

“I am not dementia”.

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*Lived Experiences of Younger People with Dementia  
and their Spouses*

**Maria Therasa Cainto-Co, RN, PG Dip Merit (HSc)  
Advanced Nursing**

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## **Abstract**

**Context:** An estimated 70,000 people in New Zealand (NZ) have dementia. Most of these people are over 65, but a significant number, approximately 5,000, of younger people are in the early stages of building a life with a partner and family.

**Aim and Objectives:** This study describes the lived experiences of younger people with dementia and their spouses. Objectives: 1) Provide a space for younger people with dementia and their spouses to talk about their thoughts and feelings and share the meanings they give to their lived experiences. 2) Describe the couples' relational dynamics and discover how their relationship evolves. 3) Present evidence of individual and shared adjustments for coping with dementia and translate this information into social and health service provisions for young people with dementia (YPWD) and their carers.

**Methods:** The participants were young people with dementia and their partners who live in Auckland, New Zealand. Their lived experiences were portrayed using Interpretative Phenomenological Analysis (IPA). Four couples were recruited from a local dementia support service. They were interviewed twice, in a dyad and individually, using a semi-structured interview approach. The interview transcripts were analysed inductively for common themes. Member validation confirmed and clarified the researcher's interpretation of the data.

**Results:** Three themes were: 1) Factors that affected the couples' lives the most, 2) Coping with dementia, and 3) Changes in spousal dynamics.

**Conclusion:** YPWD and their carers have unique experiences distinguishing them from older adults with dementia (OAD). These differences must be carefully considered to enable age-appropriate services for this minority group.

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## **Chapter 1 – Introduction**

This chapter is divided into eight sections – statement of the problem, purpose of the research, historical context of people living with dementia (PLWD) in research, shifting the focus to YPWD, aims and objectives, research questions, glossary of definitions, and the background of the researcher.

### **1.1 Statement of the Problem**

Dementia is a global health priority being in the top ten causes of death and a primary cause of older people’s disability and dependency (World Health Organisation, 2021). Fifty-five million people live with dementia worldwide, with 10 million diagnosed yearly; prevalence is expected to triple in the next three decades (World Alzheimer Report 2021). However, less than 25% are diagnosed worldwide, with less than 10% in lower-income countries (Gauthier, Rosa-Neto, Morais, & Webster, 2021).

New Zealand faces a crisis with a projected 240 percent increase in numbers in the next 30 years over the estimated 69,713 people living with dementia (PLWD), about 1.4% of the country’s population (Dementia Economic Impact Report or DEIR, 2020). Most PLWD are over 65 years old and comprise 8% of the 65+ population (Ma’u, Cullum, Yates, Te Ao, Cheung, Burholt, Dudley, Krishnamurthi, & Kerse, 2021). According to Dementia Auckland’s former Operations Manager, Barbara Fox (2019), approximately 18,000 people, the largest number in NZ, live in Auckland –

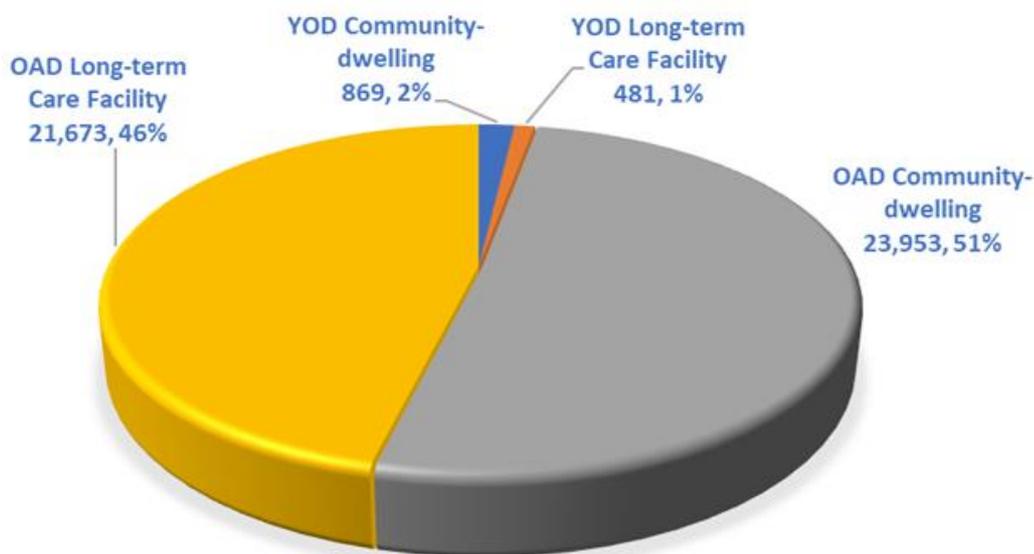
10,000 in residential care and 8,000 community-dwelling. Of the 8,000 in the community, over 2,600 were registered with Dementia Auckland (DA) services. Not everyone with dementia accesses DA's services because they may not be diagnosed yet, are getting support from others, or may have just recently been diagnosed and are unaware of DA's services (Fox, 2019).

Seventy percent of PLWD access government support services (Ryan, Martinez Ruiz, Rivera-Rodriguez, Curtis, & Cheung, 2021). YPWD in New Zealand have unique needs than the older cohorts and different clinical care and support service needs (Ryan et al., 2021). Table 1 and Figure 1 illustrate the people with young-onset dementia (YOD) and older adult dementia (OAD) in New Zealand from 2016-2019 who accessed publicly funded services reported by Ryan et al. (2021).

**Table 1: People with YOD and OAD in New Zealand based on interRAI from 2016-2019**

Variable	YOD	OAD
Community-dwelling	869	23,953
Long-term Care Facility	481	21,673
Total per age group	1350	45,626
Overall total	46976	
6.9% not accounted for	2,407	
<b>Total number of Diagnosed PLWD in NZ</b>	<b>49,383</b>	

**Figure 2: People with YOD and OAD in New Zealand based on interRAI from 2016-2019**



## 1.2 Purpose of the Study

There's still more to uncover about the lived experiences of PLWD and their spouses (Alzheimer's Disease International, 2015). While a tremendous body of knowledge about older people with dementia and their caregivers has helped foster the development of support programmes suited to their needs (Williams, 1995), a major gap remains in understanding YPWD and their caregivers' lived experiences.

The younger cohort represents an important and distinctive perspective from a psychosocial and medical point of view (Harvey, Roques, Fox, & Rossor, 1998; Luscombe, Brodaty, & Freeth, 1998; cited by Clemerson, Walsh, & Isaac, 2014; Ryan et al., 2021). YPWD deal with the same difficult symptoms as their older counterparts but with the added

problems of being at a stage in their life cycle where they focus on their careers and financial commitments and often have a young family to support (Armstrong, 2003). The psychosocial contexts of mid-life versus old age are intrinsically divergent, which is why both groups experience and cope with dementia differently (Clemerson et al., 2014).

### **1.3 Historical context of PLWD in research**

Research with the participation of PLWD started in the 1990s (Murphy, Jordan, Hunter, Cooney, & Casey, 2015). Before then, PLWD were excluded from research involvement due to concerns about communication and their capacity for informed consent (Phillipson & Hammond, 2018). This mindset of perceived difficulties (Taylor, DeMers, Vig, & Borson, 2012) or limited perceived value of participant inclusion (Wilkinson, 2002) denied any capacity PLWD had to be involved in research, resulting in intentionally excluding them from the whole process. The obstruction was also caused by the notion that testimonies of people with dementia are not reliable (Lloyd, Gatherer, & Kalsy, 2006; Smebye & Kirkevold, 2012). To describe the experience of dementia, researchers used 'proxy accounts' from the carers (Cotrell & Schultz, 1993; Downs, 1997). Although accounts by proxy have been insightful and valuable, evidence has shown that there are significant differences in the experiences and perceptions of quality of life among the people living with dementia and their carers (Cahill, O'Shea & Pierce, 2012; Gra'ske, Fischer, Kuhlmeij, & Wolf-Ostermann, 2012; Hellstro'm, Nolan, Nordenfelt & Lundh, 2007; Keady, 1996; Clarke, & Keady, 2002; Moore & Hollett, 2003;

Sands, Ferreira, Stewart, Brod, & Yaffe, 2004). It has become clear that to describe the experiences and meaning of living with dementia, we must learn from the PLWD themselves (Cahill et al., 2012; Cotrell & Schulz, 1993; Wilkinson, 2002).

People with dementia have a lot of potential as “active, insightful, and meaningful contributors to the research process” (Phillipson & Hammond, 2018, p. 10). Deviating away from the deficit-based pathological lens (Behuniak, 2011; Kitwood, 1997), people with dementia can engage as storytellers, designers, meaning-makers, filmmakers, and co-researchers (Phillipson & Hammond, 2018). Beattie, Daker-White, Gilliard, and Means (2004) challenged researchers to ask, “What are the ways to promote inclusive and participatory research for people with dementia?” rather than “Should we include the person with dementia?” (p. 366). Wilkinson (2002, p. 20) emphasized: “Not only is progression to inclusionary research an essential requirement for the development of services that meet the needs of individuals, it is an ethical and moral underpinning on which dementia research can move forwards.”

#### **1.4 Shifting the focus to YPWD**

At the ages of 40 to 65, people go through the seventh stage of psychosocial development called ‘generativity vs. stagnation,’ defined by “building a life, mastering a career and contributing to wider society, and identity during this stage is primarily defined by work and relationships with others” (Erikson, 1963, as cited by Clemerson et al., 2014, p. 452). The middle-aged YPWD misses the challenge of generativity versus stagnation

characteristic of their life stage (Clemerson et al., 2014) because their illness is progressive and irreversible, causing multiple disabilities (Peri in Prasadarao, 2014).

Carers of people with OAD experience “perceived stress and burden, chronic fatigue, lowered immune system, psychological distress, psychotropic drug use, depression, and even mortality have been amply documented in the literature” (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, 2013, p. 634). Studies of YOD are comparatively limited, and those researching the experiences of the spouses of YPWD are even fewer (Roach, Keady, Bee, & Hope, 2008).

### **1.5 Aims and Objectives**

Aim: To describe the lived experiences of younger people with dementia and their spouses.

Objectives:

- 1) To provide a space for younger people with dementia and their spouses to talk about their thoughts and feelings and share the meanings they give to their lived experiences.
- 2) To describe the couples’ relational dynamics and determine how their relationship evolves.
- 3) To present evidence of individual and shared adjustments for coping with dementia and translate this information into social and health service provisions for YPWD and their carers.

## 1.6 Research Questions

The central research question is, “What are the lived experiences of younger people with dementia and their spouses?” The meanings of the couple’s shared experiences were explored with three subordinate questions:

- 1) What are the greatest impacts of dementia on the couples’ day-to-day experiences?
- 2) How are they coping with the illness within their life cycle?
- 3) How has their relationship evolved because of dementia?

## 1.7 Glossary of Definitions

1. *Lived experience* refers to the representation and understanding of a person’s experiences, options, and choices and the knowledge gained from these (Given, 2008).
2. *Young-onset dementia* will be used interchangeably with the acronym YOD. The young person with dementia will also be referred to using the abbreviation YPWD. Younger-onset dementia describes any form of dementia diagnosed amongst people under age 65 (Ferran, Wilson, Doran, Ghadiali, Johnson, Cooper, & McCracken, 1996), also known as early-onset dementia.
3. *Carer* refers to the cohabiting spouse or de facto partner of the younger person with dementia. In this study, the spouse or partner has identified themselves as the primary caregiver of the person with dementia (Ducharme et al., 2013). The spouse or partner is also considered an informal carer (usually family, whanau, or

friend) who provides regular and ongoing care without payment (Jorgensen, Parsons, Jacobs, & Arksey, 2010).

4. *Anosognosia* is caused by physical changes in brain cells resulting in a person's inability to become aware of their illness or perceive their condition accurately. The person is unaware of their decline or difficulties, so the need to rectify anything may not be expected; it is not the same as denial (Kashiwa, Kitabayashi, Narumoto, Nakamura, Ueda, & Fukui, 2005).

NB: A list of Abbreviations is in Appendix A.

### **1.8 Background of the Researcher**

I was first introduced to dementia in the Philippines without knowing it. Some older adults I knew returned to being child-like in their ways and became forgetful or *ulyanin*, as we call it. It was believed to be an ordinary course of ageing; people laughed or joked about it, and it was not taken too seriously. That was through the eyes of a child who did not know any better.

Many years later, I was an internationally trained student concluding my nursing Competency Assessment Programme in Auckland. I met the wife of someone with severe dementia towards the end of the programme. He was 80 years old and fully dependent on all activities of daily living (ADLs). She was anxious and always beside herself with worry. I lived with them for a few months to help care for Charles (a pseudonym) and provide respite and moral support for his wife.

I also worked in a 39-bed capacity secured dementia facility doing 12-hour shifts. At first, I was scared; I thought I would not be able to see the end of my first day on the job. However, I have learned to love and care for the residents – I knew how to reassure a 90-year-old woman with her stuffed animal and when another resident had a brewing infection. I sang, danced, and laughed with the residents, and I knew each one by heart.

I then worked as a Key Worker for Dementia Auckland for four years, supporting the family/whanau of PLWD. Within the role, I did phone consultations, facilitated support groups for families/whanau, and mediated family meetings. Most of the families I supported dealt with OAD, and the devastation the individuals and their families felt was heart-wrenching. I have tried to help the families in their grief and difficulties and did everything in my role to assist them in navigating through the healthcare system, community support services, and the whole journey.

For people with YOD, the service options were limited. There weren't enough age-specific services catering to their needs. I met Linda (a pseudonym), a carer whose husband had YOD. Herbert (a pseudonym) got lost more than once while she was at work, and Linda was looking for more support options to prevent this from happening. She felt helpless when she was informed that they had been given the maximum allocated care at home. Due to their financial obligations, Linda was not ready to be a full-time carer. She was still supporting their teenage children and paying for their mortgage. Linda was also not yet prepared for Herbert to go into permanent care, for she thought “it will break him.” Owing to these

recurring circumstances, I organised a support group for Linda and other carers in the same situation. The group was later called “The Young Ones” and is still active today.

With everything I know in my professional and educational background, I felt that I had the potential to be an educator. I learned enough to impart my knowledge and experiences to families and whanau of PLWD and health professionals in the same industry. I became a full-time Educator for Dementia Auckland for five years. My primary responsibility was facilitating carer education programmes (CEP) for families/whanau of PLWD in Auckland. I would present about dementia to educate the broader public, break down stigma and teach the community how to best support the PLWD and their families/whanau.

Through the eyes of the child, student, key worker, and educator in me, I have witnessed the difficulties that families experience as one of their relatives gets diagnosed with dementia. I have heard statements about how dealing with dementia is: “possibly the hardest thing they have had to face in their lives” or “is this all there is to life?” On the other hand, I have seen and heard how resilient people can be when they say: “I have learned to be a better person because of dementia” or “I never knew I had all of these strengths in me.” I resonate with what Clare (2002) stated that as a society, our understanding of the experiences of YPWD and their partners would be an essential catalyst for efforts at psychosocial interventions. I hope this paper will contribute to this cause.

## **Chapter 2 – Literature Review**

A systematic search and review of literature were done to identify existing knowledge and trends about YPWD and their spouses' lived experiences and to determine the limitations of and gaps in knowledge, particularly in New Zealand. EBSCOHost Plus search engine enabled multiple online database searches. I utilised CINAHL Plus, MEDLINE, Academic Search Premier, Psychology and Behavioural Sciences Collection, Health Business Elite, Scopus and APA Psycinfo to find relevant research articles from top nursing and allied health journals.

The keywords used were: (Dementia OR Alzheimer\* OR "Lewy body disease" OR "Huntington\* disease" OR "Creutzfeldt-Jakob disease" or frontotemporal or vascular or "multi-infarct") AND ("young\* onset" OR "young\*-onset" OR "early-onset" OR "early-onset" OR "pre-senile" OR "middle age\*" OR midlife) AND ("person with dementia" OR "patient with dementia" OR "dementia patient" OR "people with dementia" OR "someone with dementia" OR "people living with dementia") AND ("significant other" OR spouse\* OR wife OR wives OR husband\* OR partner OR "spousal caregiver" OR partner OR "care partner" OR married OR couple OR "informal carer\*" OR "informal caregiver\*") AND ("lived experience" OR phenomenology OR "life experience" OR experience OR perspective OR narrative OR story).

Search inclusions were: English language only, academic journals published for the past 15 years where abstract is available, and peer-

reviewed articles. Other research platforms used were google scholar, The Dementia Journal in SAGE Publishing, and Research Gate.Net A hand-search of references was made for additional materials. The search yielded 214 articles, none of which were New Zealand based, with one article from Australia. Articles focusing on OAD, non-family members as carers, the bio-medical course of the illness, depression, Down Syndrome, non-research articles, editorials, and articles that highlight non-spouse carers were excluded.

After going through the screening and eligibility phase, ten articles were reviewed – five from the perspectives of the YPWD and five from the caregiving spouse's experiences. Figure 2 illustrates the flow diagram of articles included in the literature review. The identified articles were analysed for significant themes relating to the topic. Table 2 shows a summary of all the articles used.

**Figure 2: Flow Diagram of studies included in the review of literature**

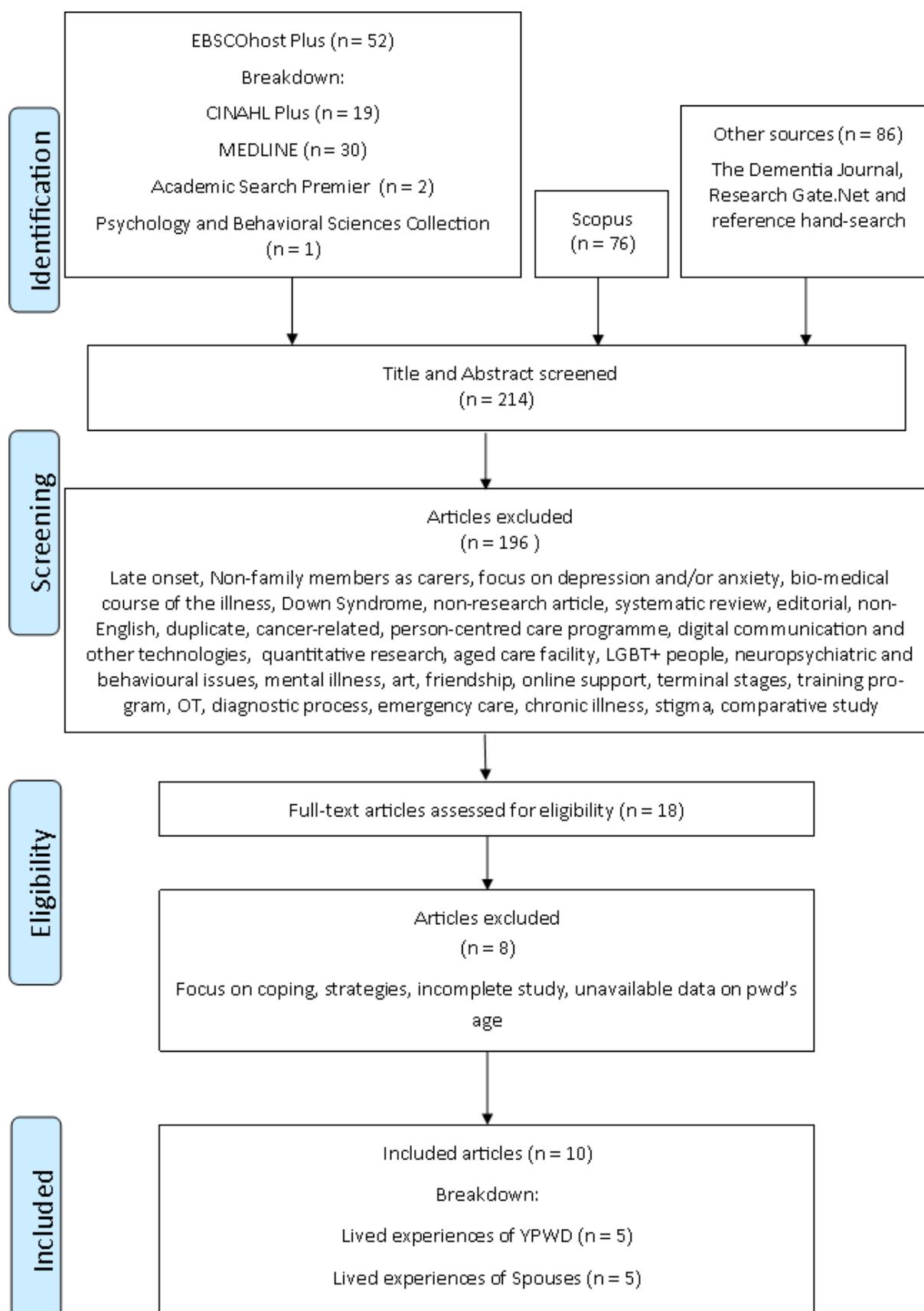


Table 2: Overview of Literature Review Articles

Category	Authors (year)	Purpose	Study Design	Data Collection	Participants	Findings
YOD	Beattie, A., Daker White, G., Gilliard, J., & Means, R. (2004)	To demonstrate how interviews can be conducted with younger people with dementia	Qualitative comparative textual analysis	In-depth interviews	14 younger people with dementia conducted in the South-west of England	4 Themes: 1. The general experience of having dementia 2. Dementia diagnosis 3. The importance of age 4. Risk and danger issues
	Clemerson, G., Walsh, S., & Isaac, C. (2014)	To provide an exploration of the individual's subjective experiences of young-onset AD.  To explore the personal, social and psychological impact of living with the disease in younger life and the processes individuals go through in adjusting to and coping with these experiences.	Interpretative Phenomenological Analysis	Semi-structured interviews	8 participants	4 Themes: 1. Disruption of the life-cycle 2. Identity 3. Social orientation 4. Agency
	Johannessen, A., & Möller, A. (2011)	To find out how people experience living with early-onset dementia, and to assess the implications for practice  To contribute to the development of services for persons with EOD	Grounded Theory	Qualitative interviews	20 informants (aged 54–67 years; 12 of them men) during 2010–2011	2 Themes: 1. The process towards a dementia diagnosis 2. Fighting for dignity
	Pipon-Young, F., Lee, K. M., Jones, F., & Guss, R. (2012)	To develop a broader understanding of the experiences of younger people with dementia  To develop an understanding of the support that has been beneficial  To identify areas in need of change  To draw out the key problem areas with the aim of developing an action based on a problem or problems identified.	Action research methodology across interviews and action research groups	Semi-structured interview	8 interviews 5 action research group 4 written information for other YPWD	3 Main Themes: 1. Exploring the experience of younger people with dementia 2. What has been helpful? 3. Developing areas for change
	Rabanal, L. I., Chatwin, J., Walker, A., O'Sullivan, M., & Williamson, T. (2018)	To explore the experiences and needs of people living with YOD and gain an understanding of the issues that impact them	In-depth qualitative study Interpretative phenomenological analysis	Semi-structured, in-depth interviews	14 people with a diagnosis of YOD from a Northern UK city	4 Themes: 1. Process of diagnosis 2. Impact of living with YOD 3. Needs of people with YOD 4. Living well with YOD

Category	Authors (year)	Purpose	Study Design	Data Collection	Participants	Findings
Carers	Johannessen, A., Helvik, A., Engedal, K., & Thorsen, K. (2017)	To examine the spouses of YO-FTLD experiences and needs for assistance in daily life	Grounded Theory	Qualitative interviews	16 informants	3 Themes: 1. Sneaking signs at the early stage of dementia 2. Other relations 3. Needs for assistance through all stages of dementia
	Millenaar, J. K., Bakker, C., Vliet, D., Koopmans, R. T. C. M., Kurz, A., Verhey, F. R. J., & Vugt, M. E. (2018)	To investigate the issues caregivers of people with YOD face.	Qualitative content analysis method	Interviews	209 caregivers as part of the Needs in Young Onset Dementia (NeedYD) study in the Netherlands  18 transcripts were used	6 Themes: 1. Acceptance 2. Perception of the relationship 3. Role adaptation 4. Availability of appropriate services 5. Social support 6. Awareness in the person with dementia and acceptance of help
	Lockeridge, S., & Simpson, J. (2013)	To explore the coping strategies adopted by six carers in order to adapt to changes in their relationship with their partner with young onset dementia	Interpretative phenomenological analysis	Semi-structured interviews	6 participants	4 Themes: 1. 'this is not happening': the use of denial as a coping strategy 2. 'let's not have anymore of this demeaning [treatment]': stigma in young onset dementia 3. 'I've had to fight every inch': struggling to maintain control of events and emotions 4. 'what will become of me?': carers' adaptation to loss
	Ducharme, F., Kergoat, M.-J., Antoine, P., Pasquier, F., & Coulombe, R. (2013)	To document the lived experience of spouse caregivers of young patients in order to inform the development of professional support tailored to their reality	Qualitative study informed by the principles of phenomenology	Semistructured interviews	12 spouses	6 Themes: 1. Difficulty managing behavioral and psychological symptoms 2. Long quest for diagnosis 3. Nondisclosure to others and denial of diagnosis 4. Grief for loss of spouse and midlife projects 5. Difficulty juggling unexpected role and daily life responsibilities 6. Difficulty planning for future
	Massimo, L., Evans, L. K., & Benner, P. (2013)	To explore spouses' perceived experiences of and responses to living with a person with FTD.  To reveal caregivers' stressful incidents, articulated meanings, and strategies used to cope with behaviors that are common in FTD  To convey the knowledge, meanings, habits and practices that participant caregivers disclose in their first person experience-near narratives	Benner's interpretive phenomenological methods	Investigator-developed guide, audio taped 60-min interviews in the form of a conversation	Wives of two persons diagnosed with probable FTD	5 Themes: 1. Identity and role change 2. Isolation 3. Anger 4. Facing the future 5. Reframing

## **2.1 Lived experiences of young people with dementia**

This section summarises the findings on YPWD's lived experiences based on the reviewed articles.

### **2.1.1 Process of diagnosis**

The process of receiving a diagnosis was a major theme in the literature on YPWD. Due to the general notion that dementia is an older person's illness, people diagnosed at a much younger age were often bewildered and felt shocked and sceptical (Beattie, Daker-White, Gilliard, & Means, 2004; Clemerson et al., 2014; Johannessen & Möller, 2011; Pison-Young, Lee, Jones, & Guss, 2012; Rabanal, Chatwin, Walker, O'Sullivan, & Williamson, 2018). Participants reported the diagnostic process as complex, with long delays due to a lack of understanding of living with YOD (Beattie et al.'s, 2004). One of the causes of diagnostic delay was the "failure of the general practitioner (GP) to recognise the signs and symptoms of early dementia; a lack of GP experience; reluctance to impart a dementia diagnosis; and the relative rarity of the condition in younger people" (Beattie et al., 2004, p. 365). YPWD also encounter health professionals who would not believe their symptoms and brush off the cognitive deficits caused by stress, depression, or burnout (Johannessen & Möller, 2011; Pison-Young et al., 2012). Two studies presented opposing ways of giving out a diagnosis. Rabanal et al. (2018) revealed health professionals who were empathetic toward the YPWD, while Beattie et al. (2004) encountered those who were blunt, brutal, and unprofessional.

### **2.1.2 Disruptions in the life cycle**

A diagnosis of dementia at a young age is perceived as a disruption in a person's life because of the significant loss of adult competencies, premature ageing, and death (Clemerson et al., 2014). There were many changes in the YPWD's life, such as being unable to cope with daily activities (Johannessen & Möller, 2011; Rabanal et al., 2018) and losing independence (Beattie et al., 2004; Pison-Young et al., 2012). YPWD experience powerlessness and a loss of agency when managing the disease become difficult (Clemerson et al., 2014), especially when losing a job involuntarily due to dementia (Rabanal et al., 2018). They want to be treated as ordinary people, free from stigma, infantilisation, and disempowerment (Pison-Young et al., 2012; Beattie et al., 2004).

### **2.1.3 What helps?**

The needs and interests of YPWD are unique and different from OAD (Beattie et al., 2004; Pison-Young et al., 2012). Therefore, services must be less formal, age-appropriate, and facilitate a sense of belongingness, independence, and empowerment (Rabanal et al., 2018). Family support is also crucial in providing emotional and practical support (Rabanal et al., 2018). Remaining autonomous for as long as possible, continuing to find reasons to 'keep fighting,' and veering the focus away from one's deficits allow the individual to cope better (Pison-Young et al., 2012). Feeling in control of the impact of the disease is an effective process for gaining acceptance of the illness because YPWD can make decisions for

themselves and find ways of keeping busy with things they enjoy (Pipon-Young et al., 2012; Beattie et al., 2014).

## **2.2 Lived experiences of YPWD's spouses**

The spouses' perspectives in previous research are summarised in this section.

### **2.2.1 Acceptance vs. Denial**

Similar to YPWD's experiences, the spouses also reported a stressful, complex, long, and troublesome diagnostic process (Ducharme et al., 2013; Lockeridge & Simpson, 2013; Johannessen, Helvik, Engedal, & Thorsen, 2017; Millenaar, Bakker, Vliet, Koopmans, Kurz, Verhey, & Vugt, 2018). A diagnosis was seen as a cause for relief (Johannessen, et al., 2017; Millenaar et al., 2018) and trauma (Lockeridge & Simpson, 2013).

Spouses who accepted the diagnosis and its consequences could adjust to life's changes, refocus and redefine their future, enabling them to find the right services suitable to their needs at varying stages of dementia (Millenaar et al., 2018). On the other hand, some spouses coped with denial and diagnostic concealment due to stigma (Ducharme et al., 2013). Some spouses also affirmed that white lies made their engagements with the YPWD less distressing and that life was more manageable (Lockeridge & Simpson, 2013). To help cope with the diagnosis, some spouses learned to distinguish the YPWD from the disease and limit their interpretation of the person's behaviour on a cognitive level (Massimo, Evans, & Benner, 2013).

### **2.2.2 Changes in the spouses' lives**

As dementia progressed, the spouses took on a new role as a caregiver, which increasingly became demanding over time (Ducharme et al., 2013; Lockeridge & Simpson, 2013;) and disruptive to daily living and other responsibilities (Massimo et al., 2013; Millenaar et al., 2018). The spouses had to learn new skills and knowledge to care for the YPWD (Massimo et al., 2013).

As spouses devoted most of their efforts to caregiving, they reported feelings of loss and grief (Ducharme et al., 2013;), isolation (Lockeridge & Simpson, 2013), anxiety, and helplessness (Johannessen et al., 2017). Some spouses can no longer work or experienced prolonged absences from work (Lockeridge & Simpson, 2013) and have diminished social lives (Millenaar et al., 2018). Notwithstanding the hardships the spouses went through, most were committed to looking after the YPWD until the end (Lockeridge & Simpson, 2013; Millenaar et al., 2018).

Millenaar et al. (2018) enumerated helpful things for spouses. First is openness regarding the diagnosis and the couples' difficulties so that others know how they could help. Second is having realistic expectations of the YPWD and the future. The third is focusing on the present moment to relieve anxiety.

### **2.2.3 Support Services**

Previous studies also revealed the spouses' evaluations of the support services or lack thereof. Some spouses reported inadequate

services that were inflexible and lacked continuity (Ducharme et al., 2013). Others had to wrestle against being forced into accepting existing services inappropriate for YPWD (Lockeridge & Simpson, 2013). Some carers were in disbelief that the healthcare professionals they encountered lacked knowledge, were inconsiderate, and didn't offer enough support or information, causing mistrust and delay in accessing support (Millenaar et al., 2018). The lack of adequate support at home also caused premature institutionalisation (Johannessen et al., 2017). On the other hand, some spouses were satisfied and found age-appropriate services invaluable such as daycares, weekend meetings, and support groups led by competent healthcare professionals (Millenaar et al., 2018; Johannessen et al., 2017).

## **Chapter 3 Methodology**

Methodology is “the description, the explanation, and the justification of methods, and not the methods themselves” (Kaplan, 1964, p. 18). The purpose of methodology is to give the researcher “an overall strategy for formulating, articulating, analysing, and evaluating their methods” (Carter and Little, 2007, p. 1318).

This chapter describes the research design, sampling and recruitment, data collection, data analysis, and ethical considerations employed in this study. A qualitative research approach, Interpretative phenomenological analysis (IPA) (Smith, Flowers, & Larkin, 2009), provided a systematic structure for collecting and analysing data. The following sections detail the theoretical basis for this and how it was performed.

### **3.1 Research Design**

A qualitative semi-structured interview research design was used to explore participants’ lived experiences and describe how YPWD and their spouses make sense of dealing with dementia in their middle age lifecycle (Creswell, 2007; Denzin & Lincoln, 2000; Parahoo, 2006).

The semi-structured interview process facilitated conversations on pre-identified constructs and allowed for a richer and in-depth discussion in understanding the experiences of living with YOD in Auckland, New Zealand.

### **3.1.1 Qualitative Research**

The appropriate theoretical framework is like the blueprint for building a house – on which the design, structure, and direction are based (Grant & Osanloo, 2014). An Interpretative Phenomenological Analysis or IPA approach (Smith et al., 2009) was used to explore, capture, and describe participants' lived experiences with YOD. In phenomenological research, lived experiences are the main phenomena of interest (Van Manen, 1997). This type of research does not aim to perceive the individuals' lived experiences as facts but to describe the understandable meaning of such experiences (Lindseth & Norberg, 2004). Phenomenology emphasises that “only the individuals who have experienced the phenomena can communicate them to the outside world” (Mapp, 2008, p. 308). A more thorough description of IPA will be discussed under Data Analysis.

### **3.1.2 Ensuring Quality**

The following measures were undertaken to ensure transparency, consistency, and quality of data:

- 1) The researcher discussed her personal and professional reflections and how they influenced her understanding of dementia, YPWD, and their spouses with her supervisors.
- 2) A journal within NVivo was updated with the researcher's reflections before and after an interview. Those written thoughts were discussed with the thesis supervisors to further understand the participants' experiences

through the researcher's point of view in making sense of the meanings the participants have applied in their lives (Smith et al., 2009).

3) Consulted with an experienced IPA researcher in interpreting transcripts of interviews. Frequent meetings with one of the supervisors helped in performing IPA for the first time.

4) Actual quotes reinforced emergent themes from the interviews with the participants called the presentation of evidence (Smith, 1996).

5) A Pilot couple was recruited to trial the Interview Schedule and determine if they would elicit the lived experiences of YPWD and their spouses. After successful and productive interviews following the protocols planned during the research proposal, the thesis supervisors have agreed to include the Pilot interviews as part of the study's data analysis and evidence in the Results chapter. The Pilot couple went through the same process with Participant Information Sheet (PIS), Consent, and Member Validation. The interviews with the Pilot couple have been valuable and added depth to the data collected.

6) Participants were consulted for feedback to confirm, expand or challenge the researcher's interpretations in a process called Member Validation (Smith, 1996). They were given a copy of the summarised themes, sub-themes, and points that emerged during data analysis. The final report was either emailed or mailed by post, and they were given at least two weeks to review it.

Only one couple did not return correspondents after several attempts. Those who participated in the member validation process (one couple and two spouses) did a ZOOM call with the researcher to brainstorm the thesis results. The spouses confirmed or corrected the researcher's interpretations of the interviews. They also recommended the titles of the points, clarified what they meant in some parts of the interview, and expressed their excitement and gratitude for participating in the study. The researcher included some transcripts from the member validation if they added value and depth to the evidence. The researcher will indicate any statement made during this process in the Results chapter.

### **3.2 Sampling and Recruitment**

IPA participants do not aim to represent a population but a perspective (Smith et al., 2009). Small sample sizes are recommended due to IPA's idiographic nature. This study requires a thorough analysis of individual transcripts, which takes a long time to accomplish (Smith et al., 2009). An optimum number of 3 to 6 participants for novice IPA researchers is advocated to produce detailed analyses for each case (Smith et al., 2009). This number will make examining each participant's data more manageable and elicit themes across all samples. In this light, the researcher recruited four couples through Dementia Auckland's (DA) services.

"Sampling in interpretative phenomenological analysis is purposive and seeks a closely defined group for whom the research question is relevant" (Lockeridge & Simpson, 2013, p. 638). Through purposive

sampling, the specific group of people consistent with a particular experience or phenomenon can offer insight only they can describe (Smith et al., 2009). To recruit the most suitable participants for this study, the researcher worked with DA's service team, who acted as gatekeepers in the recruitment process. Former Operations Manager, Barbara Fox, has consented for the researcher to collaborate with DA's staff members (Appendix B). Each staff member signed a Recruiter's Confidentiality Agreement form (Appendix C), ensuring that the participant's identities were protected.

DA staff members initially approached the potential participants. The Recruitment Flyer (Appendix D) and an Invitation letter to participate (Appendix E) with the study summary and the researcher's contact details were given to prospective participants. Once the staff had returned with information on the interested couples, they were given a PIS (Appendix F) with the details about the research and a Consent letter (Appendix G). Upon confirming participants, the researcher made the first telephone contact to schedule an introductory meeting and discuss the study.

### **3.2.1 Inclusion Criteria**

The participants are people with YOD and their spouses. Each couple met the following criteria:

- The first signs of dementia and the diagnosis happened before the YPWD's 65th birthday.

- YPWD was diagnosed no less than three months before referral to minimise the harm for those who may still be in shock with their diagnosis.
- The carers have to be the spouse or de facto partner who live in the same house and have defined themselves as the primary caregiver of the YPWD.
- YPWD must be classified as having mild to moderate levels of dementia based on their physician's judgment. This level of dementia ensures that YPWD can participate in the reflective process of qualitative research (Clemerson et al., 2014).
- YPWD should have “sufficient verbal ability to participate in research interview which required understanding the questions, answering them, and interacting with the spouse and interviewer” (Wawrziczny et al., 2016, p. 1085).
- Able to speak English fluently and give verbal or written consent.
- The couple is under the service of Dementia Auckland to ensure they have ample support.

### **3.2.2 Exclusion Criteria**

This research did not include YPWD with pre-existing learning disabilities or other neurological conditions, as they typically have diverse needs and require different support services (Williams, 2017; Clemerson et al., 2014).

### **3.3 Data Collection**

Semi-structured interviews were used to collect qualitative data. All participants were interviewed twice within a month to maintain the continuity of time for the YPWD who may have short-term memory impairment. The purpose of the first interview was to meet with the participants and gather demographic information. The second interview was aimed at employing semi-structured interviews using the interview schedule as a guide. The spouses' willingness to participate, inform, and remind their partners with dementia has tremendously helped this whole process. A more detailed account of the data collection is described below. All the participants' profiles were summarised in the Results Chapter.

#### **3.3.1 Preparation Phase**

An open line of communication was maintained with research participants. Building a solid rapport with the couples facilitate obtaining data of increasing quality (Robinson, Emden, Croft, Vosper, Elder, Stirling, & Vickers 2011). The researcher was transparent and unambiguous about the research protocols and employed participant-centred procedures throughout the research to maximise participant engagement (Robinson et al., 2011).

The protocols of the study were communicated to the participants through the PIS. The PIS contained the researcher's contact details to allow them to express their interest, questions, or concerns. Each couple meeting the inclusion criteria was called to schedule an introductory meeting. It is acknowledged that days and times may impact the participants, their

attitudes, and potentially the study's findings (Sauro, 2015). Therefore, interviews were carried out at the participants' preferred location, time, and pace. The researcher ascertained that the interview site is a comfortably familiar location that is safe for all parties, reasonably quiet, and free from disruptions (Smith et al., 2009). All interviews occurred in the participants' residences.

### **3.3.2 Introductory meeting**

Before the interview, an introductory meeting was completed to explain the research and obtain informed consent. The couples were together during this meeting. The researcher described what was expected of the participants – the length of time during the interviews, how many interviews will be done, and the use of an audio recorder. The participants were informed that the research results could be used in journal articles, presentations at conferences, education sessions, and possibly developing a more extensive study. Confidentiality and privacy were maintained at all times. All the names mentioned in the Demographics Summary, Results, and Discussion chapters are pseudonyms and have no connection with the actual participants of the study.

The researcher gave the study's written aims to remind the participants of its purpose. Upon the participant's request, the researcher showed the guide before the interview. The researcher established continued consent to ensure that the participants were comfortable continuing when sensitive issues arose.

During this phase, demographic data were collected – gender, age during the interview, age at the time of diagnosis (for YPWD), number of children and age of children (if any), family history, education, and occupation. For spouses, their caregiving duration was noted (time elapsed since the diagnosis). The initial meeting involved both husband and wife, who jointly answered the questions. One couple's 20-year-old son also participated in the interview to support his parents.

Three out of four couples prepared refreshments. Although not required, it became a means for the hosts to break the ice and know the researcher better. The introductory meetings took about one to two hours to complete. The next meeting was scheduled before the researcher concluded the session.

A Demographic Data Sheet (Appendix H) was used to guide data collection during the initial meeting with the couples. All the information gathered was summarised in Table 3 in the Results Chapter.

### **3.3.3 Actual Interview**

A few days before the interview, the researcher called the participants to remind them of the agreed-upon second meeting. Adjustments to time or day were made as needed.

The researcher emulated some of the principles of the progressive engagement approach by Robinson et al. (2011) that are relevant to this study's nature. Consent was sought continuously throughout the interview to explore both sides of this group's unique struggles and experiences. The

interviews were audio-recorded with the participant's permission. The researcher transcribed the recordings, and the data gathered were secured in a locked cabinet within the researcher's office. Electronic copies of the interviews were saved in a password-protected folder. The interview took considerable time, from 120 to 180 minutes, for the participants to think and speak their minds (Smith et al., 2009).

It was anticipated that the couples could construct their stories together as they recount and answer the questions with patterns of words, expressions, and emotions within the same context (Wawrziczny et al., 2016). However, previous researchers perceived that the partners' presence might hamper both parties' free expression (Molyneaux, Butchard, Simpson, & Murray, 2012). This study followed Wawrziczny et al.'s (2016) recommendation of combining dyadic and individual interviews. This approach offers the chance to compare and analyse any disparities (Clare, 2002).

Her husband and son aided one YPWD with moderate aphasia during the interview. The YPWD was given ample time to respond, and when she couldn't, she would always nod in approval when her son or husband answered on her behalf. The other three couples were interviewed individually, and different schedules were set for each participant. To reassure both carer and YPWD during the interview, the respective partner was requested to remain within the house but in a separate room.

Data saturation influences the number of participants. It is achieved when “no new information or themes are observed in the data” (Guest, Bunce, & Johnson, 2006, p. 59).

### **3.4 Interview Schedule**

To capture the participants' lived experiences, open-ended questions were used to facilitate the discussions (Clare, 2002). Consistent with IPA, the interviews were flexible and followed the direction taken by the participants on the specific topic (Lockeridge & Simpson, 2013). The researcher used two guides to facilitate the discussions. First, a list of constructs, seen below, a combination of topics edited from Clare's (2002) qualitative interviews with YPWD and their carers and the literature review. Second, an Interview Schedule (Appendix I) was adapted from Millenaar et al.'s (2018) guide questions and Beattie, Daker-White, Gilliard, and Means (2004) in exploring the experiences of YPWD and carers. Headings I to VII will be asked of both YPWD and their spouse/carers, while VIII is solely for the carers. Adjustments have been made to stay aligned with the research questions, aims, and objectives.

An edited version of Clare's (2002) list of topics:

- Background and life experiences pre-dementia
- Self-concept
- Changes noticed, particularly in memory and perceived explanations for these and the impact of those changes

- Different ways of coping and the nature of attempts to adjust and cope

Constructs from Literature Review:

- Feelings about the diagnosis
- Meanings of their experiences
- Greatest impacts of dementia on the individual and couples' lives
- Changes in the dynamics of the couple's relationship

### **3.5 Data Analysis using IPA**

Smith et al. (2009) conveyed that we are all sense-making beings. When a significant life event occurs, good or bad, a person inevitably develops thoughts and emotions and begins to contemplate. These experiences can permanently change a person's life and perceptions. In IPA, the first goal of the interviewer is to provide an opportunity for the participants to bring to mind these units of experiences and uncover their meanings. The second is for the researcher to interpret the participants' meanings in their lives (Smith et al., 2009).

IPA “explores lived experience and the way in which individuals make sense of their experience by focusing on the internal psychological meanings evident in their accounts” (Smith, Jarman, & Osborn, 1997; Smith & Osborn, 2004; as cited by Clare, Rowlands, Bruce, Surr, & Downs, 2008, p. 713). IPA draws on both descriptive and hermeneutic principles embedded in the philosophical traditions of phenomenology (Clare et al., 2008). In IPA, the researcher endeavours to see the world from the

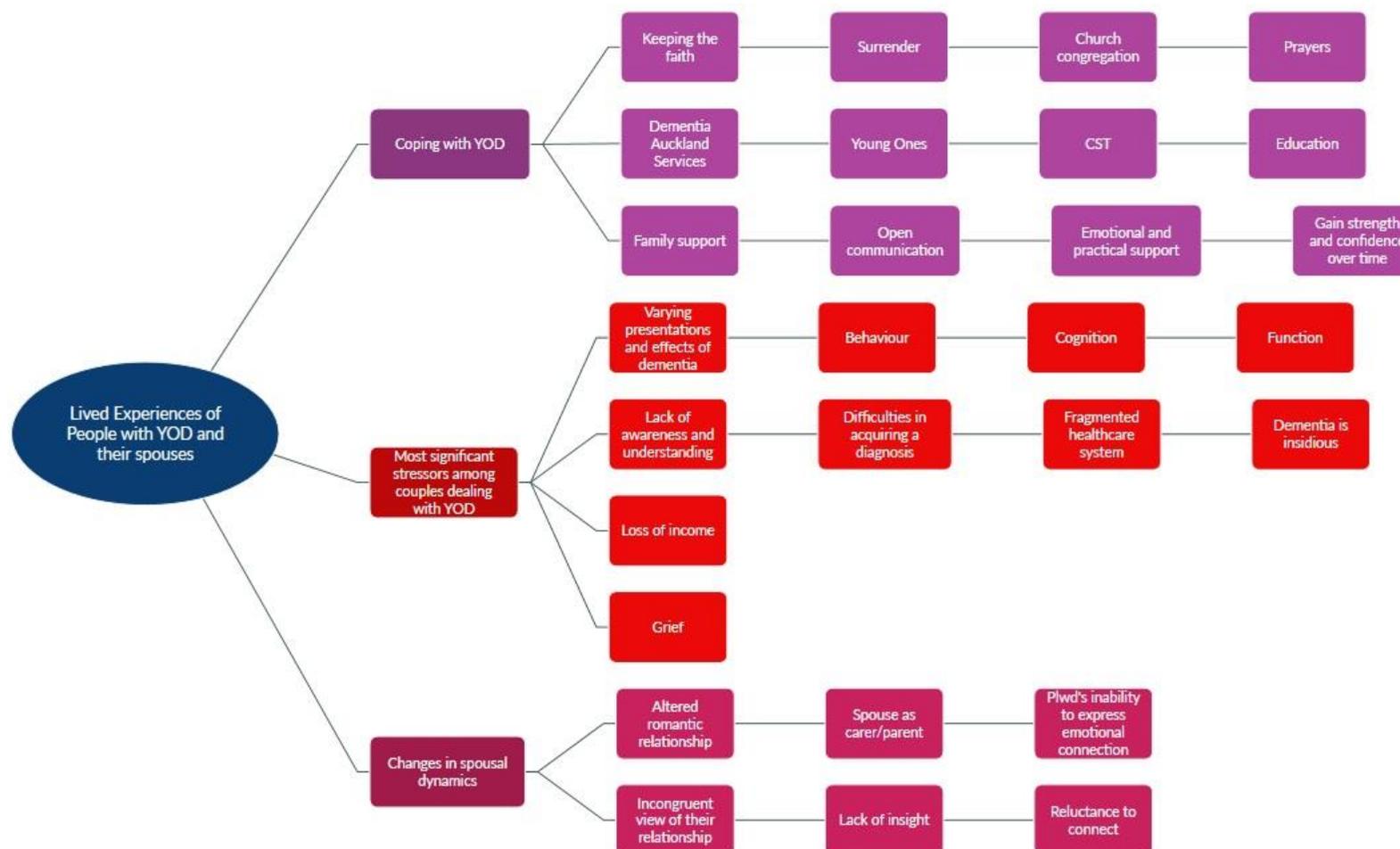
participant's subjective point of view (Wawrziczny et al., 2016). Throughout the process of compiling and analysing the data, the participant's and the researcher's thought processes emerge (Osborn & Smith, 1998; Smith, Flowers & Osborn, 1997). It was, therefore, critical for the researcher to recognise pre-existent opinions, ideals, and hypotheses that may affect the data analysis (Yardley, 2000; Elliott, Fischer, & Rennie, 1999; Stiles, 1993).

In dementia research, IPA has also been used to analyse the life perspectives of PLWD (Langdon, Eagle, & Warner, 2007) and care providers (Ducharme et al., 2013; Lockeridge & Simpson, 2013). For the present study, the researcher aimed to discover the lived experiences of YPWD and their spouses individually and capture their interactions regarding their individual and shared experiences. This research is interested in understanding what each individual is living through and discovering if their recollection of their experiences, use of vocabulary, and emotions regarding situations meet at points of divergence and convergence (Wawrziczny et al., 2016).

IPA was conducted to analyse the transcripts generated from the interviews. This research produced a thematic and conceptual representation that describes the subjective experiences of couples dealing with YOD in Auckland. NVivo software was employed to organise, analyse and visualise all the unstructured information from the transcripts. The programme helped provide tools for classifying, sorting, and arranging the data to identify themes and patterns. Figure 3 illustrates a mind map that

shows how themes and subthemes were initially organised. This is one of the drafts created with NVivo to exhibit the researcher's thinking process while determining the main themes and subthemes.

Figure 3: NVivo Mind Map



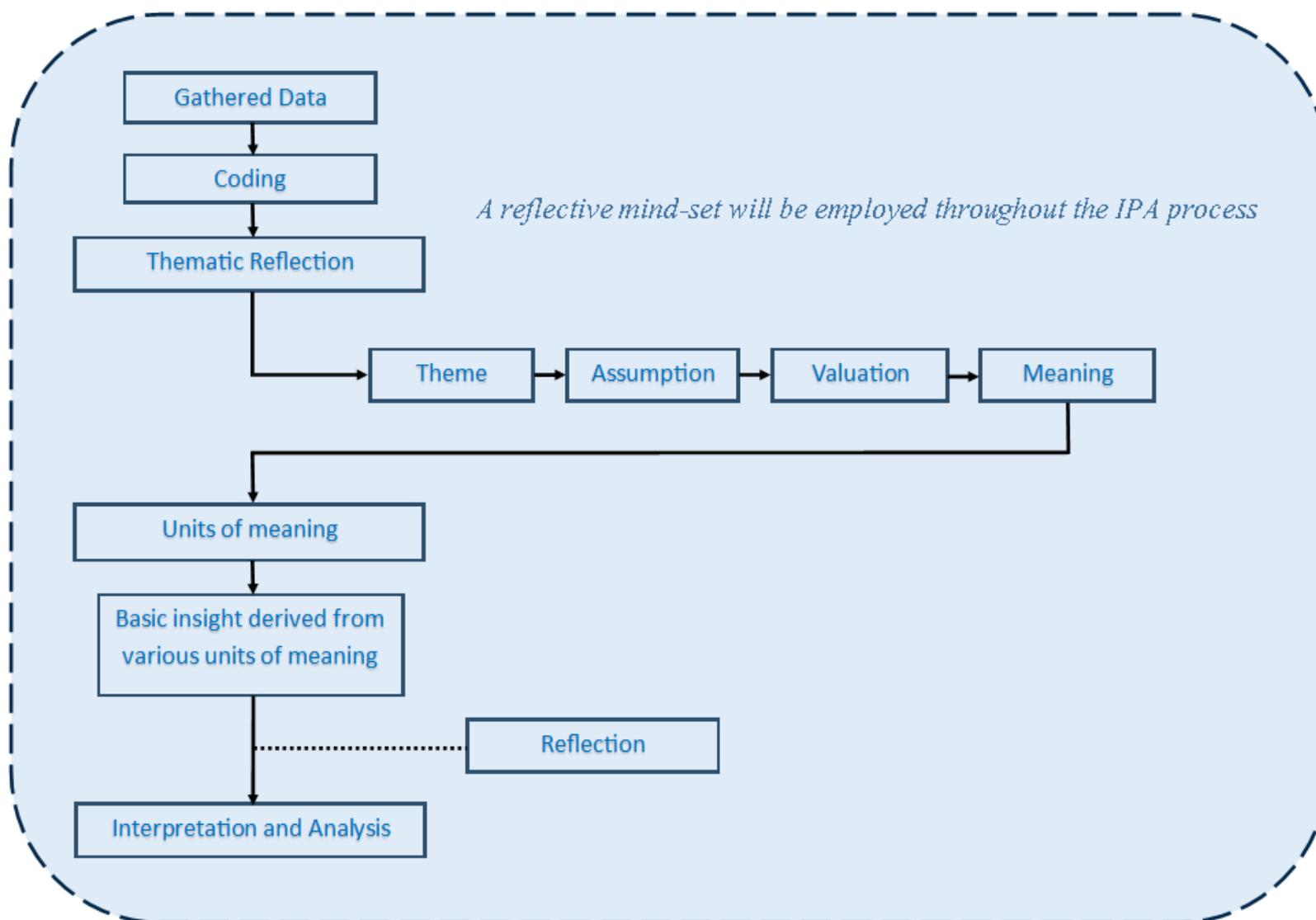
For this study, the researcher proceeded with data analysis described by Smith, Osborn, and Jarman (1999).

- “The transcripts will be analysed by noting relevant items, coding emergent themes, compiling a preliminary list of themes, and grouping the themes into related clusters.
- Pairs of participant-partner accounts were then read together in order to consider similarities and discrepancies in their descriptions and evaluations of the participant’ s experience, after which the accounts of each couple from the two time points were reviewed together in a similar way.
- Next, a summary list of themes covering all the transcripts was compiled.
- Closely related themes were grouped together under appropriate higher-order themes and clustered into sets consisting of higher-order themes and sub-themes.
- This resulted in a complete hierarchically-organised summary list of themes.
- The transcripts were re-read in relation to the list of themes to ensure that the list was comprehensive and that all instances of each given theme had been identified, and a full set of all relevant extracts was compiled for each theme.
- Further reflection on this data set resulted in the development of a schematic model of the process of responding to the onset of dementia.

- The data set was reviewed by an independent researcher experienced in using IPA in order to provide a check on the validity of the analysis and interpretation of participants' accounts.
- The role of the independent researcher was to ensure that extracts were assigned, and themes grouped, appropriately, and that the model reflected the participants' accounts.
- The independent researcher also followed the 'paper chain' through the stages of analysis for a subset of transcripts.
- Any queries or differences of opinion were discussed in order to reach a consensus. This process resulted in minor changes to the summary list of themes.
- Further checks on validity were provided through discussion with other qualitative researchers and dementia specialists, and through feedback obtained when presenting the findings to various groups including professional and family caregivers and persons with dementia." (p. 142)

Figure 4 illustrates the IPA sequence from data collection towards interpretation and data analysis as adapted from Paradis (2014).

Figure 4: Flow Diagram from Collection of Data to Interpretation and Analysis



### **3.6 Ethical Considerations**

An ethics application was approved by the University of Auckland Human Participant Ethics Committee (Appendix J). The well-being of the participants is of primary concern during the whole research process. The researcher worked closely with the YPWD and their spouses for their consent. Ongoing agreement to participate in the research was ascertained by observing verbal and non-verbal behavioural cues, as suggested by Dewing (2007). Information on accessing support was provided for the participants in case delicate topics of conversations elicit strong emotions (Lockeridge, & Simpson, 2013). Each referrer also signed a Confidentiality Agreement to secure the participants' privacy and confidentiality.

Vicarious trauma may occur when working closely with people who are going through difficult life events. The researcher gained constructive support from the regular meetings with thesis supervisors and the clinical supervisor at work.

Part of the closure and celebration at the end of the study is to 'end on a high.' Each participant was given a certificate of research participation and a token of gratitude in the form of a \$30 gift card of their choice. This step is vital in ensuring that the overall experience is positive and that the contribution will enhance a sense of achievement for the participants.

## **Chapter 4 – Results**

This chapter illustrates the participants' backgrounds to help better explain the study's results. Table 3 summarises their demographic information, and Table 4.1 encapsulates their life story.

Three emergent themes were identified reflecting the lived experiences of the couples dealing with YOD – 1) Factors that affected the couples' lives the most, 2) Coping with dementia, and 3) Changes in spousal dynamics. These themes were analysed and synthesised on the basis that they best represent the couples' narratives. Consequently, these themes address the three research questions of this study: "What are the greatest impacts of dementia on the couples' day-to-day experiences?", "How are they coping with the illness within their life cycle?," and "How has their relationship evolved because of dementia?"

The themes were further explored to form sub-themes to expound on the participants' experiences. Each sub-theme will be discussed with corresponding points and excerpts from the interview for the presentation of evidence (Smith, 1996). The researcher recognises that the narratives described critical timeframes within the couples' lives – pre-dementia, symptomatic + pre-diagnosis, and post-diagnosis. To report the findings in a historically cohesive manner, the temporal events indicative of these timeframes were included with the themes, associated sub-themes, and their points, as summarised in Table 4.

Table 3: Demographics Summary

Pseudonym	Nigel	Eva	Margarette	Isaac	Owen	Lucy	Zoey	Richard	James
Role	YPWD	Wife	YPWD	Husband	YPWD	Wife	YPWD	Husband	Son
Gender	Male	Female	Female	Male	Male	Female	Female	Male	Male
Age during interview Mean: 59.75	60 2 yrs dx	57	62 5 yrs dx	58	65 2 yrs dx	60	52 Several months dx	56	n/a
Age during diagnosis Mean: 57.5	58	55	57	55	63	58	52	56	
Age when first signs were noticeable Mean: 50.25	50	47	54	52	56	51	Concussion: 41 (2008)	Concussion: 45	
Gap in years from first signs to diagnosis	6-8 years		3 years		7 years		7 years		
Ages of adult children during interview	27-30		23		21-36		18-25		23
Ages of adult children during diagnosis	25-28		19-20		19-34		YOD: 18-25		19-20
Ages of adult children when first signs were noticeable	17-20		16-17		10-25		Concussion (2008): 7-14		11
Ethnicity	NZ Pakeha	NZ Pakeha	South African Indian	South African Indian	NZ Pakeha	NZ Pakeha	Indonesian Father is Maluku	Indonesian Chinese	South African Indian
Occupation	Draftsman	Health professional	Music professor	Educator	Health professional	Nurse, Homemaker	Account assistant	Production team leader	Student

Table 4: Summary of Themes, Sub-themes, and Points

RESEARCH QUESTION	THEMES	SUB-THEMES	POINTS		
			PRE-DEMENTIA	SYMPTOMATIC + PRE-DIAGNOSIS	POST-DIAGNOSIS
1	Factors that affected the couples' lives the most	Lack of awareness and understanding		1. Families struggled to find out what was happening	
				2. Misconception that dementia is an older person's disease	
		3. Cause of difficulty and delay in acquiring a diagnosis		4. A lot of people don't know how to deal with dementia	
		1. Anosognosia - Lack of insight 2. Declining ability to drive		3. Presence of FTD symptoms changed the family dynamics	
		Dementia affected YPWD's occupational competence	1. Reflections on previous work achievements	2. First significant signs of dementia occurred at work	3. Financial drawback
		Grief and Loss			1. YPWD's reaction towards dementia – shock, desperation, regret, anosognosia 2. Anticipatory grief 3. Loss of plans for the future 4. Acceptance – families see the silver lining amidst their difficult situation
2	Coping with dementia	Spiritual connection			1. Faith in a higher power helped ease uncertainties 2. Church offered a sense of community and belongingness
		Dementia support services			1. Support groups catering to younger couples made them feel less isolated 2. Socialisation groups for YPWD offer meaningful activities that the couples look forward to
		Family support			1. YPWD sees family as their main support 2. Family members became skillful in helping the YPWD cope 3. Families build the YPWD up for success and to be content
3	Changes in spousal dynamics	Romantic relationships evolved			1. Spouses take on a caregiving role 2. Sexual and emotional intimacy
		Couples' incongruent views of their relationship			1. Preoccupied with carer responsibilities, a spouse's need for intimate connection diminishes 2. Lack of insight hinders the YPWD from becoming aware of the changes in their marital dynamics

#### **4.1 Description of Participants**

The interviews took place at the end of 2018 and the start of 2019. Four couples were interviewed – two males and two females with YOD and their respective spouses. One of the pairs was supported by their adult son, James, due to the YPWD's aphasia.

##### **Nigel and Eva**

Nigel and Eva are both NZ Europeans. Nigel finished a certificate at Polytech in Wellington. He worked as a draftsman for many years but was challenged to keep his work numerous times due to redundancy and cognitive decline. Eva had always been in the retail industry since she left school at 15. In 2011, Eva was diagnosed with breast cancer. They sold their house when both were unemployed, making them ineligible to receive financial benefits from the government. Eva started working night shifts as a healthcare professional while undergoing treatments because Nigel was no longer working. Since then, they moved in with Eva's father in South Auckland.

At the time of the interview, Nigel was 60 years of age, and Eva was 57. They have been married for over 35 years and have two adult sons. Nigel was diagnosed with dementia just two years prior when Eva pushed for his diagnosis after 6-8 years of cognitive decline. He had a history of falls and no longer drove. He was forgetful and needed prompting and reminding. His mother had Alzheimer's and died five years before the interview. Nigel reckons Eva's dad has a form of cognitive decline, but Eva did not mention that during her interview.

### **Margarette and Isaac**

Margarette and Isaac are South African Indians, married for over 30 years with one son. The couple were born into and endured the South African apartheid – social and political legislation that upheld racial segregation policies for non-white citizens. Margarette had five degrees in music, and most of her career was spent teaching. Isaac's career in South Africa evolved around firearms – either instructing or sales. He had a public relations diploma, worked as a recruiter, and retrained to be an ESL teacher (English as a second language). He has a passion for public speaking and is involved in Toastmasters. At times, in the couple's life, Isaac would be the stay-at-home husband and dad taking care of the household.

They migrated to New Zealand in 1999. In December 2007, they started an expatriate life initiated by Margarette – from New Zealand to Qatar and Shanghai. Life was good with frequent overseas holidays and more. During the interview, Margarette was 62, and Isaac was 58. Margarette was diagnosed with Alzheimer's disease in 2014, with progressive aphasia or difficulty with speech. She could still play the piano and cook with some help from her family and needs assistance with most ADLs. Isaac and James were Margarette's hands-on carers. They were in the process of selling their house.

### **Zoey and Richard**

Zoey and Richard are from Indonesia, Zoey's father is of Maluku descent, and Richard is Chinese. They have an adult daughter and a son.

Zoey completed a diploma in business administration with accountancy after high school. She worked as an executive secretary and accounts assistant in a law firm. Richard studied engineering in Sydney for four years, where he met Zoey. He worked for a big Asian food factory in Indonesia and currently works as a production team leader in a poultry factory and thoroughly enjoys his job.

Zoey had a cerebral concussion when she got hit by a car in 2008. Zoey's paternal grandmother had Alzheimer's disease. During the interview, Zoey was 52, and Richard was 57. Zoey was diagnosed with YOD four months before the interview. She still does all the household chores and is independent in most activities.

### **Owen and Lucy**

Owen and Lucy are NZ Europeans, married for 40 years with eight children. Owen was a licensed health professional who established an outstanding career with significant contributions to the community when he co-founded a charitable clinic in Auckland. Lucy was also a health professional and worked for a short while after getting married. Due to their growing family and mobile lifestyle in New Zealand and Australia, she became a full-time mother and homeschooled all their kids.

During the interview, they were 65 and 60, respectively. Owen was diagnosed with dementia two years prior. His executive function was limited, so he needed Lucy's reasonable assistance in making decisions and putting a structure to his day. Owen and Lucy's interviews were quite different from the rest of the group. Due to Owen's disinhibitions and

inability to filter his speech, we often went out of tangent from the topic. He spoke swiftly with no full stops in between subjects. He explained many trivial things requiring him to be brought back to the conversation numerous times. The interview lasted for over two hours, contributing to the difficulty in transcribing and finding meaning in Owen's statements. Nevertheless, gems were found within his sea of words.

## **4.2 Research Themes**

### **Theme 1: Factors that affected the couples' lives the most**

This section outlines the factors that affected the couple's lives the most as they experienced YOD. This theme has four sub-themes: 1) Lack of awareness and understanding, 2) Varying presentations and effects of dementia, 3) Dementia affected YPWD's occupational competence, and 4) Grief and loss.

#### **Subtheme 1/4 – Lack of awareness and understanding**

Dementia has over a hundred causes with several stages, making its signs and symptoms incredibly diverse. One person's set of presentations is unique and multi-dimensional compared to others. Spouses in this study noted that not many people would understand YOD entirely unless they lived with someone with a diagnosis. The full range of effects of dementia, such as difficulty making decisions, unusual behaviours, and emerging new personalities, can only be observed and recognised as they go about their daily activities at home or work. Knowing the person well and using that knowledge as a baseline to compare the changes is crucial to understanding that things are not what they used to be.

It is important to note that the lack of awareness and understanding is not judging other people's incompetence. Dementia is an indistinguishable disability, and many YPWD can successfully conduct themselves within acceptable social norms, especially when they are in the presence of other people outside their households. Most are also physically healthy and may be highly functional during the first few years. Therefore, it could be hard to be appropriate and sensitive to the intricacies of dealing with the disease. Dementia is especially hard to decipher if the interaction with the YPWD took place within a short period while the person is in the mild stages with intact communication and social skills.

*Eva: So she [GP] spoke to Nigel, and he can be really plausible.*

**Member validation feedback with Isaac:**

*Isaac: Very often, when you're in company, the person with dementia seems to hide it very well. Somehow, it just kicks in, and they can conduct themselves very well. They make this façade so a lot of these people – the friends, don't see what you see.*

All participants have shared either a personal account of their lack of awareness and understanding of dementia or other people's insufficient knowledge of what YOD is. Excerpts that embody these experiences are enumerated below. Four points were itemised and divided into two temporal events to further explain this sub-theme: symptomatic + pre-diagnosis and post-diagnosis.

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## Symptomatic + Pre-diagnosis

### Point 1: Families struggled to find out what was happening

During this period, the YPWD presents trivial to significant changes in their personality and behaviour. Without seeking medical help, the families tried to find answers independently. They used the internet to search for possible diagnoses based on the signs and symptoms they could observe or ask people within their social circles. Spouses mentioned that although they did not use dementia as one of the keywords to search online, it has appeared as one of the possible diagnoses because it explained some of their partner's symptoms.

Previous experience and knowledge influenced the spouses on how they navigated this part of their journey. One of the spouses ruled out dementia entirely because of their background in counselling and leaned towards burnout or stress. They used a famous counsellor's manual on burnout to seek an explanation for symptoms such as not focusing or connecting with others and becoming so withdrawn. Their preconceived notions of what could happen steered them away from their sought answer.

*Lucy: So we were also googling what could this be. (laughs) What's up with dad? And why is this happening? We couldn't understand it. We didn't really have to go to the area of dementia; we didn't think of that at all 'cause some of us has done counselling courses and stuff. So we understood about pressure and impulse because Owen would be so anxious about work.*

Another spouse observed many subtle changes in his wife, but he could not make any conclusions because there were no concrete signs, unlike cancer. Not long before his wife's new behavioural symptoms, they learned of a lump on her left breast, and they knew the implications for such an obvious sign and what to do immediately. The doctors quickly confirmed cancer through a physical examination and a scan. In the husband's attempt at troubleshooting the current situation, though, he discussed his worries with friends for some insight. They comforted him by downplaying her symptoms, as usual for anyone who might be stressed. There was much pressure at work during those times, and feeling stressed was common. Although he was unsure of what was going on, he had a vital clue that his wife could be experiencing a neurological dysfunction and knew he had to seek medical help.

*Isaac: It's so different to things like cancer because they can detect something, but I have thought it could be something, right? Something to do with the brain. What it was, I didn't know. Of course, everybody at the school was like, "no, uh, don't worry about it. We all stress". But you get that feeling that something is not right. You can't put your finger on it. But you know, something's gotta be done.*

## **Point 2: Misconception that dementia is an older person's disease**

One of the main reasons for the family's confusion about dementia is the misconception that it does not happen to younger individuals. The concept that dementia is an older person's disease was a barrier to better understanding. This section describes two scenarios – one account was during the symptomatic + pre-diagnosis phase and the second one was after a confirmed diagnosis. In both situations, the participants reflected

on what dementia was but were stunted by either external biases or internal stigma that they had yet to overcome.

### **Symptomatic + Pre-diagnosis**

While searching for some information on the internet, one of the spouses came across Alzheimer's disease, the most common type of dementia, but he could not settle with this diagnosis. His wife was in her 50s, had a healthy lifestyle, meditated regularly, and was mentally and physically active. She was utterly remote from the descriptions he read in the literature.

*Isaac: Well, something in the back of my mind said Alzhiemers. There was a little voice in the far distance – how could it be? When I went online to check, Alzheimer's was an old person's disease. She was only 50 something!*

### **Post-diagnosis**

In this particular excerpt, the YPWD was perplexed about her diagnosis. She could not relate to what the doctor diagnosed her with because she saw her grandmother live with the disease. During the interview, she had known of her diagnosis for several months. Still, she could not identify with an illness she knew belonged to an older generation. Although she openly talked about her experiences with dementia, she still felt alienated from it. Since her younger years, she has formed a construct of what dementia must be like, what it looks like, when it can happen in the life cycle, and what it can do to an individual.

Zoey: *They said that dementia. I just didn't think [it is possible]. I am not dementia. That's what I was thinking, but I don't know.*

Interviewer: Why did you feel that – I don't have dementia? Why did you say that?

Zoey: *Because I don't. I think that I don't have dementia. Oh no! I know what dementia [is] because my grandma is dementia.*

### **Symptomatic + Pre-diagnosis**

#### **Point 3: Cause of difficulty and delay in acquiring a diagnosis**

The couples had an average of 6.5 years gap between the first signs and symptoms of dementia and the actual diagnosis. Obtaining a diagnosis within the healthcare system took one to five years. By the time of the interview, the spouses had a better understanding of dementia and could reflect on how long ago dementia may have started.

When the couples approached healthcare professionals, they met roadblocks along the way. The couples consulted professionals who were unfamiliar with the atypical YOD. Additionally, GP's tools, such as the General Practitioner Assessment of Cognition (GPCOG), did not detect YOD. They went through a long course of enquiries, did some trial and error in medications, and were given inaccurate diagnoses – possibly because the GPs saw just one of the byproducts of dementia.

One YPWD had a concussion history, initially treated and managed successfully with therapies and other interventions. However, she declined cognitively after several years, prompting the couple to seek medical help again. The doctors denied that the concussion could cause cognitive

changes because the assessments did not indicate neurological impairment. The YPWD was diagnosed with and treated for anxiety for at least four years, but the husband knew the diagnosis was inaccurate because the treatment was ineffective. No substantial improvements were taking place, and she was declining further.

*Richard: The first thing they said was anxiety [in 2011], they give her medicine, like centraline [Sertraline], to calm her down and go through neuropsychology [test]. After the neuropsychology [test], they talk to her, and [when she was] coming out from the room, she already forget [what she did].*

*It was quite slow progress. The first neurological [referral] is in 2015. We saw Doctor K. So, that's quite long some time, but from all the neurological assessment test, they just says that this is anxiety.*

*I'm already kinna prepared. I already knew, not come to real surprise. It's a very disappointing that the neurologist that I've seen many times. None of them willing to declare you have a problem with the dementia disorder, cognitive disorder.*

One spouse experienced similar difficulties with sceptical GPs. For every clinic visit, the spouses have new or more concerns to report, but none sounded clinical or severe enough to merit further investigation. In their accounts, they mentioned GPs who appeared reluctant to initiate interventions or refer to specialists to ensure coverage of all areas of concern.

*Lucy: He'd [GP] done a little test [GPCOG] with Owen. He says, "He doesn't appear to have burnout or depression." He said, "What are you*

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*worried about?" And I said, "It's his unusual behaviour." "What's the big deal about that?"*

*You doubt yourself also because even the doctors who are supposed to be able to give you some direction or so, not brushing it off to something else. Twice he said, "we all have some inappropriate behaviour sometimes, don't worry about it."*

Another spouse has had enough of the revolving door. Due to her frustrations and difficulties, she pushed the GP to make a diagnosis. Her professional background as a healthcare worker gave her the confidence to call it dementia. She knew the effects of dementia on an individual, and she had seen similar characteristics in her patients. After a while, she convinced the GP to come on board and be forthright with a diagnosis. The spouse believes the GP already knew what they were dealing with, but the GP was hesitant to give dementia as a diagnosis for some unspoken reason.

*Eva: And so she [GP] said to me, "The first thing I have to do is to put him on anti-depressants"...Yes, we do [have the same doctor]...We would go separately, and she would give more anti-depressants. After a year, she said to me, as I turn up really stressed, "How's it going?" And I said, "he's not improving." And I said, "Look, N, it's not depression. You know, and I know that I know signs of dementia". It came from me. Well, I pushed it. I just pushed her.*

## Post-diagnosis

### Point 4: A lot of people don't know how to deal with dementia

The lack of awareness and understanding can reach a scale that can affect the couples' social benefits and other services. In a phone conversation with a government agency, one of the spouses realised that she had to advocate for themselves and educate others about how dementia affects the person living with it and why she had to be her husband's caregiver. Spouses' experiences with banks, legal offices, Work and Income, Ministry of Social Development, and other agencies have made them realise that a lot of education is still needed to inform the public on what dementia is and how it affects the families living with it.

A spouse would later be prepared with her research and carry medical documents when dealing with different sectors. She learned to be proactive over time, assert herself, know what she needs and be outspoken about it. A support person was also crucial to convey their messages as clearly and effectively as possible.

*Lucy: The first person I talked to had no idea what I was talking about. I explained to her what living with someone with dementia was. This is why I need to [access funding for] carer and support. And she said, "oh my goodness, I really think that we need to get some education in the Ministry of Social Development."*

*I'm glad that I have done the research when I went to the neurologist because he said, "What do you want me to write in your letter?" I had to say, "Well, I will be looking after him." And [my daughter] Nicole said, "Mum wants you to write down that she wants to look after dad."*

*She doesn't want to have to go to work and look after dad. So she wants to get the benefit". That's the only reason why I didn't have the trouble that I had.*

## **Sub-theme 2/4: Varying presentations and effects of dementia**

### **Symptomatic + Pre-diagnosis**

#### **Point 1: Anosognosia – Lack of Insight**

During the recruitment phase of this study, I met a wife whose husband was diagnosed with frontotemporal dementia (FTD) and anosognosia. This means that he does not have the mental capacity to understand and fully grasp his illness and does not think anything is wrong with him. The wife was keen to share her story and the narratives of families dealing with this kind of dementia. Thesis supervisors unanimously encouraged the researcher to include him as long as he consented to the interview and knew what the research entails. They reckon he would be an excellent candidate to shed some light on people with anosognosia and how this affects their spouses and families. Out of the four participants with dementia, he was the only one with this condition.

To protect him and the family, the wife has unknowingly compensated her husband for several years. She just wanted to live a normal life for as long as possible. When his dementia worsened, his colleagues and their children expressed their concerns, and she knew she had to do something.

The excerpt below demonstrates how the wife struggled to get his buy-in on seeking help. The challenge was overcoming her husband's oblivion to his declining health and his firm belief that there was no need to do anything. The wife had to learn how to communicate with him, partner successfully, and agree to undergo assessments and accept services.

*Lucy: When I tried to talk to him about that, he couldn't really see what the problem was. Then he would say mad comments that were really insensitive. But I didn't know why he was doing that.*

*The doctor ordered a CT scan. We will go from there to see if something is happening inside. We came home, and Owen said, "I don't want a CT scan. A hundred percent sure there's nothing wrong with my brain."*

## **Post-diagnosis**

### **Point 2: Declining ability to drive**

When I asked the two men with YOD regarding the most impactful effects of dementia in their lives, they both mentioned driving. One was still in transition – going through driving assessments which he thinks are a nuisance and completely unnecessary. His wife further described how his lack of insight was problematic, mainly because he has a strong personality and adores his UTE – he would not easily give up his driving. On the contrary, the other male participant felt his freedom was taken from him because he was given some restrictions in driving. They were opposites – one was unyielding and thought he could still drive – he was a risk-taker

and had unsafe driving behaviours. The other person was more conscientious, knew his limitations, and would not want to take any risks that could cause grief for his wife. Regardless of their agreement with health professionals' advice, their declining driving abilities have significantly impacted their lives. After driving for so many years, this restriction has made a big impression on them.

*Owen: One of the troubles of the diagnosis was having to have a driver's license driving assessment.*

*Lucy: Driving is another big issue. When he was changing lanes on the motorway in Tauranga I said, "Don't forget to check your blind spot", and he was like, "I don't have a blind spot. My mirrors are very good."*

*Nigel: Limited driving drives me nuts. I'd rather be driving where — whenever I want, but that's limited. So, everything's just become restricted now. I would like to drive a bit, but Eva's a bit leery about it. I've had some falls. I've done—I feel I'm running out of time anyways. So I probably might have to forget that. So, yeah, it has taken the joy out of life, really.*

### **Point 3: The presence of FTD symptoms changed the family dynamics**

The participant with FTD's behaviours has changed dramatically, causing him to be disinhibited and hurtful with his words and actions. Unfortunately, he had to be left out of family communications and important gatherings. The family had to exclude their father to avoid demoralising other family members and diminishing their relationships. During member validation, the wife explained that this decision was not intended to separate him entirely from everyone else but to ensure that the

family remains intact, the young ones are protected, and the relationships are allowed to flourish. What was important was they continued connecting with him in other ways, and he is preoccupied with activities that make him contented and happy.

The example below shows how they all had to modify how they spent family traditions such as New Year's Day. The family decided to celebrate separately so that they could shelter the grandkids. Some of them are two and four years old, and in their tender age, the wife explained that they are excellent observers but not adept at interpreting things yet.

*Lucy: This is the one heartbreak that is really hard for me. Owen just got something against my son-in-law and my two grandsons. He'll call them idiots and stupid and monsters.*

*Then New Year's, we're all up North together, and he's [Owen's] on his own, so I rang up and [my daughter] she said, "yes, mom, we just need to work something out, so that dad has something to do, and [keep] the puzzle going."*

*[I was reading Russel a book, and he said] "grada doesn't like me, oma, and I see he doesn't love me." I just had a lovely talk to him, and I said, "you know grada does love you, but grada has something in his brain [that] isn't working right. Because of that, he just gets grumpy sometimes. He gets sad sometimes. So that's what's happening, but he actually does really love you". It's so hard.*

#### **Sub-theme 3/4: Dementia affected YPWD's occupational competence**

This sub-theme is one of the most telling of the participants' cohort and their unique circumstances compared to their more senior

counterparts. The common presumption for people in their forties to early sixties is that they work and are preoccupied with contributing to society. This section embodies how dementia felt like an unexpected curveball encountered towards the peak of their professional careers when they are supposedly reaping the benefits of their hard work over many years.

## **Pre-dementia**

### **Point 1: Reflections on previous work achievements**

This point is the only one drawn from pre-dementia days. As the YPWD looked back at their careers, the nostalgia was palpable as they described their experiences not too long ago. It is imperative to illustrate the participants' strengths and skillsets and how they viewed their careers before dementia took a toll on their competencies. It conveys the stark difference in their ways of life now that they have been living with a disease that limits what they can do and changes how they see themselves. Below are excerpts showing what the YPWD used to do for work and how proud they were. Other people's affirmations also made the YPWD feel good about what they have accomplished and highlighted the importance of being perceived and appreciated in a certain way.

*Zoey: I was the best secretary. And I do a lot of things like big loans, million dollars. I arrange everything, and my boss appreciate me well. [I was the] boss in the office. So they just, what is it? Trust me.*

*Nigel: Because I was well, you know, [doing] specialized work that had to be right otherwise, buildings will fall over or whatever. 'Cause mainly, they wouldn't want you if you [weren't precise].*

The spouses also took pride in what the YPWD accomplished in their careers. They shared the family's sacrifices and everything they had to endure while the YPWD tried to self-actualise in their chosen fields. Margarett capitalised on her musical talent to thrust their migration from South Africa and enter New Zealand's music academe. Another YPWD, Owen, worked weekends and did a lot of charity work to help the people in the community, in and outside of New Zealand. Ultimately, it was all worth it because they achieved the lifestyle they wanted.

*Isaac: When Margarett came here to New Zealand, she then introduced Zulu, Afrikaan music. So when we went overseas, she introduced Māori music, Afrikaan music. Music was her baby.*

*Lucy: From there, he started the rise of the Medical Centre. That was a great time too. Owen found that very satisfying to be able to make a difference. He actually won a Community Services Award.*

## **Symptomatic + Pre-diagnosis**

### **Point 2: First significant signs of dementia occurred at work**

All the YPWD in this study held professions requiring high mental aptitudes. This point describes the YPWD's experiences of cognitive decline at work before their diagnosis. One of the YPWD shared how she knew about her errors at work and tried to rectify them. She would come home late at night because she had to repeat her accounting spreadsheet, ensuring adjustments were completed before leaving the office. She would also write discreet reminders for herself not to ask questions because she started becoming repetitive. She remembered being scared and feeling

overwhelmed by the situation. The doctor has started giving her anti-depressants which eased her anxiety. Unfortunately, she made too many mistakes and experienced workplace bullying, which pushed her to resign. Although she misses going to work and feeling accomplished, she is relieved it has ended. Her husband's support of her early retirement alleviated her worries.

*Zoey: I put it in here (pointing to the palm of her hand) with Indonesian language, "do not ask question." Because I keep saying it again and again.*

*I double up all the time coz I do the accounting. So [at the] end of the day, [the accounts were] not balanced. And then my boss, she is not good. Sometimes I can know [about my mistakes]. Sometimes, she is yelling something to me, I was scared. That's why I said to my husband that maybe [it's] better [if] I quit the job.*

Another YPWD's adversities at work stemmed from six years before his diagnosis. He was let go from his job and made redundant a few times, and when he tried working as a freelance draftsman, finding clients was a challenge. He would spend the whole day in front of his computer, but he was not accomplishing anything. When the family experienced a financial crisis, they sought advice from a consultant. Before that stage, the YPWD had always managed his finances independently until his wife had to intervene. The wife learned that he was spending more money than their government benefits, and no income was coming in.

*Eva: But he wasn't working as much as I thought he was. When we got them [tax returns] together to give to our financial consultant, he was earning less than the benefit.*

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**(Note: All the succeeding themes and subthemes fall under the Post-diagnostic stage in the couples' lives).**

**Point 3: Financial drawback**

Out of the four couples, three had reported experiencing significant financial drawbacks due to dementia. The loss of a partner's higher-earning job substantially changed their living standards. All of a sudden, a lot of things needed to be reconsidered and their priorities adjusted. The couples had to forego some things as they could no longer afford their old lifestyle. One couple had to sell their home, and the other was selling due to financial strife.

The excerpts below describe the shifts from stability to scarcity and self-sufficiency to reliance on government benefits or charities for daily provisions. The plummet to a lower economic profile came unexpectedly, especially when the couples thought they had done everything conscientiously to be financially savvy and live within their means.

*Owen: Well, the greatest impact has been the fact that I was delicensed. Basically, still have to survive now in just a WINZ benefit. Because I'm not the age of 65, so I'm a bit out. Sometimes I call it a winge benefit.*

*Lucy: I can't do as much as he [Owen] would like. I think because he has lots of ideas of where he liked to visit. We can't do all those things. I've learned now [what] not to say. We can't do those things, we don't have money for that.*

*Isaac: In everything else, we were financially always secure, we had our jobs, we had our pleasures, having traveled and living a different*

*sort of life. Eventually, we had to relinquish our insurance. We had to go to Salvation Army to get food supplies. It was quite strange.*

*Nigel: So, we were fairly stable. Now, this is our toughest thing that we're trying to deal with. We thought we were gonna be fine. Our income—dual incomes, and I had a good job.*

*Eva: I told them [adult children] about the diagnosis, and they both said, leave him, and I'm going, no! It would be better for me financially if I left him. If he [Nigel] is in care, half of my inheritance will go towards the rest home. What worries the boys is that I could be homeless.*

#### **Sub-theme 4/4: Grief and Loss**

Throughout my conversations with all the participants, they reported various emotional reactions toward dealing with dementia. Their stories spoke volumes of the many losses they experienced during their turbulent journeys toward the diagnosis, the moment they discovered its dementia, and the effects of the YPWD's unceasing decline. The following points describe how the participants experienced grief and loss and their reflections on those experiences.

##### **Point 1: YPWD's reaction towards dementia – shock, desperation, regret, anosognosia**

Each YPWD had a different way of describing their thoughts and feelings regarding their diagnosis. The first YPWD's expressive aphasia, or difficulty producing speech, became apparent as she struggled to find the right words. She is a woman described by her family as successful,

confident, and eloquent. However, her ability to expound her answers is now limited, but she somehow explained why she felt the way she did.

*Margarette: Well, I- I think I was, I was just shocked. Because it was just too much for me. I think it, it just gave me a shock. I think that really I, it, it made me feel I'm not good enough or something.*

Another YPWD divulged her most intimate prayers of desperation, crying to God to spare her from dementia. She, too, could not believe she could have dementia and asked God why she had to live with it. She spoke very softly at this stage, not wanting her husband to hear her. She doesn't want to add to their stress by letting them know how she feels about having dementia.

*Zoey: I always pray for anything. And then I said to God, "God, I don't want to be a dementia! Why should I live with dementia?" "You can take me out!"*

The third YPWD had sobering thoughts about his dementia, and he regretted it. The magnitude of dementia appears impossible and hard to comprehend and, as he said, not "user-friendly." He read about the different stages of dementia and understood which phase he could identify with during the interview. Compared with all the other hardships that he and his family experienced, dementia is the most challenging thing they have encountered thus far, and regretting dementia has ever happened.

*Nigel: I don't know how dementia's side works, but there's about three stages. My mind's the first one. Maybe it could be a rapid decline or die from something. How long might I live or whether they can come up for a miracle drug to maybe save me. Whether I'm just gonna*

*decline and become a rest home patient or something, I regret that it all happened, really.*

Interviewer: I'm really sorry.

Nigel: *Ah well you don't have to be. It's just my mum probably had some sort of Alzheimer's type, herself. It's just hereditary-thing that's caught up to me.*

Amongst all the YPWD in this study, Owen was the only one who had anosognosia or a lack of capacity to have insight into his illness. What has perplexed me is this – I saw two different sides to him during the interviews. During my first joint interview with him and his wife, the wife was surprised when he slightly agreed that he has dementia. When I interviewed them together, he was adamant about not having dementia. I also observed that the wife found an opportunity to use the research interview's platform to ask Owen what she wanted to hear from him. Successfully so, it was his very first time to admit to having dementia in her presence. For her, that was a breakthrough in the few years they've dealt with the illness.

Lucy: *Owen, when [Dr.] Niel Anderson said to you "Owen, you've got frontotemporal dementia"*

I: What did you think about that?

Owen: (long pause before he answered) *Arguable, (sniffs, laughs)*

Lucy: *So, like even now do you think that you have it?*

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Owen: (long pause) *Only on the basis of an MRI scan to a certain extent. Otherwise, I can, I think through, through puzzles and stuff.*

When Owen was immersed in our one-on-one conversation about his experiences, some of his deep thoughts would reemerge about what dementia made him realise about himself. A glimpse of his reflections would surface in the middle of all the detached trajectories of his answers, the jokes he made, or the histories and trivial things he shared. He said he's human, and all humans are connected, possibly suggesting his normality. To have dementia shouldn't change what he feels about himself and perhaps how others treat him. Before, he used to help others in need and made decisions that saved lives. He may have felt powerful and almost God-like. Now, he needs some help, which may have reminded him of his mortality and humanity. He inserted a story of a character called Pinch Me at the end of his statement. Pinch me denotes disbelief or waking up someone from a dream. A part of him may have realised he has dementia but still could not grasp the idea as valid.

Owen: *I'm a human. We're all genetically related, one way or another, that's why I always remember that joke that my dad used to say he got from his grandparents. You know, Adam and Eve and Pinch Me (laughs). Adam and Eve and Pinch Me went down to the river to bathe; Adam and Eve were drowned, who do you think was saved? Pinch Me! (laughs)*

It was thought-provoking to see how someone with anosognosia thinks about dementia and peeps into their innermost thoughts underneath the barrier of mental incapacity for insight. It makes one think

about how much of their thought processes can grasp the weight of such an illness and whether they can grieve or express their emotions in specific ways. During the interview, Owen openly talked about his experiences while living with dementia; even while he's unconvinced, he has it. Overall, the wife concurs with what I witnessed – Owen's emotions were more focused on the significant life changes that happened to him and his family due to dementia than having the illness itself.

During the member's validation phase, his wife confirms that although he lacks insight, he has some emotions but cannot express them in words. She explained that Owen claims he is immortal – another way of saying dementia doesn't exist, he is invincible, his way of ending the conversation. He didn't want to plan for the future, and his claim of immortality derailed the need for such discussions. However, Owen would play the piano in various ways – very loud and measured while thumping his fingers, or sometimes, softly with feelings. Lucy reckons music has become a great outlet for expressing emotions he might have been building up underneath.

**Point 2: Anticipatory grief**

As dementia worsens over time, there is the sad expectation of death at some point in the future. Dementia's grim prognosis brings this awareness to the couples during the interview. This point describes how the couples and their children grieve in anticipation of the YPWD's continuous decline and eventual passing.

Of the four YPWD, Nigel has profoundly articulated what it must be like for his sons to know that their father has dementia. He empathised with them as he acknowledged his time was limited. He recognised that they must be grieving for him as he may not live long enough to witness their milestones and successes, support them when life becomes difficult, or be with them during the mundane moments of their lives. As a father, these are the things he would have liked to do, but his sons may already feel that they are losing him as he continues to decline physically and cognitively.

*Nigel: Sad just for our boys and things to have that happen as well. A dad, guess they thought who's gonna be there. They probably are just feeling it as well, was losing a parent.*

Nigel's wife enumerated what she already knows is unavoidable with dementia. As a health professional, she sees this happening to her patients at work. She understands that, sooner or later, Nigel will not be able to do a lot of things on his own and will, in due course, succumb to the illness.

*Eva: There's going to come a time when Nigel won't even know who I am. He will forget to eat, he will forget to stand up, he will forget everything and eventually, he will die.*

Like Nigel's sentiments, Isaac shared how their son feels the loss of a mother he could confide in, have meaningful conversations with and seek refuge when needed. For him, it felt like he was cheated because, as a young man, he could have had the privilege of being in her company, knowing her opinions on different topics such as politics, sociology, economics, and

what course to pursue in university. Being an only child, their son had a very close relationship with his mother growing up, and he would have wanted to have more time with her. Isaac recounted that Margarete wrote a thesis for her master's degree, and James used her words for his school assignment. James captured a piece of Margarete's mind, and he felt delighted to hold something tangible to remember his mother.

*Isaac: He [James] mentioned he felt cheated because when Margarete was doing well, he was too little to discuss things with her. He feels he's lost out. He can talk to me, and we love a big debate and discussion, maybe even have our argument about it or whatever, but he can't get help in it. And then in one of his essays, he took a quote out of her thesis. He said he felt very thrilled to be able to reference his mother.*

Richard mourns for losing the life companion his wife used to be and sees this as the most prominent effect of dementia in his life. As a couple, they shared experiences over the years, tried to handle life together as partners, and had each other as sounding boards for making important decisions or solving countless issues. Now, he feels alone because his wife can no longer fulfil the role of a confidante who can think for herself, have her own opinions, or even argue with him to make a point. For him, that's the kind of marriage they always had, and it has made their relationship work. With dementia, his wife became relatively passive, relying on him for many things. He feels that the overwhelming obligations they used to share are now upon him and he misses having the headstrong woman he depended on.

Richard: *I just feeling that I lose my partner because she doesn't have [the] intellectual anymore for us to discuss things. It's like I live alone now. Because [as] husband and wife, you should be complimentary like if you have problem, you can share. Try to find out or find the solution. So that kind of thing already lost. That's what I feel that quite sad.*

I: How do you cope with that?

Richard: *I just accept it. So I think that's to be my bigger problem like losing – already lost my wife who should be equal then you can debate. So that part I really lost now. She used to [be] quite smart.*

Lucy feels the psychological loss of her husband with his behaviour and personality change. Owen has become almost unrecognisable, utterly different from the person Lucy used to know. Lately, he had been preoccupied with superficial things like going through his old acquaintances on Facebook and fixating on getting in touch with them and trying to reconnect by sending them messages out of the blue. This new fascination was something he would never do in the past. Lucy explains that they have a steadily growing family with eight children and several grandchildren, and the family has always been the centre of their lives. Lucy misses the person who shared the same values and gave the same importance to the people they loved the most.

Lucy: *I just looked at him one day, and I said, "where are you, Owen?" It was like he was missing, you know? I just like, where are you? I just didn't know where he was. It was like not him, and he was just gone.*

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**Point 3: Loss of plans for the future**

Dementia has caused a lot of restructuring. One of those is losing the freedom to dream about a future and plan ahead. The focus has been more on the here and now – providing the needs of the YPWD, managing the household, and trying to stay afloat. This point relays how the couples felt disappointed that they could no longer feel excited about travelling or realise the retirement dreams they have always wanted. There seems very little optimism to look forward to, and to look beyond today adds pressure and reminds them of more difficulties that are to come.

One YPWD, Nigel, felt guilty about not fulfilling the dream of travelling with his wife. They have reached a stage where they have worked so hard, reared their two sons together, and are at a point where they're close to laying low and have more time for themselves. Instead of that imagined life, his wife is responsible for caring for him, the same job she does for work. The financial aspect and his physical limitations inhibit their ability to see more of the world. He has had falls before and would not be stable on his feet, and it would be tough for both of them to travel around Europe as they did when they first got engaged. This memory brings some consolation on his part.

*Nigel: Well, she's taken fairly hard because she's probably disappointed. And now, she's virtually doing this cared job on me. So, she's probably disappointed that we haven't [travelled]. Although after we got engaged, we did that trip to Europe as a thing to get it off our bucket list really.*

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*I don't feel capable of [traveling anymore]. It's just disappointing that we got to this stage in our relationship. And this is where we are with issues like this.*

Eva reflected on what it feels like to be responsible for looking after her husband and father. In the interview, Eva alludes to feeling stuck with the uncertainties of the future and being in a caregiving role. She could not make her plans because of the many demands from her right now, and leaving two frail men on their own was becoming too risky. Eva doesn't think it's possible to go on trips with Nigel as much as before, and going away on a short solo trip is now just her way of relief. Unfortunately, her worry is sometimes not worth the respite she takes. The anxiety could be overbearing, and she feels deprived of the freedom to live the life she wants. She also feels guilty about leaving Nigel but taking breaks is essential to keep her going. For her, what's been helpful is just winging things daily, and everything needs to be thought through – she constantly needs to plan things, foresee any possible risks or accidents, and hope nothing untoward happens.

*Eva: I'm always worried because the last time I went away for five days, Nigel had a little accident. It just worries me. So that's why I don't feel like I have the freedom to just get up and go. I feel guilty when I go away. At the moment, I do feel stuck because I can't plan my life because I don't know what's going to happen.*

One of the spouses explains that when you get to a certain age, around 50s to early 60s, some people are already eyeing a boat or an RV, planning where to go next, anticipating more free time to do pleasurable

things, and enjoying what life has to offer. Unfortunately, in their situation with dementia, as he has said, “all the best-laid plans just go out the window.” Their conversations about the future have changed so much that it now involves his wife deciding to go into full-time residential care to give them freedom from worry and the responsibility of taking care of her. She wants them to continue with their lives and not be held back by the burden of supporting her with her disabilities. The spouse does recognise the need for that later on. But personally, it’s not easy for him to relinquish the caregiving responsibility to someone else and continue life as usual. He does not feel laden by caring for his wife. For him, caring for her is his new purpose, and it has given him so much fulfilment. If he has any wishes for the future, it’s for his son to live his own life – to succeed with his plans and ambitions.

*Isaac: I know when she gets frustrated, she'll say, "put me in a home, you'll be free", but it doesn't work like that. And I've said to her – “look, the thing is that, yes, we're going to have to look at home for us”, and I said, “but James is going to need his life as well.”*

**Point 4: Acceptance – families see the silver lining amidst their difficult situation**

The act of acceptance that surfaced in this study is choosing to see the good things in life. Seeing the silver lining means that the families still acknowledge that challenges and obstacles exist, but other aspects of life can give clarity, solace, and hope. This point shows this unique part of the couples’ grieving process of choosing to see the good amidst the bad.

One of the spouses could clearly explain how he has reached a moment of clarity and come to terms with their current situation. He went

through a rough transition from being active in the workforce and trying to hang onto a persona he used to have. He was comparing himself with his friends, whose encouraging words for them to find jobs caused stress. The couple tried to respond to those pressures, but the spouse said they were “hitting walls at every avenue.” After a while, they realised they needed to make considerable adjustments. The truth is, there was immense instability – they were unemployed, his wife was becoming more unwell, and he was trying to juggle applying for social benefits, selling a house, and accessing support services for his wife.

Isaac grieved for the changes and losses in their lives, but those strong emotions diminished over time. He acknowledged that his and his wife’s welfare is the most important thing now. Isaac could forego societal expectations and become fully immersed in his new caregiving role. With this realisation, he finally felt relieved. Although there are still moments when he feels depressed, peace is more accessible. All the other things didn’t matter as much, their priorities were more specific, and he could focus his energies more carefully. He explained that he would not beat himself up the following day if they hadn’t slept well the night before. There was no pressure to get up early in the morning to work. His wife can sleep in a bit more; he’d just quickly go out to do some errands while she rests. The day can be as flexible as it needs to be.

*Isaac: Then once I realised this is my situation now, I’m gonna focus on her and myself. It’s allowed me to see things in a different light. That I’m not still trying to look for a job. It was such an amazing moment when it came to me.*

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*I think the huge grieving parts has petered out a bit. The moments of grief are shorter and less profound. When that realisation slowly came in, our ovens have stopped heating, but it glistened, and now we put more energy into the physical aspects of what we're doing for her.*

Among all the four YPWDs, Margarete was the only one who expressed happiness and comfort with her dementia. She repeatedly said, “happy, my family, my whanau,” throughout her interview. Margarete was initially shocked at knowing of her illness but grateful for her family’s help and support. She is also happy about participating in this research and sharing her experiences for others to learn. Her family has constantly reminded her of how blessed they are when she feels frustrated with herself and her condition.

*Margarete: I was frustra- I was just frustrated. I was thinking, where did this come from? You know, I think it was, uh, I was shocked. So mm... (pause) but as we, I said later on that uh everything I think is good. So and I'm very happy, I'm happy with my whanau, family.*

*I've been told by my whanau that I am very fortunate, fortunate. And people, people are quite nice actually here. Yeah. Being here, what we're doing, I feel happy.*

One of the families has embraced the diagnosis of dementia with a sense of relief. When the YPWD became withdrawn, aloof, and unemotionally connected, they initially thought their family was breaking apart from his deliberate choices. The diagnosis confirmed that he didn't willfully decide to behave that way. So even though dementia is a difficult pill to swallow, the family looked upon the physical changes in the YPWD's

brain as the culprit, saying it's a condition and not a decision. Their extended family also offered support and a positive outlook on the diagnosis. Though dementia is progressive and life-limiting, they still have more time to be with the YPWD. There are still some things to be grateful for, which they hold on to when things get them weary.

*Lucy: They were a bit like me, kind of relieved to know that Owen wasn't purposely not giving them a teaching or not being able to connect with them, not being able to hug them. The fact that it's a physical reason and not a will reason, it's not him. I think it's been, to all of them – the reveal. It's a relief.*

*[My parents said], "Oh, well, at least it's not a brain tumour. He's going to die next week." You see, there's this, the extent of reaction to it which is interesting.*

## **Theme 2: Coping with dementia**

Participants have expressed that dealing with dementia is one of the most difficult life events that happened to them, but they also reported the various ways they coped with the illness. This section describes the factors that help couples manage dementia. The underpinning sub-themes include 1) spiritual connection, 2) dementia support services, and 3) family support. Table 5 summarises sub-theme 2.

**Table 5: Theme 2 – Coping with Dementia**

RESEARCH QUESTION	THEME	SUB-THEMES	POINTS
			POST-DIAGNOSIS
2	Coping with dementia	Spiritual connection	1. Faith in a higher power helped ease uncertainties 2. Church offered a sense of community and belongingness
		Dementia support services	1. Support groups catering to younger couples made them feel less isolated 2. Socialisation groups for YPWD offer meaningful activities that the couples look forward to
		Family support	1. YPWD sees family as their main support 2. Family members became skillful in helping the YPWD cope 3. Families build the YPWD up for success and to be content

### **Sub-theme 1/3: Spiritual Connection**

All the couples in this study are Christians, a religious denomination that was not pre-determined nor anticipated during the recruitment process. Throughout the interviews, the couples often mentioned their faith and how it has helped them deal with dementia in every phase of their journey. They shared conversations with God through prayers and hopes for themselves and their families.

#### **Point 1: Faith in a higher power help ease uncertainties**

The couples have a general understanding and some expectations of dementia's prognosis. By its nature, they know that dementia causes the diagnosed person to decline in many aspects of their bodily functions. This knowledge may bring about feelings of fear and uncertainty. When asked about the future, one of the YPWDs responded with complete faith and trust in God. To alleviate possible strong emotions associated with dementia, she acknowledged and accepted that she does not control anything in her life.

Moreover, she identified herself as a child of God and would not be in harm's way. From the Bible, Jeremiah 29 verse 11 says, "For I know the plans I have for you," declares the LORD, "plans to prosper you and not to harm you, plans to give you hope and a future." These are the words the YPWD was hanging onto, giving her a sense of peace. She trusts that God will not forsake her no matter what the future brings.

I: What, how do you feel about the future?

*Zoey: The future is in God's hands. We can't do anything. God already plan for us, but I'm sure that the plan is a good plan for children of God. That's what promise of God.*

One of the spouses has a discerning prayer about the future. Her complete surrender to God's will, whatever that may be, has given her comfort. She knows it will be a hard road ahead, but she has reaffirmed her commitment to stay by her husband through sickness and health until death do they part – reminding herself of the wedding vows they have made to each other. For her, God's grace is enough to provide her with everything she needs to endure the journey with dementia and to fulfil her promise. The belief that God is all-knowing and benevolent reassures the spouse that everything will fall into its rightful place. If her husband goes into a dementia care facility, later on, she prays that he would be amenable to it and hopes that he will not struggle with the physical separation. Ultimately, she wants what is best for every stage of his illness, and she trusts that the most appropriate care and support for his needs will be provided when she can no longer fulfil them.

*Lucy: And then I just prayed, "God, I don't know what's happening with Owen, but I'm committed – 'til death do us part. So I just ask you to give me the grace for whatever it takes, that you will help me on how to be able to support and love him". After that, it was amazing, I had my whole faith in the Lord, and it felt so good.*

*I don't really want to pray about how it's going to end because I think God knows better than me. It would be very hard for him [Owen] to have to go into a dementia unit, but I am trusting that God knows all that.*

When things seemed to fall apart, a spouse asked if God continued believing in him. He did not question his faith but wondered if God had faith in him. Faith seemed to be tested in times of hardships and when the person's resolve weakened. He started questioning what he knew about the God he believed in and related his experiences of adversities or jubilation to God's faithfulness. When life becomes complicated, the person experiences a moment of doubt and anguish and turns to God for reassurance and comfort.

The spouse discovered a profound meaning in the church service he attended in this particular situation. He interpreted other people's words and actions as God's answer to his question. Unlikely events gave him hope in the guise of a lady who does not typically volunteer to read and a shy priest giving an impactful speech on the triumph of South Africa's rugby team against New Zealand's mighty All Blacks and the life of Nelson Mandela. He appointed those coincidental events as God's way of speaking to him directly. When he witnessed and heard impossible things coming to reality, he walked away with renewed faith, believing that he, too, could

overcome the hardships he was going through. Although things were not going well then, his withering spirit was recharged for yet another day. He became confident that, eventually, the sale of their house and everything else in their life would fall into place.

*Isaac: Oh! Everything was just falling apart with the sales and purchase of this [house], so I was adamant when I was going to go to church that day. I didn't want to read. I'd just do this reading, and if I saw this particular priest, I was going to just ask him, "Does God still believe in us?" But of course, when I got there, this lady who never pitches up to read was there. I was surprised, geez! And then there was a more mellow priest, and he started his whole sermon talking about Nelson Mandela and the Rugby World Cup in '95 when Springboks beat the All blacks, "What?! Okay, you got me!" I walked off and thought, "Wow, imagine?! I came with one mindset, and I'm leaving in a totally different mindset!"*

## **Point 2: Church offered a sense of community and belongingness**

Some PLWD and their families feel isolated or discriminated. A diagnosis of dementia may make other people treat PLWD differently due to stigma, but this point presents the complete opposite. The church congregation, where the couples are members, has offered a great sense of community and belongingness. The church embraced the YPWD with tolerance and patience, making the couples feel accepted.

Knowing the couple's religious beliefs, a psychiatrist encouraged attending church as a crucial part of coping with the illness. The psychiatrist recognised how difficult it is to be stripped of the opportunity to work, and the church offers comfort and a meaningful preoccupation for

the YPWD. Although the particular YPWD has anosognosia, he agreed that what had transpired was all part of God's plan. The wife was grateful that they had found a place wherein they felt safe, there was no prejudice, and somewhere they knew their welfare was in everyone's best interest.

*Lucy: We went back to the psychiatrist, "Owen, something has showed up, so you're going to need to go to a neurologist to get a proper diagnosis. But you won't be able to work again. It's not up to us as well. It's up to Him up there." He [Owen] said, "Well, that's absolutely true", and [the psychiatrist] said, "your church connections will be very helpful, very important for you."*

*We've gone to an extra group called Oasis. It's kind of a place to belong, and it's a place that you're accepted, and you're safe to be there. I'm very grateful for that.*

Another YPWD expressed a similar feeling of acceptance and belongingness from the church. Although not everyone could understand his situation, some were very supportive. He used the term user-friendly to describe agreeable or easy people he gets along with. Others who were not considered user-friendly probably didn't know how to communicate with him or were not as warm or accepting of his condition.

*Nigel: They're pretty understanding, my church group. They sympathised; take me as I am. Some of them are more user-friendly than others, some don't want to know or can't cope.*

Another YPWD feels that having church friends is necessary, especially because she's far from her family in Indonesia and Australia.

Being part of a network that shares the same faith and country of origin was a considerable advantage in coping with dementia and the loneliness of being away from home. She belongs to an extensive and closely-knit family who used to live together in one household. Being a part of an Indonesian Christian congregation reminds her of this closeness and being an essential group member. During her husband's interview, one of her girlfriends from church came to pick her up to go somewhere. Her friends take turns keeping her company and do meaningful activities together – this is something the whole family is grateful for.

*Zoey: I need friends because we live in, not in Indonesia. They are nice people. I have two, they Christians as well. Friends from church and also Indonesian people live here.*

### **Sub-theme 2/3: Dementia Support Services**

Part of this study's recruitment criteria is for all couples to be registered members of the local dementia support service. This sub-theme discusses how couples benefit from this service and how it helps them cope with dementia.

#### **Point 1: Support groups catering to younger couples made them feel less isolated**

One of the spouses learned that a support group is only beneficial if it's the right fit. The support group must be suitable for the carer to build a support network to help them cope with dementia. Unfortunately, most support groups held in the community cater to the mainstream older adult population. A group with senior members 10 to 20 years older would not

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feel relatable and practical. They do not share similar experiences and have the same difficulties as younger families.

Dementia Auckland formed a group for younger couples dealing with dementia called the Young Ones. The group is held monthly on a Saturday to cater to spouses who work during the week. Since the group is the only one in Auckland, the facilitator chose a central location to be accessible from different areas. Travelling to the group may take more than 40 minutes to drive from where one spouse lives. Nevertheless, she found this new group invigorating, and it was easy for her to carpool with other spouses to go to the monthly group together. Those Saturdays are now part of her monthly routine, and she sees it as an enjoyable day off with other carers who have become her friends.

*Eva: [Dementia Auckland Keyworker] I went to a coffee group once, but a) it was a Friday morning, and b) the people were a lot older. They weren't in my position. Some of their partners were in care. It's not worth me losing sleep over because sleep is very important when you work night shift. I didn't go back.*

*I didn't start going to the Young Ones 'til late this year. I met another spouse from CT group when she stayed one day, and we yakked and yakked. She said, "you need to come to the Young Ones" and that's how I started going.*

Apart from forming friendships and a supportive network, support group members learn from each other's experiences. They share what worked or failed in their attempts at caring for someone living with dementia. They navigate through dementia without a handbook or a roadmap to consult. Most of the time, families or spouses learn along the

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way. The following excerpts show how the spouses gained helpful ideas on dealing with complex situations such as PLWD's driving cessation and putting legal affairs in place. These are some of the most challenging realities that families must navigate, mostly on their own. Carers generously sharing their learnings, liaisons, and experiences mean other members wouldn't have to go through the same predicament. It absolves others from unnecessary or additional hardships, and they could skip to better outcomes. While all these essential decisions must be made and taxing procedures must be done, carers also feel emotionally burdened by everything happening simultaneously. However, the group can uplift each other and reassure them that they are not alone and can be successful. Carers pushing through the rugged road can motivate and inspire others to get things done, even with depression and other emotional afflictions.

*Lucy: Owen doesn't want me to drive. He's addicted to his car, so go figure how this is [going to pan out]. I've worked out a plan when it happens that he can't drive anymore. That's why the support group has been helpful. I've heard some stories about how they had to get rid of the vehicles or remove the license.*

*Isaac: The other day, somebody at our support group talked about how they got the EPA (Enduring Power of Attorney) done and set it into place. It took me quite a while because a certain amount of depression was also part of it. I only came to the decision once I met somebody else from the support group [going through it].*

One of the spouses has just been to a support group once, and he found it very helpful that he wishes to go back and probably become a regular member. He compared his situation with other carers in the group

and realised how his position was better. Other YPWD, as reported by their spouses, was argumentative and presented behaviours that were challenging to manage. His wife, on the other hand, was relatively passive and mild-mannered. Somehow, he was grateful for that. However, he expressed missing the part of his wife with whom he could discuss things, brainstorm, or even argue. Somehow, the support group has given him a sense of companionship and that he is not alone in this journey.

*Richard: Sometime[s], I feel that's better that way (laughter). Some other carer's partner is quite argumentative until now. But Zoey, luckily, she [is] the understand[ing] one or probably because she forget[s].*

*I[ve] only been once. I will come back again because it is good to maintain the connection. Hearing from the other people which is very encouraging. You don't feel you are alone.*

**Point 2: Socialisation groups for YPWD offer meaningful activities that the couples look forward to**

Three YPWDs in this study are members of Cognitive stimulation therapy (CST) or what they refer to as their CT group. CST aims to improve cognitive skills and quality of life for PLWD through different activities such as categorisation, word association, and discussion of current affairs. The YPWDs enjoy the activities and the company of the staff, volunteers, and other participants in the group. It has become a part of their weekly routine, and their spouses ensure that the YPWD religiously attend for its positive results.

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*Eva: I try to make my appointments around Nigel's cognitive therapy 'cause it's really important for him. He thoroughly enjoyed it, loves it, and he came out, and he said are we still going to that group? I call it class. He'd say, "Are we going to that class today?" And I go, "not today because it's Monday and it's on Tuesday," he misses it.*

One YPWD perceives attending the dementia socialisation groups as his preoccupation and a form of respite for his wife. He recognises that when he goes to the groups, his wife doesn't have to mind him for a couple of hours, and she can do what she needs to do – rest, shop, or do some errands. For him, the groups nurture his well-being and provide his wife with a break from her caregiving role. He is also encouraged by being around other people who share the same struggles and experiences of having dementia.

*Nigel: Well, we're getting a reasonable amount [of support]. I go to groups that have similar type [of] people with my issues, a couple of those a week. It gives Eva a bit of a rest; she's working night shift which is not the easiest thing.*

Another spouse eloquently explained how the groups substantially impacted their lives. Considering how exhausting caregiving is, it is easy to forego travelling several kilometres to a dance group. There are many other things they need to deal with, such as selling their property or liaising with the bank for their mortgage adjustments. However, Isaac depicts that the benefits of attending a social group outweigh the other hassles involved in organising to go. Every Wednesday, he would see joy come to life in his wife. The moment she steps inside the room, the happy bug bites her, him, and everyone else in attendance. They listen to music, dance, laugh, and

have heaps of fun. Going to the group means they can pause to relish the moment, forget their worries, and take a break from their responsibilities. For a short moment, being around other people helps ease their burdens, and they can let go knowing they have steady shoulders to lean on. Isaac confesses that this story is not only theirs – other couples also look for the same things: happiness and solace. This example shows that coping with dementia does not only involve physical caregiving such as meal preparations, personal care, or maintaining mental stimulation. It must also include inserting pockets of happiness and promoting the best quality of life the couples can yield. The socialisation groups create those opportunities for families dealing with dementia, making significant changes in their lives.

*Isaac: The moment she walks in, she just starts clicking her fingers and starts to move. When we leave there, we're all feeling very uplifted. I don't mind making that trip. I know that I will also get some relief and joy out of it as well.*

*It's a two-fold thing because I've come to realise that a lot of the caregivers, spouses like myself, are also there for a similar thing. Afterwards, when we have a cup of tea or break, we just talk. Sometimes people have had a bad week. I think it's also a time to just lean on somebody else.*

### **Sub-theme 3/3: Family Support**

This sub-theme explains how the YPWD perceives the support they receive and how their families best provide for their continuously changing and increasing needs.

**Point 1: YPWD sees family as their main support**

All the YPWD were asked what kind of support they needed while they tread life with dementia. The two gentlemen answered financial support from New Zealand's work and income and dementia support services, respectively. On the other hand, the two women outrightly answered: "family". They see their families as the primary providers of care and support to help them get through dementia.

Woven into most of Margarett's answers were words such as, "I love my whanau" or "my family is my whanau." She expressed happiness and gratitude for their harmonious relationship and how her family often soothed her worries. She described the full support her family gives her as they go to socialisation groups together, adjust the speed of their speech so she can understand them, and they don't make a big fuss when she can't remember something. Whenever she's having difficulty explaining herself or expounding her statement, she says, "I just love my whanau," which says a lot about how much her family understands and fulfils her needs.

Their son, James, supplemented her statement with his keen observation that Margarett has entrusted everything to them. In the beginning, small things were unnoticeable and gradual. They would arrange a taxi for her to get to work, or she wouldn't want to be in the airport's bathroom for fear of being locked in. In hindsight, they realised that Margarett's dementia had started before everyone knew it. With her natural intelligence, sense of humour, and rich cognitive reserve, she functioned independently as much as possible, needing help only on odd

occasions. James narrated how shocked they were, realising that Margarett's given up most of her independence and relied on her family to help her with her daily activities. Over time, she couldn't cope independently and required more of her family's support. James described her willingness to give up her independence in disbelief, as it was entirely out of her character. She used to be fiercely independent and capable.

*Margarette: We, we feel I- we feel very good, good camaraderie together with each other, and we uh and I love that feeling together. Sometimes we'd be dancing away. Aaand speaking quickly uh saying something and, but very, you know we very, uh I just love my whanau. And then and if we feel like, "oh we, we forgot something", or whatever like, "no, don't worry we will sort this out", and so it always I, I just love my whanau. My whanau is my family.*

*James: It's quite strange because she has put all her complete faith and trust into daddy and me. She doesn't really question that we have her best interest. I was actually kind of surprised with the amount of independence she was willing to give up. To be honest, a lot of that was happening gradually in the beginning, and we didn't notice it.*

Zoey was highly functional during the interview because she was in the milder spectrum of dementia. She does everything at home, living with her husband and their 18-year-old son. She has no doubts her family is all she needs to support her. Their story is unique because it started eleven years before the dementia diagnosis when Zoey was hit by a car and sustained a concussion. Her husband organised getting her diagnosis of dementia in 2012 when Zoey's cognitive decline started becoming more serious. He had done an education course for carers with Dementia

Auckland and made crucial decisions on her behalf when she felt overwhelmed with her anxieties. The children were 7 and 14 years old during the vehicular accident. During the interview, their daughter, 25, has been a registered nurse for a few years and knows about dementia. She has been an excellent supporter who regularly checks in on her parents. She is concerned about her mother but also ensures her father's well-being. As for their son, Zoey reckons he worries more for her because of their very close relationship, referring to him as a mama's boy.

What was interesting to note is Zoey noticed the changes in how her family talks to her. They used to correct her frequently or tell her she was repetitive. Her son also feels embarrassed when he has his friends over, and Zoey laughs it off. She continues to write herself a reminder not to ask questions, but that may not be the sole reason her family stopped correcting her. As her family grew in understanding, they modified how they communicated with Zoey to uplift her and prevent her from feeling inadequate. They also share the same value in prayer, which has been Zoey's refuge during trying times.

*Zoey: I'm very bless[ed] I have him (Richard). He knows a lot [of] things. My children also, Criselda is very care[ing]. He [son] worry[ies] that I got sick, one day I get dementia. He is worried about that. He love[s] me more. He's a mama's boy. They call me, and they worried if I got sick or papa. They pray for us. The children pray for us, and we also pray for them.*

**Point 2: Family members became skilful in helping the YPWD cope**

This point describes the specific skills that family members develop to cope with dementia and support the YPWD. Each person has actively helped deal with dementia with their talents and abilities. However big or small, whatever they pitch in contributes to the overall well-being of the YPWD and the rest of the family.

Isaac expressed how his relationship with his son thrived as they worked together to support Margarett. They have grown more confident as they acknowledge each other's strengths and least favourite chores. The synergy and mastery of their caregiving roles have made their experience pleasurable and fulfilling, increasing their self-esteem and role satisfaction. The father-son duo has learned to compensate for each other and work collaboratively. James is adept at doing Margarett's makeup which Isaac proudly embraced cleaning out the dirt. He washes the dishes and cleans the house. James is very good at Margarett's personal cares.

*Isaac: We have developed this bond. Both of us have different skills. I had to realise that we balance each other's skills. We're feeling a bit stronger now to be able to cope with ourselves and especially with Margarett.*

Owen is also highly functioning – he can still eat on his own, is in charge of his hygiene, and mows the lawns – all with Lucy's prompting and reminding. However, he cannot make decisions for himself. His brain's executive function, flexible thinking, and self-control have diminished. As previously described, his behaviour and personality have changed, and his insight into his deficits is impaired. The family does not get involved in his

activities of daily living yet. What they have done was pitch in with their research expertise. In their longing to understand what's going on with Owen's brain and why he behaves a certain way, the children have researched and shared what they know. Researching is their way of getting to know their father all over again, this time with his dementia.

*Lucy: I would share with my daughters because they were noticing too. They were looking up things because they're all bright. They know their dad too. They're also really good researchers, especially my oldest daughter and my son. It affects them, so they all wanted to know him.*

### **Point 3: Families build the YPWD up for success and to be content**

Families are aware that the YPWD could no longer be the same as they were before. They have disabilities that limit their capacity to work or function. This point illustrates how the families work towards the YPWD's success and sense of contentment.

Isaac and James have learned to be protective of Margarete. They know Margarete's frustration with herself and realise how hard it must be to feel restrained and limited by what she can do. Due to previous exposure to other people's pressures and unrealistic expectations, Isaac and James intentionally shielded Margarete from any unnecessary external stressors. Long-time friends lost touch because they did not know how to relate with Margarete and what to say during social events. Now, Isaac and James carefully choose their support circle to enrich and uplift Margarete rather than make her feel diminished or a failure. They decided to continue

with their church friends, Dementia Auckland's Living Well group, and the Young Ones support group, where they think Margarett's well-being is nurtured. Although most of their close friends from before have distanced themselves, they gained a new group of carers and families who understand and accept them as they are.

*Isaac: Margarett couldn't get a job. We were hitting walls at every avenue. We also have very pressurising community from our friends. Like, "Oh, why didn't you get a job? Maybe try this". This happens to quite a number of people that are in our support group.*

*Very often, people [with dementia] can present themselves in a way that they come across like there's no problem at all. But give them the task, what's going to happen then? James would always say, "we can't set up mom to failure." I understand that. We've also come to realise that she's never gonna be the person she used to be.*

Owen belongs to a closely-knit family. They enjoy each other's company, travelling or spending the holidays together. Unfortunately, Owen has become withdrawn and dismissive and appears to sneak out of family gatherings so he doesn't have to interact with them. He has lost his ability to mingle with the most important people in his life. Owen may have found it hard to be around the family due to embarrassment, or it must have hurt him not to know what to say or do. It is hard to gauge how much he thought about things because he could no longer express his emotions. But at least one thing is obvious, and he tried several times to get away from family gatherings for some reason.

Initially, the family thinks that Owen doesn't love them anymore. After a while, they realised he could not help himself, so they created an

atmosphere where he could feel comfortable and safe. The family has learned to set up ways where Owen can continue to feel like he belongs to the family, have fun and just be himself. They thought of making him play the piano on one family occasion while everyone else sang around him. They preoccupied him with an activity he would enjoy and feel good about himself. Music has played a significant role in bringing the family close together, especially now with dementia. The family has reimagined what Owen naturally loved and used it to connect with him in a way he knows how.

*Lucy: He wouldn't join in with anything! So they were thinking, "Doesn't he like us? Doesn't he love us anymore?" At Christmas, my daughter-in-law got some music together. Dad loved to play the piano, so they'll say, "Come on, dad, play that!" He loved playing all the carols with us all sing around the piano. That was really successful!*

### **Theme 3: Changes in spousal dynamics**

The last theme describes how dementia changed the couples' spousal dynamics. It is divided into two sub-themes: 1) romantic relationship evolved, and 2) couples' incongruent views of their relationship. Table 6 summarises the third theme, its sub-themes, and points.

**Table 6: Theme 3 – Changes in Spousal Dynamics**

RESEARCH QUESTION	THEME	SUB-THEMES	POINTS
			POST-DIAGNOSIS
3	Changes in spousal dynamics	Romantic relationships evolved	<ol style="list-style-type: none"> <li>1. Spouses take on a caregiving role</li> <li>2. Sexual and emotional intimacy</li> </ol>
		Couples' incongruent views of their relationship	<ol style="list-style-type: none"> <li>1. Preoccupied with carer responsibilities, a spouse's need for intimate connection diminishes</li> <li>2. Lack of insight hinders the YPWD from becoming aware of the changes in their marital dynamics</li> </ol>

**Sub-theme 1/2: Romantic relationships evolved**

Dementia has changed many aspects of the couple's relationship, including how they relate romantically as husbands and wives. Romance that involves expressions of affection, emotional and sexual intimacy, and companionship had evolved far from where their relationship was before dementia affected the YPWD's cognition, behaviour, and level of function. This sub-theme illustrates why the romantic relationship changed and describes the couples' sexual and emotional intimacy with dementia.

**Point 1: Spouses take on a caregiving role**

One of the main reported reasons for the couples' changing romantic relationship was the spouse's evolution from being a marital partner to a spousal caregiver. For one spouse, the role gradually came in without him noticing. It took a Dementia Auckland symposium's presentation on the most politically correct label for caregivers to realise what he has become. He has been trying to define himself within the dementia journey and has struggled for some years. Identifying himself as his wife's caregiver finally gave him a sense of relief. He could finally let go of the burden of going to work and aligning himself with the rest of his

cohort. The conversation on the caregiver label has normalised his situation and allowed him to accept his role fully. A husband learning about his wife's intimate routine – making sure she has clean underwear, what type of clothes she wears, cleaning the house, or not having a good night's sleep – is typical for caregivers. It is nothing to be ashamed of, and it was all part of their journey with dementia.

*Isaac: Quite clumsily, I've been trying to hang onto this. Still trying to keep in all the life like getting a job. In a sense, life has been pushing me along to find my place. And then in August, sitting there, R mentioned those labels, and suddenly, yes! This is me! In a way, a huge weight has been taken off my shoulders.*

As a full-time caregiver of someone with dementia, a spouse may be eligible to receive financial benefits from the government. To avail of this, the spouse must go through New Zealand's Work and Income application, providing proof of the YPWD's disability with medical information from their health practitioner. They also need to present the impact of the YPWD'S condition on the spouse's ability to work. One of the spouses had to go through this, so she made the conscious decision to make herself available to her husband, knowing that he would not cope independently. It was a natural decision for her as she raised and taught all her eight children while her husband worked. Although she would have loved to work in nursing and education, she did not grapple with the idea because she has always been and continues to be a caregiver for her family.

*Lucy: That was another reason why I didn't get employed all those years. I love to work as a nurse or in education, but I still need to be available. It was something in me that knew Owen wasn't quite right.*

**Point 2: Sexual and emotional intimacy**

All the couples were in different stages of the sexual and emotional intimacy continuum, ranging from being intimate with minimal changes to being sexually and emotionally detached. Based on the couples' historical accounts, their bondage had been strong, and they had good relationships before dementia started to show. Some have gone through more trials and tribulations than others, but they all remained committed as a couple.

There are varied reasons for the changes in couples' level of intimacy, but in this study, the YPWD's level of dementia and function was a significant factor. As the person's dementia progressed, their capacity to be intimate, both emotionally and sexually, was also affected. Dementia changes the person's interest in sex, increasing or decreasing it, or the YPWD may be overly affectionate at the wrong time or place, which may create a problem. The YPWD may also have altered capacities to emotionally express or connect with their spouse. On the other hand, the spouses may view their intimacy differently. The couples mentioned some of these reasons during the interview, described below in the following points.

The first couple faces mild dementia, and the YPWD remains independent, leaving the spouse unaffected by caregiving tasks. Both husband and wife don't think their relationship has been affected by dementia yet. The YPWD described her husband as a loving and caring man, while her husband reckons nothing has changed, apart from being impatient sometimes and getting frustrated when she forgets things or does things erroneously. The couple did not explicitly mention sexual

intimacy during the interview, but the husband confirmed there was only a “minimal change” during the member's validation meeting. He also concurs that their roles have not changed much, so their intimacy was preserved.

*Zoey: Especially my husband. He's a very lovely man. [He's a] Loving, caring man.*

I: With Zoey's dementia, do you feel that your relationship with her changed?

*Richard: I would say not*

The next couple's emotional intimacy is very much intact. There is trust and feelings of security exchanged between the two. The husband is nurturing and caring, always anticipating his wife's needs and considers her a top priority. He sought to understand what his wife was going through and empathised with her. He upheld her identity in how they went about their routine, ensuring she was comfortable and happy. The wife's expressive aphasia limits her ability to verbalise her emotions, but she has non-verbal ways of showing appreciation and love for her family. She used her unique talents in music and cooking to express her love. She opened up to her husband when frustrated or anxious, receiving patience and reassurance. They had formed a different kind of bond when dementia came into their lives, but they lived in the moment, trying to make the best of what they had and who they were with.

On the other hand, their physical intimacy had been altered by dementia. Although the hugging and kissing continued, the sexual act has

gone. In the excerpt below, Isaac described that Margarete had lost the ability to differentiate a simple farewell gesture from an intimate kiss. He was worried that she would do this again with someone else or in a public place, which would be entirely out of character and inappropriate. During the member's validation, Isaac defined Margarete's sense of physical intimacy as childlike. She has become more reserved and has been uncomfortable performing sexual acts. He felt it was no longer appropriate to do so.

*Isaac: There was a very unusual stage where she would want to French-kiss me before leaving for work. It was such a strange thing because we never did that, just as a normal goodbye. You kiss but not so intimately.*

**Member validation:**

*Isaac: Margarete has become more childlike in that she's more shy and timid, and it doesn't feel right anymore to be intimate with her.*

The third couple has always been very affectionate, affirming, and expressive. They pride themselves in attending a church's marriage encounter programme to strengthen their marriage some time ago, which has helped them have a fulfilling relationship. The wife also explained that to have a good relationship, they had to have open communication, strongly share the same values and put their family as their top priority. They had a solid connection, set their goals, prayed together for each other, went to church services, and jointly reared their children with the same beliefs and values.

Unfortunately, dementia has impaired the husband's emotional expression and connection with his wife and the family. He forgot how to pray, became withdrawn, lacked empathy, and refused to bond with them – qualities he would not have shown before dementia. He was emotionally available, a wise and steady leader, and a family counsellor.

Amidst all the changes in the husband's emotional capacity, the wife shared about his retained and ignited interest in making love. During the interview, Lucy wasn't explicit in naming the act of love-making and called it their "maritals". However, during the member's validation, she confirmed that Owen preserved this physical memory and, even more so, performed as if he was a young man. She was also grateful that Owen could utter words that affirmed his love during those moments and lovingly held her, which she thought were incomparable. Even for a short while, Lucy felt contented to see and feel a glimpse of her husband. Lucy clings to Owen's ability to connect with her when they meet eye to eye physically. She trusts that somewhere within him, his love for her lives on.

*Lucy: Even though Owen has not been so affectionate, our marital have still continued the same pretty well. They say some memories don't go, and I'm sure that that one hasn't either. For a few moments, I can imagine what Owen used to be like, I think now he's a little bit more than then.*

**Sub-theme 2/2: Couples' incongruent views of their relationship****Point 1: Preoccupied with carer responsibilities, a spouse's need for intimate connection diminishes**

The fourth couple's emotional and physical intimacy has also changed. Their stories suggest that the effects of dementia on their lives – financial strife and their wife's transition to caregiving – have altered how they relate to each other. Eva has taken her caregiving role to heart as she supports her declining husband and frail father. This role is a huge responsibility that needs more attention and consumes most of her time and energy. She confessed how exhausted she was and could no longer physically or emotionally connect with her husband. She was also not open to discussing and exploring this area of their marriage with him.

On the other hand, Nigel passively accepted the situation with guilt. To a certain degree, he felt remorseful that their marital intimacy had ended, inferring that what happened to their marriage was his fault. Although Nigel can still do many things independently, he needs prompting and reminding for basic things. His physical health was also declining, and he's had some falls.

The physical effects of dementia caused Eva to become protective of Nigel, making him feel more like her child and not a husband. She also could not tolerate Nigel's frustration when he lost things or struggled with a chore or activity. These evolved dynamics created a gap between them, changing their marital connection into a pseudo-mother-child relationship. Due to this transformation, their relationship lacked the intimacy a

husband and wife typically have. Eva felt awkward when asked if she wanted to discuss their intimacy because sex was no longer a natural part of their marriage. However, the wife explained that love, concern, and care continue to exist, but it now comes in different shapes and forms. The wife's remarks about her husband's new label for her made her chuckle, possibly because she realises that it's true – she does sound like his mother.

A few years ago, they decided to sleep in separate rooms. Nigel rummaged through their bedroom and opened the wardrobe while Eva tried to sleep, even after numerous reminders not to do so. Understandably, rest was necessary for Eva, who had a bout with cancer and works at night. She can't afford to lose sleep because she's the only one working. Her routine has been managing the household chores, preparing food for when she's sleeping or working, and taking Nigel to social activities and other appointments. She can only squeeze in about three to four hours of sleep during the day. Their physical connection has come down to just a kiss and a quick hug goodbye when she goes to work. She doesn't particularly miss the sexual act because she's too exhausted and doesn't see the need anymore.

Eva is fully aware of the changes in their relationship but doesn't want to discuss it with her husband, assuming he has not noticed any of it. She may view his dementia as more advanced – he lacks awareness, doesn't yearn for physical or emotional connection, or cannot have a deep conversation about their relationship. On the other hand, she may also feel depleted and overwhelmed with life that she doesn't have any more of herself to give. If she starts the conversation about their marital dynamics,

she may not be ready to change the status quo and commit to Nigel's emotional or sexual needs. She is in a different phase of their marriage, where the young love has gone, but the inclination for companionship remains. She has resigned to the idea that Nigel may have some needs she could not meet.

*Eva: The thing is that we do sleep in separate rooms. [It started] probably two and half years ago because he would keep coming in and waking me up. That's only because of my work, and I have to work. I support us.*

I: So before dementia, the intimacy and your relationship is still the same?

*Eva: Yeah, same*

I: The intimacy, the part of the relationship, it's not the same anymore?

*Eva: It's just not there. He sometimes calls me his mother (laughs) because I was saying, "Nigel, where's that shirt you had on yesterday?" "We need to put that in the wash."*

I: Have you talked about the change in your relationship?

*Eva: He doesn't notice it. Always when I leave for work at night, [he'd] hug me and kiss me. It's that touch, but it's always there.*

I: Do you want to talk about it?

*Eva: HUUUUHHH (high pitched) No, not really.*

I: But do you miss it?

Eva: *No, not really (laughs nervously). I know it sounds awful, but I'm just tired and exhausted. It's not something I seek out anymore.*

*I love him, but the young love is not the [same]. It's more companionship than anything. I always worry about him.*

Nigel's behaviour and words suggest submission to his fate and surrendering control over his wife. He has realised that their relationship may no longer be the same as before, and he can't do anything about it. It seemed the same way he views how he will eventually succumb to dementia. There was parallelism in his thought processes regarding his marriage and dementia – any effort to save the marriage or find a cure for his illness is futile at this stage.

I: Does [dementia] change the dynamics between you two?

Nigel: *It does, yeah. She's not quite so tolerant on me because I am not totally with it enough to be user-friendly. And if I forget something, I get myself upset. She's probably thinking here is the end of our original (pause) relationship. And now, she's just a caregiver to me. She just has to sit on the sidelines and watch me decline, really.*

**Point 2: Lack of insight hinders the YPWD from becoming aware of the changes in their marital dynamics**

Owen's dementia and anosognosia changed him from being an affectionate and romantic partner to someone unrecognisably cold and withdrawn. Feeling unwanted and unloved, Lucy reached a breaking point

when she was ready to leave. She explained how she felt agitated one day and poured everything out into a letter, but he refused to read it without giving her a reason. Lucy reached the end of her tether and exploded in one of their biggest, if not the biggest, fights, but he could still not bring himself to read the letter. She realised later that he did not read the letter, not because he did not want to, but because he couldn't. Before dementia kicked in, Owen would have known the letter was a big deal and very important to her. She would use writing to express her innermost thoughts and feelings, and it has been successful throughout their marriage.

Eventually, Lucy comes to terms with Owen's inability to express his emotions or empathise with her. Dementia almost cost them their marriage, but Lucy continues to be committed. She explained that although Owen's a changed person and cannot connect with her emotionally, she must continue to be affectionate and expressive towards him. For her, this is one of the most important aspects of her caregiving role – to make her husband feel safe and loved. With or without dementia, she will continue to be the same wife she has always been.

*Lucy: I could see we were not connecting. So I wrote a letter to him, and he didn't even read it, and he didn't even give a reason. I was getting dramatic and emotional. I just feel like I want to run away, and you're not willing to talk about anything! Owen got really agitated about that, and he said, "Please, please don't go." I just sort of sensed that he couldn't.*

*I think the most important thing is that he feels loved. I don't know how he is emotionally, but I keep reminding myself that he still needs*

*to [feel] that he's loved, and I still need to tell him and be affectionate. Every human being needs to know that they're loved and they're safe.*

Lucy shared her perspective of their marriage exhaustively, including its highs and lows and how dementia affected it. On the other hand, her husband, Owen, evaded the topic. He was asked about daily living with dementia, and he shared generously about the difficulties he experienced: de-licensure, driving assessment, and disagreements with work colleagues, among others. He admitted to having dementia for the first time but clarified that it was only based on the scan. Otherwise, he felt a hundred per cent sure he was alright.

His thoughts flowed naturally from one topic to another with detailed descriptions of events, places, names, and histories. However, his answers sounded insufficient and too concise regarding his wife and family. He veered away from the topic and, without a blink, pointed the conversation in another direction. I tried to pivot him back into the changes in his marriage and family dynamics, but he did the same thing and deflected the query. If a topic bears weight on his mind for whatever reason, he would naturally talk about it even when not asked. But it was never about his wife or his family.

As his wife said, Owen was more interested in the more superficial things and people in his distant memory, but not his current and close relationships. His family has gone through a heartbreaking discovery of his dementia and has seen massive changes in his personality and behaviour. They felt the actual loss of their husband and father. Without Owen's

insight and acknowledgment of his family's pain, one can only imagine how Lucy and the family must feel.

I: Do you feel that any of your relationships with your family changed after diagnosis?

Owen: *Hmmm, relationships? Hmmm, not really. Not completely.*

I: No? Ok. It's a good thing, isn't it?

Owen: *A couple years ago, we went across to Brisbane. Well, we ate too much food to come and get it. We've got to stay with my sister and brother-in-law because my sister, when she's married to a lovely Maltese...*

I: So I'm going to bring you back home to your relationship with Lucy. I know you said no. Relationship-wise within the family, it hasn't changed much. What about your and Lucy's relationship? Did anything change a bit?

Owen: *Since when? Oh, this carry on? From delicensing thing and stuff?*

I: Yeah Yeah, from the diagnosis and also delicensing and things like that.

Owen: *Well, Lucy's ended up doing a bit more crazy computer and paperwork that needs to be done...*

I: Any other aspects of your relationship (with wife) has changed since the diagnosis or the delicensing?

Owen: *Uhm, not that I regarded...one of the trouble of some of the stuff of the diagnosis was having to have a driver's license driving assessments and stuff...*

## **Chapter 5 – Discussion**

This chapter covers several areas. First, it discusses how the key findings from the study answer the research questions and then examines the extent to which these results have added helpful information to the literature on couples dealing with YOD. Second, the service and policy recommendations from this study's findings are detailed. Third, the strengths and limitations are evaluated. Fourth, the implications for practice catering to YOD are enumerated; and lastly, recommendations for future research for couples dealing with YOD in New Zealand are presented.

### **5.1 Discussion of Key Findings**

The discussion of the key findings is structured to respond to the three research questions below:

1. What are the greatest impacts of dementia on the couples' day-to-day experiences?
2. How are they coping with the illness within their life cycle?
3. How has their relationship evolved because of dementia?

#### **5.1.1 Factors that affected the couples' lives the most**

The most significant factors that affected couples' lives were identified as 1) people lacking awareness and understanding of YOD; 2) the varying presentations and effects of dementia; 3) dementia negatively affecting YPWD's occupational competence, and 4) grief and loss. These factors are described below.

### **Lack of awareness and understanding**

Other people lack awareness and understanding from their families, friends, acquaintances, government agencies, doctors, and even themselves. The PLWD may still be highly functioning: such as the participants in this study – Zoey is independent at home, Nigel and Owen have great physiques, and Margarett’s magnificent musicality is still intact. There is a phase called “subclinical dementia,” which occurs when the person’s signs and symptoms do not meet the clinical criteria yet to establish a diagnosis, and this can go on for several years (Brodaty & Lie, 1998; Linn, Wolf, Bachman, Knoefel, Cobb, Belanger, Kaplan, & D’Agostino, 1995).

### ***Families struggled to find out what was happening***

Families struggled to determine what was happening before a diagnosis. Spouses did not want to make a fuss or cause distress to the YPWD but were concerned about the subtle personality and behavioural changes. Before seeking professional help, the spouses accessed their resources and researched the internet to determine if the behaviours that the YPWD exhibited meant anything serious. This ‘not knowing’ phase caused great stress for the couples, often leading to a breaking point.

Lockeridge & Simpson (2012) found that although spouses wanted a timelier diagnosis, their lack of awareness and understanding of YOD contributed to a delay in this process. Cabote, Bramble, & McCann (2015) reported spouses felt uncertain about the symptoms and how to interpret them during the pre-diagnostic phase. Ducharme et al. (2013) found that

spouses independently searched for what to expect regarding prognosis, possible treatments, and changes they need to make in their homes and family lives via the internet.

***The misconception that dementia is an older person's disease***

This study shows there is still a strong misconception that dementia is an older person's disease. Isaac could not believe his wife could develop an illness mainly linked to older people. Zoey, a YPWD, refused to accept she could have her grandmother's diagnosis.

McMurtray, Clark, Christine, & Mendez (2006) report this incorrect perception limits laypeople and health professionals' insights into the broader variance of presentations among YPWD compared with later onsets, with this bias a factor in the difficulties and delays in diagnosis.

***Cause of difficulty and delay in acquiring a diagnosis***

It took an average of 6 years from the onset of the illness, and 1 to 5 years of active searching, for couples to receive an accurate diagnosis of dementia. They experienced incorrect diagnoses and sceptical primary care doctors who brushed them off and did not investigate further. Back-and-forth consultations led nowhere.

The findings in this study are supported in the literature: that acquiring a diagnosis occurred over several months and years (Bakker, de Vugt, Vernooij-Dassen, van Vliet, Verhey, & Koopmans 2010; Lockeridge & Simpson, 2012; Ducharme et al., 2013; and Cabote et al., 2015); Physicians were reluctant to give the diagnosis by virtue of the YPWD's younger age (Teel & Carson, 2003); Healthcare professionals lacked knowledge and

understanding about YOD and specialist training and resources in primary care settings (Lockeridge & Simpson, 2012; Iliffe, Wilcock, & Haworth, 2006); Health professionals were not forthright or ascribed the YPWD's behavioural and personality changes to stress at work, marital problems, anxiety, or substance abuse (Lurati, 2014; Ohman, Nygard, & Borell, 2001; Ritchie, Tolson, & Danson, 2017); The diverse initial signs of YOD exacerbated the diagnostic problems (Sperlinger & Furst, 1994); The changes occurring in the individual were gradual in nature (Liebson, Rauch, Graff, & Folstein, 2005). Resolving these issues helps alleviate families' confusion and worry, prepares them for the future, and aids individuals or families in qualifying for services (Gibson, Anderson, & Acocks, 2014).

***A lot of people don't know how to deal with dementia***

The spouses and YPWD agreed to participate in this study because not many people know about dementia and how to deal with it, especially when they meet a younger person living with it.

Gibson et al. (2014) reported that carers believed service providers and the general public "did not adequately understand their needs" (p. 598). A stigma against YOD means some couples deny its existence and may be unwilling and afraid to disclose the diagnosis to others (Ducharme et al., 2013). The fear of the stigma, biases, and inability of others to comprehend dementia makes couples reluctant to seek help from their social network (Ducharme et al., 2013).

### **Varying presentations and effects of dementia**

The varying presentations and effects of dementia significantly affect couples' lives. The key factors were anosognosia, declining driving abilities, and YPWDs' changing behaviours and cognition.

#### ***Anosognosia – Lack of Insight***

When a person has anosognosia, physical changes in their brain cells prevent them from being aware of how they feel and function. This lack of insight means that if something is wrong at home, at work, or in their health or relationships, there won't be an expectation to adjust, act, or fix anything; the person assumes that everything is in order (Doty, 2007).

In this study, one YPWD took much convincing before agreeing to do anything because he did not accept he had dementia. The wife had to learn how to be flexible and communicate in a way that was effective and respectful. During the interview, his wayward thoughts and lengthy anecdotes lacked focus, and he did not return to the topic.

FTD is one of the probable causes of anosognosia (Doty, 2007). It makes daily life increasingly difficult for spouses and families, being described as "surrealistic, awful, strange and impossible for others to understand" (Johannessen et al. (2017), p. 786).

#### ***Declining ability to drive***

Both male YPWDs reported their decline in driving had the most significant impact on their lives. They had different perspectives and

reactions about driving cessation – Nigel voluntarily gave up driving while Owen stood his ground and thought going through driving assessments was unnecessary. Nigel felt trapped and restricted by this limitation, while Owen refused to stop and continued to challenge his wife and the professional's advice.

Driving cessation is one of the most challenging things to manage and overcome (Lockeridge & Simpson, 2013). However, it is not well-researched (Velayudhan, Baillon, Urbaskova, McCulloch, Tromans, Storey, Lindsay, & Bhattacharyya, 2018). Younger women with dementia are more likely to voluntarily stop driving than younger men with dementia, being more cautious, less confident, and influenced more by family and friends (Velayudhan et al., 2018).

Young men are more fearful of losing their independence and ashamed to admit their inability to drive and, therefore, less likely to cease driving when advised to do so (Velayudhan et al., 2018). YPWDs with more intact insight and awareness of their incapacities, like Nigel, are more likely to stop driving (Velayudhan et al., 2018, p. 196). Lack of insight into the predictors of driving cessation – probable visuospatial deficits, overall cognitive decline, and risk-taking behaviours (Velayudhan et al., 2018), such as Owen's, presents a problem with compliance.

***The presence of FTD symptoms changed the family dynamics***

Owen's changing behaviours and personality caused his family to exclude him from some family communications and activities, as his disinhibitions and lack of empathy hurt their close-knit family. Lucy and

their children set some boundaries to protect the younger family members and preserve their relationships.

Spouses report that the early stages appear inexplicable as the YPWD has personality changes, mood swings, and unusual reactions (Johannessen et al., 2017). As the disease progressed, the changes in behaviour from young-onset FTD “placed heavy demands for emotional work” on the spouses and the rest of the family (Oyebode, Bradley, & Allen, 2012, p. 164).

FTD differs from other forms of dementia, with carers’ experiences being more complex due to FTD’s inherent symptoms of aberrant motor behaviour, disinhibition, and apathy (Svanberg, Spector, & Stott, 2011). Symptoms are intense and more distressing for carers (de Vugt, Riedijk, Aalten, Tibben, van Swieten, & Verhey, 2006). Close family relationships become troubled, and connections suffer due to the effects of dementia on the YPWD (Bramble, Moyle, & McAllister, 2009).

### **Dementia affected YPWD’s occupational competence**

All YPWD in this study were still working when they first experienced dementia – this is one of the most significant differences between YOD and OAD. The YPWD are at a stage in their lives when they have more responsibilities than their senior counterparts, who are more likely to be retired and in poor health. In this study, the first signs of dementia were revealed at work, and the couples experienced a significant financial drawback they had never encountered before.

***Reflections on previous work achievements***

All four YPWD had had rewarding jobs, both personally and professionally. They freely talked about what they liked about their jobs and thought they were good at them. With a sense of pride, they had a lot to share about their professional accomplishments and how much work has brought them joy and fulfilment.

Individuals often define themselves socially by their profession (Chaplin & Davidson, 2016; Harris & Keady, 2009). Their 'worker role' has been an "important, meaningful and satisfying part of life" (Ohman et al. 2001, p.40).

***The first significant signs of dementia occurred at work***

All the YPWDs were actively employed when the symptoms of dementia became apparent. Their jobs were cognitively demanding, and this illness affecting memory and other cognitive functions prevented them from working in a similar capacity. Nigel was made redundant numerous times and could not retain his job. Margarete resigned from her highly stressful position because she could no longer cope. Zoey's husband advised her to leave work due to severe anxiety and workplace bullying. Owen's employer initiated a medical investigation that caused his de-licensure.

YOD often initially affects the "domain of occupational competence" (Andrew, Phillipson, & Sheridan, 2018); Chaplin & Davidson, 2016; Ohman et al., 2001; Ritchie et al., 2017; World Health Organisation, 2017, p. 141).

The first damaging signs of dementia may be work-related, followed by behavioural or changes in personality (Sperlinger and Furst, 1994) – this matches the transitions the YPWD in this study have gone through.

When dementia causes the person to underperform and compromise their capacity to earn a living, their identity as a worker becomes “fractured” (Harris & Keady, 2009, p. 439). The YPWD lose their sense of pride, purpose, self-worth (Chaplin & Davidson, 2016; Harris & Keady, 2009, Ohman et al., 2001), sense of enjoyment and achievement (Ohman et al., 2001), and social recognition (Peisah & Wilhelm, 2007). The person goes through anxiety, depression, and loss of a sense of occupational identity (Harris & Keady, 2009; Ohman et al., 2001; Ritchie et al., 2017). YPWD can never experience the retirement milestone with an intact identity, blissfully pursuing different recreational activities as older people might hope to (Andrew et al., 2018). This was true for all YPWDs in this study: Margarete’s stellar career as a music teacher, Owen’s community award-winning health profession, Nigel’s longevity and stability as a draftsman, and Zoey’s exemplary executive secretary and account assistant roles – all gone. They were either let go or felt they had to leave the careers they had worked long and hard for due to dementia.

### ***Financial drawback***

Three of the four couples suffered monetary drawbacks due to the YPWD’s unemployment. Since they are below 65 years old, none have received pensions yet. Two couples were ineligible for Work and Income financial support because of Isaac’s collateral in another property and

Eva's sale of their old home. Both expressed their concerns about losing their home due to their inability to maintain a mortgage. Only Lucy managed to get some financial assistance as a full-time carer. The amount received could not support the lifestyle they used to lead. The couples thought they had been prudent, preparing for a comfortable retirement in several years, but had to recalibrate and alter their lives to fit their now limited resources.

Financial hardship is one of many challenges confronting YPWD and their partners (Bakker et al., 2010). Dementia disrupts their active roles in life, employment, access to benefits, and ongoing financial issues (Gibson et al., 2014; Spreadbury & Kipps, 2018).

### **Grief and Loss**

The couples had an overwhelming sense of loss for the many things they went through. They all stood in various stages of the grief spectrum, illustrated by their reactions towards dementia, anticipatory grief, loss of plans for the future, and acceptance.

### ***YPWD's reaction towards dementia – shock, desperation, regret, anosognosia***

The YPWD felt different things upon their diagnosis – shock, desperation, regret, and complete disbelief of dementia (anosognosia). With intact awareness, Margarete, Zoey, and Nigel lamented their new reality of living with a chronic and life-limiting illness. On the other hand, with limited insight and disagreement about his diagnosis, Owen was aware his life had changed due to dementia.

When a younger person is diagnosed with dementia, it is perceived as an “unacceptable threat to their self-image, and they are therefore unable to integrate the concept of dementia into their sense of self” (Clare, 2003, in Lockeridge & Simpson, 2013, p. 641). This difficulty in perceiving the union of the ‘younger self’ with dementia is one of the reasons Lockeridge & Simpson (2013) reported some carers do not think letting the YPWD know their diagnosis is beneficial and should be concealed.

### ***Anticipatory grief***

With dementia, couples lose everything their married life entails, including their dreams and hopes for the future (Ducharme et al., 2013). Nigel felt sorry for his sons, who would lose their father. Eva knew how things would go down. Nigel will forget everything and will eventually succumb to his illness. Isaac described his son as feeling cheated by dementia for losing his mom’s brilliant mind at a young age. Richard starts to mourn for his wife’s loss of spunk, their arguments, and her companionship. While the YPWD is still alive, grief is real, and it stings.

These findings convey the spouses felt the “loss of normality,” with grief seen as “anticipatory and continuous” (Cabote et al., 2015), p. 453).

### ***Loss of plans for the future***

Nigel feels guilty as he realises he can no longer fulfil his promise to travel or make life better. Eva confesses feeling stuck in the moment and by her caregiving role. Isaac is bitter as the disease has ruined his retirement

fantasies with boats or an RV. The future is grim, and they have had to restructure their lives to deal with it.

YPWD couples experience multiple losses, which start at the onset of the illness and continue as dementia progresses (Lockeridge & Simpson, 2013). Consequently, looking too far ahead causes helplessness (Ducharme et al., 2013). Carers label it as being cheated by dementia (Lockeridge & Simpson (2013) or being “robbed of the future” (Alzheimer’s Australia 2007, p. 40).

Spouses dread the future due to the mounting pressures of caring for the YPWD and continuing to contend with life, working, and supporting their young families (Lockeridge & Simpson, 2013). There are still so many years ahead of them, yet they lose their autonomy, feel stuck in their situation, and cannot plan with all the uncertainties that go with the course of dementia. The couples grieve for the loss of a shared future and miss out on planned travels upon retirement for things their families never had and will never have (Cabote et al., 2015).

***Acceptance – families see the silver lining amidst their difficult situation***

Some participants shared they reached a level of acceptance. Even with dementia being a hard pill to swallow, they allowed some space to see the good in this whole experience. Margarete was the only YPWD who was ‘happy’ about her dementia. She was frustrated with herself but has come to terms with her losses. Margarete proudly expressed how pleased she was with how her family supported her. Isaac felt relieved when he accepted that he had become a carer. He realised there was no need to struggle with

keeping up with his peers because their lives are different now. Lucy accepted dementia as the cause for Owen's personality and behavioural changes; it was a preferable explanation for an emotionally withdrawn and unaffectionate husband than an act of will.

A confirmed diagnosis gives a reason for the unusual behaviours the YPWD had been presenting (Ducharme et al., 2013) and can enable a clearer outlook on life since the couples understand what is happening (Cabote et al., 2015).

However, dementia is still hard to understand and painful to accept (Sikes & Hall, 2017). Dementia is the last thing spouses want to hear because they perceive it to be a grave threat, so they cope through avoidance and denial (Lockeridge & Simpson, 2013).

### **5.1.2 Coping with dementia**

Couples had different coping strategies in dealing with dementia: tapping on their spiritual connection, accessing dementia support services, and maximising family support. Knowing how couples dealing with YOD cope is essential for developing their "adaptive abilities and ultimately improving their quality of life" (Beuscher & Grando, 2009, p. 583).

#### **Spiritual Connection**

##### ***Faith in a higher power helped ease uncertainties***

Spiritual connectedness as a form of coping was the most talked about self-management tool in this study. The couples had God-related answers for most struggles they encountered. Zoey believes her future is in God's hands and that nothing will occur to her that God hasn't thought through. Lucy finds

solace in God's grace. Both women have fully surrendered to God because they believe He is all-knowing and has plans for them. Isaac renews his faith in himself as he gets reminded that God believes in him. When he reflected on the lives of men of faith who struggled and came out triumphant, he was reminded that he, too, would succeed in this precarious path.

Spirituality is a vital resource for older people coping with "debilitating, chronic, severe, and terminal conditions" (Beuscher & Grando, 2009, p. 584). Spiritual coping correlates with PLWD's emotional well-being and improved health (Koenig, McCullough, & Larson, 2001; Narayanasamy, 2002).

Spirituality can be an attribute and indicator of resilience in spousal caregivers of YPWD, along with "determination, flexibility, positive thinking, self-efficacy, resourcefulness, and social support" (Kobiske & Bekhet, 2018, p. 411). Resilience became a byproduct of spirituality, enhanced when meaning is associated with the caregiving role (Deist & Greeff, 2014; Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014). When caregivers recognise spirituality as an integral part of their lives, they can adapt more successfully (Deist and Greeff, 2014).

### ***Church offered a sense of community and belongingness***

Church offered a place where the couples felt accepted despite the changes caused by dementia. Attending church services was an excellent preoccupation for the YPWD. It reminded them of home and gave them a sense of belongingness.

Being a church member is a recognised coping strategy helping people with early-stage Alzheimer's disease to keep a positive attitude while living with dementia (Beuscher & Grando, 2009). Going to church engages the community and ritualistic behaviours (Beuscher & Grando, 2009). Attending church provides reassurance and hope and allows PLWD to stay connected (Beuscher & Grando, 2009). It also upholds people's identity, linking them to their pasts and providing a space to be functional and purposeful (Beuscher & Grando, 2009).

### **Dementia Support Services**

#### ***Support groups catering to younger couples made them feel less isolated***

This study has emphasised the value of joining a group suitable for young couples. The spouses in this study attend a support group designed for younger couples called The Young Ones, where they found like-minded friends to whom they could relate as they shared similar experiences. The camaraderie built within the group alleviated feelings of isolation, offered reassurance to spouses who may be new to the journey, and fostered their confidence as carers. The support group became a source of valuable information that helped the spouses make important decisions or learn strategies to cope with dementia.

Support groups offer practical guidance that encourages spouses to think about complex topics such as enduring power of attorney, wills, and how to make the future more manageable through services and social benefits (Spreadbury & Kipps, 2018). They provide a safe ground for spouses to talk about sensitive issues such as driving, anxiety about

heritability, and questions about dementia's uncertain prognoses (Spreadbury & Kipps, 2018). Spouses develop problem-focused strategies to cope with difficulties and help them improve their situation by learning from others' experiences, tips, and advice (Lockeridge & Simpson, 2013).

Young spouses deal with difficulties and issues exclusively associated with their life phase, so they need support services that understand their problems (Bakker et al., 2010). The unsuitability of mainstream services forces young couples to adjust their age-appropriate needs to fit into a one-size-fits-all support service (Lockeridge & Simpson, 2013). Hence, effectiveness and attendance are always issues (Bakker et al., 2010).

***Socialisation groups for YPWD offer meaningful activities that the couples look forward to***

Three YPWD attend local dementia socialisation groups that offer activities such as Cognitive Stimulation Therapy (CST), dancing, and walking. The YPWD look forward to the groups because their meaningful preoccupation means they feel uplifted, have a sense of belongingness, and are supported by like-minded people. The spouses observed an improved mood and overall well-being since the YPWD joined the groups. It brought joy and youthfulness and erased their worries, even for a short while. Additionally, the spouses found much-needed support, respite, and relief from their caregiving roles. Activity engagement allowed the couples to forge new relationships outside their families, making a considerable difference in their lives.

While the PLWD enjoy meaningful activities, their self-esteem increases, they cope better with dementia, they become “happier,” “more alert,” and “easier to get along with” (Roland & Chappell, 2016, p184). Activities are a valuable way to preserve role continuity and function, slowing disease progression (Roland & Chappell, 2016).

Activities also offer spouses a meaningful way to obtain respite from their caregiving tasks, prevent social isolation, and enable them to engage in activities outside the care partnership (Roland & Chappell, 2016). Socialisation groups offered couples time away from home with their cohort as they’ve lost friends due to dementia (Roland & Chappell, 2017).

### **Family Support**

Family support is the last coping strategy that emerged in this study. Although the two men thought financial aid was the most crucial support they needed, possibly coming from a former breadwinner’s point of view, the two female PLWD perceived family as their primary support.

#### ***YPWD see family as their main support***

Two YPWDs identified their families as the support they needed the most. Margarete has a more advanced level of dementia and suffers from aphasia or the loss of ability to understand or express speech. Her family was reassuring and adjusted their communication to make her feel comfortable with her deficiency. They also nurtured her identity through the simplest things, like putting on her make-up or choosing the clothes she had always worn.

On the other hand, Zoey is still relatively independent but shared how her family supports her emotionally. They regularly check on her and pray for her. They continued to learn more about dementia to better support her. Most importantly, her family encouraged her to feel confident by promoting an environment where mistakes are allowed.

Spouses and family caregivers usually provide care and support for the YPWD's basic needs (UK Government, 2016) and emotional assistance (Lockeridge & Simpson, 2013). Family support is considered the most valuable resource for PLWD (Gibson et al., 2014). Lack of this support makes the PLWD vulnerable to various unmet needs – social, psychological, environmental, and medical (Miranda-Castillo, Woods, & Orrell, 2010).

***Family members became skilful in helping the YPWD cope***

In this study, families grew into caregiving roles and used their unique skills to ensure the best quality of life they could provide for the YPWD. Isaac worked with his son synergistically to meet Margarete's various needs. They both know what they're good at and areas where the other may step in. Lucy had to upskill herself to complete the tasks that Owen used to perform. She used her previously learned skills as a parent and educator to problem-solve and was never afraid to ask for help.

When spouses feel they are skilful caregivers, they think they are fulfilling their duty as a husband or wife (Tuomola, Soon, Fisher, & Yap, 2016). Skilful caregiving would develop a spouse's sense of empowerment and confidence, especially if the YPWD had been in charge of the family before dementia (Tuomola et al., 2016). However, if the spouse doesn't

achieve self-mastery and there is a disconnection between their actual and expected selves, Higgins (1987) postulates that the carer may experience 'self-discrepancy,' feelings of dissatisfaction and disappointment in oneself. Failure as a caregiver may consequently depict a loss of pride and self-mastery (Tuomola et al., 2016).

Teamwork is advantageous in managing at home and facilitating YPWD's activities of daily living (Bannon, Grunberg, Reichman, Popok, Traeger, Dickerson, & Vranceanu, 2021). A collaborative and problem-solving approach benefits the family's relationships and the YPWD's overall health and well-being.

***Families build the YPWD up for success and to be content***

Family support protects the YPWD from failure and social strain as their disease progresses. Isaac and James ensured they prevented scenarios where Margarete may feel embarrassed or ridiculed for having dementia. They consciously try to choose the people they surround themselves with and situations where Margarete will feel successful and in control. Owen's family provides opportunities for him to be himself. They work around his disabilities and find ways to nurture their relationship even when Owen can no longer emotionally and verbally express himself.

Self-defining principles are kept intact while dementia progresses (Sabat, 2001). Families who uphold these enable the YPWD to maintain their identity and help them to better cope with their caregiving experience (Harris & Keady, 2009). As families compensate for dementia, they prevent

the YPWD from being confronted with failure and may support slowing its progression (Wawrziczny et al., 2016).

However, these protective behaviours may create tension between the YPWD and the spouse (Wawrziczny et al., 2016). Wawrziczny et al. (2016) discovered severe cases of this power struggle between couples. If spouses struggle with stress, possibly due to carer burnout and domestic load, the initial aim of protection may be lost. Caregiving may become more “intensified, distorted, and diverted from their original purpose to look more like total control” (Wawrziczny et al., 2016, p. 1089).

### **5.1.3 Changes in spousal dynamics**

This study shows dementia has caused major changes in couples’ relationships. This section describes the evolution of marital dynamics - the more advanced dementia became, the more significant changes occurred between the couple.

#### **Romantic relationships evolved**

As a result of the YPWD’s declining health, couples’ sexual and emotional intimacy changed.

#### ***Spouses take on a caregiving role***

Not all four spouses saw themselves as carers. Richard, whose wife has mild dementia, doesn’t consider himself one. Zoey mostly fends on herself, and while she can’t work anymore, she’s still independent at home. Lucy and Eva instantly knew they were their husbands’ carers. They picked up the role from the onset, even before the diagnosis was confirmed. Isaac

grew into the caregiving role and didn't realise until recently that he had become a carer. Coming to terms with his new role relieved him and allowed him to focus on his new full-time job as a spousal caregiver.

Spouses take on new roles and responsibilities out of necessity (Massimo et al., 2013). In most cases, the caregivers' absolute priority becomes the YPWD, so they alter a considerable part of their lives to meet the YPWD's needs (Millenaar, Bakker, Vliet, Koopmans, Kurz, Verhey, & Vugt, 2018). Caregiving activities take over their lives and, in the process, cause the spouses to lose their identities (Skaff and Pearlin 1992).

In a video-recorded interview with Howes (2021), psychotherapist Perel explains that to keep the marriage thriving, the partners must continue desiring the other. However, the relationship becomes challenged when one of the two starts caretaking. Perel says, "caretaking is a very powerful experience in love and a very powerful anti-aphrodisiac." (2021, video-recorded interview).

When spouses become caregivers, "the former identities as husband and wife were lost, disrupting past self-defining relationships and relational experiences" (Massimo et al., 2013. p. 303). Spouses gradually lose the YPWD as a partner or intimate person (Johannesen et al., 2017). The new roles change the couples' intimate connection as the spouse goes through the greatest negative impact of dementia (Harris and Keady, 2009).

### ***Sexual and emotional intimacy***

There were varying levels of sexual and emotional intimacy among the couples in this study. Four main factors explain these: the first two are explored in this section and the third and fourth in the next.

First, a higher level of function and independence of the YPWD positively correlates with intimacy. Zoey's dementia is on the milder end of the spectrum, which is why her sexual and emotional faculties remain intact. Richard and Zoey's emotional and sexual intimacy are unchanged due to the absence of caregiving in their relationship.

Second, the severity and type of dementia may alter behaviour and cognition, increasing or decreasing sexual urges and altering emotional expression. Margarete's more advanced dementia caused her to be childlike and naïve in this aspect of their marriage, making Isaac feel that intimacy is no longer appropriate. However, Owen's FTD caused him to be emotionally flat, but his sexual appetite intensified. Lucy compensated for the lack of emotional intimacy with love-making, hanging on to any form of connection that Owen could still convey.

In this study, spouses were courageous in talking about their emotional and sexual intimacy, to the point of being able to describe their reflections, experiences, and the meanings they put into those experiences. None of them thought the changes in their intimacy were problematic and needed assistance, but they accepted them as part of the journey because they understood what dementia entails.

There is limited study of sexual and emotional intimacy involving the YPWD and their partners. Most studies describe problematic sexual behaviours (Black, Muralee & Tampi, 2005; Buhr & White, 2007; Harris & Weir, 1998). In the early '90s, spouses of people with Alzheimer's disease were reluctant to share their sexual challenges and seek help (Litz, Zeiss & Davies, 1990). In 2013, spouses were more open but did not know who to confide in and discuss these issues (Lockeridge & Simpson, 2013).

Wawrziczny et al. (2016) found couples' intimacy deteriorates because of the caregiving load – “The daily stress, the psychological impact of the impairments for each person, and the breakdown of the couple's foundation” (Wawrziczny et al., 2016, p. 1092). As the YPWD's health becomes more fragile, the spouse consolidates their roles, significantly increasing their carer burden. As a result, emotional and sexual intimacy becomes less prioritised (Wawrziczny et al., 2016).

### **Couples' incongruent views of their relationship**

Wawrziczny et al. (2016) described divergence in separate and dyadic couples' interviews. This incongruence is referred to as “diminished reciprocity,” a misalignment that may lead to stress and conflict between the couple (Cabote et al., 2015). For example, Owen's lack of insight created a space of incongruence between his thoughts about his marriage and what it actually is based on his wife's accounts.

***Preoccupied with carer responsibilities, a spouse's need for intimate connection diminishes***

For Eva and Nigel, the couple's finances were challenged by dementia for several years, increasing Eva's carer burden and lowering her yearning for intimacy. When Nigel could not retain a job, and the only job Eva could find was evening shift work, their dynamics changed dramatically. They had to sleep in separate rooms to prevent Nigel from disturbing Eva while sleeping during the day. Campbell, Wright, Oyebode, Job, Crome, Bentham, Jones, and Lendon (2008) pointed out that spousal caregivers who get fatigued and burn out due to role overload have poorer relationship quality with the YPWD.

Nigel's memory loss requires him to be constantly reminded and prompted. Eva's caregiving ways make Nigel feel like she is parenting him, and he is saddened knowing that their relationship as husband and wife is over for Eva. The phenomenon of the YPWD becoming a care recipient is referred to as 'parentification' (Svanberg et al., 2011) – when family members provide basic care needs and become like parents to the YPWD (Alzheimer's Australia, 2007; Johannessen et al., 2017). Due to a profound change in sexual roles, spouses may feel their marriage is over (Cabote et al., 2015).

***Lack of insight hinders the YPWD from becoming aware of the changes in their marital dynamics***

Lucy would elaborate on how Owen has changed, describing him as emotionally withdrawn but more sexually involved. The compounding

effects of Owen's lack of insight, empathy, and apathy conflicted Lucy into thinking that Owen did not love her and the family anymore.

People with anosognosia emotionally disconnect due to their inability to take heed of their emotions or understand their meaning and application (Doty, 2007). Due to the person's apathetic exterior, they may appear to have lost the ability to feel, while what is truly happening is the brain does not receive any emotional signals and therefore withholds appropriate responses (Doty, 2007). Caregivers perceive this lack of emotional responsiveness as insensitive, non-caring, and unempathetic, causing what sustains a mutual relationship to diminish (Massimo et al., 2013).

## **5.2 Service and Policy Recommendations**

This study highlights the complex experiences and needs of YPWD and their spouses as dementia substantially changed their lives throughout the pre-and-post-diagnostic periods. The couples provided insights into the responsiveness and appropriateness of the services available, or lack thereof, to their specific needs at different stages of their journey.

Five critical areas of service and policy recommendations emerged as necessary for improving the couples' experiences and alleviating the hardships in dealing with YOD. These are 1) support services specific to YOD, 2) employment opportunities for YPWD with mild symptoms, 3) ongoing training and education workplaces, government agencies, and policymakers, 4) housing support for families on the verge of losing their homes, and 5) holistic psychological support for the YPWD and their families.

### **5.2.1 Support services specific to YOD**

The latest reports available to the public from New Zealand's Ministry of Health on dementia are the New Zealand Framework for Dementia Care (2013) and a publication on Improving the lives of people with dementia (2014). Both documents aim to ensure that PLWD can be as healthy and independent as long as possible. DHBs were encouraged to develop regional and local governance groups to create approaches for complex cases (e.g... young-onset dementia ...). This study and subsequent recommendations identify what this minority group needs.

Recent NZ-based research has emphasised how crucial it is to understand the differences between YOD and OAD for management and service provision (Ryan, 2021). YPWD require specialised age-appropriate services (YODAT - For You, n.d.). This study shows that YPWD can reflect on their lived experiences and give rich insight into their hardships and needs. For authentic person-centred healthcare services and activities to be successful, the participation and involvement of the YPWD and their caregivers are crucial in its development process (Granbo, Boulton, Saltvedt, Helbostad, & Taraldsen, 2019).

### **5.2.2 Employment opportunities for YPWD with mild symptoms**

When dementia is in the mild stages, the person may still be highly functional and productive with enough appropriate support or "vocational rehabilitation" (McCulloch, Robertson, & Kirkpatrick, 2016, p. 682). However, much is yet to be done to provide practical modifications and

sheltered employment opportunities for PLWD and mild cognitive impairment (MCI) (McCulloch et al., 2016).

In this current study, the termination of the person's earning opportunities was one of the most significant losses for the YPWD. There is a lack of alignment across workplace practices and legislated policies to protect people with disabilities, which should include "support for occupational participation choices and managing employment separation" (Andrew et al., 2018, p. 140).

Roadblocks identified in implementing modification strategies by employers include: "lack of information regarding legal responsibilities; lack of confidence in recognising symptoms in the workplace; and limited access to expert advice about appropriate ways to adjust work patterns" (Andrew et al., 2018, p. 141). Vocational rehabilitation and occupational modification strategies would be beneficial in preserving occupational identity amidst the changes that the YPWD are experiencing (Andrew et al., 2018).

When workplaces initiate a dialogue with the key stakeholders, including the YPWD, their families, and doctor, strategies to accommodate employee preferences for remaining at work are successfully implemented (Ohman et al., 2001; Harris & Keady, 2004; Ritchie et al., 2017). This proves that retaining employment amongst YPWD can be done.

### **5.2.3 Ongoing dementia training and education for workplaces, government agencies, and policymakers**

Lack of understanding and knowledge about YOD was the top issue that affected the couples the most, causing delayed or misdiagnoses, inappropriate services, or difficulty dealing with people at work and their cohorts. Although most caregivers feel they are coping well, they indicate that service providers and the public do not sufficiently understand their needs (Gibson et al., 2014). New Zealand Ministry of Health (2013) acknowledged this need for ongoing training for dementia in general. However, to correct the norm where services are tailored toward older adults and do not meet the specific needs of YOD, ongoing training must be implemented within particular populations: workplaces, government agencies, and policymakers.

### **5.2.4 Housing support for families on the verge of losing their homes**

I could not find NZ-based literature or any information supporting the housing needs of YPWD, who are still paying off their mortgages. Most reports on dementia and housing were on residential care placement for older adults with dementia and the lack of age-appropriate spaces for YPWD (Stamou, La Fontaine, Oyebode, Jones, Gage, O'Malley, Parkes, & Carter, 2018).

In this study, couples were challenged by being stuck with a mortgage loan with inflexible payment schemes, e.g. Isaac's case. YPWD had to give up work but still with a mortgage to pay (Mayrhofer, Greenwood, Smeeton, Almack, Buckingham, Shora & Goodman, 2021) is a complicated situation

to manage without a pension to soften the financial blow. This is compounded by the triple effect of income loss in YOD: “depleted savings, unexpected care costs, and anxieties about how to afford life now and pay for care in the future” (Mayrhofer et al., 2021. P. 665).

YPWD couples’ circumstances must be considered to allow for a straightforward process for bank amnesty and/or Housing NZ applications. Extending their home repayments or having lower interest rates could be things to consider in this regard. Families already bombarded with many things to cope with would benefit from clear guidelines, knowing the proper channels to seek help, and getting adequate support for their needs.

#### **5.2.5 Holistic psychological support for the YPWD and their families**

Carers go through physical and emotional consequences in caregiving (Lockeridge & Simpson, 2013), often diagnosed with exhaustion, burnout, anxiety, and depression (Lockeridge & Simpson, 2013; Campbell et al., 2008). Carers also tend to be more concerned about the YPWD’s health than their well-being (Lockeridge & Simpson, 2013).

The availability of specialised healthcare services for YOD remains limited in most countries (Bakker, 2010). Young couples are ill-prepared and receive insufficient psychological support or guidance on coping and adjusting to an unexpected and burdensome disease (Spreadbury & Kipps, 2017).

Easily accessible and publicly funded holistic psychological support beyond the bio-medical focus that includes spiritual, cultural, and sexual

health would benefit the YPWD. Family counselling would help (Gibson, 2014), given that dementia has a psychological effect on all family members, not just the person living with it (Arai, Matsumoto, Ikeda, & Arai, 2007; Roach & Keady, 2008).

### **5.3 Strengths and Limitations of the study**

The three main strengths are: 1) exploration of the lived experiences of couples dealing with YOD in Auckland, NZ, 2) in-depth Interpretative Phenomenological Analysis (IPA) process performed, including researcher's reflexivity, and 3) dyadic and individual interviews with member validation. Two limitations are 1) an exclusively Christian perspective on spiritual coping and 2) a short interview duration.

#### **5.3.1 Strengths**

As of this writing, there is no existing research on the lived experiences of YPWD and their spouses available in New Zealand. The main strength of this study is the in-depth qualitative information that offers new insights into this particular area of the health system. This study's focus on the experiences of couples dealing with YOD included a comprehensive view of their pre-diagnostic, diagnostic, and post-diagnostic journeys, difficulties, coping strategies, and how dementia changed their marital dynamics. This study provided a rich perspective into the untold life stories of those who go through the challenges of YOD in Auckland.

This aspect of dementia is not a well-informed area in the current health system in New Zealand and the general literature (Spreadbury & Kipps, 2017). This qualitative research provides insights into the subjective experience of YOD's lived phenomena that will provide necessary information for policymakers, healthcare professionals, service providers, and families.

A theory-driven approach was used to guide the thematic analysis and help optimise the study's structure and rigour – the Interpretative Phenomenological Analysis (IPA) by Smith et al. (2009). The IPA has helped identify the main themes through the deductive technique and offered space to determine subthemes using the inductive method. Researcher reflexivity is another crucial component of IPA research (Smith et al., 2009). The hermeneutic perspective guiding this approach highlighted the importance of interpretation, where the researcher must understand the meanings the participants have given to their experiences. A double hermeneutic approach is also essential for IPA, as the researcher needs to be aware of their interpretation of the phenomenon being presented by the participants (Smith et al., 2009).

Finally, interviews were done as a dyad and individuals, as Wawrziczny et al. (2016) recommended. The dyadic interview encouraged the couples to build on their shared experiences as they recounted them together. Individual interviews allowed free expression from both parties, enabling comparison and identification of content disparities (Clare, 2002). Giving space for couples to share their authentic selves was an empowering experience optimised through member validation. This part

of the methodology allowed the couples to confirm, expand or challenge the researcher's interpretations (Smith, 1996). The added step allowed them to co-author the interpretations of their own story, as described in this study.

### **5.3.2 Limitations**

The first limitation was unexpected – the exclusive Christian point of view of spiritual coping. The inclusion criteria did not specify the participants' religious inclination, but this became one of the study's most significant findings. Though there was no description of actual religious rituals or sacraments specific to their religion, the couples' openness in expressing their faith and relationship with God is quite characteristic of practising Christians. Therefore, the study could not capture the coping mechanisms, spiritual or otherwise, of other religious sects, agnostics, non-religious, non-practising, or atheists.

The short duration of a Master's thesis meant this study could not follow couples' experiences with YODs as the disease progressed. The literature describes couples' accounts in the later stages of YOD, such as accessing day programmes or deciding on full-time residential care (Cabote et al., 2015; Bakker et al., 2010).

### **5.4 Implications for practice**

Further training and support are necessary to accomplish three specific nursing assessment goals: 1) aid in early diagnosis of YOD, 2)

review of carer support to make it comprehensive, and 3) provision of age-appropriate services for the YPWD.

Early and timely assessment and diagnosis is the first implication for practice because it can significantly reduce the stress among the families during the pre-clinical phase when subtle changes in the person with YOD occur (Teel & Carson, 2003). As seen in this study, limited awareness and understanding from health professionals made it difficult for couples to achieve a timely diagnosis and delay in accessing support services. A thorough and ongoing assessment from a well-informed nurse can support, inform, and educate families in recognising the initial symptoms of the disease (Cabote et al., 2015). Equipped with more knowledge, nurses can be influential advocates and assist in a more manageable dementia journey from the onset.

Five out of six PLWD live in the community supported by informal carers such as family, friends, extended family, and neighbours (Gilhooly, 1986). The primary caregiving role among these carers falls upon just one person, usually the spouse or an adult child (Parker & Lawton in Nolan, 1994). Caregiving is a huge responsibility for one person, which is why reviewing the support available for carers is the second implication for practice recommended by this study. Providing appropriate services will prevent or alleviate the detrimental effects of caregiving (Gilhooly, 1986). Needs Assessment and Service Coordination (NASC) for young couples dealing with dementia must consider the carer's needs and assess their support for caregiving or rearranging their lives to pursue other goals (Bramble et al., 2009; Cutillo-Schmitter, 1996).

The provision of age-appropriate services for the YPWD is the final implication for practice. Assessing an individual's resources and aiding them to manage successfully is an important nursing goal (Beuscher & Grando, 2009). The vast disparity between young and late-onset dementia must be observed in their services and not only in how they experience dementia.

### **5.5 Future research directions**

Few researchers have focused on the lived experiences of the YPWD and their spouses. The current study appears to be the first to explore this phenomenon in New Zealand. This leaves service providers with little information on the specific needs of this cohort and how to develop and direct services. Future research findings should help the service providers better understand this population and the particular challenges of living with YOD (Gibson et al., 2014).

The recommendations for future research are as follows:

1. A study with a bigger sample that covers different areas of New Zealand. This will encompass diverse cultures, socio-economic backgrounds, rural and urban areas, and other dementia service providers.
2. Perspectives of couples with different religious or spiritual beliefs and those who are non-believers or agnostics. How do they cope? Do they perceive spirituality as an essential coping mechanism?
3. Many aspects of daily living were discussed in this research.

Focusing on any of the topics more in-depth can provide a better understanding of the couples' experiences (e.g., couples' dynamics, losing jobs, and the problematic diagnostic process, to name a few).

4. Lastly, Svanberg et al. (2011) discovered a lack of studies on the lived experiences of YPWD who live on their own and raised the issue of research for those who do not have a spouse, partner, or other familial caregivers. Individuals who don't have carers may be the most in need and more likely to be placed in residential care sooner (Newens, Forster, & Kay 1995, *Alzheimer's Australia*, 2007).

## **5.6 Conclusion**

This study has highlighted that although they are a minority, YPWD and their spouses should not fit into mainstream OAD services because they have distinct experiences, difficulties, and needs. In particular, this study identified three main themes unique to their cohort: factors that significantly impact their lives, how they coped, and the evolution of their marital relationships.

Young couples have shared that they were deeply impacted by the lack of awareness and understanding of YOD and its varying presentations, its effects on the YPWD, the impact on occupational competence, and the experiences of grief and loss. Couples coped through their spiritual connection, heavily using dementia support services and relying on family support. Dementia in mid-life causes the erosion of marital relationships

as the spouse becomes a carer, and the YPWD cannot reciprocate with their partners.

The following actions are recommended: the creation of support services specific to YOD; employers to develop employment opportunities for YPWD with mild symptoms; workplaces, government agencies, and policymakers to provide ongoing training and education; housing support to be offered to families on the verge of losing their homes; and holistic psychological support provision for YPWD and their families.

## **Appendix A – List of Abbreviations**

ADLS – Activities of daily living

FTD – Frontotemporal dementia

interRAI – International Resident Assessment Instrument

IPA – Interpretative phenomenological analysis

MCI – Mild cognitive impairment

NASC – Needs Assessment and Service Coordination services

OAD – Older adult dementia

PLWD – People living with dementia

WHO – World Health Organisation

WINZ – Work and Income New Zealand

YOD – Young-onset dementia

YPWD – Young people with dementia / young person with dementia

## Appendix B – Dementia Auckland Letter of Support



17 July 2019

To Whom It May Concern

### LETTER OF SUPPORT FOR RESEARCH PROPOSAL BY MARIA CO

Please accept this letter of support for the research proposal submitted by Maria Co.

Dementia Auckland is passionate about inspiring, empowering and enabling people affected by dementia living in the Auckland region to make the most of life. Maria has identified a potential gap in our service delivery and understanding for the lived experience of younger people living with dementia. From this gap identification, she has outlined a research proposal that has the full support of our organization.

Maria has been diligent in her approach to Ethics approval, made even more complex when the research area identifies those people living with cognitive impairment and their carers as the prime participants.

I look forward to incorporating any learning opportunities Maria discovers from this path of enquiry into our service delivery.

It's my pleasure to recommend Maria Co for approval of her Ethics Application

Kind regards,

Barbara Fox, Operations Manager  
Dementia Auckland  
[barbara@dementiaauckland.org.nz](mailto:barbara@dementiaauckland.org.nz)

PO Box 5132, Wellesley St, Auckland 1141  
0800 433 636 | 0800 4 DEMENTIA | [www.dementiaauckland.org.nz](http://www.dementiaauckland.org.nz)

## Appendix C – Recruiter’s Confidentiality Agreement

**Faculty of Medical & Health Science  
School of Nursing  
Private Bag 92019  
Auckland, New Zealand  
Tel: 64-9-373 7599  
Fax: 64-9-367 7158**



### RECRUITER CONFIDENTIALITY AGREEMENT

**Research title: "Lived experiences of younger people with dementia and their spouses."**

I agree to recruit for the research study of Maria Co. I understand that the information about the research participants are confidential and I agree that I will not disclose or discuss it with anyone other than the researcher and her supervisor(s).

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

#### **Contact Details**

**Researcher:** Maria Co  
Educator  
Dementia Auckland  
Email: maria@dementiaauckland.org.nz

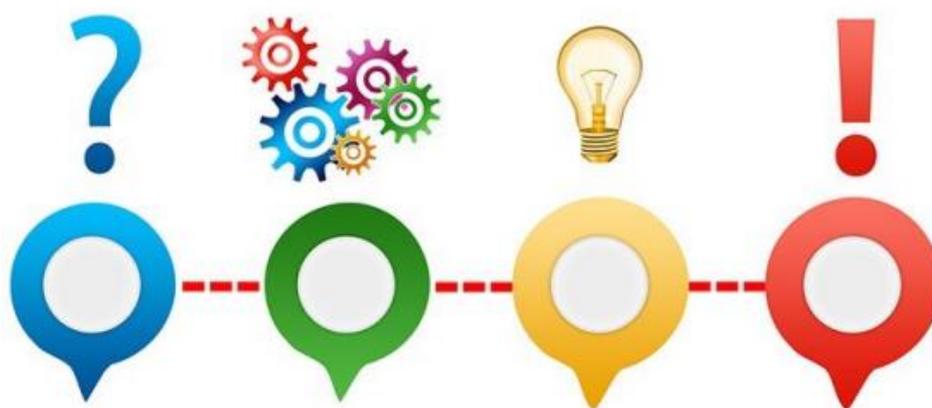
**Supervisor/Principal Investigator:** Stephen Jacobs  
The School of Nursing, Faculty of Medical and Health Sciences,  
The University of Auckland  
Ph: 09 9233975; Email: s.jacobs@auckland.ac.nz.

**Head of School:** Alexandra (Sandie) McCarthy  
School of Nursing  
Faculty of Medical and Health Sciences  
Ph: 09 923 2897; Email: alexandra.mccarthy@auckland.ac.nz

## Appendix D – Recruitment Flyer



Do you want to participate in a study about people living with young-onset dementia and their spouses or partners?



A research study is being conducted to gather information about the lived experiences of people living with young-onset dementia and their spouses or de facto partners.

Couples may qualify for the study if:

- ♦ You or your husband/wife/partner was diagnosed with dementia before the age of 65
- ♦ You live in Counties Manukau catchment area
- ♦ You have been registered with Dementia Auckland for at least 3 months

If you choose to participate in this study, you will help us collect information that may help you and others affected by young-onset dementia. Your experiences and voices will be represented within a professional and academic forum.

Please see the attached Participant Information Sheet that will provide you with more details or contact the researcher, Maria Co at [mco044@aucklanduni.ac.nz](mailto:mco044@aucklanduni.ac.nz).

## Appendix E – Invitation Letter

**Faculty of Medical & Health Science  
School of Nursing  
Private Bag 92019  
Auckland, New Zealand  
Tel: 64-9-373 7599  
Fax: 64-9-367 7158**



### INVITATION LETTER

Hello,

You are invited to take part in a research study that is currently being undertaken at The University of Auckland.

This study is being completed by Maria Co (Educator for Dementia Auckland), as part of the Master of Nursing Thesis Programme.

The Study will explore: **“The lived experiences of young people with dementia and their spouses”**.

Participation in this study will involve a one-on-one semi-structured interview. During the interview, you will be asked about your experiences in dealing with dementia – pre-diagnosis, post-diagnosis and how you are coping with it. You and your spouse or partner will be interviewed separately to promote free expression.

In order to participate, you must be living in South Auckland, under the Counties Manukau District Health Board (CMDHB) catchment area, are registered with Dementia Auckland Services for at least 3 months, and dealing with younger onset dementia.

Approved by the Auckland Health Research Ethics Committee on [date] for three years. Reference number [xxxx].

If you are interested in learning more about this study or are interested in participating, please see the attached Participant Information Sheet that will provide you with more details or contact the researcher, Maria Co at [maria@dementiaauckland.org.nz](mailto:maria@dementiaauckland.org.nz).

Kind regards,

Maria Co

## Appendix F – Participant Information Sheet

**Faculty of Medical & Health Science  
School of Nursing  
Private Bag 92019  
Auckland, New Zealand  
Tel: 64-9-373 7599  
Fax: 64-9-367 7158**



### **PARTICIPANT INFORMATION SHEET FOR SEMI-STRUCTURED INTERVIEW**

**Research title: "Lived experiences of younger people with dementia and their spouses."**

#### **Researcher introduction**

My name is Maria Co and I am the researcher on this project. I am a registered nurse working as an educator for Dementia Auckland. I am currently completing a Master of Nursing degree in the School of Nursing at The University of Auckland.

#### **Project description and invitation**

You are invited to take part in this research project that aims to describe and understand the lived experiences of young people with dementia and their spouses or de facto partners. This information will be used to guide the development of psychosocial supports based on younger people with dementia and their carers' reality.

The project has 3 objectives:

1. To provide a space for younger people with dementia and their carers to talk about their thoughts and feelings and share the meanings they give to their lived experiences, such as emerging self-identities.
2. To describe a couple's relational dynamics and determine how the relationship of a couple dealing with young onset dementia evolves over time.
3. To provide evidence of individual and shared adjustments for coping with the disease and translate this information into social and health service provisions for young people with dementia and their carers.

#### **Who is invited to participate in the study?**

You are being invited to take part in this study because you were identified by Dementia Auckland as someone who might be interested in it.

### **Do I have to participate?**

- Participation in this research is voluntary.
- Your decision to participate or not will not influence your relationship with Dementia Auckland.
- If you do decide that you would like to take part, you will be asked to sign a consent form.
- If you decide to take part, you can change your mind and withdraw from the project at any time. You do not have to give any reason for changing your mind.
- After you have been interviewed, you have 4 weeks to withdraw your data if you so choose. In this case, all data collected will be destroyed by shredding, audio-recording will be electronically deleted.

### **What do I have to do?**

If you choose to partake in this research, you will be interviewed by the researcher about your lived experiences in dealing with dementia. The researcher will conform to your preferred location, date and time.

The interview will involve 3 steps:

Step 1: Introductory meeting (30-60 minutes) – During this phase, the researcher will explain what the research is about, address any questions and provide a written guide of the aims and objectives of the study. This is also when demographic data will be collected such as date of birth, ethnicity, previous work, etc.

Step 2: Actual interview (60-90 minutes) – The researcher will make use of an interview schedule to guide the semi-structured interview. Couples will be interviewed separately to promote free expression from both parties. The interviews will be flexible and will follow the direction taken by the participants on the specific topic.

Step 3: The participants will be consulted for feedback to confirm, expand or challenge the researcher's interpretations in a process called 'member validation' (60 minutes). A copy of the printed transcription will be provided for feedback. The final interview will be emailed or mailed by post (your preference) and will have two weeks to review it.

The interviews will be audio-recorded. You may ask to have the recorder turned off at any time and you do not have to answer any questions that you do not want to answer.

**How do I participate in this research?**

Please register your interest by returning the attached reply slip to the Dementia Auckland staff that gave this letter to you. The staff will then pass on your reply slip to the researcher, Maria Co, who will then make contact with you via phone to schedule the meeting.

If you agree to participate in this study, a follow up phone call to confirm and remind the date, time and location for the interview will be provided at a later date by the researcher. An email or text reminder may also be done upon request.

On the day of the introductory meeting, you will be asked to sign a Form of Consent. The purpose of this form is to ensure you are fully informed about the study prior to participation.

**Is it confidential?**

Yes! All information provided by you will be confidential and there will be no identifying material used in the study report. All data including, email addresses, voice recordings, audio transcript will be used by the researcher and the research supervisors only. Electronic data and results will be stored on a secure password protected computer, while additional backup copies will be held on a password encrypted portable storage device. Any written data will be stored in a file marked Confidential, and will be held in a secure locked drawer at Dementia Auckland Pakuranga office.

All data will be destroyed after a period of six years as per The University of Auckland policy. Digital and electronic data will be deleted securely, while any written material including consent forms and transcripts will be shredded at the University of Auckland and securely removed.

**What are the costs, risks or benefits of participating in the research?**

The only anticipated cost is your time to participate in the interview. If you decide to hold the interview 'on location', a risk assessment of the location will be undertaken by the researcher and will be discussed with you.

If at any point, you feel upset or distressed, we will stop and give you an opportunity to talk or have time in your own personal space. If any topics or issues arise that you feel are sensitive, or that you wish to discuss further, please contact your key worker for confidential assistance. You may also contact the following organisations for counselling and support:

- Counselling Services Centre (CSC): (09) 277-9324
  - Counselling Services Centre (CSC) has been providing counselling and practical support to the Counties Manukau community since 1986.
- Dementia Auckland trunk line: (09) 622 4230
  - Key worker service: support groups, phone consultations, face to face meeting. Socialisation activities for people with Dementia. Education for families and people with mild dementia

You have a lot of potential as active, insightful, and meaningful contributors to the research process. You may enjoy the process of sharing your stories and feelings about dealing with dementia. Your contribution to this research may also shake the services you receive from social and health services.

The participants who have completed the interviews will be given a certificate of research participation and a token of gratitude in the form of a \$30 gift card for their involvement.

**What will happen with the results of this study?**

The findings of this study will be used to complete a Master of Nursing thesis. Results may also be used for conference presentations and academic journal publications.

If you would like to receive a summary of findings for this research, please indicate this on the Consent Form that will be given to you on the introductory meeting.

**Funding**

The researcher received scholarship from the ADHB Nursing Development Unit to complete a Master of Nursing degree.

**Questions?**

If you have any questions regarding the research please contact the researcher, Maria Co, or the supervisor, Stephen Jacobs. Contact details are listed below.

**Contact Details**

**Researcher:**

Maria Co, RN  
Educator  
Dementia Auckland  
Email: [mco044@aucklanduni.ac.nz](mailto:mco044@aucklanduni.ac.nz)

**Supervisor/Principal Investigator:**

Stephen Jacobs  
The School of Nursing, Faculty of Medical and Health Sciences,  
The University of Auckland  
Ph: 09 9233975  
Email: [s.jacobs@auckland.ac.nz](mailto:s.jacobs@auckland.ac.nz).

**Head of School:**

Alexandra (Sandie) McCarthy  
School of Nursing  
Faculty of Medical and Health Sciences  
Ph: 09 923 2897  
Email: [alexandra.mccarthy@auckland.ac.nz](mailto:alexandra.mccarthy@auckland.ac.nz)

For any concerns regarding ethical issues you may contact the Chair, the University of Auckland Human Participants Ethics Committee, at the University of Auckland, Office of Research Strategy and Integrity, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711. Email: [humanethics@auckland.ac.nz](mailto:humanethics@auckland.ac.nz).

Thank you for taking the time to read this information sheet.

**APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON August 30, 2019, for three years, Reference Number 023555.**

## Appendix G – Consent and Confidentiality Form

**Faculty of Medical & Health Science  
School of Nursing  
Private Bag 92019  
Auckland, New Zealand  
Tel: 64-9-373 7599  
Fax: 64-9-367 7158**



### **CONSENT AND CONFIDENTIALITY FORM**

(This form will be kept for a minimum of 6 years.)

**Research title: "Lived experiences of younger people with dementia and their spouses."**

- I have read and understand the Participant Information Sheet for Semi-structured Interviews and agree to take part in this research. I understand that participation is voluntary.
- I have had the opportunity to discuss the study and ask questions, and am satisfied with the answers that I have received.
- I understand that participation in each interview session may require between 30 to 90 minutes of my time.
- I understand that I have the right to withdraw from the study or refuse to answer a question at any time, without having to explain why.
- I understand that if I do choose to withdraw from the interview or study, I will not be able to withdraw data and information that I have contributed up to that point.
- I understand that the interviews will be audio-recorded, and later transcribed. I can request the recorder to be turned off at any time.
- I understand that I may review the transcripts of the interviews and make comments. I will have two weeks from the time I receive them to do so.
- I understand that my participation in this study is confidential.

- I understand that all data, including email addresses, voice recordings and transcripts will be accessible by the researcher and research supervisors/principle investigator only.
- I understand that electronic data and results will be stored in a secure password protected computer, while additional back-up copies will be held on a password protected USB. I further understand that any written data will be stored in a file marked Confidential, and will be held in a secured locked drawer at The University of Auckland.
- I understand that all data will be kept for 6 years and destroyed following six years as per The University of Auckland policy. Digital and electronic data will be deleted securely, while any written material, including consent forms and transcripts, will be shredded at The University of Auckland and securely removed.
- I understand that the information I will provide during this research may be reported and/or published in the future but this will be done in a way that does not identify me.
- I have had enough time to consider whether to participate in this study or not.
- I know whom to contact if I have any queries about the study.

I wish to receive a summary of results: YES NO

Results will be sent out to you via email once the study has been completed, this will take approximately 8-10 months.

I \_\_\_\_\_ (*Print Full Name*) hereby consent to take part in this study.

Signature \_\_\_\_\_

Date \_\_\_\_\_

**APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON August 30, 2019, for three years, Reference Number 023555.**

**Contact Details**

**Researcher:**

Maria Co  
Educator  
Dementia Auckland  
Email: [maria@dementiaauckland.org.nz](mailto:maria@dementiaauckland.org.nz)

**Supervisor/Principal Investigator:**

Stephen Jacobs  
The School of Nursing, Faculty of Medical and Health Sciences,  
The University of Auckland  
Ph: 09 9233975  
Email: [s.jacobs@auckland.ac.nz](mailto:s.jacobs@auckland.ac.nz).

**Head of School:**

Alexandra (Sandie) McCarthy  
School of Nursing  
Faculty of Medical and Health Sciences  
Ph: 09 923 2897  
Email: [alexandra.mccarthy@auckland.ac.nz](mailto:alexandra.mccarthy@auckland.ac.nz)

## Appendix H – Demographic Data Sheet

*Demographic Data Sheet*

Young person with dementia	
Participant code:	
Date of interview:	
Name:	
Marital status:	
Gender:	
Age during interview:	
Age at the time of diagnosis:	
Number of children and ages of children:	
Ethnicity:	
Education:	
Diagnosis:	
Family history:	
Occupation/previous work:	

Carer/Spouse of young person with dementia	
Participant code:	
Date of interview:	
Name:	
Marital status:	
Gender:	
Age during interview:	
Age at the time of partner's diagnosis:	
Length of caregiving from the time of partner's diagnosis:	
Number of children and of ages of children:	
Ethnicity:	
Education:	
Family history:	
Occupation/previous work:	

## Appendix I – Interview Schedule

### *Interview Guide*

An adaptation from Millenaar, Bakker, Vliet, Koopmans, Kurz, Verhey, and Vugt (2018); and Beattie, Daker-White, Gilliard, and Means (2004).

#### I. Background

- 1) Tell me something about yourself.
  - i) Where were you born?
  - ii) What was your childhood like?
  - iii) What did you do for work?
  - iv) How did you meet your husband/wife?

#### II. Months before the diagnosis

- 1) When did you first notice that something was going on?
  - i) What did you notice?
  - ii) What did you think was happening?
  - iii) What day-to-day changes did you experience?
- 2) For YPWD
  - i) Describe the time when you first realized your cognition was declining.
  - ii) Tell me about your experiences with memory problems.
- 3) What prompted you to seek help?
  - i) Where did you seek help?
  - ii) How did they help you?

#### III. The diagnosis

- 1) What was your experience in acquiring a diagnosis?
- 2) When was the diagnosis determined?
  - i) What did it mean to you and your family?
- 3) What was your reaction to the diagnosis?
  - i) How did you handle it?
  - ii) How did your spouse/children handle it?
  - iii) How do you feel about the diagnosis?
- 4) Did you tell other people about the diagnosis? Who did you tell?
  - i) What were the reactions of other people to the diagnosis?
  - ii) How did you handle other people's reactions?
- 5) If the couple has children
  - i) Did your children tell other people?
  - ii) What were the reactions of other people?
  - iii) How did your children handle that?

#### IV. Support Services

- 1) What kind of help did you receive after the diagnosis?
  - I. What do you think about the help that you received?
  - II. What are your views on these services?
  - III. What are good about them?

IV. What did you not like?

- 2) Was the information/support/treatment that you received sufficient?
- 3) Do you experience problems in communicating with care professionals?
- 4) What are your needs?
  - i) What kind of support you think you need now?
  - ii) What do you feel your needs are in helping you live with your memory problems?
  - iii) Do you feel they are being met?
- 5) What are your views on the needs of a person with memory problems?
- 6) Are there ways services can improve?

V. After diagnosis

- 1) How did dementia change your relationship with your spouse/partner?
  - i) What were the changes in your relationship?
  - ii) Communication?
  - iii) Intimacy?
- 2) What has changed in your:
  - i) Family?
  - ii) Social network?
  - iii) Work?
  - iv) Finances?
  - v) Self-perception?
- 3) What was the biggest impact of dementia in your life?
- 4) If the YPWD/carer has children
  - i) Did your relationship with your children change?
- 5) What do you miss the most?

VI. Coping

- 1) How do you manage with the memory loss?
- 2) Do you talk about dementia with your spouse?
  - i) How do you talk about it?

VII. Future

- 1) What do you think about the future?

VIII. Carer-specific questions

- 1) What do you think is most important in your care for your spouse?
- 2) What care do you want for your spouse?
- 3) How do you try to manage the problems, such as changes in behaviour?
- 4) How do the children manage?
  - i) How did the relationship between your significant other and your children change?
  - ii) What else changed for your children?

## Appendix J – Human Ethics Approval Letter

**Office of the Vice-Chancellor**  
Office of Research Strategy and Integrity (ORSI)



The University of Auckland  
Private Bag 92019  
Auckland, New Zealand

Level 11, 49 Symonds Street  
Telephone: 64 9 373 7599  
Extension: 83711  
[humanethics@auckland.ac.nz](mailto:humanethics@auckland.ac.nz)

### UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

30-Aug-2019

#### MEMORANDUM TO:

Dr Stephen Jacobs  
Nursing

#### Re: Application for Ethics Approval (Our Ref. 023555): Approved with comment

The Committee considered your application for ethics approval for your study entitled: **Lived experiences of younger people with dementia and their spouses or de facto partners.**

We are pleased to inform you that ethics approval has been granted for a period of three years with the following comment(s) or required minor change(s):

In the PIS document please add the Chair statement and contact details after the Head of School's name and contact details and before the approval wording on the last page: This should read: For any concerns regarding ethical issues you may contact the Chair, the University of Auckland Human Participants Ethics Committee, at the University of Auckland, Office of Research Strategy and Integrity, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711. Email: [humanethics@auckland.ac.nz](mailto:humanethics@auckland.ac.nz)

The expiry date for this approval is 30-Aug-2022.

**Completion of the project:** In order that up-to-date records are maintained, you must notify the Committee once your project is completed.

**Amendments to the project:** Should you need to make any changes to the project, please complete an Amendment Request form giving full details along with revised documentation. If the project changes significantly, you are required to submit a new application to UAHPEC for approval.

**Funded projects:** If you received funding for this project, please provide the approval letter to your local Faculty Research Project Coordinator (RPC) or Research Project Manager (RPM) so that the approval can be notified via a Service Request to the Research Operations Centre (ROC) for activation of the grant.

The Chair and the members of UAHPEC would be happy to discuss general matters relating to ethics approvals if you wish to do so. please contact the UAHPEC Ethics Administrators at [humanethics@auckland.ac.nz](mailto:humanethics@auckland.ac.nz) in the first instance.

Additional information:

1. Do not forget to complete the 'approval wording' on the PISs, CFs and/or advertisements and emails, giving the dates of approval and the reference number. This needs to be completed before you use the documents or send them out to your participants.

Please quote Protocol number **023555** on all communication with the UAHPEC regarding this application.

*(This is a computer generated letter. No signature required.)*

UAHPEC Administrators  
University of Auckland Human Participants Ethics Committee

c.c. Head of Department / School, Nursing  
Dr Stephen Jacobs

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