Informal caregivers' perspectives on the role of the environment on older persons living with dementia within a long-term care facility in Malta

Francesca Alden

A dissertation submitted in partial fulfilment of the requirements of

the Master of Gerontology and Geriatrics

Department of Gerontology & Dementia Studies

Faculty for Social Wellbeing

University of Malta

May 2023

L-Università ta' Malta

FACULTY/INSTITUTE/CENTRE/SCHOOL Social Wellbeing

DECLARATIONS BY POSTGRADUATE STUDENTS

(a) Authenticity of Dissertation

I hereby declare that I am the legitimate author of this Dissertation and that it is my original work.

No portion of this work has been submitted in support of an application for another degree or qualification of this or any other university or institution of higher education.

I hold the University of Malta harmless against any third party claims with regard to copyright violation, breach of confidentiality, defamation and any other third party right infringement.

(b) Research Code of Practice and Ethics Review Procedures

I declare that I have abided by the University's Research Ethics Review Procedures. Research Ethics & Data Protection form code SWB-2022-00341.

As a Master's student, as per Regulation 77 of the General Regulations for University Postgraduate Awards 2021, I accept that should my dissertation be awarded a Grade A, it will be made publicly available on the University of Malta Institutional Repository.

02.2023

ABSTRACT

Older persons living with dementia have lower thresholds for stress tolerance with regards to environmental stimuli which in turn results in dysfunctional behaviours and difficulty with performing activities of daily living. It is well recognised that the environment has an important role in the care of older persons living with dementia and that environmental modifications within long-term care facilities could better meet their needs.

The purpose of this study was to get an in-depth understanding of informal caregivers' perspectives on the influence of the physical and social aspects of the environment on older persons living with dementia within a long-term care facility in Malta.

This study adopted a qualitative approach based on Interpretive Description. Data was collected through semi-structured interviews with six informal caregivers of older persons living with dementia within a long-term care facility. The researcher drew on Interpretive Description methodology and reflexive Thematic Analysis to analyse the data and generate findings.

Three themes were generated: (a) social engagement, (b) supportive healthcare practices in relation to the social environment, and (c) building design in relation to the physical environment.

The participants considered the social environment to be more important than the physical environment in promoting the well-being of older persons living with dementia. The two are inter-related and should complement each other to provide quality care for older persons living with dementia within long-term care facilities.

Keywords: *dementia, dementia care, long-term care facility, care home, physical environment, social environment, caregivers' perspectives.*

DEDICATION

I dedicate this dissertation to my late grandfather Joseph. May his strength and love live on through our family.

ACKNOWLEDGEMENTS

I would like to start by thanking my supervisor Dr. Maria Aurora Fenech for her continuous support throughout this journey. Her help and insightful guidance were truly appreciated and will not be forgotten. This course has been a positive learning experience whereby, with the help of the lecturers, I have gained so much knowledge and grown as a researcher.

A heartfelt thank you goes out to the participants of this study who allowed me to explore their personal experiences. This dissertation would have not been possible without their participation. I would also like to thank the gatekeeper for his time and help in contacting the participants.

Lastly, I would like to extend my gratitude to my husband Jeremy. I am forever grateful for his constant patience and support especially throughout the past few years.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

LIST OF ABBREVIATIONS

AACC	Active Ageing Community Care
AD	Alzheimer's disease
BPSD	Behavioural and Psychological Symptoms of Dementia
FREC	Faculty Research Ethics Committee
GDS	Global Deterioration Scale
ID	Interpretive Description
LTC	Long-term care
MCI	Mild cognitive impairment
OPLWD	Older person living with dementia
OPsLWD	Older persons living with dementia
PCC	Person-centred care
PPP	Public-private partnership
PSRPDAA	Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing
REDP	Research Ethics and Data Protection Form
SCSA	Social Care Standards Authority
SCU	Specialised care unit
SVP	St. Vincent De Paul
TA	Thematic analysis
WHO	World Health Organization

DEFINITION OF KEY TERMS

The following definitions apply within the context of this research study:

Activities of Daily Living: A term used to describe basic activities needed for survival and well-being such as personal care, feeding, toileting, dressing, bathing, hygiene, and mobility (Edemekong et al., 2022).

Dementia-friendly: "A cohesive system of support that recognises the experiences of the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way" (Davis et al., 2009).

Person-centred Care: Healthcare that is guided by individuals' values and preferences to support their realistic health and life goals. It is achieved through a dynamic relationship among individuals and providers to inform decision-making according to the individuals' wishes and requirements (American Geriatrics Society Expert Panel on Person-Centered Care, 2016).

Physical environment: The properties and components of the built environment within the LTC facility make up the physical environment (Bird et al., 2018). It is recognised as an element of concrete reality whereby it is inanimate, objective, tangible, and measurable (Lawton, 1982; Wahl et al., 2012).

Serenity Manor: Serenity Manor is a fictitious name that was used to refer to the long-term care (LTC) facility drawn by lot to participate in this research project. This pseudonym was used to retain confidentiality and anonymity of the facility. Serenity Manor is state-owned but is operated and managed by a private company under the public-private partnership (PPP) scheme. The building has 4 floors with an occupancy of 131 beds, access to a large garden, a chapel, and an outdoor private parking lot. Serenity Manor has a traditional

building design with bedrooms situated on either side of a long corridor ('T' shape) along with the nursing station and dining room located in the middle of the corridor. The majority of the rooms are 2-bedded, however there are some 4-bedded rooms and 3 single rooms. The majority of the bedrooms do not have private bathrooms so shared bathrooms can be found along the corridors. Notwithstanding that there are no licensed dementia-friendly living concepts in Malta, for the purpose of this dissertation, the segregated specialised care unit (SCU) at Serenity Manor will be referred to as a dementia unit. The dementia unit is a small-scale unit secured by a locked door and consists of 7 2-bedded rooms with no private bathrooms. The layout includes an 'L' shaped corridor with bedrooms located on either side, along with a nursing station and access to an outdoor terrace found in the middle of the corridor. At the end of the corridor one can find an open-plan lounge with tables and chairs which is used for organised activities, family visitations, mealtimes, and as an area to spend time in. The dementia unit has a lot of natural light and is decorated with paintings, pictures, plants, and posters on Alzheimer's disease. Background music and dementia-friendly signage (pictures and words to describe for e.g. toilet, and bedrooms) can be found within the unit.

Social environment: "The social environment describes the social setting in which people live or act. It is comprised of human contacts, stimulation, activities, but also the larger cultural values" (Rosteius et al., 2022). It includes the immediate needs of the individual, interactions among group members, activities and cultural values (Bird et al., 2018).

Well-being: "When there is a balance between resources and challenges, positive functioning and psychological health improves" (Sturge et al., 2021).

Quality of life: "An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization, 2012). It is often considered a multidimensional concept (Bökberg et al., 2017)

CHAPTER 1
INTRODUCTION

1.0 Introduction

In this chapter, the background information related to important concepts in this study are presented. The research questions, research aims and the significance of this study are also described in this chapter. Furthermore, this chapter highlights the methodology used to conduct the research study.

1.1 Background – Setting the Scene

The number of persons aged 65 years and over in the world has increased significantly due to the fact that people are living longer due to improvements in healthcare, hygiene, living standards, nutrition and medicine (Brown, 2015). An increasing life expectancy along with declining fertility rates has resulted in population ageing. In 2019 there were an estimated 703 million persons aged 65 years and over and this was projected to double by 2050 (United Nations, 2019). Ageing is associated with an increased risk of disability and prevalence of noncommunicable diseases such as dementia, one of the main causes of morbidity and dependence in older persons (WHO, 2021). In 2021 it was estimated that there were 55 million people living with dementia globally. This was projected to increase to 78 million by 2030 (Alzheimer's disease International, 2021) and 153 million by 2050 (GBD 2019 Dementia Forecasting Collaborators, 2022). With regards to the situation in Malta, the number of older persons living with dementia (OPsLWD) in 2019 was 6,552 persons and it was estimated that this would increase to 8,695 persons in 2025 and 14,117 persons in 2050 (Alzheimer Europe, 2019). The current statistics regarding the amount of OPsLWD in long-term care (LTC) facilities in Malta is unknown.

Socio-demographic changes around the world have shown a weakening of family and community networks (Formosa, 2018), resulting in a reduction in informal support from family and friends which is no longer allowing OPsLWD to remain living at home (Eska et al., 2013). In fact, Innes et al. (2011) explored dementia care in Malta and found that informal caregivers faced several difficulties in providing care for an OPLWD in the community. This

was due to the fact that the majority of OPsLWD displayed behavioural and psychological symptoms of dementia (BPSD) which often had a negative effect on their and their caregivers' quality of life (Barbe et al., 2018). BPSD and the difficulty in carrying out everyday activities are often the first predictors of institutionalization (Toot et al., 2017). Increased rates of institutionalization have resulted in increased demands on health care systems with consequent social and economic challenges.

One way of supporting OPsLWD in their daily activities is by modifying the environment to enhance performance and diminish challenging behaviours (Woodbridge et al., 2016). Even though there is a growing amount of data on the benefits of environmental designs of LTC facilities for the OPLWD, there is still a dearth of research on informal caregivers' perspectives of the influence of these environments on the BPSD and quality of life of OPLWD (Garcia et al., 2012). Locally, there is a dearth of research exploring this phenomenon. Since informal caregivers are important observers of OPsLWD in LTC facilities, their perspectives on the role of the environment are considered essential in order to obtain a meaningful understanding in this area and help in dementia care planning (Nordtug et al., 2021).

1.2 Rationale of the Study

Through her 5-year experience working as a physiotherapist with the Active Ageing Community Care (AACC) in several LTC facilities around Malta, the researcher has witnessed first-hand that very often the environments of LTC facilities do not meet the needs of OPsLWD. In fact, Formosa and Scerri (2015) suggested that government operated services and LTC facilities in Malta were not meeting the needs of OPsLWD in Malta. Secondly, the researcher has observed a lack of human resources and a large amount of health care staff who are not well trained in dementia care even though there is a substantial amount of OPsLWD residing in LTC facilities. An inadequate environment and the lack of person-centred care (PCC) for the OPLWD has resulted in negative consequences such as an increased use of anti-psychotic medication (Bugeja, 2010) [cited in Scerri, 2017] and the

unnecessary use of physical restraint devices (Fenech, 2016). Consequently, the researcher was interested in exploring the phenomenon within the residential care sector in Malta.

The National Strategy for Dementia in the Maltese Islands (2015-2023) indicated the need for further qualitative research regarding the care being provided in LTC facilities for OPsLWD in order to ensure quality care service provision (Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing: PSRPDAA, 2014). An extensive local literature search has revealed that this local study is the first of its kind where the informal caregivers of OPsLWD are the main participants in this project.

1.3 Inspiration for Choice of Subject

The motivation for this study is accredited to both personal reflections and work experience. The researcher has had first-hand experience of a relative living with dementia and relocating from the community to a LTC setting. Unfortunately, a bed in a dementia-friendly unit was not available at the time and, in the researcher's opinion, the traditional building design and care had exacerbated challenging behaviours such as issues with wayfinding, which lead to increased confusion and agitation for her loved one. Furthermore, the lack of dementia-friendly activities had resulted in lack of social involvement which increased dependence and social exclusion. Following this experience, the researcher was further motivated to carry out research in this field with the hope of discovering possible solutions such as a more adapted and supportive environment for OPsLWD.

As a physiotherapist specializing in the field of geriatrics, encouraging older persons' independence, mobility and functionality is placed at the core of practice. Individualised non-pharmacological interventions through multidisciplinary and interdisciplinary team approaches should always be the first line of treatment in the management of BPSD (Keng et al., 2020). Beneficial interventions include structured activities, multi-sensory environments, music therapy and exercise (Fleiner et al., 2017). Through her experience working within LTC settings, the researcher has observed the use of anti-psychotic drugs

and physical restraints as a first line of treatment as opposed to non-pharmacological interventions. This is associated with increased agitation, aggression and a worse quality of life for the OPLWD (Lombardo et al., 2020) and is definitely not promoting person-centred care which many LTC settings seem to advertise. The researcher was guided to carry out this research by the need to explore the perspectives of informal caregivers on the role of the environment on OPsLWD, issues stemming from these experiences and the need to understand and generate knowledge that could inform clinical practice.

1.4 Aims of the Study

This study aimed to narrow the gap in the knowledge of perspectives regarding environmental factors that influenced OPsLWD in LTC facilities in Malta. This was achieved through exploring informal caregivers' perspectives on:

1. The role of the physical environment on the OPLWD in a LTC facility.
2. The role of the social environment on the OPLWD in a LTC facility.

1.5 Research Questions

Considering the research aims, this study (through the informal caregivers' perspectives) sought to answer the following questions:

1. How does the physical environment affect OPsLWD in a LTC facility?
2. How does the social environment affect OPsLWD in a LTC facility?
3. Does the environment of the LTC facility meet the needs of OPsLWD?
4. What can be done to improve the environment of the LTC facility to meet the needs of OPsLWD?

1.6 Research Plan

The research process began by identifying a gap in the literature in order to obtain a rationale for this study. The research questions were developed in order to study a specific phenomenon, that is, the perspectives of informal caregivers' on the influence of the environment for OPsLWD in a LTC facility. The process moved to determine the type of methodology most appropriate for this study along with the method of data collection and data analysis (Tenny et al., 2021). A qualitative approach based on interpretive description (ID) was utilised to address the research aims and objectives. A pilot study was carried out prior to the actual interviews with the purpose of fine tuning the open ended questions and to improve the quality of the research tool (Malmqvist et al., 2019). This helped the researcher practise her interview skills and familiarise herself with performing semi-structured interviews (Noon, 2018). Face-to-face interviews were carried out with informal caregivers of OPsLWD within a LTC facility. The data was transcribed using Microsoft Word (2016) and was then analysed using reflexive Thematic Analysis (TA) which will be described at a later stage in this dissertation. Finally, the results were presented and discussed in relation to other local and international research studies.

1.7 Conceptual Framework

This dissertation was based on environmental gerontology (EG) which materialised during the 1960's as a specialisation that focused on understanding the interactions between older persons and their environments in respect to the ecology theory of ageing (Isaacson et al., 2020). Several gerontological researchers have contributed to the development of EG by arguing that outcomes in later life are influenced by a person (P) – environment (E) dynamic (Lawton, 1977; Lawton, 1999, Scheidt & Windley, 1985; Wahl, 2001). The first major theory that was developed to provide an explanation for this relationship was Lawton & Nahemow's (1973) individual competence and environmental press model. This model illustrates the relationships between individuals and their environment and highlights the importance of a Person-Environment (P-E) fit on individuals' affect and behaviours (Lawton & Nahemow, 1973). A key concept of the ecological theory of ageing is 'fit' which is considered to be a definite standard of compatibility between an individual's capabilities and their environment (Ren & Strickfaden, 2018). Individual competence refers to a person's

capabilities which are related to biological health, sensory-perceptual capacity, motor skills, cognitive capacity, and ego strength. On the other hand, environmental press refers to the physical, social and interpersonal environments. When environmental demands correspond to the individual's level of competence, this results in positive affect and adaptive behaviours. On the other hand, when environmental demands exceed or fall below an individual's competence level, this results in negative affect and maladaptive behaviours (Jao et al., 2019; Jao et al., 2021).

Lawton & Nahemow's (1973) psycho-social model has been acknowledged as the foundation for the development of several theoretical frameworks for research on dementia. There is plenty of evidence accentuating the link between environmental factors and the challenging behaviours of OPsLWD (Jao et al., 2019). This model proposed that individuals with lowered physical or cognitive competence, as in dementia, is associated with increased sensitivity and susceptibility to environmental features. With this reasoning, the environment of LTC facilities may be adapted to compensate for individuals with lowered competence, such as OPsLWD, in order to improve their behaviour (Chaudhury & Cooke, 2014).

Hall & Buckwalter (1987) used the foundation of Lawton & Nahemow's model to develop the progressively lowered stress threshold model precisely for OPsLWD. This model proposed that progressive cerebral pathology is linked with a progressive decline in stress threshold (Calkins, 2018). Therefore, OPsLWD present with a decline in their level of competence due to the progressive deterioration associated with dementia (Cohen-Mansfield, 2000; Woodbridge et al., 2018). As a result, these individuals have lower thresholds for stress tolerance with regards to environmental stimuli which in turn results in dysfunctional behaviours and difficulty with performing activities of daily living (Duru Aşiret et al., 2021; O'Donell et al., 2022; Pickering et al., 2022). Chaudhury et al. (2018) carried out a literature review of 103 studies and discovered that the environmental features of LTC facilities had a considerable impact on the behaviours of OPsLWD residing in those facilities. Environmental stimuli that surpass an individual's threshold for tolerating stress result in negatives physical, psychological and social consequences (Cerga-Pashoja, 2018).

Hall & Buckwalter (1987) put an emphasis on the amount of stimulation as the main aspect that impacts functional abilities and behavioural outcomes (Calkins, 2018). While the competence-press model proposed that insufficient press is associated with maladaptive behaviours, the progressively lowered stress threshold model proposed that it is more beneficial to keep individuals below their stress threshold. Both these models provide a solid conceptual framework for the modification of environmental features to improve the P–E fit to reduce challenging behaviours (Jao et al., 2019). Furthermore, modifying environmental stimuli according to the processing skills of the OPLWD may also help support an individual's independence and quality of life by maintaining their performance potential (Chaudhury et al., 2018; Jao et al., 2021; Woodbridge et al., 2018).

The aforementioned two models were used as the researcher's conceptual framework as they provided an understanding of how the environment affects the OPLWD in LTC facilities which is in line with the project's research questions. In addition, the concept of place for dementia care will be discussed later on in Section 2.3.

1.8 Research Project Outline

This research project consists of five chapters. It began with the introductory chapter followed by the literature review which involved a discussion of OPsLWD and how the environment impacts them. In relation to this phenomenon, current international and local literature was reviewed. The third chapter involves a detailed overview of the methodological framework used by providing an explanation of the (a) research design, (b) research plan, (c) sampling and recruitment of participants, (d) data collection, (e) analysis, and (f) ethical considerations. The fourth chapter presented the findings of the study together with the interpretation of the results. The fourth chapter also contains a discussion of how the findings compared to the current literature. Finally, in the last chapter, the findings were summarised and recommendations of the implications for future policy and practice were presented.

CHAPTER 2
LITERATURE REVIEW

2.0 Introduction

This chapter will discuss the existing international and local literature regarding the effects of the environment of long-term care (LTC) facilities on older persons living with dementia (OPsLWD). The literature review begins with an explanation of dementia, its associated characteristics and challenges. This chapter goes on to provide an explanation of the relationship between the older person living with dementia (OPLWD) and LTC with a focus on the environment. A thorough literature review on different perspectives on the topic was carried out and discussed. An overview on the different types of LTC related environments that are available for OPsLWD will follow. The difference between the local and international situation regarding LTC facilities will also be presented.

The following online databases were used to carry out the literature review: Medline, PubMed, and SAJE Journals. Keywords included “dementia care”, “long-term care facility”, “care home”, “environment”, “building design”, “physical environment”, “social environment”, and “caregivers’ perspectives”.

2.1 Understanding Dementia

Normal age-related physical and cognitive changes occur in the brain as a person ages. The most common age related changes in the brain are decreased connectivity and performance, brain atrophy such as the loss of grey matter and white matter volumes, increased ventricular size and cortical thinning (Bonifazi et al., 2018). These structural changes are associated with the loss of physiological functions such as sensory, motor and cognitive functions and an increased risk for diseases (Grajauskas et al., 2019). In fact, when these changes are more severe and exceed normal age-related changes it usually indicates the presence of a neurological disease (Murman, 2015). Unfortunately, due to population ageing and the increase in life expectancy, the prevalence of cognitive impairment in later life is growing (Alzheimer’s Disease International, 2021).

Dementia, as defined by the World Health Organization (WHO), is an umbrella term that refers to a group of symptoms that is characterised by progressive deterioration in cognitive function. These include (a) memory loss, (b) disorientation, (c) difficulties with thought processing and reasoning skills, (d) impaired communication, (e) poor judgement, (f) reduced executive functioning, and (g) language and calculation problems (WHO, 2021). According to WHO, Alzheimer's disease (AD) is the most common form of dementia with other forms including vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Dementia can also occur secondary to another disease such as Parkinson's disease, Huntington's disease and amyotrophic lateral sclerosis (WHO, 2021). AD is a common and complex hereditary disease that is characterised by progressive cognitive decline which leads to the impairment of function and activities of daily living (Elliott et al., 2021).

In addition to cognitive decline, dementia is associated with deterioration of the five senses; (a) vision (b) smell, (c) taste, (d) hearing, and (e) touch (Strøm et al., 2016). Visual impairments occur due to difficulties with the interpretation of images, distinction between colours and shapes, and recognition of familiar places and faces (Smith & D'Amico, 2020). Additionally, smell and taste may be diminished as OPsLWD experience difficulties with the identification of odours due to a lack of sensory capability (Behrman et al., 2014). Likewise, the inability of OPsLWD to process and understand certain sounds results in hearing problems and confusion. Lastly, sense of touch may be altered so temperature, pressure, proprioception, and pain may be experienced differently for these individuals. Due to the presence of sensory impairments, OPsLWD are more sensitive to environmental stimulation (Pinto et al., 2020). Therefore, sensory stimulation is an integral part of environmental modifications and non-pharmacological interventions in dementia-care (Behrman et al., 2014; Smith & D'Amico, 2020).

The three main stages of dementia are considered as mild, moderate and advanced which include a worsening of symptoms as the disease progresses (Medical Care Corporation, n.d.). These have been further broken down into seven stages by the Global Deterioration Scale (GDS) developed by Reisberg et al. (1982) (refer to appendix 1A). It is important to know at what stage an individual's level of cognitive impairment is as this will help tailor their care

according to their current needs. Even though there are common features associated with each stage, every individual is affected in a different way and might experience symptoms or progress through the stages differently. Interestingly, although many abilities are lost during the course of the disease, the OPLWD still retains "their sense of touch and hearing, and their ability to respond to emotion" (Fleming et al., 2020).

Mild cognitive impairment (MCI) is the term that is used for individuals who fall between the normal age-related cognitive changes and the early stage of dementia (Pandya et al., 2016). The difference between MCI and mild dementia is that the former involves low performance in one or more cognitive domains while the latter involves low performance in more than one cognitive domain (Arvanitakis et al., 2019). The diagnostic and statistical manual of mental disorders (DSM-5) defined these cognitive domains as (a) learning and memory, (b) language, (c) complex attention, (d) executive function, (e) perceptual-motor, and (f) social cognition (American Psychiatric Association, 2013; Arvanitakis et al., 2019; Buffington et al., 2013; Jones, 2021).

While MCI does not significantly interfere with an individual's activities of daily living (ADLs), the OPLWD may find difficult in performing their usual tasks such as cooking or paying bills. On the other hand, individuals with mild dementia face substantial interference with work and their usual daily activities (Knopman & Petersen, 2014). Pandya et al. (2016) carried out a meta-analysis of 41 studies and found individuals with MCI had a higher rate of reversion to normal cognition than progression to dementia. Therefore, since MCI does not inevitably lead to dementia, clinical intervention studies should aim to identify appropriate treatments involved in this reversion (Jongsiriyanyong & Limpawattana, 2018; Pandya et al., 2016).

2.1.1 Behavioural and psychological symptoms of dementia

The deterioration in cognitive function present in OPsLWD is associated with physical limitations, behavioural problems and personality changes (Alzheimer's Disease

International, 2021; WHO, 2021). Mobility impairments are likely to result from previous physiological and neurological impairments (Tolea et al., 2016). Individuals with some sort of cognitive impairment have worse functional capacity and levels of mobility than individuals with no signs of cognitive impairment (Domenech-Cebrían et al., 2019; Gure et al., 2013; Volkers & Scherder, 2014). Physical symptoms associated with dementia include weight loss, frailty, lethargy, motor imbalance, and problems with gait, weakness, falls, and inactivity (Keng et al., 2020).

Over the course of the disease, about 98% of OPsLWD experience neuropsychiatric symptoms (Vik-Mo et al., 2020) which are known collectively as behavioural and psychological symptoms of dementia (BPSD) (Cankurtaran, 2014; Cerga-Pashoja et al., 2018). According to Cloak & Al Khalili (2022), BPSD can be further classified into five domains:

1. Cognitive/perceptual (e.g., delusions, hallucinations, confusion, and sundowning),
2. Motor (e.g., wandering, physical aggression, inappropriate behaviours, and restlessness),
3. Verbal (e.g., shouting, repetitive speech, and verbal aggression),
4. Emotional (e.g., agitation, irritability, anxiety, depression, euphoria, and sexual disinhibition),
5. Vegetative (social withdrawal, apathy, disturbances in sleep and appetite).

BPSD are associated with a decline in function, poor quality of life, and caregiver burden (Toot et al., 2017). Although there has been progress in humanising dementia care, BPSD are still treated primarily with anti-psychotic drugs and restraining methods. Accurate identification of the cause and determinant of the symptom will assist in effective treatment for BPSD (Kolanowski et al., 2017). Gaugler et al. (2014) suggested the following non-pharmacological interventions should always be implemented to ensure appropriate management of BPSD:

1. Modification of ADLs to meet the individual's needs,
2. Environmental modifications such as outdoor access, wandering areas, and reduced stimulation environments,

3. Medical intervention including bright-light therapy, sleep therapy, pain management and the removal of restraints,
4. Staff training through educational programs on specialised dementia care,
5. Integrated multidisciplinary and interdisciplinary team approaches.

Research in this field has revealed that one of the influential aspects of BPSD are unmet needs (Cohen-Mansfield et al., 2015; Cunningham et al., 2019). The unmet needs model developed by Cohen-Mansfield & Werner (1995) provides a psycho-social explanation of BPSD which describes them as consequences of unmet needs which occur due to the inability of the OPLWD to effectively communicate their needs (Cohen-Mansfield, 2000; Cohen-Mansfield et al., 2015). Some of these needs may be associated with (a) lifelong habits, (b) personality, physical or psychological discomfort, (c) uncomfortable environmental conditions, (d) inadequate levels of stimulation, or (e) social exclusion (Kolanowski et al., 2017; Black et al., 2015; Minyo, 2018). Consequently, problematic behaviours are considered as a means of expressing feelings or needs.

A systematic review was carried out by Cadieux et al. (2013) with the objective of getting a better understanding of the needs of OPsLWD in LTC facilities. This matter is of great importance due to the fact that unmet needs can lead to a reduced quality of life and increased BPSD. The findings of their study were established from the perspectives of OPsLWD, informal caregivers and staff working within the LTC facilities. The identified needs are illustrated in Table 1 below and are listed in order of the level of importance based on the findings from reviewed studies of the highest methodological quality (Cadieux et al., 2013).

Table 1: The needs of OPsLWD within LTC facilities

1. Management of behavioural problems
Staff can offer support by providing appropriate care non-pharmacological measures, such as redirection, to decrease BPSD when disruptive behaviours are exhibited.
2. Daily individualised activities and care
Engagement in meaningful daily activities which are tailored to the individual's interests and abilities. OPsLWD should receive individualised person-centred care (PCC).

3. Social needs
Social and meaningful interactions allow OPsLWD to connect and communicate with staff, family members, and other residents.
4. Emotional needs and personhood
A good emotional balance and a sense of personal identity will provide feelings of reassurance, affection, acceptance, and appreciation for the OPLWD.
5. Activities of daily living (ADLs)
Receiving assistance with ADLs such as bathing, dressing, grooming, eating, drinking, getting in and out of bed, and toileting.
6. Independence and choice
Empowering OPsLWD by providing opportunities for decision-making and personal control. Next of kin should be contacted in the case of the OPLWD being unable to make their own decisions.
7. Cognitive needs
Assistance with the interpretation of messages and surrounding environment.
8. Safety and security
Protection from self-injury, harm and abuse.
9. Physical health
Maintenance of good physical health through care, exercise, and proper nutrition.
10. A home-like comforting environment
Residence in an environment that is home-like and has a sense of familiarity with a quiet and personalised space.
11. Proper pain management
Decrease the discomfort caused by physical pain and injury.
12. Sensory needs
The environment should provide optimal sensory stimulation depending on the individual's needs. For example, lighting can be used for visual stimulation.
13. Daily structured care
Care should involve a routine with a sense of familiarity.
14. Functional needs
Receiving assistance with instrumental ADLs such as taking medication, managing money and talking on the phone.
15. Knowledgeable staff
Staff should be well trained, educated in dementia care and have experience caring for OPsLWD.
16. Sexual needs
Being provided with the opportunity and place for intimate relationships.
17. Privacy

The availability of a secluded personal and private area within the LTC facility.
18. Financial needs
Assistance with purchasing items and paying bills.
19. Spiritual needs
Provision of spiritual support and opportunities to exercise one's religion.

2.1.2 Theories of Dementia

The understanding of dementia has changed significantly over the last few centuries. It progressed from a perception of mental handicap associated with ageing to being recognised as a disease that affects the brain. While ageing requires acceptance, a disease has the potential for intervention (Vernooij-Dassen et al., 2021). The discovery of the neurological basis of AD led to a predominantly medical model which was used to manage and treat dementia. Biomedical research acknowledged that dementia is pathological in nature and that it is caused by progressive deterioration of cognitive function. Advances in neuroscience have improved our understanding of the ageing brain whereby neuroimaging and biomarker investigations have allowed us to monitor structural and functional changes in the brain associated with BPSD (Nowrangi et al., 2015). This model proposed that, in view of this, dementia has to be treated and managed by medical professionals through the use of effective medical interventions (Innes & Manthorpe, 2013). Unfortunately, this led to the development of stigma against dementia and negative stereotypes where it was perceived that OPsLWD should be marginalised from society due to being diseased and disabled (Innes & Manthorpe, 2013; Spector & Orrell, 2010).

In the 1980s, evidence arose regarding the inconsistency between the clinical presentation of dementia and neuropsychological tests (Vernooij-Dassen et al., 2021). This gave rise to researchers critiquing the biomedical approaches and exploring non-medical psychosocial models in order to provide a broader perspective of dementia (Innes & Manthorpe, 2013; Winblad et al., 2016). Vernooij-Dassen et al. (2021) explained that even though the use of biomarkers in dementia research is important, they do not provide an explanation for all the characteristics of the disease onset and progression. Research findings showed that dementia

is also influenced by psychosocial factors which led to the exploration and integration of psychosocial approaches.

Spector & Orrell (2010) proposed a biopsychosocial model with the objective of offering a more holistic view of dementia by taking into account the biological, psychological and social processes involved (refer to appendix 2A). This model provides a theoretical framework that connects neuropsychiatric symptoms to the relationship between an individual's biology, their prior experiences, and their current environment (Cloak & Al Khalili, 2022; Steele et al., 2022). According to the need-driven compromised behaviour model, OPsLWD present with both fixed and tractable factors in biological and psychosocial domains throughout the trajectory of the disease (Algase et al., 1996; Jao et al., 2015). Fixed factors relate to certain aspects that are not changeable such as (a) age, (b) genetics, (c) health conditions, (d) sensory deficits, (e) intelligence quotient (IQ), (f) major life events, and (g) personality traits. On the other hand, tractable factors are modifiable in nature and include (a) acute medical illnesses, (b) pain, (c) physical health, (d) mental stimulation, (e) coping strategies, (f) social support, (g) the social environment, (h) activity, and (i) the physical environment (Spector & Orrell, 2010). In addition to these factors, one must also keep in mind the decreased stress tolerance associated with the progression of dementia which was explained previously in Section 1.7. Dementia care and appropriate intervention such as environmental changes can alter these tractable factors in order to improve the individual's life and decrease their level of disability.

In conclusion, in order to look at dementia in a holistic way, one cannot deny the biomedical basis of dementia. However, in order to ensure a broader conceptualisation of dementia, psychosocial perspectives need to be taken into consideration (Innes & Manthorpe, 2013). Innes & Manthorpe (2013) suggested that in order to provide a better service for OPsLWD, knowledge from different perspectives must be adopted and applied to practice. Additionally, Vernooij-Dassen et al. (2021) suggested that by bridging biomedical and psychosocial research, a more integrated approach to dementia will be achieved by focusing on the three domains of physical, mental and social health.

2.2 The Need for Long-Term Care

Older persons would rather remain living in their own homes than relocate to a LTC facility (Aquilina, 2014). However, age related disease, degeneration of the brain and subsequent cognitive decline results in disability and increased dependence in older persons (Levine et al., 2018). The ability for an individual to remain living in their home of choice is challenged when they experience a deterioration in their health and are no longer able to complete ADLs (Campbell-Enns et al., 2020; Wahlroos et al., 2022). In the early stages of the disease, informal care is often focused on setting up an environment to support the remaining skills of the OPLWD (Calkins, 2018).

Home modification is one example of an environmental change that can be implemented to support an OPLWD living in the community. It is a continuous process for the OPLWD due to their ever-changing needs associated with the stage of progression of the disease and its related disabilities. Although remaining in one's own home has been proven to have numerous benefits for an individual with mild to moderate dementia, an individual with advanced dementia will require a more adapted environment to accommodate increasing disability (Wahlroos et al., 2022). As the disease progresses, more hands-on care is required (Calkins, 2018). Therefore, regardless of the option to carry out home modifications, the increased complex care needs of the OPLWD could require a move into residential care (Abdi et al., 2019; Fleming et al., 2020). Very often, institutionalisation occurs following hospital admission with a significant deterioration in health coupled with psychosocial issues such as a lack of informal support or an inadequate home environment (Harrison et al., 2017; Hollinghurst et al., 2020).

2.3 The Concept of Place

The concept of place has been used to understand the multiple dimensions of a setting. Even though it has numerous definitions, for the purpose of this dissertation it is considered as "a

space or location with meaning" or "an area having unique physical and human characteristics interconnected with other places" (National Geographic, n.d.).

The model of place (Weisman & Calkins, 1994) presented four dimensions of the environment, (a) people with dementia, (b) the physical environment, (c) the social context, and (d) the organisational context. These dimensions interact together to create a therapeutic environment for the OPLWD. This model has been used as a basis for person-centred dementia care approaches (Chaudhury & Cooke, 2014).

Bronfenbrenner's (1977) ecological systems theory argued how the environment is divided into four levels which are all interrelated and influenced by each other:

1. The microsystem which includes the relations between the individual and their immediate setting,
2. The mesosystem which involves the interrelations within major settings and the individual's experiences,
3. The exosystem that incorporates formal and informal structures that indirectly influence the older person, the organisational aspect of the building design, and the context as to why these facilities were developed,
4. The macrosystem that focuses on the element of culture (Calkins, 2018).

Based on the aforementioned model of place (Weisman & Calkins, 1994) and ecological systems theory (Bronfenbrenner, 1977), Calkins (2001) developed a holistic conceptual framework which has been implemented in place-based models of care within dementia care settings. The integrated model of place provided an overview of difference aspects of a dementia care setting and how they may influence the OPLWD. Calkins (2001) proposed that dementia care planning should acknowledge the systemic nature of a setting and take all the aforementioned aspects into consideration. This model is illustrated below in Table 2.

Table 2: Integrated model of place for dementia care (adapted from Calkins 2001)

	Microsystem	Mesosystem	Exosystem/Macrosystem
Individuals	Individuals' wants, needs, capabilities , and functional levels	Values, personality, expectations, and identity	Cultural influences, and religious affiliations
Physical environment	Size, layout, décor, acoustics, lighting, and temperature	Arrangements of the space available	Construction standards
Social environment	Interactions amongst individuals, staff, and caregivers	Goals and patterns of care, and activities	Cultural values, family structure, and group identity
Organisational environment	Staffing ratios and training, and rules of the LTC facility	Values regarding the rights of OPsLWD	Regulations and standards across different LTC facilities

Research findings have provided a better understanding of how OPsLWD make sense of and react to their environment. Therefore, individual needs, building design, organisational and operational aspects, and societal and cultural influences are all aspects of the environment that need to be incorporated into the development of supportive settings for OPsLWD (Calkins, 2018).

2.4 The Environment

A brief explanation of the environment will be given in this section, followed by a description of its physical components in Section 2.4.1 and social components in Section 2.4.2.

The environment can have a significant impact on the well-being and quality of life of OPsLWD, be it positive or negative (Calkins, 2018). It can either support an individual's functional performance and quality of life or hinder them. In fact, Calkins (2018) stated that overly stimulating environments can lead to dysfunction and stress whereas supportive environments can assist with the changing abilities of the OPLWD. Therefore, the environment is considered a critical component of a therapeutic setting for OPsLWD (Fleming & Purandare, 2010; Marquardt et al., 2014). According to Jao et al. (2021),

environmental support is vital for OPsLWD who present with cognitive impairment, sensory decline, and functional limitations. In fact, unsupportive environments have been found to contribute to BPSD such as anxiety, disorientation and agitation. On the other hand, well-designed supportive environments have been found to encourage positive behaviours such as reduced agitation and increased social contact (Chaudhury & Cooke, 2014; Woodbridge et al., 2016).

The guidelines for the development of dementia cares settings require a change in the philosophy of trying to manage challenging behaviours towards understanding and meeting the needs of OPsLWD. As explained previously in Section 2.1.1, the unmet needs model (Cohen-Mansfield & Werner, 1995) proposed that BPSD are actually the expression of unmet needs which are sometimes triggered by environmental factors. Garcia et al. (2012) developed a mnemonic 'C.A.R.E.F.U.L' for important environmental factors to be implemented in LTC facilities for OPsLWD; C: consistency, A: approach, R: ratio of staff to residents, E: environmental design, F: flexibility, U: understanding, and L: level of noise.

Even though the importance of building design has been emphasised in the literature, the environment cannot merely be defined by its physical characteristics and is required to be captured within the context of social interactions and cultural practices of the person with the environment (Campo & Chaudhury, 2012; Marquardt et al, 2014: Wahl et al., 2012). Therefore, in order to explore the influence of the environmental conditions on the OPLWD the physical, social and organisational environments need to be taken into consideration (Campo & Chaudhury, 2012; Førsund & Ytrehus 2018). Narsakka et al. (2022) carried out a recent mixed-method review to investigate the association between the physical, social, and organisational environments with physical activity in OPsLWD within LTC facilities. With regards to the organisational environment, it was found that strict policies tended to restrict the opportunity for activities such as unsupervised garden walks due to locked doors (van Steenwinkel et al., 2017). Secondly, supportive professionals, the role of others, and adequate activities to socialise and be active were three themes that were developed by Narsakka et al. (2022) in relation to the social environment. Finally, with regards to the physical environment, the authors found that the environment in LTC facilities should be

accessible, safe, and activating to facilitate mobilisation and encourage activity participation (Nordin et al., 2017).

2.4.1 The Physical Environment

According to Lawton (1982), the physical environment is recognised as an element of concrete reality whereby it is inanimate, objective, tangible, and measurable (Wahl et al., 2012). Research has shown that (a) unit size, (b) spatial layout, (c) home-like character, (d) safety, (e) sensory stimulation, and (f) orientation are all important features of the physical environment (Calkins, 2018; Chaudhury et al., 2018; Jao et al., 2021; Marquardt et al., 2014; Wood et al., 2017). Fleming et al. (2008) proposed design principles for the development of places for OPsLWD which have been implemented across several countries (Fleming & Purandare, 2010; Fleming et al., 2015; Fleming et al., 2020). In addition, these principles have been used in educational programmes, dementia training, and as the foundation for environmental assessment tools such as the therapeutic environment screening survey for nursing homes (TESS-NH) (Fleming et al., 2020; Ministry of health, 2016);

1. Risk reduction through the use of discreet safety features for easy and safe mobilisation. Obstructive objects such as steps should be removed as they can be hazardous (Narsakka et al., 2022; Wood et al., 2017). Safety features such as locked doors can result in frustration and agitation and thus should be avoided. Camouflaged doors are effective visual barriers to reduce exit-seeking (Marquardt et al., 2012).
2. The design should have an element of a human scale which takes into consideration the number of people that the OPLWD meets during the day, the size of the actual building, and the size of constituents such as doors, rooms and corridors. A small-scale home-like environment is more likely to give a sense of familiarity and safety which in turn will prevent the OPLWD from feeling intimidated and overwhelmed by the extent of the surroundings (Fleming & Bennett, 2015; Kok et al., 2018; Marquardt et al., 2014).
3. Individuals should be able to see and be seen in an easily understood environment. Facilities should have adequate visual access to assist with wayfinding and decisions regarding what to do and where to go (O'Malley et al., 2015).

4. The reduction of unhelpful stimulation such as unnecessary noise and clutter can result in agitation and stress for the OPLWD. Areas can be separated according to their level of noise with double glazing, acoustic products and soundproofing (Benbow, 2014).
5. Positive stimulation can be used as cues to orientation and diminish confusion. Recognition of mealtimes can be achieved through pleasant smells, tables and chairs which provide cues of a dining room. Other examples include activities involving music and reminiscence pictures (Fleming et al., 2020).
6. Supporting purposeful movement and social interaction indoors and outdoors (Campo & Chaudhury, 2012).
7. A place that is personalised and feels familiar will support OPsLWD in their performance and well-being.
8. Opportunities should be available for the OPLWD to spend time alone or with others. This can be achieved through several areas within the LTC facility that serve different purposes. An area should be available for OPsLWD to host friends and family outside of their bedroom, such as for celebrations, private conversations, and intimacy. Other areas can be more communal to encourage conversations and activities (Ministry of Health, 2016).
9. Maintaining a connection to the community outside the LTC facility is important to maintain one's identity and to remove the negative beliefs about dementia.
10. The building design should relate to the philosophy of care of the LTC facility and provide staff with the tools required to implement PCC.

Marquardt et al. (2014) carried out a systematic review of the literature on environmental design for OPsLWD. The authors provided a thorough description of the properties of the physical environment; (a) basic design features, (b) environmental attributes, (c) ambience, and (d) environmental information (Marquardt et al., 2014). If designed well, a good quality physical environment will support everyday functioning and enhance the well-being and quality of life of OPsLWD (Fleming et al., 2016; Wahlroos et al., 2022). Additionally, a recent integrative literature review by Wahlroos et al. (2022) found that features of the physical environment such as the elements of the building layout and private vs communal spaces affected functionality, orientation and safety of OPsLWD. Furthermore, an attractive

and comfortable environment was found to be more pleasant for OPsLWD (Wahlroos et al., 2022).

2.4.1.1 Design Features

Traditional LTC facilities are based on acute care and hospital settings (European Network of National Human Rights Institutions: ENNHRI, 2017). The characteristic traditional building design comprises of a long 'L' or 'T' shape bare corridor, a central nursing station, a chapel, a dining room, and a lounge. Alternatively, new facilities are opting for an open plan layout which increases mobility, visibility, orientation and wayfinding within the space for the OPLWD (Calkins, 2018; Nordin et al., 2017; O'Malley et al., 2015; van Steenwinkel et al., 2017). Bedrooms range from an occupancy of two to four persons and are usually fitted on either side of the long corridors (Calkins, 2018). The shared sleeping arrangements were planned to facilitate health care staff practices such as easy patient monitoring. Even though this type of layout is advantageous for the staff, it has been found to worsen BPSD (Soril et al., 2014). Furthermore, shared bedrooms and bathrooms hinders an individual's privacy and control over their personal space. In fact, Innes et al. (2011) argued on the importance for OPsLWD to create their own private area and personalise it with personal belongings for a sense of familiarity and homeliness. Outdoor areas have also been recognised as an essential part of the design of a LTC facility. The benefits of spending time outdoors include exposure to sunlight, meaningful activity, and sensory stimulation (Chaudhury & Cooke, 2014). Moreover, a literature review carried out by Whear et al. (2014) stated that gardens and outdoor spaces had several benefits for OPsLWD such as reduced exit-seeking, agitation and violence. Due to the wandering behaviour of OPsLWD, LTC facilities should contain spacious hallways, wide doorways, and automatic lifts. (Narsakka et al., 2022; Nordin et al., 2017; van Steenwinkel et al., 2017)

In recognising the importance of the environment, many living concepts around the world have opted for a dementia-friendly design or created specialised care units (SCU) designed to provide a therapeutic environment (Fleming et al., 2020). The motivation for this was based on environmental gerontology whereby it was acknowledged that the specific needs

of OPsLWD may be met by providing a dementia-friendly environment (Isaacson et al., 2020). These units consist of a dementia-friendly purposefully designed environment, individualised and group activities, and staff trained in PCC dementia care (Palm & Bartholomeyczik, 2018). It is important that these units provide adequate levels of sensory stimulation to meet the needs of the OPLWD. Marquardt et al. (2014), compared the SCU's positive impact on behaviour, social abilities and care outcomes vs the negative impact on cognition and function owing to the lack of standardisation of these units. Furthermore, Brandenburg (2013) indicated how the designs of SCU's varied greatly and how different countries had different names for the segregated and integrated living concepts. Some examples include:

1. A dementia-friendly LTC facility specifically designed for OPsLWD,
2. A segregated SCU's within a traditional LTC facility,
3. An open or secure living unit for older persons within a care home,
4. Traditional nursing homes,
5. Community-based group living concepts,
6. Green care farms,
7. Assisted living facilities,
8. Shared housing arrangements (Adlbrecht et al., 2021; de Boer et al., 2015; de Boer et al., 2017; de Bruin et al., 2017; Fleming et al., 2020; Verbeek & Mitchell, 2022).

Small-scale environments provide care for a small amount of people ranging from 5-15 individuals (Marquardt et al., 2014). It was suggested by de Boer et al. (2018) how these places may have a better person (P) – environment (E) fit for OPsLWD that include home-like characteristics such as a kitchen, a living room, a dining room, and bedrooms all equipped with domestic furnishings. These environments promote social connection, positive well-being, activity engagement, less hospitalisations and inappropriate medications (Campo & Chaudhury, 2012; Fleming et al., 2020; Jao et al., 2021; Marquardt et al., 2014). The size of a unit is related to the amount of individuals it intends to serve. It has been acknowledged that LTC facilities accommodating a large amount of residents do not meet the needs of older persons, especially those living with dementia (Nordin et al., 2017). In fact, large facilities have been linked to increased agitation, disorientation, and conflicts (Chaudhury & Cooke, 2014). Furthermore, high social density, referring to a large amount

of people per surface area, results in high levels of noise, activity and interactions which impact the OPLWD in a negative way. Additionally, high spatial density is associated with constant close contact with others and lack of personal space and privacy. On the other hand, environments with too little stimulation can result in boredom and inactivity (Marquardt et al., 2014). Calkins (2018) pointed out the favoured unit size for OPsLWD in Japan, Sweden, and Belgium that ranged from 5-9 residents while the green house model in the United States of America ranged from 10-12 residents (Fleming et al., 2020).

2.4.1.2 Environmental characteristics

Lighting, acoustics, room temperature, colours, and visual cues are all examples of environmental qualities that positively influence the OPLWD within a LTC facility. Dementia is associated with sleep disturbances, poor sleep efficiency and frequent night-time awakenings (Ooms & Ju, 2016; Suzuki et al., 2017). This is often associated with a reduction in neuronal receptiveness to environmental cues of light and dark, reduced functionality of the biological clock and an inadequate exposure to light (Figueiro et al., 2020). In severe cases of dementia, day and night sleep patterns may even be reversed (Goudriaan et al., 2021). The delay in circadian phase associated with dementia contributes to sundowning which is a syndrome that occurs in the late afternoon or early evening when OPsLWD portray a worsening of neuropsychiatric symptoms such as confusion and agitation (Ooms & Ju, 2016). It is associated with environmental factors such as the exposure to an inadequate amount of light, overstimulation, and low staff-person ratios in LTC facilities (Canevelli et al., 2016). Since OPsLWD are more at risk for developing circadian disruption, it is important for LTC facilities to ensure good quantity and quality of indoor light. Bright light during the daytime is the main factor in the co-ordination of an individual's biological clock with the 24-hour rhythm of the earth (Goudriaan et al., 2021). Therefore, light therapy has been recognised as a non-pharmacological intervention to help regulate sleeping patterns (Figueiro et al., 2020; Ooms & Ju, 2016). Exposure to morning and daytime light helps with daytime wakefulness, increased night-time sleep, and improved circadian rhythm quality (Chaudhury & Cooke, 2014. This has been found to improve sleep quality

and mobility while reducing agitation and depression in OPsLWD (Figueiro et al., 2014; Kalinowski et al., 2012).

OPsLWD differ in their tolerance for environmental stimulation and susceptibility to over stimulation (Janus et al., 2021). Unlike sensory stimulation, the acoustic environment is often underestimated in the design of dementia-friendly LTC facilities. The acoustic environment involves the physical audible sounds and how an individual perceives them (Devos et al., 2019). In view of cognitive deficits and sensory impairments, OPsLWD often used sound to make sense of their environment. Sound has been found to influence the OPsLWD both positively and negatively (Marquardt et al., 2014; van den Bosch, 2015). The acoustic environment in LTC facilities has often been described as noisy and loud (Cui et al., 2021). There is strong evidence suggesting how increased noise levels (vocal communication, TV, mobiles, air conditioners, mechanical equipment, staff conversations, alarms and nurses' station [Chaudhury & Cooke, 2014; Cui et al., 2021; Steiner et al., 2020; Torresin et al., 2020]), are associated with exacerbated BPSD and decreased social interaction (Chaudhury et al., 2017; Garcia et al., 2012; Jao et al., 2019; Marquardt et al., 2014).

Sensory and music therapies has been frequently used in settings for OPsLWD to influence behaviour and mood in a positive way (Livingston et al., 2014; Xie et al., 2020). These therapies give diverse physiological, emotional and functional benefits such as lowered blood pressure, positive emotion, improved sleep quality, decreased depression and agitation leading to decreased medication use (Devos et al., 2019; Iyendo, 2017). Natural sounds and bird sounds in particular contribute to positive feelings such as calmness, and stress recovery (Ratcliffe et al., 2016). Bird sounds can be used in the morning to increase arousal while slow songs with low frequencies can be used for their calming effects to reduce arousal. Knippenberg et al. (2022) described how individuals with moderate to advanced dementia benefitted from a calmer living environment that was more manageable and controlled. Devos et al. (2019) suggested using sound as a safety enhancer for OPsLWD such as playing the sound of church bells on the hour to help with time and place orientation. Therefore,

supportive acoustic conditions should be promoted to improve the well-being and quality of life of OPsLWD in LTC facilities (Devos et al., 2019).

According to Gaugler et al (2018), difficulty with wayfinding occurred in familiar environments, especially in the presence of visual impairments. The authors proposed how the physical environment could assist with environmental orientation such as finding the dining room, for instance including coloured floor plans, furnishings, and lighting. In fact, research has shown how enhanced lighting and colour contrast between plates, cutlery and tables, are associated with a better dining experience for OPsLWD (Chaudhury & Cooke, 2014). Calkins (2018), suggested how the visibility of the toilet could be enhanced through the use of a high colour contrast between the toilet, walls, and bathroom floor.

Meaningful environmental cues can be used to promote autonomy and well-being by supporting an individual in their everyday performance (Calkins, 2018). For example, when looking at the bathroom, the first feature that a person should see is the toilet, as this will act as a visual cue to make use of it. If only the sink can be seen from outside the bathroom, the OPLWD might just walk past it and not make the association. Therefore, easily identifiable and accessible bathrooms should be located in the central area of the unit to promote independent bathroom usage (Chaudhury & Cooke, 2014). This can be done through the use of simple readable signs, labels, pictures, and colour coding. Another example is the positioning of armchairs that could be used as a visual cue to stop, sit down and rest (Campo & Chaudhury, 2012). The positioning of tables and chairs could also be used in a way to stimulate interaction by positioning them in a sort of lounge layout rather than lined up against a wall. Having identical chairs lined up along a corridor hinders conversation between individuals. Finally, large windows overlooking gardens could stimulate conversation regarding visual events taking place outside (Kalinowski et al., 2012).

Chaudhury & Cooke (2014) suggested how a positive ambience is one that is warm, welcoming, colourful and innovative. Recent interest has been shown towards creating a home-like environment for OPsLWD with the aim of creating a more pleasant atmosphere and giving a sense of familiarity and belonging (Garcia et al., 2012), e.g. non-institutional

furniture such as upholstered armchairs, paintings and bookcases, and the absence of ceiling mounted florescent lighting, open-plan lounge and dining areas, large windows, decorative curtains, bookshelves, plants, and lampshades. Another important characteristic of home-like design is the inclusion of all the typical rooms found in a house as opposed to one central multipurpose room where all activities take place (Calkins, 2018). Home-like environments are associated with improved psychological well-being, increased levels of social interaction and community participation, and lowered levels of BPSD (Campo & Chaudhury, 2012; Chaudhury & Cooke., 2014; Marquardt et al., 2014; Wood et al., 2017). However, in order for a home-like environment to be effective, supportive care practices also need to be implemented (Chaudhury & Cooke, 2014). Unfortunately, many new LTC settings still adhere to traditional building designs and operational systems which give rise to certain challenges in providing PCC (Calkins, 2018).

2.4.2 The Social Environment

The environment of a LTC facility extends beyond the physical design to how individuals experience their surroundings. Even though the physical and social environments are interrelated and interact with each other, they are two separate constructs (Peterson et al., 2021). “The social environment describes the social setting in which people live or act. It is comprised of human contacts, stimulation, activities, but also the larger cultural values” (Rosteius et al., 2022). It also involves interpersonal relationships and the interactions that take place between individuals and groups (Jao et al., 2021; Narsakka et al., 2022; Peterson et al., 2021). Engaging in meaningful social interaction has been found to positively influence the quality of life in OPsLWD. Therefore, it is important to explore the social relationships and patterns of interactions that take place in LTC facilities (Campo & Chaudhury, 2012; Doyle et al., 2012). Daily activities comprise of routine times for self-care, meals, television, organised groups, and pastimes (Wood et al., 2017). What truly makes a place feel like home is the pattern of daily activities and social interactions, the way meals are prepared and served, and the element of personal space and privacy (Davies et al., 2009).

The social environment has often been found to be considered more important than the physical environment in promoting the well-being of OPsLWD (Adlbrecht, 2021). The built environment has little impact on social interactions if it is not complemented with adequate staff competencies and supportive care policies (Ferdous, 2019; Garcia et al., 2012; Popham & Orrell, 2012).

2.4.2.1 Philosophy of Care

A one size fits all approach cannot be used in end-of-life care for OPsLWD (Hill et al., 2016). No two individuals experience dementia in the same way and that is why care needs to be individualised and tailored to an individual's needs. The philosophy of LTC is mainly based on task-oriented care delivery (Steele et al., 2020). Strict schedules, task-oriented practice, and lack of staff and financial resources have been found to impede physical activity and social interaction within a LTC facility (Hawkins et al., 2018; Mahrs Träff et al., 2020; Narsakka et al., 2022; van Steenwinkel et al., 2017). Some LTC facilities are trying to move away from the traditional model of medical based care for older persons since this does not empower older persons nor promote an environment that encourages productivity and activity (ENNHRI, 2017). PCC is a holistic model of care whereby the focus is on the individual and their subjectively-defined needs in order to enhance their well-being and improve their quality of life. The PCC model proposed that individuals have the following six psychological needs; (a) love, (b) comfort, (c) attachment, (d) identity, (e) inclusion, and (f) occupation (ENNHRI, 2017). A flexible practice of constantly assessing individuals' needs provided better support and implementation of care plans (Hawkins et al., 2018).

Staff members have been recognised as an important part of the social environment in a LTC facility (Adlbrecht, 2021; Førsund & Ytrehus, 2018). Where organisational policies were concerned, opportunities for informal social interaction were influenced by the philosophy of care implemented and staff practices (Campo & Chaudhury, 2012). Moreover, staff consistency, adequate amount of staff, and specialised training facilitated informal social interactions between OPsLWD. This was achieved through flexibility in work roles, a better understanding of dementia, and having more time to spend with residents to become more

familiar with their social needs (Campo & Chaudhury, 2012). In fact, Revolta et al. (2016) found that following training on the biopsychosocial model of dementia, staff felt as if they could incorporate information from all the three domains (physical, social, and psychological) and integrate it into the individual's care plan. According to Aasgaard et al. (2017), it was easier for OPsLWD to interact socially with staff who were familiar to them and who they had established emotional connections with. Moreover, staff expressed that it was important to get to know the OPLWD so as to understand their history and preferences and help them feel safe (Aasgaard et al., 2017).

A PCC model of care supports an individual's autonomy and encourages social interaction (Campo & Chaudhury, 2012). PCC has several other benefits such as the improvement of BPSD and in return a reduction in the use of anti-psychotics (Kim & Park, 2017). Furthermore, PCC takes an ecological approach to encourage engagement in everyday activities and experiences through appropriate and supportive environments (Davis et al., 2009). Santana et al. (2018) described how PCC identified that each person had an equal right to a supportive environment that met their needs especially for the OPLWD who was more vulnerable to environmental circumstances. Therefore, in order to provide PCC for the OPLWD, the environment of a LTC facility has to be recognised as a crucial element (Lee et al., 2021).

2.4.2.2 Social network

Creating a social community is considered a major component in the quality of life of OPsLWD in LTC facilities (Aasgaard et al., 2017). The structure of a social network relates to the number of friends and family who are regularly in contact with the OPLWD and the relationships between them (Peterson et al., 2021). Wood et al. (2017) found that besides care staff, family and friends are also part of the social environment. "Ongoing family involvement and community connections are essential for the creation and sustainability of a dementia-friendly environment" (Davies et al., 2009). Spouses felt that sustained connection and continuous involvement were important for OPsLWD following admission into a LTC facility (Goodman et al., 2013). Having a telephone conversation and visiting

OPsLWD in a LTC facility is a means of maintaining the relationship with spouses, family members, and friends (Førsund & Ytrehus, 2018; Peterson et al., 2021). Organisational policies should allow visiting family members to stay for mealtimes to facilitate positive relationships amongst OPsLWD, their informal caregivers, and staff within the LTC facility (Davies et al., 2009). Visits from family members have been shown to positively influence levels of physical activity as they assist OPsLWD walking indoors and outdoors (Narsakka et al., 2022).

Aasgaard et al. (2017), found that OPsLWD who had larger social networks had a higher quality of life in comparison to the isolated and socially excluded individuals. Friendship and positive relationships are important for OPsLWD as they contribute to healthy socioemotional functioning and provide social support (Casey et al., 2016). Social support can relate to emotional and financial support (Peterson et al., 2021). Casey et al. (2016) suggested that LTC facilities do not meet the social needs of OPsLWD as the participants in their study reported few friendships and social isolation. Maintaining community connections can be achieved through shopping trips, attending local events, and volunteering (Brittain & Degnen, 2022). Another way of integrating the LTC facility within the community is designing the building to include a childcare centre, a coffee shop, or a gym to attract visitors. Visiting public areas and interacting with community members has been found to facilitate activity in OPsLWD (van Steenwinkel et al., 2017).

2.4.2.3 Social interaction

Social interaction is a dynamic interchange amongst two or more individuals who interpret and react to each other (Campo & Chaudhury, 2012). According to the authors, OPsLWD interact with others verbally through short conversations and also non-verbally through behaviour, body posture, eye contact, facial expressions, and physical contact. Furthermore, Fleming et al. (2020), stated that OPsLWD in more advanced stages tend to communicate predominantly through bodily movements and physical responses. The social environments in LTC facilities provide the setting and boundaries in which social behaviours take place (Campo & Chaudhury, 2012). Primarily, staff members have been found to be responsible

for initiating interactions and creating opportunities for OPsLWD to interact socially through organised activities within the LTC facility (Adlbrecht, 2021; Casey et al., 2014). Staff are responsible for helping OPsLWD with limited mobility and impaired communication in interacting with others (Ferdous & Moore, 2015). Formal social activity participation includes public meetings, religious services, along with participation in club or social activities (Peterson et al., 2021). Therapeutic group and individualised activities have been found to have positive benefits such as personal enjoyment and improved well-being. Making activities meaningful for OPsLWD means drawing on past roles and experiences to provide a more enjoyable and relevant experience. Very often, activities tend to be generalised and not match the preferences or abilities of OPsLWD (Tak et al., 2015).

Sexual needs are considered to be an important aspect of one's identity, well-being, and social interaction. However, intimacy is often an activity that tends to be overlooked in LTC facilities (Davies et al., 2009). Førsund & Ytrehus (2018) explored the role of the environment on the maintenance of relationships with spouses who are OPsLWD within a LTC facility. The authors found that having an individual room provided opportunities for more private and intimate interactions. Familiarisation of the individuals' private rooms created a home-like environment which gave a feeling of belonging and created a safe place for spouses and partners to connect (Førsund & Ytrehus, 2018).

Certain times of the day bring about different opportunities for informal social interaction. Mealtimes tends to facilitate conversation because of the close proximity to others for an extended period of time (Abbott et al., 2017; Campo & Chaudhury, 2012). According to Davies et al. (2009), the eating experience does not begin and end with the food on the table but it involves gathering ingredients, finding a recipe, preparing the food, setting the table, eating, and finally clearing up after the meal. Unfortunately, OPsLWD within LTC facilities tend to be served food as if being served in a restaurant with no opportunity to participate in the whole experience of mealtimes.

Institutionalisation is associated with a risk of social exclusion due to decreased social interaction outside of organised activities. LTC facilities tends to facilitate social interaction

through planned activities, however Campo & Chaudhury (2012) found that informal relations are also important to consider in the care of OPsLWD. The authors found that the philosophy of care, role of staff, group size, and time of day were all part of the social environment. Interestingly, with regards to group size, Campo & Chaudhury (2012) found that increased social interaction does not necessarily correspond to the amount of people in a unit but to how many opportunities there are for congregation. According to Casey et al. (2016), social interactions tens to occur in small groups which are characteristic of small-scale home-like units. Additionally, Adlbrecht (2021) carried out a mixed-methods systematic review of the social interactions that take place with OPsLWD and reported that individuals residing in SCU's (Abbott et al., 2017) and green care farms (de Boer et al., 2017) had more social interactions that those residing in traditional LTC facilities.

2.5 The Local Perspective

The provision of LTC for older persons in Malta has been around for centuries and is divided between community care and residential care (Vassallo, 2018). Active Ageing and Community Care (AACC) offers a range of services to support older persons living in the community (Formosa, 2019). Their aim is to encourage participation in society and independent living whilst only opting for institutionalization as a last resort, in accordance with Malta's 'National Strategic Policy for Active Ageing 2014-2020' (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing: PSRPDAA, 2013). The 'Ċentru Servizz Anzjan' is a centre that coordinates and manages a number of community services provided by AACC in Malta. These services include active ageing centres, home help service, respite service, handyman service, telecare+, telecare on the move, telephone rent rebate, meals on wheels, continence service, domiciliary nursing, domiciliary caring, domiciliary dietitian service, carer at home scheme, dementia intervention team, dementia activity centre, night shelter, social work, community geriatrician, psychotherapy service, podology, physiotherapy, occupational therapy, and admission to long-term care (LTC) facilities (PSRPDAA, 2013).

LTC facilities provide residential care for older persons who are no longer able to continue living within the community. LTC facilities in Malta are licensed and regulated by the Social Care Standards Authority (SCSA) and can have their license revoked if they fail to uphold the 'Social Regulatory Standards for Residential Services for Senior Citizens' (SCSA, 2021b). Locally, there are approximately 43 licensed LTC facilities, owned either by the government, church or private organisations. Some public LTC facilities operate through public-private partnerships (PPP) by having their management and certain health services operated by a private company (Formosa, 2019). Another form of PPP is when the government purchases LTC beds in private facilities as a means to keep public spending in the area to a minimum (Formosa, 2019).

These facilities vary greatly in terms of physical environment, staffing level and quality of care. St. Vincent de Paul (SVP) is the largest government-owned LTC facility with two specially designed dementia wards with staff specifically trained in person-centred dementia care (Formosa, 2019). Through unofficial communication, the number of beds at SVP stood between 1345-1379 at the time of writing the dissertation. SVP operates as a nursing facility by providing 24/7 medical care and support in all aspects of care for older persons. The other local LTC facilities are known as residential care settings, thus do not offer 24/7 medical care; the facilities range from being designed and built specifically to meet the needs of older persons to simply being refurbished hotels or apartments (Formosa, 2019).

LTC facilities are trying to meet the increased demands and specific needs of OPsLWD, however according to Formosa & Scerri (2020) they are facing some challenges. Unfortunately, due to structured routines and standard policies in LTC facilities, the needs of the group are often prioritised over the needs of the individual. While improvements have been noted in the area of LTC, building design and philosophy of care still depend on the traditional medical model of care. According to Formosa (2019), this has resulted in the specific needs of older persons in LTC facilities not being met. Innes et al. (2016) argued at length on the lack of investment surrounding specific services for the OPLWD within LTC facilities. In order to tackle this, SCSA published the 'Social Regulatory Standards' (2021a) titled 'Residential Services for Persons Living with Dementia in Homes for Senior Citizens'

in order to address the reality that an improvement in the current services for OPsLWD was needed. Some LTC facilities already have separate supportive units within the facility for OPsLWD, however to-date, there are no licensed dementia-friendly living concepts in Malta.

The National Strategy for Dementia in the Maltese Islands 2015-2023 (PSRPDAA, 2014) was developed with the aim of improving the quality of life of OPsLWD, providing support to caregivers, and promoting dementia care. The strategy identified the importance of the "implementation of dementia-friendly measures (including dementia friendly design) in all elderly homes". The strategy suggested the development of new LTC units for OPsLWD or adaptations to be carried out within current LTC facilities to provide a safer environment to support OPsLWD. The strategy also supported the development of tailored therapeutic programs and meaningful activities along with healthcare staff trained in person-centred dementia care (refer to appendix 3A).

2.6 Conclusion

This chapter discussed the characteristics and different theories of dementia. It highlighted that dementia is experienced differently between different individuals and that non-pharmacological interventions can be implemented to improve the quality of life and well-being of OPsLWD. The concept of place was presented along with a breakdown of what the environment consists of for the OPLWD. The literature provided descriptions of the physical, social, and organisational components of the environment and what effect they have on the OPLWD within LTC facilities. The next chapter will provide a detailed description of the methodological framework used in this study.

CHAPTER 3
METHODOLOGY

3.0 Introduction

This chapter involves a description of the aims and objectives of this study. It also provides a thorough explanation of the research process and the research design that was implemented. It contains (a) an outline of the theoretical and methodological frameworks used in this study, (b) the procedure of participant selection, (c) the research tool, (d) the data collection, and (e) the data analysis technique used to analyse the findings. A discussion of the strengths and limitations of the methodology chosen is also presented. Finally, ethical considerations followed throughout the research process will also be explained.

3.1 Aims and Objectives

This study explored the perspectives of informal caregivers on environmental factors that influence older persons living with dementia (OPsLWD) in long-term care (LTC) facilities in Malta. This was achieved through the following objectives:

1. Exploring how the physical environment affects OPsLWD in a LTC facility.
2. Exploring how the social environment affects OPsLWD in a LTC facility.
3. Looking at whether the current environment of the LTC facility meets the needs of OPsLWD.
4. Exploring what improvements can be made to the environment of the LTC facility in order to meet the needs of OPsLWD.

3.2 Research Design

A research design outlines the strategy chosen for a study with the purpose of addressing the research problem in an appropriate manner (Thakur, 2021). It encompasses the strategy adopted by this study in order to get an in-depth understanding of informal caregivers' perspectives on the influence of the physical and social environment on OPsLWD in a LTC

facility. A qualitative research approach was chosen to be the best approach for this study because it is a process of naturalistic inquiry that aimed to obtain an in-depth understanding of social phenomena within their natural setting. In other words, it is used to explore how people experience the world based on their own direct experiences (McLeod, 2019).

3.2.1 Theoretical Framework - Philosophical Underpinnings

The theoretical framework is a core element of the framing and design of a qualitative study. It consists of a research philosophy that outlines the beliefs and values that guide the design of a research study (Ryan, 2018). It is a common set of beliefs about how problems should be understood and addressed. It is considered as a 'worldview' and is a key aspect of any research study (Brown & Dueñas, 2019). It provides philosophical assumptions (axiology, ontology, epistemology, methodology) regarding the understanding of reality. It is important that researchers provide an explanation of their own assumptions as this influences the interpretation of research findings and the rigour of the research (Brown & Dueñas, 2019). In respect to this research study, a reflection of the researcher's philosophical assumptions was carried out.

Ontology is a branch of philosophy that is concerned with the existence and nature of reality (Hasa, 2016). An individual's ontological perspective shapes their beliefs regarding the form and nature of reality (Blackstone, 2014). Inspired by Brown & Dueñas (2019), the researcher believed that there is no single reality in life and that the same phenomenon may be experienced differently by different individuals in society within different contexts. Therefore, the researcher's ontological orientation for this study was relativism whereby it is believed that reality is a finite subjective experience. From a relativist perspective, multiple interpretations of experience lead to multiple subjective realities which are socially constructed by individuals (Levers, 2013).

Following the awareness of the ontological orientation, reflecting upon one's epistemological assumptions is necessary (Brown & Dueñas, 2019). Epistemology is a

branch of philosophy that is concerned with the nature of knowledge and how knowledge of phenomena is acquired (Hasa, 2016). An individual's epistemological perspective shapes their beliefs regarding how the person knows what the person knows and the best method to discover knowledge (Blackstone, 2014). In this research study, the informal caregiver participants voiced their different perspectives on what effect the environment of a LTC facility had on their relatives who were OPsLWD. Due to the subjectivity of multiple perspectives, the researcher believed that interpretation was needed in order to identify the underlying meaning of phenomenon. In view of this, the researcher's epistemological orientation was subjectivism where the aim of research was to narrate the meaning of subjective human experiences and obtain new understandings (Levers, 2013).

An applied disciplinary epistemological orientation was also utilised as the researcher also believed that knowledge should be implemented in practice rather than being simply of theoretical interest. Thorne et al. (2016) suggested that applied disciplinary knowledge can be used as a strong and coherent research framework. The aforementioned epistemology involves both individual human experience and knowledge that is derivative from populations (Thorne & Sawatzky 2014). This shapes the form and structure of the kinds of knowledge that will have relevance for health practice. The project's research questions were developed based on critical reflection of limitations in current knowledge regarding the phenomenon being studied. The angle of vision for conducting this study was informed by the researcher's professional knowledge as a physiotherapist as well as her inclination to apply knowledge to improve the health of individuals. The researcher also accounted for her prior assumptions and professional moral imperative by reflecting on her personal and work experiences discussed earlier in Section 1.3. The interpretive description (ID) approach does not require the researcher to bracket her preconceptions as this methodology acknowledges the researcher's theoretical knowledge and practical experience of the phenomenon under study (Thorne et al., 2016).

Axiological assumptions in qualitative research refer to the researcher's values and biases when conducting research. The researcher believes that research is value-bound which means that there is a clear link between the researcher and the participants in a study. For that reason, researcher interpretation gives meaning to the results of the research being

carried out (Levers, 2013). Following Brown & Dueñas's (2019) suggestions on careful reflection and consideration of the 'building blocks' of research paradigms, the most appropriate research paradigm was chosen and adopted by the researcher. Based on the relativist ontology and subjectivist and nursing disciplinary epistemologies, the research paradigm that this study is based on is constructivism. The research paradigm adopted enabled the researcher to effectively explore the perspectives of informal caregivers on the role of the environment on OPsLWD (refer to Table 3).

Table 3: A summary of the research paradigm adopted by the researcher in this study

Paradigm	**Constructivism**
Axiology	What is of value to research? Value-bound, the researcher is part of the research.
Ontology	What is reality? Relativism: There is no single reality or truth. There are multiple subjective realities, each of which is socially constructed by and between individuals.
Epistemology	How can reality be known? Subjectivism: Knowledge is subjective and formed at an individual level. The researcher and social world impact each other leading to multiple interpretations of reality.
Theoretical Perspective	Which approach is used to know something? Constructivism for a better understanding of phenomenon.
Methodology	How does one find this out? Interpretive description.
Method	What techniques does one use to find it out? Qualitative in-depth face-to-face semi-structured interviews.

3.2.2 Methodological Framework

Interpretive Description (ID) was used as the methodological framework for this study. This framework is an analytical and inductive research strategy that was developed by Thorne, Kirkham, and MacDonald-Emes in 1997 to create a way of understanding clinical phenomena and produce implications for practice (Thorne et al., 2004). ID has a philosophical alignment with interpretive naturalistic orientations whereby it acknowledges the constructed and contextual nature of human experience that together allows for shared realities (Thorne et al., 2004). Its constructivist paradigm formed the basis of the researcher's

theoretical approach to explore how the informal caregiver participants in this study perceived and interpreted the meaning of their experiences.

> *The philosophical underpinnings of naturalistic inquiry for research design include:*
>
> *1. There are multiple realities that can only be studied in a holistic manner. Consequently, reality is complex, contextual, constructed, and ultimately subjective,*
>
> *2. The researcher and the "object" of research interact to influence one another,*
>
> *3. No a priori theory could incorporate the multiple realities present. Therefore, a theory must emerge or be grounded in the data (Thorne et al., 2004, p. 5).*

Thorne (2013) stated that to follow the steps of ID, the researcher must (a) generate questions in the clinical field for which there is a lack of the existing knowledge, (b) carry out a review of the literature, and (c) frame a research project using strategies for a reliable study. Data analysis is characterised by a continuous relationship between data collection and analysis and should be performed repeatedly in order to identify patterns amongst the data (Thorne, 2013). This research approach generated a rich and detailed description of informal caregivers' perspectives on the role of the environment on OPsLWD by discovering associations, relations, and patterns that produced a better understanding of the phenomenon. The researcher did not simply want to describe the informal caregivers' perspectives on the role of the environment of a LTC facility on OPsLWD, but rather wanted to move beyond the available established qualitative methodologies for a deeper understanding through interpretation (Thorne et al., 2016) in order to generate findings that can be implemented in practice.

3.3 Sampling and Recruitment

ID does not have a rigid procedure for obtaining the sample group of a research study. Thorne (2016) stated that no matter the sampling technique and recruitment of participants, it is important for the researcher to maintain an integrity of interpretation of their chosen technique. With regards to sampling decisions, Thorne et al. (2016) suggested that phenomena may be expressed in infinite individual variations and therefore new variations

may always arise. Therefore, claiming 'data saturation' is not in line with ID epistemology. Thorne et al. (2016) recommended that research findings are meaningful for the individuals for whom the research was conducted for. Sample size should therefore reflect a number of cases which allows for the beginning of probable commonalities in order to get a better understanding of the phenomenon.

Since, as indicated earlier, locally there are no legal obligations towards facilities having a specialised care unit (SCU) for the older person living with dementia (OPLWD), the researcher drew by lot one facility from the 43 existing facilities. The drawn facility is state-owned but is operated and managed by a private company under the public-private partnership (PPP) scheme. A non-probability purposive sampling method was used in order to recruit participants from the drawn facility (Thompson Burdine et al., 2021). This sampling method was chosen as the research participants were of direct reference to the research questions (refer to Section 1.5) and were based on the inclusion criteria (described later in this chapter), set by the researcher. Even though qualitative samples tend to be smaller than those in quantitative research, purposive sampling permits a deep understanding of the phenomenon being studied through information rich cases (Palinkas et al., 2015; Vasileiou et al., 2018).

Thorne (2016) suggested that the sample of an ID research study may be of numerous sizes and that the majority of previous studies involved between 5 and 30 participants. The author had argued how meaningful results could be achieved through deep involvement with a small number of individuals willing to share their experiences with the researcher. According to Thorne et al. (2004), studies based on ID tend to include small samples and are part of smaller scale qualitative investigations of clinical phenomenon. The first 6-10 individuals who contacted the researcher and who fit the eligibility criteria took part in this study. This sample size was also recommended by Braun & Clarke (2013) for studies using interviews as the method for data collection.

With regards to the recruitment of participants, the facility manager was contacted to act as the gatekeeper and distribute the information letter to all the informal caregivers of OPsLWD

within the LTC facility and fitting the eligibility criteria. The information letter included a thorough explanation of the study and was provided in both the Maltese and English languages (refer to appendices 4A and 4B). Informal caregivers who contacted the researched to express their interest in partaking in the research were then provided with the consent form (refer to appendices 5A and 5B) and informed of the interview questions prior to the face-to-face interview to provide them with an opportunity to reflect on the questions in advance.

Inclusion criteria for the prospective participants included; (a) informal caregiver of an OPLWD and (b) the OPLWD is required to have been a resident in the LTC facility for more than 6 months. There were no restrictions for participation in this study with regards to gender, age, education, or socio-economic status.

3.4 Research Tool

Face-to-face semi-structured interviews were used as the instrument for data collection. This was chosen by the researcher to be the most appropriate method as the fundamental purpose of an interview is to gather information regarding an individual's experience and perspective. The interviews were carried out face-to-face in order to establish rapport with the participants, make them feel more comfortable and allow for better insight into their perspectives regarding the topic being researched (Steber, 2017). This choice of data collection method enabled the researcher to articulate a coherent and meaningful account of the participant's experiences (Thorne et al., 2004). Open-ended questions were used in order to explore personal and sensitive issues in detail. The advantage of using a semi-structured approach rather than a rigorous set of questions, was that it allowed for some flexibility during the discourse which permitted a deeper understanding of the participants' perspectives (DeJonckheere & Vaughn, 2019).

The interview tool was devised by following a five step process on semi-structured interview development (Kallio et al., 2016). This included (a) identification of its usage, (b) a review

of the existing literature, (c) formulation of the interview guide, (d) execution of a pilot study, and (e) presentation of the final result. The questions used in the interview guide were developed based on literature and knowledge of the relationship between the environment and OPLWD. The interview schedule can be found in in both the Maltese and English languages in appendices 6A and 6B.

3.5 Pilot Study

A pilot study was carried out with two female participants in order to test the suitability of the questions used in the interview tool and adapt if necessary (Noon, 2018). In addition, the pilot study helped the researcher to practise her interview skills and familiarise herself with carrying out semi-structured interviews. No changes were made to the interview tool however, since data collection and analysis took place concurrently, and areas of interest were noted and used as probes for the following interviews (Thompson Burdine et al., 2021). The two interviews were included in the data analysis.

3.6 Data Collection

Prior to the initiation of the interview a 'Profile Characteristics Sheet' was handed out to the participant to compile. This was then handed back to the researcher at the end of the interview. This sheet included, (a) gender, (b) age, (c) relation to the OPLWD, (d) whether the informal caregiver had any say in the choice of LTC facility, and (e) frequency of visitations. The purpose of this sheet was to obtain some information about the participants in order to help understand the context of their thoughts, feelings, and perspectives on the role of the environment on OPsLWD in a LTC facility.

Semi-structured face to face interviews were carried out where the participant and the researcher engaged in discourse regarding the phenomenon being studied. The interviews were audio recorded using a digital recorder when permission was granted by the participant.

The researcher also took additional notes during the interviews (refer to appendix 7A). Teodoro et al. (2013) stated that ID researchers use these notes to document and describe observations made during the interviews with regards to verbal cues and non-verbal behaviour such as facial expressions, postures and mannerisms. The interviews were conducted in the English language, were carried out at a time and place convenient for the participant and took an average of 45 minutes.

3.7 Data Analysis

Data analysis was based on ID method principles and reflexive thematic analysis (TA). Thorne (2016) proposed that the analytic process of ID is characterised by the constant comparative method. This method involves concurrent data collection and analysis whereby a continuous relationship is maintained between the two (Thompson Burdine et al., 2021). Birks & Mills (2015) stated that this strategy also permits the comparison of data with other data, codes with other codes, and categories with other categories in order to effectively make sense of the data set during the analysis process. Furthermore, Thorne (2016) argued that in order to discover new knowledge, researchers should compare and contrast data during the analysis process.

In this study, data was analysed using the reflexive TA approach which is a qualitative method used to identify and analyse data by telling stories through the interpretation of data and generation of themes within the data (Braun & Clarke, 2020). Besides using an organizational tool to classify and label the data, reflexive TA goes further to explore the explicit and implicit meanings within the data (Guest et al., 2012). In fact, the reflexive approach to TA acknowledges the researcher's active and reflective role in the production of knowledge (Braun & Clarke, 2019). Throughout the analysis process, details and aspects of meaning were explored through reading and reflective writing. This was achieved through creative and subjective interpretation during the process of selecting codes and constructing themes (Kiger & Varpio, 2020). Themes are described as "patterns of shared meaning, united by a central concept or idea" (Braun & Clarke, 2019) which are "creative and interpretive stories about the data, produced at the intersection of the researcher's theoretical

assumptions, their analytic resources and skill, and the data themselves" (Braun & Clarke, 2020). Therefore, reflexive TA was used to get a better understanding of experiences, thoughts, or behaviours of participants (Braun & Clarke, 2020). It allowed the researcher to gain awareness and insight into a particular situation within an institution by deciphering qualitative information (Braun & Clarke, 2019); in this case, regarding the perspectives of informal caregivers on the role of the environment on OPsLWD within a LTC facility. Reflexive TA is designed to identify common or shared meanings relevant to several participants rather than individual meanings from a single participant or data item (Kiger & Varpio, 2020). The researcher intended on exploring and interpreting patterns across several participants rather than a single case.

According to Braun & Clarke (2021), a distinguishing feature of reflexive TA is its flexibility; it can be used within an extensive range of theoretical and epistemological frameworks. Since it is not bound to any specific paradigm or theoretical framework, it can be applied to a wide range of research approaches, designs, and sample sizes (Kiger & Varpio, 2020). In comparison to other qualitative methods, reflexive TA is simpler to learn and apply (Guest et al., 2020; Tuffour, 2017). Since it does not require the use of theory to inform the analysis and its analytical processes are explained thoroughly, researchers have suggested that reflexive TA is a good first analytic method for beginner qualitative researchers and is easily accessible (Nowell et al. 2017).

The method outlined by Braun & Clarke (2021) is the most widely adopted method of TA. Even though their method of analysis consists of six phases, the researcher may move back to previous steps if new themes require further investigation. In this study, constant comparison was carried out to compare generated data between transcripts (Thorne, 2016). A characteristic of reflexive TA is the creation of a thematic map which provides visual presentation of the relationship between themes and codes. The result of the analysis should be the identification of a story of the data in relation to the research question (Vaismoradi et al., 2013). An explanation of Braun & Clarke's six phase process of reflexive TA can be found below in Table 4.

Table 4: Step by step explanation of reflexive TA

Stage	Data analysis activity
Phase 1:	**Data familiarisation and writing familiarisation notes** The initial step involved actively listening to each interview prior to transcription of the interviews. This was followed by transcription of the data using Microsoft Word (2016). Open-minded reading and re-reading of the transcribed data was then carried out. This allowed for familiarization with the data enabling the researcher to observe meanings and write down initial notes, observations and thoughts.
Phase 2:	**Systematic data coding** An initial set of codes was created by identifying interesting points in the data and documenting the patterns that occurred. Data that represented the same meaning had the same code applied to it. This process was done in a systematic way so that segments of data were simplified into labels or codes. Notes were taken by the researcher regarding the reasons for choices for certain codes and possible relationships between codes.
Phase 3:	**Generating initial themes from coded and collated data** This step involved combining codes together that accurately represented the data to generate themes. Methodological principles allowed the researcher to uphold a reflective mind to further develop meanings into themes.
Phase 4:	**Developing and reviewing themes** Evaluation and refinement of the themes to ensure that each one has enough data to support them and is distinct. Themes were merged together or removed if there was not enough data to back them up.
Phase 5:	**Refining, defining and naming themes** The naming and wording of themes is important to ensure meaningful findings. Defining and refining the themes allowed for a clearer description of the essence of the themes. Clarification was provided with regards to the relation between themes in the study.
Phase 6:	**Writing the report** The final step involved writing a report of the analysis with the use of vivid quotes from the data. This included the researcher's own interpretation of the findings with regards to the research question.

Thorne (2020) argued that generating themes was only one part of the analysis process and could not be the end point in studies adopting the ID approach. Researchers have to go

beyond reporting and describing themes in order to offer a thoughtful report of possible interpretations through iterative analysis which is a key element of research based on ID (Thompson Burdine et al., 2021). Iterative analysis refers to a reflexive process carried out by the researcher to provide insight and develop meaning (Thorne, 2016). In this study, a diary was used during the analysis process whereby notes were documented by the researcher explaining why certain patterns where noted and what she thought they might mean (refer to appendix 7B). Thorne (2020) argued that reflecting on these notes allowed the researcher to delve deeper and enter into a more complex line of inquisitiveness by looking beyond the patterns in the data. Furthermore, the author argued that when the researcher noted down initial thoughts, she would become aware of her own biases and assumptions that might have influenced her research (Thorne, 2020).

3.8 Strengths and Limitations of Interpretive Description Approach

Thorne (2008) described ID as a 'non-categorical methodology' meaning that it drew on elements derived from phenomenology, grounded theory and ethnography but that it did not have pre-determined specific techniques to carry out research. The problem in adapting traditional qualitative research methods, such as those proposed by anthropology, sociology and psychology, to the applied health disciplines was that these areas were more inclined to theoretical problems rather than practical problems (Teodoro et al., 2018). Consequently, when these methods are applied to health-related research, a better understanding of a phenomenon could be achieved; however, health and disease-related problems may remain unresolved. It was for this reason that ID was designed; with the aim of generating reliable and meaningful knowledge relevant for the clinical context of health practice (Teodoro et al., 2018). In fact, initially, the researcher had intended on using interpretive phenomenological analysis or grounded theory for her study. However, as further research ensued, the researcher realised that these methodologies did not provide appropriate approaches to address the research questions of this study. Through reading, the researcher became aware of ID and found that its constructivist orientation and inclination toward clinical practice were in line with the aims and scope of the researcher's project. This research approach allowed the researcher to capture the subjective perspectives of informal

caregivers of OPsLWD within a LTC facility by observing patterns of the phenomenon being studied.

ID also faces some challenges especially since it is a lesser-known methodology (Hunt, 2009). Even though it is gaining popularity, there is still a limited amount of studies based on the ID approach. Consequently, novice researchers might be unsure regarding the amount of interpretation needed to analyse the data.

3.9 Ensuring Quality In Qualitative Research

Quality and rigour of a qualitative research study depended on how applicable and relevant the findings of the study were (Thompson Burdine et al., 2021). Thorne (2016) outlined coherent principles to follow to ensure rigour when carrying out a study based on ID. Various rigour strategies were used throughout this study in order to ensure trustworthiness and transparency of the research process and findings (Miciak et al., 2018). Rigour was ensured by following the four principles explained below (Thorne, 2016).

3.9.1 Epistemological Integrity

It is important that the research questions were consistent with the researcher's epistemological position in order to produce credible results (Thorne, 2016). A thorough explanation was given in Section 3.2.1 regarding the line of reasoning of the researcher's philosophical assumptions about the nature of knowledge and the methodological rules that guided the research process of this study. As explained in Section 3.8, the researcher ensured methodological congruence by exploring different qualitative methods before selecting ID as the most appropriate one for her study (Jackson et al., 2022). Additionally, training in qualitative research was carried out prior to conducting this study. Throughout the research process, guidance and feedback were sought from the researcher's supervisor for external auditing and peer review.

3.9.2 Representative Credibility

The findings of a study should reflect the phenomenon that is being researched through appropriate sampling. Thorne (2016) advised that maximal variation sampling should be used in order to recruit a diverse set of participants which would result in a study that could be generalised and demonstrated representative credibility. Purposive sampling, the method used in this study, allowed participants with direct reference to the research questions to participate in this study. A limitation of this study was that the participants and their relatives living with dementia within the LTC facility were all female. This limited generalizability of the findings due to a lack of representation of varied perspectives. However, it is well documented in the literature that informal caregivers are predominantly women (Sharma et al, 2016) and that the prevalence for dementia is higher amongst women (Alzheimer's Disease International, 2015). Therefore, even though the sample of participants was not heterogeneous it still represented the common situation found in LTC facilities.

Prolonged engagement with participants is a technique that can be used to provide rich description and credibility in qualitative research (Jackson et al., 2022). During the interviews, the researcher took time to establish trust with the participants in order to create a comfortable and safe environment for discourse. This was carried out by conveying a positive attitude, allowing adequate time for the interviews, being mindful of the participants' emotions, and adopting a relaxed posture and tone of voice (Jones, 2022; Morse, 2015; Saarijärvi & Bratt, 2021; Thorne, 2016). Additionally, following analysis, a thick description of the findings was documented which will help other researchers evaluate the applicability and transferability of this study to a different context (Agom et al., 2020; Mackieson et al., 2019).

3.9.3 Analytic Logic

The decision-making process and analytic logic throughout this study was accounted for by explaining the researcher's decisions throughout the research process. An audit trail of the researcher's analytic process was kept in order to produce a detailed document outlining all the decisions made (refer to appendix 7C). This was done in order to enhance dependability and transferability of the findings (Thorne, 2016). Furthermore, the use of participants' quotes was used in the Chapter 4 of the dissertation in order to support the findings and illustrate concepts to provide thick description (Jackson et al., 2022).

3.9.4 Interpretive Authority

Research is considered as being trustworthy and having interpretive authority when it refers to a measure of the truth, often considered as a 'constructed truth' in research adopting an ID approach. The research findings of this study were considered as constructed truths as opposed to facts due to the fact that ID's philosophical underpinnings held that reality is subjective and constructed. Thorne (2016) proposed the use of a reflective journal, a technique that can be used to ensure rigour and trustworthiness of a study. The researcher practiced reflexivity by making use of a journal and documenting her thoughts throughout the research process (Thompson Burdine et al., 2021). Furthermore, the researcher accounted for her bias and assumptions and how they influenced the research along with the limitations of the study. It is worth noting that the researcher had previously provided professional physiotherapy services at the drawn LTC facility, however, had never met with the participants prior to the study. The interview transcriptions were transcribed by the researcher by using Microsoft Word (2016). Data analysis and the researcher's interpretations were regularly discussed with her supervisor.

3.10 Ethical Considerations

The Director and Assistant Director of Active Ageing and Community Care (AACC) together with the Chief Operating Officer of the drawn LTC facility were contacted in writing to discuss the project and for their unofficial approval of the project pending Faculty

Research Ethics Committee (FREC) clearance (refer to appendices 8A and 8B). Request for the management of the LTC facility to act as the gatekeeper was also discussed. The researcher then compiled the Research Ethics and Data Protection Form (REDP) for submission to the Faculty's FREC. The package for this submission included; (a) the information sheet, (b) the consent form, (c) the interview guide in the Maltese and English languages, and (d) the gatekeeper letter (refer to appendix 8B). FREC endorsement was eventually communicated with AACC and the LTC facility (refer to appendix 8C).

Prior to carrying out the interviews, the information letter was distributed by the gatekeeper to all the informal caregivers fitting the eligibility criteria. This included (a) the objectives of the study, (b) information regarding the research process, (c) assurance re confidentiality and anonymity issues, and (d) the request for permission to audio record. Participants were made aware that participation was voluntary, that they could withdraw from the study and could refuse to answer a question at any stage. They were also made aware that once the interviews had been transcribed they would also be given the opportunity to revisit the material within a pre agreed timeframe. Anonymity and confidentiality were maintained throughout the duration of the study. All confidential information was kept in a password-protected area and would be destroyed upon completion of this study in according to the General Data Protection Act (2016) and Malta Data Protection Act (2018). Participants interested in partaking in the research were able to contact the researcher themselves through the details provided in the information sheet previously distributed by the gate keeper.

3.11 Conclusion

This chapter has outlined the research design and methodological approach used in this study along with the principles which were followed to ensure quality in qualitative research. In the next chapter, the findings and interpretations of the data will be presented with relevance to the reviewed literature.

CHAPTER 4
FINDINGS AND DISCUSSION

4.0 Introduction

This chapter provides an integration of the findings along with the researcher's interpretations. The aims of this study were to explore (a) how the physical environment affects older persons living with dementia (OPsLWD) in a long-term care (LTC) facility, (b) how the social environment affects OPsLWD in a LTC facility, (c) whether the current environment of the LTC facility meets the needs of OPsLWD, and (d) what improvements can be made to the environment of the LTC facility in order to meet the needs of OPsLWD.

The findings were obtained from six participants who were informal caregivers of OPsLWD within the LTC facility chosen by lot. In this chapter, the themes generated are supported by direct quotations from the transcripts and are discussed in relation to the available literature. The researcher's interpretations of the research findings are grounded on her personal experience working as a physiotherapist within in the field of geriatrics. A brief introduction of the six participants will be provided in Section 4.1 below.

4.1 Profile of Participants

The characteristics of the participants and some background information on their loved ones living with dementia are presented below in Table 5 and Table 6. The purpose of gathering this data was to help understand the context of their thoughts, feelings, and perspectives on the role of the environment on OPsLWD in a LTC facility. The participants were given codes which were used by the researcher during the research project and pseudonyms which were used to ensure confidentiality throughout this chapter.

Table 5: Profile of participants and their loved ones living with dementia

Participant 001 – Ashley

Ashley is a 54-year-old lady who works as an assistant head in a primary school. She was the main informal caregiver for her mother Greta who lived with dementia but sadly passed away during the COVID-19 pandemic. Greta resided in a 2-bedded room within the dementia unit at Serenity Manor while her husband decided to remain living alone in the community and volunteering at the parish church; he was later admitted to the facility following the demise of his wife. Greta resided in a 2-bedded room within the dementia unit and was visited by Ashley on a daily basis in the evenings after she finished from work. Greta was a sociable person, loved animals, and used to enjoy spending time in the garden with her daughter. During the pandemic family visitations were restricted to 10 minutes from behind a plastic barrier, carried out online, or even disallowed completely. This resulted in confusion, disorientation, loneliness, and social isolation for Greta. "When she was passing…I asked them to let me in so I could be with her in her last few hours but they did not consent to that either and I think that was really cruel…I still have nightmares about what went on through her mind… dying and not having someone to hold her hand".

Participant 002 – Bethany

Bethany is a 48-year-old lady whose mother Hannah lives with dementia and resides in a 2-bedded room with her husband at Serenity Manor. Even though her parents live together within the facility, Bethany is still the main informal caregiver for Hannah because her father lives with chronic depression and the onset of dementia. Even though Hannah does not reside within the dementia unit, she is escorted there in the afternoons to participate in the organised dementia-friendly activities. Bethany visits Hannah everyday between Monday and Friday in the mornings while her brother visits on the weekends. Besides this, Bethany did not provide any information regarding a current job and stated that she also takes her daughter to hospital on a regular basis which suggested that she might be a housewife and a caregiver. Due to Hannah's dementia, her cognitive and functional performance tend to fluctuate thus requiring assistance to carry out activities of daily living (ADLs) and mobilise. Hannah used to be a teacher and is observant of signs, symbols, names, and pictures within the facility. She has a very calm character and enjoyed listening to music, dancing, getting pampered, and being sociable.

Participant 003 – Christina

Christina is a 59-year-old lady who works as an assistant head in a primary school. She faces certain challenges in life as she lives with fibromyalgia while her husband lives with cancer. She is also the main informal caregiver for her mother Isabella who lives with dementia and resides in a 2-bedded room in the dementia unit at Serenity Manor. About 8 years ago, Christina went through a difficult time as she had to leave her job to care for her parents who were still living in the community. Currently, she visits Isabella daily at Serenity Manor in the afternoons after she has finished from work. Isabella's husband still lives alone in the community and visits her twice daily. Isabella is very frail, bedridden, uncommunicative, and receives end-of-life care. She enjoyed listening to the music, hearing the rosary, and being cared for and visited by her daughter; "there is that odd smile every day which she gives me at one point… she does something which shows me that she's happy to see me".

Table 5: Profile of participants and their loved ones living with dementia (continued)

Participant 004 – Danielle

Danielle is a 73-year-old lady who is retired and resides at Serenity Manor. She was admitted into the facility because she offered to take care of a young woman with Down's Syndrome after her mother had passed away. Besides caring for her within the facility, she was also the main informal caregiver for her cousin John who lived with dementia but sadly passed away in 2022. Danielle spent quite a bit of time with him since they both resided at Serenity Manor. John resided in a 3-bedded room within the facility and was visited by his wife on a daily basis. During his stay at Serenity Manor, John withdrew from activities and shouted persistently as a means of expressing his need for company by his wife. He used to work as a pharmacist and used to take an interest in discourse on medication with the staff at the facility. A deterioration in his health was noted towards the end of his life; "He never accepted to come here… in the beginning he used to walk with a stick but then he ended up in a wheelchair and had a harness" which "he never accepted".

Participant 005 – Esme

Esme is a 51-year-old lady whose mother Kimberly lives with dementia at Serenity Manor in a 3-bedded room. Besides being the main informal caregiver for Kimberly, Esme is a housewife and used to do voluntary work in another LTC facility. Previous to admission, Kimberly lived with her son but was not well looked after. In fact, she was admitted to Serenity Manor as a social case following hospital admission due to poor health. Esme indicated that a social worker had to get involved in view of certain family issues between her sister and brother. Nevertheless, Esme tries to keep in contact with both her siblings and visits Kimberly daily at the facility. Kimberly had early-onset of dementia where her symptoms began at the age of 33. She is a widow as her husband passed away when she was 49-years-old. From a young age, she was faced with negative comments and stigma from her in-laws; "she's like a tape recorder". She mobilises with a walking frame and requires minimal assistance for ADLs. She suffered from repetitive speech, hearing problems, anxiety. She enjoyed being around other people, drawing, doing puzzles, music, listening to mass, and spending time outdoors.

Participant 006 – Faith

Faith is a 51-year-old lady who works as an English teacher at a post-secondary educational college. Her mother Luna lives with dementia in a 2-bedded room at Serenity Manor. Even though Faith has 2 brothers, she is the main informal caregiver for Luna and visits her 5 times per week in the evenings after she finishes from work. Prior to being admitted to Serenity Manor, Luna used to live with Faith and had two separate periods of time where she was admitted to two different facilities for respite. Luna is currently wheelchair bound, does not mobilise, and is dependent in her ADLs. She suffers from symptoms such as agitation, shouting, screaming, and repetitive speech which "is done mostly when she is on her own". She enjoyed being around other people, spending time outdoors, reading Maltese books, watching television, listening to mass, cooking, and sewing.

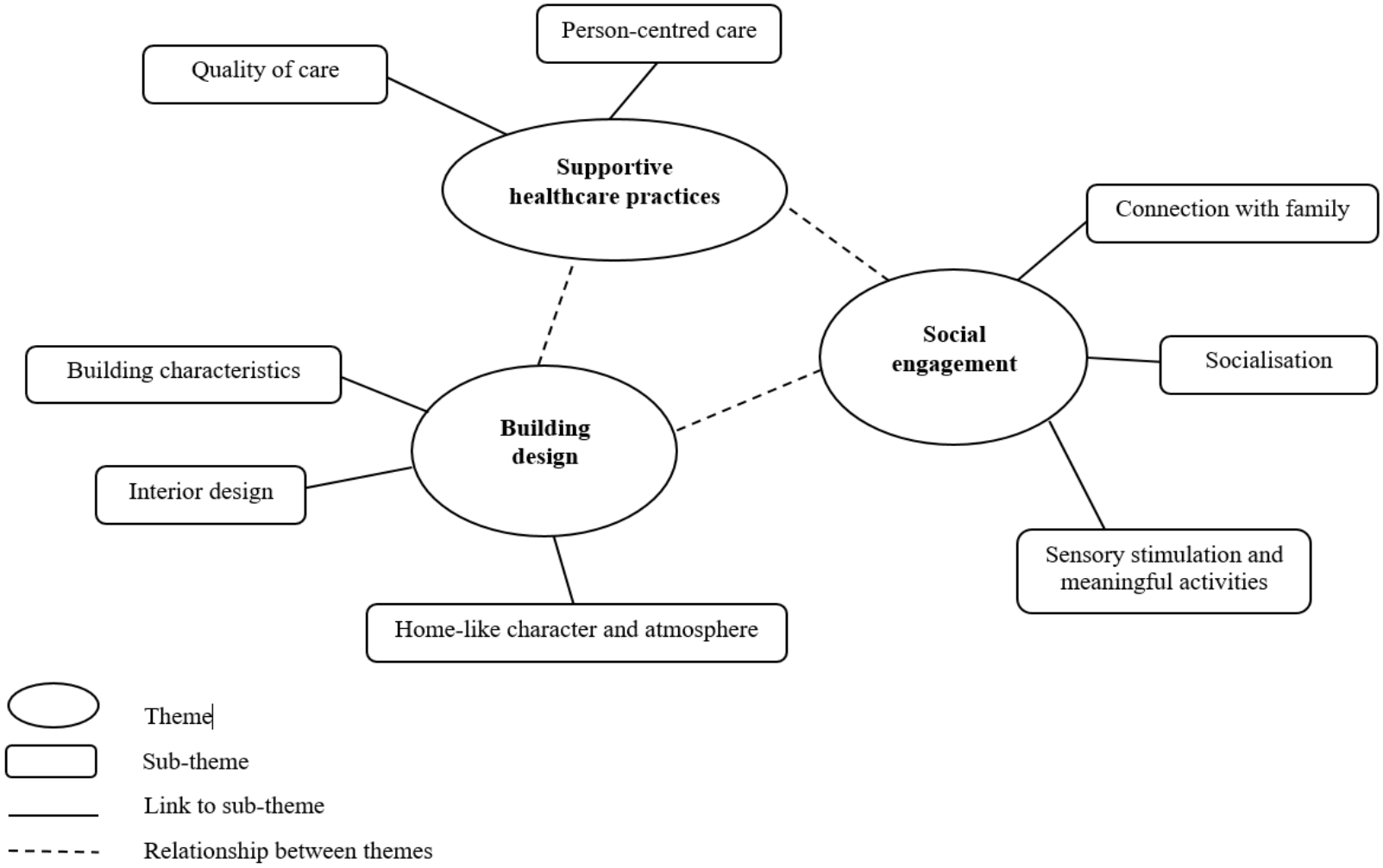
Table 6: Characteristics of participants

Participants (Pseudonyms)	**Gender**	**Age**	**Relation to the OPLWD**	**Say in the choice of LTC facility**	**Frequency of visitations**
Ashley	Female	54	Daughter	Yes	Daily (evenings)
Bethany	Female	48	Daughter	Yes	Daily (mornings)
Christina	Female	59	Daughter	Yes	Daily (afternoons)
Danielle	Female	73	Cousin	Unknown	Daily
Esme	Female	51	Daughter	Yes	Daily (mornings)
Faith	Female	51	Daughter	Yes	5 times weekly

4.2 Findings from the data analysis

Following analysis of the collected data, the themes and sub-themes illustrated in Figure 1 below were generated as a representation of informal caregivers' perspectives on the role of the environment on OPsLWD within a LTC facility. Three themes were generated: (a) social engagement, (b) supportive healthcare practices in relation to the social environment, and (c) building design in relation to the physical environment.

Figure 1: Thematic map demonstrating three themes: (a) social engagement, (b) supportive healthcare practices in relation to the social environment, and (c) building design in relation to the physical environment.



4.3 Social engagement

The theme *social engagement* explored a principal idea which was expressed continually throughout the data set – that social participation and communication within a community provided a sense of belonging and meaning in life. These results further support the idea that being engaged socially is associated with positive well-being and health-related behaviours (Luo et al., 2020). Social functioning refers to the extent an individual is socially engaged, the amount of social relationships they have, and the social activities they participate in (Mackenzie & Abdulrazaq, 2019). The authors found that it is not merely the participation in an activity that brings about these benefits, but rather the opportunity for the individual to feel engaged and connected to others. These results are in agreement with those of Machenzie & Abdulrazaq (2019) for the reason that Esme recalled how Kimberly "likes to see people because if she is alone she feels *sad*; she cannot go out with other people because she cannot hear but at least she is seeing [other people pass by]". As forming part of the social environment, the following sub-themes will be presented and discussed in relation to social engagement: (a) socialisation, (b) connection with family, and (c) sensory stimulation and meaningful activities.

4.3.1 Socialisation

In accordance with the present results, previous studies have demonstrated that cognitive impairment has a negative effect on social behaviours such as social interaction and emotion recognition (Bora & Yener, 2017) which lead to the withdrawal from social activities (Hackett et al., 2019). Therefore, staff within the LTC facility are responsible for encouraging social engagement and activity for OPsLWD. Four participants remarked that a lack of social engagement and a passive lifestyle was detrimental to one's health (Ashely, Bethany, Christina, and Faith). In actual fact, Faith blamed the lack of social interaction on shortage of staff.

> "They put them [OPsLWD] in a corridor, really I don't like this, I've seen this in other homes, they are put in a corridor *waiting for their life to end* and I'm sure that

> *nothing is stimulating them*… I understand they are *short staffed* but ideally somebody goes to talk to her because even her [Luna] speech now is becoming less since she doesn't need to speak." (Faith)

The aforementioned participants felt as if there was a lack of informal social interaction between staff and residents at Serenity Manor and how they wished for the staff to spend more time with their loved ones.

> "They [staff] didn't encourage her [Greta] to *socialise*. For sure, if they're on their mobile they don't care if someone went to lock themselves up in a room, that's convenient… things get worse when there are *no aims at all* and there is nothing to do. The *mind becomes really lazy* and then it [dementia] progresses really fast… I prefer not to see the elderly in their beds at 10 o'clock in the morning" (Ashley)

> "I don't like it that they [staff] leave my mum in the bedroom after she's washed and she's just there. A person *feels isolated* and then it affects the dementia… and how alert the mind would be and how motivated she would be". (Bethany)

Ashley described the lounge in the dementia as "*unattractive*" as her "mother always retrieved to her own room and never used the common area" because "there was *no one to interact with*". Additionally, Ashley and Christina both suggested that conversation could be stimulated by matching roommates with similar social capabilities. Ashely claimed that Greta's "roommate was somebody who didn't speak and had full blow dementia" so she depended on her daughter to participate in a conversation. Moreover, Christina stated that "when the person is still sociable, it's healthy for them [management team] to match characters and have two in a room".

Four participants voiced that the COVID-19 pandemic resulted in a lack of social interaction with their loved ones due to the restrictions for LTC facilities (Ashely, Bethany, Christina, and Danielle). Comparison of findings from those of other studies (Keng et al., 2020: Knippenberg et al., 2022; Lombardo et al., 2020) confirmed that disrupted visitations from family members resulted in loneliness, lack of human contact, social exclusion and disturbed daily routines which exacerbated behavioural and psychological symptoms of dementia (BPSD). For instance, Danielle explained how John's confusion and agitation increased

significantly due to his wife being unable to visit him. Additionally, the lack of family visitations in addition to the hindrance of online communication by staff caused anxiety and confusion for Greta.

> "There was a time when I could only speak to her [Greta] on Skype and she missed *physical contact* as she was very loving and *wanted hugs* and to go out for coffee. When I used to tell her "I can't come because of the pandemic" she couldn't understand… they [staff] gave me a hard time to speak to her on a phone or on Skype". (Ashely)

4.3.2 Connection with family

Comparison of the findings with those of other studies (Førsund & Ytrehus, 2018; Goodman et al., 2013) confirms that family involvement has been recognised as a crucial component in dementia care. Truly knowing a person for a substantial amount of time, as in the case of family members, facilitated recognition of unfamiliar behaviours which indicated a problem. For example, Christina had realised that Isabella's glucose level had been very high due to unusual restlessness, which had been missed by the staff at Serenity Manor.

> "It's because I am near her [Isabella] for a considerable time and I see that she opens up. It's when she doesn't open up that I realise that something is not right". (Christina)

The family structure has a direct influence on the support and care for the older person living with dementia (OPLWD) (Smith et al., 2022). All the participants expressed that they had a strong relationship with their loved ones and visited them on a daily basis. In John's case, Danielle stated that even though his wife "used to come every single day" her absence used to trigger his symptoms which showed how important regular contact with her was. An increase in Luna's agitation was also noted when her daughter Faith would leave the LTC facility leading to questions such as "so you're leaving me alone?", "you're not coming back?", and "how do I get to bed?" which showed a sense of reliance on her daughter to feel safe. Esme had a similar experience:

> "I was abroad for three weeks last summer… and the carers told me that in the night she [Kimberly] used to ask "Where is my little one?" because *we are very close,* they [staff] used to tell me "it's you she looks for, she's wandering about looking for you"." (Esme)

Enhancing caregiver education could facilitate care for OPsLWD and provide support for informal caregivers (Poole et al., 2020; Sousa et al., 2016). Interestingly, Bethany had attended a couple of talks on dementia and learned that sticking to a routine and having a daily schedule helped with orientation for the OPLWD and reduced BPSD. Ashley also took initiative and researched about dementia as she felt as if "she needed information" since "it was a first time experience".

Caregiving approaches and the presence of BPSD during mealtimes could also affect OPsLWD from obtaining appropriate nutrition (Lee et al., 2021). Similarly, four participants in this study mentioned that providing assistance to their loved ones during mealtimes facilitated food intake (Ashley, Bethany, Christina, and Danielle) in comparison to being assisted by staff. It is well documented that in large facilities, one-on-one attention during meal times is difficult in LTC facilities due to existing staffing ratios (Douglas & Lawrence, 2015).

> "I used to observe the carers feeding the people who can't eat alone, they [staff] wouldn't give them [OPLWD] the whole portion. If they saw that they've eaten more or less they'll be happy and say "okay, that's it". I would continue insisting to feed her [Hannah] and distract her because obviously *she's my mother* and *I just have her* but if a carer is trying to feed a patient and she sees that the patient doesn't want then what can they do?…They have other people… I mean, you can't point fingers because at the end of the day they have so many and only a pair of hands you know? (Bethany)

4.3.3 Sensory Stimulation and Meaningful Activities

Within a dementia care setting the immediate needs and abilities of the individual need to be incorporated into the goals of care (Calkins, 2018). As explained previously in Section 2.1.1, previous studies have demonstrated that the unmet cognitive and sensory needs of OPsLWD could result in BPSD (Cohen-Mansfield et al., 2015; Cunningham et al., 2019; Kales et al., 2015). This study supports this evidence as all participants believed that environmental stimulation within a LTC facility is important for the well-being and cognitive functioning of OPsLWD. Bethany and Faith both expressed that ensuring there is enough light, switching on the television, and communicating with their mothers assisted with orientation, consciousness, and awareness of their surroundings. Overall, the participants in this study felt that the overall environment at Serenity Manor lacked stimulation and informal interaction which led to boredom and inactivity in Greta's, Hannah's, and Kimberly's cases, apathy and withdrawal in Isabella's case, and increased shouting and screaming in John's and Luna's cases. This unstimulating environment was associated with a sense of simply existing and not living.

> "I used to go and find her [Isabella] with her head bent down… I don't expect them [staff] to spend hours but some *interaction is important*… they are all gathered there [lounge in the dementia unit] but why doesn't anybody tell them to move their hands or get them to move? That's why all *the senses go away*." (Christina)

Danielle suggested that soft background music could be beneficial in creating a livelier environment for "the residents that are upstairs in the corridor *doing nothing*". Christina pointed out that even though music was played in the dementia unit, the presence of "an animator" would have provided more social engagement. In fact, Bethany happily recalled one morning during the summer when the staff put on "old time music and some of the carers would go out [in the garden] dancing and clapping… and it put a smile on her [Hannah's] face and *she'd be happy* and tap to the music and clap". These results confirm the association between music and positive stimulation suggested by Fleming et al. (2020).

A weekly schedule consisting of two activities daily was planned by the activity co-ordinator at Serenity Manor. A separate plan with dementia-friendly activities was created for the residents residing in the dementia-unit. Ashley pointed out that "there is still room for

improvement because two activities a day are still not enough". Bethany, Christina, Esme, and Faith also wished for more formal activities and informal interaction throughout the day whilst Ashley suggested that interaction with animals should be encouraged because they are "very therapeutic". This finding supports the work of Peluso et al. (2018) which suggested that animal-assisted therapy is a non-pharmacological intervention with emotional and psychological benefits.

The five participants emphasised that organised activities in LTC facilities should be tailored to the individual's needs and capabilities in order to encourage better participation and enjoyment (Ashley, Bethany, Christina, Esme, and Faith). These findings are consistent with several other studies accentuating the benefits of tailored activities (Bertoncello et al., 2021; Tak et al., 2015). Furthermore, by getting to know the interests of the OPsLWD (mentioned previously in Table 5), activities could be purposeful and more attractive. Bethany suggested that activities should engage the senses and provide mental stimulation through the use of colourful "flash cards or even children's books" with pictures "to keep their mind going". She stated that since Hannah did not reside in the dementia unit she was not always included in dementia-friendly activities. Christina felt that since Isabella was bed-ridden and could not partake in organised activities, some form of interaction or "reaching out" was still important. She pointed out that it is up to the management team to implement such policies. Esme detailed how Kimberly enjoyed the varied activities available and that staff "try to do their very best" to facilitate participation for individuals with impairments such as showing the number during bingo and using pictures with subtitles when playing music.

Ashely proposed that organising new activities based on the individuals' interests may offer better job satisfaction, creative thinking, and a sense of empowerment for staff. Furthermore, older persons themselves should also be given the opportunity to organise activities which encourages active ageing, community contribution, and empowerment.

> "He [a resident at Serenity Manor] organises outings for them [other residents] and *takes initiative* himself. That's very admirable in my opinion and sometimes they go for a 'fenkata', sometimes they go for a pizza. He doesn't do it often but at least once

> a month he organises transport and everything. I mean, these things should be encouraged". (Ashely)

Whilst organised outings were difficult for the participants' loved ones due to the lack of one-on-one attention, all the participants mentioned that the OPsLWD enjoyed day trips with family members. Even though John did not really enjoy participating in organised activities at Serenity Manor, he looked forward to his weekly Sunday outing with his wife to his local town.

An important matter that was highlighted by four participants was the need for daily physical activity to be incorporated in care plans (Ashely, Christina, Esme, and Faith). These findings are consistent with a study carried out by Cadieux et al. (2013) which stated that OPsLWD have needs related to ensuring good physical health and exercise. A negative mentality was portrayed by the staff regarding premature use of wheelchairs to make life easier. This was associated with a regression in the level of mobility of the OPsLWD due to a passive lifestyle and inactivity, which is a common occurrence in LTC facilities. In fact, Ashely stated that "they really need to have an exercise plan… he [her father] can barely walk these days because he is always sitting down, obviously [this is going to happen] if you don't exercise". In addition, Faith noted that an increase in human resources is required to allocate more time for physical activity and implement regular exercise classes. From an organisational aspect, strategies and regulations need to be implemented to enhance physical activity in LTC facilities (Forster et al., 2021).

> "The best way would be somebody giving them attention… there's a little garden, they [staff] don't take them for walks or just push them in the wheelchair, I'm sure *they don't have enough staff*". (Faith)

4.4 Supportive health-care practices

Due to the challenges associated with dementia, supportive health-care practices could improve the quality of care provided by promoting quality of life and independence (Surr et al., 2017). Therefore, as forming part of the social environment, the following sub-themes

will be presented and discussed in relation to supportive health-care practices: (a) quality of care, and (b) person-centred care. All the participants agreed that being an informal caregiver for an OPLWD was a difficult situation to be in. This is in line with international studies that suggested that access to education, development of coping strategies, and receiving support could facilitate care and also decrease caregiver stress (Bressan et al., 2020).

> "My husband is going through a third lymphoma but I tell you that this [dementia] is worse because you see your loved one deteriorating… so, as a relative, it would be soothing to have a *support system* within the home." (Christina)

As an individual who resided at Serenity Manor, Danielle had first-hand experience of living with OPsLWD and acknowledged that "it's not easy to live with them [OPsLWD]" and care can be challenging for both formal and informal caregivers. Therefore, staff training in dementia care should be invested in to improve the well-being of both the OPsLWD and their caregivers. It is encouraging to compare this finding with that found by Spector et al. (2016) who found that dementia care training and educational programs completed by staff improved their well-being by being more knowledgeable on managing BPSD. Furthermore, an improvement in the quality of life of OPsLWD was noted following dementia care training in a study carried out by Yasuda & Sakakibara (2017).

> "What's important is that the carers attend these [dementia care] courses… It all boils down to the *management*, if we are going to improve the system that's the way forward, you can't see everything on a monetary level. That's how you provide a better service." (Bethany)

Two participants valued the importance of staff being knowledgeable on dementia care and providing reassurance regarding the care of their loved ones (Bethany and Christina). Bethany felt that the staff's little knowledge on dementia was obtained through "routine" (experience) rather than education. Christina expected that health-care professionals would be more knowledgeable than her and was upset regarding the lack of handover from staff regarding the well-being of her mother.

> "I know it's a problem to find the *appropriate qualified people* … I can't say that I've met somebody [staff] who tells me what's going on… when I ask them, they remain silent or one thing that occurred a lot was "I wasn't here" or "I'm replacing her". (Christina)

4.4.1 Quality of care

Quality of life in OPsLWD is substantially reliant on the quality of care that they receive (Bökberg et al., 2017). This finding supports evidence from a previous study carried out by Nakanishi & Tei-Tominaga (2018) regarding the association between staff professionalism and quality of care. Danielle believed that carers should always be professional when working with OPsLWD as they tend to depend on them for everyday assistance. Faith claimed that "the carers and nurses are extremely *dedicated*" at Serenity Manor. This was also consistent with Bethany's and Esme's experiences where they felt as if there was good communication between the staff and relatives as well as the professional management of medical problems.

> "She [nurse] was *extremely professional* [following her father's fall], she called the polyclinic and there was *regular communication* which I appreciated a lot because they are your parents and they're here [at Serenity Manor] not because you don't want to take care of them but because you understand you can't be with them 24/7 so when you see them getting this *attention* you feel good and *your mind is at rest*". (Bethany)

> "If she [Kimberly] has something, for example she was coughing and they phoned the doctor… the pills are always given, I have *my mind at rest*… she's *safe* here" (Esme)

Three participants spoke highly of the manager and nursing officer at Serenity Manor (Ashley, Bethany, and Esme). According to Esme, "they tackle it [a problem] as soon as you complain about something… they follow it up and they don't ignore anyone". Any issues were always dealt with immediately and professionally by offering helpful and practical

solutions. This finding corroborates the thoughts of Evans et al. (2018) which suggested that values and attitudes of managers in LTC facilities directly influence the autonomy and dignity of OPsLWD.

> "My mum was a wanderer and they [management team] tried to find the *happy medium* because when my mum went down in the mornings to the dementia unit it affected my dad negatively… so now as things are we found the best way… they even saw the effect on my dad". (Bethany)

Another instance that occurred was when the staff at Serenity Manor left Hannah with a soiled pad because she was from a different floor. Urinary and faecal incontinence had a negative impact on a person's dignity and should not be neglected (Kangasniemi et al., 2022). When the manager at Serenity Manor was approached by Bethany he showed empathy and responded with immediate action. He had told Bethany: "Please always come to me for this because we need to *respect the elderly* that they are not soiled". Furthermore, Ashley noted a "great improvement" since the current manager started working there especially with regards to provision of care and weekly activity schedule.

All the participants attributed certain problems to the lack of human resources which according to Lee et al. (2022) is common in LTC facilities around the world. Thake et al. (2020) stated that similar to Western European countries, Malta has also experienced staff shortages in the public health sector. This study supports the evidence regarding shortage of staff in local LTC facilities. Due to residing at Serenity Manor, Danielle empathised with the staff regarding completion of tasks and used to explain this to John to reduce his shouting when waiting for assistance for bathing. Bethany also empathised and stated that "you have to realise that the carers *do what they can*… I think they [Serenity Manor] can afford to have a bigger number of carers".

Another common issue in LTC facilities is communication problems between residents and staff. In accordance with the present results, an unpublished local study carried out by Farrugia (2018) demonstrated that communication barriers existed between migrant care workers and older persons in LTC facilities. Two participants pointed out that this is attributed to language barriers and unfamiliar features of foreign staff (Ashley and Esme).

According to Al Shamsi et al. (2020), language barriers resulted in miscommunication and reduced quality of care. In fact, Esme expressed that relatives of residents at Serenity Manor preferred communicating with local staff over foreign staff.

> "Almost all the *carers are foreign* which is confusing to old people. It's not just that she [Greta] doesn't see *familiar faces* but she doesn't see *familiar features* at all. I mean they are all dark so she knows that they're not family for sure. Also, they [staff] don't always understand what they [OPsLWD] are trying to tell them as they don't understand the language." (Ashely)

Since OPsLWD are not always able to express their needs, attentiveness by staff will ensure that they are well looked after. For example, Ashely commented on how the lack of attention with regards to personal hygiene led to mouth ulceration as a result of dirty dentures. Secondly, Esme noted that regular health checks should be carried out to prevent health issues. Christina also pointed out that health care professionals working with OPsLWD need to be "professional and knowledgeable" to understand what they need since they may not be able to communicate well. She stated that she had been the one to notice when Isabella had suffered a stroke or when she developed bed sores. Thus, she suggested that a qualified nurse should always be available especially in the dementia unit. In fact, an important matter that was interpreted from the data was the involvement of the multidisciplinary and interdisciplinary teams in the care of the OPLWD. This finding supports previous research by Vernooij-Dassen et al. (2021), which found that an integrated team approach allowed for better care regarding by focusing individual's physical, psychological, and social health. For example, appropriate falls prevention and management could have a significant impact on the well-being of the OPLWD.

> "Unfortunately with dementia patients the *trauma of a fall* has a big impact and is irreversible on the mind. Bodily injuries heal but that trauma sets them back and affects the dementia". (Bethany)

Character traits were also mentioned as being an important factor to take into consideration to improve the quality of dementia care by Ashely, Bethany, and Danielle. Awareness regarding Greta's generous, calm, loving, and sociable character would help tailor her care

to reduce BPSD. For example, since she was a sociable person she would prefer being around people rather than being alone in her room. Additionally, if she was feeling agitated or anxious the staff could use physical contact such as "hugs" to calm her down. As mentioned in Section 1.2, a lack of person-centred care (PCC) is associated with an increased use of anti-psychotics and unnecessary use of physical restraint devices (Bugeja, 2010 [cited in Scerri, 2017]; Fenech, 2016). In fact, in view of John's cognitive impairment, risk of falls, and lack of supervision available at Serenity Manor, a pelvic T-harness was applied against his will which negatively affected him. Moreover, Christina, Danielle, Esme, and Faith all mentioned that their loved ones had been administered anti-psychotic medication in view of their BPSD. Bethany was aware that "medication affects dementia and progresses it" but there was no mention by the participants of non-pharmacological interventions implemented by the LTC facility for the management of BPSD.

Five participants claimed that there was a good relationship between staff and their loved ones (Bethany, Danielle, Christina, Esme, and Faith) as Serenity Manor was a small facility in comparison to other local ones.

> "There's place at San Vincenz [St. Vincent de Paul] but it's a bit busy over there. I'd rather a *smaller place* like here [Serenity Manor] so that the carers all know who my mum is, *not you're just a numbe*r like at Mater Dei [local hospital]. Here *everybody knows everyone* because the carers shift every so often from different floors so it's good. With dementia patients I believe in a *personal approach* because my mum would *recognise the face* so it helps and the carers get used to how my mum is because *each person is an individual and has their own needs*." (Bethany)

Staff incorporated John's previous occupation in conversation and included him while carrying out administrative tasks. Besides providing cognitive stimulation, this was also beneficial for him as he frequently expressed his needs regarding company and social inclusion.

> "The carers all know him [John]… they used to take him near the desk near the seniors and carers… he was a pharmacist… the nurse used to show him medication and he would tell her what it's for". (Danielle)

Esme mentioned that Kimberly had had a similar experience whereby the staff took her hobbies (being around other people and drawing) into consideration.

> "Sometimes I see the nurses writing their handover and… it's not always the same person but they sit with her and that tiny bit of attention *counts for her*… she is drawing and they are working but for her *they are with her*". (Esme)

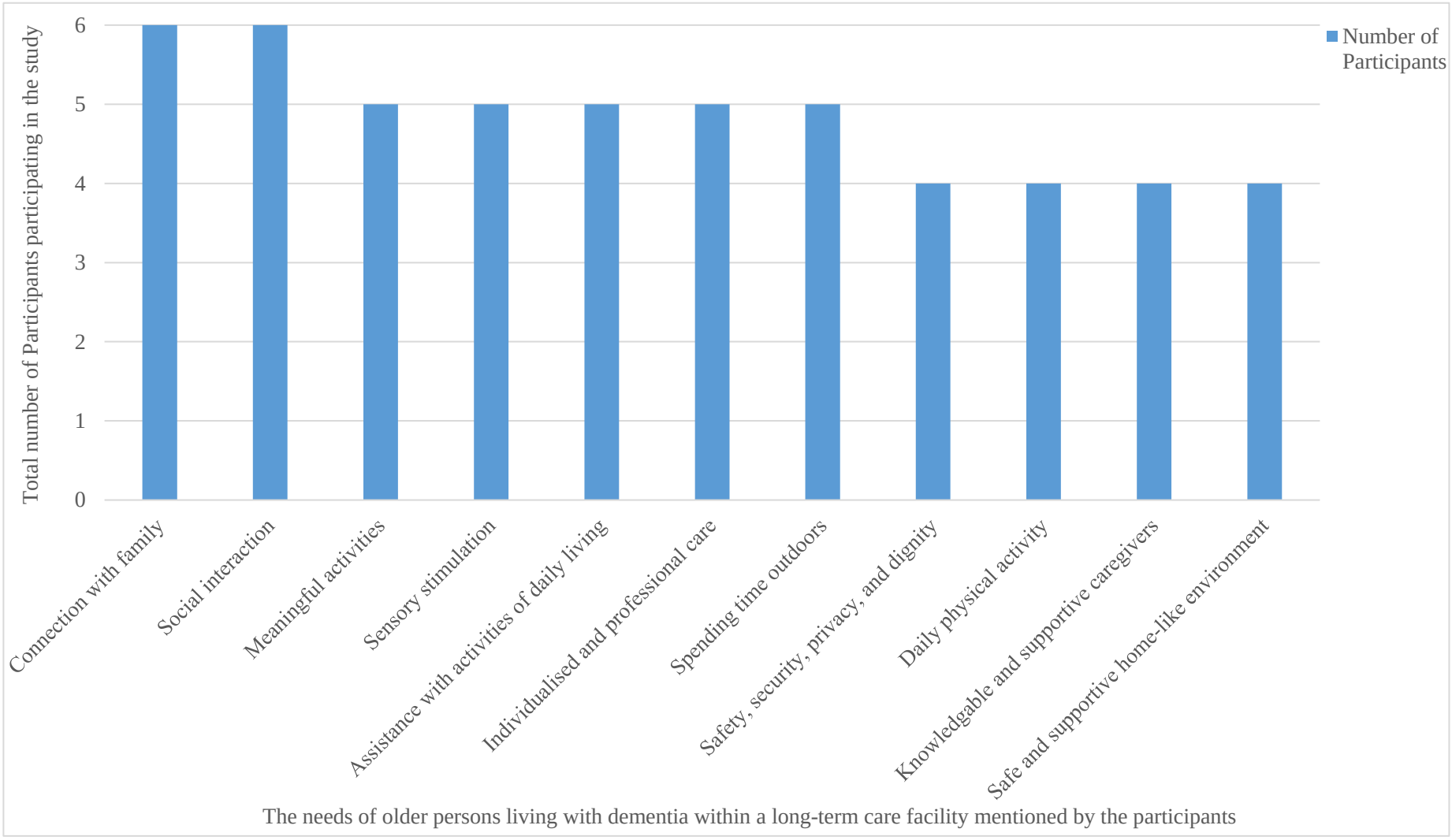
4.4.2 Person-centred Care

Care should always be tailored to the needs of the individual by providing person-centred care (PCC). Ashely stated that OPsLWD need "lots of care, hugs, *being there*, reminding them that you're *taking care of them* so they don't need to worry". Likewise, Christina said that "*physical contact works miracles*" and that it is important to create a safe space both emotionally and physically for OPsLWD; "it is important to have someone beside her [Isabella] *not judging her*… and removing things which are hazardous". She also mentioned that social needs are important because "when she [Isabella] was there [Serenity Manor] it helped her to see others… she comes alive when we *communicate*". All the participants highlighted the importance of company, social interaction, and human contact especially with family members. Comparison of these findings with those of other studies (Calkins, 2018; Campo & Chaudhury, 2012; Førsund & Ytrehus, 2018; Peterson et al., 2021) confirms that the aforementioned aspects need to be incorporated into the development of support settings for OPsLWD. Figure 2 illustrates a detailed overview of the participants' perspectives on the needs of OPsLWD within LTC facilities.

Unmet needs have a considerable effect on the portrayal of BPSD (Cohen-Mansfield et al., 2019) which was noted by the participants in this study. For example, John's shouting occurred when he was alone and Danielle noted that "all he wanted was somebody next to him" because he would calm down when accompanied. Additionally, Luna's screaming tended to decrease significantly in the presence of her relatives or when watching television which showed that she was screaming as a way of expressing boredom.

"Now she [Luna] is screaming, it's called *vocalisation,* when we are there or I take her in front of the television, she doesn't scream as much… the screaming is done mostly *when she is on her own*". (Faith)

Figure 2: The needs of older persons living with dementia within a long-term care facility in relation to the physical and social environment



Unfortunately, the philosophy of care and building design of the LTC facilities in Malta are based on the 'quantity over quality' mentality to boost revenue. This has resulted in the needs of the group being prioritised over the needs of the individual (Formosa & Scerri, 2020), thus providing challenges in providing PCC. For example, a loss of autonomy, choice, privacy, and independence can be seen in Esme's recollection of Kimberly's frustration when not allowed to close her bedroom door, as this would have hindered staff supervision.

> "You have to see her [Kimberly] point of view because she lived on her own so she could do anything she wanted. Here [Serenity Manor] it's not what you want, it's what is good for you. You cannot close the door". (Esme)

Faith emphasised that more "one-on-one attention" is required in dementia care in view of the challenges associated with dementia. This is in line with current literature that has documented that small-scale environments have a better person (P) – environment (E) fit for OPsLWD (de Boer et al., 2018; Marquardt et al., 2014), which was discussed previously in Section 2.4.1.1.

4.5 Building design

The design of a building should cater for individuals with different capabilities to support functionality and independence (Fleming et al., 2020). Different rooms should be available for different purposes; e.g. places for socialisation, calm and relaxing spaces, areas for activities, and private rooms for personal use. Furthermore, design can be used to empower older persons to remain active and retain choice and control. For OPsLWD, a dementia-friendly design provided a therapeutic and supportive environment (Fleming et al., 2020). When asked what the ideal environment would be for an OPLWD, Christina responded as follows:

> "Because there are stages it's very *difficult to generalise*. So, if a demented person comes into the home [LTC facility] in the early stages, it's nice for her to make some tea herself with a little *kitchenette* maybe and a *sitting room* but then when the stage is developed, the plainer the room is the *safer*, but then there have to be

areas where they can *socialise* and *similar to a home* that's what comes to my mind". (Christina)

As forming part of the physical environment, the following sub-themes will be presented and discussed in relation to building design: (a) building characteristics, (b) interior design, and (c) home-like character and atmosphere.

4.5.1 Building characteristics

It is well-known that Malta suffers from density and land-use issues which has led to the redevelopment of the townscape over the years (Micallef Costa, 2019). Large terraced and town houses have been converted into compact high-rise apartment blocks which has left a negative impact on the Maltese people. The depth of the influence of the construction activity could be seen in Esme's comment that Serenity Manor "is the perfect establishment because it is *flat* and does not have *high stories*". This type of design reflects the values of a traditional town house which older persons appreciate (Milte et al., 2016). A spacious layout was also preferred over one that is crammed and difficult to manoeuvre especially when catering for individuals with mobility problems. Serenity Manor was described as having "big nice corridors" by Christina which facilitated movement around the facility. Moreover, Bethany established that Serenity Manor was better than other facilities due to its "*space*". These findings are consistent with the key design principles proposed by van Buuren & Mohammadi (2020) which indicated that a dynamic interaction occurs between the OPLWD and their spatial environment.

Ashely and Bethany explained that since Serenity Manor was located in or near their loved ones' hometowns, it provided them with a sense of identity since "they are from there and that is where they were brought up so it's their community". This is in line with the concept of *place identity* which is evident in the Maltese culture. This concept was defined by Proshansky (1978) as "those dimensions of self that define the individual's personal identity in relation to the physical environment by means of a complex pattern of conscious and

unconscious ideas, feelings, values, goals, preferences, skills, and behavioural tendencies relevant to a specific environment".

A study by Konetzka & Perraillon (2016) reported that transportation and geographic location of a LTC facility impacted the ability of informal caregivers to visit their loved ones. Similar to previous research, four participants claimed that the location and accessibility of a LTC facility affected the frequency of visitations by family members (Ashley, Bethany, Christina, and Esme). Due to local issues of traffic and parking, accessibility was highlighted as an important factor considered when choosing the facility. The aforementioned participants were able to visit daily due to living or working nearby. Additionally, the large parking with an adjacent garden was considered as a very positive advantage in comparison to other facilities which lacked outdoor access.

All participants acknowledged that spending time outdoors in the "beautiful" garden was healthy and enjoyed by their loved ones. They emphasised that it should be encouraged on a daily basis due to benefits of "*fresh air and sunlight*", "*environmental stimulation*", "*interaction and distraction*", stimulating conversation, connecting with nature, and finding a private space to spend time with their loved ones. In accordance with these results, previous studies by Magnussen et al. (2021) and van der Velde-van Buuringen et al. (2021) both demonstrated that daily garden use had positive effects associated with a place to connect, find comfort, and feel healthy and alive. Christina had used the garden to meet Isabella's spiritual, sensory, and social needs.

> "When the weather was nice I used to take her [Isabella] with the wheelchair around the garden and she used to like it. We used to say the rosary together near the fountain". (Christina)

The importance of safety has been well documented in the literature (Calkins, 2018; Chaudhury et al., 2018; Jao et al., 2021; Marquardt et al., 2014; Wood et al., 2017). In accordance with this evidence, five participants highlighted safety as an important part of the environment especially for persons with impairments or disabilities (Ashley, Bethany,

Christina, Esme, and Faith). Safety features should be implemented in bathrooms in order to support functionality and prevent falls. Christina stated that private bathrooms can be dangerous without the supervision of staff in view of that fact that generally OPsLWD need assistance with bathing and toileting. Moreover, facilities and equipment should be kept up to standard to ensure health and safety measures.

> "The environment outside [garden and parking lot] should be resurfaced to be *friendly to the elderly* because the elderly drag their feet… the metal benches that they have here [Serenity Manor] are not fit for the elderly because they are low and when you sit you sink in from the back and they can't get up… it all boils down to money… the pavement is *uneven* and is not what you should find near an elderly home, it has to be a *smooth surface*… it would be ironic if you get her [Hannah] out for a little walk *for her own good* but then she ends up with a fall and ends up in hospital… the elderly can't stay skipping here and there because there are holes and rubble". (Bethany)

4.5.2 Interior Design

With regards to interior design, colours, lighting, and signage can all be used as meaningful environmental cues to provide information and support OPsLWD (Calkins, 2018; Chaudhury & Cooke, 2014; Gaugler et al., 2018). Bethany acknowledged that colour could be used to help OPsLWD by stimulating the senses and triggering memories; unfortunately this was not implemented at Serenity Manor. She also observed how lighting had affected Hannah's orientation to her surroundings and how signs on doors and wardrobes provided mental stimulation for her, especially considering that she was a former teacher.

> "San Vincenz [St. Vincent de Paul] is so equipped in the dementia unit that the walls have to be certain colours. There are studies apparently about *colour schemes that help the mind*… colours of the walls and colours of the fabrics… here [Serenity Manor] you don't see it". (Bethany)

> "When my mum was at home, my dad suffers from depression and didn't like opening up for light in the morning, they used to just sit down in the living room and

> barely put on a light. That environment affected my mum a lot because she used to be just existing and *not aware of anything around her* but the minute I open up for *light* she starts talking. Even though there is my dad near her, he is just sitting down and there's no communication so my mum's mind starts wandering and she gets confused thinking she is somewhere else because they are *in the dark*… the light and the dark affect a lot *how alert the mind* would be and how motivated she will be." (Bethany)

As discussed previously in Section 2.4.1.2, OPsLWD differ in their tolerance for environmental stimulation and are susceptible to over stimulation (Janus et al., 2021). Therefore, multi-sensory environments within LTC facilities can be used as non-pharmacological interventions for BPSD (Fleiner et al., 2017). Christina suggested that these rooms should be used for OPsLWD within LTC facilities.

> "We have a *multi-sensory room* here [primary school] and when there is *huge stimulus* in students they go there and they have a session. We have *music* and *lights* and they *relax*." [It could be due to] "a tantrum or they are agitated, we have many children with special needs and autism. I imagine in geriatrics there is a science which talks about how old people can feel relaxed. When I put music on for my mother, her eyes open and I notice there is a change". (Christina)

4.5.3 Home-like character and atmosphere

The physical environment at Serenity Manor included hospital-like features. For example, the traditional 'T' shaped layout was designed to facilitate work practices of staff. In fact, Esme commented that armchairs were lined up in a row along the corridors, allowing staff to monitor residents from the nursing station situated in the middle of the corridor. Three participants commented that the environment at Serenity Manor resembled that of a "*hospital*" (Ashely, Bethany, and Faith). Even though structurally it resembled a hospital, furnishings and décor can play an important part in providing a home-like atmosphere and are simple to implement. Some suggestions by the participants regarding enhancing

homeliness of the place included a livelier environment, memorabilia, personal photos, plants, and home-like furnishings such as television, curtains, and furniture. These results are in agreement with previous research carried out by Campo & Chaudhury (2012), Chaudhury & Cooke (2014), Marquardt et al. (2014), and Wood et al. (2017).

> [OPsLWD need] "A *livelier environment* because it's [Serenity Manor] more like a *hospital* environment rather than a *home*. I know from reading, that dementia patients would like to *feel that they're still in their own home*. From the day they [her parents] came here, I went to their house and got a lot of frames with photos of her parents, my dad's parents, ourselves at different ages, and the grandchildren. During COVID when she was refusing to eat I used to put them in front of her on the table and she'd smile and it helped because she was seeing *familiar* things… Ideally, they have some more *soft furnishings* and *colour schemes* to make them feel more like there isn't a big *change* from where they were. Because even this, apparently changing them around from one place to another, that's why I said stick to a *routine* and we don't shift mum up and down and here and there because it affects them. So if they have a *cosy home* at home and now they're like in a *cold* hospital environment obviously it has an effect. Even these recliner chairs that they have upstairs are very hospital like. I mean would you have a chair like this in your house? Maybe they can put loose covers and have them laundered you know? Little things that." (Bethany)

Kimberly had referred to Serenity Manor as "*home*" which showed that she considered it as a safe place where she felt that she belonged. On the other hand, Greta knew that she wasn't "home" because she had incidents where she would pack up her belongings and ask the security man for the exit. Personalisation of one's bedroom is one way that could help provide a sense of familiarity and ownership of a place to call it one's own. A study conducted by van Steenwinkel et al. (2014) found that a sense of home is not only influenced by the physical environment but also by personal and social characteristics. A sense of home is developed gradually through personal experiences, emotions, and memories (Rijnaard et al., 2016).

4.6 Conclusion

This chapter provided a representations of the findings of this research project which shed light on how different parts of the environment impacted OPsLWD within a LTC facility. The findings articulated the participants' perspectives on the needs of OPsLWD and how the environment can be used to meet their needs and promote well-being. As previously discussed in Section 2.1.2, dementia care approaches should be based on a biopsychosocial model of dementia. The next and final chapter will provide a summary of the findings and will discuss the implications for policy and practice along with recommendations for future research.

CHAPTER 5
CONCLUSION

5.0 Introduction

This chapter provides a summary of the key findings of this study and identifies its strengths and limitations. The outcomes of this study will be discussed in relation to the research questions mentioned previously in Section 1.5. Additionally, recommendations for practice and future research will be put forward. Finally, the researcher will conclude with her final reflections and remarks.

5.1 Summary of the Key Findings

This study explored the perspectives of informal caregivers on environmental factors that influence older persons living with dementia (OPsLWD) within a long-term care (LTC) facility in Malta. Methodological principles of interpretive description (ID) allowed the researcher to uphold a reflective mind to interpret patterns and shared meanings across the six participants. In line with the constructivist paradigm adopted by the researcher throughout this study, it should be acknowledged that the participants' experiences were subjective and that the findings were constructed by the researcher through the interpretation of the meaning of their experiences. This research was influenced by the researcher's professional knowledge as a physiotherapist as well as her experience working in LTC facilities in Malta. Consequently, this study was able to provide a rich and detailed description of the phenomenon and raise awareness on the significance of the environment in supporting OPsLWD during the end of their lives.

The interpretation of the informal caregiver participants' perspectives provided a deep understanding of the associations, relations, and patterns in the data. Overall, this study's findings are in accordance with international literature confirming that the physical and social environments of a LTC facility directly influenced the lives of OPsLWD (Adlbrecht, 2021; Calkins, 2018; Campo & Chaudhury, 2012; Chaudhury & Cooke, 2014; Chaudhury et al., 2018; Fleming et al., 2020; Førsund & Ytrehus 2018; Gaugler et al., 2018; Gracia et al., 2012; Jao et al., 2019; Jao et al., 2021; Marquardt et al., 2014; Narsakka et al., 2022; Nordin et al.,

2017; O'Malley et al., 2015; Popham & Orrell, 2012; Wood et al., 2017; van Steenwinkel et al., 2017).

This study identified how aspects of the environment within a LTC facility impacted the well-being and quality of life of OPsLWD. Moreover, from the participants' perspectives, it explored the needs of OPsLWD residing in a LTC facility (illustrated in Figure 2) and how the environment can be adapted to better suit their needs. Three themes were generated in this study: (a) social engagement, (b) supportive healthcare practices in relation to the social environment, and (c) building design in relation to the physical environment.

With regards to building design, a dementia-friendly layout could provide a therapeutic and supportive environment to cater for individuals with different capabilities and support functionality and independence. Informal caregivers valued a spacious layout, access to a garden, health and safety measures, a home-like character, and a lively atmosphere. Furthermore, geographic location and accessibility affected the choice in the LTC facility selection for their loved ones along with family visitations. Regarding interior design, colours, lighting, and signage were meaningful environmental cues that provide information and mental stimulation for OPsLWD. Suggestions to improve the physical environment included creating areas within the facility to be utilised for different purposes such as for socialisation, activities, or for private use. Additionally, multi-sensory rooms can be used as a non-pharmacological intervention for behavioural and psychological symptoms of dementia (BPSD).

Overall the participants praised the physical environment at Serenity Manor and voiced that it has a lot of potential. However, the built environment needs to be complemented with adequate staff competencies and supportive healthcare practices. The structure of care within a LTC facility should promote quality of life and protect human rights. Informal caregivers emphasised that staff should be trained in dementia care and support systems should be available for caregivers of OPsLWD. Additionally, the provision of quality care necessitates an integrated team approach, staff professionalism, attentiveness, dedication, and good communication. Care should always be tailored to the needs of the individual by providing

person-centred care (PCC). All the participants highlighted the importance of company, social interaction, and human contact especially with family members. Maintaining a strong relationship with family members has many benefits for OPsLWD such as detecting acute health problems, facilitating meal times, providing a sense of familiarity, and reducing BPSD.

Social engagement is associated with a sense of belonging and meaning in life. Social and meaningful interactions allowed OPsLWD to connect and communicate with staff, family members, and other residents within the LTC facility. For that reason, social participation within LTC facilities is important to meet an individual's social, cognitive, and emotional needs. Participants also indicated that, for their loved ones, social interaction and communication depended on family visitations. This was due to the shared opinion that Serenity Manor faced certain challenges, resulting in diminshed socialisation, sensory stimulation, physical activity, and meaningful activities for OPsLWD. These challenges included (a) shortage of staff, (b) ratio of staff to residents, (c) task-oriented practice, (d) staff values, (e) communication barriers, (f) the large amount of residents within the facility, and (g) individuals with impairments. Organised activities in LTC facilities should be tailored to the individual's needs and capabilities in order to encourage better participation. Additionally, environmental stimulation should be utilised to enhance well-being and cognitive functioning of OPsLWD.

5.2 Strengths and Limitations

This research project was the first local study that explored informal caregivers' perspectives on the role of the environment on OPsLWD within a LTC facility. By adopting a qualitative research approach and conducting face-to-face semi-structured interviews, the participants were given the opportunity to voice their experiences and perspectives. This was considered as a strength as the study generated rich information which is relevant to practice and clinical settings.

A pilot study was carried out to test the suitability of the questions used in the interview tool and help the researcher to practise her interview skills. No changes were made to the interview tool however areas of interest were noted and used as probes for the following interviews.

Another strength of this study was that ID methodology provided a coherent logic to guide the structure and design of a study. This methodology valued clinical experience and knowledge which allowed the researcher to reflect on the disciplinary biases that affected her research. Rigour strategies were used throughout this study in order to ensure trustworthiness and transparency of the research process to produce applicable and relevant findings. Rigour was ensured by following the four principles suggested by Thorne (2016) which were explained in detail in Section 3.9: (a) epistemological integrity, (b) representative credibility, (c) analytic logic, and (d) interpretative authority. A limitation of this study is that verifications of the interview transcriptions and findings could not be carried out with the participants due to time constraints.

A limiting factor of this study was its small sample size and generalisability. Besides this, the sample only included informal caregivers as opposed to a variety of individuals from different settings. Due to the subjectivity of experiences, phenomena may be expressed in infinite individual variations and therefore new variations may always arise. However, Thorne et al. (2016) recommended that research findings are meaningful for the individuals for whom the research was conducted for. Purposive sampling permitted a deep understanding of the phenomenon being studied through information rich cases. Meaningful results were achieved through deep involvement with a small number of individuals willing to share their experiences with the researcher.

5.3 Recommendations for Policy

1. Designers of dementia-friendly living environments should use published resources for guidance. As part of the 'World Alzheimer Report 2020', Fleming et al. (2020) published an outstanding report on the principles for designing for individuals living with dementia (explained thoroughly in Section 2.4.1). Therefore, it is important to bring about awareness on the topic to ensure that designers, architects, and policy makers implement these principles.
2. Green care farms and small-scale supportive living facilities should be implemented in Malta as innovative alternative options to traditional LTC facilities.
3. The 'Social Regulatory Standards for Residential Services for Persons Living with Dementia in Homes for Senior Citizens' (Social Care Standards Authority [SCSA], 2021a) assert that the layout of the LTC facility and its surrounding grounds are appropriate for OPsLWD and that adaptations should be carried out to assist with orientation and wayfinding. It also states that the environment should be "engaging, welcoming, familiar, pleasant and conductive towards the needs of the residents" (SCSA, 2021). Thus, it is important that facilities implement these policies and that they are followed-up to ensure they are being upheld.
4. The 'Social Regulatory Standards for Residential Services for Persons Living with Dementia in Homes for Senior Citizens' (SCSA, 2021a) declare that service providers within LTC facilities should be adequately trained to work with OPsLWD. Therefore, it is advised that all personnel working within LTC facilities should undergo continuous training in dementia care as part of continuous professional development to ensure that OPsLWD are being provided with the best service possible.

5.4 Implications for Practice

1. The philosophy of care needs to change from task-oriented practice to the provision of person-centred care. Furthermore, LTC facilities should implement polices to provide more flexibility to staff during work in order to spend time with residents and build better relationships

2. Staff working with OPsLWD should take responsibility for providing a good service and ensure that the human rights of each individual are always upheld.
3. Staff should take initiative to interact socially with residents and promote social engagement amongst residents.
4. Educational programs and support systems should be set up for formal and informal caregivers of OPsLWD.
5. LTC facilities should be safe, accessible, facilitate movement, have an adequate level of stimulation, offer areas for privacy, have a positive ambience, and be home-like in nature.
6. The size of the LTC facility should complement the amount of residents and staff present to ensure adequate staffing ratios and use of the space available.

5.5 Recommendations for Research

This study gave insight into the importance of the role of the environment in the care of OPsLWD within a LTC facility. The findings from this study can be used as a platform for further research in this field. Further research adopting a mixed-methods approach is recommended to give a more in-depth overall view of the phenomenon. Since this study had a relatively small sample size, larger scale studies are recommended in order to provide stronger and more reliable results which are representative of the general population. Research could guide the development of educational programmes to offer support for OPsLWD and their caregivers.

The aim of this study was to study the phenomenon from the perspectives of informal caregivers of OPsLWD. It would also be interesting to explore the perspectives of OPsLWD themselves since they are the ones who are directly being impacted. Similar studies could also be conducted with healthcare professionals, staff, and managers working within LTC facilities to get different viewpoints and provide a more holistic picture of the phenomenon. It is also important to note that the concept of place (discussed in Section 2.3) in dementia care involves: (a) the individual, (b) the physical environment, (c) the social environment, and (d) the organisational environment. This study focused on the physical and social

environment in relation to the microsystem and mesosystem. Therefore, future research would also be beneficial to explore what individual and organisational components impact OPsLWD such as cultural influences, group identity, and regulations and standards across LTC facilities.

5.6 Concluding Reflections

Due to increased sensitivity to environmental stressors in OPsLWD, the environment of LTC facilities should be designed appropriately to support functionality and quality of life. Therefore, understanding how the environment can be used therapeutically, to lessen BPSD and meet the needs of OPsLWD, is crucial. It must be acknowledged that elements of the social environment were considered more important than the physical environment in promoting the well-being of OPsLWD.

It would be contradictory to design a dementia-friendly unit accompanied with a care philosophy violating human rights. On the other hand, the provision of quality care would also face challenges if not supplemented with a space that is designed to support functionality and independence in OPsLWD. Therefore, the physical and social environments within LTC facilities should complement each other to provide therapeutic benefits.

The researcher hopes that Malta will follow in the footsteps of other countries to move away from traditional LTC facilities towards small-scale home-like living environments that offer individualised care and facilitate healthy living for OPsLWD.

The researcher will conclude with this heartfelt quote by Leo Buscaglia– “Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.”

REFERENCES

References

Aasgaard, H. S., Landmark, B. T., Öresland , S. (2017). Healthcare personnel's experiences of enhancing social community for people living in dementia special care units. *Nordic Journal of Nursing Research*, 37(4), 186–193.

Abbott, K. M., Sefcik, J. S., & van Haitsma, K. (2017). Measuring social integration among residents in a dementia special care unit versus traditional nursing home: A pilot study. *Dementia (London, England)*, *16*(3), 388–403. https://doi.org/10.1177/1471301215594950

Abdi, S., Spann, A., Borilovic, J., De Witte, L., & Hawley, M. (2019). Understanding the care and support needs of older people: A scoping review and categorisation using the WHO international classification of functioning, disability and health framework (ICF).BMC Geriatrics,19(1), 195–195. https://doi.org/10.1186/s12877-019-1189-9

Adlbrecht, L., Bartholomeyczik, S., Hildebrandt, C., & Mayer, H. (2021). Social interactions of persons with dementia living in special care units in long-term care: A mixed-methods systematic review. *Dementia (London, England)*, *20*(3), 967–984. https://doi.org/10.1177/1471301220919937

Agom, D. A., Ominyi, J., Onyeka, T. C., & Anyigor, C. N. (2020). Exploring Organizational Culture Regarding Provision and Utilization of Palliative Care in a Nigerian Context: An Interpretive Descriptive Study. *Indian journal of palliative care*, *26*(3), 358–364. https://doi.org/10.4103/IJPC.IJPC_39_20

Al Shamsi, H., Almutairi, A. G., Al Mashrafi, S., & Al Kalbani, T. (2020). Implications of Language Barriers for Healthcare: A Systematic Review. Oman medical journal, 35(2), e122. https://doi.org/10.5001/omj.2020.40

Algase, D. L., Beck, C., Kolanowski, A., Whall, A., Berent, S., Richards, K., & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. American Journal of Alzheimer's disease, 11(6), 10-19.

Alzheimer's Disease International. (2015). Women and Dementia: A Global Research Review. https://www.alzint.org/u/Women-and-Dementia.pdf

Alzheimer's Disease International. (2021). World Alzheimer Report 2021. https://www.alzint.org/u/World-Alzheimer-Report-2021.pdf

Alzheimer Europe. (2019). Dementia in Europe yearbook 2019: Estimating the prevalence of dementia in Europe. https://www.alzheimereurope.org/Publications/Dementia-in-Europe-Yearbooks

American Geriatrics Society Expert Panel on Person-Centered Care. (2016). Person-Centered Care: A Definition and Essential Elements. *Journal of the American Geriatrics Society*, *64*(1), 15–18. https://doi.org/10.1111/jgs.13866

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*. (5th Ed.) Washington, D.C.: American Psychiatric Association.

Arvanitakis, Z., Shah, R. C., & Bennett, D. A. (2019). Diagnosis and Management of Dementia: Review. *JAMA*, *322*(16), 1589–1599. https://doi.org/10.1001/jama.2019.4782

Aquilina, D. (2014). *The role of the Family in the Institutionalisation of Older Persons: A Maltese Case Study.* [Unpublished master's thesis]. University of Malta. https://www.um.edu.mt/library/oar/bitstream/123456789/73189/1/M.GER._Aquilina_Doris_2014.pdf

Barbe, C., Jolly, D., Morrone, I., Wolak-Thierry, A., Dramé, M., Novella, J. L., & Mahmoudi, R. (2018). Factors associated with quality of life in patients with Alzheimer's disease. BMC geriatrics, 18(1), 159. https://doi.org/10.1186/s12877-018-0855-7

Behrman, S., Chouliaras, L., & Ebmeier, K. P. (2014). Considering the senses in the diagnosis and management of dementia. Maturitas, 77(4), 305–310. https://doi.org/10.1016/j.maturitas.2014.01.003

Benbow, W. (2014). Benbow Best Practice Design Guidelines: Nursing home complex care and dementia. Canada: people A Benbow, Development Consultant: Seniors Housing and Care.

Bertoncello, C., Sperotto, M., Bellio, S., Pistellato, I., Fonzo, M., Bigolaro, C., Ramon, R., Imoscopi, A., & Baldo, V. (2021). Effectiveness of individually tailored exercise on

functional capacity and mobility in nursing home residents. British journal of community nursing, 26(3), 144–149. https://doi.org/10.12968/bjcn.2021.26.3.144

Birks, M., & Mills, J. (2015). Grounded theory: A practical guide, 2nd. ed. Sage.

Black, B. S., Johnston, D., Leoutsakos, J., Reuland, M., Kelly, J., Amjad, H., Samus, Q. M. (2019). Unmet needs in community-living persons with dementia are common, often non-medical and related to patient and caregiver characteristics. *International Psychogeriatrics*, *31*(11), 1643–1654. doi:https://doi.org/10.1017/S1041610218002296

Blackstone, A. (2014) Principles of Sociological Inquiry: Qualitative and Quantitative Methods (v. 1.0) https://open.umn.edu/opentextbooks/textbooks/139

Bökberg, C., Ahlström, G., & Karlsson, S. (2017). Significance of quality of care for quality of life in persons with dementia at risk of nursing home admission: a cross-sectional study. BMC nursing, 16, 39. https://doi.org/10.1186/s12912-017-0230-6

Bonifazi, P., Erramuzpe, A., Diez, I., Gabilondo, I., Boisgontier, M. P., Pauwels, L., Stramaglia, S., Swinnen, S. P., & Cortes, J. M. (2018). Structure-function multi-scale connectomics reveals a major role of the fronto-striato-thalamic circuit in brain aging. *Human brain mapping*, *39*(12), 4663–4677. https://doi.org/10.1002/hbm.24312

Bora, E., & Yener, G. G. (2017). Meta-Analysis of Social Cognition in Mild Cognitive Impairment. Journal of geriatric psychiatry and neurology, 30(4), 206–213. https://doi.org/10.1177/0891988717710337

Brandenburg, H. (2013). Quality of life of people with severe dementia in nursing oases: Empirical results and methodological implications. *Zeitschrift Für Gerontologie Und Geriatrie*, 46(5), 417–424.

Braun, V., & Clarke, V. (2013). Successful qualitative research: A practical guide for beginners. London: Sage.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise & Health, 11*(4), 589-597.

Braun, V., & Clarke, V. (2020). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. Couns Psychother Res; 21: 37– 47. https://doi.org/10.1002/capr.12360

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qualitative Research in Psychology, 18:3, 328-352, DOI: 10.1080/14780887.2020.1769238

Braun, V., & Clarke, V. (2021). Thematic Analysis: A Practical Guide. London: Sage

Bressan, V., Visintini, C., & Palese, A. (2020). What do family caregivers of people with dementia need? A mixed-method systematic review. Health & social care in the community, 28(6), 1942–1960. https://doi.org/10.1111/hsc.13048

Brittain, K., & Degnen, C. (2022). Living the everyday of dementia friendliness: Navigating care in public spaces. *Sociology of health & illness*, *44*(2), 416–431. https://doi.org/10.1111/1467-9566.13442

Bronfenbrenner, U. (1977). Toward and experimental ecology of human development. American Psychologist 32, 513–531.

Brown G. C. (2015). Living too long: the current focus of medical research on increasing the quantity, rather than the quality, of life is damaging our health and harming the economy. EMBO reports, 16(2), 137–141. https://doi.org/10.15252/embr.201439518

Brown, M., & Dueñas, A. N. (2019). A Medical Science Educator's Guide to Selecting a Research Paradigm: Building a Basis for Better Research. Medical science educator, 30(1), 545–553. https://doi.org/10.1007/s40670-019-00898-9

Buffington, A. L., Lipski, D. M., & Westfall, E. (2013). Dementia: an evidence-based review of common presentations and family-based interventions. *The Journal of the American Osteopathic Association*, *113*(10), 768–775. https://doi.org/10.7556/jaoa.2013.046

Cadieux, M. A., Garcia, L. J., & Patrick, J. (2013). Needs of people with dementia in long-term care: a systematic review. *American journal of Alzheimer's disease and other dementias*, *28*(8), 723–733. https://doi.org/10.1177/1533317513500840

Calkins M. P. (2001). The physical and social environment of the person with Alzheimer's disease. *Aging & mental health*, *5 Suppl 1*, S74–S78. https://doi.org/10.1080/713650003

Calkins, M. P. (2018). Memory Care and Alzheimer's Units. In Environmental Psychology and Human Well-Being (pp. 365–386). Elsevier. https://doi.org/10.1016/b978-0-12-811481-0.00014-7

Campbell-Enns, H. J., Campbell, M., Rieger, K. L., Thompson, G. N., & Doupe, M. B. (2020). No Other Safe Care Option: Nursing Home Admission as a Last Resort Strategy. *The Gerontologist*, *60*(8), 1504–1514. https://doi.org/10.1093/geront/gnaa077

Campo, M., & Chaudhury, H. (2012). Informal social interaction among residents with dementia in special care units: Exploring the role of the physical and social environments. Dementia. 11(3):401-423. doi:10.1177/1471301211421189

Canevelli, M., Valletta, M., Trebbastoni, A., Sarli, G., D'Antonio, F., Tariciotti, L., de Lena, C., & Bruno, G. (2016). Sundowning in Dementia: Clinical Relevance, Pathophysiological Determinants, and Therapeutic Approaches. *Frontiers in medicine*, *3*, 73. https://doi.org/10.3389/fmed.2016.00073

Cankurtaran, E. (2014). Management of Behavioral and Psychological Symptoms of Dementia. DOI: 10.5152/NPA.2014.7405

Casey, A. N., Low, L. F., Goodenough, B., Fletcher, J., & Brodaty, H. (2014). Computer-assisted direct observation of behavioral agitation, engagement, and affect in long-term care residents. *Journal of the American Medical Directors Association*, *15*(7), 514–520. https://doi.org/10.1016/j.jamda.2014.03.006

Casey, A. N., Low, L. F., Jeon, Y. H., & Brodaty, H. (2016). Residents Perceptions of Friendship and Positive Social Networks Within a Nursing Home. *The Gerontologist*, *56*(5), 855–867. https://doi.org/10.1093/geront/gnv146

Cerga-Pashoja, A., Doukani, A., Giannakopoulou, P. (2018) Behavioral and Psychological Symptoms of Dementia: An Overview of Theoretical Frameworks and Associated Non-Pharmacological Treatments for BPSD. http://dx.doi.org/10.14283/cw.2018.11

Chaudhury H, Cooke H. (2014). Design matters in dementia care: The role of the physical environment in dementia care settings. In M Downs and B Bow-ers (Eds.), Excellence in dementia care (2nd Edition). UK: Open University Press; p. 144–58

Chaudhury, H., Cooke, H. A., Cowie, H., & Razaghi, L. (2018). The Influence of the Physical Environment on Residents With Dementia in Long-Term Care Settings: A Review of the Empirical Literature. The Gerontologist, 58(5), e325–e337. https://doi.org/10.1093/geront/gnw259

Clarke, V., Braun, V., Terry, G & Hayfield N. (2019). Thematic analysis. In Liamputtong, P. (Ed.), Handbook of research methods in health and social sciences (pp. 843-860). Singapore: Springer.

Cloak, N., & Al Khalili, Y. (2022). Behavioral And Psychological Symptoms In Dementia. In *StatPearls*. StatPearls Publishing.

Cohen-Mansfield, J. (1995). Assessment of disruptive behavior/agitation in the elderly: function, methods, and difficulties. J Geriatr Psychiatry Neurol [Internet].

Cohen-Mansfield, J. (2000). Theoretical Frameworks for Behavioral Problems in Dementia. Alzheimers Care Q.

Cohen-Mansfield, J., Dakheel-Ali, M., Marx, M. S., Thein, K., & Regier, N. G. (2015). Which unmet needs contribute to behavior problems in persons with advanced dementia? Psychiatric Research, 228, 59-64.

Council, E., P. (2016). General Data Protection Act. Official journal of the European union.

Cui, P., Zhang, J., & Li, T. T. (2021). Research on Acoustic Environment in the Building of Nursing Homes Based on Sound Preference of the Elderly People: A Case Study in Harbin, China. *Frontiers in psychology*, *12*, 707457. https://doi.org/10.3389/fpsyg.2021.707457

Cunningham, C., Macfarlane, S., & Brodaty, H. (2019). Language paradigms when behaviour changes with dementia: #BanBPSD. *International Journal of Geriatric Psychiatry*, *34*(8), 1109–1113. doi:https://doi.org/10.1002/gps.5122

Data Protection, (2018). *Malta Data Protection Act*. Malta

Davis, S., Byers, S., Nay, R., & Koch, S. (2009). Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia: The International Journal of Social Research and Practice, 8*(2), 185–203. https://doi.org/10.1177/1471301209103250

de Boer, B., Beerens, H. C., Katterbach, M. A., Viduka, M., Willemse, B. M., & Verbeek, H. (2018). The Physical Environment of Nursing Homes for People with Dementia: Traditional Nursing Homes, Small-Scale Living Facilities, and Green Care Farms. *Healthcare (Basel, Switzerland), 6*(4), 137. https://doi.org/10.3390/healthcare6040137

de Boer, B., Hamers, J. P., Beerens, H. C., Zwakhalen, S. M., Tan, F. E., & Verbeek, H. (2015). Living at the farm, innovative nursing home care for people with dementia - study protocol of an observational longitudinal study. *BMC geriatrics*, *15*, 144. https://doi.org/10.1186/s12877-015-0141-x

de Boer, B., Hamers, J. P., Zwakhalen, S. M., Tan, F. E., Beerens, H. C., & Verbeek, H. (2017). Green Care Farms as Innovative Nursing Homes, Promoting Activities and Social Interaction for People With Dementia. *Journal of the American Medical Directors Association, 18*(1), 40–46. https://doi.org/10.1016/j.jamda.2016.10.013

de Bruin, S., de Boer, B., Beerens, H., Buist, Y., & Verbeek, H. (2017). Rethinking Dementia Care: The Value of Green Care Farming. *Journal of the American Medical Directors Association, 18*(3), 200–203. https://doi.org/10.1016/j.jamda.2016.11.018

DeJonckheere, M., & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: a balance of relationship and rigour. *Family medicine and community health, 7*(2), e000057. https://doi.org/10.1136/fmch-2018-000057

Devos, P., Aletta, F., Thomas, P., Petrovic, M., Vander Mynsbrugge, T., van de Velde, D., De Vriendt, P., & Botteldooren, D. (2019). Designing Supportive Soundscapes for Nursing Home Residents with Dementia. *International journal of environmental research and public health, 16*(24), 4904. https://doi.org/10.3390/ijerph16244904

Domenech-Cebrían, P., Martinez-Martinez, M., & Cauli, O. (2019). Relationship between mobility and cognitive impairment in patients with Alzheimer's disease. *Clinical*

neurology and neurosurgery, *179*, 23–29. https://doi.org/10.1016/j.clineuro.2019.02.015

Douglas, J. W., & Lawrence, J. C. (2015). Environmental Considerations for Improving Nutritional Status in Older Adults with Dementia: A Narrative Review. Journal of the Academy of Nutrition and Dietetics, 115(11), 1815–1831. https://doi.org/10.1016/j.jand.2015.06.376

Doyle, P. J., de Medeiros, K., Saunders, P. A. (2012). Nested social groups within the social environment of a dementia care assisted living setting. Dementia. 11(3):383-399. doi:10.1177/1471301211421188

Duru Aşiret, G., Kütmeç Yılmaz, C., & Sayın Kasar, K. (2021). Investigation of the effects of interventions made according to the Progressively Lowered Stress Threshold Model on the care outcomes of Alzheimer patients and their families: a randomized clinical trial. Psychogeriatrics : the official journal of the Japanese Psychogeriatric Society, 21(5), 738–748. https://doi.org/10.1111/psyg.12734

Edemekong, P. F., Bomgaars, D. L., Sukumaran, S., & Schoo, C. (2022). Activities of Daily Living. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan. Available from: https://www.ncbi.nlm.nih.gov/books/NBK470404/

Elliott, M. L., Belsky, D. W., Knodt, A. R., Ireland, D., Melzer, T. R., Poulton, R., Ramrakha, S., Caspi, A., Moffitt, T. E., & Hariri, A. R. (2021). Brain-age in midlife is associated with accelerated biological aging and cognitive decline in a longitudinal birth cohort. Molecular psychiatry, 26(8), 3829–3838. https://doi.org/10.1038/s41380-019-0626-7

Eska, K., Graessel, E., Donath, C., Schwarzkopf, L., Lauterberg, J., & Holle, R. (2013). Predictors of institutionalization of dementia patients in mild and moderate stages: a 4-year prospective analysis. Dementia and geriatric cognitive disorders extra, 3(1), 426–445. https://doi.org/10.1159/000355079

European Network of National Human Rights Institutions. (2017). Applying a Human Rights-Based Approach to Long-term Care for Older Persons: A Toolkit for Care Providers. http://ennhri.org/wp-content/uploads/2020/01/Applying-a-HRBA-to-Long-Term-Care-for-Older-Persons-A-Toolkit-for-Care-Providers.pdf

Evans, E. A., Perkins, E., Clarke, P., Haines, A., Baldwin, A., & Whittington, R. (2018). Care home manager attitudes to balancing risk and autonomy for residents with dementia. Aging & mental health, 22(2), 261–269. https://doi.org/10.1080/13607863.2016.1244803

Farrugia, C. (2018). *Migrant care workers and Maltese older persons in long term care homes: experiences, attitudes and relationships.* [Unpublished master's thesis]. University of Malta. https://www.um.edu.mt/library/oar/handle/123456789/40377

Fenech, M. A. (2016). Physical restraint use within long term care settings for older persons in Malta. https://www.researchgate.net/publication/315838997_Physical_restraint_use_within_long_term_care_settings_for_older_persons_in_Malta

Ferdous, F. (2019). Well-being in memory care facilities: identifying the role of spatial design for social interaction in empirical literature.

Ferdous, F., & Moore, K. D. (2015). Field observations into the environmental soul: spatial configuration and social life for people experiencing dementia. *American journal of Alzheimer's disease and other dementias*, *30*(2), 209–218. https://doi.org/10.1177/1533317514545378

Figueiro, M. G., Plitnick, B. A., Lok, A., Jones, G. E., Higgins, P., Hornick, T. R., & Rea, M. S. (2014). Tailored lighting intervention improves measures of sleep, depression, and agitation in persons with Alzheimer's disease and related dementia living in long-term care facilities. *Clinical interventions in aging*, *9*, 1527–1537. https://doi.org/10.2147/CIA.S68557

Figueiro, M. G., Sahin, L., Kalsher, M., Plitnick, B., & Rea, M. S. (2020). Long-Term, All-Day Exposure to Circadian-Effective Light Improves Sleep, Mood, and Behavior in Persons with Dementia. *Journal of Alzheimer's disease reports*, *4*(1), 297–312. https://doi.org/10.3233/ADR-200212

Fleiner, T., Leucht, S., Förstl, H., Zijlstra, W., Haussermann, P. (2017). Effects of short-term exercise interventions on behavioral and psychological symptoms in patients with dementia: A systematic review. Journal of Alzheimer's disease: JAD, 55(4), 1583–1594. doi:10.3233/JAD-160683

Fleming, R., & Bennett, K. (2015). The Environmental Audit Tool: High Care. Australia: Department of Social Services Dementia Training Study Centres and University of Wollongong.

Fleming, R., Crookes, P. A., Sum, S. (2008). A review of the empirical literature on the design of physical environments for people with dementia. University of Wollongong Research Online.

Fleming, R., Goodenough, B., Low, L-F., Chenoweth, L., Brodaty, H. (2016). The relationship between the quality of the built environment and the quality of life of people with dementia in residential care. Dementia;15(4):663-680. doi:10.1177/1471301214532460

Fleming, R., Kelly, F., Stillfried, G. (2015). 'I want to feel at home': establishing what aspects of environmental design are important to people with dementia nearing the end of life. BMC Palliative Care 14: 26.

Fleming, R., Purandare, N. (2010). Long-term care for people with dementia: Environmental design guidelines. International Psychogeriatrics 22(7): 1084–96.

Fleming, R., Zeisel, J. & Bennett, K. (2020). World Alzheimer Report 2020: Design Dignity Dementia: dementia-related design and the built environment Volume 1, London, England: Alzheimer's Disease International.

Formosa, M. (2018). Active and Healthy Ageing in Malta: Gerontological and Geriatric Inquiries. Malta: BDL Publishing. https://www.researchgate.net/profile/Marvin-Formosa/publication/333810770_Conclusion_Active_and_healthy_ageing_in_Malta_Gerontological_and_geriatric_inquiries/links/5d063eaba6fdcc39f11ea3ef/Conclusion-Active-and-healthy-ageing-in-Malta-Gerontological-and-geriatric-inquiries.pdf

Formosa, M. (2019). Long-term Care Facilities for Older Persons in Malta: Policies, Trends, and Challenges. Turkish Journal of Geriatrics. https://www.um.edu.mt/vle/pluginfile.php/1005989/mod_resource/content/1/GER%205037%20-%204%20-%20Reading%205%20of%205%20-%20LTC%20for%20older%20persons%20in%20Malta.pdf

Formosa, M., & Scerri, C. (2020). Punching Above its Weight: Current and Future Aging Policy in Malta. *The Gerontologist*, *60*(8), 1384–1391. https://doi.org/10.1093/geront/gnaa120

Formosa, M. & Scerri, C. (Eds.) (2015). Population ageing in Malta: Multidisciplinary perspectives. Malta: Malta University Press.

Forster, A., Godfrey, M., Green, J., McMaster, N., Airlie, J., Cundill, B., Lawton, R., Hawkins, R., Hulme, C., Birch, K., Brown, L., Cicero, R., Crocker, T. F., Dawkins, B., Ellard, D. R., Ellwood, A., Firth, J., Gallagher, B., Graham, L., Johnson, L., … Farrin, A. (2021). Strategies to enhance routine physical activity in care home residents: the REACH research programme including a cluster feasibility RCT. NIHR Journals Library.

Førsund, L. H., & Ytrehus, S. (2018). Finding a place to connect: A qualitative study exploring the influences of the physical and social environments on spouses' opportunities to maintain relationships when visiting a partner with dementia living in long-term care. *Dementia (London, England)*, *17*(7), 858–879. https://doi.org/10.1177/1471301216656087

Garcia, L. J., Hébert, M., Kozak, J., Sénécal, I., Slaughter, S. E., Aminzadeh, F., Dalziel, W., Charles, J., & Eliasziw, M. (2012). Perceptions of family and staff on the role of the environment in long-term care homes for people with dementia. International psychogeriatrics, 24(5), 753–765. https://doi.org/10.1017/S1041610211002675

Gaugler, J. E., Yu, F., Davila, H. W., & Shippee, T. (2014). Alzheimer's disease and nursing homes. *Health affairs (Project Hope)*, *33*(4), 650–657. https://doi.org/10.1377/hlthaff.2013.1268

Goodman, C., Amador, S., Elmore, N., Machen, I., & Mathie, E. (2013). Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes. *International journal of nursing studies*, *50*(12), 1639–1647. https://doi.org/10.1016/j.ijnurstu.2013.06.008

Goudriaan, I., van Boekel, L. C., Verbiest, M. E. A., van Hoof, J., & Luijkx, K. G. (2021). Dementia Enlightened?! A Systematic Literature Review of the Influence of Indoor Environmental Light on the Health of Older Persons with Dementia in Long-Term

Care Facilities. *Clinical interventions in aging*, *16*, 909–937. https://doi.org/10.2147/CIA.S297865

Grajauskas, L. A., Siu, W., Medvedev, G., Guo, H., D'Arcy, R., & Song, X. (2019). MRI-based evaluation of structural degeneration in the ageing brain: Pathophysiology and assessment. *Ageing research reviews*, *49*, 67–82. https://doi.org/10.1016/j.arr.2018.11.004

Gray, J. R. & Grove, S. K. (2021). Burns and Grove's The Practice of Nursing Research (9th ed.). Elsevier.

Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied thematic analysis*. SAGE Publications, Inc. https://dx.doi.org/10.4135/9781483384436

Guest, G., Namey, E., & Chen, M. (2020). A simple method to assess and report thematic saturation in qualitative research. PloS one, 15(5), e0232076. https://doi.org/10.1371/journal.pone.0232076

Gure, T. R., Langa, K. M., Fisher, G. G., Piette, J. D., & Plassman, B. L. (2013). Functional limitations in older adults who have cognitive impairment without dementia. *Journal of geriatric psychiatry and neurology*, *26*(2), 78–85. https://doi.org/10.1177/0891988713481264

Hackett, R. A., Steptoe, A., Cadar, D., & Fancourt, D. (2019). Social engagement before and after dementia diagnosis in the English Longitudinal Study of Ageing. PloS one, 14(8), e0220195. https://doi.org/10.1371/journal.pone.0220195

Hall, G., Buckwalter, K. (1987). Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's Disease. Archives or Psychiatric Nursing, 1 (6), pp. 399-406

Harrison, J. K., Garrido, A. G., Rhynas, S. J., Logan, G., MacLullich, A. M., MacArthur, J., & Shenkin, S. (2017). New institutionalisation following acute hospital admission: a retrospective cohort study. *Age and ageing*, *46*(2), 238–244. https://doi.org/10.1093/ageing/afw188

Hasa. (2016) Difference Between Ontology and Epistemology. https://pediaa.com/difference-between-ontology-and-epistemology/

Hawkins, R., Prashar, A., Lusambili, A., Ellard, D., & Godfrey, M. (2018). 'If they don't use it, they lose it': How organisational structures and practices shape residents' physical movement in care home settings. *Ageing and Society, 38*(9), 1817-1842. doi:10.1017/S0144686X17000290

Hill, S. R., Mason, H., Poole, M., Vale, L., Robinson, L., & SEED team. (2017). What is important at the end of life for people with dementia? The views of people with dementia and their carers. *International journal of geriatric psychiatry*, *32*(9), 1037–1045. https://doi.org/10.1002/gps.4564

Hollinghurst, J., Fry, R., Akbari, A., Watkins, A., Williams, N., Hillcoat-Nallétamby, S., Lyons, R. A., Clegg, A., & Rodgers, S. E. (2020). Do home modifications reduce care home admissions for older people? A matched control evaluation of the Care & Repair Cymru service in Wales. *Age and ageing*, *49*(6), 1056–1061. https://doi.org/10.1093/ageing/afaa158

Hunt M. R. (2009). Strengths and challenges in the use of interpretive description: reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative health research*, *19*(9), 1284–1292. https://doi.org/10.1177/1049732309344612

Innes, A., & Manthorpe, J. (2013). Developing theoretical understandings of dementia and their application to dementia care policy in the UK. *Dementia (London, England)*, *12*(6), 682–696. https://doi.org/10.1177/1471301212442583

Innes, A., Abela, S., & Scerri, C. (2011). The organization of dementia care by families in Malta: The experiences of caregivers. Dementia, 10(2), 165-184.

Innes, A., Kelly, F., Scerri, C., & Abela, S. (2016). Living with dementia in hospital wards: a comparative study of staff perceptions of practice and observed patient experience. International journal of older people nursing, 11(2), 94–106. https://doi.org/10.1111/opn.12102

Isaacson, M., Tripathi, A., Samanta, T., D'Ambrosio, L., & Coughlin, J. (2020). Giving Voice to the Environment as the Silent Partner in Aging: Examining the Moderating Roles of Gender and Family Structure in Older Adult Wellbeing. *International journal*

of environmental research and public health, *17*(12), 4373. https://doi.org/10.3390/ijerph17124373

Iyendo, T., O. (2017). Sound as a supportive design intervention for improving health care experience in the clinical ecosystem: A qualitative study. *Complement. Ther. Clin. Prac.t*; 29:58–96. doi: 10.1016/j.ctcp.2017.08.004.

Jackson, J., Maben, J., Anderson, J., E. (2022). What are nurses' roles in modern healthcare? a qualitative interview study using interpretive description. Journal of Research in Nursing. doi:10.1177/17449871211070981

Janus, S., Kosters, J., van den Bosch, K. A., Andringa, T. C., Zuidema, S. U., & Luijendijk, H. J. (2021). Sounds in nursing homes and their effect on health in dementia: a systematic review. *International psychogeriatrics*, *33*(6), 627–644. https://doi.org/10.1017/S1041610220000952

Jao, Y. L., Algase, D. L., Specht, J. K., & Williams, K. (2015). The Association Between Characteristics of Care Environments and Apathy in Residents With Dementia in Long-term Care Facilities. The Gerontologist, 55 Suppl 1, S27–S39. https://doi.org/10.1093/geront/gnu166

Jao, Y. L., Liu, W., Chaudhury, H., Parajuli, J., Holmes, S., & Galik, E. (2021). Function-Focused Person-Environment Fit for Long-Term Care Residents With Dementia: Impact on Apathy. The Gerontologist, 61(3), 413–424. https://doi.org/10.1093/geront/gnaa111

Jao, Y. L., Liu, W., Williams, K., Chaudhury, H., & Parajuli, J. (2019). Association between environmental stimulation and apathy in nursing home residents with dementia. International psychogeriatrics, 31(8), 1109–1120. https://doi.org/10.1017/S1041610219000589

Jones, K. C. (2021). Update on Major Neurocognitive Disorders. *Focus (American Psychiatric Publishing)*, *19*(3), 271–281. https://doi.org/10.1176/appi.focus.20210004

Jones, S., M. (2022). Taking the Time: Developing Trust with the Hospitalized Patient. *Research and theory for nursing practice*, *36*(2), 139–155. https://doi.org/10.1891/RTNP-2021-0024

Jongsiriyanyong, S., & Limpawattana, P. (2018). Mild Cognitive Impairment in Clinical Practice: A Review Article. *American journal of Alzheimer's disease and other dementias*, *33*(8), 500–507. https://doi.org/10.1177/1533317518791401

Kales, H. C., Gitlin, L. N., & Lyketsos, C. G. (2015). Assessment and management of behavioral and psychological symptoms of dementia. *BMJ (Clinical Research Ed.)*, *350*, h369. doi:https://doi.org/10.1136/bmj.h369

Kalinowski, S., Wulff, I., Kölzsch, M., Kopke, K., Kreutz, R., & Dräger, D. (2012). Physical activity in nursing homes--barriers and facilitators: a cross-sectional study. *Journal of aging and physical activity*, *20*(4), 421–441. https://doi.org/10.1123/japa.20.4.421

Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of advanced nursing*, *72*(12), 2954–2965. https://doi.org/10.1111/jan.13031

Kangasniemi, M., Papinaho, O., Moilanen, T., Leino-Kilpi, H., Siipi, H., Suominen, S., & Suhonen, R. (2022). Neglecting the care of older people in residential care settings: A national document analysis of complaints reported to the Finnish supervisory authority. Health & social care in the community, 30(4), e1313–e1324. https://doi.org/10.1111/hsc.13538

Keng, A., Brown, E. E., Rostas, A., Rajji, T. K., Pollock, B. G., Mulsant, B. H., & Kumar, S. (2020). Effectively Caring for Individuals With Behavioral and Psychological Symptoms of Dementia During the COVID-19 Pandemic. *Frontiers in psychiatry*, 11, 573367. https://doi.org/10.3389/fpsyt.2020.573367

Kiger, M., E. & Varpio, L. (2020). Thematic analysis of qualitative data. AMEE Guide No. 131, Medical Teacher, DOI: 10.1080/0142159X.2020.1755030

Knippenberg, I. A. H., Leontjevas, R., Nijsten, J. M. H., Bakker, C., Koopmans, R. T. C. M., Gerritsen, D. L. (2022) Stimuli changes and challenging behavior in nursing homes during the COVID-19 pandemic. *BMC Geriatr* 22, 142 (2022). https://doi.org/10.1186/s12877-022-02824-y

Knopman, D. S., & Petersen, R. C. (2014). Mild cognitive impairment and mild dementia: a clinical perspective. *Mayo Clinic proceedings*, *89*(10), 1452–1459. https://doi.org/10.1016/j.mayocp.2014.06.019

Kok, J. S., Nielen, M. M. A., & Scherder, E. J. A. (2018). Quality of life in small-scaled homelike nursing homes: an 8-month controlled trial. *Health and quality of life outcomes*, *16*(1), 38. https://doi.org/10.1186/s12955-018-0853-7

Kolanowski, A., Boltz, M., Galik, E., Gitlin, L. N., Kales, H. C., Resnick, B., van Haitsma, K. S., Knehans, A., Sutterlin, J. E., Sefcik, J. S., Liu, W., Petrovsky, D. V., Massimo, L., Gilmore-Bykovskyi, A., MacAndrew, M., Brewster, G., Nalls, V., Jao, Y. L., Duffort, N., & Scerpella, D. (2017). Determinants of behavioral and psychological symptoms of dementia: A scoping review of the evidence. *Nursing outlook*, *65*(5), 515–529. https://doi.org/10.1016/j.outlook.2017.06.006

Konetzka, R. T., & Perraillon, M. C. (2016). Use Of Nursing Home Compare Website Appears Limited By Lack Of Awareness And Initial Mistrust Of The Data. Health affairs (Project Hope), 35(4), 706–713. https://doi.org/10.1377/hlthaff.2015.1377

Lawton, M. P. (1977). The impact of the environment on aging and behavior. In J. E. Birren & K. W. Schaie (Eds.), Handbook of the psychology of aging (pp. 276–301). New York: Van Nostrand.

Lawton, M. P. (1999). Environmental taxonomy: Generalizations from research with older adults. In S. L. Friedman & T. D. Wachs (Eds.), Measuring environment across the life span (pp. 91–124). Washington, DC: American Psychological Association.

Lawton, M. P., & Nahemow, L. (1973). Ecology and the aging process. In C. Eisdorfer & M. P. Lawton (Eds.), *The psychology of adult development and aging* (pp. 619–674). American Psychological Association. https://doi.org/10.1037/10044-020

Lawton, M. P., Windley, P. G., & Byerts, T. O. (1982). *Aging and the environment: Theoretical approaches* (Vol. 7). Springer Publishing Company.

Lee, H. Y., Short, S., Lee, M. J., Jeon, Y. H., Park, E., & Chin, Y. R. (2022). Improving the quality of long-term care services in workforce dimension: expert views from Australia and South Korea. Archives of public health = Archives belges de sante publique, 80(1), 112. https://doi.org/10.1186/s13690-022-00872-9

Lee, J. Y., Lee, K. H., & McConnell, E. S. (2021). Mealtime caregiving approaches and behavioral symptoms in persons living with dementia: a longitudinal, observational study. BMC nursing, 20(1), 104. https://doi.org/10.1186/s12912-021-00621-3

Levers, M.-J. D. (2013). Philosophical Paradigms, Grounded Theory, and Perspectives on Emergence. SAGE Open. https://doi.org/10.1177/2158244013517243

Levine, M. E., Lu, A. T., Quach, A., Chen, B. H., Assimes, T. L., Bandinelli, S., Hou, L., Baccarelli, A. A., Stewart, J. D., Li, Y., Whitsel, E. A., Wilson, J. G., Reiner, A. P., Aviv, A., Lohman, K., Liu, Y., Ferrucci, L., & Horvath, S. (2018). An epigenetic biomarker of aging for lifespan and healthspan. *Aging*, *10*(4), 573–591. https://doi.org/10.18632/aging.101414

Livingston, G., Kelly, L., Lewis-Holmes, E., Baio, G., Morris, S., Patel, N., Omar, R. Z., Katona, C., & Cooper, C. (2014). A systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia. *Health technology assessment (Winchester, England)*, *18*(39), 1–vi. https://doi.org/10.3310/hta18390

Lombardo, F. L., Salvi, E., Lacorte, E., Piscopo, P., Mayer, F., Ancidoni, A., & Nursing Home Study Group. (2020). Adverse events in Italian nursing homes during the COVID-19 epidemic: a national survey. Frontiers in Psychiatry, 11. https://dx.doi.org/10.3389%2Ffpsyt.2020.578465

Luo, M., Ding, D., Bauman, A., Negin, J., & Phongsavan, P. (2020). Social engagement pattern, health behaviors and subjective well-being of older adults: an international perspective using WHO-SAGE survey data. BMC public health, 20(1), 99. https://doi.org/10.1186/s12889-019-7841-7

Mackenzie, C. S., & Abdulrazaq, S. (2021). Social engagement mediates the relationship between participation in social activities and psychological distress among older adults. Aging & mental health, 25(2), 299–305. https://doi.org/10.1080/13607863.2019.1697200

Mackieson, P., Shlonsky, A., & Connolly, M. (2019). Increasing rigor and reducing bias in qualitative research: A document analysis of parliamentary debates using applied

thematic analysis. Qualitative Social Work, 18(6), 965–980. https://doi.org/10.1177/1473325018786996

Magnussen, I. L., Alteren, J., & Bondas, T. (2021). "Human Flourishing with Dignity": A Meta-Ethnography of the Meaning of Gardens for Elderly in Nursing Homes and Residential Care Settings. Global qualitative nursing research, 8, 23333936211035743. https://doi.org/10.1177/23333936211035743

Mahrs Träff, A., Cedersund, E., & Abramsson, M. (2020). What promotes and what limits physical activity in assisted living facilities? A study of the physical environment's design and significance. J. Aging Environ. 10.1080/02763893.2019.1683669

Malmqvist, J., Hellberg, K., Möllås, G., Rose, R., & Shevlin, M. (2019). Conducting the Pilot Study: A Neglected Part of the Research Process? Methodological Findings Supporting the Importance of Piloting in Qualitative Research Studies. International Journal of Qualitative Methods. https://doi.org/10.1177/1609406919878341

Marquardt, G., Bueter, K., & Motzek, T. (2014). Impact of the design of the built environment on people with dementia: an evidence-based review. *HERD*, *8*(1), 127–157. https://doi.org/10.1177/193758671400800111

McLeod, S. (2019). What's the difference between qualitative and quantitative research?. https://www.simplypsychology.org/qualitative-quantitative.html

Medical Care Coporation. (n.d.). Education: MCI and Dementia. https://www.mccare.com/education/mcidementia.html

Micallef Costa, M. (2019). *Malta's high-rise building policy: a stakeholder analysis.* [Unpublished master's thesis]. University of Malta. https://www.um.edu.mt/library/oar/handle/123456789/52133

Miciak, M., Mayan, M., Brown, C., Joyce, A. S., & Gross, D. P. (2018). The necessary conditions of engagement for the therapeutic relationship in physiotherapy: an interpretive description study. *Archives of physiotherapy*, *8*, 3. https://doi.org/10.1186/s40945-018-0044-1

Milte, R., Shulver, W., Killington, M., Bradley, C., Ratcliffe, J., & Crotty, M. (2016). Quality in residential care from the perspective of people living with dementia: The

importance of personhood. Archives of gerontology and geriatrics, 63, 9–17. https://doi.org/10.1016/j.archger.2015.11.007

Ministry of Health. (2016). Secure Dementia Care Home Design: Information Resource. Wellington: Ministry of Health. https://www.health.govt.nz/system/files/documents/publications/secure-dementia-care-home-design-information-resource.pdf

Minyo, M. J. (2020). *Understanding the unmet needs and need-driven behaviors of individuals with mild to moderate dementia*. [Unpublished master's thesis]. University of Cleveland State University. https://etd.ohiolink.edu/apexprod/rws_etd/send_file/send?accession=csu1600185840965772&disposition=inline

Morse, J., M. (2015). Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry. *Qualitative health research*, *25*(9), 1212–1222. https://doi.org/10.1177/1049732315588501

Nakanishi, M., & Tei-Tominaga, M. (2018). The Association between Quality Improvement Initiatives in Dementia Care and Supportive Psychosocial Work Environments in Nursing Homes. Healthcare (Basel, Switzerland), 6(2), 44. https://doi.org/10.3390/healthcare6020044

Narsakka, N., Suhonen, R., Kielo-Viljamaa, E., & Stolt, M. (2022). Physical, social, and symbolic environment related to physical activity of older individuals in long-term care: A mixed-method systematic review. *International journal of nursing studies*, *135*, 104350. https://doi.org/10.1016/j.ijnurstu.2022.104350

National Geographic. (n.d.). Concept of Place. https://education.nationalgeographic.org/resource/resource-library-concept-place

Noon, E. (2018). Interpretive Phenomenological Analysis: An Appropriate Methodology for Educational Research?. Journal of Perspectives in Applied Academic Practice. 6. 10.14297/jpaap.v6i1.304.

Nordin, S., McKee, K., Wallinder, M., von Koch, L., Wijk, H., & Elf, M. (2017). The physical environment, activity and interaction in residential care facilities for older

people: a comparative case study. *Scandinavian journal of caring sciences*, *31*(4), 727–738. https://doi.org/10.1111/scs.12391

Nordtug, B., Malmedal, W. K., Alnes, R. E., Blindheim, K., Steinsheim, G., & Moe, A. (2021). Informal caregivers and persons with dementia's everyday life coping. Health psychology open, 8(1), 20551029211000954. https://doi.org/10.1177/20551029211000954

Nowell, L., Norris, J. M., Mrklas, K., & White, D. E. (2017). Mixed methods systematic review exploring mentorship outcomes in nursing academia. Journal of advanced nursing, 73(3), 527–544. https://doi.org/10.1111/jan.13152

Nowrangi, M. A., Lyketsos, C. G., & Rosenberg, P. B. (2015). Principles and management of neuropsychiatric symptoms in Alzheimer's dementia. *Alzheimer's research & therapy*, *7*(1), 12. https://doi.org/10.1186/s13195-015-0096-3

O'Donnell, E., Holland, C., Swarbick, C. (2022) Strategies used by care home staff to manage behaviour that challenges in dementia: a systematic review of qualitative studies. International Journal of Nursing Studies. https://doi.org/10.1016/j.ijnurstu.2022.104260

O'Malley, M., Innes, A., & Wiener, J. M. (2015). Decreasing spatial disorientation in care-home settings: How psychology can guide the development of dementia friendly design guidelines. Dementia, Published online before print June 24, 2015. doi:10.1177/1471301215591334

Ooms, S., & Ju, Y. E. (2016). Treatment of Sleep Disorders in Dementia. *Current treatment options in neurology*, *18*(9), 40. https://doi.org/10.1007/s11940-016-0424-3

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. Administration and policy in mental health, 42(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y

Palm, R., & Bartholomeyczik, S. (2018). Specialist dementia care units. In Michel J. P. Beattie L. Finbarr M., Watson J.(Eds.), *Oxford textbook of geriatric medicine, third edition*(pp. 281–285). Oxford University Press.

Pandya, S. Y., Clem, M. A., Silva, L. M., & Woon, F. L. (2016). Does mild cognitive impairment always lead to dementia? A review. *Journal of the neurological sciences, 369*, 57–62. https://doi.org/10.1016/j.jns.2016.07.055

Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing. (2013). National strategic policy for active ageing: Malta 2013–2014. Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing.

Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing. (2014). National Strategy for Dementia in the Maltese Islands (2015-2023). https://activeageing.gov.mt/en/Documents/book_english_book.pdf

Peluso, S., De Rosa, A., De Lucia, N., Antenora, A., Illario, M., Esposito, M., & De Michele, G. (2018). Animal-Assisted Therapy in Elderly Patients: Evidence and Controversies in Dementia and Psychiatric Disorders and Future Perspectives in Other Neurological Diseases. Journal of geriatric psychiatry and neurology, 31(3), 149–157. https://doi.org/10.1177/0891988718774634

Peterson, R. L., George, K. M., Tran, D., Malladi, P., Gilsanz, P., Kind, A. J. H., Whitmer, R. A., Besser, L. M., & Meyer, O. L. (2021). Operationalizing Social Environments in Cognitive Aging and Dementia Research: A Scoping Review. *International Journal of Environmental Research and Public Health*, *18*(13), 7166. https://doi.org/10.3390/ijerph18137166

Pickering, C., Yefimova, M., Wang, D., Maxwell, C. D., & Jablonski, R. (2022). Dynamic structural equation modelling evaluating the progressively lowered stress threshold as an explanation for behavioural symptoms of dementia. Journal of advanced nursing, 10.1111/jan.15173. Advance online publication. https://doi.org/10.1111/jan.15173

Pinto, J. O., Dores, A. R., Geraldo, A., Peixoto, B., & Barbosa, F. (2020). Sensory stimulation programs in dementia: a systematic review of methods and effectiveness. Expert review of neurotherapeutics, 20(12), 1229–1247. https://doi.org/10.1080/14737175.2020.1825942

Poole, M., Davis, N., & Robinson, L. (2020). Massive Open Online Courses: enhancing caregiver education and support about dementia care towards and at end of life. Age and ageing, 49(2), 171–174. https://doi.org/10.1093/ageing/afz150

Popham, C., & Orrell, M. (2012). What matters for people with dementia in care homes?. *Aging & mental health*, *16*(2), 181–188. https://doi.org/10.1080/13607863.2011.628972

Proshansky, H. M. (1978). The city and self-identity. Environ. Behav. 10, 147–169. doi: 10.1177/0013916578102002

Ratcliffe, E., Gatersleben, B., Sowden, P., T. (2016). Associations with bird sounds: How do they relate to perceived restorative potential? *J. Environ. Psychol.*; 47:136–144. doi: 10.1016/j.jenvp.2016.05.009.

Reisberg, B., Ferris, S.H., de Leon, M.J., and Crook, T. (1982). The global deterioration scale for assessment of primary degenerative dementia. American Journal of Psychiatry, 139: 1136-1139.

Ren, H., & Strickfaden, M. (2018). The Active Role of Material Things: An Environment-Based Conceptual Framework to Understand the Well-Being of People with Dementia. Open Journal of Social Sciences, 6, 11-23. doi: 10.4236/jss.2018.66002.

Revolta, C., Orrell, M., & Spector, A. (2016). The biopsychosocial (BPS) model of dementia as a tool for clinical practice. A pilot study. *International psychogeriatrics*, *28*(7), 1079–1089. https://doi.org/10.1017/S1041610215002379

Rijnaard, M. D., van Hoof, J., Janssen, B. M., Verbeek, H., Pocornie, W., Eijkelenboom, A., Beerens, H. C., Molony, S. L., & Wouters, E. J. (2016). The Factors Influencing the Sense of Home in Nursing Homes: A Systematic Review from the Perspective of Residents. Journal of aging research, 2016, 6143645. https://doi.org/10.1155/2016/6143645

Rosteius. K., de Boer. B., Staudacher. S., Schols. J., & Verbeek. H. (2022). How the interrelated physical, social and organizational environment impacts daily life of residents with dementia on a Green Care Farm. *Front. Public Health* 10:946962. doi: 10.3389/fpubh.2022.946962

Ryan, G. (2018). Introduction to positivism, interpretivism and critical theory. Nurse researcher, 25(4), 14–20. https://doi.org/10.7748/nr.2018.e1466

Saarijärvi, M., & Bratt, E. L. (2021). When face-to-face interviews are not possible: tips and tricks for video, telephone, online chat, and email interviews in qualitative research. *European journal of cardiovascular nursing*, *20*(4), 392–396. https://doi.org/10.1093/eurjcn/zvab038

Scerri, A. (2017). Implementing person-centred dementia care in a rehabilitation hospital through an appreciative inquiry approach. https://www.um.edu.mt/library/oar/handle/123456789/27015

Scheidt, R. J., Windley, P. G. (1985). The ecology of aging. In J. E. Birren & K. W. Schaie (Eds.), Handbook of the psychology of aging (pp. 245–258). New York: Van Nostrand.

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family - caregivers of people with mental illnesses. *World journal of psychiatry*, *6*(1), 7–17. https://doi.org/10.5498/wjp.v6.i1.7

Smith, B. C., & D'Amico, M. (2020). Sensory-Based Interventions for Adults with Dementia and Alzheimer's Disease: A Scoping Review. Occupational therapy in health care, 34(3), 171–201. https://doi.org/10.1080/07380577.2019.1608488

Smith, L., Morton, D., & van Rooyen, D. (2022). Family dynamics in dementia care: A phenomenological exploration of the experiences of family caregivers of relatives with dementia. Journal of psychiatric and mental health nursing, 29(6), 861–872. https://doi.org/10.1111/jpm.12822

Social Care Standards Authority. (2021a). Social Regulatory Standards: Residential Services for Persons Living with Dementia in Homes For Senior Citizens. https://scsa.gov.mt/en/Documents/Publications/Dementia/Dementia-SRS-ENG.pdf

Social Care Standards Authority. (2021b). Social Regulatory Standards: Residential Services for Senior Citizens. https://scsa.gov.mt/en/Documents/Publications/Senior%20Citizens%20-%20Residential/Residential%20Services%20ENG.pdf

Soleimani, R., Shokrgozar, S., Fallahi, M., Kafi, H., & Kiani, M. (2018). An investigation into the prevalence of cognitive impairment and the performance of older adults in

Guilan province. *Journal of medicine and life*, 11(3), 247–253. https://doi.org/10.25122/jml-2018-0017

Soril, L. J., Leggett, L. E., Lorenzetti, D. L., Silvius, J., Robertson, D., Mansell, L., Holroyd-Leduc, J., Noseworthy, T. W., & Clement, F. M. (2014). Effective use of the built environment to manage behavioural and psychological symptoms of dementia: a systematic review. *PloS one*, *9*(12), e115425. https://doi.org/10.1371/journal.pone.0115425

Sousa, L., Sequeira, C., Ferré-Grau, C., Neves, P., & Lleixà-Fortuño, M. (2016). Training programmes for family caregivers of people with dementia living at home: integrative review. Journal of clinical nursing, 25(19-20), 2757–2767. https://doi.org/10.1111/jocn.13266

Spector, A., & Orrell, M. (2010). Using a biopsychosocial model of dementia as a tool to guide clinical practice. *International psychogeriatrics*, 22(6), 957–965. https://doi.org/10.1017/S1041610210000840

Spector, A., Revolta, C., & Orrell, M. (2016). The impact of staff training on staff outcomes in dementia care: a systematic review. International journal of geriatric psychiatry, 31(11), 1172–1187. https://doi.org/10.1002/gps.4488

Steber, C. (2017). In-Depth Interviews: Data Collection Advantages and Disadvantages. https://www.cfrinc.net/cfrblog/in-depth-interviewing

Steele, C., Berry, K., & Brown, L. J. E. (2022). Healthcare professionals' experiences of using a biopsychosocial approach to understand behavioural and psychological symptoms of dementia: A qualitative interview study. *International journal of older people nursing*, *17*(2), e12427. https://doi.org/10.1111/opn.12427

Steiner, V., Ames, A., Milz, S. A., & Dubin, S. (2020). Nursing Home Staff's Perceptions of Noise Compared to Measured Noise Levels: A Descriptive Study. *Journal of gerontological nursing*, *46*(9), 37–45. https://doi.org/10.3928/00989134-20200706-03

Strøm, B. S., Ytrehus, S., & Grov, E. K. (2016). Sensory stimulation for persons with dementia: a review of the literature. Journal of clinical nursing, 25(13-14), 1805–1834. https://doi.org/10.1111/jocn.13169

Sturge, J., Nordin, S., Sussana Patil, D., Jones, A., Légaré, F., Elf, M., & Meijering, L. (2021). Features of the social and built environment that contribute to the well-being of people with dementia who live at home: A scoping review. *Health & place*, *67*, 102483. https://doi.org/10.1016/j.healthplace.2020.102483

Surr, C. A., Gates, C., Irving, D., Oyebode, J., Smith, S. J., Parveen, S., Drury, M., & Dennison, A. (2017). Effective Dementia Education and Training for the Health and Social Care Workforce: A Systematic Review of the Literature. Review of educational research, 87(5), 966–1002. https://doi.org/10.3102/0034654317723305

Suzuki, K., Miyamoto, M., & Hirata, K. (2017). Sleep disorders in the elderly: Diagnosis and management. *Journal of general and family medicine*, *18*(2), 61–71. https://doi.org/10.1002/jgf2.27

Tak, S. H., Kedia, S., Tongumpun, T. M., & Hong, S. H. (2015). Activity Engagement: Perspectives from Nursing Home Residents with Dementia. *Educational gerontology*, *41*(3), 182–192. https://doi.org/10.1080/03601277.2014.937217

Tenny, S., Brannan, G. D., Brannan, J. M, Sharts-Hopko, N. (2021). Qualitative Study. https://www.ncbi.nlm.nih.gov/books/NBK470395/

Teodoro, I. P. P., Rebouças, V., Thorne, S. E., & Souza, N., Brito, L. S., Alencar, A. M. P. G. (2018). Interpretive description: a viable methodological approach for nursing research. Escola Anna Nery. 22. 10.1590/2177-9465-ean-2017-0287.

Thake, A. M., Azzopardi, M., & Unah, K. (2020). Nurse Shortages in the Maltese Public Health Sector. https://www.researchgate.net/publication/358356593_Nurse_Shortages_in_the_Maltese_Public_Health_Sector/citations

Thakur, H. (2021). Research Design. https://www.researchgate.net/publication/353430802_Research_Design

Thompson Burdine, J., Thorne, S., & Sandhu, G. (2021). Interpretive description: A flexible qualitative methodology for medical education research. *Medical education*, *55*(3), 336–343. https://doi.org/10.1111/medu.14380

Thorne, S. (2008). Interpretive Description. Left Coast Press edition, Walnut Creek

Thorne S. (2013). Interpretive Description. In: Beck CT, ed. Routledge International Handbook of Qualitative Nursing Research New York: Routledge; p. 295-306.

Thorne, S. (2016). Interpretive description: Qualitative research for applied practice (p. 336). New York, NY: Routledge.

Thorne S. (2020). Beyond theming: Making qualitative studies matter. Nursing inquiry, 27(1), e12343. https://doi.org/10.1111/nin.12343

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The Analytic Challenge in Interpretive Description. International Journal of Qualitative Methods, 1–11. https://doi.org/10.1177/160940690400300101

Thorne, S., & Sawatzky, R. (2014). Particularizing the general: Sustaining theoretical integrity in the context of an evidence-based practice agenda. ANS. Advances in nursing science, 37(1), 5–18. https://doi.org/10.1097/ANS.0000000000000011

Thorne, S., Stephens, J., & Truant, T. (2016). Building qualitative study design using nursing's disciplinary epistemology. Journal of advanced nursing, 72(2), 451–460. https://doi.org/10.1111/jan.12822

Tolea, M. I., Morris, J. C., & Galvin, J. E. (2016). Trajectory of Mobility Decline by Type of Dementia. *Alzheimer disease and associated disorders*, *30*(1), 60–66. https://doi.org/10.1097/WAD.0000000000000091

Torresin, S., Albatici, R., Aletta, F., Babich, F., Oberman, T., Siboni, S., Kang, J. (2020). Indoor soundscape assessment: A principal components model of acoustic perception in residential buildings. *Build. Environ.* 182:107152. 10.1016/j.buildenv.2020.107152

Toot, S., Swinson, T., Devine, M., Challis, D., & Orrell, M. (2017). Causes of nursing home placement for older people with dementia: A systematic review and meta-analysis. International Psychogeriatrics, 29(2), 195-208. doi:10.1017/S1041610216001654

Tuffour, I. (2017). A Critical Overview of Interpretative Phenomenological Analysis: A Contemporary Qualitative Research Approach. J Healthc Commun. 2:52. doi: 10.4172/2472-1654.100093

United Nations. (2019) World Population Ageing 2019. https://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldPopulationAgeing2019-Highlights.pdf

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nursing & health sciences, 15(3), 398–405. https://doi.org/10.1111/nhs.12048

van Buuren, L. P. G., & Mohammadi, M. (2022). Dementia-Friendly Design: A Set of Design Criteria and Design Typologies Supporting Wayfinding. HERD, 15(1), 150–172. https://doi.org/10.1177/19375867211043546

van den Bosch, K., A. (2015). Safe and Sound: Soundscape research in special needs care. *Gron. Univ. Gron.*; 13:61–68. doi: 10.1111/jppi.12147.

van der Velde-van Buuringen, M., Achterberg, W. P., & Caljouw, M. A. A. (2021). Daily garden use and quality of life in persons with advanced dementia living in a nursing home: A feasibility study. Nursing open, 8(3), 1243–1253. https://doi.org/10.1002/nop2.740

van Steenwinkel, I., Dierckx de Casterlé, B., & Heylighen, A. (2017). How architectural design affords experiences of freedom in residential care for older people. *Journal of aging studies*, *41*, 84–92. https://doi.org/10.1016/j.jaging.2017.05.001

van Steenwinkel, I., van Audenhove, C., & Heylighen, A. (2014). Mary's Little Worlds: Changing Person-Space Relationships When Living With Dementia. Qualitative health research, 24(8), 1023–1032. https://doi.org/10.1177/1049732314542808

Vasileiou, K., Barnett, J., Thorpe, S., Young, T. (2018) Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. BMC Med Res Methodol 18, 148. https://doi.org/10.1186/s12874-018-0594-7

Vassallo, M. (2018) ESPN Thematic Report on Challenges in long-term care: Malta. https://ec.europa.eu/social/BlobServlet?docId=19860&langId=en

Vernooij-Dassen, M., Moniz-Cook, E., Verhey, F., Chattat, R., Woods, B., Meiland, F., Franco, M., Holmerova, I., Orrell, M., & de Vugt, M. (2021). Bridging the divide

between biomedical and psychosocial approaches in dementia research: the 2019 INTERDEM manifesto. *Aging & mental health*, *25*(2), 206–212. https://doi.org/10.1080/13607863.2019.1693968

Verbeek, H., & Mitchell, G. (2022). Changing the long-term care spectrum. *BMC geriatrics*, *22*(1), 303. https://doi.org/10.1186/s12877-022-02909-8

Vik-Mo, A. O., Giil, L. M., Borda, M. G., Ballard, C. and Aarsland, D. (2020). The individual course of neuropsychiatric symptoms in people with Alzheimer's and Lewy body dementia: 12-year longitudinal cohort study. Br J Psychiatry, 216, 43-48.

Volkers, K. M., & Scherder, E. J. (2014). Physical performance is associated with working memory in older people with mild to severe cognitive impairment. *BioMed research international*, *2014*, 762986. https://doi.org/10.1155/2014/762986

Wahl, H.-W. (2001). Ecology of aging. In N. J. Smelser & P. B. Baltes (Eds.), International encyclopedia of the social and behavioral sciences (Vol. 6, pp. 4045–4048). Amsterdam: Elsevier.

Wahl, H. W., Iwarsson, S., & Oswald, F. (2012). Aging well and the environment: toward an integrative model and research agenda for the future. *The Gerontologist*, *52*(3), 306–316. https://doi.org/10.1093/geront/gnr154

Wahlroos, N., Narsakka, N., Stolt, M., & Suhonen, R. (2022). Physical Environment Maintaining Independence and Self-management of Older People in Long-Term Care Settings—An Integrative Literature Review. *Journal of Aging and Environment*, 1–19. https://doi.org/10.1080/26892618.2022.2092927

Weisman, G. D., Calkins, M., & Sloane, P. (1994). The environmental context of special care. *Alzheimer disease and associated disorders*, *8 Suppl 1*, S308–S320.

Whear, R., Coon, J. T., Bethel, A., Abbott, R., Stein, K., & Garside, R. (2014). What is the impact of using outdoor spaces such as gardens on the physical and mental well-being of those with dementia? A systematic review of quantitative and qualitative evidence. *Journal of the American Medical Directors Association*, *15*(10), 697–705. https://doi.org/10.1016/j.jamda.2014.05.013

Winblad, B., Amouyel, P., Andrieu, S., Ballard, C., Brayne, C., Brodaty, H., Cedazo-Minguez, A., Dubois, B., Edvardsson, D., Feldman, H., Fratiglioni, L., Frisoni, G. B., Gauthier, S., Georges, J., Graff, C., Iqbal, K., Jessen, F., Johansson, G., Jönsson, L., Kivipelto, M., … Zetterberg, H. (2016). Defeating Alzheimer's disease and other dementias: a priority for European science and society. *The Lancet. Neurology*, *15*(5), 455–532. https://doi.org/10.1016/S1474-4422(16)00062-4

Wood, W., Lampe, J. L., Logan, C. A., Metcalfe, A. R., & Hoesly, B. E. (2017). The Lived Environment Life Quality Model for institutionalized people with dementia. *Canadian journal of occupational therapy. Revue canadienne d'ergotherapie*, *84*(1), 22–33. https://doi.org/10.1177/0008417416656207

Woodbridge, R., Sullivan, M., Harding, E., Crutch, S., Gilhooly, K., Gilhooly, M., Mcintyre, A., Wilson, L., (2016). Use of the physical environment to support everyday activities for people with dementia: A systematic review. Dementia. 17. 10.1177/1471301216648670.

Woodbridge, R., Sullivan, M. P., Harding, E., Crutch, S., Gilhooly, K. J., Gilhooly, M., McIntyre, A., & Wilson, L. (2018). Use of the physical environment to support everyday activities for people with dementia: A systematic review. Dementia (London, England), 17(5), 533–572. https://doi.org/10.1177/1471301216648670

World Health Organization. (2012). WHOQOL: Measuring Quality of Life. https://www.who.int/toolkits/whoqol

World Health Organization. (2021). Dementia. https://www.who.int/news-room/fact-sheets/detail/dementia

Xie, H., Zhong, B., Liu, C. (2020). Sound environment quality in nursing units in Chinese nursing homes: A pilot study. *Build. Acoustics* 27, 283–298. 10.1177/1351010X20914237

Yasuda, M., & Sakakibara, H. (2017). Care staff training based on person-centered care and dementia care mapping, and its effects on the quality of life of nursing home residents with dementia. Aging & mental health, 21(9), 991–996. https://doi.org/10.1080/13607863.2016.1191056

APPENDICES

APPENDIX 1A

GLOBAL DETERIORATION SCALE (GDS) DEVELOPED BY REISBERG ET AL. (1982)

The Global Deterioration Scale for Assessment of Primary Degenerative Dementia

The Global Deterioration Scale (GDS), developed by Dr. Barry Reisberg, provides caregivers an overview of the stages of cognitive function for those suffering from a primary degenerative dementia such as Alzheimer's disease. It is broken down into 7 different stages. Stages 1-3 are the pre-dementia stages. Stages 4-7 are the dementia stages. Biginning in stage 5, an individual can no longer survive without assistance. Within the GDS, each stage is numbered (1-7), given a short title (i.e., Forgetfulness, Early Confusional, etc. followed by a brief listing of the characteristics for that stage. Caregivers can get a rough idea of where an individual is at in the disease process by observing that individual's behavioral characteristics and comparing them to the GDS. For more specific assessments, use the accompanying Brief Cognitive Rating Scale (BCRS) and the Functional Assessment Staging (FAST) measures.

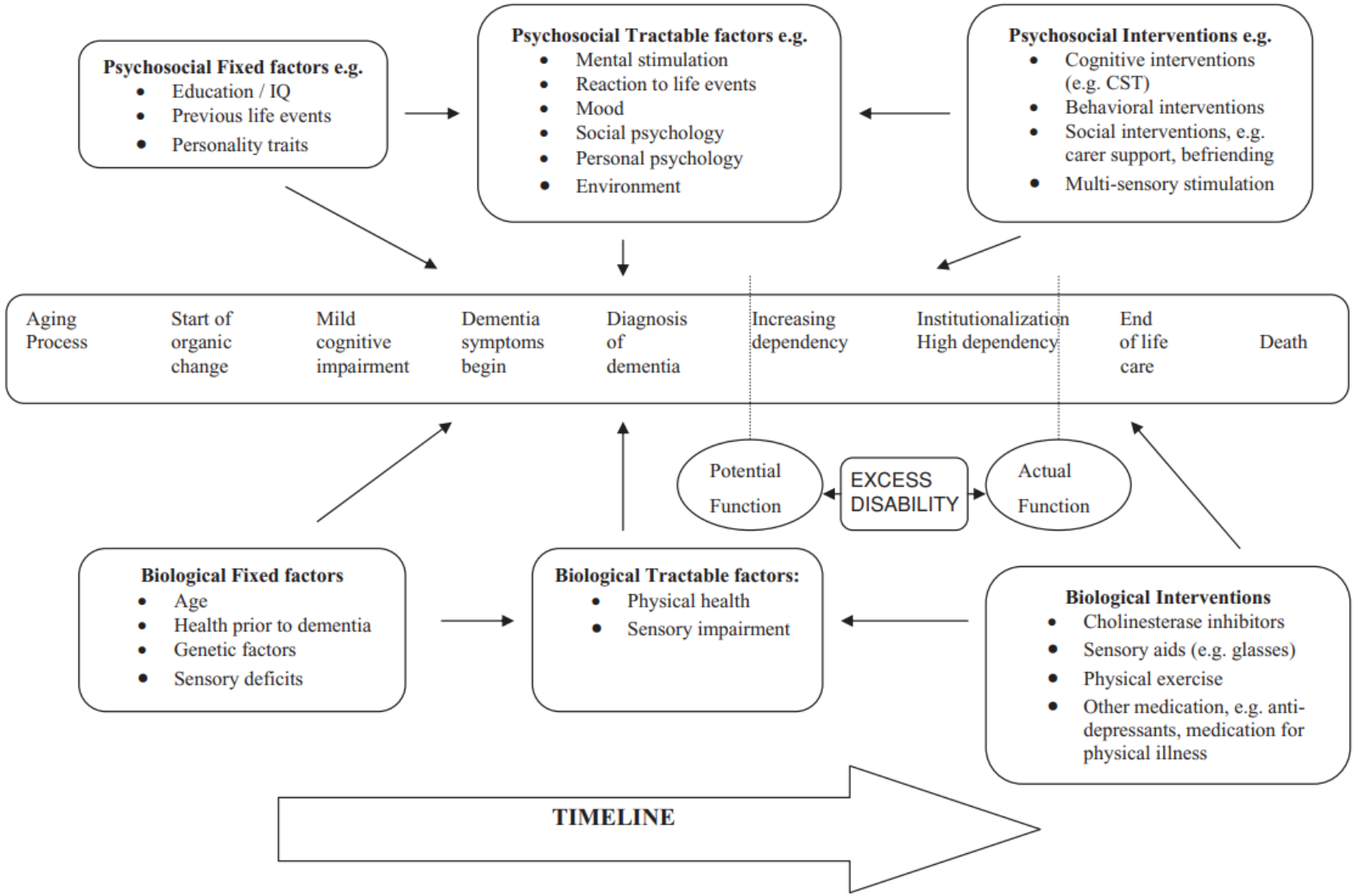
Level	Clinical Characteristics
1 **No cognitive decline**	No subjective complaints of memory deficit. No memory deficit evident on clinical interview.
2 Very mild cognitive decline **(Age Associated Memory Impairment)**	Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.
3 Mild cognitive decline **(Mild Cognitive Impairment)**	Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient's relatively poor performance; (c) word and name finding deficit becomes evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.
4 Moderate cognitive decline **(Mild Dementia)**	Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of ones personal history; (c) concentration deficit elicited on serial subtractions; (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and place; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations frequently occur.

5 Moderately severe cognitive decline **(Moderate Dementia)**	Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives, e.g., an address or telephone number of many years, the names of close family members (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses' and children's names. They require no assistance with toileting and eating, but may have some difficulty choosing the proper clothing to wear.
6 Severe cognitive decline **(Moderately Severe Dementia)**	May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and, sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will be able to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulla, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.
7 Very severe cognitive decline **(Severe Dementia)**	All verbal abilities are lost over the course of this stage. Frequently there is no speech at all -only unintelligible utterances and rare emergence of seemingly forgotten words and phrases. Incontinent of urine, requires assistance toileting and feeding. Basic psychomotor skills, e.g., ability to walk, are lost with the progression of this stage. The brain appears to no longer be able to tell the body what to do. Generalized rigidity and developmental neurologic reflexes are frequently present.

Reisberg, B., Ferris, S.H., de Leon, M.J., and Crook, T. The global deterioration scale for assessment of primary degenerative dementia. American Journal of Psychiatry, 1982, 139: 1136-1139.

APPENDIX 2A

BIOPSYCHOSOCIAL MODEL OF DEMENTIA DEVELOPED BY SPECTOR & ORRELL (2010)


Psychosocial Fixed factors e.g.
Education / IQ
Previous life events
Personality traits
Psychosocial Tractable factors e.g.
Mental stimulation
Reaction to life events
Mood
Social psychology
Personal psychology
Environment
Psychosocial Interventions e.g.
Cognitive interventions (e.g. CST)
Behavioral interventions
Social interventions, e.g. carer support, befriending
Multi-sensory stimulation
Aging Process
Start of organic change
Mild cognitive impairment
Dementia symptoms begin
Diagnosis of dementia
Increasing dependency
Institutionalization High dependency
End of life care
Death
Potential Function
EXCESS DISABILITY
Actual Function
Biological Fixed factors
Age
Health prior to dementia
Genetic factors
Sensory deficits
Biological Tractable factors:
Physical health
Sensory impairment
Biological Interventions
Cholinesterase inhibitors
Sensory aids (e.g. glasses)
Physical exercise
Other medication, e.g. anti-depressants, medication for physical illness
TIMELINE

APPENDIX 3A

A NATIONAL STRATEGY FOR DEMENTIA IN THE MALTESE ISLANDS 2015-2023 (PARLIAMENTARY SECRETARIAT FOR THE RIGHTS OF PERSONS WITH DISABILITY AND ACTIVE AGEING, 2014)

6.4.3 STRATEGY OBJECTIVE

The main objective is to *provide patient-centred dementia long-term and palliative care* through:

(i) providing high quality care to individuals with dementia in residential and/or nursing homes

(ii) adopting legislation on standards of care in homes accommodating older adults including those housing individuals with dementia

(iii) adopting policies that limit the use of restraint

(iv) implementation of dementia-friendly measures (including dementia-friendly design) in all elderly homes

(v) providing end-of-life and palliative care and support to individuals with dementia, their caregivers and family members

6.4.4 OBJECTIVE DELIVERY

a. Develop new long-term housing units for individuals with dementia. Homes managed by private entities should be encouraged to also provide specific dementia-friendly units.

b. Adapt care/nursing homes for older people so as to provide a safe physical environment for patients with dementia. This should include a secure open space area (preferably a dementia-friendly garden).

c. Develop programmes of purposeful and therapeutic activities that keep the individual with dementia active and engaged in meaningful occupation. This can be developed in collaboration with the Active Ageing Unit and in accordance with the recently launched National Strategic Policy for Active Ageing.

d. Provide training to personnel as well as increasing the number of recruited and retained staff in order to provide high quality dementia care.

e. Provide palliative and end-of-life care to individuals with advanced stage dementia, including having adequate pain relief as well as psychological support to caregivers and family members.

f. Devise a number of recommendations for pain assessment in nonverbal individuals with dementia who are unable to self-report.

g. Ensure that government and privately run care and nursing homes accommodating individuals with dementia have the necessary quality standards and managed by staff adequately trained in dementia management and care. Regular monitoring ensures that such standards are kept and dementia-friendly measures incorporated. A team of experts in various aspects of dementia management and care should act as a consultative entity to the monitoring process.

APPENDIX 4A
INFORMATION LETTER FOR PARTICIPANTS

Dear Participant,

My name is Francesca Urry and I am a student at the University of Malta, currently reading for a Master in Gerontology and Geriatrics. I am conducting a research study for my dissertation titled *Informal caregivers' perspectives on the role of the environment on older persons living with dementia within a long-term care facility*. This project is being conducted under the supervision of Dr. Maria Aurora Fenech, from the Department of Gerontology and Dementia Studies, Faculty for Social Wellbeing, University of Malta.

The aim of this study is to explore informal caregivers' perceptions of the effect the environment has on older persons living with dementia (OPLWD) in a long-term care (LTC) facility. Your participation in this study will help contribute to a better understanding of how the physical and social environment may influence the management of behavioural and psychological symptoms of dementia and as a result improve their quality of life. The results are intended to help improve dementia care in long-term care facilities. Any data collected from this research will be used solely for the purpose of this study.

The first 6 to 8 informal caregivers who contact me, the researcher, and who fit the eligibility criteria: (a) informal caregiver of an OPLWD and (b) the OPLWD is required to have been a resident in the LTC facility for more than 6 months, will take part in the project. If you accept to take part in this study, you are invited to take part in a one-to-one interview, where you will be asked to share your perceptions of the effect the environment within a long-term care facility has on the older person living with dementia. A date and time will be set up to carry out a face-to-face interview, at a time and place that is convenient for you, which will last for approximately one hour. Interviews may be conducted in English or Maltese based on your preferred language.

Data collected during the interviews will be treated with confidentiality and your real name will not appear on the interview transcripts; a pseudonym will be used instead. Please note that participant quotes used in the writing of the dissertation or in presentations, to enable clarity in the results, will be used with a pseudonym so as not to reveal your true identity. Should you, the participant, or myself, the researcher, at any point or on revisiting the data become aware that other people might identify you in spite of the fact that a pseudonym is being used, this data will be brought up prior to submitting the study, be further analysed, discussed and modified or eliminated until you are comfortable with final outcome. Personal information will be pseudonymised and will be stored securely and kept separate from the actual data. Data collected from the interview will be kept strictly confidential and will only be used for the purpose of this study. The researcher, her supervisor, examiners and reviewers will be the only people who have access to it. All data collected will be destroyed by December 2023.

If permission is granted by yourself, the interview will be audio-recorded since this will help to draw out a more accurate transcript of your perceptions. If not, I will instead take notes. In

the Consent Sheet, you will be requested to tick the appropriate box which indicates whether you accept for the interview to be audio recorded or not.

Participation in this study is entirely voluntary; meaning that you are free to accept or refuse to participate without needing to give a reason. You are also free to withdraw from the study at any time, without needing to provide any explanation and without any negative repercussions for you. Should you choose to withdraw, any data collected from your interview will be deleted right away if this is technically possible, unless erasure of data would render impossible or seriously impair achievement of the research objectives. You as the participant, have the opportunity to re-visit the transcribed interview material. It is important to note that you can withdraw from the study until 2 weeks after the interview and transcriptions have been carried out. If you choose to participate, please note that there are no direct benefits to you and does not involve any known or anticipated risks. You have the right to access, rectify and where applicable ask for the data concerning you to be erased under the General Data Protection Regulation (GDPR).

A copy of this Information Sheet is being provided for you to keep and for future reference.

It would be highly appreciated if you consider participating in this study. Thank you for your time and consideration. If you have any questions or concerns, please do not hesitate to contact me.

Sincerely,

Researcher: .....
Francesca Urry
[redacted]

Supervisor: .....
Dr. Maria Aurora Fenech
[redacted]

APPENDIX 4B

ITTRA TA' TAGHRIF GĦALL-PARTEĊIPANTI

Għażiż/a Parteċipant,

Jiena jisimni Francesca Urry u jiena studenta fl-Università ta' Malta. Bħalissa qiegħda nagħmel Masters fil-Ġerontoloġija u l-Ġerjatrija. Qiegħda nikteb it-teżi tiegħi bl-isem "Informal caregivers' perspectives on the role of the environment on older persons living with dementia within a long-term care facility". Dan il-proġett qed isir taħt is-superviżjoni ta' Dr Maria Aurora Fenech, mid-Dipartiment tal-Ġerontoloġija u Studji dwar id-Dimensja fil-Fakultà għat-Tisħiħ tas-Soċjetà fl-Università ta' Malta.

L-għan ta' dan l-istudju huwa li jesplora il-perspettivi tal-persuni li jieħdu ħsieb l-anzjani b'mod informali f'dar tal-kura tal-anzjani dwar l-effett li għandu l-ambjent fuq l-anzjani li jgħixu bid-dimensja f'dawn ir-residenzi. Sehmek jgħin biex ikun hawn iżjed għarfien dwar kif l-ambjent fiżiku u dak soċjali jistgħu jinfluwenzaw l-immaniġġjar tas-sintomi fl-imġiba u dawk psikoloġiċi tad-dimensja, u bħala riżultat itejjeb il-kwalità tal-ħajja tagħhom. Ir-riżultati huma maħsuba biex jgħinu fit-titjib tal-kura tad-dimensja f'dar tal-kura għall-anzjani. L-informazzjoni kollha li tingabar fir-riċerka tintuża biss għall-fini ta' dan l-istudju.

Se jieħdu sehem fil-proġett l-ewwel 6 sa 8 persuni li jikkuntattjaw lili, ir-riċerkatriċi, u li jaqblu mal-kriterji ta' eliġibbiltà: (a) persuna li tieħu ħsieb l-anzjani bid-dimensja b'mod informali u (b) li l-anzjani inkwistjoni bid-dimensja jkunu residenti fil-faċilità għal aktar minn 6 xhur. Jekk taċċetta li tieħu sehem f'dan l-istudju, inti mistieden biex tieħu sehem f'intervista, fejn se tintalab taqsam il-perspettivi tiegħek dwar l-effett li għandu l-ambjent f'faċilità tal-kura għall-anzjani fuq l-anzjani li jgħixu bid-dimensja. Jiġu stabbiliti data u ħin biex issir intervista wiċċ imb wiċċ, f'ħin u post li jkunu konvenjenti għalik. L-intervista se ddum madwar siegħa. L-intervisti jistgħu jsiru bl-Ingliż jew bil-Malti, abbażi tal-lingwa preferuta tiegħek.

L-informazzjoni miġbura waqt l-intervisti se tiġi ttrattata b'kunfidenzjalità u ismek mhux se jidher fuq it-traskrizzjonijiet tal-intervisti; minflok se jintuża psewdonimu. Il-kwotazzjonijiet tal-parteċipanti użati fil-kitba tat-teżi jew fil-preżentazzjonijiet, biex ikun hemm ċarezza fir-riżultati, se jintużaw b'psewdonimu, sabiex ma jiżvelawx l-identità tiegħek. Jekk int, il-parteċipant, jew jien stess, ir-riċerkatriċi, f'xi punt jew meta terġa' tara l-informazzjoni, insiru nafu li nies oħra jistgħu jidentifikawk minkejja l-fatt li qed jintuża psewdonimu, din l-informazzjoni se tittieħed qabel ma jiġi sottomess l-istudju biex tkun analizzata, diskussa u mmodifikata jew eliminata sakemm int tkun komdu bir-riżultat finali. Jekk tagħti l-permess tiegħek, l-intervista se tiġi rrekordjata fil-format awdjo peress li dan jgħin biex toħroġ traskrizzjoni aktar preċiża tal-perċezzjonijiet tiegħek. Jekk le, minflok jittieħdu n-noti. Fil-Formola tal-Kunsens, int tintalab timmarka l-kaxxa adattata li tindika jekk taċċettax li l-intervista tiġi rrekordjata fil-format awdjo jew le. Informazzjoni personali se tkun psewdonimizzata, u se tinżamm b'mod sigur u se tinżamm separat mid-data attwali. L-informazzjoni miġbura mill-intervista se tinżamm kunfidenzjali u se tintuża biss għall-iskop ta' dan l-istudju. L-informazzjoni se tingħata kodiċi biex ikun żgurat li l-informazzjoni personali ma tkunx identifikabbli u tinżamm l-anonimità. Ir-riċerkatriċi, is-superviżur tagħha,

l-eżaminaturi u r-reviżuri se jkunu l-uniċi nies li jkollhom aċċess għaliha. L-informazzjoni kollha miġbura se tinqered sa Diċembru 2023.

Il-parteċipazzjoni tiegħek f'dan l-istudju tkun għalkollox volontarja; fi kliem ieħor, inti liberu/a li taċċetta jew tirrifjuta li tieħu sehem, mingħajr ma tagħti raġuni. Inti wkoll liberu/a li twaqqaf il-parteċipazzjoni tiegħek fl-istudju meta tixtieq, mingħajr ma jkollok tagħti spjegazzjoni u mingħajr ebda riperkussjoni. Jekk tagħżel li tirtira mir-riċerka, l-informazzjoni li tkun laħqet ittieħdet fl-intervista miegħek titħassar dment li dan ikun teknikament possibbli (ngħidu aħna, qabel ma tiġi anonimizzata jew ippubblikata), u sakemm l-għanijiet tar-riċerka jkunu jistgħu jintlaħqu u ma jintlaqtux serjament. Huwa importanti li tinnota li inti tista' tirtira mill-istudju sa ġimagħtejn wara li jsiru l-intervista u t-traskrizzjonijiet. Jekk tagħżel li tipparteċipa, jekk jogħġbok innota li m'hemm l-ebda benefiċċju dirett għalik u ma fiha l-ebda riskju magħruf jew mistenni. Għandek id-dritt li taċċessa, tikkoreġi u fejn hu applikabbli, titlob li l-informazzjoni li tikkonċernak titħassar skont ir-Regolament Ġenerali dwar il-Protezzjoni tad-Data (GDPR).

Qed ngħaddilek kopja ta' din l-ittra biex iżżommha bħala referenza.

Ikun apprezzat ħafna jekk tikkunsidra li tipparteċipa f'dan l-istudju. Grazzi għall-ħin u l-kunsiderazzjoni tiegħek. Jekk għandek xi mistoqsijiet jew tħassib, jekk jogħġbok, tiddejjaqx tikkuntattjani.

Tislijiet,

Riċerkatriċi: .....
Francesca Urry
[redacted]

Superviżur: .....
Dr Maria Aurora Fenech
[redacted]

APPENDIX 5A
CONSENT FORM

Participant Identification Code: _____

Consent Form

Title of Project: Informal caregivers' perspectives on the role of the environment on older persons living with dementia within a long-term care facility

I, the undersigned, give my consent to take part in the study conducted by Francesca Urry. This consent form specifies the terms of my participation in this research study.

(1) I confirm that the purpose and details of this study have been explained to me and any questions I had were answered.

(2) I understand that I am free to accept to participate, or to refuse or stop participation at any time without giving any reason and without any penalty.

(3) I understand that I have been invited to participate in an interview that will last approximately one hour in which the researcher will ask questions regarding the role of the environment on older persons living with dementia in a long-term care facility. I am aware that my participation in this study will contribute towards improving dementia care in long-term care facilities. I understand that the interview will be conducted in a place and at a time that is convenient for me in either the English or Maltese languages.

(4) I understand that my participation does not entail any benefits or risks for me.

(5) I understand that the interview will be transcribed verbatim. I understand that I can refuse audio recording and the researcher will take notes instead during the interview.

(6) I understand that my personal details will be pseudonymised, stored securely and kept separate from the actual data. I understand that certain quotes from the interview might be used with a pseudonym, during the write up of the project or in future presentations. Together with the researcher, only the supervisor will have the right to access this information and in some exceptional circumstances the examiners as well.

(7) I confirm that I have the right to not answer questions which may cause discomfort. I have the right to visit the transcribed interview material. I also understand that I can withdraw from the study until 2 weeks after the interview and transcriptions have been carried out and re-visited by myself. If at any point on re-visiting the data, the researcher or myself note that my identity will be revealed in spite of the fact that a pseudonym is being used, the data regarding this issue will be brought up, further analysed, discussed and modified or eliminated altogether until I am comfortable with the final outcome, prior to the submission of the study, as per the General Data Protection Regulation (GDPR) and national legislation. I understand that should I choose to withdraw, any data collected from the interview would be deleted right away if this is technically possible, unless erasure of data would render impossible or seriously impair achievement of the research objectives. I understand that all data collected will be destroyed on completion of the study, which is by December 2023.

(8) I was given a copy of the Information Sheet for my safekeeping and I understand that I will also be give a copy of the Consent Sheet.

With regards to my consent regarding audio recording of the interview:

- ☐ I agree to the interview being audio recorded.
- ☐ I do not agree to the interview being audio recorded.

I have read and understood the above statements and agree to participate in this study.

Name of participant: .....
Signature: .....
Date: .....

Researcher: .....
Francesca Urry
[redacted]

Supervisor: .....
Dr. Maria Aurora Fenech
[redacted]

APPENDIX 5B

FORMULA TA' KUNSENS

Kodiċi ta' Identifikazzjoni tal-Parteċipant: _____

Formola tal-Kunsens

Titlu tal-Proġett: Informal caregivers' perspectives on the role of the environment on older persons living with dementia within a long-term care facility

Jiena, hawn taħt iffirmat/a, nagħti l-kunsens tiegħi li nieħu sehem fl-istudju ta' Francesca Urry. Din il-formola tal-kunsens tispjega t-termini tas-sehem tiegħi f'din ir-riċerka.

(1) Nikkonferma li l-iskop u d-dettalji ta' dan l-istudju ġew spjegati lili u kull mistoqsija li kelli ġiet imwieġba.

(2) Nifhem li jiena liberu/a li naċċetta li nieħu sehem, jew li nirrifjuta, jew li nwaqqaf il-parteċipazzjoni tiegħi meta nixtieq mingħajr ma nagħti spjegazzjoni jew mingħajr ma niġi penalizzat/a.

(3) Nifhem li ġejt mistieden/mistiedna nipparteċipa fl-intervista li se ddum madwar siegħa fejn ir-riċerkatriċi se tistaqsi mistoqsijiet dwar l-irwol tal-ambjent għall-anzjani li jgħixu bid-dimensja f'dar tal-kura għall-anzjani. Nifhem li l-parteċipazzjoni tiegħi f'dan l-istudju se tikkontribwixxi lejn it-titjib tal-kura tad-dimensja f'dar tal-kura għall-anzjani. Nifhem li l-intervista se ssir f'post u f'ħin li huma komdi għalija, bl-Ingliż jew bil-Malti.

(4) Nifhem li l-parteċipazzjoni tiegħi ma fiha l-ebda benefiċċju jew riskju għalija.

(5) Nifhem li l-intervista se tkun traskritta verbatim. Nifhem li nista' nirrifjuta rrekordjar fil-format awdjo, u f'dal-każ, ir-riċerkatriċi tieħu n-noti minflok waqt l-intervista.

(6) Nifhem li d-dettalji personali tiegħi se jkunu psewdonimizzata, se jinżammu b'mod sigur u se jinżammu separati mid-data attwali. Nifhem li ċerti kwotazzjonijiet mill-intervista jistgħu jintużaw b'psewdonimu, waqt il-kitba tal-proġett jew fi preżentazzjonijiet futuri. Flimkien mar-riċerkatriċi, is-supervizur biss se jkollha d-dritt li taċċessa din l-informazzjoni u f'ċerti ċirkostanzi eċċezzjonali, l-eżaminaturi wkoll.

(7) Nikkonferma li għandi d-dritt li ma nwiġibx mistoqsijiet li jistgħu jikkawżaw skumditá. Għandi d-dritt li nara l-materjal tal-intervista traskritt. Nifhem ukoll li nista' nirtira mill-istudju sa ġimagħtejn wara li l-intervista u t-traskrizzjonijiet ikunu saru, u wara li nkun rajthom jiena stess. Jekk fi kwalunkwe punt meta nara d-data mill-ġdid, ir-riċerkatriċi jew jien ninnotaw li l-identità tiegħi se tiġi żvelata minkejja l-fatt li qed jintuża psewdonimu, id-data dwar din il-kwistjoni tittieħed, tiġi analizzata, diskussa u modifikata aktar jew eliminata għalkollox sakemm inkun komdu bir-riżultat finali, qabel is-sottomissjoni tal-istudju, skont ir-Regolament Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-liġi nazzjonali. Nifhem li jekk nagħżel li nirtira mill-istudju, kwalunkwe data miġbura mill-intervista titħassar minnufih jekk dan ikun teknikament possibbli, sakemm it-tħassir tad-data ma jirrendix impossibbli jew ifixkel serjament il-kisba tal-għanijiet tar-riċerka. Nifhem li d-data kollha miġbura se tinqered mat-tlestija tal-istudju, li huwa sa Diċembru 2023.

(8) Ingħatajt kopja tal-Ittra ta' Tagħrif sabiex inżommha u nifhem li se ningħata wkoll kopja tal-Formola tal-Kunsens.

Fir-rigward tal-kunsens tiegħi dwar irrekordjar fil-format awdjo tal-intervista:

- ☐ Naqbel li l-intervista tiġi rrekordjata fil-format awdjo
- ☐ Ma naqbilx li l-intervista tiġi rrekordjata fil-format awdjo

Qrajt u fhimt l-istqarrijiet t'hawn fuq, u naqbel li nipparteċipa f'dan l-istudju.

Isem il-parteċipant/a: ……..
Firma: ……..
Data: ……..

Riċerkatriċi: …….
Francesca Urry
[redacted]

Superviżur: …….
Dr Maria Aurora Fenech
[redacted]

APPENDIX 6A
INTERVIEW SCHEDULE

Participant Identification Code: _____

Interview Schedule

A) Profile Characteristics

1) Age: .....
2) Gender: Male ..... Female ..... Other .....
3) Relation to the older person living with dementia: .....
4) Frequency of visitation: .....

B) Interview Schedule for the participant

Interview Questions: 1-15

Opening Questions

1) Approximately, how long has it been since your relative's diagnosis of dementia?
2) Approximately, how long have they been in a long-term care facility?
3) What was the reason for admission?
4) Has your relative ever been relocated from one facility to another?
   a. If so, why?
5) Had you had any say in the choice of long-term care facility?
6) Can you please describe your experience of how the environment affects your relative?

To probe more information relating to the physical environment, the following questions may also be asked:

7) What do you think are the most important factors of the physical environment? (Probe if more information is needed e.g.: Basic design features, environmental attributes, ambience)
8) How does the physical environment affect the behaviour and well-being of your relative?

To probe more information relating to the social environment, the following questions may also be asked:

9) What do you think are the most important factors of the social environment? (Probe if more information is needed: e.g.: Social interaction, living experience, meaningful activities, dining experience, bedroom experience)
10) How does the social environment affect the behaviour and well-being of your relative?
11) What do you think regarding the provision of care by the health care staff?

Current environment

12) In your opinion, what are the needs of an older person living with dementia?
13) Do you think the current environment meets their needs?
14) What changes would you like to see to improve the environment?
15) What would be the ideal environment for an older person living with dementia?

Concluding question

16) Is there anything about environmental factors affecting older persons living with dementia that has been left out in this interview?

Probes

The following are examples of other probes which will be used:

"What do you mean?" / "Would you like to clarify on that?" / "Can you give examples?" / "Would you like to explain further on this/that?"

APPENDIX 6B

SKEDA TAL-INTERVISTA

Kodiċi ta' Identifikazzjoni tal-Parteċipant: _____

Skeda tal-intervista

A) Profil tal-Parteċipant

1) Età: .....
2) Sess: Raġel ..... Mara ..... Ieħor .....
3) Relazzjoni mal-anzjan/a li jgħix/tgħix bid-dimensja:.....
4) Frekwenza ta' viżti: .....

B) Skeda tal-Intervista għall-Parteċipant

Mistoqsijiet tal-Intervista: 1-15

Mistoqsijiet introduttorji

1) Bejn wieħed u ieħor, kemm ilha li saret id-dijanjosi tad-dimensja tal-qarib/a tiegħek?
2) Bejn wieħed u ieħor, kemm ilha din il-persuna f`dar tal-kura għall-anzjani?
3) X'kienet ir-raġuni għaliex il-persuna marret toqgħod f`din id-dar?
4) Il-qarib/a tiegħek qatt ġie rilokat jew ġiet rilokata minn faċilità għal oħra?
   a. Jekk iva, għaliex?
5) Kellek xi sehem fl-għażla tad-dar tal-kura għall-anzjani?
6) Tista' tiddeskrivi l-esperjenza dwar kif l-ambjent tad-dar tal-kura għall-anzjani jaffettwa l-qarib/a tiegħek?

Sabiex tinkiseb aktar informazzjoni relatata mal-ambjent fiżiku, jistgħu jsiru l-mistoqsijiet li ġejjin ukoll:

7) X'taħseb li huma l-aktar fatturi importanti tal-ambjent fiżiku? (Sabiex tinkiseb aktar informazzjoni eż.: karatteristiċi bażiċi tad-disinn, attributi ambjentali, atmosfera)
8) L-ambjent fiżiku kif jaffettwa l-imġiba u l-benessri tal-qarib/a tiegħek?

Sabiex tinkiseb aktar informazzjoni relatata mal-ambjent soċjali, jistgħu jsiru l-mistoqsijiet li ġejjin ukoll:

9) X'taħseb li huma l-aktar fatturi importanti tal-ambjent soċjali? (Sabiex tinkiseb aktar informazzjoni eż.: interazzjoni soċjali, esperjenza ta' għajxien, attivitajiet sinifikanti, esperjenza tal-ikel, esperjenza tas-sodda)
10) L-ambjent soċjali kif jaffettwa l-imġiba u l-benessri tal-qarib/a tiegħek?
11) X'taħseb dwar l-għoti ta' kura mill-persunal tal-kura tas-saħħa?

Ambjent attwali

12) Fl-opinjoni tiegħek, x'inhuma l-bżonnijiet ta' persuna anzjan/a li tgħix bid-dimensja?
13) Taħseb li l-ambjent attwali jissodisfa l-bżonnijiet tal-persuna?
14) Liema bidliet tixtieq tara biex jitjieb l-ambjent?
15) Liema jkun l-ambjent ideali għall-anzjan/a li jgħix jew tgħix bid-dimensja?

Għeluq

16) Hemm xi ħaġa dwar fatturi ambjentali li jaffettwaw lil anzjani li jgħixu bid-dimensja li tħalliet barra f'din l-intervista?

Mistoqsijiet

Eżempji ta' mistoqsijiet oħra li jistgħu jsiru jekk hemm bżonn ta' aktar tagħrif fuq suġġett partikolari:

"Xi trid tfisser?" / "Tixtieq tiċċara dak li qed tgħid?" / "Tista' tagħti eżempji?" / "Tixtieq tispjega ruħek aħjar dwar dan?"

APPENDIX 7A

NOTES TAKEN BY THE RESEARCHER DURING THE INTERVIEWS

Ashley – Participant 001

Interview carried out on Tuesday 27th September at 5pm at the participant's private home. Comfortable setting sitting near each other on two separate sofas in the lounge in a relatively dark room.

Observations

-Forward leaning posture showing confidence with legs crossed

-Well-spoken and assertive in conversation

-Mentioned that she has 1 sister but did not give any more information regarding relationship or visitation/support for their mother.

Throughout the interview the participant gave detailed responses without needing too much prompting.

Tended to focus on mostly negative experiences and negative comments. Even though the participant was very composed during the interview from the way that she was talking it showed that she was upset about the situation. It could be that she was composed because she is a principal of a school and it is part of her job/requirements to be calm and collected. She is also probably used to public speaking so feels relaxed in discourse.

Tended to prioritise the social environment over the physical environment.

Bethany – Participant 002

Interview carried out on Tuesday 28th September at 9am at Serenity Manor in a private room. The participant came about half an hour late as she got stuck in traffic. She had called me from her car to start the interview over the phone but I did not agree to it so that she could read and sign the consent form prior to the interview.

Recording cut off after 2.30minutes, the following notes were taken until the recording was re-started:

Participant: *Recently even my dad is showing the onset of symptoms but he is not so bad. My mum has certain days when she is very confused. In the morning she is more alert but if the carers leave her in her room then she gets confused. It makes a difference when she goes out. I visit daily from Monday to Friday and my brother visits Saturday and Sunday. It helps because she always has someone who knows her well and a familiar face. Visiting in the evening is difficult because of sundowning so it's upsetting because mum will be very confused. She fell in May-June-July 2021, something like that.*

<u>Observations</u>

-Participant arrived flustered and explained that is very out of character for her to be late and apologised many times.

-We sat opposite each other with a table separating us.

-Forward leaning posture showing confidence.

-Well-spoken and talks fast in conversation.

-Long answers and mostly positive comments.

Mentioned taking her daughter to hospital as if it is a regular occurrence – could participant be the primary caregiver to two generations (children + parents?)

-Very caring from the way she speaks

-Good family relationship with parents and brother. Good family support as all members visit regularly.

Christina – Participant 003

Interview carried out on Tuesday 28th September at 10.30am in participant's private work office. Sitting opposite each other across a table. Minimal background noise of children running around and playing.

Participant explained that she had to leave work for a while prior to her parents' admission into the home but it was not practical.

The participant required quite a bit of probing throughout the interview. Tended to give short answers and needed probes to elaborate and explain further. Participant did not continue conversation much herself and the interviewer had to initiate discourse.

Observations

-Non-verbal behaviour throughout interview included sighs, pauses, stutters, tongue clicks (disapproval), deep breaths indicating a difficult conversation to have.

Posture: Hands crossed, leaning away

-Facial expression and tone of voice throughout the interview was upset and subdued

-Box of tissues present on the table in front of participant

-Cared a lot about her mother and was upset about what happened to her, mentioned many times that she is upset with the provision of care at the home and her mother's dementia

-It was an emotional conversation for the participant to have so the interviewer offered reassurance throughout

-She had to think a lot about the answers (many pauses and unfinished sentences)

-She needed further explanation of the questions.

-Good family relationship with parents and brother. Good family support as all members visit regularly.

Note: participant has fibromyalgia and her husband has cancer and her mother has dementia which is a lot to deal with.

Danielle – Participant 004

Interview carried out on Friday 21st October at 9am at Serenity Manor in a private room. We sat opposite each other with a table separating us.

She is also a resident at Serenity Manor and was admitted there primarily for assistance in in caring for a young person with special needs (she is not her mother) as she was the main caregiver. In addition to this she was also the main caregiver of an OPLWD residing at the facility as well, who she spent a lot of time with (relation: cousin).

Observations

-Relaxed posture, ready for the interview, very willing to talk

-Very complimenting towards her cousins wife with regards to her love for him, her cooking, her character, her visiting the home.

-Easy flowing conversation during the interview, no pauses however very often tended to drift off and lose track of the scope of the discussion, starts talking about other things which are not of value. Her response did not always answer the questions, she needed probing throughout the interview to get answers that were relevant to the topic. Following reflection of the interview it was noted that a large amount of the script was actually relevant to the research questions, from a different perspective: of a person actually residing within the facility and knowing what goes on day-to-day.

Esme – Participant 005

Interview carried out on Friday 21st October at 10:30am at Serenity Manor in a private room. We sat opposite each other with a table separating us.

The participant indicated that her mother had early onset of symptoms at 33 so she always knew her mother like that. Negative and rude comments from the participant's aunts regarding her mother "like a tape recorder" (enforcing negative beliefs and stereotypes). Participant was 10 years old when she started hearing these comments so they could have shaped her belief of dementia in a negative way.

While her mother was living in the community she was living with participant's brother (he had P.O.A) who did not used to take care of her well (element of abuse and neglect). She claimed that she felt helpless and burnt out and ended up opening up to a nurse about the situation once her mother was admitted to MDH. She indicated that there were family issues and that there were problems between the siblings that required a social worker getting involved.

<u>Observations</u>

-Non-verbal behaviour throughout interview included sighs, pauses, stutters, tongue clicks (disapproval), deep breaths indicating a difficult conversation to have.

-From the beginning, participant indicated that the whole process of taking care of her mother and admitting her into a home was not easy.

-Prioritised the involvement of family

-Had a good understanding of dementia and what an individual needs

Faith – Participant 006

Interview carried out on Friday 21st October at 12pm in participant's private work office. We sat next to each other on two chairs side to side in a relaxed environment.

Participant expressed that she wanted to carry out the interview in order to help provide information about improvements to be made for OPsLWD and to increase the awareness so it's not so much of a taboo. Possibly eager to participate in research since she works in the academic field.

Observations

-Fluent conversation throughout, assertive and confident when speaking (profession: teacher).

-Showed quite a good and reasonable understanding of dementia.

-She was well prepared as she offered a lot of solutions and practical examples.

-Occasional pauses throughout the interview indicating embarrassment regarding BPSD (Ex: portrayal of hallucinations)

-Short laughing bursts with light conversation

-Participant expressed that she wanted to carry out the interview

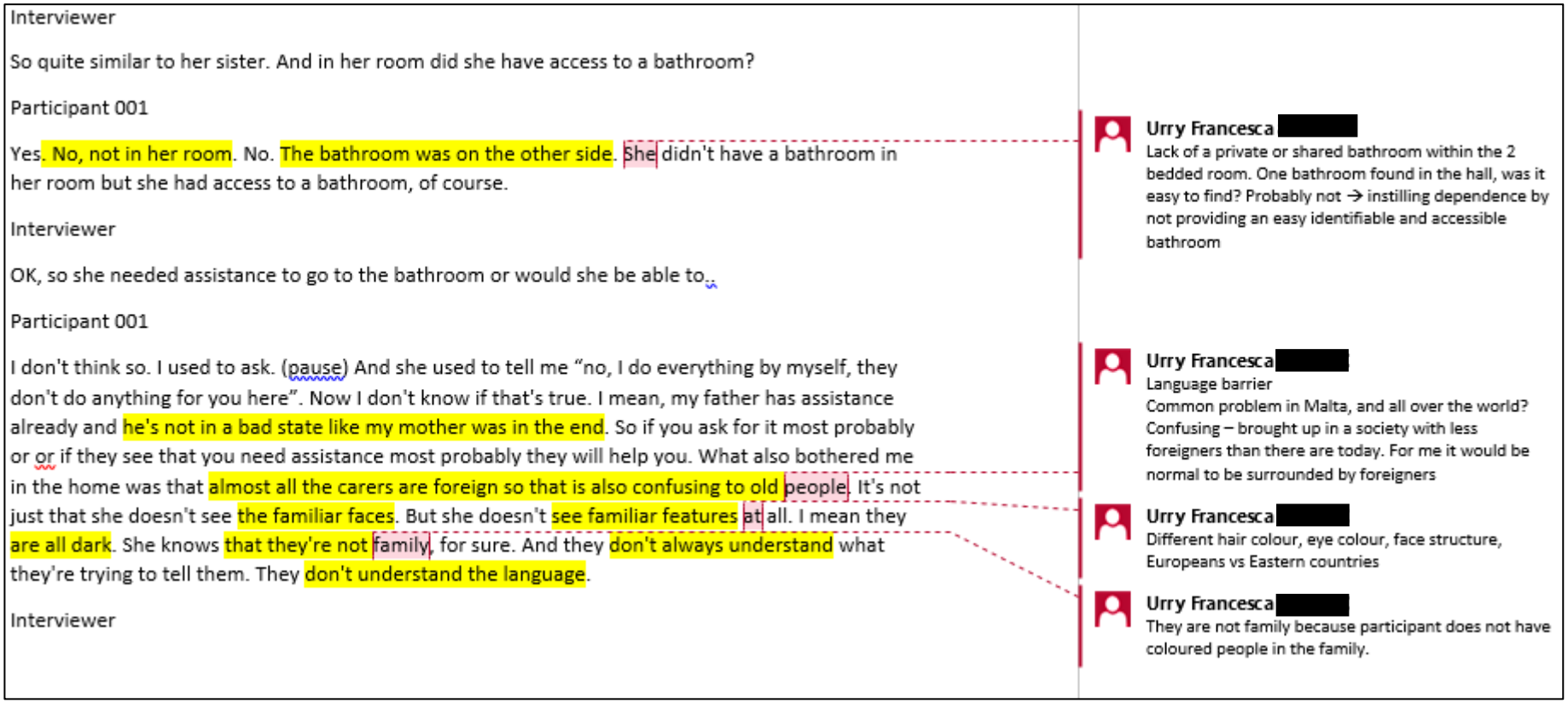
-Very diplomatic when speaking

-Prioritised using the environment in a positive way to provide cognitive stimulation and promote active ageing rather than just waiting to die (felt very strongly about this ++)

APPENDIX 7B

SAMPLE OF THE RESEARCHER'S REFLECTIVE JOURNAL

1. Sample of preliminary notes taken during phase one of data analysis



2. Sample of reflections on the above transcription extract

My first thought regarding this transcript was that the facility did not have private bathrooms for older persons to use. Bathrooms are intimate places and should be comfortable and safe for users. I think it is important that individuals can put their personal belongings since it is part of their home. Bathrooms should also be accessible and encourage older persons to perform some tasks by themselves. The fact that the participant mentioned that her mother did not have her own private bathroom indicated that a part of her independence, privacy, and control was taken away from her. My viewpoint comes from my perspective as a physiotherapist who tries to encourage functionality in day to day activities. In my opinion, the lack of private bathrooms is a hindrance for OPsLWD within LTC facilities. On the other hand, private bathrooms, if not equipped properly, can be associated with risk of falls due to safety issues such as unsupervised showering.

In Malta, some people show negative attitudes towards foreigners. Older persons, especially, tend to have mind-set barriers regarding foreigners. It could be that throughout their life they were surrounded by local people and are now hesitant to change. Older persons express that they feel uneasy communicating with foreign staff in English as opposed to Maltese. This created communication barriers and has negative consequences especially for OPsLWD. If carers have a basic level of Maltese, this would create a better level of trust with the older person and improve their relationship and in turn would facilitate care. There is a large amount of foreign carers in Malta so policies need to be implemented in order to tackle communication difficulties to enhance care provision.

With regards to the participant's mention of "unfamiliar features", I think that with time that mentality/mind-set/issue will decrease substantially due to the younger generations being brought up with more diversity and awareness regarding stereotypes. It is important that education and awareness is available to all the population to diminish stereotypes about immigrants.

3. Sample of reflections regarding theme generation and organisation

Braun and Clarke (2012, p. 65) proposed a series of key questions that the researcher should address when reviewing potential themes:

• Is this a theme (it could be just a code)?

• If it is a theme, what is the quality of this theme (does it tell me something useful about the data set and my research question)?

• What are the boundaries of this theme (what does it include and exclude)?

• Are there enough (meaningful) data to support this theme (is the theme thin or thick)?

• Are the data too diverse and wide ranging (does the theme lack coherence)?

These questions guided my analysis process.

For the majority of the analysis process, family involvement was considered a major theme in this study. As a healthcare professional providing physiotherapy services in long-term care (LTC) facilities, very often care plans require the involvement of family members. So naturally, I was inclined to keeping this as a main theme.

Family involvement had the following initial sub-themes: relationship with family, family visitations, and dementia care. I realised that a large amount of the codes under this theme were related to informal caregiver knowledge and support in view of the challenges associated with dementia. I reflected on my research questions and realised that, although important, this information was lacking relativity. Therefore, the theme family involvement was changed into a sub-theme and renamed to supportive relationships after organising the codes under it to include: the significance of family members and their relationships.

The sub-theme supportive relationships then included (a) family, and (b) staff. However, this was later changed to connection with family under the theme social engagement as it was too wide ranging. The aspect of staff was then included under the theme supportive healthcare practices as it provided more useful information on that topic.

APPENDIX 7C

SAMPLE OF THE RESEARCHER'S AUDIT TRAIL

1. Sample of audit trail illustrating the development of data items to sub-themes

Individual quotes	**Initial notes**	**Initial codes**	**Final codes**	**Sub-themes**
"She was never a moaner or a complainer. She was a strong woman and kept things inside. So I think even in this state she's a fighter. It's because I am near her for a considerable amount of time and I see that she opens up. It's when she doesn't open up that I realise something is not right." (Christina)	Voice breaks while she is speaking indicating an element of sadness regarding her mother's condition. Knowing a person's character can help with detecting health issues	Knowing a person facilitates provision of care	Familiarity of residents facilitates provision of care	Quality of care
"Sometimes the carers don't realise or don't check that she needs a nappy change and my mum would feel very uncomfortable and it affects the confusion." (Bethany)	Older persons still have the right to dignity even though some people do not believe that. Participant got quite upset which indicates that it seems to be a recurring issue.	Lack of attention to staff with regards to maintaining a person's dignity	Dignity in the care of older persons	Quality of care

"The best way would be somebody giving them attention, doing activities and not senseless ones… There's a little garden, they [staff] don't take them for walks or just push them in the wheelchair, I'm sure they don't have enough staff". (Faith)	Lack of physical and social activities attributed to lack of human resources. Staff portrayed a negative mind set about physical activity and did not encourage it.	Daily physical activity needs to be encouraged and incorporated into their care plan	The importance of daily physical activity	Sensory Stimulation and Meaningful Activities
"It's not the ideal though inside. It could have been more homely. It's very bare like a clinic or hospital. It could have better furniture. Even the corridor is institutional." (Faith)	Participant feels very strongly about her disapproval re residents lined up in the corridor with no stimulation. The place needs to be livened up and feel more homey.	The physical environment of the LTC facility should be home-like	The physical design should be home-like in character	Home-like character and atmosphere

2. Sample excerpt of code changes

Health and Safety	
Initial code	Iteration 2
Safety is an important factor of the environment Stairs as a hazard for OPsLWD (4)	The environment needs to be safe (5)
The bathroom needs to be safe and accessible (2) Accessibility of a bathroom An inappropriate bathroom layout can be hazardous	The bathroom needs to be accessible and safe (4)
The outdoor space needs to be renovated due to safety issues (6)	There are safety issues with the outdoor area (6)
Health and safety issues need to be addressed within the LTC facility not just the dementia unit Health and safety issues need to be addressed within the LTC facility Health and safety measures need to be implemented within the LTC facility (2)	Health and safety measures need to be implemented to address current issues (4)
Facilities and equipment should be kept up to standard to ensure health and safety measures (5)	Facilities and equipment should be kept up to standard (5)
Lack of safety and security regarding personal belongings Missing personal belongings Care should be taken to ensure security of personal belongings especially for people with cognitive impairment Lack of privacy and security of belongings in three bedded rooms Feelings of lack of safety, privacy and security	Lack of security regarding personal belongings (5)

APPENDIX 8A

APPROVAL BY THE DIRECTOR AND ASSISTANT DIRECTOR OF ACTIVE AGEING AND COMMUNITY CARE (AACC)

L-Università ta' Malta

Francesca Alden [redacted]

Request for permission to conduct research

5 messages

Francesca Urry [redacted] 28 May 2022 at 15:30

To [redacted]

Cc: Maria Aurora Fenech [redacted]

Dear [redacted]

My name is Francesca Urry and I am a student at the University of Malta, currently reading for a Master in Gerontology and Geriatrics. I am conducting a research study for my dissertation titled *Informal caregivers' perspectives on the role of the environment on older persons living with dementia within a long-term care facility*. This project is being conducted under the supervision of Dr. Maria Aurora Fenech, from the Department of Gerontology and Dementia Studies, Faculty for Social Wellbeing, University of Malta.

The aim of this study is to explore caregivers' perceptions of the effect the environment has on older persons living with dementia (OPLWD) in a long-term care (LTC) facility. This study will help contribute to a better understanding of how the physical and social environment may influence the management of behavioural and psychological symptoms of dementia and as a result improve their quality of life. Consequently, the results are intended to help improve dementia care in LTC facilities.

I have drawn a Public Private Partnership LTC facility by lot and I am hereby seeking your permission, as the Active Ageing and Community Care CEO, to carry out my study in [redacted] I am keeping [redacted] Chief Operating Officer, at CareMalta, in copy in this correspondence. Permission will also be sought from [redacted] and if permitted the facility manager will be invited to act as the gatekeeper for this project, and forward the Information Sheet to informal caregivers fitting the eligibility criteria: (a) informal caregiver of an OPLWD and (b) the OPLWD is required to have been a resident in the LTC facility for more than 6 months. There will be no restrictions for participation in this study with regards to gender, age, education, or socio-economic status. My data collection methods will involve one hour semi-structured face-to-face interviews with informal caregivers at a time and place convenient for the participant. The first 6 to 8 participants who contact me would partake in this research project.

Participation will be entirely voluntary and participants will be free to withdraw at any point, without any repercussions. Data collected from the interview will be kept strictly confidential and will only be used for the purpose of this study. Data will be given a code to ensure that all personal information is non-identifiable and anonymity is maintained. The researcher, her supervisor, examiners and reviewers will be the only people who will have access to it. All data collected will be destroyed on completion of the study which is by December 2023.

Should you require further information, please do not hesitate to contact me via email on [redacted] or by telephone on [redacted], or my supervisor via email on [redacted] or by telephone on [redacted].

Thank you for your kind consideration of this request. Kindly note that your endorsement to this request will be submitted to the Faculty's research and ethics committee and you will be forwarded the official ethical clearance granted by the Faculty prior to initiating the fieldwork.

Kind regards,

Francesca

[redacted] 29 May 2022 at 09:04
To: Francesca Urry [redacted]
Cc: Maria Aurora Fenech [redacted]

Dear Ms Urry

No objection from my end. Copying [redacted] regards other requirements.

Regards

[redacted]
Chief Executive Officer
Head Office
Active Ageing and Community Care

[redacted]
www.gov.mt | www.publicservice.gov.mt | fb.com/servizzpubbliku

Kindly consider your environmental responsibility before printing this e-mail

MINISTRY FOR SENIOR CITIZENS
AND ACTIVE AGEING

FXB BUILDING, 346, TRIQ L- IMDINA,
QORMI, MALTA

C[redacted] 30 May 2022 at 09:14
To: Francesca Urry <[redacted]
Cc: [redacted], Maria Aurora Fenech <[redacted]

Dear Ms Urry

Further to [redacted] consent, you are being requested to apply the necessary safeguards as a condition for carrying out this research, namely:

a. The personal data accessed or given are only to be used for that specific purpose to conduct the research and for no other purpose;

b. At the end of the research, all personal data should be destroyed;

c. All references to personal data should be omitted in the report unless consent is specifically obtained from the person being identified in the research report;

d. Participation by the elderly in the research being conducted should be at their discretion, and they can refuse any participation whatsoever if they so wish; and

e. This office is to be provided with a copy of the research report.

This approval is only valid upon approval from the Faculty Research Ethics Committee, a copy of which should be forwarded to this office.

I wish you success in your studies.

Regards

[redacted]
Assistant Director
Residential Care
Active Ageing and Community Care

[redacted]
www.gov.mt | www.publicservice.gov.mt | fb.com/servizzpubbliku

[Quoted text hidden]

MINISTRY FOR SENIOR CITIZENS
AND ACTIVE AGEING

FXB BUILDING, 346, TRIQ L- IMDINA,
QORMI, MALTA

Francesca Urry [redacted] 30 May 2022 at 12:34
To: [redacted]
Cc: [redacted] Maria Aurora Fenech [redacted]

Dear [redacted],

Thank you for your quick response and for your endorsement.

May I take this opportunity to re-assure you that all the necessary safeguards listed in your email (points a - e) to ensure professionality and confidentiality in this study will be maintained.

I would just like to clarify on the following points with respect to your email:

b. For this part, all data collected will be destroyed on completion of the study by December 2023.

c. Data collected during the interviews will be treated with confidentiality and participants' names will not appear on the interview transcripts; a pseudonym will be used instead. Please note that participant quotes used in the writing of the dissertation or in presentations, to enable clarity in the results, will be used with a pseudonym so as not to reveal participant's true identity. Should the participants or myself, the researcher, at any point or on revisiting the data become aware that other people might identify them in spite of the fact that a pseudonym is being used, this data will be brought up prior to submitting the study, be further analysed, discussed and modified or eliminated until the participants are comfortable with final outcome. Personal information will not be revealed in any publications and will be stored securely. All this will be explained in the Information Letter and handed to the participant. If they consent to participating in the study they will sign the Consent Form.

d. As per my initial email, the research study does not involve older persons living with dementia. I plan to interview the relatives/ informal caregivers of older persons living with dementia and residing with the long-term care facility.

Thank you once again for your time and consideration.

Kind regards,

Francesca

[Quoted text hidden]

Francesca Urry [redacted] 30 May 2022 at 12:41
To: [redacted]
Cc: Maria Aurora Fenech [redacted]

Dear [redacted]

Thank you very much for your endorsement, it is much appreciated.

I have copied you in the trail of emails with Ms. Cauchi.

Kind regards,

Francesca

APPENDIX 8B

APPROVAL BY GATE KEEPER AND CHIEF OPERATING OFFICER OF THE DRAWN LONG-TERM CARE FACILITY

L-Università ta' Malta

Francesca Alden <francesca.urry.12@um.edu.mt>

Request for permission to conduct research

Francesca Urry <[redacted]> 28 May 2022 at 15:51
To: [redacted]
Cc: Maria Aurora Fenech [redacted]

Dear [redacted]

My name is Francesca Urry and I am a student at the University of Malta, currently reading for a Master in Gerontology and Geriatrics. I am conducting a research study for my dissertation titled *Informal caregivers' perspectives on the role of the environment on older persons living with dementia within a long-term care facility*. This project is being conducted under the supervision of Dr. Maria Aurora Fenech, from the Department of Gerontology and Dementia Studies, Faculty for Social Wellbeing, University of Malta.

The aim of this study is to explore caregivers' perceptions of the effect the environment has on older persons living with dementia (OPLWD) in a long-term care (LTC) facility. This study will help contribute to a better understanding of how the physical and social environment may influence the management of behavioural and psychological symptoms of dementia and as a result improve their quality of life. Consequently, the results are intended to help improve dementia care in long term care facilities.

As per earlier correspondence wherein you were copied, kindly note that [redacted] was drawn by lot to take part within my project. I am hereby seeking your permission, as the Chief Operating Officer at [redacted] to carry out my study within [redacted] If you consent to the project then I will be inviting the facility manager to act as the gatekeeper for this study and forward the Information Sheet to informal caregivers fitting the eligibility criteria: (a) informal caregiver of an OPLWD and (b) the OPLWD is required to have been a resident in the LTC facility for more than 6 months. There will be no restrictions for participation in this study with regards to gender, age, education, or socio-economic status. My data collection methods will involve one hour semi-structured face-to-face interviews with informal caregivers at a time and place convenient for the participant. The first 6 to 8 participants who contact me would partake in this research project.

Participation will be entirely voluntary and participants will be free to withdraw at any point, without any repercussions. Data collected from the interview will be kept strictly confidential and will only be used for the purpose of this study. Data will be given a code to ensure that all personal information is non-identifiable and anonymity is maintained. The researcher, her supervisor, examiners and reviewers will be the only people who will have access to it. All data collected will be destroyed on completion of the study which is by December 2023.

Should you require further information, please do not hesitate to contact me via email on [redacted] or by telephone on [redacted] or my supervisor via email on [redacted] or by telephone on [redacted]

Thank you for your kind consideration of this request. Kindly note that your endorsement to this request will be submitted to the Faculty's research and ethics committee and you will be forwarded the official ethical clearance granted by the Faculty prior to initiating the fieldwork.

Kind regards,

Francesca

L-Università ta' Malta

Francesca Alden <[redacted]>

Request for permission to conduct research

[redacted] 29 May 2022 at 08:06
To: Francesca Urry <[redacted]>
Cc: Maria Aurora Fenech [redacted]

Dear Franccesca,

Thank you for your mail.

[redacted] grants approval subject to FREC. Please note that [redacted] this permission is only valid if [redacted] will operate the premises.

Wish you luck. Once research is completed, we apricate if the findings are shared.

Sincerely,
[redacted]

L-Università ta' Malta

Francesca Alden <[redacted]>

Request for permission to conduct research

Francesca Urry <[redacted]> 30 May 2022 at 12:39
To: [redacted]
Cc: Maria Aurora Fenech <[redacted]>

Dear [redacted]

Thank you very much for your endorsement and for the information provided.

I would be more than happy to share the findings.

Kind regards,

Francesca

L-Università ta' Malta

Francesca Alden <[redacted]>

Research Ethics Application - Approved by FREC, no UREC decision needed

Francesca Urry <[redacted]> 5 August 2022 at 22:05
To: [redacted]
Cc: Maria Aurora Fenech <[redacted]>

Dear [redacted]

Per my last email, please find the approved FREC ethical clearance in the email below.

Kind regards,

Francesca

L-Università ta' Malta

Francesca Alden <[redacted]>

Research Ethics Application - Approved by FREC, no UREC decision needed

[redacted] 6 August 2022 at 08:27
To: Francesca Urry <[redacted]>
Cc: Maria Aurora Fenech <[redacted]>

All noted and confirmed.

Good luck Francesca. It would be appriciated if the findings are shared for better practice.

[redacted]

APPENDIX 8C

APPROVAL BY FACULTY RESEARCH ETHICS COMMITTEE

L-Università ta' Malta

Francesca Alden <[redacted]>

Research Ethics Application - Approved by FREC, no UREC decision needed

5 messages

SWB FREC <research-ethics.fsw@um.edu.mt> 11 July 2022 at 13:29
To: [redacted]
Cc: Maria Aurora Fenech <[redacted]t>, Christian Borg Xuereb UoM <[redacted]>

REDP Application ID: SWB-2022-00341

Dear Francesca Urry,

Your ethics application regarding your research titled *Informal caregivers' perspectives on the role of the environment on older persons living with dementia within a long-term care facility* has been **approved**.

Faculty Research Ethics Committees are authorised to review and approve research ethics applications on behalf of the University of Malta, except in the case of sensitive personal data. In this regard, your ethics proposal **does not need to be sent to UREC-DP**. Hence, **you may now start your research**.

Disclaimer: *The research team should note that only the English versions of the documents submitted have been reviewed by FREC. It is the duty of the research team to ensure that all documents in Maltese (or any other language) are faithful translations of the English version.*

Regards,

L-Università ta' Malta

Faculty Research Ethics Committee

Faculty for Social Wellbeing
Room 113, Humanities A Building
+356 2340 2237
um.edu.mt/socialwellbeing/students/researchethics