Perspectives on Walking and Supportive Interventions Provided by Residential Care Staff for Residents with Dementia Who Walked: A Critical Ethnographic Study

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2025

A thesis submitted to
Auckland University of Technology
in partial fulfilment of the requirements for the degree of
Doctor of Health Science

School of Clinical Sciences

Faculty of Health and Environmental Sciences

Dedication

This thesis is dedicated to my late mother:

Mrs Florence Omolara Adetuberu

I wish you were here

I know your spirit is

Watching over us

With your Creator

I know you know about Tutu

I know you are in a better place

Thank you for all your sacrifice

Continue to rest in perfect peace

This is for you!

Abstract

Walking (commonly referred to as ‘wandering’) has been seen as problematic and stigmatised in persons living with dementia who walk. Walking is one of the increased symptoms of dementia (BPSD) as it progresses uniquely in each person. Studies indicate 15% to 60% persons with dementia will walk. In New Zealand, currently, 70,000 persons live with dementia, 78,000 persons are projected to live with it by 2026 and 170, 212 by 2050. The stigma associated with walking and dementia has been consequential, resulting in dehumanisation, a lack of respect for personhood, and social disregard as equal and social citizens. This impacts the psychological, holistic well-being and the quality of life of persons affected, with ripple effects on families. International studies reported a questionable common practice of administering antipsychotic medications to manage BPSD in residents in aged care facilities in urban and rural settings worldwide. This was widely condemned due to adverse effects of the medications. Best practice guidelines recommend non-pharmacological strategies as first-line interventions with antipsychotic medications as a last resort.

This research set out to explore how residential care staff provided relational and supportive interventions to residents living with dementia who walked. The study had five aims: to explore the perspectives of all participants on the walking of residents with dementia; to investigate the supportive interventions provided in two aged care facilities in a city in New Zealand; to explore the concept of person-centred care; to examine the impact of built environment on residents’ walking; and to contribute to the destigmatisation of the residents, advocating for a shift to using dignifying language for residents’ optimal support.

Critical ethnography with a social construction theoretical orientation was used to conduct the qualitative study. The design gives authority to participants’ voices to be heard. Social constructionism argues that no single meaning is sufficient to explain a human activity, that knowledge is constructed in every interaction using language, and that every new knowledge created as a result, needs to be acknowledged. Purposive sampling was used to recruit residents living with dementia who walked, their EPAs, RNs and HCAs. Data were collected through participant observations, in-depth interviews, and unobtrusive methods. All data were transcribed and thematically analysed. Three main themes were identified with ‘Carrying on normal life’ permeating throughout. First, ‘Perspectives on walking’ revealed residents wanted to ‘carry on normal life’. Second, ‘Supporting walking’ unfolded how staff used empathy, and relational solidarity to support residents’ walking by being proactive, reinforcing positive behaviours, and providing non-pharmacological interventions and third, ‘Environment

and walking', highlighted the importance of environment for residents' walking. With the evidence presented in these findings, I argue that it is time to provide alternative and salutogenic support for residents to carry on normal life. In addition, there is a need for a national policy that supports the walking of the residents with dementia. All stakeholders should consider this support as an ethical obligation and work collaboratively and independently to achieve person-centred care goals for the residents using humanising language that enhances the psychological health, well-being, and quality of life of the residents.

Acknowledgements

First and foremost, I thank Almighty God for making it possible to complete this thesis.

My sincere appreciation to all the Study participants: the residents with dementia who walked, the main motivation for this study; the Enduring Powers of Attorney; the residential care staff, made up of the registered nurses and the Health Care Assistants; the Clinical and Facility Managers for the consent to conduct the study at their aged residential care facilities. Without you all, this study would not have been possible.

My deepest appreciation to all my supervisors and their Advisors: Associate Professor Tula Brannelly, my primary supervisor, for her insightful advice, unwavering support, guidance, mentorship, and dedication, which helped to bring this work to successful completion; Professor Eleanor Holroyd for her insights, expertise, experience, and the roles played on this research project; Associate Professors Jed Montayre and Elissa MacDonald, and their Advisor, Professor Stephen Neville, for their guidance at the start of this research project. My thanks to my Māori Advisor on this study, Sandra McDonald, Ngati Whatua, Te Uri o Hau, for her support.

My profound appreciation to Emeritus Professor Liz Smythe, DHSc Programme Leader for her encouragement and support since enrolment in this programme to its completion. Your weekly writings have been and continue to be sources of motivation and inspiration. My sincere thanks to the DHSc teaching team, including Professor Valerie Wright-St Clair. My thanks to Associate Professor Jean Gilmour, Dr G. Allen Power, Dr Kay Shannon, Dr Nilo Atefi, Marla Burrow, Clare Teague, and Delanie Halton.

I am most grateful for the AUT Doctoral Scholarship – Faculty of Health and Environmental Sciences. My thanks also go to Faculty leadership, School of Clinical Sciences Postgraduate Research, Graduate Research School, DHSc Faculty office staff including Julie Balloch and the Library staff for the support and resources which have been beneficial to me on this research over the years.

I am deeply grateful for the CHT Aged Care Fund Grant provided by the CHT Board of Trustees, the CEO and Chair in April 2022. The grant enabled me to travel on study visit to The Hogeweyk (Dementia Village) in The Netherlands to learn about the care concepts of a model dementia village. The fund also enabled me to visit The CARE Village in Rotorua, here, in New Zealand, which was inspired by Hogeweyk's Care concepts.

My gratitude goes to Associate Professor Deborah Rowe, Head of School at MIT and Associate Head of School, Sheona Watson for the support given, approving my time off to complete this thesis. My appreciation goes to Nuddy Pillay, former MIT General Manager, Principal Lecturer Dr Louise Rummel MNZM, Senior colleague Joan MacKie and other colleagues. Thanks to my former students and those I had met at Conferences and writing retreats whose interests and stories increased my motivation on the study.

This acknowledgment will not be complete without mentioning some other key people, here and overseas, who have made this doctoral journey enjoyable, rewarding and have been great support and encouragement during a difficult and defining moment for me in life and on this research journey. Great thanks to my 'accountability study-partner', now, Dr Kathy Carter-Lee (Congratulations!), Dr Blessing Kanengoni, Dr Jane Yuanyuan Chen, Dr Reem Abbas, Preet Kamal, Chung Nguyen and her husband, Dr Khan Ton, Engineer Oriyomi Oladeji, his wife, Dr (Mrs) Nike Oladeji and Mrs Lola Olugbode. Thanks to my former MH206 Whanau Study peer group, many of whom have since completed their doctoral degrees: Dr Maria Margarita R Lavides, Dr Soana Muimuheata, Dr Daniel Dantzic, Dr Edmond Fehoko, Dr Ekta Dahiya, Dr Isaac Amoah, Dr Jeanne Teisina, Dr Katharine Hoskyn, Litiuingi Ahio, Dr Shabnam Jalili-Moghaddam. My thanks also go to my MA203 study peers and the South Campus Potluck study group.

I thank Faye Angelo and Alan Knox for initial thesis chapter proofreading, Sue Knox for the thesis formatting and Dr Agnes Terraschke for the final proofreading.

I deeply thank my extended family on both sides: My siblings and their families and my in-laws and their families. I especially acknowledge my late sister, Dr (Mrs.) Eunice Adetutu Awoyemi, who passed away towards the end of this research journey but whose encouragement before she passed on, continued to spur me on.

Finally, my profound appreciation to my husband, Oladapo, for his immense support, and patience over these years which allowed me the time I needed to study both at home and at the university library. I also sincerely thank my children, Emmanuel, Favour and Jono (son-in-law) and Dami for their understanding and moral support over these years.

To everyone, I offer my heartfelt thanks.

Ethics Approvals

- Full study approval from the Southern Health & Disability Ethics Committee (HDEC) was received on 28/01/2021: Reference 20/STH/162 (Appendix A)
- Full study approval from Auckland University of Technology Ethics Committee (AUTEC) was received on 01/03/2021**:** Reference 21/47 (Appendix B)
- Amendment approval to the study from HDEC was received on 29/06/2021: Reference 20/STH/162/AM01 (Appendix C)
- Amendment approval to the study from AUTEC on 23/07/2021: Reference 21/47 (Appendix D)

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List of Abbreviations

ARC	Aged Residential Care
ARCF	Aged Residential Care Facilities, used interchangeably as ARCF, ARC Facilities or Facilities
ARRC	Aged-Related Residential Care, Agreement/contract with Health New Zealand/Te Whatu Ora (used interchangeably with ARCF or as ARRC Facilities)
CE	Critical Ethnography
GP	General Practitioner
HCA	Health Care Assistant
NASC	Needs Assessment Coordination Service
Participant1–7	Resident with dementia who walked - Participants 1 to 7
Participant-EPAs 1-7	Enduring Powers of Attorney Participants 1-7
Participants-HCAs 1-8	Residential care staff-Health Care Assistants 1-8
Participants-RNs 1-4	Residential care staff-Registered Nurses 1-4
PCC	Person-Centred Care (UK)/Person-Centered Care (USA)
RCS	Residential Care Staff, used interchangeably with staff
RN	Registered Nurse
SC	Social Constructionism
UNCRPD	United Nations Convention on the Rights of Persons with Disability
WHO	World Health Organization

Attestation of Authorship[i]

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor used artificial intelligence tools or generative artificial intelligence tools (unless it is clearly stated, and referenced, along with the purpose of use), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

18 October 2024

Signature Date

Chapter 1 Introduction and Overview

1.1 Introduction

"… part of our moral challenge in adapting to ageing populations is about semantic choice. Making subtle alterations in the way we talk about a disorder can guide us towards a more humane approach to brain ageing…" (George, D.R., 2010, p. 587)

This thesis presents a critical ethnographic study on the relational and supportive interventions provided by residential care staff (RCS) to residents living with dementia who walked in two Aged Residential Care Facilities (ARC Facilities or facilities) in an urban setting in New Zealand. Through participant observations and interviews with residents, Enduring Power of Attorneys (EPAs) and the RCS, the study uses a critical lens to bring the participants' voices to the open to create awareness of their views on the five aims of the study. This chapter introduces the study by presenting its background with definitions of dementia, its prevalence, types, its impact together with walking. It presents the various national strategies and policies by the government in improving the care and support provided for residents with dementia and the global strategy for persons living with dementia. In addition, the chapter introduces the key concepts applied to the study, including person-centred care, using The Hogeweyk Dementia Village in The Netherlands as a model example. The CARE Village in Rotorua, has been built in New Zealand replicating this model example. Furthermore, the chapter presents the positionality and motivation for the study, the research problem, aims, significance, overall structure of the thesis, and concludes with a summary.

1.2 Definition of Terms

Best Practice Advocacy Centre New Zealand (BPACNZ, 2024): A not-for-profit independent organisation established in 2003 in contract with the Ministry of Health, District Health Boards, and various healthcare organisations in the country and internationally to advocate and communicate evidence-based best practice to all health and medical practitioners in New Zealand (NZ). It is known for its expertise and innovations in delivering education and professional development in any healthcare setting (BPACNZ, 2024).

EPA: Enduring Power of Attorney as it relates to personal care and welfare (Ministry of Justice, n.d.) - A family member, friend, or other who is legally appointed to make personal care and welfare decisions on behalf of a donor (such as a resident with dementia who walks) when they can no longer make decisions for themselves.

Health consumer: the resident with dementia who walks, client, patient, or anyone who accesses public healthcare services in New Zealand.

National Institute for Health and Care Excellence (NICE, 2024): The guidelines by NICE are evidence-based recommendations for health and care in England and Wales. The board recommends guidelines to health and social practitioners on safe practices to prevent illness, promote health and improve the quality of health services provided to health consumers (NICE, 2024)

Persons: Used instead of the plural form ‘people’ in this study in line with the theory of Social Constructionism applied to this study, viewing each person for who each individual is, rather than viewing them as numbers

Stakeholders: Any interested party in the care or decision-making regarding persons/residents with dementia who walk, such as families, whanau, EPAs, professional groups, organisations, health practitioners, healthcare service providers, policymakers, and governments (Vinay & Biller-Andorno, 2023; Backhouse et al., 2017). For the purpose of this study, the residents with dementia who walk are exempted from this definition.

1.3 Background to the Study

Dementia is a global as well as national health concern and was declared a public health priority by the World Health Organization due to its increased prevalence (World Health Organization, 2012). Dementia has been described in various simple and clinical terms. Dementia is a broad term for many conditions that lead to changes in the brain. It is a syndrome, a collection of signs and symptoms which in turn affects memory, communication, cognition, behaviour and the person’s ability to carry out daily basic functions, leading to a major cause of disability globally (Brittain et al., 2017; Carr, 2017; Downs & Bowers, 2014, p. xxi; Kitwood & Bredin, 1992; Gonzalez et al., 2015; Scott et al., 2015; Vafeas & Slatyer, 2021). It is characterised by cognitive decline, functional impairment and changes in behaviour (McLeod & Storey, 2021). Furthermore, dementia is described as a neurodegenerative condition (Cheung et al., 2022), due to physical changes in the brain which affect the ability of a person’s memory, reasoning, behaviour, and ability to carry out daily activities such as personal care (Brittain et al., 2017; Carr, 2017; Kitwood & Bredin, 1992; McLeod & Storey, 2021; Scott et al., 2015; Vafeas & Slatyer, 2021). Dementia is progressive, and in its trajectory, the symptoms increase which is referred to as behavioural and psychological symptoms of dementia (BPSD) (Moran et al., 2004). These symptoms occur in each person diagnosed in unique ways and one of them, which this study

focuses on, is ‘walking’, commonly referred to as ‘wandering’ (Blake, 2014; Finkel et al., 1997; Moran et al., 2004; Graham, 2015; O’Sullivan et al., 2013; van de Linde et al., 2013).

Though dementia is not a normal part of ageing, the underlying medical conditions in ageing can be risk factors (Scott et al., 2015). In addition, the end stages of many diseases such as Parkinson’s and Huntington’s may lead to dementia (Prince et al., 2013; Scott et al., 2015), but this is not automatic in every disease (Scott et al., 2015). Dementia can occur in younger people below 65 years, referred to as Younger Onset dementia or Early Onset dementia (Alzheimers Disease International, 2021; Withall et al., 2014). This study focussed on older persons, aged 65 years and above who lived with dementia and walked in two participating ARC facilities in Auckland, an urban area in New Zealand.

1.4 Prevalence of Dementia and Walking

Globally, approximately 55 million ‘persons’ currently live with dementia (World Health Organisation, 2022). Approximately 10 million are diagnosed every year (World Health Organization, 2024), with an estimated projection of 150 million by 2050 (Vinay & Biller-Andorno, 2023) and by 2030, the projected number of persons is estimated to be 74.7 million (Alzheimer’s Diseases International, 2015). Dementia is common in both men and women but because women live longer (Scott et al., 2015), they are more affected. This is disproportionate (World Health Organization, 2024) and studies show one in five persons diagnosed with dementia will walk (Cipriani et al., 2014). Furthermore, studies indicate the prevalence of persons living with dementia who will walk is between 15% to 60% (Gu, 2015; Robinson et al., 2006) and up to 50% among older persons with severe dementia (Lai, 2003).

In New Zealand, dementia is a national health concern (Alzheimer's Disease International, 2021). An estimated 48,000 persons lived with dementia in 2011 (Ministry of Health, 2013), and over 62,000 persons in 2016 (Vafeas & Slatyer, 2021), due to longevity (Shannon et al., 2018). Currently, more than 70,000 persons live with dementia (Dementia New Zealand, 2023) and 78,000 are predicted to live with it by 2026 (Ministry of Health, 2013) and 170 212 by 2050 (Deloitte, 2017). Dementia is prevalent in societies with high numbers of older people.

1.5 Types of Dementia

Hundreds of diseases may lead to dementia, but Alzheimer's disease is the most common type, accounting for 60-70% of persons diagnosed (Best Practice Advocacy Centre New Zealand [BPACNZ], 2024; Kitwood, 1997; Scott et al., 2015, Vafeas &

Slatyer, 2021; World Health Organization, 2024). Other types include Vascular dementia, Dementia with Lewy bodies, Frontotemporal dementia (BPACNZ, 2024; Calsolaro et al., 2021; Vafeas & Slatyer, 2021; World Health Organization, 2024), alcohol-related dementia (World Health Organization, 2024; BPACNZ, 2024; Scott et al., 2015), Creutzfeldt-Jacob disease (Calsolaro et al., 2021), Parkinson's disease type, and Korsakoff's syndrome (Scott et al., 2015). Many times, the boundaries between each are indistinct (World Health Organization, 2024), and General Practitioners, Geriatricians, and specialist medical physicians carry out comprehensive assessments before a diagnosis is made, including history-taking, cognitive assessments, diagnostic tests, physical examination, and other considerations (BPACNZ, 2024; Kitwood, 1997; Vafeas & Slatyer, 2021).

1.6 Impact of Dementia and Walking

Dementia "pathologizes the body and consequently its movement" (Graham, 2015, p. 734). As mentioned earlier, not every person diagnosed with dementia walks. However, researchers have identified that the diagnosis and the walking or movement of persons with dementia have been pathologised, stigmatised, and socially constructed over the years and decades, primarily, through biomedical language (Graham, 2015; Kitwood, 1997). The language and expression used in describing the persons diagnosed or communicating with them were found to be dehumanising, patronising, undermining, and regarded as malignant social psychology (Kitwood, 1997), though these were not intentional by the users, but a result of cultural inheritance (Kitwood, 1997). In addition, persons diagnosed with dementia are "subjected to ageism in its most extreme form" (Kitwood, 1997, p.13-14). The impact of dementia on the individual include social isolation, low or poor quality of life, disenfranchisement, loss of personhood, social disregard, social death, and lack of recognition as social citizens (Bartlett, 2022; Brannelly, 2011; Brooker, 2007; Cook et al., 2022; Human Rights Act 1993; Kitwood, 1997; Sweeting & Gilhooly, 1997). In low to middle-income countries, approximately 75% to 90% are undiagnosed due to the stigma attached to the syndrome (Alzheimers Disease International, 2021).

Dementia prevents persons diagnosed from participating socially "on equal terms with other citizens" (Ong et al., 2024; p. 58). In some cultures, persons affected are locked up at home or institutionalised instead of finding ways to reduce their disabilities (Johnston et al., 2024). As a result, they are separated and treated as if they have committed crimes (Swaffer, 2020). Walking, as a result of the increased symptoms of dementia is a common reason individuals affected go into care homes (Turner, 2005). Furthermore, persons with dementia are denied their human rights despite having

equal citizenship rights with others (Bartlett & O'Connor, 2007). Under the declared United Nations Convention on the Rights of Persons with Disability (UNCRPD) (United Nations, 2022), persons with dementia have equal rights to be included in community decision-making, to participate fully and to live independently.

In addition to the stigma attached to dementia and walking of residents with dementia, international studies have reported a common routine use of antipsychotic medications to manage BPSD, including walking, residents in aged care facilities in urban and rural settings worldwide. This practice has had adverse effects on the residents, such as increased risks of falls, strokes, and fractures. This practice has been questioned as it is not in line with Best Practice Guidelines (Blake, 2014; Best Practice Advocacy Centre, 2024b; Ervin et al., 2013; Livingston et al., 2014; Martini de Oliveira, 2015; Turner, 2005) This will be further discussed in Chapter Two.

To de-stigmatise dementia and enable people to get an early diagnosis, the classification of dementia was changed in 2013 to be under mild and major neurocognitive disorders in the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) (American Psychiatric Association, 2024). While the effectiveness of this classification change has not yet been measured, a shift in the language used can be observed in discourses and practice; however, some are still using 'wandering' with its inflexions, such as 'wanderers' (Graham, 2015), to refer to persons with dementia who walk. Some care providers have been taking a stance in their person-centred care philosophies and models of care to reflect input from the residents and replacing expressions (Fransden, 2009; Ulrich, 2005) such as 'wandering' to "people who like to walk" (Graham, 2015, p. 733). In this study, they will be referred to as 'persons with dementia who walk'. As mentioned earlier, dementia affects each person in unique ways and with differing symptoms (Livingston, 2014), and there is no one-size-fits-all that will effectively support the residents with their walking as they will need individualised person-centred care. The residential care providers and staff such as Clinical Managers; Care/Facility Managers; Clinical Coordinators; Registered nurses (RNs); Enrolled nurses (ENs); and Health care assistants (HCAs) work together in ARC Facilities in most independent non-governmental facilities (Burrow et al., 2017), to provide care and support for residents with dementia who walk and those who do not walk. Staff need creativity and interactive competence (Kitwood, 1997) to maintain a duty of care in ensuring a balance is maintained between residents' safety and autonomy for independence and social citizenship (Bartlett, 2022; Brannelly, 2011; Brooker, 2007; Cook et al., 2022; Human Rights Act, 1993; Kitwood, 1997; Sweeting & Gilhooly, 1997).

Emerging research and evidence on dementia continue to support the persons diagnosed to live with the condition and enjoy a “high quality of life” (Vinay & Biller-Andorno, 2023, p. 1). While there is no cure for dementia yet, the care for persons with dementia is being moved from a medical model of care to a focus on the individual which is person-centred care (O’Sullivan et al., 2013). This has been challenging to achieve for some providers for residents living with dementia who walk due to many factors. Successive governments have developed strategies, policies, and action plans over the years for person-centred care goals to be achieved in providing care to residents with dementia in ARC Facilities. The next section presents the government strategies.

1.7 New Zealand Government Strategies

In New Zealand, government policies and strategies shape the directions of care provided for persons living with dementia to ensure the care is person-centred and respectful and that the environment is home-like (Ministry of Health, 2016; 2013). The strategies are similar to policies from many other Western countries such as the United Kingdom, the United States of America, and Canada. The strategies were informed by human rights principles to meet the needs of older persons as outlined in 1991 by the United Nations (United Nations, 1996-2022) and the World Health Organization (WHO, 2024). Some of these strategies are presented briefly below and on how they impact or are relevant to the care of persons with dementia.

1.7.1 *New Zealand Disability Strategy 2016-2026* (Office for Disability Issues, 2019)

The *New Zealand Disability Strategy 2016-2026* is a 10-year plan on how government agencies will be guided in the work and services they provide (Office of Disability Issues, 2019). The Strategy referred to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), where dementia was included with some other conditions as disabilities in 2006. New Zealand, as a member country, ratified it in 2008 and started its independent monitoring, actively reporting and responding to the committee's recommendations as required. Recognising dementia as a disability was a significant milestone reached. The United Nations urged countries all over the world to plan strategies to improve the lives of people affected and to develop inclusive policies to promote dementia-friendly, accessible and enabling communities. It also urged reducing the use of antipsychotic medications in caring for persons with dementia (United Nations, 2022). The strategy highlights that the way disability is viewed has changed as it evolves with time. Some regard disability as a source of identity, some as a source of pride, while others see it as a barrier existing within the society of diverse

groups. The term “disabled people” (Ministry of Social Development, 2016, p. 13) means different things to different people and its inclusivity keeps expanding. The updated strategy builds on the UNCRPD stance with emphasis that those with disabilities are experts in their own lives and that they have the right to be involved in decisions. Statistics released by the Ministry of Social Development (2016) showed that people living with disabilities in New Zealand accounted for a quarter of the population (24%), which is approximately 1.2 million people. In 2013, 59% of older people aged 65 years and above lived with disabilities or age-related impairments, which is likely to increase with time (Ministry of Social Development, 2016).

The New Zealand Disability Strategy 2016-2026 (Office of the Disability Issues, 2019), updated from its 2001 version is of particular relevance to the residents with dementia who walk as its vision states “New Zealand is a non-disabling society - a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand work together to make this happen” (Office of the Disability Issues, 2019, p. 11). This vision points to three areas that may be beneficial to the well-being of residents with dementia who walk: One, the deconstruction of the social construction of stigma associated with persons with dementia who walk to restore their personhood and for them to be regarded as social citizens (Bartlett, 2022; Bartlett & OConnor, 2011; Brannelly, 2011; Brooker, 2007; Cook et al., 2022; Kitwood, 1997). Two, residents with dementia will be able to pursue and choose what they want to do and enjoy what they want with their loved ones if they are still able and capable of doing so (Bartlett, 2022; Bartlett & O’Connor, 2011; Brannelly, 2011; Cook et al., 2022; George, 2010; Kitwood, 1997; The Office for Seniors, 2019)), and three, that it is the collective responsibility of everyone in the society to ensure that this vision is accomplished (George, 2010; Kitwood,1997). However, the Disability strategy cautions, just as many scholars and pioneers have done, on the need to be sensitive to the language used to refer to dementia disability or the person living with the diagnosis to stop the stigma attached to dementia and walking (George, 2010; Kitwood, 1997; Sweeting, 1997). The strategy recommends that everyone should be sensitive to how persons with disability want to be addressed, as they want to be seen as persons before their disabilities. This is what residents with dementia who walk want, to be seen as persons first (Ulrich, 2005). All eight outcomes of the Disability strategy are beneficial to the residents but more particularly the outcomes of choice and control, attitude, accessibility and the right to protection and justice (Office of the Disability Issues, 2019). These will bring high quality of life, well-being, equality, social citizenship, and emancipation to residents living with dementia who walk.

1.7.2. Better Later Life He Oranga Kaumātua 2019 to 2034 (The Office for Seniors, 2019)

Better Later Life He Oranga Kaumātua 2019 to 2034 (The Office for Seniors, 2019) is a leading national strategy relevant to residents living with dementia. It replaced an earlier strategy called *The New Zealand Positive Ageing Strategy 2001*. This strategy aims to put policies in place for older persons 65 years and above from 2019 to 2034 when they are estimated to be 1.2 million. As previously mentioned, the projection for persons with dementia by 2026 will be 78,000 (Ministry of Health, 2013) and by inference, this estimate will increase by 2034 as well. As a result, this strategy is also relevant for persons with dementia who walk.

Among the reasons for developing the strategy was that older people encountered challenges at work, including “negative attitude towards older workers (ageism) …” (The Office for Seniors, 2019, p. 8). While some older persons may be highly respected by some in the community, others see them as a burden. This attitude can be seen transferred when older persons are diagnosed with dementia and some start to walk, which is a common reason for admission for institutional care (Robertson et al., 2006). The five principles guiding the strategy are “Valuing people as they age ... keeping people safe … recognising diversity and that everyone is unique … taking a whole-of-life and whanau-centred approach to ageing … and taking collective responsibility to plan and act for later life...” (The Office for Seniors, 2019, p. 20-21). These principles, together with the five key areas to be actioned, when applied, will be effective in achieving person-centred care for the residents and destigmatise the residents diagnosed with dementia who walk. All these five key areas of action are beneficial to the residents with dementia who walk as well and will enhance their quality of life and well-being and ensure they are seen as equal citizens, free of stigma, so that respect for their personhood can be restored. The key areas are: ”achieving financial security and economic participation … promoting healthy ageing and improving access to services … creating diverse housing choices and options … enhancing opportunities for participation and social connection and making environments accessible“ (The Office for Seniors, 2019, p. 23). This strategy is linked to another key strategy relevant to the care of residents living with dementia - the New Zealand Framework for Dementia Care (Ministry of Health, 2013), which is discussed next.

1.7.3 *New Zealand Framework for Dementia Care* (Ministry of Health, 2013)

A key national strategy is the *New Zealand Framework for Dementia Care* (Ministry of Health, 2013), which was developed because:

> Ministry of Health … together with the health and social support sector, recognises that dementia care needs to be improved nationwide in a way that maximises the independence and wellbeing of the person with dementia and their family and whānau while ensuring safety and affordability of services. (p. 1)

The Framework aims to reduce the negative stigma surrounding dementia and in line with evidence-based practice and to shift from a medical to a social model of care that focuses on optimising the well-being, quality of life and independence of persons living with dementia. In addition, it aims to improve early diagnosis for opportunities for persons affected to contribute to their care and preferences. Furthermore, the framework is to provide education, support, a dementia-friendly environment and relevant services needed from the moment of diagnosis to the end stage of their lives using person-centred care and people and people-directed approach with their whanau and families (Ministry of Health, 2013). Its nine overarching factors include education and training for the people with dementia and their families; training and educating the workforce; readily accessible information; governance; family and whanau support; culturally appropriate services; funding streams; monitoring and evaluation; and advocacy (Ministry of Health, 2013). The key elements in the strategy are to create awareness of dementia in society and to reduce its risks, to emphasise early intervention, assessment, and diagnosis and to provide ongoing support that will enable the population to live well and meet challenges adequately which will, in turn, maximise their independence and wellbeing (Ministry of Health, 2013).

Due to service providers not meeting best practice standards of care for the persons living with dementia in the above framework, field experts from academia, clinicians, service providers, and non-government agencies jointly developed a five-year action plan referred to as *Improving dementia services in New Zealand-Dementia Action Plan 2020 to 2025* (Carers New Zealand, n. d.; Dementia Cooperative, Alzheimer's New Zealand & Dementia New Zealand, 2020)**.** The plan was to improve the quality of life, health, and independence of people living with dementia.

1.7.4 *Secure Dementia Care Home Design Information Resource* (Ministry of Health, 2016

Another New Zealand government initiative is the *Secure Dementia Care Home Design Information Resource* (Ministry of Health, 2016), developed to shape the way facilities are designed to give people with dementia living there their human rights, dignity, and person-centred care, a gold standard, to enhance their quality of life. This information resource guide was a collaborative work of New Zealand stakeholders based on

current research and international guidelines.

1.7.5 *Dementia Mate Wareware* (Health New Zealand Te Whatu Ora, 2024)

Dementia mate wareware is the te reo Māori name for symptoms caused by different diseases that affect a person's brain, such as memory, thinking, and social skills (Health New Zealand Te Whatu Ora, 2024, para. 1). In 2021, its Action Plans were submitted to the government in a bid to enhance the care being provided for people living with dementia among Māori as there is a health disparity compared to non-Māori (Dudley et al., 2019). Mate wareware means 'becoming forgetful and unwell' (Dudley et al., 2019) and the five-year action plan (2020-2025) is a collaborative work of providers, clinicians, academics, non-governmental organisations (NGOs), and Mate wareware Rōpū to find solutions towards improving the care, quality of life, and health of people living with dementia (Alzheimer's New Zealand, 2023). The plan was based on Kaupapa Māori with cultural competence built into it and was accepted by the government in April 2021 for implementation.

Dementia mate wareware has four objectives: One, reducing the incidence of dementia wareware to be led by Māori Health Authority and the public health agency. Two, supporting people living with dementia mate wareware, family, whanau, and their care partners or supporters to live the best possible lives under the leadership of Māori Health Authority and Health New Zealand. Three, building communities that are accepting and understanding with the suggestion that this be led by Māori Health Authority, Ministry of Social Development, and Health New Zealand. Four, strengthening all capability and leadership throughout the sector with the suggestion of it to be led by Health New Zealand, the Ministry of Health, Māori Health Authority, and the Health Quality and Safety Commission (Alzheimers New Zealand, 2023).

1.7.6 *The Global Action Plan on the Public Health Response to Dementia 2017-2025* (World Health Organization, 2017)

On the world stage, an earlier international strategy focusing on persons living with dementia is *The Global Action Plan on the Public Health Response to Dementia 2017-2025*. The strategy was developed by the World Health Organisation (2017) in recognition that dementia has financial implications not only for each country but also for the individuals affected, their families, and their informal carers. In this strategy, seven action areas to be improved include a focus on: dementia awareness and friendliness, dementia risk reductions, dementia diagnosis, treatment, care and support; support for dementia carers, and the importance of dementia research and

innovations. The goal of the strategy is for each country to include all persons with dementia, their carers, communities, organisations, and the government to work together to achieve the goal of decreasing the impact of dementia and to promote the vision of preventing dementia. Another goal of the global strategy is to support those living with dementia and their carers to live well and be well-cared for so persons with dementia can “fulfil their potential with dignity, respect, autonomy and equality” (World Health Organization, 2017, p. 4).

Before I present the research question and the aims of the study, it is important to introduce the Aged Residential Care (ARC) Facilities in New Zealand, where residents with dementia who walk live and receive care and support. Many ARC Facilities have person-centred care or individualised care as their care philosophy or model of care.

1.8 Aged Residential Care Facilities in New Zealand

Aged Residential Care (ARC) is described as “when an older person requires care in a facility that offers long-term care…” (Central Region Technical Advisory Services Limited [TAS], 2021, para. 2). Going into care to live in an ARC Facility (ARCF) long term is well structured in New Zealand and standards for compliance are laid down by the government for organisations that want to provide these services of care. Aged residential care has four levels of care: rest home level of care, hospital (continuing care or private hospital level of care), secure dementia level of care, and specialised (psychogeriatric) level of care (Ministry of Health, 2020; New Zealand Government, n. d). Any ARCF set up to provide care to older persons in their community must comply with and have certification to meet the standards required to provide care services for the population. Compliance with the Health and Disability sector standards of 2001 (Ministry of Health, 2022) and certification of the Health and Disability Services (Safety) Acts 2001 must have been achieved. Each ARCF operates on the national agreement in the National Aged Residential Contract and is guided by two national agreements: Age-Related Residential Care Services Agreement and Aged Residential Hospital Specialised Services (ARHSS) (Ministry of Health, 2020b). All agreements are reviewed nationally every year to maintain the national standards. If any variation is required, it is agreed upon by the two parties involved, the District Health Boards, devolved with the contract responsibilities by the Ministry of Health and the ARCF service providers (Health New Zealand/Te Whatu Ora, 2024). The agreement reached is then updated as amendments to the contract (Central Region Technical Advisory Services Limited [TAS], 2021). Audit and certification are carried out in all facilities

under the Health and Disability Services (Safety) Act 2001 every three years, usually after a 10 working days' notice. HealthCERT enforces the legislation and compliance and also reviews audit reports, issues certificates and manages legal issues (Ministry of Health Manatū Hauora, 2020).

All these measures are in place to ensure that ARC Facilities are compliant and meet the required standards for delivering care to residents in their facilities. Non-compliance carries various consequences, including the ARCF to address identified issues or termination of contract with the facilities by the DHB (TAS, 2021). To explain further the obligation of the care providers, section D15.1 of the Age-Related Residential Care Services Agreement (Health New Zealand/Te Whatu Ora, 2024) between the Ministry of Health/Health New Zealand/Te Whatu Ora and the residential care service provider highlights that "…The buildings, facilities and equipment shall meet the accommodation needs of older people and reflect the special needs of the Residents …" (Health New Zealand/Te Whatu Ora, 2024, p. 46; TAS, 2021, p. 47).

As outlined in the Residential Care and Disability Support Services Act 2018, any older person accessing the disability support services for funding to live in ARCF long-term is required to follow the process outlined in the Ministry of Health guidelines (Ministry of Health, 2020a). The decision to move into residential care could be for a variety of reasons, such as not being able to self-care independently at home any longer (Shannon, 2020); no resident carer in the whanau to provide the care; sudden change in health affecting cognitive ability; decision by the Enduring Power of Attorney (EPA) under the Protection of Personal and Property Rights Acts 1988 due to the legal loss of competence to make decisions as a result of cognitive impairment, or decision made by a Court-appointed Welfare Guardian (Ministry of Justice, 2021) due to lack of capacity to make informed choices about their health and welfare. Such individuals will then be assessed by the Needs Assessment Service Coordination (NASC) team with the District Health Board (DHB) (Ministry of Health, 2021, New Zealand Government, n.d.). Needs Assessment and Service Coordination is a dedicated agency assigned to carry out the role of coordinating and working together with the individual and their families to decide the choice of ARCF they prefer in the DHB of their choice. First, the individual's income, assets, and other giftings are assessed by Work and Income under the Ministry of Social Development to determine if they are eligible. If they are above the government's stipulated financial threshold for residential care subsidy (Ministry of Health, 2020a; Ministry of Health, 2010), they pay for their care independently. If equal or below the threshold and eligible, their health needs are then assessed by specialists, including Gerontology Clinical Specialists, Geriatricians, or General Practitioners (GP), after comprehensive geriatric assessments and other required diagnostic tests to

determine their levels of care needs. These assessments can also be done while the individual is awaiting discharge from a public hospital admission. Referral to the NASC team is done for placement into preferred choices of ARC Facilities, and in some cases no other choice due to over-subscription of the ARC Facility or the level of care that their family members require (Ministry of Health, 2020). The outcomes of these needs assessments determine the level of care a person is allocated, be it to a rest home, hospital, secure dementia or psychogeriatric level of care (Ministry of Health, 2020a; 2016).

A review of ARC Facilities was carried out for approximately 12 months in the last decade, and it was regarded as “the most extensive review of this sector ever undertaken in New Zealand and had the highest provider participation rate of any comparable international study. It represents an accurate and thorough assessment of the current position and future projections” (Thornton, 2010, p. 6). In the report, reference was made to the structures and stock as having a “usable life” (Thornton, 2010, p. 7) of 25 years, after which their relevance is affected by residents’ care needs; expectations; changing norms of the society, and the codes of the building architecture Thornton, 2010).

Before presenting the research question, aims, scope of study, positionality and motivation for the study, and structure of the thesis, this next section presents the concepts informing the study, including personhood and person-centred care, as well as ‘The Hogeweyk’ and other models where these concepts are used.

1.9 Concepts Informing the Study

1.9.1 Personhood and Person-centred Care

Person-centredness is seen as an attribute and cornerstone of aged care nursing with personhood at the centre and the basis of person-centred care (Dewing, 2008). Person-centred care is a philosophy of care that is based on the needs of persons living with dementia: knowing the person and building an interpersonal relationship with them to achieve therapeutic impact (Fazio et al. 2018; Love & Pinkowitz, 2013). Many ARC Facilities base their care concepts or philosophy of care on this framework. The definition is not simple as it has been interpreted from different perspectives (Brooker, 2007; Goodrich, 2016; van der Cingel et al., 2016), such as the meaning of individualised care, values, communication technique, made-to-measure, phenomenology, or techniques of caring for people with dementia. Person-centred care has also been referred to in various settings as resident-centred, resident-focussed, relationship-centred, person-directed, or person-centered (Fazio et al., 2018; Love &

Pinkowitz, 2013). Though the term originated from the work of Carl Rogers in the 1960s which focussed on personal experience as the standard of care for therapeutic impact, Tom Kitwood used the phrase ‘person-centred approach’ first, to differentiate specific ways of caring for people with dementia from other medical behavioural approaches to show genuine contact, communication, and relationships (Brooker, 2007; Fazio, Pace, Flinner & Kallmyer, 2018). Personhood is described as “the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust … and the failure to do so, have consequences that are empirically testable” (Kitwood, 1997, p. 8) and must be from an external person to the person with dementia as a way of regarding them, honouring them for who they are as persons. Personhood needs relationship and inclusion and as pointed out by another expert it is “an ethical issue as everyone has intrinsic value. We should recognise that we must respect the cognition abilities in everyone as everyone has cognitive abilities such as language, memory and executive functions which allow everyone to exercise” (Ney et al., 2021, p. 3618) their personhood. Personhood was a new idea towards moving away from the medical approach which was believed to have contributed to the stigmatisation of persons with dementia through pathologising the syndrome because of the focus on treating the condition. The concept of personhood is also to welcome new knowledge, innovations, treatments, and expertise that invite improvement into the care of persons living with dementia. It is a new shift towards regarding the residents diagnosed with dementia as individual persons who have inherent values first and relate with them with kindness and empathy. ‘Positive person work’ (Kitwood, 1997) is important for personhood to thrive. It consists of positive interaction that “enhances personhood in a different way: strengthening a positive feeling, nurturing an ability or helping to heal some psychic wound” (Kitwood, 1997, p.89). The interaction quality is generally warm and rich and includes recognition, negotiation, collaboration, play, timalation, celebration, relaxation, validation, holding, facilitation, oration, and giving (Kitwood, 1997). Some of these concepts are applied to the study.

Person-centred care (PCC) was first developed by Kitwood (Kitwood, 1997; Kitwood & Bredin, 1992) who himself acknowledged that it has been in use instinctively (Terkelsen et al., 2020). It was applied to the care of persons living with dementia as a shift away from the biomedical model that Kitwood (1997) argued resulted in loss of personhood. The main PCC principles include treating the person with respect, compassion, and dignity, coordination of care, treatment and support by nurses, as well as personalised support, care, and treatment from the nurses to enable persons with dementia to develop their abilities and strengths for independence and fulfilment in living (Terkelsen, 2019). PCC acknowledges the uniqueness of each person

diagnosed, and the nurse is expected to be an expert, creative, and with varying skills and knowledge to work with the resident with dementia and collaborate with the team and residents' families through effective communication (Vafeas & Slayter, 2021).

Person-centred care as a framework has been operationalised as a structure by another set of experts (Love & Pinkowitz, 2013). Operational practices and individual practices, the core values and philosophy, are the first and foundation of its framework. It refers to the meaning of life that each person has at every stage of their life in terms of interest, history, and needs to continue living life. It emphasises the importance of focussing on the strengths of the person with dementia rather than on their disabilities or reduced abilities. The person is not their dementia illness; rather, the condition is only one aspect of their current being. To help support their personhood, it is important to "enter the world of the person living with dementia to best understand" (Love & Pinkowitz, 2013, p. 26). Kitwood suggested ways that influence the ways a person with dementia experiences their subjective world include biography, personality, physical health, neurological impairment, and social psychology including interaction with other people (Vafeas & Slaytyer, 2021)

The second part of their framework (Love & Pinkowitz, 2013) contains eight interconnected domains that facilitate the achievement of desired or sustained outcomes which are: relationships, community, (or sense of belonging), governance, leadership, care partners or workforce services, meaningful life and engagement, environment, and accountability. The third part of the framework relates to operational practices which include incorporating interesting daily activities that are purposefully designed to engage the person living with dementia to make a meaning of life. These practices are meant to support the eight domains in the framework mentioned above (Love & Pinkowitz, 2013). Lastly, the fourth part of their framework is individualised practices (Love & Pinkowitz, 2013), which involves individualising interactions with a person with dementia in a unique way to indicate one is honouring and respecting their preferences, choices, needs, and interests. These practices are flexible and can be customised.

1.9.2 Caring

Caring is one of the key qualities of a nurse. Caring "is an intentional human action characterised by commitment and a sufficient level of knowledge and skills to allow you to support basic integrity" (Boggs, 2023, p. 148). To look after persons with dementia, this quality is important as it focuses on interactions when planning and providing the resident's care. Furthermore, caring

> begins with being present, open to compassion, mercy, gentleness, lovingkindness, and equanimity toward and with self before one can offer compassionate caring to others. It begins with the love of humanity… actively, joyfully participating in all of it, the pain, the joy, and everything. (Watson, 2008, p. xviii)

The above definitions emphasise the attitude, knowledge, dedication, and empathy required in looking after residents with dementia who walk whether one is a regulated or unregulated staff, paid or unpaid carer, formal or informal carer. The rationale is to support the residents to good health by being aware of the vulnerability of their current health status (Jennings, 2018).

1.9.3 Relational Care

Relational care is the care between the carer and the person being cared for. Lack of relational care means that care is one way, making those receiving care seem “passive and unable to contribute” (Novy et al.,.2021, p. 1). Relational care is therapeutic, as the nurse joins in an alliance to work together with the resident for a defined period to achieve pre-planned health goals using therapeutic communication (Boggs, 2023). It conveys continuity of care (Dyer et al., 2022) between the health practitioner (residential care staff) and the health consumer (residents with dementia who walked). This relationship may be between a staff consistent in caring for the resident possibly due to a resident’s language barrier. This was the case with Participant4 in the study who was assigned a nurse from the same ethnic group who spoke her first language. Such consistency in care enables continued relationship that provides a therapeutic relationship that enhances the health and wellness of the resident. The application of relational care is not restricted to one staff but extends to all staff who apply empathy and relationship solidarity to advocate for the resident (Brijnath, 2024; Jenning, 2018).

1.9.4 The 'Then’ Self and ‘Now’ Self

These are moments of clarity for the resident with dementia and their informal or professional carers when carers hear and see the resident regain their normal selves, for example, recalling an event or person they had not been able to, previously. These moments are “short-lived episodes of apparent lucidity and clear communication that people with dementia sometimes show particularly when near to the point of death” (Kitwood, 1997, p. 63). In the trajectory of dementia, ethicists and clinicians have spoken of a person having two selves that is the “then self” and the “now self” (Klein & Karlawish, 2010; Ney et. al., 2021; Sweeting & Gilhooly, 1997). In many clinical settings, ethically charged expressions are used by some people to refer to persons

living with dementia as having ‘loss of self’ or ‘death before death’, implying that one must have cognitive abilities to be socially alive. The ‘then’ self represents who they were before the diagnosis and the ‘now’ self refers to who they are in the current stage of the syndrome. This raises an ethical dilemma for carers as they are conflicted and questioning whether they are making decisions for the ‘former person’ they know in their loved ones or the ‘new person’ they see when caring for them (Ney et. al., 2021).

1.9.5 Five Psychological Needs of Persons Living with Dementia

Five psychological needs identified in persons with dementia are comfort, attachment, inclusion, occupation and identity (Kitwood, 1997). These are inherent and overlap in everyone, leading to a central need for love. Having one of these needs met leads to the fulfilment of the other four, as the boundaries are not distinct. Kitwood (1997) postulated that these needs are based on one’s history, personality, and intensity and are easily identified in persons with dementia, as they are more vulnerable and are not able to take those steps towards having their needs met.

Comfort is a psychological need required by persons living with dementia. It means being soothed from sorrow or pain, tenderness, calm when anxious, closeness, and a sense of security. There is a high probability of this need in persons with dementia as they may be dealing within themselves, the loss of their independence, self, abilities, or they may be reflecting on their previous well-established life. This need for comfort will keep occurring in them (Kitwood, 1997).

Attachment, (Bonding) a second psychological need, is postulated as important and impossible for anyone to function well without having it as it brings reassurance. It is compared to the experience of children who bond with their parents/caregivers when they face uncertain circumstances. Persons with dementia from all cultures seek bonding or attachment when they find themselves in strange or unfamiliar situations (Kitwood, 1997).

Inclusion is a third psychological need in a person with dementia. It is a need to be included and involved in social life as human beings are social beings who require interaction. Lack of it will lead to deterioration while meeting this need will make the person thrive and not decline in condition (Kitwood, 1997). As Kitwood (1997), put forward, sometimes to achieve this, a resident will seek attention through various means such as being disruptive or hovering over someone else. This need emphasises the need for individualised and person-centred care for persons with dementia (Kitwood, 1997).

Occupation is the fourth psychological need of a person with dementia whose key need is to get involved in "the process of life in a way that is personally significant for the person with dementia as their abilities, capabilities and powers are utilised" (Kitwood, 1997, p.83). It is strongly postulated that residents with dementia are involved in meaningful engagements so their abilities and capabilities are not rendered ineffective (Kitwood, 1997).

Identity is the fifth and last psychological need of a person/resident with dementia. Identity relates to being aware of who one is at present and in the past, which forms a consistent story of the person. How each person with dementia constructs their identity is considered unique and to a certain extent, giving of identities is done by others. The argument is to support persons with dementia by knowing at least part of their life history which makes them unique and having empathy in interacting with them with this uniqueness.

If one of these psychological needs is met, it influences the other needs and the health and well-being of persons with dementia are enhanced. If all of the needs are met, then there will be an "enhancement of the global sense of self-worth, of being valuable and valued" (Kitwood, 1997, p. 84)**.** Achieving this global sense is also referred to as the salutogenic approach which is presented further in this chapter.

1.9.6 Social Citizenship

As a concept applied to this study, social citizenship (Bartlett, 2022; Bartlett & Brannelly, 2017; Brannelly, 2011; Cook et al., 2022; George, 2010; Kitwood, 1997) depicts how rights and responsibilities can be accessed daily (Bartlett, 2022). For the residents with dementia who walk, social construction (Burr, 2015) of their walking and their diagnosis have deprived them of their rights as social citizens. The stigma and stereotyping have reduced them to being viewed as socially dead (Brannelly, 2011; Sweeting & Gilhooly, 1997) though they are still alive. The residents with dementia who walk are disregarded (Brannelly, 2011) in the community due to seclusion and isolation as a result of loss of self-esteem and self-confidence. Furthermore, all persons and residents with dementia are still members of the community.

> Citizenship is a sensitising concept. It reminds us that people with dementia are not only 'patients with needs' but persons with a right to experience freedom from discrimination and despair and be regarded as equal members of the socio-political sphere to which they have belonged all their life. Now with the disease, they are still members of and still belong, but in different ways and with different hopes and desires. (Bartlett & Brannelly, 2019, p. 3)

1.9.7 Social Death

Social death is a concept applied to this study. It refers to “when people are considered unworthy of social participation and deemed as dead when they are alive” (Brannelly, 2011, p. 662). The concept can be traced back to a member of Durkheim’s school, Hertz, who first referred to the idea in 1907 (Sweeting & Gilhooly, 1997). The most recent use of the concept dates back to the 1960s in the medical-thanatological literature where terms such as ‘non-person’ and ‘hopelessly comatose’ were used to refer to patients living but regarded as dead as social attributes are not used to address them. The term over the decades alludes to the residents with dementia through stigma and ageism (Sweeting & Gilhooly, 1997). The researchers, in an exploratory study, identified three major groups whose conditions might result in being socially dead in contemporary society: those with “lengthy fatal illness, the very old and those loss of personhood” (Sweeting & Gilhooly, 1997, p. 98). Social death, as a concept and terminology has been related to Persons and residents with dementia over the decades as their personhood have been taken away from them (Kitwood, 1997) through focus on its pathology or overpowering language pattern used presenting dementia as “death that lives the body behind” (George 2010, p.586). Social death is associated with the care the residents or persons with dementia receive. In the explorative study mentioned, Sweeting and Gilhooly (1997) conducted used 100 semi-structured questions to interview relatives caring for family members with dementia to determine their social death in their perceptions of the persons receiving care. Results indicated a scaling in the perception of social death held by the carers from “belief to behaviour” (Sweeting & Gilhooly, 1997, p. 103) towards the persons with dementia with (60%) majority believing it but not relating with them as such. However, to further explore social death, Brannelly (2011) reframed Sweeting & Gilhooly’s (1997) argument and conducted a qualitative study among 15 practitioners to find out citizenship and participation as facilitated by these professionals with persons living with dementia and their families. Brannelly introduced the concepts of social regard and disregard and applied analysis of care ethics. Findings revealed that out of the 15 practitioners that participated in the study, nine made every attempt to include the persons with dementia in the decision-making, four assessed the extent to which to include individuals based on their perception of the level of participation of that individual and lastly, two practitioners did not make any attempt to involve the individuals with dementia. So, the concept of social death exists in the care and support residents living with dementia receive but at varying degrees.

The effects of social death in relation to persons living with dementia can be far-reaching associated with stigmatising language. In some cultures, persons with

dementia can be subjected to isolation or beaten as “that’s the devil inside” (Johnston, et al., 2024). During consultation, the professional will ask other people around them questions about the individual with dementia rather than asking the individual the questions first (Power, 2017). This discourages others suspecting they have dementia from seeking early diagnosis and treatment.

1.9.8 Salutogenic Approach

Salutogenesis is a model of health proposed by Antonovsky, who himself changed his perspective from pathogenesis to salutogenesis, due to its origin of health and assets for health for a person as opposed to disease and the risk factors in the health of that person. (Mittlemark et al., 2017). Thus, the concept focuses on factors that promote health and well-being in a person rather than what causes diseases (Bauer & Jenny, 2013; Mittlemark & Bauer, 2016). It asks the question “… how does one move towards the health pole on the ease-dis-ease continuum - that constituted the major philosophical change in thought, from the traditional pathogenic orientation to the salutogenic view of the mystery of health” (Antonovsky & Sagy, 2017, p.16). It is not a question about why people are sick but asking the right question on how to get well. Two of the meanings introduced in the concept include a **sense of coherence** which implies the person’s ability to cope with stress by engaging with resources available; and **a global orientation,** that is, the origin of health and its assets for the person, rather than the origin of disease and its causes (Mittelmark & Bauer, 2016).

Salutogenesis is about developing a positive attitude toward human activities and life. **Sense of coherence (SOC)** provides an immediate sense of comprehensibility, manageability and meaningfulness of life which leads to health (Vaandrager et al., 2022). As salutogenic model was originally developed as a stress and coping model, experienced many times by residents living with dementia, nursing professionals are expected to play a key role in assisting the residents with dementia who walk to achieve this SOC, supporting them to recognise and use the available resources left to them and around them to cope and to gain strength (Super et al., 2015). **Comprehensibility** refers to the residents’ capacities to transform their environment stimuli, causing them stress, into meaningful uses. It involves participation and looking for creative ways to solve problems arising. **Manageability** is the individual’s understanding of the resources available to them and their ability to use these to meet their daily needs. Manageability involves mutual trust between the residents and the nursing staff. This is why it is essential to have consistent professional care staff looking after the residents, so residents can build rapport with the staff and get used to

their familiar faces, in their familiar environment. It involves a relaxed atmosphere where the residents have the reassurance that they are not alone in any difficulties they face and that they can depend on the collective responsibility of all the staff to support them with their needs. This thought is the most fundamental for residents as it enables them to settle down into their environment (Vaandrager et al., 2022).

SOC also includes **meaningfulness**, which indicates the extent a resident feels that life makes sense emotionally despite challenges and difficulties around them or with things they are unable to accomplish. This is relevant towards achieving person-centred-care goals for persons with dementia. When developing individual care plans for each resident during admission to the facility, information needs to be gathered from the residents themselves, their family members or EPAs, as well as from other clinical records such as discharge summaries and referrals of residents, and incorporate this into the care being provided. The staff are expected to support residents in achieving these goals including organising day trips, individual walking, group walking sessions and other activities that will enable residents to feel a sense of belonging and a sense of home (Vaandrager et al. 2022).

Health literature increasingly shows that there is a link between the physical environment and the well-being of a person (Dilani, 2009) and that the performance of a person can be enhanced through appropriate management of their physical and social environment which interact together (Mittelmark & Bauer, 2016). While the physical environment enhances the health of a person, any stressor there can impact the health of the individual. A salutogenic approach to providing care has therefore become a basic theoretical framework for providing quality care for increasing comfort for people. It is a psychosocially supportive design that includes good lighting, inviting spaces to interact socially, spaces for privacy, access to practice one's spirituality, interior environments that offer engaging positive experiences, access to nature, sound, daylight and other facilities that will promote health and wellness in the people (Dilani, 2009). This concept works hand-in-hand with the 10 principles of architectural designs for care building (Fleming et al., 2020).

Antonovsky discussed the role of culture in salutogenesis, shaping one's life and giving it meaning (Mittelman et al., 2017). Social and physical environments can be used to enhance the well-being and performance of a person's health and these are referred to as "supportive environments" (Mittelman et al., 2017 p. 8). In other words, salutogenesis, as a theory focuses on the:

> forces that support life and engagement rather than on preventing or treating disease … Though the task is not easy, it focuses on not removing the disease

> but improving resilience and a person's capacity to engage in life more completely, fortifying the ability to cope with the challenges that are a normal part of life's passage-even the challenges associated with ageing and dementia. (Golembiewski & Ziesel, 2022, p.48)

It has been projected that by 2030, more older people will choose to live in ARC settings. A "setting", according to the World Health Organization (2022b) is described as "the place or social context in which people engage in daily activities in which environmental, organizational, and personal factors interact to affect health and wellbeing" (para 4). The salutogenic approach is to be advocated for in those settings that care for older people in healthcare settings and communities (Bauer, 2017). The World Health Organization (2022b) refers to health as being "created and lived by people within the settings of their everyday life, where they learn, work, play and love" (para 1; WHO 1986, p.7). Since ARC Facilities are homes for life for older people with dementia who walk, more emphasis needs to be focused on the varying interventions to meet their needs (Wicking Centre for Dementia, 2022). This is also in line with the *United Nations Decade of Healthy Ageing (2021-2030)* (WHO, 2022), which through global collective actions, seeks to improve the quality of lives of older people, their whanau, and their communities. There are four areas where these actions are advised to be directed: one,

> changing how we think, feel and act towards age and ageism; two, developing communities in ways that foster the abilities of older people; three, delivering person-centred integrated care and primary health services responsive to older people; and four, providing older people who need it with access to quality long-term. (WHO, 2022a, para 19)

Salutogenic care is the desired care for the residents with dementia who walk as it incorporates within it, the concept of person-centred care.

The next section presents an example of a model of care - The Hogeweyk, the Dementia Village in The Netherlands and a summary of my study visit to the village as well as to The CARE Village in New Zealand, modelled after The Hogeweyk care concept.

1.10 The Hogeweyk

Since starting this research project, I have always desired to visit the Dementia Village called 'The Hogeweyk' in The Netherlands as I have read and heard about it being the world's first example of a village that was designed exclusively for persons living with dementia and where they are given best care. I wanted to visit the village to confirm

this and gain evidence that may be beneficial to include as a recommendation in my thesis, if possible. The opportunity to visit came through the CHT Aged Care Fund Grant in April 2022 and I went on a study visit to The Hogeweyk in The Netherlands in July 2022. While there, I learned about a recently established village in New Zealand, The CARE Village, in Rotorua, which was modelled after their care example. On my return to New Zealand, I made a study visit The CARE Village in Rotorua and information gained during this visit is presented further below in 1.10.1.

Below is some key information gained firsthand from my study visit to the Hogeweyk:

The dementia village is referred to as Hogeweyk, meaning ‘Neighbourhood’. It is situated in the town of Weesp, on the outskirts of Amsterdam in the Netherlands (Be Advice, 2015 -2023). The letter ‘k’ was added to the area name, ‘Hogewey’, to give it the neighbourhood meaning and to remove the focus on ‘dementia’ in the persons living in the village (Be Advice, 2015-2023). ’Be Advice’ was chosen as an alternative name because it was difficult for non-Dutch people visiting the village to pronounce the Dutch name. The vision for the village was born in 1992 when the founders asked one another this question: “What would you want for yourself or for your loved ones if you moved to a nursing home?” (J. Spiering, personal communication, 12 July 2022), and later research was incorporated into it. Establishing the village was a continuous process over the years and operationalised step by step. This vision to promote normal life for people with dementia and to take the ‘institution’ out of the nursing home drove the establishment of the village till its official opening in 2009. Its philosophy is a social relational model instead of a medical model, as the founders wanted the focus to be on possibilities and not on residents’ disabilities. The care concepts include the following: a culture change in the care provided for people living with advanced dementia; disrupting the view on traditional nursing home care; focusing on experiencing health and quality of life; enabling and respecting individuals to continue to freely make their choices; continuous support provided by best healthcare professionals; creating a lively community where residents can meet and participate; living safely with autonomy and independence and lastly enabling residents to stay part of society (Be Advice, 2015-2023). The Hogeweyk is for persons living with severe dementia who have been officially assessed (with indications/Care Profile) 5 (severe dementia) or 7(severe dementia with extreme behaviour) by the government which subsidises and pays for the care while the resident pays directly to the government. The average age of residents living in the village is 85 years old, though there are younger people aged 50 or 60 years.

Guided tour of the Village: The village is designed as a self-sustaining entity with 27 homes. The buildings are like typical Dutch houses and have street names such as Boulevard Street, the main street with most amenities. Each house is built like a normal Dutch home, with a total of 180 people in all houses. There are eight houses on the ground floor, and six to seven people live in each. One house has three bedrooms on each side with a big living room (construction work was underway to add an additional bedroom to each house, as I was told, for financial reasons). Each house has a large living room and a laundry, and residents cook their meals together. Everything institutional in nursing homes has been taken away to give the people normal life they used to live, such as cooking in the kitchen. The village has a supermarket, restaurant, cafe, pub, courtyard, pond park, club rooms, physiotherapy, hairdressing salon, garden outside some homes, and a theatre. People and groups from the mainstream community visit the restaurant as groups or from other rest homes. People from the neighbourhood also make use of the pub and utilise the theatre for different functions. It was not possible to differentiate staff from volunteers or even residents as all intermingled, except when a couple was pointed to me, one, outside the pub with her husband and the other in the elevator. Staff wore no uniforms; everyone was walked around freely and the environment felt safe. In the future, as I gathered they would like to keep the entrance/exit door open so residents could freely come in and go out, but that is balancing risk versus safety, as often care was focussed on the risk more than the freedom. I was not able to view the set-up inside of any of the houses as much as the Advisor tried to get an empty house for me to view. It was during the COVID-19 pandemic period and restrictions were still in place for visitors to enter the residents' homes, to protect the vulnerability of the residents. This was a common practice in many other aged residential care facilities at that time as I learnt, same as in New Zealand. However, as we stood outside one of the houses, the Advisor called one of the Caregivers to meet with me outside to answer any questions I had. The Advisor later organised another staff, the Dementia Social Coach to meet with me to answer other questions I had relating to the management of residents' behaviour at the village vis-à-vis antipsychotic medications. During this visit, in addition to the presentation and guided tour of the village by the Advisor, Iris van Slooten, I met two of the co-founders of Hogeweyk, Jannette Spiering and Eloy van Hal, and I had the opportunity during lunch with the Advisor and Jannette to ask Janette questions about how the village was founded, its vision and how care was being managed, especially for the residents who walked as this was my study focus. I had earlier included a request to meet with one of the Founders of the Village during this study visit so as to ask them questions about the village that might be beneficial for my study recommendations. Part of the conversation is presented further below under 'Walking'.

Operations: Each home/household is managed by a level three qualified caregiver with three years of education, together with a home supporter with level one qualification. The village also has an experienced Social Coach, the Dementia Behaviour Specialist (Dementia Social Coach) who acts as a resource person for staff and families on different non-pharmacological interventions to provide the residents including diversion. The village has 120 volunteers, managed by a Coordinator and all are trained to care for persons living with dementia, as 40% of residents are in wheelchairs and need volunteers. Only four of the residents were bedridden at the time of the visit.

Clubs and Entertainment: The Advisor did not like the word ‘activities’ to be used for residents' engagements as it sounded ‘kind of institutional’ (I. van Slooten, personal communication, July 12, 2022), so I will interchangeably use engagements and entertainment. At the time of visit, there were 35 different clubs for the residents, which were managed by a Coordinator who engaged residents to have approximately two and a half hours of engagements weekly. Engagements could take place in the mornings, afternoons and evenings. The clubs included one each of the following: gym club, Painting club, Coffee club, Physiotherapy, Professional Singer club, Dual bike club, Baking club, Beauty and hair salon club, and Swimming club which were all coordinated volunteers. There used to be seven Lifestyle groups which had been updated to four, namely urban, traditional (including Christianity, Indonesian), formal (including folk music, folk dancing, classical lifestyle, posh, served with linen), and cosmopolitan. This aspect was important as residents lived together according to their lifestyles. Sometimes during the weekends, there were live performances or people playing piano and families and residents attended.

Use of antipsychotic medication: Medication use is very low as mentioned by the Dementia Coach. When her input was required for any resident, she would first observe the challenging behaviour and then come up with solutions to avoid the use of antipsychotic medications for such residents. She trained the other staff and had lots of ‘tricks’ in place as interventions, but when none of these interventions worked, she organised multidisciplinary team meetings which involved doctors to discuss such residents' behaviour.

‘Walking’: On the question of the walking of persons with dementia, co-founder Jannette asked why walking is connected to negativity if people with dementia want to walk around. “Is it because people do not have a purpose to walk to?” (J. Spiering, personal communication, July 12, 2022). On whether residents walked at night, stated that residents did not walk at night. They walked around the village during the day, they

would have had good meals with cups of coffee so they just slept in the night. She added that the quality of life offered to the residents would have contributed to their being able to walk around because, in other nursing homes, such people would have been put in wheelchairs. She emphasised the importance of the environment in the care of persons with dementia, that people with dementia react positively to a new place/environment if it is a conducive environment.

Visiting hours: There are no visiting hours. others. Residents go home sometimes, for the weekend or end of life and as in normal life. On a prepared question that the co-founder was asked with regards to intimacy among the residents, she responded that it is an ethical discussion as the question that needs to be asked is “Are you choosing for your own happiness or the resident’s happiness? (J. Spiering, personal communication July 12, 2022).

Future care of persons with dementia and advice: Furthermore, Jannette revealed that in 2030, the government stated that there would be no more nursing homes built and elderly people with dementia have to live at home. She referred to the shortage of nursing staff at the hospitals which is a global issue. As a result, she advised informal carers, volunteers, neighbours, and families to step up to contribute to the care of their loved ones living with dementia at home.

The Hogeweyk has become an inspiration and a pioneer model for humanising the care being provided to persons living with dementia and many such villages are being established all over the world to emulate the person-centred care model. Such a model gives residents autonomy, and advocates for inclusion and integration into the general community. This in turn improves residents’ functionality, mental health and quality of life, reducing the need for pharmacological interventions. Many facilities in Canada, the United States of America, Australia, and also New Zealand are following this leading example and The Be Advice Paradigm, set up by the founders of The Hogeweyk has been supporting organisations wishing to carry out such transformation (CNN, 2013; Haraldseid, 2018; McLaughlan et al., 2018; Vinick, 2019). One of such village in New Zealand is presented next.

1.10.1 The CARE Village Rotorua

The CARE Village in Rotorua, Te Manaaki a Tura, (The CARE Village, 2021) is the first village in New Zealand to be established, inspired by the care concept of The Hogeweyk in The Netherlands. I visited the village with my supervisor and was able to enter the living room of one of the homes as the pandemic restrictions were easing in New Zealand at the time, although my supervisor and I both still had to do COVID-19

screening tests, had negative results before being allowed to enter the village and guided through including to the residents' households. This was acceptable to us as the health of the residents needed to be prioritised. Through this visit, I learnt that another village was being built on the South Island, to emulate the same care concept of 'The Hogeweyk', humanising the care being provided to residents with dementia. The CARE Village, Rotorua itself transitioned from Whare Aroha Rest Home and Hospital and was opened in 2017, on Lake Rotorua Shore, with a vision "inspired by de Hogeweyk's 'normal living' … and to reflect lifestyles that are 'normal' to New Zealanders" (The CARE Village, 2021a, para. 4). Not everyone in the village has dementia. It has three levels of care: rest home, private hospital, and secure healthcare/dementia, and sometimes residents with the three levels of care are mixed. It is designed to be culturally appropriate to Aotearoa New Zealand and is another example of the de-institutionalisation of the care of persons living with dementia to normal living. The village has cultural houses for those who identify as Māori, a Māori Advisory Team, and a couple of Kaumātua or Māori elders (Hokowhitu et al, 2020). The Village has 81 beds, 13 houses with six people in each, and four lifestyles, allowing residents to choose Simple, Cultural, Middle New Zealand, and Classical lifestyles. Engagements and clubs include scrabble games, bingo, cards, knitting, poets, waiata (Māori song) (Trinick & Dale, 2015), Be Active Be Fit, men's shed, and ukulele, and is open to any more suggested by residents. The village also has volunteers as in The Hogeweyk model, and engagements such as trips to the town, rickshaw bike rides, attending and participating in musical performances, and Happy-hour visits to one another's homes. A supermarket is on-site with products from multiple providers such as Countdown and PAK'nSAVE. Staffing includes the Chief Executive, Thérèse Jeff, the Clinical Leader, RNs, caregivers and five other staff members are undergoing nine months dementia training course at the time of visit in September 2022. Families are welcome at the village, to normalise residents living in an inclusive environment. The residents carry out their normal routines in their homes: they have pets, do gardening as they choose, and feel comfortable, engaging in stimulating activities that enhance their quality of life individually (Shannon, 2020; The CARE Village, 2021b).

The next and last section of this chapter presents my positionality and motivation for the study, the scope of the study, the research question, aims, significance of study structure of the thesis and summary of the chapter.

1.11 Positionality and Motivation for the Topic

As a researcher, it is important to reflect on my positionality in this study as it relates "to

the ‘position’ from which one ‘chooses’ to speak…” (Liamputtong, 2017, p. 165), as I brought in my values, belief, culture, knowledge, skills, professional and life experience to the study and allowed them to guide my research. As a self-motivating person, I always challenge myself in the different roles I have had in my nursing career, asking myself questions such as: Why am I in this role? What impact do I want to make while in this position? How else can I make a difference in the lives of my patients/clients/patients/residents/students? One of the philosophies I developed to guide my nursing practice since re-training to be a registered nurse is: ‘Make a difference - no matter how little! The ripple effect will go a long way positively!’ I have seen positive outcomes over these past 17 years and received positive feedback that has motivated me to keep making that difference by developing myself professionally.

Three things motivated me to choose this topic: First, I have always had a caring heart for older people. A possible reason may be that I lost my grandparents when I was very young, so I tend to see every older person as my grandparent and want to give them the best care that I would have given my biological grandparents if they were still living. Second, though, when I started this doctoral programme, I was working in a university setting; my prior role was working as a Gerontology Clinical Specialty Nurse. A reflection on a specific referral received and on general observations of a category of clients in the clinical setting led me to choose this topic. I also supported the nursing staff at approximately 23 ARC-allocated facilities as a resource nurse, providing support for the care they provided to their residents. I was curious about other ways to meet the needs of residents with dementia who walked. The referral was a request for a level of care assessment for a resident. However, the resident was 102-years old, female, Caucasian, with a diagnosis of dementia. She came into care six months prior and had walked out of the ARC facility many times with the staff having to involve the community Police department in the search for her until found. Her history, including social history gathered, indicated she had lived an active life. She had walked from her home to work, kilometres apart, each day of her life. After retirement, she had dedicated some days to looking after her grandchildren and used the remaining days doing volunteer work, mostly walking to places. She had a good life, had a favourite granddaughter and a favourite food. After carrying out a comprehensive geriatric assessment on her and obtaining more information from her family, staff, and clinical records, I consulted with the Geriatricians in reviewing her case as per our service protocol. Recommendations were made, and I referred her to another specialist team for follow-up, as the outcome was not within the scope of our service specialty. I had reflected on this referral previously and had asked how else we could have met her needs to walk or how could the healthcare system have assisted her to continue living the way she used to live actively, walking, enjoying the company of her family and

especially her favourite granddaughter and her favourite food. I had asked myself if any alternatives were available for her and if available, how to achieve them and if these were realistic. I was curious to research more for possible answers.

The third reason for choosing this research topic was the outcome of an education package project I designed for my Master's degree programme on Reminiscence Therapy. I adapted a study from a quasi-experimental design by Gonzalez et al. (2015). I recruited eight RN participants from five facilities to do an online module where they earned a certificate each from BMJ Online Learning as their professional development evidence. The second phase of the education package was for the participants to attend an education session presentation by me and a practical session on non-pharmacological interventions which I facilitated. I carried out pre- and post-evaluations on each session. The post-evaluation feedback showed a 100% uptake, and participants' comments indicated that they gained new knowledge and information to improve their practice from the education package and wanted to go and apply the knowledge gained in their practice. When it was time to choose a research project for this DHSc programme, I was convinced of the topic to choose and I allowed myself to be guided and expanded the project and participants so I could gain increased knowledge and current evidence from the study that could equip the students I teach on evidence-based practice, enabling them to make a difference in the care they provide persons/residents/patients/clients living with dementia.

1.12 Scope of the Study

This is a critical ethnography study, focussing on residents living with dementia who walked in two aged residential care facilities (ARC Facilities) in Auckland, a city in New Zealand. Initially, three facilities consented to participate in the study but due to the pandemic situation, which impacted each ARC Facility in different ways (as ARC Facilities had restrictions in place on visiting facilities due to increased number of cases of Omicron, a COVID-19 variant virus, in the community), the third Facility closed down. The benefit was weighed against the risk of carrying out research among the vulnerable older adults who needed to be protected and it was decided that the data collected from two facilities were substantial enough to be analysed to complete the study.

1.13 Research Question

How do residential care staff provide relational and supportive interventions for residents living with dementia who walk?

1.14 Research aims

This study aims to provide an explanation using social constructionist theory (Burr, 2015) on the meaning of the walking of residents with dementia, and the relational care the residential care staff provide to support their walking.

The study has five aims:

- to explore the perspectives on walking from all participants; to investigate the interventions being provided to the residents by the residential care staff
- to investigate the relational and supportive interventions provided to the residents with dementia who walk
- to explore the concept of person-centred care from the approaches being provided
- to examine the impact of the built environment on the walking of the residents and lastly
- to contribute to the destigmatisation of the residents with dementia who walk by advocating for a shift to using language that dignifies them for their optimal support

1.15 The Significance of the Study

The overall significance of this critical ethnography study is to find alternative and better ways to support residents living with dementia who walk to live well holistically, free of stigma, to enhance their quality of life and well-being. The study contributes to existing literature on the interventions provided by residential care staff in two of the aged residential care facilities in a city in New Zealand. The study intends to provide other constructions of knowledge on the perspectives on walking of the residents with dementia by giving authority to participants' voices through their quotes, to invoke social consciousness and awareness, and to see the person behind the walking first (Ulrich, 2005). The critical focus of the study is to investigate the relational support being provided for the residents by the staff and the residents' relational engagements with their living environments. The critical ethnography study further intends to contribute to existing knowledge and literature on the subjective experience of residents' meanings of their movement (Graham, 2015) and walking (Graham, 2015) and to identify new interventions that are person-centred focussed to add to existing literature on non-pharmacological interventions for residents with dementia who walk. Lastly, the study also intends to provide evidence for all stakeholders on the need for individualised or person-centred care (Best Practice Advocacy Centre New Zealand, 2008; Love & Pinkowitz, 2013).

1.16 Structure of Thesis

The overall structure of this thesis covers eight chapters.

Chapter One

Chapter One introduces the study, dementia, prevalence, BPSD, walking prevalence and types. It presents the prevalence, impact, and stigma of dementia and walking on the residents. It introduces the national strategies and the global strategies that guide the care being provided for persons with dementia. It also introduces the ARC facilities in New Zealand and the person-centred care focus. The chapter further presents the concepts applied in the study, such as personhood, person-centred care, social citizenship, social death and salutogenic approach to care. Chapter One further presents the scope of the study, the research question, aims, significance, positionality and motivation for the study, the structure of the thesis, and a summary of the chapter.

Chapter Two

Chapter Two presents the search strategy and reviews the literature on walking, especially the debate around the definition of the term. It reviews BPSD, personal and social costs of stigma, how negative use of language contributes to stigma, the voices of persons living with dementia and the economic implications of dementia. The chapter also reviews best practice guidelines, pharmacological and non-pharmacological interventions, the role of nurses, the research problem and the gap in the literature and concludes with a summary.

Chapter Three

Chapter three presents the research design with the ontology, epistemology, methodology, and methods used in conducting the research project. Social Constructionism, the theoretical orientation of the study and Critical ethnography are discussed extensively and their appropriateness for the study. Ethical considerations and approvals are presented and the recruitment process of four groups of participants for the study. The trustworthiness of the research was also discussed.

Chapter Four

Chapter Four begins by presenting the framework of the study, an integration of five stages of data collection for critical ethnography (Carspecken, 1996), and Braun and Clarke’s (2006) six phases of reflexive thematic analysis that were applied to the data. Chapter Four further presents details about the participant observations and reflections and methods used for the data collection of the study.

Chapter Five

Chapter Five presents the finding for Theme One ‘Perspectives on Walking’ Each of the four groups of participants (the residents with dementia, their EPAs, the RNs, and the HCAs) gave their views on what the walking of the residents meant to them and this theme was presented using the social constructionism critical lens.

Chapter Six

Chapter Six presents the findings for the second theme ‘Supporting Walking’. The various strategies and interventions used by the residential care staff (RCS) to interact and relate with the residents to support their walking are also presented with a critical lens.

Chapter Seven

Chapter Seven presents the findings for the third and last theme, ‘Environment and Walking’. This finding, evidenced by the participants’ quotes, reveals the role that environment plays in the walking of the residents with dementia. The chapter also presents a summary of the various suggestions from the participants to all stakeholders on improving the care for residents with dementia who walk.

Chapter Eight

Chapter Eight presents the summary of the findings and discusses them in line with the theoretical orientation of the study, comparing them with existing literature The chapter further answers the research question and identifies whether the aims of the study have been achieved or not. Furthermore, the chapter presents the original contribution of the study to knowledge, its implications to practice, education, building designs, research, policy, and makes recommendations. The chapter also presents the strengths and limitations of the study and concludes through the lens of social construction, provoking all stakeholders to allow their views to change through evidence constructed in the findings and to work collaboratively towards salutogenic and innovative ways to support the walking of the residents living with dementia in the ARC facilities in New Zealand and beyond. The study ends with a poem in support of normal life for residents and persons living with dementia.

1.17 Summary

In this chapter, I have introduced the study and provided the relevant background to dementia and walking with various definitions and descriptions of dementia. I have presented how it is not only a global health concern but a national health issue. I have

introduced the prevalence of dementia and walking, its progressive nature, BPSD, the impact of dementia and walking, and the stigma on individuals and their families. Also presented were the various national strategies supporting person-centred care goals for residents with dementia. The ARC Facilities in New Zealand have been presented with its well-monitored process for compliance for standard care delivery to residents with dementia by service providers having a contract with the Ministry of Health. The level of care provided by ARCFs, the process for admission for aged care and funding have also been discussed.

In addition, I have presented a summary of a study visit to a village, The Hogeweyk, The Netherlands, known for being a model for providing person-centred care to people living with dementia. Also presented the study visit locally to The CARE Village in Rotorua, inspired by the Hogeweyk care concepts. Furthermore, in the chapter, I have presented my positionality and motivation for the study, the research question, aims, scope, significance of the study and the structure of the thesis and concluded the chapter with a summary. The next chapter presents a review of the literature on the study.

Chapter 2 Literature Review

Dementia-ism underpins many of the shortfalls within service provision. Its eradication has to form part of the definition of person-centred care, if people with dementia are to be admitted as full members of the 'people club'. If this part of the definition is not made explicit in value statements, training, staff selection, standards, policies, and procedures, national frameworks, etc., then services will not maintain a person-centred approach for long (Dawn Brooker, 2004, p.217)

2.1 Introduction

This review focuses on the body of literature relevant to the debate on the definition of walking. It discusses the prevalence of dementia by ethnicity, the relationship between BPSD and walking, the personal and social cost of dementia brought about by the stigma attached to them, how negative use of language contributes to the stigma and reveals some views from persons living with dementia through their voices recorded and transcribed. It also examines the economic implications of dementia. The chapter goes further to review best practice guidelines on managing BPSD in persons with dementia, pharmacological and non-pharmacological interventions and the roles of nurses in caring for persons with dementia. In addition, the chapter identifies and highlights the research problem and gap in the literature that necessitated the study to be carried out. It states the research question and aims and provides a summary for the chapter.

2.2 Search Strategy

The search strategy involved databases through the university library website, starting with key terminologies in the research question. The databases were CINAHL Complete (via EBSCO), MEDLINE PLUS, Cochrane Library (via Wiley), Scopus, Joanna Briggs Institute Evidence-Based Practice, EBSCO health databases, MEDLINE (via EBSCO), ClinicalKey Nursing PsycINFO, and the Google Scholar search engine. The search also included relevant textbooks that discussed the topic to retrieve details. In addition, I explored grey literature found on the Ministry of Health website, World Health Organization, Alzheimers websites, Alzheimers Dementia International, and other similar websites. The search was conducted between 2018 and April 2019, when preparing for the confirmation of the candidature for the doctoral programme and was initially limited to the previous 10 years. However, as I read the articles, I discovered there were pioneers and scholars on dementia research whose work, written earlier, needed to be included in the review. As a result, I removed the date limiter and left the search open. By the time I presented for Confirmation of Candidature, I had retrieved over 200 articles. The literature I excluded included those that focused on acute and home-care settings. Furthermore, current literature was incorporated during the write-

up of the findings and their interpretations and during comparisons with existing literature.

Search terms used included a single or combinations of these words: dementia, nurses, nursing staff, dementia, Alzheimer*, wandering, walking, best practice, non-pharmacological interventions, non-drug interventions, pharmacological interventions, BPSD, behavioural and psychological symptoms of dementia, medication interventions, carers, healthcare staff, nurses' interventions, nursing homes, built environment, residential care facilities, aged residential care, long-term care, relational, supportive. Only the literature available in English focusing on persons with dementia, aged 65 or above were considered.

2.3 Estimated Prevalence of Dementia by Ethnicity

In New Zealand, dementia is often under-diagnosed (Cheung et al., 2022) and in other parts of the world, due to the stigma attached to it which means that people often do not get help or information needed for it. Māori that lived with dementia in 2011 were estimated to be 1,928. It is projected that by 2026, the number will reach 4,500. With no formal statistics, it was estimated that the number of Māori could be higher, as older Māori are less likely to access primary care for consultation and treatment (Dudley et al., 2019). In 2016, the prevalence of persons who lived with dementia after the age of 75 years was higher among females (35,254 or 56.6%) compared to males (27,033 or 44.4%) (Deloitte, 2017). The estimated 170,212 increase of persons that will live with dementia by 2050 reflects 2.9% of New Zealanders, 59% is predicted to be female while 41% will be male (Deloitte, 2017). By ethnicity, a projection for 2038 suggested that the prevalence of dementia in total will change from what it was in 2016. Prevalence among European or other unspecified ethnicities will decrease from 87.5% to 77.0%; Asians will increase from 5.1% to 11.7%; Māori from 5.1% to 8.0% while Pacific peoples will increase from 2.3% to 3.3% (Deloitte, 2017). A recent study linking seven health data sets over four years from July 2016 July to June 2020 found that the crude prevalence of dementia diagnosis over 60 years and above is 3.8% to 4.0%, while among 80 years and above, it is between 13.7% to 14.4% (Cheung et al., 2022). . The prevalence of dementia in its early or mild stage is 55%. The persons diagnosed are still able to carry out their daily functions with minimal assistance. At moderate stage, the prevalence is 30%, with assistance required for most daily tasks while the severe stage estimate is 15%, with full dependence on others for activities of daily living (Deloitte, 2017).

There is scant information and a dearth of studies on the epidemiology or prevalence specifically for dementia in New Zealand. As a result, estimates were based on international sources and Australasia and estimates from consultation with General Practitioners and informal carers (Deloitte, 2017). A study found was focused on Older Person's Ability Level (OPAL) scores and it was carried out in ARC Facilities from 1988 to 2008 (Boyd et al., 2010). The findings indicated that there was an increase of 2% in residents with occasional wandering from 10% to 12%; an increase of 3% from 4% to 7%; and in the rest home, an increase from 5% to 8% in those wandering.

Walking in persons living with dementia has been socially constructed to be problematic to manage (Brittain et al., 2017). Walking by residents living with dementia has been stigmatised because dementia has been pathologised by the biomedical model due to its focus on treatment (Kitwood, 1997). The media also has contributed to the dehumanisation of the persons living with dementia by their portrayal of persons diagnosed, attributing the causes as medical and conveying negative effects on the family while portraying the persons as ”powerless, child-like, vulnerable, dependent and a burden“ (Cullum et al., 2020, p. 27).

It is of relevance to this study to note that there are no published statistics or studies found on the prevalence of persons living with dementia who walk in New Zealand. A possible reason may be the predictable but not well-reported increased behavioural and psychological symptoms of dementia (BPSD), which makes it challenging to record these events.

2.4 Behavioural and Psychological Symptoms of Dementia and Walking

As dementia progresses, some people exhibit increased symptoms, classified as Behavioural and Psychological Symptoms of Dementia (BPSD), which describe “a broad range of psychological reactions, psychiatric symptoms and behaviours occurring in people with any form of dementia” (Scott et al., 2015, p. 359). BPSD fluctuates in the majority of persons with dementia, “causing great suffering” (Calsolaro et al., 2021, p. 2). One of these symptoms is walking (Graham, 2015), commonly referred to as “wandering” (Yamakawa et al., 2014). As dementia is pathologised, so too are the movements of the persons diagnosed. As a result, when a person with dementia walks beyond certain parameters laid out for them, they are labelled as ‘wanderers, which carries social stigma, whereas if a non-diagnosed person with dementia goes beyond that same boundary, they are not labelled nor given derogatory names (Graham, 2015).

2.5 Definition of 'Walking' Debate

There have been debates on what 'walking' in residents with dementia means over the decades (Brittain et al., 2017; Dewing et al., 2016; Graham, 2015), and this in itself has become a "persistent problem" (Cipriani et al., 2014) with literature on its own. There has been no agreed standard definition of wandering as there are so many perspectives and questions raised. Such questions include: What determines walking? How far does a person have to go to be referred to as wandering? When does walking become wandering? What types of movements are being referred to? (Brittain et al., 2017; Graham, 2015). In addition, scholars did not agree on the intentionality of persons who walk or the aetiology of walking or its benefits (Dewing, 2006; Jeong et al., 2016; Robinson et al., 2014; Robinson et al., 2006). To further show the complexity of agreeing to a standard definition, an author developed 70 definitions in her doctoral work over the years (Dewing et al., 2006) and in addition, other authors view some descriptions of walking ('wandering') as problematic (Brittain et al., 2017).

A group of researchers, building on the existing definitions of walking argued why previous definitions did not capture what walking was and instead proposed a scientific definition. Some of their arguments were - using Alzheimers disease as an example, that 'walking' was not the same as agitation, that it was not swaying or shifting foot, though it could related. In addition, they put forward that 'walking' was not "spatial disorientation or navigational deficits" (Algase et al., 2007, p. 688). Based on their critique of existing definitions, they put forward a definition they perceived was more comprehensive. Walking, in their view is "a syndrome of dementia-related locomotion behaviour having a frequent, repetitive, temporally-disordered, and/or spatially-disordered nature that is manifested in lapping, random, and/or pacing patterns some of which are associated with eloping, eloping attempts, or getting lost unless accompanied" (Algase et al., 2007, p. 696).

Other groups of researchers defined or described walking from other perspectives such as a common behaviour of BPSD that leads to getting lost, losing weight, and a reason for earlier admission to aged residential care (Jeong et al., 2016). Walking is a collection of a group of abnormalities in behaviours which include aimless walking, checking, exercises, pottering, walking in the night, attempts to exit a personal or care home, having to be brought back home and walking with frequencies not appropriate or purpose (Jayasekara, 2009). It is a disoriented walking behaviour in different ways such as pacing or lapping (Kwak et al., 2015) and an agitated behaviour or agitation (Brittain et al., 2017). Walking is also viewed as a normal action in human beings, and

others view it as walking aimlessly, and “the inability of older adult with dementia to find their way while pursuing a need or goal” (Adekoya & Guse, 2022, p. 239).

Another group describe ‘walking’ as a behaviour that is challenging and a safety problem in care homes (Schonfeld et al., 2007). To them, walking is not limited to the use of two legs but it can involve the use of mobility aids such as wheelchairs or walking sticks (Schonfeld et al., 2007). Some studies refer to walking as aimlessness, without a purpose, which carries negative connotations and stigma (Graham, 2015), while another regards it as a complex collection of different behavioural abnormalities in dementia, including checking; pottering; aimless walking; walking with inappropriate purpose; walking with appropriate purpose but inappropriate frequency; excessive activity; night-time walking; brought back home and attempts to leave home (Cognitive Decline Partnership Centre, 2016; Robinson et al., 2006). Other researchers focus on walking as having a purpose (Kiely et al., 2000). Moreover, some researchers stated that walking has been used confusingly to mean agitation (Cipriani et al., 2014). Walking has been described as challenging for caregivers (Lai & Arthur 2003). Another description of walking put forward was when a person is lost or when their walking away is dangerous for them (Rowe, 2008). Some scholars viewed the walking activity as constituting a high social burden for family carers and the cause of burnout for nurses (Murata et al., 2022; Turner, 2005; van de Linde et al., 2013). While a group of scholars including ‘elopement’, ‘exiting’, ‘getting lost’ or ‘missing’ as part of their definition of walking/wandering, others thought it was time to clarify the differences between wandering and elopement, attempt to elope or getting lost alone (Algase et al., 2007; Rowe et al., 2011).

Various studies have identified different prevalence of walking considered problematic in persons living with dementia. Brittain et al. (2017) and Cipriano (2014) suggested that 20% of persons with dementia walk during the trajectory of the syndrome, and Murata et al. (2022) identified that worldwide, 30% of older adults with severe cognitive decline developed the walking behaviours. Robinson et al. (2006) stated that 15%-60% persons with dementia walk (Cerejeira et al., 2012; Robinson et al., 2006) while Lai and Arthur (2003) found that up to 50% of older people with severe dementia walk. These variations in prevalence suggest the need for approaches that provide individually tailored interventions for persons with dementia. The movements of persons who live with dementia have been given many labels, such as wandering, elopement, or exit-seeking, which are socially constructed (George, 2010; Graham, 2015; Kitwood, 1997). While there is no consensus on a definition for wandering, what is clear is that the term ‘wandering’ connotes a label, a stigma, and is socially constructed. The social justice question is why a person diagnosed with dementia is regarded as a wanderer and their

movement is regarded as wandering if they walk outside a certain space laid down for them, but when another individual with no diagnosis of dementia goes outside that same space, it is regarded as normal and not wandering (Graham, 2015).

Three factors have been identified that could explain why some residents and persons with dementia walk: a lifelong strategy of coping with stress, a search for place or person that provides security and previous profession before the diagnosis (Goldsmith et al., 1995). Walking can also be triggered when the environment is unfamiliar to the person (Hong & Song, 2009). Walking usually occurs when the person with dementia is alone by themselves (Kolanowski et al., 2002; Rowe et al., 2011).

Some researchers in describing or defining walking focussed on the outcomes of walking for the residents, stating that they may get lost, suffer abuse, lose weight, experience sleep disturbance, fatigue, accidents, be at risks of falls that may lead to fractures or hospitalisation and may ultimately be fatal (Blake, 2014; Gu, 2015; Murata, 2022; Rowe, 2008; Schonfeld et al., 2007). Elopement is viewed as the most dangerous form of walking as it involves running away from a safe place into danger (Rowe et al., 2011).

Preventive measures have been suggested by some experts and researchers (Gu, 2015) to prevent the outcome of danger some persons with dementia experience. With human rights legislation and evolving research a couple of these measures may require ethical considerations:

- Use of mirrors: A study conducted to determine whether the use of mirrors would deter ‘wandering’ in persons with dementia was carried out over a two-week period with mirrors placed at the exit doors of a psychogeriatric ward. The reduction rate of exiting was from 76.2% to 35.7% (Mayer & Darby, 1991). Another study carried out with 100 patients with dementia used mirrors to determine if a change in behaviour would occur recorded positive outcomes looking into the mirror reminded patients of self-care and enhanced communication between the patients and staff (Tabak et al., 1996).
- Camouflaging exit doors and changing the floor patterns or carpet: – this intervention was recorded as not as effective as the other interventions (Robert, 1999).
- Electronic tagging system (Miskelly, 2004). This involved the persons with dementia who walked given electronic bracelets to wear at various settings such as inpatient, residential and home for different duration. The outcome was recorded as successful with excellent compliance. It however raised ethical questions on tagging cognitively impaired persons without their consents.

- Non-pharmacological interventions: These interventions beneficial in encouraging more staff-resident interactions in following key areas of non-medications strategies (Allen-Burge et al, 1999), environment interventions (Yao & Algase, 20008) and behavioural interventions (Kohn & Surti, 2008).
- Increasing staff–resident interaction interventions (Goldsmith et al., 1995; Okawa et al., 1991).
- Environmental interventions – Points to consider: architectural designs, low stress and noise, establishing familiar feeling with environment (Yao & Algase, 2008)
- Behavioural interventions – for instance checking resident has proper hearing aid, glasses, dentures (Kohn & Surti 2008, p. .337).
- Upskilling and training of staff on various ways to manage changing behaviours of residents with dementia (Allen-Burge et al. 1999).
- Organisation policy-led interventions – this includes organisation polices such as specific wandering screening tests carried out during admission or policy on individual care planning (Moor et al, 2009).

As the debates on reaching a consensus definition on walking continues, solutions are being put forward towards supporting the residents to have optimal quality of life. In recent years, there has been advocacy to shift from labelling persons or residents with dementia who walk as ‘wanderers’ or using pathologised language (Frandsen, 2009; Graham, 2015; Ulrich, 2005). Some scholars have argued that it is the resident/person’s unvoiced needs which are unmet that are responsible for their walking. The shift from a negative social construction and labelling (Graham, 2015) to a focus on understanding the individual living with dementia is growing and it is highlighting a person-centred care approach (Kitwood, 1993). The shift also encourages the use of dementia-friendly language and words in describing the individuals, their condition, and their carers (Dementia Australia, 2022). They further put forward that to meet these needs, the individual histories, lifestyles, and collateral information from their whanau (family) need to be taken into account so that their personhood can be understood and appropriate interventions planned that meet their needs (Graham, 2015). For the purposes of this study, I have adopted term “the residents (living) with dementia who walk” in line with the language shift.

While to some authors, walking has been described as negative that can be distressing for the person living with dementia and their families, to other authors, the question is whose parameter was used to measure and determine what walking is(Graham, 2015). Walking has also been said to pose a great challenge to the nursing staff ability to fulfil duty of care in balancing the residents’ freedom to walk with their responsibilities to

keep the residents safe at all times. In addition, staff also have a duty of care to other residents allocated to their care. A possible question asked is whether simple modification of the environment could bring positive effect and change the walking behaviour residents (Cipriani et al., 2014). This raises the issue of disempowerment of the persons living with dementia and their autonomy. It has been argued that the unmet needs of the persons living with dementia who walk which they may no longer be able to verbally express include loneliness, pain, looking for someone, hunger, thirst, or wanting to leave a noisy environment (Graham, 2015). Their movement phenomenon is an individual experience, so, it has been argued that there needs to be a shift from labelling them as wanderers to using dementia-friendly language of dignity to describe them and their movements (Cognitive Decline Partnership Centre [CDPC], 2016).

Usually, residents with dementia have varying degrees of physical vulnerability with underlying co-morbidities, and they are often on medications that may further lead to the deterioration of their cognitive functions and health. If they sustain fractures, these may substantially reduce their quality of life (Ballard et al., 2011). Injuries through falls may lead to hospital admission, extended hospital stays with other complications, and sometimes mortality. Hospitalisation incurs substantial healthcare costs for the government, which further adds to the discordances. In exploring new areas of research regarding walking of the residents with dementia, the World Health Organization (2024b) commented on the use of chemical and physical restraints in some homes caring for older people and even in acute settings despite regulations that “uphold the rights of people to freedom and choice” (World Health Organization, 2024b, para. 16). Staff in residential care facilities may prioritise a routine work pattern, particularly when there are staffing shortages, and therefore consider the residents' walking problematic in achieving their goals of tasks completion. The residents who walk themselves experience reality and time in a different way from the other residents who do not walk (Kolanowski et al., 2010) and desperately need staff who understand, empathise, and can walk with them to meet their psychological needs and holistic well-being (Kitwood, 1997).

2.6 The Stigma: Personal and Social Cost of Dementia

The following section presents some descriptions and definitions of stigma and discusses how it relates to dementia and walking. “Stigma is one of the biggest barriers for people living with dementia to live fully with dignity and respect” (Dementia New Zealand, 2023b, para. 1). “When a person is labelled by their illness, it creates an “us and them” divide, where the person is seen as the illness and not who they are as an individual” (Alzheimer’s Western Australia, n.d.). Goffman, in his classical work, (1963),

referred to stigma as “an attribute that is deeply discrediting” (p. 3) and “an undesired differentness from what we had anticipated ” (p. 4). Stigma is regarded as “marked differences from what is ‘normal’ for a group of people, and to negative emotional and/or behavioural responses to those differences” (Young et al., 2019, p. 17).

These meanings suggest that dementia has negative connotations that isolate persons post-diagnosis (Alzheimer’s New Zealand, 2024). However, this is not so with other diagnoses such as diabetes. The components of stigma include power, stereotypes, prejudice, and discrimination (Young et al., 2019). Persons diagnosed with dementia may experience significant fears of not being independent and losing one’s memory. As a result, Individuals diagnosed with dementia do not want this illness. Even when they suspect they have the symptoms, they do not seek an early diagnosis because of the stigma, de-inclusivity, and dehumanisation that they will experience as a result, as they are reduced to their illness and seen as socially dead (Brannelly, 2011; Kitwood, 1997; Sweeting, 1997). Individuals diagnosed are aware there is no cure for dementia, they perceive themselves as objects of their illness and feel embarrassed to seek the help they need to maintain a good quality of life (Power, 2017; Rahman, 2015). Stereotyping has occurred through labelling and stigmatisation of the diagnosed individuals which impacts the person psychologically, socially, and in other ways together with their families, the caregivers, the healthcare system, and the society at large (Gerand et al., 2009). In addition, Dementia has been described as a condition with long good-bye, a condition of living death, or the worst illness a person could have, which suggests that the person who is affected slowly disappears (Power, 2017).

The newsprint media also contribute to the social construction and stigmatisation of dementia (Cullum et al., 2020). An evaluation of newsprint media coverage on dementia in New Zealand over four years from 2012 to 2016 indicated in one of the findings that medical causes were responsible for the negative social construction and the impact on the person, their families, and society were negative, with high catastrophic effect on the person diagnosed (Cullum et al., 2020). Expressions used by the media to portray the person living with dementia often described them as having lost their personhood, that they are vulnerable to being abused, and likely to end in aged residential care. Furthermore, the persons diagnosed with dementia were regarded as “powerless victims of their disease, victims of their carers, and victims of health and social care services”(Cullum et al, 2020, p. 25). In addition, Cullum et al. (2020) evaluated media as portraying persons with dementia as “powerless victims of their circumstances, and powerless to alter their prognosis, contributing to victimhood frame” (p. 26). It also suggests that the persons diagnosed were blamed for their “lifestyle choices” (p. 26) due to the impact of dementia on social care and health

systems. The medical model has identified modifiable causes as a cause of dementia and these include those that sustained head injuries as a result of rugby sports.

These are all social constructions of the persons living with dementia and persons living with dementia who walk. Persons with dementia acknowledge the cause of nature and the ageing brain, and while they cannot provide answers to its occurrence, they are making the best use of opportunities available to them. An example is Kate Swaffer (Alzheimer's Society, 2024; kateswaffer.com, n. d.), who has written books about her lived experiences and advocates for others living with dementia, including raising awareness about the clinical syndrome of dementia (Alzheimer's Society, 2024).

Inadvertently, well-meaning organisations, groups, and advocates, when promoting dementia awareness have used stigmatising language, words, and expressions that they did not realise have negative connotations (Power, 2017). In education, topics and explanations about dementia are stigmatised and the words used dehumanise persons living with dementia, creating fear of the syndrome as well as a barrier to people to go for early diagnosis. Such expressions include: 'dementia as a condition where new learning cannot take place'; 'people with dementia cannot make decisions independently' and 'their caregivers are taking over to make decisions for them'. Such expressions create obstacles for persons having symptoms to seek early help early as they know how they will be dehumanised, treated, secluded and stigmatised in the society. Furthermore, the experiences of people with dementia are also labelled as challenging behaviours or behavioural problems. On this, Power (2017) stated that medication interventions have not had much effect as this behaviour reflects more of the imbalances of chemicals in the brains of those affected and recommends a different way of describing such behaviour as "changing behaviours". Providing interventions to the persons living with dementia has to be approached with humaneness, empathy, and respect for their personhood (Kitwood, 1997, Brooker, 2007; George, 2010; Power, 2017).

The example of a non-communicable disease below, taken from Power (2017), a certified internist geriatrician, serves to invoke consciousness and awareness of the situation the persons living with dementia are in:

> imagine for a few moments that you have been diagnosed with diabetes. I am choosing this disease because it is a common condition about which most of us have a fair degree of awareness. It [diabetes] is incurable, but treatments are available… Imagine that you are not feeling quite right, and so you visit your physician to find out what is wrong … How would you feel if your doctor insisted

> that your spouse, son, or daughter accompany you to your follow-up visit? The doctor [during the consultation] speaks to your family member instead of directly to you and says: “Your loved one has diabetes. This is an incurable and progressive disease; everyone who is diagnosed with diabetes will die. I think that you need to start thinking about planning for when your loved one can no longer do things without assistance and start talking about advanced directives for end-of-life care”. I doubt that most people receive the news of diabetes in such dire terms. And yet this is common when someone receives a diagnosis of dementia, even when it is in its very early stages. (p.22-23)

In addition to the above, the current global drive towards being fit and healthy, aided by mass media promotions, has driven many persons living with dementia into living in a disenfranchised way, to feel helpless about the situation (Rahman, 2015). Furthermore to societal attitudes and discrimination, persons with dementia are intrinsically affected, withdrawn, and dying internally even before the trajectory of the syndrome takes its course. Power (2017) sums up this negative impact on them, stating, “dementia is a powerful label that starts a long slide into the world of disempowerment, often long before abilities are lost” (p. 23).

Strategies to reduce stigma include public awareness of dementia, education and public advocacy led by persons with dementia (Young et al., 2019) as stigma stems from what is not known about the syndrome. In addition, involving persons with dementia in activities and performances as an “art-based approach” (Young et al., 2019, p. 19) such as music performance and short films are other strategies to showcase what their capabilities are. In addition, “challenging negative stereotypes” (Young et al., 2019, p. 19) and prejudices, creating specialised education on dementia and in public policy (Young et al., 2019) such as in employment settings, “adjusting power imbalances” (Young et al., 2019, p. 19) socially, economically or politically relating to their care and including more persons with dementia in social life, advocacy and in research are other ways to remove stigma in persons living with dementia (Young et al., 2019).

2.7 Negative Use of Language Contributes to Stigma

The use of language and choice of words when talking to, describing, or referring to residents or persons with dementia who walk and those who do not walk can impact negatively and contribute to stereotypes, discrimination, and stigma (Alzheimer’s Western Australia, 2024; Dementia New Zealand, 2023; Vafeas & Slatyer, 2021). It also impacts their families, even when unintentionally done and this contributes to the stigma attached to persons with dementia which easily diminishes their self-esteem

(Alzheimer's Western Australia, 2024). This, in turn, leads to social withdrawal and isolation. Language is a powerful tool that influences the way people think, perceive, and interact with persons with dementia (Alzheimer's Australia, 2024; Vafeas & Slatyer, 2021) and builds barriers between them and other people in the community (Alzheimers New Zealand, 2024; Alzheimer's Western Australia, 2024; Dementia New Zealand, 2023). To destigmatise, it is important to use language that empowers and enables the residents with dementia. It is beneficial to use language that focuses on what they can still do, not on what they cannot (Vafaes & Slaytyer, 2021).

2.8 Voices of Persons Living with Dementia - Dementia Diaries

Dementia Diaries (Dementia Diaries, n.d.) is a website with a collection of over 3,000 audio and video diaries of the lived experiences of persons with dementia for public access. It is a UK-based project where the diverse experiences of daily lives are recorded and transcribed as public records with the goal that public attitudes toward them will change. Two of the voices, Dory and James, are presented below to draw attention to the experiences of other persons living with dementia. The transcripts of their recordings are as follows:

> Hi, this is Dory and I'm lost but I'm not alone, so that's a good thing. People might say I'm wandering but I'm wandering with a purpose, trying to find our way home. We've been through fields and muck, sheep – and s[---]! (Laughs) I have fallen in the mud – and why is it, when you fall, you always land on your bad knee?
>
> Anyway, I'm covered in mud, but it's been lovely to be out in the – with nature and we're still trying to find our way home. The sun's shining but it's very cold, but with walking we're nice and warm. So, I'll carry on.(Laughs). We can see home – we're just so near but so far away! (Laughs.) Ok, bye.

(Dory's Video diary, Having a Voice, Dementia Diaries, posted 12 February 2021)

Above, Dory, (Dementia Diaries, 2021), shared her experience of walking, giving a sense that she was with other persons with dementia who walked, so she was not alone. Despite having lost her way, stepping on dirt and possibly hurting herself, she still enjoyed walking as she expressed her enjoyment of connecting with nature. She articulated her sense of 'walking for a purpose' - to find her way home. She also revealed her sense of humour that must have been part of her personality. Next is the voice of James:

> Good sunny afternoon. James, speaking, thanking you for sitting there, doing all this.
>
> I was at a conference on the 6th June 2001, and I heard the words used to describe us: suffering with dementia, dementia sufferer, demented – so on the 10th June 2001, I wrote an article, describing how this is a terrible thing to do, terrible words to use, and over the years I have sent to every national newspaper that used these words, and it was over 19 years before I got one reply; I was totally ignored. So, I sometimes see this cropping up again; as I said, I've been trying since 2001 to raise this issue.
>
> I remember being at a conference and I think there was a professor, a doctor professor or something, called us demented people. So, I challenged him, and he says, that's right – people with epilepsy are epileptics, people with diabetes are diabetic, people with dementia are demented. So, we got into an argument and the Chair had to intervene. And afterwards, people came up, congratulating me.
>
> What I don't understand is, doctors get I think seven years' training, and they don't seem to realise that demented is a totally different condition from having dementia. They should go to a dictionary, read up the word 'demented' and see that it does not apply to us people living with dementia. Bye bye.
>
> (James's Video diary, Dementia/Public Perceptions, Dementia Diaries, posted 25 March 2021)

James (Dementia Diaries, 2021) spoke about his efforts to correct the derogatory language used to describe dementia or people living with it. He recounted an occasion at a conference where he argues with a professor on his use of the word 'demented' as he had high expectation from the educated professor to know what not to use as words in describing him and others that live with dementia as they still have capacities and abilities to do various things. James advocated for himself and for people living with dementia.

It is evident that persons living with dementia are affected by the language the society uses to address or describe them. Words or language used for them should reinforce their abilities and capabilities. This is the support James was asking for from the public, and he advocated to remove the negative social construction and stigma around dementia that prevented them from living their normal lives.

2.9 Economic Implications

Dementia poses increasing challenge in developed countries economically and within their healthcare systems. Moreover, the care of persons with dementia is being changed from a medical model of care to an approach that focuses on meeting individual needs (O'Sullivan et al., 2013). Records below indicate that the economic cost of dementia care is high, although no comparative statistics or study was found comparing these costs with the costs of other medical conditions. In 2018, dementia was said to be "one of New Zealand's greatest health and social challenges which was now at a tipping point" (Health Central New Zealand, 2018, para. 2). The cost of caring for the population affected was $954.8 million in 2011, covering General Practitioner consultations, pharmaceuticals, and residential care (Ministry of Health, 2013). In 2016, the cost of care was estimated at $1.676 billion, an increase of 75% from 2011, which is likely to go up to $2.7 billion by 2030 (Alzheimer's New Zealand, 2017). The actual cost per person in 2016 was $26,904, with a total cost of $1.7billion for all the people affected, including production loss, resources spent, and value of the disease, value of loss of healthy life as a result of the disease (Alzheimers New Zealand, 2017). In 2016, aged care costs were $849.2 million, the cost for those in the community was $67.3 million, hospital inpatient cost was $159.9 million, outpatient cost was $13.8 million, pharmaceuticals cost was $0.8 million while research cost was approximately $4.8 million. All these costs were over 80% more than the expenditure in 2011 and over 150% than it cost the government in 2008 (Alzheimers New Zealand, 2017). By 2050, due to the ageing population, the number of people living with dementia is likely to reach 170,212. The estimated total cost of caring for people with dementia in New Zealand in 2018 was $1.7 billion (Alzheimers New Zealand, 2018). By 2040, it is projected to increase to $3.8 billion annually (Alzheimers New Zealand, 2017), and by 2050, it will reach an estimate of $5 billion (Alzheimers New Zealand, 2018). These costs from a critical lens are good investments to future-proof better quality of life and living for persons with dementia and their well-being. However, in these records, there is no mention of extra budgeting for persons living with dementia ' who walk', as they need to be well supported as well with their walking.

2.10 Best Practice Guidelines

The National Institute for Health and Care Excellence (NICE) and their counterpart in New Zealand, Best Practice Advocacy Centre New Zealand (BPACNZ), advocate and communicate best practice which is evidence-based to health and medical practitioners in New Zealand for managing episodes of BPSD in persons with dementia. Their guidelines recommend using non-pharmacological interventions such as music, massage, reminiscence therapy, cognitive stimulation therapy, and exercise (Azcurra,

2012; BPACNZ, 2024; Cohen-Mansfield, 2005; NICE, 2024) as first interventions in managing BPSD in persons living with dementia. Psychotropic medications were discouraged from being prescribed or administered as the overall risks were found to outweigh their overall benefits (Drug Therapeutic Bulletin, 2014; NICE, 2024; BPACNZ, 2022). Anti-psychotic interventions are recommended to be taken as a last resort only when the person's actions pose a danger to them or those around them (BPACNZ, 2022: Drug and Therapeutics Bulletin, 2014; NICE, 2024). In addition, it is recommended that staff carry out various assessments to understand the cause(s) of resident's behaviour that poses harm and to mitigate where possible (Best Practice Advocacy Centre [BPAC], 2022; NICE, 2024).

The guidelines clarify what to do if evidence for the need for anti-psychotic medications is not strong enough and the risk is low: it recommends non-pharmacological interventions to be considered first as they are person-centred and tailored towards meeting the resident's needs, with the persons' progress monitored (BPAC, 2022; NICE, 2022). Experts have commented that even though these guidelines exist (Best Practice Advocacy Centre, 2022; NICE, 2022), they are rarely or universally implemented (Cognitive Decline Partnership Centre, 2016; Cohen-Mansfield & Jensen, 2008). A systematic review done by Janus et al. (2016) compared the use of psychotropic prescribed medications in various nursing homes in Western European countries and the result showed that the use of antidepressants by residents was between 19% to 68% while the use of antipsychotic medications ranged from 12% to 59%. The complexity of the situation was that 'there is no one size fits all' in managing the BPSD, including walking, as the neuropsychiatric symptoms are different for each individual living with dementia (Livingston, 2014). However, it was recommended that with adequate staffing, accurate assessment, and good history gathering, person-centred care is the better option. Non-pharmacological interventions have been advocated as first interventions in many studies as they are safer for residents and are person-centre focussed. Some experts commented on the implication of this recommendation of non-pharmacological interventions as first interventions, noting that more time is spent with residents, resulting in higher cost of care and higher level of depressive symptoms and distress for caregivers, especially if they are not skilled (Gitlin et al., 2010). However, Cohen-Mansfield (2005) and de Oliveira et al. (2015) argued that non-pharmacological interventions are effective as they reduce agitation, offer comfort, positive experience, enhance cognition, improve socialisation, and enable some of the residents to carry out their Activities of Daily Living (ADLs) independently.

2.11 Pharmacological Interventions

Antipsychotics constitute the main pharmacological interventions for alleviating BPSD in residents (Calsolaro et al., 2021). Examples are Haloperidol noted as overprescribed (NIHER, 2022), Quetiapine, Risperidone, and Clozapine (BPACNZ, 2022; Drug and Therapeutics Bulletin, 2014; NICE, 2024). The effects include over-sedation, postural hypotension, dizziness, weakness, increased fall risks, fractures, dyskinesia, urinary incontinence, malnutrition, dehydration, increased overuse, cognitive decline, increased risks of cardiovascular events, hospitalisations, extended hospitalisations, and increased mortalities (BPACNZ, 2022; Best Practice Journal, 2013; Blake, 2014; Drugs and Therapeutics Bulletin, 2014; Livingston et al.; 2014; National Collaborating Centre for Mental Health, 2007; NICE, 2024; Thomas, 2010).

As introduced in Chapter One, many aged care facilities worldwide were found to routinely administer antipsychotic medications to manage BPSD in residents. Examples of the medications are Quetiapine, Risperidone, Clozapine, Quetiapine and Olanzapine as the first line of treatment in managing BPSD in residents which is against best practice guidelines (Blake, 2014; Ervin et al., 2012; Gee & Coucher, 2011; Turner, 2005). One study suggested that nurses influence GPs to prescribe these medications (Blake, 2014). This widespread practice was questioned and has met strong criticisms (Ervin et al., 2013; Martini de Oliveira, 2015) due to the adverse and undesirable effects on the residents such as overuse, sedation, dizziness postural hypotension, gait disturbance, increased falls, cognitive decline, dyskinesia, Parkinsonism, incontinence, dehydration, malnutrition, increased cardiovascular events, hospitalisation, extended hospital stays, reduced quality of life and mortalities (Ballard et al., 1999; Best Practice Advocacy Centre, 2022; Blake 2014; Calsolaro et al., 2021; Dewing, 2006; Drugs and Therapeutics Bulletin, 2014; Ervin et al., 2013; Gee & Coucher, 2011; Gonzalez et al., 2015; Livingston et al., 2014; New Zealand Medicine and Medical Devices Safety Authority (MEDSAFE), 2015, Thomas, 2010; Turner, 2005). Administering Haloperidol to a resident with Dementia with Lewy bodies (DLB) causes dangerous extrapyramidal effects, complicating their morbid condition; and for those with Parkinson's Disease dementia, their motor condition worsen (BPACNZ, 2018; National Institute for Care Excellence, 2019). In this study, I aim to investigate the practice of the residential care staff on what interventions they provide residents with dementia who walked in their ARC Facilities.

2.12 Non-Pharmacological Interventions

Non-pharmacological interventions aim at person-centred care, which are in line with best practice guidelines as first interventions, adhere to the principles of person-

centred care and are individually tailored to meet the needs of the residents with dementia who walk (BPACNZ, 2022; Ministry of Health, 2013; NICE, 2018). Examples have been discussed in the literature, such as music, massage, reminiscence therapy, cognitive stimulation therapy, touch massage (touch therapy), physical exercises, aromatherapy, light therapy, animal-assisted therapy, arts therapy, acupuncture, light stimulation, sensory touch, recreational activities, and validation therapy (Azcurra, 2012; Cohen-Mansfield, 2005; Cooney et al., 2014; Curtin, 2010; de Oliveira et al., 2015; Macleod et al., 2021; O'Neil et al., 2011). While some researchers discussed specific intervention or specific group of interventions, such as behavioural techniques for non-confrontational interactions and distractions (Kolanowski et al., 2010), others focused on classifying all known interventions into groups. The following is a classification of interventions into five groups according to their functions as proposed by O'Neil et al. (2011):

- Group one –cognitive or emotion-oriented interventions such as validated therapy, simulated presence therapy, and reminiscence therapy;
- Group Two – sensory stimulation interventions, such as acupuncture, light therapy, aromatherapy, massage and touch, Snoezelen Multisensory Stimulation Therapy, Transcutaneous Electrical Nerve Stimulation (TENS), and music therapy;
- Group Three – Behaviour management techniques, such as communication training, habit training, behavioural or cognitive-behavioural therapy, and progressive muscle relaxation;
- Group Four – other psychosocial interventions such as animal-assisted therapy and exercise;
- Group Five – various interventions targeting specific behaviours such as walking, inappropriate sexual behaviour and agitation (O'Neil et al., 2011).

Various studies have been carried out to determine the effectiveness of some of these non-pharmacological interventions. A systematic review of non-pharmacological interventions provided strong evidence that cognition improved through using cognition stimulation therapies, emotional disorders were reduced through the use of music, daily activities were maintained or improved through the uses of light therapy and exercises, while behaviour responses were reduced significantly through using validation therapies, music, and sensory stimulation (Meyer et al., 2018). While every study on each non-pharmacological intervention was not able to show statistically significant results when compared to controls, there is consensus that the use of non-pharmacological interventions demonstrates a positive trend, as they enhance social interactions. In addition, they have no adverse effects on the person living with

dementia, and are individualised, allowing person-centred care to be achieved. Furthermore, their uses are based on understanding the person's unmet needs, history, and assessments. This understanding of their unmet needs emerges as the doorway to providing quality care and sustained health outcomes (BPACNZ, 2022; Cohen-Mansfield, 2005).

Moreover, various studies were carried out in various settings to demonstrate the effectiveness of non-pharmacological interventions: systematic reviews were carried out to investigate how non-pharmacological interventions of behavioural symptoms compare effectively with pharmacological approaches, with other non-pharmacological approaches, or with no treatment at all (de Oliveira et al., 2015; O'Neil, 2011). Other studies carried out explored quasi-experimental to determine the significant benefits of reminiscence therapy (Gonzalez et al., 2015). Furthermore, pilot-controlled trials were explored on the effectiveness of music as an intervention for the residents (Choi et al., 2009). Randomised control trials were also carried out to determine the effectiveness of Reminiscence Therapy (Azcurra, 2012), and another study was done to determine effectiveness of comparison of non-pharmacological intervention with each other, with pharmaceutical interventions, and with no treatment (O'Neil et al., 2011). Other studies were carried out to determine the effectiveness of non-pharmacological interventions in improving residents' functionality and psychosocial well-being (Choi et al., 2009; Gitlin et al., 2010). Despite all these studies demonstrating the effectiveness of non-pharmacological interventions in various settings worldwide (Azcurra, 2012; de Oliveira, 2015; Curtin, 2010 & O'Neil et al., 2011), there is evidence that these interventions are still not being provided for the residents with dementia who walk nor have they been delegated by nurses to other staff as first interventions as per guidelines on best practice (Drugs and Therapeutics Bulletin, 2014; National Collaborating Centre for Mental Health, 2007).

2.13 Role of Nurses

The role of nurses in caring for residents with dementia who walk cannot be underestimated nor over-emphasised as they are key to providing the complex care required. Nurses liaise with the residents' General Practitioners, Geriatricians, and other healthcare professionals who have input into residents' care (Hickman et al., 2016). In many cases, the GPs rely mostly on nurses for updates on the residents' health status during their routine reviews or emergencies. Ideally, the staffing ratio to residents (Scott et al., 2015) should be based on the number of patients and the nature of interventions to be carried out for each resident to allow tailored person-centred care (Kitwood, 1997). However, as discussed earlier, this is not usually the case as there

are staff shortages as well as focus on tasks to be carried out to the detriments of residents. RNs have a key role in care coordination. Nurses have influence to ensure that the social environment of the resident is positive so that the health and wellbeing of residents are enhanced (Vafeas & Slatyer, 2021).

The responsibilities of RNs include administration of medications and delegation of tasks to other unregulated nursing staff such as the health care assistants (HCAs). They also work collaboratively with all nursing staff, such as enrolled nurses, HCAs, and the multidisciplinary team of Physiotherapists, Diversional Therapists, and Activity Coordinators, in order to achieve the optimal health outcomes for each resident.

From the current prevalence of dementia in the community and the reality that walking, though undesired, occurs in one out of every person diagnosed and occurrence is about 15% to 60% and 50% in those at the severe last stage of the condition (Robinson et al., 2006), it is evident that there will be an increase of diverse needs when providing interventions to this population which all stakeholders need to prepare for in light of future increased projections of those who will live with dementia.

As New Zealand has grown to be a multicultural society, plans and strategies to address future challenges of diverse cultural needs among residents with dementia are urgently needed (O'Sullivan et al., 2013). The diversity is also a as result of immigration due to climate change (Piguet et al., 2011). Nurses' decisions to provide non-pharmacological interventions is based on various theoretical orientations and residential care staff (RCS) should base their clinical decisions on the whole person that a resident with dementia is and not look at their walking or movement as the problem (Cohen-Mansfield, 2005; Ulrich, 2005). The staff need to focus on what interactions that need to happen between the residents with dementia who walk and them, the environment, and the system of care. To provide the interventions, many factors have to be taken into consideration by nurses such as the possible causes of the behaviour (Cohen-Mansfield, 2005; Kolanowski et al., 2010). The phenomenon of walking may be a determined effort by the residents living with dementia to leave the care home as they would prefer to be in their own homes or they may be in search of someone or something. The walking may also be a result of unmet needs such as boredom, hunger, pain, loneliness, need for exercise, restlessness, or their premorbid active lifestyle (Cognitive Decline Partnership Centre [CDPC], 2016; Graham, 2015).

Health practitioners including nurses need to engage in self-questioning before providing any interventions to persons with dementia, such as asking themselves whether a resident's walking behaviour is a problem, and if it is, for whom is it a problem, for themselves or the resident with dementia (Cohen-Mansfield, 2005;

Kolanowski et al., 2010). Such questions should focus on the goals of the intervention, whose problem is being addressed, whose reality is being considered and whose needs and preferences need to be met. The authors postulated that answering such questions would lead to the ultimate goal of choosing the right intervention and treatment for person living with dementia. Further self-questioning that demonstrate critical thinking would lead the RNs to make appropriate clinical decisions for each resident. Other questions to ask include: the meaning of a selected non-pharmacological intervention for each resident, influence of each staff caring for the residents, if the intervention requires a simultaneous use of pharmacological and non-pharmacological and non-pharmacological interventions, whether the selected non-pharmacological intervention requires specialised training before it can be used, and whether other nursing staff or unregulated care staff are allowed to administer the medications. Other self-questions should focus on whether enough resources and time are needed to care for the residents have been allocated and if the subjective and objective information gathered about each resident is sufficient to inform which non-pharmacological intervention to provide. Issues of ethical dilemma also need to be addressed, such as applying tracking devices before they start walking around, far and wide. The residential care providers and the residential care staff, such as Clinical Managers; Care/Facility Managers; Clinical Coordinators; RNs; enrolled nurses (ENs); and health care assistants (HCAs), who work together in most independent non-governmental facilities, (Burrow et al., 2017), need creativity and interactive competence (Kitwood, 1997) to maintain duty of care in ensuring a balance between residents' safety and autonomy as residents need independence and social citizenship (Bartlett, 2022; Brannelly, 2011; Brooker, 2007; Cook et al., 2022; Human Rights Act 1993; Kitwood, 1997; Sweeting & Gilhooly, 1997).

2.14 The Research Problem and Gap in Literature

Literature searches were carried out to explore existing literature on the walking associated with dementia commonly, although problematically, referred to as wandering, among residents in aged care facilities. Literature was also reviewed on best practice as provided by residential care staff in aged residential facilities. The research problem was the evidence from the literature that antipsychotic medications are routinely being administered as first interventions in rural and urban ARC Facilities to manage BPSD in residents instead of non-pharmacological interventions as stipulated for health practitioners in Best Practice Guidelines nationally and internationally. Pharmacological interventions or chemical restraints are to be used as last resort when a resident is severely distressed and at immediate risk of harm to themselves and to others around them. Assessments are also advised to weigh the

evidence and to rule out causes that can be addressed using non-pharmacological interventions.

This study seeks to investigate the interventions residential care staff provide for residents with dementia who walk in two facilities in an urban centre in New Zealand. To date, no study has been carried out on interventions provided to residents living with dementia who walk in aged residential facilities in New Zealand. In addition, no study has explored the perspectives on walking behaviour from the perspectives of residents living with dementia who like to walk, the nursing staff and the Enduring Powers of Attorneys in New Zealand in order to identify better ways to enhance the care the residents receive.

Furthermore, no study was found on the prevalence of persons living with dementia who walk or on residents with dementia who walk in New Zealand. To gain a further understanding of this problem and collect evidence of interventions provided to the residents who walk, the following research question and five aims were formulated:

2.14.1 Research question

How do residential care staff provide relational and supportive interventions for residents living with dementia who walk?

The study aims:

- to explore the perspectives on walking from all participants;
- to investigate the relational and supportive interventions provided to the residents with dementia who walk;
- to explore the concept of person-centred care from the interventions provided;
- to examine the impact of the built environment on the walking of the residents and;
- to contribute to the destigmatisation of the residents with dementia who walk by advocating for a shift to using dignifying language for them for optimal support.

2.15 Summary

In this chapter, I have presented the search strategies used to retrieve existing literature on the study. I have reviewed the prevalence of dementia globally and specifically in New Zealand. I have discussed BPSD and walking as a symptom of the progressive nature of dementia. I have discussed the argument and lack of consensus on a definition for walking due to many questions raised which no one definition could adequately address. I have discussed the economic and personal costs and stigma of

walking with voices of persons with dementia as evidence, sharing their lived experiences. The impact of the negative connotations of the language used when talking about dementia has also been discussed. Best Practice Guidelines to managing BPSD, pharmacological and non-pharmacological interventions, and the recommendation to use non-pharmacological interventions as the first step to allow person-centred goals to be achieved have been discussed. I have also discussed anti-psychotic medications recommended as a last resort when the resident poses danger to themselves and those around them. As the literature review highlighted, these guidelines have not always been followed by health practitioners, including residential care staff in urban and rural settings and this was a reason for choosing to explore the interventions provided in ARC facilities in New Zealand but focussing on two facilities in an urban centre. I acknowledge the effort being channelled towards persons living with dementia by all stakeholders, but as indicated in the literature review, no budget was found allocated specifically for ‘persons with dementia who walk’ despite future estimated projections of over 170,000 persons to have dementia by 2050. Out of these figures, studies have also indicated that 15% to 60% of persons with dementia will walk (Gu, 2015; Robertson et al., 2006) and 50% in the severe stage will also walk (Lai, 2003). As a result, urgent attention and planning are needed to future-proof the quality of care they receive as citizens. Furthermore, this chapter has presented the research gap, the research problem, the research question and the five aims of the study. The next chapter presents the theoretical orientation and methodology of the study.

Chapter 3 Methodology

Social Constructionism … re-locates problems away from the pathologised
(Burr, 2015, p. 11)

3.1 Introduction

This chapter presents the ontology, epistemology, and theoretical orientation of social constructionism (Burr, 2015) underpinning this study. Critical ethnography (CE) is applied in this qualitative study. The justification for choosing this methodology and recommended stages adopted in carrying out the study and the thematic analysis applied to the data sets integrated as a framework are explained. The ethical considerations, recruitment, selection criteria and the research rigour are also presented.

3.2 Research Question and Aims

The study seeks to explore the interventions New Zealand residential care staff from two ARC facilities provide for residents with dementia who walk through five aims: one, explore participants' perspectives, including the residents with dementia who walk, on the meaning of walking; two, investigate the various interventions provided by the staff to support the walking; three, explore the concept of person-centred care in the approaches provided; four, examine the impact of built environment on the walking of the residents with dementia and five, contribute to the shift to destigmatise residents with dementia who walk by advocating for language use that dignifies the residents for their optimal support.

This study further aims to provide an explanation using social constructionist theory on the findings after analysing the data sets.

3.3 Ontological and Epistemological Assumptions of the Study

My ontological and epistemological positions regarding this study are informed by personal observations and assumptions (see Chapter One). Researchers are guided by their assumptions as these help in the choice and approaches to research problems (Kant, 2014; Cresswell & Cresswell, 2023). The underpinning theory for this study is a social constructionism (Burr, 2015, 1995), and the chosen methodology is critical ethnography.

When the opportunity came to do a research project as part of this doctoral programme, I chose to focus on the walking by persons living with dementia, curious to

find out more and to use my ontological and philosophical assumptions to investigate this issue more (Cresswell, 2023). Since I always ask the question of “how else?”, to challenge myself to maintain best practice and to make a difference in the care I provide, I allowed myself to be guided in the philosophical and theoretical orientation of social constructionism and critical ethnography methodology.

As a researcher, I brought into this study my own set of values, beliefs, culture, as well as my life and professional experience, which combined have influenced my approach. Caring (Savieto & Leão, 2016), therapeutic relationships (Boggs, 2023), with a goal to always make a difference, no matter how little, with relational solidarity (Brijnath et al., 2024; Boggs, 2023; Jennings, 2018), advocacy, and emancipation are all values that guide my practice and research.

Ontology is the “study of nature of things” (Liamputtong, 2017, p.363), what we know regarding this world (Marsh & Furlong, 2002), and what to know (Kant, 2014) to relate it to this study. It is concerned with “what is … with the nature of existence” (Crotty, 1998, p. 10). This is viewed to be achieved in the aims such as one of the aims: exploring the perspectives on walking from all participants, including residents living with dementia who walk. Ontology is a theoretical foundation of social constructivism's qualitative paradigm, which holds that social phenomena or activities such as walking are socially constructed. The social phenomenon in this study refers to the residents with dementia who walked and their walking, which have been pathologised and stigmatised.

This study aims to investigate the approaches the staff used to support the residents who walk. This theoretical orientation is apt for this study as one of its advantages is allowing the in-depth understanding of the cultural, contextual, and historical factors that have influenced the phenomenon. Ontology asks questions about existence, what exists independently, what can be studied, and how such a phenomenon can be studied. In this study, ontology guided my choice of approach. Epistemology on the other hand, is studying “the beliefs about the nature of knowledge” (Liamputtong, 2017, p. 364) and methods used in acquiring the knowledge. It is concerned about knowing. It is “the theory of knowledge embedded in the theoretical perspective and thereby in the methodology” (Crotty, 1998, p. 3). Epistemology has the interpretivism or constructivism paradigm (Liamputtong, 2017). It values experience that is subjective and meanings that human beings construct through their interactions (Crotty, 1998, Liamputtong, 2017). It asks questions about how knowledge is acquired and what makes evidence (Burr, 2015).

Social constructionism prioritizes the nature of knowledge, how we construct it, and the various meanings constructed (Andrew, 2012; Burr, 2015; Lock & Strong, 2010). This

knowledge construction is gained through human or social interactions subjectively and inter-subjectively and it is specific (Andrew, 2012; Berger & Luckmann, 1966; Burr, 2015; Lock & Strong, 2010).

Ontology and epistemology influence how research questions are asked and how the answers are provided. Some scholars argue that “if an ontological position reflects the researcher’s view about the nature of the world, their epistemological position reflects their view of what we can know about the world” (Marsh & Furlong, 2002, pp. 17-18). I acknowledge that knowledge is subjectively created and focus on qualitative methods that will help in answering the research questions and achieving the aims of the study. The critical ethnography methodology and the methods used were selected to uncover relevant meanings to make sense of both the walking of the residents with dementia and the approaches being provided for them by the residential care staff. Choosing social constructionism theory and critical ethnography will enable the research questions to be answered in-depth, and the study aims achieved towards deepening understanding of the support needed by the residents living with dementia who walk.

The next section discusses social constructionism as an underpinning theory for this study, followed by critical ethnography.

3.4 Social Constructionism: Theoretical Approach and Philosophy

> “Taking a critical approach to “taken-for-granted knowledge”” (Burr, 2015, p. 2)

The theoretical approach and philosophy selected for this study is social constructionism (Burr, 2015). What follows is what it stands for and the rationale for choosing it to guide the study. Social constructionism (SC) can be referred to as:

> a theoretical orientation which, to a greater or lesser degree, underpins all of these newer approaches, which are currently offering radical and critical alternatives in psychology and social psychology, as well as in other disciplines in the social sciences and humanities. (Burr, 2015, p. 1).

It originated from the classic work of Berger and Luckmann (1966) who were influenced by the work of Marx, Mead, Schutx, and Durkheim (Burr, 1995, 2015). Berger and Luckmann (1966) posited that knowledge is socially constructed through interactions. Social construction is concerned with the meaning of things and the explanation that no single meaning is sufficient to explain any concept or activity which can be simple or complex (Burr, 2015; Hjelm, 2014; Lock & Strong, 2010). This will be evidenced in Chapter Five, the first finding, where each participant gave their own meaning of the

walking of the resident with dementia, including the residents. Social constructionists are more concerned with how knowledge is created and not in its ontology (Burr, 1995, 2015). Social constructionism (SC) focuses on the interactions people have every day with one another and the importance of language which is used to construct. that reality (Andrew, 2012). It develops the concepts and thoughts that structure the way we experience the world (Burr, 2015). As such, SC is referred to as a "broad church" (Lock & Strong, p. 10), an approach (Burr, 2015), and a theoretical orientation for research (Stam, 2001). However, there are four "family resemblance" (Burr, 2015, p. 2) or commonalities, identified which in SC which are presented next.

First, SC "functions as critique" (Burr, 2015, p. 17). It calls for a critical stance, to ask questions and not accept the world or observations presented conventionally as the way things are or the way the world is being experienced (Burr, 2015; Lock & Strong, 2010). Taking such a stance can reveal the social and political powers operating covertly in ways that the majority has taken for granted (Burr, 2015; Danzinger, 1997; Lock & Strong, 2010). SC challenges us to reject positivism and empirical knowledge and to suspect all assumptions as there are other ways of seeing the world or phenomena. Applying this to the current study, SC rejects what has been presented to us about dementia, about its pathology and about residents who walk as status quo and challenges us to see their walking from a different perspective.

"…all ways of understanding are historically and culturally relative" (Burr, 2015, p. 4)

Second, social constructionists argue that meanings and understandings are not permanent nor universal but are based on cultural context, time in history, and on the location where one is. The argument is that there is "a way of meaning-making" (Lock & Strong, 2010, p. 7). Meanings of social interactions are seen as contextual and evolving, and these challenge scientific progress (Burr, 2015). The ways we understand the world are specific to the history of the times and the cultures prevailing where one is (Burr, 2015). For example, contemporary Western society places more value on the young as productive. Older people, especially those cognitively impaired, are viewed as having less value and lacking citizenship (Bartlett & Brannelly, 2019; Bartlett & O'Connor, 2011; Kitwood, 1997). Since ways of understanding are historical and culturally relative and evolving; and interactions bring knowledge construction, it is about this former knowledge of walking of the residents changes.

"Through daily interactions between people… our versions of knowledge become fabricated" (Burr, 2025, p. 4)

A third commonality is the argument that knowledge is constructed during interactions and that language is used in constructing that reality (Andrew, 2012; Burr, 2015). Social constructionism focuses on meanings, the understanding derived from human activities and the different meanings these convey (Lock & Smith, 2010). While some social constructionists are anti-essentialists, those who reject the idea that there is essence in things, those who are not, deny the objective reality of things, arguing that they are more interested in how the knowledge in that community is "created, negotiated, sustained and modified" (Andrew, 2012, p. 40). Social activities are not from nature but from people who each day of living in the world interact with one another and produce knowledge from such interactions. Social constructionists argue that we use language to interact which is unique to human beings. In addition, what occurs between people every day is shared and constructed and not unilateral.

Applying this third social constructionists' stance to the study, over the years and decades, dementia and the walking of the residents diagnosed have been socially constructed with stigma through the exchanges between those diagnosed, their families, EPAs, and residential care staff and all who have input into the care and diagnoses of the residents using dehumanising language. (Kitwood, 1997). Language is still is the medium of communication and means of social interaction. Social constructionists argue that what is regarded as truth or the objective ways of doing things do change, such as the breakthroughs and changes brought by information technology, artificial intelligence, and social media in the way we communicate with one another verbally and in written forms today. From the social constructionists' lens, this should be the same with the residents with dementia who walk. As people interact with one another and with the residents, new knowledge should be created through this process to view the residents and their walking with new meanings. Furthermore, SC challenges the world to change their views that stigmatise residents with dementia who walk with new evidence and knowledge created through research. SC persuades us to allow our perspectives to change to creating new meanings that dignify the residents.

> Knowledge and social action go together (Burr, 2015, p. 5)

A fourth family feature common with social constructionists is the argument that social interactions that occur as a result of new understanding and knowledge lead to positive social construction and improvement (Burr, 2015). With research evidence of the experience of persons with dementia and new ways of supporting their care better than before, SC calls for actions that will humanise and make dementia acceptable as equal to other health issues, and for all communities to deconstruct and remove stigma from the diagnosis and from the walking of the residents living with dementia. Social

constructionism insists that many meanings can be created through many social exchanges, thus suggesting that social action and constructions of meanings go together. The significance of this study is to invoke social action towards a realistic person-centred care that aims for optimal support and holistic well-being of residents living with dementia who walk. With the lens of SC, one can view the way dementia is portrayed in the community as well as the support provided to support the walking of the residents in the ARC facilities. As this study reveals, each participant has a different perspective on the walking of residents with dementia and each residential care staff different approaches to support their walking. Social constructionism calls for each participant's views to be considered and acknowledged (Pawson & Tilley, 1997).

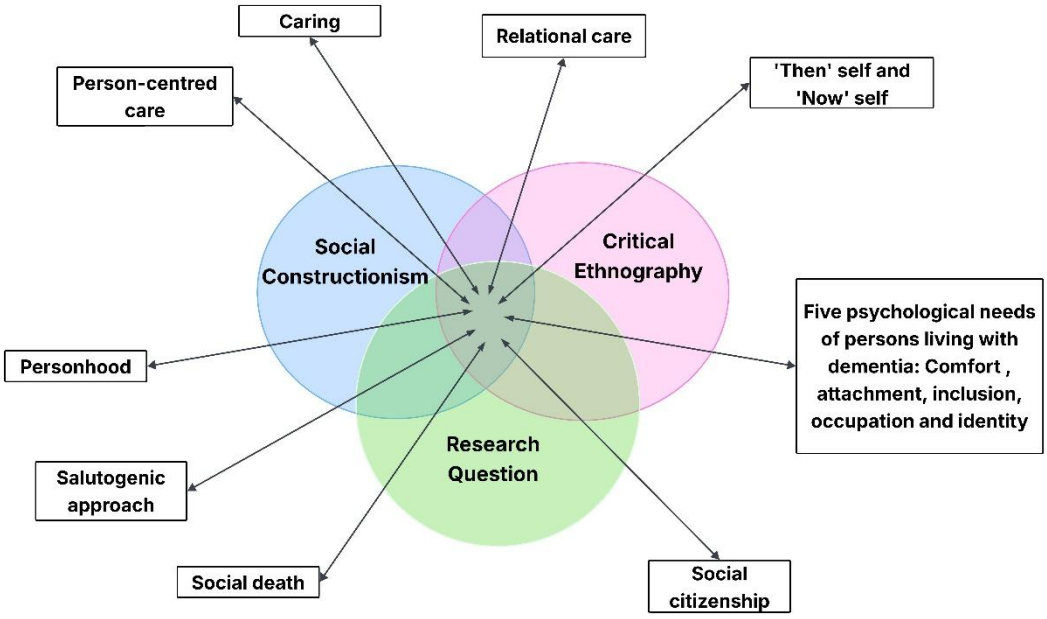
Although this next SC view is not categorised separately as a family resemblance, its depth, as relating to this study, has motivated me to make it a fifth resemblance of social constructionism (Burr, 2015): To social constructionists, 'our construction is our reality'. This means to each person constructing the knowledge, their meaning(s) or perspective(s) of such activities, social phenomena, or interactions are what they have constructed them to be. One of the key goals of SC is to relocate or move away problems away from the persons affected. This study calls for the same, that is, to remove the pathology and stigma socially constructed, away from the walking of the residents who also live with dementia. Not only will this action reduces the negative impact of the diagnosis on families, communities, nations, and the world but also will give individuals suspecting they have dementia, the confidence to seek early diagnosis and intervention. This will also provide assurance of social inclusion and support as equal and social citizens (Bartlett & Brannelly, 2011; Bartlett & O'Connor, 2011; Brannelly, 2011; Cook et.al., 2022; Human Rights Act 1993; Kitwood, 1997; Sweeting & Gilhooly, 1997; United Nations, n.d.) with others seeking treatments for non-stigmatised and non-communicable diseases. Failure by our society to give the status of citizenship to residents with dementia who walk has negative implications on the person living with it as this reduces them to be regarded as socially dead (Brannelly, 2011; George, 2010; Kitwood, 1997; Sweeting & Gilhooly, 1997).

To summarise, SC is a suitable theoretical orientation to this study as first, it is a qualitative study that focuses on the walking experience or activities of the residents with dementia who walk. Second, as interactions with participants occurred during data collection, they created and constructed knowledge needed for the findings, which can be accounted for within the SC framework. Third, the theory enabled me to explore various semantic and latent meanings from the data collected during the analysis stage. In addition, this approach is appropriate as the complexities in the meanings and knowledge of the meanings and perspectives on walking were revealed to enable each

of the aims of the research question to be achieved. Care facilities can adopt approaches that allow persons living with dementia to achieve emancipation, health, and well-being so that they can live with dignity and their personhood restored (Brooker, 2007; Kitwood, 1997).

Critical methodology, the methodology applied to this study, presented next together with Social Constructionism, the theoretical orientation of this study and the nine concepts applied to this study, all constitute the conceptual framework for the study in investigating the research question. This is represented graphically in Figure 1.

Figure 1. Conceptual Framework of the Study



Note. Christianah Adesina's conceptual framework of study showing how social constructionism, critical ethnography and the nine concepts all link together

Next section presents Critical Ethnography, its details and the rationale and justification for its selection for the study.

3.5 Methodology: Critical Ethnography

Critical ethnography (CE) is an ethnography that applies a critical theory approach. It is also referred to as critical qualitative research (Carspecken, 1996; Madison, 2012; Thomas, 1993). It takes the question of 'what is' to 'what it could be' to make it critical. This involves asking a lot of questions to uncover hidden power relationships and issues of inequality among the population being studied (Thomas, 1993). This is achieved through the use of different enquiry instruments such as participant observation, face-to-face interviews, photography, video and audio recordings to

enable a researcher to understand how people see the world and how they interact with everything around them (Liamputtong, 2017; Madison, 2012; Silverman, 2004). In this study, the ‘what is’ is the walking of the residents with dementia, and ‘what it could be’ is the enquiry this study set out to achieve through the use of some ethnography methods such as participant observation, in-depth face-to-face interviews, audio recordings and unobtrusive methods (such as guidelines provided by ARC facilities) in an etic-emic manner: first as an outsider and, later, as an insider who participates in activities and builds relationships with participants to collect rich data (Liamputtong, 2017; Madison, 2012; Silverman, 2012). Critical ethnography tends to elicit unstructured data, and sample sizes are always small (Atkinson & Hammersley, 1998). CE scrutinises the specific social phenomena being studied in an inductive manner (Liamputtong, 2017). In this study, the residents living with dementia who walk are the phenomenon. CE is different from other ethnographic studies in that it is a form of interpretive social research that can be descriptive in nature (Higginbottom, 2013), challenging implicit assumptions (Thomas, 1993), and calling for a critical stance to be taken against the “taken-for-granted” (Burr, 2015, p. 5) things presented as truth to the community.

The methodology compels us to take an ethically responsible stance on processes and issues of injustice and unfairness in people’s lived experiences on specific issues in their communities. This means that CE involves a “compelling sense of duty and commitment based on principles of human freedom and well-being and … a compassion for the suffering of living beings“ (Madison, 2012, p. 5). Critical ethnography is a qualitative research methodology that focuses on the scientific study of the lived culture of individual groups, groups of people, or cultural groups in their natural environment (Liamputtong, 2017). In this study, the lived culture is the interactions of the residential care staff (RCS) in two ARC Facilities, with the residents with dementia who walk in an urban centre in New Zealand. They are scientifically studied using participant observation in Stage One of Carspecken’s (1996) five stages recommended for conducting CE, which will be introduced later in this chapter. CE can be both emancipatory and hermeneutic simultaneously as it is a science of understanding. It reveals power and politically hidden agendas which could lead to critical thinking and questioning of the power that be. The methodology is a powerful way of critiquing the culture of ARC facilities in a direct way, thinking about relationships created within the structures, the knowledge shared, and the political undertakings, which include the policies and guidelines being used (Thomas, 1993) in supporting residents who walk.

In this study, residents with dementia who walk are the marginalised population who suffer from the consequences of their diagnoses (Silverman, 2010) and are not well supported in their walking. CE provokes critical thinking from what the activity of walking is to what it could be (Burr, 2015; Hibberd, 2005; Lock & Strong, 2010; Madison, 2022; Thomas, 1993). This methodology provokes and raises the question of what other meanings could exist for the walking of the residents with dementia. Critical ethnographers "describe, analyse, and open to scrutiny hidden agendas, power centres, and assumptions that inhibit, repress, and constrain" (Thomas, 1993, p. 3). Critical ethnography focuses on power and how different powerful discourses shape people's understandings and their experiences in life (Burr, 2015; Dreher, 2016; Madison, 2022; Oladele, 2012). Different perspectives on walking will be sought from the four groups of participants in this study to examine power relationships. The four groups of participants are residents with dementia who walk, (Participant1-7), their Enduring Powers of Attorneys (Participant-EPA 1-7), the registered nurses (Participant-RN1-4), and the health care assistants (Participant-HCA1-8).

Furthermore, CE is a type of reflection, as it "examines culture, knowledge, and action. It expands our horizons for choice and widens our experiential capacity to see, hear, and feel" (Thomas, 1993, p. 3). CE challenges through a reflective process to make valued judgements about the study by providing different options, leading to choosing between good or bad depending on the standards applied (Bidabadi, 2019; Liamputtong, 2017, 2012; Oladele, 2012). CE goes further to reveal meaning from the perspectives of the participants being studied, giving them voices and making them visible, heard, and dignified (Thomas, 1993). Critical ethnographers speak on behalf of their participants to empower them and to give more authority to their voices (Burr, 2015; Liamputtong, 2012; Oladele, 2012; Tinney, 2005). In addition, they study culture for the purpose of creating awareness so there can be a collective responsibility in providing better support for residents living with dementia who walk (Burr, 2015; Liamputtong, 2012; Madison, 2012; Oladele, 2012; Tinney, 2005).

A key purpose for using critical ethnography to conduct a qualitative study is the focus it gives on power and its different discourses and how these affect or influence people's understanding and experiences. Another rationale to justify the use of CE is to allow it to challenge social and cultural assumptions that have been historically and socially constructed with regard to 'walking' and the residents with dementia who engage in this activity (Kincheloe & McLaren, 1994; Madison, 2022). CE invokes social consciousness and societal change (Burr, 2015; Liamputtong, 2012; Oladele, 2012; Tinney, 2005) and aims to facilitate positive change in social institutions such as in ARC facilities, challenging the status quo towards achieving emancipation for the

residents (Brodkey, 1987; Kitwood, 1997; Madison, 2022). This emancipation is being done through this research as it creates awareness, education, advocacy, and collective responsibility towards a complete removal of the unconscious societal stigmatisation and stereotyping which have consequently led to the inability of the residents to live normal lives as social citizens (Brannelly, 2011; Cook, 2022; George, 2010; Kitwood, 1997; Sweeting, 2019).

One purpose of CE is the issue of representation (Oladele, 2012; Richter et al., 2012), which sometimes puts researchers in the middle of new and refracted old issues (Oladele, 2012). As much as possible, I was guided by a focus on the research question, its aims, theoretical perspective, methodology and methods.

3.6 Applying Both Social Constructionism and Critical Ethnography to the Study

Both social constructionism and critical ethnography enable an in-depth analysis of data gathered to uncover overt and covert factors influencing the support of the walking of residents with dementia. Together with social constructionism as a framework, CE advocates for the residents living with dementia who walk for their voices to be heard. Using these ontological and epistemology approaches with inter-subjectivity (shared meaning through interaction and communication), knowledge is created during data collection, leading to the findings of the study after analysis. Social constructionism argues that knowledge constructed has the power to bring change and improvement to the phenomenon studied. The aim of this study is to bring improvement and optimal support to all residents living with dementia who walk through the findings of this study (Andrews, 2012; Berger & Luckmann, 1966; Dreher, 2016; Madison, 2022). CE widens our imagination and deepens our experience capacity, challenging our ethical commitment with actions through a “capacity to see, hear, and feel” (Thomas (1993, p. 3). This study intends to show these through the participants’ quotes that provide evidence to the findings.

3.7 *Including People with Experience and Residents with Dementia Who Like to Walk*

The rationale for including the residents with dementia was to fulfil an ethical obligation based on evidence that the persons with dementia want to be included in research about them (National Ethics Advisory Committee, 2019; Digby et al., 2016; O’Sullivan, 2011; Nygard, 2006). This was also evidenced during Conferences attended where representatives of persons with dementia gave presentations such as during 2018 Conference (Alzheimers New Zealand, 2025) stressing the importance of including them in research projects. I reflected on the study’s theoretical approach of social

constructionism and critical ethnography methodology which was to give voices to the marginalised and those who have not been heard. I weighed the risk and benefits of including the residents with dementia who walked in the study against their request to participate in the study. The risk is specifically in terms of possible discomfort if length of interview is long. The benefit was that their voices would be heard, as the marginalised, through the theroretical approach of social construction and critical ethnography, the methodology applied to the study. I concluded that the benefit outweighed the risk and included them in the study. To mitigate against the risk, I designed only one question for them -unless they wanted to engage in more conversation and reduced the length of their interview to two to five minutes to ensure it was comfortable for them. In addition, I searched for literature to equip me with methods to apply when interviewing them (Cubit, 2010; Diaz et al., 2021; Dementia Alliance International, 2017; Digby et al., 2016; Hubbard et al., 2003).

A recent German national study using participatory research reported that persons with dementia found it beneficial to participate in research, being perceived as competent co-researchers, and that the residents experience joy contributing (Seidel et al., 2024). In addition, an article on the engagements of persons living with dementia from a pan-Canadian evaluation of collaborators advisory group described how persons with dementia used initiatives and engaged in multiple roles, such as research, co-authorships of papers, co-grant applicants and video project based on their interests, needs, gender, ethnicity, and age. The article further suggests tips on engaging and supporting them in events and research meetings (Snowball, 2024). Furthermore, recent research involving persons with dementia have reported that the participation had given them a sense of purpose and identity. They were happy, felt respected, and had a sense of autonomy, accomplishment, and being productive. As indicated, in these studies, such engagements enhance the well-being and quality of life of persons with dementia (Beuscher & Grando, 2009; Diaz et al., 2024; Digby, 2016; Dementia Alliance International, 2015; Hubbard et al., 2003; National Ethics Advisory Committee, 2019; Nygard, 2006; O'Sullivan, 2011; Seidel et al., 2024; Snowball et al., 2024).

3.8 Ethical Considerations

I am aware that Māori are tangata whenua (people of the land) of Aotearoa New Zealand and a treaty partner. In this research, I upheld the principles of the Te Tiriti o Waitangi. Though this study does not have a Māori focus, it is relevant to Māori health. A projected forecast showed that by 2038, dementia prevalence will increase from what it was in 2016 for all ethnicities: for Māori, it will increase from 5.1% to 8.0% (Deloitte, 2017). The prevalence of dementia and its worsening symptoms are global issues

cutting across all ethnicities. As a priority population, the findings of the study will benefit Māori being aware of the health disparities in Māori and non-Māori. I had an initial consultation with Sandra McDonald, Ngati Whatua, Te Uri o Hau, who consented to be my Māori Advisor for the study for support so I could have continued guidance in Kaupapa Māori principles and ideologies and to ensure study partnership potential participants. Sandra volunteered to support any Māori participant at each facility during their interviews as a Kaumatua. I had only one Māori participant in the study who was s staff. This could have been due to their underrepresentation, according to the literature (Harris et al., 2022). This participant did not request a support person.

In total, four ethics approvals were received for the study, two from each ethics committee at different times as follows: two approvals from the Southern Health and Disability Ethics Committee (Reference 20/STH/162 dated 28/01/2021 and Reference 20/STH/162/AM01 dated 29/06/2021), one of the Ministerial Committees in the country (Health and Disability Ethics Committees (HDEC), 2023) and two approvals from the Ethics Committee from my University, Auckland University of Technology Ethics Committee (AUTEC) Reference 21/47 dated 16/03/2024 and Ref 21/47 dated 23/07/2024 (Auckland University of Technology, n. d.) which worked together with HDEC as delegated authority. Approval dates and details, together with the reasons for the two amendment approvals from each ethics committee are in the Appendices (Appendices A, B, C and D).

Ethical issues included informed consent and ability to withdraw from the research. After recruiting participants from staff and the Enduring Powers of Attorney (EPAs), it became apparent that I could not gain written consent directly from any resident living with dementia due to their diagnoses of cognitive impairment which made them vulnerable. It was a condition from HDEC that, before anyone could participate in research, informed written consent had to be given after full information about the study was given and potential participants have had the opportunity to ask questions and gain clarifications. In this case, due to their diagnosis, these steps could not be carried out directly with the residents except through staff and residents' whānau (families) or EPAs of residents. Since all the residents in the two facilities had in place their activated or legally appointed EPAs (Ministry of Justice, 2023). I went back to request for an amendment from the Ethics Committee and they approved that the legally appointed EPAs could sign the consent forms on behalf of the residents interested in participating in the study.

I resumed the recruitment process immediately after amendment approvals from both Ethic Committees and recruited residents with dementia who walk in July 2021. At this

point, majority of written consents from the EPAs and staff had been received. The process of gaining ethics approval from the different committees took approximately 10 months.

I treated all participants with respect and upheld their dignity and mana. I ensured my conduct was professional and study was beneficial to them and did not cause any actual or potential harm (non-maleficence) to them. I acknowledged their human rights to have informed consent and their right to refuse to participate or withdraw from the study. The interviews with the residents who walked were carried out when they were well, not distressed and able to sit down for a period of time to have conversation for a maximum of five minutes as planned. In a few instances, there were indications that the participant residents wanted to engage more in conversation with me. In addition, I took the decision once to postpone an interview with a participant as he was unwell on the day scheduled for his interview together with his EPA. Instead I interviewed only the EPA and postponed his own till he was better. Interviewing them when they were well was to show beneficence, non-maleficence, empathy, care and respect for their personhood (Brooker, 2004; Kitwood, 1997; Kitwood & Bredin, 1992; Marczyk et al., 2005). I was guided by my professional and ethical principles when conducting research (National Ethics Advisory Committee, 2019; Auckland University of Technology, 2019; New Zealand Nurses Organisation, 2019) throughout the study. Written consent was gained from each aged residential care facility where the study was carried out to allow their facility to be used for the study.

There was a break in the data collection due to COVID-19 restrictions but when the restrictions were eased, I was able to continue the study. Before starting the study, I explained the purpose and process of the research to each potential participant during information sessions and gave potential participants information sheets (PIS) and time to go over them. I also ensured each potential participant had the chance to clarify any issue they may have had before they consented to participate in the study. Four groups of participants were recruited: residents with dementia who walked, their EPAs and two groups are from the residential care staff: the registered nurses (RNs) and the healthcare assistants (HCAs). Written consent was gained from all participants. As continuous consent was also necessary in an ethnographic study (Bidabadi et al., 2019), I ensured I applied this throughout the interviewing process. I gained verbal consent at the start of each interview and reminded participants that they could withdraw from the study at any stage if they wanted to, and if they were not comfortable with a question asked, they could ask to move to the next question. Throughout, I introduced myself as a student of AUT, always putting on my name badge, and used my business card as a researcher so that I was not mistaken for one of the residential

care staff or permanent staff (Tinney, 2008). I pointed visitors who asked me questions to the reception desk even if when I knew the answer to ensure the lines between my role as a student researcher and my professional position were not blurred. In addition, apart from being open and identifying the key people in the research field, I maintained a level of rapport with all the staff and participants that was professional so the study was not compromised.

3.9 ARC Facilities and Participant Recruitments

The study was carried out in Auckland, “a leading city by population and contributor to national GDP” (Insch, 2018, p.38) in New Zealand. I used a non-probability purposive sampling technique (Creswell & Cresswell, 2023; Liamputtong, 2017) to recruit facilities and participants. In recruiting facilities after selection criteria has been done (discussed further below), initial phone calls were made to selected ARC facilities/Clinical Managers and to facilities suggested through academic contact, to check if they were interested in participating in the study. Information on the purpose of the study was verbally given, and when they expressed interest, was followed up with emails on the study, after confirming their email addresses retrieved from Statistics New Zealand and Ministry of Health websites. These websites feature provide a list of facilities that provide residential care for persons living with dementia in New Zealand. At the time the research was conducted in early 2020, there were approximately 179 aged residential care facilities (ARCF) in Auckland and approximately 662 in New Zealand (Ministry of Health, n. d.).

The emails sent to interested facilities’ managers contained an introduction about myself, my programme, AUT, why I was contacting the facility, the study, its purpose, and its benefits. These emails were also followed up with phone calls between November and December 2020. I sent out emails to approximately eight facilities. In the emails, I indicated if any facility was interested in participating, I could come to present an information session to the leadership and staff of their facilities. Immediately, I received three positive responses. These were the three facilities that consented to participate in the study.

Information sessions were held for staff and interested whānau at each of the three facilities at difference dates. I took along morning or afternoon tea as appropriate to each presentation. The study presentation to staff covered the research topic, purpose, potential benefits, how the facility was identified, selection criteria, potential risks involved, how it can be minimised or removed, support services contact numbers, how the study would be carried out, consent forms, right to withdraw and other key pieces of information. Following the presentation, questions were asked and clarifications were

provided. Participant Information sheets and Consent forms were distributed, and extra copies were left with the Managers for staff in other shifts. The forms featured my contact details for anyone interested or with further questions to contact me directly. In addition, I left my student business cards with the Managers at each facility so staff could contact me. Requests were made to the managers to disseminate the information to other staff members on other shifts, through their communication books, during handovers, staff meetings, and for the recruitment information to be placed on Facilities' Notice boards for residents, their whānau and EPAs who might be interested. Facilities' Clinical Managers also assisted in sending email notices to residents' whānau and their EPAs. Two weeks later, I picked up the majority of the signed consent forms of staff and EPAs that I was told were ready for collection and few more were picked up as the study started. The study started approximately six months after the first full ethics approval was received. I received amendment approval from HDEC, followed closely by AUTEC's approval, which allowed the EPAs to sign written consents on behalf of their donor residents (Participants1-7) as they had been legally appointed to make decisions regarding residents' personal care and welfare. Details of the need for this Amendment application were discussed earlier under Ethical Considerations (see section 3.8).

3.9.1 Sampling

Purposive sampling was used in recruiting participants for the study with a criterion sampling strategy (Creswell, 2023; Liamputtong, 2012, 2017), This was to enable me to rely on my sound judgement in choosing the facilities, staff, and potential participants' representative of the population to participate in the study (Creswell & Cresswell, 2018; Dudovskiy, 2018; Leavy, 2017; Liamputtong, 2017). The technique also enabled me to strategically choose facilities providing care for residents with dementia who walk and to meet other pre-determined specific selection criteria, which are crucial in enabling accurate and robust data to be collected (Leavy, 2017; Liamputtong, 2012, 2017). For example, I targeted large facilities where there was the likelihood of recruiting a large number of participants with potentially large and rich data that could generate quality findings.

The sample size recruited initially was 44 participants. However, due to reason provided further below, participants who completed the study were 26 in number, an appropriate number consistent with a qualitative study (Brinkmann, 2013; Cresswell & Creswell, 2023, 2018; Dudovskiy, 2018; Leavy, 2017; Liamputtong, 2017, 2012; Patton, 2002). While I did not experience any problem gaining access to these facilities for recruitment or conducting the study at any time as I went through the appropriate routes (Pope, 2005; Liamputtong, 2017), I was not able to complete the study at

Facility Three due to the impact of pandemic on their facility and the restrictions that were put in place at the time. As a result, it was decided to withdraw the consented five participants from the study (two residents, two EPAs and one RN).

The whole country moved to the new system of the COVID-19 Protection Framework (traffic lights) after the COVID-19 Alert system ended on 2 December 2021 (New Zealand Government, 2022). Aged residential care facilities put restrictions into place, understandably, to protect vulnerable residents. I received an email communication from the Clinical Manager of Facility Three advising restrictions to visitors in the meantime, to protect the residents from contracting the virus as it mutated and spread in the community. When the restrictions were eased a little bit, I quickly started Stage One Participant Observation at their facility with one of the participant- residents, but as there was only one RN participant who was on annual leave, the fluctuating restrictions interrupted again before we could continue the study. Since I had collected substantial data from the first two facilities, with substantial information power (Braun & Clarke, 2021; Lavakas, 2015; Liamputtong, 2017; Malterud, 2016), key foci of depth, quality, and flexibility needed in qualitative studies (Liamputtong, 2012), my supervisor advised that I focused my data analyses on the first two facilities only where I had completed data collection. Approximately, middle of last year, 2023, I received a call from the Clinical Manager of the third facility that the pandemic had impacted their facility severely and that the ARC facility was closing down at the end of that week.

3.10 Selection Criteria

The selection criteria used in recruiting the Aged Residential Care Facilities (ARC Facilities), the residential care facilities (RNs) and participants were as follows:

3.10.1 Aged Residential Care Facilities (ARC Facilities)

Inclusion criteria:

- Must be an ARC facility providing long-term care for residents with dementia who walk, at rest home level of care, private hospital level of care, dementia level of care in any geographical area of Auckland city;
- Can be a day care service for residents with dementia who walk in any geographical part of Auckland city.

Exclusion criterion:

- The only **exclusion criterion** was if the ARC facility was a provider for psychogeriatric level of care (Rationale: Not to cause any distress to any resident as one of the ethical principles of the study was beneficence).

Outcome:

All three facilities recruited matched the criteria and signed a written consent form to participate in the study. Then the recruitment of staff, residents and families started.

3.10.2 Residential Care Staff (RCS): Registered Nurses (RNs), Enrolled Nurses (ENs) and Health Care Assistants (HCAs)

Inclusion Criteria:

- Must be an RN, EN, or HCA;
- Working predominantly in Must have been working in an ARC facility or any long-term residential facility in the city for at least 6 months at the time of recruitment months for the reason provided below:
- Core job: Must have been looking after ‘residents with dementia who walk’. (Rationale: To ensure potential participants have enough experience and have built therapeutic relationships with residents to be able to answer interview questions);
- Must have experience in the care of residents with dementia who walk.’

Exclusion Criterion:

- RNs, ENs, HCAs working in acute care settings such as in public hospitals (Rationale: as these clinical settings are short stays, interested nursing professional might not have had enough time with residents to answer interview questions).

Outcome:

Though ENs were included in the selection criteria, no EN was working in these two facilities at the time of recruitment. Four RNs and eight HCAs recruited from both facilities signed written consent forms. It was important to include the HCAs in the study as HCAs work closely with the RNs in delivering care to residents and service providers have responsibilities to ensure the quality of care stipulated is achieved. However, research suggests that at times, those working in these two roles may sometimes work parallel to each other rather than collaboratively (Burrow et al., 2017)

3.10.3 Enduring Powers of Attorneys

Inclusion Criterion:

- The Enduring Powers of Attorney (EPA) (Ministry of Justice, n.d.) must have cared for or have been caring for the residents with dementia who walk for a minimum of one week or to have been visiting and caring for the residents in the various facilities for the same period. This is to ensure that the

whānau/carers/friend/EPA have enough experience to discuss with researcher about the interventions they provided or ever provided to their loved ones during the interview.

- They must have been legally appointed as EPAs and had to be known to the facility staff.

Exclusion Criteria:

- Family members or friends not legally appointed as EPAs.

Outcome:

Seven EPAs participated in the study.

3.10.4 Residents with Dementia Who Walk

Inclusion Criteria

- Resident must have received a diagnosis of dementia /or in addition to other diagnoses tests, resident must have had an equivalent cognitive assessment test done by a General Practitioner (GP), Geriatrician, Nurse Practitioner, Gerontology Clinical Nurse Specialist, Gerontology Clinical Specialty Nurse, Clinical Manager, or by an experienced Senior RN. Examples of such cognitive assessment tests are the Mini-Mental State Examination (MMSE) score of <23/40 or less than 23; and the Montreal Cognitive Assessment (MoCA) with a score <26/30 or less than 26. (Bosco et al., 2017; Carson et al., 2018; Health Navigator, 2014);
- Resident with any form or type of diagnose can participate;
- In addition, resident must have walking behaviour confirmed at any of the stages of dementia evident at the facility.

Exclusion Criterion:

- Residents with dementia who does not have walking behaviour.

Outcome:

Seven residents with dementia who walked participated in the study. Due to my experience working with residents with dementia who walk in the past, I was prepared to walk along with them if they chose to walk during the interview. The residents were interviewed with their EPAs present or in one case with a delegated staff consented to by the EPA as they were unable to be present at the interview.

Summary of all participants in the study:

Tables 1, 2, and 3 at the beginning of the next chapter (Chapter Four) show the demographic characteristics and highlight the heterogeneity of all participants in the study:

- Seven Residents with dementia who walked (Participants1-7),
- Seven EPAs (Participants-EPAs 1-7 – Wife, Son, Daughter and a Friend),
- Four RNs (Participants- RNs 1-4) and,
- Eight HCAs (Participants-HCAs1-8)

3.10.5 Participants Withdrawn from the Study and Rationale

Eighteen Participants in total were withdrawn from the study, 14 of them due to circumstances they could not control: Five participants from Facility Three were withdrawn due to factors already discussed earlier above. Six participants, including three residents from Facilities One and Two were withdrawn as they were transferred to other facilities as a result of changes in their levels of care before data collection started. The other three were their EPAs. One participant, whose interview was postponed till when he was well, passed away in Facility Two by the time restrictions were eased at the facility to visit and interview him. I had interviewed the daughter before the national traffic light system and restrictions to visiting facilities came into force, but he was unwell that day. As a result, I made the decision to give him some time to recover before interviewing him. I sent my condolences to the daughter who was his EPA and the entire family. Six other participants were withdrawn from Facility: one resident with dementia who walked denied having dementia but admitted having Parkinson's disease (PD) and would be happy to participate in a research on PD, so she and her daughter EPA were withdrawn from the study. An EPA-wife changed her mind and wanted an intervention study so that her husband, a participant could be treated. I explained to her my limitation as a nurse and the scope of my observation study and as a result, withdrew the two from the study. Lastly, another EPA and a resident were withdrawn as the EPA who was recently bereaved, underwent a surgery and confessed not being comfortable with an interview at such period.

3.10.6 Reflections and COVID-19: No Negative Pandemic Impact on Recruitment of Participants:

The pandemic impacted the study in two ways. First, it extended the timeline needed for collecting the data, and secondly, a third facility, which eventually had to close down, could not participate due to the restrictions and impact of the pandemic. I modified the plan and started the analysis of the data already gathered. I interviewed participants across both facilities in between the lockdowns and restrictions. As substantial and rich data had already been gathered, under supervision, I was advised

that I discontinued data collection in Facility Three, which I agreed with. Evaluating the plan at the end, the outcome was positive: I had planned to recruit and interview a total of 15 participants for the study. At the end, I had 26 participants, 11 more participants than I had originally planned. In addition, not knowing exactly how many participants I would be able to recruit in each facility, I had drafted a plan to spend a total of 32 hours to cover the participant observations and the in-depth interviews stages of data collection. As it turned out, in the end, I spent approximately 32 hours in the two facilities as planned.

3.11 Research Methods

The methods used in collecting data for this study were chosen in line with Carspecken's (1996) recommendations for carrying out a critical ethnography study- also known as Critical Qualitative Research (CQR). This methods are in line with other ethnographic research (Liamputtong, 2017, 2012; Oladele, 2012; Tinney, 2008; de Laine, 1997). The methods used were participant observations, in-depth semi-structured interviews, reflections, and unobtrusive methods such as collecting data on the frequency of residents' walking as well as existing guidelines and policies that guided staff in supporting residents who walk, and researcher's reflexivity. Participant observation involves immersing oneself in another's culture as a researcher, observing and participating in activities that are typical in that setting to gain more understanding of the socially constructed action of the group (Liamputtong, 2017). Other supplementary data included training or courses undertaken by staff that guided the support provided to residents such as accredited and non-accredited online courses: Health and Wellbeing NCEA Level 4 for HCAs, regular in-service educational training, and annual training updates on various topics, including on dementia. I was invited by one of the Facility leaders to attend with them one of their in-service teaching sessions on dementia provided by a guest Specialist from the community. I attended the session to learn more about the education that informed their practice.

3.12 Data Collection and Data Analysis Stages

3.12.1 Pre-Data Collection Stage: My Value Orientation

Carspecken (1996), recommended that before researchers start the CE study, they should explore their value orientations to reduce or stop any bias they might have, to add to the rigour of the study. I followed this recommendation and explored my value orientation writing down in my journal my values, beliefs, and expectations on the study including what I expected to find or things I did not expect to find and strategies for how to mitigate what could influence the data collection and the findings such as being

professional during the data collection. I also journalled throughout the course of the research, writing down my experience each day.

3.12.2 Introduction: Recommended Five Stages of Data Collection for Critical Ethnography Study by Carspecken (1996)

Carspecken's (1996) recommendation of five stages is a first and unique methodological theory guiding social researchers on how to carry out critical ethnography or critical qualitative studies to achieve positive social change (Hardcastle et al., 2006; Smyth & Holmes, 2005). This is done through uncovering social inequalities and removing invisibilities, which eventually lead to emancipation for the people affected (Carspecken, 1996; Hardcastle et al., 2006; Smyth & Holmes, 2005). Critical researchers such as Carspecken (1996) argued that "criticalists find contemporary society to be unfair, unequal, and both subtly and overtly oppressive for many people. We do not like it, and we want to change it" (Carspecken, 1996, p. 7). Dementia has been unfairly stigmatised compared to other health issues such as diabetes (Power, 2017) and as a result, persons living with them are dehumanised, their personhood taken away from them (Brooker, 2007, 2004; Kitwood,1996; Kitwood & Bredin, 1992;), and they are socially disregarded (Bartlett, 2022; Bartlett & Brannelly, 2019; Brannelly, 2011, Cook et al., 2022; George, 2010). Carspecken's (1996) recommended five stages are appropriate for investigating the research question and its five aims and these stages are described further below. In following these stages, Carspecken (1996) also suggested that researchers can be flexible in using these stages and can modify the stages to suit the specific cultural and social problems and their research questions. I took this advice and integrated Carspecken's (1996) five stages with Reflexive Thematic Analysis by Braun and Clarke (2006, 2021), especially as Stage 4 of Carspecken's requires a theory to discuss the social issues which I have already selected as social constructionism for the study. With the two, I developed a framework (Figure 2) that enabled me to integrate and work through the data collection to data analysis processes smoothly/.

Before I describe the integration of Carspecken's (1996) five stages of data collection and Braun and Clarke's (2006, 2021) Reflexive Thematic Analysis, I present briefly the five stages of data collection for a critical ethnography study by Carspecken (1996). The five stages of CE data collection are as follows:

- Stage 1: Compiling primary records using participant observation
- Stage 2: Preliminary reconstructive analysis
- Stage 3: Dialogical data generation
- Stage 4: Discovering systems relations and

- Stage 5: Using systems relations to explain findings (Carspecken, 1996)

How data were collected and analysed in each of these stage are discussed comprehensively in the next chapter. However, some core concepts and terminologies interpreted differently by Carspecken (1996), from their conventional uses are presented below and some were applied to this study to add richness to it:

Social Sites: Social sites are spaces where some interactions and activities occur. They are “delimited both geographically and temporally” (Carspecken, 1996, p. 34). Social sites are created when people coordinate activities together or interact within specified times and locations. These sites are determined by a researcher during the data collection. In this research, social sites are residents’ dining rooms, lounges, facilities, activity rooms, and the built environment in general. These are the public spaces where the data collection for this study took place. This is the concept that is used mostly in this thesis.

Settings: In this thesis, the term settings is not used to relate to a geographical location such as east, west, south or north, but to a tacitly shared understanding that changes each time people interact. Settings can be regarded as the rules that each person uses in guiding themselves, sometimes agreeable to others and sometimes not. Even though Carspecken (1996) postulated that settings may not be observed directly, in this study, my interpretation of a setting is the walking of the residents with dementia. The residents, as actors, are self-directed to walk to certain areas using their autonomy and freedom, unaware that staff have a professional duty of care to ensure they are safe. The staff, on the other hand, also as actors, have their own settings, parameters and boundaries to walk in. Sometimes there are disagreements over these boundaries, where and when the residents can walk, when not to and issues of human rights.

Social settings: Social settings occur when actors or participants meet one another in person and negotiate a form of interaction that is acceptable to both parties, which is a process Carspecken referred to as the system that integrates which is different from the conventional social interaction (Carspecken, 1996).

Locales: This term loosely denotes routine activities that are influenced by social sites, usually externally. They are considered to be small social systems that surround the social site (Carspecken, 1996). It can be geographical, social and cultural activities, small, large, blurred, or focussed, but the activities are based on the researcher’s topic and the site.

Social systems: Social systems occur as a result of internal and external influences on actions (Carspecken, 1996). The systems are not limited by time and space and are well-distributed. In this study, the social systems refer to the other ARC facilities. Full details of Carspecken's five stages are presented in the next chapter.

3.12.3 Preparation for Data Analysis: Cleaning and Transcribing Data

Full data analysis started in Stage 4 of the integrated data collection (Carspecken, 1996) and reflexive data analysis (Braun & Clarke, 2006, 2021) framework designed for the study. Data was collected in Stage 3 during the one-on-one in-depth interviews with four groups of participants comprising of seven residents with dementia who walked (Participant1-7), seven EPAs (Participant-EPA1-7), four RNs (Participant-RN1-4) and eight HCAs (Participant-HCA1-8). In total, 26 interviews were carried out with total hours as 11hours 36 minutes and 2 seconds. All interviews were audio-recorded with participants' consents. Two professional transcribers were engaged to transcribe 11 out of the 26 audio-recorded interviews. Each signed a Confidentiality Agreement form (Appendix I) before being sent the audio-recorded interviews to transcribe. The remaining 15 recorded interviews were transcribed by me so I could familiarise myself with the data as I transcribed them. Intelligent verbatim or intelligent speech recognition technology (Eftekhari, 2024) was used to transcribe the recorded interviews to ensure readability. Microsoft Office Word Translator and online Otter software through subscriptions were used in transcribing the recorded interviews. Prior to analysis, all transcripts of interviews were de-identified to maintain their confidentiality, remove any bias or label, for ethical reasons and to be able to have a clean transcript to work with (Kolanowski et al., 2009). To ensure that the transcribed data were reliable and done correctly, I listened to each audio interview recorded with the transcribed interviews. I applied intelligent verbatim or intelligent speech recognition technology (Eftekhari, 2024) to the data I personally transcribed and the same was done by the professional transcriber so I could focus on the meaning of data in a concise and clear manner. It was not done word for word as filler words were removed in many cases to clean the data. However, to show the diversity and heterogeneity of the participants, some participants transcriptions were left untouched.

In addition, I gave each participant a code name for the data analysis and these names were improved on during the process of writing out the findings. Data analysis commenced once this process was completed.

3.13 Data Analysis using Reflexive Thematic Analysis by Braun & Clarke (2006, 2021)

Thematic analysis is referred to as interpretive thematic analysis (Braun & Clarke, 2021, 2006). It is “a method for identifying, analysing, and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 6). It can be accessed easily and used flexibly in qualitative research to analyse and identify themes in any set of gathered data (Byrne, 2022). The patterned manner reveals semantic and latent interpretations that give a rich and in-depth understanding of the findings (Braun & Clarke, 2006). An analysis is an integral component of the research to qualitative researchers as words expressed indicate a lot more than numbers (Liamputtong, 2017). Thematic analysis (Braun & Clarke, 2006) is “a useful and flexible method for qualitative research in and beyond psychology” (p. 2). I integrated it with the five stages for data collection by Carspecken (1996) to develop a framework (see Figure 2) for data collection and data analysis of the study.

Braun and Clarke’s (2006, 2021) approach to thematic Analysis (Reflexive TA or RTA) consists of six phases:

- Phase One: Familiarisation of data
- Phase Two: Generating initial codes
- Phase Three: Generating initial themes
- Phase Four: Developing and reviewing themes
- Phase Five: Refining, defining and naming themes
- Phase Six: Writing the report

These phases will be explained in detail in the next chapter along with a discussion of how the five stages of data collection and the six phases of Reflexive TA are interwoven to generate the findings of the data. This process was not an easy task as there were substantial data gathered in each of the four groups of participants. The process was iterative and recursive and I did this with each group dataset. At a point, I entered all 26 interview transcripts into NVIVO software. The process was useful in being a ‘one-stop shop’ that I could store all data permanently and easily accessed them. I reverted to my initial generated themes done manually through RTA and continued with the framework process and phases till I reached Phase Six when I wrote the thesis (report writing). Detailed description of how the framework was used is presented in the next chapter (Four).

3.14 Research Rigour and Quality

In carrying out this qualitative study, I applied approaches that ensured rigour (Connelly, 2016) and quality to strengthen the trustworthiness of the methods of the study. Trustworthiness is “the degree of confidence in data, interpretation and methods used to ensure the quality of a study” (Connelly, 2016; p. 435). I ensured the four criteria used in measuring the quality of the study are maintained which are credibility, dependability, confirmability, and transferability of its findings, with the continuous use of reflexivity throughout the research process (Liamputtong, 2017; Stenfors et al., 2020). In ensuring credibility, which relates to the plausibility and believability of the findings (Cresswell, 2014; Liamputtong, 2017; Stenfors et al., 2020), I ensured there was alignment of the research question, social constructionism theory applied, the critical ethnography methodology, the selection criteria, the richness and depth of the data collected, the framework developed for the data collection as well as the data analysis processes.

Dependability of a research project entails whether the study can be replicated or its consistency can be applied at a different period (Bryman, 2016; Liamputtong, 2017; Stenfors et al., 2020). I ensured I have provided comprehensive details about the study such as my positionality and motivation for the topic, ethics approvals, recruitment of ARC Facilities and the four groups of participants, the design of the framework for the data collection and data analysis of the study. In addition, I incorporated reflection throughout the data collection process and in the last chapter of the thesis to ensure transparency is maintained for replication of the study at other times.

Confirmability entails providing clear links between the data gathered and the findings generated with the use of relevant quotes as evidence (Bryman, 2016; Liamputtong, 2017; Stenfors et al., 2020). Findings in this study are evidenced with many relevant quotes from the participants. The findings were also analysed critically through the lens of social constructionism, highlighting their implications and significance.

In addition, by ensuring the quality and standard of the study, the study has been transparent, providing detailed explanation of the research context and how this informed the findings, to increase transferability of the results.

Finally, triangulation was also used in the study with multiple methods used in collecting the data analysed, such as in-depth interviews and participant observations. Unobtrusive data methods were used in gathering data as well such as the provided guidelines on dementia care used by the facilities, the staff training courses and record of frequencies of walking of residents with dementia. I also adhered to three guidelines

for data collection recommended by other researchers (Bidabadi, 2019**;** Oladele, 2012; Horner, 2004) which are: working collaboratively with all participants to gain deep rich data; multivocality which refers to ensuring participants were able to "…speak in the text…" (Horner, 2004, p. 23) and self-reflexivity which is to engage in continuous self-reflection to check biases (Bidabadi, 2019**;** Horner, 2004; Oladele, 2012).

3.15 Reflection on Data Collection

The data for this study were collected over a 10-month period (July 2021 to April 2022) due to the COVID-19 pandemic alert level lockdowns and the COVID -19 Protection Framework traffic light system changes in the country (New Zealand Government 2021; New Zealand Government, 2022). Out of these months, the actual data collection took place approximately four months. The five stages recommended by Carspecken (1996) were followed, though with slight modifications to accommodate the nature of my research. Despite the pandemic disruption to data collection, the framework developed for collecting data (Carspecken, 1996) and analysing data (Braun & Clarke, 2006, 2021) was followed and it was effective in in generating the findings for the study.

3.16 Reflexivity

I applied continuous self-reflection at every stage and phase of the study (Bidabadi et al., 2019; Horner, 2004; Oladele et al., 2012). The rationale for using self-reflection was to identify my biases on the study or on the data gathered. This is very important in critical ethnography studies as it is a key element in promoting the rigour of the study. Self-reflexivity refers to "the ability of a researcher to constantly question his/her motives, practices, and interpretations to avoid the colonizing discourse of traditional ethnography" (Horner, 2004, p.27). It is also important for me to maintain self-reflexivity to recognise my own beliefs and values even though I am an integral part of the study, I should not allow my beliefs, ideologies, experiences, and values to influence the study, yet I need to maintain my positionality. I maintained transparency (Stanley, 2019) in my research methodology and methods as to when I adopted the etic objective approach during participant observation in data collection stage one (Carspecken, 1996), when I took the emic-subjective stance during stage three dialogical in-depth interview stage (Bidabadi et al., 2019)

As I previously worked various roles in aged residential care nursing for approximately 11 years and since being in my current teaching role, I have also been supervising nursing students placed for clinical practice in ARC Facilities from time to time. This inside experience added to the rigour of the study. However, I constantly reminded

myself while carrying out this study that I was a researcher who was there to learn from the staff and to collect data that would help in answering the research question. I was not there as a professional working in the ARC Facilities. To maintain the integrity of the study, I always took the position of an outsider to obtain a general understanding and to make fair representations of the study (Oladele et al., 2012; Stanley, 2019). I also presented adequately the participant's experiences, keeping accurate and regular audit trails of the processes. I discussed regularly with my study-accountability partner, my Peer-study groups, journalled regularly and debriefed with my supervisors regularly throughout the data collection period, after and during the writing phase of the findings. Using critical ethnography methodology enabled me to explore the perspectives that could exist through a reflective process which could be seen as critical (Burr, 2015; Oladele et al., 2012; Thomas, 1993).

3.17 Summary

In summary, in this chapter, I discussed my ontological and epistemological orientations to the study. I presented the theoretical framework of social constructionism that guided the research, the critical stance it provokes readers to take in questioning things taken for granted in the society. I discussed how social constructionism challenges our consciousness to think how else we see the walking activities of the residents with dementia and to destigmatise their walking so as to restore their personhood. The study was designed to challenge the readers to stop and to listen to the voices in the quotes and to acknowledge and consider their views for alternative ways to support residents with dementia with their walking as they are part of the community. The chapter suggested that the findings chapters would provide invaluable knowledge and insights into the state-of-the-art of lived experience of the residents with dementia who walk, how their walking is socially constructed, and how their overall health and well-being are impacted by their walking. In addition, this chapter discussed the methodology of the study, Critical Ethnography, and how it fits in appropriately with social constructionism in investigating the research question. Ethical approvals from two ethics committees of Southern HDEC and AUTEC were obtained and how amendments was requested for so the residents with dementia could be included in the study. Also discussed in this chapter was the ethical obligations for including the residents with dementia who walked in the study. The selection criteria and the recruitment process of the ARC Facilities and the four groups of participants were comprehensively presented. The integrated framework for data collection (Carspecken, 1996) and reflexive thematic analysis (Braun & Clarke, 2006; 2021) was discussed together with the rationale for the integration and each stage introduced.

Research rigour and trustworthiness of the findings were also discussed in detail. The chapter ends with a summary.

The next Chapter starts the presentation of the findings by first discussing in detail the framework of the study and how it was used. It also unfolds details of the participants, a summary of participant observations made, the process of data collection and the data analysis phases and some reflections.

Chapter 4 Data analysis

Critical epistemology … gives us principles for conducting valid enquiries into any area of human experience (Carspecken, 1996, p. 8)

4.1 Introduction

This chapter presents the framework of the research following the recommendations of Carspecken's (1996) data collection method for critical ethnography, commonly referred to as Critical Qualitative Research (CQR) (Carspecken, 1996), and its integration with Thematic Analysis (Braun & Clarke, 2006; 2021). The previous chapter mentioned the flexibility of Carspecken's five stages of data collection and Braun and Clarke's Reflexive Thematic Analysis. I decided to explore these flexibilities by combining the two processes to answer the research question. This chapter also presents an overview of the participants, featuring participant tables showing their characteristics, preliminary steps to data collection, and the duration of the different interviews. A presentation of the data collection and analysis includes a graphical representation of the framework using figure and in tables. Moreover, an overview of the five stages of data collection and analysis, an overview of participant observations in stage one of data collection, the five stages of data collection, the six phases of the thematic data analyses, and reflexibility are also presented in this chapter.

4.2 Overview of Participants for participant observations and in-depth interviews

Table 1. Participants1-7 Residents with dementia who walked

Participant	Social site (Facility One/ Two)	Participant Observation possible	One-on-one (In-depth) Interviews conducted	EPA present during interviews as requested*
Participant1	Facility One	Yes	14 July 2021	EPA1 (friend) present
Participant2	Facility One	Yes	22 July 2021	EPA1 (friend) present
Participant3	Facility One	Yes	26 July 2021	EPA1 (friend) present
Participant4	Facility Two	Yes	10 August 2021	EPA1 (friend) present
Participant5	Facility Two	No	11 August 2021	EPA1 (friend) present
Participant6	Facility Two	Yes	13 August 2021	EPA1 (friend) present
Participant7	Facility Two	Yes	11 April 2022	**Participant-HCA4

Note. * EPA present as studies indicate that unfamiliar situations and people can cause persons with dementia disruptions, that they seek attachment with familiar people to give them reassurance (Kitwood, 1997; Hong & Song, 2009; Dyer et al., 2018). ** Participant-HCA4 present as familiar to resident and delegated by resident's EPA (daughter) to be present as she was unable to.

Table 2. Participants-EPAs 1-7

Participant- EPAs	Social site (Facility One/Two)	Participant observation possible?	Date of One-on-one (In-depth) Interviews conducted
Participant-EPA1(friend)	Facility One	No	14 July 2021
Participant-EPA2(Son)	Facility One	No	22 July 2021
Participant-EPA3(Wife)	Facility One	No	26 July 2021
Participant-EPA4(Daughter)	Facility Two	No	10 August 2021
Participant-EPA5 (Son)	Facility Two	No	13 August 2021
Participant-EPA6(Wife)	Facility Two	No	13 August 2021
Participant-EPA7(Daughter)	Facility Two	No	11 August 2021

Table 3. Participants-Staff: RNs1-4 and HCAs 1-8

Participant-staff	Social site (Facility One/ Two)	Participant Observation possible?	Date of One-on-one (In-depth) Interviews conducted
Participant-RN1	Facility One	No	14 July 2021
Participant-RN2	Facility One	Yes	14 July 2021
Participant-RN3	Facility Two	No	10 August 2021
Participant-RN4	Facility Two	No	11 August 2021
Participant-HCA1	Facility One	Yes	14 July 2021
Participant-HCA2	Facility One	Yes	14 July 2021
Participant-HCA3	Facility Two	No	02 August 2021
Participant-HCA4	Facility Two	No	28 July 2021
Participant-HCA5	Facility Two	Yes	03 August 2021
Participant-HCA6	Facility Two	No	11 August 2021
Participant-HCA7	Facility Two	No	16 August 2021
Participant-HCA8	Facility Two	Yes	16 August 2021

Seven residents living with dementia who walked (Participants1-7) from two participating social sites or ARC Facilities participated in this research. They all met the inclusion criteria and in this study were referred to as Participant1, Participant2, Participant3, Participant4, Participant5, Participant6 and Participant7 as indicated in Table 1. Participant observation was carried out on each one of them using an etic (outsider) approach and applying Stage One of Carspecken's(1996) recommendation on carrying out a critical ethnographic study as presented in the previous chapter. They were observed in the public spaces of their respective facilities such as in the dining rooms, the lounges and when walking in the Hallways. The exception was Participant 5, whose son, Participant-EPA 5, invited me into her room to introduce me to her. I gathered that she was recently discharged from the public hospital and had not been

walking as she used to. After the brief introduction, I quickly left the room as I was aware I was not to observe the residents in their rooms. Over the days of participant observation of the other participants walking in the public spaces of Facility Two, I noticed that she was not among them. During Stage 3 of the data collection process (Carspecken, 1996, Dialogical data generation), I conducted one-on-one in-depth interviews with each Participant-resident. Having in mind, the knowledge that persons with dementia seek reassurance, bonding and attachment when they find themselves in unfamiliar situations (Kitwood, 1997) including in unfamiliar environment and unfamiliar faces (Kitwood, 1997; Hong & Song, 2009; Dyer et al., 2018; Meyer & O'Keefe, 2020; Vafeas & Slatyer, 2021). I guided myself with the ethical principles of beneficence and non-maleficence in carrying out these interviews to be beneficial to the residents. As a result, I requested residents' EPAs to be present during the interviews During the interviews, sometimes, the EPAs spoke to the residents to speak up or repeated the question to them. This was expected, but the focus was on the residents' responses. Each of the EPAs had their own one-on-one interview session with me, immediately after rounding up the session with the residents, thanking them for their time. The residents' interviews and data collected provided more evidence that persons with dementia wanted to be involved in studies about their them. The minimum duration of a resident's interview was four minutes, while the maximum was 17 and a half minutes. Part of the goals for the interview was to ensure residents were able to contribute to the interviews, felt comfortable during the process and had autonomy like the other interviewees the length of time they engaged in conversation with the researcher. The overall process was guided by beneficence, non-maleficence and other ethical principles. As a result, the duration of some interviews were longer than the others and certainly more than two to five minutes originally planned. This again shows that the residents enjoyed the process and wanted to engage more in conversations. Each resident was interviewed according to their comfort level and intrtviews were audio-recorded with their consents. I treated all participants with respect, dignity, and Manaakitanga and maintained ethical standards throughout the data collection stages (Auckland University of Technology, 2019; National Ethics Advisory Committee, 2019). Observations of the participants in their care environment and staff (Participants RNs and HCAs) interactions with them were recorded in the thick note (Carspecken, 1996). Information about Participants-residents observed are presented in Table 1, their demographics and characteristics in Table 4. Details of Stage One Participant Observations in Facilities One and Two are in Section 4.8.1, and its summary is in Section 4.8.2 in this chapter.

A total of seven Participant-EPAs1-7 (Table 2) were interviewed. Most EPAs were family members of the residents and one was a family-friend. Their codenames are as

follows: Participant-EPA1(family friend), Participant-EPA2(Son), Participant-EPA3(Wife), Participant-EPA4(Daughter), Participant-EPA5(Son), Participant-EPA6(Wife) and Participant-EPA7(Daughter). As EPAs, they are legally authorised (Ministry of Justice, n.d.) to look after and make decisions on the personal welfare of the residents and each had played this role directly or indirectly before the resident got admitted to their respective ARC facility. All Participant-EPAs were present during the interview of their respective relative or friend, as requested by the researcher. The only exception to this was the EPA for Participant7, who could not be present due to medical reason (and was withdrawn from the study). She, however, had requested that one of the staff be present on her behalf. A reflection further in this chapter showed my initial introduction to Participant7's daughter (EPA) when she previously visited the facility to take her mother out. In terms of Participant observations, not all Participant-EPAs visited the residents when the participant observation took place, which meant that their interactions with the staff and residents could not be observed, but they were present for their interviews of their family members or friend. Interviews were audio-recorded and later analysed. The demographics and characteristics of the EPAs are in Table 5.

Four RNs (Participant-RN1-4) (Table 3)**,** part of the residential care staff (RCS), participated in the study and were also interviewed and audio-recorded with their consent before data was analysed. Only Participant-RN2 could be observed interacting with the residents due to each facility's routine and schedules. All the RNs were regulated nurses, registered under the New Zealand registered nurse scope of practice (Nursing Council of New Zealand, n.d.), and three were New Zealand citizens. Only Participant-RN2, who started working in New Zealand two years ago after her arrival in the country, was not yet a New Zealand citizen but had gained the needed experience working with residents with dementia who walked since her arrival to the country. All RNs were fully qualified and three had either a postgraduate degree or undertaking postgraduate education. All four Participant-RNs met the inclusion criteria for the study, which required at least six months' experience caring for residents with dementia who walked in ARC Facilities. The RNs' experience ranged from 2 to 15 years. Their demographics and characteristics are presented in Table 6.

Eight Health Care Assistants (Participant-HCA1- 8 (Table 3)**)** were also part of the RCS group, and eight of them from both Facilities/Social sites were interviewed for this research. Audio recording of the interviews was done with their consent, before analysis of data was carried out. HCAs work with RNs to provide care to residents. They are directed, delegated, and supervised by the RNs to carry out tasks such as personal care and other tasks depending on their years of experience in the role

(New Zealand Government, 2024; New Zealand Nurses Organisation, 2014). They each held at least one qualification in health, such as a New Zealand Certificate in Health and Wellbeing (Level 3) to work in hospitals and rest homes. Four of them, Participant-HCA1, Participant-HCA2, Participant-HCA5, and Participant-HCA8, were observed interacting with the Participant-Residents with dementia who walked. As with the RNs, one of the inclusion criteria was a minimum of six months of experience caring for residents with dementia who walked at a residential care facility. Among the Participant-HCAs, the number of years of experience ranged from five years to 25 years. Table 6 presents details of their demographics and characteristics.

4.3 Data Collection and Data Analysis

Presentation on Data Collection and Data Analysis

The data collection (Carspecken, 1996) and data analysis (Braun & Clarke, 2006, 2021) were integrated into one comprehensive framework as there was alignment in the two processes. The five stages of Carspecken's (1996) critical qualitative research are "designed to study social action taking place in one or more social sites" (p. 40). The data collection for this study was carried out using a framework where the five stages recommended by Carspecken (1996) as presented in previous chapter and reflexive Thematic Analysis by Braun and Clarke (2006, 2021) were integrated. Two of the aims of this research was to gain "experiential orientation focus on what the participants think, feel and do" (Terry et al., 2017, p. 19) about the walking of the residents with dementia and the relational and supportive interventions provided for the residents. The total number of participants was 26.

4.4 Participants Tables

Table 4. Demographics Characteristics of Residents with Dementia Who Walked

Participant	Date of Interview	Age	Ethnicity	Gender	Year of Diagnosis dementia	Former Occupation
Participant1	14 July 2021	86	NZ European	M	2014	Businessman
Participant2	22 July 2021	87yrs	NZ European	F	2019	Pharmacist
Participant3	26 July 2021	77yrs	British	M	2017	Truck driver
Participant4	10 August 2021	80	Indian	F	Mixed dementia? Rudaz 16/30- (not available)	Full time mom
Participant5	11 August 2021	87	NZ European	F	2013	Registered nurse
Participant6	13 August 2021	89	NZ European	M	Dementia MOCA13/30 (not available)	Finance
Participant7	11 April 2022	93	NZ European	F	Alzheimers Dementia (not available)	Accountant

Table 5. Demographics Characteristics of Enduring Powers of Attorney (EPAs)

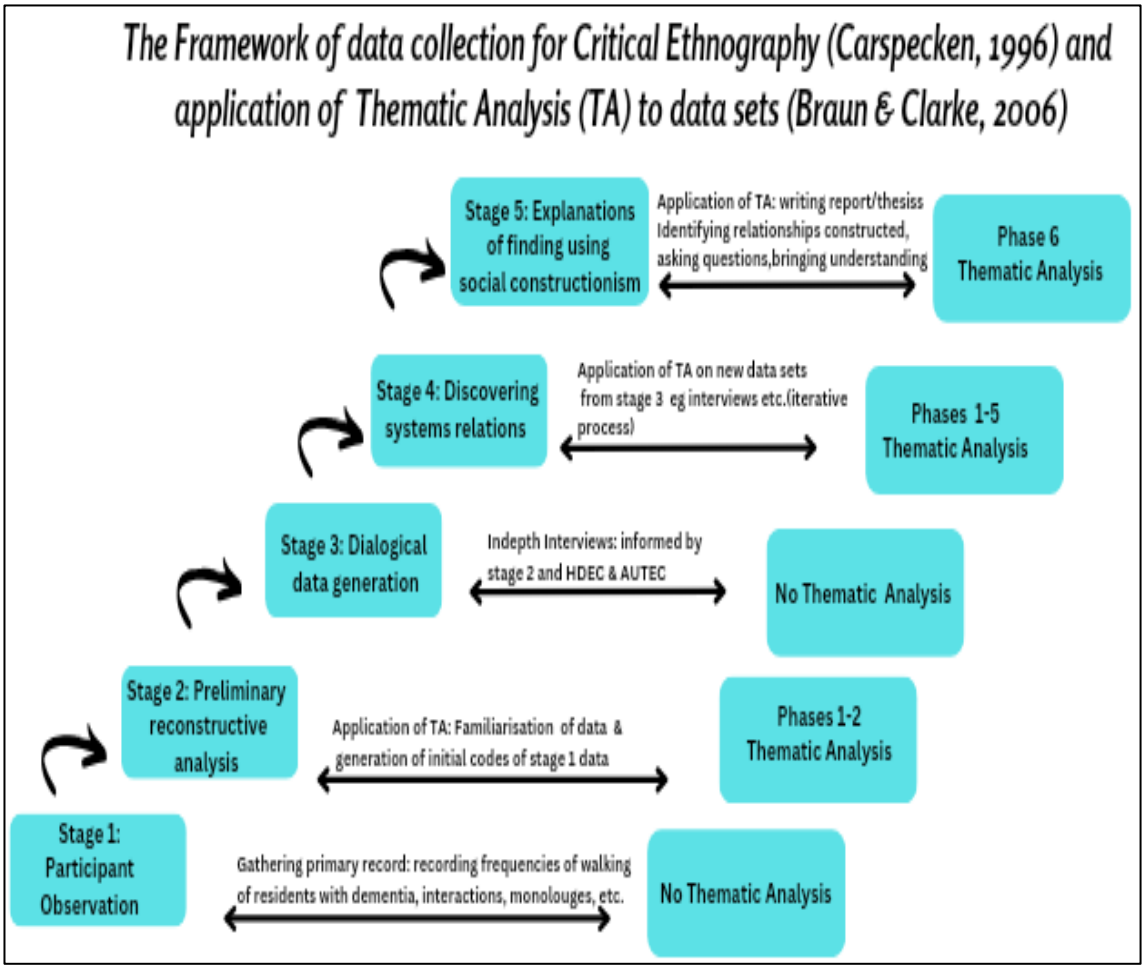
Participant	Date of interview	Age	Ethnicity	Gender	Relationship	Duration of caring before admission	Citizenship
Participant-EPA1(friend)	14 July 2021	65	NZ European	F	Friend	6 months	New Zealand
Participant-EPA2(Son)	22 July 2021	63	NZ European	M	Son	3 months	New Zealand
Participant-EPA3(Wife)	26 July 2021	75	NZ European	F	Wife	1 year	New Zealand
Participant-EPA4(Daughter)	10 August 2021	45	Indian	F	Daughter	3-4 years	New Zealand
Participant-EPA5(Son)	13 August 2021	4	NZ European	M	Son	2-3 years	New Zealand
Participant-EPA6(Wife)	13 August 2021	94	NZ European	F	Wife	7 years	New Zealand
Participant-EPA7(Daughter)	11 August 2021	70	NZ European	F	Daughter	4 weeks	New Zealand

Table 6. Demographics Characteristics of Residential Care Staff (RCS)

Participant	Date of Interview	Age	Ethnicity	Gender	Qualifications	No of years' experience caring for Resident who walked	Citizenship
Participant-RN1	14 July 2021	46	Filipino	M	Business & Care Manager, NZ Registered Nurse, Post graduate Diploma in Age Care Management	11	New Zealand
Participant-RN2	14 July 2021	34	Filipino	F	New Zealand Registered Nurse	2	Filipino citizen
Participant-RN3	10 August 2021	39	Filipino	F	Masters (Philippines), Bachelor in Nursing, Clinical Manager	15	New Zealand
Participant-RN4	11August 2021	30	Filipino	M	Bachelor of Nursing, Postgrad paper, Clinical Coordinator	9	New Zealand
Participant-HCA1	14 July 2021	53	Filipino	M	Health and Wellbeing 3 including Dementia series	12	New Zealand
Participant-HCA2	14 July 2021	58	Filipino	F	Health and Wellbeing 4 including Dementia series	18	New Zealand
Participant-HCA3	02 August 2021	51	Māori	F	Health & Wellbeing	5	New Zealand
Participant-HCA4	28 July 2021	33	Fijian	F	Physiotherapy (Fiji) Level 4 Health & Wellbeing	5	New Zealand Permanent Resident
Participant-HCA5	03 August 2021	58	Tongan	F	Healthcare Assistant Level 4	25	New Zealand
Participant-HCA6	11 August 2021	48	Fijian	F	Health & Wellbeing Level 3	8	New Zealand Permanent Resident
Participant-HCA7	16 August 2021	53	Indian	F	Diploma in Nursing	25	Australia & New Zealand
Participant-HCA8	16 August 2021	39	Filipino	M	Health & Wellbeing Level 4, currently doing Dementia course	6	New Zealand

4.5 The Framework of Data Collection and Data Analysis

Figure 2. The Framework of Data Collection, Combining Critical Ethnography with Thematic Analysis



Note. Christianah Adesina's adaptation and application of Carspecken's (1996) five stages of data collection for Critical Ethnography and Braun & Clarke's (2006) Thematic Analysis of data sets.

Table 7. Overview of the Integration of Five Stages of Data Collection (Carspecken, 1996) and Reflexive Data Analysis (Braun & Clarke (2006)

Carspecken's (1996) Five Stages of Critical Ethnography (CE) Data Collection	Name of Stage & Phase	Integration and interpretation taking place in the framework	Braun & Clarke's Six Phases of Reflexive Thematic Analysis (RTA) (2006, 2021)
Stage 1	Participant observation (CE)	Report of observations	No Reflexive Thematic Analysis required
Stage 2	Preliminary analysis (CE) = Phase 1 + Phase 2 (RTA)	Familiarisation of Participant observation data + generating initial codes from them = Observations inform interview questions	Reflexive Thematic Analysis Phases 1-2 applied to participant observation summaries in Table 6
Stage 3	Dialogical data (CE): One-on-one in-depth interviews with 26 participants	Interviews with four sets of participants	No Thematic Analysis required
Stage 4	Discovering systems relations (CE)= Phase1, Phase 2, Phase 3, Phase 4 & Phase 5 of RTA	Applying RTA on each dataset collected in Stage 3: in-depth interviews of four different groups (Participants1-7; Participants-EPAs1-7; Participants-RNs1-4 + Participants-HCAs1-8) =Reflexive Thematic analysis builds relationships. The write-up of the findings had already started at this stage as the theoretical orientation of the study. Social constructionism was used to examine the relationships at these two social sites in relation to the research question.	Thematic Analysis Phases 1-5 applied to each of the four datasets from the interviews to find common patterns in each. Afterwards, patterns of convergence and divergence were identified in all four datasets – an iterative process. Phases 1-5: (Familiarisation, Generation of initial codes, Generating/Constructing themes, Reviewing themes, Defining and naming themes)
Stage 5	Explanation	Answering the research question	Reflexive Thematic Analysis Phase 6 -Writing the report/findings/thesis

Note: Integration of Carspecken (1996) and Thematic Analysis (Braun & Clarke, 2006).

4.6 Preliminary Steps

Prior to getting to Stage One, Carspecken's (1996) preparatory steps recommendations were carried out. I had identified the research problem, the facilities where the research would take place as residents with dementia who walk lived there (social sites), and the categories of potential participants required for the research. Three preliminary steps were taken: First, some flexible but general questions were

brainstormed and put together as a list. The questions related to what type of built environment the residents lived in, what the interior of the facilities looked like, how long the residents had been living in the facility, and what the philosophy of care at the facility was. The second step was listing the key information to gather and key questions to ask during the data collection stage that would answer the research question. This was a crucial step in the study and in this research. The specific and indicative questions for each of the four sets of participants had been listed and were approved by the Health Disability Ethics Committee (HDEC) and Auckland University of Technology Ethics Committee (AUTEC) before the study started and these can be found in the Appendices: Participants with dementia who walked (Appendix I); Participants-EPAs Participant-RNs (Appendix J) and Participant-RNs and HCAs (Appendix K). The third preliminary step taken before commencing this research was to explore my own value orientation on the research topic (detailed in section 3.10.1). I kept a reflexive journal throughout this study and journalled regularly about my feelings and experiences. This process was necessary to check any bias that could influence the data collection, analysis or the findings of the research. This process also served to strengthen my research and make it more transparent to the readers,

4.7 Explanation of the Integration of Data Collection (Carspecken, 1996) with Reflexive Thematic Analysis (Braun & Clarke, 2006, 2021) for Critical Ethnography Study

4.7.1 Stage 1: Participant Observations in Facilities One and Two

Stage 1 is the first stage of collecting data for a Critical Ethnography study as recommended by Carspecken (1996). It starts with the compilation of primary records of the study which plays a key role as I passively observed, writing in my thick notebooks and journals (Carspecken, 1996; Hardcastle et al., 2006; Smyth & Holmes, 2005). It was at this stage that I entered the social site (Carspecken, 1996) or research field of each social site as an outsider and I took the position of a third person, taking notes on everything (Liamputtong, 2017; Pope, 2005) to gather objective information on a social issue on a social site. Monological data (Carspecken, 1996) was the main type of data gathered as only my voice as the researcher was heard at this stage through the etic observations recorded, the journal and my reflections. All participant observations were done in the public spaces of the facilities, such as lounges, dining rooms, activity rooms, and hallways.

Observations were made of each facility's external environments and the interactions of the Participant-Residents living with dementia who walk with Participant-RNs and Participant-HCAs. The objective of this stage was to identify the participants who

walked, frequencies of walking, the interactions between staff and Participant-Residents, and those factors in their environment that supported their walking. The first general data gathered for each social site at different dates were analysed in the next stage (Stage 2) and initial codes were used as guides to the interview questions in Stage 3, the In-depth Interview stage (Dialogical data generation stage) (Carspecken, 1996).

4.7.2 Summary of Participant Observations in Stage One

Observations carried out at Stage 1 included identifying the participants with dementia who walk; the frequency of their walking; whether they were relaxed, restless or agitated; whether any mobility aid was used when walking; and if so, which type; whether they were frail, able to sit, or stand easily; whether any effort was made to open the door to exit the facility (if observable); any obvious agitation or tiredness; and any staff interactions with residents and their EPAs. No audio or video recording was done at this stage to keep the privacy and integrity of the study population, which was in line with the ethical principles of dignity and to maintain their privacy and confidentiality. Only note-taking and sketch drawings of the facilities were, and sketches were not included in the Appendices for the same privacy and confidentiality purposes. Some of the reflections journalled are presented towards the end of this chapter as they are part of the recommendations (Carspecken, 1996) for data collection for critical ethnography. They helped in checking my biases and refocusing my objectivity to the data being collected. The environments of the social sites were observed for ease in wayfinding by residents, for presence of gardens, walking routes, and relaxation spots in and around the social sites. The buildings, locations in the community, aesthetics and access to nature were noted down. Social Site One was certified to provide three levels of care (rest home, private hospital, and secured dementia levels of care), while Social Site Two provided two levels of care (the rest home and private hospital). Participating residents and staff were observed in the public spaces of their facilities, that is, in the lounges, the dining rooms, activity rooms, and hallways of each facility. I located myself in an unobtrusive spot where I could observe participants without disturbing them, but sometimes my presence attracted some residents' attention, and they come over to ask me questions and chatted with me. Anytime an interaction between the staff and participating residents was observed, I wrote down the scene in my field journal notebook so I could follow it up during interviews. When I initially started the observations in Facility One, I observed the wide hallways and soft music playing in the background during residents breakfast time. The data recorded during participant observations in Stage 1 were analysed in Stage 2 of the framework. Data for each social site were analysed using Phases One

(Familiarisation with Data) and Phase Two (Generation of Initial Codes) of Braun and Clarke's Thematic Analysis (2006, 2021) as in *Figure 1* and Table 8 which is discussed next. I observed all participants with dementia who walk and noted down all key information required. Table 8 presents details of the participant observations with dates, days of observations, length of observation, total hours and each social site or facility's participants were observed and the total hours used in collecting the data.

Table 8. Details of Stage1 - Participant Observations Hours in Facility One and Facility Two

Date of Observation	Day of observation	Facility	Length/Duration
14 July 2021	Only Day	Facility One	6hrs
28 July 2021	Day One	Facility Two	4 hrs 30mins
02 July 2021	Day Two	Facility Two	I hr 55 mins
03 July 2021	Day Three	Facility Two	7hrs 50mins
Total hours of Participant observations = 20hrs 15mins			

4.7.3 Stage 2: Preliminary Reconstructive Analysis Stage: Here, Phases 1-2 of Reflexive Thematic Analysis (RTA) Was Carried out:

Application of the first two phases of RTA, (Familiarisation with the Data and Generating Initial Codes) (Braun & Clarke, 2006; Byrne, 2022; Terry et al., 2017) was applied in Stage 2 of Carspecken's (1996) recommendation to identify patterns recorded in the thick observation book and journal note-bool taken during the participant observations in Stage 1. Factors that were not articulated during the observations, including meanings and issue of power that could be followed up with questions during the In-depth Interview stage 3 Dialogical Data Generation/In-Depth Interview Stage (Carspecken, 1996) were also considered here. An example of a possible power dynamics issue was an interaction I observed between Participant1 and Participant-RN2 during the participant observation stage: I observed Participant1 refused his medications being administered to him during breakfast and then walked out of the dining room. I noted Participant-RN2 did not follow him but turned to her medication trolley beside her and pushed it to another resident's dining table and administered their medications which they accepted. Curious to know the outcome, I later asked RN2 during her interview session how she managed this situation with Participant1 as I did not know the outcome. She stated that she later approached Participant1 with the medications and he accepted them. This dispelled the issue of power I had previously suspected as during the interviews I gathered that at first refusal of residents, give them space that they need and if they are approached later with the

same request, usually they would have a changed demeanour and would be positively disposed towards the request.

Table 9 shows the initial codes (in colours) that were generated based on the analysis of the participant observations, These codes were then incorporated in the questions asked during Stage 3, Dialogical Data Generation or Interview stage (Carspecken, 1996).

Table 9. Stage 2 Preliminary Analysis (Critical Ethnography (Carspecken, (1996)): The use of Phase 1 and Phase 2 Reflexive Thematic Analysis (Braun & Clarke, 2006, 2021)

Participants	Key Observations/Initial codes generated highlighted
Participant1	Walked frequently half of the times observed; unable to walk independently; no mobility aid used; held on to the handrail installed on both sides of corridor; able to transfer desired hand without assistance to the handrail in the direction he was facing; rested between morning tea and lunch time
Participant2	Walked frequently, independently, three quarters of the times observed; followed researcher around after breakfast till morning tea (shadowing); friendly; enjoyed engaging in conversations
Participant3	Walked frequently, more than three quarters of the time observed; walked independently; full of humour; inquisitive and enjoyed engaging others in conversations
Participant4	Walked most times independently, more than three quarters of the times observed, friendly, enjoyed engaging in conversations
Participant5	Frail, complained of not being allowed to walk; sick and in bed; did not walk during times observed; used to walk 12 hours a day
Participant6	Frail, calling out for help when wanting to walk; walked with assistance of one staff using mobility aid; walked one third of times observed
Participant7	Walked frequently with mobility aid; walked more than three quarters of times observed; friendly and humorous; enjoyed engaging others in conversations

Note: Some codes that informed the in-depth Interview Stage 3 - Dialogical Data Generation stage

4.7.4 Stage 3: Dialogical data generation: Conducting In-depth Interviews with the Residents with dementia who walked, their EPAs, the HCAs and RNs

This is the stage where the voices of the participants were brought in to be heard and to build the primary record. Interviews were conducted in a face-to-face interaction (Carspecken, 1996) to gain subjective views from each participant using an emic approach. “In-depth interviewing is a method of qualitative data collection that does not use fixed questions but aims to engage the interviewee in a guided conversation to elicit their understandings and interpretations” (Liamputtong, 2017, p. 163). This was the stage where each participant was interviewed on their perspectives on the walking of the residents and other various questions. Only Participants1-7 were asked one

question each to ensure their comfort throughout the interview session except when they wanted to engage in a longer conversation. Indicative semi-structured questions approved by HDEC and AUTEC and the codes generated in Stage 2 informed this dialogical data generation stage, also referred to as the in-depth interview stage (Carspecken, 1996), where “each participant was able to construct or reconstruct their experience” (Liamputtong, 2017, p. 163). Each participant was interviewed at a time convenient for them at each ARC Facility. Continuous consenting process was gained as planned as I gained their consent again before each interview started with each participant. Interviews were held only once following the framework and it was audio-recorded. No video recording was done to protect participants’ privacy and confidentiality. The lead-off question for Participants1-7, residents with dementia, was:

I can see your body wants to walk a lot, what is that like for you?

The duration of interview for Participants 1-7 (residents) was between five minutes to approximately 18 minutes as five of them enjoyed the conversation. The initial plan was to keep resident interviews between two and five minutes in view of their comfort. I was also willing to walk with them if they chose to during the interview or postpone it to another date them if any inconvenience was observed (Digby et al., 2016; Hubbard et al., 2003). For the remaining participants: the EPAS, RNs and the HCAs, the duration of the interviews ranged from approximately 30 minutes to one hour. The total hours of the interviews were 11 hours, 36 minutes and 2 seconds. Table 7 presents details of the interviews including participants, facilities, dates, duration of each and total hours.

Data collection was done following the five stages recommended by Carspecken (1996). Specifically, data collection was done in Stage 1 through Participant observations and collection of walking behaviour record of residents from staff; through collection of guidelines used by facilities staff specifically on supporting walking of residents and different trainings staff had on dementia syndrome and supporting walking of residents with dementia.

Stage 3 continued the data collection through the one-on-one in-depth interviews carried out with each of the 26 participants. Though the questions were put in the Appendices, examples of each have now been placed in this section and their Appendix figure given for more details as the numbers are many.

Figure 3. Semi-structured In-depth interview question for Residents with dementia who walked (Appendix I-One main question)

Introduction & Welcome: My name is Christianah, a Doctoral student from AUT. I am carrying out a research at your facility to find out how nurses care for you (Researcher speaks slowly, maintains eye contact and pauses to wait for them to be ready, respecting their persons)

- **Lead off question1**: I can see your body wants to walk a lot, what is that like for you? (Researcher pauses and waits for them to respond with great flexibility and patience. Depending on their ability to engage in more conversation, researcher follows up with some of these prompt questions: (Is it tiring to walk? Does walking make you happy? Do you like to walk by yourself? Do you like to walk with someone? Do you feel safe to walk? Do people ever stop you from walking? Is it hard to stop walking? **Please tell me about that…)
- **Question 2**: Depending on response received to the lead off question above and if they are able to accommodate it, a follow-up question that can be asked such as "Do the nurses try to stop you when walking? When you walk, what would you like nurses to do?

Closing: Thank you for your time.

*Nurses are used here to represent Registered Nurses, Enrolled Nurses and Health Care

Figure 4. Semi-structured In-depth interview questions for EPAs (Examples-Please see Appendix J for the 12 questions)

Introduction: Welcome & purpose of the study to be stated again

1 **Lead off question:** Before your family member came to live in the facility, what impact did caring for them have on your life? (*Please tell me more…)

2 Were there safety issues when you looked after them at home?

3 What was it like for you to look after a family member/spouse/partner/friend with dementia who walked?

4 What does their walking behaviour mean to you?

- Was there any particular thing that increased their desire to walk?
- Was there any particular thing that reduced their desire to walk?

5 What did you normally do for them when they started walking or when they walked?:

- How far did they walk from where you both lived?
- Give an example of how you cared for them when they walked

Figure 5. Semi-structured In-depth interview questions for RNs and HCAs (Examples)- (Please see Appendix K for the 21 questions)

Researcher: Christianah Adesina

Introduction & purpose of the study to be explained again, apart from when signing the consent form

Some lead off questions will develop from what was observed during Participant observation, so Researcher will start the interview like:

1. I noticed that when you were walking with the resident, they wanted to see what was in the dining room or go out of the facility. I'm really keen to understand how you managed that. (*Please tell me more … What strategies would you like to use to see a different result such as, if you would want them to go to the lounge instead?)
2. What training or education have you had on how to manage this walking behaviour in residents with dementia?
3. Does your facility have a guideline on how you care for the residents with dementia who walk or is it something you figure out by yourself and if there is guidelines, do you follow this all the time?
4. What is it like for you to care for a resident with dementia who like to walk and how does it affect you or your workload?
5. Please give an example of a time you cared for a resident with dementia that walked and what interventions you provided for them?
6. What does their walking behaviour mean to you?

Table 10. Details of One-on-One Interviews and Total Hours

Participant	Relationship/ Role	Date of interview	Venue	Length of interview (mins)
Participant1	Resident	14 July 2021	Facility one	07:01
Participant2	Resident	22 July 2021	Facility one	09:30
Participant3	Resident	26 July 2021	Facility one	09:00
Participant4	Resident	10 August 2021	Facility two	08:30
Participant5	Resident	11 August 2021	Facility two	07:13
Participant6	Resident	13 August 2021	Facility two	04:55
Participant7	Resident	11 April 2022	Facility two	17:31
Participant-EPA1	Family friend	14 July 2021	Facility one	23:14
Participant-EPA2	Son	22 July 2021	Facility one	19:44
Participant-EPA3	Wife	26 July 2021	Facility one	33:45
Participant-EPA4	Daughter	10 August 2021	Facility two	31:27
Participant-EPA5	Son	13 August 2021	Facility two	24:46
Participant-EPA6	Wife	13 August 2021	Facility two	52:25
Participant-EPA7	Daughter	11 August 2021	Facility two	29:18
Participant-RN1	RCS	14 July 2021	Facility one	31:14
Participant-RN2	RCS	14 July 2021	Facility one	22:48
Participant-RN3	RCS	10 August 2021	Facility two	60:40
Participant-RN4	RCS	11 August 2021	Facility two	57:20
Participant-HCA1	RCS	14 July 2021	Facility one	38:13
Participant-HCA2	RCS	14 July 2021	Facility one	28:14
Participant-HCA3	RCS	02 August 2021	Facility two	24:46
Participant-HCA4	RCS	28 July 2021	Facility two	52:40
Participant-HCA5	RCS	03 August 2021	Facility two	32:21
Participant-HCA6	RCS	11 August 2021	Facility two	31:00
Participant-HCA7	RCS	16 August 2021	Facility two	22:39
Participant-HCA8	RCS	16 August 2021	Facility two	44:48

Note: Total hours of In-depth interviews = 11 hours 36 minutes 2 seconds

4.7.5 Stage 4: Phases One to Five of Reflexive Thematic Analysis (RTA)

After cleaning the transcribed interviews, the analysis of the datasets started at Stage 4 of the framework for data collection and data analysis. Overall, four datasets were collected: Participant1-7 (residents with dementia who walked), Participants-EPA1-7, Participants-RN1-4 and Participant-HCAs1-8. As the groups were not homogenous and asked different from two of the groups, Participant 1-7 and Participant-EPAs1-7, I had to analyse each group separately, applying Phases 1-5 of Braun and Clarke's RTA (2006, 2021) to each. I started with what thematic analysis stands for, namely

searching across a data set … to find repeated patterns of meaning" (Braun & Clarke, p.86).

- **Phase One (RTA)**: **Data familiarisation:** Data familiarisation with each transcript in the four out, one after the other (Braun & Clarke, 2006; Byrne, 2022; Terry et al., 2017). I read each transcript in each group multiple times to familiarise myself with the data, to gain insight into the participants' perspectives, and to identify (Terry et al., 2017) relevant information relating to my research question (Byrne, 2022) and aims and used highlighters as I read through. I started with the dataset for the seven residents (Partipant1-7) as they only had one question. All the same, the shortest number of pages for each transcript was five and the longest transcript for the residents was 17 pages. I re-read the transcripts to get a good sense of each. Familiarisation is the "bedrock" (Terry et al. 2017). of carrying out Thematic analysis and is referred to as the first opportunity to get "immersion in the dataset" (Terry et al. 2017, p. 23). During this phase, I listened to some of the audio recordings again to clarify unclear sections in the transcripts, recalling the interview sessions and the aside notes taken on the days of interviews for each one of the participants. I wrote some notes on the side of the transcripts with a red pen as I read them, since it was my copy, and highlighted sections in different colours to note the occurrences of different patterns. An example is Appendix N.
- **Phase Two (RTA): Generation of initial codes:** This stage involves the generation of initial codes for each transcript in each of the four datasets. Codes have been referred to as fundamental building blocks that make up the themes later (Byrnes, 2022). I developed some codes or labels from the comments I made on the margins of the transcripts or sometimes on Word documents as I read the transcripts. At this point, I focused on the research question 'How do residential care staff provide relational and supportive interventions for residents with dementia who walk?' as well as the five aims taped to the computer monitor used throughout the research process. I coded any related ideas on each script and at one point, I wanted access to the codes easily, so I used the walls in the hallway at home (Appendix O) to post all the codes for different groups, and afterwards saved all data to a spreadsheet using NVIVO (Appendix Q). I also used the software to double-check if I could generate additional codes. While there were no new codes, it confirmed the codes already generated using RTA. I returned to my initial analysis of the datasets satisfied with the list of codes generated (Braun & Clarke, 2006; Byrne, 2022; Terry et al., 2017), (Examples: Appendices O and P). An iterative process then took place to improve the codes.

- **Phase Three: Generating initial themes:** In this phase, initial themes were generated from the codes in Phase 2. At this point, I started linking together all codes generated from each dataset, collapsed them and reduced them by looking for patterns that were similar across each dataset and bringing these out as initial themes. Generating initial themes is where the “Interpretative analysis” (Braun & Clarke, 2006) with the social constructionism theory for the study began. (Braun & Clarke, 2006; Byrne, 2022; Terry et al., 2017). Phases One to Three were carried out for each group’s dataset so that common patterns could be identified in each (Appendix W). I could see patterns and descriptions of ‘normal’ in the codes. I continued to look at my research question, the five aims taped to my computer's second screen and the copy of it that I placed in my top drawer so I had to view it each time I opened it. In that period, I arrived at what can be called “initial candidate themes" (Bryne, 2022, p. 1404) and discussed them with my supervisors. The development of the themes was an iterative process and to achieve the first aim of the research question, on the meanings of walking to each participant, I developed a thematic map indicated in Appendix R.
- **Phase Four: Developing and reviewing themes:** The goal of Phase Four was the development and review of themes, This phase was also recursive and iterative as it involved a review of codes for the four datasets (Braun & Clarke, 2006; Byrne, 2022; Terry et al., 2017). In this phase, I reviewed the initial themes generated so far and defined them. I checked whether all the codes on the list were well represented in the initial candidate themes developed, whether they answered the remaining four aims, and also ensured the themes were telling a story that captured and answered my research question the aims. In addition, I ensured that there were enough relevant data to be used as quotes to support the findings or theme to be presented. The unobtrusive information collected such as guidelines and Online Courses were separately analysed. It was easy to identify the similar patterns they had as being under existing general guidelines on caring for persons with dementia. I continued reviewing the themes and discussed these during supervision meetings. I ensured there was balance between the internal homogeneity of the themes and the external heterogeneity. Theme One ‘Meaning of walking’ was later refined to be ‘Perspectives on walking’ with parent and child sub-themes (Appendix S).
- **Phase Five: Refining, defining and naming themes**: After the themes of each of the four datasets had been reviewed, redefined, and named, I then looked for to find patterns of convergences/commonalities and divergences in the four datasets. This was not an easy task and it was time-consuming as the datasets

were not homogeneous but heterogeneous. These reviewing and redefining are in line with the analysis processes of RTA (Braun & Clarke, 2006; Byrne, 2022; Terry et al., 2017). Apart from the first question on the meaning of walking that all participants were asked during the interviews, there was no other question common to all four groups of participants. I re-analysed and gradually reduced the data by identifying common patterns in all four datasets till I gained considerable satisfaction that the named themes duly represented the data analysed. Where I found some divergences, these stood out from the rest of the data. However, there were many areas of convergencies on the first theme across all datasets. Phase Four transitioned smoothly into Phase Five, where I focused on “presenting a detailed analysis of the thematic framework” (Byrne, 2022, p. 1407). In the iterative nature of the process, the names of the three themes changed multiple times before their final forms in Theme one: ‘Perspectives of Walking’: Theme Two: ‘Supporting to Walking’ and Theme Three ‘Environment and Walking’. Since these themes have an interpretive approach, their meanings go beyond the meaning of the words of their name. At this Stage 4, relationships between the two social sites- the two facilities were explored in line with Carspecken’s (1996) recommendation. In doing this, he advised a researcher to use a theory to discover these relationships in the systems. Since I already had social constructionism as the theoretical orientation for the study, I applied this in analysing and presenting each finding/theme (and sub-themes) using a critical lens to critically examine the relationships of these two social sites to the research question. The relationships found can be used to compare with other social sites in the city or country, but because this research project is for the Doctor of Health Science degree, I had to stay within the scope of my project, carrying out the comparisons among the two social sites where the study took place. Braun and Clarke (2006, 2021) suggested that if at the end of Phase Five one could define clearly each of the themes and their scope in two sentences, then one has achieved this phase successfully. I tested myself on these and I could define clearly each of these three themes and their scopes. After this, I progressed to stage 5 of the CE (Carspecken, 1996) and RTA Framework (Braun & Clarke, 2006). Carspecken (1996) considered this stage to be important as it discovers the findings, the influences, and the systems, historical or social, that need reconstruction. During supervision meetings, these findings were discussed to confirm the validity of the evidence (Carspecken, 1996, Smyth & Holmes, 2005). Supplementary data such as guidelines were examined separately on their appropriateness, relevance, and relationship to the

systems, which in turn, influence the support given by staff to the residents with dementia who walk (see Appendix U for X).

4.7.6 Stage 5: CE Explanation of findings using Social Constructionism = Phase Six of RTA-Writing the Report/Findings/Thesis

Stage 5 of Carspecken (1996) involved explanations of the findings referring to broader systems such as staff, the care, or service providers and other stakeholders in the care of residents with dementia who walked. The stage also corresponds to Phase Six of Reflexive Thematic Analysis (Braun & Clarke (2006, 2021), which involved the write-up of the findings for this thesis. “Often, it is this fifth stage that really gives one’s study its force and makes it a contribution to real social change” (Carspecken, p. 43). This study intends to be able to achieve this. While the point of separation between Phase Five and Six may not be so distinct (Byrne, 2022), in writing the findings and this thesis, I have ensured that the themes are presented logically and meaningfully and that each theme is internally consistent in that it can present its message independently if isolated from other themes (Byrne, 2022). All six phases of Braun and Clarke (2006, 2021) were carried out, which resulted in the final three themes. The appropriateness of flexibility in both Carspecken’s (1996) data collection stages for the Critical Ethnography study and Braun and Clarke’s (2006) six phases of Reflexive Thematic Analysis enabled the integration of the two processes to achieve its goal resulting in three findings.

4.8 Reflections

Below are some of the reflections written during the data collection stages at the two social sites (facilities).

4.8.1 Reflections: Facility One

> ***Reflection****: (0730hrs) I arrived at Facility One…given orientation to the facility by Manager… Participant1-3 were having breakfast with others as per their routine… After her breakfast, Participant2 when walking in the hallway, located me in the corner where I thought I could not be easily spotted by the residents. She was friendly and started chatting with me as if she had known me for years. I returned the gesture but was very attentive, actively listening to all that she was telling me and answering her questions as simply as possible. She chatted and told me about her children before I met one of them in the afternoon who was her EPA. She sometimes leaned into me to whisper some word about the staff whenever any passed by us- as if she was confiding in me as a close family member or friend, telling me with different expressions to indicate how nice they were to her. As I moved around the unit observing other participants and interactions with staff, she moved along with me and soon I grew fond*

of her. I reflected later whether Participant2's action was shadowing (Harrison & Aldridge, 2012) or attachment (Kitwood, 1997; Neils et al., 2013), one of the five psychological needs of everyone, especially for persons living with dementia.

Reflection: *(1233hrs) Since entering the unit in the morning, some old-time, familiar songs and music were being played in the background. The music could be heard in the whole dementia unit. Some residents walking up and down the hallway were singing along to it. For example, "…whatever will be, will be, Que sera sera …" I could hear the humming of the songs in the different corners of the unit, including from the staff … I noted down this non-pharmacological intervention… Participant2 … was still eating in the dining room as she had not finished her lunch. Participant-HCA2 was with her, serving her dessert, and attending to her….*

4.8.2 Reflections: Facility Two

Day One: 28 July 2021

Reflection: *(1250hrs) Some staff, in their kindness, wanted to help with my study by asking me to come and observe Participant4 to see how she walked around in her room. I reminded myself of the condition of my ethics approval, which limited my observations to the public spaces of each facility. I also wanted to prevent the possibility of Hawthorne's effect (McCambridge et al., 2014) occurring. I thanked the staff, politely informed them of the reasons and declined the offer. In doing so, I kept to the integrity and ethical principles of the research.*

Day Two: 02 August 2021

Reflection: *As I sat at the nurses' station, observing the frequency of walking by Participant4, another resident at the facility returned from an outing, entering through the door to the rest home. She wanted to sign in digitally as it was during the pandemic period and part of the facility's protocol. She appeared to need assistance. She audibly expressed her frustration. I was sitting at the Nurses 'station. Not wanting to sit there and watch her frustrated as there was no staff around, I got up to check if I could help in case it was just a matter of pointing the resident to the right line. I saw it was the residents' signing-in template which might have information of other residents not participating in the study. To keep to the ethical approvals and principles, I told her I would get her a staff to help her, which I did.*

Day Three: 03 August 2021

Reflection: *The daughter of Participant7 held her EPA. She had signed the consent forms for both of them to participate in the study. She visited her mother on the third date of conducting the participant observation at the facility. The receptionist introduced her to me, and I introduced myself and the study. The daughter confirmed that her mother had dementia and 'walked all the time'. As we were chatting, her mother walked towards us using her low walking frame -mobility aid. Mother and daughter embraced each other, and the daughter then introduced me to her mother as follows: "… she is a student who is studying about older people and what happens to them, and she*

will be chatting with you afterwards". I noted that in introducing me to her mother, the daughter did not mention the word 'dementia'. I later reflected on this and the possible reasons for her to choose not to mention the word to the mother as she had mentioned it in our prior discussion. A possible reason might be that mentioning it would upset her mother, because of the stigma associated with dementia and walking in the community. The pathologisation of the syndrome has made many people distance themselves from the word or anyone diagnosed with it which may be responsible for the person diagnosed not accepting it. Some studies alluded to the loss of friends and living in isolation as a result of isolation and social exclusion the diagnosis brings. Another possible reason could be a non-acceptance or denial of such a diagnosis by the mother. As I reflected on what just took place, I got more motivated to complete the study, curious to find out more, as one of the aims of the research was to contribute to the destigmatisation of dementia and walking so there could as much societal acceptance of the syndrome as there is for any other medical condition, that there should be collective responsibility to support their walking and accept them as social citizens (Bartlett, 2022; Bartlett & Brannelly, 2018; Brannelly, 2011) for their self-esteem and personhood to be restored (George, 2010; (Kitwood, 1997). Another example of non-acceptance encountered is an account of another resident whose daughter, the EPA, signed the consent form for both of them to participate in the study. Information received from the daughter and Clinical Manager confirmed the mother had a dementia diagnosis, but at the scheduled hour of the interview, when I introduced myself and the study, she declined, not wanting to have anything to do with dementia and emphasised she was diagnosed with Parkinson's disease. Her daughter was silent throughout, probably not to upset her mother or cause any distress to her. As a result, I apologised to the mother and informed both mother and daughter that I would withdraw them from the study.

4.9 Summary

This chapter has presented the framework of this research, which is a combination of two processes: the five stages of data collection recommended for Critical Ethnography Study or Critical Qualitative Research by Carspecken (1996) and the six phases of Thematic Analysis by Braun and Clarke (2006). The chapter featured an overview of participants, tables of participants, an outline of the preliminary steps taken before the commencement of the study, and a summary of participant observations of the two social sites. The chapter has also provided a graphic representation of the framework developed for data collection and analyses of the study, a table of summary of these two-in-one processes, a detailed explanation of how the two processes were carried out and except of reflections and reflexivity written during the process. This chapter provided a detailed account of the research methodology and methods applied to the research to ensure transparency of the processes and to demonstrate rigour and credibility of the research. The next chapter, Chapter Five, presents the first Finding of the study: Perspectives on walking.

Chapter 5 Thematic Map and Theme One – Perspectives of walking

I feel better … I think it's important I walk … I'd like to think that I can get around
(In-depth interview, Participant6 living with dementia who walked, 13 August 2021)

5.1 Introduction

Chapters Five to Seven present the study's thematic map and the findings organised into three main themes, each with sub-themes, with theme two having sub sub-themes. This chapter begins by providing a brief summary of the data analysis and the thematic map, its components, and how these themes were developed, refined and renamed to the final themes. A comprehensive account of the analysis undertaken using the developed framework, which integrated the recommended five stages of data collection for critical ethnography (Carspecken,1996) and the six phases of Reflexive Thematic Analysis (Braun & Clarke, 2006), is discussed extensively in the previous chapter, from section 4.7.1 to 4.7.6.

5.2 Summary of data analysis and Thematic map

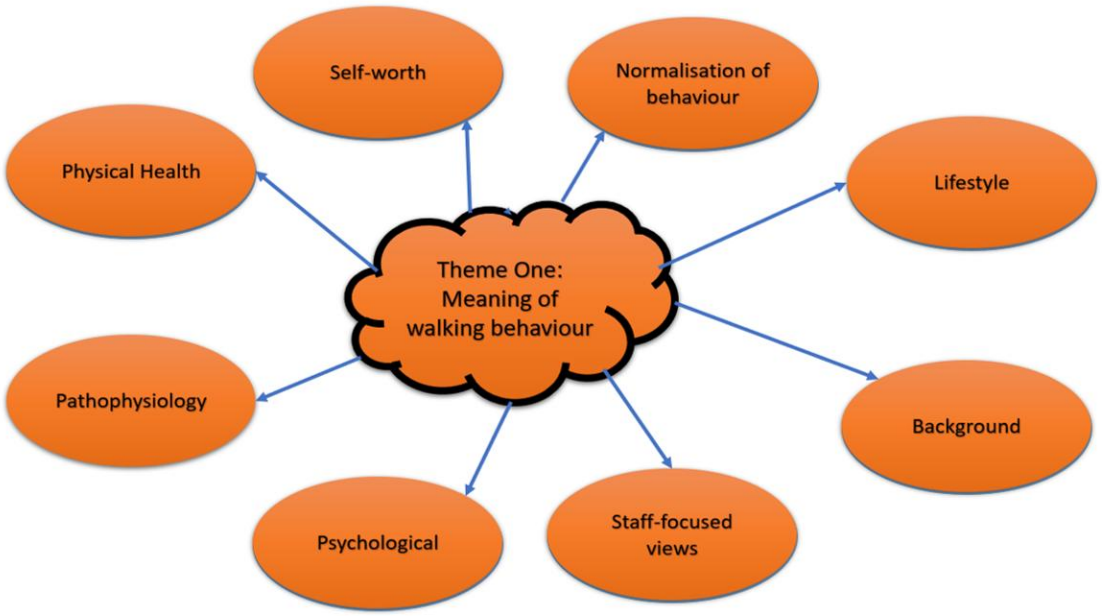
The first two phases of Reflexive Thematic Analysis (Braun & Clarke, 2006), that is, Familiarisation with the data and Generating initial codes, were applied during Stage 2, Preliminary reconstructive analysis of Carspecken's data analysis (1996) in this integrated framework, as in chapter section 4.7.3. This first dataset from the primary record in Stage 1 contained information such as Participant observations and the recorded walking frequencies of the residents. No data were available for a separate or specific guideline dedicated to supporting residents. The data were read and re-read to be familiar with them (Phase One, Braun & Clarke, 2006) and to identify patterns and factors that were not articulated during Participant observations, including the issue of power and meanings that could be followed up ((Chapter section 4.8.3) during the interview stage or the dialogical data generation Stage 3 (Carspecken,2006). Please see Table 9.

After carrying out all interviews in Stage 3 Dialogical data (Carspecken, 1996) RTA Phases One to Five were applied in analysing each of the data sets from seven residents (Partiipant1-7), seven EPAs (Participant-EPA1-7), four RNs

(Participant-RNs 1-4) and eight HCAs (Participant-HCAs1-8) after the interview had been done with each one in Stage 3- Dialogical data generations stage of - Carspecken's (1996). A step-by-step process of analysing each dataset in five phases was time-consuming spanning over months, iterative and recursive but became rewarding when the phases were productive and meaningful as the phases graduated from one to the next higher phase. Familiarisation with each data set, highlighting recurring and common patterns, writing notes on the sides of the transcribed interviews, generating several initial codes from each (Phase Two), Generating or constructing initial themes (Phase Three); Developing and reviewing themes (Phase Four); Refining, defining and naming themes (Phase Five) and Phase Six (Writing the thesis/report) (Braun & Clarke, 2006);which is this thesis.

During, at the end and throughout these phases, themes, sub-themes, sub-sub themes were identified in the datasets as well points of convergence and divergence. What follows is the visual representation of the links between the themes with their sub-themes, and where applicable the sub-sub themes. This map is followed by an example of analysis in Phase Three and in Phase Four.

Figure 6. RTA (Braun & Clarke, 2006) Phase Three example: Meaning of walking behaviour



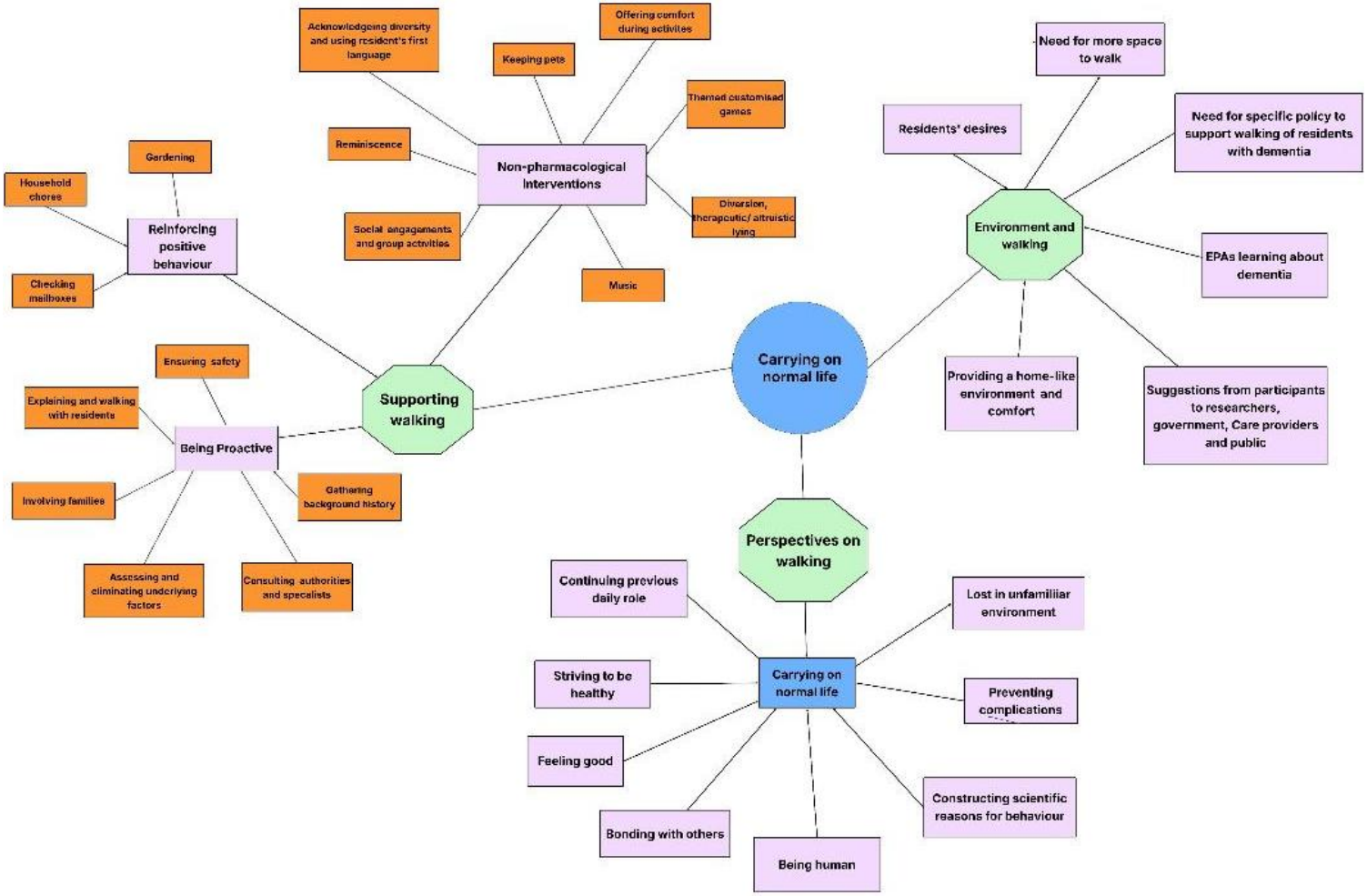
Note: Phase Three - Generating initial themes – Example of data analysis of Theme One, which was later refined and named in Phase Five as 'Perspectives on walking'

Table 11. Example: Phase Four Thematic Analysis: Theme One: Meaning of walking behaviour

Sub-theme one: Striving to be healthy	**Sub-theme two: Feeling good**	**Sub-theme three: Carrying on normal life**	**Continuing with previous daily living**	**Preventing complications in care**	**Constructing scientific reasons for behaviour**
-Exercise eg 'Yeah, its to keep his legs from sitting up. You know, if you keep sitting down all day and then your legs off then … yeah, because it	Coping or defence mechanism -To avoid boredom -Makes me feel good (psychological) -I'd like to think that I can get around -Freedom	-Part of normal life -confused of new environment/new faces -ways of communicating or engaging -Looking for something or someone -Exploring -Something we can do together, "So personally it's just a good thing	-Walked during active days -Related to previous daily living -related to their previous job (background)	-less worry for staff when they walk -Prevents complication of breakdown of skin integrity and and more care from staff -related to previous job (Staff-focused views)	-Chemical imbalance -Impulse that cannot be controlled, eg. I ca talk about his wife and son and people that we have in common, but yeah, I think once he's had enough, he just wants to

Note: Phase Four -Developing and reviewing theme (Braun & Clarke, 2006) – Example of Theme One Meaning of walking behaviour'' with six sub-themes. In Phase Five, Refining, defining and naming themes, this theme was refined and named 'Perspectives on Walking'.

Figure 7. Thematic Map of the Study Findings



Note. Christianah Adesina's Thematic map of the study findings and the interrelationship among all the three main themes and their sub-themes. 'Carrying on normal life' was an overarching theme that permeated throughout.

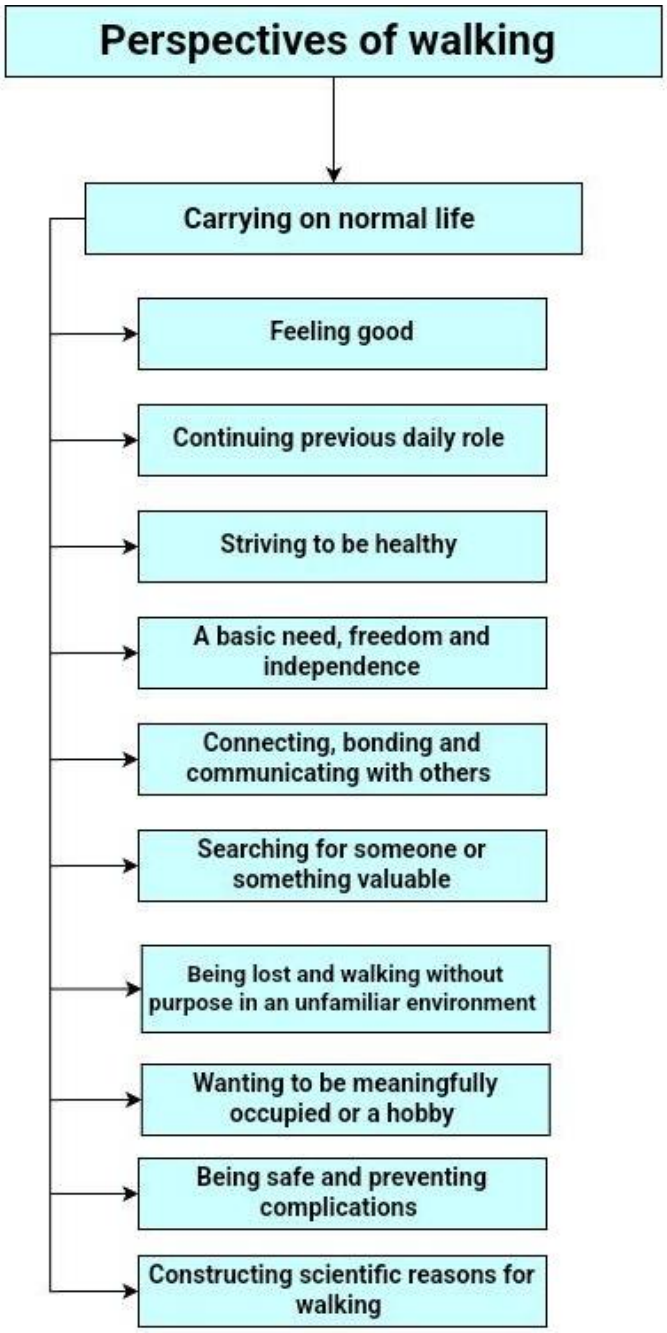
The chapters present the data and analysis using theoretical lens of social constructionism to answer the research question: **How do residential care staff provide relational and supportive interventions for residents who walk?** Furthermore, Chapter Five provides answers to three of the research question aims the research, namely, first aim - explores the perspectives of participants, including the residents with dementia who walked, on the meaning of walking; the third aim: explore the concept of person-centred care through the approaches of the staff to the residents and the fifth aim, contributes to the destigmatisation of residents with dementia who walk by advocating a shift to using language that dignifies the residents.

The first main theme is entitled: Perspectives on walking, with the sub-theme Carrying on normal life further broken down in Figure 8 into more specific child sub-themes - feeling good, continuing previous daily roles, striving to be healthy, a basic human need, freedom and independence; connecting, bonding and communicating with others, searching for someone or something valuable, being occupied meaningfully or a hobby, being lost and walking without purpose in an unfamiliar environment, being safe and preventing complications, and constructing scientific reasons for walking. The second main theme is Supporting Walking (Chapter Six), with the sub-themes: Being Proactive and Providing Individualised care, reinforcing positive behaviour, and non-pharmacological interventions. The third main theme is Environment and Walking (Chapter Seven), with sub-themes: Desire to live at home, providing home-like environment and comfort, EPAs learning about dementia, need for more space to walk, and need for specific policy to support residents with dementia who walk. Chapter Seven further reveals participants' suggestions to all stakeholders towards enhancing the walking of residents with dementia who walk, in response to questions they were asked.

Chapter Eight presents the discussion of the study results, featuring a summary and explanation of the findings and comparing them with existing literature. It presents the study's implications for practice, education, and research. In addition, it presents the strengths and limitations of the research, the recommendations and the conclusion to the research.

Figure 11 presents the theme and all the sub-themes. This will be followed by a presentation of each of these views with quotes from the participants, as evidence.

Figure 8. Theme One: Perspectives on walking - Theme and Sub-themes



Note: Theme One -Perspectives on walking - Residents wanted to carry on normal life

The first theme, Perspectives on walking, is presented below with its subsequent parent and sub sub-themes.

5.3 Perspectives on Walking

Meanings are shared knowledge, and multiple meanings can be ascribed to the same activity or concept as these reveal how else an activity or concept can be seen (Burr, 1995; 2015). Putman (1975) posited that the meaning one attaches to a concept determines one's reaction to that object, which subsequently leads to the way one relates to it. This meaning was applied to the responses given by all the participants

during the In-depth interviews on their perceptions of walking of the residents with dementia. The meanings they ascribed to the walking determined the way and extent to which they related to the residents with dementia to support their walking.

A reason for presenting this main theme first is to provide an organised understanding of the participants' responses to the research question. Theme one: Carrying on normal life was generated as a key sub-theme from the majority of the participants' responses, including the participants living with dementia who walk. From their perspectives, walking is normal for the residents. It is their normal way of carrying on their lives. This normalcy of life involves several other things that any other human being would do. So, this parent sub-theme was further grouped into more sub sub-themes:

5.3.1 Carrying on Normal Life

A common theme among all participants is Carrying on normal life. As presented in Chapter Two, the term "normal" implies a shared understanding of what a naturally occurring or expected action is (Davis & Bradley, 1995). In interpreting their various views, the majority of participants viewed walking as an expected action and activity by the residents with dementia. The views of residents who walked highlighted positive emotions, pleasure, connections, and a sense of accomplishment they derived from it. Walking gave them autonomy, and independence, and allowed them to continue their roles and identities, despite the challenges of cognitive decline. The perspectives of the residential care staff signified the importance of supporting the residents to walk, as it brought residents holistic health and autonomy. In addition, the staff acknowledged the positive impact that residents' walking brought as it meant that no resident was confined to bed with complications requiring extra time and care. The EPAs also recognised the importance of supporting their loved ones in their walking, as this contributed to the preservation of their dignity, identity, and personhood (Kitwood, 1997).

Walking is Feeling Good

Walking brought positive emotions and sensations for participants with dementia who walk. Three participants expressed that walking made them feel good.

> Researcher: *What does it mean for you to walk?*
>
> Participant1: *I don't know.*
>
> Participant-EPA1 (family friend): *How does it make you feel when you're walking?*

Participant: *Oh, it made me feel good.*

(Participant1)

Participant1 was earlier observed at the dining room. He declined to have breakfast and got up from the table, walked up and down the hallway and came back in. When asked what walking meant to him, he initially expressed not being sure, then responded eventually. He expressed the positive emotions, sensations and self-satisfaction he got from walking. Participant-EPA1 (family friend) agreed with him during an interview with me later, stating that when Participant1 lived with her family, she allowed him to walk whenever he felt like it:

> Participant-EPA1(family friend): *As far as sitting at a table [for meals] ... Well, once he's decided he's had enough to eat. He'll go. He doesn't want to eat anymore, so he'll just stand up and walk away… we could be sitting around chatting and he'll just stand up and walk away. He's not involved in the conversation unless it's something that he would be very interested in, which is very little. I can talk about his wife and his son and people that we know in common but once he's had enough, he just wants to go walk.*
>
> Researcher: *So personally, how do you see that?*
>
> Participant-EPA1 (family friend): *You mean do I feel offended by it or not?*
>
> Researcher*: Just your views.*
>
> Participant-EPA1 (family friend): *I just accept that's what he wants to do. I'm not going to tie him down.*
>
> (Participant-EPA1 (family friend))

Participant-EPA1 (family friend) provided more insight into Participant1's background before being admitted for care at the secured dementia unit. Participant1 was a widower. His late wife was a friend to Participant-EPA1 (family friend), and her family adopted him after, as his children were not available to care for him. Her family had noticed a change in him after his wife passed away as he could no longer manage at home independently. He had taken to alcohol and ate less. When they went out together shopping, Participant1 would buy more alcohol than groceries. Participant-EPA1 (family friend) disclosed she had limited knowledge in caring for a person with dementia. Participant1 initially got a placement in a rest home where he had more freedom to go outside of the facility to buy more alcohol which he lived mostly on, until he fell sick and was admitted to a public hospital. He was afterward placed in the current dementia-secured unit where she thought the care he was receiving was more effective than she could have provided him if he were still living with them. During that period at home, when having meals together, Participant1 did not have much interest in conversations, unless they revolved around his wife, son or other people known to him.

When lost interest, he would get up and go walking. Participant-EPA1 (family friend) stated she had observed that walking brought him some satisfaction and it was probably therapeutic for him, so she encouraged it in him and would not restrain him from walking as she considered it normal for him.

Another resident, Participant6, as can be seen in the quotation below, saw walking as his identity (Burr, 1995; Kitwood, 1997) and a self-assurance. It was something he could still accomplish. Participant6 used to walk independently but due to being too weak, he could no longer do so by himself and required one person assistance to get up and walk using a mobility aid. During the participant observations, I observed how he called out for help anytime he wanted to get up to walk but could not do so independently. He wanted to do as he used to, before his diagnosis, when he was still living at home with his wife. He wanted to continue with his “then self" (Klein & Karlawish, 2010; Ney et. al., 2021), determined not to allow his current health status or his “now self” (Klein & Karlawish, 2010; Ney et. al., 2021), as discussed in Chapter One, reduce his mobility and quality of life. Participant-EPA 6 (wife), who was the main carer, was present during the interview and extended the question to her husband as below:

> Participant-EPA6 (Wife): *Why you walk? What enjoyment you get out of walking?*
>
> Participant6**:** *I feel better … I think it's important I walk … I’d like to think that I can get around*
>
> (Participant6)

In the excerpt above, Participant6 stressed the importance of maintaining his ability to walk. This is an example of the emotional connection that he had with walking. It also points to the concepts of his personhood (Kitwood, 1997), discussed in Chapter Two, his self-worth and psychological fulfillment in being able to walk. His wife, Participant-EPA6, agreed with his response. Participant-EPA6 saw the importance of respecting this desire to walk in her husband and supported his walking to maintain his identity and personhood. She recognised this was a way she could contribute to his overall well-being and quality of life. She regarded his walking as innate, essential, and normal for him.

Participant5 also emphasised her need to keep walking as part of her identity. She was frail but expressed her dislike of not walking. She did not consider her identity fulfilled by being confined to bed. She was the only participant not observed walking during the study as she was in her room in bed mostly. She used to walk 12 hours daily within the facility but recently fell sick, was hospitalised, and discharged back to the facility, but

for most part, confined to bed. Her response during the interview was to the point, as shown in the example provided below:

> *I can walk, definitely, not in bed*
>
> (Participant5)

In the quote above, Participant5 wanted her identity to be restored. She wanted to walk. She wanted to return to her normal life of "then self" (Klein & Karlawish, 2010; Ney et. al., 2021). Participant5 indicated how much she valued her regular walking. She did not feel satisfied being in bed, unable to walk around the facility and relate with other residents as she used to do. It appeared like her sense of accomplishment was being challenged as she lay bed bound. This means she attributed her self-worth and personhood to being able to walk. Walking was part of who she was, and she wanted her family and staff to recognise this need for her identity to be fulfilled (Kitwood, 1997). Walking was so important to her personhood that this was a topic of her conversation whenever her son visited. She emphasised that her walking need was her priority and the ability to accomplish this was being threatened by her bed confinement due to frailness. Her son, Participant-EPA 5, shed more light on how active his mother was in the following quote:

> *… she would get up, always went to the dining room to have her meals, wandered around, talked to people so she was rarely in her room! I had to go and look for her. She was mobile and now she's not, and she keeps going back to it. She wants to be mobile, but I don't know if she knows how to do that now…*
>
> (Participant-EPA5)

In the excerpt, Participant-EPA5 described how his mother's mobility and socialising nature were normal until a couple of months ago. She would usually not be found in her room whenever he visited her and he would have to go around looking for her, only to find her socialising and chatting with her fellow residents as she walked around. She had become very frail and unable to walk. Participant5 still wanted her son and staff to see her 'then self'(Klein & Karlawish, 2010; Ney et. al., 2021) and, as his son alluded to in the excerpt above, her desire to walk was her main point of conversation whenever he visited. His son still saw the "then self" in his mother, though at times, he has become torn in-between his mother's 'then self' and the 'now self' (Klein & Karlawish, 2010; Ney et. al., 2021) due to the current health status of his mother. His mother wanted to walk regardless of the "considerable personal challenge" (Bartlett & Brannelly, 2019, p. 2) this would bring. In the light of the above quotes, it is clear that participants with dementia who walk derived positive emotions, pleasure, self-worth, and a sense of accomplishment when walking, and expressed the benefits gained from

it innately. In essence, it is normal to feel good about oneself as that maintains one's identity, self-worth, accomplishment and personhood. This normalcy in walking is linked to continuing past daily roles presented next.

Walking is Continuing Previous Daily Role

A few participants linked the walking of the residents with dementia to their previous daily roles before the diagnosis. To these staff, walking was normal as it reflected residents' past lifestyles and preferences and enabled them to continue their identities. Staff observed residents' patterns of walking and saw how these aligned with the social histories written in residents' clinical notes, gathered from their families. Such information included former occupations, hobbies, daily routines, and lifestyles. The staff could see that the walking of the residents mirrored their previous routines, roles, and habits. To support this perspective are the following excerpts starting with Participant-RN2:

> *It [walking] could be related with … previous daily living when they were at home. So, like there is one particular resident, like, after she ate her lunch, she would just walk and get up and like, you know, doing kitchen dishes, kitchen stuff, like washing your hands and you know, … fixing the cutlery like that…*
>
> (Participant-RN2)

Participant-RN2 had observed this resident's pattern of walking and habits such as walking to the dining room before lunch to help staff set the tables with plates and cutlery for lunch for other residents and joined them in tidying up the tables afterwards. She attributed these to residents' past daily roles and lifestyles. Participant-RN2 appeared not to have been surprised at such behaviour and accepted the walking and carrying out of other activities by the resident as normal. Burr (1995), in explaining how else an action or activity can be viewed, highlights that this identity attributed to walking of residents has more to do with the "purposes than the 'nature' of the thing itself" (Burr, 1995, p. 30). For residents who walked and carried out other activities, the purpose of walking to maintain their identities by continuing their daily roles was paramount to them.

In line with this attribution, another staff member, Participant-HCA1, who has 12 years experience working with the residents, also linked residents' walking to their past roles after observing similar patterns in other residents:

> *…she's always going to the room of other people and opening their rooms and sometimes they [the staff] notice that she is always making her clothes, getting to the hanger … I think because sometimes that is their job before, that's why they like to do that …if you understand that, because that is their job before…, they're busy*

> *cleaning or doing, like, making the bed, I think because of their thinking that it's their job…*
>
> (Participant-HCA1)

She added further:

> *You need to help them, that's why we have activities. We need to refer them all, she [pointing to a resident with dementia tidying up the dining room table after breakfast] like this … that was background before, [her] job, that's why she's doing that, then during activities, give them another task for them to become, yeah …*
>
> (Participant-HCA1)

Participant-HCA1, who stated the above with unwavering confidence, normalised their walking as a result of many years of experience working with the residents. She evaluated the residents' actions as their wanting to continue their identities and previous roles.

A family member, Participant-EPA5 (son), drew a connection between the walking and the occupation of his mother and her busy motherly routines in the following quote:

> *I mean, she spent her whole life on her feet, and she was a nurse, and she worked in [public] hospital, she was … a head … of the … department and so highly functioning person and very selfless person! I'm sure she gave great care and service … she's always been pretty mobile …*
>
> (Participant-EPA5(son))

A residential care staff, Participant-HCA2, gave insight on what informed her practice and her understanding of the walking of the residents. The following captures her perspectives:

> *It's just, for me, my understanding of that, is, as I said, how busy they were, we read their history, their lives, they have always had the history of what they used to do before, and so I just adjust myself to be in their shoes.*
>
> (Participant-HCA2)

In addition, in the quote below, Participant-EPA 2 (son) confirmed his mother's habit of walking in the past which could have influenced her current walking. She loved walking and had a route she took, spending considerable time walking and gardening:

> *… she was, when she was home had a couple of routes that she would walk during the day… So, it meant that essentially mum could walk around the backyard, and she enjoyed gardening and trees and*

> *stuff, she often would spend hours just walking around, pulling weeds out and doing that sort of thing. So, she really enjoyed doing that.*
>
> (Participant-EPA2 (son))

Participant-EPA2 (son), above, highlights the continuity of identity that his mother's walking meant to him by recounting her love of walking.

This view of carrying on normal life was further confirmed below by a resident, Participant7, who was observed to have walked three-quarters of the times observed at Facility Two using her mobility aid. She was a 93-years-old, a retired professional:

> *I do like to walk. how I've always walked all my life! Walk, yes, I walked in north London because my mum and dad lived in north London…*
>
> (Participant7)

In the excerpt, Participant7 traced her walking to her childhood's background, history, and routine, which has influenced her walking to date. Her current walking suggests a determination to continue that identity.

Another residential care staff member, Participant-HCA3, voiced her perspective on humanising the walking of the residents, indicating it socially acceptable. She also used a parent-figure analogy to convey her acceptance of their walking as normal:

> *These are people who have been walking their whole life and to come here, they feel, I mean they don't see their family members every day or every morning or something because some of them [the family] just come once a week or even twice a week, something like that. So, if we start stopping them [the residents with dementia who walk] from doing these basic things that they have been doing throughout their whole life, I mean I'd hate for my parents to [experience] that. Someone telling them 'Oh no, you can't do that'- when they have been walking their whole life. So, I don't feel comfortable telling a person – 'no, you can't do it'. It's more of encouragement and their safety. I feel if they can walk good enough, as long as they are safe and I'm safe with them, I don't see a problem.*
>
> (Participant-HCA2)

From the above quote, it can be inferred that Participant-HCA3 did not see the residents as numbers but as persons, socially alive (Brannelly, 2011; Cook et. al., 2022; Kitwood, 1995) and gave them social regard (Brannelly, 2011). She respected and valued the residents like she valued her own parents and would prefer them walking, if in a similar situation. This leads to another view of walking shared by participants - Striving to be healthy, which is presented next:

Walking is Striving to be Healthy

In the interview, the majority of participants viewed walking as helping residents to be healthy. The Participants: residents, their EPAs, the RNs, and the HCAs brought out deeper implications of walking as a health-promoting activity. Presented below are some perspectives viewed from a social constructionism critical lens:

When asked what walking meant to her, Participant2, a retired Pharmacist:

> *Yeah, it's good exercise*
>
> (Participant2)

Her succinct reply indicates she recognised walking as a very beneficial activity for her and possibly due to her health background as a retired Pharmacist, she knew the importance of maintaining physical activity despite her cognitive decline. Her family member, Participant-EPA2 (son), confirmed this perspective, and stated how he joined his mother in the activity:

> **…** Well, it's just a good thing that we *can* do together that she enjoys
>
> (Participant-EPA2 (son)

To the son, this shared activity indicates the multiple meanings of walking and functions derived from it, apart from the exercise it provided. It strengthened familial bonds between him and his mother in her current situation, which goes far beyond that of ordinary exercise. During Stage One of data collection at Facility One, Participant2 grew attachment to me as soon as she came out of the dining room and saw me after having her breakfast. She came to where I sat in a corner in the hallway. She was friendly and personable and followed me around as I moved around observing participants who were walking in the hallway. She engaged and chatted like I was her old-time close friend or close family member, sometimes leaning into me to whisper some sentences. She told me about each staff member that passed by us, how nice they were and told me about her family before I met the son, her EPA, later in the afternoon. In addition, I observed that Participant2 walked independently three-quarters of the Participant observation times at their social site. Based on this data gathered, it could be inferred that she used her walking as a form of social interaction and possibly a way to enhance her cognition as it allowed her to start and maintain the conversation throughout.

Next was another resident, Participant4, a full-time mother and a speaker of English as a second language. Her daughter, Participant-EPA4) was present to support and interpret for her. She gave her perspective on her frequent walking and her daughter *contributed to it. Participant4 stated:*

> *Good exercise for me, I don't like sit[ting] down and everything, you know. Get my body, you know, be alright… But sit[ting] down [is] not very good. I don't like me sit[ting] down. [I] walk all the time, [I] like it*
>
> (Participant4)

She expressed a strong dislike of sitting down which showed how much she wanted to remain physically active, highlighting she took her walking as crucial to her being healthy. Her daughter, Participant-EPA4, supported her mother's belief that exercising was healthy. She disclosed that her mother had an underlying medical condition and was following medical advice on staying active and healthy. She stated that walking was the way her mother understood what her doctor's advice was and she enjoyed doing this regularly, even when she was tired:

> *She doesn't like sitting, doesn't want to sit still…*
>
> (Participant-EPA 4(Daughter))

The daughter, in her quote above, highlighted the intentionality and motivation in the habitual nature of her mother's walking.

Participant-RN1, who was also a manager, provided various professional insights as to the meanings of walking. These will be discussed under their appropriate subthemes later into the chapter, but one of his perspectives aligned with the theme of striving to be healthy:

> *They are trying to have a physical exercise … For me, my understanding is … They want to exercise walking, a hobby … it means a lot. Actually, for me, it's a form of exercise, a form of activity*
>
> (Participant-RN1).

The views of the RN and manager aligned with those of other residents and EPAs in recognising walking as a meaningful engagement in a health-promoting exercise. Another RCS, Participant-HCA5, showed empathy in her approach to relating with residents with dementia who walk, and related them to her parents:

> *I think that person [a resident with dementia who walked], at the same time, they want to exercise but some people [who live with dementia] I think they forget that they're to have a rest … they don't even know they've got dementia. It's us, we have to help them to keep them safe, keep them comfortable… Yes, to me personally I feel, [I feel] for them. It's like my own parents, I look after them …*
>
> (Participant-HCA5)

Participant-HCA5 believed that each resident with dementia was a person (Kitwood, 1997) who needed support to achieve their unique planned and positive health

outcomes. This highlights the contributions of staff who applied the concepts of relational care and solidarity to support residents' walking, as these enhance residents' well-being.

To Participant-HCA8, motivation was an innate key drive for the walking of the residents:

> *I think it's got something to do with what makes them motivated, I think it's the only- I don't know, 'cause I, I couldn't really tell because of their dimension, but so far, they're happy doing the happy walking. So, we just let him because it's something that they look forward to … It's the only thing that works for them at the moment. And it's so much better than just [letting] them sit down 'cause their dementia could get worse so long as they don't pose a threat to the other residents and everyone in the facility.*
>
> (Participant-HCA8)

In the excerpt presented above, Participant-HCA8 also highlighted a benefit to the residents' walking, namely to prevent further deterioration of their cognitive health. In the example below, he highlighted another benefit:

> *That's why they just carry on walking. It's a good exercise. The form of exercise to just take out there. You know the benefits of walking. Form of exercise. They are healthier, the muscles are working … mobile on the heart rate, it helps with the blood flow and everything… it's a form of exercise for them.*
>
> (Participant-HCA8)

Participant-HCA8 mentioned a second benefit of walking, noting that it is physical activity that keeps residents healthy. This perspective reveals a paradox where the innate drive to walk and exercise remains despite the disadvantage of residents' cognitive decline.

A resident, Participant3, in answering the question of what walking meant to him, demonstrated how walking is intertwined with daily living, humour, and significance. He was a 77-year-old a former truck driver. During Participant observation Stage one, apart from noting down that he walked more than three-quarters of the time, I noted down as well his warm personality and inquisitive nature. Each time he passed by me, he would engage me in a brief conversation or make a humorous statement, before continuing on with his walking. This sense of humour was also evident during the interview with his wife present. He would make comments that made all of us laugh, including his wife. An example is presented below when his wife asked him to expand on his response to the question of what walking meant to him:

> *Participant3: Why I walk? Saves me getting the car out! (laughter) saves petrol!*
>
> *Participant-EPA3 (wife): Yes, to me, yeah, good point to move these legs because as they say, "use it or lose it" that's the saying. Everybody says, if you don't use it, you lose it! … Yeah, it's to keep his legs from sitting up. You know, if you keep sitting down all day and then your legs off it '… does his legs good … yeah*
>
> (Participant3 and Participant-EPA3 (wife))

The adage "use it or lose it" mentioned above by Participant-EPA3, highlights the health benefits of walking by her husband. With the observations made about Participant3, there were multifaceted meanings of his walking. Using a critical lens, the significance of Participant3 engagement while walking shows that walking goes beyond physical activity to social interaction and cognitive engagement. Across all the groups of participants above, it is evident that there is intentionality in the walking. There is a shared and socially constructed (Burr, 2015, 1995; Lock & Strong, 2010) understanding of an inherent drive that made residents keep striving to be in good health. Table 12 shows the responses and views of the Participants on the walking of residents with dementia.

Table 12. Theme One: Participants' Responses on Perspectives on Walking Behaviour – (Walking is Carrying on Normal Life)

Participant	Feeling good	Continuing previous daily role	Striving to be healthy	A basic human need, freedom and independence	Connecting, and communicating with others and bonding	Searching for someone or something valuable	Being lost in an unfamiliar environment and walking	Being occupied meaningfully and a hobby	Safety & preventing complications	Constructing scientific reason
Participant1	✓									
Participant2			✓		✓					
Participant3			✓							
Participant4			✓	✓						
Participant5	✓									
Participant6	✓									
Participant7	✓	✓				✓				
Participant- EPA1	✓		✓	✓						
Participant- EPA2		✓	✓		✓	✓				
Participant- EPA3			✓							
Participant- EPA4		✓	✓							
Participant- EPA5		✓	✓	✓						
Participant- EPA6	✓									
Participant- EPA7										
Participant- RN1			✓	✓	✓	✓		✓	✓	
Participant- RN2		✓					✓			
Participant- RN3				✓	✓	✓	✓	✓	✓	✓
Participant- RN4				✓						✓
Participant- HCA1		✓								
Participant- HCA2		✓								
Participant- HCA3		✓							✓	
Participant- HCA4				✓		✓				
Participant- HCA5			✓						✓	
Participant- HCA6						✓	✓	✓		
Participant- HCA7						✓		✓	✓	
Participant- HCA8	✓	✓	✓						✓	

Note; Table 12 indicates the multiple perspectives of all participants on 'walking' of residents with dementia

Presented next are other perspectives on walking given by the participants, including walking being a fundamental need in human beings, a way of connecting, bonding and communicating with others, which are all normal in human beings:

Walking is a Basic Human Need, Freedom and Independence

Walking is viewed by the participants as a basic need for the residents and their fundamental human right to personal autonomy and freedom. Participant1, Participant-RN4, Participant-HCA4, and Participant-EPA1(family friend), one from each of the four groups of participants, are examples of participants who shared this view.

Participant-RN3, whose facility provided rest home and private hospital levels of care, gave a vivid account, mentioning not only how a resident's health status changed after his wife passed away, but also the facility's creative ways of supporting the resident's walking and the outcomes:

> *We have got one resident who does that [walking] … But the staff doing the night shift will pretty much have to sit outside his room and really have to organise the activities within the wing, [planning] 'that's ok, if I'm gonna do rounds, I just need to make sure that he's still in bed or if he wanted to stand up [and walk] what are the activities that we can offer to him? So, like they would, even at three o'clock in the morning, they will say 'Would you like to have a cup of tea?', and if he wants to, then he will be assisted, he will sit up on the chair. And then, they will have to have the sensor mat in place… and they will also have to give him the call bell to remind him. Then at the same time, if he sort of like becomes agitated, then the nurse will really need to assign someone to be with him, just to allow him to walk until such time that he tires himself, and he wants to go back to bed again*
>
> (Participant-RN3)

According to Participant-RN3, the staff, with the best intentions, provided individualised care for one resident during a night shift despite having other residents to give equal attention to. They showed empathy, compassion, and relational solidarity (Brijnath, 2024; Jennings, 2015, 2018) and supported the resident to meet his needs with intensive monitoring and interventions, though there was a minimal number of staff available for the shift - two HCAs and one RN who had to look after over 40 other residents at the same time. The implication of this situation is the potential challenges of achieving person-centred goals that it brings if more than one resident is awake and walking overnight with few number of staff on shift to support them. The other night routines, such as checking other residents, assisting with toileting or changing incontinent pads, turning some residents in bed, or preparing the morning medications will be impacted. The alternative approach some facilities might be compelled to take is to administer chemical restraints to the residents, which may have many adverse

effects, including risks of falls as discussed in the health literature review presented in Chapter Two. However, the quote above gives insight into staff dedication and creativity in supporting residents with their needs and the proactive measures taken to ensure comfort and safety for the residents and the challenges involved in doing so. Furthermore, the criticality in the account asks the question of what other alternatives were there to meet the walking needs of the residents apart from the interventions provided by the staff.

A resident, Participant4, asserted her choice, autonomy and preference to walk during her interview with me, with her daughter present, who interpreted for her. As English was her second language, she spoke where she could and had earlier given a reason for her walking:

> *I don't like me sit down. Me walk all the time, me like it*
>
> (Participant4)

My observation of Participant4 confirmed her autonomy for walking as over the three days of I carried out the Participant observation at the facility, she walked approximately 75 per cent of the time. I noted down in my reflections how she was pleasant, friendly, sociable and engaging in conversations when I was first introduced to her. Excerpt of my monological data (Carspecken, 1996) summarising what I observed in each resident Participant at the end is presented below:

Summary of Participant Observation, Day Three – Facility Two

> *Which residents are walking?: Participant4 …*
>
> *Frequency of walking: Participant4 walked independently, no mobility aid used but did not walk in this section many times today as in the last two times*
>
> *Are they relaxed, agitated, hurrying?: Participant4 was relaxed, not hurrying, nor agitated*
>
> *Is there any use of walking aids? No*
>
> *Which ones?: Participant4 walked independently*
>
> *Can they stand or sit easily?: Yes, Participant4 could stand and sit easily*
>
> *Is there any effort to open the doors?: No*
>
> *Is there any agitation to get out?: None observed. She appeared to know her boundaries as she was independent.*
>
> *Is there any behaviour that suggests sedation?: None observed*
>
> *Is there anyone sedated on anti-psychotic medications: None that I was aware of. In addition, the study does not have this scope, I do not have the scope to investigate resident's medication as a social researcher. In addition, in line with the ethical approval given, I did not access residents' medication charts.*

> *Is anyone looking exhausted from relentless activity?: None that I observed.*
>
> (Participant Observation, Day Three, Facility Two)

Furthering on the subtheme of walking as a basic need, a way of promoting freedom and independence, Participant-RN4, who was also the Clinical Coordinator of Facility Two, quickly responded to the question of the meaning of walking with an emphatic statement when asked:

> *… It's their freedom …*
>
> (Participant- RN4)

This suggests the staff respect the personal rights of the residents in their care to walk freely, and that walking is regarded as normal. He continued to make an analogy between walking and impulses present in everyone:

> *…, like I said before, a lot of this is just impulse. You and I have impulses. Sometimes a lot of times they control it, we can control our impulses. There are times when we just can't control our impulses, like Monday morning, it had a long weekend. First thing in the morning, your first impulse is 'get me a coffee', or no one's gonna be happy. I'm not gonna be happy. It's almost uncontrollable, or after work, and it's been a really long day of work, when you get home, the impulse is 'give me something to eat', or I'm not gonna be very happy. So, for the residents [who] do have dementia, imagine that, but infinite the times more because they can't control it. When they feel like I have to walk there, I have to do something, they just go. And it's fulfilling that impulse. It's, it's a basic need, that a lot of times, they lack that impulse control, they lack that reason. And it's their freedom…*
>
> (Participant-RN4)

In his analogy above, Participant-RN4 compared walking to impulses that are common in every human being. He related this to everyday impulses that everyone experiences, saying that sometimes we can and sometimes we cannot control them. In essence, by providing this relatable example of the urge for a cup of coffee (which for others can be tea, chocolate, food, or any other basic need), Participant-RN4 highlighted the uncontrollable urges faced by the residents with dementia, just like any other person. This construction of this perspective on walking emphasises that it is normal, and that staff need to support residents to manage the impulses safely, ensuring their needs for freedom and independence are met while at the same time, removing potential risks or harm that may be experienced if walking into danger.

Participant-RN4 however, in sounded a note of caution to care providers:

> *… it is freedom for the residents … it is their quality of life. As a professional, as a core provider, we need to be aware of these things, because it is a huge risk, It's a risk for the residents, it's a risk for the staff. So, we need to be able to, we need to know these things are happening and we need to be able to manage it safely. If we find that the behaviour, this wandering behaviour is not safe, because they are constantly walking outside and banging on the doors, they are trying to find ways to get out of the building. We need to be aware of this or else we're putting the residents at risk, and we cannot guarantee safety. It's a health and safety hazard … So, it's a huge risk. That's what it means to me. It's a huge risk. We need to be able to make that decision before residents come in … we need to find a suitable facility for the residents to be able to be looked after safely.*
>
> (Participant-RN4)

Participant-RN4 cautioned above the need for appropriate levels of care placements for residents who walk so facilities do not run the risk of putting such residents at risk if they cannot provide the service that meets residents' walking needs. This issue is further discussed in Chapter Seven.

A staff, Participant-HCA4, alluded to the residents' right and freedom to move around which is normal for every human being. In addition, she made her stance known on the topical issue of restraints. She stated:

> *it's very hard for us to watch our residents and watch somebody that's wandering as well, because we don't like to restrain our residents here, they didn't ask for this and we like them, have the freedom to walk around the facility. But, also the dangerous part is for them to leave and walk out there and not knowing whether they're safe or they've fallen*
>
> (Participant-HCA4)

In this quote, she expressed staff empathy towards the residents and disapproval of the use of restraints in managing residents' walking. This highlights ethical and practical dilemmas faced by many staff in balancing residents' freedom to walk inside and outside the facility with ensuring they are safe from injuries. Her quote called for compassionate caring for the residents who are not responsible for their diagnosis.

Walking is Connecting, Bonding and Communicating with Others

In furthering the theme of carrying on normal life as one of the meanings of walking, two participants viewed it as a way connecting, bonding, and communicating with others. To Participant-RN3, the walking is a natural behaviour essential for human social needs:

> *Well, to me personally, it might also get to do, because part of the human behaviour is to be able to have that kind of engagement with people, and when they're walking, it may not necessarily [be] that they have got a sense of purpose. But it's also happening to have the ability to see people, to see activities, and they get stimulated.*
>
> (Participant-RN3)

Participant-RN3 suggested above that there was a possibility that the residents who walk might be stimulated to join in and socially interact after seeing other people and activities going on in the environment they walked into. She stated further*:*

> *….and perhaps it's [their] way of communicating that, "hey, I'm here. I'm a person, I'm needing someone to talk to". I mean, I believe in that saying that 'no man is an island', that you cannot exist on your own. So, perhaps this is true way of expressing themselves that, "I'm actually here and I'm needing some sort of communication or engagement*
>
> (Participant-RN3)

In addition, Participant-RN3, in the quote above, saw walking as a subtle and unspoken way the residents announce their arrival, existence, and the desire to interact with other people. She referred to the adage of no man being an island to emphasise human beings as social beings who require social interactions with one another to maintain psychological and physical health in being alive. This is in line with the concept of five psychological needs of persons living with dementia: Identity and Inclusion (Kitwood, 1997), which contribute to the quality of life and well-being of residents.

A family member, Participant-EPA2 (son), in his earlier reference that walking is striving to be healthy for his mother, also saw walking as a way of connecting and bonding with her so they could communicate. He stated:

> *a good thing that we can do together*
>
> (Participant-EPA2)

It is usual to do activities together as a family as it builds familial intimacy (Cook et. al., 2022) and strengthens relationships. During his interview, Participant-EPA2 (son) gave more information on how his mother liked walking; how, when walking together with his mother, they would both point to interesting sights and objects and greet people in the neighbourhood who are mutually known to them. In terms of the ARC Facilities, this suggests the need to maintain a dementia-enabling care environment that allows residents with dementia and their loved ones to make such connections.

Walking is Searching for Something or Someone Valuable

Six participants from across all groups of participants saw walking as a search for someone or something valuable to the residents. While Participant7, Participant-RN1, Participant-RN2, Participant-RN3, Participant-HCA4, Participant-HCA6, and Participant-EPA1(family friend) all considered the walking of the residents normal, they were also of the view that there was some purpose behind the walking. In some instances, participants provided circumstantial evidence to corroborate these views. This applies to Participant7, 92 years old, who had a friendly, warm personality and enjoyed engaging her fellow residents and the staff in conversations. She walked independently using a mobility aid. She cited curiosity, inquisitiveness, and interest in exploration as her main reasons for walking:

> *If I'm on my own or not, it doesn't worry me because I find most places if I'm walking on my own, I go to places I know. you know if there's something unusual and I have been and seen it once and I can see it again, I will do so.*
>
> (Participant7)

For Participant7, walking is not just walking around the facility, but a meaningful activity. She indicated that she knew her boundaries by stating she visited only places she was sure of. The implication of such a quote coming from a resident with dementia who walks is that all residential care staff should try and understand the residents' reasons for wanting to explore their environment, and to incorporate activities that can meet these needs in their care plans. This disclosure from the resident further suggests that, if this understanding can be gained and included in residents' unique care plans, the stress of not knowing how to meet residents' needs would be removed.

The view of an RCS, Participant-RN1, aligned with that of Participant1 with regard to the curiosity and exploration being reasons for walking:

> *…Their walking behaviour means to me that they came to explore something they want to seek more, more activity, …then of course another thing that you have to take into consideration is just the behaviour as part of the [person]… wandering.*
>
> (Participant-RN1)

Participant-RN1 suggested the likelihood of walking being a habit and lifestyle and that residents might simply want to explore more of their environment, just like everyone else. This view implicates that staff who look after the residents with dementia who walk should create more compassionate and effective approaches in meeting the needs of the persons living with dementia who walk.

Participant-RN1 gave an account of a resident who wanted to see the world outside the secured dementia unit:

> *… there is one particular resident who always watched the door and by the time that the staff walked out, then she would follow. She was just really curious of the outside that she just wanted to go [out]*

This creates an understanding of the experience of persons with dementia. The quote suggests a need to incorporate more walking strategies into the daily activities of the residents to prevent boredom.

Participant-RN3, who is also the Clinical Manager, linked the walking of the residents to looking for someone valuable and gave an account of a resident as evidence:

> *… one of our residents, who unfortunately we had to send to the [public hospital] and have to say no to, for him coming back to us [after hospital discharge] … sometime this year, his wife passed away. And they had been together for the past 50, 60 years … [When] he was here, the wife came here every day, from seven o'clock in the morning until six o'clock in the evening. So again, we encouraged that because we wanted him to feel that this was home and that he had some sort of family, familiar person that he could relate with. Unfortunately, the wife passed away. The time that the wife passed away, that was when we noticed that he started to have the behaviour, the wandering behaviour … and he would be walking just around the carpark and actually calling for his wife, looking for her…*
>
> (Participant-RN3)

This touching account of a resident above appears to unfold four key issues in caring for residents with dementia: one, that the reasons residents walk may be linked to underlying emotional and psychological needs, especially where significant loss or changes have occurred in their lives. They need dementia specialists to psychologically support them during any crucial period of loss. Two, the staff need support and resources to ensure holistic needs of residents are met, using a person-centred care approach. Three, the quote emphasises the important role family plays in caring for their loved ones living with dementia. Families want to continue to support their loved ones in care in various ways that they can still do so.

Participant-HCA4 reflected on her experiences and mentioned that the residents' walking was a purposeful search for someone or something they treasured:

> *… I think for them, when asked, we've had quite a few wanderers, but when asked, [they said] they're just going somewhere, they don't know where but they're just going … I'm going to find a daughter or I'm going to find my cat or I'm going to find this. I think, maybe*

> *something they've remembered. I'm not sure, but for them, they're still doing the same thing they've always done, so that's how I see it…*
>
> (Participant-HCA4)

Participant-HCA4 in the quote above revealed residents might be searching for someone or something very dear to them or the search might be influenced by their memories of relationships, routines, habits, or lifestyles. This quote has implications, especially for the staff or RCS, that meaningful care tailored to meet residents' needs should be provided. Staff need to be equipped with knowledge and resources to access the seven routes of gaining insight into the residents' subjective world (Kitwood, 1997) such as "attending carefully and imaginatively" (pp. 73-79) to what they verbalise, observing their actions which can be coping mechanism strategies; making meaning of what they share in groups or interviews; learning from their autobiographies written earlier in the syndrome stage; consulting those who have had illness with dementia features like depression and meningitis; using one's "poetic imagination" (p. 76) and role-playing as someone living with dementia.

Walking is Being Lost and Walking without Purpose in an Unfamiliar Environment

For the next sub-theme, two of the participants saw walking as being lost and walking without purpose. Participant-RN1 and Participant-HCA6 voiced this view; however, in answers provided to further questions, support and compassion for the walking of the residents were evident:

> *Researcher: … This walking behaviour that the residents have, what do you think it means to them?*
>
> *Participant-RN1: … for them, they are like wander … You know, like there's no purpose to walking without purpose … I would just let them walk because they are still independent with walking, it is a part also of exercise…*
>
> (Participant-RN1)

In the above quote, even though Participant-RN1 stated residents' walking might not have a purpose, she demonstrated her support for residents' walking, stating how she would not deny their independence to walk as they were still capable to do so. Further into the interview, she mentioned how she would ensure safety before they started walking: thus, she ensured residents had appropriate walking aids and clutter-free rooms and paths to prevent falls. In addition, I observed her interaction with Participant1 during the etic participant observation at Stage 1 of the data collection and noted that Participant1 refused his medications and walked away. When asked during

the interview how she managed this situation, she responded that she gave the resident space but approached him later and he accepted the medications.

Another RCS, Participant-HCA6, shared that walking meant the residents were lost. However, further in her response to safety issues, she gave a supportive and compassionate response:

> Researcher: *… what does their walking behaviour mean to you? First, as a staff…*
>
> Participant-HCA6: *Yes, I feel like they are lost … Their safety yes. For example, the lady, the one I was talking about, she, it was two weeks ago, she almost just collapsed, she said she was so tired, her legs were so tired [from walking] and it actually swell, only a little bit, her feet, so, I said 'okay, I think, maybe we need to go to bed now, put your feet up for a bit of a rest. And she did that, but only for half an hour and then she stood up again…*
>
> (Participant-HCA6)

Although the initial responses of both participants could be considered negative, it reiterated the need for more research to be carried out in understanding the lived experience of persons living with dementia who walk and why they walk.

Walking is Wanting to be Meaningfully Occupied and a Hobby

As part of the main theme of carrying on with normal life, walking is also seen as wanting to be meaningfully occupied and a hobby. Four participants gave this perspective. Participant-HCA6 saw walking as filling a void or avoiding boredom, citing story of her grandmother as an example:

> *Something to do or they're missing something… [because] I remember, when my grandmother, back in the days, 30, 40 years ago, she was partly like that where she was a wanderer and I used to ask her 'So, why do you wander? 'Oh, because I'm looking for something to do, there's nothing to do'…*
>
> (Participant-HCA6)

Making reference to her mother in this quote, Participant-HCA6 added a personal dimension, showing how she related to the situation the residents found themselves in. The quote indicates the way the residents managed boredom by occupying themselves meaningfully with tangible things such as walking, which revealed a sense of purpose to walking. This opposes earlier views of some participants that there was no purpose to the walking. The implication of this view is the importance of staff to plan more engaging activities for residents based on their backgrounds, past histories, routines and lifestyles to meet their unique needs. Love and Pinkowitz (2013), in their *Dementia initiative person-centered care framework,* (Love & Pinkowitz, 2013) postulated that to

help support the personhood of persons with dementia, it is important to “enter the world” (p. 26) of the person with dementia to understand them better. Participant-HCA6 demonstrated an understanding of the experience of the residents with dementia in her care by personalising her view, probably due to her past experience with a relative who had dementia and walked, Next, Participant-HCA7 shared a similar view of wanting to be meaningfully engaged as a meaning of walking:

> *I think they feel that they are occupied, keeping themselves busy and I notice one resident, she thinks, the doctor told her that if you walk you will reduce your blood pressure, so that’s in her mind, she walks all the time. She thinks ‘walking is going to do all the best for me’.*
>
> (Participant-HCA7)

Participant-HCA7 showed that determination not to lead a solitary life at the facility was a motivating factor for the resident’s walking to achieve an overall health based on medical advice. This also shows intentionality behind the walking to achieve specific goal.

Participant-RN3, who had earlier shared two perspectives, added that the walking may be an accessible activity for the residents to counter any boredom they might be having:

> *I think a third reason might be boredom. They feel that they need to do something, and the most accessible activity for them to do is to walk...*
>
> (Participant-RN3)

Persons with dementia have been studied to make use of the only available resource(s) they still have (Kitwood, 1997). Participant-RN3 referred to this in her quote above noting that the simplicity of walking makes it a readily available activity for residents to occupy themselves with meaningfully. Walking is a common practice for human beings and taking a walk fulfils this meaningful way of occupying oneself. The implication of this view is to provide a safe walking environment for the residents.

Participant-RN3, in his quote below, indicated that not only was it that walking was accessed as a way to stay occupied, but that there was an intention and determination behind the walking, which was for more exploration, physical activity, and as a hobby:

> *Their walking behaviour means to me that they came to explore something they want to seek more, more activity trying to have a physical exercise…*
>
> (Participant-RN1)

As with the view of Participant-RN3, Participant-RN1 highlights the need for an internal and external environment that is safe and secure for the residents to walk inside and outside.

Walking is Safety and Preventing Complications to Care

That walking is a safe activity that helps prevent complications in the residents was another meaning constructed for walking by staff. Participant-HCA3 considered the walking of the residents as mutually beneficial in that walking keeps the residents physically active and not bed bound, which, in turn, prevents staff from having to manage complications that may result from being bed-bound, such as pressure injuries that reduce residents' quality of life (Health Quality & Safety Commission, 2023; Joyce et al., 2018). This is also viewed as beneficial for the staff who may need to provide extensive physical care of repositioning residents and other monitoring care if pressure injuries or other complications occur. Furthermore, Participant-HCA3 gave her personal stance:

> *… for me personally as a healthcare assistant, the more active I can keep them, the lesser for me to worry about them 'cos they're not likely to end up bed-bound if they're more physically [active] and able to do stuff. So, if they are walking around, they are maintaining their muscle integrity, they're doing such stuff for themselves, they have the sense of independence or able to walk, I can go and get a glass of water for myself. So, I definitely don't want to stop that as long as they're safe and they're able to do it.*
>
> (Participant-HCA3)

Participant-HCA3 highlighted the potential reduction of heavy workload if residents with dementia walk. From the in-depth interview with Participant-HCA6, data gathered indicated that two staff work in pairs to look after 40 residents' care with one RN who helped when required, as too busy fulfilling other responsibilities such as administering medications. This highlights the challenges staff may face in meeting the needs of the total number of residents in their care, including those who walk during their shifts. This implicates service providers in ARC Facilities to make allowances in staffing allocations to shifts so staff can meet the varying needs of all residents, including those who walk during each shift.

Participant-HCA5 reiterated the challenges faced by staff in supporting the walking of residents with dementia as they have equal responsibility to other residents in their care during their shifts. Her quote reveals this meaning:

> *… it's meant a lot to them to be cared [for] and to be, how do you say, like, before, when I say it's a challenge for us, that we pick up people with dementia…*
>
> (Participant-HCA5)

The participant staff highlighted the challenges they faced in caring for the residents with dementia who walk, pointing out that the residents may not be aware of their condition. As a result, it was their responsibility to ensure the safety and comfort of these residents.

Participant-HCA7 focused her view on the complications and injuries being prevented through the walking done by the residents:

> *Actually, it is good for us because then they are keeping themselves occupied and it is good for us that they are a bit busy, they don't like, stay in the room or fiddle around or have a fall and stuff, they are safe to walk so they are in front of our eyes all the time, especially if they walk around the facility, everybody is watching them where they are. If they isolate themselves in the room[s] there's not much to do in the rooms apart from watching TV or reading books or lying in bed …*
>
> (Participant-HCA7)

In the above quote, the staff highlighted the practical benefits of residents' walking, how it kept them physically active, prevented them getting injured and kept them occupied (see section 5.2.1.8). Staff would easily supervise and monitor residents' movements to ensure their safety. Participant-HCA7 pointed out a negative effect of not walking, which is social isolation if residents remained in their rooms. In addition, the staff pointed out the additional workload that constant supervision by staff would bring if residents remained in their rooms. This would be challenging in many healthcare facilities due to the current situation of understaffing, nationally and globally (Buchan et. al., 2022).

Participant-HCA8 expressed the relief and satisfaction gained from seeing residents walking independently:

> *I'm happy if they're mobile if they're able to walk on their own without assistance, and that is really good for me. So long as they don't pose a threat to the other residents. But so far, I haven't seen this, residents are currently mobile…*
>
> (Participant-HCA8)

The view above highlights the many roles that staff play in caring for residents and the heightened supervision and vigilance involved in balancing the independence of residents to walk and their safety in care.

A Clinical Manager, Participant-RN1 shared their view of how challenging it was initially to care for the residents who walk, but pointed out that with time, this experience would change into something positive:

> *I can see that it would be a very challenging one at first, but then again, as time goes on, you tend to learn, you tend to understand [residents with dementia who walk]. You tend to come to have knowledge, or an input, combined with the theory. So, it is challenging, but then again, at the same time, it's good to look after or to work with them, actually. So, it's an amazing responsibility here.*
>
> (Participant-RN1)

The manager shared the same view that Participant-HCA5 and others gave on how challenging and demanding supporting the walking of the residents could be but went further to state the benefits such as professional knowledge, skills and enriching experience. While the expression of being an “amazing responsibility” was not put to others to respond to, Participant-RN1 had added that with time staff experience of the care they were providing would change to positive.

Facility Two Clinical Manager, Participant-RN3, shared their perspective that the walking of the residents was safe and prevented complications in residents’ care. She shed light on her role, responsibilities and considerations in caring for the residents: staffing workload, residents' and family involvement in care, interventions planned to support residents’ walking and above all residents’ safety, She gave an account with an outcome to demonstrate her prioritisation of residents’ safety:

> *Well, from a manager’s perspective, it's more to do with… that I need to be able to support the staff and the residents because one of the significant foci of care, when you have got someone who constantly likes to walk, is safety. They become a fall risk. So, it's having to put some interventions in place in discussion with the team, and in discussion with the family and if the residents are able to understand as well, because we need to have them involved. I mean, it doesn't mean that we are the carers, that we would just tell them what to do. It's having for them to be part of the group. So, that to me, would be sort of like, my point of view… In terms of the staff point of view, I have to be honest, some of them would say it's quite exhausting because they're aware of the safety issues, and that they need to make sure that, yes, they will allow the rest of them to walk, but at the same time, they need to be cautious of the risk factors that would really, sort of like, put the residents at risk of falling …*
>
> (Participant-RN3)

The quote above highlights the managerial prioritisation of residents’ safety in care. It sheds light on the leaders' role in providing adequate staff-to-residents ratio and staff support to ensure the care being provided to residents is effective and safe. It also highlights the need for collaboration between residents, their EPAs, families, and the

facility staff, to develop effective plans that will effectively support residents' walking towards positive outcomes. It further reveals the nature of supervision and monitoring of residents walking, acknowledging the physical and emotional tolls these tasks had on the staff when balancing residents' freedom to walk and needs. This is further illustrated below on what transpired during a typical night shift:

> *… We have got one resident who does that…This is Mr. Z, he is also experiencing sundowning, but more so, he doesn't sleep at night. He has got some medications to relax, because when we discuss it with the doctor, with the family, we felt that, when they increased the sleeping medication, that made him really have increase in falls. So, instead of that, we, we were discussing whether there are other options for us to be able to offer to him that don't really pose a risk of increasing his falls. So, he was given a medication that sort of like, just relaxes him. It did make a slight difference, of which he would only be ringing and wanting to stand up every two hours. But the staff doing the night shift [will] pretty much have to sit outside his room and really have to organise the activities within the wing … [saying] 'if I'm gonna do rounds, I just need to make sure that he's still in bed or if he wanted to stand up, what are the activities that we can offer to him?' So, like they would even, at three o'clock in the morning, they will [say] 'Would you like to have a cup of tea?', and if he wants to, then he will be assisted. He will sit up on the chair and then, …they will have to have the sensor mat… then at the same time, if [he] sort of like becomes agitated, then the nurse really needs to assign someone to be with him, just to allow him to walk until such time that he tires himself, and he wants to go back to bed again.*
>
> (Participant-RN3)

This specific account above highlights the extent the staff on night shift went to prevent a resident from having potential injury through falls which may lead to potential complications that may impact the resident's quality of life. This account also highlights the extent staff went to advocate for a stop to the medication of which adverse effects may lead to falls and injuries in the resident. This account highlights the need for individualised care for residents and more staffing. Using a critical lens, the support to this resident reflects best practice by the staff- managing the resident's complex needs, prioritising resident's safety, and staff advocating for medication review to enable the resident to live a normal life are worthy of emulation.

Walking is Constructing Scientific Reason for Walking

Participant-EPA7 (Daughter) and Participant-RN3 both gave different but deeper meanings to the activity of walking, giving reasons considered scientific in explaining their perspectives of walking. Participant-EPA7 (Daughter) was a retired registered nurse, while Participant-RN3 was still working clinically as an RN. First, the quote from Participant-EPA 7 (Daughter) is presented with an authorial comment, followed by that of Participant-RN3.

> *I think this part of his brain that still belongs to his younger years … he would see a job that needed to be done and wanted to get onto it straight away …That part of his brain has always been very active … He just doesn't see that it's unsafe to move by himself anymore …*
>
> (Participant-EPA7(Daughter))

Participant-EPA7 (Daughter) was referring to her father who sadly passed away before he could be interviewed. She suggested there was a gap between what he could realistically do and his cognitive awareness, which suggests walking is influenced by cognition. Her quote also implies that the urge to act immediately on seeing a task shows the lingering youthful mind her father had that ignored his current limitations. This shows that due to her background training, she had some understanding of what her father could be experiencing which made her compassionate towards him. The implication of this is the benefit that education, knowledge, and training bring to the community. It creates a deeper understanding of the syndrome, its symptoms, and the lived experience of persons affected. It produces creative solutions and strategies to support the persons with empathy which enables them to live and thrive. The greater the public awareness of what dementia is, the greater the support the persons affected will receive. This is one of the ways to reduce the stigma (Young et al., 2019). Most importantly, all stakeholders will provide optimal support that will lead the residents with dementia who walk to live a normal life (Kitwood, 1997).

Participant-RN3 approached her view on residents' walking from a physiological and psychological perspectives:

> *… it might have got to do [with]… our own physiological aspect that when your brain is quite active, or the information between the brain and the environment and your [co]ordination… is not really sort of like being organised, what happens is that, as part of your defence mechanism or coping mechanism, the body sort of like, lets you do some activities, so that perhaps, it makes you feel calm, and be just having to release that surge of energy that you have got. I mean, a good example is one of the ladies that we have got … [in] the rest home side. This is Participant7. She pretty much, she walks from seven o'clock in the morning until nine o'clock in the evening, although she will have a rest in-between. But she would just like to walk all over the unit …*
>
> (Participant-RN3)

Participant-RN3 offered a scientific rationale for walking behaviour, suggesting that the way the brain processes some information with the environment triggers a coping mechanism that leads to walking. The participant suggested walking was a way the residents dealt with situations they found themselves in. It was their way of creating solutions either to meet their needs or to cope with the situation. Participant-RN3 linked

this to Participant7's continuous walking, which might be her way to self-regulated. Using a critical lens to examine the quote, two possible rationales emerged. Firstly, this scientific explanation highlights the complexity behind the walking for residents with dementia and how it may be impulsive and risky but at the same time necessary for the residents. Secondly, it highlights the needs for empathetic approaches to supporting the residents as the urge to walk may be uncontrollable, which would require the provision of environments where residents can safely walk.

5.4 Summary Perspectives on Walking

In summary, this chapter has presented the first finding of the study as theme one: Perspectives on walking. It has answered the first aim of the research question by uncovering many multifaceted and complex meanings of walking as viewed by all participants, including the residents. As a result, this first finding has addressed the third aim of the study, which was exploring the concept of person-centred care from the staff's attitudes and views of the walking of the residents. In addition, the chapter has also provided answers to the fifth aim of the research, which was to contribute to the destigmatisation of the residents who walked by, shifting to using dignifying language to restore their personhood and dignity (Kitwood, 1997). In each interview, the participant spoke of each of participant-resident as a person, not their diagnosis. They used humanising language to address them. All participants, including the residents themselves, saw their walking as normal. Non-resident participants respected residents' desires to walk, providing various reasons why they did. This aligns with social constructionism, which underpins this research, which argues for a shift of the stigma away from the residents. What permeated throughout the subthemes was the reoccurrence of carrying on normal life. The walking of the residents was viewed as a way of feeling good, gaining utmost pleasure. It was a way of continuing with their previous daily roles, a way the residents kept physically active, fit, and healthy. Walking was viewed as human in nature and a basic right to freedom, autonomy, and independence. Walking was a way of bonding, connecting, communicating, and keeping socially engaged with others. Walking is constructed as searching for someone or something invaluable. Walking was viewed as wanting to be meaningfully occupied, and since no one likes being bored, this was seen as normal. Furthermore, walking was seen as being lost in an unfamiliar environment and without purpose, trying to find one's way to a familiar environment. Walking was seen by the staff as normal because it prevented the residents from having the types of health complications associated with being confined to bed, such as pressure injuries, which

reduced their workload. Managing and supervising the walking of the residents with dementia could also be difficult and challenging especially with staff shortage, heavy workload, and limited support and resources, but residents' freedom and independence to walk and their safety were considered priorities in their care. Lastly, walking was perceived as normal as it was a coping mechanism for the residents who were trying to compensate for what deficient in their body systems functions, which was also considered in everyone.

Social constructionism argues that this constructed knowledge need to be acknowledged as there are multiple and alternative meanings to human interactions and activities and no single interpretation is sufficient to explain such phenomenon as the walking of the residents with dementia. The next chapter presents the second finding and main theme two 'Supporting walking".

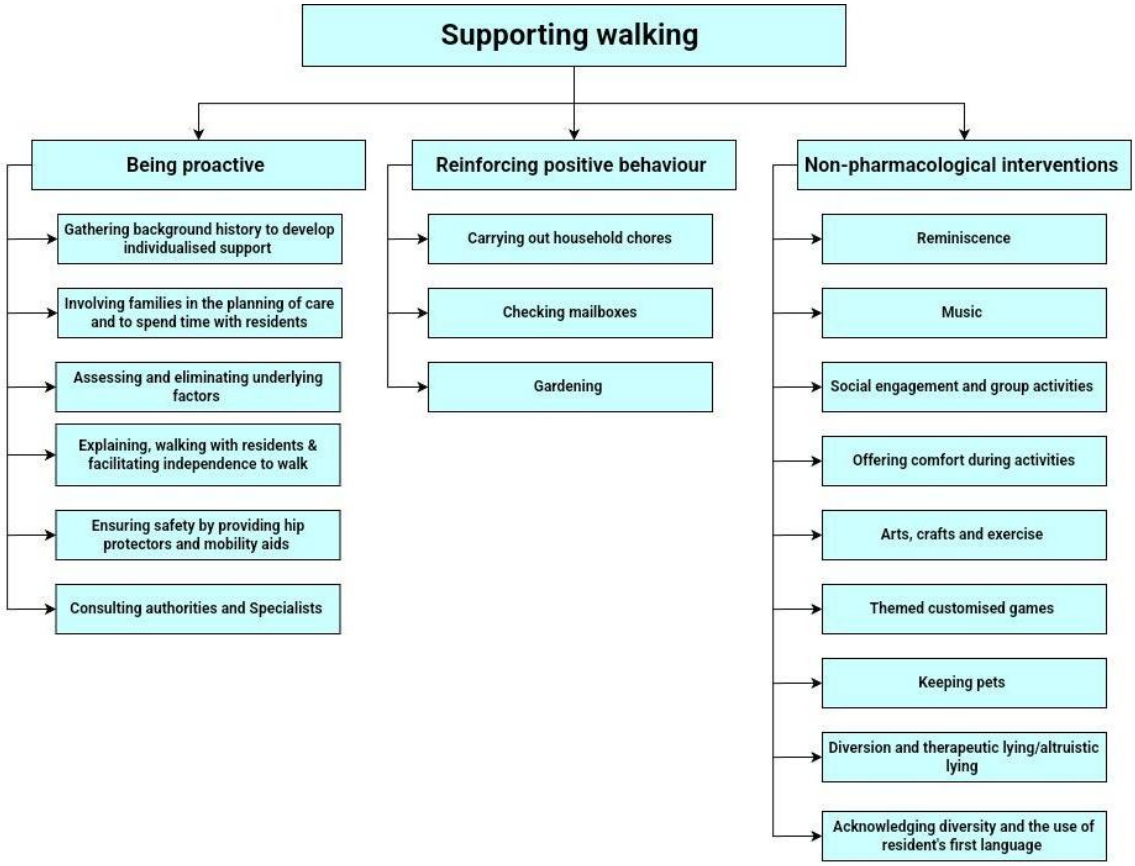
Chapter 6 Supporting Walking

> *…Interaction is not a matter of simply responding to signals, but of grasping the meanings conveyed by others; it involves reflection, anticipation, expectation and creativity … (Kitwood, 1997, p. 87)*

6.1 Introduction

In Chapter Five, the study's first finding was presented under the main theme Perspectives of walking. This chapter presents the second finding of the study, addressing the second study aim, which was to investigate the relational and supportive interventions provided to the residents with dementia who walked. The finding is presented with the main theme entitled ‘Supporting walking’. This is further broken down into three subthemes, namely, ‘Being proactive’, ‘Reinforcing positive behaviour’ and non-pharmacological interventions’. Each of these themes is further broken down into sub-sub as shown in Figure 9.

Figure 9. Theme Two: Supporting Walking



Note: Figure 9 shows ‘Supporting walking’ with its three subthemes, further broken into sub sub-themes

The next section focuses on presenting each of the three sub-themes, starting with ‘Being proactive’. This parent sub-theme is further broken down into six sub-themes,

namely: Gathering background history to develop individualised support; Involving families in planning care and requesting them to spend time with residents; Assessing and eliminating underlying factors that may trigger walking; Explaining, walking with residents and facilitating independence to walk; Ensuring safety by providing hip protectors and mobility aids, and Consulting authorities and specialists. These are reflected in Figure 10.

Figure 10. Being Proactive

Note: Figure 10 shows six ways the residential care staff were ‘being proactive’

Table 13 presents the participants' nuanced responses to ‘Being proactive’ in the ways they supported the walking of residents with dementia. Each approach is presented in detail with relevant quotes to give voices to the participants without making assumptions which critical ethnography, the study's methodology, seeks to explore:

Table 13. Theme Two: Supporting walking: Being Proactive – Participants' Responses on Ways They Supported Residents with Dementia Who Walked

	Gathering background history for individualised plan	Involving families in planning care and spending time with residents	Assessing and eliminating triggering factors and monitoring walking	Explaining to, walking with residents and facilitating independence to walk	Ensuring safety: providing hip protectors and mobility aids	Consulting authorities and Specialists
Participant- EPA1 (family friend)				✓		
Participant- EPA2 (Son)	✓			✓		
Participant- EPA3 (Wife)				✓		
Participant- EPA4 (Daughter)						
Participant- EPA5 (Son)						
Participant- EPA6 (Wife)						
Participant- EPA7 (Daughter)						✓
Participant- Staff RN1	✓	✓	✓	✓		
Participant- Staff RN2					✓	
Participant- Staff RN3	✓	✓	✓			✓
Participant- Staff RN4				✓	✓	
Participant-HCA1						
Participant- Staff HCA2				✓		
Participant- Staff HCA3						
Participant- Staff HCA4				✓		
Participant- Staff HCA5	✓					
Participant- Staff HCA6						
Participant- Staff HCA7						
Participant- Staff HCA8	✓					

Note: Participants' responses on six areas of Being proactive in supporting walking

6.2 Being Proactive

When asked about how they managed the walking of the residents, the topic of 'being proactive' was prominent in views expressed by a majority of the staff in these specific areas.

6.2.1 Gathering Background History to Develop Individualised Care

Participant-RN1, an experienced clinical manager at the secure dementia facility, provided an insight into approaches taken by their facility to support the residents with dementia who walk:

> *… So, on their admission, we have to get a collateral information from the clinical notes, from family members, the discharge summary and … from the GP and then we … identify their activities that [will be] included in their care plans that is called 'About me' … then we identify [if] the resident likes to walk, then we will include that one in the care plan and then we will implement these, of course, on a regular basis…*
>
> (Participant-RN1)

The experienced clinical manager explained their first step of carrying out a thorough admission process, which demonstrated their proactiveness. This included collecting background information on residents from various sources, which is part of the Best practice guidelines recommended (BPACNZ, 2020). Examples of such sources are residents' public hospital discharge summaries, clinical notes, family members, EPAs, GPs, and clinical notes. Background information gathered included family history, social history, culture, religious values, spirituality, medical history, occupation, lifestyle, hobby, and resident's favourites, such as food, clothes, or television programmes. This approach suggests a commitment to personalised care, which is crucial to the care being provided for residents with dementia.

Participant-RN3, another experienced clinical manager from social site two (Facility Two) certified to provide rest home and private hospital levels of care gave her views on their proactiveness during admission processes and the steps taken if there was any concerns of changing behaviour (Power, 2017) in the information gathered about the residents:

> *…, especially if there is some sort of challenging behaviour, I would really be needing to discuss it with the Nurse Specialist from the Mental Health Team, because I need to make sure the suitability of the patient to come to [our facility]. [So that's one of the things that as a as a team, we have to get the background information about the patient so that we can understand the need. And from there, we will be able to discuss as to how we will be able to manage the behaviour.*
>
> (Participant-RN3)

In the above quote, Participant-RN3 explained their admission process, pointing out the collaboration involved with the Nurse Specialist and Mental health team whenever there was evidence of changed behaviour in the information gathered on any resident

placed in their facility. This highlights the need for care staff to collaborate with other community agencies for support in caring for residents with dementia who walk. However, the facility had limitations, as the facility was not a secure facility or certified to provide care for residents with dementia who walked. Participant-RN3 shed light on the purpose of collecting residents' background histories and related information:

> *What we do is actually … individualised care*
>
> (Participant-RN3)

In his interview, Participant-HCA8 raised an important point that is key to providing proactive and individualised support to the residents:

> *Every resident is different … so far, I have observed maybe two that are constantly going around like the whole day … With regards to physical abilities, they are quite really able … With their mobility they're quite independent and they do use walking frames. They actually don't need full assistance 'cause they could carry on walking by themselves. Yeah, we just keep an eye on them that they don't…go straight out of the place… but they haven't done that so far … they know their boundaries…*
>
> (Participant-HCA8)

He recognised the uniqueness of each resident in their care and emphasised the need for individual observations to establish a tailored support plan that meets the residents' walking needs. When Participant-HCA8 was asked if there was any guideline available in the facility that staff could apply in caring for residents with dementia who walk, the question was not directly answered, but references were made to the dementia courses and in-service education sessions undertaken by staff. Analysing the data on these educational sessions and unobtrusive data gathered, indicated that these are very beneficial courses on general dementia care. Though walking would have been mentioned as part of changing behaviour, considering the prevalence of those that will walk with the syndrome in Chapter Two Literature review, residents 'walking' with dementia syndrome would want specific guidelines that support their walking for their normal and quality of life.

Participant-HCA5 also referred to the detailed documentation and individual care plan, stating, that it was important for all staff to take note of them and to be aware of the different needs of residents as each is different to the other. When asked further if their facility had guidelines for supporting residents with dementia who walk specifically, she responded:

> *Each resident, they have their file and then they have a care plan, and the care plan tells you what is the person's … how do you look after them. For example, if that person wants assist[ance] or two assist. If that person got wandering [behaviour]- that means that when they've got wandering and they're going from room to room. It's all in the care plan.*
>
> (Participant-HCA5)

Although there was no direct response to this question, the emphasis on the plan of care and documentation signified continuity of care by staff to effectively and consistently implement the strategies and assistance each resident needed to support their walking.

During the first stage of the data collection (participant observation), I met Participant2, Participant-EPA2 (son)'s mother, at the secured unit and later interviewed her and her son at Stage Three, the in-depth interview stage. At the beginning of my monological data collection and gathering primary record stage (Carspecken, 1996), I observed Participant2 and the frequency of her walking in the hallway of the unit before and after breakfast. She looked relaxed when walking, not distressed nor agitated. Participant-EPA2 (Son) noted how frequently his mother walked in the hallway after lunch. My interactions with her and some reflections about it are recorded in Chapter Four. The significance of including this account of Participant-EPA2 (son) and his mother, Participant2, is that it highlights the crucial role that family plays in the care of their family member, the persons with dementia. The family member, Participant-EPA2 (Son), referred to his proactive approaches when caring for his mother when she was still in his care. This was in response to a question on what impact the care had on him. A quote from his response is given below:

> *So, I'll go round and have tea with Mum every other day and … we would go for walks so there's a local park and we have a small dog [name withheld] and so we would take Mum for a walk with [our dog] …*
>
> (Participant-EPA2 (Son))

In the excerpt provided above, Participant-EPA2 (Son) stated how he visited his mother, Participant2, regularly and engaged in walking with her, interacting and communicating with her as they walked down to the local park. This shows that to support his mother's walking, he took various initiatives proactively, especially because she liked to walk. He made the following comment:

> *… she always, when she was home, she had a couple of routes that she would walk during the day … that was always around the local, a couple of local roads, so she had like a couple of circuits where she had walked and walked back. And she did that a lot but obviously as*

> *she got more and more vague and a bit confused, we ended up having to put a gate so that essentially it blocked off the whole back of the section, … and we got a fence on the back of the section as well. So, it meant that essentially mum could walk around the backyard …*
>
> Participant-EPA2 (Son)

In addition, he recounted other steps he had taken to support his mother's care and walking so that she was safe when he was away at work. Participant- EPA2 (Son) recalled the mother needing a bit of help with cleaning the house. In addition, he dropped off his mother at an organised gathering run by a group in the community twice a week, and by arrangement, they would drop off his mother at home by the time he returned from work. The actions he took enabled his mother to take the walks she enjoyed while still living with them at home. The son's regular visits and walks with his mother were beneficial to her as these provided physical, social and emotional connections beneficial to the mother's well-being (Kitwood, 1997). Furthermore, the proactive initiatives taken by Participant-EPA2 (son) in providing a safe walking space for his mother at the back of the house show how the environment can be modified to create safe walking spaces for residents to enable them to remain active without having their safety compromised.

6.2.2 Involving Families in Planning Care and Spending Time with Residents

Participant Staff RN1, Participant-RN3, and Participant-RN4 mentioned involving families in the planning of the care of the residents. This is probably because the residents with dementia feel vulnerable "within the self" (Bartlett & Brannelly, 2019, p. 3). They feel they are no longer the same person as the syndrome has affected them but having their family or EPAs with them may provide assurance and emotional support to them as they are familiar to one another, especially if newly admitted to the facility. However, each participant mentioned a crucial element for proactiveness to be effective. Participant-RN1 stated:

> *We have to occupy their space by providing activities and then yes and then calling family members to spend time with them …*
>
> (Participant-RN1)

From the quote, it is crucial that the residents are provided with stimulating and engaging activities to keep them occupied while in care. Participant-RN1 also highlighted the importance of the role family or EPAs play in the life of the residents and encouraged families to visit and spend time with their loved ones in care facilities. Spending time with their loved ones in the facilities enhances residents' emotional and

psychological well-being. Another RCS, Participant-RN4, shared the following view on the importance of involving family in the planning and care of their loved ones:

> *Huge part of that is also involving the family, making sure that the family are involved in the planning stage to say, Hey, this is mom or dad's behaviour. We're not going to stop them. We're not going to restrain them, but we are supporting them in what they're doing. If they end up, going to fall, they're going to fall. We're never going to stop that. But we are doing all these different steps along the way to minimise the risk of them falling and minimise the risk of them suffering from any kind of injuries …*
>
> (Participant-RN4)

Participant-RN4 raised the issue of restraint above, which was a common practice in some facilities to manage or reduce the walking of their residents. This subject will be further discussed in the discussion chapter along with the stance on antipsychotic medications.

> *… So once the patient is here, we also need to understand that number one, having to have a change in the environment, can make them unsettled. And apart from that, it's also got to deal with the different faces of the staff…*
>
> (Participant-RN3)

In the quote above, Participant-RN3 highlighted the challenges and confusion that come with new and unfamiliar environments for residents with dementia (Davison et al., 2019; Young et al., 2019) which may cause them distress or make them unsettled in their new facility. To many staff, including Participants-RN1, RN3, and RN4, having family members there constantly or regularly to visit the residents would give the residents initial familiarity and assurances needed to settle in and to be orientated to the facility. This would make them calm and not frustrated that they were lost, which could trigger in them, the need to keep walking to find their way back home.

The implication of this sub-theme of involving the family in the care planning and encouraging them to spend some time with their family members at the facility is the constraints brought on the process of caring by the wider organisation through environments that do not adequately meet residents' needs (Cook et. al., 2022). For instance, buildings can be designed to accommodate spouses staying overnight to continue providing the intimacy and emotional support (Cook et al., 2022) needed by residents for their well-being; the fact that this is not possible yet makes it challenging for facilities to fully achieve the goals of person-centred care.

6.2.3 Assessing and Eliminating Underlying Factors

Assessing and eliminating underlying factors triggering residents to walk were identified as proactive measures taken by two staff participants using systematic assessments. These are reflected in the following quotes by Participant-RN1 and Participant-RN3 below:

> *… we have to address if there is pain because that could be a trigger for the walking and mak[e] sure that the patient is not constipated or and there's no hunger or thirst. So, we have to rule out everything because they could be using walking as their scapegoat …*
>
> (Participant-RN1)

In addition, Participant-RN1 said:

> *… Assessing for pain, then re-prioritise their personal cares…*
>
> (Participant-RN3)

Both staff recounted how they took the initiatives to improve residents' care by carrying out various assessments to identify underlying needs and factors that could cause residents to want to walk so they could address them. Such factors include pain, constipation, or basic needs such as hunger or thirst, which some residents might not be able to communicate to their nurses. This emphasises the importance of staff being vigilant and observant to promptly identify and address the physical discomfort in the residents. The implication is for nurses to prioritise holistic assessments of patients to meet their specific needs, thereby, eliminating the root cause or factors that may trigger walking in the residents.

The frequency, time, and other characteristics of the walking of the residents are documented to provide evidence for the need for better strategies to support the walking at those specific times or to refer residents to appropriate services, if beyond the nursing scope of practice (Nursing Council, n. d.). Participant-RN3 expanded on this documentation in the quote below:

> *Normally the behaviour monitoring, we will do that between two to three weeks, because the behaviour monitoring will be used as a form of documentation to identify trends of the behaviour of the patient and at the same time, it's also a way for us to present to the mental health team, if there are things that we're not able to manage, or perhaps if we're needing more support from them, and of course, it's also having to present evidence to the family that this is the behaviour, this is what we're doing. And that we wanted to be honest with you that these are the things that we're able to do, and in the event that- unlikely we will be able to manage the behaviour [of the family member- resident], then, we are also being able to evidence*

> *that one[too], and everyone is on the same page about what we can do to help the patient.*
>
> (Participant-RN3)

In the quote above, Participant-RN3 highlighted the importance of having appropriate support strategies for the residents in place, which requires the identification of underlying issues that need immediate interventions which serve as evidence for collaboration. Part of the unobtrusive date received included the frequency of resident's walking, fraction/percentage of the activities residents participated in as recorded in the Behaviour monitoring chart/documentation. Examples of such data are the following:

> *Participant3: 'Always, pacing back and forth, one-third of activity'*
>
> *Participant4: 'Walks around the facility: complained of sore legs at times and constipation'*
>
> (Except from Summary of Participant Observation, Social sites- One and Two)

6.2.4 Explaining, Walking with Residents and Facilitating Independence to Walk

Explaining to the residents what needed to be done, walking with them when they wanted to walk, and facilitating their independence to walk were perspectives given by five participants: two Participant-RNs, two Participant EPAs, while one Participant-HCA highlighted the implication of this proactive approach. By walking with residents, participants felt this reduced the continuous walking in some residents as some of them got tired afterwards. An interesting perspective was put forward by experienced Participant-RN4 in the quote below:

> *So, my view on wandering is actually a lot of the interventions for dementia, I find a proactive approach is a lot better than reactive approach. What I mean by that is [with] dementia, a huge part of it is you lose your impulse control. So, my way of getting around that is before you get the impulse, we do something about it, be proactive. So, a person that has dementia would want to wander because all of a sudden, they would see something of interest, or something will come into mind, and they just do it because they can't control the impulse. So instead, for us, what I would like, what we've been doing is, to be a bit more proactive. So, we take a lot of the residents who do have dementia for a bit of a walk throughout the day. You'll see that with a lot of the staff members that are encourage[ing] some of the residents like Mrs. A, Mrs B, they will go for a bit of a walk. And you'll see them around about 10 o'clock, 11 o'clock, and some in the afternoon as well. You see them going for a bit of a walk around the facility, just throughout the court … and that helps a lot.*
>
> (Participant-RN4)

Participant-RN4's example in the above quote suggests a model example of a proactive approach where residents were engaged with exercises and mobility before residents started walking, which enhanced their well-being.

Participant Staff-RN1 highlighted the regularity of this routine practice of accompanying residents on their walks:

> *…We take them for a walk on a regular basis and then, yeah, we also give them space to walk on their own, and normal time …*
>
> (Participant Staff-RN1)

The above quote highlights the enhancement of the overall health of the residents through accompanying them to walk, and facilitating and empowering them to be free to walk. It also highlighted the importance of respecting the residents' choices in walking to maintain their autonomy (Brooker, 2004, 2007; Kitwood,1997). This illustrates how staff respect the personhood of the residents and regard them as equal and as social citizens (Brannelly, 2011; Bartlett, 2022).

Participant-HCA4 demonstrated that she understood the resident, which is crucial factor and skill in providing support to residents with dementia who walk. However, she went further to allude to another key relevant issue in supporting residents' walking:

> *There are times when residents want to walk on their own and not be followed, but it's a risk to the resident as they might fall, they have an accident and it's our job to keep them safe and it's really hard trying to explain to a resident that suffers from dementia that you're only there to look after them and yeah, that's one issue… But like I said before, we don't restrain them. I don't think I'd ever want to see a family member strapped or pinned to a chair, hence why half the time the Nightingale table, if you lock the brakes, that's confining them to one spot and I don't see that as a very good thing because if you're not able to push your table away, you're being confined to one spot, which is abusive.*
>
> (Participant-HCA4)

One of the relevant issues raised is the use of physical restraint, which may present an ethical issue in ensuring residents' safety. As this approach is unsafe (Evans & Cotter, 2008) and encroaches on the rights and dignity of the residents with dementia (United Nations, 2022; Human Rights Acts 1993), Participant-HCA4 made her stance clear. This implicates all RCS to uphold the rights and dignity of the persons with dementia who walk in any approach they implement to support residents walking (Brooker, 2007; Human Rights Acts 1993, Kitwood 1997; UNCRPD, 2022).

Furthermore, in emphasising the safety approach taken by RCS in using proactive support for the residents who walk, Participant -RN2 made reference to the independence of residents to walk as they were still capable:

> *… Actually, I would just let them walk because they are still independent with walking, it is a part also of exercise…*
>
> (Participant-Staff, RN2)

However, in recognising the capability to walk by the residents, the participant highlighted the need to continue this for the physical exercise benefit it brought, contributing positively to their health. This means that residents capabilities need to be continuously assessed to identify when residents need assistance.

However, Participant-HCA1 cautioned against agitating the residents:

> *…Yeah, communicate properly for them, it's only the thing in dementia you need to, if they cannot hear, you need to just tell them properly, communicate properly …[they don't] want to hear your voice loud. You need to follow also on that because they're agitated if they hear the voice that's very loud…*
>
> (Participant-HCA1)

Participant HCA1, demonstrating 12 years of experience working with residents with dementia who walked, suggested that it was best to modify loud voices and tone down one's voice when communicating with the residents as this may unsettle them (Downs & Collins, 2015; Vafeas & Slatyer, 2021). The implication of this is for facilities to enlist experienced staff such as Participant-HCA1 in mentoring new staff or sharing knowledge or experience during in-service training sessions to build the capacities and skills of other staff to support the care and walking of the residents with dementia.

On the sub-theme of walking with or accompanying resident with dementia to walk, a family member, Participant-EPA2 (Son), used this approach so his mother could enjoy nature and walk safely when under his care at home. The following quote provides evidence for the sub-theme:

> *But during that time, we would always go for walks each night at a local park with the dog. So, she's always like doing the walking and that helps with sleeping and calming her down and different things as well.*
>
> (Participant-EPA2 (son))

Participant-EPA2 (Son), in the above quote, demonstrated his holistic way of supporting his mother's walking, especially in a natural setting with the dog as a companion pet, which is therapeutic for persons with dementia (BPACNZ, 2020;

Mitchell & Agnelli, 2015). This approach of going for walks in nature appears to have positive physical, emotional, and psychological effects on the mother, including helping her sleep easily. This proactive approach also models the incorporation of residents' histories, routines, lifestyles and favourite practices into individual care plans and implementing them, which have implications for all staff in supporting the walking of the residents with dementia.

This topic of restraints implicates all RCS to find appropriate approaches and strategies that support the dignity, autonomy, freedom, and holistic care of each resident with dementia in their desire to walk. The quote above also raises the need for nursing staff to be supported with specialised education and resources so they are equipped to provide individualised care to residents who walk, which is the goal of person-centred care (Brooker, 2004; Kitwood, 1997). This implicates all stakeholders, including the Ministry of Health, to support more groups and organisations to create more awareness through education and training sessions on issues relating to dementia and walking of the persons diagnosed (Dementia New Zealand, 2023). Such an awareness campaign would enlighten and equip all stakeholders on the syndrome and ways of supporting those already diagnosed or those to be diagnosed due to projections, so stigma can be reduced and ultimately removed as discussed in Chapter Two. Implications will include well-informed and inclusive communities, normal life for those living and walking with dementia currently and confidence to seek help for early diagnosis and support in others projected to live with it in the coming decades.

While providing her view on the proactive approaches she supported the residents with, Participant-HCA2 exposed the challenges faced by staff, especially, inexperienced staff when they supervised or accompanied residents to walk in the public domain, for instance on the roads:

> *… Sometimes, if we take them out for a walk outside this unit, it could be a little bit scary if you don't know how to redirect, because when they go out from the door, they don't wanna to come back in*
>
> (Participant-HCA2)

In the above quote, Participant-HCA2 mentioned her proactive steps in walking with residents in the public. However, the quote by Participant-HCA2 also unfolds many prevailing and critical issues that need to be addressed for this support to be effective: Firstly, it exposes the challenges faced by RCS and the risks involved when they accompany residents to walk in the public, which may prove difficult to manage if not well-planned. The residents may be distressed finding themselves in yet another unfamiliar environment, or the residents may try to find their way back to a familiar

environment, which may be their original homes (Kitwood, 1997). The quote raises the critical issue of safety of the residents' care due to the disorientation and the difficulty for staff to redirect them back to the facility. This also raise the important issue environment plays in affecting residents' behaviour, making them settled or unsettled.

Participant -EPA3 (wife) in discussing her view, gave an incident that happened with her husband whom she visited each day. He had been living at the facility for approximately four years but always wanted to return home. She expressed that she always wanted to take him home on the weekends, but at her age (75years), there was a limit to what she could do and how she could do it. She had taken him out with their daughter previously and when it was time to return to the facility, the husband did not want to. He even cried sometimes when it was explained to him why he had to return to the facility. The except below reflected the grief and loss she experienced due to this separation from her husband:

> *I could - you're allowed to take them home; you're allowed to take them out for rides. You can do what you want. I can take him along for a weekend or the week for change. But I can't. I can't get, I won't be able to get him back. And that's the part that worries me … the last time we took him out to my house. When my daughter from [another country] was over. We took him to see we've been painting our house. And when we brought him back in the door, he called us "bastard" ... because he was coming back in here when he'd been home….*
>
> (Participant-EPA3 (Wife))

This quote provides a glimpse of understanding the experience of a resident with dementia who walks and who wants to live at home; it seems likely that the wife's account of her perspective and that of her husband rings true to others as well. The quote reveals the resident's disenfranchisement, loss of choice, relationships, intimacy (Cook et al., 2022), and autonomy. It further unfolds the residents' anger and grief over his 'now self' (Bartlett & Brannelly, 2019; George, 2010; Ney et al., 2021), and his powerlessness over what was once in their control.

In addition, the quote above unfolds the need for EPAs, caregivers, and families to be supported with counselling to meet their own emotional, physical, psychological, and spiritual needs as they continue to be great pillars of support to the residents with dementia, whether at home or during their regular visits to their loved ones living in an ARC facility (Bartlett & Brannelly, 2019; Kitwood, 1997).

6.2.5 Ensuring Resident's Safety

Ensuring safety of the residents was paramount as Participant-RN4 explained:

> *So, you [the RCS] tried to make sure that they have the hip protectors on, to make sure that if they do end up falling, you minimise the risk of them breaking their hips … so for the particular resident, we were talking about who loves just walking around non-stop, it's making sure that they have the hip protectors on if they had that or they have their walking aids, whichever one they may need.*
>
> (Participant-RN4)

In the above quote, Participant-RN4 emphasised their proactive measures of injury reduction. Participant-RN1 mentioned her proactiveness in ensuring residents environment is free from tripping hazards and in maintaining vigilance to prevent falls.

Furthermore, in terms of proactive measures, Participant-RN1 shed further light on two proactive measures taken to prevent of falls when residents walk:

> *… there are a lot of, like, safety issues. The first thing is the clutter things in their rooms, residents, you know they have dementia, they tend to throw the things on the floor. So, you have to be observant as a nurse, you have to pick it up and put it back in an organised way and maybe in their drawer. So, in here, I always see the flow, like you know, some drops of water, like the residents tend to spill it all over the floor. So that's also a risk. So that will make the floor slippery. So, once they get up and walk, so, they [will] have a fall. So, I always make sure it's nice to like to wipe it as soon as I see when the floor is wet. And also, you know, the … yellow one … caution board … I have to remove it because once the residents walk around … they might hit that object and also have a potential to fall down…*
>
> (Participant-RN1)

In the above quote, proactive steps were taken to reduce the risk of falls.

Participant-RN1 was of the opinion that residents should be left to walk independently:

> *… Just letting them walk freely within the secured unit …*
>
> (Participant-RN1)

Through allowing residents to walk freely within the secured unit, Participant-RN1 highlighted the importance of balancing residents' safety with their independence to walk.

6.2.6 Consulting Authorities and Specialists

Lastly, a proactive strategy mentioned was to consult the local law enforcement authority, such as the community police department, to assist with searching for lost residents. Care and placement input were also sought from the Mental Health Service for Older People, the General Practitioner (GP), the Needs Assessment Coordination service, and other network agencies in the community. Participant-RN1 provided the

following account in response to the question if the facility had had any episodes of a missing resident:

> *We have a couple of instances. Then we had to seek assistance from the police and eventually what is happening. Then we have to call the attention and the mental health people. Also, we have to consider the fact that a new environment will create confusion. So, for the benefit of doubt, before calling the mental health, we will create a work line, like having an early check or making the resident busy with something so that they will be preoccupied [with] and of course reinforcing talking to them and then of course involving the family members. Yeah, and making the resident … settled!... If these interventions are not effective and then we will consider the mental health people to change their level of care after the GP has seen them and changed [reviewed] the medications*
>
> (Participant-Staff -RN1)

The two quotes below from two experienced RNs, Participant-RN3 and Participant-RN4 revealed similar *consultations with specialists practices done by the staff for the safety of the residents with dementia who walked:*

> *… what we would normally do is if there is an increasing challenge us with the behaviour or more so, that it is now paired with some sort of aggression, we would normally get the mental health team involved. And before they will get involved…we need to actually root out any possible causes of the unusual behaviour. So, we do Delirium screening, because we all know that, if they will have infection, this will pretty much change their behaviour and or if they are dehydrated*
>
> (Participant- RN3)

> *one of the first things I ask is what kind of behavioural issues do they have? Specifically, I go into wandering behaviour, regardless that it is a freedom for the residents. … As a professional, as a care provider, we need to be aware of these things, because it is a huge risk. It's a risk for the residents, it's a risk for the staff. So we need to be able to know that these things are happening. And we need to be able to manage it safely. If we find that this wandering behavior is not safe, because they're constantly walking outside and banging on the doors, they are trying to find ways to get out of the out of the building. We need to be aware of this or else we're putting the resident at risk and we cannot guarantee their safety. We're had a recent resident who walked out of the [facility] had an accident outside. And we've had people in the community come in and say 'Help! Help! Help!'. So, it's a huge risk. …We need to be able to make that decision before residents come in -whether we can manage it or if the residents are already in here with us….and just through time, they've deteriorated, age- related and their behaviours deteriorate upon that we cannot manage those kind of behaviors, we need to find a suitable facility for the residents to be able to be looked after safely…*
>
> (Participant-RN4)

These quotes above reveal the layers of professional support that ARC facilities and their leadership received from law enforcement agencies, specialists, and other services in the community in their decision-making towards helping to provide person-centred care to their residents which demonstrated their proactive approaches in supporting residents with dementia who walked.

The next section presents Reinforcing positive behaviour and Non-pharmacological Interventions, the two remaining sub-themes the staff used in supporting the walking of the residents with dementia. Table 14 reveals the responses of the Participants on each of these sub-themes:

Table 14. Sub-themes: Reinforcing Positive Behaviour and Non-pharmacological interventions

	Reinforcing positive behaviour	Non-pharmacological approaches
Participant- EPA1 (family friend)		
Participant- EPA2 (Son)	✓	✓
Participant- EPA3 (Wife)		
Participant- EPA4 (Daughter)		✓
Participant- EPA5 (Son)		
Participant- EPA6 (Wife)		
Participant- EPA7 (Daughter)		✓
Participant-RN1		✓
Participant-RN2	✓	✓
Participant-RN3	✓	✓
Participant-RN4		✓
Participant-HCA1		
Participant-HCA2		✓
Participant-HCA3		
Participant-HCA4	✓	
Participant-HCA5		✓
Participant-HCA6		✓
Participant-HCA7		✓
Participant-HCA8		✓
TOTAL		

Note: Responses on Reinforcing positive behaviour and Non-pharmacological interventions offered

6.3 Reinforcing Positive Behaviour

Some participants expressed engaging the residents with dementia who walk in meaningful activities after observing some positive habitual behaviours in them such as doing household chores or walking outside to check the mailboxes. Participant-RN1 shared the following example of a resident who always did the dishes after meals:

> *… like there is one particular resident, like, after she ate her lunch, she would just walk and get up and like, you know, doing kitchen dishes, kitchen stuff like washing … and you know … fixing the cutlery like that…*
>
> (Participant-RN1)

The staff engaged the resident meaningfully by inviting her to join other staff to lay the tables for lunch. This refocused the resident on a different activity other than walking, giving her a sense of satisfaction, normalcy, and accomplishment in looking after her fellow residents. This quote emphasises the importance of careful observations to identify residents' strengths and not their weaknesses (walking) and to channel their walking to other beneficial ways for their well-being. Apart from the satisfaction gained, this engagement may give residents a sense of purpose and reduce any anxiety and agitation that may occur. "Positive person work" (Kitwood, 1997, pp. 89-93) is advocated to be used as supporting the residents as it enhances personhood and counteracts the negatives referred to as malignant social psychology (Kitwood, 1997) which dehumanise and stigmatise residents with dementia who walk.

The following quotes featured other interventions that reinforced positive behaviours observed in the residents with dementia who walked, gave the following quotes:

> *… and one of our patients, because we have a letterbox, yeah, one of our patients usually goes out there and checks if there is a mail …*
>
> (Participant-HCA2)

> *…We have a resident right now, she does have dementia, it is progressing. She has multiple behavioural traits. One of them is she loves walking around. She's always been a busybody. She's lived by herself majority of her life. So, she is very used to do[ing] everything [by] herself. But she just loves cleaning, she would walk around the facility, you'll see when she used to walk outside the facility, she'll be cleaning … grabbing leaves. You're not going to stop her. And there's no harm about it [what she is doing]. She just loves to walk around. She just likes to do things. When she has her cleaning tools, she's not wandering. Dementia is kind of - Wandering is classified as someone who's walking- walking without a purpose. But when she's walking around with a rake, or trying to clean, she has a purpose, which is not wandering …*
>
> (Participant-RN4)

The two quotes above show how staff focussed on residents' strengths and capabilities and provided interventions that met these needs: a mailbox was constructed in the garden within the facility for one resident and the other provided with safe cleaning tools to meaningfully engage them with other beneficial activities. This is an example of the salutogenic approach to providing person-centred support to the residents as these provided residents with a sense of continuity, identity, and self-worth (Kitwood, 1997).

Participant-RN4 contributed to the debate on walking by rejecting the general notion that some persons with dementia who walk are walking without purpose. He differentiated between walking with and without a purpose. This is part of an ongoing debate that prevents a standard definition of walking to have a consensus. Using a critical lens of social constructionism, the varying definitions of walking are acceptable as they provide alternative ways of looking at the phenomenon and also creative solutions that will increase the quality of life and health to the residents.

6.4 Stance on Antipsychotic Medications

As discussed in the literature review presented in Chapter Two, it used to be common practice to routinely administer antipsychotic medications in aged care settings in the urban and rural setting. However, the majority of RNs and HCA participants demonstrated awareness, knowledge, and understanding of the best practice guidelines by BPACNZ and NICE on using antipsychotics medications as a last resort in managing BPSD, including walking. All examples in their responses were non-pharmacological interventions and they advocated for these for their residents, some passionately. Some of their quotes are as follows:

> *… we actually understand that the need to offer medications for the patients might be necessary, but there are always risks involved. So, as long as the patient is not harming himself, the patient is not also becoming a danger or a threat to the residents and to the staff. We don't resort in medicating patients …*
>
> (Participant-RN3)

> *… Actually, it depends on the residents. We're not giving the medications [to] the resident for their walking, we're giving the residents, the RN giving, if they're very agitated and we cannot manage them, because if the residents [are] allowed for the PRN that needed under the prescription from the doctor, then you [are] allowed to give, but for their walking, we're not giving the residents …*
>
> (Participant-HCA1)

> *I think it's not good because as much as possible, we need to promote independence in the residents as much as they can, and know that eventually they will deteriorate, but as much as we can, so it's not good for them to [have] medications that could affect their ability to walk.*
>
> (Participant-RN1)

All three participants above made their stance known against the administration of antipsychotic medications, referred to the best practice guideline for when these drugs could be administered, and advocated for non-medication interventions. This is significant as this awareness and knowledge demonstrates a high level of safe practice common in both ARC facilities or social sites. HCA1 showed good knowledge of the

scope of the different professional roles involved in aged care, articulating the role of other members of the healthcare team. However, Participant-RN4, in the quote below, raised a very important point on ethical dilemma surrounding antipsychotic medication administration:

> *Researcher: … You may be aware that medication is often used to manage this walking behaviour. What's your view on this?*
>
> *Participant-RN4: Um, I have I have a bit of a complicated view around this because I both support and don't support it. It's very, it's a very case-by-case basis. Like, I said before, it's a huge concern, health and safety risk and having someone wandering a lot. And depending on how the resident is, we may need to use medications to minimise the risk of walking out of the facility. Sometimes, even with medication, their behaviour is so strong, or sometimes it makes it very unsafe for them to mobilise. One of the few, biggest side effects of the medications is drowsiness. So, if you give someone who is very mobile, something that will get them really drowsy, you're increasing the risk of falls exponentially, and they're going to end up on the ground. However, if you don't intervene with some kind of medication, their risk for themselves and to others also increases. So, it's almost as if you're trying to live within a middle ground, to where you're keeping the residents safe and other residents, as safe as possible, but also minimizing the risk to that resident…*
>
> (Participant-RN4)

In her quote, Participant-RN4 unpacks many prevalent issues surrounding the provision of support for residents with dementia who walk and the administration of antipsychotic medications. Firstly, he revealed the ethical tension and complexity involved in making a decision, weighing the rights of residents to dignity and independence with protecting them from potential harm to themselves and those around them, which was his duty of care. His quote reveals the challenges faced by many staff in reaching that middle-ground decision, which highlights the need for continuous assessments and re-prioritisation of resident's needs by staff. The quote implicates service providers to keep providing ongoing support, training, and adequate staffing to enable the goals of person-centred care to be achievable by staff (Kitwood, 1997). Second, the reference to the case-by-case approach highlights that there is no one-size-fits-all approach to achieving holistic health for the residents; the uniqueness of each resident calls for innovative and careful consideration when making decisions for residents' overall well-being. Thirdly, the quote unfolds the risks involved in using medication due to drowsiness and other adverse effects; due to these adverse effects, benefits must be weighed against potential harm to ensure resident's safety (BPACNZ, 2020; Foebel et al., 2016; Lee et al., 2024; NICE, 2024). Fourth and lastly, the quote raises the issue of what other alternatives were available.

6.5 Non-Pharmacological Support and Walking

All RCS indicated they used non-pharmacological approaches in relating with and supporting the walking of the residents. The approaches included reminiscence, music, redirection and therapeutic lying, social engagements, group activities, acknowledging diversity, and use of resident's first language.

Participant-HCA5 recounted how she used reminiscence to interact with and support a resident in the quote below:

> *… I take the person back to his room, if there's any photos, things like that in the room, I start talking to that person, 'Look, is this your wife? That's your beautiful [wife]! I try to think of little things that make him remember although, sometimes they remember, sometimes they don't, but maybe when you put the picture there, she remembers.*
>
> (Participant-HCA5)

The participant used photographs and memorabilia familiar to the residents, especially of their loved ones, with the hope that it would trigger their memories into positive memories and personal connections and engage them in conversations if possible. The goal would be to personalise this approach to bring some calmness, comfort and reorientation to the residents without the use of medication (Cooney, 2014; Robinson et al., 2006). Though this approach is individualised and gives dignity to the residents, it has the potential to have the opposite effect if the photographs shown triggered some past pain and hurt in the resident which may lead to potential agitation. The implication is for staff to ensure they have a thorough background on the resident's a social history, lifestyle, and preferences before embarking on using this non-medication approach, as ethically the goal is to achieve beneficence for the residents.

Another non-pharmacological approach suggested was music. Participant-HCA7, in answering the question about the strategies she used in supporting residents who walk, said the following:

> *… Every day, with the music, when the activity coordinators are here, with the music…*
>
> (Participant-HCA7)

The staff was referring to the music played in the background each morning. In the participant observation, I commented on the music that was playing in the background in Facility One that many residents, as they were doing their walking up and down the hallway, were singing along to. I also observed the staff singing along as well and I observed some calmness and serenity around the residents as they kept walking and singing along to the music (Cooney, 2014; Dyer et al., 2018; Meyer & O'Keefe, 2020;

Robinson et al., 2006). Studies have shown strong efficacy in the use of music in bringing calmness and comfort (Cooney, 2014; Dyer et al., 2018; Robinson et al., 2006) as a non-pharmacological intervention and have the strongest evidence in reducing emotional disorders (Dyer et al., 2018; Meyer & O'Keefe, 2020). The implication for service providers seeking to achieve their goals of person-centred care (Kitwood, 1997) is to invest in resources, including humans, to implement these, as music needs not be limited to a few hours a day but available throughout the day, as a group and individual therapy. While caution is to be made to prevent overuse, the choices of music preferred by the generation and individual preferences needs to be invested into, through biographies investigations, to enhance the overall quality of life and well-being of the residents.

A majority of the RCS and few EPAs mentioned social engagements and group activities as non-pharmacological approaches they used in supporting and interacting with the residents who walk. Some quotes are presented below, first by Participants-RN1 and Participants-RN3 who have dual roles as RNs and Clinical Managers:

> *… we have a couple of activities that are in place for residents that are able to walk or are walking. Number one is that we take them out for walking sessions, and that is on a regular basis, I mean, I'm saying five times a week. Yeah, so about a kilometre away... to help their freedom… with respective stops, looking after them. So, that's the number one activity, then taking them out for a Van trip, that is, scheduled every Monday and then once in a park or Plaza, … as a normal person…, so they can still have their freedom. But, of course… exercise plays an important role for them … for activities, mainly the Health Care Assistants, because every time we do the walking, it needs the activities person themselves and, of course, with my supervision… and we have to list the residents that are going out for safety, in the event for security or when there is a disaster… they will be accounted for. How the residents walk like that are helpful walking sessions [to them]…*
>
> (Participant-RN1)

> *… we have got some programs in the morning, of which the Activities coordinator has been doing the walking programs with all of the residents. So, this is not just for those residents who walk even, those residents who are in wheelchairs, we do a morning walk with them. And what happens is that, that also depends as to how many residents in a particular wing have got that kind of behaviour … we think about safety and being we also need to think about how we divert the attention of the residents. So, one of the things that we have been [putting] in place is actually involving them in a group in which they will be having meals together. And there's a healthcare assistant who's supervising them. At the end of the day, even though they have got this specific behaviour, that shouldn't [matter]. We shouldn't be changing our perception that they're different from the others. It's just having to understand that this is the particular behaviour and it's up to us how to enhance the environment for them*

> *to be able to continue that behaviour, as long as they're safe and other residents and staff are safe.*
>
> (Participant-RN3)

Both participant managers itemised various engagements and activities beneficial in promoting the well-being and health of persons with dementia (Evans et al., 2019). Social interactions during group meals and group activities were also provided to socially stimulate and enhance residents' overall well-being. However, both participants mentioned the issues of safety, which is paramount and crucial to the residents' care. While the managers have mentioned some measures to ensure residents' safety, such as keeping a list of residents going out and staff supervision of walking, the implication of this approach requires careful planning by staff and support of service providers for resources as this requires creativity, vigilance, a deep understanding of each resident, and sufficient staffing and trained staff to ensure the safety of residents indoors or outdoors. To date, no evidence has been found that exercises, group engagement, and activities have any adverse impacts on the residents compared to the administration of antipsychotic medications (Dyer et al., 2018; NIHR, 2024). Conversely, non-pharmacological interventions such as group activities and outdoor visits have been found to enhance the personhood, autonomy, and independence (Kitwood, 1997; Brooker, 2007) of the residents as they need to be socially regarded (Brannelly, 2011) as social citizens (Bartlett & Brannelly, 2019; Cook, 2022). This point was highlighted by Participant-RN3, who suggested that that the residents were the same as everyone, they just needed to be understood (Kitwood, 1997).

Participant-HCA 7 and Participant-HCA8 mentioned the following non-medication activities they carry out with the resident to support their well-being as they walk:

> *…whoever wants to go for a walk, we have a walking activity for them…*
>
> (Participant-HCA7)

> *… like arts and crafts. The other [lady resident] joins in to arts and crafts classes… this particular lady, she did participate twice, but, yeah, she didn't really stay for too long, maybe; halfway during the class, she left but, at least she was there. She was invited, and then she came…*
>
> (Participant-HCA8)

Both Participants-HCAs referred to groups and individual activities they provided for the residents, which highlighted the variety of activity options the residents were supported with. However, the quote from Participant-HCA8 highlighted an important point worth taken note of by health practitioners new to caring for people living with dementia.

Activities designed for the residents should not be long but short with a focus due to the short-term memory at this stage. Participant-Staff was quite happy that the lady resident could attend the activity group for a customised game.

During the etic participant observation in Stage One of the study in Facility Two, I noted down a group of staff with a small group of residents in the lounge carrying out their Facility's Olympic games. After getting to know the participants during the emic stage of the in-depth interview, I requested more information on the event. Participant-HCA8 who led the team, gave this response below:

> *We did a group activity with that cos that was during the Olympics, last month or earlier, or this month. There was a group activity for those who weren't able to come down to other group activity- we do it one-on-one with [residents]. We would be sitting them in their rooms and documented, took a photo that they did participate.*
>
> (Participant-HCA8)

Participant-HCA8 and his team carried out the themed and customised Facility Olympic games as a non-pharmacological initiative that brings current world-stage events to the residents' world at the facility. The XXXII Olympiad, officially referred to as the 2020 Olympic Summer Games (Gallego et al., 2020; Wang & Jiang, 2021), took place in Tokyo, Japan, from 23 July 2021 to 8 August 2021. Participant6 was part of the three residents taking part in this game. He was given a toy gun and a target to shoot. I read my record of the events and how enthusiastic Participant6 was about the game and how he quickly stretched out his hands to grab the toy gun when it was his turn. It lasted for a few minutes, and he appeared to have gained satisfaction from participating. Kitwood (1997) recommended creativity in interacting with residents with dementia to meet their psychological and other needs and the Activity staff appeared to have modelled this.

Two participants staff and one EPA referred to their use of diversion and therapeutic lying, which I regard as altruistic lying as it was done for the highest good of the residents. Their quotes are presented next, followed by authorial comments:

> *… so just trick her, that okay, 'let's do this', 'we will, I will take you to go home' … we just distract her like that …*
>
> (Participant-RN2)

> *… some of them they got a very busy life, … so, they still carry on … 'I need to pick up my grandchildren at school'. So, we just tell them when they are getting agitated, we just tell them that 'it's no school today, it's a public holiday' and, they do listen…*
>
> (Participant-HCA2)

> *… I say to [daughter], … don't tell him how long he has been here [at the facility], I said, cos if you do, it'll probably kill him … We just tell him he's been here a few weeks or a month, and he's quite happy with that, so I dare not ever anybody mentions he's been here nearly 4 years or 3 years …*
>
> (Participant-EPA3 (Wife)

The three quotes above are three untrue statements made intentionally to the residents with dementia to make them settle, reduce agitation, or prevent them from harmful behaviours toward themselves or people around them when in distress. These interventions are also done through the use of persuasive explanations and sometimes untrue statements in the interest of and for the good of the resident with dementia. The quotes are also representations of care practice to date. This approach of therapeutic lying, though debatable, has been commonly used in practice and is regarded as a non-pharmacological intervention (Carcavilla-González et al., 2023; Mills, et al., 2019). This challenges and implicates all staff, EPAs, families, and communities to how else to better and socially construct the approach despite the best intention to protect the resident from potential emotional, psychological, and physical harm. The quote unfolds the ethical considerations of the principle of beneficence (doing good) to the residents versus non-maleficence (doing no harm). It shows a violation of the resident's autonomy, breaching the principle of truthfulness and trust instilled in the relationship. It also raises cultural and social norms regarding truth-telling as some cultures are against telling lies while other cultures are flexible about it as long as it is therapeutic.

The last approach identified was the acknowledgement of other ethnic groups at the facility and the use of the resident's first language. When interviewing Participant4 with her daughter present to translate my communication to her mother in her first language, the daughter mentioned she borrowed books from the local library for her mother to read and the books were written in her first language:

> Participant-EPA4 (Daughter- referring to her mother, sitting next to her in the meeting room): *She's reading her [book]. It's a religious book but kind of force her to sit in the afternoon and read - part of it stops her from walking.*
>
> Participant4: *Indian*
>
> Researcher: *Okay. Is that helpful to you?*
>
> EPA4: *So, I have got some books from the library. It's all in her language.*
>
> Researcher: *So, she can still read her language.*
>
> Participant-EPA4 (Daughter): *Yes, yes. So, just to, in my mind- it was just one to keep her mind taken over, but the other [book] was just from walking so that she's forced to sit and read. I am, I guess, in*

> *some cases, there's not been that ability to do puzzles or other things to keep her occupied with words.*
>
> (In-depth interview, Participant4, Participant-EPA4 (Daughter) and Researcher)

Research has suggested the retention of the first language is longer than any second language that may have been learned. The staff are aware and acknowledge the diversity in the community at the facility. Acknowledging the diversity of the group and supporting Participant4 to use her first language is acknowledging her unique identity and her life history and respecting her autonomy to express herself in her first language. This aligns with the goals of person-centred care which facilities and service providers need to consider (Kitwood, 1997). However, more research is needed to determine the efficacy of using first language to enhance cognition. The is an area of interest for the daughter who hopes to keep her mother's mind active.

Non-pharmacological interventions or approaches (; Cooney et al., 2014; Dyer et al., 2018; Macleod et al, 2021; Meyer & O'Keefe, 2020; Robinson et al., 2006) carried out individually or in groups have many benefits for residents for shared interactions and communication. Reminiscence stimulates their memories by focusing on positive events in their lives. Van trips, bus trips, and walking sessions, apart from providing opportunities for social interactions, provide avenues to keep physically active. Music enhances their sensory skills while word-finding puzzles stimulate them mentally. Individual or group activities, themed games, and parties enhance their personhood and dignity (Brooke, 2004; Kitwood, 1997), making them feel included (Kitwood, 1997) and like social citizens (Bartlett & Brannelly, 2019) who are socially regarded (Brannelly, 2011) as equals. Outdoor visits to parks and gardens provides opportunities for them to enjoy and engage with nature, which has been found to improve their overall wellbeing (Evans et al., 2019).

To conclude this chapter on RCS approaches in caring for residents with dementia who walk as a person, I will share the story of 80-year-old Participant4, a former full-time mother. She smiled and chatted with everyone. She used to live independently at home, receiving help for showering occasionally from staff from an agency in the community. She came into care due to concerns for her safety when she was out walking in the community. At the facility, she walked around as many times as she wanted each day while the staff kept an eye on her. Unobtrusive information gathered on her walking monitor chart indicated that she constantly walked around the facility and then complained of sore legs and constipation. Participant4, with her daughter, Participant-EPA4, gave written consent for the interview (Participant4's form was signed by her daughter, EPA4, as legally required as she made decisions regarding

her mother's health and welfare and acted on her mother's personal welfare). I noted in my field notebook at the beginning that Participant4 had walked many times up and down the hallway, probably to her room and back to the dining room, the lounge, and to the hallway inside the facility many times. I could not follow her around to confirm if she had gone around the whole loop design of the facility building, as this would have attracted her attention and probably caused her distress seeing a new face following her. Still, where I sat at the nurse's station, I could see her walking in some areas many times due to the transparent windows. She acknowledged the staff and smiled as she walked. She acknowledged me as I sat initially at the Nurses' station, and thought I was one of her nurses. I pointed her to one of the permanent staff for what she wanted done. I later had the opportunity to interview her and her daughter the same day for their interviews. She was a speaker of English as a second language, so her daughter acted as the translator and interpreted to both of us, but Participant4 sometimes spoke some words in English that she was confident of. When I asked Participant4 how walking made her feel, she replied:

> *… Really good, well…*

Then she explained why she didn't like sitting down:

> *Exercise you know, [I] don't like… Sit[ting] down and everything, you know. Get my body …be alright*
>
> (RDW4)

Participant4 said she enjoyed walking because it was good exercise for her. Her daughter, Participant-EPA4, told me that her mother had once been told by her GP that she had to increase her exercise for her to be healthy due to another health challenge that she presented, but since then, Participant 4 has taken to walking religiously every day.

6.6 Summary

This chapter has presented the second finding of the study with the main theme 'Supporting walking'. The chapter provided answers to the second aim of the study, which investigated the various interventions provided by the staff for the residents with dementia who walked. It further provided answers to two other aims of the study: exploring the concept of person-centred care from the three major interventions provided to the residents to support their walking and contributing to the destigmatisation of the residents with dementia and their walking through using language that respects their personhood and autonomy

(Kitwood, 1997; Brooker, 2004,2007) and regard them as equal and social citizens (Brannelly, 2011; Bartlett, 2022).

Being proactive, Reinforcing positive behaviour, and Non-pharmacological interventions were the various approaches residential care staff used in supporting the residents to walk. Their proactiveness included gathering background information – including social and medical history from professional sources as well as from the family to develop individualised care for each resident. They acknowledged each person is different, so the resident's needs could be met. Families were also invited to input into the care plan and to spend time with residents as familiarity play a crucial role in supporting residents emotionally and psychologically. In addition, having a familiar face the residents could relate to especially after admission would prevent confusion and distress for the resident in an unfamiliar environment. Part of being proactive was carrying out assessments such as a pain assessment, to eliminate any underlying factor that could trigger walking in the residents. Staff explained to residents in simple language what needed to be done, walked with residents and helped them walk independently, promoting their autonomy. Resident's safety was maintained as they made sure residents had hip protectors and used mobility aids when walking and collaboration and consultations were done with specialists and authorities as necessary. Another way staff supported walking was to use a salutogenic approach, reinforcing the positive behaviours observed in the residents as strength and built their capabilities. Staff had a high level of safe practice as they all demonstrated an awareness, knowledge, and understanding of the best practice guidelines on the use of antipsychotic medications as last resort after all other tests had been done to eliminate underlying factors. They advocated for the use of non-pharmacological interventions and some examples they gave were reminiscence, social engagements, bus trips, exercises, arts and craft, music, and use of first language of residents. The next chapter presents the third and last finding for this study, Environment and walking.

Chapter 7 Environment and walking

> "*The environment in which a person with dementia lives can be a positive therapeutic intervention on its own …" (Ministry of Health, 2016)*

7.1 Introduction

In this chapter, the study's final finding is presented with the main theme 'Environment and walking'. The chapter, though, intending to address the fourth aim of the study, namely, to examine the impact of built environment on the walking of the residents, acts as an umbrella and widely addresses all the other four aims of the study: to explore the perspectives of all participants on walking; to investigate the relational and supportive interventions provided to the residents by the residential care staff; to explore the concept of person-centred care on the approaches provided to the residents by the staff and to contribute to the shift towards destigmatisation of the residents by advocating for a shift towards using language that restores their dignity. This main theme is further divided into five sub-themes, namely, Desire to live at home, Providing a home-like environment and comfort, EPAs learning about dementia, Need for more space to walk, and Need for a specific policy to support walking of residents with dementia. As a result, the data was focused on where the person with dementia wants to be, and how the built environment supports walking, and their needs. It focused on the data which gave some insights into the experiences of the residents with dementia. Kitwood (1997) acknowledged that, even though it is impossible to gain full access to the experiential frame of others due to the uniqueness of each person, through much research into personalities by pioneers, it is possible to gain insights into the subjective world of persons living with dementia through several ways (Kitwood,1997) of the persons living with dementia. This chapter seeks to present some of those insights, to bring to light those voices with inclusivity and social regard (Brannelly, 2011).

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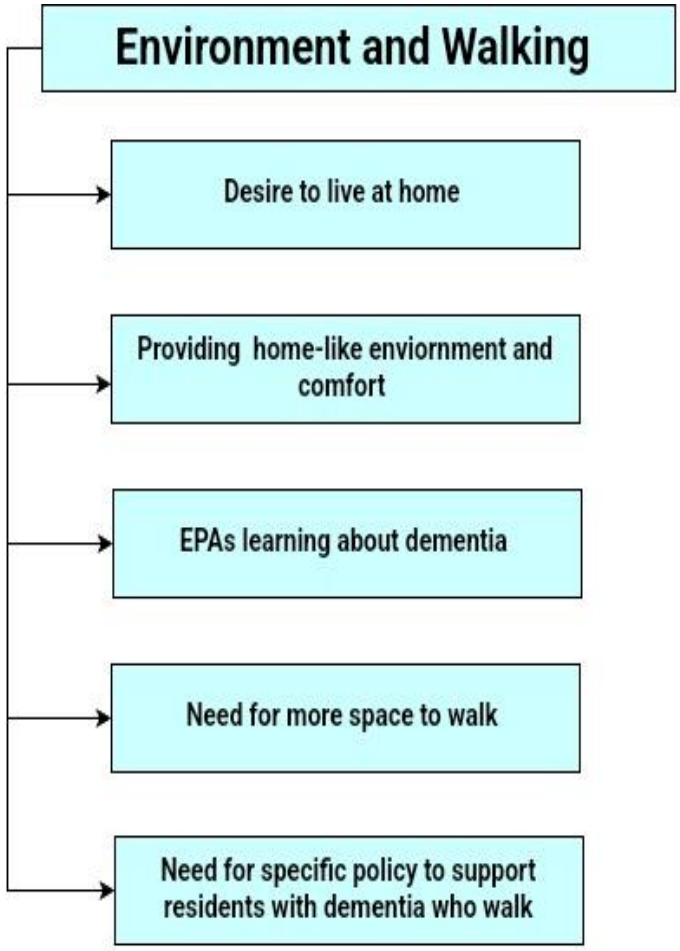
Figure 11 presents a graphical representation of Theme Three and its sub-themes.

Figure 11. Theme Three: Environment and walking



Note: Theme Three: Environment and walking with its five sub-themes, showing reflecting the subjective world of residents living with dementia and their needs in the environment

What comes next is the critical analysis and criticality of the sub-themes of Environment and walking, and the participant responses represented in Table 11.

7.2 Desire to Live at Home

Various quotes indicate that residents with dementia who walked preferred to live in their own homes and be cared for there. First, Participant-EPA3 (Wife) quoted below, when asked by the researcher why she did not want to tell her husband (Participant3), who lives in the secured unit, how long he had been living there. She responded by stating that telling the husband the truth that he had been living at the facility for three or four years, would “kill” him. This was presented in previous chapters. She then went on to say below:

> *… he’s always wanted to come home. ‘When am I coming home?’ He’ll say, ‘Why can’t I come home?’ So, he’ll have to be here to be looked after, you know, so I can’t tell him, you know…*
>
> (Participant- EPA3 (Wife)

Participant-EPA3 (Wife) recalled having taken her husband home many times, most recently when their daughter from overseas visited, but on each occasion he refused to return to the facility and would ask the questions above. These questions symbolise a deep-rooted yearning for familiarity with a known environment, which obviously was his home for comfort, attachment, and security. As presented in earlier chapters, comfort and attachment are two of the five psychological needs of persons living with dementia suggested by Kitwood (1997). The remaining three are inclusion, occupation, and identity, all of which centre on love. Kitwood (1997) postulated that the need for comfort and attachment for persons living with dementia increases due to the sense of loss they are dealing with. With attachment comes the sense of security and the need for bonding as we are all "highly social species" (p. 82) and these become our "safety net" (p. 82). These needs become more obvious in the persons with dementia, and as a result, it could be argued that Participant3 wanted closeness and intimacy with his family (Cook et al., 2022) and the feeling of security that home brought.

Furthermore, Participant- EPA3 (Wife) referred to an emotive incident regarding her husband (Participant3) wanting to continue to live at home:

> *… Because the last time we took him out to my house when my daughter from [overseas] was over, we took him to see we've been painting the house. And when we brought him back in the door, he called us "bastards" … You know, because he was coming back in here when he'd been home … No, he didn't want to come back in here. And I felt awful*
>
> Participant-EPA 3 (Wife)

Participant3 indicated a high level of frustration, distress, and feeling of disempowerment due to not being allowed to stay in his own home. The 'awful' feeling expressed by the wife suggests a feeling of guilt and pain in spouses or unpaid carers who, due to their age, lack of capacity, limited knowledge of dementia care or other key factors, had to make the difficult decision of letting their loved ones go into care. This quote also highlights the misunderstanding and disunity that may occur in a once-united family and relationships during this stage in the resident's life.

In terms of this sub-theme of desiring to live in their own home, Participant-*EPA 5* (Son) also referred to his mother's desire to go back to her home to live:

> *… I mean her dementia, I'm sure, again, I repeat, changed the dynamic and she thinks she's more capable of being mobile and -she certainly thinks she can go home and live …*
>
> (Participant-*EPA 5)*

Participant- EPA5 (Son) stated that his mother, Participant5, had lived independently in her home for several years after their father passed away, and when it became obvious she could no longer cope independently and safely after the diagnosis, she came into care at the rest home. She was still active and walked independently at the facility until recently when she was hospitalised, but still wanted to go back to her own home to live independently. This suggests another insight into the psychological challenges, frustration, and feelings of loss of autonomy and independence experienced by persons with dementia. As Brooker (2004) posited regarding person-centred care, an individual's subjective experience is a reality which should be seen as a beginning step in explaining their behaviours for a therapeutic outcome. Another participant, Participant-EPA7 (Daughter), referred to her father's desire to go home with them in the two excerpts below:

> *… several times yesterday, when I came to visit. He was very, very confused yesterday, and he was having a real problem understanding that this was his home to live in and he was wanting me to take him home to our house. And he was going to get out of the chair about half a dozen times. When I first came here and each time I said 'No, we are just staying today''. He was very agitated …*

She also referred to another incident below:

> *I think he only walked to the entrance from his room which isn't a long distance and then one of the staff members saw him and brought him back but he again was having a determination to leave the facility and he wasn't happy about returning to his room*
>
> (Participant-EPA7(Daughter))

The daughter's references to many attempts by the father to leave the facility suggest further insights into the resident's desire for autonomy and independence. It suggests a frustrating experience of confinement and disempowerment by the father and his reaction towards an environment that limits his walking. In addition, the quote highlights the ongoing delicate balance the staff have to make in respecting the independence and autonomy of the residents to walk with their safety in walking.

The quotes presented above collectively highlight the deep desires and needs of the residents with dementia to keep living their homes for life and to be cared for there. Their frustration, loss of autonomy and independence and the feeling of powerlessness on the part of the residents are highlighted. It reveals the EPAs' and the families' guilt and pain. The quote further highlights the continuing balancing act of residential care staff in respecting the autonomy and independence of residents and their safety. In addition, the quotes highlight expert's recommendations that these psychological

needs should be prioritised and be met to achieve person-centred care where personhood is maintained (Kitwood, 1997).

Table 11. Theme Three: Participants' Responses on Environment and Walking

Participant	Desire to live at home	Providing home-like environment and comfort	EPAs learning about dementia	Need for more space to walk	Need for specific guidelines and policies supporting residents with dementia who walk
Participant1					
Participant2					
Participant3	✓				
Participant4					
Participant5	✓				
Participant6					
Participant7					
Participant- EPA1					
Participant- EPA2					✓
Participant- EPA3	✓		✓	✓	
Participant- EPA4					✓
Participant- EPA5	✓				
Participant- EPA6				✓	
Participant- EPA7	✓		✓		✓
Participant- RN1		✓		✓	
Participant- RN2					✓
Participant- RN3		✓	✓	✓	✓
Participant- RN4		✓			✓
Participant- HCA1				✓	
Participant- HCA2					
Participant- HCA3					
Participant- HCA4				✓	
Participant- HCA5					✓
Participant- HCA6					
Participant- HCA7					
Participant- HCA8				✓	

Note: Table 11 shows some participants' responses in Theme Three Findings-Environment and walking

7.3 Providing a Home-Like Environment and Comfort

Providing comfort and a safe and familiar environment to make residents feel at home and not walk into potential danger was a sub-theme reflecting proactive measures being used by staff. Participant-RN3 gave an example of how individualised care was provided to meet residents' needs, providing Participant 7 as an example:

> *…[we] provide home-like environment…* [Participant 7], *she is so used to doing her walk. While she was at home, she normally goes out on the community and just have a quick walk around the locality. And it's something that she wanted to do. So, you know, part of the goal of safety is having to provide a sense of home. And that would mean replicate a home-like environment of which they will be able to feel comfortable with. And with her, this is a very good example of which we're trying to individualise her care. We're allowing her to do her walkabout. But we were very specific with her as to where she is allowed to go her walkabout. There was a point in time [when] she actually went outside that … area, on the outside and she managed to come back in here, but it took her time because she didn't really know the street…*
>
> (Participant-RN3)

Participant7 was supported with orientation at the facility so that she could continue her routine of walking within safe boundaries, which provided a sense of familiarity and comfort for her. Staff unravel the potential risks involved in getting lost and the need to mitigate this by balancing this risk with the resident's freedom and independence to walk. Participant-RN4, in the quote below, mentioned their proactive approach taken by ensuring residents had various views through the glass windows built into the architectural design of the facility building:

> *…And making sure that someone's at least got some varying views. That's why you see a lot… of windows, there's a lot of things that you can see, a lot of things at the same time. We look at the lounge, and look in one direction, you'll see a large part of the rooms, part of that room, part of the courtyard. And it's just having a lot of visual clarity about what's coming on. That kind of behaviour going to happen and making sure that you support the residents as much as you can, in what they're doing. And they're doing it as safe as possible … they do have an accident,*
>
> (Participant-RN4)

Third, communicating with the residents was seen as a proactive measure of providing a home-like atmosphere, being respectful of choices made by residents, and giving a sense of relationship in which listening and persuasive explanation play key roles, just as they would in any family. A quote from Participant-RN1 highlights this approach:

> Researcher*: When I arrived this morning, you introduced me to some of the residents living with dementia who like to walk and, later, as they were having breakfast, one of them didn't want to have breakfast*

> *and stood up, sat down, stood up again … walked out … to the end of the hallway …He came back again and walked out … So, how do you manage their walking in such situation?*
>
> Participant-RN1: *… we normally manage those things by explaining to them what the things are to be done. But then again, if they refuse, then we'll just give them some space and then give them time to settle. And then we normally [would] come back later, and usually their demeanour [would have] changed. Most of them, most of the time … will have good demeanour when you come back to them, and that's the time that we will take them to the dining area for the meals…*
>
> (Participant-RN1)

The quote above shows how Participant-RN1 respected the resident's choice by giving him space. It also highlights that Participant-RN1 regarded the participant as socially alive and socially regarded as a person to be treated with respect and dignity (Brannelly, 2011; Brooker, 2003; Cook et al., 2022; Kitwood,1997). During the first stage of data collection, I made observations documented in my field journal that the resident care staff (RCS) frequently engaged with the residents about if they wished to take a walk in a specific direction within the facility.

Literature has shown that several factors, including new environments, can disrupt persons with dementia (Dyer et al., 2018; Meyer & O'Keefe, 2020; Vafeas & Slatyer, 2021), and it may create or increase distress and agitation in them when trying to find a familiar face, a familiar place, or an environment to connect with. Many persons with dementia prefer to live in their own homes, but studies have also shown that dementia is also the reason for going into care (Kuske, et al., 2007; Vasse et al., 2006), which suggests this may be possibly due to the dearth of information on dementia care to families, EPAs, and the public. The above quote also alluded to the involvement of the Police Department, which worked with local volunteer groups, such as Wandersearch (Wandersearch et al., 2024) and the Mental Health Service, in managing the situation. The staff, though well-intentioned, involved the family members in a reactive rather than preventive measure, possibly also due to their powerlessness in changing the process of placements of residents. A key in this quote is the need for a review to have a suitable assessment or a process of placing residents with dementia who walk in an environment that will meet their walking needs.

Participant RN4 remarked:

> *… And the difficulty then is that when they wander, and sometimes you don't know where they're going to wander, we're not a locked facility. We are not allowed to lock our doors except for safety purposes where we can lock in between six o'clock in the evening until the following day. When the staff are coming out at six o'clock … we are a locked facility. In the rest home, it's even worse because we*

> *have sliding doors. So, any resident that has dementia that does not have the capacity to know that it's not safe to go outside, can just walk outside and we've had a number of incidences where residents have gone outside. Some have gone a lot further than just the carpark, out to the parks around the places down the road, all those different places. And that's the biggest difficulty when I was on the floor...*
>
> (Participant-RN4)

Here, Participant-RN4 in Facility Two gave similar examples that occurred in their facility where some residents with dementia who walked had been placed in the rest home section that was not specifically designed to meet their walking needs. This poses an ethical dilemma for the facility. Similar challenges were faced by the staff when the residents got lost after going on their walks as their facility was an independent one with a no door-locked policy until evenings for security. The inherent risks presented in such a situation highlight that safety is paramount for person-centred care to be achieved. The residents with dementia are not able to identify the risks by themselves but depend on others who look after them to be kept safe. Other causes, such as delirium and the intrinsic pathology of the dementia syndrome (Vafeas & Slatyer, 2021), can contribute to the confusion for residents and trigger the behaviour of walking. The implication for all staff is the importance of continuing to regularly use careful observations and clinical assessment tools to identify underlying factors triggering walking in the resident so that necessary medical attention can be sought in time.

It is worth following the account of Participant-RN3 below to see how she ultimately prioritised the safety of the resident respecting the resident's dignity and right to freedom to walk and not restraining them from walking:

> *And again, the team had to re-adjust their schedules, their routines in order to accommodate the [nature of dementia in the resident] … being safe. Now, I think two or three weeks ago, unfortunately, he made another attempt … because he knows the exits … he actually went out and he was found on the pavement [near a community club] … The staff were just panicking because they could not find him and the people from the [community] club were actually attending to him [as he had sustained some injuries], and good that he took his walker with him as he has a label. Again, that's one of the things we've been doing- we put some on bracelet, or some indicator in case they wander out of the facility, and if something happens, people can actually identify who they are and can ring us*
>
> (Participant-RN3)

7.4 EPAs Learning about Dementia

Furthermore, Participant- EPA1 (family friend) shared a view of her limited knowledge about dementia or how to care for a person diagnosed as she recounted what happened to Participant1, a family friend in this excerpt:

> *… And it was at that stage, yeah, so when he was released from [public hospital]. It was to an unsecure unit. He just wandered off looking for the uh, what do they call a liquor shop in England off licence? Looking for the off licence ...*
>
> **(**Participant-EPA1(family friend))

Participant-EPA1(family friend) shared the background of Participant1 when asked during the interview what the impact of looking after someone with dementia who walked had on her. She recounted that she and her husband were family friends with Participant1 and his late wife, but the loss of his wife had a significant change in his life. With no family available to look after him, Participant-EPA1 and her husband adopted him and took responsibility for caring for him with limited knowledge and skills on dementia or caring for a person living with dementia. Participant1 lived with them and had the freedom to go walking anywhere he wanted which they accepted as normal and what he wanted. Whenever they went shopping, Participant1 would buy more alcohol than groceries. If they were all eating at a table, he would just get up whenever he was no longer interested in conversations apart from his wife and son. He was admitted to the public hospital after which the above quote occurred. Participant-EPA1 expressed satisfaction of the care Participant1 received in his current dementia secured unit. She admitted it was better than what she would have provided him due to not knowing much about dementia.

Another significant sub-theme identified from the data was the limitations of sole carers - EPAs and families. Participant-EPA3 (Wife), 80 years old, visited her husband almost every day. She made the following statement about her husband and their relationship:

> *But I would love to take him home for a week, he'd love it, to be home, but it would be getting him back in here, and people say you can't look after them on your own, so what do you do? I'd have him tomorrow if I could, If I think I could cope …*
>
> (Participant- EPA 3(Wife))

The quote above reveals the longing of Participant- EPA3(Wife) to provide familiarity and comfort to her husband. She wanted to fulfil the wish of her husband to live at home but she was faced with the reality of her limited capacity to fulfil this wish - with no member of her family around in the city to help her if needed. This highlights the weight of responsibility carried by sole carers in families and friends, and the need for

collective family responsibility (Johnston et al., 2024). The quote also shows how difficult decisions and choices are sometimes made by families to let their loved ones be admitted for professional care in ARC facilities.

Through the voice of Participant-EPA3(Wife), below, some of the limitations of sole carers and needs of EPAs, sole/main carers and families are revealed:

> *…You see, I could, you're allowed to take them home, you're allowed to take them out for [breaks], you can do what you want. I could take him home for a weekend or the week for a change, but I can't, I won't be able to get him back, and that's the part that worries me ...*
>
> (Participant- EPA 3(Wife))

Furthermore, she commented:

> *… many a day, I have guilt, I lie in bed in guilt because I can't have him home… but you can have him home. But people say, well, you can't have him home to look after because he can go wandering from inside…*
>
> (Participant- EPA 3(Wife))

Participant-EPA3(Wife) acknowledged above that families could take their loved ones home temporarily. However, she also revealed her lack of training and skills in supporting her husband and the difficulty involved in convincing him to return to the facility. These issues, sometimes, caused stress leading to feelings of inadequacy, guilt, grief, and distress in the EPAs and spouses/partners (Gilhooly, 2016; Jackson & Browne, 2018), compounding their decisions to put their loved ones into care facilities as highlighted with the Participant-EPA3(Wife) excerpts. The quotes collectively highlight the internal struggle of guilt, sense of duty, inadequacies, societal expectations, labels, and stigma that make supporting persons with dementia more challenging. Persons with dementia need emotional and psychological support during these crucial times, and not only they, their EPAs- family and friends also, as they play vital roles in the care ecosystem of the residents with dementia who walk, which contributes to the quality of life and wellbeing of the residents. In addition, more family members need to join in supporting their family members living with dementia, whether at home or in professional care at the ARC facilities, so that the responsibilities of caregiving are evenly distributed to avoid the burnout of the sole or main carers (Johnston et al., 2024). The last quote from Participant-EPA3(Wife) above further highlights the need for information, education, access to resources and support services and empowerment that will lighten the weight of EPAs and families on the care they provide to their loved ones living with dementia.

EPAs learning about dementia are also reflected in the quote below by Participant-EPA5(son). He mentioned how he earlier noticed some changes in his mother (Participant 4) when she was living independently but did not link it to dementia:

> *she kind of quickly developed the dementia you can see now, which is a little bit different from before, which was a little bit of forgetfulness, but it didn't occur to me that it's linked to dementia*
>
> (Participant- EPA5(son))

Here, Participant-EPA5 reminisced how active and mobile his mother was while working and due to her high functionality, he did not connect the forgetfulness she sometimes showed to dementia until formally diagnosed. He thought it was a condition that suddenly developed, not realising that the dementia had gradually built up over the months or years. At a point, he stated he had even told his mother she could 'shake' it off if she wanted to, knowing her strong determination in the past:

> *… how can I say this without sounding cold-hearted, but - it's almost like you've got the power, Mum, to do it if you are dedicated enough or motivated enough to do it, but it's not just something that resonates, that rings a bell with her.*
>
> (Participant-EPA5(son))

Participant-EPA5(son) also added what he noticed during this time while encouraging his mother to be her usual self again:

> *… after being about a couple of years here, I could be short with her about my impression that she is not trying hard enough to read a book or watch TV. She says she reads but she doesn't read anything. She's quite, … but I don't know, she has strange ideas about things … I've come to terms with her declining dementia*
>
> (Participant- EPA5 (son))

Also learning about dementia and walking, Participant-EPA4(Daughter), referred to the anxiety involved when her mother went walking:

> *"…not so much a burden, it was just that it impacted on, I guess, feeling like all was well with the whirlwind, you know! that anything can happen because we're only because Mum was having falls and we never knew which day it might happen that she was feeling dizzy… "*
>
> (Participant-EPA4(Daughter)

The daughter of Participant4 above minimised the notion of providing support to her mother as a burden. She, however, referred to the heightened anxiety and constant vigilance involved when her mother went out walking as she had an underlying condition which made her susceptible to falls. This quote raises the social constructionist question of how else Participant-EPA4 and her mother can be

supported with the mother's walking. Participant-EPA4(daughter) and her mother (Participant4) can be seen as representatives of other families in similar situations.

Another participant shared her view below:

> *… Originally, when they first moved here, they were quite capable of coming out and having a meal with us in our own home. And then dad had several falls, which have made it now impossible for us to get him into the car and bring them back to our place. So, I only visit him here now…*
>
> (Participant-EPA7(Daughter))

From the quote above by Participant-EPA7, the progressive nature of dementia syndrome is revealed. Participant-EPA7 described how her father's condition deteriorated and the bonding activities such as having meals and regular visits could no longer be sustained. Her account highlights the erosion of bonds and challenges faced by families as dementia not only affects the individual diagnosed but impacts the whole family. It also highlights the need for families to be adequately equipped with training and resources to support their family members affected through the evolving stages of dementia. Such resources could include education, easy access to mobility aids, community support services, and transportation options (Donnelly et al., 2015; Gilhooly et al., 2016; Glueckauf et al., 2005; Jackson & Browne, 2018; Zimmerman et al., 2018).

7.5 Need for More Space to Walk

Identified in the data is the need for more space for the residents with dementia to walk. Participant-RN1 was asked about his view on the built environment supporting the residents' walking. His response is given below:

> *… It's helping them to walk because we have a space that is provided for walking, like, for example, the garden. I understand, that is already a requirement from the Ministry of Health for dementia unit, or a dimension to have that extra space solid. So, … I do believe that because we have met the requirements, then that is suitable for them to walk, really.*
>
> (Participant-RN1)

When answering the same question, Participant-RN3 recounted a difficult but safe decision she made when they realised one of their "family members" at the facility needed more space to walk. The staff members felt fear and anxiety as a result of missing a resident under their care as he had walked out of the facility. They carried out the protocol, informing their leaders, families, and authorities according to their facilities' policy when a resident was missing. As they considered the residents as a

family at the facility, this carried huge psychological, moral, professional, and legal consequences for them. Participant-RN3 stated that the resident's son expressed his desire for his father to return to the facility after hospital discharge following his recovery from the injuries he had sustained when falling while walking outside of the facility. The public hospital also rang to find out if the facility wanted the resident transferred back after discharge but Participant-RN3 stated that though the resident was a family to them, she explained to the son the risks involved if the father returned to their facility which was not suitable for his walking needs, and they declined the resident's re-admission to the facility. The rationale given was the safety risk involved as the resident might come into harm if he returned to a facility that was not appropriate for his walking care needs. Participant-RN3 made the statement below:

> *… we've got a duty of care to actually make sure resident's safety comes first …*
>
> (Participant-RN3)

Participant-HCA1, working in a secured unit, mentioned how the environment enabled the residents to walk:

> *we have a garden there… Yeah, safe. They can walk around here. Sometimes if it's raining, they are brought here, allowed to walk. We can open that door to the second lounge or the first lounge.*
>
> (Participant-HCA1)

Participant-RN1 earlier referred to their facility meeting the specific requirements outlined by the Ministry of Health for providing dementia care and mentioned the garden and the walking space, which were to do two things; they provide access and exposure to nature, known to be health-giving, and they provide a space for exercise and recreation. Participant-HCA1, also mentioned the suitability of the unit's built environment as it provided the freedom and safety the residents needed for walking. However, Participant- EPA3(Wife), whose husband lived in this facility, saw this differently:

> *In these places… I don't, I wouldn't say this is the best of homes for dementia, I haven't seen many, but I'm sure there'll be some places where they have a proper garden they can go out in, that's safe, you know, all because he's got to be there without, the other side, just to walk, … I think a larger space with a very safety-proof garden that they can't climb out or do anything, that would be lovely where they could all sit out in the garden on benches in the sun, but they don't go out there in the half … [Her husband's room] got a little…they've got a nice little patio, it's off the dining, off the lounge and look at [referring to her husband's] bedroom goes out on the patio, there's some seats out there, but you don't see anyone sitting out there, hardly …*
>
> (Participant-EPA3 (Wife)

Participant-EPA3(Wife) disagreed with the view that the built environment had enough space for walking for her husband to live a normal life (Phinney, 2021). Reflecting on the staff comments and the EPAs' comments, a question emerged on why the space and garden mentioned by the three participants were not being utilised as expected. A possible reason could be pressure on staff time in looking after every resident due to insufficient staff or low staff-resident ratio. During the interview, the staff mentioned that two staff looked after 21 residents, and only about three of them were cared for in bed; all the others walked. Each shift had two HCAs and one RN, except for morning shifts, which had three, including an Activity Coordinator. It is also a known fact that there is global and national shortage of nurses in clinical settings. Thus, the social constructionist's question of how else the walking needs of the residents be met with insufficient staff to achieve a person-centred care goal calls for creative solutions.

Participant-HCA4 had a complete different perspective of what the living environment of the residents with dementia who walk should be, as reflected in the excerpt below:

> *I think that will probably be the worst thing ever because it's [secure dementia unit] like being a locked box. You should be enjoying your freedom… if it was a locked down building, they sent for you to watch over them, it's just, for me it defeats the purpose. We should have open doors, beautiful gardens for them to walk around in.*
>
> (Participant-HCA4)

To Participant-HCA4, the idea of a secure or lockes facility was not acceptable to her as it defeated the purpose of establishing a person-centred care facility which can support residents to live normal lives. Participant-HCA4 preferred for resident to be allowed to exercise their basic human rights to autonomy, freedom, and independence; and to walk wherever they wanted while still being supervised.

This is the care concept applied at the Hogeweyk Dementia Village (Be Advice, n.d.) in The Netherlands where residents had space to walk anywhere independently within the Village (Chapter One), including to the restaurant, the supermarket, to their various clubs, all constructed on the village grounds, and staff and volunteers supervised them, wearing no uniform. Currently, this model of care has been replicated in New Zealand in The CARE Village in Rotorua, with the Māori name Te Manaaki a Tura (Shannon, 2020; Shannon et al, 2021; The CARE Village, 2021). It is the first to model after the Hogeweyk Dementia Village in New Zealand. On a study visit to The CARE Village in Rotorua with my supervisor, it was evident that this village transitioned from a former care institution, Whare Aroha Care, to the current village (Chapter One), where residents live in small households, engage in chores of their own and are looked after by consistent staff who are familiar with their households and their needs (Shannon,

2021; Shannon et al., 2024; The CARE Village, 2021). This model has already been replicated in other parts of the world such as Norway (Strømmehaven), Australia, (New Direction Care Microtown), and Canada (The Village at Crossmount) (Be Advice, 2023; Sturge, 2024). With time, research needs to be conducted on the effectiveness of this model for other service providers to emulate.

Participant-RN2, as shown in the quote below, referred to the space in her dementia unit as wide enough for the residents to walk, and if they wanted to go outside the secured unit, the garden was there to enjoy nature as well:

> *… It [the space] helps them to walk ... because this place is … considered big for them to walk. There is outside garden, so they have space for them to walk around them…*
>
> (Participant-RN2)

While Participant-RN2 was of the opinion that the walking space in the garden within the facility was ideal for the residents to walk in, Participant-EPA6(Wife) was of the opinion that the space was inadequate and added suggestions on how to improve the current built environment to making it walk-friendly for the residents. Only two out of the seven Participant- EPAs were satisfied with the current space for walking in the care environment where their loved ones were. The following quote from Participant-EPA6(Wife) gives evidence to this:

> *… I thought of people walking, and all they have at this stage are the halls. What about a walking circle around, in front of the back of house, or unit or whatever they are called. It would have to be soft, so if they fell, they wouldn't hurt themselves. …so, if one had a frame and the other had a bigger walker thing and they wanted to stop, they would have a little side thing, where they could walk off to, and sit down in the seat wide enough, as I say, everything would have to be safety first… you might know, you would have to have some cases people with nurses or whatever they're called, - carers, that's not the name they use here [in this facility]. If the people lying in bed could see them [those walking through their windows], it might give them inspiration … I don't know, all things are possible once I start thinking about this… but the government would have to [come] up with all the money here…*
>
> (Participant-EPA6(Wife))

Participant-EPA6(Wife) voiced her displeasure with the current situation where the space is confined for her husband to walk within the halls of the facility and suggested walking circles outside the unit or living environment of the facility or at the back of their home, if the person with dementia were living at home, with some seats provided for rest or to relax when needed. She also highlighted one of the Dementia-Enabling Environment principles, namely that of allowing people to see and be seen, to support

movement and engagement, and to provide opportunities to be alone or with others (Charras et al., 2024; Fleming et al., 2020; Fleming et al., 2021; Fleming & Zeisel, 2024).

In the quote below, Participant-RN1 pointed out their facility's compliance with the Ministry of Health's requirements (Ministry of Health, 2016) specified for designing secure dementia facilities providing care for residents with dementia:

> *…with our dementia care here, it's a secured unit, so it's safe … they can have access to outdoors by way of our garden-which is part of the requirement from the Ministry of Health to help [them] in the garden. But then again, all the plants and vegetables are edible. So, it lets us minimise the risk to the person. So, the only thing that [they] cant see is to wander outside the facility.*
>
> (Participant-RN1)

As pointed out, care buildings and philosophies must align with key overarching principles of dignity, human rights, person-centred care, cultural identity, and design principles (Ministry of Health Manatū Hauora, 2016). Though guidelines are recommended and compliance is enforced by HealthCERT, (Ministry of Health, 2020) which issues certificates, reviews audit reports, manages legal issues, administers and enforces the legislations in Health and Disability Act 2001, the implication is what Charras (2024) identified as "proof of care" (Charras, 2024, p. 50) - to involve all users, including the residents with dementia who walk.

7.6 Need for Specific Policy and Guidelines on Supporting Walking

Identified from the data was also the need for specific policy and guidelines for supporting the walking of residents with dementia who walk since studies indicate that 15% to 60% of persons diagnosed with dementia will walk (Gu, 2025; Robertson et al., 2006) as dementia progresses in each person diagnosed and 50% will walk during its severe stage (Lai et al., 2003). All 12 RCS were asked if their facilities had specific guidelines for supporting the walking of the residents with dementia. Only one of them said they did not have guidelines and another was not sure how to answer the question, while the remaining staff referred to guidelines, courses, and other useful resources and training on dementia care that were not specifically designed for persons with dementia who walk. The following are examples of their responses:

> *… there is no specific guideline on residents and how to care for residents who would like to sort of wander within the facility because there's a difference between wandering outside the facility and wandering just within the facility. The moment they start to wander out of the facility, then that's something that we need to actually reflect on. We would*

> *have to do further investigation and if their safety is at risk, then likely they would have to be changed into a dementia level of care …*
>
> (Participant-RN3)

While Participant-RN3 was very clear that there were no specific guidelines to support residents with dementia who walk, she raised an interesting point contributing to the debates discussed in the Chapter Two literature review on the meaning, definition, and description of walking – whether within or outside of the facility.

Participant-RN2 had a different opinion on whether or not their facility had specific guidelines for caring for the residents with dementia who walked, as shown in the following response:

> *…Yes. We have guidelines, you know, for, like, the other activities of daily living. So, there are guidelines that we have to follow on what time they're going to have their breakfast and then also, you know, safety. So, also, we are also trained, always like every year. The management would train us on, like , for this fire and safety team, how to exit the residence during the event of a fire …*
>
> (Participant-RN2)

Participant-HCA4*,* while not sure whether the facility had a specific guideline or not, made this experiential statement below:

> *… Gosh! I've never been asked that question. They all suffer different, to me different types of dementia ... it's really hard to explain but dealing with it is knowing the person. I look into their files to look at their lifestyle, their occupation, what they loved in their life and try and bring that within the facility. So, speaking about things that they loved, photos. We had quite a few people here with dementia [and a resident] that nobody knew how she wore her hair. So, I looked through her drawer and found some photos of how she loved looking, and that's the only reason why our hairdresser then cut her hair in a way that she used to look. And then, her daughter was quite shocked that, 'How did we know? ... So, yeah … I really don't know, I don't know how to express that because they're all different …*
>
> (Participant-HCA4)

With being asked the question for the first time, it appeared there may not be a guideline and Participant-HCA4 had to use her initiatives through years of experience working with the residents to create solutions to support residents' needs, including walking.

Apart from asking the staff, the EPAs were also asked how various stakeholders could enhance the care and support being given to the residents who walked. There were three responses that aligned with the sub-theme of lack of guidelines, policies, and

specialised education are presented next, with quotes and a discussion of their criticalities:

> *Researcher: Is there anything you think the government should be focusing on around their [residents with dementia who walk] care, especially with regards to walking?*
>
> *Participant-EPA 2 (Son): Not particularly, I suppose you know if there were guidelines in terms of facilities. You know, some facilities might have more things for walking in, but yeah, no*
>
> Researcher and Participant-EPA2(Son)

Participant-EPA2(Son), above, identified that there were no particular guidelines around walking of the residents and therefore suggested reluctantly "…more things for walking in …"(Participant-EPA2(Son), 22 July 2021). This highlights that families and EPAs notice when things are not working properly and can identify them when asked. His reluctance or hesitancy in making suggestions and ending it negatively also conveys a lot of meanings, including familiy's feelings of powerlessness, acceptance of the current situation, resignation to fate, and despair regarding the lack of resources that would enable the residents to walk.

Another quote suggesting a formal incorporation of walking into the care provided to residents with dementia who walk was a quote from Participant-EPA4(Daughter) presented below:

> *… I guess for those who, yeah, for those who do like to walk, maybe managed walking. That would rely on volunteers' help, but if there was some, the way mum went to a day program like that, perhaps some sort of program where they have assisted walking or supervised walking, but that might be a little bit difficult to implement because of where everybody lives but I guess it would. [It] could even be under the same sort of person who helps to come shower. Perhaps they could do some assisted walking with that person, and that could be part of their role and [they] get paid for that. As long as somebody recognised and assessed them as having, the need for that care …*
>
> (Participant-EPA4(Daughter))

In the above quote, Participant-EPA4(Daughter), suggested three things: first, volunteering, as used in the Dementia Village in the Hogeweyk, The Netherlands. There were about 120 volunteers at the time of visit in July 2021 who were trained to support the residents with dementia living in the village with a coordinator in charge of this. Second, in the quote, Participant-EPA4 suggested the formal incorporation of walking assistance into the job description of paid carers who work with persons with dementia who live at home and like to walk. When the mother, Participant 4 lived at home, apart from being assisted with her activities of daily living, no assistance was

incorporated to accompanying her mother walk as she enjoyed the activity. As a result, the mother had some falls on public roads when walking. In addition, a role can be created for providing walking assistance for persons living with dementia both living at home and in care. Another role that could be created is that of a Dementia Social Coach, as incorporated at The Hogeweyk to support the staff with various tricks or activities, as referred to at the Village when staff run out of options. This is another way to support residents who walk through equipping the staff. I remember when I asked if the residents at the Village in the Hogeweyk walk at night, one of the founders of the Village responded that the residents did not, as they had walked freely during the day This conveyed good care and supporting especially on residents' walking needs.

Another family member, Participant-EPA7, made a key suggestion regarding equipping staff 0n the quote below:

> *…I just think staff that are working within these facilities are encouraged to up their education levels to the extent that they can truly understand who they're working with so that they can really be helpful to the elderly. And I think… as I said before, staffing numbers have to be good so that the staff can work comfortably and not feel pressured because that pressure tips over to the patient. And the patient can feel you know, they're being rushed … And I don't think that's good for the elderly*
>
> (Participant-EPA7(Daughter))

Two key points are raised in the quote above by Participant-EPA7(Daughter): specialised education and sufficient staffing-resident ratio. She emphasized the importance of these two elements to achieving person-centered care (See Chapter One, section 1.9.1) for residents with dementia who walk.

The next section below presents a summary of the suggestions given by the participants RNs, HCAs, and EPAs on how to enhance the relational and supportive approaches being provided to residents living with dementia who walk:

7.7 Participants' Suggestions for Improvement

All participants were asked to give suggestions to all stakeholders: care providers, the staff, the government and policymakers, researchers and the public on how to improve the current support being provided to residents with dementia who walk. Below is a summary of their suggestions:

7.7.1 Suggestions for Researchers

The topmost suggestion was for researchers to continue their research for breakthrough treatments for a cure for dementia. An EPA would also like research

carried out on the medical benefits of walking for residents with dementia since many of them like to walk - whether walking improves their quality of life and mental health or not. In addition, another EPA requested research be done on whether reading books could keep the minds of residents with dementia who walk active and delay the progression of dementia. The request was from an EPA (daughter) as she was getting her mother to read regularly, books written in her first language.

7.7.2 Suggestions for Care Providers and Staff

Appreciation was expressed by some EPAs for the care being provided to the residents at the facilities by the staff. However, the majority suggested specialised education and training on supporting residents with dementia, especially those who walked. Some staff would like families to be more involved in the care and support of their loved ones residing at the facilities and a staff added that families should provide appropriate footwear for the residents. Some EPAs strongly suggested increases in staff salaries and pay parity with their counterparts working in public hospitals. They also advocated for an increase of staffing, including physiotherapists so that staff workload could be reduced to adequately support the residents who wanted to walk, as needed. In addition, it was suggested that facilities should encourage volunteer work so they could have more support for residents who like to walk as some people in the communities would be happy to step into this role. Also suggested was a request for more outings for the residents to remove boredom. While acknowledging the challenges involved, an EPA suggested facilitation of secure walking tracks or a fenced area where residents could be allowed to have dogs as walking companions. More engaging activities with residents and staff to spend more time relating with residents were other suggestions made.

7.7.3 Suggestions for the Government and Policy Makers

Appreciation was given to the government for the support being provided to residents with dementia who walk. To enhance the care of the residents, it was suggested that the government fund more facilities to care for the residents with dementia who walk and establish villages for residents with dementia who walk, like the Dementia Village in The Netherlands. It was suggested that the government changes the interRAI assessment systems of classifying residents with dementia who walk as requiring dementia level of care as these assessments have no personal touch and do not meet the uniqueness of the person with dementia - a better system of “home for life” was suggested to be created which does not move residents to other facilities during the progressive stages of the syndrome. It was also suggested that staff salaries should be increased as this would serve as incentives for other nurses to work in aged care

facilities. Lastly, specific guidelines for supporting residents with dementia who walk were suggested to be created, as separate from guidelines on general dementia care.

7.7.4 Suggestions for the Public

The participants suggested a campaign of more awareness on dementia and how to care for people living with dementia who like to walk. More education was suggested on the inclusivity of the residents with dementia in their communities. More residents wanted to live in their own homes and be cared for and supported with appropriate resources. In addition, it was suggested to use volunteers from the community to help at the residential care facilities, but training would need to be provided to support them as they support the residents with dementia who like to walk and are complementing the staff support as well.

7.8 Summary

In summary, this chapter not only addresses the fourth research aim of the study, which examined the impact of the built environment on the walking of residents with dementia, but also addressed all four other aims of the research as outlined in the introduction to this chapter. It highlighted a central theme of ‘carrying on normal life’ which permeated through. It provided insights into the subjective world of the residents on their walking. It presented answers that gave further perspectives of the participants on the built environment in which the residents lived and its impact on the residents' well-being and quality of life. The chapter reveals frustration, a sense of confinement and disempowerment and the deep-rooted longing of some residents to live at home and be supported there as the environment provided them with familiarity, security, attachment and comfort. Attachment and comfort were identified as part of the psychological needs of persons with dementia, which made them feel secure and loved (Kitwood, 1997). Studies indicate that unfamiliar environments confuse the residents and may lead them to experience distress. Furthermore, the data presented in this chapter revealed a sense of guilt carried by EPAs and family carers for putting their loved ones into care and not being able to provide the needed support as a result of their limitations in knowledge, skills, training and resources on dementia syndrome. This chapter highlights the misunderstandings and disunity that occur in families with their family member living with dementia and walking, due to frustrations and powerlessness on both sides. In addition, the chapter presented how staff showed caring, empathy and

relational care, supported the walking of the residents and provided comfort and a homelike environment to make residents feel at home and be part of the family at the facilities. However, though well-intentioned, their preventive measures were reactive when a resident who went walking was missing. This may possibly be due to their powerlessness in changing the process of admitting residents who walk when the facilities cannot meet their walking needs. The chapter presented the need for more walking space for the residents so their independence could be balanced with residents' safety. In addition, there appears to be a need for a specific policy to support the walking of the residents with dementia, which could provide guidance and support for the staff who aim to achieve person-centred care goals for each resident. The implementation of a volunteering system, an example cited in the chapter, could supplement the support the staff are providing to the residents, as evident in the care being provided at the Hogeweyk in the Netherlands. The chapter also highlighted the various suggestions made by all participants to all stakeholders on enhancing the support being provided to the residents with dementia who walk.

Chapter 8 Discussion, Recommendations and Conclusion

8.1 Introduction

This study set out to answer the research question**:** *How do residential care staff provide relational and supportive interventions for residents living with dementia who walk?* Its five aims were as follows:

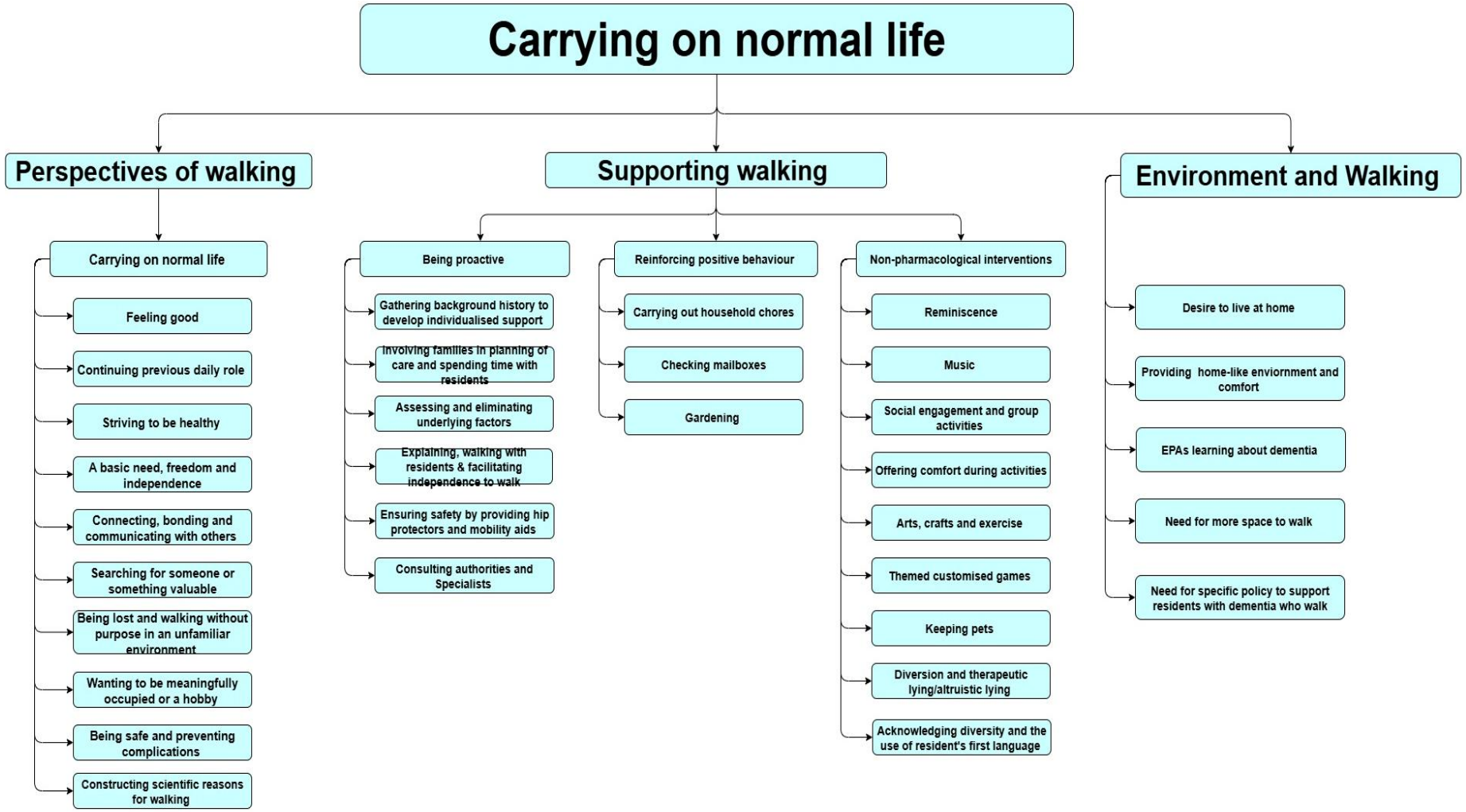
- to explore the perspectives on walking of residents with dementia from all participants.
- to investigate the interventions being provided for the residents by residential care staff in two facilities in a city in New Zealand.
- to explore the concept of person-centred care from the approaches provided by the residential care staff towards enhancing best practice.
- to examine the impact of the built environment on the walking of residents.
- to contribute to the destigmatisation of residents with dementia who walk by, advocating a shift to using language that dignifies the resident for optimal support

In this chapter, I provide a summary of the key findings under the five aims of the study and how they answer the research question. The chapter also incorporates the concepts applied to this study under each aim and summary and discusses my interpretations of these findings to show the interrelatedness of the findings and to link them to existing literature. In addition, I highlight what the study contributes to knowledge as original research, its strengths and limitations and my reflections. I also provide the implications of the study for practice, the built environment, education, research and policy. Furthermore, I put forward recommendations from the suggestions given by the participants: the residents, their EPAs and the residential care staff, that their voices may continue to be heard throughout the study for an anticipated change in the support to residents with dementia who walk. I conclude the study with a statement to all stakeholders with a call for a collective responsibility in supporting residents with dementia who walk with salutogenic or abilities or strengths-based person-centred care for the residents. The thesis ends with a poem to all of us to support the residents to live normal lives. It provokes us to that ethical obligation to provide quality of life that supports the residents' well-being, as they have previously contributed immensely to society. Now they trust the systems they once served and are part of to support them in carrying on their normal lives.

This study challenges norms associated with walking (frequently referred to as wandering) as a problem symptom of dementia and provides evidence about the walking of residents with dementia, the interventions provided to support their walking, the environment of their care facilities, and the goal of person-centred care set by many facilities to achieve in caring for their residents. Social construction highlights the need to be open to multiple realities of socially constructed knowledge which can be subjective, inter-subjective, socio-cultural, and historical. By inference, social construction calls for the knowledge constructed by the participants in this study, as well as the criticality in the authorial voices on each of the findings in previous chapters, to be considered (Pawson & Tilley, 1997). The critical ethnography design, complemented by the theoretical orientation of social constructionism, also challenges us to take a critical approach to all assumptions about things taken for granted and let the participants “speak in the text” (Horner, 2004, p. 23) for positive changes to occur (Burr, 2015).

Applying the above social constructionism and critical ethnography to the study, three key themes were generated from the data collected: Perspective of walking, Supporting walking, and Environment and walking. All three themes were further broken down into child sub-themes according to similar patterns identified but have the theme of wanting to stay “normal” permeating through. As a result, the overarching theme for this study is Normal life for residents living with dementia who walk as represented in Figure 12. All findings from all participants from the two ARC Facilities interrelate as they share the same systems, same philosophy of person-centred care, and their foci were the residents living with dementia who walk. All staff in both facilities respected the personhood in the residents, regarded them as social citizens, and did not disregard them as equal citizens (Bartlett, 2022; Brannelly, 2011; George, 2010; Kitwood, 1997). In addition, this interrelatedness determines the health and well-being of residents with dementia who walk.

Figure 12. The Overarching Theme: Carrying on normal life



Note: The overarching theme of Carrying on normal life with three main findings presented as themes, sub-themes and sub-sub themes

8.2 Summary of Findings

This section is discussed under the aims of the study to reveal how the research question was answered by each of the five aims of the study.

8.2.1 Aim one: To explore the perspectives on walking of residents with dementia from the perceptions of all participants.

The first finding of this study uncovers a main theme: *Perspectives on walking*

'Carrying on normal life' was important to participants. Findings from this study showed that participants constructed new knowledge and alternative meanings (Burr, 2015) of the walking of the residents which is worth acknowledgement and consideration (Pawson & Tilley, 1997). These provide evidence that there are alternative ways of seeing walking of residents with dementia that challenge previous understanding (Burr, 2015). This represents a critical stance, a key element of social constructionism (Burr, 2015; Lock & Strong 2010).

Residents with dementia who walked

Findings showed the constructed perspectives and subjective experiences of residents living with dementia who walk, revealing that they focused on what they could still do. They focused on their capabilities and strengths - that is, they focused on walking and not on things they could not do. They focused on their "then self", (Klein & Karlawish, 2010; Ney et. al., 2021), determined not to allow their current health status – their "now self" (Klein & Karlawish, 2010; Ney et. al., 2021) – prevents them from living a normal life, notwithstanding the "considerable personal challenge" (Bartlett & Brannelly, 2019, p. 2) that they were facing. They wanted to carry on with their identities (Kitwood, 1997), feel good, keep physically active, connect and bond with loved ones, and move around. They wanted to occupy themselves doing meaningful things and avoid boredom. They searched for someone or something very dear to them and got lost as the environment was new, unfamiliar, and full of unfamiliar faces, which can also happen to others. They wanted to walk, and wanted to exercise their freedom to walk and be independent to go anywhere without being stopped, which, again, is normal for everyone to be curious to explore their environment.

Enduring Powers of Attorney (EPAs)

EPAs supported their loved ones to carry on their normal lives. In addition, they saw that walking gave their loved ones, the residents, their identities (Kitwood, 1997), self-worth, satisfaction, and a sense of accomplishment. Since it was an exercise that would keep them fit, the walking was acceptable to the EPAs meaning that if residents

did not stay active, they would be bed-bound. In their interviews, the EPAs wanted their loved ones living with dementia to be able to walk around, have general views of the environment or walk freely to just as all human beings do. The EPAs viewed this walking as normal for the residents. Walking was a way of bonding in families that helped them strengthen relationships and intimacy (Cook et. al., 2022).

Residential Care Staff

Residential care staff constructed alternate knowledge that the walking of the residents was their way of carrying on their normal lives. The care staff did not see the residents as numbers or their pathologies but they saw them as 'persons' giving them the status of personhood (Kitwood, 1997). The staff saw the residents as socially alive (Brannelly, 2011; Cook et. al., 2022; Kitwood, 1995) and viewed them with social regard (Brannelly, 2011). They saw the person in each resident first, before seeing the diagnoses (Ulrich, 2005). They saw each resident as different to the other, which informed the individualised care plan and the way care was provided for each resident. The residential care staff viewed the residents as equal and social citizens (Bartlett, 2022; Bartlett & Brannelly, 2019; Brannelly, 2011). They viewed residents' walking as normal and they humanised the residents. The language they used to describe or refer to residents was not demeaning or patronising. This will allow residents and persons with dementia who walk to live a socially inclusive normal life.

Perspectives on walking revealed the subjective experience of residents living with dementia who walk, together with the perspectives of their EPAs and residential care staff. This is consistent with existing literature in a study conducted by Phinney (2021) on the experience of living with dementia from the perspective of the persons diagnosed. Five persons living with Alzheimer's disease type of dementia were interviewed and observed with their spouses at home. The findings revealed two things: The persons with dementia were frustrated in their experience of not being sure of themselves as unfamiliarity around them increased and secondly that they put in effort to counter the effect of dementia so they could continue their daily roles to live normal life. These findings highlight the effect of the syndrome on the persons and their spouses and the need to consider the perspectives of persons living with the syndrome and support them appropriately to meet their needs. This study finding one also reflects these.

The participants all constructed the perspective that walking of the residents with dementia how they were carrying on their daily roles, feeling good, striving to be healthy, carrying out their basic human nature, having freedom to walk and independence. They saw the residents as persons and not their diagnoses (George,

2010; Kitwood,1997; Ulrich, 2005) and they respected the personhood of the residents, recognising that they were carrying on their identities (Brooker, 2007; Kitwood, 1997).

8.2.2 *Aim Two: To investigate the interventions being provided for the residents by residential care staff of two facilities in a city in New Zealand:*

This study identified that the care staff and EPAs showed caring, empathy, compassion, and relational solidarity (Brijnath, 2024; Jennings, 2018, 2015), supporting the residents in meeting their needs. Care staff gave accounts of the different actions taken to support the walking of residents with dementia. The staff carried out this by being proactive; reinforcing positive behaviours observed in the residents; and by providing non-pharmacological interventions for the residents. They respected the residents' personhood, identities. and dignity (Brannelly, 2011; Brooker, 2007; 2004; George, 2010; Kitwood, 1997). The staff treated the residents with social regard (Brannelly, 2011; Sweeting & Gilhooly, 1997). They interacted with the residents as social citizens (Cook, 2022; Bartlett & Brannelly, 2019; Kitwood, 1997;) and as equal citizens (Kitwood, 1997) who deserved to be given attention and listened to with relational solidarity (Brijnath, 2024; Jennings, 2015, 2018). Staff provided proactive interventions aimed at individualising support such as gathering the background history of residents to provide person-centred care. Staff involved families in the care and encouraged them to spend time with the residents.

Being proactive

Staff reported a thorough admission process where they gathered background information on the residents to develop individualised care plans for the residents as the facilities' care philosophies or concepts were to achieve person-centred care goals for each resident. This information was used to build a picture of family, medical, social, and lifestyle histories to plan care tailored to meet each resident's walking needs as dementia affects each person in unique ways (Blake 2014; Kitwood, 1997). A key part of the finding was that staff encouraged families and EPAs to visit the residents. This highlights the central roles that families and EPAs play in supporting the residents emotionally and psychologically (Johnston et al., 2024).

Part of being proactive was carrying out assessments on the residents, for instance, staff reported carrying out pain assessments to eliminate any underlying factors that could trigger walking in the residents. The RCS also communicated with residents using simple language and accompanied the residents to walk. There appeared to be no specific policy on walking of residents with dementia at the facilities featured in this study as no specific policy was sighted; however, reference was made to it as part of the changing behaviours that could occur in residents with dementia. A specific policy

and guideline would be helpful for staff in planning care and in guiding them on ethical issues in balancing safety and independence to walk by the residents. The study also found staff walked with residents and facilitated their walking, encouraging them to walk while ensuring their safety with supervision.

Reinforcing positive behaviours

Staff observed behaviours in the residents as they went walking and engaged in activities along the way. They then reinforced these behaviours and capabilities in the residents by strengthening their natural inclinations which gave the residents a sense of purpose and accomplishment. For example, the facility administration provided safe cleaning and gardening tools for a resident after they observed that when she walked, she would turn to cleaning and clearing the environment and garden. All residential care staff were aware of and advocated for the use of non-pharmacological interventions as the first interventions to manage walking in residents with dementia who walk.

Non-pharmacological interventions

Group activities and outdoor visits as non-pharmacological interventions enhance the personhood, autonomy, and independence (Brooker, 2007; Kitwood, 1997) of residents to meet their needs of being included and socially regarded (Brannelly, 2011) as social citizens (Bartlett & Brannelly, 2019; Cook, 2022). The study also found that some participants demonstrated a high level of safe practice by being aware of the Best Practice Guidelines (BPACNZ, 2024; NICE, 2024) on administering anti-psychotic medications as a last resort after all other assessments have been carried out to rule out any underlying factors. However, while the majority condemn the use of antipsychotic medications for residents on any ground, a minority stated that it could be considered on a case-by-case basis. This is consistent with existing literature on the administration of antipsychotic medications with no consensus and Best Practice Guidelines (BPACNZ, 2024; NICE, 2024).

8.2.2 Aim Three: to explore the concept of person-centred care from the approaches provided by the residential care staff towards enhancing best practice.

This third aim answered the research question and was achieved through alternative perspectives on walking given by the residential care staff and through the interventions provided to the residents to support their walking. The staff humanised the residents and did not pathologise their walking or link the walking to dementia. They showed caring, compassion, empathy, relational care, and solidarity in their interaction with the residents and the way they addressed them.

Staff showed their nursing quality empathy and awareness of their professional responsibilities, working toward achieving the individualised person-centred care goals for the residents. They endeavoured to strike a balance between freedom of walking of the residents with the safety for the residents when they walked independently time with the resources at their disposals to meet the needs of the residents. The residential care staff demonstrated high level of safe practice by being aware and knowledgeable about Best Practice Guidelines on the use of antipsychotic medications as a last resort. They advocated for non-pharmacological interventions as first line of interventions in their effort to provide tailored person-centred care to the residents.

Participants demonstrated a sense of humour during the in-depth interviews and expressed that walking made them ‘feel good’. The residents-participants also wanted to be physically active, maintain connection with people and bond with loved ones. They wanted to move around, and view things that interested them like other human beings do. Their other psychological needs are inclusion and occupation (Kitwood, 1997). By walking, they expressed they wanted to occupy themselves doing meaningful things and avoiding boredom, just like other people do. They searched for someone or something very dear to them and got lost as the environment was new, unfamiliar, and full of unfamiliar faces. They wanted to walk around and “see general” (Participant6, in-depth interview,13 August, 2021) without being stopped, which, again, is normal for everyone to be curious to explore their environment.

Regarding the perspectives on walking by the EPAs, the findings also unfolded that the EPAs deviated from traditional view of dementia and constructed alternative and positive perspectives, supporting their loved ones to carry on their normal lives. In addition, they saw that walking gave their loved ones, their identities, self-worth, satisfaction, and a sense of accomplishment, which aligns with the five psychological needs of persons living with dementia (Kitwood, 1997). Since it was an exercise that would keep their loved ones fit, the walking was acceptable to the EPAs. In their interviews, the EPAs wanted their loved ones living with dementia to be able to walk around, have general views of the environment or walk freely. Walking was a way of bonding in families that helped them strengthen relationships and intimacy (Cook et. al., 2022). This implies that the EPAs respected the residents-participants as persons, with identities. They respected their autonomies and recognized their choice to walk if they chose to, giving them their status as human beings as stated by Kitwood (1997).

Furthermore, the findings revealed that the residential care staff had constructed the same knowledge that the walking of the residents was their way of carrying on their normal lives. The care staff did not see the residents as numbers but as persons and

socially alive (Brannelly, 2011; Cook et. al., 2022; Kitwood, 1995) and viewed them with social regard (Brannelly, 2011). They saw the person in each resident first, before seeing the diagnoses (Ulrich, 2005). They viewed residents' walking as normal and they humanised the residents.

8.2.3 Aim Four: To examine the impact of the built environment on the walking of residents.

This aim of the research question was answered with *Finding Three 'Environment and Walking*'**.** The Finding revealed that environment was important for the resident with dementia and there was a deep desire of some residents to live at home. The finding also revealed the need for more space for the residents to walk in. EPAs learning about dementia, and need for a specific guideline to support the walking of the resident

On whether the space available at the facilities was sufficient or not for walking, there were different perspectives of what constitutes an ideal walking space for residents during these independent interviews with each participant, including the residents' EPAs, and the residential care staff. Staff participants expressed that the spaces were sufficient for walking and complied with the Ministry of Health regulations, while some EPAs disagreed. All participants agreed that safety was paramount in the care and support of residents with dementia who walk. The residents could not identify the risks by themselves but depended on others caring for them to keep them safe (Kitwood, 1997). There were suggestions given by all participants on how to improve the care being provided to the residents with dementia who walked. The importance of space to walk is beginning to be advocated for in caring for the well-being of the residents. Dementia-Enabling environment principles, which, include supporting movement and engagement of residents and persons with dementia enable person-centred care goals to be achieved (Fleming et al., 2020, Charras et al, 2024) This calls for a review of the standards of environment for care facilities, so that walking is enabled in a safe space that is accessible for residents.

Some residents wanted to live and be cared for at home. Kitwood (1997) posited a possible reason for this: All human beings have five psychological needs, namely comfort, attachment, inclusion, occupation, and identity, but in persons with dementia, they are more visible and need to be met due to the inability of the person with dementia to meet them any longer by themselves. Familiar environments such as their homes bring them comfort and attachment, which in turn makes them feel secure, while unfamiliar environments disrupt them (Dyer et al., 2018; Meyer & O'Keefe, 2020; Vafeas & Slatyer, 2021). It is this security of a familiar environment why these residents long for the homes they were in and for the people they are familiar with. A possible

reason for increased agitation was advanced in being in unfamiliar places or seeing faces that were completely new to them.

8.2.4 Aim Five: To contribute to the destigmatisation of residents with dementia who walk by advocating a shift to using language that dignifies them for their optimal support.

One of the rationales for choosing this research project was to contribute to improving the quality of life and psychological health and well-being of aged care residents with dementia and to deconstruct stigma in the lives of the resident with dementia who walk. The findings of this study have revealed that residents wanted to carry on normal life like everyone else with caring, compassion, relational solidarity and use of dignifying language by all stakeholders. Social constructionism applied to this study postulates that these views should be acknowledged. I also discussed 'stigma', how it is a label, creating "marked differences from what is 'normal' … to negative emotional and /or behavioural responses to those differences" (Young et al., 2019, p.17) and how it impacts the individual affected, their families, communities and nations significantly. The importance of using dignifying language for the residents and persons with dementia who walk is also highlighted as this will continue to reduce the socially constructed stigma until it is finally removed. Language is very important as a key element of social constructionism is the use of language. It is used in constructing knowledge in any interaction (Burr, 2015). As a result, the language to be used in addressing persons and residents with dementia should not be demeaning or patronising. In the past, residents and persons living with dementia had been stigmatised as it was the culture to believe in the stigma and language is a key part of culture (Burr, 2015). This study calls for positive use of language on the walking and dementia which can help re-construct a more positive attitude towards person with dementia who walk to effectively remove the stigma. This will allow residents and persons with dementia who walk to live a socially included and normal life

Social construction (Burr, 2015; Berger & Luckmann, 1966; Lock & Strong, 2010), uses language in every interaction to construct knowledge. It is the aim of this study, that all the walking of residents with dementia will be duly acknowledged as a everyday human activity and not referred to as a problem, using humanising language for the residents. I have conveyed this in the chapters of this thesis and the conclusion of this study.

8.3 Systems relationships and Inter-relatedness:

All findings from the participants from the two ARC Facilities interrelate as they all point to the residents' desire to live a normal life and be acknowledged for who they are. They want to carry on their identities and their daily living as they used to -their 'then'

self. They feel at home and comfortable with friends and family members that they trust and are familiar with in a familiar environment, and not an unfamiliar environment. The findings also interrelate as they share the same systems of aged residential care, share the same care philosophy of care: person or individual-centred care, and their foci are the residents living with dementia who walk. All staff in both facilities respected the personhood in the residents, regarded them as social citizens, and did not disregard them as equal citizens (Bartlett, 2022; Brannelly, 2011; George, 2010; Kitwood, 1997). Additionally, this interrelatedness significantly impacts the health and well-being of residents with dementia who walk.

Both facilities included in this study shared similarities in their systems but still differed slightly in terms of building structures and schedules, possibly because of the different levels of care each was certified for. As evident from their characteristics, both facilities had qualified staff with many years of experience as registered nurses and health care assistants. No enrolled nurse was working in the facilities at the time of study. Both facilities used individualised or person-centred philosophies of care to guide staff practice. They had different schedules of activities, but overall, activities appeared similar, with each having its uniqueness but both facilities used these activities for the same purpose of creating communication and social interactions and providing standard and best care to residents with dementia who walked to meet their varying needs.

8.4 Original Contribution to Knowledge

This research contributes to knowledge as it is original and the first research carried out to explore the perspectives on walking from the perspectives of the residents living with dementia who walk, their Enduring Powers of Attorney, the registered nurses, and the health care assistants working at the aged care facility. In addition, this research is a first and original study carried out to investigate the relational and supportive interventions used by residential care staff for residents living with dementia who walk in two aged residential care facilities in Auckland in Aotearoa New Zealand. Furthermore, this study contributes to the destigmatisation of persons living with dementia who walk as the findings revealed the perspectives and meaning of the walking of the residents as carrying on with normal life, which provided insights into their subjective experience. This study further contributes to the fulfilment of evolving research and growing international evidence on researcher’s ethical obligation to involve the persons living with dementia in studies regarding their care for their subjective experience to be included in decisions, policies, strategies or guidelines that

are being developed about them (Diaz et al, 2021; Seidel et al., 2024; Snowball et al., 2024).

8.5 Strengths of the Study

The greatest strengths of the study are the combined use of social constructionism, (Berger & Luckmann, 1966; Burr, 2015; Lock & Strong, 2010) and the theoretical orientation and critical ethnography (Carspecken, 1996; Madison, 2012; Thomas, 1993). Both social constructionism and critical ethnography laid the foundation for the depth and richness of data collected as both involve critical exploration of social relationships. Social constructionism provokes consciousness, takes a critical approach and asks questions to uncover hidden meanings, challenging observations that have been taken-for-granted (Berger & Luckmann, 1966; Burr, 2015; Lock & Strong, 2010) in the community. Social constructionism calls to seek alternative meanings to those presented observations asking every alternative meaning and knowledge constructed to be acknowledged (Burr, 2015; Lock & Strong, 2010). Critical ethnography, complementing the theory, with its emancipation goals, gives voices to the marginalised so that they can be heard through their quotes in any research. This study enabled me to observe the ‘walking’ of the residents and be able to gain insider information through the in-depth interviews conducted to let all Participants speak so their voices could be heard (Carspecken, 1996; Madison, 2012; Thomas, 1993). These two critical approaches enabled the collection of rich data that constructed new knowledge through the analysed data collected. The strength of the study is further enhanced by the integration and combination of the five stages of data collection recommended by Carspecken (1996) and the six phases of Reflexive Thematic Analysis by Braun and Clark (2006). Though the processes were intensive, rigorous, thorough and time-consuming, the framework provided a step-by-step approach that I followed meticulously as I did not want to leave out any useful data or analyses that resulted in the three main findings: Perspectives on Walking; Supporting Walking and Environment and Walking.

8.6 Limitations to the Study

This study has its limitations. Firstly, the methodology used in carrying out the study could have been different. Further studies can be carried out using mixed methodology research to investigate the research question. Secondly, I was not able to observe participants 24/7 during Participant Observation Stage 1 at the two facilities as my ethical approval did not cover such hours. Thirdly, 26 participants from two facilities took part in the study. This is not a representation of all ARC facilities in New Zealand and as a result, generalisation is not possible using the findings from this study.

However, this small number of participants was appropriate as this is a qualitative study. The four groups of participants in the study may be seen as representing various groups of stakeholders in our communities that the findings may apply to. In addition, the rich data and the findings challenge conscience, attitudes and actions, which is in line with the theoretical orientation and methodology used.

Methodology**:** This research applied critical ethnography underpinned by social construction for its theoretical orientation. Future research may apply other philosophies and methodologies, such as hermeneutic phenomenology to explore different subjective realities of each of the categories of similar participants that took part in the study, especially for residents with dementia who walk in the early stage of their diagnosis.

Heterogenous samples**:** As samples of this research were heterogeneous rather than homogenous, different questions were asked to each category of participants (residents with dementia who walked, EPAs, registered nurses and health care assistants), it was not possible to carry out outright convergences and divergences of views across all groups, categories and questions throughout, but whenever possible, these were done.

Impact of COVID-19 pandemic: Firstly, Data collection for this study was done over 10 months when the actual collection plan was approximately four months. This was due to the pandemic situation globally and nationally during this period. Acknowledging that my study population was vulnerable, my research adhered to the ethical principles guiding my research including beneficence and non-maleficence and worked with the Facility and Clinical Managers, checking with them regularly by phone and email communication when safe to visit and visited only when advised. On arrivals at their social sites, I observed all safety protocols laid out including wearing of masks. However, one of the participant-resident passed away during this period, though participant observation of them had been carried out earlier. Secondly, three social sites/facilities consented to take part in the study initially but the third facility and their participants that had given written consent to participate in the study were withdrawn as they were impacted by the pandemic which led to the closure of the facility.

8.7 Final Reflection

I worked previously as a Gerontology Clinical Specialty Nurse with core responsibility working with Aged residential care facilities staff and their residents referred to our service. At the time of carrying out and completing this research, I had been teaching undergraduate nursing students, for many years supporting many of them allocated to

me with clinical education and supervision as they had their clinical placement in the Aged residential care facilities. I was aware that my knowledge, skills and experience could influence the interpretations of the data but with regular self-reflection, journaling and meetings with my supervisors to discuss the data collected and analysed, I was able to maintain my position as a researcher throughout.

8.8 Implications and Recommendations

While participants were appreciative of the support the ARC facilities and the staff are providing the residents, the participants suggested ways to enhance the support for the residents with dementia who walk and these have been categorised into four: recommendations for researchers; recommendations for aged residential care providers and their staff; recommendations for the government and policy makers; and recommendations for the public which includes, families, friends and everyone in the community. These are presented below:

8.8.1 Recommendations to Aged Residential Care Providers and Care Staff

- Staff-resident ratio to be improved by employing more staff, including physiotherapists, to distribute the workload so that residents with dementia who walk can be adequately supported to walk
- Aged residential care facilities to set up a volunteering system to support the walking of residents and to ease the workload of staff. There are individuals in the communities willing to step into this role in a voluntary capacity to complement the support staff provide for residents, so person-centred care goals could be achieved for each resident. However, this system requires a coordinator to ensure it is well-organised and safely monitored to protect the vulnerable residents. The Hogeweyk in the Netherlands is a model example and evidence that this volunteer system could be successfully implemented. As of July 2022, when a study visit was conducted, the village had 120 volunteers supporting individuals living with dementia in the village, as discussed in earlier chapters.
- Specialised education and training to be provided to the staff on specifically supporting residents with dementia who walk
- More outings and more engaging activities to be planned for residents to prevent boredom in the residents
- A secure walking track or a fenced area for residents to walk independently and safely, and for dogs to be allowed for residents to have as walking companions. Environment is particularly important to residents with dementia who walk, as

evidenced by the study's findings. The environment provides residents with a sense of familiarity and a feeling of belonging. It is recommended that access to more space for walking be created for residents in the aged residential care facilities. This is starting to be recognised as a key part in designing a good care home for the residents.

8.8.2 Recommendations to the Government and Policymakers

- It is recommended that the government fund more facilities and establish more villages for residents with dementia who walk, like the dementia village in the Netherlands (The Hogeweyk)
- Government to have a better system where residents could have a stable and familiar ‘home for life’ to walk in and live a normal life, and not be transferred from their homes or from one facility to another when their health status changes or when the progressive nature of their diagnoses increases.
- Government to provide salutogenic and alternative ways of supporting their walking based on their strengths and abilities that will enhance their wellbeing and holistic health
- Government to create policy on specific guidelines that support the walking of residents with dementia, which is different to existing guidelines on dementia care as not everyone living with dementia walks during the trajectory but equally studies have shown that 15% to 60% of persons will walk during this period and 50% of older people with severe dementia will walk (Cerejeira et al., 2012; Robinson et al., 2006)
- More campaign and education for public awareness is needed on dementia syndrome and how to support persons living with dementia who walk to remove the stigma from individuals living with dementia who walk so they can live a normal life, and others would feel societal support to seek early medical diagnosis and treatment.

8.9 Conclusion to the Study

This thesis has presented a study on the perspectives and supportive interventions provided for residents with dementia who walked in two of the aged residential care facilities in Auckland, a city in New Zealand. Walking has been socially constructed and stigmatised in persons living with dementia who walk. Dementia, itself, is one of those health conditions challenging humanity, especially as ageing occurs and as research evolves, there is need to support those living with the syndrome to live and have a good quality life. Globally, there has been a concerted effort to find a cure through research but while the world awaits a breakthrough, the consequences and impact of

the stigma for those living with dementia and who walk needs an alternative approach as the UNCRPWD declared dementia a disability and every country should try to find ways to support and make them inclusive. The stigma attached to walking for the residents and persons with dementia have been consequential. These consequences include social isolation, social disregard, dehumanisation, disrespect of their personhood, lack of recognition as equal citizens, and use of infantilisation language, even though these might not have been intentional, as suggested by experts. International studies revealed a common use of antipsychotic medications to manage increased symptoms (BPSD) in residents in aged care facilities in urban and rural settings worldwide against best practice guidelines.

This study set out to investigate the relational and supportive interventions provided for residents with dementia who walked by residential care staff in two of the aged care facilities in Auckland, a city in New Zealand. Critical ethnography methodology with social constructionism theoretical orientation was used to carry out the study. The design gave participants authority to speak through quotes and social constructionism argues that their views are constructed knowledge achieved through the use of language and these need to be acknowledged as no single meaning is sufficient to describe an activity; that there are always other alternative ways. Purposive sampling was used to recruit participants, and data were collected through participant observations, in-depth interviews, and unobtrusive methods and that data were thematically analysed. This study identified three findings with an over-arching theme of Normal life for residents living with dementia who walk. The theme of the first finding is Carrying on normal life. These were the perspectives of all participants in the study: residents with dementia who walked, their EPAs, the RNs and the HCAs. They viewed walking as normal. The second finding is Supporting walking revealed the various ways the staff provided proactive support for the residents with empathy, relational care and solidarity, respecting residents' personhood. The support provided was creative and individualised to meet each resident's unique needs. Staff also reinforced positive behaviour seen in residents and provided non-pharmacological interventions as first interventions as part of their supportive interventions to the residents, in line with the Best Practice Guidelines. All staff demonstrated knowledge of the recommendations in the Best Practice Guidelines as to when to use pharmacological interventions and non-pharmacological interventions. The third finding, Environment and walking, revealed the importance of the environment to the walking of the residents in furthering their desire to carry on their normal lives with appropriate and creative support.

Some of the residents expressed the desire to live at home and be supported there to live normal lives and some needs were identified that would enable residents to walk

autonomously and independently either at home or at the residential care settings. The residents and EPAs expressed their appreciation to the ARC Facilities staff and the government and provided various suggestions to enhance the support for walking for the residents and persons with dementia. The residents' voices, as well as those of their families, friends and professional carers, have spoken through the quotes throughout the findings. I argue that it is high time we looked into other alternatives and salutogenic ways of improving the support being provided for residents with dementia who walk, how the support is provided and where. Dementia needs to be seen as any other health issue, and the residents diagnosed to be considered as any other citizens who deserve to have their personhood respected, and our language needs to reflect this. This study argues that based on the evidence of these findings, all stakeholders have ethical obligations and responsibilities to play their part in working together as a team to support the residents with dementia who walk to carry on living normal lives, socially, physically, emotionally, psychologically, and familially. The national strategies and Dementia Framework that support dementia care offer great strategies supporting older people with dementia. Due to the prevalence of persons with dementia that walk and the projected increase of persons to live with dementia by 2050, a policy is needed with specific creative guidelines to support their walking at home or at the various ARC Facilities so they can carry on their normal lives wherever they are, for their optimal health, quality of life, and well-being.

8.10 A poem in support of normal life for residents and persons with dementia who walk

-by *Christianah Adesina, May 2024*

They are speaking to us!

I glance, I peer, I squint, I gaze
I can see them now
Hardworking Achievers!
I move closer
Yes, I can see them clearly
Persons and residents with dementia who walk-
They are speaking to us!
Did you hear them?
But wait-
They seem so connected, beautifully united!
Helping the others, staying on course!
Their unity is compelling! Their synergy is irresistible!
Beauty and Vibrance combined!
Embodiment of wisdom!
"But wait, I have a question-
"What did you say? "How did you achieve this unity?"
Is there anything you need?
Then came the response-
"You know the answer"! "You 'all' know the answer"!
"You have the solution" "You 'all' have the solution"!
I repeated the response:
I have the answer! We 'all' have the answer!
I have the solution! We 'all' have the solution!

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Appendices

Appendix A. HDEC full approval with non-standard condition

Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

hdecs@health.govt.nz

28 January 2021

Mrs Christianah Adesina
c/-Doctor of Health Science Office
Graduate Research School, Faculty of Health & Environmental Sciences
School of Clinical Sciences, 90 Akoranga Avenue
Northshore campus
Auckland 0627

Dear Mrs Adesina,

Re:	**Ethics ref:**	**20/STH/162**
	Study title:	How do residential care staff use relational and supportive interventions with residents living with dementia who like to walk?

I am pleased to advise that this application has been *approved with non-standard conditions* by the Southern Health and Disability Ethics Committee. This decision was made through the HDEC-Full Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Southern Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.

2. Before the study commences at *each given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

Non-standard conditions:

3. You must only include participants who can consent for themselves. Please remember that you may use the EPOA as an assessment tool but you must not use consent from the persons named as attorneys to include the individual in the research. They can only be included if they have given their own consent.

Non-standard conditions must be completed before commencing your study, however, they do not need to be submitted to or reviewed by HDEC.

If you would like an acknowledgement of completion of your non-standard conditions you may submit a post approval form amendment through Online Forms. Please clearly

identify in the amendment form that the changes relate to non-standard conditions and ensure that supporting documents (if requested) are tracked/highlighted with changes.

For information on non-standard conditions please see section 128 and 129 of the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz)

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your next progress report is due by 28 January 2022.

Participant access to ACC

The Southern Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs. Helen Walker
Chairperson (Acting)
Southern Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A
Documents submitted

Document	*Version*	*Date*
Understanding Dementia Certificate of Completion	5.1.7	01 February 2018
Confirmation Letter from Maori Advisor-Sandra McDonald	5.1.7	27 August 2020
CV for CI: CV_Christianah_Adesina	5.1.7	01 July 2020
Question Guide: Indepth Interview of Whanau/Carer of residents with dementia who like to walk	5.1.7	01 September 2020
Question Guide: Interview with residents living with dementia who like to walk	5.1.7	01 September 2020
Protocol: Form PGR9 Confirmation of Candidature Research Proposal Christianah Adesina	5.1.7	26 November 2019
Protocol: HES Signed PGR6 Variation of Record Form	5.1.7	11 March 2020
Protocol: Approval for PGR6 Variation of Record Form 19/03/2020	5.1.7	19 March 2020
Protocol: Supervisor's letter regarding Change in Methodology for Christianah Adesina	5.1.7	11 September 2020
Protocol: Confirmation of Candidature Christianah Adesina	5.1.7	19 March 2020
Protocol: New Methodology: Critical Ethnography	5.1.7	15 July 2020
Protocol: How the Study will be Carried Out: Data Collection	5.1.7	24 July 2020
PIS/CF: PIS/CF for Residents with dementia who like to walk	5.1.7 no 2	11 December 2020
PIS/CF: PIS/CF for Whanau/Family Carer of Person with dementia who like to walk	5.1.7 no 2	11 December 2020
PIS/CF: Amended PIS/CF for Residential Care Staff	5.1.7	11 December 2020
Covering Letter: Cover Letter for Ethics Application	5.1.7 no 2	11 December 2020
PIS/CF: Participant Information Sheet and Consent Form for Aged Residential Care Facility	5.1.7	24 August 2020
PIS/CF: Amended PIS/CF for Aged Residential Care Facility	5.1.7	11 December 2020
Question Guide: Interview for Residential Care Staff	5.1.7	01 September 2020
Protocol: Evidence of including persons with dementia in the study	5.1.7	01 July 2020
Evidence of scientific review: Form PGR9 Confirmation of Candidature Proposal Christianah Adesina	5.1.7	26 November 2019
Application		18 September 2020
Covering Letter: Response to HDEC Recommendations	5.1.7 no 2	11 December 2020
Completed Data Management Plan	5.1.7 no 3	11 December 2020
Transcriber's Confidentiality Agreement	5.1.7	11 December 2020
Response to Request for Further Information		
PIS/CF		25 January 2021
PIS/CF		25 January 2021
PIS/CF		25 January 2021
Other (No Description Entered)		26 January 2021

Appendix B
Statement of compliance and list of members

Statement of compliance

The Southern Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008713) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*
Mrs Helen Walker	Lay (consumer/community perspectives)	19/08/2020	19/08/2021
Dr Pauline Boyles	Lay (consumer/community perspectives)	05/07/2019	05/07/2022
Dr Paul Chin	Non-lay (intervention studies)	27/10/2018	27/10/2021
Mr Dominic Fitchett	Lay (the law)	05/07/2019	05/07/2022
Dr Sarah Gunningham	Lay (other)	05/07/2016	05/07/2022
Assc Prof Mira Harrison-Woolrych	Non-lay (intervention studies)	28/06/2019	28/06/2020
Professor Jean Hay-Smith	Non-lay (health/disability service provision)	31/10/2018	31/10/2021
Dr Devonie Waaka	Non-lay (intervention studies)	18/07/2016	18/07/2019

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

http://www.ethics.health.govt.nz

Appendix B. AUTEC - Ethics full approval

Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

16 March 2021

Catherine Cook
Faculty of Health and Environmental Sciences

Dear Catherine

Re Ethics Application: **21/47 How do residential care staff use relational and supportive interventions with residents living with dementia who like to walk?**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 16 March 2024.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: vrb7730@autuni.ac.nz; elissa.mcdonald@aut.ac.nz

Appendix C. HDEC's Amendment Approval

Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

hdecs@health.govt.nz

29 June 2021

Mrs Christianah Adesina
c/-Doctor of Health Science Office
Graduate Research School, Faculty of Health & Environmental Sciences
School of Clinical Sciences, 90 Akoranga Avenue
Northshore campus
Auckland 0627

Dear Mrs Adesina

Re:	**Ethics ref:**	**20/STH/162/AM01**
	Study title:	How do residential care staff use relational and supportive interventions with residents living with dementia who like to walk?

I am pleased to advise that this amendment has been *approved* by the Southern Health and Disability Ethics Committee. This decision was made through the HDEC Full Review pathway.

Summary of Study

1. Observational study of supportive interventions for dementia patients who 'like to walk' (wander). Dementia patients and carers will be observed by the researcher and will complete questionnaires about wandering. Southern HDEC approved this study in January 2021 on the basis that all participants would provide informed consent. This amendment submission seeks to allow Enduring Power of Attorney (EPOA) to consent for residents who are unable to provide independent informed consent.

Summary of resolved ethical issues

The main ethical issues considered by the Committee and addressed by the Researcher are as follows.

2. The researcher described that the progression of the disease is different per resident, and some may have the ability to still write, some may have the ability to still read, and some do not have it at all. Some can verbally consent, some cannot. After summarising the introduction to the study, some residents have varying difficulty depending on their respective needs. Some may be able to provide informed consent but unable to communicate their consent. The Committee stated that in particular they are primarily concerned with how capable someone is of providing informed consent. Enduring Power of Attorney (EPOA) should only be used when a resident lacks capacity to consent, rather than lack the ability to communicate their consent.

3. The Committee queried how the researcher will determine capacity to consent. The researcher responded that people who are in this agitated walking phase of dementia have a blurred capacity to consent, and anybody requiring rest home or hospital level care is in a heightened state of not being able to manage their own lives. It is quite unpredictable. The researcher feels it is most appropriate to involve the EPOA in the consenting process as it's not possible to absolutely determine the person has capacity to consent. Family members are likely to be around and could be disturbed if they are not consulted about study participation.
4. The Committee noted that this is a low risk observational study that takes place in the public spaces of the residential care facility and were satisfied that the study does not constitute a medical experiment.
5. The Committee further noted that the principal risk consideration for participants is data harm (privacy or confidentiality breach). Appropriate data safety measures are in place as per the approved application to mitigate this risk.
6. The Committee agreed with the point raised by the researcher that there is strong evidence that people with dementia like to be included in research.
7. Given these points, the Committee agreed that the argument put forward by the researcher for allowing activated EPOAs to provide consent on behalf of participants who lack capacity to provide independent informed consent was valid.
8. The Committee noted, however, that EPOA could not be used for a participant who has capacity to provide independent consent. Further, if any participant who is enrolled under an activated EPOA consent indicates in any way - either verbally or through their behaviour - that they do not wish to participate, the researcher must respect that.

Decision

This amendment was *approved* by consensus, subject to the following non-standard conditions:

- please ensure all points raised by the Committee and incorporated into the conduct of the study, with documentation amended accordingly.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Acting Chairperson
Southern Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A
Documents submitted and approved

Document	Version	Date
Covering letter: Cover Letter for Request for Amendment	Version 1 Amendment	03 May 2021
Evidence of scientific review: Evidence from CHT Lansdowne Hospital & Resthome	Version 1 for Evidence	03 May 2021
Evidence of scientific review: Evidence re Request for Amendment from Takanini Lodge Oceania	Version 2 for Evidence	03 May 2021
Post Approval Form	AM01	04 May 2021
Previous Health Legal Advice for Application		

Appendix B
Statement of compliance and list of members

Statement of compliance

The Southern Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
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- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
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List of members

Name	*Category*	*Appointed*	*Term Expires*
Mrs Helen Walker	Lay (consumer/community perspectives)	19/08/2020	19/08/2021
Dr Paul Chin	Non-lay (intervention studies)	27/10/2018	27/10/2021
Mr Dominic Fitchett	Lay (the law)	05/07/2019	05/07/2022
Dr Sarah Gunningham	Lay (other)	05/07/2016	05/07/2022
Assc Prof Mira Harrison-Woolrych	Non-lay (intervention studies)	28/06/2019	28/06/2020
Professor Jean Hay-Smith	Non-lay (health/disability service provision)	31/10/2018	31/10/2021
Dr Devonie Waaka	Non-lay (intervention studies)	18/07/2016	18/07/2019

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

http://www.ethics.health.govt.nz

Appendix D. AUTEC's Amendment Approval

Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

23 July 2021

Catherine Cook
Faculty of Health and Environmental Sciences

Dear Catherine

Re: Ethics Application: **21/47 How do residential care staff use relational and supportive interventions with residents living with dementia who like to walk?**

Thank you for your request for an amendment to your ethics approval..

The amendment to allow the Enduring Power of Attorneys for residents with dementia who like to walk, to sign written consent on their behalf is approved as per HDEC's approval.

I remind you of the **Standard Conditions of Approval**.

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted. When the research is undertaken outside New Zealand, you need to meet all ethical, legal, and locality obligations or requirements for those jurisdictions.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: vrb7730@autuni.ac.nz; elissa.mcdonald@aut.ac.nz

Appendix E. Patient Information sheet with Consent Form for Aged Residential Care Facility

Auckland University of Technology
Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999
www.aut.ac.nz

Participant Information Sheet (Aged Residential Care Facility)

Date: ___/___/_____

Study title: Residential care staff use of relational and supportive interventions for residents living with dementia who like to walk

Invitation

Kia ora/Talofa/Malo e lelei/Namaste/Ni hao/Ola/Hello, my name is Christianah Adesina. I am currently undertaking the Doctor of Health Science programme at Auckland University of Technology (AUT). I am inviting you to participate in the study above so that researcher and residents being studied could share their views on interventions provided for residents living with dementia who like to walk. This population are commonly referred to as 'wanderers'. Dementia continues to increase in our communities with some residents have various and different symptoms including walking behaviour which is seen differently by each person.

Your participation is voluntary (your choice) and you are free to withdraw at any time during the research without any disadvantage to you. If you do want to participate now and change your mind later, you can pull out of the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What is the purpose of this study?

The purpose of this study is to find out various relational and supportive interventions that residential care staff, that is, Registered Nurses, Enrolled Nurses and Health Care Assistants provide for residents with dementia who like to walk and to find out their views on the walking behaviour and challenges faced. This study is not sponsored by any organization.

How was I identified and why am I being invited to participate in this research?

- You are an aged residential care provider and you employ staff that provide care for the residents including persons with dementia who like to walk.
- Researcher would like to carry out participant observation study in your facility with your consent. They would like to observe staff caring for the residents living with dementia who walk and family interactions with residents with dementia who walk in the public spaces of the facility such as in the lounge, dining room, hallway, activity room, outside, within the facility building.
- The observations will be for four to eight hours weekly - between two to four weeks (depending on the national or regional COVID-19 alert level lock downs). The Researcher is flexible around these weekly hours/shifts as the Facility, Clinical Managers and Staff know best the period when their residents with dementia like to walk and they can advise researcher best time period to visit.

Approved by Health & Disability Ethics Committee on 28/01/2021. Ref :20/STH/162
Approved by Auckland University of Technology Ethics Committee on 01/03/2021. Ethics ref.: 21/47
Amendment approved by Health & Disability Ethics Committee dated: 29/06/2021.Ethics ref: 20/STH/162/AM01
Amendment approved by Auckland University of Technology Ethics Committee on 23/07/2021. Ethics ref.: 21/47

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- The residents that would be included in the study are those diagnosed with early and moderate dementia by a GP or a Geriatrician, confirmed with cognitive test done such as Mini Mental State Examination or Montreal Cognitive Assessment (MoCA). Recent studies have given evidence that persons with dementia want to be included in the studies about them.
- The researcher would be requesting from the facility the following pieces of information (which will be de-identified and anonymised before analysis) on residents who have consented to participate in the study: age, ethnicity, gender, date of dementia diagnosis, record of walking behaviour; guidelines; policies or any relevant information on the care of the residents of study.

What will be done during the study?

- During the first stage of the study, the researcher will observe nurses' and families' interactions with the residents
- During the second stage, researcher will carry out one-on-on interview with the staff or with their support person culturally if they wish to include them
- The interview will be audio-recorded, and notes taken by the researcher
- The interview will last up to one hour

What are the possible benefits of the study?

- This study will provide current up-to-date interventions being provided for the residents in Auckland New Zealand, adding to international knowledge base on interventions appropriate for the population of study. It will shed light on the meaning of walking behaviour from the perspectives of the various participants, highlight the various gaps and challenges faced by all and it is the hope that this study may influence government policies in the allocation of more funding in providing enhanced quality of life for the residents. Your participation in this study will also assist me complete the Doctor of Health Science programme

What are the possible risks?

- There is no forseeable risks in participating in this study. Privacy will be maintained, and participants can ask the interview to be stopped at any stage if they feel uncomfortable. If they choose to do so, there will be no consequence and data may be destroyed if they wish so. If in the final stage of analysis, this may be difficult to retrieve. I will uphold ethical standards of beneficence (doing good); non-maleficence (do no harm); justice (providing health equity) and application of the three principles of the Treaty of Waitangi/Te Tiriti o Waitangi. I will also maintain the respect, dignity and

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whakapapa (genealogy) of all participants. Telephone contact details of support and counselling services are included below for participants if required.

What will happen to my information? How will my privacy be protected?

- Your facility and participant information are kept private and confidential and any information that identifies either will be replaced with code in any report. It will not be used in future research. Electronic data will be stored in external hard drive, password-protected and locked in the cabinet as per AUT protocol and data generated will be stored for a minimum of six years and if health data, will be stored for ten years and will be destroyed as per AUT protocol.

Who do I contact for more information or if I have concerns?

Name: Dr Catherine Cook
Position: Senior Lecturer (Primary Supervisor)
Auckland University of Technology, North Campus
Telephone number: (09) 921 9999 ext 6651
Email: Catherine.Cook@aut.ac.nz

Name: Dr Elissa McDonald
Position: Senior Lecturer (Secondary Supervisor)
Auckland University of Technology, North Campus
Telephone number: (09) 921 9999 ext.7656
Email: Elissa.McDonald@aut.ac.nz

Name: Dr Elissa McDonald
Position: Senior Lecturer (Secondary Supervisor)
Auckland University of Technology, North Campus
Telephone number: (09) 921 9999 ext.7656
Email: Elissa.McDonald@aut.ac.nz

Independent health and disability advocate:

Telephone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@advocacy.org.nz
Website: https://www.advocacy.org.nz/

Health and disability ethics committee (HDEC):

Telephone: 0800 4 ETHIC
Email: hdecs@health.govt.nz

Approved by Health & Disability Ethics Committee on 28/01/2021. Ref :20/STH/162
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Age Concern New Zealand Counselling Service
Telephone: (09) 279 4331

Are you anxious, overwhelmed, feeling down or just want to chat with someone?
Free call or text 1737 at any time (a free service to all New Zealanders)

Please keep this Information Sheet and the copy of your signed Consent Form for your future reference.

I do hope that your facility finds the information of this study interesting and you choose to participate. Your contributions will be highly invaluable to the study.

Looking forward to working with you on this study!

Kia Ora/Fa'a fetai/Mālō 'aupito/Dhanyavaad/Salamat/Xiexie/ Thank you so much!

Christianah Adesina
Doctor of Health Science (DHSc) student,
Auckland University of Technology (AUT)

Faculty of Health & Environmental Science

Telephone: +64 9 976 0586

Email: vrb7730@autuni.ac.nz

Approved by Health & Disability Ethics Committee on 28/01/2021. Ref.:20/STH/162
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Consent Form for Aged Residential Care Facility

Please tick to indicate you consent to the following:

We have read and understood the Participant Information Sheet.	
We have been given sufficient time to consider whether or not to participate in this study.	
We are satisfied with the answers given regarding the study and have a copy of this consent form and information sheet.	
We understand that if we choose to withdraw from the study, we will be offered the choice between having any data that is identifiable as belonging to us removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.	
We consent to the researcher carrying out their study in our facility and approaching our residential care staff, residents and their whanau/families to participate.	

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We understand that our participation in this study is confidential and that no material, which could identify our staff and residents and their families will be used in any reports on this study.		
We understand that any resident living with dementia and who walks that consents to participating in the study will have had a diagnosis of early or moderate dementia by their GP/Geriatrician or would have had a cognitive assessment carried out by the authorised Clinician including Senior Nurse/Nurse Practitioner/Clinical Nurse Specialist such as MMSE or MoCA		
We understand that the researcher will be requesting from the facility the following pieces of information (which will be de-identified and anonymised before analysis) on residents who have consented to participate in the study: age, ethnicity, gender, date of dementia diagnosis, record of walking behaviour; guidelines; policies or any relevant information on the care of the residents of study.		
We understand that all electronic data will be stored in external hard drive, password-protected and locked in the cabinet as per AUT protocol and data generated will be stored for a minimum of six years and if health data, will be stored for ten years and will be destroyed as per AUT protocol		
We know who to contact if we have any questions about the study in general.		
We understand our responsibilities as a provider of facility and study participants		
We agree that in the event of any witnessed abuse or unsafe practice, researcher will discuss with management first, as welfare of residents take precedence		
We understand that the researcher has an obligation to inform the facility if any of the practices observed poses any risks to participants, and to report it if serious		
We wish to receive a summary of the results from the study.	Yes ☐	No ☐

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Declaration by representative of Facility
We hereby consent to take part in this study.

Participant's Facility's name: _____

Name of Facility's representative/Manager: _____

Signature: _____ Contact No: _____

Postal address/Email address if you want summary of study at the end (Optional):

_____

_____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: Christianah Adesina _____

Signature: _____ Date: _____

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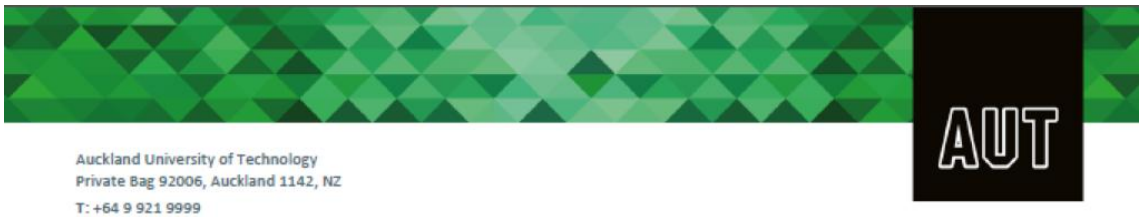
Appendix F. Patient Information sheet with Consent Form for residents with dementia who walk



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Participant Information Sheet for Residents with dementia who like to walk

Date: ___/___/_____

Study title: How staff care for you when you want to walk

Invitation

- Hello, my name is Christianah, and I am a student doing a doctoral degree. I am inviting you to participate in a study about how staff care for you. Taking part in the study is your choice. You can withdraw at any time, and this will not affect the care that you receive. If you choose to withdraw from the study, you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What is the purpose of this study?

- To find out from you, your carer and the staff about the care that you receive when you walk. The purpose is also to find out what your walking means to you, to your carer and to the staff. No company is funding this study. I am carrying it out to get a degree.

How were you identified and why were you invited to participate in this research?

- You are a potential participant as you live with dementia, and you like to walk

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- Studies have shown that persons who have dementia want to have a say in studies about them.

What will be done during the study?

- The whole study will be 16 hours, to be carried out between two to four weeks.
- If you are interested in participating in the study, the only pieces of information about you that the researcher will request from the facility after you have consented are your age, ethnicity, gender, date of diagnosis and how often you walk.
- The study will be in two stages.
- First stage: I will be observing how staff look after you and how they interact with you and your family. These will be observed in the public spaces of the facility, such as, in the lounge, dining room, hallway, activity room or outside the building.
- Second stage: I will be asking you one or two questions on what walking means to you.
- The interview can be 5 minutes or up to 30 minutes. This will be as convenient for you the same day or another day.
- The interview will take place in a meeting room allocated for the interview at your facility. You are welcome to bring a support person with you.
- I will record our conversations and also write some notes down (Showing of audio recorder to be used)
- A qualified person who has signed a confidentiality agreement will write out the words of the recorded interview.

What are the possible benefits of the study?

- The study is very unlikely to have any personal benefit for you, but it aims to let other people understand what walking means to persons that live with dementia who like to walk

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Amendment approved by Health & Disability Ethics Committee. Letter dated: 29/06/2021.Ethics ref: 20/STH/162/AM01

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What are the possible risks?

- Talking about your condition may be emotional for you. This is a risk in participating in the study. You can stop the interview if you do not feel comfortable to carry on or you may postpone it till another time. I will protect your interest throughout. I will respect you and your views. If you need counselling, some telephone numbers are written below for your use.

What will happen to my information? How will my privacy be protected?

- Your personal information is kept private and confidential
- Any information that identifies you will be replaced with a code and your details will not be used in any report on this study or in future study
- Information provided will be stored, secured and destroyed after six to 10 years according to protocol

Who do I contact for more information or if I have concerns?

Name: Dr Catherine Cook
Position: Senior Lecturer (Primary Supervisor)
Auckland University of Technology
Telephone number: (09) 921 9999 ext. 6651
Email: Catherine.Cook@aut.ac.nz

Name: Dr Elissa McDonald
Position: Senior Lecturer (Secondary Supervisor)
Auckland University of Technology
Telephone number: (09) 921 9999 ext.7656
Email: Elissa.McDonald@aut.ac.nz

Independent health and disability advocate:

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Telephone: 0800 555 050
Email: advocacy@advocacy.org.nz
Website: https://www.advocacy.org.nz/

Health and disability ethics committee (HDEC):

Telephone: 0800 4 ETHIC
Email: hdecs@health.govt.nz

Age Concern New Zealand Counselling Service
Telephone: (09) 279 4331

Are you anxious, overwhelmed, feeling down or you just want to chat with someone?
Free call or **text 1737** at any time (a free service to all New Zealanders)

I will be visiting your facility at a scheduled time early to middle of 2021 to give you more detailed information about the study and to answer your questions.

Please keep this Information Sheet and the copy of your signed Consent form for your future reference. I hope you can participate.

I look forward to working with you on this study.

Christianah Adesina (Researcher)

Doctor of Health Science (DHSc) student,
Auckland University of Technology (AUT)

Faculty of Health & Environmental Science

Telephone: 021 089 16463

Email: vrb7730@autuni.ac.nz;

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Consent Form for Residents with dementia who walk

Please read and sign the declaration below:

I have read/It has been read to me and I understand the Participant Information Sheet.
I have been given sufficient time to consider whether to participate in the study or not.
I am satisfied with the answers I have been given regarding the study and I have a copy of the consent form and information sheet.
I understand that taking part in this study is my choice and I may withdraw from the study at any time without this affecting the care that I receive.
I understand that if I choose to withdraw from the study, I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

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I consent to the researcher collecting information about my age, ethnicity, gender, date of diagnosis and frequency of walking		
I understand that my participation in this study is confidential and that no details identifying me personally will be used in any report on this study or in any future study		
I understand that all information will be stored and secured according to AUT protocol for a minimum of six years. If health information, it will be stored for ten years and afterwards destroyed according to the same protocol.		
I know who to contact if I have any questions about the study in general.		
I understand my responsibilities as a study participant.		
I wish to receive a summary of the results from the study (Please tick one box).	Yes ☐	No ☐

Postal address/Email address if you wish to receive summary of study at the end (Optional):

_____

_____

***Enduring Power of Attorneys (EPOAs) have been approved by HDEC to sign on behalf of residents who are unable to provide independent informed consent on 29/06/2021. Please sign as applicable in the appropriate section below:)**

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Amendment approved by Health & Disability Ethics Committee. Letter dated: 29/06/2021.Ethics ref: 20/STH/162/AM01

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Declaration by participant (resident):

I hereby consent to take part in this study (for residents who can sign):

Participant's name: _____

Signature: _____ Date: _____

Declaration by EPOA of resident:

I ..... (your name), am the authorized Enduring Power of Attorney (EPOA) for .....(name of resident) at ..... (name of facility) and hereby consent on their behalf that they can participate in the study.

Signature: _____ Date: _____

Declaration by Researcher:

I have given a verbal explanation of the research project to the participant and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: Christianah Adesina

Signature: _____ Date: _____

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Approved by Auckland University of Technology Ethics Committee on 01/03/2021. Ethics ref: 21/47
Amendment approved by Health & Disability Ethics Committee. Letter dated: 29/06/2021.Ethics ref: 20/STH/162/AM01

Appendix G. Patient information sheet with Consent Form for Enduring Powers of Attorney

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Participant Information Sheet: Whanau/Family/Carers of Residents with dementia who like to walk

Date:____/____/_____

Study title: Ways that residential care staff provide care for residents living with dementia who like to walk

Invitation

Kia ora/Talofa/Malo e lelei/Namaste/Ni hao/Ola/Hello, my name is Christianah Adesina. I am currently undertaking the Doctor of Health Science programme at Auckland University of Technology (AUT). I am inviting you to share your views with me on how you care for the residents living with dementia who like to walk. When dementia progresses, its symptoms are different for each person and one of the symptoms is walking, usually referred to as 'wandering'. This walking behaviour is seen differently by each person.

Your participation is voluntary (your choice) and you are free to withdraw at any time during the research without any disadvantage to you or to your family member. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What is the purpose of this study?

The purpose of this study is to find out various interventions that residential care staff, that is, Registered Nurses, Enrolled Nurses and Health Care Assistants, provide for residents with dementia who like to walk and their views about the walking behaviour. The purpose is also to find out your views about your family member's walking behaviour whenever you visit them and at home. This study is not sponsored by any organization. I am carrying it out to complete a programme.

How was I identified and why am I being invited to participate in this research?

You were identified because you are a family/whanau/carer/friend to a resident at the facility who lives with dementia and who likes to walk. You are being invited to participate in this study because of the following:

- You are a carer of a person at the facility living with dementia who likes to walk
- You have been a carer for a minimum of one week
- You are willing to share your views in an interview with the researcher for up to one hour

What will be done during the study?

- The whole study will be in two stages, approximately 16 hours in total, to be carried out between two to four weeks
- During the first stage of the study, the researcher will observe nurses' and families' interactions with the residents with dementia who walk, those who consented to

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participate in the study. The observations will be in the public spaces of the facility such as in the dining room, lounge, activity room and in the hallway

- The researcher will not take record of anything said or done by any person who has not consented to participate but who happens to be at the place of observation
- During the second stage, which may be on the same day or another day, to be negotiated with you, the researcher will carry out interview with you
- The interview will take place in an allocated meeting room at the facility
- It will be audio-recorded, and notes will be taken by the researcher
- The recorded interview will be anonymised, that is, your name will be removed from the information you provide during interview and replaced with a code
- A professional who has signed confidentiality agreement will transcribe the interview recorded

What are the possible benefits of the study?

- There is no personal benefit to you in this study. However, your participation is likely to help find out about interventions being provided for the population of the study. I am interested to hear about your experience in supporting your family member with their walking behaviour.

What are the possible risks?

- There is no foreseeable risks in participating in this study. However, you are being asked to share your experience looking after your family member/spouse/partner/friend. If at any stage, you feel uncomfortable talking, you can ask the interviewer to stop. There will be no consequence for you if this happens and data may be destroyed if you wish so. Your privacy will be maintained but if in the final stage of analysis, this may be difficult to retrieve. I will uphold ethical standards of beneficence (doing good); non-maleficence (do no harm) and justice (providing health equity). I will respect and maintain your dignity. I will also apply the three principles of the Treaty of Waitangi/Te Tiriti o Waitangi throughout the study and acknowledge the whakapapa (genealogy) of all participants.
- Telephone contact details of support services are provided on this information sheet for you to access if needed.

What will happen to my information provided during interview? How will my privacy be protected?

- The information you provide during the interview will be kept private and confidential. Any information that identifies you will be replaced with a code before it is analysed for any report.

How will information collected be managed?

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- Any information that can identify you will be removed and your details will not be included in any report or future research
- To maintain confidentiality, information that identifies you will be replaced with a code in any report generated from the study
- The information you provide may be added to other information from other studies to form a larger set of information

Security and Storage of your Information

- All information provided during interview will be stored as electronic data, secured in an external hard drive, password-protected and locked in the cabinet following AUT protocol and guidelines. Data generated will be stored for a minimum of six years and finally destroyed according to AUT protocol.

Who do I contact for more information or if I have concerns?

Name: Dr Catherine Cook
Position: Senior Lecturer (Primary Supervisor)
Auckland University of Technology, North Campus
Telephone number: (09) 921 9999 ext. 6651
Email: Catherine.Cook@aut.ac.nz

Name: Dr Elissa McDonald
Position: Senior Lecturer (Secondary Supervisor)
Auckland University of Technology, North Campus
Telephone number: (09) 921 9999 ext.7656
Email: Elissa.McDonald@aut.ac.nz

Independent health and disability advocate:

Telephone:	0800 555 050
Fax:	0800 2 SUPPORT (0800 2787 7678)
Email:	advocacy@advocacy.org.nz
Website:	https://www.advocacy.org.nz/

Health and disability ethics committee (HDEC):

Telephone:	0800 4 ETHIC
Email:	hdecs@health.govt.nz

Age Concern New Zealand Counselling Service
Telephone: (09) 279 4331

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Are you anxious, overwhelmed, feeling down or just want to chat with someone?
Free call or text 1737 at any time (a free service to all New Zealanders)

I will be attending a scheduled staff meeting and information session between early to middle of this year 2021, at the facility where your family member is a resident, to introduce the study. I am happy to meet with you and explain the study in detail. I will also explain the recruitment process which includes a selection process on how to be a participant. Invitation to participate will be made and Participant Information Sheets and Consent Forms will be provided. A list of interested participants will be collected at the end. Follow-up contact will be made only with those who have signed the written consent form within a month and an agreed date will be set for the start of the study.

Please keep this Information Sheet and the copy of your signed Consent Form for your future reference.

I do hope you find the information of this study useful and you choose to participate. If so, your contribution will be invaluable to the study. I am looking forward to working with you.

Kia Ora/Fa'a fetai/Mālō 'aupito/Dhanyavaad/Salamat/Xiexie/ Thank you so much!

Christianah Adesina
Doctor of Health Science student,
Auckland University of Technology (AUT)

Faculty of Health & Environmental Sciences

Telephone: +64 2108916463

Email: vrb7730@autuni.ac.nz;

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Appendix H. Patient information sheet with Consent form for Residential Care Staff (RNs and HCAs)

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Participant Information Sheet - Residential Care Staff

Date: ___/___/_____

Study title: Residential care staff use of relational and supportive interventions for residents living with dementia who like to walk

Invitation

Kia ora/Talofa/Malo e lelei/Namaste/Ni hao/Ola/Hello, my name is Christianah Adesina. I am currently a student, undertaking the Doctor of Health Science programme at Auckland University of Technology (AUT). I am inviting you to share your views with me on how you care for the residents living with dementia who like to walk, who are referred to as 'wanderers'. Dementia continues to increase in our communities with some residents having walking behaviour and this behaviour is seen differently by each person.

Your participation is voluntary (your choice) and you are free to withdraw at any time during the research without any disadvantage to you. If you do want to participate now and change your mind later, you can pull out of the study at any time and no further information will be collected from you. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What is the purpose of this study?

The purpose of this study is to find out various relational and supportive interventions that residential care staff, that is, Registered Nurses, Enrolled Nurses and Health Care Assistants provide for residents with dementia who like to walk and to find out their views on the walking behaviour. This study is not sponsored by any organization. I am carrying out the study to complete the programme.

How was I identified and why am I being invited to participate in this research?

You were identified because you are a staff working at the facility, caring for residents living with dementia who like to walk.

You are being invited to participate in the study because of the following:

- You are a registered nurse, an enrolled nurse, or a health care assistant working at the facility
- You have been looking after residents with dementia who like to walk for about three months
- You are willing to share your experience and views on the interventions you provide for them and what their walking behaviour means to you
- You are willing to share your perspectives in an interview with the researcher for up to one hour

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What will be done during the study?

- The whole study will be in two stages, approximately 16 hours in total, to be carried out between two to four weeks
- During the first stage of the study, the researcher will observe nurses' and families' interactions with the residents who consented to participate in the study, in the public spaces of the facility such as in the dining room, lounge, activity room and in the hallway
- The researcher will not take record of anything said or done by any person who has not consented to participate but who happens to be at the place of observation
- During the second stage, (which may be the same day or another negotiated day), the researcher will carry out interview with you at an allocated room in the facility. You are free to bring a support/cultural person with you if you wish to do so
- The interview will be up to one hour, it will be audio-recorded, and notes will be taken by the researcher
- The recorded interview will be anonymised, your name will be removed and replaced with a code
- A professional who has signed confidentiality agreement will transcribe the interview

What are the possible benefits of the study?

- There is no personal benefit to you from participating in this research, however, your participation is likely to help find out about interventions being provided for the population of the study. I am very much interested to hear about your practice experience on what works best in supporting residents with these walking behaviour and what the challenges are.

What are the possible risks?

- There is no foreseeable risks in participating in this study, However, there may be a potential risk when your observations are critical of the residential facility. In this case, your privacy will be maintained throughout, except when you have given consent to the researcher to discuss this with the facility
- If at any stage you feel uncomfortable, you can ask to move to the next question or ask the interviewer to stop. There will be no consequence for you if this happens and data may be destroyed if you wish so. Your privacy will be maintained but if in the final stage of analysis, this may be difficult to retrieve.
- I will uphold ethical standards of beneficence (doing good); non-maleficence (do no harm) and justice (providing health equity). I will respect and maintain your dignity. I will also apply the three principles of the Treaty of Waitangi/Te Tiriti o Waitangi throughout the study and acknowledge the whakapapa (genealogy) of all participants.

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- Telephone contact details of support services are provided on this information sheet if you need support or counselling services

What will happen to my information? How will my privacy be protected?

- The information you provide during interview will be kept private and confidential. Any information that identifies you will be replaced with a code in any report generated and will not be used in future research.

How will information collected be managed?

- Any information that can identify you will be removed and your details will not be included in any report or future research
- To maintain confidentiality, information that identifies you will be replaced with a code in any report generated from the study
- The information you provide may be added to other information from other studies to form a larger set of information

Security and Storage of your Information

- All information provided during interview will be stored as electronic data, secured in an external hard drive, password-protected and locked in the cabinet following AUT protocol and guidelines. Data generated will be stored for a minimum of six years and finally destroyed according to AUT protocol.

Who do I contact for more information or if I have concerns?

Name: Dr Catherine Cook
Position: Senior Lecturer (Primary Supervisor)
Auckland University of Technology, North Campus
Telephone number: (09) 921 9999 ext 6651
Email: Catherine.Cook@aut.ac.nz

Name: Dr Elissa McDonald
Position: Senior Lecturer (Secondary Supervisor)
Auckland University of Technology, North Campus
Telephone number: (09) 921 9999 ext.7656
Email: Elissa.McDonald@aut.ac.nz

Employee Assistance Programme (EAP):
Your facility will contract to an Employee Assistance Programme (EAP) Provider and you are entitled to free counselling sessions with them or **free call 0800 327 669** for enquiries

Independent health and disability advocate:

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Approved by Auckland University of Technology on 01/03/2021. Ref.: 21/47

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Telephone:	0800 555 050
Fax:	0800 2 SUPPORT (0800 2787 7678)
Email:	advocacy@advocacy.org.nz
Website:	https://www.advocacy.org.nz/

Health and disability ethics committee (HDEC):

Telephone:	0800 4 ETHIC
Email:	hdecs@health.govt.nz

Age Concern New Zealand Counselling Service
Telephone: (09) 279 4331

Are you anxious, overwhelmed, feeling down or just want to chat with someone?
Free call or text 1737 at any time (a free service to all New Zealanders)

I will be attending a scheduled staff meeting and Information session at your facility early to middle of 2021, to introduce the study. I will explain the study in detail and the recruitment process which include a selection process on how to be a participant. I will also answer your questions on the study. Invitation to participate will be made and Participant Information Sheets and Consent Forms will be provided. A list of interested participants will be collected at the end. Follow-up contact will be made only with those who have signed the written consent form within a month and an agreed date will be set for the start of the study.

Please keep this Information Sheet and the copy of your signed Consent Form for your future reference.

I do hope that you find the information about this study useful and that you choose to participate. If so, your contribution will be invaluable to the study. I am looking forward to working with you.

Kia Ora/Fa'a fetai/Mālō 'aupito/Dhanyavaad/Salamat/Xiexie/ Thank you so much!

Christianah Adesina
Doctor of Health Science (DHSc) student,
Auckland University of Technology (AUT)

Faculty of Health & Environmental Science

Telephone: 021 089 16463

Email: vrb7730@autuni.ac.nz

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Consent Form for Residential Care Staff

Please read and sign the declaration below:

I have read and understood the Participant Information Sheet.		
I have been given sufficient time to consider whether or not to participate in this study.		
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.		
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without any disadvantage to you.		
I understand that if I choose to withdraw from the study, I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.		
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study or in future research.		
I understand that all electronic data will be stored in external hard drive, password-protected and locked in the cabinet as per AUT protocol and data generated will be stored for a minimum of six years and finally destroyed as per AUT protocol		
I know who to contact if I have any questions about the study in general.		
I understand my responsibilities as a study participant.		
I wish to receive a summary of the results from the study (please tick one box as preferred).	Yes ☐	No ☐

Approved by Health & Disability Ethics Committee on 28/01/2021. Ref.:20/STH/162
Approved by Auckland University of Technology on 01/03/2021. Ref.: 21/47

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Declaration by participant:

I hereby consent to take part in this study.

Participant's name: Contact No:

Designation (Pls indicate title(s), e.g. Business & Care Manager/Clinical Manager/RN/EN/HCA/etc.):

Signature: Date:

Postal address/Email address if you want summary of study at the end (Optional):

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: Christianah Adesina

Signature: Date:

Approved by Health & Disability Ethics Committee on 28/01/2021. Ref.:20/STH/162
Approved by Auckland University of Technology on 01/03/2021. Ref.: 21/47

Appendix I. In-depth interview question for residents with dementia who walk

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Question Guide: Interview with Residents living with dementia who like to walk

Project Title: How do *nurses care for residents living with dementia who like to walk?
Project Primary Supervisor: Catherine Cook
Project Secondary Supervisor: Elissa McDonald
Researcher: Christianah Adesina

Introduction & Welcome: My name is Christianah, a Doctoral student from AUT. I am carrying out a research at your facility to find out how nurses care for you (Researcher speaks slowly, maintains eye contact and pauses to wait for them to be ready, respecting their persons)

- **Lead off question1**: I can see your body wants to walk a lot, what is that like for you? (Researcher pauses and waits for them to respond with great flexibility and patience. Depending on their ability to engage in more conversation, researcher follows up with some of these prompt questions: (Is it tiring to walk? Does walking make you happy? Do you like to walk by yourself? Do you like to walk with someone? Do you feel safe to walk? Do people ever stop you from walking? Is it hard to stop walking? **Please tell me about that…)
- **Question 2**: Depending on response received to the lead off question above and if they are able to accommodate it, a follow-up question that can be asked such as "Do the nurses try to stop you when walking? When you walk, what would you like nurses to do?

Closing: Thank you for your time.

*Nurses are used here to represent Registered Nurses, Enrolled Nurses and Health Care Assistants for the residents living with dementia who walk so as not to confuse them in having to differentiate the roles.
** Please tell me about that ..." This method will be applied to the second and third question with great flexibility and patience on the part of the Researcher)

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Approved by Auckland University of Technology Ethics Committee on 01/03/2021. Ethics ref: 21/47
Amendment approved by Health & Disability Ethics Committee. Letter dated: 29/06/2021.Ethics ref: 20/STH/162/AM01
Amendment approved by Auckland University of Technology Ethics Committee on 23/07/2021. Ethics ref: 21/47

Appendix J. In-depth interview questions for Enduring Powers of Attorney

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Questions Guide: Indepth interview of Whanau/Carer of Resident living with dementia who like to walk

Project Title: How do residential care staff use relational and supportive interventions for residents living with dementia who like to walk?

Project Primary Supervisor: Catherine Cook

Project Secondary Supervisor: Elissa McDonald

Researcher: Christianah Adesina

Introduction: Welcome & purpose of the study to be stated again

1 **Lead off question:** Before your family member came to live in the facility, what impact did caring for them have on your life? (*Please tell me more…)

2 Were there safety issues when you looked after them at home?

3 What was it like for you to look after a family member/spouse/partner/friend with dementia who walked?

4 What does their walking behaviour mean to you?
- Was there any particular thing that increased their desire to walk?
- Was there any particular thing that reduced their desire to walk?

5 What did you normally do for them when they started walking or when they walked?:
- How far did they walk from where you both lived?
- Give an example of how you cared for them when they walked

Approved by Health & Disability Ethics Committee on 28/01/2021. Ethics Ref :20/STH/162
Approved by Auckland University of Technology Ethics Committee on 01/03/2021. Ethics ref: 21/47
Amendment approved by Health & Disability Ethics Committee. Letter dated: 29/06/2021.Ethics ref: 20/STH/162/AM01
Amendment approved by Auckland University of Technology Ethics Committee on 23/07/2021. Ethics ref: 21/47

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6 What particular thing(s) did you do that worked in stopping them from walking? What particular thing(s) did not work in stopping them from walking?

7 What difficulties or barriers did you face when caring for them at home?

8 What support did you receive from government, agency or organisation when caring for your family member/spouse/friend at home?

9 What suggestion(s) do you have for the facility caring for them now?

10 What suggestion(s) do you have for policymakers/government regarding their care?

11 What would you like to see implemented in order to enhance the care of persons living with dementia who walk?

12 Do you have any other comment to contribute to this research?

Closing: Thank you so much for your time.

*("Please tell me more …"). The Researcher will use this statement where appropriate to build on participant's response at specific time(s). This is to be able gain more details and specific experience of the participant on that question where possible.

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Appendix K. In-depth interview questions for Residential Care Staff (RNs and HCAs)

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Questions Guide: In-depth interviewing of Residential Care Staff (Registered Nurses, Enrolled Nurses & Health Care Assistants)

Project Title: How do residential care staff use relational and supportive interventions for residents living with dementia who like to walk?

Project Primary Supervisor: Catherine Cook

Project Secondary Supervisor: Elissa McDonald

Researcher: Christianah Adesina

Introduction & purpose of the study to be explained again, apart from when signing the consent form

Some lead off questions will develop from what was observed during Participant observation, so Researcher will start the interview like:

1. I noticed that when you were walking with the resident, they wanted to see what was in the dining room or go out of the facility. I'm really keen to understand how you managed that. (*Please tell me more … What strategies would you like to use to see a different result such as, if you would want them to go to the lounge instead?)
2. What training or education have you had on how to manage this walking behaviour in residents with dementia?
3. Does your facility have a guideline on how you care for the residents with dementia who walk or is it something you figure out by yourself and if there is guidelines, do you follow this all the time?
4. What is it like for you to care for a resident with dementia who like to walk and how does it affect you or your workload?
5. Please give an example of a time you cared for a resident with dementia that walked and what interventions you provided for them?
6. What does their walking behaviour mean to you?
7. What do you think walking behaviour mean to the resident with dementia who walk?
8. What other tasks/workload did you have when managing their walking behaviour?

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9. Please give me an example of another resident with dementia who walked and what did you do for them?
10. Are there safety issues in their walking behaviour?
11. When residents with dementia walk, are there workload issues that you are concerned about?
12. Which other staff are involved in providing these interventions with you?
13. In your experience, what are the difficulties, barriers or benefits in providing these interventions?
14. How do the residents that walk relate with the other residents in the facility who do not walk? Please provide an example such as if they enter other residents' rooms, or go through their possessions and what was the reactions from the other residents?
15. How well do you think the built-in environment help people to walk or not to walk?
16. You may be aware that medication is often used to manage this behaviour. What in your view is the place of medication in looking after the residents with dementia who walk? Do you apply medications to them? What is this medication called? Are medications used by other staff in the facility to manage walking behaviour of these residents with dementia?
17. What particular intervention did you carry out that in your view that worked in stopping residents with dementia from walking and what interventions did not work?
18. What suggestion(s) do you have for the facility to help with caring for these residents?
19. What suggestions do you have for policy makers or government in caring for these residents?
20. What would you like to see implemented in order to help with the care of these residents?
21. Do you have any other comment to contribute to this research?

Closing: Thank you so much for your time.

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*("Please tell me more …": The Researcher will use this statement where appropriate to build on participant's response at appropriate time(s). This is to be able gain more details and specific experience of the participant on that question)

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Appendix L. Confidentiality Agreement for Transcriber

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Confidentiality Agreement for Transcriber

Study Title: How do residential care staff use relational and supportive interventions with residents living with dementia who like to walk?

Primary Supervisor: Dr Catherine Cook
Secondary Supervisor: Dr Elissa McDonald
Researcher: Christianah Adesina

- I understand that all information I will be asked to transcribe is confidential
- I understand that all the contents of the audio recorder/tape can only be discussed with the researcher
- I will not keep any copy of the audio recording or transcripts nor allow a third party to access them

Transcriber's name: ……
Transcriber's signature: ……...
Transcriber's contact details: ……
Date: ……

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Amendment approved by Health & Disability Ethics Committee. Letter dated: 29/06/2021.Ethics ref: 20/STH/162/AM01

Appendix M. Confidentiality Agreement for Proofreader/Formatter

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Confidentiality Agreement for Proofreader/Formatter

Research Title: How residential care staff provide relational and supportive interventions for residents living with dementia who walk

Primary Supervisor: Associate Professor Tula Brannelly
Researcher: Christianah Adesina

- I understand that all information in the thesis I am asked to proofread/format is confidential
- I understand that all the contents of the thesis can only be discussed with the researcher
- I will not keep any copy of the thesis nor allow a third party to access them.
- I will delete the copy from my computer/drive/cloud as soon as work is completed.

Proofreader/Formatter's name:

……

Proofreader/Formatter's signature:

……

Proofreader/Formatter's contact details:

……

Date: ……

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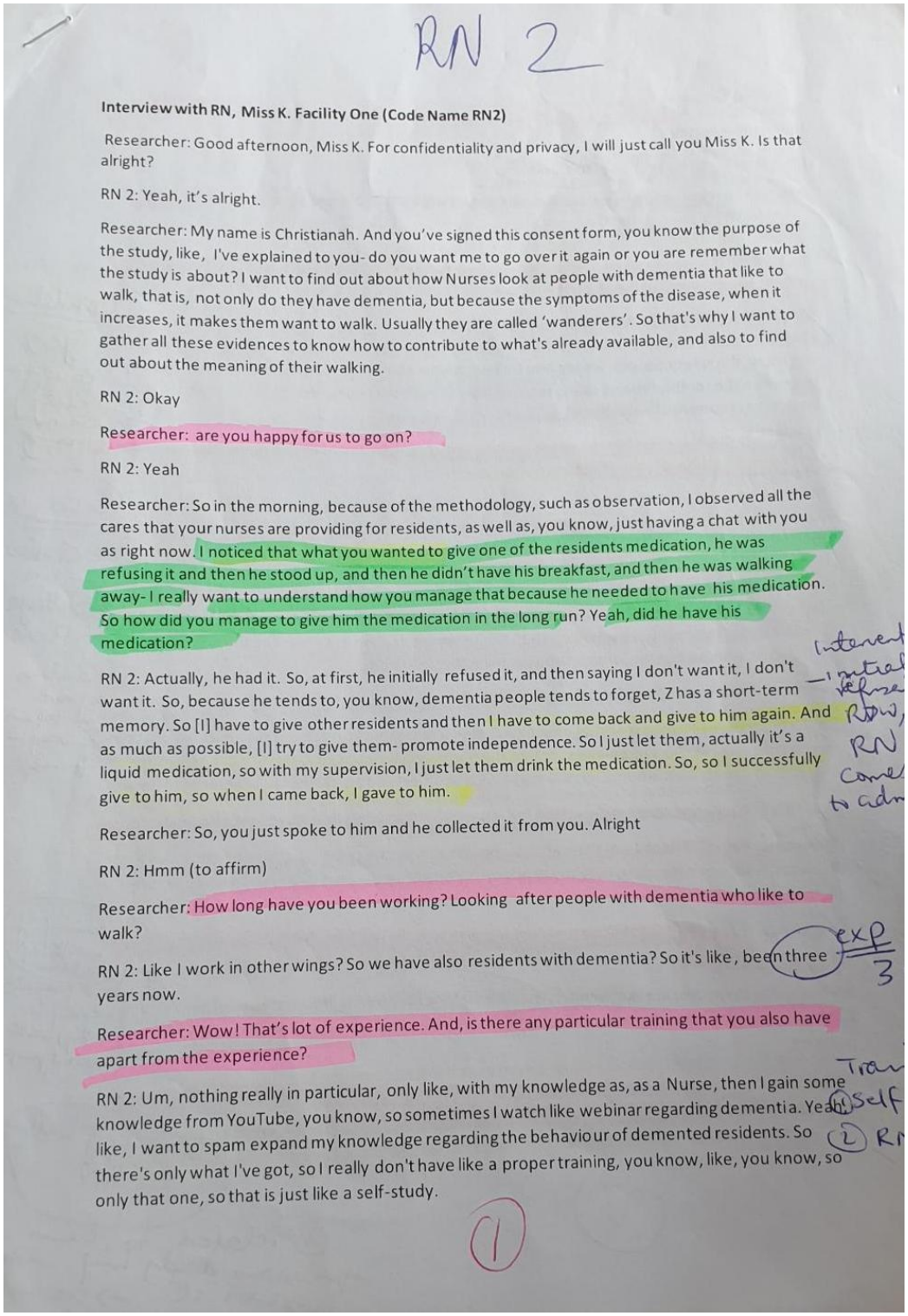
Appendix N. Example: Phase One Reflexive Thematic Analysis



RN 2

Interview with RN, Miss K. Facility One (Code Name RN2)

Researcher: Good afternoon, Miss K. For confidentiality and privacy, I will just call you Miss K. Is that alright?

RN 2: Yeah, it's alright.

Researcher: My name is Christianah. And you've signed this consent form, you know the purpose of the study, like, I've explained to you- do you want me to go over it again or you are remember what the study is about? I want to find out about how Nurses look at people with dementia that like to walk, that is, not only do they have dementia, but because the symptoms of the disease, when it increases, it makes them want to walk. Usually they are called 'wanderers'. So that's why I want to gather all these evidences to know how to contribute to what's already available, and also to find out about the meaning of their walking.

RN 2: Okay

Researcher: are you happy for us to go on?

RN 2: Yeah

Researcher: So in the morning, because of the methodology, such as observation, I observed all the cares that your nurses are providing for residents, as well as, you know, just having a chat with you as right now. I noticed that what you wanted to give one of the residents medication, he was refusing it and then he stood up, and then he didn't have his breakfast, and then he was walking away- I really want to understand how you manage that because he needed to have his medication. So how did you manage to give him the medication in the long run? Yeah, did he have his medication?

RN 2: Actually, he had it. So, at first, he initially refused it, and then saying I don't want it, I don't want it. So, because he tends to, you know, dementia people tends to forget, Z has a short-term memory. So [I] have to give other residents and then I have to come back and give to him again. And as much as possible, [I] try to give them- promote independence. So I just let them, actually it's a liquid medication, so with my supervision, I just let them drink the medication. So, so I successfully give to him, so when I came back, I gave to him.

Researcher: So, you just spoke to him and he collected it from you. Alright

RN 2: Hmm (to affirm)

Researcher: How long have you been working? Looking after people with dementia who like to walk?

RN 2: Like I work in other wings? So we have also residents with dementia? So it's like, been three years now.

Researcher: Wow! That's lot of experience. And, is there any particular training that you also have apart from the experience?

RN 2: Um, nothing really in particular, only like, with my knowledge as, as a Nurse, then I gain some knowledge from YouTube, you know, so sometimes I watch like webinar regarding dementia. Yeah, like, I want to spam expand my knowledge regarding the behaviour of demented residents. So there's only what I've got, so I really don't have like a proper training, you know, like, you know, so only that one, so that is just like a self-study.

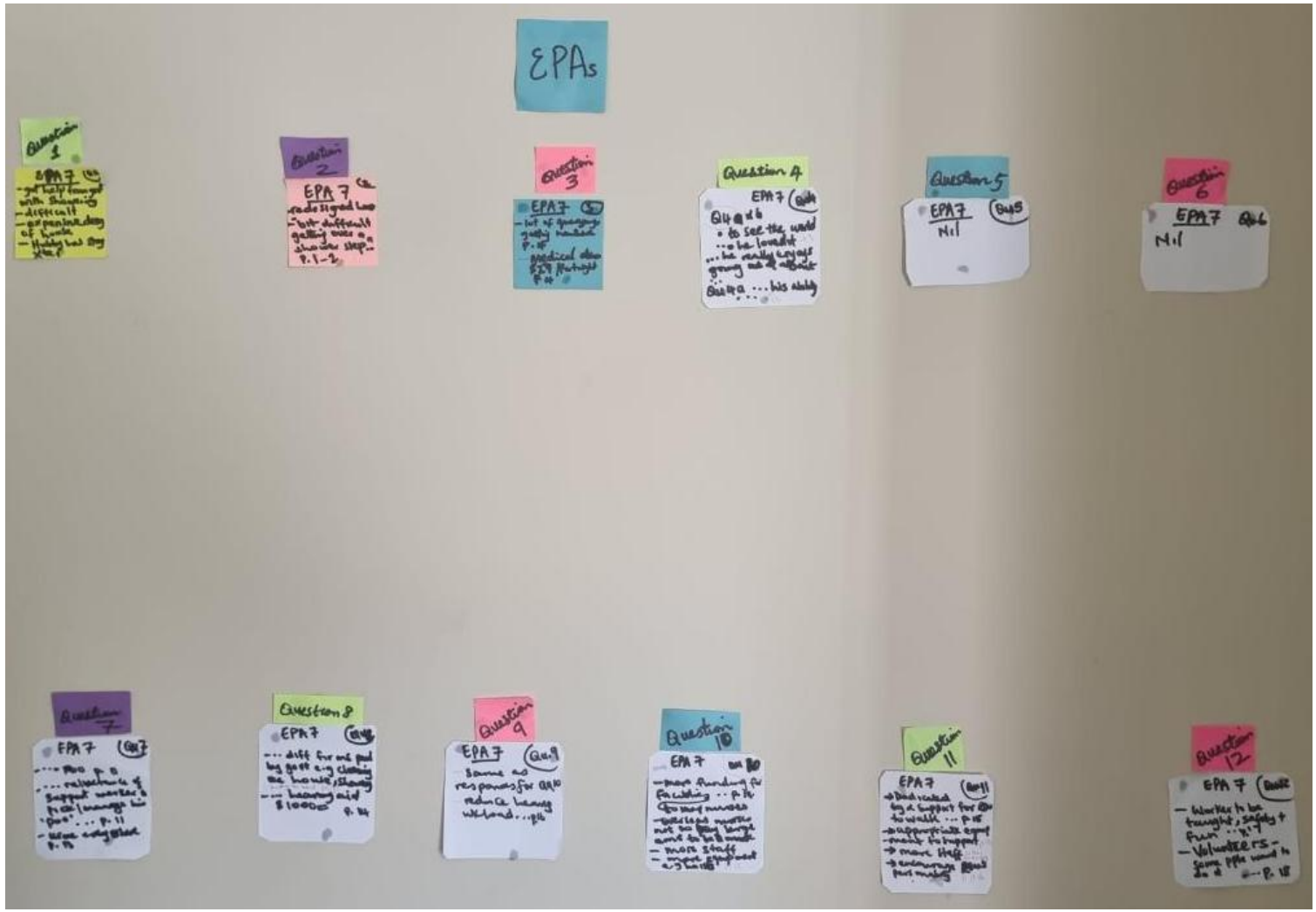
(1)

Appendix O. Example: Thematic Analysis Phase One to Two (copy one)

Appendix P: Example Thematic Analysis Phase Two

I need to make sure the suitability of the patient to come to [our facility]. [Our facility] is not a secured facility, we're only allowed to look after rest home and hospital level of care. So that's one of the things that as a as a team, we have to get the background information about the patient so that we can understand the need. And from there, we will be able to discuss as to how we will be able to manage the behavior. Researcher: Umm RN3: So once the patient is here, we also need to understand that number one, having to have a change in the environment, environment can make them unsettled. And apart from that, it's also got to deal with the different faces of the staff. So what we would normally do is, especially if we have got someone that's been referred from the community, or referred from [public hospital name withheld for privacy reason], hospital Ward [privacy], that deals with geriatric, er, psychogeriatric residents, we do, number one, we put in place and the behavior monitoring. And normally the behavior monitoring, we will do that between two to three weeks, because the behavior monitoring will be used as a form of documentation to identify trends of the behavior of the patient. And at the same time, it's also a way for us to present to the mental health team, if there are things that we're not able to manage, or perhaps if we're needing more support from them. And of course, it's also having to	• If RDW has changing behaviour, will discuss with the Mental health team • Got backgd info of RDW to determine their needs • New environment & new staff faces trigger changing behaviour in RDW • Behaviour monitoring chart to identify the

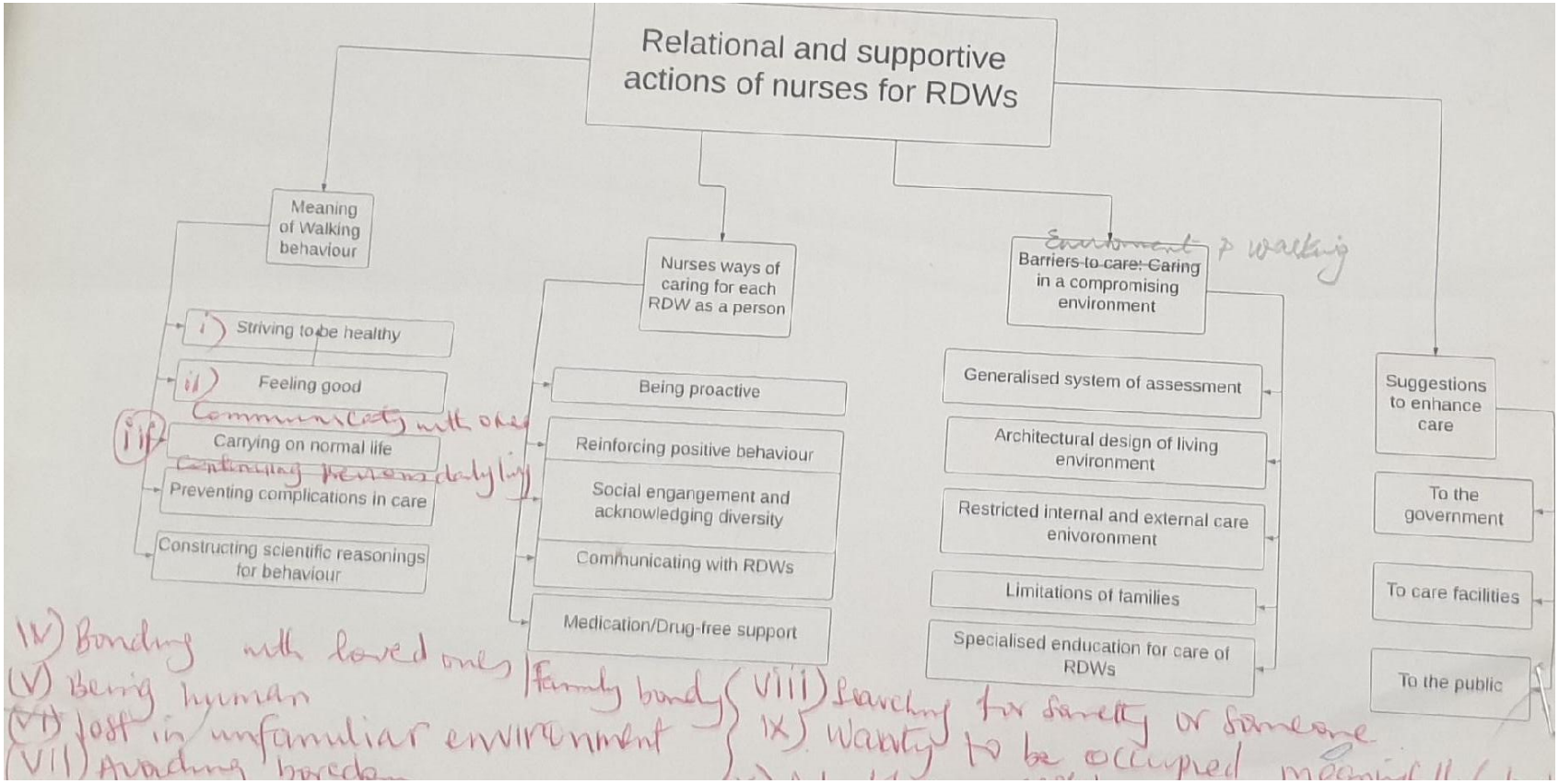
Appendix Q. Example: Phase Two Thematic Analysis- -EPAs dataset



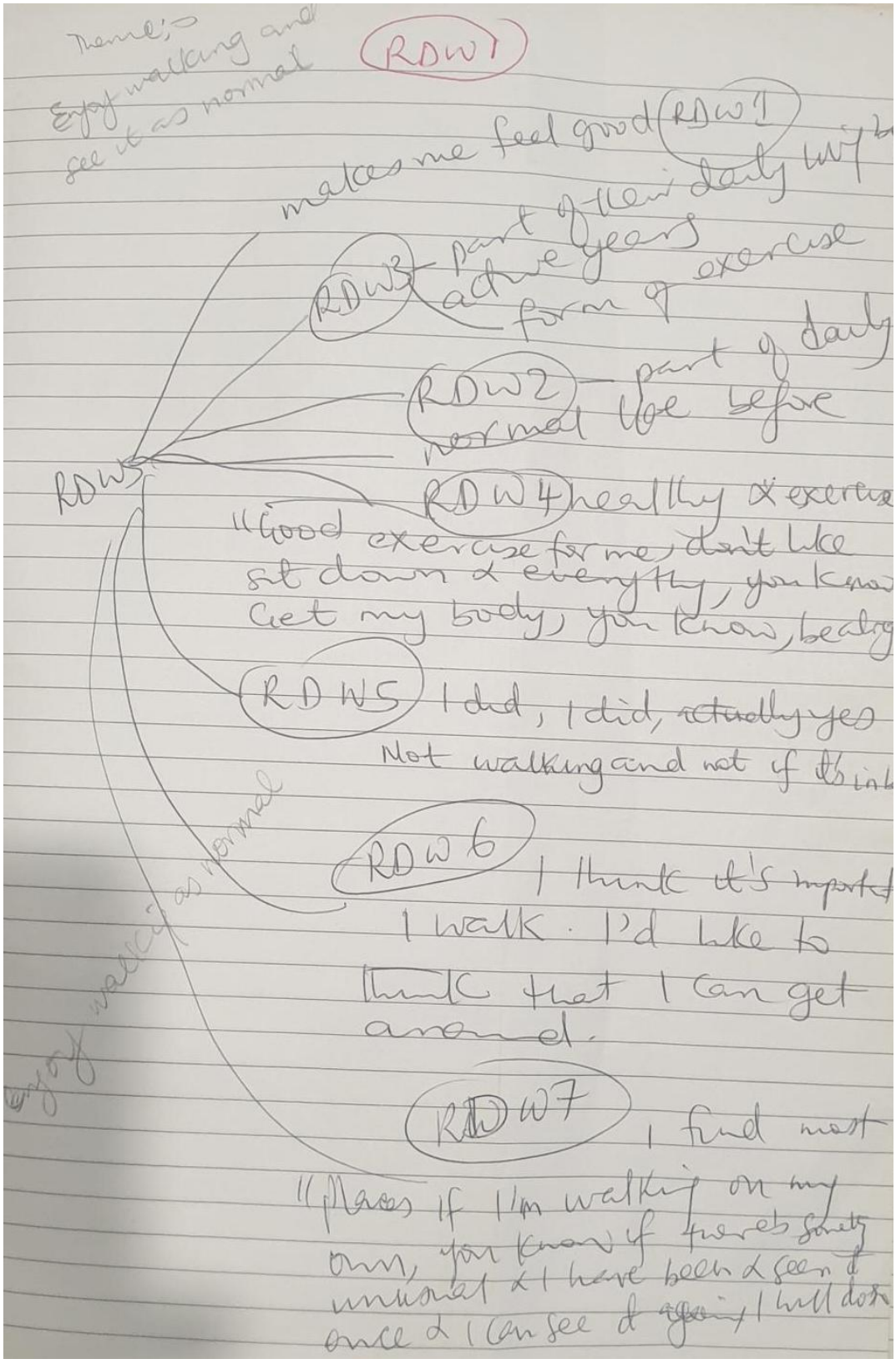
Appendix R. Example: Thematic Analysis Phase Three (copy one)

29	Have guidelines and protocols in caring for RDWs	5	5
30	Healthcare agencies to employ and equip staff with skills	1	1
32	Intervention -assess pain, mobility ensure safety, reprioriti	2	2
34	Intervention- diversion- from unrealistic expectations-war	3	4
35	Intervention- Observe and take proactive steps	1	1
36	Intervention- Redirection and persuasive explanation with	3	6
37	Intervention-Ask your colleague for help or work as buddi	3	3
38	Intervention-caring for them as a person	1	1
39	Intervention-Encourage them, provide safe tools for them	2	3
40	Intervention-First assess if there have needs they cannot	1	1
41	Intervention-Giving books in the language of RDWs to ke	1	1
42	Intervention-Lead and they follow you to sit down; provid	1	1
43	Intervention-Monitoring for balance between independer	2	2
44	Intervention-need to undestand them-give them tasks to	1	2
45	Intervention-Research the benefits of ready and occupyin	1	1

Appendix S. Example: Phase Five Thematic Analysis



Appendix T. Example-Residents' Dataset: Thematic Analysis-Phase Three



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