		
Male	4	26.6%
Female	11	73.4%
Age		
20-25	1	6%
26-30	3	20%
31-35	4	27%
36-40	3	20%
41-45	2	13.3%
46-50	2	13.5%
Average Length of experience for all staff participants in care of the older person	7.76 years	
Private	8	53%
Public	7	47%
Average length of Experience-PRIVATE	4.42 years	
Average Length of Experience-PUBLIC	11.57 years	
Registered Nurses	9	60%
Healthcare Assistants	6	40%
Registered Nurses average Length of experience	7.6 years	
Healthcare Assistant average length of experience	7.9 years	
Average Length of the interview	19:20min	
Longest interview	26:00min	
Shortest interview	11:44min	

¹² The original plan was to have three facilities included in recruitment of staff, however one facility had a prolonged COVID-19 outbreak.

The interviewer did not specifically ask about the nationality of the staff participants; however, this was disclosed by the participants themselves, often during their descriptions of work experience. Three participants (one nurse and two healthcare assistants) disclosed their identity as Irish in the conversation. Two nurses were from European countries and the remaining participants (n=10) were from outside Europe. This may have influenced the data in the understanding of human rights and perception of the care of the older person as there may be differences between cultures and countries in how these are perceived.

A significant disparity in demographics was noted in relation to the length of experience in the care of older persons, where the average length of experience in private facilities (n=8) was 4.42 years compared to 11.57 years in public facilities (n=7). In other words, there was a significant difference in the average length of experience between public and private facilities. Furthermore, a small number of staff participants (n=3) who were working in a public setting at the time of the interview but also historically had worked in a private setting disclosed experiencing a difference in management between the two settings. Yet, they did not mention whether this difference had any impact on the provision of care or human rights of older people.

7.2.4 Researcher Reflections on data collection

Reflective journal notes provided insights into contexts that were not captured by the text. These reflections shed light on how all discourses are constructed, how the knowledge of rights is constructed, and how they are disseminated in the LTC facility. Data from the reflection notes provided findings related to subjectification, knowledge, and 'hidden' truths that emerged in the analysis. Illustrations of reflection notes are presented throughout the three findings' chapters.

Owing to different factors, such as frailty, medical conditions, and environment, residents may appear tired or disengaged after a time while the interview was progressing. It was important to engage with the residents; however, because of these factors, the interviews needed to be kept precise and on topic. A challenge as some of the residents were keen to chat about everything. Residents often mentioned that they would think of things to say after the interviews had been completed, indicating they felt they had more to say.

Interviewer: Anything else you want to say?

Resident Participant S1R6: I don't think so. After you're gone, I will think of things.

Residents, due to chronic illness, age or surrounding disruptions, may have had difficulty hearing and talking. During one of the interviews, it was noted that the participant, due to nature of her illness, preferred to answer yes and no questions instead of the open-ended questions.

Interviewer: I think, do you prefer if I ask you yes or no questions? Is it easier to answer yes or no questions?

Resident Participant S3aR5: Yes. [participant appears to be relieved]

Interviewer: Yeah, so I'll ask you yes and no questions. Is that ok?

Resident Participant S3aR5: Yes.

Changing to yes and no questions provided relief to the participant, and they were able to, consequently, find their own words in answering the questions. These adaptations to the interviews were necessary for the residents to open up and have conversations. These illustrations provided data on how the resident subject positioned themselves as well as the researcher, which is further examined in the next section. Observations of family members' interviews showed that they were articulate, well-spoken, and similar to residents, wanting to make sure their contributions mattered, thus determined to provide data that would be beneficial.

Talking about COVID-19, (a fairly recent event when interviews were held), the majority of participants referred to it as a 'blur' or 'I don't remember'. In particular, staff mentioned that they felt that it was ages ago, although they were still working with restrictions. Data from staff interviews could have been affected by interviews conducted in the work environment. This contextual power is significant in determining the truth of the rights of older adults. It pinpoints the power relationships that occur, and staff could position themselves as being representative of the LTC facility and not as an individual healthcare professional. The following reflection note after an interview with a participating staff member highlights this point.

Completed interview with staff participant. Participant was extremely nervous, I kept reassuring that it was not a test of any kind. But participant seem to be cautious in all the answers and often referring back to me 'is that what you mean?' or 'I don't know if that is the right answer'. Despite reassuring that there is no right or wrong answer,

participant seem to relax after interview was concluded. After recording was stopped [I] asked whether participant still was happy to have participated which they said they were and commented: 'it wasn't as bad as I thought'. Recruitment of participants have been difficult but I cannot wonder whether the staff have agreed to participate to show goodwill to gate keeper or director of nursing, who is promoting the study. Also, despite all my efforts of conducting the interview outside of facility, this is [...] was the only way to conduct interview with participant and may be a limiting factor in participant being open during the interview. A part that is frustrating for me in the research process. (Journal note, 17th February 2022)

This reflection points to a dilemma between the researcher's own power-knowledge relationship and the participants' ability to express themselves as naturally as possible. All interviews with staff participants were conducted in the workplace; the staff appeared to be more nervous, and there was a sense of giving the correct answer. Some participants expressed this as feeling that they were being tested for their knowledge. Upon reflection, conducting interviews outside of the workplace would have been more suitable; however, this was impractical and staff preferred the LTC facility for the interview due to convenience. The staff participants' workplace was a significant element of data collection to take into account as the site of power relations of the research questions.

Although convenience may have played a role in the venue of interviews, the reluctance of participating staff members to conduct interviews outside of the LTC facility points to their identity as a homogenous group, not to be seen as an individual professional but as part of the organisation and the institution of the LTC facility. As described in the section on the reflexive observations regarding interviews, staff were reluctant to show any weakness or errors, wanting to say the 'correct' answer which would again suggest alignment with the organisation of the LTC facility.

Interviewer: [At the end of the interview] Now, anything else you want to add regarding human rights and older people?

Staff Participant NS1S2: I don't exactly know what you are looking for [participant appears unsure].

This is further explored in the subjectification of the staff detailed in 7.3.6 and in Chapter Nine under institutional rules section 9.4.3.

7.3 Subjectification

Subjectification is concerned with how an individual is constituted as a subject contingent on the construction of discourses and power relations. After describing the demographics of the participants, the following section continues with Foucault's (1977) subjectification approach within the genealogical analysis of the discourse. Subject positioning, which is how the subject experiences himself/herself in the 'hidden truths', plays a key role in discourse construction.

The following section presents the subject positions traversing from the researcher's own position within the discourse to the participants' construction of subject positions, with older person in LTC and their rights at the centre of the discourse. As presented in previous chapters (Two and Six), subjectification is made up of how participants observe, analyse, interpret, and acknowledge themselves as a domain of the knowledge produced within the discourse. An older person is constructed through discourse, meaning, power, and regulation. Figure 15 demonstrates how the older person is positioned in relation to all participants in the discourse, including the researcher.

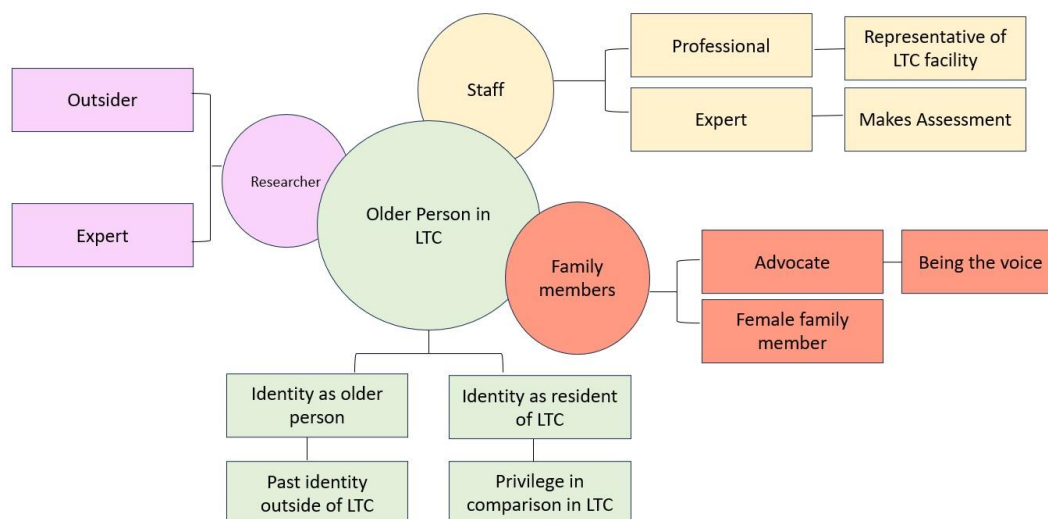


Figure 15: Subjectification of participants in the discourses

7.3.1 Researcher's positioning

The researcher's subject positioning began with my own fractured subjectivity. How I experience myself in the study affects the findings and I am part of the discourse, not only as a researcher of the study but also as a female nurse (with experience in the LTC sector),

visitor to the LTC facility, and confidant in the interview process. A more detailed description of how that process has affected my own outlook is provided in chapter Ten under the discussion of reflexivity, section 10.8. Figure 16 illustrates my position in the discourse as an outsider, yet from my expert position as nurse I have insight into the LTCFs and how they operate.

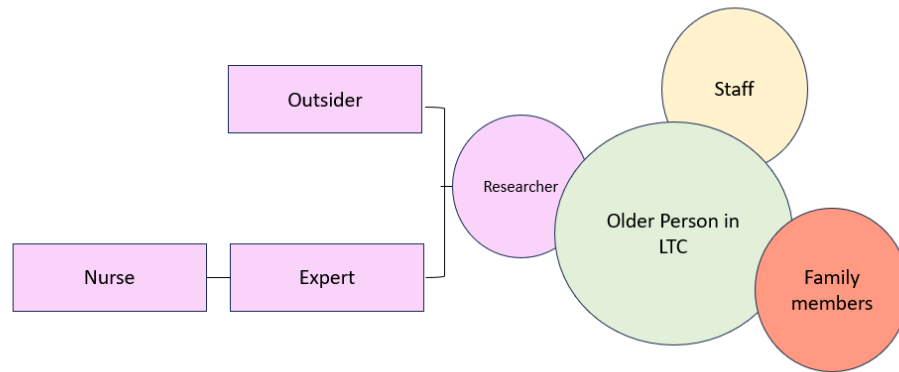


Figure 16: Researcher's subject position

My position in the discourse was impacted by discursive statements provided to me, the researcher, with the 'right legitimized' information. As mentioned in the previous section, all the participants wanted to provide valuable information. For example, some participating residents (older people) were worried that what they said may not matter during the interviews. This shows their own positioning as someone who may not be sure of their own contribution or its legitimacy, which points to a perceived 'othering' or invisibility. Yet, their eagerness to please me with the 'right' information may have been a way to prove their significance.

Interviewer: Now, that's it and it was nice talking to you.

Resident Participant S1R5: I hope I was any help.

Like residents, family members wanted to know whether their contribution had any meaning; they did not necessarily feel it was a test but could ask if what they were saying was what I needed as a researcher.

Interviewer: Anything else you want to add regarding long-term care rights, older people, anything, like any of the topics?

Family Participant S1F1: No, I don't think so, no. Have you got what you want?

Staff were apprehensive, and before relaxing in the interview, could come across as suspicious of the topic, and hence, also suspicious of me as a researcher applying normalising judgement. They often viewed the interview as an assessment of some sort, concerned with whether they 'passed the test'.

Staff Participant NS1S5: Feel like it's an exam. [laughter]

While the statements reflected how the participants' subject positioned the researcher, as a person with knowledge and therefore a person of power, they also reflected the uncertainty regarding "truths" pertaining to two aspects of the topic. First, human rights, as an overall subject, can feel abstract and difficult to define, which means that participants doubt their contributions because of the limitations of what can be said. The second aspect was the motivation of the participants to provide data. All participants were keen to participate in the study, indicating that paradoxically, they perceived their contributions mattered.

7.3.2 Older persons' subject positioning of self

Identifying the subject positions of participating older people is a key aim in the establishment of a discourse on the rights of older people. Two key subject positions or identities acknowledged in the archaeological analysis were further legitimised and sustained through the genealogical analysis of the data. These are as follows: first, the identity as an older person and second, as a resident of the LTC facility. Such identities are crucial for capturing further power knowledge relations in the next chapter when the object of the discourse (rights) is explored. Figure 17 shows the main subject identities that the resident takes on in the LTC facility.

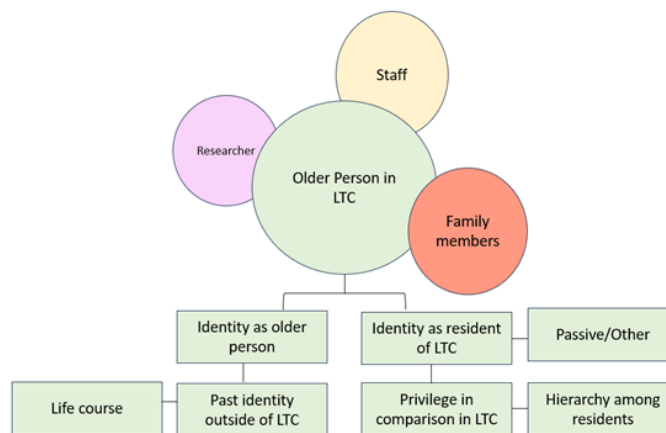


Figure 17: Illustration of Older Person subject position in LTC

7.3.3 Identity as an older person

As a result of the data collected and analysed through a genealogical process, there were two main subject positions constructed by the participating residents: that of an older person and that of an older person living in an LTC facility. There was a key distinction as older participants often spoke about the person they were before living in the LTC facility. The residents who participated in the study appeared to have longed for the person they were before becoming a resident in the LTC facility, indicating that their previous identities became less legitimate upon admission. This was initially distinguished by how the resident spoke about the past, both in personal and occupational references. In the excerpt below, a resident spoke about his/her house which the resident was pressured to sell the house even though the resident acknowledges the LTC was their place of residence now.

Resident Participant S3R2: But you see I would have the house on my own. And then it felt right. If you get me, you know. That's rights. No, I wouldn't do it. They kept saying 'that's right' and I wouldn't budge. I wouldn't share the house, but I'm not going to sell the house. I would leave the house, but I wouldn't sell the house. That's my baby.

Interviewer: Do you miss it? Do you miss the house?

Resident Participant S3R2: Oh yes. Oh, I am. Sitting here thinking about it. But I just can't well, see I can't after I had the stroke. As expected, the left side and I can't stand and I can't walk. And I was

getting then. I was falling and no peace at all. Just falling on to the ground.

The contrasting subject positions could also be evident in the identities of the self in relation to the residents' previous occupations and how that defined them. They spoke about their occupation with a yearning, particularly those who had enjoyed their profession, identifying positions of status.

Interviewer: Is there anything you miss doing? [discussing daily activities in the NH]

Resident Participant S1R6: I was, before, I was hard going. I was the National development officer for [activity programme] and it was great opportunity [...].

Interviewer: Oh yeah. You were busy [laughter]. Do you miss being busy, do you?

Resident Participant S1R6: You do, you do.

This focus on the past person points to an intricate conditional view of oneself as 'not relevant' due to assumed ageist views. The older person expressed a longing for their younger identity and residents may not be able to identify themselves as being old. One participant who had just turned 65 years expressed not identifying as old.

Interviewer: OK, you wouldn't think. You know the media and there's a lot of talk about rights of older people. You don't think that applies to you?

Resident Participant S1R2: Currently? No no no no.

The above example of a resident saying that rights do not apply to them could indicate that they feel they have no rights but also not identifying as an older person with rights. . There was a lack of association with the concept of human rights of older people.

This contrast of 'old versus young' was also expressed by the participants as the younger generation had more power. As an older person, they take on a passive role and believe that some areas of life should be left to the 'younger' generation, although who is this 'younger' generation is not defined.

Resident Participant S1R5: No. Well, I'm kind of the age I am. I'm 83 and you kinda go with the flow. I mean I would have a lot more to say

about 20 years ago [laughter]. About 20 years ago I probably try to organise them [community members] and get things changed, but now I just don't, but I have to say I've lost interest in that.

Taking on this passive role was evident in the context of COVID-19, and residents seemed quite blasé about talking about COVID-19. They mentioned visiting and vaccination, but in general, they did not say that COVID-19 had an overall impact on their lives. They accepted the public health restrictions, conditioned by paternalistic views that the older people in LTC required protection from COVID-19 infection.

Interviewer: Did you understand the restrictions?

Resident Participant S1R1: Oh yes yeah yeah.

Interviewer: Yeah, you didn't think that they were unfair?

Resident Participant S1R1: Oh no no no no no no. Once we were all safe, yeah, that was the main thing... keeping us safe yeah yeah.

As the residents placed themselves in a position of vulnerability tacitly agreeing that they needed to be kept safe, they accepted it. Acquiescing with the public health protection discourse was evident through archaeological analysis (chapters three and four) and genealogical analysis supported this.

7.3.4 Identity as a resident of LTC facility

Further reinforcing the altered subject position and subjectivities of their lives as residents, older people made a distinction between their being pre- and post-admission. In the process of admission to the facility, the older person assumes the role of the resident, a role that is valued less and therefore talks more about the past person who had a status. When asked the resident about their life, they often described the past, not recalling their life in the LTC facility unless asked specifically about it. Yet, there was recognition of the connection within some residents' discourses, as demonstrated below.

Interviewer: So, tell me a little bit about yourself, just in general.

Resident Participant S1R1: The present or past?

Interviewer: Whatever you want.

Resident Participant S1R1: Well, I mean my past would be part of it [life in NH].

On admission to the LTC facility, the older person had to give up not only the identity of the person they were but also the majority of their physical belongings. Thus, the move represented the technology of the self through which the older person (re-) constituted him/herself. However, this appears to be a difficult process.

Resident Participant S1R7: I mean like, you know, it is hard coming here. You kind of lose everything like you know. All your bits and pieces. Everything needs to fit in the room and they want to know where you are going.

There is an element of passive acceptance of their new identity in not questioning their position, but accepting it as part of their age and increasing dependency. Being a resident in a facility required the older person to internalise the institutionalisation and accept the normalising practices of the facility. Thus, this represents the tacit acceptance of normalising practices and legitimisation of their new subject position as they submit to biopower, governmentality within the disciplinary power of LTC.

Interviewer: You have everything you need here?

Resident Participant S3aR6: Yeah, well. Life changes all the time. As you get older. And I accept that, yeah.

However, such a transformation and altered subjectivity are not unproblematic; there is an element of loss, not only the person they used to be but also a loss of belonging, both spiritual and material. The older person's sense of self is altered as interactions with the LTC facility and institutions themselves influence their self-subjectivity. One participant spoke about how the house she had shared with her husband was now 'all locked up', and there was an element of sadness in her voice. This is significant for subject positioning in the discourse, as the older people in the LTC facility have lost a large part of their being. They find themselves in a position of 'other', those that are vulnerable and frail, needing care.

Further findings were related to the positioning of the self as a resident. The residents identified that the autonomous nature of rights may be more fragile for some of their peers; thus, they were in a different position in being more able to exercise self-determined decisions and advocate for their own rights, as demonstrated below.

Interviewer: But you know the way, [name of participant], they talk in the media and in the newspaper. They talk about how older people

don't have rights, and you know that their rights are not upheld. Do you feel that that's correct?

Resident Participant S1R1: No no no no no. I don't yeah, but whatever about out there [points outside of nursing home] here no no. But I pity the people [points outside].

There was a sense of resistance among the participant residents of not identifying with “those”- referring to residents that may be living with dementia. This was an othering that the participants referred to in comparison to other residents with cognition challenges. A part of the subjectification and identity as a resident in the LTC was that of an older person who did not cause any problems. They have fallen into a subservient role that positions older people as not relevant, nor are their perspectives constructed as valuable, as shown by a simple remark by a resident during the interviews.

Resident Participant S3R1: Now I hope I'm not boring.

Interviewer: No, you're not, [name of participant]. This is a good conversation. It's good.

Resident Participant S3R1: I think I'm boring you.

The older person in the LTC facility did not seem to question or complain. There could be passive acceptance of what is offered as they go along with that choice. This is contradictory to staff (as seen in the next chapter), who describe that the resident, at least in theory, has a choice, yet in reality, residents could describe instances where they have transformed into docile bodies, accepting the governmentality within LTC. The older person assumes an identity that submits to normalising practices and the strong biopower that exists. This is evident in the narrative exchange below.

Interviewer: Can you tell me what you do throughout the day here?
After you get up in the mornings?

Resident Participant S3aR3: Just what's going around. I don't bother with anything, just what is there.

This is a form of compliance where the residents form their subject within the discourse, meaning they do not want to be in trouble or disrupt “normal” daily routines. Thus, data demonstrates complex subject positions of self in relation to their own construction of self, drawing on pre-admission identity but describing current transformed identities assuming the subject position of “resident”. The older person residing in a LTC facility relies on their past

identity to define who they are; however, in the present, they rely on being the person the LTC facility expects them to be. Equally, subject positions regarding residents' identities can reflect identity diversity within the population of residents, illustrating a hierarchy of constructions related to cognitive and physical status. For instance, within the discourses of some residents, some acknowledged themselves as having a privileged position compared to other residents, particularly those with cognitive impairment. This demonstrates a form of ageism within the older people themselves, a form of prejudice of those that are old and vulnerable, and subsequently in a worse position than other residents.

Resident Participant S3R3: [...]. But I'm very lucky in a way like that I was able to afford to come here. To have my own room. And have good meals and company, have company if I want company. [...]

Interviewer: Do you think everyone else is that lucky?

Resident Participant S3R3: No, I know some of these poor creatures [referring to other residents] were on their own before the came in. And nobody wanted to come in and see them. And no family to know of. That kind of thing. Some people mightn't think about seeing the older people or whatever. No, I'm. I feel I'm lucky now. I'm well off. [...]

This hierarchy of privileges was further demonstrated when discussing COVID-19, where some residents felt that the perception of COVID-19 in the media was not fair or a description of the facility they were in. The participating residents acknowledged that COVID-19 challenges may apply to other facilities, but not to the ones they are in. Yet, the participating residents may not have the full knowledge of the COVID-19 status in the facility they reside in.

Interviewer: Yeah, you know the way they have portrayed in in on the news, how bad it's been throughout the COVID-19 in nursing homes. Do you think that's a fair picture of how it's been?

Resident Participant S1R4: For some of the homes it was. I don't think this one. I think it was pretty good in this one. I don't know. Most of the people seem to...[pause]

Interviewer: So that's not applicable here?

Resident Participant S1R4: No, I think, I think. It didn't. I don't think COVID actual came in? [referring to COVID-19 outbreak in NH but does not sound sure]. You know the prevention thing works, you know? I'm not saying there wasn't something.

This is another example of a form of hierarchy among the older people themselves. They were able to recognise that they were ‘others’ that may not be as lucky as them, whether in the same facility or the participant acknowledged that ‘other’ facilities were not as well off as the one they were in. It exemplifies an internalised position of not wanting to be one of the older people needing care, that there are the ones that require more assistance or are in a further vulnerable position.

7.3.5 Family Member’s subject positions of the older person

As stated in the demographics section, all participating family members were female, and the majority were in a daughter/parent relationship. Family members predominantly positioned themselves as the ‘voice’ of their older relative. The figure 18 shows how family members are connected to the position the older person.

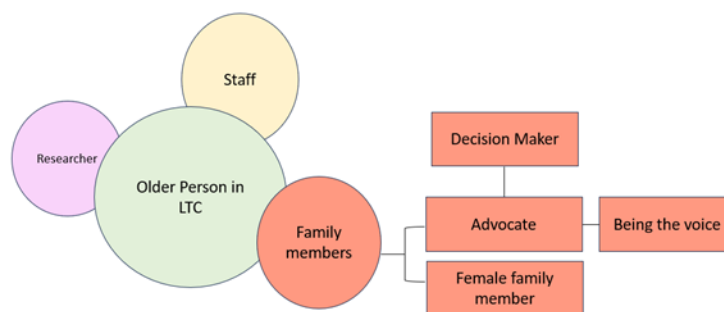


Figure 18: Illustration of Family Member’s subject positions of the older person

Family members overwhelmingly drew on the older person’s need for an advocate and family members took on that role for the resident. Advocacy has different definitions and functions depending on context (Reid, 2000), but the word advocate stems from the Greek word ‘advocare’ which means ‘towards a voice’ (Cloyes, 2010). Chapter Nine further explores the findings around advocacy and its consequences in the discourse of conditional rights. All the participating family members played an active role in their relative’s care. This was further demonstrated when there could be a cognitive impairment diagnosis for the resident.

Interviewer: Do you feel that you are her [parent who is a relative] voice? Her kind of...[interrupted].

Family Participant S2F1: Very much so, very much so, yeah. She doesn't have a voice [family member had disclosed resident has had a stroke]. And I think. And it's very important that I. And I wouldn't be a very forward person myself, you know. But I I feel that I have to be really in the foreground as her voice.

Being an advocate meant that it was important for family members to demonstrate their presence in the LTC facility. They did not say the word 'surveillance', but there was a sense of engaging in staff surveillance. In this sense, the majority of participating family members were complimentary of staff, but acknowledged that you would not know what goes on all the time.

Interviewer: And you, you used the word advocate, you see yourself as your dad's advocate?

Family Participant S4F1: Yeah, yeah. Well, in a sense, I see that you know, if you're involved with, if you're involved with your parent or you know and and parent are your other relative and your other care rep I think it is your duty to be their advocate and speak when necessary. Not, not not to criticize. You know. No, no, not to criticize, but to ask, to ask.

Family members took being 'the voice of the resident' seriously as part of their duty, even if this meant that their own relationship with the LTC facility may have been affected. Part of advocacy was not to be seen to question the disciplinary power that staff had. Nevertheless, some family members did describe a form of resistance to the disciplinary power that staff have. An example of that resistance is presented below where a family member describes herself as an 'annoyance', even though her interactions with staff were reasonable.

Family Participant S1F2: Well, yeah, and and, you know, they [staff] would be very respectful to me. And I I'm probably the one that gives them the most annoyance, uhm, you know.

Interviewer: In what way would you consider yourself an annoyance?

Family Participant S1F2: Well, you see, I... I because I am mom's advocate. You know, I... I, I deal with all her medical issues, her food. And any sort of, I'm the go to person for the nursing home. You know, if there's any problems, they ring me and for information. They need to be about. It's me. Uh, if the GP needs to be called, it's me they ring. They don't, they don't contact Dad at all. And so if she's constipated for six days, they ring me to tell me you know, so I'm also the one that will say, 'well, why wasn't this done?' Why? Why?' You know, 'why are her 27 pairs of socks missing?' You know, 'why is this?' You know,

'why is this resident lying on her bed?' You know, because they wander, you know?

One aspect found in the analysis of the subjectification of participating female family members was the element of family dynamics. By being the voice of an older person, family members also spoke about their own identities as caregivers. Female family members described a generational change in the family dynamics of who cares for the older person. In the excerpt below, this included traditional historical genderised views of caregiving and women in the home.

Interviewer: And you feel by family connection that it comes natural to you? There's not a force, a pressure on it? [Follow up question about being advocate]

Family Participant S4F1: It does, it does, if anything, we were not frowned upon? But I feel that, you know, if my mother said, says 'oh, I have six children'. Then, 'what are you doing in a home? Why are you in a nursing home if you have six children?' [referring to outsiders' reaction to her mother being in a NH] And I mean people have said it to me, but not directly. 'You put your mother in a home and there's six of you?' But not all six are on the ground here in Dublin, there's two of us, you know. And I just, I would if I could, but unfortunately. [...] I think it's generational as well. I mean, it's... My dad is of an age where women didn't work. They stayed home, I am among the first generation in my family who work. And so, like, so Dad wouldn't expect the same of my brother, but he would of me. So that's that.

Although most family members mentioned this generational change in family dynamics, only a few residents supported this perspective. These residents observed similar changes in that family structure was not what it used to be, and how that has changed how care is provided and what kind of access to care there is.

Resident Participant S1R4: [...] They [referring to older people] live roughly the same age we are now until that accord, and as you do, there's going to be less family to look after them. Like years ago, you have big families, standard families. And they were just automatically included. Like as in many modern things. At work, the mothers are at work and the family, and usually it's not that they don't want a large family. Yeah, well, that's that seems to be the trend.

While it may not affect the older person's subject position in the current episteme, it highlights a change in perceptions. As family dynamics change, the roles of those supporting older persons needing LTC may also change. This could have implications when rights are upheld.

Family Participant S4FG3: They [healthcare professionals] say well, you know she'll have to leave home and like. And then you go 'well where we're going to put her?' She can't go home because now she's gone from this to being doubly incontinent where we're going to go. And then you say, 'do I need to look at nursing homes?' So you start going around looking at nursing homes and a lot of it kind of falls back on to you. So your identity does change and I notice when I came back in [to the nursing home] I went back to being mother daughter as opposed to mother, daughter, mother, caretaker, mother have to go to court to get whatever she's. All of that other stuff.

A family member's subject position of 'being the voice' is a form of paternalism¹³-they assume authority to speak for the older person. There was no reference by family participants related to discussing the wishes or decisions with the residents; they often became advocates due to family relations and necessity in the care needs process. This perpetuates the ageist perspective and validates the subject position of older person that the residents have internalised. As seen in previous quotes, if there was any indication of cognitive impairment, this role of advocacy would be stronger. Family members felt they were the voice when the older person had no voice due to illness.

7.3.6 Staff's subject positioning of the older person

While older persons in LTC facilities are the main subjects within the discourse, it was noted how the staff were described by residents and family members. While residents and family members represent informal subjectification, staff represent professional subjectification within the discourse. Figure 19 is a more detailed figure of how staff position themselves in relation to the older person in the LTC facility. In relation to the older person's position, staff have a professional role. That is not to say they cannot speak of the relationship with the older person, however staff are a representation of the LTC organisation.

¹³ Following definition of paternalism as defined by Sánchez-Izquierdo et al. (2019 p. 1516) will be used: "paternalistic means under which caregivers of older adults make decisions in another person's best interests, without that person's request, consent, or awareness of that person's welfare".

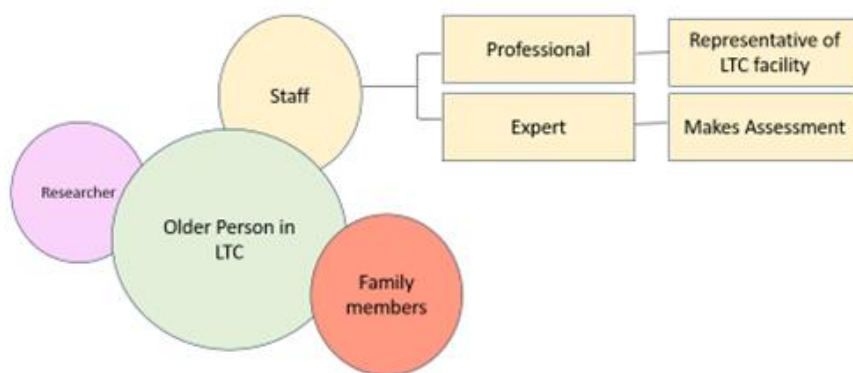


Figure 19: Staff position in older person's subject position

Staff tacitly assume the role of the expert. This is what Foucault (1977, 2003) would refer to as the medical gaze. Both healthcare assistants (HCAs) and staff nurses were seen as “the healthcare professionals”, however the staff nurses’ role was more extended in terms of authority. In this context, it was the staff nurse’s role to make assessments of older persons, this is further explored under normalising practices in Chapter Nine. This role was acknowledged by all the staff participants including HCAs who mentioned that they received their information on residents and related duties from staff nurses.

Staff members were referred to as a collective, homogenous group, and only a few staff members were mentioned by name. Both residents and family members spoke highly of staff but seldom identified any particular staff member, indicating the distinction between personalised relationships and professional relationships. Staff automatically play the role of a professional, and their subject identity lies within that role.

Interviewer: Oh, it's a lovely place yeah, yeah.

Resident Participant S1R3: Oh, it is and the staff are excellent, God bless them, they're lovely. [...] Just lovely now. You only want something, you ask them.

Staff were seen as the extension of the LTC facility, when describing their work. However, when asked about rights, the participating staff often described routine and reporting to line managers (normalising practices and incidences of biopower). This further legitimises the

institution as a source of power-knowledge and a hierarchical structure in which the staff ascertain a position. The assumption of a professional's position as an extension of the institution may also mask a lack of knowledge. By following routine and reporting to the line manager, the staff members supported the surveillance in the institution, particularly the surveillance of the older passive person. Care provision was described often as routine and task-orientated.

Staff Participant HS1S4: So, and every day it's nearly **the same thing** every day. You know you have to **keep a routine** for the residents. You know **we** come in, **we open** the curtain and **sit the residents up** for their breakfast, the breakfast trolley comes down. **We give them their breakfast.** Then **we do personal care, get them up,** wash, dress **ready for today visitors, activities.** Then lunch, again the trolley comes down. **We give them** their dinner. And usually then after that there's activities or in the afternoon activity. So, **we** already go to the reception. Then in the afternoon. And **we give them** their tea and then in the evening they usually get into pyjamas if they want to go to bed or if they don't want to go to bed. **So, we just got them ready either way.** So, if they want to.

The quote above with words and statements in bold exemplifies the procedures (often referred to as routines) and behaviours dictated by the institution. As part of the staff's professional role, they follow this level of being, regulating self and the residents. By applying these behaviours, the staff members claimed their disciplinary power and in this the subject position of the older person is validated as passive. Although staff may not be aware of their power position in the description of routine and how care was provided, there is a sense of de-humanisation of the older person. Yet again this function in positioning the older person as 'other'. In the data within the following chapters (Eight and Nine), the power-knowledge-discourse nexus is further presented as staff often tacitly describe how they (staff) decide whether a resident can exercise their rights. This disciplinary power is crucial in how the discursive positionings of rights are constructed, as it provides the accepted taken-for-granted truths and underpins the reasoning of whether older people are knowledgeable of being rights' holders or supported or constrained in exercising their rights.

Staff Participant NS1S1: And they have the freedom to do whatever they want here, but there will be some, you know, we will make sure they are safe. You know the environment is safe for them. Yeah, that's our responsibility.

In terms of staff discourses on older people's subjectification, one staff member with many years of experience described how older people place themselves in society by identifying as not having the same rights as younger people. This was the only staff participant who described the positioning of older people in society as a person who does not have as many rights as the younger generation.

Staff Participant NS3aS1: Their rights as an individual in society and in the community and their value. You know these people [referring to older people] have worked all their lives and brought up families and pay their tax. And then as soon as they get elderly and infirm and not as independent or more depending on care, it's like they don't feel like they're entitled to as much as a younger person you know, and they feel that you know and they don't ask for much.

The staff's position as a homogenous group and the extension of the institutional biopower was further exemplified during COVID-19. Staff positioned themselves as a group when talking about COVID-19 and spoke about how they, as a collective, were challenged during COVID-19. Staff participants appeared tired and drained when discussing COVID-19, and there was also a sense of bitterness when describing COVID-19. However, yet again it was about them, the staff, as a group and very few spoke about the older person in that context.

Staff Participant NS3S4: In the beginning it was scary because we had loads of cases and especially when the cases started. We had staff that went out with the COVID so it's really short of staff at time. Yeah, and plus we didn't have loads of full PPE. [...]. I think one day only myself and another care assistant turned up for the whole unit. More than 20 beds and we didn't have the enough masks, so I had the argument with the manager, but I think everybody was under pressure.

7.4 Conclusion

This chapter presents the first of the three findings chapters from stage two genealogical analysis. Drawing from the data gathered through individual interviews, a focus group with family members, and the researcher's reflective journal, the analysis identified three separate participant groups tied by their shared experiences in LTCFs. The data collected from 43 participants, including those from private (20), public (17), and voluntary (6) LTCFs, provided initial insights into how the rights of older people are discursively situated in LTC by determining the context (such as demographics and observations) and subject positioning. An analysis of the demographic data offered valuable insights into participants' subject positions. Specifically, demographic information helped to identify subject positions within the

three participant groups. The identities of older people in LTC facilities have their identity shaped by various factors. First, they often refer to their past identity rather than their identity as residents of an LTC facility. When they speak about themselves as residents, they acknowledge their need for care and align with the position of a passive 'other' who requires care. This phenomenon is exacerbated by the presence of family and staff members. Family members, driven by paternalism, see themselves as the 'voice' of an older person, especially if the older person exhibits cognitive impairment due to conditions such as dementia. The role of family members as advocates intensifies the position of the older person as a subject in need of care, reinforcing their status as passive recipients of care and in need of an advocate. Staff members are often viewed as a homogenous group, which is an extension of the institution they represent, in this case, the LTC facility. The facility, as an institution, supports staff as having the function of using disciplinary power to regulate everyday activities within the facility.

In conclusion, the construction of older persons in LTCFs positions them as passive, docile bodies within the category of 'other'. This is a crucial aspect of genealogical analysis, as it provides insight into the construction of discourses and the lack of resistance and acceptance of subject positions by older people. The next Chapter presents further findings from the genealogical analysis of data and examines the power-knowledge nexus in the construction of human rights discourses within the LTC setting. This is followed by Chapter Nine, which focuses on the main discourse surrounding the rights of older people in LTCFs.

8.0 CHAPTER EIGHT

Discourse of human rights

8.1 Introduction

The first research question asked how the rights of older people in LTC were discursively constructed by residents, staff, and family members in Ireland. Fundamental to this was how older people in LTCFs were subject positioned by self, family members, and staff within practices which contribute to the construction of these rights. The findings concerning this question were introduced in Chapter Seven, and Chapter Eight continues the exploration of how human rights are understood and constructed within the power-knowledge discourse nexus. This chapter is divided into three main parts, based on the interview questions. First, all participants were asked about their general understanding of human rights, followed by their understanding of older people's human rights. Second, all participants were asked specifically about the principles of FREDa (detailed in Chapter Five) (HIQA, 2019). Staff and family members were asked about the FREDa principles as part of the formal framework of human rights-based approach (HRBA) to care. However, the principles were introduced as individual concepts (fairness/freedom, respect, equality, dignity, and autonomy) to all participants. The final section presents findings related to participants' understanding on more formal structures supporting human rights of older people such as declarations, legislation, and conventions. Figure 20 highlights the development of the discourses within the interviews.

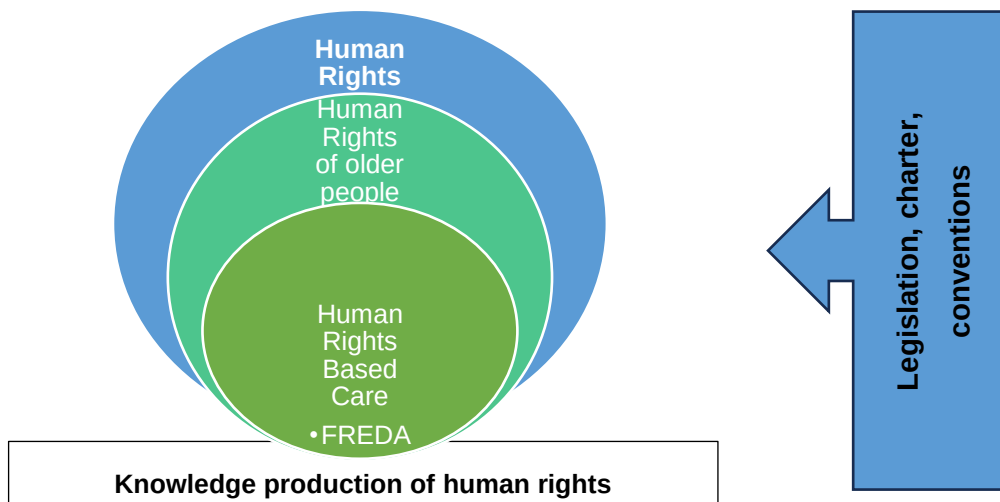


Figure 20: Illustration of discourse development within the interviews.

It is crucial to bear in mind the previously discussed subject positions, the individuals and the systems of either legitimization or discursive constraint involved in shaping knowledge. As the FCDA recognises the inherent interdependence between power and knowledge, it is essential to be mindful of the context in which the knowledge is produced.

8.2 General understandings of human rights

For all participants, the question on understandings of human rights was often answered with silence or long pauses, particularly by the participating residents and staff. In FCDA, silence or lack of statements related to a topic is significant in the construction of discourse. If the participants do not articulate any discourses in relation to human rights, it may relate to being too abstract, or there is uncertainty; for example, the staff did not want to show their lack of knowledge instead offered conditional narratives. For example, as part of data collection, the researcher made some notes on observations during the interviews. As demonstrated below, one observation was made how the staff participant became silent when talking about human rights.

Completed an interview with a staff nurse, young not that experienced in LTC. Initially very chatty, talking generally about LTC. But then seemed extremely quiet, hard to get any answers. Wondering if my own role as experienced nurse may have been intimidating but body language of the participant would indicate that there was uncertainty and the participant seemed to be reluctant to give any answer. What does the participant's silence represent? Thoughts on silence; is it a way of not acknowledging the rights of older people? Or is it not knowing how to apply to the rights? But frustrating to get complete silence to questions and worrying for me as to what does that silence mean. (*Journal note, 2nd of February 2022*)

This observation is further supported in the following sections related to the more detailed topics as some concepts such as equality and autonomy caused similar silences and participants appeared to have difficulties describing these concepts.

8.2.1 Residents' understanding of human rights

Asked about their understandings of human rights, the majority of participating residents were quiet, could shrug their shoulders, and did not seem to be able to associate any reaction with the question of human rights; their body language and expressions were blank. It became apparent that the term was abstract and unclear. As seen in the subjectification of older persons in LTC, some residents did not seem to be able to associate human rights with self

and therefore their everyday life. In contrast, a macro consideration was presented by some residents who spoke about human rights in the context of war or political goals, such as democracy.

Interviewer: Yeah, so if I say the word human rights, what do you think of?

Resident Participant S1R2: War.

Interviewer: If I say rights, human rights of older people, what does that mean to you? What do you think of them?

Resident Participant S1R4: Human rights. [short pause] Well, I mean... That's such a thing in law, everyone has legal rights. You have a well I mean. I suppose the main reason for it is if... Yeah, that it was brought in like... or basically as through to democracy.

A few participants attempted to describe what human rights meant to them. Again, these attempts were uncertain, and the resident wanted reassurance from the researcher to affirm that the answer was correct, which indicated that the researcher was in a powerful knowing position.

Interviewer: So, when I say rights and human rights, what does that mean to you? [pause] What do you think of when I say human rights?

Resident Participant S1R3: Human rights, yeah, your right to do what you want to do. Am I right in saying that?

Some participating female residents (n=2) linked human rights to the women's rights movement. They expressed that women did not have the same rights as men, and could associate this with their own experiences. These residents described an imbalance of power in traditional gender inequality which within FCDA demonstrates forms of biopower and governmentality. For example, in the excerpt below resident participant details how the woman was dependent on the husband.

Resident Participant S3R1: There was a sign like that about it, like back in... my husband got it but now we have our own pension. Before you got the pension from your husband, which would be pretty terrible. Once you're married, you're just a part of the man, you know? And that's all.

Interviewer: Yeah, and it was interesting what you mentioned there in the sitting room [before the interview had started] about women's rights? Equal pay. So, you fought for that, did you, yeah?

Resident participant S3R1: I did stand up for it, when I was a young girl. I was the type to mention it. The job was the same but fellas got more pay than women, doing the same job. So we kinda did some organisation there...And I work with that. Did not want any trouble just equal pay.

Despite some application to self and experience, overall, residents did not seem to understand individual human rights and could not connect how human rights would be applicable to them, either within Irish society or in the LTCFs. This initial level of understanding is significant when attempting to review the construction of rights in Chapter Nine, where all these micro-relations between understanding, power, knowledge, and subject positions create 'truths' in the context of how dominant discourses gain authenticity and are constructed.

8.2.2 Family Members' understanding of human rights

As indicated in the demographics and subject positioning of family members, they were well-spoken, and most held middle management positions in organisations that would be dependent on policies. This background in knowing formal rules was also reflected in general knowledge and understanding of human rights. Family members associated rights with decision-making and were able to relate it to care, although this was generally abstracted and not necessarily to a specific care situation. Furthermore, compared to residents and staff, family members were clearer and confident in describing how human rights may relate to their older relative in LTC. This could involve drawing on human rights approach principles or language.

Family member participant S1F3: And human rights in my and I'm talking about in the genetic, geriatrics sense, is like the right to be involved in your own care and you know, have the decisions. Made for you at **your best interest and your voice heard**. That's really what I think this was. I suppose, yeah.

The above quote demonstrates how rights are linked with having 'the voice' heard which seem to be important to the family members. Family members referred to the 'voice' of the older person and how to have that voice heard. This would then align with family members' position as advocates for the older person. Similarly, in the excerpt below, the participating family member disclosed how the older person has rights, but claimed these are constrained due to

the illness. Thus, the family member self-positions herself as assuming a role of advocate to promote her Mother's rights.

Family Participant S1F2: Well, I I... I do in in the general sense of like human rights. Like what we are entitled to, whatever. And I suppose in relation to my mum. It would be, uh as in what freedoms she would be entitled to in one way, but also take into consideration that she is a vulnerable person. You know, someone with dementia who is now immobile, immobile and... In in one way, whether she has her own, you know. What's the word I'm looking for? Not entitlements... But she has her own freedoms in one way. But in... But part of that is also mine in the sense of her advocate, you know. So I suppose like, you know. Her... Her freedom to choose, her freedom to uhm, to say what she wants to say, to go where she needs to go. I suppose that's the sort of thing that you're looking at.

No family member indicated that the resident had expressed preferences prior to admission to the LTC, nor did any family member refer to any conversation or document in relation to decision-making when asked about the human rights of older people. As the family members often positioned themselves as advocates, the responsibility related to the human rights of the older person seemed to align with their voicing the rights of residents. However, those rights were still conditioned for the older person as a resident in LTC facility and whether he/she had the ability to make decisions (discourse of conditional rights is further detailed in Chapter Nine, section 9.3). Family members also tended to make paternalistic references to human rights, referring the role as keeping the older person safe and protected.

Interviewer: When, if I say human rights, is there anything that comes up in your mind [name of family participant], in terms of what it means to you just here [in the NH] for your brother [participant's family member]?

Family Participant S4FG2: His security? Yeah, that way. Yeah... For his security. He is being well looked after and he has to be here, which is kind of helps to ease your mind. We have no choice. He couldn't possibly be anywhere else.

Consequently, when a family member describes that the older person has rights, their discourses are conditioned or constrained by the older person's need for care, whether due to cognitive impairment or physical needs. Rights are therefore narrow. This advocacy role was amplified during COVID-19 where safety became the key focus. Thus, the right to family life was mediated on safety pre-requisites.

Family Participant S2F1: They [staff in NH] were looking to the big picture. It was the welfare of the resident all the time and it may have been difficult for us, but it was always about keeping the... The keeping [of] the residents safe.

8.2.3 Staffs' understanding of human rights

Like residents, staff also seem to struggle to describe what is meant by general human rights. In general, questions about human rights seemed to create long pauses or no replies from staff participants. As staff positioned themselves as professionals with disciplinary power, silence can be seen through Foucauldian analysis as a process of power (Foucault, 1972, 1978). Some staff participants attempted to describe human rights, yet again, it was rights moderated by health status, with the main justification (similar to relatives) of protecting the resident.

Staff Participant NS1S5: Generally? We can start from the human rights to leave, human rights to... Uhm, to protect them from the harm. Human rights to like just to cover all their needs, from the... Like from the food and drinks until the... I don't know, social social needs and like just to give them all their needs they have and they need help. Because it's hard, they're here with in this stage, dementia and they can't say... They're not able to say, but they still have the right, so we're here to... How to say... To help, to help yeah.

This lack of understanding extended when asked specifically about the human rights of older people. When asked about the rights of older people, staff members both generalised and compartmentalized. This is when contradictions are noticeable in language. Staff could say that older people had the same rights, but added conditions to those rights. Similar to family members, these conditions stemmed from a paternalistic view of keeping older persons safe. Rights of older people are present in the LTC yet they are constrained and conditioned by the institutional imperatives, as demonstrated below.

Interviewer: And what is your understanding when I say human rights of older people? What is your understanding?

Staff Participant NS1S2: Yeah, same like us, everyone, you know. They...they also have rights. There is some residents, they 'on't have the mental capacity to make the decisions, but still they have their own rights, you know. So we understand that everyone [has] rights and we respect them.

A healthcare assistant with over 15 years of experience provided the following description of older people and their human rights. In the excerpt, there are contradictions as there are

examples of power ('I'm not cleaning you again') and language that recognises how care practices, behaviours and discourses do not support a rights-based approach and do not align with person-centred care language ('feeding').

Staff Participant HS1S3: Ehm. OK, for me. Human rights, when it more popped into my head is like let's say you have a resident where he was not incontinent but has incontinent moments. For me it would be, say, human rights. I would think which of when certain staff just wanted to put incontinent wear on a resident who was fully in the right mind, and it's their right not to wear that. I mean, even if they, if you know they're going to soil themselves in 10 minutes and they do, they refuse point blank, they don't want [it]. It's against... That's maybe going against somebody's human rights, is to say you're wearing that you know 'cause 'I'm not cleaning you again'. That be from against the human rights. Or like feeding, 'you're having chicken', 'you're not having beef'. Yeah, you know, 'you are having sandwiches', 'you are not getting soup'. For me that would be working against human rights of the residents.

In conclusion, staff members predominantly appeared hesitant when asked about human rights, whether generally, or the rights of older people. This was evident in the initial responses, which exhibited a lack of comprehension, followed by prolonged silence that inhibited their ability to discuss human rights issues. These responses tended to reinforce a discourse of "othering", characterised by paternalistic and protectionist attitudes, which corresponded with family members' understanding of the human rights of older people. If staff demonstrated low or no knowledge of the human rights of older people, this also means that there is no legitimization of rights.

8.3 Human Rights Based Approach to Care

Following general questions about the human rights of older people, staff and family members were asked if they had heard of human rights-based approach (HRBA) to care. The logic of not asking residents if they had heard of it as care receivers was that they would only experience it if they had been provided with HRBA and were provided with an explanation of that care. In addition, the use of human rights-based care terminology falls under policy statements and is more relevant to staff and family members.

Through the archaeological analysis of literature in chapters four and five, related to LTC and human rights of older people, there was evidence of policies and regulations in relation to the provision of human rights-based care (HIQA, 2016, 2019; ECHR, 2022; UN CRPD, 2007;

Equal Status Acts, 2018). Genealogical analysis concludes that there is a disparity between policy and practice. This is demonstrated in the following response, which was a typical response from staff participants.

Interviewer: And have you heard of human rights-based care, have you ever heard of that?

Staff Participant HS3S5: Not really.

However, when asked about person-centred care, which draws on principles of human rights, staff were able to offer interpretations of what it meant, as demonstrated in the excerpt below. Person-centred care has been part of policies in LTC longer than HRBA to care and would be a key focus in care delivery.

Interviewer: And when I say person centered care, what does that mean to you?

Staff Participant S1S3: That you're not just doing the job, as in a number like you're going from one resident to another. You know, it's about their dignity and about their needs and their wants. And everything from a person-centred care is everybody is different. They all have different ones, needs and musts, and you know, like I could have two female residents that are completely different, sharing the same room. But I mean, one could want one thing and one could need another, you know. So for me it's so not just about numbers. They're the people you have to know them, personal needs, but you know.

Participating family members were also asked if they had heard of human rights-based care to establish whether the term was familiar to them. However, similar to staff, family members had not heard of this term.

8.3.1 Discourse of FREDA Principles

Based on the archaeological analysis in Chapter Five, FREDA principles emerged as central in human rights-based care (HIQA, 2019). These principles, Fairness/Freedom, Respect, Equality, Dignity, and Autonomy (FREDA) guided the interviews, as it was evident that human rights as a topic was abstract. Staff and family members were asked if they had heard of or understood FREDA principles as a framework: 'have you heard of FREDA principles?' Residents were asked about the principles themselves; for example, 'What does dignity mean to you?'. Each principle is presented separately and is based on Willig's (2013) steps of action orientation and practice to construct the discourse of rights.

Staff were asked whether they had heard of HIQA guidance (HIQA, 2019), where the FREDA principles were outlined. This was to establish the level of knowledge of not only HRBA to care, but also FREDA principles. Similar to the overall knowledge of HRBA, the majority of staff had not heard of the FREDA principles (HIQA, 2019).

Interviewer: HIQA has published this guidance on human rights-based care and they called them FREDA principles. Have you ever heard of them?

Staff Participant HS1S4: No, I haven't heard of the FREDA principles.

Only one member of the participating staff, a staff nurse with over 20 years of experience, had tentatively heard of the FREDA principles but was unable to describe how they could be applied in the delivery of care in LTCFs.

Interviewer: Have you heard of FREDA principles?

Staff Participant NS3aS1: I think so, it that to do with intellectual disability services? Or in social work? [unsure voice].

Family members also had not heard of the FREDA principles or any guidance documents regarding the human rights-based approach to care. While from a professional point, staff may have an obligation to know about human rights-based care and FREDA principles, family members do not share the same obligation.

Interviewer: There are some guidance called FREDA principles, have you heard of them before?

Family Participant S1F1: I hadn't. I, yeah, I hadn't heard, hadn't heard that.

8.3.2 Freedom/Fairness

For the purpose of this study, F in FREDA was referred to either as freedom or fairness. While older residents were not specifically asked about the FREDA principles, the residents were asked about freedom and fairness. Residents expressed that they had freedom, but when this was probed; freedom was constructed as conditional. For example, when the resident below describes freedom as being everything, yet then acknowledges that freedom in a LTC facility only applies to 'a certain extent' and uses the phrase 'I get out', meaning that this participating resident does get out (with permission) from the LTC facility. Freedom was further limited during COVID-19 restrictions.

Interviewer: And have you heard of human rights or rights of older people? Have you heard of rights of older people?

Resident Participant S1R7: No... No, I don't know much about rights.

Interviewer: But if I say something like freedom, what does that mean to you?

Resident Participant S1R7: Oh freedom means... [gesticulates with hands that it is everything] [laughter]

Interviewer: I know [laughter], everything? Do you feel like you have freedom here?

Resident Participant S1R7: To a certain extent. But not like I would be at home, no. But I do have freedom here, I get out. Yeah, they're pretty good. Like yeah, my daughter takes me out every Sunday and if I want to go out, they are very good. Except when the lockdown was on of course. But other than that...[pause].

Equally, when describing freedom, the following staff participant argues that residents are free to go anywhere yet continues to describe that some areas (like the kitchen) may not be available for free access. This is another example of the many contradictions that occur in the descriptions. For instance, referring to the LTC facility as a home for residents, yet they are not allowed to go to the kitchen demonstrating power-knowledge-discourse intersections as expressed by this staff participant.

Staff Participant NS1S1: The freedom. They should be able to mobilise, wherever they want, you know. This is like a home for them. Like you know, we don't treat them like residents here like they are... This is their home like. We are here to treat, you know. Take care of them. So, they have their own right to go to any place. We won't restrict, even in... In kitchen, like, they don't allow to enter inside the kitchen. But even we have uh, residents walking around the dining room, and sometimes they go this, you know, to the kitchen area here. And they have the freedom to do whatever they want here, but there will be some you know. We will make sure they are safe. You know the environment is safe for them. Yeah, that's our responsibility. And yeah, in in... In my perspective, freedom is freedom, in every sense. You know not to restrict anything. Uh, you know? Yeah, make them safe. If they [not clear who they are] keep the environment safe for their freedom, you know.

In the quote above, the phrases 'here to treat' and 'take care of them' demonstrate how the care provision relies on disciplinary power and staff to be 'expert' which in turn produces residents as docile bodies and consolidates biopower. While freedom was constructed as

geographical, freedom can, as per FREDA principles, mean more than just the ability of residents to walk around. This includes the freedom to choose, decide, and be free from any kind of discrimination (HIQA, 2019). However, these aspects were not mentioned by any participant, and the discourses on freedom orientated towards a spatial understanding, with a focus on freedom to walk or access areas in the facility. As described by staff participant NS3S4 below, freedom appeared to be conditioned and restricted due to staffs' disciplinary power.

Staff Participant NS3S4: [mumbles] think in nursing homes they lost some kind of freedom because they cannot really go to the garden whenever they want. But we will try our best if we have time, we will try our best to bring them out. If they... Some of our ladies like to go for a walk or something.

Family members expressed that the older person had freedom, but as mentioned in relation to human rights, freedom was conditional on the older person's ability. However, family members did mention how freedom had changed throughout the COVID-19 pandemic, but again this focused on freedom of movement which was further limited during the pandemic within the facility.

Family Participant S1F2: So, there was freedom, the freedoms were there in relation to her. Going places and freedom to go to bed whenever she wants to go to bed. Get up whenever she wants to get up. But I mean, that's kind of changed now, I think to a certain degree because they have to... Get her because she is... Because the hoist it takes longer to... to do her intimate care, her personal care, and so they probably get her up as soon as possible. [...] Yeah, there's no problem there with freedoms, I would say. You know, they she... She has as much freedom as, as I would you know, you know the the the...[pause] Where would she not have a freedom now [referring to COVID-19 restrictions everywhere]? In a pre-COVID... and like I think of it as a, pre COVID is everything.

COVID-19 restrictions seem to have a significant on the principle of freedom. Staff acknowledged this.

Staff Participant NS1S5: The residents..., I think it [COVID-19] did take some of their freedom, like a lots of freedom. They used to go, oh gosh they used to go outside a lot. Now this is coming back slowly. Our activity staff she, she started to bring them out as well. But now we're in outbreak, so it's not happening and they used to go like to the shops. The ladies, they used to love it. They used to go for, like how do you say it... Like to visit places.

Regarding fairness, residents and staff could associate this with equal treatment for all or getting what you want when you need it. Residents in their description of fairness emphasised that if you need anything, you will get it. However, one resident referred to this as 'attention', which would align with the subjectification of the older person as not to be a 'troublemaker'.

Resident Participant S1R3: [...] Everyone is treated the same and if you look for attention you get attention. If you don't need attention, you don't look for it. And that's [the] idea like that.

Fairness in LTC for older people, as described by staff participants, centres on the concept of equal treatment. Their perspective simplifies the notion of fairness, which means that everyone should receive the same level of care and attention irrespective of their individual circumstances.

Staff Participant NS3aS2: Fairness, it it it... It needs to be applicable to all the residents. It's like... It's like we, we can't... the nurses or the other management... can't decide what they need to do, what they wanted like that. So that is a that is common that is common to all the individuals we need to look after, like in that way.

Staff described how fairness was perceived by everyone, that management was applying the same for all residents. In the quote below staff describes how all older people receive the same treatment and how no resident gets any special treatment. It could be perceived as a 'blanket' treatment for all.

Staff Participant HS3S3: They [management] always give proper care to them in a fairness way. [...] Specifically, do other residents be different from the others, you know. Always do fair in terms of visiting, in terms of you know what food they eat. Everyone gets fairly treated. There's no special treatment.

Family members, when asked about fairness, were able to relate it to decision-making, which aligns closer to the official definition. However, yet again it could also be linked with ageism and decisions with an age bias.

Family Participant S1F1: [...] Suppose the fairness has to do with 'would you do this if the person's 30 years younger or something'. You know, like is it different because they're older like you know, and stuff like that?

8.3.3 Respect

Respect and dignity were the two principles best described by all the participants. Residents said that all individuals must have respect. They reported experiencing respect in their corresponding facilities; however, when asked to describe this in further depth, residents were not able to detail how they were respected. In addition, when asked how staff show their respect, the most common answer was 'they are so good', without any details. Below quote demonstrate the vagueness of navigating responses.

Interviewer: And if I say respect?

Resident Participant S3aR3: Ah respect you must have.

Interviewer: Yeah, you must have that, yeah. Yeah you have it here?

Resident Participant S3aR3: Ah yeah, its great.

Interviewer: Staff and and the other residents respect each other?

Resident Participant S3aR3: Yeah its great.

Family members were able to describe the principles of respect in more detail. However, it was, as with all principles, contingent on the care needs of older people. Family members did not seek or mention being respected themselves, but it was important that they observed respect for residents or other visiting family members. One family participant reflected, as demonstrated in the excerpt below, how respect was evidenced in relation to the resident and the family members visiting.

Family participant S1F2: Respect, yes, I would say on the whole, uh, generally the carers would be very respectful to her. Now whether she [Mother] would give it back or not is another thing, depending on whether she likes it or not and depend[ing] on whether you're taking her trousers down or not. [laughter], you know. So... but on the whole, yeah, the... the respect would be there. But one good thing I noticed as well is that they're very respectful to my father [who visits the NH]. Well, yeah, and...and, you know, they would be very respectful to me.

Staff could also implicitly link respect with dignity, for example, by contextualising it with the action of providing personal care. As respect, together with dignity, were the two principles that staff participants spoke about, they often referred to personal care and how they provide care while maintaining respect for the resident. This is evident in the following quote where a

staff member immediately associates dignity with continence wear, yet uses non-person-centered language while describing the act of providing dignity.

Staff Participant NS1S1: And we [know] who are not able to verbalize, we respect their dignity. Like you know, even if we're doing a [continence] pad change and we are providing the personal care we explain to them like what we're going to do.

8.3.4 Equality

Together with autonomy (presented in 8.3.6), equality seems to be the concept that all participants had difficulty understanding and describing. Residents did not seem to associate equality with themselves in their current situations. Similar to human rights in general, some female residents were able to associate it with equality between genders.

Resident Participant S3R1: Yeah, yeah. It's an equality for women all the time.

Interviewer: Yeah, yeah... so the same way that you fought for equality for women, does older people...should have equality as well, yeah?

Resident Participant S3R1: Oh yeah. They should. Yeah, I think so yeah.

The comment shows that the principle is important, yet the older person was not able to provide a context of equality for the older person in the LTC. Similar to residents, staff did not seem to know how to describe equality and struggled with either the word equality or describing same.

Interviewer: Equality? If I say equality, any thoughts? [pause]

Staff Participant NS3S4: I don't really know.

A few staff members attempted to describe equality and described it as equal for all, describing it as the same care for everyone. Through the researcher's reflective journal, it was found that staff tended to have rehearsed phrases as responses.

Tough interview for me, difficult to probe. It is like the staff have remembered these lines in their heads of what to say. The correct phrases and they do not get comfortable in verbalizing what is going on in practice. I feel they are not honest or sharing the true practice, instead giving me what they think the organisation wants them to say.

(Reflection note after interview with staff participant S3S3, 27th of January 2022).

As mentioned in Chapter Seven, staff seem to look at the interview as an exam and could appear cautious in their answers. This description aligned with a rehearsed statement of care provision as a staff member describes below.

Staff Participant NS1S2: [...] Some people are, you know, they're from, you know, we even have people from royal families like you know. But what everybody is saying here, like you know everyone is getting the same menu. They are getting the same care, you know, same treatment. It's all the same here. Like nobody is treated, nobody getting any extra care or anything like, everybody is treated equal here.

Unlike staff, who were not able to express in detail what equality was, family members were able to reflect deeper into equality as a concept. They stated that equality should focus on the older person's own level, rather than being universal; this was an expression from the family members as their position as advocates and reflected the concept of equity.

Family Participant S1F2: Equality [pause]. Equality for my mother. We see, I suppose. I don't know where... that actually should be equity, instead of the equality. I have I have I have issues with the word equality, you know. [...] Yeah, you know, it should be everybody at their own level rather than bringing people up to a certain level. And because you cannot bring my my mother to another level [family member has dementia]. And her right up to the same level as a resident who is in because of old age or no one to look after them, but they're still compos mentis¹⁴.

8.3.5 Dignity

All participants appeared to be most confident in describing the concept of dignity. Together with respect, dignity was understood and described, and some participants mentioned dignity before being specifically asked about it. Dignity seemed to be quite personal, and residents seemed to have their own subjective ideas of dignity.

¹⁴ Compos Mentis: Old terminology used by both staff and family members in interviews. Cambridge Dictionary (2023) defines it as able to think clearly and be in control of and responsible for your actions.

Interviewer: If I, if I mentioned the word dignity, what does that mean to you?

Resident Participant S1R7: Well dignity is pride in yourself, you know.

Interviewer: [name of the participant], what does dignity mean for you? [quiet] What does dignity? If I say dignity, what does that mean for you?

Resident Participant S3R1: This means independence. Be responsible for your own life and will. I think [sound unsure].

Residents' understanding of dignity differs from the official definition by HIQA (2019), and residents had differences in what dignity was to them. However, all participants said that they had dignity in the LTC facility. Although they did not necessarily define what dignity was, they acknowledged whether they had it or not.

Interviewer: Yeah, yes. And do you find that you have dignity here in the nursing home?

Resident Participant S3aR6: Oh I have, I have yeah. [quiet]

Some residents' response about dignity was only an agreement that they had dignity, as seen in the above quote; they did not further develop what or how dignity existed in the LTC facility. Residents' descriptions of dignity could be broad, and no one gave a clear definition; their description seemed to align with a feeling or for them to be acknowledged and seen. This feeling could be in relation to other residents, not only as part of the interaction with staff or family members as described by a participant in the excerpt below.

Interviewer: Yeah. Do you have it [dignity] here? Do you think? Yeah, and you have it here in [name of NH]? [quiet, no answer] Do you think you have dignity here?

Resident Participant S1R7: Yeah I do. [pause] Just at the moment I'm having a hard time with some of the people and I mean with like, yeah, they all have it [referring to residents with dementia] You can't have a conversation with them or they forget. Well, you couldn't say like something to them [other residents with dementia].

However, when probing dignity as a feeling about other residents, the same participant did not seem to want to talk about it. This experience was conditional, as dignity was also linked to privacy. However, if there was an inconvenience associated with it, resident participants

did not seem to want to talk about it. Their narrative would have suggested that they did not want to cause any problems which would align with their subject positioning of passive docile body. For example, residents adhered to the routine and schedules of the facility (further explored in next chapter under institutional rules). Below is a quote exemplifying that despite the lack of privacy, the resident seemed to have no control. This in turn suggests that their experience of the human rights principle of dignity was not upheld.

Interviewer: Do you share a room?

Resident Participant S1R7: I do. Then like that they're [staff/management] supposed to get me a room. To you know get the space, hopefully I will get it. It's nice to have a little bit of your own space. Everything is on top of you, and you have no privacy at all.

Interviewer: You don't feel like you have privacy in the room?

Resident Participant S1R7: No, not at all [quiets, looks unsure].

While participating residents associated dignity with their own private selves and something personal to them individually, staff participants linked it with keeping the residents private during personal care. Dignity appeared to be the concept that staff members were most confident in describing and explaining, yet the description had a narrow view of its application only to the physical personal care provided. Most staff participants mentioned how important it is and provided practical examples of how they would maintain residents' dignity.

Staff Participant NS1S2: To keep their dignity, for example, if like if we go to them for their personal hygiene and make sure that the doors are locked like. And they have privacy for their changing. And if they prefer a male or female carer, yeah, we'll try to arrange for that. And uhm [short pause]. Like call by their by their name or surname, uhm. [pause].

Dignity was often associated with privacy in the physical environment, but in the description of dignity, routine-based, non-person-centred language could be used. This would be in contradiction to residents' description of dignity, which included personal independence and pride.

Staff Participant HS1S4: So dignity, you know they have each resident again, unless they are in a shared room, have their own room. You close the door, shared rooms, you have curtains. So when you're **doing personal care** like washing or dressing or **change the pads** that it's just you and the resident. If it's a **double** obviously you and

other carer, you know, but no one else should be in the room at the time. Sometimes when they come out of the shower, some of the women like to come out and get their clothes then, you pull the windows pull the curtains. You know door close always knock when you're going in. If someone is able to use the toilet, you know, you don't need to **crowd them**. You don't need to watch them go. You close the door and say 'I'm out here when you're ready', you know or someone who can maybe walk in to the toilet you just say 'are you OK?'. and then walk away, you know. Just to always make sure that their dignity and they are kept private.

While dignity for residents was described as something deeper and personal, linked to their being, staff and family members described dignity in the context of personal care, as an act of maintaining an older person's dignity. No resident mentioned going to the bathroom or toilet as part of their description of dignity. Yet, like staff, family members also linked dignity to personal care and to going to the bathroom. Their role as advocate may be required to ensure that dignity is maintained.

Family Participant S1F2: One of the issues that I do have is and I have brought this up at the home, so it's it's nothing, nothing that they don't know, is when she is sitting on the toilet. I have asked that they come out of the bathroom to give her the privacy. You know it's bad enough that she's on a in a, you know, in a hoist, you know, but to have somebody there having a conversation between themselves while trying to do whatever you're trying to do is just you know and so I think sometimes the staff forget, but it's just something that's not excusable anymore. You know it. It's kind of. She is 82. She does have dementia, but she still is very much aware of her own dignity, you know. And it is when it comes to, as I say, the intimate care.

8.3.6 Autonomy

The last FREDa principle is autonomy, which can be considered the freedom to make decisions and exercise self-determination. Autonomy, together with equality, appeared to be a challenging concept for both the residents and staff. The related question was met with confusion, silence, or asking me (the researcher) what it meant. There were also signs that it was the hardest word to understand, thus creating a language barrier, particularly with staff members whose first language was not English. The meaning was lost in translation. Residents did not associate self with autonomy and could not describe it.

Family members were better than staff at distinguishing what autonomy meant for the older person. This could reflect this participant group's subject positioning themselves as an advocate, as well as their ability to articulately express themselves. They also perceived a

loss of autonomy related to the resident's admission to the LTC facility, although they did not provide any description of how to maintain or support that autonomy.

Family Participant S1F1: Autonomous was, is is really important and it's probably something that I see now with my parents. That they... You lose that quite quickly when you're not in a position to make decisions and yet you want decisions [as part of the admission process].

However, among the principles discussed, autonomy was also the most difficult for family members to describe and define what it meant for the resident and could be presented as limited and its scope unknown.

Family Participant S1F2: Now you see, this is a difficult one for me. Autonomy to choose, I presume in this case. Yes, she can choose when she wants to go to bed. I know that one because she's also said 'I want to go to bed' and choose to... [pause] I don't know whether she chooses the clothes she wears. I think they're chosen for her, and I don't know how much opportunity she gets to choose.

Comparable to residents, staff seemed to find the word autonomy difficult. Staff participants who did not have English as their first language did not understand the word autonomy, adding another layer of constraint to the discourse on this principle.

Interviewer: If I say the word autonomy, what do you think that means for the residents? From your point of view as a nurse?

Staff Participant NS1S5: Hmm autonomy. It would be like, uh. The same way like self-centric [not clear what is meant] care like? [pause, participant looks unsure]

Interviewer: Autonomy is kind of self-decision making. It means make a decision or be allowed to make a decision. [pause]

Staff Participant NS1S5: Autonomy? [unsure voice] right now I don't know.

When attempting to provide an answer regarding autonomy, staff could draw on a disciplinary discourse embedded in nursing knowledge, based on clinical assessment (explored further in the next chapter), and staff participant NS3aS2 was the only staff member to use the word capacity in relation to autonomy to make decisions. Similar to freedom, autonomy was linked to assessment and the ability to exercise that right.

Interviewer: Do you think the residents have freedom and autonomy?

Staff Participant NS3aS2: Some of them I think so yeah, yeah they do have it.

Interviewer: All of them?

Staff Participant NS3aS2: What that means we need to see their level of you know, like capacity also is still there. Yeah, we can't like for everyone.

8.4 Declarations, Conventions and Legislation of Human Rights

The focus of the study was not to establish an understanding of legislation, yet as demonstrated through archaeological analysis in previous chapters, legislation works as a powerful mechanism for creating statements that define discourse and is influenced by epistemic taken for granted truths. Therefore, asking what is known about legislation reveals where gaps are in relation to the understanding of rights, which in turn may have implications for practice. In these gaps are where the 'hidden' truths are, where the dominant discourse emerge.

Staff and family members were asked more specifically if they had heard of the Assistant Decision-Making Capacity Act (2015) described in chapter five. While not fully implemented at the time of data collection, only one participant, a family member, had heard of the Assistant Decision-Making Capacity Act¹⁵ (2015) and that participant did not think it applied to older people, only to those with intellectual disabilities. No staff member had heard of it, and, as previously noted, only one nurse used the word 'capacity'.

Interviewer: Have you heard of Assisted Decision-Making Capacity Act?

Staff Participant NS1S6: Never heard of it.

In the interviews, questions were asked about protection and whether older people's rights should be protected under specific legislation. When asked specifically if an explicit UN charter for older people's rights is needed, the majority of participants in all three groups agreed.

¹⁵ The Researcher was aware that at the time of interviews (Spring of 2022) the Assisted Decision Act (2015) was not fully operational, yet the principles of functional capacity and consent were in place since the Act commenced in the end of 2015.

However, there was little suggestion on what that legislation or specific charter would look like as well as lack of understanding why it may be needed. Yet, the responsibility could be seen as needing political ratification.

Interviewer: So, when I say older people rights so the rights of older people. Who's, whose duty is it to protect those rights?

Resident Participant S3aR6: Oh, I think the government should.

Furthermore, there was very little known about what legislation and declarations which support human rights were already in place, and particularly staff participants were under the impression that legislation to specifically protect older people was already in place in Ireland. Staff participants referred to safeguarding legislation and were under the impression it existed. Data uncovered large gaps concerning staffs' knowledge of legislation and conventions and declarations and what is in place.

Interviewer: So, UN, the United Nations have proposed that there should be a specific charter just like children have a specific charter of rights that older people have a specific charter of rights which they don't have at the moment, do you think that's needed? For older people?

Staff Participant NS3aS1: Yes, [we] don't have it in Ireland?

Some participating staff were adamant that specific legislation to protect older people was already in place, often referring to it as safeguarding. Although national safeguarding policies and frameworks are in place, no current legislation pertaining to adult safeguarding has been enacted.

Interviewer: [...] Do you think older people need a specific law regarding human rights?

Staff Participant HS3S1: We have already the safeguarding here in Ireland. So I think that's the one of the rights, then you know.

Misconceptions such as those stated in the above example show the uncertain knowledge of the staff. Staff referring to a policy such as safeguarding as legislation demonstrates a lack of understanding of the status of policy versus legislation. However, not all participants agreed that specific legislation is needed, particularly when family members expressed that rights should be universal. One family participant expressed as a society that the distinction between vulnerable groups should not be made.

Family Participant S1F1: We do have human rights, you know, like that. There is a... There is... there is a convention for human rights. And why do we need to? Why do we need to start saying but this special group and this special group. We should be really working hard that everybody has access to those human rights, no matter where they live or what they believe in, or or anything else. That's how I feel. [laughter]

Similarly, another family participant was unsure of whether a specific convention was needed. However, the findings indicate that understanding of and knowing how UN conventions are applied is lacking. Although knowledge about legislation and UN conventions may be considered expert knowledge, establishing the general knowledge of all participants provides insight into how the discourse is constructed.

Interviewer: The UN has a specific rights convention for those with that are disabled. Do you think that that is needed for older people?

Family Participant S4F1: Well, I'm...I'm not 100% sure like because the period that somebody is older that need long- term care is probably much more limited than a disabled person, isn't it? So it's a pity that you know, if we could, as a society we could manage it differently than our have the UN impose something on us, you know.

Despite staffs' position as the professional expert, the data demonstrates a low level of knowledge about what legislation was in place. They seemed to be more reliant on policies that were in place and under the illusion that policies were part of legislation. Although questions about legislation, charters and declarations were asked in the interviews, a general awareness of any legislation or what is in place in Ireland was unclear. Similarly, understandings of conventions and charters to which Ireland had ratified, was also low. From observations, it was noted that no legislation concerning COVID-19 restrictions was brought up; nor did participants question whether the restrictions fell under any legislative discourse.

8.5 Conclusion

Chapter Eight focused on the findings related to knowledge and how the human rights of older people are constructed and understood by the three participant groups. The chapter unpacks the tacit operation of knowledge and power related to human rights and how they are known or applied in LTC. In particular, discourse on the rights of older people was determined by asking about the principles of human rights-based care; freedom/fairness, respect, equality, dignity, and autonomy. In all participant groups, there were gaps in how human rights are understood and applicable to older people in the LTC. Even general questions about human

rights generated confusion and silences that show how abstract the topic may be. Residents displayed limited comprehension of individual human rights and were unable to recognise the relevance of these rights to their personal circumstances, either within Irish society or within LTC facilities. Staff silence in relation to understanding the concept of human rights showed a strategy of not disclosing the lack of knowledge, but at the same time revealing an unconscious power strategy in terms of not acknowledging the rights of older people. The demographics of staff (in Chapter Seven) highlight the diverse cultural background that may affect the understanding of rights and, subsequently, the application of rights. As seen through the findings staff hold significant disciplinary power. Despite being unaware of having this power, that power shapes the discourse on the human rights of older people in LTC. It follows Foucault's assumption that power is a process and production in the creation of knowledge. Although findings suggest that staff are not in any way confident in their knowledge, they are key positioned to either produce or constrain knowledge in relation to rights of older people in LTC. In contrast, findings from family members' interviews show that their ability to articulate rights makes them strong advocates. Family members being 'the voice' of the resident, while articulate and significant, lack the disciplinary power that staff members hold.

The construction of human rights discourse showed that there is a difference in how standards may be defined by the participants due to knowledge gaps. Staff constructed freedom as highly conditional and generally applied it in a geographical spatial sense where residents were able to go freely or not. This was compared to residents, who expressed that freedom was everything and appeared to have significant meaning to the residents. The fairness principle applied was expressed as everyone to receive the same care and this principle may have been confused with equality. Dignity and respect were two principles that all participants were able to describe and define but participants failed to have the same level of description in relation to equality and autonomy. Autonomy seemed to be hard to grasp even at a language level and caused confusion, particularly for staff participants whose first language was not English. Paternalistic references to the human rights of older people in the LTC were made by both staff and family members. Staff referred to these as residents' abilities to exercise their rights, while family members referred to the 'best interest' of the resident. These all stemmed from protecting the 'vulnerable' older person from harm. These issues are further explored in the next chapter.

CHAPTER NINE

Discursive Positioning of Human Rights of Older People in LTC

9.1 Introduction

Chapter Nine continues the analysis of the second research question which concerns the discursive positioning of the human rights of older people and addresses the third research question which relates to the consequences of these discourses. Chapter Nine integrates the findings at a deeper level, examining the practices within the discourses and their consequences. This draws on the findings in Chapters Seven and Eight, but also on findings from the archaeological analysis. This combined process of archaeology (history of the present through literature) and genealogy (the interview data) provides a comprehensive schematic of discourse, resulting in three dominant discourses: protection, conditional rights, and governance.

The three main dominant discourses are interlinked through subject positioning, power-knowledge relationships, and the institution (LTCFs) in which the discourse exists. These connections reveal hidden 'truths' that constitute the discursive positioning of older people's rights in LTC facilities. Examples of these connections and the power relationship within discourses are revealed through quotes from participants' interview transcriptions. Some of these examples have been presented in the previous two chapters, representing how the consequences of the discourses are action-oriented. This chapter presents the discursive practice and its consequences, which are legitimized and sustained as 'truths' (Willig, 2013).

Within the data, power relationships occurred in small interactions that participants were often not aware of. This reflects Foucault's construction of a network of power relations (August, 2022). In the interviews, contradictions provided 'hidden truths' as the descriptions of older people and their rights were contradictory, and in particular, staff participants used discursive silences as a form of meaning. Figure 21 details those three dominant discourses protection, conditional rights, and governing, including each one's constituent elements.

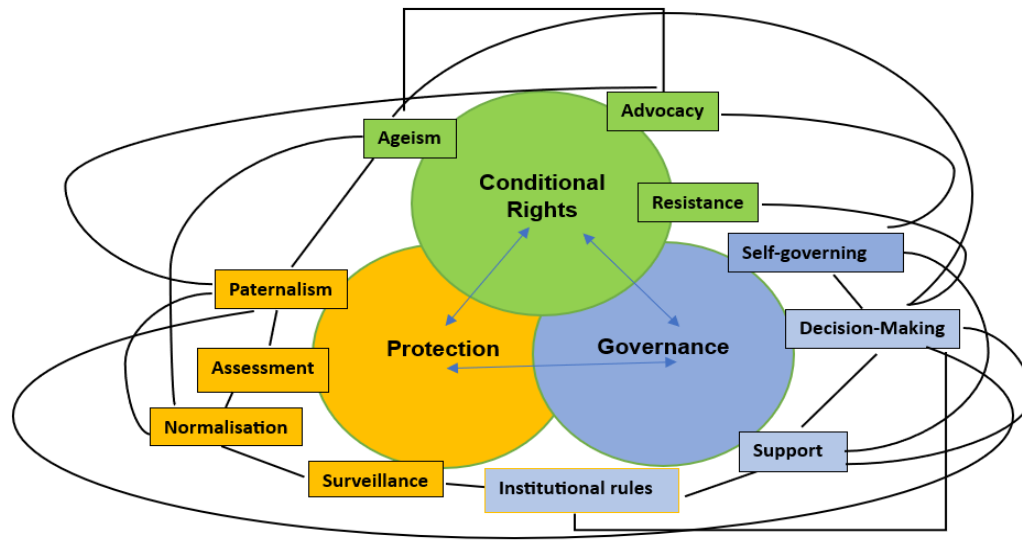


Figure 21: Illustration of network of relationship within the discourses of rights of older people in LTC

Each discourse has inherent concepts (figure 9.1), yet all are enmeshed in a system of complex relationships constituting the games of 'truth'. While containing distinct factors, the three discourses overlap and cohere within their contingent impacts on each other founded on discourse formations in the current episteme.

9.2 Discourse of Protection

Protection is the strongest discourse emerging from both archaeological and genealogical analyses. Consequently, protection refers to protection at different levels: a staff or family member protecting resident (the action of protecting), the policies (national and local) that are put in place, the legislative imperatives and the institutional practices put in place for protection (i.e. the assessments and the care plan). Within the milieu of protection are procedures concerning health and safety as well as risk assessments to protect the vulnerable older person. The protection discourse stems from paternalism, and although it may be conceived as altruistic, it constitutes a form of discrimination. Protectionist approaches are also bolstered through biopower's normalising judgements (normalising practices), which are based on disciplinary power and knowledge as well as family privilege, perceptions of old age and age discrimination. The COVID-19 pandemic, in many ways, strengthened the protection (public health-risk) discourse, manifested through national guidelines.

9.2.1 Paternalism

Discourse on protection is driven by paternalism. Paternalism limits a person's liberty or autonomy and is caregiver centred (staff or family member), not person-centred for the older person (Sánchez-Izquierdo et al., 2019). Residents are often unaware of paternalism because of their own subjectification as vulnerable or someone that requires assistance. Paternalism stems from a place that keeps residents (older persons) safe and away from harm, as explained below.

Staff Participant HS3S2: They [Residents/Older people] have the freedom to say anything that they want here and we listen to them. What they feel. And what they would like to do. For example, what they would like to do, what they would like to eat.

Interviewer: So you would you find that anything they want they would get it?

Staff Participant HS3S2: It depends. It depends. You know, for example the food they want to eat this one, but they are not allowed so.

Interviewer: And how do you explain that to them?

Staff Participant HS3S2: And we'll explain it then that **it's for their own good**. 'This one is not OK'. But they listen.

Paternalism is seen in the subjectification of the discourse, how the older person positions themselves as 'other', family members as their advocate, and staff participants as a homogenous group with the professional expert role. Staff participants recognised that all staff had a duty to protect the rights of older people in LTC; however, how and to what degree was not expressed and lacked a fulsome understanding of how to balance it with upholding rights. The consequence for the older person in LTC is that they rely on protection, yet in this, their rights are not upheld.

Staff Participant NS1S1: I think it's, uh, our our like you know as a team yeah. Uh, everyone responsibility to protect their rights. No, no, it's not just the nurses or not just as director of nursing or CNM¹⁶ like, you know. For example, like if a cleaner is going to the bedroom and they don't want to be disturbed at that time, and then we should

¹⁶ CNM Refers to Clinical Nurse Manager.

respect that, you know they they, they have the right to sleep at that time and they can't just say this is my time to clean the room like we have to respect that. So I think it's all together. We all have. You know every staff has a responsibility.

Similar statements as the excerpt above regarding the staff's responsibility to protect residents were made by most participating staff members. However, as seen in the understanding of the human rights of older people, they linked it to safeguarding, which also draws on protectionist discourses.

A clinical assessment, underpinned by normalising practices (discussed further below) and conducted by staff nurses, legitimised the protection imperative. In interviews with staff, it was noted that the staff described a position of power, circumscribing what the residents were able to do and not do, yet their disciplinary power perspective eclipsed an overt recognition or acknowledgment that they had a position of power exercised in daily care delivery.

9.2.2. Normalising Practices

The clinical practice of assessment and its use in normalising professional decision-making came through strongly, not only in staff interviews but also with family members. Staff participants, particularly nurses, described the assessments such as Mini-Mental State Examination¹⁷ (MMSE) and Geriatric Depression Scale¹⁸ (GDS) as key in their professional role to assist in determining the ability of the older person to claim their rights within the domain of “compos mentis”.

Interviewer: And when you mentioned Compos Mentis, how do you assess that? [Participant was mentioning compos mentis when talking about residents' decision-making capacity]

Staff Participant NS1S1: We have assessments for that because when we come here we have, we'll get their medical history. Again, if they're diagnosed with this dementia or any Alzheimer's like then we know. That there are, you know, mental strategies, like what is their mental strategies? [not clear what is meant by mental strategies] And

¹⁷ MMSE refers to Mini-Mental State Examination, a 30-item cognition mental test developed by Folstein et al. (1975). Low score levels can indicate cognitive impairment, max score is 30.

¹⁸ GDS refers to Geriatric Depression Scale (GDS-30), a 30-questionnaire to assess depression in older adults developed by Yesavage & Sheikh (1986).

also, we have MMSE and GDSSs. We have assessments to assess if they are, you know, *compos mentis* of mental state.

Admission to LTC has been triggered by older persons being vulnerable or frail, prompting the need for care. Disciplinary power includes assessing residents as vulnerable and is constituted and legitimised as the responsibility of staff nurses, with HCAs as part of the apparatus of governmentality. Part of the assessment discourse is the notion that residents in LTC facilities are judged based on their ability to make a decision, which is clinically assessed, evidenced-based and therefore legitimate. Only one staff participant used terminology capacity. However, the old terminology of '*compos mentis*' was more frequently used as seen in the previous above quote. In the quote below, a staff member described how information about a new resident may be gathered. Significantly, the participant described if a resident had dementia that would be an indicator of engagement in the context of how much the nurse required to talk to the resident.

Staff Participant NS3S4: Normally before they [new resident] come, we will have their medical background from the GP already, and sometimes our coordinator for the respites. They will gather the information basically for us know we know some basic background first. If I'm doing the admission before...before the admission comes in, I will look at her charts and because we have loads of people with dementia. So we will decide how much I need [to] talk with residents, how much, how many questions I need, [to] ask from the family. The admission takes time because we need to get the loads of assessment with the resident and normally they be quite anxious the first day.

Assessment discourses support the normalising practice that staff practice through clinical gaze, such as MMSE or collecting information based on previous diagnosis (such as dementia). Using terms as MMSE, GDS and '*Compos mentis*' staff enforce their expert position and in this the assessment becomes legitimized. Yet, when probing into these terms staff participants are not sure how to define the terms.

Interviewer: [participant had mentioned compos mentis as decision maker] And what is your, as a nurse now... What is your understanding of compos mentis?¹⁹

Staff Participant NS1S2: [Compos Mentis] Uh, like they are well oriented to time, place. Uhm... Yeah oriented to time and place and like they are well oriented in their senses and uhm... [Pause]

Interviewer: How would you assess that?

Staff Participant: Uhm. [Pause]

Interviewer: How would you decide? How would you know as a nurse who is compos mentis? [pause, no answer] Just by the fact that they're aware of time and place?

Staff Participant NS1S2: We do some assessments like uhm... MMSE, GDS. Observations like that [voice is low and unsure].

The assessment, whether referred to as MMSE or GDS, is what Foucault (1978) would refer to as medical gaze legitimised by normalising practices. It provides power to healthcare professionals, who have professional knowledge (disciplinary power) about residents' capacity. Nurses did not understand that their assessment of the resident through objective measurements could affect whether the resident exercised their rights. Nor was the revised truth articulated. Similar to the staff, family members observed how decision-making was based on assessments and align with the discourse. One family member described how her father's decision making was based on the MMSE assessment, which seemed to be an assessment that legitimized the protection argument.

Family Participant S1F1: Yeah. So, I think he [own father] scored 25 out of 30 and he was like fist pumping. He was delighted himself. We were concerned about him in July and my sister walked him over to the to the GP and she said 'he felt he would be lower than that at that stage'. But by October, when he was in the nursing home after we had our first meeting with them, when he'd been in about a month, they said he was at, I think they said he was at 17. But actually I...I thought that was quite a good score for Dad.

¹⁹ Clarification regarding the use of the word compos mentis: As the interviewer, I did not say the word Compos mentis until a staff participant used the terminology and only then did I probed the participant in the understanding of the word.

Family members subscribed to the staff's disciplinary power and highlighted such assessments, and some even saw clinical assessments as legitimising care practices related to rights. Accepting the taken-for-granted truths of disciplinary power, most family members referred to keeping their family members safe and protected and used normalising practices to justify the dominant protection orientation of the staff.

Family Participant S1F1: ...I suppose that personal... your, you know, your ability to just make decisions for yourself and to have those taken into consideration as much as it's possible. And and I suppose as regards uh, older people to...to allow them to be part of that decision making in as much as possible. Until...until there's a, you know, a health and safety issue.

The data demonstrated that nurses played a key role in providing knowledge about the residents, including their assessments and abilities. In the discourse of assessment, nurses do not only have a role in assessing, but after assessment, there is a normalising judgement and a role of disseminating the information, that is, passing on knowledge of the resident. Healthcare assistants rely on nurses and nurse managers to provide this information. As seen in Chapter Eight, staff, particularly nurses, hold disciplinary power in the LTC environment in relation to expert power-knowledge.

Interviewer: [...] and if you have a new admission so new resident, where would you get information of how to look after that resident?

Staff Participant HS3S5: It normally the nurse, the one who's assessing anyway. But before they [resident] come in. They it... normally they...they [nurse/nurse manager] telling us what's a condition and everything so, the nurse. The manager first telling us everything on the handover.

These examples of normalising practices and the medical gaze inherent in disciplinary power are ways in which power exists. By contrast, the residents did not mention any assessment or that they were dependent on clinical judgment in the context of exercising their rights or being allowed to do something. No participant, whether staff or family member, questioned the assessment or expressed any concern about an assessment deciding the resident's ability to exercise their rights. These assessments are taken for granted and legitimized as gateways to 'truth'.

9.2.3 Surveillance

Another way of exercising micropower relationships inherent in disciplinary power is through the element of surveillance. No participant used the word “surveillance” but family members who participated stated how reassuring it was knowing where their family members were and had confidence in care.

Family Participant S4FG4: [...] At least when you know here, if you get a phone call in the middle of the night, something has happened, but she's being looked after. You're being right. You're getting a phone call just to tell you what's happened. And if you need to go to the hospital or whatnot. So, it's like you can sleep at night a lot better.

Surveillance is also closely linked to the idea of institutional rules described in the discourse on governance and represents a mechanism of governmentality. The surveillance discourse was identified through the participants' descriptions, the physical environment in which the interviews were held (LTC facility), and the contradictions used when asked about human rights. Surveillance was already identified in the context of attending the LTC facility. The following reflection note exemplifies surveillance techniques.

Back attending LTCF1. Noticing the steps taken when entering the facility; sign in sheet and health check completed first. Again, I'm noticing the large reception space with a large reception desk (panopticon?). Receptionist is friendly and chatty, and as most likely instructed by their job position ask me loads of questions; 'who am I to see?' and 'where am I to go?'. I ask for [DoN's name] and explain my study. I'm conscious of all the steps required to see someone in the facility and there is a lack of privacy in those steps. (Reflection note, 22nd of January 2022)

Surveillance not only refers to the environmental surroundings (such as CCTV or a sign-in sheet) and practices but also the self-governing that occurs as the older person conforms to the institution. However, Foucault (1977) proposes that within complex networks of power, there is also resistance. Under the description of resistance later in this chapter, a resident described feeling watched and being in prison. In the excerpt below is an example of how COVID-19 restrictions increased surveillance and therefore also limited physical movement.

Interviewer: And how was that? Like the lockdown or the restrictions?

Resident Participant S1R7: Ah it was terrible. You know, 'cause I came from [urban area] with the lockdown in here. Had to go into isolation and that's the way I came in here into isolation.

Interviewer: And and how was that 14 days to be in one room and not being able to see other residents?

Resident Participant S1R7: Well, there was nothing I could've done. It was hard enough. Very hard.

The above quote shows how COVID-19 once again amplified this discourse; through public health regulations, older people in LTC facilities were closely monitored to avoid any exposure to the virus. This meant that there was a limitation in movement and a tightening of power relations; staff were required to know where residents were at all times able to perform close contact tracing. Surveillance increased during COVID-19 and was accepted because of the protection argument.

9.3 Discourse of Conditional Rights

The second discourse, conditional rights, refers to how older people in LTC facilities are placed into a separate category from other adult populations, which in turn means that the certain rights have been conditioned or ascribed to the residents in LTC facilities. This discourse is closely linked to protection and the conduct of assessments to justify the application of rights. The consequences of othering and the subject position of a passive resident constitute these conditional rights. Following this discourse, conditional rights highlight ageism and the marginalisation of older people in LTC.

Conditional rights were visible through identified contradictions, particularly among staff participants. As discussed in Chapter Eight (under section 8.1.3- Staffs' understanding of human rights), staff participants stated that older people have the same rights as the rest of the population; however, there was a condition attached to that right, often through assessment, the legitimate normalising practices that restricts rights. The discourse on conditional rights stems from ageism, the subjectification of the older person as a 'passive' subject, and institutional conditions that allow residents to exercise their rights. For older people in LTC to exercise their rights, they need support which can be seen as advocacy for their rights.

9.3.1 Ageism

A discourse of ageism was evident when the participants spoke about the rights of older people. It is also evident through self-subjectification (as mentioned before), where the older person places himself or herself in a different group than the rest of the population. Ageism

was implicit in the description of rights, as demonstrated below, where the universality of rights was acknowledged but its equal enjoyment was constrained.

Interviewer: So [name of participant] if, if I say the word human rights, what do you think of?

Resident Participant S3aR1: Human rights... [short pause] We all have. All the people in the room have human rights. So if you want to talk about something and we want to do something, it's our human right. I don't know if that is what you want to hear but that what I see it.

Interviewer: Yeah no that's ok. So when I say human rights of older people, do you think older people have the same rights as everyone else?

Resident Participant S3aR1: Oh I do, I do. Ah well, I mean. There are things that we [residents] couldn't do. I mean, that's... that's no good.

Although the resident did not elaborate on activities that the residents could not do, they implicitly accepted it as part of the LTC facilities' conditions of living there. Within the narratives, ageism is deeply rooted, and participants do not identify it. Participants were unable to recognise this as ageism or any form of discrimination because of the 'games of truth' of life in LTC. However, there could be a self-ageist view produced by older people themselves. The distinct difference between younger (not always defined as what is meant by younger people) and older people in daily life was apparent in some comments. For example, the resident participant below describes older people being left out when talking about technology.

Interviewer: So in one way, [name of participant], what you're saying [name of participant] is that if you don't know if you are left behind, you're actually more likely to kind of get used?

Resident Participant S1R4: Oh yes. Most of the [older] people I know... They wouldn't be computer literate. They feel totally left out and can't deal with their finances [referring to banking through smart phone].

Ageism is widespread and includes how care delivery in LTC is compared to that in other healthcare organisations. A constituted hierarchy of environment and status emerged in the interviews with staff when comparing acute care with LTC care for older people. An experienced nurse described working in LTC for older people could be perceived as having

lower professional prestige than nursing in acute hospitals. This hierarchy pivots on ageist discourses-the impression that care of the older person does not have the same status, complexity, or importance as other settings within (more valued and desirable to work in) healthcare services.

Interviewer: [Participant is talking about differences in care delivery] Do you don't think that there's the same status in nursing homes compared to a nurse in a hospital?

Staff Participant NS3aS1: Definitely not. Even for my own peers, girls I've trained with, you know they... I live locally and I love working here and I did... I just changed to the [name of the NH] for the hours for my children. And my friends that are working in the hospital, they would always say; 'but it's not really nursing'. You know what I mean? And I often wonder, you know, are they getting the same job satisfaction and you know for saying [this]. I've love [my job] 'cause I, I never changed it, you know.

9.3.2 Advocacy and Support

The discourse of conditional rights indicates that participants acknowledged that older people had rights; however, they were conditional. The findings also suggest that advocacy and support for these conditional rights are not clear in terms of duty bearer responsibilities. As discussed previously, when reviewing family members' subjectification, their narratives demonstrate that they assume the role of advocate. Advocacy as part of discourse takes a deeper meaning and is linked to who is and is not advocating. Advocacy, like all discourse characteristics, may be, in some instances misplaced and closely linked with paternalism, ageism and decision-making. For instance, the family member below described dementia as a key factor in deciding if a resident needed an advocate.

Family Participant S4FG5: And I think that, you know when somebody has say something like dementia, they can't communicate on their own behalf or or act on their own behalf.

As mentioned in the description of the family members participating in the study, many were highly involved in the care of residents. However, all participants, including the residents, acknowledged that it was not clear who advocated for those who had no family members. The participating family members were particularly concerned about advocacy for those who had nobody supporting them.

Family Participant S4F1: [...] Need, I suppose what I see is possibly that the people who are in long-term care and have regular visitors, their families are very involved with [care]. And they're obviously trying to make the best decision for everybody, you know. But maybe there is, you know, there is some other people. Do they have their needs? Have their voices been heard?

Apart from family members acting as advocates and staff referring to contacting family members if a resident could not express their wishes or needs, there was no other comments regarding advocating or supporting older persons' rights. There was no consideration of staff acting as advocates or mention of any advocacy group. In addition, there was no description of the residents being empowered or assisted in self-advocacy. One staff member mentioned that a social worker (public facility) was available. However, the staff member acknowledged that the social worker was only involved if there were any issues with care (rather than routine support), specifically safeguarding concerns. Staff participants did not use the word advocate for themselves and did not describe any situations in which they would have been acting on behalf of the residents. Family members also did not speak of staff as advocates and it could be implied that staff may not be suitable to advocate for residents. In the excerpt below, a family member described how staff pointed to the family member as the decision maker for admission to the LTC facility and that staff were unhelpful in stating this.

Family Participant S4FG1: I personally think that you need to be very careful, you know. Only certain staff and how they would convey that message. Because again, you know and and I keep going back to my dad. But like, you know. My dad can be difficult and you know... And [I] put my hand up and say that's just it. And because he's not settled and he wants to go home, want to go home. And one staff member told him last year that it was like, 'well, it's your daughter who signed you in here' Like that you know, that is not helpful. I did help him in there and all, you know. But.... [pause].

True and independent advocacy has a strong relationship with counteracting paternalism, which indicates the power-knowledge of who will be the voice of an older person in the LTC, if self-advocacy is problematic. Advocacy also relates to autonomy as its enhancer; through advocacy, a sense of autonomy can be achieved (Sánchez-Izquierdo et al., 2019). However, as presented in Chapter Eight section 8.3.6, autonomy was the concept that all participants struggled to describe and define.

Advocacy was also discussed as threatened during the COVID-19 public health regulations. Due to a suspension of face-to-face visitation, family members expressed that their ability to

advocate was limited. It did not matter if the family member lived next door to the facility or abroad; all relatives had a barrier to physical visits. Family members participating were all complementary and appreciated the care provided by the facility during COVID-19, however, they also acknowledged how difficult it was not to see the resident and reassure themselves of care adequacy-such physical engagement was seen as the ultimate way of ensuring the quality of care.

Family Participant S1F2: The other thing, sorry...The other thing just about COVID, sorry, just say about the COVID. The one thing that I found is like I couldn't check up on her. See, when I go in, I like to check up on her. I like to make sure she's being... Her personal care is done, that her room is cleaned, that she's getting the food that she's meant to be getting. You know, and basically how the carers are interacting with her and how she's reacting to the carers too.

Interviewer: Do you think that changed during COVID?

Family Participant S1F2: Do I think it changed? I don't know. See, I don't know. No, I... No, I would say not. I would say not on the whole, I would say I'd say they looked after her well. But I, I sometimes I like to see it with my own eyes you.

This is linked to surveillance and control aspects of the discourse; surveillance of staff is a way for family members to have power. This indicates that power is everywhere in every interaction, as Foucault suggested. Yet, it is unclear how the rights of older people benefit from this power relationship as family members' advocacy role may be paternalistic. As a counter-discourse, participating residents spoke highly of staff and knew who to go to if they had any concerns regarding their rights. However, as seen in the understanding of rights, participating residents do not know how rights apply to them. This is an example of the complicated element of human rights of older people in LTC; residents themselves may not have information or knowledge of their rights and therefore do not raise them with staff.

Resident participant S3aR1: But they're [staff] good. The really are, honest to God. And if I was worried, I know I could go to one of them. And I could say 'stick on the kettle' and we could have a chat. And it is great that you can be that way, you know. I feel at ease. Not worried.

Overall, residents felt supported by the staff and that the staff would do anything for them. Yet, in the context of rights, this was contradictory. In chapters seven and eight, there were examples presented of where staff have described how residents' rights may be limited, often due to assessment (normalising practices) articulated under the disciplinary power of nurses.

No resident participant, apart from the resident who attempted to leave the facility (see quote under 9.3.3 resistance), spoke about what occurred if you wanted something outside of the institutional rules. This demonstrates their positioning as docile bodies, enmeshed in the taken for granted truths of life in a LTC facility. Yet, some residents considered themselves fortunate in their facility and not all nursing home residents might be as lucky.

Interviewer: Do you think everyone is lucky?

Resident Participant S3aR1: I yeah, yes, coming here I really do. To come into this place, yeah. Yeah, I really do.

Interviewer: Yeah, yeah, do you think all every place is like this?

Resident Participant S3aR1: Ah no, I wouldn't say so, no. Here like, you couldn't just pick one thing out. You know what I mean?

One way to see how rights are supported at the management level is to consider how complaints are addressed. The participating family members mentioned complaints as a way to advocate for their family members in the LTC facility. However, the quote below shows an example of surveillance by comparing the situation with a personal experience of working with children in a school. There is an example of formal resistance to disciplinary power, where nurses encourage family members to fill in a complaint.

Family member participant S1F1: [...] I do see. I do see very nice care down there, you know. And some things that I'm I... I'm kind of not happy about, but then I've I've, I've spoken about them and and the the the nurse manager said to me 'do you want to make a complaint?' And the first time I said no and second time he said ... he said I am actually going to put it in his complaint and he's... And I realize where he's coming from because if it isn't sent to the complaint then nothing gets... Nothing changes so I get that. So and a friend of mine who ran and worked in a nursing home for years, she said 'just make your presence felt a lot'. Because and I said, I know, I know from school, if I've got a parent on my back who's watching everything, I'm much more careful with that child, you know. Then saying I'm going to have to be able to account for what I've done all the time, which is what we want, accountability, you know, for our actions. And it's really important if you got someone who cannot complain for themselves that you... We are really account for account for each other about how, how that care is delivered, you know, and I see... I see very nice care down there. Yeah, there, you know I do.

9.3.3 Resistance

According to Foucault's fundamental ideas, resistance always exists within a power–knowledge relationship. However, very few examples of resistance were found in the discursive positioning in this study. When asking a resident about the principle of freedom, the clear attempt of resistance was described.

Interviewer: It's means like freedom. Do you feel like you have freedom?

Resident Participant S1R2: No, no.

Interviewer: Free to choose and?

Resident Participant S1R2: Kind of. I'm watched, I know that.

Interviewer: Yeah, yeah. And how does that feel?

Resident Participant S1R2: Pardon?

Interviewer: And how does that feel to be watched?

Resident Participant S1R2: Like a prison.

Interviewer: That's what it feels like?

Resident Participant S1R2: At times, yes. I tried to escape. [short laughter] well not escape but...[pause]

Interviewer: So, you wanted to get out?

Resident Participant S1R2: I lost my [...]. Oh yeah, I had an argument, but... to get. I won't mention... But she [nurse?] came in and said 'the smell of smoke in this room. God you can't be smoking'. I said 'I wasn't smoking but you can smell it from me'. I go out so ask the girl on the switch [reception]. She could smell that smell, yeah? I lost the head. I shouted 'get the f*ck out of here out of me room' I said 'you barge in, I could be doing anything and you come in waving your hands'. She said 'you can smell it down the corridor' and I said 'that is bullshit' and said 'that's it'. Packed a bag. [pause]

Interviewer: You wanted to go?

Resident Participant S1R2: Yeah, I went. Made it to the road. As soon as I cut through, three security men came out of nowhere. 'Get back here'.

The description above describes a resident's desire to leave a facility. It describes a form of resistance to the institution and its rules, by packing a bag and wanting to leave. It also provides an example of imprisonment in the way the resident was confronted by security men and asked to 'get back here'. The resident continued on the interview, explaining that since the attempt to leave (which is a right), he has not made any further attempts of resistance-the impact of power has rendered him docile. Other instances of resistance were few, but they were embedded in the descriptions by residents and family members. No staff describe resistance. Whereas the above example clearly shows that the resident did not want to be in the facility, other examples are more subtle.

Family Member Participant S4F1: That's kind of interesting because like that, I'm nervous about specifically medical opinion, you know, medical decisions. And recently, Dad had stopped eating and, you know, drinking and that. And so, they they asked me in for meeting etcetera. And like, you know, they were asking did they... 'Did I want them to put Dad on a drip' and these things and the other, you know. And while there is, that's the humane thing to do. But there's part of me saying, is this the only thing he feels he can control? Yeah, you know, that kind of way. Because he's so unhappy, you know. Now they did... they did put him on a different tablet that he's never before, that, like, had to come to terms a bit better and he's performing and he's eating better now, you know...

The family member describes the resident not eating and drinking, and wondering whether there is an element of resistance as this withdrawal could constitute one of the few domains of the resident's control. As seen in section 9.3.2 complaints can be seen as a form of complaints. No resident participating mentioned lodging any complaints and one way to see how rights are supported at the management level is to consider how complaints are addressed. The participating family members mentioned complaints as a way to advocate for their family members in the LTC facility. From FCDA point the complaints can be seen as a resistance to current practices.

Under governmentality, Foucault (1984) described resistance as an important aspect of all power regimes and institutional rules. However, residents living in the LTC showed little evidence of resistance. As previously presented, one resident spoke of his attempted "escape". Another cited form of resistance may have been represented in the description of a resident who stopped eating and drinking. It is one of the aspects of self-control that a person who has lost autonomy has, and is a form of resistance. However, it may be difficult to isolate this between a conscious decision and the consequences of an organic illness.

In this study, COVID-19 public health regulations did not increase resistance or reveal new examples of resistance. Residents did not question the restrictions or the reasons behind the restrictions. Residents that participated did feel that their everyday life altered due to COVID-19, but did not resist the situation. One resident in the below quote felt that COVID-19 did not affect them at all.

Resident Participant S3aR1: In all honesty, it hasn't. As far I'm concerned, it hasn't really affected me. Now I know, I have heard things and things can be very, very sad and I know that a lot of people can be affected, but I can't say anything bad about anything because I'm here. No and I'm... They are doing the best to help me along and I'm doing the best I can get along. So that's the only way I can put it.

9.4 Discourse of governance

Governing occurs at all levels and can be located in policy, systematic governing within a society, or in an organisational culture, such as the LTC facility. Governance within organisations is defined as the system, principles, and process by which organisations are directed and controlled (WHO, 2021c), not necessarily only official procedures but also unofficial ones. This section examines the discourse governing the rights of older people in the LTC, which includes self-governing, decision-making, and institutional rules. Governing discourse is the result from FCDA where examples of governmentality, biopower and the institutional rules emerged.

An example of governance was that all staff had heard of HIQA, the regulating body of LTC facilities, which formed part of the governance of LTC facilities through regulations and standards. However, as mentioned in the previous chapter, the guidance of human rights-based care and FREDIA principles were not acknowledged. Governmentality, a form of power as explained in chapter six under genealogy, provides administrative institutions (such as HIQA, NMBI, and healthcare organisations) with the means to govern people (all stakeholders in LTC).

9.4.1 Decision Making

The decision-making sub-discourse emerged from the interviews from the perspectives of who, what, and when decision-making occurs. It is part of governing rights and is linked with protection discourse, particularly regarding normalising practices. Decision-making can occur at the micro-, macro-, and meso-levels. However, the focus is on who determines the ability

of residents (older people) to exercise their rights. Residents expressed that they had the freedom to make decisions, and answered that they had choices. However, this was contradicted in the text; residents often referred to family members when asked about decisions, particularly the decision to move to the LTC facility. The following quote is from a resident who moved into the same LTC facility as their spouse. However, the self-decision for admission was influenced by the perception of declining health and not being a burden on the family. This indicates that although residents were able to make independent decisions and supported to self-determination, they were dictated by their own perceptions of being old (subject positioning).

Resident Participant S1R5: [...] Last Christmas I know 'cause I came. I spend Christmas Day with him and I just thought, I was on my own. He was getting frailer and while I had all that working that my.. I have two daughters, one in America. And when you say Yale, her husband was in Yale [laughter. Refers to Yale and not jail]. And one [daughter] here and she's married and has got 2 girls. You know they had their own homes and like and they have all the other things and whatever. And I thought really was time. Then I didn't like this with him. Now if she [daughter] was talking to you she should tell you I was getting forgetful and getting dodgerry and all sorts. Yeah, she was over anxious about me. She had her own family to worry about. So it was a simple thing I felt it was time. He was a very good husband and father. He was, you know, his whole his whole life was centered around us so it's alright it was my time to be here with him.

The most significant decision brought up by participants was the admission to the LTC facility. When asked about decision-making, participating residents and family members referred to the decision to be admitted to the LTC. The participating staff spoke about the medical or care decisions within the LTC facility. Only a few participating residents spoke about being part of the LTC decision, thus negating FREDA principles. If they were part of the decision, they could describe the process in detail and why the facility was chosen.

Interviewer: And then that's the route you went to, come here? and how do you find it here?

Resident Participant S3aR6: Oh well they are ok. I looked at two other places before I came here. And I didn't like them.

Interviewer: Why didn't you like them if I can ask you that?

Resident Participant S3aR6: I was brought into a room and all the people were sitting along the wall.

Interviewer: Oh yeah, you didn't like that?

Resident Participant S3aR6: No, there was something about the situation that I didn't like. And it works better here. It's more spacious.

By contrast, there were more descriptions of not being involved in the decision to move to the LTC. The narratives represented total infringement of rights, yet the participating residents complied with family decisions.

Interviewer: But here you're happy?

Resident Participant S3aR2: Oh yeah. But you see I wasn't told I was coming in here. I was in for respite and my brother came in on this Sunday and he told me 'sit down', so I sat down. He said 'I've got something to tell you' and I asked 'am I going home?'. And he said 'no this is your home now'. And I went that colour [pointing at a grey cup]. And I never forget. And I couldn't, just couldn't. Yeah, so I really couldn't. Uh, and he went then. And I just couldn't get over it. [voice breaking]. They said they should have told me, but they didn't.

Interviewer: So, before you came in, they didn't tell you that it was permanent?

Resident Participant S3aR2: No, no.

Interviewer: And how does that make you've feel?

Resident Participant S3aR2: I, I have never gotten over it now, but you know. [shrugs the shoulders]

The resident above, who expressed not being told about the permanent move to the facility, had been there for several years and considered it her home. However, the process of not being told and not being part of the decision to move to the facility still made her upset. This is an additional example of paternalism where the decision is taken for the resident in the sense of 'their own good' and 'other' know best. Thus, rights here are silenced by norms of ageing and dependency, and the assumed assumption that LTC admission is unproblematically acceptable.

In contrast, some family members expressed how the decision to admit to an LTC facility was taken away as family members. In their role as advocates, they also unproblematically assumed the role of the decision maker, a form of power which was described as being taken away from them. From this perspective, this process is often rapid and dramatic. Even when LTC admission is planned, circumstances can change quickly and become more urgent.

Interviewer: So obviously you said you weren't involved in the decision. Do you think the decision was then made kind of the by the hospital who kind of said that he's not able to go home, social workers were involved in that and the consultant or or nurses?

Family Participant S1F1: Yeah, there was quite... There was quite a group there. The consultant and his his doc. And the doctors there that I had spoken a lot. And and there was the the the..., the OT²⁰ and the physiotherapist and the nurse in charge. There was, yeah. Yeah, there was.... I I'd have to say it and I'd been wrong about what was their situation.

They also felt that there was a lack of options in choices and that the only choice was LTC, which was a decided deal for them. They did not know or could not ask for options. As such, families succumb to the disciplinary power of professionals.

Family Participant S4FG3: Yeah, you're too, you're afraid to upset [hospital staff]. Because so, so much of the power of her future is in their hands.

The decision to be made within the LTC facility was described by staff as in the resident's best interest or as previously described as part of the assessment that nurses undertook of capabilities. One participant, a family member, proposed that decision making can be in the 'best interest', even if it goes against the wishes of the resident. The family member did not associate this with the resident's individual rights, instead it aligns with family members view of being the advocate and decision maker.

Family Participant S1F2: [...] And she really abhors the hoist. She hates it. Or, and she hates the carers taking her trousers down. And and you know, all that intimate care, she will say 'No, no, no, no, no, no.' That and they have to do it. I understand. They have to do it because otherwise, you know she'll be in a wet incontinent pad, not be whatever you want to call it. And for her general health and well-being, that just can't be so. It's a little bit of a, you know, discomfort for her and annoyance to her. But in that case. I you know, I have to kind of overrule her in that way and 'go ahead. Do what you need to do'. So that's where she would be in her own ability to to say yes or no to certain things.

²⁰ OT=Occupational Therapist.

The above quote also describes some resistance by the resident; there is no description from the family member of whether there are capacity issues. Presumably there are, as family member did describe the resident as having dementia. By saying that the resident has dementia, staff and family members legitimised their actions as decision makers and devalues the resistance of the resident. The staff also acknowledged that family members were decision makers, particularly if an assessment had been made that the older person (resident) lacked capacity or had a dementia diagnosis.

Staff Participant H S1S4: Well obviously a lot of families are voices for the residents.

Subsequently, both staff and family members described families as a source of decision-making. Family members being the decision-makers was a strong finding in the data, and it was not clear whether the resident was unable to make the decision autonomously. Staff describing decision-making showed examples of paternalism and assessment legitimized the decision as well as discursive associations to protection discourse. Keeping residents safe is often a significant reason to act against a resident's wish or their own decision-making and this could privilege the family's power in this activity.

Interviewer: Let's take the example of the vaccination, which is, has been topical in the last year or so. And also, if a resident doesn't not want to get vaccinated but a family member insists that they should get vaccinated?

Staff Participant NS1S1: Yeah, then we'll make the decision according to the resident's ability to make the decision. Yeah, you know, if they have a severe like advanced dementia, if they are not in a position to make the decision for them, then definitely we'll contact the family. Because, you know, for compos mentis residents, that's their decision they need [it] or not. If they don't have the decision to make. I mean, if they don't have the ability to make the decision and we are doing it for for them, you know just to make them safe. So, if the family is willing to do that, then definitely we'll make that decision with the family. We'll include in the GP in that decision making and nurses are not the one who is going to make that decision. Like you know, we'll include family.

Nevertheless, one family member described how she was asked about the crucial medical decision which she felt was beyond her expertise in the area. In the descriptions of decisions, it was relief for family members that healthcare professionals had made the decision. Family members, but also residents themselves, rely on the disciplinary power of expertise to make

decisions. However, no participating family members expressed whether the resident (older person) had been assisted in making their own decisions or if they were included in any decision-making process. This demonstrates the invisibility of individualised human rights.

Family Participant S4FG4: But I think we were more relieved when the doctors made that decision and we had to rely on their expertise and they had spent you know that we didn't have to sit down as a family and go, 'OK? Mum's going into a home', you know [...].

9.4.2 Institutional Rules: Contradicting realities

Power relationships, even at the micro- level, create rules for discourse institutions in the production of knowledge. In the data, institutional rules could be visible or hidden in practices within the LTC facility. A visible rule was that of the environment, which was noticeable even prior to the interviews. The difficulty in accessing LTC facilities for data collection even prior to recruitment is presented in Chapter Six; however, when entering the LTC facility, there was a health and safety rule of signing in with name and purpose. This functioned to overtly delineate the governmentality and scope of remit of the centre, visually reinforcing power and knowledge in the institution. Such power relationships are further demonstrated within the architecture of the building and within symbols of disciplinary power, such as the nursing station, staff uniforms, and resident access areas versus clinical, isolation, and domestic areas.

When describing rules under this section, it is not to implicate that rules are 'bad' or negative. They are simply rules that determine practices within the given episteme and are therefore represented in and through discourse formations within the institution. While some rules and statements of power are explicit, they may also be hidden, and it is in the description of how care is delivered that one can detect them. In the quote by a staff member back in Chapter Seven section 7.3.6, when a staff member describes the routine and tasks, contradictions are highlighted as the rules of daily life, closely linked to task schedules, which are dictated by staff. Below is the quote again, as it is a significant description of institutional rules with highlighted bold text to illustrate both institutional rules as well as the disciplinary power staff have.

Staff Participant HS1S4: So and every day it's nearly the **same thing** every day. You know you have to **keep a routine** for the residents. You know **we come in, we open** the curtain and **sit the residents up** for their breakfast, the breakfast trolley comes down. **We give them**

their breakfast. Then **we do** personal care, **get them up, wash, dress** ready for today visitors, activities. Then lunch, again the trolley comes down. **We give** them their dinner. And usually then after that there's activities or in the afternoon activity. So **we** already go to the reception. Then in the afternoon. And **we give** them their tea and then in the evening they usually get into pyjamas if they want to go to bed or if they don't want to go to bed. **So we just got them ready either way.** So if they want to.

In this description, the use of 'we' refers to staff and the contradiction is that the routine is claimed for the benefit of the residents, yet the routine is for staff with the 'we' indicating they dictate and control the daily activities. This legitimises control practices. Yet, the same staff participant also alluded to contrary realities drawn from person-centred care.

Staff Participant HS1S4: [...] But the right to just live here and to be free to do whatever they want to do you know, there's no stopping or restricting anyone from doing what they want to do. This is their home. I work in their home, you know.

These institutional rules were also found when residents described their days. Once again, the contradiction presented in these accounts which referred to the routine of the institution, not their own routines. This does not mean that residents are not asked about their choices and wishes, but that there are institutional rules reflecting normalising practices that staff follow that dictate the provision of care within the institution's apparatus of governmentality. This illustrates the conditions of possibility which reveal the impact of bio-power both at the institutional level and at the technology of self-level:

Interviewer: Do you get to choose what time it is, what time you go up there [referring to communal day room]?

Resident Participant S3R1: Well, they bring us over. They come in and bring us up. Up along the corridor there are rooms we are not allowed to go into or they are not allowed to come out [referring to COVID-19 isolation?]. Yeah, so we came up yesterday and there's somebody who says 'time to go'.

Thus, older people can position themselves in the role of being looked after and requiring care. This, together with institutional rules, provides a power network resulting in residents following the routine of the facility, not necessarily their preferred routine. Together with previous examples of normalising practices and surveillance, this positions the older person within a rigid routine in the facility, rendering the resident docile.

Because of the risk assessments (discussed earlier), some institutional rules related to the process of activities enmeshed in normalising practices and the mechanics of power are put in place as part of discourses on health and safety which are also part of the protection discourse. However, in these cases, there is a restriction on movement or personal choices which are succumbed to under the knowledge/discourses/power relationship inherent in biopower. The following quote describes a resident's routine; of note is the receptive, docile body which constitutes modality and accepts powers that work on it through institutional rules.

Resident Participant S1R5: Routine I would get up about by get up about half, about 8:30. Yeah and have my shower or wash and things like that. No, they're not letting me shower on my own at the moment and but that's alright I can wash up 'the stairs'.

Interviewer: Yeah. Is it because of the risk of falls or have they explained to you?

Resident Participant S1R5: Yeah, well, I would imagine that would be it you know I you know it's [sounds unsure what is the reason]. And I'm at that stage that I'm just making sense of what's happening here.

Institutional rules became a stronger power mechanism through governmentality during the COVID-19 pandemic. Under the dominant discourses of public health and risk, institutional rules were enforced in a structured manner, particularly during a suspected or confirmed outbreak where residents were told to stay in their room or not allowed any visitors. This was presented under section 8.3.2, when participants were asked about freedom and referred to limited spacial freedom during COVID-19 restrictions.

9.5 Conclusion Discursive positioning of human rights of older people in LTC

The genealogical analysis of this study, which focused on how the rights of older people in LTC are constructed and the consequences of this, is presented in the three chapters. These chapters present pivotal findings and are drawn together from a diverse data source: semi-structured individual interviews, a focus group, and reflective notes. Chapter Seven provided findings on how older people position themselves within the LTC and the broader discourse of their rights. Their position as a passive subject created a form of 'othering', where staff had professional responsibility and family members were the 'voice of' the older person. This subject position revealed the mechanisms of power, where older persons' resistance appeared to be overshadowed by the dominant discourses. Chapter Eight provided insights into the knowledge of human rights and how they are action-oriented. The lack (discursive

silences) of core knowledge around human rights, particularly among staff, can be viewed as a form of disciplinary power. Older people in LTC facilities are subject to the norms and regulations set by the authorities, in this case, the institutional structures of LTCFs. Furthermore, this knowledge gap may be a deliberate strategy employed by staff to maintain the existing situation and to control the narrative surrounding the rights of older people. The lack of knowledge may serve as a mechanism to perpetuate the dominance of certain discourses, such as those on protection and conditional rights, which may disempower residents.

This chapter provides evidence of how residents, staff, and family members construct the rights of older people in LTC. Contradictions and the unsaid truth around the rights of older people were established. Discursive positioning, using both archaeological and genealogical analyses, were based on three main discourses. The first is protection, followed by conditional rights and a third of governance, all of which are interlinked through a complex system of relationships. The first of these discourses, protection, underscores the overarching responsibility of LTCFs in protecting the well-being of older residents. Within this discourse, rights are often framed in the context of benevolent paternalism, in which residents' autonomy may be curtailed in the name of their safety. The dichotomy between protection and autonomy was a recurring theme, highlighting the tension between safeguarding residents and respecting their rights. Conditional rights emerged as the second prominent discourse, reflecting the notion that the rights of older individuals in LTC were often contingent upon their compliance with the norms and expectations set forth by the facility and its staff. Residents found themselves navigating a complex landscape where their rights were not absolute, but subject to conditions. The third discourse, governance, highlights the intricate system of power relations within LTC facilities. It underscores how these institutions are governed by a web of policies, regulations, and hierarchies that shape the experiences and rights of older residents. In the LTCFs a set of rules is put in place, and tacit power relationships occur. Power lies within the institution and staff and impacts the (non) ability of older people in LTC to claim rights. The consequences of these discourses are the lack of promotion of rights for the older person, often based on the assessment and normalising practices of what and what not the resident can do. Using terminology such as 'compos mentis' and referring to residents' underlying conditions (for example dementia) as a rationale for the protection discourse (and practices) is driven by paternalism which is significant in constraining the full enjoyment of human rights by residents.

In conclusion, the findings of the genealogical analysis in this study reveal the intricate web of discourses that influence the (non) construction of rights for older people in LTC. The data demonstrates the power-knowledge-discourse relationship which is contingent to the passive subjectification of residents and repeatedly legitimizes perspectives imbued with protectionist approaches, the allocation of conditional rights, and associated governance activities. To make sense of this, the following chapter, Chapter Ten, will discuss in detail the implications of these discourses in LTC in Ireland and contextualise this in the extant literature.

CHAPTER TEN

Discussion

Where, after all, do universal human rights begin? In small places, close to home—so close and so small that they cannot be seen on any map of the world. Yet they are the world of the individual person: The neighborhood he lives in; the school or college he attends; the factory, farm or office where he works. Such are the places where every man, woman and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world. (Eleanor Roosevelt, 1953²¹)

10.1 Introduction

Using the FCDA, this study explored the text and language used by residents, family members, and staff regarding older people's human rights. Aim was to examine participants' knowledge and discourse construction of rights of older people in LTC. The findings provide critical insights and reveal complex interrelationships among three dominant discourses: protection, conditional rights, and governance. This chapter provides an analytical synthesis to enable an interpretation and evaluation of the findings situated within the extant literature. The discussion takes the micro-, meso-, and macro-level approach, and as advocated by Roosevelt (1953), focuses on the implications at every level to uphold human rights 'close to home'. How we interact with each other is often taken for granted and ingrained in everyday life; however, such perspectives may negate equating these routine experiences with constituting human rights. However, in those micro-actions in everyday life, human rights are either upheld or restricted.

This discussion starts with how participants and FCDA contribute to the knowledge of the human rights of older people in the LTC. This is followed by probing into the subject position of the older person and how this position places the older person in a group of 'othering'. The three main discourses—protection, conditional rights, and governance—are explored, along with the consequences of knowledge (or lack of) within these discourses. The discussion

²¹ In March 1953 Eleanor Roosevelt delivered a speech to UN that included this quote. Eleanor Roosevelt was a key leader in the UN Declaration of Human Rights in 1948.

focuses on how governmentality and biopower are contingencies of the human rights of older people in the LTC. This study did not aim to examine COVID-19; yet, due to the timing of the study and its significant and lasting impact on older people, COVID-19 has relevance in the study. Particularly in LTCFs, it created conditions that impacted both the conduct of the study and the participants' discourses. As detailed in previous chapters, reflexivity was an important element in the study, contributing to rigour and acknowledging the personal, sociopolitical, and cultural contexts within which the study was conducted (Palaganas et al., 2017). Thus, this chapter ends with a critical reflection on how my fractured subjectivities were impacted by the research process as well as the effects of my subjectivities on the research.

10.2 Participants' and Foucault's contribution to Rights of Older People in Long-Term Care in Ireland

Using FCDA, this study was able to provide insights into a detailed power-knowledge network of relations related to older people's rights as residents in LTC. As FCDA looks at knowledge production and the construction of 'truth', analysis commenced in the literature, through an examination of systems of thought, contingencies, and discourses of legitimised knowledge using archaeology. This encompassed a careful consideration of how and why knowledge was produced or constrained, and through the 'digging' into the past dominant discourses emerged in text that still define policies, practices, and standards. The study then continued with stage two: the genealogical analysis, consisting of interviews with older people in LTC, family members of residents, and staff who worked in LTCFs. Once access was provided to the facilities, older people themselves were keen on participating. This indicates that there is a demand for studies in this sector, and older people in LTCFs should be encouraged to voice their experiences despite barriers such as complex participation information leaflets and obtaining consent (Fiordelli et al., 2021; Goodwin et al., 2023). Older people in general and in LTCFs continue to be underrepresented or even excluded from research, which in turn leads to less evidence-based care provision (Nocivelli, 2023). Therefore, upholding rights begin with the inclusion of an older person's voice in research.

The female voice was overrepresented in this study, with 75 percent of participants identified as female. Worldwide reports indicate that approximately 70 percent of all formal workers in health and social care are women (International Labour Organization, 2018), and higher female participation was not unexpected. Additionally, most family members involved in informal care provision are women (Family Carers Ireland, 2022; Teahan et al., 2020).

Moreover, there is a substantially higher number of female residents in LTCs than males, accounting for 66 percent of all residents in LTCFs (CSO, 2022). Within the data, a female voice was observed in some sub-discourses that emerged. Thus, a small number of female residents were able to associate rights with equality and women's rights movement. Their descriptions would have been a reflection of their experiences of Ireland 40-50 years ago, when women were dependent on the male family figure in their lives, whether their father or husband. By being able to see this struggle, they had some association with their rights. From the perspective of changing society, these participants' descriptions concurred with a change in the women's workforce, for instance, the 1973 marriage bar abolishment to the 1977 Equality Act. The years after these societal changes in the 1970s were significant for women's position in Ireland (Fine-Davis, 2014). For example, in the 1981 census, 55 percent of women over the age of 15 classed themselves as 'looking after home/family', compared with just 17.5 percent three decades later in 2011 (CSO, 1981, CSO, 2011). The figure further decreases in both 2016 and 2022 censuses (CSO, 2016, 2022). This societal change in women's position was also referred to by the participating female family members, who described being in full-time employment and not able to provide care at home which may have been a norm in the past (Russell et al., 2019). As the majority of the participating female family members were in a daughter-parent relationship, this also mirrors the gender alliance of caregiving with females (FCI, 2022; Stall et al., 2023; Swinkels et al., 2019). The change expressed in this study aligns with society and is part of what Foucault (1972), referred to as a change in epistemes. Not referred to as progress, Foucault did not compare different epistemes with each other, but there is a contingency in that change in the rights (and acknowledgement) of women working outside the home and the subsequent reduction of their availability (or expectation) to care in the community. However, the recruitment of participants suggests that the caregiving role remains biased in terms of supporting older people in LTC. Thus, the interpretation of rights drew on the experiences of women's positions at different periods with which participants identified.

The staff participants in the study represented a diverse group, with 80 percent of all staff participants disclosing nationality other than Irish. The LTC sector is typical of female-dominant, low-paid jobs (Llena-Noza et al., 2022; OECD, 2019). Additionally, there have been low levels of recruitment in this sector at the national level in Ireland (Loughnane & Edwards, 2022), which has led to increased recruitment of healthcare professionals outside Ireland (Cullen, 2019). Eurofound (2020) pointed out in their European report that many nurses in the

LTC in Ireland were trained outside the jurisdiction. In this study, the majority of staff nurses had received undergraduate training in their home country. In relation to human rights, this could have implications for the understanding of human rights principles and how these principles have been introduced in general training. Culture impacts the understanding of human rights (Veer & Dezentje, 2019), and staff should be supported to understand approaches and standards in the health systems in which they work (NCCRI & IHSMI, 2002). In particular, there are arguments that nursing education should be harmonised across the globe to reflect systematic evidence-based knowledge (Baker et al., 2021; WHO, 2020c).

10.2.1 The Hidden Truths in silence and contradictions

This study suggests that language is an influential tool for determining views on a topic such as human rights of older people, as it provides insight into the power-knowledge nexus and uncovers hidden ‘truths’ (Foucault, 1986). How participants engage in discursive practices, including their thoughts, actions, and speech, plays a significant role in uncovering these truths (Foucault, 1972). Similar to this study, Pierce et al. (2016) conducted a study with older people who had been diagnosed with mild cognitive impairment using the process of discursive psychology, as informed by Potter and Wetherell (1987). Their findings indicated that the participants’ use of pauses, hesitations, silences along with narratives provided discourse formations of how the subject was positioned and viewed, not only in relation to dementia but ageing in general, often with a negative view (Pierce et al., 2016). Similarly, in this study, not only language and text provided data for discourse formation. Silences, contradictions, and environmental contexts also became significant in their ways of providing meaning. Silence exists in the language (text) of discourse. Foucault (1978) noted in his research how multiple silences can exist in the discourse and that silences are a form of strategy that subjects use. They can be part of the power-knowledge-discourse nexus by deciding what to talk about and when, as well as who is permitted or constrained.

Silence itself—the thing one declines to say, or is forbidden to name, the discretion that is required between different speakers—is less the absolute limit of discourse, the other side from which it is separated by a strict boundary, than an element that functions alongside the things said, with them and in relation to them within over-all strategies. (Foucault, 1978, p. 28)

The most noticeable silence was by staff. Bengtsson and Fynbo (2018) pointed out that within a post-structuralist view, silence is more than a hurdle in data collection, and silence has a

multifaceted relationship with power. Compared to this study, silence provides a wider meaning by exposing power dynamics (Bengtsson & Fynbo, 2018). Although the population was not older people but youth delinquents, their findings showed that silences are powerful mechanisms in discourses related to vulnerable, marginalised groups and provide meaning. The creation of meaning in silence is influenced by an unequal power dynamic and can unfold unexpectedly, (Bengtsson & Fynbo, 2018).

Like silences, contradictions were another function of language that provided hidden ‘truths’ in the construction of discourse. Contradictions were elusive and could occur between the three different participant groups or within the participant group. In particular, staff participants could have contradictory narratives. For instance, contradictions were noticeable in the descriptions of residents’ everyday lives and the staff’s description that the facility was the residents’ home, yet they were not able to use all the facilities offered and rules applied. This deviates from the idea of a person’s home where there is environmental freedom. Additionally, contradictions were particularly noticeable when asking staff participants about person-centred care (PCC). PCC was described in detail by the staff participants, often with long details of its meaning in providing individualised care to residents. However, there was a discrepancy between the theoretical verbalisation and description of person-centred care and the actual practice described. The practice was described as task-based and dictated by institutional rules. In an extensive systematic review of PCC practices among staff (the review included both nurses and healthcare assistants) in LTCFs, Güney et al. (2021) found that staff generally understood the framework of PCC, but due to task-based practices, it was not actualised in reality. As the archaeological review also showed a strong link between PCC and human rights (McCormack & McCance, 2017; Phelan et al., 2020; WHO, 2021a), the questions regarding PCC in this study revealed the challenges in providing care at a practical level.

10.3 Othering- Those who are dependent, frail and vulnerable

Both Chapter Three and Four presented how older people are positioned, not only in LTCFs but also in society. The subject positioning of older people is fundamental to the construction of their human rights in the LTC. The archaeological analysis stressed a knowledge base founded on the statements of theories of ageing, with a focus on successful and healthy ageing (DoH, 2013; Rowe & Kahn, 1998; WHO, 2015b). This counteracts older persons dependency on care which indicates a loss in personhood, becoming passive and seen as a

burden, both in the socioeconomic context as well as burden in healthcare (Anderson et al., 2022; Roubal, 2023). In this study, the subject positioning of the older person impacted the realisation of rights. This subject positioning, developed from the data, identifies older people as being othered. Othering is a sociocultural process expressed as a discursive practice that refers to the marginalisation of certain groups, emphasising differences or treating them as outsiders, although no overarching definition exists (Akbulut & Razum, 2022; Dervin, 2021; Rohleder in Teo, 2014). In this study, the older person in the LTC facility is constructed in power relationships, and there is a distinction of othering by the practices in the LTC facility, often practices of boundaries and restrictions. These practices create privileged positions within a facility (Powell, 2012; Roberts & Schiavenato, 2017) and are further discussed under institutional rules within LTC facility 10.5.

Othering is not a deliberate or conscious act; it is a result of norms and stereotypes that people inherently have and are unaware of (Vestgarden et al., 2023). This research aligns with the observations of othering in various aspects of society. The vulnerable and frail positioning of older people contributes to their marginalisation, which can have significant implications for their rights. Stereotypes of older people are widespread across European countries and the adverse view of older people is negatively associated with active ageing, as promoted by most European countries (in Ireland as 'healthy ageing'). Fernández-Ballesteros et al. (2020) noted this in their multilevel statistical analysis of stereotypes of older people in European countries, and a negative association can be seen at both the individual and national levels. This position argues that any national healthy ageing policy or framework needs to include how to combat ageism and stereotypes for the policy to be successful. Othering and its link with stereotypes stem from ageism, and while this is observed in society (Kang & Kim, 2022; Weir, 2023; WHO, 2021), its impact is normalised in LTC facilities and older people do not have the same application of human rights as the rest of the population.

This view extends to older persons themselves, often placing themselves as different from the rest (at times referred to as the 'younger' population). The older person's internal view of themselves, assisted in the positioning of them as 'other', which can be explained by Levy's (2009) theory on stereotype embodiment, a psychosocial approach to ageing that can have physical impact on the older person. Levy (2009) studied self-perceptions of ageing among older people and found that a negative self-perception could have more than seven years less life expectancy than a positive perception. Moreover, such negative self-perceptions can lead older people to act and respond to others in line with such internalised beliefs. The internal

stereotype is unconscious and occurs across the life course in multiple ways (e.g. societal and individual). Extensive research has confirmed Levy's (2009) theory of stereotype embodiment (Bellingtier & Neupert, 2018; Levy et al., 2018; Siebert et al., 2020) and has enforced the robust hold stereotypes of older people. Similarly, the internalised ageism was seen in this study as residents were passive, not wanting to be a 'burden' or a person that caused any problems. Furthermore, this was seen in the archaeological review in chapter three as part of disengagement theory, as proposed by Cumming and Henry (1961). Through increased care needs, the older person disengages from society. By establishing the older people's subject position as 'other' and finding evidence in the data of stereotype embodiment, internal ageism, disengagement, and marginalisation of the older person in LTC, discourse formations of protection, conditional rights, and governance emerged.

10.4 The paradox between protection and human rights principles

The findings from both archaeological and genealogical analyses highlight how the protection discourse is balanced against the principles of human rights. The conditional rights discourse showed that rights, as dictated by and articulated in rights treaties, are tacitly conditioned, restricted, and limited for older persons in LTCFs. Added to the navigation of the protection discourse was poor knowledge of human rights, whether through human rights legislation and conventions or principles such as autonomy, dignity freedom, or equality. Thus, through silences and the consequent lack of knowledge from staff, the facilitation of rights is constrained. In addition, the conditions of acting as duty bearers (primarily staff) to ensure that duty holders (residents) can exercise the rights of autonomy and self-determination are diminished (Gutting, 2005; Lammers et al., 2016). This is exemplified in figure 22 by an imbalance between protection and rights.

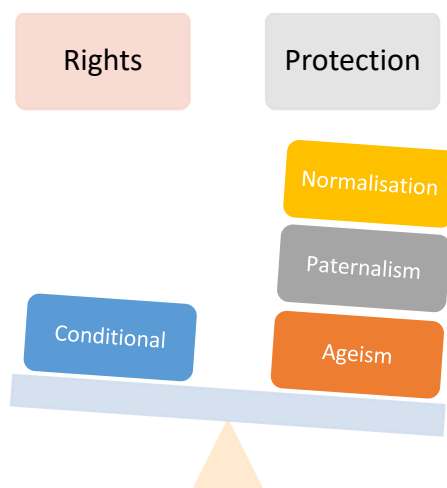


Figure 22: An illustration of the balance between protection and rights of the older person

According to legislation, regulations, and standards (Health Act, 2007; HIQA, 2016), LTCFs do have a duty to protect residents. This contributes to the legitimisation of a strong protection discourse related to older people. In contrast, standards and guidance (HIQA, 2016; 2019) also emphasise the promotion of rights, causing a balance between protection driven by paternalism and ageism versus exercising and supporting residents as rights bearers with associated entitlements. Evans et al. (2018) identified this balancing act in their interview study with care home managers in England. Managers balanced care between protection (keeping residents safe) and their rights, particularly autonomy and dignity. The managers also admitted that at times, the safety of the entire facility may be prioritised over the needs of individual residents (Evans et al., 2018). This finding concurs with the observations of this study, particularly in the context of COVID-19.

Older residents are dependent on the knowledge of staff to be able to realise rights, and if there is no awareness, it raises a range of challenges for the older person (Love & Lynch, 2018). Poor knowledge and discursive silences on human rights do not assist older adults in upholding their rights. This study concurs with the findings of Mpouzika et al. (2021), who conducted a systematic review of nurses' knowledge of patients' rights. Despite this systematic review not being specific to the care of older persons or LTC, the 13 reviewed studies demonstrated low levels of knowledge regarding rights, particularly in the context of components of the rights framework such as freedom (particularly freedom of choice) and autonomy. However, Mpouzika et al. (2021) also found a lack of education and information

on how nurses can focus on rights, indicating that it is not a topic of priority in either formal education or continuous professional development. Similarly, Newham et al. (2021) found a general lack of interest in human rights training among managers in healthcare organisations, which in turn contributed to even less interest in human rights from healthcare professionals. Fitzgerald et al. (2020) conducted an extensive review which included focus group with a range of stakeholders in how to implement a HRBA to care in social care in Ireland. Their findings are consistent with what was found in this study and show a lack of knowledge in HRBA. They also developed a range of resources that HIQA (2019) implemented in their overall guidance of HRBA (Fitzgerald et al., 2020).

The interviews with all participants showed that human rights principles, whether individually or as part of a human rights-based framework, seemed to be difficult to grasp, particularly the principles of autonomy and equality. The principle of dignity appeared to be best understood by all participants, aligning with the archaeological review of the literature, which found that dignity has been developed and researched in LTC facilities in relation to caregiving (Kisvetrová et al., 2022; Moilanen et al., 2022; Oosterveld-Vlug et al., 2013; Sunzi et al., 2023). An archaeological review of the literature showed how interlinked human rights principles are, in particular, autonomy, self-determination, and freedom; however, these studies also demonstrated how the principles were challenged by paternalistic attitudes by staff, as well as institutional barriers, such as lack of access to managers, lack of resources, and limited free movement within the LTC facility (Caspari et al., 2018; Tuominen et al., 2016). Autonomy, the principle that participants in this study had the hardest time describing, was found by Kloos et al. (2019) to have the strongest and most consistent relationship with the well-being of residents of LTCFs. Kloos et al. (2019) conducted a longitudinal study of older people residing in Dutch LTC facilities. There appeared to be a loss of autonomy once a resident entered the LTC facility; the findings suggested that the residents had limited control over their daily lives, including choices about their routines and activities. This lack of autonomy contributes to othering, where residents are treated as passive recipients of care rather than active participants in their own lives in the LTC facility.

10.4.1 Freedom or Deprivation of Liberty

The findings of this study align with those of previous studies, where the participating residents said they had freedom, but when asked practically, they lacked the freedom to freely move around (Caspari et al., 2018; Kloos et al., 2019; Tuominen et al., 2016). Several examples in

this study indicate that autonomy and freedom were limited and that there was even a loss of these rights once they resided in the LTC facility. Residents' rights were conditional, based on assessment or due to the staff and family members' orientation to the protection of the older person. Accordingly, the lack of autonomy and freedom infringed upon the right to liberty. As detailed in Chapter Five, in the archaeological analysis of the human rights of older people, the right to liberty is the cornerstone of most human rights treaties (CRPD, 2007; ECHR, 1950; UN, 1948). There is further conflict between the right to liberty (freedom), deprivation of liberty, and the infringement of one's freedom. Although LTC facilities have moved from being institutions and have attempted to associate their experience with a 'home' (i.e. the older person's home) discourse, in the context of care provision, institutional practices persist. The realities of caregiving for older people with high care needs complicate these two constructs ('home' and institution), yet they are entwined for older people in LTCFs (Series, 2022). In a home, one would not be limited to accessing certain areas, but as the findings suggested, some areas were not accessible to older persons residing in the facility.

The paradoxical balance between upholding human rights and protection under the disguise risk management has led to discussions on the deprivation of liberty in LTCFs (Pinilla-Roncacion et al., 2020; Sage Advocacy, 2023a; Steele et al., 2020). Because there is a connection between freedom, liberty, and autonomy, once an older person is admitted to an LTC facility, there is an automatic loss of liberty (Tuominen et al., 2016). This was seen in this study by participating residents' descriptions of their past identity; they knew that they had lost some of their autonomy and applied more importance to the person they were before admission. This study did not ask specific questions about restraint or deprivation of liberty; however, raising discussions about freedom is fundamental to promoting genuine conversations regarding the rights of older people in LTC facilities. The level of containment is determined by the older person's abilities and wishes (wills and preferences); yet, limiting their freedom limits these abilities and raises questions about when deprivation of liberty occurs (Eldergill, 2019; Steele et al., 2020).

10.4.2 Decision-Making in LTC

As seen in the findings, part of the rights discourse is related to an individual's decision-making capacity and who ultimately decides for the older person in LTC. Decisions are not only related to large life-changing decisions such as moving into the facility; they can be everyday micro choices such as 'what time I would like to get up at?', 'what do I want to do today?', or 'I want

to have a shower every day' (O'Neill et al., 2022). These everyday choices have been confirmed to be key to sustaining an overall sense of control over one's self-being (McCabe et al., 2021; Ryan & Deci, 2017). Another consequence of the staff's poor knowledge of human rights was their perception of decision-making. The study showed that although staff and family members described choice as part of the care of the older person, the residents' description was an adaptation to the institutional rules of the LTC facility and was not reflective of their own neutral choice. There is a recognised association between autonomy and decision-making; if there is a loss of autonomy, the older person in the LTC can also be left out of the decision-making process (Pocock et al., 2021; Wikström & Melin-Emilsson, 2014). The findings from this study concur, as autonomy appeared to be a difficult concept to grasp, and family members were unproblematically mentioned as proxy decision makers, particularly if any capacity issues were present. This demonstrates a fundamental challenge in the discourse on rights due to medical conditions (in this study, often dementia) as there is an implicit presumed decision-making issue. This contradicts ADMA (2015), which states that capacity is assumed unless proven otherwise. Consequently, everyday decisions are often made by staff and family members under the guise of protection, legitimised by assessment within normalising practices. In relation to decision-making, the staff participants, particularly nurses, normalised assessments such as MMSE and GDS as determinants in who is 'allowed' to make their own decisions. This represents a medical model for the assessment of cognition. Within the data, participants rarely referenced their own or the older person's decision making by applying a functional approach and how that process could be supported.

In this study, the terminology of 'compos mentis' was frequently used by nurses as part of the nursing gaze and legitimizing assessments. This may reflect the pre-problematisation of the issue of capacity inherent in the games of truth in public discourse and former (to the ADMA 2015) nurse education, policies, and professional development. 'Compos mentis' has been used frequently in the past within medicine to determine the ability to reason and decision making. However, although 'compos mentis' is mentioned by the nurse participants in this study, few were able to clearly outline how they would assess an older person within criteria for 'compos mentis'. Despite the nurses' clear lack of knowledge of decision-making capacity, they have a powerful position regarding how residents exercise their rights within the facility. The ADMA (2015), fully operational since April 2023, is clear about functional capacity and how healthcare professionals (or other professionals that may be involved) are responsible for explaining options in a way that is easily understood. However, few participants (including

staff and family members) had heard of ADMA (2015). While only operational since April 2023, the legislation has been in place since 2015 with a functional approach existing in legal domains since 2008 through the case of *Fitzpatrick v FK*. in which Judge Laffoy referred to functional capacity in the assessment of capacity.

10.4.3 The need for a specific charter/legislation for older people and their rights

Despite human rights principles underpinning standards and regulations (HIQA, 2016; 2019), the Code of Professional Conduct and Ethics for Registered Nurses (NMBI, 2021), principles of human rights in Irish legislation (Constitution and ECHR), and being part of the person-centred care approach (McCormack & McCance, 2017), there are still large gaps in how to recognise and support these to be operationalised in practice (Byrnes, 2020; Dixon et al., 2020; Emmer De Albuquerque et al., 2022; Newham et al., 2021). Lack of knowledge, as found in this study, about these policies and legal frameworks can result in various negative consequences. This may lead to substandard care as staff may not be aware of their legal and regulatory obligations to protect residents' rights and well-being (Fauziah et al., 2020; Phelan, 2015). Residents may face violations of their rights, including issues related to informed consent, freedom from abuse and neglect, and access to appropriate healthcare and services (Doron in Meenan et al., 2016; Emmer De Albuquerque Green, 2017). Additionally, the 'scandal' discourse discussed in Chapter Four does raise questions about what residents are protected from within the protection discourse.

Furthermore, when staff are unaware of legislation and conventions, it can be challenging for residents and their families to advocate their rights and seek redress when necessary. As seen in this study, staff's lack of knowledge also indicated a lack of advocacy and speaking up for residents' rights. Lack of knowledge may also lead to a culture of impunity, where abusive or neglectful behaviour goes unchecked because of a lack of understanding and accountability (Moilanen et al., 2022; Myhre et al., 2020). Although the CRPD (2007) is aimed at people with disabilities, it technically includes older people (Morrison-Dayana, 2023). This is particularly relevant for residents in LTCFs, as a functional or cognitive disability would have precipitated admission (Reilev et al., 2020). As this convention emphasises the importance of respecting the autonomy, dignity, and freedom of individuals with disabilities, it should also be fundamental to LTC.

As current knowledge regarding the human rights of older people in LTC is poor, it raises the question of whether further legislation or conventions are required to raise awareness, or if a different approach is required. Staff had not heard of the ADMA (2015), were not fully aware of any universal declaration of human rights, and were under the impression that the safeguarding policy was legislative. This reveals an insufficient comprehension of the existing legislation within LTC facilities, and highlights the necessity for extensive training and education regarding legislative matters. The lack of awareness and knowledge of human rights hinders the staff from providing some types of supports to older people, but also indicates a lack of belief in the possibility of changing current practices within LTC. Consequently, issues such as elder abuse in LTC facilities, inability to support older people in their autonomy, and ageist attitudes persist (Love & Lynch, 2018). Addressing this issue requires comprehensive staff training and education regarding the relevant legislation and conventions. LTC DoNs/leadership/providers should ensure that their staff are well versed in these legal frameworks and their practical implications. This knowledge is crucial for upholding the highest standards of care, protecting residents' rights, and ensuring that LTCFs serve as places of comfort, safety, and respect for older people (Newham et al., 2021).

10.5 The voice of older people

A clear finding from the genealogical analysis was that the older person in the LTC, due to the subject position, lacked voice. There is a link between having a voice and dignity, referring to being heard and recognised (Bayer et al., 2005). Older person losing their voice raises the question of who will act as their voice. Subsequently, the provision of voice to older people has been associated with advocacy (Field & Fenton, 2014; Williams et al., 2021). Advocacy refers to voicing on behalf of a person or group, and involves making arguments to achieve an outcome (Dixon et al., 2018). Advocacy is a way of providing support and maintaining autonomy, self-determination, and social inclusivity (Peisah et al., 2023). However, advocacy has been ad hoc, based on voluntary work or family involvement (Dixon et al., 2020). In this study, the advocacy role was seen to fall on family members who expressed that they were the voices of an older person in the LTC. Furthermore, family members were acknowledged by both the participating staff and family members as decision makers. No reference to self-advocacy or support for older people in decision making was made. Again, this contradicts nurses' narratives of person-centred approaches in care delivery.

Several different reviews, both in Ireland and internationally (often conducted by voluntary organisations) (Age Action, 2017; ENNHRI, 2017), have emphasised how the voice of an older person is linked to choice and control and, in turn, are important factors in self-determination and human rights (Age Cymoru, 2019; Sage advocacy, 2023a). These organisations have also called for robust and systematic independent advocacy services for older people. In Ireland, ADMA (2015) may assist in strengthening advocacy using a three-level decision-making framework. However, as it is still in its early operational stage, its practical impact as a tool for stronger advocacy and decision-making for older persons in LTC is not known. Interestingly, early legal comments by Judge O'Connor in the circuit court point to cases under ADMA (2015), demonstrating a lack of families' insight into conflicts of interest (Carolan, 2024) compared to the findings of this study on family members being advocates and decision makers. The call for more independent advocacy services has been followed by the establishment of an independent commissioner for older people in Ireland (Age Action, 2022; Alliance of Age Sector NGOs, 2024). In February 2024, the Alliance of Age Sector NGOs, which include a range of organisations such as the Irish Hospice Foundation and Third Age, made a call for an Independent Commissioner for Ageing and Older People. The argument for a commissioner was made because despite producing a range of policies for older people, there has been a lack of implementation. Northern Ireland and Wales have appointed an independent commissioner for older people and their main role is to safeguard older people's rights; a similar role has been asked for in Ireland (Age Action, 2022; COPNI, 2023; Gov. Wales, 2022).

10.5.1 The Role of staff in promoting rights of older people in LTC

As the context of the study was related to gerontological nursing, the role of staff in LTCFs in aiding and supporting older persons in exercising their rights is a considerable focus. Advocacy has always been a fundamental part of nursing, and nurses play a role in promoting equity in healthcare systems (Chiu et al., 2021). Staff, particularly nurses, have, through their positioning as experts in facilities a powerful role in disseminating the knowledge of rights of older people and are in a position to advocate for the residents (Hedman et al., 2019; Kim & Chang, 2023). However, as observed in this study, they are unaware of this role and lack key knowledge. Findings from the interviews did not seem to find a consensus in staff acting as advocates for residents. There seem to be a lack of alignment with the role of advocate from all participants, with family members questioning whether staff are the 'right' person to advocate for the resident. In other studies, despite the staff's powerful position, they encounter

several challenges if they are to act as advocates (Kim & Chang, 2023; Tomaschewski-Barlem et al., 2017). These challenges include nurses' working conditions, their professional role in relation to other healthcare professionals (often medical professionals), and the healthcare institution's lack of acknowledgement of nurses as advocates. Tomaschewski-Barlem et al. (2017) conducted a Foucauldian analysis of nurses advocating for their patients in Sao Paulo, Brazil. Although their study was conducted in the acute sector, they found that nurses advocated through open dialogue with patients. They also found challenges in doing so, such as a lack of knowledge and power structures within the healthcare organisation. The authors also noted that advocacy can have different meanings in different cultures. Tomaschewski-Barlem et al. (2017) concluded that it was the support and encouragement of the institution (hospital) that enabled the nurses to advocate for their patients. Advocacy may also require nurses to raise difficult and confronting arguments which they may avoid by fitting into a discourse of busyness and silence (Perron, 2023). As highlighted, silence was a significant feature in the interviews with staff. However, if a real change is to be achieved in the rights of older people in LTC, nurses must be aware of their role in promoting those rights. This may require questioning the epistemological underpinnings of the healthcare institution, as well as their own belief system that may have been conditioned by the training they have received.

Nurses have as part of the professional registration, not an obligation to respect the rights of a person but as Nurses and Midwives' code of conduct states; "Nurses and midwives advocate for patients' rights" (NMBI, 2021 p.13). This is a significant wording which highlights the role of nurses in supporting rights principles, and thus advocates for older persons. Healthcare assistants (HCAs) are also in a suitable situation to be advocates, as they create close relationships with residents and provide intimate private care (Delgado, 2019). None of the participants mentioned HCAs as potential advocates. Additionally, while nurses acquire advocacy terminology through their professional standards, there is a lack of similar standards for HCAs (Drennan et al., 2018). As building relationships is significant for older people in LTCFs to maintain autonomy and self-determination, HCAs are vital staff members that may be overlooked in this advocacy role. However, further investigation and training are required to establish the role of HCAs in advocacy.

For staff to act as advocates or to support residents in self-advocacy, there is a need for increased awareness and knowledge of HRBA within care delivery. The dilemma is when in the nursing training program is it appropriate to provide this knowledge. HRBA requires an introduction early in the training of future nurses (undergraduate and graduate) on how to

provide care under the principles of human rights. Moreover, there is a need to contextualise human rights as a key within person-centred care approaches and their operationalisation. Consequently, related language, frameworks, and legislation should be introduced at an early stage of nursing education at all levels, but also throughout their careers, as continuous practice development (Newham et al., 2021; Walshe et al., 2020). As highlighted in Section 10.2, the staff is a diverse group with training from outside Ireland. This indicates that, although education in human rights is fundamental in undergraduate training, there is a greater need for training programs for nurses already working in LTCFs for older people in Ireland (i.e. continuous professional development). Advocacy is vital for upholding the rights of older people and staff are in a crucial position to advocate by assisting the older person in finding their voice (Farrer et al., 2015).

10.6 Long-term care facilities and the institutional rules

The driver behind all the findings in this study is governance discourse which includes the governmentality and biopower present in LTCFs. Governmentality refers to the institutions, procedures, and knowledge legitimising and exercising the power of the government, institutions (LTC facilities), authorities (such as HIQA) as well as education institutions etc. Biopower refers to the exertion of (often conditioned by the taken-for-granted games of truth) control over the older person and is linked to the dependency position of the resident which renders the older person docile. As discussed in the section on othering, several examples were found in which the older person's passive subject position and the disciplinary power of staff further created docile bodies, which impacted the rights of older people. Other studies have referred to this as becoming an institutional body, which refers to an older person adapting and conforming to the institutional framework (O'Neill et al., 2022; Paternity, 2000; Villar et al., 2021; Wiersma & Dupuis, 2010). Governmentality in LTC facilities was observed through both archaeological and genealogical analyses of the regulations, policies, and guidelines dictating how these facilities are run. It included the rules that the institution imposes, some unwritten, that govern the behaviour and practices of both staff and residents. Hoff and Kuiper (2021), using FCDA, argued that governmentality and the nursing profession are not two separate entities; instead, nursing can be seen as a strategy of advanced governmentality, and nurses were an extension of the governmentality of the institution they worked in. These findings align with those of this study, where staff appeared to be an extension of the governmentality apparatus of LTCFs. By using disciplinary power, staff became the representation of institutional rules by focusing on the biopower control of the

residents in the discourse of protection. Decisions about treatment, choices, and care provided were made by staff, and staff nurses used assessments to normalise the practice.

In the interviews, residents expressed that they decided on what to do for the day, but through the contradicting descriptions from the staff, it was apparent that it was based on the routine of the facility. This was observed in the expression of the daily routine and surveillance techniques. Surveillance was performed in LTCFs in various formats throughout the study period. First, concerning space, the overall layout of the facility, and how it is planned or functions through surveillance (resembling a panopticon). Not only the sign-in sheet and the monitoring of me as an outsider visiting the facility, but surveillance includes technological surveillance in relation to CCTV, monitoring in and out going, and any alarms (e.g. alarms for high-risk falling residents, wrist alarms, or door alarms) that were visible in the facilities. Hence, the second form of surveillance is in the form of assessments, the clinical record of evidence-based assessment used as a form of surveillance of the residents in LTCFs (as previously discussed within the context of discourse-power knowledge within normalising practices).

These strict rules, motivated by protection and regulation, influence the human rights principles of older people in the LTC (Tuominen et al., 2016; Wikström & Melin Emilsson, 2014). Wikström and Melin Emilsson (2014) studied autonomy in Swedish LTC facilities for older people and found three themes regarding how residents experienced autonomy. The first theme was ambiguity regarding whether the LTC facility was a place to live in or a place to be cared for, which would further question the 'home' discourse in LTCFs. The second theme was the staff's power embedded in the organisation, and the third theme was an ageist approach to care, often seen through paternalistic practices (Wikström & Melin Emilsson, 2014). This concurs with the results of this study, as staff have disciplinary power over residents in their everyday lives. This included the surveillance and monitoring of residents to maintain a certain level of order, routine, and control within the facility. These techniques would align with the idea of panopticon and the microphysics of disciplinary power (Foucault, 1977). In these surveillance arguments, the defense of their application draws on concerns of residents needing surveillance, protection against abuse, risks, safety, and so on. However, these surveillance practices, which are inherent to the institution, are not questioned. These techniques demonstrate the range of practices in which older people have been surveyed (Mortenson et al., 2015). Additionally, Tuominen et al. (2016), in a Finnish study on free will in LTCFs, found that some participating residents felt like being in prison because of

supervision and security orders. Similarly, in this study, one participant mentioned the feeling of being in prison and watched.

The institutional rules found in this study through the FCDA align with the work and theory of institutions produced by Goffman (1961). Erwin Goffman (1922-1982), a sociologist in USA, and contemporary of Foucault, developed similar ideas of social construction, institution and resistance. Foucault acknowledged Goffman's work on institutions, indicating their merit in navigating their complex power relationships (Leib, 2017). Goffman (1961) proposed in his work *Total Institutions* that those living in institutions are subject to strict regulation and control, with little autonomy over their lives. The key characteristics of all institutions include a highly structured environment, rigid schedules, and imposition of authority by staff. Goffman's (1961) main focus was mental health institutions (similar to Foucault's work on madness), but he also applied the principles of total institutions to LTCFs for older people, prisons, and the military (Goffman, 1961; Marson & Powell, 2014). As shown in this study and aligning with findings related to the dehumanisation of the older person once admitted to LTC facilities, Goffman (1959, 1961) argued that those who move into institutions undergo a process of deindividuation, where their personal identities are subsumed by the institutional role. Goffman's work highlights what Foucault's theory suggested; that the institutional environment has a profound impact on individuals, emphasizing the need for understanding the social dynamics, power structures, and effects of institutionalization on those within these enclosed systems. This study corresponds with the theory of total institutions by Goffman (1961), who showed how the LTC facility has a comprehensive management of residents' daily activities, routines, and social interactions. In the facilities, staff exerted authority over various aspects of residents' lives, including their schedule, environment, and even personal decisions.

10.6.1 Resistance

The institutional rules described above may engender resistance strategies (Foucault, 1977). Older people in LTCFs may have limited ways of resisting the rules of the institution due to various reasons, such as frailty, compliance with routine, their medical condition(s), and the positioning of the older person in an LTC facility. The literature shows that older people may demonstrate resistance on admission through depression and anxiety, as they perceive that they are losing control of their lives (Bom et al., 2022). This study identified several examples of resistance, but these were not frequently described. For instance, an 'escape' attempt was recounted by one resident and family members mentioned complaints and using their voices

to advocate for the older person, which can be seen as resistance to current practices and policies. However, not all family members spoke about complaints, and residents said they did know who to complain to; thus, they did not use this avenue, once again positioning with the institutional rules of not causing a problem and accepting the status quo. Resistance can be seen in micro actions that may not be considered an act of resistance; for example, resistance may be observed in older persons' refusal of treatment, such as nutrition or medication (Featherstone et al., 2019). However, this is often labelled as part of the medicalised view of symptom progression, rationalising the use of (often medical) treatment. In the interviews, one family member brought up this type of situation and spoke about her father's refusal to eat, and whether that would be a way to control their agency. Notably, no staff member spoke about an older person refusing treatment or making a connection to rights in refusal.

There is a range of modes of resistance, yet these warrant recognition not only from staff but also from LTC systems. Resistance modes, such as residents refusing to accept the passive roles imposed on them. This resistance can manifest in the form of vocal residents in resident committees who challenge the dynamics within the LTC facility (Ettlinger, 2017; Novek et al., 2022). The current model of care is then challenged by acknowledging resistance as an instinctive response to power structures within LTC facilities. This area requires further investigation, as it is significant if human rights are to be upheld in everyday micro choices (Novek et al., 2022). Few empirical studies have been conducted on resistance in LTCFs for older adults. What may influence increasing resistance in facilities is the introduction of independent advocacy, education of both residents and staff and providing older people with information about their rights. If strengthened, staff advocacy could be considered a suitable method of resistance. This requires the LTC sector to be open to implementing systematic changes.

10.7 COVID-19 pandemic-a magnifying glass on human rights of older people in LTC

COVID-19 was a catalyst to legitimize public health restrictions and brought attention to the human rights of older people in LTCFs, not just in Ireland, but across the world (Anand et al., 2022; Kelleher & Twomey, 2022; WHO, 2020). As demonstrated in this study, access to LTCFs to recruit participants was limited which exemplified the isolation of older people during the COVID-19 pandemic. The COVID-19 pandemic has led to increased isolation due to visitor restrictions and quarantine measures due to the public health discourse of keeping older

persons 'safe' (Voinea et al., 2022; Williams, 2021). Othering was further deepened in relation to LTC residents, and their position was even further marginalised during COVID-19. This was partly due to the protection discourse of older people in LTC, with frailty and vulnerability considered a high-risk group for adverse effects of COVID-19 infection (D'Cruz & Banerjee 2020; WHO 2020). Physical and social isolation were implemented for a significant period for older persons in LTC, with family members feeling excluded from the care provision as they were not allowed to visit (Giebel et al., 2022). This study found that visiting restrictions had an emotional impact on both residents and family members, with staff acknowledging that the lack of interaction with family members caused deterioration in older persons and that family members were missing out of being part of the care provision. Similar results have been reported in other Irish studies (Connolly et al., 2022; Cornally et al., 2022). The visiting restriction in the LTC facility was met with resistance mainly from family members, both in Ireland and internationally (Kemp, 2021), but protection discourses still prevailed, and the ban was in place for a long time. By 2021, some countries allowed a family member or friend to be nominated as a person who could visit. In Ireland, by 2021, visitors were allowed to nominate one family member and allocate visits to gardens or pods (HSPC, 2021); however, this was limited in relation to numbers, time, and social distancing.

This governmentality and its biopower of limiting access to the community outside the facility strengthen and further legitimise the discourse on protection (Colombo, 2021). The COVID-19 pandemic has had contrasting consequences in several countries. On one hand, it underscores the significance of safeguarding human rights, including the right to healthcare, non-discrimination, and privacy protection (Ayalon et al., 2021; Bilková, 2023). Conversely, owing to the gravity of the public health crisis, limitations on human rights have been imposed in the interest of public health. The primary objectives were to mitigate the spread of the pandemic, alleviate strain on healthcare systems, and foster robust community protection against COVID-19 (Thompson et al., 2020). Undoubtedly, there were risks for the older person, and particularly in the early stage of COVID-19, it was difficult to plan any public health response due to the unknown nature of COVID-19.

The separation of LTC in the planning and management of COVID-19 was experienced by the staff participants in the study. Staff in LTCFs felt that, compared to healthcare professionals in the acute sector, they were blamed for poor practices resulting in rising mortality and morbidity rates or considered at a lower rank in terms of care competence, other studies have confirmed similar results (Connolly et al., 2022; Phelan et al., 2022; Sarabia-

Cobo et al., 2021). There are reports of increased staff burnout in LTC since COVID-19, resulting in staff intention to leave their profession and challenges in recruiting staff (Conolly et al., 2022; Phelan et al., 2022; Sarabia-Cobo et al., 2021). This study did not probe staff's intention to leave as part of the COVID-19 pandemic, nor did it aim to capture the experiences of staff during COVID-19. Nevertheless, the staff in the interviews, their tone of voice, and their demeanour appeared tired and demotivated. As part of the LTC organisation and its rules, staff were given even more disciplinary power to survey older people through legitimised public health restrictions. One way to cope is to further dehumanise the older person, revert to task-based care, and reducing the older person's personhood (Testoni et al., 2022), further limiting the citizenship of the older person.

On a broader scale, governmental measures implemented in response to COVID-19, which were predominantly ageist in nature, have been criticised for their inadequate consideration of older individuals residing in LTCFs. Prior to COVID-19, LTCFs were already dealing with negative stereotypes, and as evidenced in this study, the loss of autonomy, choice, and control was real for residents in LTC facilities. COVID-19 was a significant event for a large part of the population to notice how the older people in LTC are treated; however, in formal government responses, it was noted that the sector was represented in sub-committees related to planning despite COVID-19's disproportionate impact on the setting. COVID-19 pandemic impact on LTC facilities as the rapid spread of infection and increased morbidity was another 'scandal' that showed how fractured the sector was, rooted in systematic ageism and attitudes about older people (Anand et al., 2022; D' Cruz & Banerjee, 2020). Ireland is not alone in having a fragmented LTC sector; other countries such as the United Kingdom and Canada have dealt with similar problems (Phelan et al., 2022). However, Estabrooks et al. (2021) argued that these are, despite complexities, solvable problems by revising approaches in LTC and creating multiple choices for older people related to their care needs.

In response, new forms of advocacy and activism for older individuals' human rights have emerged (Emmer De Albuquerque et al., 2022). These efforts include calls for inquiries into situations that arose when older people were unable to access resources and interventions or were abandoned. Such inquiries have already commenced in Scotland and England (Finch & Tinson, 2022; McKay et al., 2022), and there is an intention to conduct an inquiry in Ireland in 2024 (Irish Times, 2023; Bray, 2024), with reports of LTCFs having to hand over pandemic files (Fagan, 2024). As this study has illustrated, to ensure the strengthening of the human rights of older individuals in LTC, a multifaceted approach is necessary that may extend

beyond the scope of an inquiry. The primary objective of a COVID-19 inquiry should be to learn lessons and enhance responsiveness in future pandemics.

In Chapter Four, under the archaeological analysis of LTC, Kelleher and Twomey's (2020) report in COVID-19 management in LTC facilities for older people in Ireland was presented. The report highlighted numerous systemic gaps in the care of older individuals and in LTC in Ireland. Although Kelleher and Twomey's (2020) expert report is not specifically related to the human rights of older people, this study has shown that governance and its power within the LTC system are significant and have a contingent impact on residents' rights. The governance discourse shows how governmentality operates within the sector, and how the system enables governmentality and biopower to operate. From this perspective, the report and its progress are relevant to determine how the rights of older people are protected. The fourth and final progress report was published in July 2022, with an update on over 80 recommendations (DoH, 2022). Some key actions have been implemented and several recommendations have been made. For example, all healthcare professionals, including those working in private settings, were given access to HSEland, a public health service training site with online modules. Other recommendations, such as financial oversight and access to community resources, seem to be ongoing but with no completion in sight. It is crucial to question why all these recommendations have not been prioritised. A potential inquiry may be seen as a form of resistance to the current power structures in the Irish LTC sector. However, as this research has shown, the inquiry needs to include the voices of the older person in LTC to capture representative inclusivity. COVID-19 revealed macro- and meso-level inequalities in the LTC sector, which had a detrimental impact on the micro-level care delivery and care context. This study has shown that in relation to the human rights of older people in LTC facilities, the COVID-19 pandemic did not aid in the progress of upholding human rights, yet it has magnified and brought concerns to the fore and has been a catalyst and potential driver for systematic change that may improve the human rights of older people in LTC (Anand et al., 2022; Hardwick et al., 2022; Pesiah et al., 2023).

10.8 Reflexivity & My Fractured subjectivities

This section considered how I used reflexivity in the conduct of the study. This reflexive stance provides disclosures how certain decisions or conclusions have come to be in the conduct of the study. As Olmos-Vega et al. (2023) explain, reflexivity is a qualitative researcher's description of how interpersonal, methodological, and contextual factors impact the research

conducted. Those fractured subjectivities, meaning both my personal and professional characteristics are part of the research process. In times of uncertainty, such as the COVID-19 pandemic, reflexivity has become even more important. The pressure to complete a study during the pandemic could compromise the research process, and the steps taken may be affected by that pressure (Bramstedt, 2020; Mourad et al., 2020). Reflexivity provides transparency during the process and early on in this thesis, I clarified the importance of reflexivity. Reflexivity and its importance have become the key to not only my study but also my own development as a researcher. Attia and Edge (2017) refer to this process as becoming; by adapting to interactive learning through reflexivity one becomes a researcher. This aligns with my own use of reflexivity and the PhD journey has been a process of learning competencies, standards, techniques, and skills to become a researcher with certain levels of knowledge and ethical values. Arksey and Knight (1999) advised researchers of the multiple challenges in conducting research, a common advice given at the beginning of the PhD journey that the PhD study would not necessarily go as planned or to plan for the unknown. Nevertheless, I do not believe I could have imagined or even planned how COVID-19 would affect my PhD journey. Not only has it affected the area of study but also the professional and personal level of being a qualified gerontological nurse working in LTC, it has been one of the most stressful times in my nursing career.

10.8.1 Conducting a study

Early in the study process, some conscious bias decisions were taken by me as part of my own experience as gerontological nurse working in the LTC sector. One of those first decisions was not to use the term 'nursing home' in the thesis as I find the term has a negative association. Also, from my own linguistic point of view, the term nursing home is deceiving; the facilities I have worked in are not purely nursing care nor is it a 'home' (as we understand home in the community) for the resident. It also became clear early on for me that for the study to be significant, it needed to include the older people (residents) in the study. This was discussed during the various stages of the study supervision and the decision did bring challenges such as access, recruitment and consent into the forefront. However, a study determining the discursive positioning of human rights of older people would not have been a complete study if the voices of older people were excluded. Also, due to my own experiences of LTCFs, I made the conscious decision of not including DoNs or nurse managers as participants in the study. Their role in the study was to provide access and assist in the recruitment of participants. In many ways, this role has highlighted the power position they are

in as without the permission of DoNs, I would not have been able to conduct the study. Excluding other staff such as administrators, kitchen staff or support staff, was a pragmatic choice and the focus was on staff that provided direct care to the residents and thus, supported or constrained their exercise of rights.

While conducting the interviews, I was struck by the importance of ending the interview in a way that provided closure for both me and the participant, as well as not spending too long with the participant due to the risk of COVID-19 transmission. Staff participants were more aware of time from a work perspective and seemed to be concerned at times to return to their clinical work. This is one of the reasons why interviews with staff would have benefited from being outside of the workplace. However, conducting interviews in the workplace was convenient and provided a context that was vital for understanding discursive positioning. My reflection notes after conducting one of the first interview with a resident on 13/12/2021, expressed my uncertainty.

It is busy around the place. Is there a Christmas party going on? I'm nervous, but I do feel prepared. I don't know what to expect but trying to be positive that something will come out of this. (Journal note, 13th of December 2021)

Conducting interviews in person includes a focus on body language and the setup of the various aspects of the interview. In times of COVID-19, some aspects of communication could be limited; for example, the need for physical distancing and facemasks. The interaction was recommended to be 15 minutes but most of the interviews lasted longer than 20 minutes. LTCFs were understanding of this public health measure, although the additional 5 minutes was permitted; this limitation was eased in the early part of 2022. Ethical dilemmas around COVID-19 impacted the research progress. The following is a reflection note from January 2022 regarding facility two, which ended up having a lengthy COVID-19 outbreak. The commitment to conduct the study is one commitment, but in the times of COVID-19, I was also obligated to comply with the protection discourse, which is constructed to keep older people safe from infection. This led to ethical perspectives in my reflections and illustrates (as described in chapter Six), the dynamic impact reflection provided in my own research progress.

Another antigen test done, negative. Emailed the DoN to confirm that interviews can be held. She said there was one area of the nursing home affected by COVID-19 outbreak. But it was up to me to come

in. I do not think it is suitable to go at this time, but will I get delayed? Also, due to go into another site soon, may not be fair to attend here first and then another site with the possibility of transmission. Very hard to make the call but need to think of the residents and potential risks, even for me. (Journal note, 27th of January 2022)

Once I was given access to the LTCFs and started recruiting and interviewing, I got caught in a sprint. I needed to remind myself of the importance of reflection as I felt it was a race to complete the interviews. In particular, as one facility's access was limited due to the COVID-19 outbreak, I was under constant fear of the same occurring in other facilities. There was no framework or guidance on how to conduct interviews in a LTC facility during a pandemic with public health regulations, and there was a need to adapt as much as possible. For example, I could see the faces of the residents as they did not need to use a face mask (one resident did), but they could not see my full facial expression. Staff were obligated to wear facemasks at the time of the interviews. This means that some of the communication nuances may have been lost. This is something that I considered in data analysis. Using reflexivity to go through the interviews, many similar ethical dilemmas needed to be reflected on.

10.8.2 From nurse to a novice researcher- and all the roles in between

In my process of becoming a researcher, reflection around my position as a nurse, woman, non-Irish, and student have all been part of that reflexivity; these roles have each come with their own fractured subjectivities and provide me with a power position. As a qualified gerontological nurse, I needed to step out of the nurse's role and remind myself of my position was as a researcher, particularly during social distancing restrictions. For example, one participant looked uncomfortable in their chair and adjusted the pillow they had, but I could not help them as I was to keep my distance. It was challenging but also part of the ethical thinking of 'why am I there?', and completing the interviews needed to be my focus. Also, there was always the risk of contracting COVID-19 myself, so this was also a fear I held. After avoiding COVID-19 infection until June 2022, it then drastically knocked me back. I got the infection at the time of data collection and transcribing. Consequently, a large part of summer 2022 was disrupted and could have been a factor in recruitment of family members. Although the initial recovery was quick, the fatigue caused disruptions in both the PhD journey and my overall professional progression. From June 2022 onwards, testing positive for COVID-19 caused a downward spiral in my personal health that was also marked by back problems and eventually a small procedure to assist with the pain in March 2023. By this stage, data

collection and transcription were mostly performed, but the overwhelming task of data analysis was a mountain to climb. However, slow consistent progress was made.

Throughout the PhD programme, which is self-funded, I have continued to work as a staff nurse in an LTC facility completing at least one shift a week, providing care in units of 17 to 22 residents together with HCAs. The facility is privately owned with a significant bed size (over 115 beds), and I was part of providing care during the COVID-19 pandemic. This professional clinical role is important throughout this PhD journey as it has provided me with more insights into the staff perspective. This may have impacted the analysis although I have been aware of this bias. In addition, I have often reflected on how my clinical practice fits into human rights-based care and concluded that it does not always fit. Even though I try to keep human rights-based principles such as FREDIA in mind, I am also conditioned by the institution within which I work and subject to the discourses. I have observed (and in some way been part of it as well) how non-person-centered language has been used in LTCFs, like referring to residents as 'doubles' (needing assistance of 2 people) and derogative remarks such as 'she/he would not know, they have dementia' in front of the resident. Similarly, paternalistic practices were experienced; for example, where I as a nurse asked a resident a question, but this was answered by a staff member, preventing the resident's answer.

As an experienced staff nurse, I observed how the practice changed during the COVID-19 pandemic. I witnessed how care became routine and task based, focusing mostly on infection prevention control. Staff detached themselves from the stress of COVID-19 and even further de-humanised the older person in need of care, which concurred with the findings from data. Also, I will always remember the resident living with dementia who screamed when I, dressed in full PPE, came into their room to provide care. COVID-19 changed practices further and in my own reflection, the progress made in PCC was quickly overturned with routine work, basic care and detachment from the person in need of the care.

I felt that my own advocacy role has been limited or weak, leading to a questioning of my own clinical practice in a system that does not seem to empower nurse advocacy. I have attempted to advocate for residents, yet have met with resistance or simple answers such as 'it is for their own good', even at managerial level. Throughout the PhD journey both in research and clinical work, including during COVID-19, the older person's voice was seldom heard. If there was any resistance from the residents, it was through responsive behaviours, their resistance through attempts to refuse medication, food, or personal care. Through this study, I appreciate

how ageing is complex and how the majority of us are tacitly ageist. My own view of older people and the study of ageing has changed. I would have had ageist attitudes, and I would also have 'best interest' discourse in my role as a nurse. However, this study has opened my awareness of my own ageist bias and how it affects my role as a nurse.

There is a need for a significant cultural shift on all levels in LTCFs to change the ageist, paternalistic and rights reduced practices that occur daily. Awareness of the powerful position staff have over older people in LTC requires regular discussion and training. All these reflection points have prompted me to reflect on where change is required, how to change, and what change would the older person want? There are no easy answers, as the findings of this study have suggested, they are complex, intertwined questions that require multi-level solutions. Nonetheless, as gerontological nurse and novice researcher, I do believe there are solutions and we must listen to older people when they voice (even if it is only a scream) their wishes, preferences, needs and feelings. After all, human rights begin in those 'small places close to home'.

10.9 Conclusion

This chapter discusses the findings from archaeological and genealogical analysis in comparison to the current literature, and the progress made both internationally and in Ireland in relation to the human rights of older people in LTC. Because similar empirical evidence is limited to the LTC context, further studies are important. Using FCDA as a methodology was efficient in exploring the hidden truths that exist in the discourse. As other researchers within discourse and post-structuralism point out, meaning is found in silences, contradictions, and hesitations. Discussion and comparison with other studies highlight how older persons' subject positions in LTCFs impact their ability to exercise human rights. Older people in LTC by their position as 'other' have become a marginalised group that has lost their voice. Not only have older people lost their voice, but due to significant ageist culture, they have internalised their own position as irrelevant and docile. In this othering, the advocacy and support offered seemed to align with the family members. However, advocacy and support often enforce ageism through othering and paternalistic practices. Staff play, unknowingly, an influential role in shaping the discourse surrounding the human rights of older people in the LTC. Through their daily interactions and decision-making processes, staff wield disciplinary power and are an extension of the governmentality apparatus of LTC institutions. However, similar to other studies cited in this chapter, staff lack vital knowledge of human rights, and

such knowledge does not seem to be a priority. In many of the studies compared to in the discussion, staff are the gatekeepers of information, enforcers of regulations, and those who set the tone for the environment within LTCFs and therefore in excellent position as advocates. Their attitudes, beliefs, and practices significantly influenced the lived experiences of the residents and their ability to exercise their rights. Staffs' power to control and shape the discourse surrounding human rights is a testament to the Foucauldian idea that power is not merely repressive but productive. Understanding the power dynamics at play in an LTC is crucial for both knowledge production and advocacy. This discussion underscores the need for a more inclusive and holistic approach to empower all stakeholders involved, particularly older people. Ensuring that their voices are not only heard but also integrated into decision-making processes is essential for creating a more just and rights-based LTC environment. Chapter Eleven concludes this thesis by providing strength and limitations as well as recommendations.

CHAPTER ELEVEN

Conclusions

11.1 Introduction

From the onset, this study aimed to examine the discursive positioning of older people's rights in the LTC in Ireland. By introducing the Foucauldian perspective early on in Chapter Two, this thesis sheds light on the significance of applying critical discourse analysis to unravel the subtle mechanisms that govern and regulate the human rights of older people in the specific context of LTC. This study is unique in its examination on how language matters, and shows through language (and lack of language) how the rights of older people in the LTC are upheld or restricted. As Chapters Three to Five unfolded, the archaeological analysis of literature navigated the complexities of language in statements, offering a critical lens to understand how discourse contributes to the construction, negotiation, and contestation of human rights in LTCFs. This revealed an often overlooked older person in LTC as the subject to ageist policies (discrimination). Despite human rights principles being embedded in conventions, legislation, and policies, archaeological analysis revealed that these principles seldom reach practices related to the older person who is dependent on formal care.

With the detailed steps outlined in Chapter Six of the methodology, the genealogical analysis delved into power relations, language, and societal norms shaping the human rights landscape for residents in LTCFs, providing an argument for the use of the FCDA to critically examine the topic. Rigour was achieved by detailing the steps in data analysis and being trustworthy in the process. Despite the challenges of access to LTCFs and subsequent recruitment barriers, the methodological steps provided the analysis with rich amount of data. The large amount of data generated from interviews with residents, family members, and staff exposed the nuanced interplay between institutional practices, policies, and the lived experiences of older people. These findings, presented in Chapter Seven to nine, present the complex power-knowledge nexus. Genealogical aligned with archaeological analysis revealed large gaps in knowledge, strong institutional practices, and a lack of HRBA in LTC settings.

Chapter Nine presented the three dominant discourses on the rights of older people in LTC: protection, conditional rights, and governance, which reveals a complex interlinked system in place in relation to the rights of older people in LTC. These discourses are driven by deep-rooted ageism and paternalistic practices that have left the older person a docile body and

accept that human rights are not applied equally to them. These findings were meticulously dissected, contextualised, and synthesised in Chapter Ten of the discussion section. Despite the lack of similar empirical evidence, theories such as othering, stereotype embodiment theory (Levy, 2009), and Goffman's (1961) theory of total institutions confirm that the older person is in a position of other, excluded from decision-making, and in the power apparatus of governmentality and biopower. There are very few opportunities for older person to resist these power dynamics, illustrating the strong institutional rules that are present.

A critical consideration of COVID-19 has been part of the process of this PhD, not necessarily highlighting any new discourse formations, but spotlighting how the human rights of older people in LTC are not a priority and how ageist policy planning is, making it difficult for older residents in facilities to exercise their fundamental rights. This final chapter concludes the thesis by outlining the strengths and limitations of the study, providing recommendations based on the findings, and presenting some final remarks.

11.2 Strengths and Limitations

Similar to any previous research, this study has both strengths and limitations. The primary strength of qualitative research is its ability to capture in depth the intricate nuances of human experience. In this study, the researcher was able to delve into various perspectives pertaining to the human rights of older people. However, this study also has some limitations and the subsequent section outlines the initially strengths, followed by limitations.

11.2.1 Strengths

- The key strengths of this study are its uniqueness and approach. By critically examining discourse positioning, this research can question the system and raise those vital subsequent questions of why, how, and what? This in-depth analysis aligns well with the research aim and demonstrates the complexity of the topic. The uniqueness extends, as is currently known, to the fact that there are no similar studies on the human rights of older people in LTCFs in Ireland and few international studies (Lloyd-Sherlock et al., 2019; Emmer De Albuquerque Green, 2020).
- An additional strength lies in the inclusion of older people (residents) in this study. The inclusion of older people and, subsequently, staff and family members provided insight into the relationships within the LTC system. By including all three participant groups, the study was able to identify the deep meaning of the rights of older people in LTC, and the formation of discourse was detailed.

- The open-ended nature of detailed semi-structured interviews with the three participant groups allowed for a deep exploration of individual narratives, capturing the richness and diversity of perspectives on discourse formation. Through these detailed interviews, the researcher revealed nuanced details about residents' human rights, daily lives, preferences, and challenges, thereby providing a holistic understanding that quantitative would have limited. Additionally, qualitative interviews foster a trusting and empathetic environment, enabling participants to share personal stories comfortably.

11.2.2 Limitations

This study had several limitations that should be considered. The research approach, recruitment methods, urban location, and sample of participants all contributed to the constraint of whether the study's findings could be generalised to settings other than those examined in the study. Additionally, the prevalence of female voices in the results presents another limitation to the study's transferability.

- As a gerontological nurse, researcher, and female, my own unconscious and conscious bias may have guided the study to fit the narrative that I possess. I tried to be transparent in my rationale for the research process and the decisions made in the steps of conducting the analysis. However, my role in the research process, from the topic chosen for analysis, generates limitations for the study.
- This study did not include any diagnoses. All participants, including the older people in the LTCFs, were required to have the capacity to consent to participate in the study. Some guidance from the DoNs was required to determine who initially had the potential capacity to consent to the study. Further research should incorporate those residents who have a specific dementia diagnosis, as previous research has continuously reported a high incidence rate of dementia diagnosis among residents in LTCFs.
- This study was limited to older people in LTCFs. Although it is the main source of formal LTC in Ireland, it is not the only one. The study did not include older people receiving LTC at home or in any other clinical facility, such as an acute care environment, specific palliative care, or rehabilitation facilities.
- The DoN at each facility acted as a form of gatekeeper by providing access to the LTC facility. DoNs that provided access to LTCFs would have some investment in presenting a relatively positive view of the facility. This may have biased highlighting

the study to the staff that aligned with that view. There may have been bias in the DoN and, subsequently, the appointed gatekeeper, often an administrator, for the recruitment of participants, having some insight into who is participating. It is possible that they targeted the most suitable participants, thereby masking potential problems (although there is no specific evidence of this). It was not the researcher's opinion that this was the case; nevertheless, this cannot be ruled out. In contrast, participants appeared to be genuine and candid, particularly residents and family members, during their interviews, which supports the findings.

- The participants were from LTCFs in the greater Dublin Urban area; thus, the results reflect facilities in one large city (Dublin) and should not be extended to other cities, countries, or contexts other than LTCFs. Yet, due to the achievement of saturation and good representation of facilities, this study can provide significant insight into the rights of older people in LTCFs in Ireland, and may be used as part of discussions on how to improve the rights of older people in this setting, both in Ireland and internationally. This is particularly important in the context of the full implementation of ADMA (2015).
- All family members were white females and appeared to have middle-class backgrounds (not asked specifically) based on opportunistic self-disclosure of their profession. They were all highly involved in caring for their family members (LTC residents). These characteristics reflected the Irish female discourse on LTC, ageing, and human rights; however, it does limit the conclusion of whether other family members would have had different discourses. Family members from other genders and racial, cultural, and socioeconomic backgrounds might generate different or even conflicting discourses, as older people, care provision, and human rights may be viewed or experienced differently.
- Due to staff interviews being held in the LTC facility, staff may have been constrained in their descriptions. As mentioned previously in the thesis, ideally, staff interviews would have been held outside of the LTC facility; however, this was not practical, as staff were not in position to meet outside of the facility and in any event, appeared to prefer the convenience.
- Due to restrictions on family members visiting the LTC facility, the recruitment of family members was slow and required a different approach, leading to the addition of a focus group. The focus group can provide social bias, meaning that the group will agree on a point collectively by not disagreeing with the statement. However, for this study, the

focus group provided confirmation of the data derived from individual interviews with family members.

Despite these limitations, this study contributes essential evidence to the rights of older people in LTC and highlights the enormous gap between policy, standards, legislation, and practice. Knowledge of the human rights of older people is fragmented and requires further action, not only research, but also measures from a micro-, meso-, and macro-level perspective. Some of these recommendations are presented in the next section.

11.3 Recommendations

Recommendations are based on the two-stage analysis of this study and findings that have highlighted the complexities in the context of the human rights of older people in LTC in Ireland. The intention of the recommendations is to bridge the apparent gap between human rights principles and the practical implementation of these principles in the context of older people in LTCFs. They are also driven by the goal of improving opportunities for older people to exercise their human rights in LTCFs in Ireland. The recommendations are summarised in three sub-headings: first, an increase in knowledge through education and training. The second recommendation is the recommendation of inclusion, and the last recommendation is related to legislation, policies, and standards. These recommendations are also arguments to implications for further research in section 11.3.4.

11.3.1 Education and Training in the area of human rights of older people

One of the key findings was the lack of knowledge and awareness in the subject; thus, the first recommendation is to increase the level of knowledge through education and training. This study highlights the strong need for education and awareness campaigns to challenge negative stereotypes and promote a more inclusive understanding of older people's rights. Training and education on the human rights of older people for staff require the topic to be introduced at an early stage of education. For nurses, this needs to be at the undergraduate level and can be integrated into a person-centred theory curriculum delivery. Additionally, the issue of human rights and person-centredness needs to be threaded into and connected to modules on care planning, ethics, and law (including the implications and responsibilities under the ADMA (2015) at both undergraduate and postgraduate levels.

Equally, as the findings of this study identified human rights gaps, rights need to be understood and ingrained in service delivery cultures for all staff in LTCFs. This indicates that

training and education must continue in the services (in this case, LTCFs) used by older people. Furthermore, different training modes must be used. For example, HSEland has produced online modules on topics, such as HRBA and ADMA (2015). Additionally, HIQA (2021) launched an online module for staff working in health and social care services for the application of HRBA to care. Outside Ireland, the Scottish Human Rights Commission (2018) has launched comprehensive training materials for organisations and has created an Equality and Human Rights Impact Assessment to use in any policy and procedure planning to ensure practices align with human rights. While online training modules with the theoretical aim of explaining human rights are beneficial, this study has shown the complexity of this topic. Therefore, continuous professional development on this topic requires robust and structural problem-solving discussion training for staff in LTCFs, including both staff nurses and HCAs. In light of this, the additional integration of a practical case study approach would be more beneficial, where those attending could find solutions by applying a human rights-based framework and the principles of ADMA (2015). By combining educational approaches, there is an additional benefit of reflecting on current practices, which could subsequently result in staff being aware of their power position and, consequently, may be in a position to generate change and understand the myriad complexities in everyday care delivery.

Furthermore, increasing awareness of ageism, not only for staff but also in general, is required through targeted interventions. Education, training, and awareness campaigns all are strategies that can provide societal change. Because the finding of ageism in LTCFs reflects societal systemic ageism, raising awareness should be a priority. Raising awareness would require training and campaigns against ageism at every level (micro, meso, and macro levels) and maintaining an open discussion about power dynamics in the LTC sector.

11.3.2 Inclusion of older people and long-term care facilities

Based on the strong finding of othering, the second-theme recommendation stems from the principle of inclusion. The inclusion of older people and their voice needs to be improved, as well as the inclusion of LTCFs in the overall healthcare structures and research. This aligns with the strengthening of advocacy structures. As observed in this study, older people's lost voices require support to be empowered or supported via a proxy. This voice of a proxy is currently provided by family members, yet it should extend to staff at every level, as well as to independent advocates. Advocacy by staff for older people could be a significant enabler for older people's rights and requires organisations to acknowledge and support this advocacy

role for staff. However, both staff and families have subjectivities which may impact the support of older residents. Therefore, as advocated by Sage Advocacy and Safeguarding Ireland (2018), legislative rights to access an independent advocate are key aspects of articulating rights. Nurse advocacy should be strengthened to align with professional standards, which may require a review of how advocacy is contextualised within the nursing profession, both in Ireland and internationally.

The inclusion of older people also implies that there is a need to improve their involvement in research and quality improvement projects. When conducting the archaeological analysis of LTC in Ireland, comparable data between private, public, and voluntary settings were lacking. Overall, validated independent data are lacking for the LTC sector. One recommendation is to strengthen data collection from LTC settings to make comparisons and improvements in relation to rights. This aligns with the further integration of the LTC sector. HIQA (2016) publish individual inspection reports, which are publicly available on their website; however, independent cross-sectional studies in the sector are lacking. Further data collection may provide insights and aid in decision-making in HRBA.

11.3.3 Legislation, policies and standards

The final recommendations emerging from the findings relate to how the human rights of older people in LTC can be strengthened or upheld in a much more systematic way. This recommendation is not only in relation to legislation, but also the policy, procedures, standards, and attempts to bridge the gap between the theory and practical application of human rights. The progress of the human rights of older people in LTC depends on the changing cultures which are underpinned by legislative imperatives. It should be noted that even if legislation is implemented, cultural changes and the jettison of 'old' practices require sustained effort and may take time to change, hence institutional rules persist. However, the current process seems tardy, as the ADMA (2015) took eight years to be operational, and Ireland's ratification of the Convention on the Rights of Persons with Disability did not occur until 2018. Although ADMA (2015) is a landmark in human rights advances in Ireland, there continues to be a delay in legislation that may further consolidate the human rights of older people. Legislation, such as that of adults at risk in the context of safeguarding and deprivation of liberty legislation, has remained stagnant. Legislation also needs to align closely with advocacy, thus creating structural systems for older people to be heard.

The findings suggest that LTCFs are immersed in risk-based policy-driven discourse. Traditionally, such policies were founded on protectionism which can result in paternalism. Such approaches are not person-centred, but rather support an outcome approach to capacity, where decisions are made by another person based on risk, subsequently impacting rights bearers, such as older residents. All policies, procedures, and standards should be reviewed and integrated in compliance with the principles of the human rights framework. Some of this work has begun but requires further review and implementation at all levels. This requires questioning whether a policy or procedure is ageist and/or paternalistic in nature and whether the voice of the older person is included in the development of the policy. In policy development, training, and approaches to care, human rights-based approach (HRBA) frameworks may assist in care delivery and align an organisation's ethos with human rights principles. As human rights principles are closely linked with the principles of person-centred care, a HRBA would strengthen both human rights in LTC and person-centred care.

11.3.4 Implications for further research

There is no doubt that further studies are required on the topic of older people residing in LTC and their human rights, and these studies need to include the experiences of the chief stakeholders and older people themselves. Further studies should include those with dementia diagnoses and capture their human rights' experiences, as this group is significant in LTCFs (Begley et al., 2023). Research that includes older people should also capture diverse backgrounds such as immigrants or older people from the LBGTQIA+ community. Such studies of intersectionality can capture the human rights of older people that are not only marginalised due to age but are further marginalised due to race, gender, background, or sexual orientation.

Further longitudinal studies are necessary to track changes in discourses over time and cross-cultural comparisons to assess variations in discourses related to older people's rights. While the current study applied a qualitative approach, mixed-method research approaches enable multiple dimensions to be compared with similar studies within and outside Ireland. A key to any future study is to capture what older people want and explore human rights further to enable a deeper, more comprehensive picture of the topic (Wasti et al., 2022). This needs to include what kind of information and knowledge would older people want and need to know as the right bearers of human rights who reside in LTCFs. As the literature related to empirical studies on the human rights of older people in LTCFs is limited, it is imperative to conduct studies of various sizes and paradigms, and to capture the voice of older people to consolidate

understanding. Capturing the voices of older persons is significant, yet studies from multiple perspectives are needed, such as family and staff perspectives. Also, macro perspective of societal perspective is key, including authorities such as HIQA to include the regulating perspective. Additionally, exploring rights of older people in a range of settings such as community, acute care and any other healthcare setting would provide a comprehensive picture of the human rights of older people.

11.4 Dissemination

This research was primarily conducted to obtain a PhD; however, the dissemination of the findings to a wide audience is crucial. The dissemination of a research study involves the strategic distribution of its findings to a targeted audience to maximise its impact and applicability (Kwan et al., 2022). Part of the dissemination is to ensure that the knowledge gained reaches those who can benefit from it as well as a broad audience. To date, the findings have been presented at various Irish and International conferences, such as poster presentations at the Irish Gerontological Society Conference in 2023 and the Nordic Gerontology Conference in 2024. Oral presentations have also been conducted at Trinity Health and Education International Research Conference THEconf2023, RCSI Faculty of Nursing and Midwifery conference 2024, and British Gerontology Society conference in Newcastle 2024.

The dissemination plan also includes peer-reviewed journals for effective engagement with academic audiences. Four manuscripts have been identified in the process: one that includes the findings from positioning human rights of older people as part of the COVID-19 pandemic, the second one that includes the findings in relation to staff knowledge of the human rights of older people, third one that includes the three dominant discourses in human rights of older people in LTCFs, and fourth, reflection on how to implement a human rights-based approach to care in residential care facilities. Additionally, engaging with public stakeholders allows the research findings to be applied in a practical context by disseminating them through executive summaries and infographics suited to the general public. The ultimate goal of dissemination is to bridge the gap between research and practice, foster informed decision-making, advance knowledge, and promote evidence-based practices in the area of the human rights of older people in LTC in Ireland.

11.5 Concluding remarks

This PhD thesis contributes to the broader scholarly dialogue on the human rights of older people, emphasising the value of a Foucauldian lens for comprehending the intricate nuances of power and discourse in the lives of older people residing in LTCFs. Subsequently, in this comprehensive exploration through FCDA, I have unveiled the layers of power, knowledge, subject positions and institutional rules within this complex system of human rights of older people in LTC. By conducting interviews with residents, family members, and staff, I unearthed the often-overlooked power dynamics at play. This has ultimately revealed staff members, unknowingly, as central to the power-knowledge-discourse nexus in LTC with such discourses also legitimised in the narratives of both residents and family members. Language, in the form of text and statements, has been a robust indicator of care practices regarding the rights of older people. Additionally, recognising the central role of staff in shaping the discourse highlights the importance of training, education, and ongoing professional development. Staff members should be equipped with knowledge and awareness to foster a culture that respects and upholds the human rights of older people in LTC. For staff to achieve this at a practical level, there needs to be an acknowledgement of older people's rights and how these rights are impacted in the healthcare sector on a systematic level. Moreover, society needs to address issues of ageism and promoting duties and responsibilities as rights bearers. This requires legislation, structures, and provisions that provide equitable solutions for older persons who want to exercise their rights.

As a conclusion to the analysis of human rights in LTC through the Foucauldian lens, there is a reminder that power is not neutral or a fixed, unchanging entity. It is fluid, situational, and influenced by the interactions between various actors. By acknowledging and deconstructing these power dynamics, we can work toward a more equitable LTC environment that respects the dignity and human rights of older people. This requires LTCFs to fundamentally reconsider their approach to catering to the needs of older people by viewing them as rights bearers rather than merely recipients of care. This may need LTC sector to re-design the care context from focusing on the biomedical needs to empowering residents to enjoy all their fundamental rights. Equally, others, particularly staff and families, have an obligation as duty bearers to support residents' autonomy, dignity, and self-determination and ensure respect in everyday encounters. On a larger macro scale, this involves questioning the normative and legal purposes of human rights for older people. Existing norms and laws seem to suggest that they do not adequately address the rights of older people, supporting the need for a specific UN

convention for older people's rights. As this study suggests, the process of translating legal rights principles into practical applications is fraught with difficulties, and various factors must be considered when implementing human rights-based approach to care for older people in LTC settings.

At the end of his career and life, Michael Foucault turned his focus on ethics and human rights (Whyte, 2012; Oksala, 2008). This PhD thesis concludes with a quote from one of Foucault's public appearances when he gave a speech in 1981 named 'Confronting Governments: Human Rights' at the UN in Geneva, in connection with an International Committee against Piracy. The speech was short but impactful, as it spoke of the need for humanised democracy (Whyte, 2012). Although Foucault's speech was in relation to asylum seekers from Vietnam, it is also relevant to this thesis, as the covert dehumanisation of older people creates a position of othering. It is a quote that I will remind myself of in my commitments to improve the rights of older people in the future. I am, after all, an international citizen, who, through my professional role as a nurse, and now a researcher, will commit to speaking out against abuse of power.

There exists an international citizenship that has its rights and its duties, and that obliges one to speak out against every abuse of power, whoever its author, whoever its victims. After all, we are all members of the community of the governed, thereby obliged to show mutual solidarity. (Foucault in Whyte, 2012, p. 11)

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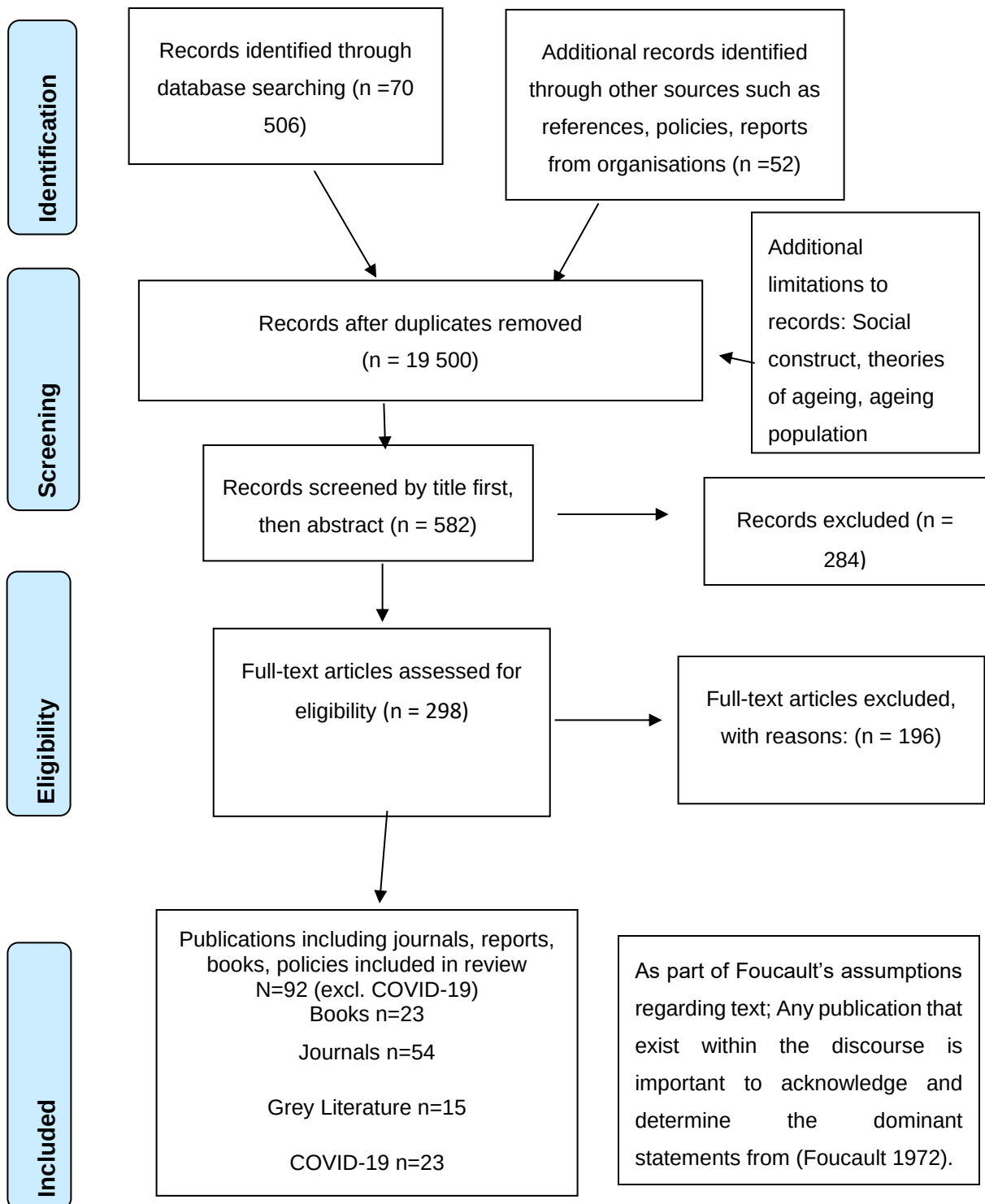
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Appendix 1: Literature review: Old age

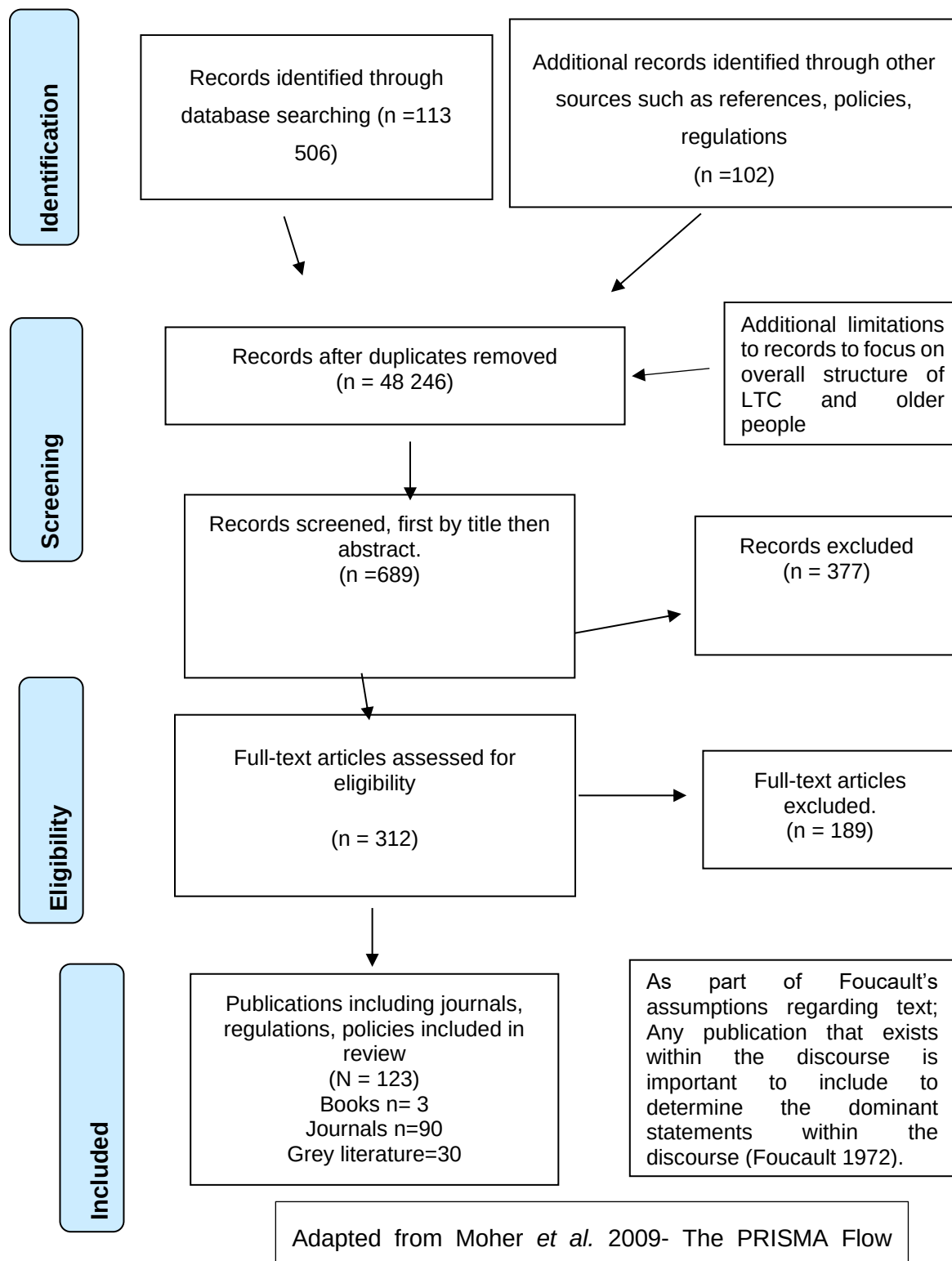
Database used: PubMed®, CINAHL®, MEDLINE®, Google Scholar



Adapted from Moher *et al.* 2009- The PRISMA Flow chart.

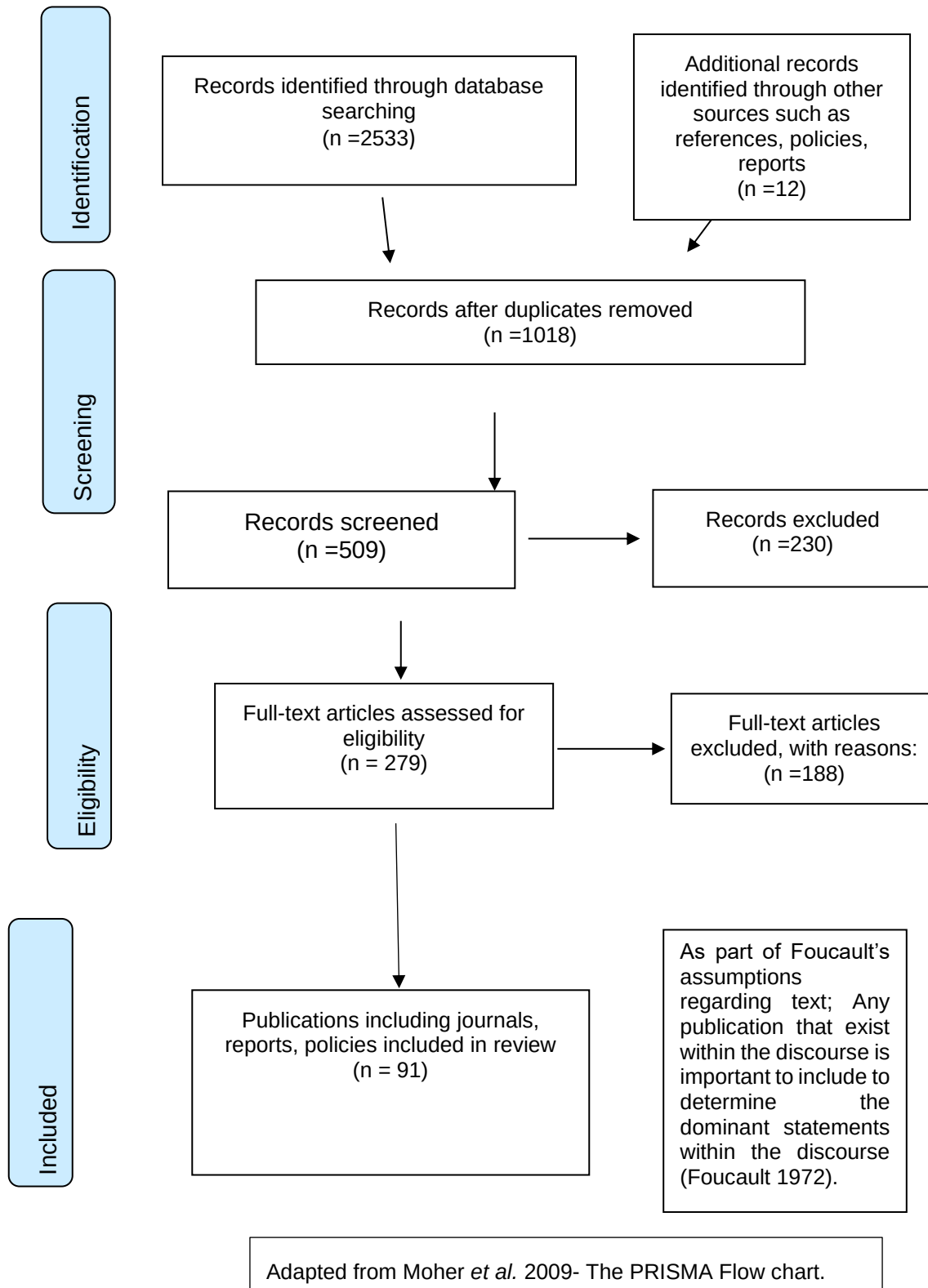
Appendix 2: Literature review: Long-term care

Database used: PubMed®, CINAHL®, MEDLINE®, Google Scholar



Appendix 3 Literature review: Human rights of older people

Database used: PubMed®, CINAHL®, MEDLINE®, Google Scholar



Appendix 4: Invitation letter to the Director of Nursing

Study: Discursive positioning of rights of older people in long-term care

Dear Director of Nursing [Name of Director of Nursing],

Thank you for supporting me in conducting a research study. The following is a brief summary of why the research is being done and what it would involve for you and for the participants. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information and if you decide that [name of the nursing home] cannot facilitate this research that is understandable.

As a PhD student at Trinity College Dublin School of Nursing and Midwifery, I am doing this study on rights of older people in long-term care as part of my PhD dissertation. It is an interview study that attempts to capture the understanding and knowledge of rights of older people. Interview with residents, staff nurse and family members will be conducted individually.

Your support in facilitating the posters, leaflets and a gatekeeper in [name of the nursing home] means that I will be able to recruit participants to the interview study.

Your guidance on functional approach to capacity to participate in the group of residents will determine which of the residents will be able to participate. Those (list) you deemed as having functional capacity to participate should be given to the gatekeeper who will distribute the information pack. Similarly, your knowledge of family members contact details should be given to the gatekeeper who then distributes the information pack and consent form. Staff can contact me directly through the poster and leaflet.

I will not need access to any medical, nursing, social or administrative notes and will collaborate in all public health regulations. I have received my full COVID-19 vaccination.

Here are the inclusion criteria for the three participant groups:

	Inclusion criteria	Exclusion criteria
Older people	Be a resident in the long-term care facility [Name of the nursing home] for at least 4 months. Be 65 years or older Be able to give informed consent using a functional capacity approach. Able to have a conversation.	Under 65 years of age. Not able to give informed consent. No verbal communication
Staff	Be a staff nurse or healthcare assistance and have worked at least 6 months in the long-	Management, ancillary staff (kitchen, housekeeping,

	term care facility. And be involved in providing direct care to residents.	maintenance).
Family member	Be a spouse, partner, child, nephew/niece of a resident in the long-term care facility [Name of the nursing home]	Friends, not named family members according to the resident.

Each participation information pack and consent form are in three separate coloured envelopes:

- Green for residents
- Dark blue for staff
- Yellow for family members

The potential participants need to contact me directly but they might want your assistance with that. It is important to maintain confidentiality and integrity in regards to who will participate in the study. If you have any queries regarding the study, please contact me- details are below.

THANK YOU

Kind regards

Katja Savolainen

Please do contact Katja Savolainen, email: [REDACTED]@tcd.ie Phone No: 087xxxxxxx for any questions or further information.

You can also contact supervisor Professor Amanda Phelan at Trinity College Dublin School of Nursing & Midwifery, email: [REDACTED]@tcd.ie.

Appendix 5: Support letter from LTC Facility No.1

[Redacted]

To,
Ms Katja Savolainen (PhD Student)
School of Nursing and Midwifery,
Trinity College,
Dublin

From,

[Redacted]

Subject: Discursive positioning of Rights of Older people in long term care in Ireland.

Dear Katja,

I can confirm that we can facilitate your research here in [Redacted]
[Redacted] bed capacity Residential care service.

I can designate [Redacted] to liaise with you in a capacity of a gate keeper.

I would be willing to meet with you to discuss the specifics closer to the date.

Please do not hesitate to get in touch with me if you need any further assistance in this matter.

Sincere Regards,

[Redacted]

[Redacted]

Appendix 6: Support letter from LTC facility No.2



Dear Katja,

We have received your research proposal and we believe that many staff members, the residents and their families would be interested in participating in your study. Indeed, it seems that this research is very much needed in the current circumstances. We are ready to assist in the in the recruitment of participants and to facilitate on-site interviews whenever possible. We are [redacted] private nursing home located in the [redacted] We provide respite and long-term care accommodation to individuals over the age of eighteen with a wide variety of conditions.

Please, do let us know how we can assist in the above and do not hesitate to contact us if you have any further queries.

All the best with your investigation and we look forward to hearing from you soon.

Regards,

[Redacted signature]

[Redacted line]

Appendix 7: Support letter from LTC facility No.3



Eagraíocht Cúram
Sláinte Pobail

Community Healthcare
Organisation

Stiúrthóir Altranais do Péróin Scothaosta
Eagraíocht Chúram Sláinte Pobail HSE

11/05/2021

Re: Rights of older people in long term care in Ireland- an interview study

To whom it may concern

[Redacted]
[Redacted] am happy to support the above named project."

- I understand that the involvement of our Nursing Homes, is to assist the Research Team to accomplish this project. Asking nursing management to assist in the identification of potential participants, residents, and support in nominating a gatekeeper to provide information to staff, suitable residents and family members study information.
- Individual semi-structured interviews with residents (who demonstrate functional capacity), staff (nurses and HCAs) and family members of residents will be undertaken in the latter part of 2021/beginning of 2022.

I am happy to support the project in any way possible during this time.

I can confirm that I have read through the above-named research proposal, discussed the proposal and any related queries with PhD student: Katja Savolainen, and fully support our involvement. I look forward to working with the Research Team.

Sincerely,

[Redacted]
Interim Director of Nursing

Seirbhís Sláinte
Níos Fearr
& Forbairt

Building a
Better Health
Service

Appendix 8: Ethical approval from Trinity College Dublin



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Katja Savolainen,
School of Nursing & Midwifery,
Trinity College Dublin,
24 D'Olier Street,
Dublin 2

5th August 2021

Ref: 210604

Title of Study: Discursive positioning of rights of older people in long term care- Foucauldian Critical Discourse Analysis.

Dear Katja,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in June 2021. We are pleased to inform you that the above project has ethical approval to proceed.

This study has been ethically approved. We would advise you to seek review and comments on your DPIA from the DPO if required prior to study commencement'

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

Yours sincerely,

Prof. Jacintha O'Sullivan
Chairperson
Faculty Research Ethics Committee

Dámh na nEolaíochtaí Sláinte
Foirgneamh na Ceimice,
Coláiste na Tríonóide,
Ollscoil Átha Cliath,
Baile Átha Cliath 2, Éire.

Faculty of Health Sciences
Chemistry Building,
Trinity College Dublin,
The University of Dublin,
Dublin 2, Ireland.

www.healthsciences.tcd.ie

Appendix 9: Invitation letter, Participation information leaflet and consent form for residents

Invitation to Participate in Study

Study Title Discursive positioning of rights of older people in long-term care

Dear Resident of [Name of nursing home],

I'm a PhD student at Trinity College Dublin, School of Nursing and Midwifery and I am inviting you to participate in an interview study regarding rights of older people in long-term care (nursing homes). As a resident of [Name of the Nursing home], you are an ideal position to give me valuable first-hand information about your life in the nursing home.

The interview will take approximately 30 and 60 minutes and is a conversation between you and me, PhD student Katja Savolainen. I'm simply trying to capture your experiences and perspectives in your everyday life in the nursing home in regard to your rights. Your responses to the questions will be kept confidential. Each interview will be assigned a number code to help ensure that personal identifiers are not revealed during the analysis and write up of findings.

Participation in this interview study is completely voluntary and you may choose to withdraw from the study or not answer questions that you do not feel comfortable answering. There is no compensation for participating in this study. However, your participation will be a valuable addition to the research and findings could lead to improvements and understanding of rights of older people in long-term care.

If you are willing to participate please read through the Participation Information Leaflet and consent form. If you have any questions, please do not hesitate to ask me (Katja) on phone 087xxxxxxx or email: [redacted]@tcd.ie.

If you would like to participate, call or email me (Katja) and we will agree a day and time that suits you. I (Katja) will arrange the interview which will take place in a confidential, private area.

Thank you for taking time to read this letter.

Warm regards,

Katja Savolainen

PhD student

Trinity College Dublin, School of Nursing and Midwifery

Email: [redacted][@tcd.ie](mailto:[redacted]@tcd.ie)

Phone number: 087xxxxxxx



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Participant Information Leaflet

For Resident of [Name of Nursing Home]

Discursive positioning of rights of older people in long-term care



Participant Information Leaflet

Site	Long-term care residential [Name of Nursing Home]
Principal Investigator(s) and Co-Investigator(s) (insert names, titles and contact details)	Katja Savolainen, PhD student, Trinity College Dublin, School of Nursing and Midwifery Email: [REDACTED]@tcd.ie Phone number: 087xxxxxxx Co-Investigator/supervisor: Professor Amanda Phelan, School of Nursign & Midwifery, Trinity College Dublin Email: [REDACTED]@tcd.ie
Study Organiser/ Sponsor (if applicable)	Not applicable
Data Controller	Trinity College Dublin (for research data)
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2
Name of Study:	Discursive positioning of rights of older people in long-term care- A Foucauldian Critical Discourse Study



Discursive positioning of rights of older people in long-term care

Rights of older people in long-term care in Ireland is an emerging topic and this study is to provide further knowledge and understanding in the topic. You are being invited to take part in a research study that is being done by Katja Savolainen, PhD student at Trinity College Dublin, School of Nursing and Midwifery at [Name of the nursing home].

Before you decide whether or not you wish to take part, please read this information sheet carefully.

Ask Katja Savolainen any questions or if you need anything clarified. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with your family, friends or nurses.

This leaflet has four main parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Costs, Funding and Approval

Part 4 – Further Information



Part 1 – The Study

Why is this study being done?

This study is being done as part of doctoral studies at Trinity College Dublin, School of Nursing and midwifery. I (PhD student Katja Savolainen) am the main investigator in the study and it is conducted under the supervision of Professor Amanda Phelan. I am doing this study to increase understanding and knowledge of rights of older people that are living in nursing homes. I am interviewing residents, staff and family members of those living in nursing homes.

Why have I been invited to take part?

You have been invited to take part as you are a resident of [Name of the nursing home]

- You are 65 years or older.
- You are able to have a conversation and you are able to give informed consent.

Do I have to take part? Can I withdraw?

Your participation is voluntary and you don't have to take part in this study. If you not to take part it won't affect your current or future care.

If you want to participate, you need to fill in a consent form located at the end of this information letter.

What happens if I change my mind?

You can change your mind at any time by contacting Katja Savolainen on phone 087xxxxxxx or email [REDACTED]@tcd.ie. If you wish, you can ask for your data stored to be destroyed. If you request this, we will destroy all data that are still in our possession. We will no longer use or share your data for research from this point onwards. However, it will not be possible to destroy data already used in analysis prior to this time as it is



anonymised and not possible to detect who's' data it is.

How will the study be carried out?

If you agree to take part, we will have an interview where I will ask you questions about your life in [the name of the nursing home]. The interview method I am using is open-ended. I will have some pre-set questions, but it is a conversation between us two about your experiences regarding your rights in your nursing home. The interview will last between 30-60 minutes and will be at a place of convenience to you. If you agree, I will record the interview and I will also take notes during the interview.

I hope to do the interview face to face with you. I am fully vaccinated against Covid-19. If the interview takes place face to face, it will be in a location where no one can interrupt (your own personal room or visitor's area that is confidential) and any disruptions are minimised. The interview is confidential between you and the principal investigator Katja Savolainen.

What will happen to me if I decide to take part?

- Once you have decided to participate, you can contact Katja Savolainen either through email, text or phone. You can also use one of the pre-stamped envelopes with your interest available next to the poster. Once I receive the envelope I (Katja) will contact you in [name of the nursing home].
- If you decide to participate, you will also need to fill in the attached consent form and send/deliver it to Katja Savolainen.
- Katja will then contact you regarding a date and time for an interview. This interview will be in person and Katja will follow all public health guidelines in regard to social distancing and visiting.
- The location will be of convenience for you. As long as there is access to a confidential area where disruptions are minimised.
- Once the date and time for interview is set, there is still time for you to ask questions or withdraw from the study. You can withdraw at any time even during the interview.
- Directly before the interview takes place, Katja will ask again if you have any questions. Katja will show you the audio recorder or if virtual how the interview is recorded.
- The interview will ask questions about your life in the nursing home.
- The interview will take about 30- 60 minutes.
- Katja may stop the interview if you appear upset.
- If any safeguarding issues are disclosed, I (Katja) am obliged to follow up with the safeguarding officer of [name of the nursing home]. But this will be explained and



discussed with you. Any illegal disclosure is required to be reported to Gardaí.

- After the interview is stopped, Katja will ask again if you have any questions and if you like a transcript of the interview. If you do want to review your transcript, Katja will send this to you once it is completed. If you want to change anything in the transcript you can do so by contacting Katja.
- Your interview data (transcript) will only be used for this study. You can ask for a copy of the interview transcript.

What will happen to my Samples and Data?

- After the interview, your interview is considered your personal data. The audio recording will be stored safely by Katja on a password protected file on an encrypted laptop.
- Following your interview, I will transcribe the recorded interview. No audio recordings will be made available to anyone other than Katja, nor will any such recordings be replayed in any public forum or presentation of the research. The soft copy of this transcript will then be held in an encrypted file on a password protected computer. The hard copy (paper form) will be kept in a locked secure cabinet at Trinity College Dublin.
- Once the transcript is completed, the audio recording is deleted.
- Professor Amanda Phelan will have access to the transcripts.
- The transcript will have a code, not your personal details. Your information will not be used in any other study without your explicit consent. The study will comply with the General Data Protection Regulation (GDPR) 2018, at all times.
- Once transcribed the data is anonymous, your identifiable record will only be known by researcher Katja Savolainen. Any reports, publications and the PhD submission will not have any identifiable information.

The consent form and your personal data (Interview) will be held for 7 years for audit purposes. But it will not be used or accessed for any other research or to be used in any disclosing way.

Are there any benefits to taking part in this research?

There may be no direct benefit to you, but you may enjoy sharing your experiences and opinions. Your participation will help me (Katja) know more about the rights of older people in long-term care. By participating, you are helping to create an understanding of rights of older people in long-term care in Ireland.

Are there any risks to me or others if I take part?



- There is a risk that you may share some personal or confidential information that you do not wish to speak about or that you may feel uncomfortable talking about. However, I do not wish for this to happen. At any time, you may decline to answer any question or stop the interview.
- If you get upset you may want to talk to the SAGE Advocacy representative of [name of the nursing home]. Katja has the details to SAGE Advocacy if needed.
- There is a risk that a connection to your identity could be made. Great care will be taken to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low.
- These risks have been mentioned to Trinity College Dublin Ethics Committee who has approved the study.

Will I be told the outcome of the study?

The results of the study will be reported in /scientific journals and disclosed at scientific conferences. The results of the study are part of PhD dissertation. A copy of said dissertation can be found in Trinity College Library once published. No information which reveals your identity will be disclosed.



Part 2 – Data Protection

What information about me (personal data) will be used as part of this study?

Your personal data that will be used is the interview you provide, which will be anonymised after transcribing. Details such as your age, gender and length of stay in the nursing home will be also be collected.

Who will access and use my personal data as part of this study?

- Katja Savolainen, the primary investigator for this study will have access to your contact details, personal details such as age, gender and length of stay in the nursing home. Other data will be the interview text that will be collected during the interview. No other data will be collected. No healthcare records, care plans or care details will be accessed.
- Professor Amanda Phelan will have access as part of her supervisor role.
- The Director of nursing at [Name of the nursing home] has identified potential participants and provided these names to the gatekeeper of [Name of gatekeeper and nursing home] who has distributed the information packs. They are not involved in deciding who will end up participating.
- The gatekeeper of Nursing home [Name of Gatekeeper and nursing home] will give you the information pack and consent form, but they will not know whether you end up participating or not.
- Although all steps are taken to maintain your confidentiality in participating in the study, due to help of Director of Nursing and gatekeeper, they may become aware you are participating in the study, as I will be visiting you. However, your data is not shared and is anonymised in any publicly available material.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is the most important in the study. Steps will be taken to make sure your confidentiality and your data is protected. It is of importance that your data is kept safe. Here are details of how it is kept safe:

All personal details are kept in a password file on an encrypted laptop only accessible by Katja Savolainen and Professor Amanda Phelan.

A Data Protection Impact Assessment was carried out by the Data Protection Officer in Trinity College Dublin and the level of risk was identified to be low.

I (Katja Savolainen) have completed Research integrity training and General Data Protection training to make sure all legal and ethical steps are maintained.



What is the lawful basis to use my personal data?

By law,²² we can use your personal information for scientific research²³ (in the public interest²⁴). We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

What are my rights?

As per Data Protection (GDPR) laws internationally and in Ireland, You are entitled to:

- The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format and to have it transferred to another data controller
- The right to request deletion of your data

By law you can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting your study researcher Katja Savolainen, phone number 087xxxxxxx or email ████████@tcd.ie or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

²² The European General Data Protection Regulation (GDPR)

²³ Article 9(2) (j))

²⁴ (Article 6(1)(e))



Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by Trinity College Dublin's Faculty of Health Science Research Ethics Committee. Approval was granted on 10th of August 2021.

Who is organising and funding this study? Will the results be used for commercial purposes?

This study is not funded by any organisation. The research is conducted in the purpose of obtaining a PhD and not for commercial purposes. It is self-funded by the PhD student Katja Savolainen.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

There is no compensation to take part in the study. It will also not cost you anything to take part. We appreciate your participation as it will provide important knowledge in the topic of rights of older people in nursing homes.

Part 4 – Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

- Principal Investigator: Katja Savolainen, email: [REDACTED]@tcd.ie Phone: 087xxxxxxx.
- Supervisor: Professor Amanda Phelan, School of Nursing and Midwifery email: [REDACTED]@tcd.ie
- Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep.

Consent Form

Please read the information below.

Tick Yes if you are happy with each statement.

Tick No if you are not happy with each statement.

Sign this consent form if you wish to take part in this study.

I agree with the following statements:

	I have read the information about this study.	Yes ☐	No ☐
	Any questions that I had were answered.	Yes ☐	No ☐
	I know who to contact if I have any more questions.	Yes ☐	No ☐
	I understand that, if I take part, I will be asked questions about my life in the nursing home.	Yes ☐	No ☐
	I know that it is my choice to take part in this study.	Yes ☐	No ☐
	I know that I can stop taking part in this study when I want to. I do not have to give a reason.	Yes ☐	No ☐

	I understand that all information I give during this study will be kept safe and private.	Yes <input data-bbox="1086 353 1177 427" type="checkbox"/>	No <input data-bbox="1236 353 1327 427" type="checkbox"/>
	I know that I will not be named in any reports.	Yes <input data-bbox="1086 562 1177 636" type="checkbox"/>	No <input data-bbox="1236 562 1327 636" type="checkbox"/>
	I know that risks are low. And that there are not any direct benefits to me from this study.	Yes <input data-bbox="1086 772 1177 846" type="checkbox"/>	No <input data-bbox="1236 772 1327 846" type="checkbox"/>
	I know this study is being run by researchers from Trinity College Dublin.	Yes <input data-bbox="1086 996 1177 1070" type="checkbox"/>	No <input data-bbox="1236 996 1327 1070" type="checkbox"/>
	I am happy to take part in this study.	Yes <input data-bbox="1086 1272 1177 1346" type="checkbox"/>	No <input data-bbox="1236 1272 1327 1346" type="checkbox"/>



Your Consent

Your _____ name:

Your _____ phone _____ number:

Your _____ address:

Please _____ sign _____ your _____ name:

Date:

Witness

signature: _____ Date: _____

For any questions, contact:

Katja Savolainen, PhD Student

Phone: 087xxxxxxx

Email: [REDACTED]@tcd.ie

Appendix 10: Invitation letter, Participation information leaflet and consent form for family members

Invitation to Participate in Study

Study Title: Discursive positioning of rights of older people in long term care

Dear family member of resident in [Name of nursing home],

I'm a PhD student at Trinity College Dublin School of Nursing and Midwifery and I am inviting you to participate in an interview study regarding rights of older people in long term care (nursing homes). As a family member of a resident at [Name of the Nursing home], you are in an ideal position to give me valuable first-hand information about your perspective of the resident's life in the nursing home.

The interview will take approximately 30 to 60 minutes and is a conversation between you and me, (PhD student Katja Savolainen). I am simply trying to capture your experiences and perspectives of the residents' everyday life in the nursing home in regard to rights. Your responses to the questions will be kept confidential. Each interview will be assigned a number code to help ensure that personal identifiers are not revealed during the analysis and write up of findings. Participation in this interview study is completely voluntary and you may choose to withdraw from the study or not answer questions that you do not feel comfortable answering. There is no compensation for participating in this study. However, your participation will be a valuable addition to the research and findings could lead to increase understanding of rights of older people in long term care. If you are willing to participate, please read through the Participation Information Leaflet and consent form. If you have any questions, please do not hesitate to ask Katja on phone 087xxxxxxx or email [redacted]@tcd.ie. If you would like to participate, please, call or email me (Katja) and suggest a day and time that suits you. I (Katja) will arrange the interview which will take place in a confidential private area.

Thank you for your time to read this letter of invitation,

Warm regards,

Katja Savolainen, PhD student, Trinity College Dublin, School of Nursing and Midwifery

Email: [redacted]@tcd.ie

Phone number: 087xxxxxxx



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Participant Information Leaflet

For family member of resident in [Name of Nursing Home]

Discursive positioning of rights of older people in long term care



Participant Information Leaflet

Name of Study:	Discursive positioning of rights of older people in long term care- A Foucauldian Critical Discourse Study

Site	Long term care residential [Name of Nursing Home]
Principal Investigator(s) and Co-Investigator(s) (insert names, titles and contact details)	Katja Savolainen, PhD student Trinity College Dublin School of Nursing and Midwifery Email: [redacted]@tcd.ie Phone number: 087xxxxxxx Co-Investigator/supervisor: Professor Amanda Phelan, Trinity College Dublin Email: [redacted]@tcd.ie
Data Controller	Trinity College Dublin (for research data)
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2



Discursive positioning of rights of older people in long term care

Rights of older people in long term care in Ireland is an emerging topic and this study will provide further knowledge and understanding in the topic. You are being invited to take part in a research study that is being done by Katja Savolainen, PhD student at Trinity College Dublin School of Nursing and Midwifery at [NAME OF NURSING HOME].

Before you decide whether or not you wish to take part, please read this information sheet carefully.

Ask Katja Savolainen any questions or if you need anything clarified. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with your family or friends.

This leaflet has four main parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Costs, Funding and Approval

Part 4 – Further Information



Part 1 – The Study

Why is this study being done?

This study is being done as part of doctoral studies at Trinity College Dublin School of Nursing and midwifery. I (PhD student, Katja Savolainen) am the main investigator in the study and it is conducted under the supervision of Professor Amanda Phelan.

I am doing this study to increase understanding and knowledge of rights of older people that are living in nursing homes. I am interviewing residents, staff and family members of those living in nursing homes.

Why have I been invited to take part?

You have been invited to take part as you are a family member of a resident in [Name of the nursing home].

- If you are a spouse, partner, child, niece/nephew or sibling of a resident in the [Name of the nursing home], you can participate in this study.
- We will involve around 15 individuals in each category (residents, staff and family members); divided into individual interviews and focus group. I am using focus groups with family members.

Do I have to take part? Can I withdraw?

Your participation is voluntary and you don't have to take part in this study. If you do not to take part, it won't affect your family member's current or future care.

If you want to participate you need to fill in the consent form attached to this information leaflet.

What happens if I change my mind?

You can change your mind at any time before participating in the focus group by contacting Katja Savolainen on 087xxxxxxx or email [redacted]@tcd.ie. However, if you decide to withdraw from the study, either during the focus group or after, it will not be possible to remove your narrative from the focus group as data would be anonymised and therefore, it is not possible to detect who's' data it is.

How will the study be carried out?

If you agree to take part, I will ask you to sign a consent form and will arrange for a suitable



date to participate in the focus group. In total there will 7-8 participants that will be part of the focus group. It will last 45 to 60 minutes and it is focussed on a discussion about rights of older people in long term care and your understanding as family member of same. I will ask questions and lead the discussion. All public health regulations at the time of the focus group interview will be adhered to. If you agree to participate, I will record the interview and I will also take notes during the focus group. The focus group is confidential and no identifiable markers will be used.

What will happen to me if I decide to take part?

- Once you have decided to participate, you can contact me (Katja Savolainen) either through email, text or phone call. You can also use one of the sealed boxes available in the units of Leopardstown Park Hospital or by sending it to Katja. Once I receive the envelope, I will contact you regarding the study.
- If you contact me, I will discuss the study with you and answer any questions. If you are happy to proceed, you will also need to fill in the attached consent form and send/deliver it to Katja Savolainen.
- I (Katja) will then contact you regarding a date and time for the focus group. This will be in person within a focus group in a private room in [nursing home]. I (Katja) will follow all public health guidelines in regard to social distancing and visiting. I (Katja) am fully vaccinated against COVID-19.
- Once the date and time for interview is set, there is still time for you to ask questions or withdraw from the study. When the interview takes place Katja will ask again if you have any questions before starting the interview.
- When the interview takes place Katja will ask again if you have any questions before starting the interview. Katja will show you the audio recorder or if virtual how the interview is recorded.
- The interview will ask questions your perceptions on the rights of your family member in the nursing home.
- The focus group interview will take about 45- 60 minutes.
- If during the interview you want to stop, at any time, this is your right.
- If any safeguarding issues are disclosed, I (Katja) am obliged to follow up with safeguarding officer of [name of the nursing home] and report any concerns. But this will be explained and discussed with you. Any illegal disclosure is required to be reported to Gardaí.
- After the interview is stopped, Katja will ask again if you have any questions. Your data (transcript) and the focus groups data will only be used for this study.

What will happen to my Samples and Data?

- After the focus group interview the audio recording will be stored safely by Katja on a password protected file on an encrypted laptop.
- The focus group audio will be transcribed by Katja Savolainen. No audio recordings will be made available to anyone other than Katja, nor will any such recordings be replayed in any public forum or presentation of the research. The



soft copy of this transcript will then be held in an encrypted file on a password protected computer. The hard copy (paper form) will be kept in a locked secure cabinet at Trinity College Dublin.

- Once the transcript is completed, the audio recording is deleted.
- Professor Amanda Phelan will have access to the transcripts.
- The transcript will have a code, not your personal details.
- Your information will not be used in any other study without your explicit consent. The study will comply with the General Data Protection Regulation (GDPR), 2018, at all times.
- Once transcribed, the data is anonymous and your identifiable record will only be known by researcher Katja Savolainen. Any reports, publications and the PhD submission will not have any identifiable information.

The consent form and your personal data (Interview) will be held for 7 years for audit purposes. But it will not be used or accessed for any other research or to be used in any disclosing way.

Are there any benefits to taking part in this research?

There may be no direct benefit to you, but you may enjoy sharing your experiences and opinions. Your participation will help me (Katja) know more about the rights of older people in long term care. By participating, you are helping to create an understanding of rights of older people in long term care in Ireland.

Are there any risks to me or others if I take part?

- There is a risk that you may share some personal or confidential information that you do not wish to speak about or that you may feel uncomfortable talking about. However, I (Katja) do not wish for this to happen. At any time, you may decline to answer any question or withdraw from the focus group. However, we will not be able to extract your individual narrative from the focus group recording. There is a risk that a connection to your identity could be made. Great care will be taken to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low.
- These risks have been identified to Trinity College Dublin, Faculty of Health Sciences' Ethics Committee who has approved the study.
- If you are a woman of childbearing age, you may participate in this study as there is no risk or intervention to you as part of the interview. If you feel worried about the psychological impact on your fetus please talk to researcher Katja Savolainen.

Will I be told the outcome of the study?

The results of the study will be reported in scientific journals and presented at scientific



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conferences. The results of the study are part of Katja Savolainen's PhD dissertation. A copy of said dissertation can be found in Trinity College Dublin Library after publication. No information which reveals your identity will be disclosed in any publication.



Part 2 – Data Protection

What information about me (personal data) will be used as part of this study?

The personal data that will be used includes the interview you provide, which will be anonymised after transcribing. Details such as your age, gender and family connection to the resident in the nursing home will be also be collected.

Who will access and use my personal data as part of this study?

- Katja Savolainen, the primary investigator for this study, will have access to your contact details, personal details such as age, gender and connection to family member in [name of the nursing home]. Other data will be the interview text that will be collected during the interview. No other data will be collected. No healthcare records, care plans or care details will be accessed.
- Professor Amanda Phelan will have access as part of her supervisor role.
- The Director of Nursing at [Name of the nursing home] has identified potential participants and provided these names to the gatekeeper of [Name of gatekeeper and nursing home] who has distributed the information pack. They are not involved in who will end up participating.
- The gatekeeper of the Nursing home [Name of Gatekeeper and nursing home] will give you the information pack and consent form, but they will not know whether you ended participating or not.
- Although all steps are taken to maintain your confidentiality in participating in the study, due to help of Director of nursing and gatekeeper of [name of the nursing home], they may know you are participating in the study. However, your data is not shared and is anonymised in any publicly available material.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is the most important in the study. Steps will be taken to make sure your confidentiality and your data is protected. It is of important that your data is kept safe. Here are how it is kept safe:

All personal details are kept in a password file on an encrypted laptop only accessible by Katja Savolainen and Professor Amanda Phelan.

A Data Protection Impact Assessment was carried out by the Data Protection Officer in Trinity College Dublin and the level of risk was identified to be low.

I (Main principal investigator, Katja Savolainen) have completed Research integrity training



and General Data Protection training to make sure all legal and ethical steps are maintained.

What is the lawful basis to use my personal data?

By law,²⁵ we can use your personal information for scientific research²⁶ (in the public interest²⁷). We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

What are my rights?

As per Data Protection (GDPR) laws internationally and in Ireland, You are entitled to:

- The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format and to have it transferred to another data controller
- The right to request deletion of your data however this may not be possible if not able to decipher your data.

By law you can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting your study researcher Katja Savolainen, phone number 087xxxxxxx or email [REDACTED]@tcd.ie or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

²⁵ The European General Data Protection Regulation (GDPR)

²⁶ Article 9(2) (j)

²⁷ (Article 6(1)(e))



Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by Trinity College Faculty of Health Science Research Ethics Committee, approval was granted on 10th of August 2021. Additional amendment was approved on 25th of October 2022.

Who is organising and funding this study? Will the results be used for commercial purposes?

This study is not funded by any organisation. The research is conducted in the purpose of obtaining a PhD degree and not for commercial purposes. It is self-funded by the PhD student Katja Savolainen.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying anyone to take part in the study. It will also not cost you anything to take part. We appreciate your participation as it will provide important knowledge in the topic of rights of older people in long term care.

Part 4– Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

- Principal Investigator: PhD student Katja Savolainen, email: [REDACTED]@tcd.ie
Phone: 087xxxxxxx.
- Supervisor Professor Amanda Phelan email: [REDACTED]@tcd.ie
- Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie. If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep.



STUDY NAME: Discursive positioning of rights of older people in long term care- A Foucauldian Critical Discourse Analysis

Centre ID:

Identification Number for study:

Consent Form

There are 12 sections in this form. Each section has a statement and asks you to initial if you agree. The end of this form is for the researchers to complete.
Please ask any questions you may have when reading each of the statements.
Please Initial the box if you agree with the statement. Please feel free to ask questions if there is something you do not understand.

General	Tick box
I confirm I have read and understood the Participant Information Leaflet for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study is entirely voluntary, and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason. I understand that deciding not to take part will not affect the care of my family member.	
I understand that all information will be kept private and confidential and that my name will not be disclosed.	
I understand that I will not be paid for taking part in this study.	
I know how to contact the principal investigator if I need to.	
I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information leaflet which I have been provided with.	
I agree to being contacted by researcher by either email or phone as part of this research study.	
Data processing	Tick box
I agree to allow personal information about me to be used in the academic research for the purpose of PhD dissertation as described in the Information leaflet.	
I understand the anonymised data will be used in publications.	
I understand that personal information about me, including the transfer of this personal information about me outside of the EU, will be protected in accordance with the General Data Protection Regulation.	
I understand that there are no direct benefits to me from participating in this study. I understand that results from analysis of my personal information will not be given to me.	



I understand that I do not need to take part of this study but once I participate withdrawal is not possible due to anonymisation of data.	

Participant Name (Block Capitals)	Participant Signature	Date

Witness Name (Block Capitals)	Witness Signature	Date

To be completed by the Principal Investigator.

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team

Researcher name

Title and qualifications

Signature

Date

2 copies to be made: 1 for participant, 1 for PI

Appendix 11: Invitation letter, Participation information leaflet and consent form for staff

Invitation to Participate in Study

Study Title Discursive positioning of rights of older people in long-term care

Dear staff member of [Name of nursing home],

I am a PhD student at Trinity College Dublin, School of Nursing and Midwifery, and I am inviting you to participate in an interview study regarding rights of older people in long term care (nursing homes). As a staff member of [Name of the Nursing home] you are in an ideal position to give me valuable first-hand information about residents' lives in the nursing home.

The interview will take approximately 30 to 60 minutes and is a conversation between you and me- PhD student Katja Savolainen. I'm simply trying to capture your experiences and perspectives of the residents' everyday lives in the nursing home in regards to their rights. Your responses to the questions will be kept confidential. Each interview will be assigned a numerical code to help ensure that personal identifiers are not revealed during the analysis and write up of findings. Participation in this interview study is completely voluntary and you may choose to withdraw from the study or not answer questions that you do not feel comfortable answering. There is no compensation for participating in this study. However, your participation will be a valuable addition to the research and findings could lead to improvements and understanding of rights of older people in long term care. If you are willing to participate, please read through the Participation Information Leaflet and consent form. If you have any questions, please do not hesitate to ask me (Katja) on phone 087xxxxxxx or email [redacted]@tcd.ie. If you would like to participate, please, call or email me (Katja) and suggest a day and time that suits you. I (Katja) will arrange the interview which will take place in a confidential private area.

Thank you for your time to read this letter of invitation.

Warm regards,

Katja Savolainen,

PhD student Trinity College Dublin, School of Nursing and Midwifery, Email: [redacted]@tcd.ie Phone number: 087xxxxxxx



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Participant Information Leaflet

For Staff of [Name of Nursing Home]

Discursive positioning of rights of older people in long term care



Participant Information Leaflet

Name of Study:	Discursive positioning of rights of older people in long term care- A Foucauldian Critical Discourse Study

Site	Long term care residential [Name of Nursing Home]
Principal Investigator(s) and Co-Investigator(s) (insert names, titles and contact details)	Katja Savolainen, PhD student Trinity College Dublin School of Nursing and Midwifery Email: [REDACTED]@tcd.ie Phone number: 087xxxxxxx Co-Investigator/supervisor: Professor Amanda Phelan, Trinity College Dublin Email: [REDACTED]@tcd.ie
Data Controller	Trinity College Dublin (for research data)
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2



Discursive positioning of rights of older people in long term care

Rights of older people in long term care in Ireland is an emerging topic and this study is to provide further knowledge and understanding in the topic. You are being invited to take part in a research study that is being done by Katja Savolainen, PhD student at Trinity College Dublin, School of Nursing and Midwifery at [NAME OF NURSING HOME].

Before you decide whether or not you wish to take part, please read this information sheet carefully.

Ask Katja Savolainen any questions or if you need anything clarified. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with your family or friends.

This leaflet has four main parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Costs, Funding and Approval

Part 4– Further Information



Part 1 – The Study

Why is this study being done?

This study is being done as part of doctoral studies at Trinity College Dublin, School of Nursing and midwifery. I (PhD student Katja Savolainen) am the main investigator in the study and it is being conducted under the supervision of Professor Amanda Phelan.

I am doing this study to increase understanding and knowledge of rights of older people that are living in nursing homes. I am interviewing residents, staff and family members of those living in nursing homes.

Why have I been invited to take part?

You have been invited to take part as you are a staff member of [Name of the nursing home].

- If you are a staff nurse or healthcare assistant who has worked at least 6 months in [Name of the nursing home] and you are involved in providing direct care to residents, you can participate in the study.
- We are trying to involve around 15 individuals in each category (residents, staff and family members); in total 45 interviews.

Do I have to take part? Can I withdraw?

Your participation is voluntary and you don't have to take part in this study. If you not to take part it won't affect you're your current or future employment.

If you want to participate, you need to fill in the consent form attached to this information leaflet.

What happens if I change my mind?

You can change your mind at any time by contacting Katja Savolainen on phone



087xxxxxxx or email [REDACTED]@tcd.ie. If you choose not to take part any more, you will be asked to fill in a withdrawal form. If you wish, you can ask for your data stored to be destroyed. If you request this, we will destroy all data that are still in our possession. We will no longer use or share your data for research from this point onwards. However, it will not be possible to destroy data already used in analysis prior to this time as it is anonymised and not possible to detect who's' data it is.

How will the study be carried out?

If you agree to take part, I will ask you to sign a consent form and we will have an interview where I will ask you questions about the residents every day in the Nursing Home. The interview method I am using is open-ended. I will have some pre-set questions, but it is a conversation between both of us about rights of older people in nursing homes. The interview will last about 30-60 minutes and will be at a place of convenience to you and in a location where any disruptions are minimised. All public health regulations will be followed at the time of the interview. If you agree to participate, I will record the interview and I will also take notes during the interview. The interview is confidential between you and the principal investigator Katja Savolainen.

What will happen to me if I decide to take part?

- Once you have decided to participate, you can contact me (Katja Savolainen) either through email, text or phonecall. You can also use one of the pre-stamped envelopes available in [Name of the Nursing home] by sending it to Katja.
- You will also need to fill in the attached consent form and send/deliver it to Katja Savolainen.
- On receiving the signed consent form, I (Katja) will then contact you regarding a date and time for an interview. This interview will be either in person or virtual, depending on what you prefer and current public health regulations. I (Katja) will follow all public health guidelines in regard to social distancing and visiting.
- The location will be of convenience for you, as long as there is access to a confidential area where disruptions are minimised.
- Once the date and time for the interview is set, there is still an opportunity for you to ask questions or withdraw from the study. You can withdraw at any time even during the interview.
- When the interview takes place, Katja will ask again if you have any questions before starting. Katja will show you the audio recorder and how the interview is recorded.
- The interview will ask questions about how you see older people's rights being facilitated in the nursing home.
- The interview will take about 30- 60 minutes.



- If during the interview you want to stop, at any time, this is your right.
- Katja may stop the interview if you appear upset.
- If any safeguarding issues are disclosed, I (Katja) am obliged to follow up with safeguarding officer of [name of the nursing home] and report any concerns. But this will be explained and discussed with you. Any illegal disclosure is required to be reported to Gardaí.
- After the interview is stopped, Katja will ask again if you have any questions and if you like a transcript of the interview. If you do want a transcript, Katja will send this to you once it is completed and ask you to revert with comments within a week. If you want to change anything in the transcript you can do so by contacting Katja.
- Your interview data (transcript) will only be used for this study.

What will happen to my Samples and Data?

- After the interview, your interview is considered your personal data. The audio recording will be stored safely with Katja on a password protected file on an encrypted laptop.
- Following your interview, I will transcribe the recorded interview. No audio recordings will be made available to anyone other than Katja, nor will any such recordings be replayed in any public forum or presentation of the research. The soft copy of this transcript will then be held in an encrypted file on a password protected computer. The hard copy (paper form) will be kept in a locked secure cabinet at Trinity College Dublin.
- Once the transcript is completed, the audio recording is deleted.
- The transcript will have a code, not your personal details. This is called pseudo anonymised.
- Once the transcript is used in analysis and is pseudo anonymised, it is not possible to retrieve your data from it.
- The pseudo anonymised transcript will always be kept private, be held for no longer than seven years, and then both hard and soft copies will be destroyed. Your information will not be used in any other study without your explicit consent. The study will comply with the General Data Protection Regulation (GDPR) 2018 at all times.
- Once transcribed, your identifiable record will only be known by the researcher, Katja Savolainen and subsequently supervisor Professor Amanda Phelan. Any reports, publications and the PhD submission will not have any identifiable information.

The consent form and your personal data (Interview) will be held for 7 years for audit purposes. But it will not be used or accessed for any other research or to be used in any disclosing way.



Are there any benefits to taking part in this research?

There may be no direct benefit to you, but you may enjoy sharing your experiences and opinions. Your participation will help me (Katja) know more about the rights of older people in long term care. By participating, you are helping to create an understanding of rights of older people in long term care in Ireland.

Are there any risks to me or others if I take part?

- There is a risk that you may share some personal or confidential information that you do not wish to speak about or that you may feel uncomfortable talking about. However, I (Katja) do not wish for this to happen. At any time, you may decline to answer any question or stop the interview.
- There is a risk that a connection to your identity could be made. Great care will be taken to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low.
- These risks have been identified to Trinity College Dublin's Faculty of Health Sciences' Ethics Committee who has approved the study. If you are a woman of childbearing age, you may participate in this study as there is no risk or intervention to you as part of the interview. If you feel worried about the psychological impact on your foetus, please talk to researcher Katja Savolainen.

Will I be told the outcome of the study?

The results of the study will be reported in scientific journals and disclosed at scientific conferences. The results of the study are part of Katja Savolainen's PhD dissertation. A copy of said dissertation can be found in Trinity College Dublin Library after publication. No information which reveals your identity will be disclosed in any publication.

Part 2 – Data Protection



What information about me (personal data) will be used as part of this study?

Your personal data that will be used is the interview you provide, which will be anonymised after transcribing. Details such as your age, gender and family connection to the resident in the nursing home will be also be collected. These details will not be identifiable.

What will happen to my personal data?

Your name, your interview and responses to the questions will not be disclosed to other parties. I (Katja Savolainen) will use a code to identify you rather than your real name.

Only I and Professor Amanda Phelan will know this number and will not share it with or give to anyone else. I will use a pseudonym in any write up or publication of the project and will ensure that no clues to your identity appear. Any extracts from what you say that are quoted in the thesis write up will be entirely anonymous. If you say anything that might reveal who you are, I will remove this from the write up and instead refer to it in general terms. Your interview data will be used for the purpose of this project only and will not be used in any other project without your explicit consent.

Your pseudo anonymised data will be stored for 7 years after the completion of the study. It will be stored in an encrypted file on a secure drive. It will only be accessible for auditing purposes or ethical queries emerges after the study is completed. After 7 years it will be destroyed and not be able to access again.

Data will not leave Republic of Ireland as per GDPR regulations.

Who will access and use my personal data as part of this study?

- Katja Savolainen, the primary investigator for this study, will have access to your contact details, personal details such as age, gender and your experience as staff at [name of the nursing home]. Other data will be the interview text that will be collected during the interview. No other data will be collected. No healthcare records, care plans or care details will be accessed.
- The Director of Nursing at [Name of the nursing home] has given permission to place this participation information and posters in [Name of the nursing home] staff areas and the gatekeeper of [Name of gatekeeper and nursing home] is assisting in the distribution of the information packs. They are not involved in who will end up participating.



- Although all steps are taken to maintain your confidentiality in participating in the study, due to help of Director of Nursing and gatekeeper of [name of the nursing home], they may know you are participating in the study.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is the most important in the study. Steps will be taken to make sure your confidentiality and your data is protected. It is of important that your data is kept safe. Here are how it is kept safe:

All personal details are kept in a password file on an encrypted laptop only accessible by Katja Savolainen.

A Data Protection Impact Assessment was carried out by the Data Protection Officer in Trinity College Dublin and the level of risk was identified to be low.

I (Main principal investigator Katja Savolainen) have completed Research integrity training and General Data Protection training to make sure all legal and ethical steps are maintained.

What is the lawful basis to use my personal data?

By law,²⁸ we can use your personal information for scientific research²⁹ (in the public interest³⁰). We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

What are my rights?

²⁸ The European General Data Protection Regulation (GDPR)

²⁹ Article 9(2) (j))

³⁰ (Article 6(1)(e)



As per Data Protection (GDPR) laws internationally and in Ireland, You are entitled to:

- The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format and to have it transferred to another data controller
- The right to request deletion of your data

By law you can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting your study researcher Katja Savolainen, phone number 087xxxxxxx or email [REDACTED]@tcd.ie or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.



Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by Trinity College Faculty of Health Science Research Ethics Committee, approval was granted on 10th of august 2021

Who is organising and funding this study? Will the results be used for commercial purposes?

This study is not funded by any organisation. The research is conducted in the purpose of obtaining a PhD degree and not for commercial purposes. It is self-funded by the PhD student Katja Savolainen.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

There is no compensation to take part in the study. It will also not cost you anything to take part. We appreciate your participation as it will provide important knowledge in the topic of rights of older people in nursing homes.

Part 4 – Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

- Principal Investigator: PhD student Katja Savolainen, email: [REDACTED]@tcd.ie
Phone: 087xxxxxxx.
- Supervisor: Professor Amanda Phelan, School of Nursing & Midwifery email: [REDACTED]@tcd.ie
- Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You will be given a copy of this information leaflet and the signed Consent Form to keep.



STUDY NAME: Discursive positioning of rights of older people in long term care
Centre ID:
Identification Number for study:

Consent Form

There are 2 sections in this form. Each section has related statements and asks you to initial if you agree. The end of this form is for the researcher to complete. Please ask any questions you may have when reading each of the statements. Thank you for participating. Please Initial the box if you agree with the statement. Please feel free to ask questions if there is something you do not understand.

General	Tick box
I confirm I have read and understood the Participant Information Leaflet for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study is entirely voluntary , and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason. I understand that deciding not to take part will not affect my employment.	
I understand that all information will be kept private and confidential and that my name will not be disclosed.	
I understand that I will not be paid for taking part in this study .	
I know how to contact the principal investigator if I need to.	
I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information leaflet which I have been provided with.	
I agree to being contacted by researcher by either email or phone as part of this research study.	
Data processing	Tick box
I agree to allow personal information about me to be used in the academic research for the purpose of PhD dissertation as described in the Information leaflet.	
I understand the anonymised data will be used in publications.	
I understand that personal information about me, including the transfer of this personal information about me outside of the EU, will be protected in accordance with the General Data Protection Regulation.	
I understand that there are no direct benefits to me from participating in this study. I understand that results from analysis of my personal information will not be given to me .	
I understand that I can stop taking part in this study at any time without giving a reason and this will not affect my employment.	



Participant Name (Block Capitals) Participant Signature Date

Witness Name (Block Capitals) Witness Signature Date

To be completed by the Principal Investigator.

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team

Researcher name, Title and qualifications

Signature

Date

2 copies to be made: 1 for participant, 1 for PI



Appendix 12: Invitation letter to the gatekeeper

Study: Discursive positioning of rights of older people in long-term care

Dear Gatekeeper [name of gatekeeper],

I would like to invite you to assist me in conducting a research study. Before you decide you need to understand why the research is being done and what it would involve for you and for the participants. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Take time to decide whether or not to facilitate this research.

WHO I AM AND WHAT THIS STUDY IS ABOUT

My name is Katja Savolainen and I am a PhD student at Trinity College Dublin, School of Nursing and Midwifery. I am doing this study on rights of older people in long-term care as part of my PhD dissertation. It is an interview study that attempts to capture the understanding and knowledge of rights of older people. Interview with residents, staff nurse and family members will be conducted individually.

WHAT I NEED YOUR ASSISTANCE WITH

I need your assistance in distributing the participation information leaflet and consent form to potential participants. Residents, staff nurses and family members are to be included in individual interviews. You will be given names (list of) potential participants in the three groups; residents, family members and staff by the Director of Nursing. You are to distribute to these potential participants. Potential participants will also be able to see the poster can contact me directly through those.

Inclusion criteria for the three participant groups:

	Inclusion criteria	Exclusion criteria
Older people	Be a resident in the long-term care facility [Name of the nursing home] for at least 4 months. Be 65 years or older Be able to give informed consent using a functional capacity approach. Able to have a conversation.	Under 65 years of age. Not able to give informed consent. No verbal communication



Staff	Be a staff nurse or healthcare assistance and have worked at least 6 months in the long-term care facility. And be involved in providing direct care to residents.	Management, ancillary staff (kitchen, housekeeping, maintenance).
Family member	Be a spouse, partner, child, nephew/niece of a resident in the long-term care facility [Name of the nursing home]	Friends, not named family members according to the resident.

Each participation information pack and consent form are in three separate coloured envelopes:

- Green for residents
- Dark blue for staff
- Yellow for family members

The potential participants need to contact me (Katja, researcher) directly but they might want your assistance with that. It is important to maintain confidentiality and integrity in regards to who will participate in the study. Refer back to the information pack if the potential participants want to ask questions and let me (Katja) know that there are queries regarding the study.

Once Information packs have been given to the different potential participants, I (Katja) would like to know how many has been distributed. I will not require the names of any potential participants, they will contact me directly. If a potential participant contact you of interest please direct them to my contact details. You will not have any input into the study following the distribution of the information packs. If you have any queries regarding the study, please contact me-details are below.

THANK YOU

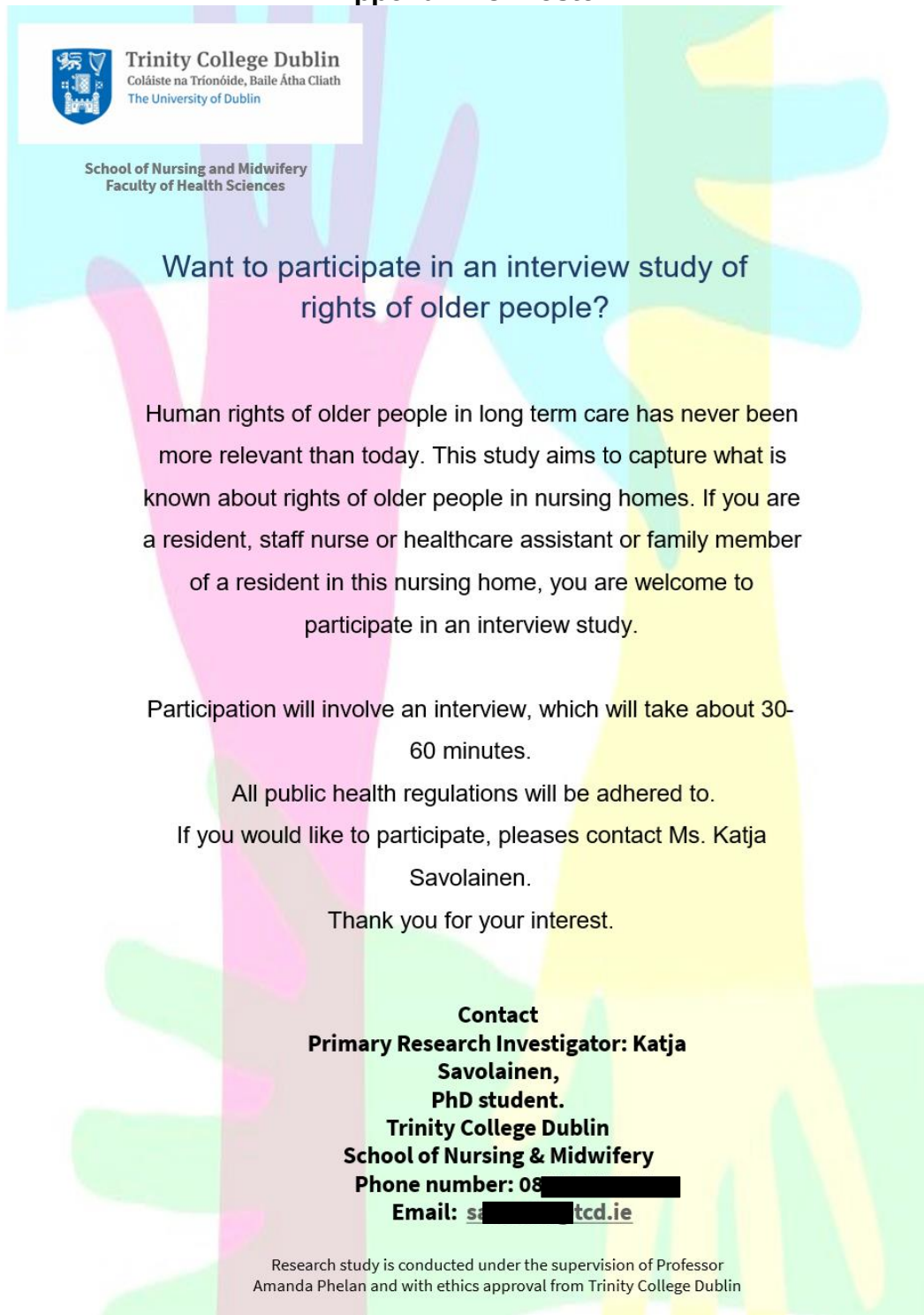
Kind regards

Katja Savolainen

Please do contact Katja Savolainen, email: [REDACTED]@tcd.ie Phone No: 087 xxxxxxxx for any questions or further information. You can also contact supervisor Professor Amanda Phelan at Trinity College Dublin, School of Nursing & Midwifery, email: [REDACTED]@tcd.ie



Appendix 13: Poster



 **Trinity College Dublin**
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

School of Nursing and Midwifery
Faculty of Health Sciences

Want to participate in an interview study of rights of older people?

Human rights of older people in long term care has never been more relevant than today. This study aims to capture what is known about rights of older people in nursing homes. If you are a resident, staff nurse or healthcare assistant or family member of a resident in this nursing home, you are welcome to participate in an interview study.

Participation will involve an interview, which will take about 30-60 minutes.

All public health regulations will be adhered to.

If you would like to participate, please contact Ms. Katja Savolainen.

Thank you for your interest.

Contact
Primary Research Investigator: Katja Savolainen,
PhD student.
Trinity College Dublin
School of Nursing & Midwifery
Phone number: 08 [redacted]
Email: s[redacted]tcd.ie

Research study is conducted under the supervision of Professor Amanda Phelan and with ethics approval from Trinity College Dublin



Appendix 14: Support email from LTC Facility No.4

[Redacted]

Sent: [Thursday 29 September 2022, 13:23](#)

To: Katja Savolainen <[Redacted]>

Subject: Re PHD study

Dear Katja.

I refer to your enquiry regarding the above.

I wish to advise we are happy to support focus

[Redacted]

Dublin

Get [Outlook for Android](#)

"Information in this email (including
attachments) is confidential.



Appendix 15: Ethical Amendment approval



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Katja Savolainen,
School of Nursing & Midwifery,
Trinity College Dublin,
24 D'Olier Street,
Dublin 2

25th October 2022

Ref: 210604
Title of Study: Discursive positioning of rights of older people in long term care- Foucauldian Critical Discourse Analysis.

Dear Katja,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in October 2022, we are pleased to inform you that the above project (as amended with the following changes) has ethical approval to proceed.

Please give specific details of the requested amendment(s):

Due to challenges in the recruitment of family members to participate in semi-structured interviews, I am requesting an amendment to conduct data collection with this cohort through two focus groups. I have reached my targets in recruitment for the other groups, staff and residents. The aims and objectives of study have not changed.

To assist in the focus groups, a new recruitment site has been identified [REDACTED] (appendix 13) who have agreed to disseminate the revised invitation letter (appendix 15) and participant leaflet (appendix 9) and display a study poster. In addition, [REDACTED] will nominate a gatekeeper (appendix 16) and provide a private room where the two focus groups will be conducted. The same procedure will be applied in relation to obtaining consent, questions asked and transcribing the focus groups through audio recording. In addition, participants will be advised of the confidentiality of the discussion within the focus groups.

One change for participants is that the ability to opt out of study is not possible after participation in the focus group. This due to the challenge in recognising and extracting individual voices in focus group interview. This change is advised in the revised participant information sheet (appendix 9) for family members
Study is to be extended to December 2022 to allow for focus groups to be conducted.

Appendix numbers referred to are from level II application with tracked changes.

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

Yours sincerely,

Prof. Jacintha O'Sullivan
Chairperson Faculty Research Ethics Committee



Appendix 16: Gatekeeper letter for Focus Group.

Study: Discursive positioning of rights of older people in long term care

Dear Gatekeeper [name of gatekeeper],

I would like to invite you to assist me in conducting a research study. Before you decide you need to understand why the research is being done and what it would involve for you and for the participants. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Take time to decide whether or not to facilitate this research.

WHO I AM AND WHAT THIS STUDY IS ABOUT

My name is Katja Savolainen and I am a PhD student at Trinity College Dublin School of Nursing and Midwifery. I am doing this study on rights of older people in long term care as part of my PhD dissertation. It is an interview study that attempts to capture the understanding and knowledge of rights of older people. Interviews with residents and staff have been conducted individually. Focus group interviews will be conducted with family members, this is what I need your assistance with.

WHAT I NEED YOUR ASSISTANCE WITH

I need your assistance in distributing the participation information leaflet and consent form to potential participants. Family members are to be included in two separate focus groups. Any family member that fit the inclusion criteria below is a potential participant. Potential participants will also be able to see the poster and can contact me directly through those.

Inclusion criteria for the participant group:

	Inclusion criteria	Exclusion criteria
Family member	Be a spouse, partner, child, nephew/niece of a resident in [REDACTED]	Friends, not named family members according to the resident.

The potential participants need to contact me (Katja, researcher) directly but they might want your assistance with that. It is important to maintain confidentiality and integrity in regards to who will participate in the study. Refer back to the information pack if the potential participants want to ask questions and let me (Katja) know that there are queries regarding the study. I will also require your assistance in finding a private confidential room where the focus group can take place.

Once Information packs have been given to the different potential participants, I (Katja) would like to know how many has been distributed. I will not require the names of any potential participants, they will contact me directly. If a potential participant contact you of interest please direct them to my contact details. You will not have any input into the study following the distribution of the information packs. If you have any queries regarding the study, please contact me-details are below.

THANK YOU

Kind regards

Katja Savolainen Please do contact email: [REDACTED]@tcd.ie Phone No: 087 xxxxxxxx for any questions or further information.



Appendix 17: Poster for Focus Group Recruitment





Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

School of Nursing and Midwifery
Faculty of Health Sciences

Invitation to participate in a focus group interview of rights of older people

Human rights of older people in long term care has never been more relevant than today. This study aims to capture what is known about rights of older people in nursing homes. If you are a family member of a resident in this facility, you are welcome to participate in a focus group interview.

Participation will involve a focus group meeting, which will take about 45-60 minutes.

All public health regulations will be adhered to.

If you would like to participate, please contact Ms. Katja Savolainen.

Thank you for your interest.

Contact
Primary Research Investigator: Katja Savolainen, PhD student.
Trinity College Dublin
School of Nursing & Midwifery
Phone number: 08 [REDACTED]
Email: [sa\[REDACTED\]@tcd.ie](mailto:sa[REDACTED]@tcd.ie)

Research study is conducted under the supervision of Professor Amanda Phelan and with ethics approval from Trinity College Dublin



Appendix 18: Invitation letter to participate in Focus Group

Invitation to Participate in a focus group interview,

Study Title: Discursive positioning of rights of older people in long term care

Dear family member of resident in [REDACTED],

I'm a PhD student at Trinity College Dublin School of Nursing and Midwifery and I am inviting you to participate in a focus group interview regarding rights of older people in long term care (nursing homes). As a family member of a resident at [REDACTED], you are in an ideal position to give me valuable first-hand information about your perspective of the resident's life in the nursing home.

The focus group will take approximately 45 to 60 minutes and is to capture your experiences and perspectives of the residents' everyday life in the nursing home in regard to rights. Your contribution in the focus group will be kept confidential. Your name will not be used and personal identifiers will not be revealed during the analysis and write up of findings. Participation in this focus group is completely voluntary and you may choose to withdraw from the study or not answer questions that you do not feel comfortable answering. There is no compensation for participating in this study. However, your participation will be a valuable addition to the research and findings could lead to increase understanding of rights of older people in long term care. If you are willing to participate, please read through the Participation Information Leaflet and consent form. If you have any questions, please do not hesitate to ask Katja on phone 087 xxxxxxxx or email [REDACTED]@tcd.ie. If you would like to participate, please, call or email me (Katja) and provide your availability to participate in a focus group. I (Katja) will arrange for the focus group to take place in a confidential private area.

Thank you for your time to read this letter of invitation,

Warm regards,

Katja Savolainen, PhD student, Trinity College Dublin School of Nursing and Midwifery
Email: [REDACTED]@tcd.ie Phone number: 087 xxxxxxxx



Appendix 19: Interview guide for Residents

Participant Code:
Nursing Home Code:

Interview guide- residents

Before starting: Any questions? You have signed the consent form but I want to reassure that if you want to stop the interview and withdraw your consent you are entitled to do so.

You are happy to continue with the interview? YES No

I will record the interview (show device if in person, explain how if video call). If you want to stop at any time, you can say so.

Demographics: What age bracket do you belong to?

65-70	71-75	76-80	81-85	86-90	91-95	>96

What gender do you identify with?	Female	Male	Other

How long have you lived in the Nursing Home (name of Nursing home)? (Months)	

1. *Ice- Breaker:* Tell me a little a bit about yourself. Prompt; are you from this area/town?
2. Can you tell me about the decision to move to the nursing home (name of the nursing home)?
Prompts: Why did you choose this nursing home (name of the Nursing home)? *Prompts:* Can you give me details of who was involved in the decision?
3. Have you discovered any benefits to moving to a long term care facility? Could you tell me of those benefits?
4. How has the move to the nursing home affected your daily life?
5. Tell me about your day in the Nursing home (name of Nursing Home)? *Prompts:* What time do you get up at? Have your meals? Do you participate in any activities?
6. What is your understanding of human rights? How do you think they affect older people in Nursing home?



7. What does (each separately) Fairness, Respect, Equality, Dignity, Autonomy mean to you?
8. UN has specific rights documents for women, children and those with disabilities. Do you think older people require a specific rights document? *Prompt:* The charters specifically talk about rights in these groups and how they need special measures to enable them to access general human rights standards on an equal basis with others, do you think older people need that as well?
9. Who has the duty to protect older people's rights? *Prompt:* Who would assist in defending older people's rights?
10. How has your daily life been impacted by the COVID-19 restrictions?
11. Do you think your rights have been affected by the restrictions? *Prompt:* Could you give me an example how they are affected?
12. Anything you want to add in regards to human rights and older people in long term care (nursing home)?

Thank you for your participation and taking time for this interview.

Would you like to receive a transcription of this interview?

YES

NO



Appendix 20: Interview guide for family members

Interview guide family member of resident

Participant Code:
Nursing Home Code:

Before starting: Any questions? You have signed the consent form but I want to reassure that if you want to stop the interview and withdraw your consent you are entitled to do so.

You are happy to continue with the interview? YES NO

I will record the interview (show device if in person, explain how if video call). If you want to stop at any time, you can say so.

Demographics:

What age bracket do you belong to?

20-25	26-30	31-35	36-40	41-45	46-50	51-55	56-60	61-65	66-70	71-75	>76

What gender do you identify with?

What category of family member do you belong to (i.e. your family bond to the resident)

Spouse/Partner	Daughter/Son	Sister/Brother	Niece/Nephew	Other:

1. How long has your family member been a resident in the nursing home (name of nursing home)?
2. Could you tell me about the circumstance for long term care for your family member (resident)?
3. How did your relative decide on this nursing home as their long term care facility?
Prompt: Did you and/or relative see the facility before the admission? How did you hear about it?
4. Could you tell me who was involved in the decision to move to this NH?
5. What do you think is important for your family member's every day life in the NH?
6. What is your understanding of human rights of older people in long term care?
Prompt: What does human rights mean to you? How do they relate to your family



- member in the nursing home?
7. How do you feel about your family member being in the nursing home? *Prompt:* Would you prefer it differently?
 8. What does (separately) Fairness, Respect, Equality, Dignity, Autonomy for older people mean to you?
 9. UN has specific rights documents for women, children and those with disabilities. Do you think older people require a specific rights document? *Prompt:* The charters specifically talk about rights in these groups and how they need special measures to enable them to access general human rights standards on an equal basis with others, do you think older people need that as well?
 10. Who has the duty to protect older people's rights? *Prompt:* Who would assist in defending older people's rights?
 11. How has the life of your relative been impacted by the COVID-19 restrictions?
 12. Anything you want to add in regards to human rights and older people in long term care?

Thank you for your participation and taking time for this interview.

13. Would you like to receive a transcription of this interview? YES NO



Appendix 21: Interview guide for staff

Nursing home code:
Participant Code:

Interview guide- Staff

Before starting: Any questions? You have signed the consent form but I want to reassure that if you want to stop the interview and withdraw your consent you are entitled to do so.

You are happy to continue with the interview? YES No

I will record the interview (show device if in person, explain how if video call). If you want to stop at any time, you can say so.

Demographics

What age bracket do you belong to?

20-25	26-30	31-35	36-40	41-45	46-50	51-55	56-60	61-65	>66

What gender do you identify with?	Female	Male	Other

Your staff title in the nursing home?	

How long have you worked in this nursing home (name of nursing home)	
How long have you worked with care of the older person?	
How long of experience do you have working in healthcare?	
What level of qualification do you have? <i>Example: A specific qualification such as MSc in dementia care or certificate in healthcare speciality</i>	

1. Could you tell me about your working day here in the nursing home (name of the nursing home)? *Prompt: how many residents do you look after? How would you organise your work day?*
2. When there is an admission of a new resident, how do you gather information of the new



- resident? Can you talk through the admission process of a new resident?
3. How do you assist a resident in their every day choices, needs and wishes?
 4. What does person centred care mean to you?
 5. What is your understanding of human rights of older people in long term care [nursing home]?
 6. Have you heard of the FREDA principles? *Prompt:* Have you heard of human rights approach to healthcare?
 7. What does (separately) Fairness, respect, equality, dignity and autonomy mean in delivering care to older people?
 8. UN has specific rights documents for women, children and those with disabilities. Do you think older people require a specific rights document? *Prompt:* The charters specifically talk about rights in these groups and how they need special measures to enable them to access general human rights standards on an equal basis with others, do you think older people need that as well?
 9. Who has the duty to protect older people's rights? *Prompt:* Who would assist in defending older people's rights?
 10. How has the residents life been impacted by the COVID-19 restrictions and what are your thoughts about the restrictions?
 11. Anything you want to add in regards to human rights and older people in long term care?

Thank you for your participation and taking time for this interview.

Would you like to receive a transcription of this interview? YES NO



Appendix 22: Interview guide Focus Group

Before starting:

Thank you all for participating in this focus group. My name is Katja Savolainen and as you have completed consent form you know that I'm completing a study for my PhD in relation to human rights of older people in long term care facilities.

Your participation in the focus group is voluntary, but once you participate you cannot withdraw from the study after this interview due to practical reasons. As the researcher, I will not know who has contributed what.

It's all right to abstain from discussing specific topics if you are not comfortable.

All responses are valid—there are no right or wrong answers.

Please respect the opinions of others even if you don't agree.

All is confidential and we help protect others' privacy by not discussing details outside the group.

Speak as openly as you feel comfortable.

If you want to discuss anything with me afterwards please do. I will record the interview (show device if in person, explain how if video call).

Any questions or anything that is worrying before we start?

Demographics:

What age bracket do you belong to?

20-25	26-30	31-35	36-40	41-45	46-50	51-55	56-60	61-65	66-70	71-75	>76

What gender do you identify with?

What category of family member do you belong to (i.e. your family bond to the resident)

Spouse/Partner	Daughter/Son	Sister/Brother	Niece/Nephew	Other:

1. Anyone want to tell how your family member was admitted to [name of the LTC facility]?
2. Could you tell me who was involved in the decision to move to this NH?
3. What comes to mind when I say human rights?
4. What is your understanding of human rights of older people in long term care?
5. *Prompt:* What does human rights mean to you? How do they relate to your family member in the nursing home?



6. What do you think is important for your family member's every day life in the NH?
7. How do you feel about your family member being in the nursing home? *Prompt:* Would you prefer it differently?
8. What does (separately) Fairness, Respect, Equality, Dignity, Autonomy for older people mean to you?
9. UN has specific rights documents for women, children and those with disabilities. Do you think older people require a specific rights document? *Prompt:* The charters specifically talk about rights in these groups and how they need special measures to enable them to access general human rights standards on an equal basis with others, do you think older people need that as well?
10. Who has the duty to protect older people's rights? *Prompt:* Who would assist in defending older people's rights?
11. How has the life of your relative been impacted by the COVID-19 restrictions?
12. Anything you want to add in regards to human rights and older people in nursing homes?

Thank you for your participation