Behind closed doors: Using talanoa to understand the experiences of Samoan caregivers taking care of loved ones with dementia

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ABSTRACT

Dementia is a growing health challenge affecting thousands of New Zealanders. With the New Zealand government encouraging initiatives for dementia individuals to live longer within the community, and with the increasing dementia cases impacting the Pacific population at a faster rate, there is a subsequent demand for family members to assume the caregiver role. Given the negative caregiver outcomes associated with dementia caregiving, conducting research on Pacific dementia family caregivers is essential in improving caregivers' overall quality of life and well-being.

This research aims to explore and seek a better understanding of the experiences of Samoan caregivers of loved ones with dementia within the Auckland region. This study explored the knowledge and awareness of dementia at an individual level, the Samoan understandings of care, the knowledge and awareness of support services, service utilisation and engagement, and recommendations to enhance current processes and services in place.

This qualitative research design employed a Samoan methodology, *Fa'afaletui* model, warranting culturally appropriate and meaningful processes. The data was collected by conducting eight *talanoa* via Zoom, guided by the three theorised perspectives of the *Fa'afaletui*, and the data analysis process was guided by the conception of weaving of the *Fa'afaletui*.

The findings revealed extensive negative experiences with a direct impact on adverse caregiver outcomes. Current dementia-related support services in New Zealand are lacking, highlighting the need to improve approaches to care that reflect Samoan dementia caregiver needs. To improve service utilisation and engagement, Samoan dementia caregivers have recommended implementing and delivering culturally competent care and support.

This study concludes that a great deal remains to be done in terms of providing support for dementia caregivers entirely. With an improved understanding and integration of *fa'a Samoa* in service delivery, this can assist in shifting attitudes and perceptions towards service utilisation and engagement for Samoan dementia caregivers. A review to adjust current practices and policies is necessary to ameliorate overall caregiver experiences and outcomes.

DEDICATION

This thesis is dedicated to my *aiga*.

To my late grandparents: Fuesina (Nana), Faailoga (Papa), Fetepa'i (Nana), and Eneliko (Papa) – thank you for being my prayer warriors and for continuing to watch over me from above as I continue to navigate through life as a young *tamai'ta'i Samoa*.

To my parents: I'aulualo Pouvi II Simone (Dad) and Lyncroft Faailoga (Mum) – for allowing me to explore life independently, make mistakes, and never failing to support me each time I was knocked down. This is for all the days that you both worked tirelessly doing overtime each chance you could, for the days you both had to spend less time with us kids growing up, and for all the days you both went without just so we could have it all. You both have taught me more than any University degree ever could, and I thank you both with all my heart.

To my siblings: Simon, Isaac, Katarina, and Malelega – thank you all for never folding on me. It will always be us, in this life and the next. WE DID IT!

And to my nieces and nephews: Eli, Simon, Zion, Tobias, Sarah-Maleka, Ikey Jr, Katarah-Goku, and Aliyah-Rina – I pray that God continues to guide and watch over you all. Thank you for all the smiles, laughs, and for brightening my days. You all are my world!

Alofa atu mo outou uma, always.

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Although it is just us three here in New Zealand, you both continue to stand strong and ensure it is always us before anyone else. To you all, thank you for always having my 6, and for blessing me with my beautiful nephews and nieces. I appreciate you all so much and I thank God for the bond I have with you all - love and loyalty unmatched. Forever us!

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Lastly, a very special mention to my late grandmother, Fuesina Vaotuua. You have been the driving force behind this research. Here is to your last wishes you asked of me before you departed to be with God. You will forever be the Queen of my Heart.

Alofa'aga,

Malia

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ABBREVIATIONS

Abbreviation	**Definition**
AD	Alzheimer’s Disease
ARC	Aged Residential Care
CSAP	Carer’s Strategy Action Plan
DEIR	Dementia Economic Impact Report
interRAI	International Resident Assessment Instrument
LMIC	Low-middle-income countries
MOH	Ministry of Health
MSD	Ministry of Social Development
NZFDC	New Zealand Framework for Dementia Care
PLWD	People living with dementia
PWD	Person with dementia
RCS	Residential Care Subsidy
WINZ	Work and Income New Zealand
WEAG	Welfare Expert Advisory Group
WTHC	Watson’s Theory of Human Care

SAMOAN GLOSSARY

Samoan term	**English translation**
Aiga	Family
Agaga fesoasoani	Willingness to help
Alofa	Love
Alofa'aga	Love from
Alofa atu mo outou uma	I love you all
Atua	God
Fa'aaloalo	Respect
Fa'afaletui	'Ways of' [fa'a] 'weaving together' [tui] deliberations of different groups or 'houses' [fale]
Fa'afetai tele lava	Thank you very much
Fa'aleagaga	Spirituality
Fa'amanuia le Atua	God bless
Fa'amaualalo	Humility
Fa'a Samoa	Samoan way of life/Samoan way of being
Faife'au	Pastor
Fala	Mat
Feagaiga	Covenant
Fesoaa'iga	Reciprocity
Gagana	Language
Ia e ava lou tamā ma lou tinā	Honour your father and your mother
'Ie toga	Fine mat
Laufanua	Environment

Laufala	Pandanus tree
Lalaga	Action of weaving
Malu	Traditional female tattoo
Matai	Chief
Meaalofa	Gift
Palagi	Person of European descent
Pule ia tautua	Lead to serve
Tagata	People
Talanoa	Conversation, talk, discuss
Tama'ita'i Samoa	Samoan woman
Tapu	Sacred bonds
Tautua	Serve/Reciprocal service
Tautua ia pule	Serve to lead
Tautua ia tautua	Serve to serve
Tautua malele	People who live abroad, supporting family
Tautua matalilo	Someone who serves out of public view/Protecting and honouring the family name
Tautua tuavae	Serving with abundance of provision
Tautua upu	Person with oratory skills
Tausi	Take care of/Care for
Tausi lo'omatua, tausi toea'ina	Look after the old lady, look after the old man
Tausi matua	Caring for elders
Teu le vā	Nurture the space-between/relationship

Tui	Weaving
Vā	Space of mutual respect/Space-between
Vafealoa'i	Relationships: maternal/paternal
Va fealoaloa'i	Relational connections
Va fealofani	Sacred, sibling love
Va tapua'i	Worshipful space
Viia le Atua	Praise God

Samoan proverb	**English translation**
E lele le toloa ae ma'au i le vai	The bird flies far but will always return to the water
E māmā se avega pe a ta amo fa'atasi	My strength does not come from me alone, but from many
O le ala i le pule o le tautua	The pathway to leadership is through service
O le tautua o le ala lea i le fa'aeaina	Service is the path that leads to elevation

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CHAPTER ONE: INTRODUCTION

Chapter One of this thesis is an introductory chapter. This chapter will begin by introducing the researcher's positionality, providing a foundation that highlights the significance of this research study to the researcher. It will then provide a brief background of dementia followed by an account of the prevalence of dementia on a global scale, the total New Zealand population, and the Pacific and Samoan populations in New Zealand. Next, it will then provide a brief background of New Zealand caregivers and then detail the impacts of dementia associated with caregiving as well as critically appraise the gaps within the literature. This chapter will then provide and introduce the key aims and objectives of this research study and conclude with a chapter overview of all chapters for this thesis.

THE ROLE OF THE RESEARCHER

'E lele le toloa ae ma'au i le vai – The bird flies far but will always return to the water'

As a young *tama'ita'i Samoa* raised in Māngere South Auckland, New Zealand – adversity has been a face I have become accustomed to, impacting my ability to fully comprehend and recognise the existing inequities and disparities within my community. Navigating through the University journey has been a difficult feat, particularly being exposed to societal changes. This instilled fear and self-doubt, questioning my identity and capabilities as a student, as I often found myself within uncomfortable learning spaces. Coming from South Auckland is an eminent part of my identity; however, time and again, it is unfortunately stigmatised, making it easy to conform to the ideologies of the dominant group. '*E lele le toloa ae ma'au i le vai'* – has been purposeful in encouraging me to stand firm in all that I have learned as a *tama'ita'i Samoa* from South Auckland. As the Bible poetically quotes*: "God is within her, she will not fall"* (Psalm 6:45); this has served as the perfect reminder that the values I carry as a Samoan and where I come from are a strength in itself. Since embarking on my education journey, I have been blessed to have attained two degrees with a background in Psychology. The knowledge I have gained has been fundamental in my understanding of the importance of culture, appreciating its unique and empowering place in this world, especially within the academic world that is conventionally constructed around Eurocentric philosophies.

‘E māmā se avega pe a ta amo fa’atasi – My strength does not come from me alone, but from many’

Growing up, I was blessed to have hard-working, humble parents who valued God, family, and education. These values remain the motivating force in my life and a crucial part of my decision to embark on this thesis journey. With that said, my fondest childhood memories were being taken care of by my Nana as my parents both worked full-time. My Nana’s love and loyalty to my family were unparalleled - the love, respect, and appreciation I have for my Nana knows no bounds. Fast-track to my early adulthood years, my Nana was formally diagnosed with dementia. To see the patriarch of my family - who modelled independence and the most resolute faith in God - steadily fade before my eyes is one thing I would never wish upon anyone to experience. My Nana’s dementia afforded my family and I the opportunity to become dementia caregivers. I experienced first-hand the impacts of dementia on my family, overall well-being, and quality of life; I quickly realised the significance of having proper support that my family and I, unfortunately, did not receive. Although our dementia journey came with its downfalls, *fa’a Samoa*, faith in God, and the strength of my family enabled my family and I to persevere even during the most challenging of times.

‘O le ala i le pule o le tautua – The pathway to leadership is through service’

My positionality is shaped by my understanding of the power of education and its ability to make meaningful change. By leading this research, I offer my knowledge as a *tama’ita’i Samoa*, raised in Māngere South Auckland, with lived experiences providing care and support for a loved one with dementia. I hope this research will be able to serve, give back, and add value not only to Samoan dementia caregivers but to the Pacific dementia community as a whole.

A BACKGROUND OF DEMENTIA

A prevention and care approach

Dementia is an 'end-of-life' health condition, understood as a neurodegenerative disease resulting in brain cell deterioration (Akter et al, 2012; Dyall, 2014; Smith et al, 2020). The onset of dementia is slow (Smith et al, 2020) and can either start suddenly or progress over time (Dyall, 2014). Dementia is represented by a cluster of symptoms (Weir & Fouche, 2017; Smith et al, 2020) that include a range of behavioural disturbances, emotional outbursts, personality changes, and neurological disorders (Mousourakis, 2013; Lindeza et al, 2020). It typically involves the declination of cognitive function which means that the brain gradually loses its ability to perform certain functions (Dyall, 2014). To date, no data suggests a cure for the disease (Lindeza et al, 2020); the only current solution to counteract dementia is to slow the progression of the disease (Higuera, 2021). Despite there being no current cure for dementia, the quality of life and well-being of a person with dementia (PWD) and their families is an area of focus within the literature that can arguably be improved (Akter et al, 2012; Lindeza et al, 2020). That said, recent research around dementia has shifted its approach from trying to discover a 'cure' to an approach of 'prevention and care', with a significant focus on the needs and supports of dementia caregivers (Cullum et al, 2020).

A public health issue

Dementia has created a serious international public health issue (Cova et al, 2017; Clemmensen et al, 2019). Broken down, dementia raises economic, medical, social, and political issues (Weir & Fouche, 2017; Wu et al, 2017) involving health decisionmakers, policymakers, civil organisations, and multidisciplinary researchers (Dyall, 2014; Zimmerman et al, 2014). There remain high rates of undetected dementia worldwide (Martinez-Ruiz et al, 2020). The literature reports that living alone, limited social engagement, experiences of significant recent life events, and limited house accessibility are common factors related to the lack of dementia diagnosis (Martinez-Ruiz et al, 2020). A dementia diagnosis is vital because it affects both the individual with the condition and their families. Ultimately, the implications that stem from learning that one has been diagnosed with dementia extend across health, economic, and social inequalities for all involved (Dyall, 2014). According to Dyall (2014), the poverty and social marginalisation experienced by Pacific populations are determinants of dementia diagnosis.

Dementia symptoms and impacts

A PWD can experience a multitude of symptoms at various stages that can negatively impact their overall health and well-being. Dementia symptoms include and are not limited to difficulty retaining information, a disruption in stored memory, both verbal and physical agitation including aggressive behavioural patterns (Mousourakis, 2013; Varik et al, 2020), depression, sleep disturbances (Akter et al, 2012), disorientation, anxiety, wandering, as well as a loss of personhood (Weir & Fouche, 2017). Of all these known symptoms, memory and cognitive impairment are the most prominent early signs and symptoms of dementia (Mousourakis, 2013; Egbert, 2014). The severity of the disease has a direct detrimental effect on the independence of a PWD (Lindeza et al, 2020). Generally, people with dementia experience a loss of their overall well-being which has substantial adverse effects on their overall quality of life (Perkins et al, 2015). This is evident from the negative correlation between the self-independence of a PWD and the progression of the disease with heightened symptoms (Smith et al, 2020). It has been widely stated that the impacts of dementia symptoms have damaging consequences in relation to a PWD's ability to independently and safely live and function (Akter et al, 2012; Lindeza et al, 2020). A PWD becomes heavily dependent over time and eventually arrives at a state of progressive incapacity to carry out daily living tasks or instrumental functions without assistance (Akter et al, 2012; Mousourakis, 2013; Weir & Fouche, 2017; Smith et al, 2020). Due to a PWD’s functional limitations, assistance from a caregiver is often required (Jutkowitz et al, 2019).

DEMENTIA PREVALENCE

Dementia prevalence: Global scale

In recent years, the prevalence of dementia cases has exponentially increased becoming a serious healthcare challenge of the 21st century (Lindeza et al, 2020). On a global scale, the number of people living with dementia (PLWD) has continuously increased over the years (Nichols et al, 2019) and is expected to proliferate in the years to come (Varik et al, 2020). In 1990, the number of people reported to be living with dementia was 20.2 million, which has since more than doubled to an estimated 43.8 million in 2016 (Nichols et al, 2019). Most recent figures report that close to 47 million people are living with dementia (Smith et al, 2020), and it is projected to reach up to 135 million by 2050 (Webb & Dening, 2016), which is precedent for a predicted dementia epidemic (Wu et al, 2017). These estimated prevalence rates foreground the demand for dementia caregivers altogether.

Dementia prevalence: New Zealand population

New Zealand is a bicultural country (Ma'u et al, 2021) located in the South Pacific Ocean, populated by 5.1 million people (Statistics New Zealand, 2018; Parr-Brownlie et al, 2020). In 2011, 1.1% of the total New Zealand population had dementia, whereby 1.9% of that population accounted for the Pacific population who had dementia (Dyall, 2014). Similar to the pattern observed on a global scale, the prevalence of dementia cases of the New Zealand population is expected to continuously grow. The most recent estimates report approximately over 60,000 PLWD in New Zealand (Cullum et al, 2020; Martinez-Ruiz et al, 2021). By 2026, 78,000 New Zealanders are estimated to have dementia (Hale et al, 2020), which will increase almost three-fold by 2050 (Cullum et al, 2020; Yates et al, 2020; Martinez-Ruiz et al, 2021). These estimates are alarming, given that the spike in the dementia prevalence rates is predicted to be observed across the main ethnic minority groups in New Zealand (Cullum et al, 2020).

Ageing population phenomenon

The increasing ageing population is the most substantial known risk factor for developing dementia (Webb & Dening, 2016; Cova et al, 2017). The ageing population is a recent phenomenon created in most recent centuries; it is represented by the increasing numbers of older peoples aged 65 years and over, which is rapidly increasing and is expected to treble to 2 billion by 2050 (Mousourakis, 2013; Webb & Dening, 2016). In New Zealand, at least 15% of the New Zealand population is aged 65 years and over (Perkins et al, 2015; Statistics New Zealand, 2018; Parr-Brownlie et al, 2020). Throughout the past decade, the number of older New Zealanders has nearly doubled, growing from 0.44 million to 0.74 million (Parr-Brownlie et al, 2020). By the year 2036, New Zealand's ageing population is estimated to increase to 40% (Badkar et al, 2019), and over the next twenty years, the ageing population in New

Zealand is expected to double to 1.30 million due to an increase in life expectancy (Parr-Brownlie et al, 2020).

Dementia prevalence: Older aged population

The global prevalence of dementia in people aged 60 years and over is between 5.6% and 7.6% (Martinez-Ruiz et al, 2021). As the population continues to age, so does the number of dementia cases among older adults (Kang et al, 2018), which means that dementia-related financial costs will increase too (Weir & Fouche, 2017). For instance, the total financial cost of dementia in New Zealand in 2011 was an estimated $845.8 million, which increased by a quarter of a billion New Zealand dollars. Just three years earlier than this, the total financial cost of dementia in New Zealand was $712.9 million (Weir & Fouche, 2017). In response to the ageing population, policies promoting 'ageing in place' has been a central focus for the New Zealand government. This is an effort by the government to minimise the expenses associated with aged residential care (ARC), also identified as 'formal caregiving' (Alpass et al, 2017).

Dementia prevalence: Pacific population in New Zealand

Auckland, New Zealand has the largest Pacific population in the world (Dyall, 2014) and is the fourth largest ethnic group in New Zealand, following European, Māori, and Asian ethnic groups (Seiuli, 2016). The Pacific population living in New Zealand, also referred to as Pasifika, consists of Samoans, Cook Islanders, Tongans, Niuean, Fijians, Tokelauans, Tuvaluans, and I-Kiribati (Foliaki et al, 2020). This population is considered a sizable ethnic minority population making up 8.1% of the total population (Ioane & Tudor, 2017; Ma'u et al, 2021). The prevalence of dementia within the Pacific population indicates that Alzheimer’s Disease (AD) and other forms of dementia are higher in Pasifika compared to non-Pasifika (Abey-Nesbit et al, 2021). Pasifika are also more likely to present with advanced dementia compared to New Zealand Europeans (Cullum et al, 2018). Reported instances of dementia cases reveal that the expected growth among the Pacific population in New Zealand will reach 2.6% by the year 2026 (Dyall, 2014; Webb & Dening, 2016). These estimates will determine the number of Pacific family caregivers providing care and support for their loved ones with dementia within the home setting, given that the Pacific way of being is guided by collectivist attitudes.

Dementia prevalence: Samoan population in New Zealand

Samoans in New Zealand mainly make up almost half of the Pacific group in New Zealand, making them the largest Pacific ethnic group (Ioane & Tudor, 2017; Yamada et al, 2019). Due to the high percentage of Samoans living in New Zealand, most reported Pacific issues are primarily influenced by Samoan perspectives (Ioane & Tudor, 2017). Currently, the reported dementia statistics in New Zealand are based on projected figures extrapolated from overseas data. Accordingly, a population-based dementia prevalence study specific to the Samoan population is yet to be completed in New Zealand. Essentially, this means that there remains no specific nor clear data that fully expresses and represents the true extent, understanding, and impacts of dementia in New Zealand in relation to the Samoan people (Yamada et al, 2019; Cullum et al, 2020; Walesby et al, 2020; Yates et al, 2020; Martinez-Ruiz et al, 2021).

NEW ZEALAND UNPAID CAREGIVERS

Caregivers in New Zealand

Given the progressive nature of dementia, providing care for a PWD is assumed to be more challenging and demanding than providing care for a person with other illnesses or disabilities (Ory et al, 1999). Caregivers in New Zealand play an empowering role in society in the sense that they 'enable people to live and participate in their communities' and 'help reduce dependence on health and aged care systems' (Ministry of Social Development [MSD], n.d.). Caregivers in New Zealand are a diverse group. They most likely comprise family members, who are often women caring for older relatives, partners, or children with an illness or disability (Welfare Expert Advisory Group [WEAG], 2019). In the most recent 15 years, a consistent and significant source of caregivers in New Zealand for the elderly has been Pacific migrants (Badkar et al, 2019). Pacific ethnic caregivers are 'often younger compared with the general caregiver population in New Zealand and may not always self-identify as caregivers' (MSD, 2019). This raises several implications, such as accessing and utilising relevant support services or understanding the impacts of cultural norms. Current estimates suggest that 480,000 people provide regular care to someone with a disability or illness (Burholt et al, 2022). Equally important to note is that this statistic underrepresents caregivers who are spouses, Māori, or Pacific Islanders (Burholt et al, 2022). This is important to address because underrepresented communities are typically predisposed to adverse outcomes.

Care in the home setting

The demand for caregivers in New Zealand continues to grow due to people having higher life expectancies, multiple long-term health conditions, and remaining in their homes rather than going into institutional care (MSD, n.d.). Due to the projected impacts of the ageing population, the idea of older aged people remaining in their homes is highly encouraged (Jorgensen et al, 2010). A study by McAllum et al (2021) posits that older adults prefer to remain at home which has resulted in prioritising care within the home setting. As it happens, providing care within the home setting is a leading component of government policies because of its cost-effective support measure (Weir, 2018). Recent figures show that up to 75% of expected PLWD are taken care of by informal caregivers in New Zealand (Varik et al, 2020). This equates to approximately 40,000 unpaid caregivers, providing 45 million hours of care annually to PLWD (Hale et al, 2020; Burholt et al, 2022; Alzheimer’s New Zealand [ANZ], n.d.). Compared to paid workers (i.e., formal caregivers), the replacement cost would cost about NZ$1.19

billion (Ma’u et al, 2021). For caregivers that would have been in employment had it not been for their role as family caregivers, the opportunity cost is an estimated NZ$111 million for all PLWD. For the Pacific population, the total replacement cost is NZ$36.6 million, while the total opportunity cost is NZ$3.4 million (Grimmond, 2014; Ma’u et al, 2021). Along with these costs, the burden of dementia on unpaid caregivers is 12% higher among Pacific caregivers than European caregivers – the lack of ARC service utilisation accounts for these statistics. For Pacific people, the tendency to provide unpaid care for a household member is high (Grimmond, 2014). This is common among Pacific communities and is highly influenced by their cultural values and belief systems.

IMPACTS OF DEMENTIA ASSOCIATED WITH CAREGIVING

The experiences of caregivers are well-documented within the literature. Compared to the experiences of non-dementia caregivers, the experiences of dementia caregivers have minuscule differences, such as psychosocial and physical health effects (Sörensen & Conwell, 2011). Almost all existing literature concerning the caregiver experience, dementia-related or not, recounts adverse caregiver outcomes. Dementia caregivers, in particular, report several impacts of caregiving such as increased levels of stress and more significant depression and anxiety symptoms. Physical health outcomes that are impacted include compromised immune response, more significant cognitive decline, and higher levels of stress hormones (Sörensen & Conwell, 2011; Springate & Tremont, 2014). In one study, over 80% of caregivers reported a clinically significant burden (Springate & Tremont, 2014).

Several factors influence the impacts of caregiving. These factors include and are not limited to issues related to the condition itself, such as dementia symptoms or the severity of dementia, as well as issues particular to the caregiver, such as financial status or the relationship to the patient (Garcia-Ptacek et al, 2019).

Other studies and dementia-specific reports also detail the economic burdens that result from caregiving. For caregivers who provide care to PLWD in the community, this can result in significant physical, emotional, social, psychological, and economic strain (Burholt et al, 2022). Most research addresses psychological outcomes such as caregiver burden, stress, depression, and psychological distress (Burholt et al, 2022). The provision of care within the community is often undervalued despite health systems heavily depending on family caregivers. To date, existing literature that has assessed the caregiver experience has had scarce positive reflections or positive results concerning the delivery of care from the health system.

The increasing prevalence rates of dementia will have subsequent causes for major health equity issues. Currently, New Zealand support services for dementia are inadequate. They are far from reaching a stage that can provide a sufficient response to the dementia challenge that will face New Zealand in years to come. Additionally, these services cannot serve the Pasifika community (along with Māori and Asian communities) as dementia continues to rise across these ethnic groups (ANZ, n.d.).

Dementia in New Zealand will have substantial economic impacts on different areas. In 2020, the burden of dementia was an estimated NZ$6.2 billion, increasing by 24% from the Dementia Economic Impact Report (DEIR) 2016 (Ma'u et al, 2021). For the Pacific population, there is a more significant early onset of dementia of 18% compared to the European population of only 8%, which subsequently has more significant financial income impacts on families in this community (Ma'u et al, 2021). The social care costs in New Zealand are also estimated to be NZ$1.39 billion, an increase of 47% since the DEIR 2016 (ANZ, n.d.).

For Pacific populations, the social care costs for a PWD are lower (NZ$16,020) compared to European (NZ$20,530), which is indicative of lower ARC utilisation by Pacific people (Ma'u et al, 2021). Cultural and familial preferences including concerns about the appropriateness of the services, limit Pacific people from accessing ARC facilities three times more frequently than Europeans. The lack of division of social care costs by ethnicity indicates the need to assess the equity of resource allocation and utilisation.

THE RESEARCH STUDY

Research significance

In general, there is not enough detailed information about each Pacific subgroup in the literature regarding dementia caregiver experiences in New Zealand. Typically, the literature comprises information that categorises all Pacific subgroups under the 'Pacific population' on which to base their findings. This has created a gap in the literature where no studies have researched ethnic-specific dementia caregiver experiences, particularly family caregivers of their loved ones with dementia who provide care in the home setting. This gap makes it imperative to explore this area to address ethnic and cultural differences among caregivers.

This research intends to raise the profile of Samoan dementia caregivers providing essential care and support to their loved ones with dementia. This research study will focus on the experiences of Samoan caregivers, both past and current, who provide care for their loved ones with dementia within the home setting. This research study will showcase the realities of Samoan dementia caregiver experiences to address health inequities, establish caregiver outcomes associated with providing dementia care, and contribute to the gap within the literature.

The findings from this research can shed light on the unique experiences of Samoan dementia caregivers, drawing on their cultural values and understanding of care. Concurrently, this research can utilise any positive outcomes and learn from any negative outcomes to improve the quality and delivery of care provided by support services. These findings hope to inform the planning and developing stages of healthcare plans as a reference of what can be considered when creating such plans for Samoan dementia caregivers and their families.

The findings from this research also intend to improve the engagement and utilisation of dementia-related services by exploring the experiences of Samoan caregivers of loved ones with dementia in New Zealand. The findings from this research can address current health inequities and improve the quality of current healthcare regimes. This can be demonstrated by creating support initiatives that cater to ethnic-specific cultural differences. This will hopefully decrease adverse caregiver outcomes while improving the quality of life for caregivers, their loved ones with dementia, and their families.

Research design

This qualitative, observational study conduct semi-structured interviews in the form of *talanoa* in order to gain insight from the perspective of Samoan main caregivers, understanding the different components of care when caring for someone with dementia.

Research objectives

The aim of this research was to explore and gain a better understanding of the experiences of Samoan caregivers of loved ones with dementia, both past and current, who currently reside in the Auckland region. This will contribute to the research gap that evidently exists concerning informal Samoan caregivers in New Zealand.

The research questions included:

- What are the experiences of Samoan caregivers of loved ones with dementia in the Auckland region?
- How does the current health system work for Samoan caregivers - exploring the available resources or sources of support that they access?
- How aware are Samoan caregivers of the available public health services in New Zealand?

THESIS CHAPTER OVERVIEW

Chapter One of this thesis contains the introductory chapter. This chapter will specify the background context relevant to this research study and will open up the story or groundwork that will be carried throughout the remaining chapters.

Chapter Two of this thesis contains the literature review. This chapter is a critical review of existing literature relevant to the caregiver experiences of those with dementia. This involved a comprehensive search of the scientific literature as well as a document analysis of relevant government sources; and has been broken down into three different parts that explore the knowledge, understanding, and awareness of dementia, the Samoan understanding and practices of care, as well as accessing healthcare.

Chapter Three of this thesis contains the methodological approaches utilised for this research study. This chapter details the frameworks that have been employed that have guided this research study.

Chapter Four of this thesis comprises the study findings. This comprises the main themes identified in participants’ *talanoa*, which explores their knowledge and awareness of dementia, lived experiences as caregivers, Samoan perspective of care, knowledge of support services, access to healthcare support, and support service recommendations.

Chapter Five, the final chapter of this thesis, is the discussion chapter. This chapter will include a discussion of the study findings, study strengths and study limitations and then conclude with future recommendations to inform potential future research in this field.

CHAPTER TWO: LITERATURE REVIEW

INTRODUCTION

Chapter Two of this thesis will contain the literature review. This review will be separated into three parts:

(1) Dementia knowledge and caregiver experiences,
(2) The Samoan understanding and practices of care, and
(3) Accessing healthcare.

All three parts are essential components that are relevant to the posed research questions. Part 1 of this literature review will detail emergent subthemes across the literature related to the knowledge, understanding, and awareness of dementia as well as the experiences of family caregivers of loved ones with dementia. Part 2 of this literature review will focus on the literature around different components of Samoan understandings and practices of care. The main focus will be on *fa'a Samoa* related to taking care of the elderly and family members, as well as the duties and responsibilities that must be upheld within the family to meet the different obligations as a Samoan. Finally, Part 3 of this review will detail relevant literature associated with dementia-related support services. Gaps in the literature and a rationale for my thesis are presented.

BACKGROUND

Dementia is the umbrella term that represents a group of diseases that impacts brain functionality caused by the deterioration of brain cells. The affected areas of the brain determine the dementia symptoms people experience. Impairments typically characterise this to memory and thinking, as well as changes in personality, emotions, and behaviour, all reported to directly affect a person's autonomy and performance of everyday tasks (ANZ, n.d.).

Dementia continues to affect millions of people worldwide. As of 2020, global estimations of the number of PLWD sit at 50 million, projected to double within the next 20 years with overwhelming potential impacts on ill-equipped health systems (ANZ, n.d.). Though these increasing prevalence rates will likely impact developing countries, statistical evidence demonstrates that the increasing prevalence rates will still impact New Zealand. With that said, dementia in New Zealand is a rapidly growing health challenge. By 2050, the total number of PLWD is projected to reach over 170,000 people (Ma'u et al, 2021; ANZ, n.d.) with several varying impacts.

Based on 2020 estimates, about 2.8% of the Pacific population in New Zealand will account for individuals with dementia (Burholt et al, 2022). A numerical figure demonstrates that the prevalence rate of dementia among Pacific people in New Zealand will reach approximately over 4,000 by 2038 (ANZ, n.d.). According to the DEIR, dementia cases are expected to spike significantly among Māori, Pasifika, and Asian communities, with cases expected to be more than double by 2050. This is parallel to the growth curve observed among European New Zealanders, with an added concern for health equity among these populations (ANZ, n.d.). Since 64% of Pacific people reside in Auckland, this proportionately creates the importance of addressing the dementia challenge that will impact Pacific people overall. Furthermore, since the Samoan population makes up most of the Pacific population, both in Auckland and New Zealand, this causes further concern with respect to the dementia challenge that the Samoan people will face.

SEARCH STRATEGY

In order to provide a comprehensive review of the supporting documents in this field and provide a rationale for my thesis, I conducted a comprehensive search of the scientific literature and a document analysis of relevant government sources. The search began by highlighting keywords from the research aims, organising the keywords into three different vital concepts, searching up synonyms for each highlighted keyword identified, and constructing final search terms relevant to these key concepts. The key concepts outlined above were turned into the search terms below:

(1) Samoa OR Samoans OR Pacific OR Pasifika,
(2) New Zealand OR Auckland,
(3) Knowledge OR Understanding,
(4) Experience OR Awareness,
(5) Dementia OR Alzheimer’s Disease,
(6) Auckland OR New Zealand,
(7) Family Caregiver OR Informal Caregiver,
(8) Service Utilisation OR Service Engagement, and
(9) Health Barriers OR Health Challenges.

The search for scientific literature was completed through online search engines including Google Scholar, Scopus, and PubMed. Other search engines were utilised such as Medline (Ovid), Embase, and CINAHL however, no new search fields or related articles were found to be relevant to the key search terms used and inclusion/exclusion criteria. The search fields were either already listed and used as part of this review from the previous search engines, or they did not meet the inclusion criteria. A few search engines had zero search field outcomes, which served as an indication to move on to the next search term. Following the scientific search, a further relevant search was made to access grey literature from a range of governmental and non-governmental websites e.g., Ministry of Health and Alzheimer’s New Zealand.

Documents were included if they had a focus on dementia caregivers with a specific focus on informal or family caregiving; the Samoan practices of care or caregiving, specifically for the elderly; and the health systems challenges/barriers related to dementia-related care (Table 1). Due to the scarce existing literature pertaining to the experiences of specifically Samoan caregivers of loved ones with dementia in New Zealand, an inclusion of articles involving other collectivistic, ethnic-minority cultures exploring the experiences of becoming a caregiver to their spouse or relative with dementia were included too. This was to provide more context in terms of the caregiver experience of people with dementia. Documents that were unrelated to the essence of the research aims were excluded. Excluded documents included those that had a focus on caregiving but on other specific health conditions or other chronic illnesses i.e., not dementia-related, and caregiving provided by formal caregivers/formal care.

Relevant documents were sourced from the most recent previous ten years (2010 - 2021). This allowed the most recent literature that exists to be reviewed. The types of literature that were utilised included books, scientific papers, scoping and systematic reviews, as well as New Zealand health organisation sites, New Zealand government policy, documents, or reports.

Table 1. Inclusion and Exclusion Criteria

Inclusions	**Exclusions**
Ethnic minorities including Pasifika peoples	Ethnic majorities
Informal or family caregivers of people with dementia	Formal caregivers of people with dementia
New Zealand health system or policies	Caregivers of people without dementia
Samoan practices of care	Dementia individuals within aged residential care or hospitals, including care provided outside of the family home setting
2010-2021 publications	Publications prior to 2010

121 references were sourced and deemed relevant to ethnic minorities, Pasifika peoples, caregiving, Samoan practices of care, dementia-related care, and challenges/barriers of the health system, therefore, were used as part of this review. Following the literature search, there were several predominant subthemes under each part, which will guide the structure of this review (Figure 1).

Part 1			Part 2			Part 3		
Theme 1.1	**Theme 1.2**	**Theme 1.3**	**Theme 2.1**	**Theme 2.2**	**Theme 2.3**	**Theme 3.1**	**Theme 3.2**	**Theme 3.3**
Knowledge, understanding and awareness of dementia	The informal caregiver	Dementia caregiver experiences	Health models	Obligations to care	*Fa'a Samoa*	Dementia frameworks and strategies in New Zealand	The New Zealand health system	Recommendations

Figure 1. Themes derived from the literature review

PART 1: DEMENTIA KNOWLEDGE AND CAREGIVER EXPERIENCES

Theme 1.1: Knowledge, Understanding, and Awareness of Dementia

Dementia knowledge and awareness

Very little research has been conducted that investigates the knowledge, understanding, and awareness of dementia among Samoan family caregivers of relatives with dementia. With the limited research that does exist, the knowledge pertaining to the complexities of dementia remains substantially poor among Samoan caregivers of persons with dementia (Williams et al, 2021). Misattribution has accounted for such misunderstandings of dementia, influencing individuals to lean on their own lay understanding of the condition (Hulko et al, 2019). A qualitative study based on family members of dementia individuals posits that the causes of dementia were not fully understood, and that the majority of the family members depended on lay understandings (Andrews et al, 2017). This is critical as accurate knowledge, understanding, and awareness of dementia are elemental to dementia diagnosis, help-seeking behaviours, and the overall experiences of family caregivers. A pilot study by Williams et al (2021) provided a basis for dementia knowledge and attitudes from a Samoan perspective. 50% of participants in this study identified AD as a normal part of ageing and 83% as a mental illness. These figures demonstrate the lack of dementia awareness and poor understanding of dementia present among this specific sample of Samoans, which could potentially impact their ability to detect dementia symptoms and achieve early diagnosis. When compared to findings of other similar studies with culturally and linguistically diverse samples, there are minimal differences too (Wong, 2019).

Research has also underlined that non-European cultures predominantly misattribute dementia symptoms as a normal part of ageing (Gallagher-Thompson et al, 2012; Meyer et al, 2015; Wong, 2019). These ethnic groups tend to deviate from understanding dementia from a medical stance and use other factors such as their spirituality, to help make sense of the condition instead. This is important to address, given that misperceptions of dementia can mean that Western health approaches are completely resisted against, as mild dementia symptoms may not be perceived as pathological (Hulko et al, 2019). Subsequently, this can also lead to the formulation and use of alternative management methods such as culturally specific home remedies rather than relying on medicalised management strategies (Meyer et al, 2015).

Given the nature of dementia, several studies have highlighted the need to improve dementia awareness and understanding (Andrews et al, 2017). An insufficient understanding of dementia and inadequate training likely leads to stigmatisation and additional barriers which impacts diagnosis and care for the PWD overall (Xiao et al, 2015; Jokogbola et al, 2018). A poor understanding of dementia can cause caregivers to overestimate the capabilities of a PWD which can lead to increased instances of anger, frustration, and depression (Sörensen & Conwell, 2011). A lack of dementia knowledge can result in family caregivers struggling to find quality information that could assist in the way they provide care and support as well as seek and access support services (Stokes et al, 2014). A study based on Asian family caregivers of persons with dementia in Singapore reported that 30% of caregivers had no knowledge of any available dementia services (Lim et al, 2012). Other studies further report that the condition is typically learned more in-depth throughout the caregiver journey rather than at initial diagnosis (Lee Casado et al, 2015). This could indicate that healthcare providers do not routinely inform caregivers about the available services unless necessary (Lim et al, 2012). It also reflected the need for better efforts to disseminate information systematically (Lim et al, 2012), which is crucial for being adequately informed about the condition and to reduce the potential for adverse outcomes.

Culture and understanding dementia

According to Chan (2010), there are different ways of understanding dementia. In fact, cultural beliefs are influential in how diseases are perceived (Gallagher-Thompson et al, 2012) and profoundly shape how a person comes to understand and define the meaning of an illness (Cipriani & Borin, 2015). Gaining an understanding of cultural beliefs is important because it can assist in understanding the unique health needs of individuals (Cipriani & Borin, 2015). Like many other ethnic minority groups, the understanding of dementia differs from the predominant Western understanding of dementia (Dudley et al, 2019). Dementia can be understood by biomedical, folk-like, or mixed-folk explanations (Chan, 2010). For many ethnic minority groups, dementia is understood by folk-like explanations. For example, Asian New Zealanders understand dementia to be a bad reflection of the PWD and their family reputation. Their beliefs can be about deservedness based on karma such as receiving punishment for past deeds (Cheung et al, 2019). Such beliefs prompt the need to destigmatise dementia across ethnic minority communities (Cheung et al, 2019).

Culture also allows individuals to interpret and give meaning based on personal experiences, which ultimately affects how dementia is understood or described (Chan, 2010). For example, Confucianism believes that blessings would be received as a result of accepting illnesses (Chan, 2010). The positives of this are that culture can help with coping, acceptance, and endurance of illnesses. On the other hand, it can also mean that family caregivers are in a state of denial or guilt (Chan, 2010). Further research based on Chinese American dementia caregivers demonstrated that dementia was depicted as a result of either fate, wrongdoings, or over-worrying, and often viewed as contagious or a state of insanity rather than a brain dysfunction (Sun et al, 2012). These views impacted help-seeking behaviours, adding barriers to receiving a timely diagnosis and implementing interventions.

Acculturation and understanding dementia

The role of acculturation and understanding dementia was another prominent concept mentioned across the literature. Studies have reported that higher acculturated caregivers understand dementia from a biomedical perspective, whereas lower acculturated caregivers understanding and belief system of dementia mainly stem from folk-like explanations of illness (Lee et al, 2010; Meyer et al, 2015). This is evidenced by Xiao et al's (2015) study on migrant Vietnamese family caregivers who reported a positive shift in responding to the diagnosis of dementia, improving family caregivers' acceptance and openness to accessing services as a consequence of acculturation. Despite these promising results, further research with more comprehensive measures must be conducted (Lee et al, 2010). Moreover, these findings can be indicative of the lack of ethnic-specific resources for lower acculturated caregivers in accessing culturally appropriate information about dementia too. For that reason, more efforts to reach less acculturated family caregivers are required (Lee et al, 2010).

Religion and understanding dementia

Religion also plays a role in shaping individual values and belief systems (Cipriani & Borin, 2015). For several ethnic minority groups, religious beliefs influenced how individuals understand and respond to the condition. For example, African Americans in the United States believe that AD is developed through 'God's will'. This spiritual belief system treats medicalised treatments to be ineffective. For Māori, dementia is part of a spiritual journey in the sense that the PWD is preparing to join their ancestors (Dudley et al, 2019). This is important to address, considering that the biomedical model of health that often dominates the New Zealand health sector does not consider individual subjectivity (Ministry of Health [MOH], 2010), stressing the significance of a holistic approach to health when working with ethnic minority groups.

Benefits of understanding dementia

A greater understanding of dementia is important for several reasons. One main reason is that it has a positive impact on family caregivers' quality of life (Andrews et al, 2017). Not only does this help with improving caregiver quality of life, but it also allows family caregivers to provide the best support and care for their loved ones (Andrews et al, 2017). Receiving information and raising awareness about dementia is important for preparing for the unexpected that comes with caring for a PWD, as it plays a significant role in recognising and detecting dementia symptoms (Stokes et al, 2014; Van Wijngaarden et al, 2018). Early detection of dementia is important for making appropriate healthcare plans to meet the needs of the PWD, their caregiver, and the family (Lee Casado et al, 2015). It allows people with dementia and their families to be involved in the decision-making processes when it comes to organising management and care plans too (Kenigsberg et al, 2016). Given the projected figures of dementia, particularly early-onset dementia among Māori and Pasifika peoples, acquiring relevant knowledge about dementia through increased awareness and education can alleviate possible stress outcomes and improve the timing of diagnosis. Zimmerman et al's (2018) study proved that educational resources that helped dementia caregivers manage medical problems significantly improved their confidence and decreased caregiver strain, depression, and anxiety. Steenfeldt et al (2021), along with a vast majority of studies also pinpoint that the time of receiving dementia information matters. Information can be emotionally weighted for family caregivers to immediately process hence why the timing of delivering information is crucial (Stokes et al, 2014). Research proposes that information is most beneficial when provided incrementally over a period. Much like reaching the developmental milestones of a child, information can be similarly delivered by meeting the developing needs of a PWD. This can alleviate caregiver burden as it primes them to respond to dementia symptoms accordingly (Stokes et al, 2014). If information is not adequately delivered, family caregivers along with their loved ones are posed with the risk of mental and emotional overload (Steenfeldt et al, 2021). Another benefit of understanding dementia is that effective adjustments can be made to caring methods, and it could also play a role for caregivers to manage emotional responses in a healthier way too (Stokes et al, 2014).

Theme 1.2: The Informal Caregiver

Informal caregiver: Overview

Informal caregivers can be either family members (who are the most common), friends, or acquaintances that voluntarily provide unpaid care in the home setting for their loved ones (Jorgensen et al, 2010; Egbert, 2014; Gelman et al, 2014; Varik et al, 2020; McAllum et al, 2021). Informal caregivers work hard to maintain the independence of and fulfil the best interests of their loved ones and is considered a highly skilled role (Egbert, 2014; Webb & Dening, 2016; Hale et al, 2020). The informal caregiver, which is used interchangeably with the term family caregiver, is an essential role - especially when providing care and support for a PWD (Egbert 2014; Hale et al, 2020; Lindeza et al, 2020) which has been described to be complex and diverse (Dyall 2014; Gelman et al, 2014). Because a PWD progresses through various stages of changed behaviours and functional dependence, research suggests that taking care of a PWD is more stressful and demanding compared to taking care of a person with a physical disability (Chan et al, 2021). Informal caregivers are incredibly resourceful and are heavily depended upon as they generally become the primary source of support and care for a PWD (Crellin et al, 2014; Smith et al, 2020; Ma'u et al, 2021). Informal caregivers are also fundamental in the continuum of care for older people. Currently, there remains a gap in the current New Zealand system pertaining to inadequate support and training for informal caregivers (PGDipPhys, 2010; Mousourakis, 2013). Adequate training has several implications for improving dementia knowledge and creating more positive caregiver outcomes.

A female prominent role

A prominent subtheme throughout the literature pertaining to the family caregiver role was the gender expectations and gender roles within the family structure (Innes et al, 2011). Across the globe, informal caregivers are primarily constituted by women (Zygouri et al, 2021). Cross-cultural context reports that female family caregivers are more prominent than male family caregivers and that the role of becoming a caregiver, for females mainly, is motivated by societal expectations and cultural imperativeness (Wang et al, 2014; McAllum et al, 2021; Zygouri et al, 2021). This notion is further supported by Egbert (2014), reporting that the adult daughter naturally takes the responsibilities of the caregiving role for a family member needing full-time care. Additionally, the caregiver role is conceptualised as an internalised responsibility among daughters or daughters-in-law, explained by their gender, birth order, or relationship by marriage (McAllum et al, 2021). Since gender expectations of women determine who assumes the caregiver role, it does put female caregivers at risk of experiencing depression too. A systematic review by Xiong et al (2020) reported that female caregivers experience increased depressive symptoms and are at a greater risk of clinical depression. Other studies reported similar findings. Depression rates were formally higher in female caregivers compared to male caregivers - this was proven by higher stress scores produced by female caregivers compared to male caregivers in New Zealand (Jorgensen et al, 2010). These findings stress the importance of understanding the relationship between gender differences and negative mental and emotional outcomes. Fundamentally, understanding gender expectations or gender roles can inform and develop specific services that can cater to this specific subgroup, thereby potentially improving the adverse outcomes as a female caregiver.

Caregiver responsibilities

The progression of dementia poses significant challenges for family caregivers as the PWD requires higher levels of care (Fekete et al, 2019). Family caregivers can be responsible for several different matters pertaining to themselves, their families, and the PWD. One reason for the increased responsibilities family caregivers undertake is to ensure the family structure is maintained without disruption (Clemmensen et al, 2019). A caregiver’s responsibilities involve a multitude of tasks ranging from housekeeping duties, attending to personal care matters, administrative tasks such as organising doctor visitations or appointments, managing finances, consistent monitoring of a PWD’s overall safety and well-being, protection from threatening circumstances or anything that damages their dignity or self-image, and engaging in activities that interest the person they are taking care of (Egbert, 2014; Lindeza et al, 2020). They also find themselves responsible for making decisions for a PWD; this responsibility continues to increase as the disease progresses, which becomes difficult to carry out due to the conflicting ethical and emotional responsibilities that ensure the best health outcomes and optimal quality of life for a PWD (Egbert, 2014; Lindeza et al, 2020). The constant state of being in anticipation of what to expect for the future, not only for themselves as a caregiver but for their loved ones with dementia too, can be very strenuous to manage and cope with (Clemmensen et al, 2019; Varik et al, 2020). In some cases, family caregivers are also responsible for making the tough decision about end-of-life for their relatives with dementia which is associated with increased stress levels (Varik et al, 2020). Evidently, the stress and burden that stem from providing informal care have significant impacts on the caregiver and their families (Egbert, 2014). Given the complex nature of the caregiver role and responsibilities, it is important that their experiences are explored to guide systematic changes for dementia services (Wang et al, 2014).

Hours of care

The caregiver role requires optimal, frequent care that demands exhaustive hours of care entirely (Badkar et al, 2019; Lindeza et al, 2020). The amount of care and support informal caregivers provide is considered a never-ending process. Realistically, informal caregivers cannot put a time cap on their role as a caregiver and the responsibilities that come with being a caregiver either. Research suggests that the caregiver role is a '24-hours, 7 days a week' role (Jorgensen et al, 2010). A more recent study indicates that up to 120 hours of care is provided for a PWD on a monthly basis. Specifically, 30% of care hours are provided by spouses, 32% of care hours are provided by adult children, 12% of care hours are provided by other relatives, and 25% of care hours are provided by non-relatives or paid support (Jutkowitz et al, 2019). These numbers show that the cumulated care hours provided by individuals who would fall under the 'family caregiver' category is almost triple the amount compared to non-relatives or paid support. Because of such extensive hours dedicated to providing care, it is common for informal caregivers to take on the role full-time, partially due to inflexible working arrangements and prominently because of the high needs of a PWD. One study, in New Zealand, reported that 32% of caregivers for a person with AD have had to leave paid employment to fulfil their caregiver role full-time (Jorgensen et al, 2010).

Theme 1.3: Dementia Caregiver Experiences

Culture and caregiver experiences

The experiences of dementia caregivers have been well-documented across the literature. A vast majority of the literature is based on qualitative research pertaining to the experiences of caregivers of a PWD. It is important to note that although caregivers may experience similar challenges, they are all affected in different ways (Fekete et al, 2019). Caregiver experiences can be influenced and established by cultural beliefs, values, and expectations (Lee Casado et al, 2015; Meyer et al, 2015). Research suggests that caregiving differs across ethnicities. These differences are linked to a range of factors including culture, socioeconomic status, and language (Napoles et al, 2010). Such differences suggest potential mediators and moderators that can explain ethnic differences in health outcomes too (Napoles et al, 2010). For example, African American caregivers of persons with dementia have more positive appraisals of caregiving compared to other ethnic minority groups therefore, experience better mental health outcomes (Napoles et al, 2010). This underlines cultural imperatives and the nuances that are unique for caregivers from different ethnic backgrounds which impacts the way the caregiver role is experienced.

Cultural principles and caregiver outcomes

Although the concept of reciprocity and the sense of obligation to care are typically associated with positive connotations, research proposes that they can potentially increase the risk of negative caregiver outcomes such as burden, stress, and depression (Meyer et al, 2015). This may also cause healthcare providers or other support services to lessen the entirety of such concepts and the extent of its impacts on family caregivers. Expectations in the context of caregiving is the social pressure for family members to provide care and support for older family members (Sagbakken et al, 2018). Filial piety is strongly valued in Asian cultures (Meyer et al, 2015). Although it is highly valued, filial piety can equally contribute to increased levels of caregiver burden (Xiao et al, 2015). The value of familism increases self-affirmation too. This study demonstrated that those that valued familism more were inclined to have greater appraisal and caregiver satisfaction (Liu et al, 2012). Research suggests that positive appraisal is an important coping resource, although more research needs to be done in this area (Liu et al, 2012). A REACH (Resources of Enhancing Alzheimer’s Caregiver Health) study proved that less acculturated Hispanic caregivers were more likely to identify positive aspects of caregiving compared to more acculturated Hispanic caregivers. Being less acculturated was influential in delaying institutionalisation (Coon, 2012). Programmes such as REACH can effectively improve coping strategies and caregivers’ quality of life by addressing caregivers cultural needs and nuances (Napoles et al, 2010). The principle of duty can also strongly motivate one to assume the family caregiver role. How this principle is valued differs though (Tretteteig et al, 2017). Family involvement is extremely important for care. Sharing information and building on knowledgebase has an empowering impact in the sense that it can encourage caregivers to manage dementia in their unique ways (Dudley et al, 2019). For Māori, collective obligations to the family unit are especially important for *wairua* (the spirit or the soul) (Dudley et al, 2019). This indicates the need for family involvement and engagement in all stages of developing care plans and management strategies. Enhancing family cohesion can contribute to more positive appraisals (Lindeza et al, 2020). Māori are more likely to provide care for their loved ones compared to non-Māori. The need for Māori to provide care for family members can be explained by the high morbidity rates among Māori (Alpass et al, 2013).

Impact on caregivers

A difficult part of being a family caregiver is the dichotomous position they are placed in, particularly when it comes to the conflict between prioritising the needs of all parties involved (Webb & Dening, 2016). Caregivers typically find themselves having to balance their role alongside other roles they may have such as being a parent (O'Sullivan, 2011). Family caregivers ultimately struggle to find the balance between personal needs, family needs, as well as the needs of their relatives with dementia (Webb & Dening, 2016). As mentioned, a person presenting with dementia symptoms can display heightened, unfavourable behaviours such as aggression, depression, anxiety, and a loss of personhood. These behaviours have been reported to have negative impacts on a caregiver's mental, physical, as well as emotional well-being (Crellin et al, 2014; Egbert, 2014; Weir & Fouche, 2017; Weir, 2018; Varik et al, 2020). Informal caregivers for a PWD often battle with elevated levels of depression, stress, caregiver burden, feelings of entrapment and guilt, as well as low self-efficacy (Laparidou et al, 2019). As a result of these impacts, it is imperative to highlight the caregiver role while recognising that a caregiver's quality of life is just as much of a priority as the relative they are providing care for (Farina et al, 2017; Cullum et al, 2020; Hale et al, 2020).

When an individual transitions into the caregiver role, they are often overshadowed by what is 'needed' before getting the chance to seek support and strategise optimal methods that will help to maintain balanced family and social relationships as well as decrease negative emotions that arise from the caregiver role (McAllum et al, 2021). In essence, caregivers sacrifice their self-independence to be able to support the independence of others (Tolhurst et al, 2019), often adjusting their livelihoods to keep up with the responsibilities that come with the caregiver role (Smith et al, 2020). Ultimately, the impact of providing care is associated with negative health implications, especially for family caregivers that live with a PWD (Webb & Dening, 2016). One study highlights that the increasingly negative impacts of caregiving for a PWD leads to caregiver burnout. Here, 13.9% of the sample in New Zealand presented with caregiver burnout. The results of this study specifically highlight that caregiver burnout is significantly higher for those living with the care-recipient ($p<0.0001$) compared to those who are not (Chan et al, 2021). Dementia caregivers are reported to have poorer health outcomes compared to non-dementia caregivers - depression and stress rates are reported to be greater for caregivers compared to non-caregivers too (Alpass et al, 2013).

Impact on caregivers: Mental well-being

The mental health issues associated with caregiver burden include depression, nervousness, and hopelessness. In extreme cases, high caregiver burden is linked with suicidal ideation too (Kang et al, 2018). Depression and caregiver burden are examples of psychological outcomes caregivers experience due to the lack of social support and feelings of loneliness within their roles (Fekete et al, 2019). These psychological outcomes are affected by the changes in the quality and quantity of social interactions (Fekete et al, 2019), understood to be 'rare occasions' when it comes to self-care routines, socialising, recreational activities, and rest (Jorgensen et al, 2010; Egbert, 2014). The behavioural changes that occur in a PWD have direct and indirect effects on caregivers' psychological health (Liu et al, 2012).

Impact on caregivers: Physical well-being

The physical health impacts associated with caregiver burden include hypertension, heart disease, mortality, decreased immunity (Crellin et al, 2014), health palpitations, chest tightening and sleeplessness (Kang et al, 2018; Chan et al, 2021). Along these several physical health issues associated with caregiver burden, stress is the most predominant (Kang et al, 2018). The main contributing factors to caregiver stress include the personality changes of their loved one with dementia, inadequate respite, financial pressures, and minimal free time for their personal needs (Jorgensen et al, 2010). Health consequences of the caregiver role is that less time is spent on the self, which could have a potential risk of caregivers' health declining (Boughtwood et al, 2011).

Impact on caregivers: Emotional well-being

The emotional impact associated with caregiver burden is emotional turmoil which leads to feelings of demotion of their overall well-being to be able to fulfil their responsibilities as caregivers (Clemmensen et al, 2019). Particularly, the negative emotional impacts caregivers often report include anger, anxiety as well as stress. These have been linked to the loss of identity, marital and family conflicts as well as the loss of wages (Egbert, 2014). The financial constraints are mainly due to unsustainable employment from conflicting responsibilities between work and the caregiver role (Laparidou et al, 2019).

Impact on caregivers: Misattribution

Caregivers also tend to misattribute behaviours of individuals with impaired cognitive ability which is strongly associated with relationship dissatisfaction. With that said, family caregivers often misattribute the negative behaviours of their loved ones to the condition instead. This means that caregivers become blinded by the condition and place blame on the PWD rather than the disease itself. Caregivers begin to find it difficult to distinguish between what behaviours are being caused by the condition and what behaviours are not caused by the condition. Within the field of psychology, misattributions are likely to cause caregivers to feel immense and uncontrollable frustration with the person receiving care (Egbert, 2014).

Impact on caregivers: Family conflict

Family can equally be a source of stress rather than helpful (Lee Casado et al, 2015). Examples of where stress stems from within the family unit can include disagreements, dissatisfaction, lack of involvement or unwanted advice from other relatives. Dementia can put a strain on family relationships (Jokogbola et al, 2018). Family is viewed as an emotional unit, if following the Bowen Family Systems theory (Jokogbola et al, 2018). This theory follows an interconnected system, proposing that family members are intensely emotionally interconnected. With this understanding, it means that members' psychologies are influenced by one another and can only be understood when intact with the system as a whole. This theory is made up of eight principles: differentiation of self (core concept), triangles, nuclear family emotional process, family projection process, multigenerational transmission process, emotional cut-off, sibling position, and societal emotional process. Although this theory values interdependence, this theory can potentially cause family dysfunction; Jokogbola et al (2018) report that interdependence can be a source of conflict and stress. This study opposes what we understand to be highly valued, especially within collectivist cultures – basically, this provides another stance on the principle. It could be understood as closely aligning to the individualist perspective too. A supportive family system is generally associated with enhanced caregiver well-being. This has proven to not always be the case, for example, Hwang and Han (2020) studied the behaviour of Chinese caregivers and proved that they would likely deal with challenges on their own, and that their motivation to provide care was impacted by feelings of shame and embarrassment rather than relying on extended family support (Gallagher-Thompson et al, 2012). Changes within family dynamics can also mean that family caregivers are more likely to become socially isolated (Steenfeldt et al, 2021). Caregivers also tend to enter social isolation from the overwhelming intricacies that come with the caregiver role (Perkins, 2013).

Impact on caregivers: Positives

Equally important to note is that not all caregivers experience the detrimental effects of the caregiver role (Fekete et al, 2019; Laparidou et al, 2019). In fact, the positive aspects of caregiving have been well-documented, but it is a topic that is still considered less investigated (Abdollahpour et al, 2018). The positive aspects gained from caregiving ranged from improved companionship, gratitude for the opportunity to care for a loved one, and adding meaning to life (Chan et al, 2010). Positive aspects include personal accomplishment and strengthening relationships. These are further enhanced by the presence of strong support systems in place (Lindeza et al, 2020). Examples of the positive outcomes associated with the caregiving experience include personal growth, satisfaction, and a sense of fulfilment – all of which have positive impacts on one’s overall health and well-being (Grover et al, 2017; Lynch et al, 2018). A qualitative study that interviewed focus groups of informal caregivers reported that a caregiver could adapt effectively to change and experience less stress or burden on account of access to intrapersonal resources and developing more positive emotions and outlooks towards caregiving (Laparidou et al, 2019).

Building resilience is often portrayed as a positive outcome of the caregiver experience too. Resilience is defined as ‘adapting successfully or positively in the face of a stressful experience’ (Coon, 2012; p. 233). It is central for supporting caregivers of persons with dementia (Parkinson et al, 2017). At the same time, it creates an internalised consequence of facing problems in private without the need to seek external support (McAllum et al, 2021). In cases where inadequate support is provided, faith-based beliefs are a means of coping with the challenges that come with providing care. The negative impact of this coping mechanism is that caregivers unconsciously become wired to avoid asking for support; they view this as bothersome and burdensome to others – an emotion that they are 'experts' on – and quickly associate this method with feelings of shame and embarrassment to the self and the family (McAllum et al, 2021). Maintaining normalcy among dementia caregivers and people with dementia is no easy feat. The contributing barriers to maintaining normalcy includes both health and legal issues, dementia symptoms as well as the lack of knowledge about available services (Hale et al, 2020). A lack of knowledge is a gateway to caregiver incompetency and increased caregiver burden. Caregivers eventually experience burnout which consequently affects the way they provide care (Smith et al, 2020). On the other side, the contributing enablers to maintaining normalcy include social contact, knowledge, and the quality of social services (Hale et al, 2020).

Coping and coherence

Dementia caregiving is largely guided by Lazarus and Folkman’s Stress and Coping model (Sun et al, 2012). The Stress Process model is an adaptation of Lazarus and Folkman's (1984) theory of stress, coping, and adaptation. The Stress Process model is a dominant theoretical model of family caregiving that has been modified to include cultural values. Cultural values in this model are represented by filial piety, familism, obligation, support from family and family as referents (McCleary & Blain, 2013) – all of which are strong values within the Samoan culture. Several studies argue the significant role culture plays in coping strategies (McCleary & Blain, 2013; Fekete et al, 2019). For example, Foliaki et al (2020) propose that cultural identity, cultural practices, cultural beliefs, and cultural values become prominently important for an individual whose health is threatened or is approaching the end-of-life stage - which is a common experience for a PWD. Another study by Chan et al (2021) highlights how the role of cultural values, family structures as well as the service delivery of models can influence the different experiences of caregivers of a PWD too. Differences in stress responses can theoretically be explained by individual coping strategies and cognitive appraisals (Liu et al, 2012). Learning to manage challenges that come with caregiving is associated with the caregiver role becoming more meaningful (Tretteteig et al, 2017). Examples of the negative aspects of informal care include inappropriate formal care support, the progression of the condition, and the cost of the condition. Such negative aspect contributes to negative caregiver appraisals (Lindeza et al, 2020). Behavioural changes that become problematic could make caregivers believe that they cannot be helped or changed. However, studies show that this is due to a lack of understanding of how to manage problematic behaviours. When incidences like this occur, it is likely that caregivers result in choosing less positive coping strategies and instead choose negative coping strategies (Liu et al, 2012). Coherence was another underlying subtheme found across the literature. This was deemed important and resourceful for coping (Orgeta & Sterzo, 2013). Research suggests there is an association between low sense of coherence levels and self-reported anxiety and depression (Orgeta

& Sterzo, 2013). According to Orgeta & Sterzo (2013), caregivers' quality of life can be strongly predicted by the levels of sense of coherence and that positive coping strategies lead to improved psychological health too (Liu et al, 2012).

Service utilisation

Informal caregivers of people with dementia play a crucial role when it comes to the utilisation of care interventions and accessing dementia-related services. Informal caregivers have intimate knowledge that will help determine the best services and supports to access and utilise for the PWD that they support (Hale et al, 2020). It is possible that caregivers find the available services culturally unsafe or unresponsive to their needs or the needs of those for whom they are caring for (MSD, 2019). One study reported caregiver satisfaction by the services available to them however, the majority (i.e., two-thirds) of the caregivers felt that the services offered were not useful and thus deemed ineffective to their caregiver needs (Laparidou et al, 2019). Any negative experiences with services raise the potential for caregivers to restrain or limit their opportunity to access support services (MSD, 2019). Understanding what enables a caregiver in their role is important to address and understand; caregivers are essentially key facilitators of service uptake. Because of this, they will be able to optimise formal service uptake for those they support with dementia (Hale et al, 2020).

PART 2: SAMOAN UNDERSTANDING AND PRACTICES OF CARE

Theme 2.1: Health Models

Fonofale model

Health expectations, health literacy, help-seeking behaviour, and self-management skills are all impacted by culture, language, and ethnicity (McKinlay et al, 2015). Pacific culture embodies attitudes that are inclusive and collaborative (Vakalahi & Hafoka-Kanuch, 2019). A Pasifika perspective on health considers the person as a whole, that addresses spirituality, customs, and traditions (Seiuli & Malaela, 2013). Pacific models of health and well-being are unique but fundamentally similar. All Pacific models holistically include the physical, mental, social, and spiritual domains, including cultural and environmental factors too (Vakalahi, 2012). Similarly, Samoans also view health and well-being from a holistic perspective (Vakalahi, 2012). A health model that encapsulates the holistic nature of the Samoan worldview is the *Fonofale* model (Silulu & Melanie, 2021). This model is established on the values and beliefs of Pacific peoples and provides a culturally appropriate and holistic way of exploring Pasifika health (Ioane & Tudor, 2017). In line with other holistic models of health, the *Fonofale* includes elements of culture, family, spirituality, physical, mental, and other elements (e.g., age, sexual orientation, etc.) (Ioane & Tudor, 2017; Silulu & Melanie, 2021). When perceiving health from the *Fonofale* model, the concept of wellness thrives when all dimensions are interconnected harmoniously (Silulu & Melanie, 2021). Such models are useful in understanding family caregiver experiences too.

Ho'okele model

The *Ho'okele* model highlights the role of Pacific elders within their families and communities, signifying intergenerational relationships and multiple systemic connections. The *Ho'okele* model portrays Pacific elders as navigators, being the gateway to understanding the individual's lived experiences within their social context. Within Pacific families, the elderly symbolises the 'pillars' of their families, held at the highest pedestal for their inherent responsibilities that hold the *aiga* (family) together. Pacific elders are understood to be the preservers and transmitters of cultural beliefs, practices, and values to younger generations (Vakalahi & Hafoka-Kanuch, 2019). Given these responsibilities, the wellness of Pacific elders is of utmost importance (Ihara & Vakalahi, 2011). The *Ho'okele* model helps to justify why the elderly are highly valued and respected in Pacific cultures (Vakalahi, 2012; Vakalahi & Hafoka-Kanuch, 2019), and considers the needs of Pacific elders as it creates culturally relevant responses to meet such needs (Vakalahi & Hafoka-Kanuch, 2019).

Within Samoan communities, the elderly are acknowledged as the most prominent figures within the family structure. In the Samoan culture, old age is also representative of a peaceful time of life whereby the elderly can rely on the family to look after them (Egbert, 2014). The wellness of a Samoan person understood through a Samoan worldview is represented by sacred, interdependent relationships between the people, land, and spiritual world, which opposes the Western ideology of independence and free will. These relationships are essential as they appropriate the use of language, proximity, and boundaries for a Samoan person (Ihara & Vakalahi, 2011). For example, an exploratory qualitative study based on Samoan and Tongan American elderly immigrants in Hawaii proved that the commitment to cultural practices within the family has protective influences on the health and well-being of the elderly (Vakalahi, 2012).

Theme 2.2: Obligations to Care

A cultural obligation to care

Culture can motivate the act of providing care (Egbert, 2014). Families from collectivist cultures are less likely to consider institutionalisation or formal home-based care services. In New Zealand, Pacific people are less likely to be placed in ARC. From a Pacific perspective, the idea of institutionalisation or placing family members into ARC is considered culturally inappropriate and is frowned upon among Pacific peoples (Cullum et al, 2020). It is also believed that the values of *fa'a Samoa* are preserved when providing care within the home setting (Fernandes et al, 2021). The idea of caregiving from a collectivist perspective focuses on social harmony and emotional closeness (Egbert, 2014). Much like the Pacific perspective, it highlights a collective, harmonious, and positive interrelationship between *Atua* (God), *tagata* (people), and *laufanua* (environment) that is underpinned by five core values. These five core values consist of *tapu* (sacred bonds), *alofa* (love), *tautua* (serve/reciprocal service), *fa'aaloalo* (respect), *fa'amaualalo* (humility), and *aiga* (Ihara & Vakalahi, 2011).

A familial obligation to care

One of the many reasons that providing care within the home setting is essential within collectivist cultures is that it can be deemed a fulfilment of familial responsibility (Chan et al, 2021). Familism is a concept that creates the expectation for families to take care of their own (Lee Casado et al, 2015; McAllum et al, 2021). Often, children that become caregivers from collectivist cultures believe that their responsibilities are an act of reciprocation of the sacrifices that their parent(s) or relative has made for them as children (Egbert, 2014). The transition to becoming a family caregiver is described to be a natural process that arises without doubt. When the act of providing care integrates with cultural values, it conditions one to accept and carry out the family caregiver role (McAllum et al, 2021).

For Pacific communities, it is natural to provide care kept within the family. To live alone or without a family member or relative is extremely sparse among Pacific communities. The concept of 'looking after your own' is a natural part of a Pacific family's value system (Foliaki et al, 2020), which is highly commendable and is acknowledged as a family obligation, especially when a family member becomes ill. In New Zealand, Pacific people are more likely to live with family members or relatives compared to Māori and non-Pacific ethnic groups (MSD, 2019; Foliaki et al, 2020). In relation to dementia, it is no different. Pacific families in New Zealand are more likely to provide care and support for older-aged relatives with dementia at home. This has been reported to have potential influences on a PWD's survival too (Cullum et al, 2020). One study suggests that providing care within the home setting is preferred among the elderly as they avoid institutionalisation and feel that their identity, independence, and way of living are all maintained (Foliaki et al, 2020).

Theme 2.3: Fa'a Samoa

Collectivism versus Individualism

The behaviours and decisions of Pacific peoples are commonly driven and influenced by similar Pacific cultural values such as kinship, collectivism, relationships, respect, and the vital role of the family (Foliaki et al, 2020). Pacific people live and reflect a collectivist approach (Ioane & Tudor, 2017). Collectivism among Pacific populations is a central attribute; the concept of family and personal relationships is paramount and held with high regard (Foliaki et al, 2020). By way of family, Pacific populations are responsible for the development, care, and support of young children and adolescents as well as other dependent relatives who are often unwell (Dyall, 2014).

The dynamics of collectivist cultures are opposite to that of individualistic cultures. Individualistic cultures value independence above all, which can sometimes cause conflicting interpersonal relationships. Caregivers from individualistic cultures have an outlook on life that emphasises independence and individuality. Among individualistic cultures, there is a mutual understanding that the needs of the 'self' are prioritised above all and that social networks are loosely structured, meaning there are fewer expectations, obligations, and familial responsibilities to uphold. On the opposing end, collectivist cultures have a collective understanding where dependency among family members for resources and assistance is natural. Social networks are more intricately connected, meaning the various responsibilities, obligations, and expectations are shared among the family for assistance (Egbert, 2014).

Collectivism: Fa'a Samoa

For Samoans, individualism, independence, and autonomy are not prioritised nor encouraged due to its Westernised nature (Ioane & Tudor, 2017). In essence, the livelihoods of Samoan people are guided by their respective understandings of *fa'a Samoa* which is understood as the practices and rituals that define the Samoan way of being (Ioane & Tudor, 2017). A general understanding of *fa'a Samoa*, is that it is the foundation that preserves, supports, elevates, and upholds the pillars of family, cultural values, beliefs, spiritual faith, and identity. In addition, the collectivist values embedded in *fa'a Samoa* believe that the family and others are placed before the individual self (Seiuli, 2013). In relation to caregiving, these values are innate and act as markers that ensure family members fulfil their duties to care for their older family members should the circumstances arise (Chan et al, 2021). The fundamental principles that underpin *fa'a Samoa* are *fa'amaualalo, fa'aaloalo*, and *alofa* (Ioane & Tudor, 2017). Overall, these principles form a unique part of Samoan social identity (Seiuli, 2013) understood to reflect ones upbringing (Ioane & Tudor, 2017). The collectivist aspect of the Samoan culture can be expressed through ensuring that Samoans collectively represent their families, village, ancestors, and culture (Nomani-Brown, 2021). Seiuli & Malaela (2013) described a collective approach as the ‘we’ approach, which is elemental to keeping Samoans together. A strong sense of affiliation, loyalty, and oneness is prominent when guided by a ‘we’ approach. As a result of European influence and global modernisation, the Samoan culture has continued to evolve over time. Within these globalised settings, preserving *fa’a Samoa* is especially important (Nomani-Brown, 2021). *Fa’a Samoa* prioritises the family unit above all. Samoans are reputable for their strong family-oriented lives (Nomani-Brown, 2021). *Fa’a Samoa* is the root of Samoan identity. Its foundation upholds and acknowledges cultural and spiritual values, and *aiga* that preserves and elevates customs, beliefs, and identity (Seiuli & Malaela, 2013). Family is a key element of *fa’a Samoa*. Other key elements of *fa’a Samoa* include the Samoan language, church, and the Samoan chiefly system (Nomani-Brown, 2021).

Understanding the Vā

The principles that define and govern Samoans also develop the *vā*. *Vā* is a multifaceted and multi-dimensional concept best understood as a space of mutual respect and ensuring the 'space-between' is kept sacred (Ioane & Tudor, 2017). In the Samoan culture, there are different perspectives of the *vā* which are context dependent. For example, *va fealoaloa'i* (relational connections) is understood as 'the various spaces and places within which Samoan people interact in a meaningful and non-coincidental way' (Seiuli, 2016; Ioane & Tudor, 2017, p. 291) or the 'mutual and reciprocal respect in socio-political and spiritual relationships' (Ihara & Vakalahi, 2011, p.416); *va fealofani* is a 'sacred, sibling love that people show one another' and *va tapua'i* is a 'worshipful space' (Ioane & Tudor, 2017, p.291). Collectivism within the Samoan culture particularly motivates Samoans to maintain *va fealoaloa'i* which forms self-integrity. Understanding the concept of *va fealoaloa'i* is to embody the *aiga*, which is understood to be the foundation of ones survival (Ihara & Vakalahi, 2011). The Samoan concept of the *vā* (the space between) resonates with the dynamics of the space-time continuum, where space and time are inseparable and operate simultaneously (Gabbard, 2017).

Tautua: Overview

A fundamental principle within the Samoan culture is *tautua* (Fa'aea & Enari, 2021). *Tautua* in the Samoan culture is an unconditional concept (Ioane & Tudor, 2017). An important part of *tautua* is honouring and upholding *fa'a Samoa*. Equally important are strong familial connections; without these, it is likely that *tautua* is not as prevalent or strong within families (Fa'aea & Enari, 2021). Serving your *aiga,* village, God, and country is the embodiment of the *tautua* concept. A part of the Samoan culture highly commends the act of service, especially within the family structure. The Samoan people customarily believe that service brings honour, respect, and protection to the family name. When an individual can portray this level of service, it is understood that they have reached what is known as *tautua matalilo* (protecting and honouring the family name), in which words and actions seek to elevate the family (Fa'aea & Enari, 2021). Living out the importance of the *tautua* concept strengthens family connections as it helps them confidently make decisions without conflict (Fa'aea & Enari, 2021). In the Samoan culture, three intergenerational spheres of service are understood as the *tautua* lifecycle. These spheres of service are *tautua ia tautua* (serve to serve); *tautua ia pule* (serve to lead); and *pule ia tautua* (lead to serve) (Fa'aea & Enari, 2021). There are also four types of *tautua fa'a Samoa* in the Samoan literature: *tautua tuavae* (serving with abundance of provision), *tautua matalilo* (serves out of public view), *tautua malele* (people who live abroad, supporting family) and *tautua upu* (oratory skills) (Fa'aea & Enari, 2021). In the Samoan culture, there is an expectation for families to care of their elders. To uphold this expectation is considered a blessing in the Samoan culture (Vakalahi, 2012).

Tautua and Fa'a Samoa: Samoans living in New Zealand

As reported, *tautua* is second nature to Samoans - to be Samoan is to personify the principle of *tautua* regardless of where one is in the world (Fa'aea & Enari, 2021). That said, *fa'a Samoa* can be different across Samoan communities such as New Zealand-born Samoans compared to island-born Samoans (Ioane & Tudor, 2017). Understanding culturally prescribed gender roles can help us to better understand the expectations within the family unit (Yeo et al, 2014). Samoans living in New Zealand or in diaspora communities can either partially or fully implement *fa'a Samoa* in their everyday lives. This is shown through their actions that reflect the traditional values, customs, and beliefs of the Samoan culture, which continue to thrive in Samoa itself (Ioane & Tudor, 2017). Many Samoans in New Zealand demonstrate their understanding of *fa'a Samoa* through *tautua* to their *aiga* and church by following a code of *fa'aaloalo* (Seiuli, 2016). The structure of the *aiga* within diaspora communities is vital to the maintenance and observation of *fa'a Samoa.* The practice of *fa'a Samoa* in diasporic locations strengthens familial ties and aligns with the familiar Samoan proverb '*o le ala i le pule o le tautua*' (Seiuli, 2016). Another proverb that is common among Samoans is '*o le tautua o le ala lea i le fa'aeaina',* which translates to 'service is the path that leads to elevation' (Fa'aea & Enari, 2021). The values of *fa'aaloalo,* obedience and diligence are central to *fa'a Samoa* within the traditional village context that has remained within diaspora communities when it comes to honouring elders and families (Fa'aea & Enari, 2021). Other values such as *va fealoaloa'i, alofa,* and *agaga fesoasoani* (willingness to help), are all reinforced by actively engaging in *fa'a Samoa* too (Seiuli, 2016). The practice and maintenance of *fa'a Samoa* for Samoans living in New Zealand establishes an understanding that they are obligated to take care of their parents or older aged family members with the belief that it is an honour to uphold these duties. This is known as *tausi matua* (care for elders). *Tausi matua* is a principal value held with high regard within *fa'a Samoa* as it encourages the provision of care for the elderly within the family structure. *Fa'a Samoa* expects families to take care of their own. Children are expected to permanently serve and care for their parents, more so when they become old. If this expectation is not fulfilled and elders are placed in institutional care instead of being taken care of by the family, they are looked down upon and bring shame to their family (Fernandes et al, 2021).

PART 3: ACCESSING HEALTHCARE

Theme 3.1: Dementia Frameworks and Strategies in New Zealand

Understanding the government policies and health system of New Zealand is important if exploring the experiences of caregivers in New Zealand. The New Zealand Framework for Dementia Care (NZFDC) is a government-funded framework that was developed in response to the rapid figurative growth of New Zealanders with dementia (MOH, 2013; Chan et al, 2021). This framework attempts to address different issues associated with dementia with recognition of improving dementia care needs, optimising the overall quality of life of both the PWD and their *aiga*, while ensuring safe and cost-effective services. It is guided by principles that follow a person-centred approach to develop the highest possible standard of care and aims to provide flexible, accessible, proactive, and integrated services to meet a variety of needs. The NZFDC have five key goals to achieve and maintain normalcy through structured care which includes: (1) keeping the peace, (2) facilitating participation, (3) facilitation of independence, (4) ensuring safety and (5) facilitating happiness (MOH, 2013; Hale et al, 2020). New Zealand also has two primary government strategy documents that have framed the policy framework concerning the provision of care for PLWD: (1) the MSD Positive Ageing Strategy and (2) the MOH's Health of Older People Strategy. Broadly speaking, both documents encourage improving the quality of life for the ageing population. Despite the positive intentions behind these said frameworks, they are equally limited due to their generalised nature. This means that both strategy documents fall short to acknowledge and cater to individual needs (Weir & Fouche, 2017), such as the unique experiences and perspectives embedded across Pacific communities.

Allied health services are provided through a Needs Assessment and Service Coordination Services following an International Resident Assessment Instrument (interRAI) under the NZFDC (Chan et al, 2021). interRAI is an internationally recognised evidence-based best-practice approach that constitutes a suite of comprehensive clinical geriatric assessment instruments to improve the quality of care (MOH, 2018; Martinez-Ruiz et al, 2020). In New Zealand, just over 54,000 people had interRAI home care assessments, where 3.4% of this total were made up of Pasifika (Abey-Nesbit, 2021). interRAI is generally used by trained nurses and registered healthcare workers to evaluate individual care planning, resource allocations, quality measurement, and outcome evaluation of older peoples within the community that require publicly funded home services or ARC (Connolly et al, 2011; MOH, 2018; Abey-Nesbit, 2021). The interRAI also covers a range of areas relating to the capabilities, abilities, and functionality of an individual with dementia such as their understanding, physical well-being, health conditions, mood, medications, living circumstances, and so forth (MOH, 2018). This evaluation serves to ensure informed decisions are made regarding the care needs of an individual (MOH, 2018).

In response to the challenges informal carers experience and to formally acknowledge the carer experience, the New Zealand government introduced the Carer's Strategy Action Plan (CSAP) (Jorgensen et al, 2010; Rea et al, 2010). The CSAP is the government's vision for carers to reflect the improvement of caregiver support and their overall well-being (MSD, 2019; WEAG, 2019). This approach is reported to be a step forward for Māori and Pacific family caregivers in Auckland (Dyall, 2014). The CSAP contains 'objectives with actions that the government will undertake to address areas of key priority identified by carers and the government agencies' (MSD, 2019, p. 32). It is guided by four main principles which recognises diversity, encourages proactivity, supports inclusivity, and enables caregivers (MSD, 2019).

Caregivers also have access to a Carer Support subsidy which aims to lessen the burden experienced by full-time care (MOH, 2022; Kahui tuitui tangata, 2019). Despite its positive intentions, it is equally limiting to access as it is only available for full-time unpaid caregivers. A full-time caregiver is defined as an individual who provides unpaid care to a disabled person for more than 4 hours per day (MOH, 2022; Kahui tuitui tangata, 2019). Based on this set criteria, it means that Pasifika, who naturally share the caregiver role among family members, are likely to be ineligible to access this support despite policies promoting that financial support can be tailored to meet family caregiver needs. This highlights that current action plans are not serving caregiver needs at an individual nor cultural level.

Theme 3.2: The New Zealand Health System

A youthful population

The Pacific population is a youthful population where about 4% are aged 65 years and over (Dyall, 2014). Over the next two decades, the rate of the older Pacific population is expected to grow by 160% to 240% compared to just 50% for the older European population (Parr-Brownlie et al, 2020). Because the Pacific population is a youthful population, it introduces the implications of improving current healthcare models of delivery and ensuring that the delivery of health services is prudent for Pacific communities by providing culturally appropriate health and support services (Ioane & Tudor, 2017). This implication can be supported by the current statistics that outline the likelihood of Pasifika accessing healthcare services. For example, Abey-Nesbit et al (2021) report that Pasifika peoples are less likely to seek healthcare services compared to non-Pasifika. It suggests the possibility that older Pasifika peoples are more vulnerable than non-Pasifika because they are not accessing the support services that currently exist.

Dementia diagnosis

Diagnosis of dementia is a complex matter changing across time and geographies (Dyall, 2014; Wu et al, 2017). Receiving a diagnosis is a crucial step in accessing care and support services (Connolly et al, 2011). Due to the exponential growth of the number of people presenting with dementia, there currently exists an increasing concern on a worldwide scope to see if adequate, suitable health and support systems are in place (Hale et al, 2020). These include medical, social, and institutional care - all of which are in high demand due to the rise in dementia cases (Lindeza et al, 2020). General practitioners and memory clinics play a vital role in diagnostic processes. Their role includes informing, educating, and communicating with the patient and their families about the condition and the relative local support services available (Varik et al, 2020). Obtaining a dementia diagnosis can be exceedingly difficult for family members to process (Varik et al, 2020). The literature states that as soon as a relative receives a diagnosis of dementia, that is when the official caregiving begins for family members (Smith et al, 2020). This highlights how abrupt and unexpected the role of being a caregiver is, especially when dealing with a PWD.

Dementia diagnosis: Pacific versus European populations

The typical age of dementia onset is over the age of 65; however, research proposes that dementia is being diagnosed for Pasifika at a younger age compared to New Zealand Europeans, which can be partly explained by the higher rates of cardiovascular risk factors among the Pacific populations in New Zealand. (Martinez-Ruiz et al, 2021). This can also be explained by the Pacific population having a lower life expectancy and being predisposed to chronic health conditions at an early age compared to the total New Zealand population (Dyall, 2014; Abey-Nesbit et al, 2021). In first-world countries, minority ethnic groups, particularly indigenous people, often have worse health than the majority (Abey-Nesbit et al, 2021). Because of this, research proposes that Pasifika who are at statistically greater risk of dementia will remain undiagnosed (Martinez-Ruiz et al, 2021). According to Sayegh & Knight (2013), delayed diagnosis is prominent among many minority ethnic older adults.

Pacific populations in New Zealand also have a higher comorbidity score despite being youthful nations (Cullum et al, 2020). With a prevalence of chronic and comorbid conditions, a demand of caregivers for Pacific peoples who present high health needs will be required to provide formal and informal support too (Dyall, 2014). Due to the age that a person is likely to present with dementia, there are typically comorbidities that exist for that person too. This means that the care provided for a PWD becomes more strenuous as there are adaptations that must be made and kept for their specific care plan (Lindeza et al, 2020).

For older populations with complex chronic health conditions, early-onset of dementia can be typically missed or ignored. Reason being is that cognitive testing is atypical during check-ups that will focus more on the chronic illness; barely any require cognitive testing (Dyall, 2014). One study reported that Pacific patients are, on average, 5.3 years younger than New Zealand European patients when diagnosed with dementia. This raises the growing concern for dementia among the Pacific population as well as the required care and support that will inevitably come with it (Cullum et al, 2018; Cullum et al, 2020).

Research also reports that only 60% of overall dementia cases are diagnosed, essentially meaning that prevalence rates are underrepresented in New Zealand (Dyall, 2014).

Different risk factor profiles

There is potential that the prevalence of dementia and risk factor profiles differ across ethnic groups within the same communities (Martinez-Ruiz et al, 2021). Arguably, different ethnic groups experience ageing in different and unique ways too (Hulko et al, 2019; Parr-Brownlie et al, 2020). Pasifika people have higher rates of smoking, obesity, hypertension, stroke, diabetes, and heart disease – all of which can place higher risk of dementia. Other risks of dementia can be formed by the impacts of social determinants such as poverty and lower levels of education too (Hulko et al, 2019). Failure to address cultural determinants of health suggests a lack of cultural safety and can affect dementia advice being delivered to them (Hulko et al, 2019). Ma'u et al (2021) propose twelve potential modifiable risk factors that account for approximately 40% of worldwide dementia cases. These include less education, hypertension, obesity, alcohol, traumatic brain injury, hearing loss, smoking, depression, physical inactivity, social isolation, diabetes, and air pollution – the majority of which have high incidences among Pasifika. With these modifiable risk factors, it is contested that the understanding and elimination of particular risk factors could potentially reduce the prevalence of dementia too (Ma'u et al, 2021). To answer this possibility, it is necessary that each population undergoes careful assessment to gain insight on community-specific risk factors and a better understanding of the prevalence of dementia within those communities (Martinez-Ruiz et al, 2021). Addressing risk factors is important as one-third of AD cases are attributable to risk factors and thus can potentially be prevented (Kenigsberg et al, 2016).

Inadequate support

Current healthcare approaches within clinical practices are driven by Western models of health (Wivell & Mara, 2010). Wong-Cornall (2020) highlights that the current system in New Zealand is ‘set up to provide support only to those who self-identify as caregivers’ (WEAG, 2019; p.3). Two contributing factors to health inequalities in New Zealand are socioeconomic status and ethnicity (Alpass et al, 2013). Caregivers from low-middle-income countries (LMIC) are challenged by several barriers to accessing support (Wang et al, 2014). This is important because Pacific peoples are likely to reside in socioeconomically deprived areas therefore, accessibility to health services can be challenging (Foliaki et al, 2020). For example, the wait times to be seen by healthcare practitioners in low socioeconomic areas can potentially lead to underdiagnosis or misdiagnosis. Consultations typically take 10 minutes which leaves insufficient time for patients to be properly informed or diagnosed (Symon et al, 2021). Given the progressive nature of dementia, these consultation times are unrealistic and impractical for proper diagnosis. The reality for many Pacific elderly is that they depend on family members for transportation. This has a subsequent ripple effect on the rest of the family, seeing that a family member would either have to organise a day off from work or make arrangements to reschedule their working week, which can be financially demanding and timely (Symon et al, 2021). The barriers and facilitators to dementia service utilisation is complex (Hale et al, 2020). There are several barriers to accessing healthcare support services including poor quality of support services, mistrust of support services, the inability to readily and easily locate information, personal beliefs about obligations to care, inflexible processes of support services, and resistance of the PWD (Macleod et al, 2017). Such barriers are additional sources of stress for caregivers too (Macleod et al, 2017). Sociocultural factors can also impact healthcare utilisation among different ethnic groups (Chan et al, 2021). The discourses about informal caregiving contribute to dehumanising representations of dementia and can affect the utilisation of available health and care supports (Tolhurst et al, 2019). Informal caregivers of relatives with dementia encounter a range of challenges such as the lack of available and accessible programmes and services that can assist with lessening the negative load for both the caregiver and the PWD. Informal caregivers often do not have adequate support systems in place such as formal caregiver training, particularly those from LMIC. On the opposing side, informal caregivers from high-income countries have a variety of different accessible support services that range from specialised in-home care, respite care, Alzheimer's cafes, meeting centre support groups, etc., but are frequently unaware of all these several types of support (Smith et al, 2020).

Inadequate support: Self-directed research

Caregivers have been described to be self-reliant. To meet the complex care demands of people with dementia, caregivers find themselves doing their own research to improve their own knowledgebase around providing care for complex care demands and identify social supports by relying on technology (Ruggiano et al, 2019). However, the appropriate information and professional advice about navigating through the transition into the caregiver role and the relative support services to care for their relatives has reported to be insufficient (Varik et al, 2020). Family members often receive inadequate support from health providers that are not helpful after being handed a diagnosis for their relatives with dementia (Varik et al, 2020). Additionally, the way caregivers identify themselves is just as crucial in how the current system is set up to provide support services. Caregivers may not access support due to not self-identifying as caregivers (WEAG, 2019). Family caregivers among Pacific communities do not necessarily self-identify being in a caregiving role either (McAllum et al, 2021). This can be explained by the foundation of the Pacific cultural beliefs for example, the importance of the *tautua* concept in the Samoan culture (Fa'aea & Enari, 2021).

Stigma

Another barrier in accessing healthcare and support which was highlighted across the literature was stigma. Stigma has been identified to have subtle impacts on support-seeking behaviour, accessing and utilising services, and is associated with a negative impact on a caregiver's quality of life too (Innes et al, 2011; Werner et al, 2014; Xiao et al, 2015; Nguyen & Li, 2020). Examples of the impacts of stigma can include discrimination in health services and public fear (Nguyen & Li, 2020). Stigma also plays a role in how the family responds to the condition such as avoiding or dismissing any type of discussion around dementia (Meyer et al, 2015). This is referred to as 'saving face' so that they avoid the shame of having a family member who is typically perceived as mentally ill by extended relatives or the outside world (Lee Casado et al, 2015; Gallagher-Thompson et al, 2012; Sun et al, 2012). For example, Chinese fear the possibility of unwell family relatives being discovered and opt to keep their family matters confidential. This is due to the stigma associated with dementia and the shame they believe is associated with having a sick relative (Chan, 2010; Xiao et al, 2015). The fear of 'losing face' can lead to social isolation and compressed emotions, and so family members are likely to be reluctant to speak outside of the family unit. Essentially, this 'fear' is self-impeding to seeking social and emotional support (Gallagher-Thompson et al, 2012). In order to destigmatise and transform the knowledge and attitudes of people with dementia, culturally sensitive terminology needs to be developed and disseminated (Williams et al, 2021). This will partially contribute to improving service utilisation too.

Accessibility

Accessibility is a prominent contributing factor that can help explain the lack of support received among marginalised groups (Dyall, 2014). Many caregivers face challenges when accessing services or support (Laparidou et al, 2019). There are pronounced differences among contextual variables such as income, education, health, and access to resources that are linked to ethnicity and race (Gelman et al, 2014). Poor health outcomes are often associated with the inequalities and existing privileges, as well as the available and accessible supports among different ethnic communities (Dyall, 2014). For the Pacific populations in New Zealand, they are likely to live in areas that are socioeconomically deprived with subsequent poor access to a range of different healthcare services (Foliaki et al, 2020). One study reports that Pacific populations have limited access to available hospice and palliative care services in New Zealand due to the misperceptions and misunderstandings of these health services (Foliaki et al, 2020). One further study proposes that health services are only likely to be accessed when members feel valued, their sense of identity is acknowledged, and their self-esteem is protected (Dyall, 2014). Several other existing factors have affected the Pacific population's access to services or support. These include the lack of accurate and informative information available, drastic changes within the family structure when taking on the caregiver role, past- or hear-say experiences with palliative services as well as the need for effective and efficient communication and information (Foliaki et al, 2020). This notion is further supported by Martinez-Ruiz et al (2020), reporting that language and communication are contributing barriers in accessing services too. Existing social inequities also impact one's ability to access services for example, 50% of issues that are raised are social determinants, yet general practitioners continue to adopt a biomedical framework to address such issues (Symon et al, 2021). This, therefore, becomes a matter of improving cultural competency and understanding health from different worldviews for best practice when working with ethnic minority communities. Various studies and criticisms have demonstrated that medical knowledge of dementia is scientifically flawed and heavily influenced by ageist cultural and social perspectives (King, 2021). Jackson & Minster (2012) further postulate that social determinants such as lack of financial resources, poor housing, and the lack of knowledge about the available care they can access impacts the caregiver role within Pacific families in New Zealand too. Further research into Samoan caregivers' perspectives and relationships with the health system is critical to improving services for all in New Zealand.

Accessibility: Cultural conflict

The current services in place may not be perceived or understood to be culturally safe nor culturally responsive to the needs of Pacific caregivers and those they provide care for in New Zealand (MSD, 2019). Because of the generic, umbrella-like structure of the current health and welfare supports that are in place, health and social services are being challenged to deliver culturally safe and equitable care (Parr-Brownlie et al, 2020). Health care professionals failing to acknowledge and understand caregivers' issues is a barrier limiting caregiver accessibility to the correct services. This means that the needs of caregivers are not being met nor are they receiving adequate information that is specific to their individual circumstances (Ragnat et al, 2018). Amidst shared commonalities across Pacific communities, it is important to note that Pacific perspectives are unique and cannot be understood from one lens, often referred to as 'the Pacific lens' (Seiuli, 2016). Each Pacific nation brings forth unique and diverse perspectives and experiences (Seiuli, 2013) that are important when catering to individual needs.

One probable reason for the low access rate to services could be the lack of inclusion of ethnic-specific groups in public health policy programs (Martinez-Ruiz et al, 2020). Services currently lack the cultural understanding that would offer the best assistance for caregivers and their related responsibilities (WEAG, 2019). Despite the current policies in New Zealand embedding equity for Māori and Pacific Islanders in healthcare, it remains challenging to implement in practice (Abey-Nesbit et al, 2021). One study highlights the importance of acknowledging cultural understandings. If not adequately addressed, the consequences of care provided can lead to avoidable health outcomes, unsatisfactory interactions, and a build-up of mistrust in health services altogether (Foliaki et al, 2020). Consequently, a negative experience can alter the perceptions of Pacific caregivers to trust and access support services altogether (MSD, 2019).

For Samoan communities, a contributing factor to the poor utilisation of health services is the misalignment between the Samoan wellness-based and Western deficit-based perspectives of mental health (Yamada et al, 2019). Cultural views on dementia may be different across ethnic groups, which has an impact on families delaying seeking support services (Weir & Fouche, 2017). Western-based models of caregiving are irrelevant to cultural traditions which prioritise family obligation to care (Yeo et al, 2014). A cornerstone of Western biomedical ethics is individual autonomy in healthcare decision-making that does not correspond with many cultural traditions (Yeo et al, 2014). Dementia remains a misunderstood disorder which calls for an essential service that provides education with local communities to improve awareness (Cullum et al, 2020). The delivery of healthcare assessments and plans tends to steer in a more service-oriented direction instead of a client-centre direction (Weir, 2018). Accessing services for support that address the differing needs of caregivers from different government agencies is complex and can be time-consuming. The available supports among government agencies are fragmented, creating barriers to access the most efficient support (WEAG, 2019). For health and social services to deliver culturally competent care for all older New Zealanders that reflects culturally safe and equitable principles, an effective response is encouraged to deal with these said issues (Parr-Brownlie et al, 2020).

Accessibility: Language barrier

Language barrier is the greatest challenge that impacts accessing support services (Lee Casado et al, 2015; Xiao et al, 2015). Adequate assessment cannot be achieved with the use of interpreters as a way to overcome language barriers. This is because language equivalents for many concepts are non-existent. For instance, the questioning within assessment instruments developed in the United States are inappropriate for other cultures or languages. Family members may be inclined to protect their older relatives or not fully understand the importance of exact translations which can be problematic during the diagnostic process (Yeo et al, 2014). Therefore, it can be difficult to initiate discussions when there are no words that can describe medical concepts in a person's language (Foliaki et al, 2020). One study by Macleod et al (2017) reported that accessing information was still challenging even for English-proficient individuals too. This raises concerns for culturally and linguistically diverse individuals, given that language is already a barrier for them too. Given the age that older adults are likely to get dementia, the likelihood of first-generation Samoans in New Zealand will be greatly affected. This means that because of the language barrier as well as the lack of Pacific cultural supports or ethnic-specific supports, this could potentially be another reason that Pasifika are reluctant to access formal support or ARC. In a study by Sayegh & Knight (2013), the second most common (33%) barrier to help-seeking behaviours is the language proficiency barrier among minority ethnic older adults. Information specific for Pacific peoples was deemed to be insufficient (Symon et al, 2021).

Accessibility: Delivery of information

The way information is delivered serves as another barrier to accessing adequate information to support services (Symon et al, 2021). For example, the available Pacific language-specific brochures poorly reflect a Pacific worldview. Brochures are typically a direct translation from the English version (Symon et al, 2021) therefore, it is not resourceful considering that the meanings of specific terminologies can be different depending on one's cultural background. Another example includes the online dissemination of information. This can leave specific subgroups out such as spousal caregivers for elderly adults, given the high probability they are not able to navigate online sites and heavily depend on children for information too. At the same time, reliance on children for accurate information must be carefully considered, given the risk of misinformation on online platforms and any misconstrued experiences of other caregivers that could potentially influence their actions to seek support services and so forth. Lack of trust is tainted by knowledge of widespread historical discrimination and exploitation in healthcare (Yeo et al, 2014). The mistrust can be linked to the historical trauma experienced by ethnic minorities. Historical trauma therefore demands the need for the decolonisation of research (Racine et al, 2021). Therefore, this stresses the importance of having adequate and accurate information available for caregivers to easily access.

Affordability

Dementia is associated with significant healthcare and social care costs (Weir, 2018; Ma'u et al, 2021). Most of the social costs are due to residential care (Cullum et al, 2020). The economic costs related to dementia will inevitably increase the strain on healthcare resources. The current national annual costs of dementia and the related direct and indirect health systems is currently ~NZ$1.9 billion. This figure is projected to increase up to NZ$2.7 billion by 2030 (Cullum et al, 2020) and NZ$4.5 billion by 2050 (Ma'u et al, 2021). The New Zealand MOH acknowledges the economic challenges of dementia however, a time is yet to come for the planning and implementing stages to address the future demands of dementia on healthcare and social care systems. Due to the lack of qualified staff along with resources, elderly care can be refused which effectively leads to an excessive use of informal care (Varik et al, 2020).

The financial burdens that come with caregiving have negative impacts on a range of outcomes including family conflicts, caregiver strain, coping difficulties, as well as sudden life changes such as relocation (Gardiner et al, 2016). One main issue caregivers are burdened with is affordability which causes financial constraints (Varik et al, 2020). Affordability can help explain the lack of support accessed and received among marginalised groups (Dyall, 2014). Research suggests that the detrimental effect on the well-being and daily living of caregivers is the cost of the illness itself (Lindeza et al, 2020). Compared to non-Māori and non-Pacific ethnic groups, Pacific peoples (and Māori) are affected by the costs of medical prescriptions where they are twice as likely not to collect prescriptions because of costs (Abey-Nesbit et al, 2021).

Affordability: Residential care

For some, there is no choice but to seek external care methods such as institutional care, due to limited job opportunities available and the rate of low wages (Fernandes et al, 2021). For caregivers, they can eventually lose employment altogether to provide full-time care, placing them in a circumstance with no stream of income (Gardiner et al, 2016). This leads to a barrier to accessing formal care due to the constant worries over trying to maintain finances and meet the excessive costs of formal care (Lindeza et al, 2020), which have been reported to be very high (Varik et al, 2020). The option for long-term residential care is both costly and difficult to be admitted into due to its limited capacity (Varik et al, 2020). According to a study by Jorgensen et al (2010), 81% of caregivers felt that obtaining support or funding was not readily accessible and difficult to navigate through. Since services provided by residential care facilities are self-funded (Department of Internal Affairs, 2021), extra fees are required for premium rooms which only provide an ensuite or a bigger space compared to a standard room. The added costs of accessing residential care are clearly unrealistic for caregivers with no income to afford. ARC in New Zealand is costly to the economy and oversubscribed therefore, it is important for the development of strategies that can enhance ‘ageing well in place’ initiatives (Gibson & Gander, 2021). The New Zealand government policies promote ‘ageing in place’, which tends to follow a ‘one size fits all’ approach. The implications that are brought forth when following a ‘one size fits all’ approach is that it presumes all older people can live independently which is unrealistic (O’Sullivan, 2011). The encouragement of ageing in place is paradoxical, given that care provided within the home setting is sanctioned within a biomedical frame of knowledge. The biomedical explanation of dementia is accepted by caregivers as a means of resolving uncertainties (King, 2021).

In New Zealand, the process of admissions in residential care services is restrictive. An older person can only be admitted into ARC if their needs meet an assessment criterion. There are four levels of ARC: (1) rest home, (2) hospital, (3) secure dementia, and (4) specialised (psychogeriatric) nurse (Kahui tuitui tangata, 2022). One way to receive financial assistance in residential care is through the Residential Care Subsidy (RCS) which is funded by the MOH. The application process demands four steps to be completed before payments can be approved and begin. The four-step process involves: (1) arranging for a care needs assessment, (2) completing and submitting an RCS form, (3) having a financial means assessment and (4) a waiting process to hear back from Work and Income (Department of Internal Affairs, 2021). On top of this, there is also a criterion that must be met for a person to be eligible for the RCS that is: individuals who are aged either 65 and over or aged between 50 – 64, single with no dependent children, need long-term residential care in a hospital or rest home and receive contracted care services (MSD, n.d.). One study reports that the quality of institutional care and the limited activities provided within institutions contribute to caregiver dissatisfaction which has subsequent effects on utilising available services (Varik et al, 2020). As mentioned, Pacific people are reported to present with dementia at younger ages and thus, the existing criteria needs to be revised.

Theme 3.3: Recommendations

Proposed changes to the system

The 2018 New Zealand Census is arguably poorly conducted, producing a lack of reliable, robust, and incomplete data that is reflective of older populations. This could potentially lead to exacerbating issues regarding the prevalence of older-aged conditions such as dementia being inadequate in Pacific, Māori, and Asian peoples. Consequently, information about older age disorders in relation to its burdens and distribution can be deemed inefficient in New Zealand (Parr-Brownlie et al, 2020). As such, healthcare systems must address inequities that stem from discrimination, as noted by the World Health Organisation (Parr-Brownlie et al, 2020). Dementia outcomes differ across different communities therefore, it is vital that the research designs among distinct cultures are independent of each other (Cullum et al, 2020). Despite little research existing in this area, it can be said that dementia outcomes are different across different populations due to the different approaches to health and delivery of health. It is vital that existing healthcare and support programmes steer away from a 'one size fits all' approach and instead engage in the opportunity to produce unique, culturally specific tailored programs (Cullum et al, 2020). Cultural-specific practices are recognised as valuable because the delivery of care can be altered to the needs of ethnic-specific groups. In this case, the needs of Samoan communities can likely be met when cultural-specific practices are implemented throughout support and care systems (Seiuli, 2016). For example, a holistic approach to care is vital in understanding and attaining a PWD's spiritual needs (Perkins et al, 2015).

Recent reports noted by the World Alzheimer's Report show that interventions and counselling have produced effective results, particularly with technology and care management plans (Varik et al, 2020). Examples of support services that people require include community nursing, day-care, respite care, counselling services, and training (Varik et al, 2020). Counselling services, psycho-emotional support services as well as additional support service recommendations are all helpful resources for caregivers that have the potential to empower them. Fundamentally, this underlines the need for training and related support groups to create a learning and education space to share caregiver experiences with others (Varik et al, 2020).

It is therefore considered essential to learn about and understand caregivers’ perspectives because it can factor out the most appropriate and suitable interventions for a PWD and effectively create more positive experiences for the caregiver and the person receiving care (Lindeza et al, 2020). A person-centred care approach aids in recognising the individual before the condition, i.e., dementia (Kirkman, 2011). This emphasises that understanding the individual before the condition is an important concept for family caregivers of loved ones living with dementia, which can only be achieved by following through with the proposed changes.

Interventions

Evidence-based interventions for ethnic-specific groups remain dearth - there continues to be a large gap across the literature (Meyer et al, 2015). Gaps in knowledge can impact the development of effective interventions that could be specifically tailored to the unique needs and preferences of families (Corcoran, 2011). Interventions that focus on one aspect of caregiver functioning are less effective than multi-component interventions (Tremont, 2011). The positive effects of multi-component interventions include improved physical health, service utilisation and delayed institutionalisation (Tremont, 2011).

Psychosocial interventions have proven to be successful. Family caregivers experience less burden, greater satisfaction, and delayed institutionalisation with the implementation of psychosocial interventions (Dahlrup et al, 2011). Psychosocial interventions are supported by an increasing number of researchers and community activists. They argue that Indigenous cultural values, beliefs, traditions, and histories of oppression must be considered within psychosocial interventions for improved caregiver health outcomes and accessibility to services (Browne et al, 2017). Family caregivers experience fewer negative consequences with the implementation of psychosocial interventions too (Tremont, 2011). To promote the health of ethnically diverse dementia caregivers, psychosocial support interventions must consider cultural attitudes and preferences for providing care without the support from formal care (Napoles et al, 2010).

Culturally based knowledge, beliefs, meanings, and actions are important for conceptualising caregiver models (Corcoran, 2011). Understanding the influence between culture and caregiver burden is important for developing holistic models that focus on family-centred care (Chan, 2010). Support services should exist to alleviate the negative impacts of caregiving (Innes et al, 2011). With the right supports in place, it can contribute to decreasing depressive symptoms or increasing family social networks and self-efficacy (Chan, 2010). Xiao et al’s (2015) study support this notion by highlighting the importance of incorporating ethnic-specific care within dementia care services.

Lee Casado et al (2015) stress the importance of an educational component to better prepare family caregivers too. Dementia education is key, as well as using community resources and networks to be able to raise awareness. Doing so can assist in achieving diagnosis at earlier stages which is vital for a PWD and their family caregivers (Xiao et al, 2015). Psychoeducation can teach caregivers about best practices of coping. Psychoeducation may even possibly be linked to improved caregiver well-being, decreased depressive symptoms, and decreased reports of stress (Gallagher-Thompson et al, 2012). Although no significant changes have been observed in delaying institutionalisation to reflect the benefits of psychoeducation. Cheung et al (2019) suggest that psychoeducation and public awareness can address stigma within Asian communities in New Zealand too. There is a clear need to ensure evidence-based programmes focus on educating and supporting caregivers to identify triggers, understand symptoms, and provide coping strategies to deal with dementia symptoms (Moore et al, 2013). Other recommended interventions for caregivers included specialised skill training, multi-component intervention programmes, and psychotherapy. Although psychotherapy (short-term cognitive behaviour therapy) shows promising results with clinically depressed dementia family caregivers, it is just as costly as it requires highly trained, specialised staff (Gallagher-Thompson et al, 2012).

Wang et al (2014) suggested that nurses would be more useful in coordinating dementia services rather than providing the care themselves to best support family caregivers. Stokes et al (2014) stress the need for support to come from experienced workers as well as the need for a main point of contact with readily available and accessible information. The same idea is echoed by Chan et al (2010), proposing that a resourceful person needs to be readily available to contact to obtain information or advice about the specifics not normally known by caregivers. The authors suggested a ‘one-stop’ service rather than having to source different information from different avenues. Family caregivers found good communication to be elemental for service uptake (Macleod et al, 2017). Concerns have been raised regarding the cultural competency of services that can act as a barrier to service utilisation (Dudley et al, 2019). A study based on Swedish caregivers perceived important types of supports and services included having a main point of contact to talk to and receiving relevant information (Alwin et al, 2010).

More innovative ways to deliver caregiver services is recommended by Lim et al (2012). Effective outcomes could potentially be achieved through integrating Pacific traditional and cultural family practices within information about hospice and palliative care (Foliaki et al, 2020). Services specific for caregivers can provide educational opportunities to gain knowledge and develop skills as well as be provided with emotional support (Lim et al, 2012). ‘Walking in Another’s Shoes’ is an eight-month training programme developed to promote a person-centred approach to dementia care. Despite the programme being well-received by participants thus far, the programme is only offered to formal caregivers in residential facilities, home-based support workers, and registered health professionals (Gee & Scott-Multani, 2014). How effective this programme could be for family caregivers is yet to be examined. Dementia-friendly communities are also important for social inclusion and reducing stigma (Novak et al, 2020). A study in Christchurch, New Zealand interviewed residents living with dementia. The findings of this study highlighted that it takes more than knowledge about dementia to create dementia-friendly communities and the perspectives of the person living with dementia, their caregivers as well as other community organisations, members, and stakeholders are involved in the design and development of such communities (Novak et al, 2020). Understanding the impacts of marginalisation and inequality related to service utilisation and community participation is invaluable for healthcare practitioners to best support those affected (Shannon et al, 2019).

CHAPTER SUMMARY

Dementia continues to be a difficult disease to understand. The disease itself is incurable, causing a shift in focus from an approach of ‘cure’ to an approach of ‘care’ for the person diagnosed with dementia and their families. The symptoms of dementia vary in staging and severity that gradually become detrimental to a PWD, which equally becomes difficult for those who provide care for them too.

The knowledge, understanding, and awareness of dementia continues to be poor across several ethnic groups, which calls for efforts to implement awareness initiatives to raise awareness at the community level. Raising awareness is associated with several benefits, the main one being early detection of dementia symptoms. Early detection affords family caregivers with the opportunity to better prepare for the caregiver role. Dementia awareness also allows us to understand the historical and cultural backgrounds when working with ethnic minorities. This serves to best understand how to engage and support these groups.

Due to the increasing cases of dementia and the impacts it will have economically, the demand for caregivers has grown too. In New Zealand, there is an increasing number of informal caregivers of those with dementia. The body of literature that does exist concerning the experiences of caregivers for a PWD, are often associated with negative outcomes to their overall well-being or other challenging barriers, with little research that focuses on the positives. The challenges caregivers face is largely influenced by their social and economic conditions, which are both determining factors when it comes to the utilisation of health and support services too. The experiences of caregivers for people with dementia have been well-documented. However, the literature relevant to the informal caregiver experience of those with loved ones with dementia in the context of New Zealand is scarce, particularly for Pacific ethnic caregivers, which would be helpful to showcase comparable differences between caregiver experiences.

When other variables or factors are considered when understanding health and care procedures such as culture, it is inevitable to observe the differences between Pacific worldviews and Western worldviews in their understanding of care. Pacific ways of being determine an understanding of care which are often driven by cultural values, principles, moral obligations, and belief systems. Insight into the Samoan practices of care is an important step in understanding Samoan caregiver experiences of loved ones with dementia. In the Samoan culture, *tautua* is a central principle that has great influence on the caregiver role. Unpacking cultural understandings of care offers insight and clarity about the obligations prioritised within Pacific families.

Current health and care procedures in place are mainly driven by Western approaches to care. In spite of the government and other relevant support groups that attempt to highlight a more holistic approach to care by creating frameworks and adapting strategies and action plans, there still remains no clear improvement based on existing literature on caregiver experiences. In New Zealand, dementia-related frameworks and strategies have attempted to incorporate an understanding of care from a Pacific worldview. Undoubtedly, this is a progressive change however, these formulated strategies and frameworks fall short of acknowledging the differences in individual ethnic knowledge systems, belief systems, and ways of being. Although commonalities can be found across Pacific communities, nuances still exist but are not considered when framing such frameworks and strategies. This is important to consider as family structures, cultural values, and belief systems will differ, considering the effects of acculturation and migration too.

Naturally, the body of literature and dementia-related service supports often cater to the PWD themselves, highlighting the gap that exists in acknowledging and assisting with the individual needs of caregivers. Existing literature reports that the New Zealand health system imposes great challenges for caregivers of those diagnosed with dementia. The two prominent challenges being accessibility and affordability. Much of what has been reported continues to imply that insufficient support is available that caters to the individual needs of caregivers. Without effective changes being implemented, this poses different risks to both the PWD and their caregiver. These are important issues to address due to the projected prevalence rates of dementia and the growing need for caregivers in years to come.

CHAPTER THREE: METHODOLOGY

Chapter Three of this thesis explains the research methodology utilised and outlines the steps taken to carry out this research study. First, it will present the main theories underlying the research study and the research methods that have been specifically chosen. This will entail a brief summary of the qualitative data approach and why the employability of a Pacific framework has been chosen to appease the research aims of this study. It will then present details of the research setting, the recruitment process, data collection and then the data analysis. The *Talanoa* framework will be used to further support the data collection method and theorised perspectives of the *Fa'afaletui* model, and its application will be described to present its relevance and significance to the proposed research method. The *Fa'afaletui* model will also be conceptualised as the metaphoric expression of weaving to navigate the steps taken for the data analysis process. This chapter will then be concluded with ethical considerations for this research study.

RESEARCH DESIGN

Qualitative design

The design of this research study will follow a qualitative research design, specifically utilising the *talanoa* methodological framework. The aim of this research study has an exploratory element which places an important emphasis on understanding different components of the caregiver role within a specific population. Accordingly, a qualitative research design was deemed best suited to fulfil what is set out to be achieved and explored via the research aims of this study. Qualitative research is best understood for its interpretative, naturalistic approach (Pietkiewicz & Smith, 2014; Aspers & Corte, 2019), as opposed to the more formal investigations that test hypotheses using objective, systematic methods to establish statistically significant conclusions (Lowhorn, 2007; Bloomfield & Fisher, 2019). The motive of qualitative research is to either make sense of, interpret, or draw meaning from the perspectives of participants via interviews and observations. In specific settings, the qualitative design can unpack the human experience holistically too (Orb et al, 2001; Almalki, 2016; Aspers & Corte, 2019). This is most beneficial for this research study as it builds an understanding by depth (Male, 2016), when exploring the experiences of Samoan caregivers for loved ones with dementia. Essentially, this research will take on a phenomenological approach; it provides meaning to experiences in terms of 'what was experienced and how it was experienced' (Neubauer et al, 2019, p. 91). Its usage offers the opportunity to generate descriptive data relevant to Samoan caregivers who take care of their loved ones with dementia, that the use of a quantitative research design is unable to offer with its more numerical-based approach (Taylor et al, 2015).

Western versus Pacific frameworks

Western forms of knowledge have been dominating academia for centuries. Understanding the lived experiences and knowledge construction of the individual self is central to Western research paradigms (Tuia & Cobb, 2021). As such, the beliefs and underlying assumptions of Western frameworks cannot truly reflect the values and beliefs of Pacific peoples (Amituanai-Toloa, 2009), which have unfortunately misunderstood and misrepresented indigenous knowledge and people in many instances (Naepi, 2019). These said disadvantages prompt research that involves the Pacific population to consider and incorporate Pacific values and beliefs, which are imperative in maintaining harmonious relationships (Health Research Council of New Zealand, 2014).

Study population

The population in focus of this research study are Samoan caregivers of loved ones with dementia, both past and current, who currently reside in the Auckland region. Samoan values guided by *fa'a Samoa* are imperative to consider when conducting research with Samoan people. These Samoan values include *alofa, fa'aaloalo, fesoaa'iga* (reciprocity), *vafealoa'i* (relationships: maternal/paternal), *tautua, feagaiga* (covenant), *fa'aleagaga* (spirituality), *meaalofa* (gifting), and *gagana* (language). This research study will acknowledge and incorporate, where relevant, these cultural values to ensure a culturally responsive, inclusive, and appropriate methodology is implemented for all participants to experience (Health Research Council of New Zealand, 2014).

A Pacific framework

The introduction of Pacific worldviews is a phenomenon that has emerged in recent decades (Tuia & Cobb, 2021). Pacific research frameworks are empowering for Pacific peoples (Naepi, 2019) as they challenge the Western-centric ways of being within research (Enari, 2021). Pacific frameworks can be understood as a form of decolonial resistance. It enables research to be transparent and reflective of Pacific peoples while recognising and legitimising Pacific ontologies and epistemologies (Naepi, 2019). Pacific worldviews interwoven with Pacific knowledge, skills, and research values are very important throughout the research process (Enari, 2021). Pacific people are termed as the 'knowledge experts' of their communities with the power to define and critique ideals from a Pacific perspective (Naepi, 2019). The experiences, values, and ideas of Pacific peoples make up an essential part of Pacific research frameworks. When factored in, cultural knowledge systems form a culturally inclusive approach for people to engage in (Tuia & Cobb, 2021).

Of utmost importance when researching with the Samoan people is to ensure a culturally appropriate methodology is incorporated (Enari, 2021). As such, this research study will use and incorporate a Pacific methodological framework. Employing a Pacific research framework reinforces the idea of conducting research *'with'* Pacific people rather than *'on'* Pacific people. A Pacific methodology ensures that Pacific populations are dealt with in a culturally appropriate and beneficial way. A focus on participant interests has an empowering effect that can represent participants having ownership of the research rather than the researcher themselves (Health Research Council of New Zealand, 2014).

Fa'afaletui model

The Pacific framework that will be used for this research study is the *Fa'afaletui* model. The *Fa'afaletui* model has been conceptualised as a research methodology in several different ways. For the purpose of this research study, two separate conceptions of the *Fa'afaletui* will be used for the data collection method and data analysis process. The data collection method will be guided by theorised perspectives of the *Fa'afaletui* model, and the data analysis process will be guided by the original conception of weaving of the *Fa'afaletui* model (Tuia & Cobb, 2021).

Fa'afaletui: Three theorised perspectives

The *Fa'afaletui* model has a collective and holistic approach that is underpinned by Samoan cultural values and principles including love, humility, respect, obedience, faith, and relationship (Goodyear-Smith & 'Ofanoa, 2022). It requires the involvement of different social groups to reach a consensus. Knowledge that is shared and consolidated through *Fa'afaletui* is articulated as three perspectives. McCarthy et al (2011) introduce the long-, middle-, and close-perspectives which suggest that issues can be explored and assessed comprehensively while achieving a mutual understanding (Tuia & Cobb, 2021). As part of the *Fa'afaletui*, the views of Samoan people can be gathered from the top of the mountain (long-distance), from the top of the tree (middle-distance), and from the canoe (close-distance) (Goodyear-Smith & 'Ofanoa, 2022), which are elemental to Samoan decision-making (McCarthy et al, 2011).

Long distance perspective: 'from the top of the mountain'

This perspective is symbolic of 'overlooking the entire landscape (Goodyear-Smith & 'Ofanoa, 2022). It can also symbolise the high chief who opens and closes the meeting of the *Fa'afaletui* (Tuia & Cobb, 2021). In this research study, this perspective can be likened to the process of the literature review which has provided the intricacies of the overarching issue at hand. It can also represent the role and positionality of the researcher regarding the researcher's motive behind carrying out this research study.

Middle distance perspective: 'from the top of the tree'

This perspective is symbolic of the bridge between the long-distance and close-distance perspectives (Goodyear-Smith & 'Ofanoa, 2022). It can also represent those with high status such as chief orator or individual *matai* (chief) to speak and provide topics for discussion (Tuia & Cobb, 2021). In this research study, the researcher positions themself from this perspective to act as the bridge between what is observed from the top of the mountain compared to the realities from the person in the canoe fishing. The topic brought forth for discussion is understanding the experiences of Samoan caregivers for loved ones with dementia.

Close distance perspective: ‘the person in the canoe fishing’

This perspective can represent those who are most affected by the issue (Goodyear-Smith & ‘Ofanoa, 2022). In this research study, this perspective is similar to the recruited participants and learning about their experiences as a Samoan caregiver for their loved ones with dementia. For the purposes of this research study, data has been collected using the close-distance perspective of the *Fa’afaletui* model.

Fa’afaletui: Weaving

The *Fa’afaletui* model is also a widely used Samoan research methodology that metaphorically describes the traditional practice of weaving (Fosi Palaamo, 2018). The *Fa’afaletui* model’s literal translation is ‘ways of’ (fa’a) ‘weaving together’ (tui) deliberations of different groups or ‘houses’ (fale); in this research study, the researcher is the weaver (Goodyear-Smith & ‘Ofanoa, 2022, p.35). Weaving is a significant concept in the *Fa’afaletui* model. *Tui* and *lalaga* are synonymous, which translates to ‘weaving’ or the ‘action of weaving’ (Goodyear-Smith & ‘Ofanoa, 2022).

The traditional practice involves the weaving together of sundried strands of the leaves from the *laufala* (pandanus tree), to create a *fala* (mat). As part of the preparation process, the most appropriate *laufala* are gathered, carefully chosen, and then used for the weaving process, creating a *fala* that meets its intended design (Fosi Palaamo, 2018). A collective approach while gathering knowledge is central to *Fa’afaletui* (Tuia & Cobbs, 2021).

In the Samoan culture, the practice of weaving is a form of art that has been carried by women for many generations. The art of weaving is sacred; it shares a strong historical and cultural meaning between generations within the family that serves to highlight cultural ties and the preservation of memories. For Samoans, weaving is a metaphor that can represent connectedness with others, the maintenance of tradition, and spiritual expression (Goodyear-Smith & ‘Ofanoa, 2022).

When applied as a research methodology, the *Fa’afaletui* model follows the same steps that is, selecting the best *laufala* to interweave various perspectives that have been gathered about the self to offer a Samoan perspective of self (Fosi Palaamo, 2018).

1) As mentioned, the practice of weaving involves the selection of the best *laufala*. The long leaves are selected and cut from the plant and taken back to the village (National Park Service, 2019; Semi, 2020).

The first step of the selection process of the *laufala* can be likened to the Western research process of recruitment while preparing to collect data. This involves knowing the requirements prior to the start of the research and selecting research participants based on the objectives of the research study.

2) The leaves are then prepared by soaking them in boiling water followed by drying and bleaching them in the sun. Once dry, the leaves are rolled and tied into bundles in preparation for weaving. The long-dried leaves are then stripped into thin strands for weaving (National Park Service, 2019; Semi, 2020).

This second step of preparing for the weaving can be likened to the Western research process of data analysis which deals with the sorting, selecting, and analysing of the collected data. Here, the researcher reads, categorises, and extracts useful data, collates themes, and moves on to creating concepts that reflect the main findings of the data.

3) Once weaving has been completed, its intended design of the *fala* will have its own specific purpose. One example is the *'ie toga* (fine mat) - Samoa's most valued form of currency. If not passed down from generation to generation, one way that the *'ie toga* is used is through the exchange and presentation at different types of events. These include weddings, *matai* title bestowals, or any other form of special occasion (National Park Service, 2019; Semi, 2020).

This final step can be likened to the Western research process of study dissemination, which includes the exchange and presentation of findings of this research study to whom it may benefit most.

ETHICAL CONSIDERATIONS

This research study obtained ethical approval on 28 January 2022 from The University of Auckland Human Participants Ethics Committee for a period of three years. This serves as recognition of the responsibility the researcher has for conducting research with human subjects that will share their personal experiences and knowledge about being a caregiver for a loved one with dementia within New Zealand. This approval acknowledges that ethical standards have been met in regard to the research study's aims and objectives, methods of data collection and data analysis, as well as the dissemination of findings. This provides a safety precaution for all participants from any harm while upholding the quality and integrity of this research study.

Role of the researcher

It is important for the researcher to conduct and facilitate the *talanoa* sessions without bias. In saying this, it is imperative that the researcher does not allow their individual experiences to cloud their judgement or to sway the *talanoa* sessions toward their personal beliefs. The researcher will listen attentively to the participants' experiences being shared without interruption or judgement too. The researcher will be understanding, patient, and empathetic while maintaining the values and principles of *fa'a Samoa.*

Confidentiality and security

The identity of participants remained confidential. The identities of participants were not revealed in any report or publishing. Where direct quotations were used in the report, the participants' identity was protected by creating an alias. All information, both written and verbal, was protected with the utmost care and stored safely; access is only granted to the researcher and the researcher's supervision team. All consent forms were securely locked in a filing cabinet on the University of Auckland premises. Likewise, all consent that was given verbally was audio-recorded and was safely stored on a University of Auckland approved electronic storage system (Google Drive) with two-factor authentication only accessible to the researcher. Upon reaching the six-year timeframe of being stored, all acquired information will be destroyed.

Informed consent

All participants were provided with a Participant Information Sheet (PIS) along with a Consent Form (CF). The PIS will provide information pertaining to this research study including the focus of this study, the procedures, research aims and objectives, risks and benefits of participating, compensation, confidentiality, and the right to withdraw. The CF will include a list of statements consenting to voluntary participation, audio recording, transcription of data, and how data will be stored and destroyed. CF are to be obtained and completed in full before the commencement of each *talanoa*. All participants will be verbally informed by the researcher of their consent to all the statements specified in both PIS and CF documents before the *talanoa* is initiated.

Reciprocity

As a *meaalofa* (gift) to acknowledge the participants time, effort, and contribution to this research study, a $50 grocery voucher along with 1-2 voucher(s) from South Auckland local businesses will be given out. A free T-shirt sponsored by a local business will be included as part of the *meaalofa* too. The practice of reciprocity ensures that the community reap the benefits from the research (Naepi, 2019). Reciprocity establishes harmonious relationships between all parties involved in the research and avoids exploitation and harm (Health Research Council of New Zealand, 2014). Reciprocity also allows Pacific communities the chance to have active roles within the research themselves (Naepi, 2019). By performing reciprocity, it acknowledges the *vā* that has been formed between the participant and researcher and represents the gratitude and thankfulness from the researcher to the participants.

RECRUITMENT

Sampling

Snowball sampling was used to recruit the target population of this research study. This sampling method is particularly applied when the participants that fit the target characteristics are not easily accessible (Naderifar et al, 2017). Due to the lack of ethnic-specific data that currently exists related to Samoan caregivers, specifically for dementia-related caregivers in the Auckland region, it was deemed the most appropriate to apply this sampling technique for this research study. This sampling approach allowed the researcher to also seek out known acquaintances of the first few samples to partake in the research study, allowing the opportunity to find participants alike (Naderifar et al, 2017) while attempting to further increase the sample size overall.

Study advertising

The research study was advertised in the form of a research poster via public advertising by utilising social media platforms which included Facebook and Instagram. A support group called Polymentia Movement as well as an organisation called Steps for Dementia Auckland also advertised the research poster to their respective networks which extended to dementia-related caregivers, specifically in the Auckland region. The snowball approach was utilised throughout the advertisement process of this study. This allowed for recruitment to extend beyond the researcher's existing networks due to the sharing functionality on these social media platforms. As a result, this opened up the opportunity of the study advertisement to reach a much wider audience across the Auckland region. This form of advertising was chosen because it was the best option to source Samoan caregivers within the Auckland region, given the lack of existing and available databases related to the target characteristics. The study advertisement included a link that would directly take individuals to a Google form to complete a brief survey to show their interest in partaking in the research. The contact details of the researcher (i.e., University email) was also included in the study advertisement for individuals to seek further details should they have any questions pertaining to their involvement in the study.

Eligible participants

This research study recruited eight participants in total. To be eligible to partake in this research study, individuals must be:

- An adult caregiver for a relative (loved one) who has been diagnosed with dementia,
- Of Samoan descent,
- A current OR a past caregiver,
- Currently residing in the Auckland region OR resided in the Auckland region if they are a past caregiver.

The adult age defined in this study is at least 20 years and over. The term ‘Samoan’ is defined as an individual with any Samoan descent. The timeframe for being a past caregiver will need to have been within the most recent past year that is, between the years 2020 to 2021. Participants deemed eligible for this study were all contacted by the researcher via email to acknowledge their interest in being a participant. Each email had the PIS (Appendix A) and CF (Appendix B) attached to complete should they wish to continue to partake in the study. Both documents were encouraged to be thoroughly read before signing and returning them back to the researcher. Initially, there were a total of twelve eligible participants; however, four participants did not respond to the researcher’s email response despite further follow-up emails and thus, were excluded from this study. Once a CF was signed by a participant and returned to the researcher, the researcher organised times and dates to schedule a *talanoa* with the participant that best suited their preference and availability. Once a time, date, and preferred method to meet-up were confirmed, participants were officially considered a recruited participant for this study.

Ineligible participants

A total of 16 individuals responded to the study advertisement where four individuals did not meet the eligibility criteria. To be excluded in this study, individuals would have identified with at least one of the following criteria below:

- Is younger than 20 years of age,
- Is not of Samoan descent,
- Past caregiver history exceeds one year,
- Lives or lived outside of the Auckland region as a caregiver or while being in the caregiver role and,
- Does not identify as the primary caregiver for their relative with dementia.

Participants deemed ineligible received an email that acknowledged their time taken to fill out the survey and outlined they had unfortunately not met the eligibility criteria for this study.

DATA COLLECTION

The collection of data was completed via one-to-one Zoom *talanoa* sessions between the researcher and participant. The *talanoa* framework guided the conversations during data collection without a rigid framework (Vaioleti, 2006). Data collection was carefully guided by the theorised perspectives of the *Fa'afaletui* model as a means of incorporating culturally responsive data collection methods. Both frameworks laid out the foundation to consider different components of *fa'a Samoa* while exploring the experiences of the participants in the most culturally appropriate and sensitive way (Sauni, 2011).

Data collection method

Data was collected by conducting semi-structured interviews in the form of *talanoa*. Semi-structured interviews are exploratory in nature, which is most beneficial when researching areas whereby little-to-none is known (Low, 2013). Comparable to the free-flowing dialogue that occurs during a *talanoa* (Vaioleti, 2006), following a semi-structured format in this form allows the researcher to adapt and form relevant questions that elicit further elaboration (Bullock, 2016). Equally important to note is that this method of data collection creates a relational space between the participant and researcher to equally engage in (Vaioleti, 2006; 'Otunuku, 2011). As such, this plays an important role in generating data that is contextual, providing 'inter-related information as co-constructed stories' (Vaioleti, 2006, p.24). Furthermore, the concept of storytelling is strongly valued in the Samoan culture too (McCarthy et al, 2011).

Talanoa

Talanoa creates a space that allows for the researcher and participant to engage as equals ('Otunuku, 2011). The utilisation of *talanoa* among Pacific people provides a space of natural familiarity which is helpful in the research process. The discussions that occur in the form of t*alanoa* are understood as 'non-linear, inclusive and fluid, encompassing holistic approaches to perceiving phenomena' (Cammock et al, 2021, p.122). *Talanoa* essentially establishes rapport between the researcher and the participant(s) and allows the researcher to 'gain an understanding of the environment that each exists in', allowing authentic discussions to be carried out (Cammock et al, 2021, p.123). Generally, the term *talanoa* is a verb. In the Samoan language, *talanoa* is a noun, *talanoaga,* which refers to discussions based on familial or community matters in a formal gathering (Tunufa'i, 2016). For Samoans, *talanoa* represents a 'means of oral communication' and translates to 'talk', 'discuss', 'tell stories', and so forth (Tunufa'i, 2016, p.229).

Talanoa question schedule

The *talanoa* question schedule was comprised of open-ended questions that were aimed to encourage participants to share their understandings related to:

- Dementia knowledge or awareness
- Experiences as a caregiver for a loved one with dementia
- Samoan perspective of care
- Dementia-related support services
- Access to dementia-related healthcare resources
- Support service recommendations

To ensure that information was collected in a consistent manner, each *talanoa* was guided by the same semi-structured question schedule (Appendix C). Incorporating *talanoa* provides a shared and relational space for participants to be the narrator of their own issues, realities, and aspirations (Vaioleti, 2006; Tuia & Cobb, 2021). The space created was versatile – providing participants with the opportunity to ‘probe, challenge, clarify and realign’ (Vaioleti, 2006, p. 25). Open-ended questions were considered useful in understanding processes in-depth (Weller et al, 2018). By utilising open-ended questions, it requires more than a ‘yes’ or ‘no’ response which can contribute to rich data collection (Gill et al, 2008). For example, open-ended questions can produce shorts answers, lists, or lengthy narratives. These responses will be collected until interviews reach what is known as saturation (Weller et al, 2018), thereby forming rich data.

Interview process

All participants opted to be interviewed via Zoom. For some, the Zoom option was more convenient due to being full-time carers or having other obligations and commitments with family or University, while for others, it was due to unforeseen circumstances related to COVID-19. Each participant was sent Zoom links of the intended scheduled meeting time agreed upon. To ensure full security and confidentiality of the *talanoa,* the settings of each Zoom meeting was altered by enabling the waiting room and meeting passwords and disabling the screen sharing function. All recorded Zoom sessions were audio-recorded and directly stored to the researcher’s University of Auckland Cloud storage with two-factor authentication that is only accessible to the researcher.

At the start of each *talanoa,* the researcher greeted the participant while acknowledging their presence, time, and effort to be a willing participant of this study. The researcher then went on to ask permission to conduct a prayer while also giving the opportunity for the participant to lead the prayer if they would like to. Once the prayer was completed, the researcher asked the participant for verbal consent before proceeding on with the *talanoa* schedule. After verbal consent was obtained, the researcher allowed time for introductions between both the researcher and the participant. The researcher then outlined important points pertaining to the participant’s rights and ensuring the confidentiality and security of their experiences being shared. Additionally, the researcher sought to empower participants by reminding them that they can share as much as they are comfortable with, and that no answer they provide can be wrong or will be judged. In this case, the *vā* was being honoured in creating a safe environment for participants to share their experiences openly and freely as a caregiver for their loved ones with dementia. The *vā* is a concept that identifies and defines culturally appropriate and inappropriate behaviours. Breaching the *vā* would hinder relationships within such contexts (Fosi Palaamo, 2018).

The duration of all *talanoa* lasted approximately one and a half hours up to three hours long. This allowed for adequate time for participants to provide in-depth accounts of their experiences as caregivers for their loved ones with dementia. Upon completion of the question schedule, the researcher allowed the participant to provide any concluding thoughts, including the opportunity to ask the researcher questions themselves. The *talanoa* was then concluded with acknowledgements of thanks to the participant, and with a closing prayer where once again, the researcher gave the opportunity for the participant to lead the prayer if they wished.

At the end of each *talanoa*, the researcher organised a time and day to drop off the participant's *meaalofa*. Each *meaalofa* was prepared with gratitude for gifting this research study with their time and experiences that they have shared. The *meaalofa* was in the form of a $50 Countdown voucher, vouchers gifted by South Auckland local businesses (i.e., @ _lovejanette, @bloomboxbakery, and @hairybyloa), a T-shirt sponsored by a local business (@backyardheroz), and a box of chocolates.

DATA ANALYSIS

The data analysis process of the research data was guided by the weaving conception of the *Fa'afaletui* model. The origins of the *Fa'afaletui* stem from the works of Tamasese et al (2005). The original conceptions of the *Fa'afaletui* refer to *tui* as weaving. The concept of weaving within *Fa'afaletui* interconnects the 'different expressions of knowledge from within various groupings' (Tuia & Cobb, 2021, p. 277). Further construction to this model by Suaalii-Sauni and Fulu-Aiolupotea (2014) emphasises collaboration and the sharing and gathering of stories, ideas and narratives until an agreement is made (Tuia & Cobb, 2021).

The *Fa'afaletui* model can be compared to the epistemological paradigm of constructivism. It has a central focus on discussions, interactions, and weaving different perspectives in order to reach a consensual, collective, and mutual understanding (Goodyear-Smith & 'Ofanoa, 2022). The *Fa'afaletui* in the analysis process strengthens and privileges Pacific cultural values and ensures these are embedded when analysing Pacific research data. This will hinder any potential risks during the data analysis and dissemination processes, ensuring what Pacific research is all about.

The analysis process itself refers to the *lalaga* (or *tui*) of the *Fa'afaletui*, that is, the practice of weaving. Considering the role of the researcher, it acknowledges the close vicinity between the researcher and the data therefore, the researcher would be the most appropriate to conduct the data analysis.

Once all *talanoa* were completed, all audio recordings were manually transcribed verbatim by the researcher at the University of Auckland South Auckland Campus – Te Papa Ako o Tai Tonga. The researcher reviewed and edited each transcript in separate Word documents to ensure that transcripts were precise. Each transcript was then printed in paper form to aid the manual analysis completed by the researcher. The data analysis process adopted components within the *Fa'afaletui* model including the preparation process of the *laufala* and the process of *lalaga.* An outline of the preparation process will provide proficient detail regarding how the data has been deemed considerably relevant to include throughout the data analysis. This will fortify that the preparation of data includes the most practical and salient fragments among each participants' dataset.

Preparing the laufala

Before the weaving can begin, leaves from the pandanus plants must be prepared in advance. Different techniques are used for the preparation process, which is dependable on the type of pandanus plant chosen (Goodyear-Smith & 'Ofanoa, 2022).

Step 1, of the *Fa'afaletui* preparation process is cutting the leaves close to the trunk of the pandanus plant and removing the spiky teeth from the leaves (Goodyear-Smith & 'Ofanoa, 2022). 'Cutting the leaves' is interpreted by the researcher as reading, examining, and reviewing transcripts multiple times. Doing so will aid in creating distinct concepts or themes that are purposeful in answering the aims and objectives of this research study. 'Removing the spiky teeth from the leaves' is interpreted by the researcher as a further step of annotating and analysing transcripts. This step allows the researcher to leave out information from the dataset deemed to be irrelevant to the main themes or concepts corroborated. Leaving out information that is unrelated to the research aims and objectives effectively means that the most purposeful fragments of information from the dataset have been extracted.

Step 2, of the *Fa'afaletui* preparation process is boiling the leaves in water followed by drying and bleaching them out in the sun. Once dried, the leaves are rolled and tied into bundles. This step is interpreted by the researcher as organising concepts into relevant and salient themes. In this step, themes derived from the dataset have been sorted and analysed thoroughly and are now preparing to be weaved.

The principal themes included:

- Dementia awareness,
- Experiences as a caregiver for a loved one with dementia,
- Samoan perspective of care,
- Dementia-related support services,
- Access to dementia-related healthcare resources, and
- Support service recommendations.

These themes helped guide whether or not information from the *talanoa* data would be considered relevant to include. As a more manageable method, the researcher allocated different coloured highlighters to each theme. This acted as a colour-coding system to aid in categorising the most relevant data to include in this research study. The colour-coding system included:

- Dementia awareness – yellow
- Experiences as a caregiver for a loved one with dementia – green
- Samoan perspective of care – blue
- Dementia-related support services – orange
- Access to dementia-related healthcare resources – pink
- Support service recommendations – red

Lalaga – Practice of weaving

Once the sorting, selecting, and analysing of the dataset was completed, the process of *lalaga* commenced. *Lalaga* was best understood by the researcher as identifying important themes and creating relevant connections between these themes. This has been detailed below as separate stages for more clarity throughout the data analysis process.

Stage 1: of *lalaga* involves stripping the dried leaves into thin strands, ready for weaving (Goodyear-Smith & ‘Ofanoa, 2022). This stage was interpreted by the researcher as extracting the key points from the two-step preparation process of the *laufala*, and further arranging them into more specific and purposeful subthemes.

Stage 2: of *lalaga* included transferring the key points collated in a separate Word document in a tabulated form. All themes were separated into different tables with two columns: Column 1 for the subtheme and Column 2 for the key sentences and phrases that were relevant to that specific subtheme.

Stage 3: of *lalaga* involved further examination and decoding of themes. This stage enabled the researcher to collate categories and themes, which contributed to modifying and developing existing themes as well as construct new theoretical relationships between identified themes too. Overall, a summation of key themes and findings would be produced, considered to be a sufficient representation of overall research findings – this would involve creating a report that contains the research results intended for the final research study document.

The finalised main themes were also reviewed and analysed via thematic analysis. Thematic analysis is a flexible method often used to systematically identify, analyse, and interpret patterns of meanings that emerge from the data (Braun & Clarke, 2012). Data can have numerous different focal points that the researcher can build upon, helping the researcher to make sense of shared experiences too (Braun & Clarke, 2012). The preparation process of the *laufala* and the *lalaga* of the *Fa'afaletui* model can be comparable to an inductive approach. An inductive (data-driven) approach is a bottom-up approach that allows the analysis of data without restraints imposed by structured methodologies (Thomas, 2006; Braun & Clarke, 2012). This approach involves persistent and significant themes to emerge that are inherent in raw data. This also allows the researcher to make interpretations based on the dominant themes (Thomas, 2006).

An intentional design

The final component of the *Fa'afaletui* is the intended design of the *fala*. The intention of the design of the *fala* is indicative of its purpose. This step is interpreted by the researcher as the exchange and presentation of research results to the research participants, which were summarised in a two-page document with the main findings of the research for those who agreed to receive it. The overall research findings were disseminated to communities, groups, and societies that it would be most beneficial for such as other Pacific caregivers providing care for loved ones with dementia or other dementia-related support groups or organisations.

CHAPTER SUMMARY

This chapter describes the methods and methodologies used to guide this research study. It utilises a qualitative research design in the form of *talanoa* to collect data. *Talanoa* sessions were independently organised as one-to-one Zoom meetings which considered the three theorised perspectives of the *Fa'afaletui* model. The application of *talanoa* and the theorised perspectives of the *Fa'afaletui* as a method of collecting data, served to culturally empower and enhance the *vā*, offering deeper insight into the experiences of Samoan caregivers who take care of their loved ones with dementia in New Zealand.

Pacific frameworks have been specifically chosen as a means of cultural appropriation when conducting research *'with'*, rather than *'on'* Pacific participants. The employability of Pacific frameworks is purposeful and embodies a holistic and collective approach to research that is strongly embraced among Pacific and Samoan communities. This is especially important considering that the Western-based research paradigms that are mainly carried out conflict with Pacific worldviews. For instance, respect, reciprocity, holism, and communal relationships are Pacific cultural values that are not prioritised within the Western worldview.

Fa'afaletui model conceptualised as the metaphoric expression of weaving, has been used to inform the data analysis of this research study. This original conception involves weaving together the perspectives from various groupings. Respect, relationality, and formality are key principles within the Samoan culture that underpin the *Fa'afaletui* model. These ensure that the voices of participants are at an advantage by following proper protocols that are culturally sensitive.

This research study has ethically considered the confidentiality, security, informed consent, and reciprocity of each participant. Ethical approval has been obtained from the University of Auckland Human Participants Ethics Committee. This puts in place preventative measures from disadvantage and exploitation of the research participants.

CHAPTER FOUR: PRESENTATION OF FINDINGS

Chapter Four of this thesis presents the findings of this study. It will start with a brief outline of the demographic background of each research participant and then discuss the main themes and subthemes gathered from each *talanoa*. This chapter will then end with a summary of the main research findings.

PRESENTATION OF FINDINGS

Eight participants were recruited for this research study with the demographic table below. Table 2 provides a summary of each participants' characteristics that were collected prior to and throughout each *talanoa*.

The participants' ages range from 24 years old to 33 years old. Most participants reside in South Auckland (Ōtara, Māngere East, Māngere, or Manurewa), while the remaining two participants reside in Central Auckland (Mount Roskill) and West Auckland (Rānui). Most participants (7) are females, with only one male participant.

The majority of participants are full Samoans, with three having mixed ethnic backgrounds. Participant Five (P5) is Samoan/Tuvaluan, Participant Seven (P7) is Samoan/Chinese/German, and Participant Eight (P8) is Samoan/Cook Island. Three participants are married, and two out of the three have children. Participant One (P1) also has children but is in a de facto relationship. Participant Six (P6) is also in a relationship but does not live with her partner and has no children. The remaining participants, four (P4), five (P5), and eight (P8), are not in a relationship and have no children either.

Six out of the eight participants are current caregivers, all providing care within the home setting. Two participants identified as past caregivers, providing care until 2021. Participant One (P1) was classified as a past caregiver, given that her father with dementia was no longer under her care within the home setting and was placed in ARC. P7, also classified as a past caregiver, provided care for her mother-in-law until her mother-in-law unfortunately passed away in 2021. All participants have at least three years or more experience as a caregiver for their loved ones with dementia.

Table 2. Participant demographics

Participant:	***P1***	***P2***	***P3***	***P4***	***P5***	***P6***	***P7***	***P8***
Age:	*30*	*32*	*33*	*25*	*29*	*24*	*32*	*30*
Gender:	*Female*	*Female*	*Female*	*Female*	*Female*	*Female*	*Female*	*Male*
Place of residence:	*Mount Roskill*	*Ōtara*	*Māngere East*	*Manurewa*	*Māngere*	*Māngere East*	*Rānui*	*Manurewa*
Caregiver status:	*Past*	*Current*	*Current*	*Current*	*Current*	*Current*	*Past*	*Current*
Providing/ provided care for:	*Father*	*Grandmother*	*Grandfather*	*Grandmother*	*Grandmother*	*Grandmother*	*Mother-in-law*	*Grandmother*
Samoan ethnicity:	*Full*	*Full*	*Full*	*Full*	*Mixed*	*Full*	*Mixed*	*Mixed*
Marital status/ Relationship status:	*In de facto relationship*	*Married*	*Married*	*Single*	*Single*	*In a relationship*	*Married*	*Did not say*
Children:	*Yes*	*No*	*Yes*	*No*	*No*	*No*	*Yes*	*No*

Theme 1: Knowledge and Awareness of Dementia

The first theme describes participants' knowledge and awareness of dementia. This theme explored questions regarding the participants' loved ones with dementia, which allowed participants to speak on their knowledge, awareness, and understanding of dementia at the time of diagnosis.

I don't really know what dementia is

The majority of participants indicated that their knowledge and awareness of dementia lacked a full understanding of what the condition consisted of. This was informed by their responses when questioned about their experience of learning about the dementia diagnosis of their loved ones. The level of understanding among most participants varied between making an association to memory loss, forgetfulness, and a normal part of ageing, while some participants were completely unaware of what dementia was altogether.

> *"...I kind of knew like something about memory loss but I didn't know like anything of the disease..." - P1 (Female, Age: 30)*
> *"...I was actually quite lost. I was confused, because I was like, that was the first time I ever heard of that kind of sickness..." - P5 (Female, Age: 29)*

Participants' lack of knowledge and awareness of dementia resulted in conducting self-directed research using Google to seek further information about dementia. This in itself highlighted the lack of support provided around receiving adequate information about dementia at the time of diagnosis. When discovering the full extent of the condition, most participants found it difficult to understand or were shocked.

> *"...when I got home, kind of Googled everything up and like when I just started reading about it, I was like 'What the hell?'...I didn't know it was like this bad..." - P1 (Female, Age: 30)*

The lack of knowledge and awareness of dementia among participants highlighted concerns around the need for raising dementia awareness and improving the knowledge around dementia. This is important to consider due to the high possibilities of misattribution of dementia and subsequent delays in diagnosis. For example, although dementia symptoms were present, P4 and her family waited two years before seeking an official diagnosis. Participant Two (P2) also explains that forgetfulness is easily understood as a normal part of ageing, and due to the lack of dementia education (at the time), getting a diagnosis for dementia was not considered.

> *"…we knew she had dementia and there wasn't until like two years later that she was finally diagnosed with it…because we knew she was forgetful; it wasn't until like she was officially diagnosed that we were all like… 'someone needs to be her full-time caregiver'…" - P4 (Female, Age: 25)*
>
> *"…we noticed she just started to forget stuff and I guess because I'm not like educated in dementia Alzheimer's…so at the time I just thought she's just older like you know, she had just forgotten things normally…" - P2 (Female, Age: 32)*

Notably, due to the lack of knowledge and awareness around dementia, this created further challenges for one participant (P4) to explain dementia to family members as dementia is not conceptualised in the Samoan language. P1 also reported that it was difficult to help her family understand the condition. This highlights that knowledge about dementia could have been helpful to explain to parents or elderly in the family whose first language is Samoan, as well as improve awareness around dementia within the home to avoid added stress.

> *"…there's a massive like lack of understanding with dementia around our household…my family just think she's just forgetful, that's it, but then that's all that they understand…there's no real clear understanding…I wanted like someone to speak to explain to my grandparents in Samoan, like what dementia is… like my understanding in Samoan is probably different and probably wrong but there wasn't much to offer…" - P4 (Female, Age: 25)*
>
> *"…with My mum too, she made things really hard…I would try and tell her like… 'Don't get angry at him like it's not him, it's the disease'…" - P1 (Female, Age: 30)*

Some level of understanding of dementia or at least exposure to the condition proved to have better equipped Participant Three (P3) and her family in preparing for the journey as caregivers. This meant that they were able to anticipate the progression of dementia symptoms and prepare for change without being as overwhelmed compared to other participants who found it difficult to accept. This did not mean that P3 experienced challenges to a lesser degree but did demonstrate that some understanding of or exposure to the condition was quite helpful in P3's case.

> *"…Dad's brother has dementia that we've always known of…watching my uncle and his journey we were like, you kinda know what to expect a little bit…" - P3 (Female, Age: 33)*

Describing what it means to care for a person with dementia

When participants were questioned to describe what it means to provide care for someone with dementia, most participants described it as 'challenging', 'hard,' 'not easy', or a 'long goodbye'. This was most attributable to observing the personality changes and deterioration of brain functionality of their loved ones over time.

> *"…it's a really really hard job, it's not like a walk in the park…you're looking after this person that you love and I'd say like, describe it as a long goodbye - the person that you know and love, like your whole life like slowly, like fading in front of your eyes. I feel like you say goodbye now and then they pass away…you gotta say bye again…" - P1 (Female, Age: 30)*

Despite the challenges that have been specified, some participants also described their roles as caregivers to be a 'blessing' and a position they are 'grateful', 'glad', and 'unregretful' to be in. This reflected their love and the type of relationship they had with their loved ones.

> *"…when it comes to how I describe caring for Nana in general, I always try and point out that it's a blessing just because people are always like, 'Oh wow, that's such a big sacrifice'... it's not a sacrifice, it's a blessing..." - P2 (Female, Age: 32)*
> *"...I wouldn't trade this for anything and I have no regrets at all, and I would like do it all again if I had to…" - P6 (Female, Age: 24)*

Theme 2: Experiences as a Caregiver for a Loved One with Dementia

The second theme will present the personal lived experiences of participants within their role as caregivers for their loved ones with dementia. This will involve exploring participant experiences and feelings related to the caregiver role, specifically within the home setting. The questions allowed participants to explore their realities within the home as caregivers for a loved one with dementia, which uncovered a number of similar yet unique experiences.

Stress

The progression and severity of dementia symptoms were the main sources of participants' stress. This was mainly due to the changes in the behaviour and personality of their loved ones. Almost all participants experienced similar feelings of 'frustration' and 'anger'.

> *"…I could feel myself getting really angry because you know, it's frustrating trying to care for someone…I'm trying to tell him and he's not listening…"* - P1 (Female, Age: 30)
>
> *"…every day is a challenge with him, anything new we try with him is a challenge because he's so unmotivated…every day is a challenge with his mood swings… every day is stressful…I feel like I am now the teacher and he's the student…"* - P3 (Female, Age: 33)

Other sources of stress included the lack of knowledge around different methods to support a PWD, unstructured planning of days, repetitive days, caregiver responsibilities, not knowing how to respond to dementia symptoms, and not knowing how to deal with change.

> *"…I don't know if she's in pain or if she's unwell or uncomfortable, it's just not knowing that because she can't speak and that stresses me out the most…that gets me worried because I don't know what to do or like what medicine to give her because I don't know what's wrong with her…"* - P5 (Female, Age: 29)
>
> *"…it is hard…it's very hard to cope with changes. Us, we're used to making change but for changes to come to us, especially with our loved ones, it's very hard…"* - P7 (Female, Age: 32)

Stress also stemmed from prioritising the health, well-being, and needs of others before themselves. For example, P2 expressed that catering to the needs of others left little time to focus on herself.

> *"…I felt like I thought that putting everyone else first was the way to go about looking after her… it can be a bit much, not a bit much; so it can be a lot, and so I feel like the stress was trying to do everything for everyone and then not having enough energy for myself…"* - P2 (Female, Age: 32)

Mental impacts

Negative mental health impacts were specified among some participants. The behavioural changes that are associated with the progression of dementia was the main cause of mental strain experienced among participants. For example, P4 highlighted that her loved ones mental state began to decline without improvement, which directly began to affect her own mental health. Having to deal with her loved ones 'mental fits' without much knowledge about this symptom contributed to the mental toll she experienced.

> *"…it took a toll on me mentally because like the mental fits were just happening, like almost every day…bit by bit, it's been chipping away, like deteriorating - I didn't really know much on mental health…" - P4 (Female, Age: 25)*

For P5, the mental impact she experienced was associated with the uncertainties related to decision-making for her loved one. As a consequence, she began to experience moments of self-doubt in her ability to provide care.

> *"…I've had my days where I just want to give up…I've had my ups and downs and I'm just like, 'Am I doing the right thing?'...for me, it's mentally draining in a way…"- P5 (Female, Age: 29)*

P5 further reported that the repetitive daily routines of caring for a PWD within the home setting was also a contributing factor affecting her mental health.

> *"…I'm just like, you try sit in a house day in day out and do the same thing over and over again, same thing different days, and you see how much of a toll it is on you mentally…" - P5 (Female, Age: 29)*

Notably, P6 reported that the mental effects of providing care had a ripple effect; the mental strain she was experiencing began to have an impact on her family too. As such, P6 additionally dealt with having to consider and work through the mental load that her family was experiencing too.

> *"…It's not just my mental health that has been affected but like everyone else's as well, and then you kind of carry what they are as well…" - P6 (Female, Age: 24)*

Emotional impacts

Most participants reported some form of emotional distress within their role as caregivers. Participant responses demonstrated a range of different emotional effects as caregivers, which often stemmed from having more than one role within the home such as being mothers, wives, or a tertiary student. Most responses were associated with negative emotional outcomes. For example, P1 reported that balancing the different roles within her home alongside being fully employed intertwined with the effects of COVID-19 eventually led to experiencing deep depression.

> *"…I found it really hard to juggle like being a Mum, trying to do like wife duties, work and and being a carer at the same time – because I was working full-time while I was*

> *caring for my Dad, I found that really really hard and like 2020 when COVID hit, oh my gosh I like went into deep depression...”* - *P1 (Female, Age: 30)*

P3 reported feelings of frustration having to balance her role as a caregiver while simultaneously attending to her role as a mother and catering to the needs of everyone within her home.

> *“…it’s frustrating, not just Dad, like not Dad alone. It’s also frustrating you know, having the kids at home like it’s everything you know, together…”* - *P3 (Female, Age: 33)*

P6 also found it challenging to balance her responsibilities as a caregiver and as a tertiary student, specifically the pressure to find part-time employment to avoid financial burden.

> *“…or just having to like find a part-time job… I didn’t really want to work and study, but just to be able to like support myself so I don’t have to lean on my Mum too much because she’s already taking care of that financial burden…”* - *P6 (Female, Age: 24)*

Other prominent emotional impacts that were expressed among participants were self-perceptions of being a burden and feelings of guilt, which hindered participants’ views on seeking support. For example, P6 reported that the feeling of being a burden often led to overthinking and consequently made her avoid seeking support from extended family members.

> *“…it would be selfish of me too… like sometimes I just overthink and I feel like I can't ask them for help…”* - *P6 (Female, Age: 24)*

For P2, feeling guilty conflicted with her personal views as a caregiver. For example, P2 viewed her caregiving role as her ‘duty’ therefore, having instances of feeling overwhelmed was an emotional challenge in itself to navigate through.

> *“…the guilt of feeling guilty when we have our ‘this is too much’ moments; we feel bad for feeling bad because we feel we shouldn't feel bad for doing our duty…”* - *P2 (Female, Age: 32)*

The struggle to navigate through ones’ emotions was also expressed among participants, which resulted in the suppression of emotions because of the fear of judgement. For example, P4 and P6 experienced moments of overwhelming stress but felt that they needed to conceal their emotions to portray strength and emotional reassurance around their loved ones with dementia and family members.

> *"…I try pick myself up before I get to that stage only because you know, we can't afford to have little breakdown moments…"* - P4 (Female, Age: 25)
> *"…I'll have my moments but like at the same time I have to realise you know, she's the priority…just always making sure that like yeah, that she doesn't see us you know feeling down…"* - P6 (Female, Age: 24)

Relevant caregiver experience is helpful

Despite the mental and emotional challenges mentioned above, one participant (P7) did acknowledge that although the initial stages of her journey as a caregiver was challenging, the skills gained from being a mother made her caregiver responsibilities 'easier' to deal and cope with.

> *"…for me it was easy because being a Mum, changing diapers is just a normal thing…in the start it was challenging…because um she wasn't able to walk…"* - P7 (Female, Age: 32)

Prior experience in a similar role to being a caregiver appeared to be advantageous for participants. For example, P5 and P7 both had prior work experience that involved working with individuals with special needs. Work experience taught P5 and P7 the necessary skillset and knowledgebase when it came to providing care and seeking out support.

> *"…because I worked as a teacher aide for seven years at a special needs school and then I started working at a rest home, so I don't really need the training because I learned while I was working…"* - P5 (Female, Age: 29)
> *"…I work at a special needs school and I know what my Mum can get and I know the funding that we can get, so I'm not going to let those OTs [Occupational Therapists] and STs [Speech Therapists]…come and muck me around because I know what Mum deserves and I know what she should get…"* - P7 (Female, Age: 32)

Social impacts

Social impacts were also reported by all participants and were often associated with negative experiences. Social isolation and changes within family dynamics were principal areas of concern associated with the social impacts experienced by participants. For example, P5 and P7 felt they experienced some form of social isolation due to not being able to engage in normal everyday activities they would have typically participated in had it not been for their caregiver role.

> *"…that's why I say it's pretty sad because like, I can't do much things…if I want to go out I've got to make sure that I have her sorted, like to make sure that she has someone here...that knows her routine and knows her feeding schedule and all that stuff…so just knowing that I have all of that on my shoulder…"* - P5 (Female, Age: 29)
> *"…it's hard because it gets in the way of your family time…a lot of times we* - *I had to give up…going to places just to stay with Mum…we always had to support her needs before all of ours…"* - P7 (Female, Age: 32)

Most participants further reported that other life commitments had to be set aside to be able to prioritise their role as caregivers. For example, participants often expressed that their 'life,' 'schooling,' and 'work' had to be put on hold to provide full-time care.

> *"…just to me it's just like, I put my life on hold for her…"* - P5 (Female, Age: 29)
> *"…I've had to put school on hold for like, for five years but like I don't regret it…"* - P6 (Female, Age: 24)

Although these said impacts were reported, participants continued to express feelings and thoughts of gratitude toward their roles as caregivers. The decision to put employment on hold highlighted the impacts on participant family dynamics. For example, P2 reported social division among her family members, which stemmed from mistrust related to finances.

> *"…I've taken time off work, like I don't work at all now. When it comes to finances and stuff, there's always like a questioning around you know, 'Oh well then where does Nana's pension go?'…like that kind of stuff and it hurts…"* - P2 (Female, Age: 32)

P2 also noted that the expectation from others to be employed while caring full-time was an added stressor that led to feelings and thoughts of inadequacy as she was not able to contribute to house-related costs. P2 further noted that the perception that others had related to being a 'family caregiver' was another form of judgement because it was often viewed as not a 'real job'.

> *"…I think about the like stressor is expectation. When people ask me, 'What I do for work?,' I'm like, 'Oh I don't work, I look after my Nana.'…I always feel, well I try not to but I have felt like what I did wasn't a real job or like wasn't contributing too -*

> *especially because I don't contribute financially to the household…"* - *P2 (Female, Age: 32)*

The impact it had on my family

When participants were questioned about any changes or impacts related to their family dynamics, all participants shared different views. One of the main ideas that were highlighted included the importance of having a strong support system. A strong support system was strongly associated with more positive family interactions and outcomes. This was demonstrated through 'sharing' the mental, emotional, and physical loads of caring, which effectively reflected a decrease in caregiver burden, strengthened family connections, improved self-awareness, and assisted in emotional healing. For example, P7 and P6 reported the benefits of being able to disseminate caregiver responsibilities that resulted in building closer relationships.

> *"…when we started caring for Mum it was a team effort, you know like everyone came together, everyone played a part – everyone, and made us so close…"* - *P7 (Female, Age: 32)*
>
> *"...I'm just grateful to you know, have like the amount of support even in just just our household, like just knowing that we can you know, lean on each other and stuff..."* - *P6 (Female, Age: 24)*

The absence of family support was a determinant of family breakdowns or disrupting family dynamics which led to feelings of anger and animosity. This was echoed among a few participants who underlined the need for consistent family support within the home because without it, it established negative emotions and a change in family relationships. For example, the lack of family support eventually led one participant (P1) to place their loved one into ARC after several years of providing care within the home. This decision had detrimental effects on this participant's mental and emotional well-being, which was mainly characterised by the breakdown it created within her family and her fear of judgement from family, especially knowing that it was against *fa'a Samoa.* For P8, the focus of providing care shifted due to the impacts of dementia; the changes in family dynamics caused the provision of care to become less of a priority.

> *"...I don't have help from my siblings…and that's probably the other thing, I'm pissed off at them too – not here physically, financially, mentally like you know, 'What can you do?'..."* - *P1 (Female, Age: 30)*

> *"…it felt like there's too much family politics and less caring…like in my family at least, there was like a lot of battles going on with all my Aunties and Uncle…" - P8 (Male, Age: 30)*

Coping mechanisms for stress

Having coping mechanisms in place was extremely important for all participants to be able to function to the best of their abilities as caregivers, which had positive impacts on their overall well-being. All participants reported several different coping mechanisms during moments of feeling mentally and emotionally challenged as caregivers. Most participants found that having quality time to themselves and removing themselves from the environment of 'caring' was a constructive coping mechanism. Examples of participants removing themselves from the 'caring' environment included listening to music, cooking, cleaning, visiting family, quality time spent with family, and going for drives. Other coping mechanisms participants reported included engaging in physical activity/exercise, breathing techniques, following a set routine, journaling, reflecting, alcohol consumption, social media, and maintaining a balanced caregiver-social life. All of these were listed as methods of de-stressing or de-escalating rising emotions of either frustration, anger or stress, or a method of avoiding moments of sadness.

> *"…trying to go to the gym to get myself moving physically to get like that frustration and stuff out has been a massive help this year…it's changed the way that I'm able to look after her as well…" - P2 (Female, Age: 32)*
>
> *"… I walk away and I cook…I'll walk outside, you know and I'll sit outside or I'll come to the kitchen and you know cook, cook his food to get away from him…I'll cook or hang the washing or something because just that little break makes all the difference…" - P3 (Female, Age: 33)*
>
> *"…I don't think I'll be sane enough to – to be here if I wasn't able to you know, take that little break off because it's not it's not easy…" - P8 (Male, Age: 30)*

Most participants also reported that their faith in God, engaging in the practice of prayer, and attending church was an empowering coping mechanism that helped them to escape and release suppressed thoughts and emotions. Some participants also reported the benefits of visual cues and quotations of positive affirmations, which urged and reminded them to remain mentally and emotionally positive through stressful situations. This helped these participants to make more positive connections between their thoughts, feelings, and responses to stress. For example, P7 and her family found that positive affirmations helped them to acknowledge and respond to any problematic behaviour or situation in a more positive way.

> *"…there was sticky tabs with good words of affirmation for us, you know like reminding us if we open the fridge, remember like always reminding us 'member (remember) if Mum tips the milk, it's okay, you know Mum tips the milk…it's okay. Brain - move on. You know it's just always, it's all right – smile…" - P7 (Female, Age: 32)*

Interestingly, the majority of female participants also expressed that 'crying' was an effective emotional outlet that enabled them to express and manage their frustrations. Crying permitted the release of the mental and emotional build-up caused by caregiver burdens and was deemed as the remaining option for participants to cope with their stress.

> *"…one of my coping mechanisms was just to cry. I had to just cry you know…seriously when I used to be in my mind, I used to just cry, just cry; I had to let it out some way…" - P7 (Female, Age: 32)*

The positive side of caregiving

Despite the majority of caregivers reporting pessimistic experiences, all participants also shared positive outcomes associated within their roles as caregivers that had beneficial impacts on their overall well-being. For example, almost all participants reported a new sense of self-discovery. These participants specifically appreciated the personal growth they experienced within their caregiver roles such as becoming more optimistic, resilient, and developing and gaining new skills.

> *"…I feel like it's built my resilience a lot like if I wasn't looking after her, I don't know, I don't even think I would have thought about my own health and my own journey…" - P2 (Female, Age: 32)*

Another positive outcome associated with the caregiver role was strengthening familial relationships. Almost all participants expressed that the caregiver role unified their immediate family's connections and nourished the 'caregiver-loved ones with dementia' dyad.

> *"…my relationship with my Nana has honestly like, we've gotten a lot closer because I've had to care for her…" - P6 (Female, Age: 24)*

Participants also expressed that acquiring new knowledge related to the health system and exploring new methods of consolation was a positive outcome associated with their role as caregivers.

> *"…I think just getting the to know the ins and outs of our health system, like the pros and the cons of our health system…another positive was like I got out of the...me and my husband stepped out of the box; out of our own circle…"* - P7 (Female, Age: 32)

Theme 3: Samoan Perspective of Care

The third theme will present each participant's cultural perspective and understanding of care as a Samoan. This explored questions around *fa'a Samoa* in regard to providing care as a family caregiver and cultural values, beliefs, and practices that have been beneficial as caregivers.

It is my duty; it is my turn to give back

Fa'a Samoa was an important, influential aspect for all participants in their understanding of providing care. When participants were questioned about 'how they came to be' caregivers, most participants reported that 'not much thought' was considered when deciding to become caregivers, especially providing care within the home. The idea of reciprocity was strongly expressed by all participants. All participants shared a similar moral sense of duty to 'repay' their loved ones for playing a special role in their upbringing and that by doing so, it was their way of showing their love, respect, and honouring the teachings as a Samoan.

> *"…never crossed my mind to like put her in a um yeah, in a rest home or anything like that…just because she's literally like raised all of us, like from my parents right down to like the youngest grandchild; like my Nana has been there for all of us…when she was her strongest, she was taking care of all of us and it's only right that you know, we give back and take care of her at our strongest…"* - P6 (Female, Age: 24)
> *"…our culture played a huge part in me looking after Mum – tausi matua, I'm sure you heard that, um tausi matua and just being respectful…"* - P7 (Female, Age: 32)

Participants' belief in God and attending church were also essential factors related to the decision-making around providing care within the home. Most participants referenced the same Bible scripture that highlighted the significance of parental figures and the belief in God, which is highly valued within the Samoan culture.

> *"…I think religiously probably just a lot of like prayer…yeah religiously and culturally because we're just such a spiritual-based culture as well…a lot of prayer for her and for me, and for my family and just anyone else out there that's looking after elderly because it's, it's such - it's an honour and it's like it's our place…like the Bible says, 'Honour your father and mother', and I feel like that's so much more than just being*

> *obedient but it's like you know, giving back that love that they had for us…like sharing that same love and blessing"* - P2 (Female, Age: 32)

Some participants also noted that their belief in God reinforced the idea that they were 'blessed with the opportunity' to be able to give back to their loved ones. For example, P7 acknowledges the importance of providing care to parental (or elderly) figures in the Samoan culture because it is a way of receiving blessings in life.

> *"…you know the Samoan culture, the Samoan way is you tausi [care for/take care of] your parents…you want to live longer, you know you do things for your parents, you look after them, you care for them and that's where all your blessings come from…"* – P7 (Female, Age: 32)

Furthermore, participants felt an intrinsic sense of duty because of the position they held within their families, especially as a Samoan. Participants also reported that 'expectations' were also intrinsically built based on *fa'a Samoa*. For example, participants who were the eldest sibling or eldest grandchild automatically knew that the responsibility of providing care for their loved ones was a duty and an expectation for them to specifically fulfil.

> *"…it's not like my parents or my family has told, like directly come out and say like say it, like instructing me to do but it's more the fact like it's an unspoken - it's like an unspoken command…"* - P4 (Female, Age: 25)

Interestingly, P5 made an association between receiving her *malu* (traditional Samoan female tattoo) and the expectations to carry herself as a young *tama'ita'i Samoa*, which influenced her role as a caregiver. The *malu* is a symbol of Samoan identity considered to be sacred within the Samoan culture. Traditionally, the *malu* guides the expectations of a Samoan female to act and behave in a manner that protects, serves, and upholds the obligations within her family (Miesnieks, 2014).

> *"…now that I have my malu it's more responsibilities, like responsibilities and just knowing that I'm just giving back to her for giving me...for giving her time to me, for raising me and being the biggest part…yeah so just just having that responsibility of being the oldest…"* - P5 (Female, Age: 29)

Other participants also noted the importance of cultural values and how these values shaped their understanding of care. The values and principles embedded in the Samoan culture such as *alofa* and *fa'aaloalo* were predominantly echoed among all participants and helped participants to better understand their duty as caregivers within the family.

> *"…it really just comes down to the values that are instilled in you as a child um that you, you know when you're at the age of being able to carry out those duties um, you know you feel like happy, like you actually want to do it and stuff…the biggest one is love…two other values that I feel like my Nana's instilled in a lot of us is just like, just you know respect and just even like, just fa'a Samoa…" - P6 (Female, Age: 24)*
>
> *"…your cultural values…all of that really helped me as a, as a Mum, as a wife, and as a caregiver for Mum because it helped me understand not to give up…no matter what, Mama is relying on you. This is your duty; this is your job. As a young Samoan woman, this is your duty…" - P7 (Female, Age: 32)*

Participants' sense of moral obligation to fulfil their duty as a Samoan also directly affected their perceptions of seeking support. For example, some participants reported that they did not feel the need to seek support because of their cultural beliefs as a Samoan. Their responses highlighted the fact that seeking support was a 'last resort' option because of 'the Samoan way'.

> *"…we're Samoans, we don't go looking for support, you know we're supposed to care for our elders, care for our parents, like that's our job…that's really I think that was probably one of the main things as well, that was kind of holding me back…" - P1 (Female, Age: 30)*

Furthermore, some participants particularly acknowledged the shortcomings associated with the expectations as caregivers such as the detrimental effects on mental health as well as reaching a point of accepting a lifestyle they would have not initially preferred.

> *"…the only disadvantage that I find is that like, is the fact that it's expected of us…and it's like probably a disadvantage on mental health as well…like such pressure has been put on your shoulders…" - P4 (Female, Age: 25)*
>
> *"…there was a lot of like expectations and certain standards that I had to live up to and it just kind of got to the point where just like, I just accepted it and I was like you know this is how it's gonna be…" - P6 (Female, Age: 24)*

Rest homes are not for Samoans

All participants shared the same belief about placing their loved ones in rest homes (or ARC). Despite there being only one participant (P1) who utilised a rest home service, all participants (including P1) felt that the idea of rest homes opposed *fa'a Samoa*. Placing a loved one in a rest home, yet alone the suggestion of shifting their loved one into a rest home, was viewed to be disgraceful. One of the many reasons was due to the patriarchal role and significance the elderly hold within the Samoan culture. For example, some participants emphasised the importance of *tausi matua* within the Samoan culture and that their perception of placing their loved ones in a rest home was linked to the abandonment of their relatives.

> *"…the thought that you don't abandon your family and in their time of need, I think that's such a massive part that I'm grateful for culturally and religiously…just because it gets harder doesn't mean you give them away, like you put them in a home or something…" - P2 (Female, Age: 32)*

Participants also felt that they would be shamed and judged for choosing to place their loved ones in a rest home. This was evidently demonstrated through P1's responses compared to other participants who had strong views against placing their loved ones in a rest home.

> *"…I didn't want to be judged and stuff from family members, like outside and like looking in like, 'Oh, she's she's a useless daughter'…'She doesn't even care for her Dad'…" - P1 (Female, Age: 30)*
>
> *"…we weren't brought up that way too, you know that Samoan way is 'tausi lo'omatua, tausi toea'ina' (look after the old lady, look after the old man) the way that they did for you – don't, you know just chuck them in a rest home…" - P5 (Female, Age: 29)*

Fa'a Samoa can be tough to uphold as caregivers

Some participants shared that becoming more of an authoritative figure over their loved ones was morally conflicting. These participants described it to be an uncanny position to be in as it challenged cultural principles such as *teu le vā* (nurture the space-between/relationship). For example, the participants who were grandchildren to their loved ones with dementia were challenged by the boundaries of *fa'a Samoa* and *teu le vā*. Some participants also expressed the moral difficulty in transitioning from 'the one being taken care of' to becoming 'the one now providing care'.

> *"…the whole teu le vā, like knowing your your place when it comes to the adults and the eldest like you know the elderly, because I tend to have to bite my lip when it comes*

> *to people trying to come and intervene and try like tell me what to do with her and how to do it…"* - *P5 (Female, Age: 29)*

For instance, P2 and P8 noted that although they were the main full-time caregivers for their loved ones, the principle of 'respecting your elders' (which is highly valued in the Samoan culture) was morally and culturally challenging to deal with because they felt like they should have more say in the decision-making processes given their caregiver roles.

> *"…there's such a blurred line between decision-making for her…it was like I'm her caregiver, but my responsibility is only up to a certain point and then all the bigger decisions come down to her kids, if that makes sense…"* - *P2 (Female, Age: 32)*
>
> *"…when it came to to my Nana…a lot of my Aunties and Uncles had this thing in their minds that you know, they should have a say more than the nephews and the nieces yet we're the ones looking after them, well mostly me…"* - *P8 (Male, Age: 30)*

Theme 4: Knowledge of Support Services and Accessing Healthcare Support

The fourth theme will present participant knowledge and awareness of available support services related to dementia. This will be followed by participant experiences related to accessing healthcare support. This theme dealt with questions that explored participants' thoughts, feelings, and challenges related to accessing support services.

We knew nothing about any support services

Most participants reported a lack of knowledge and awareness of dementia-related support services. This was demonstrated through participant responses which ranged from having either zero or extremely limited knowledge of dementia-related support services for their loved ones, with the only exception of finding out about specialised teams or specialists such as the memory team or occupational therapists. Other than these said examples, no other dementia-related support services were reported to be readily available or accessible among participants unless it was found through their own research or recommended by health workers. The support that participants expected to receive from health workers was described to be very poor therefore, most participants reported that they had to turn to self-directed research to source any relevant information, which was also considered to be an additional stressor.

> *"…I had to search up online to find out that there's like, there's this Alzheimer's Foundation and all these like Alzheimer's NZ organisations…but I didn't find out through the hospital, I had to find out myself, like Googling online…"* - *P1 (Female, Age: 30)*

> *"…just like trying to understand what the illness actually is and then finding the solutions out there because I feel like we've had to do a lot of our own research on what's available, and that's been a bit stressful…" - P2 (Female, Age: 32)*

Almost all participants reported no knowledge or awareness of support services available to them as caregivers. Participants communicated that they were left unguided when it came to accessing support for themselves as caregivers. When questioned about their knowledge and awareness of caregiver-related support services, some participants were shocked and surprised as they expressed that access to support for caregivers was not easily accessible nor publicly offered for them to utilise.

> *"…I don't know what's out there because no one's told me anything…" - P1 (Female, Age: 30)*
> *"…I don't know any – of anything to do with caregiver support, like as in to support the carers…" - P5 (Female, Age: 29)*
> *"…I didn't get any of that from anyone like, I didn't know that there was anything for us…" - P6 (Female, Age: 24)*

The cons outweigh the pros

All participants reported that the delivery of care was paramount in building rapport and developing and improving client relationships. The experiences recounted among participants were associated with receiving inadequate support to care. Participants highlighted that the way information was communicated and delivered, including the language used, was 'offensive' or triggering for their loved ones to hear, which eventually related to heightened emotional responses.

> *"…I was a bit mad because I was just like, you're giving us a lot of stuff but you're not literally sitting us down and talking to us…" - P5 (Female, Age: 29)*
> *"…my mindset was like, 'he's not dying'…and then the doctor goes, 'Oh no no, I didn't mean that' and I go, 'Oh that's fine but you know change your approach in the way it's said because it can offend people'… it was just the way he said it made it like it was a death sentence…" - P3 (Female, Age: 33)*
> *"…we always remember the doctor visits, she hated um hearing that she was ill um she called us silly and stupid…" - P7 (Female, Age: 32)*

For example, all participants reported that even the suggestion of placing their loved ones into a rest home was deemed culturally inappropriate and was 'offensive' to them. Based on participants' cultural understanding of care as Samoans which has been detailed in Theme 3, this exemplifies that the current approaches to recommending ‘support’ is not deemed culturally appropriate.

> *“…that is not something I could ever do…it was the cultural aspect…I felt like they, they leant real strongly on the ‘put him in a rest home option’, you know which is probably their job, but I found it quite offensive…”* - P3 (Female, Age: 33)
>
> *“…I remember them telling me when she was sick in the hospital, that to me she might need you know to go in a home or something, I’m like ‘What?…we’re an island(er) family, we don't get brought up like that’, I would never put my Mum in the home so that was not an option…”* - P8 (Male, Age: 30)
>
> *“…every time they come in the first thing is, ‘Oh you know, she should really be in a residential care home’…and I just looked at them like, ‘Are you stupid?’, you know ‘Do you know the Samoan way is you look after your parents?’…”* - P7 (Female, Age: 32)

Some participants also reported experiences of feeling undermined by healthcare workers and that their approach to care or delivery of care lacked empathy and understanding of their realities as caregivers. The delivery of care from healthcare workers failed to construct a foundation that participants felt they could build and place their trust in.

> *“…we just kind of felt like we didn't really matter and we were just a number, like another family with someone who's got dementia…it kind of felt like it was a bit rude just how they, you know put everything on us to try and like just go out look for the help and stuff…”* - P6 (Female, Age: 24)

Participants described poor experiences when it came to completing assessments to access healthcare resources. In addition, the response rate from support services were all reported to be extremely slow, and that by the time a response was received, it was pointless because incidents had occurred already. Due to the delayed response rates, participants resulted in self-funding for equipment which should typically be provided for free.

> *“…I told the doctor at the hospital that we had bought our own things and they're like, ‘No, you should you know call in…they supply that stuff’, but I was like, the process is so long and like by the time she needs it and by the time she gets it, she's already fallen somewhere…”* - P2 (Female, Age: 32)

> *"…you go through the process of having to wait for responses as well from these people but when you're requesting or when you're making an inquiry, it's like you wait like two weeks and that's two weeks that she – at the end of it you ended up just getting yourself anyway, so it was like she could have just had it earlier so yeah that's annoying… it kind of puts you off trying because you kind of just feel like you're not really getting anywhere and then on top of that, like in my head I'm just like… 'just go and get it myself'…" - P6 (Female, Age: 24)*

Most participants also reported the lack of follow-ups from support services and how it was a frustrating process to experience. Some participants noted that it was not until their loved ones reached a point of being (re)admitted to the hospital that they were then able to receive an update about their loved ones' health.

> *"…I just remember all of that: needs assessment, occupational therapist and then it was like nothing for a while, and then she got into hospital and then it was - and then she was back on the radar…" - P2 (Female, Age: 32)*

These participants were burdened with the additional task of having to follow up on the status of their loved ones' health. This contributed to some participants' reluctance or loss of motivation to seek further support from services or eventually cease further support-seeking behaviours altogether.

> *"…we get burdened with a task of having to follow up with everything that they said that they would, you know all the help and the support that they said they would provide us…then it just ends up you know falling back on us to kind of like adjust, and just like work our lives around…it's kind of like you give hope to families you know with this, you know the kind of support and help that they say they're going to give us um and then yeah, it's just kind of doesn't work out that way…" - P6 (Female, Age: 24)*
>
> *"...the annoying thing is you always have to call up, you have to follow up, follow up, follow up and like you're always following up to make sure you get it, which is ridiculous because they should be following up on you letting you know… that's why I think for me, I quit…" - P7 (Female, Age: 32)*

Support that was received

Participants' experiences in regard to receiving support from services differed. Most participants reported negative encounters, while few described positive encounters. Almost all participants reported that the equipment that was provided made a stark and positive difference in providing care. That being said, such positive encounters were only experienced after the fact of several attempts to address the issues.

> *"...it was very hard but then as we got along, as we got the funding, as we got the things that we needed then it just became normal life – after we sorted out the GP [General Practitioner], after we sorted out the OTs, after we sorted out nearly everyone who was part of the health department..." - P7 (Female, Age: 32)*

Some participants also received in-home support services. For these participants that did utilise in-home support services that were recommended and suggested, they reported similar experiences in that their decision to use government-funded caregivers was short-lived. One main reason is that the support that was being provided was associated with unpleasant experiences among these participants. Many of these participants noted that communication and punctuality were inconsistent and thus, their relationship with the in-home support services were cut. Importantly, without the proper support, participants felt that the support was not reducing their risks to stress but rather increasing their risks to stress. In fact, only one participant (P5) could vouch that her experience with government-funded caregivers was pleasant and found no issue with it. From these results, it evidently shows that only 1 in 8 participants have a positive experience with in-home support services, exemplifying the need for immediate action.

> *"...communication was so bad, like so I'd be at work and would place the carer to come in at like say 10 in the morning. This was not just me – like I've heard similar from a lot of other people that were using them. It's not just like one organisation, it was like three different places that were under the government funding whatever thing for the carers and they came, they'd come at like, honestly like four o'clock in the afternoon and so if I didn't come from work on my break to shower him and change him, my Dad would be sitting there until like I'd finished work for him to be like changed and like, oh to me that was like unacceptable – and it wasn't like a one off thing; it was every time that I use them...so I didn't use them long. Like I actually told them, 'You guys are not helping me, yous are stressing me out even more'..." - P1 (Female, Age: 30)*
>
> *"...they are no help to us, 'What's the point?'...like me and my Mum were still doing everything ourselves. There was no point in them coming..." - P3 (Female, Age: 33)*

In saying this, P6 also noted she received impractical advice and felt that although recommendations were given to seek in-home support services, none of the options that she was provided were suitable to cater to her Nana's specific needs. The recommendations were limited to the point that seeking in-home support became hopeless.

> *"…the options that I was given, one of them actually just like didn't exist anymore…they were shut down. So, it's just like you give me an option but you don't even check if they're like still active. So that was like frustrating – my options just kept like being limited and then like I'll call another one up and then they'd be like, 'Oh we don't really have Pacific healthcare caregivers', and then that was another one that I couldn't go through…" - P6 (Female, Age: 24)*

They lacked 'Pacific-ness'

The lack of Pacific representation was a determinant related to the disuse of support services and other general support sought by participants. This was the case for some participants who focused their search for Pacific support for Pacific people with dementia. Unfortunately, these participants in the search for Pacific-ethnic support did not come across as much as they had hoped for. For example, P6 acknowledged the lack of support for Pacific people with dementia when trying to search for available Pacific support. P4, who investigated available Pacific initiatives for Pacific peoples, struggled to find available Pacific initiatives too. P4 detailed feelings of disappointment when she came across programmes that she felt only best suited 'white people'. As such, P4 found accessing available support pointless due to the lack of available Pacific-ethnic tailored support services.

> *"…because I'm a Pacific Islander that's what was lacking… help for Pacific Islander dementia people…" - P6 (Female, Age: 24)*
> *"…I remember trying to like reach out to like certain programmes, like to see if they can help with my Nana…but there's not much – like there's programmes but for 'white' people…but there's not much programmes for Pacific elderly people that have dementia…" - P4 (Female, Age: 25)*

In saying that, participants found that Pacific-like inclusivity shifted their attitude to utilise support services. Participants expressed that having Pacific workers and workers that were the same gender as the person they provided care for made the process to utilise their support services easier, especially when their needs as Pacific people were being met. This looked like building trustworthy provider-client relationships within the home and their family.

> *"…they were Islanders, you know which made it so much easier…they came and met us at home, they wanted to see Dad, you know and then they said, 'Hey, we've got*

> *males, would you like males or females?'...they really catered to our needs, you know we met halfway…and they actually gave us a homecare plan…they are awesome…they made us feel comfortable…" - P3 (Female, Age: 33)*

I needed someone that could communicate

P6 highlighted that finding Pacific support with workers that could speak Samoan was especially important. Being able to communicate effectively was desired among participants, whether it be explaining what dementia was or being able to communicate with their loved ones whose first language was Samoan. Ineffective communication was proven to be associated with not being able to place trust in support workers. That said, finding appropriate and effective methods to overcome the language barrier was a key area that participants felt needed more consideration. For P6, the language barrier was a determinant of not wanting to utilise organisations that offered support for a PWD such as rest home facilities. Participants were exposed to the limitations of seeking support by not being able to find support services that offered effective communication.

> *"…because of the language barrier and stuff like um I guess that's one of the reasons why I also would never put her in a home care or a rest home..." - P6 (Female, Age: 24)*
> *"...I was trying to look for one that specifically spoke and understood Samoan so that my Nana could communicate with them – that was tough…" - P6 (Female, Age: 24)*
> *"…the other nurse she rang me in the middle of the night to tell me…'Do you speak English?, because your Nana doesn't speak English and we don't know how to communicate with her', and then I was like, 'She does understand English, you're not just giving her the time to process the stuff that you're saying'..." - P2 (Female, Age: 32)*

Difficulty accessing support: Rest home facilities

All participants reported several different challenges when it came to accessing healthcare support. This covered accessibility to financial support, support for healthcare resources, and house-related support. For the one participant (P1) that looked into accessing rest home facilities for her Dad, she reported that she was challenged by many barriers that made her question whether she was making the right decision for her Dad at the time. A couple of challenges P1 reported included the lack of guidance throughout the application process and the financial costs that came with putting her Dad in the rest home. This displayed that although support such as rest home facilities were available, feelings of stress continued to be present. P1 did, however, outline that once she was able to find an organisation that approved her application, the service provided within that rest home facility was satisfactory for her Dad.

> *"…putting him into the home was so hard like so many barriers, like everything like stopping me from putting him in. I was like, 'Am I doing the right thing?'… just trying to even get help from the rest home themselves; like they had no idea…I was like, 'How do you place like all these people with dementia in your guys facility and you guys have absolutely no idea about how to fill out these forms?'…I felt like I was getting turned away from like – I'd go to this person and they'd send me to another organisation – I'd go to them and they'd say, 'Oh call this number' and I was going around in circles…" - P1 (Female, Age: 30)*
>
> *"…when I work now, basically like my whole pay goes towards my Dad's bill because I don't get help financially from my siblings – they're not helping at the moment. So, $860 goes a fortnight…it's like I'm paying for rent…I try not to take sick days because my whole pay basically pays for it…" - P1 (Female, Age: 30)*

In spite of the financial support available, P1 reported that accessing financial support to assist with rest home costs was too laborious. The application process and the different requirements that needed approval to receive financial assistance was reported to be a barrier for P1.

> *"…even like stuff of WINZ [Work and Income New Zealand] and stuff…I can't remember what it's called like some subsidy or whatever – to put him into the home…like the paperwork and stuff, it was so hard…" - P1 (Female, Age: 30)*

Difficulty accessing support: Financial support

All participants reported unfavourable experiences with accessing financial support. Participants noted that the processing times were unbelievably delayed, and the application process was difficult to digest and navigate through. Moreover, some participants expressed that the questions and criteria when applying for financial support were emotionally discouraging. This was due to the delivery of care of support workers, which these participants felt the support they were receiving was slack and did not accommodate their specific needs.

> *"…that process is so freakin' long and we got our GP to sign up/sign off on me to get it and then when they apply to the Regional Health Team, WINZ said we needed proof that she needed full-time care…and I was like, she's Alzheimer's, she's like in her 80s, she obviously can't – 'Oh, but we need proof.' and that was really, that was really disheartening because how do you prove how much…" - P2 (Female, Age: 32)*

> *"…it was sad because when I was talking to the lady on the phone, she was one of our own people, you know and she's like, 'But why can't you work?'…and I'm like, 'Okay, I just explained myself to you'…'I've got two babies at home and I look after my Granddad you know, full-time', and she's like, 'Is there no one else in your family?', and I'm like, 'Um are you like trying to advise me? All I want to know is there any kind of financial help I can get?'…and she was like trying to do a whole background check, that didn't sit well with me…" - P3 (Female, Age: 33)*
>
> *"…that's the thing which kind of was frustrating is that these government agencies, which is you know some of them are not as bad, but they get some of these people that they expect you to get the bare minimum…" - P8 (Male, Age: 30)*

Furthermore, such negative experiences with accessing support impeded participants from seeking further support. This was the case for most participants who dealt with seeking financial support from WINZ and eventually ceased seeking further support.

> *"…I'm getting worked up on the phone…it wasn't a nice experience like, so I was like you know some some people will you know understand the situation and then others don't…ever since that, I've just left it there…" - P3 (Female, Age: 33)*

Some participants also reported the dissatisfaction of not being able to receive financial support based on spousal salary. Despite participants whose husbands financially earned too much, these participants were still experiencing financial strain.

> *"…then they were like, 'Oh your husband makes too much money so you can only get a certain amount' and then I was like, 'What was the point of the six-month process?'…" - P2 (Female, Age: 32)*
>
> *"…he earns too much that the government can't fund you know anything – which is hard. Like it's so hard because it's like yeah, he's a courier driver but he pays you know so much taxes, everything, you know it's like owning your own business, like you know what we're left with is enough just to get us by you know, he gets paid monthly. I think that's the hardest…" - P3 (Female, Age: 33)*

Participants who were homeowners also echoed similar responses in terms of the misconception that because they were homeowners, they were financially well off; however, in their realities, it was not the case – these participants also experienced some form of financial strain.

> *"…even though we own places and we have things, but we don't have the money. It's not like we're going to sell our house…like you know, 'Oh yeah but you have a house, your parents own properties'… and 'Okay yeah but do you want my parents to sell the house? Do you want us to go through another mortgage just to get the stuff that we need when you guys can just give it to us?'…" - P7 (Female, Age: 32)*

Accessing the caregiver benefit

Participants that did receive the caregiver benefit reported that the amount of money they were entitled to was insufficient. These participants reported that the financial assistance they received insubstantially compensated for the amount of workload they were responsible for as caregivers.

> *"…I'm getting it, but I feel like we don't get enough…I guess it's just like, we're working basically 24 hours and I just feel like, I think what I just felt like we're taken for granted in a way…" - P5 (Female, Age: 29)*

Finding employment would have a direct impact on the amount of financial assistance received. P5 reported dissatisfaction with restrictions placed on finding employment due to being a full-time caregiver. The financial assistance she was receiving was evidently insufficient, and because of this, she had to discreetly find employment. P5 was able to report the difference in pay between the amount of financial support being received compared to working only two nights (20 hours in total). P5 noted that she was paid more from working just two nights compared to the '24-hour' job of being a caregiver for her loved one.

> *"…when I went to see (WINZ), drop off her form again to let them know that I'm still her caregiver and she's still here, I had asked the receptionist if that was still…if we were still able to do it (find a job) and she said, 'No, because you're her full-time caregiver, that's what we're paying you for' and I go, 'What happened to whether or not we can do less than 30 hours a week?' and so I just went behind their backs and I found a job…" - P5 (Female, Age: 29)*

One participant (P8) reported that he was unsuccessful in accessing the caregiver benefit due to the several complications encountered and lack of flexibility for support while trying to apply. For example, the expectations to have specific documents prepared were impossible for P8 to access at the time without putting his loved one at risk, yet no alternatives were offered.

> *"...I tried to go on a carers benefit and man, they have so much things that you have to do just to get on there...they need me to go and take her into a doctor to get them to umm again, you know kind of diagnose her, if she is able to look after herself. And not only that, I need to get the specialists to write me a recommendation...I said to them, 'Listen, my Grandma was not not really mobile and she's very sick and very immune compromised, so taking her out of bed is a no – absolutely not!'. They basically just said, 'Oh well then'... no alternative, no nothing..."* - P8 (Male, Age: 30)

Interestingly, only one participant (P7) reported knowledge about applying for a lottery grant instead, which was the only way she was able to receive financial support too. Information regarding the lottery grant was provided by the parents and colleagues from her workplace, and concluded to that measure as she was not receiving help, advice, or support from healthcare providers.

> *"...I went through a lottery grant; I went through grants and that's how I got access to what I have for my Mum now..."* - P7 (Female, Age: 32)
> *"...we weren't getting the help that we needed from from the health system and then um I went through my job, it was through my work - my OTs, the occupational therapists, speech therapists, all the therapists who I work with, who I who I put my trust in, they're the ones that helped me get the funding..."* - P7 (Female, Age: 32)

For the remaining participants who did not access financial support, this was entirely due to not being aware of the financial support available for them to access. Notably, one participant (P4) noted that her cultural understanding and beliefs contributed to not knowing about the types of support that were available to access.

> *"...I've never really explored that option, only because like you know it's new to us and like getting paid to be a caregiver...we didn't even know that if that's even possible..."* - P4 (Female, Age: 25)
> *"...it's in our culture, like that we look after our elderly...we've always been conditioned to look after them, like without getting paid..."* - P4 (Female, Age: 25)

Accessing healthcare resources

Most participants reported challenges with accessing healthcare resources. Both negative and positive experiences were reported among participants when accessing healthcare resources. For example, some participants reported that they were left with no choice but to self-fund equipment due to the insufficient support they were receiving and delayed response rates to inquiries, while few other participants reported positive interactions with accessing healthcare resources. Despite the positive experiences, the negative experiences were more prominent among participant responses.

> *"…I had bought stuff from independent living because the process was just so long, like trying to wait for the needs assessment and then for them to come through and then for them to tell us that we only had limited like quota on things…"* - P2 (Female, Age: 32)

Most participants also reported that accessing house-related support was challenging too. This was evident through the majority of participants detailing the different barriers they had to overcome when inquiring about house-related support. The main issue with accessing house-related support was the extremely delayed time to receive the support. For some participants, it took months to receive support, and for others, it took years. Some participants also reported that support was not followed up on from healthcare providers despite being advised that they would receive a follow-up.

> *"…four years ago, we asked for rails around the house just to help her when she's walking, um but didn't get that…we were told at the hospital that we would get it, we were told at like a house inspection that she would get it; we've been told by so many different parties that you know, she'll get it but she ends up not getting it…"* - P6 (Female, Age: 24)
>
> *"…trying to get help with that kind of thing was so hard even getting her to transfer, it took us almost three years. I had to basically get all her medical records, all her hospital visits um records, and email different types of MPs [members of parliament], for Housing/Social Development, the Health Minister…I explained to them that I didn't want my Nana's last few years to be in this cold little house…"* - P8 (Male, Age: 30)

Theme 5: Support Service Recommendations

The fifth and final theme will present recommendations for dementia-related support services based on participant experiences. This explored questions about how to best support dementia caregivers, suggested improvements to better support caregivers, and recommendations of what the best practice of support looks like.

A community for caregivers

When participants were questioned about their thoughts on what they perceived as what would be the best support for them as caregivers, most participants noted the importance of building a community for dementia caregivers. Participants reported the need for a dementia-based community for caregivers to be able to access and felt that it was a key component that was missing within their own local communities. By creating a community for dementia caregivers, participants noted that it would have added value to raising dementia awareness and serve as an additional outlet for them.

> *"…maybe if we like had a group that understands or is going through what we're going through that understands us, then that'll be cool as because they know and understand what we're going through…"* - P5 (Female, Age: 29)
>
> *"…having a community, you know like us PIs [Pacific Islanders], we needa build a community, we need to make this more regular talking to other families in the Pacific community. We need to talk more, we need to let it be known that you are struggling, you are suffering, you have a loved one that has dementia. It's normal, we have to make it normal…we got to make it normal. We got to, we got to change our our perspective of life or like in our culture, we got to change it when someone's sick with dementia – we got to make it normal, we got to make it like it's okay. You know, we just keep keep going…"* - P7 (Female, Age: 32)

Furthermore, some participants also recommended building community support groups that are easily accessible for dementia individuals too. All participants noted that the well-being of their loved ones was their top priority and suggested day programmes specific for dementia individuals only. It was important to create a space where participants could trust to leave their loved ones with support services that specifically catered to dementia individuals rather than a general support service for all elderly. One participant (P4) specifically highlighted the need for formal caregivers that had dementia-specific training to build and strengthen client relationships.

> *"…I would want like a community support group where dementia patients or people like go, and when they go to that community group or like day, whatever they are given like things that can benefit them…"* - P4 (Female, Age: 25)
>
> *"…just a group where there are people like her that she would be able to, I don't know, I guess relate to and then have like certified people like looking after them as a group. Like I would feel comfortable if there was a caregiver…looking after them as a group for a day… just something to look forward to…"* - P4 (Female, Age: 25)
>
> *"…everyone needs to know where like, like a safe place…like a hub for us to meet at…we need to normalise talking about dementia and bringing our loved ones to be (with) others who are just like them…"* - P7 (Female, Age: 32)

Participants noted that having a community support group would have positive impacts on raising dementia awareness as well as dementia education. This could look like acquiring knowledge to deal with the different components of being a caregiver. This could also be demonstrated through education around what specific terminologies mean or assistance with application processes in accessing support. For example, P1 noted that help with understanding the 'legal side of things' and understanding documentation would have been beneficial in ensuring that she was better prepared to care for her Dad.

> *"…it was help with…what is the thing called…welfare guardianship…I was told like early on like, 'Oh you need to go get like enduring power of attorney'…and that time Dad wasn't that sick so I was just like, 'Oh yeah whatever, I'll just look at it after', and then I wasn't aware that like once they become like, like really severe…they can't think for themselves, that you have to apply for that welfare guardian(ship) to become like a guardian for them…when I found out about it I was like, 'Oh my God', they were like...lawyers and stuff...I was like, 'I can't afford a lawyer'…like I'm struggling right now. Like yeah really just help with that, like more information about that…" - P1 (Female, Age: 30)*

Support services need to improve their approaches

Participants reported a number of different recommendations for support that they felt would have made a difference in their journey as caregivers and utilising support services. When participants were questioned about the expectations they had as caregivers in terms of receiving support, the majority noted the importance of receiving culturally competent support. Participants further highlighted the importance of family involvement and family engagement, as well as sustaining relationships and ongoing support throughout their journey as caregivers. Based on participants' experiences, positive outcomes (such as service utilisation) would have likely occurred had there been access to support services that were culturally relatable and incorporated family involvement and family engagement.

> *"…if you come to do an assessment, make sure you mention, oh you know 'Bring your family, I can meet them', you know build a relationship or something…" - P7 (Female, Age: 32)*

Participants also noted the importance of improving the delivery of care from support services. Participants suggested potential changes when it came to the delivery of care by support services. For example, some participants highlighted the importance of client treatment and cultural understanding. These were key components to building a foundation of trust to continue utilising support services and to strengthen client relationships further. Another matter that received attention was receiving support that was purposeful and independently catered to the individual needs of the family, their loved one, and themselves as caregivers. Some participants also recommended for more healthcare resources to be readily available for them to access.

> *"...just really like an empathetic attitude towards it, that would be a big help because yeah, it's so like 'admin' or so like 'ticking boxes' that it's like so rushed..." - P2 (Female, Age: 32)*
>
> *"...she felt like...she wasn't treated like a patient, she was just treated like a person and they were able to just connect just as as if she were like my Aunty coming over, and um that relationship that she built with Nana was really helpful yeah, and it built great rapport between the two and like she, like she had a good relationship with us as well..." - P6 (Female, Age: 24)*
>
> *"...they gotta look into the culture and look into how families are you know...you've got to know their way of life - their culture. 'What offends them?', 'What doesn't offend them?', you know because I reckon if they had that, I don't think we would have changed Mum's OT; I think we changed six times...like it's not like a nine to five job (where) you just walk into a house, assess it, go home, get paid..." - P7 (Female, Age: 32)*

Revision on the period of time in-home caregivers visited was also an area of improvement highlighted among participants. Participants noted that the lack of time being provided by support services influenced their decision to cease ongoing service utilisation.

> *"...just having somebody come in daily, not just...for like half an hour, or like someone to like just genuinely spend time with with her, like just trying to improve on her daily tasks..." - P6 (Female, Age: 24)*
>
> *"...like daily support...like even if it was just like three days a week or something... just something that's consistent, like consistent, consistent support..." - P6 (Female, Age: 24)*

Most participants also highlighted the need for Pacific-specific support to improve service utilisation. This included providing support that could overcome language barriers and having readily available Pacific support for caregivers (and family) to access, particularly at the time of finding out about the diagnosis. This would have looked like having a Pacific support person or an allocated support worker throughout their journey as caregivers.

> *"…if we had some kind of Pacific support person or something within the hospital that was there to yeah, like just kind of explain, like break everything down…" - P1 (Female, Age: 30)*
>
> *"… if we were allocated somebody that was like our person through it because after that initial stuff, we were just left to our own devices…" - P2 (Female, Age: 32)*

For one participant (P7), Pacific-specific support would have looked like having funding specific for Pacific people to access, which was especially important in understanding her individual cultural needs.

> *"…it'd be nice if they have like a Pacific Island funding trust for us…then we can go directly to our people, you know like go through our people that that understand our cultural needs and understand why we're fighting…" - P7 (Female, Age: 32)*

They need to make changes to the criteria

When participants were questioned about what they would like to see differently, some participants reported that the criteria to accessing support needed revision. This recommendation stemmed from participant experiences of struggling to access support, either because their loved one 'was not a priority' or they did not meet the eligibility criteria for financial support.

> *"…her priority level was lower than others and I looked at them and I said, 'You need to kind of change that priority level'. I don't know how your fellas priority level works until they showed me but you still kind of separate the elderly from you know the general other people because you know the elderly don't have very long to live, but the least we could do is you know separate that priority list with you know bigger families and elderly…" - P8 (Male, Age: 30)*
>
> *"…there's a lot of loopholes…I think they got to bring down the criteria, they got to bring down the criteria for for us to access it easier. That's what they got to bring down, the criteria is too high. Like they always bring up all your assets and all of that; you know you may have a house, honestly Mum and Dad own the houses, they may have a property and that, but they don't have the money to you know…they don't have the money to buy a wheelchair straightaway, they (don't) have the money to buy a van straightaway…" - P7 (Female, Age: 32)*
>
> *"…that's the problem, the criteria is too high. The threshold's too high. Like if you guys are earning over this much, then you can't get the funding. I just think it's ridiculous. I just think like even if you're a millionaire, even if you're not a millionaire,*

> *anyone that's struggling, anyone that's going through what we we have gone through - everyone deserves help. That's it. Simple...” - P7 (Female, Age: 32)*
> *“…the criteria is just ridiculous like, if you're sick, you're sick. That's it, you get help - like depending what situation you're in, depending how bad it is, then yeah at least you get something everyone deserves something everyone deserves to get some help…” - P7 (Female, Age: 32)*

Some participants also reported improving access to house-related support too. Participants highlighted that the ‘caring’ environment is vital to be able to provide care to the best of their abilities. By improving accessibility to house-related support, it would contribute to less burden and challenges faced within the home. This was the case for most participants who detailed their challenges with accessing house-related support and how much easier caregiver responsibilities would have been (or became) with accessing such support.

> *“…for me, it would be the place where the person (is) staying because you know your environment plays a lot, you know plays a lot of on I think any carers mind because you know if you don't have access to a place where it's easy to shower and all that kind of stuff and accessibility around your home, it's going to be even more hard…” - P8 (Male, Age: 30)*

They need guidelines for us to follow

When participants were questioned about improvements that could be made by the healthcare system to better support them as caregivers, most participants noted ‘ongoing’ and ‘consistent’ support. Based on the lack of knowledge and awareness of dementia for most participants, ongoing support would look like a ‘timeline of expectations’, a ‘list of phone numbers of faces’ to contact, and progress logs of their loved ones’ health status; all reported to be beneficial had it been offered. In addition, consistent check-ups on caregivers and their loved ones would have been appreciated and easier for participants to seek support and utilise services. Having follow-up appointments to do welfare checks and whether further support was required was another aspect participants felt needed to be included in support services.

> *“…probably just like, like follow-up appointments, more follow-up appointments. Even if it's just a phone call, like on the phone because like just to see how we're doing after the diagnosis and like you know, is there anything else that we need from them…” - P1 (Female, Age: 30)*

> *"…if there was some kind of, like timeline expectation like in the beginning – 'so it seems like your Nana has this and this; so from here we're going to…' – and they just lay out, plain and simple, what's gonna happen…" - P2 (Female, Age: 32)*
> *"…maybe just like a basic understanding, like a cheat sheet on…what to expect…" - P4 (Female, Age: 25)*
> *"…like something that we can actually be provided with to actually to be able to monitor like her progress…" - P6 (Female, Age: 24)*

This further emphasised the need for specifically tailored home-care plans to help guide caregivers and their families. Participants noted that receiving more support within the home in terms of different activities, methods, or techniques they could implement in their routines would be useful. Some participants also highlighted the importance of family support and how impactful it would have been if received. Developing better home-care plans for families could have a positive impact on family dynamics within the home. This was evident through the association between participant experiences of family support and maintaining healthy family relationships, which led to more positive outcomes such as having less caregiver burden.

> *"…the main support will probably just be like daily support, just helping her exercise…like physical exercise, and something to exercise like her brain and stuff…if I had that kind of help or support, it would actually benefit all of us, most importantly her a lot…" - P6 (Female, Age: 24)*

Another key theme highlighted by participants as a recommendation was providing access to counselling services. Being able to discuss challenges with people outside of the family was an idea some participants felt strongly about because it avoided judgement or being labelled as 'complainers'. Being able to discuss the caregiver experience was instrumental in realising and releasing any suppressed mental and emotional loads.

> *"…also some counselling as well you know, like yeah you get fed the Word of God from your faife'aus [pastors]…but you just need some real talk sometimes…sometimes you don't need people to talk, you just need some people to listen…" - P7 (Female, Age: 32)*
> *"…for people like us who looked after the elderly with dementia or any type of sickness, just to have like a…like a phone number to ring to talk about it and stuff like that, it would have been…would have been nice because this was, this was quite relieving to talk about…makes me feel significant now…" - P8 (Male, Age: 30)*

One participant (P5) also expressed that having more recognition for the work caregivers do would be helpful in terms of gaining more positive emotional outcomes such as feeling adequate and appreciated as caregivers.

> *"...I don't want to be selfish but us to be noticed more in a way that we – that there is carers that exist, that we do exist, and you know I think that's the main one is just us getting, yeah just being noticed for all the stuff that we do, not just for myself but any other...because I don't know any other caregivers in our community at all, like I don't know anyone that does what I'm doing with her…" - P5 (Female, Age: 29)*

CHAPTER SUMMARY

The findings demonstrate that most participants lacked knowledge of dementia, highlighting the need for raising dementia awareness. Participants' understandings of dementia were limited by making associations to memory loss, forgetfulness, and a normal part of ageing which had subsequent consequences in the delay of diagnosis. This pinpointed the lack of support provided at the time of diagnosis as most participants conducted self-directed research and had to deal with, behind closed doors, a new understanding of the full extent of the condition, which was mentally and emotionally overwhelming for some. Notably, the term 'dementia' is not conceptualised in the Samoan language, and some participants highlighted the difference in understanding dementia had it been normalised within the Samoan culture.

The subsequent experiences of providing care for a loved one with dementia were mostly associated with negative caregiver outcomes. Most participants spoke about the mental and emotional challenges they faced as dementia caregivers attributable to the progression of the disease and life experiences, such as managing more than one role within the household or the effects it had on family dynamics. Participants also reported the social impacts as a result of assuming the caregiver role, which accordingly resulted in social isolation. Notably, there was a clear difference between participants who received adequate family support compared to those that did not receive family support. This highlighted the key role family support can have for participants to experience less caregiver burden. That said, participants also named several coping mechanisms to deal with mental and emotional distress and were mostly associated with different methods of removing themselves from the caregiver environment, such as using another space within the home to listen to music or engage in breathing techniques, or keeping their minds occupied by cooking or cleaning.

Fa'a Samoa was central to participants' understanding of care, especially providing care for their loved ones. All participants underlined a moral and cultural obligation to provide care and support for their loved ones. It was perceived as an 'opportunity' or 'blessing' or 'their duty' to be able to repay their loved ones by serving them by providing care and support for them. Participants' religious beliefs also played a central role in their understanding of care. That being said, all participants also shared similar views that seeking support and utilising services such as rest homes went against *fa'a Samoa*. These views were attached to the stigma of abandonment and were also driven by fear of judgement and shame from extended relatives. Additionally, some participants were conflicted by *fa'a Samoa* and caregiver duties which had an effect on the dynamics of their families.

Collectively, most participants had very poor knowledge of available support services and the type of support they were entitled to access. Most participants also experienced similar challenges in regard to accessing support for themselves as caregivers. A key issue that hindered service utilisation among participants was the delivery and approach to care by support services or healthcare providers. Most participants felt that support services lacked cultural depth in their delivery of care, which led to experiences of being offended or insulted by healthcare professionals. Poor delivery of care essentially impacted some participants' decisions to cease ongoing support from services such as in-home care or built mistrust of utilising other support services too.

Participant experiences in accessing healthcare support were mostly negative which contributed to increased caregiver burden. Some challenges faced by participants ranged from barriers with communication and language, slow turnaround times for application processes, and poor follow-up processes. Another key issue associated with accessing support services was affordability. Due to the lack of support being offered or accessible, most participants were unaware of the financial assistance available to them and so resorted to out-of-pocket expenses that were extremely costly. Seeking access to financial support was also obstructed by not meeting the criteria to receive funding; participants voiced the financial hardship their families continued to experience, despite being categorised under the ‘criteria’ as financially secure. Additional issues related to accessing financial support was the rigid system currently in place, which impacted the number of financial entitlements participants could receive and not being able to find employment. As such, other avenues were explored by some participants such as lottery grants to be able to gain any sort of financial aid.

The most prominent recommendation expressed by almost all participants was the need for a dementia-based community for both the caregiver and their loved ones. Creating a community was a desirable outcome for these participants as they strongly felt it would have helped in their understanding of different areas that come with caring for their loved one with dementia. This would have helped with raising knowledge and awareness of dementia, beginning discussions around normalising dementia within communities, and ultimately leading to more positive caregiver health outcomes. Other recommendations participants strongly felt about were improvements in approaches to care, revision of current eligibility criteria and thresholds, development of individually tailored care plans, and ongoing, consistent support that is readily and easily accessible.

CHAPTER FIVE: DISCUSSION, CONCLUSION & RECOMMENDATIONS

The final chapter of this thesis presents the final discussion, conclusions, and recommendations. This chapter begins by discussing the findings of this study compared to the wider literature on dementia caregivers, followed by the study’s strengths and limitations and resultant policy implications. This chapter then concludes with future research recommendations within the domain of Pacific dementia caregivers and summarises overall study conclusions.

DISCUSSION OF FINDINGS

This research study aimed to explore and gain a better understanding of the experiences of Samoan caregivers of loved ones with dementia, both past and current, who currently reside in the Auckland region.

1) **The first research objective was to conduct semi-structured interviews in the form of *talanoa* in order to gain insight from the perspective of Samoan main caregivers, understanding the different components of care when caring for someone with dementia.**

This objective had two main components: (1) Knowledge and awareness of dementia and (2) Experiences as a caregiver for a loved one with dementia. Accordingly, relevant findings will be presented.

Theme 1: Knowledge and Awareness of Dementia

If only I had known about dementia

Across several studies, clear deficits are observed regarding dementia knowledge. The same trend is observed within the findings of this study, whereby all participants collectively had poor knowledge and awareness of dementia too. The difference for participants who had little knowledge about dementia compared to those who had no knowledge whatsoever was minimal – both sides reported a level of understanding that was lacking, which inevitably led participants to conduct self-directed research (using Google) to find information about the full extent of dementia. This raises several questions around current public health awareness initiatives and the extent of accessible information available to the public too. This also suggests that there is a need for improved dementia awareness among communities as well as the need for improved access to dementia information. Existing literature points out that good knowledge of dementia is crucial for the provision of appropriate care and decision-making as caregivers. It also points out that gaining the correct information about dementia is a vital part of long-term management of dementia (Robinson et al, 2014; Soong et al, 2020). Improving knowledge can develop caregiver confidence which leads to positive outcomes on caregiver burden and anxiety (Teichmann et al, 2022). Similar to the findings of this study, had participants known the full extent of dementia, they may have experienced less burden in the early stages of dementia diagnosis and be better prepared with methods of providing care for a PWD.

One of the prominent consequences from the lack of knowledge and awareness of dementia was the misattribution of dementia. This was the case for almost all participants who made associations between dementia symptoms, such as memory loss and it being a normal part of ageing. Resultantly, this delayed the diagnosis of their loved ones. The findings of this study show that most participants observed behavioural changes attributable to dementia yet did not receive a formal diagnosis until their loved ones required medical attention. This highlighted the importance of raising awareness of dementia as it could be crucial in identifying key dementia symptoms, particularly for early onset of dementia. Given that there is a projected increase within the Pacific population attaining early-onset of dementia, this is important to consider. Based on the findings of this study, it can be assumed that knowledge of dementia could have potentially prevented late detection of dementia and delayed diagnosis too. Knowledgeable caregivers function as early-warning systems in early detection of dementia symptoms (Sadak et al, 2017). By detecting symptoms early, symptoms can potentially be delayed, and families can adequately adjust and plan for the future (Teel & Carson, 2003; Bullard et al, 2016). At the same time, Fox et al (2013) argues otherwise that no absolute evidence exists regarding early diagnosis and improved health outcomes for people with dementia and their caregivers. Despite these views, participant experiences of this research study suggest otherwise.

The findings also show that the lack of knowledge and awareness of dementia had emotional impacts on some participants too, which was reflective of being ill-equipped to deal with the progressive stages of dementia symptoms. This raises concerns regarding the need for dementia education to improve the knowledge and awareness of dementia. With adequate preparation, caregivers will have the knowledge to make early detections of symptoms and potentially prevent the risks of their loved ones sustaining further injuries (Sadak et al, 2017). This is highlighted in relevant literature that places emphasis on understanding dementia as it is crucial for decision-making, particularly during the more advanced stages of dementia (Andrews et al, 2017).

The findings also highlight the need for dementia to be conceptualised within the Samoan language. This demonstrates the absence of the term ‘dementia’ within the Samoan culture, which suggests the need for raising dementia awareness within Samoan communities that is culturally meaningful. For example, one study reports that the current (American) Samoan terminology used to describe dementia include: *‘vale vale matua’, ‘magalogalo’, and ‘lotogalo’*, all of which reflect derogatory language (Williams et al, 2021). Such terminology could potentially discourage individuals from seeking a formal diagnosis due to the associated stigma attached to having a family member with dementia. It can also create misunderstandings or the chance to spread misinformation about the condition within Samoan communities which can have indirect negative effects. For example, the stigma associated with dementia could make family members embarrassed about the condition. Therefore, they do not seek support from extended family members in fear that they would be putting themselves in a position to be judged, meaning family caregivers become more socially isolated. This underlines the importance of having dementia properly conceptualised within the Samoan context. It can also aid in the design of culturally appropriate information that healthcare professionals can provide or incorporate into their delivery of care.

Theme 2: Experiences as a Caregiver for a Loved One with Dementia

Caregiver stress

The findings of this study demonstrate high levels of stress among participants which is consistent with multiple studies. Caregiver stress is important to address, given that it can affect several dimensions of caregiver health and health-behaviours, ultimately leading to negative health outcomes (Son et al, 2007). Caregiver stress has been reported to be harmful (Bertrand et al, 2006; Zahed et al, 2020) and has been observed to be higher in dementia caregivers compared to non-dementia caregivers (Bertrand et al, 2006).

Mental impacts

The findings of this study show that all participants had challenging experiences as caregivers for their loved ones with dementia. The progression of dementia symptoms, behavioural and personality changes, lack of dementia knowledge, and caregiver responsibilities all contributed to the mental, emotional, and physical decline and distress participants experienced. Notably, the consequences of experiencing mental impacts for some participants influenced the mental health of their family members too. Dementia family caregivers must face the reality of the condition which can make the caregiver role mentally difficult to cope with. Essentially, family caregivers experience the loss of intellectual and emotional reciprocity between their loved ones, which continues to increase as the condition progresses over time (Bertrand et al, 2006). Existing literature details very similar caregiver experiences (Zahed et al, 2020) consistent with the findings of this study. Interestingly, Brodaty & Hadzi-Pavlovic (1990) reports that dementia caregivers are not distinctively depressed but instead experience general psychological distress. However, the current findings demonstrate that psychological distress had strong associations with depressive symptoms and were experienced simultaneously.

Emotional impacts

Dementia can be emotionally challenging to cope with too (Bertrand et al, 2006). According to Zahed et al (2020), dementia caregivers often experience emotional strain that can eventually result in emotional fatigue and occupational burnout. In the present study, emotional strain was predominantly experienced by all participants which affected several different aspects of their caregiver experience. A main contributing factor that impacted the emotional well-being of participants was the struggle to cater to and fulfil the dual roles they had within- and outside- of the home. Consistent with the findings of Zahed et al (2020), participants who cater to motherly duties, support their children as well as provide support for their older parents at the same time can affect the quality of their family life and interfere with their ability to provide care for their family too. Bainbridge et al (2006) report on the idea of depletion perspective, which effectively forces trade-offs between over-committing to one role while reducing energy and resources that could be assigned to the other. The findings of this study also showed that the feelings of being a burden and guilt were strongly felt among participants which prevented them from seeking external help or support. In addition, the fear of judgement was another strong emotion associated with the decision-making in utilising services such as rest homes. This effectively caused suppression of emotions and mental and emotional distress by some participants. Although judgement from others is unavoidable, support with learning to manage ones' emotions and interventions around learning how to deal with changes can be useful. Implementing effective social support can assist dementia caregivers to prepare and adjust to changes that occur post-bereavement too (Dempsey et al, 2020).

Social impacts

The present study demonstrates the same 'isolating effect' caused by most of the mechanisms described. For example, some participants experienced some form of social isolation, forcing them to put life commitments on hold such as ceasing employment which directly impacted their family dynamics. The expectation to be simultaneously employed and provide full-time care was associated with feelings of inadequacy because being a family caregiver on its own was perceived as 'not a real job' by others. As such, this could have possibly played a role in clouding participants' perceptions around support-seeking behaviours, further solidifying the importance of improving current supports in place. The social isolation and social inactivity experienced by participants further reiterate the need for caregiver support. Brodaty & Hadzi-Pavlovic (1990) report that dementia has an isolating effect which can be attributed to several possible mechanisms such as dementia individuals' need for intensive support, financial constraints, anxiety and guilt in caregivers, or social stigma and embarrassment by friends and family. This is important to address because social isolation is associated with increased morbidity and is linked to several diseases such as cardiovascular disease (CVD) and stroke (Kovaleva et al, 2018). Given that Pacific peoples have higher prevalence rates of CVD risk factors, these findings help highlight more target areas that would benefit future action plans and implementation of interventions when supporting dementia family caregivers.

Prior formal caregiver experience made a difference

Previous experience in caring for a PWD is associated with significantly lower caregiver stress scores compared to those that have assumed the caregiver role for the first time (Zahed et al, 2020). The findings from the current study highlight this need for training, given that some participants had more positive experiences with prior knowledge and training compared to those that did not. Prior caregiver experience proved to be beneficial and helpful for those specific participants in this study. Teel & Carson (2003) support this notion as they emphasise the need for education and training in the caregiver role as family caregivers are not intuitive. They further argue that knowledge about caregiving and the ability to apply that knowledge into practice are critical skills to have in the caregiver role. This eventually raised the implication that prior experience within the caregiver role may be able to lessen the mental, emotional, and physical burdens experienced by caregivers overall. This is consistent with the findings of Zahed et al (2020), who stress the importance of relevant training in understanding and managing dementia behaviours as well as how to deal with emotions to experience less stress overall. This outlines the importance of dementia-specific training and education, as these findings were able to show the difference in attitudes and experiences within the caregiver role. This meant that dementia-specific training would have been extremely helpful for all participants considering that the lack of knowledge about knowing what to do simultaneously impacted participants' mental health too. This further highlights the need for dementia-related training and interventions to better support family caregivers too. Hepburn et al (2001) suggest that improving knowledge of dementia and providing dementia-related training is associated with positive caregiver outcomes. The findings of Hepburn et al (2001) outlined a notable difference between the treatment group and the control group (i.e., those who received training versus those that did not receive training). Resultantly, there was an association between better caregiver outcomes such as more positive emotional effects and receiving training.

Family impacts

All participants reported some form of impact on their family dynamics as a result of taking care of a loved one with dementia. A strong family support system proved to have mental, emotional, and physical benefits as caregivers for the participants of the current study. At the same time, a lack of family support proved to have negative impacts including pressuring one participant to be morally and culturally conflicted, eventually leading to adverse outcomes. This reflected the importance of strong family support systems within the home; the management of care must look beyond the PWD and begin including both caregivers and their families too. Although dementia-related care plans and action plans already strive for this, the findings of the current study show that much more effective work needs to be done within these spaces. This is consistent with the findings of several studies, highlighting the importance of acknowledging the impacts of having strengthened familial relationships for better outcomes. For example, family involvement/engagement can help relieve caregiver burden. One study shows that family conflict negatively impacts the family caregivers' ability to cope (Meyer et al, 2015). Family conflict can be a source of stress for dementia caregivers. A factor to consider is the impacts of acculturation from the dominant country and its social norms. The impacts of acculturation can influence one's decision to assume caregiver responsibilities and thus, look into institutionalisation as the best decision. Different levels of acculturation to Western values can cause intergenerational tension causing additional burdens (Sun et al, 2012). The emotional relationship between family caregivers and their loved ones with dementia is also a contributing factor to caregiver stress (Zahed et al, 2020).

Coping mechanisms

Participants reported several different coping mechanisms that alleviated their stress. All coping mechanisms were essentially activities that allowed participants to remove themselves from the caregiving environment or situation and focus their minds and enjoy other activities to mitigate any feelings of stress. All coping mechanisms had benefits to participants' overall well-being. These types of mechanisms are well-documented across several studies (e.g., Sun et al, 2012). Evidently, the mental, emotional, and social impacts are ongoing issues that can be addressed for the betterment of all parties involved. These findings show the possible things to consider in the development of interventions or different types of support that services may be lacking in, so they can be implemented to best support dementia family caregivers for future reference.

It is also a blessing

Almost all participants reported that although caring for a PWD was challenging, they also formed positive perspectives of the caregiver experience based on their relationship to the person they were providing care for – these participants described their experience as a 'blessing'. This highlighted the importance of the role of family caregivers. Not only do these findings emphasise that families provide the best form of care but they also demonstrate the positive side of the caregiver role, which is rarely discussed in the literature. These findings demonstrated several different positive outcomes as caregivers, all of which had direct effects on participants' overall well-being. The findings showed that a shift in attitude and perception of dementia can effectively lead to more positive outcomes and reduced mental and emotional stress. Acceptance of the caregiver role is linked to decreasing anxiety and resistance to care, so it is always important to assess 'acceptance of' and 'preparation for' the caregiver role (Huang et al, 2015).

2) **The second research objective was to understand whether the current health system works for Samoan caregivers by exploring the available resources or sources of support that they can access and how aware they are of the available public health services in New Zealand.**

This objective had two main components: (1) Samoan perspective of care and (2) Knowledge of support services and accessing healthcare support. Accordingly, relevant findings will be presented.

Theme 3: Samoan Perspective of Care

Culture has played a huge part as a caregiver

Fa'a Samoa guided all participants in their understanding of the provision of care. All participants highlighted that their role in becoming caregivers was influenced by their moral sense of duty and valuing reciprocity. Participants felt indebted to their relatives and that the caregiver role was a means of repayment and service. These findings are consistent with Pharr et al (2014) who emphasise that caregiving is culturally ingrained. These authors proceed to describe the provision of care for a loved one as being deeply rooted in cultural subconsciousness, and that caregiving occurs naturally without any given thought to it.

The findings of this study show the important role culture plays within the caregiver role, offering a Samoan lens in the provision of care. Understanding care through a Samoan perspective highlights fundamental factors that can improve the delivery of care as well as the development and implementation of support services. This can extract key deficits while addressing the issue of inadequate ethnic-specific support for caregivers that exist. A cultural lens can also help us to understand the effects of the Stress Process model, which is beneficial for dementia caregivers in the long run (Sun et al, 2012).

Furthermore, belief and faith in God, which is an important aspect of *fa'a Samoa*, contributed to the understanding of the provision of care. A frequent Bible scripture participants referred to was, *'Ia e ava lou tamā ma lou tinā'* (Honour your father and your mother). Participants strongly felt that providing care was an act of service. Christianity has always been important in the Samoan social construct. These findings show that faith-based environments could contribute to less stressful situations. This shows the importance of value systems in the provision of care too. As such, recognising cultural and religious beliefs are important aspects of culturally competent and safe care (Frey et al, 2016).

The findings of this study also show that participants' roles within the family also influenced their understanding of care and expectations as Samoans. The role, responsibilities, and expectations of being the eldest in a Samoan family contributed to participants' decisions to become caregivers too. These findings are consistent with several studies detailing the importance of one's position and their role within a Samoan family or social construct. Research proposes that fulfilling or upholding cultural obligations can come at the cost of dementia caregivers experiencing stress and burnout (Sun et al, 2012). Although the findings of this study demonstrated similar effects, it also showed that upholding cultural obligations had positive effects too, such as understanding their caregiver role through a lens of gratitude and blessings.

Fa'a Samoa and support-seeking behaviours

Cultural beliefs, values, principles, and attitudes are elemental for seeking support (Sun et al, 2012). The findings of this study reflected this notion, whereby cultural beliefs influenced support-seeking behaviours among participants. Abiding by *fa'a Samoa* meant that seeking external support was never considered. At the same time, the findings also highlight that the fear of judgement and shame in relation to *fa'a Samoa* were prominent reasons as to why support was not sought after either, which is consistent with other studies too (e.g., Macleod et al 2017; Parveen et al, 2017). Research suggests that without adequate support, it could potentially lead to caregiver burnout and the institutionalisation of loved ones (Robison et al, 2009). However, the findings of this study showed that cultural values and cultural understandings of care opposed this perspective. The current study demonstrated that even without adequate support, most participants felt that their cultural obligations solidified their decision to avoid institutionalisation and to provide care and support within the home setting. This further accentuates the important role of culture in understanding the provision of care to be able to provide the best form of support among Pacific communities.

Samoan care versus Palagi care

Some participants also reported conflicts between *fa'a Samoa* and providing Western practices of care. Otis-Green & Juarez (2012) notes that the way family members define caregiving is influenced by culture. The Samoan cultural orientation is deeply rooted in collectivism, where family involvement is highly valued and thus, has a holistic understanding of care (Joines & de Chesnay, 2011). Similar to Zahed et al (2020), the findings of this study also highlight that unpacking cultural nuances can contribute to improved understanding for clinicians and support services to provide culturally competent care.

Differences in cultural values and norms also shape the caregiving experience (Pharr et al, 2014). For instance, differing cultural views can create high levels of discomfort and anxiety based on decreased feelings of familiarity (Frey et al, 2016). The findings show that having a lack of cultural understanding raises the risks of cultural conflict and confusion between health and support workers, and family caregivers, which may inhibit further support-seeking or returning for care. Factors that contribute to the conflict between healthcare providers and Samoans include language barriers, unclear communication, and lack of knowledge around health policies (Joines & de Chesnay, 2011), all of which have been reflected in the findings of this study.

Health and support workers also need to understand that the perceptions and meanings of health and illness are critical when working with those of a different ethnic or cultural background before providing any teachings or care (Joines & de Chesnay, 2011). The findings of this study support this notion seeing that participants' cultural understanding of care was pivotal in their decision-making to provide care and support for their loved ones. One psychology-based theory that can contribute to a better understanding of how culture influences well-being towards more culturally competent care is Watson’s Theory of Human Care (WTHC). Watson’s theory consists of 10 ‘carative’ factors that have an intrinsic focus on what is meaningful to the individual. This theory asserts for the mind, body, and soul to work in holistic harmony (Joines & de Chesnay, 2011). Therefore, WTHC can be a steppingstone in understanding the Samoan perspective of care from a Eurocentric lens which can be useful to guide non-Pasifika clinicians and support service providers that are unaccustomed to Pacific cultural constructs of caregiving.

Theme 4: Knowledge of Support Services and Accessing Healthcare Support

Knowledge of support services

The findings from the current study showcase that available support services were either inaccessible or unknown among participants. Macleod et al (2017) and Parveen et al (2017) echo similar results to the findings of this study in terms of inadequate access to information about relevant services, poor quality, mistrust, or inflexibility of services which effectively has a direct impact on service utilisation. This demonstrates the lack of health promotion around dementia-related support services, highlighting how much it needs to be improved at the community level. Notably, research argues that the level of uncertainty by healthcare providers can leave important issues unaddressed, as they subconsciously make assumptions and stereotypes regarding patient wishes. One study reported that limited information was provided for Māori, Pacific and Asian patients based on the assumption that they would not utilise the service (Frey et al, 2016). Although the findings highlight the importance of raising dementia awareness or awareness around support services, it should be understood that raising awareness does not directly facilitate help-seeking behaviours either (Parveen et al, 2017).

The delivery of care

The findings of this study also reflect similar trends in other studies, highlighting the little improvement that has occurred within the care delivery system over time. The findings of this study show that the principal reason that affected participants’ engagement in utilising support services was the poor quality of delivery of care. This was clearly demonstrated by the several bad experiences reported by the majority of participants. Factors such as poor communication, poor punctuality, participant needs not being met, and delayed response times from support providers were prominent reasons as to why the utilisation of in-home support services was short-lived. Addressing such issues is crucial because poorer health service utilisation contributes to poorer health status (Wright & Hornblow, 2008). For example, one study by Robinson et al (2013) reported that dementia caregivers who did not utilise services were more depressed, less burdened, and received less social support. An important aspect to keep in mind though, is that the dementia caregivers in the study by Robinson et al (2013) supported people with dementia who were less impaired and had fewer behavioural problems, which explained the less burden participants experienced.

Pacific representation is important

Several additional factors hindered participants from accessing support services including the lack of Pacific representation, language barriers, affordability, difficulty with application processes, and bad initial experiences from service providers. In New Zealand, the bio-psycho-social model predominantly guides health practices, which excludes the spiritual domain that is central for Pasifika peoples (Fa'alogo-Lilo & Cartwright, 2021). This highlights the misalignment of cultural perspectives and expectations compared to the current health approaches in place (Tevaga, 2021). It also highlights the importance of addressing systemic biases and unmasking disparities, which can uncover the impacts this has on valuing Pacific ways of being (Tevaga, 2021). Creating a comfortable environment that integrates and reflects 'Pacific-ness' was especially important for participants in the present study. This is important because building and maintaining relationships are central to the Pacific way of being (Tevaga, 2021). It is also important because having a system of knowledge and practices that is culturally understandable is needed as it can shape responses to treatment (Fa'alogo-Lilo & Cartwright, 2021).

Communication is important

Effective communication and overcoming language barriers were important for service utilisation for some participants. The fact that information is typically provided in English means that accessing services can be difficult for caregivers from linguistically and culturally diverse backgrounds (Macleod et al, 2017), which underlines the importance of effective communication. Research suggests that effective communication can be impacted by gaps in knowledge about cultural differences and the lack of intercultural communication skills, which is associated with the quality of care (Frey et al, 2016). Addressing the issues within cross-cultural communication can tease out ethnic disparities in accessing healthcare therefore, identifying intercultural communication is a critical step to adapting and working with diversity (Frey et al, 2016).

Accessibility to support

In the findings, participants reported several different challenges in accessing different forms of support including financial support, support for healthcare resources, and house-related support. Consistent with the findings of this study, the results of a study by Robison et al (2009) demonstrate that inadequate support and financial burden are the strongest predictors of health and psychosocial outcomes. Several components have impeded dementia family caregivers from utilising services such as stigma, financial concerns, caregiving beliefs, lack of information on available services, and poor service quality overall in terms of its trustworthiness and effectiveness (Macleod et al, 2017). Parveen et al (2017) report that identifying (mis-)conceptions around dementia can serve to inform initiatives or dementia-specific awareness work. This is important because it can address caregiver burdens that have a direct negative impact on caregiver health outcomes. One way to resolve such issues could be through finding employment. The findings of this study show that employment outside of the caregiver role was associated with lower stress outcomes. Similar findings can be found by Bainbridge et al (2006), where multiple roles may reduce stress due to the role of the enrichment effect, which contends that energy can be expanded leading to net gratification, meaning that having multiple roles can outweigh the associated costs. Though at the same time, employment outside of the caregiver role can simultaneously be just as stressful, so interpretation must be done with this in mind.

Service utilisation is important

Service utilisation and interventions have proven to be beneficial for dementia caregivers. Service users have been demonstrated to improve targeted problematic behaviours, enhance confidence in managing problematic behaviours, reduce negative reactions to all behaviours, decrease caregiver burden, and improve overall well-being compared to non-service users (Robinson et al, 2013). Lower levels of depression have also been reported for caregivers who utilised services compared to those that did not (Robinson et al, 2013). For dementia caregivers who did not utilise services, 53% reported depressive symptoms. Important to note is that most of the sample used in this study were well-educated (91%) and white (93%), which reflects a lack of cultural diversity therefore, being less representative of ethnic minorities and so does not reflect the population sample of this study. Based on the findings of this study, utilising services was an added stressor for some participants due to the poor quality of delivery of care and the lack of culturally competent support being provided. Even with the engagement with support services, some participants continued to encounter mental, emotional, and social burdens of the caregiver role.

3) **The last research objective was to contribute to the research gap that evidently exists concerning informal Samoan caregivers in New Zealand.**

This objective had one main component: (1) Support service recommendations. Accordingly, relevant findings will be presented.

Theme 5: Support Service Recommendations

They need a community for caregivers

These findings indicate several implications for clinical practice and policy-making. Findings show that participants had several recommendations in terms of improving support services that would effectively lead to increased engagement and utilisation of support services. The findings strongly advise the need for developing community initiatives and Pacific-based support groups for dementia caregivers. Participants also strongly advised on ethnic-specific day programmes for people with dementia to access too. This was perceived as the most suitable way to build trust between families and service providers as it aligned with their cultural beliefs of not placing their relatives in ARC. It was also just as important for participants to leave their loved ones with caregivers who had dementia-specific training compared to those without dementia-specific training. According to Chavis et al (1986), four elements are integral to a sense of community: membership, influence, integration and fulfilment of needs, and shared emotional connection. As suggested by the findings of this study, these four elements were desired among participants bringing forth the importance of creating a sense of community. In addition, these elements happen to also align with aspects of *fa'a Samoa* and the holistic view of providing care. Integrating these elements in relation to *fa'a Samoa* can be significant in the development of future dementia communities.

Building rapport through a Samoan lens

The findings show that relationship building and involving the family were critical points that participants felt would have made a difference in service utilisation. The findings further show that involving the family and improving family support systems within the home would have reduced caregiver burden and caregiver stress. Research around understanding care from the Samoan perspective points out that care is viewed holistically, whereby collective family involvement is highly valued (Joines & Chesnay, 2009). Based on the findings of this study, independently assessing, and guiding the diverse needs of family caregivers can improve the quality of life within the home and decrease caregiver workload and stress (Azevedo et al, 2021). It may also be beneficial for service providers to review and adjust their approach to community engagement work too (Parveen et al, 2017), given that bad experiences with support services were extensive in the current study.

The findings also strongly advise for culturally competent approaches to care because it was perceived to add value to overall client treatment. Culturally competent care brings forth positive health outcomes as it can meet the health needs of diverse communities (Kim-Godwin et al, 2001). To develop effective interventions, it is especially important to integrate the values that are embedded in the Samoan culture. The findings of Parveen et al (2017) support this notion whereby culturally sensitive health promotion interventions could be beneficial. As such, it is imperative to integrate Samoan culture into care plans to provide the most appropriate care alongside Samoan communities (Joines & de Chesnay, 2009).

Criteria changes and additional resources

The findings also strongly advise for the revision of the criteria for accessing different forms of support. Two key points included creating both a safe and accessible environment for caregivers as well as receiving information at the start of the caregiver journey, such as a timeline of expectations and progress logs throughout the journey as well as overall welfare checks not only for their sick relatives but for them as caregivers too. This introduced the need for receiving individually tailored healthcare plans and frequent revision of care plans. The need for learning different methods and techniques that could improve their provision of care was also highlighted. As a result, this would lead to more positive experiences with support services thus, improve service utilisation overall too. Similar findings are detailed in research whereby key facilitators that enhance caregiver accessibility to support services include good communication, an ‘expert’ point of contact, and caregiver beliefs that enable caregivers to utilise services (Macleod et al, 2017). The findings also recommended the need for other avenues of support to access, such as counselling services specifically for caregivers. Given the mental and emotional strain the role of caregiving presents in these findings, counselling services can be immensely impactful. The benefits of sufficient counselling and support is associated with achievable health and overall well-being caregiver outcomes (Mittelman et al, 2006). Not only do these findings highlight the lack of information and support provided for caregivers in accessing such supports, but it also demonstrates that caregivers continue to be seen as less than for the valuable work they do. Overall, this demands to ameliorate implementations for better caregiver health outcomes and service utilisation specific to Samoan (and Pacific) communities.

STUDY STRENGTHS

This study had several strengths. This is the first study of its kind to explore a previously unresearched Pacific subgroup (Samoan caregivers, past and current, of loved ones with dementia in the Auckland region). This adds value to Samoan-specific experiences as current research typically investigates the Pacific population as a whole. This study theorised and implemented a Samoan-specific research methodology (*Fa’afaletui* model) which acknowledged and considered *fa’a Samoa* and afforded the Samoan worldview. This study is also the first to use this Samoan-specific methodology in the context of dementia caregiving. When doing research with minority groups, the positionality and lens of the researcher is an important element to consider. This study has employed the role of the researcher, as a young *tama'ita'i Samoa* raised in the Auckland region for the past 25 years, with a strong knowledgebase of *fa'a Samoa*. This ensures that the overall research was implemented and delivered in a culturally appropriate and culturally meaningful way. All participants also had no prior or pre-existing relationship to the researcher therefore, any conflict of interest was avoided. As such, participants had a strong willingness to share their experiences in-depth openly and thoroughly as caregivers, particularly when it came to sensitive topics such as family dynamics.

This study also had a section that focused on participants' positive outcomes related to their role as caregivers, presenting a different angle compared to what is typically investigated in existing literature related to dementia caregiver experiences. This demonstrated the importance of *fa'a Samoa* and the way it shaped participants' perspectives as caregivers from a holistic point of view. Despite the small scale of participants ($n=8$), the challenges and barriers of all participants were similar, whereby the negative experiences outweighed the positive experiences. As such, this study has provided descriptive and detailed data that offers participant experiences that address the gaps within research and the complex issues and inequities that remain within the New Zealand health system. The information from this study can provide a knowledgebase to develop and deliver more appropriate support services to support Samoan (and Pacific) families who provide care for their loved ones with dementia and can serve as a guide for developing future ethnic-specific interventions.

STUDY LIMITATIONS

This study also had limiting factors despite its strengths. This study initially aimed to recruit between ten to twenty participants but only recruited a total of eight participants. The sample size of this study is small therefore, the generalisability of findings is not completely representative of all Samoan caregivers of loved ones with dementia living within the Auckland region. The period of time this study was conducted was particularly difficult given the restrictions of COVID-19 during the time recruitment was being advertised. This restricted face-to-face form of advertisement, which could have had potential impacts on recruitment.

Given the nature of the caregiver role, it was especially difficult to adjust and schedule times to meet via Zoom, which naturally comes with unavoidable issues such as Internet issues, access to an electronic device, or knowing how to function Zoom. This would have affected recruiting the population of possible dementia caregivers who are not confident in using technology either. The definition of 'past caregivers' in this study also needs to be considered a limiting factor. Past caregivers were limited to have at least been a caregiver within the most recent past year (2020 – 2021), the same year that COVID-19 occurred, and New Zealand went through a nationwide lockdown. This could have had potential implications for some of the challenges presented in this study, given the unprecedented circumstances New Zealand was in at the time. For instance, COVID-19 has had major behavioural, emotional, and physical consequences for dementia individuals and dementia caregivers (Azevedo et al, 2021). The term 'dementia' was also broadly used in this research study and did not consider what stage of dementia or the type of dementia participants' loved ones had. This study is also measured through self-reporting, which means that participants' overall knowledge and experiences related to dementia and caregiving could be skewed by reporting bias and recalling bias.

Gaps in the literature

There are also several existing gaps in the literature with respect to the experiences of dementia caregivers of loved ones with dementia in New Zealand. The literature regarding the experiences of ethnic-specific dementia caregivers in New Zealand is just as scarce too. Currently, there are no studies that have investigated the experiences of Samoan caregivers who provide care for a loved one with dementia within the home setting. Research studies have yet to investigate individuals from rural regions who have limited access to health information too. The literature concerning the caregiver experience is also inconclusive due to the differentiating psychological outcomes. The research outcomes of some literature emphasise the importance of the caregiver experience, while others report little-to-no significance of the caregiver experience (Fekete et al, 2019). There is also research suggesting that there is little research concerning caregiving dyads, creating a research gap in informal caregiving altogether (Egbert, 2014).

FUTURE RECOMMENDATIONS FOR RESEARCH

The recommendations for further research in this area should consider:

Towards a dementia community

- The findings in this study strongly recommend the need to develop a space specific for dementia caregivers to help create a 'dementia community'. Building a community aligns with the value of relationship building, which is important within the Samoan culture. These findings imply that by developing a dementia community, it could improve dementia awareness and knowledge regarding the process of what to expect as caregivers throughout the dementia journey. This offers the opportunity for dementia caregivers to easily access information and receive support that is not being provided by healthcare providers after initial diagnosis.
- The findings also suggest the need for improved access to community-based support services specific for dementia-related caregivers and dementia individuals. Based on these findings, there are no support services or support groups specific for dementia caregivers within the

community that are easily accessible nor available. This demonstrates the lack of social support that exists for dementia caregivers to access within the Auckland region and implies that dementia caregivers continue to be less prioritised. This also drives the need for the implementation of dementia initiatives at the community level.

Pacific support

- The Samoan participants within this study strongly expressed the need for Pacific support that can understand the cultural perspectives related to the values and beliefs of *fa'a Samoa*. This implies that a holistic view to care within current support services is absent or not acknowledged enough. Future research could, therefore, explore *fa'a Samoa* and the provision of care so that similar applications can be integrated within support services or support group initiatives.

Family

- *Fa'a Samoa* holds the elderly at the highest regard. Their position is typically observed as patriarchal, as they are the pillars of the family unit. *Fa'aaloalo* drives the relationship between generations and there lies an intrinsic understanding of the *vā* between generations too. Future research among the Samoan population could explore the role of the elderly and the importance of *fa'a Samoa* in the provision of care. This could further delve into the differences between New Zealand-born Samoans versus island-born Samoans and the role of acculturation in their understanding and provision of care for the elderly. This may contribute to a better understanding of the stigma associated with service utilisation and could possibly pinpoint whether differences exist in understanding support-seeking behaviours between New Zealand-born and island-born Samoans.

Dementia-related caregiver research

- Despite the existing literature regarding the caregiver experience, research involving ethnic-specific experiences of caregivers remains an area that needs further investigation. As such, it is important to consider, investigate, and acknowledge the realities from a caregiver's ethnic-specific perspective to better understand the possibilities of improving the overall quality of life for caregivers.
- Further research can look into young Pacific caregivers. In the Samoan culture, it is natural to have younger generations take on the caregiver role. This is evidently seen in the participant demographics of this study, whereby most participants were grandchildren taking care of their grandparents. Given that the decline in the mental health of younger generations continues to rise in New Zealand, future research can explore the association between the impacts on mental health and being a young Pasifika dementia caregiver.

- Based on these findings, the lack of dementia awareness within the Samoan community and the way dementia is understood is another area of research that can be further investigated. This may contribute to enhancing health literacy within the Samoan community in relation to normalising dementia as well as shifting the stigma associated with dementia too.
- Currently, there is a lack of Pacific ethnic-specific research regarding dementia family caregivers, specifically in the Auckland region. Investigating the experiences of dementia family caregivers from the wider Pacific community can highlight the nuances between cultural structures and serve as a key reminder that Pacific subgroups are heterogeneous. This can acknowledge cultural differences that could have a direct influence on the specific health promotion methods for raising dementia awareness and developing ethnic-specific interventions too.
- Future research can also delve into the available dementia-related support services and the frameworks that form these initiatives, exploring where the issues lie associated with low levels of service utilisation. This will allow another avenue for family caregivers of dementia relatives to have their voices brought to the forefront while detailing the realities of what has worked and what has not worked with services. Therefore, this could potentially create opportunities for developing and adjusting current approaches in place that benefit Pacific communities.

Service delivery

- The findings show that culture plays a pivotal role in the provision of care therefore, it is imperative to consider cultural aspects in the delivery of care. Following Westernised health approaches have not provided the best foundation of support for Samoan caregivers and their perspectives of care, which is evident in these findings. Therefore, future research can investigate a treatment group versus a placebo group, exploring the differences in delivering culturally competent care compared to the current delivery of care guidelines to prove how effective inclusivity of one’s culture can be in the engagement and utilisation of services.

Policy implications

- This study highlights that the current dementia action plans and frameworks in New Zealand are far from attaining their intended goals in terms of improving the quality of life for dementia caregivers too. This demands the need for revision of current support services and their approaches to engaging with the community. The findings imply that to achieve such goals, the ways in which these communities understand the concept of care in relation to their experiences, needs to be implemented in the delivery of care of dementia-related support services. Such changes will likely lead to more Samoan dementia caregivers to utilise and engage in support services in hopes of more positive caregiver health outcomes.

CONCLUSION

To the researcher's knowledge, the current study is the first to explore the experiences of Samoan caregivers of loved ones with dementia living within the Auckland region. Understanding the experiences of Samoan caregivers of loved ones with dementia has contributed to the gap within the wider literature. Enabling such research has also allowed Samoan dementia caregivers to bring their realities of the caregiver experience to the forefront, showcasing the complex needs of the caregiver role and highlighting the unique cultural influences to providing care.

The dementia caregiver journey was mainly associated with negative experiences, ultimately leading to negative caregiver health outcomes. The challenges and barriers experienced by Samoan dementia caregivers have evidenced to be no different than what already exists within the wider literature. This demonstrates the little improvement that has been made over time despite the development of dementia-related frameworks and action plans in New Zealand.

Exploring the experiences of Samoan caregivers of loved ones with dementia has also addressed the gaps and inequities within the current New Zealand health system too. The findings suggest the need for current dementia-related support services to actively integrate a culturally inclusive approach to care by reflecting the needs of the community they are serving.

Acknowledging the Samoan understanding of care can assist with the implementation of and development of future care plans and engagement with families within more clinical settings. Providing culturally competent care has proved to influence engagement in support services. The findings suggest that in order to improve the response to utilising support services, there is a need for cultural appreciation and the understanding and integration of the values, beliefs, and principles of *fa'a Samoa*.

Although the New Zealand government continues to promote initiatives such as ageing within the community to reduce overall economic costs on institutions, there remains no effective support to achieve such goals. Albeit the small sample size of this study, the need to improve the quality of care and support provided for dementia caregivers remains an issue of concern that needs to be reviewed.

This cohort highlighted that culture plays an integral role in their understanding of the provision of care. As such, this study strongly recommends developing a community for dementia caregivers and their loved ones as a main point of support system for them to access. While dementia caregivers generally have negative experiences, it is possible to facilitate real change among this group by developing a community and providing recommendations that align with the collective viewpoint of Samoan caregivers and facilitate progress toward the goals outlined in New Zealand dementia frameworks.

APPENDIX A: PARTICIPANT INFORMATION SHEET

THE UNIVERSITY OF
AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

SCIENCE
SCHOOL OF PSYCHOLOGY

PARTICIPANT INFORMATION SHEET

Project Title:
Behind closed doors: Using Talanoa to understand the experiences of Samoan caregivers taking care of loved ones with dementia.

Researcher Introduction:
Talofa lava, my name is Malia Tagatanuu and I am a Master of Science (Psychology) student at the University of Auckland. The motivation behind this research stems from my family's personal experiences; once being in the position of providing care for a loved one with dementia. With this experience, I naturally gravitated towards finding a way to bring the experiences of Pasifika family caregivers to the forefront.

Invitation:
You are humbly invited to participate in this research because you identify as someone of Samoan heritage with experience as a primary caregiver for a loved one with dementia (within the home setting). It is important to note that the decision to participate in this study will be entirely voluntary and you will not be obligated to participate in this study if you do not wish to.

Study Focus:
The focus of the talanoa will be on your experiences as a caregiver for a loved one with dementia, understanding components such as: awareness of available services of support, available access to healthcare resources, stressors, impacts on family dynamics, coping mechanisms, as well as acknowledging the positive outcomes as a caregiver.

Study Procedures:
If you agree to volunteer to proceed as a participant, a talanoa (free-flowing conversation) session will be coordinated. The talanoa will honour the *vā* (space between) to create an environment that will allow you to safely share your experiences as a caregiver. *Alofa* (love and compassion) and *fa'aaloalo* (respect) are concepts that will be acknowledged during the talanoa.

The talanoa will be set up at either an agreed-upon space of your preference or at any of the two University of Auckland campuses (Auckland City Campus or South Auckland Campus). The talanoa is anticipated to take 90± minutes. In the event of a Level 3 or Level 4 COVID-19 lockdown, the talanoa will instead be conducted via Zoom in which a Zoom audio recording will occur. At the start of the talanoa, you will be given a consent form to complete and sign and will be required to verbally consent to collaborating in this study.

I will be audio recording the talanoa to transcribe, and my supervisors and I will be the only individuals to have access to the audio recordings. Once I have completed transcribing, you will have the opportunity to review and edit your transcript for up to two weeks upon receiving the transcript. After this, I will then do an analysis of the talanoa which will not be possible to withdraw from the study.

For reassurance, if you wish to withdraw your participation from the talanoa session at any time, you can do so without reason. If you wish to withdraw your data collected from the talanoa at any time, you can do so without reason with a grace period of up to two weeks after receiving your transcript to review and edit. The data analysis process will commence after two weeks and will therefore not be able to be withdrawn from that point. A copy of a summary of the findings and/or final report can be obtained with a “YES” indication on the consent form. Please note that the collected data may be used for future research and that there is also the possibility that the findings of this study may be published or disseminated in different forms including journal publications, public meetings, conference presentations, thesis/dissertation, and other publications.

Confidentiality:
The identity of participants will remain confidential. The identities of participants will not be revealed in any report or publishing. In the case of direct quotations being used in the report, the participant’s identity will be protected by creating an alias. All information, both written and verbal, will be protected with the utmost care and stored safely; access is only granted to my supervisors and I. All consent forms will be securely locked in a filing cabinet on the University of Auckland premises. Likewise, all consent that is given verbally will be audio-recorded and will be safely stored on a University of Auckland approved electronic storage system (Google Drive). Upon reaching the six-year timeframe of being stored, all acquired information will be destroyed.

Study Incentive:
As a meaalofa (gift) to show my appreciation for your time and contribution to this study, light refreshments will be provided during the talanoa. A $50 grocery voucher along with 1-2 voucher(s) from South Auckland local businesses will also be given. Vouchers will still be handed out if you decide to withdraw from the study. Vouchers will be mailed out to your postal address in the event that a COVID-19 lockdown were to occur. It is your responsibility to inform the researcher of any dietary requirements, prior to the talanoa session commencing.

Further Questions and Contact Details:
If you have any further questions or concerns, please do not hesitate to get in touch with either of my supervisors or myself. We will be more than happy to accommodate.

Please find our contact details below.

Fa’afetai lava,
Malia

CONTACT DETAILS:

Student Researcher:
Miss Malia Tagatanuu
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Secondary Supervisor:
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Email: v.nosa@auckland.ac.nz

For any queries regarding ethical concerns, you may contact the Chair, University of Auckland Human Participants Ethics Committee, Ethics and Integrity Team, University of Auckland, Private Bag 92019, Auckland 1142.

Ph: 09 373-7599 Ext. 83711.
Email: humanethics@auckland.ac.nz

APPENDIX B: PARTICIPANT CONSENT FORM

School of Psychology
Private Bag 92019
Auckland 1142, New Zealand

SCIENCE

SCHOOL OF PSYCHOLOGY

Behind closed doors: Using Talanoa to understand the experiences of Samoan caregivers taking care of loved ones with dementia

[THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF SIX YEARS]

Student Researcher:
Miss Malia Tagatanuu
MSc Student
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Primary Supervisor:
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Secondary Supervisor:
Associate Professor Vili Nosa
Head of Pacific Health Section
School of Population Health
The University of Auckland
Ph: +6 49 3737 599 Ext 86906
Email: v.nosa@auckland.ac.nz

Declaration by participant:

I have read and understand the Participant Information Sheet (PIS). I understand the process and purpose of the study and why I have been selected to collaborate. I have had the opportunity to ask questions of the researcher and have had them answered to my satisfaction.

- I agree to take part in this research.
- I understand that my participation in this research is entirely voluntary.
- I understand that I have the right to withdraw from this study at any time without giving an explanation. Withdrawal may range from not answering specific questions, stopping the audio recording during the talanoa, or leaving the discussion entirely.
- I agree with the discussion being audio-recorded.
- I am aware that I will be required to provide verbal consent at the start of the talanoa.
- In the event of COVID-19 restrictions, I consent to having the talanoa via Zoom of which only the audio will be recorded. I understand the researcher will abide by any government laws around COVID-19.
- I am aware that I will be given in-person a $50 grocery gift voucher and 1-2 voucher(s) sponsored by South Auckland local businesses as a meaalofa for my contribution to the research. I am aware that if this research is conducted during COVID-19, I will receive the meaalofa via post.
- I understand that the researchers will guarantee the identity of participants will remain confidential and will not be revealed in any report or publishing.
- I understand that no material that could identify me will be published.
- I am aware that any information disclosed that might pose a risk to myself or others may be reported by the research to the appropriate authorities.
- I am aware that Malia will transcribe the discussion.
- I understand that Malia's supervisor's may have access to a transcript of my discussion following the removal of identifiable information.
- I am aware that I can discuss my own experiences within the talanoa with my *aiga*.
- I am aware that extracts from the discussion transcripts that have identifiable data removed may be quoted in publications and presentations derived from the study.
- I am aware that any collected data may be used for future research and there is the possibility that the findings of this study may be published or disseminated in different forms including journal publications, public meetings, conference presentations, thesis/dissertation, and other publications.
- I know whom to contact if I have any questions about the study.
- I understand all collected data will be kept on the University of Auckland premises for a minimum of 6 years and maybe kept for future research. After this time, all data will be destroyed.

- I would like a copy of my transcript. YES/NO
- I would like a copy of the summary of the findings for this research. YES/NO
- I would like a copy of the final research report. YES/NO

Name: ____

Signature: _____________________________________ Date:_______________________

Email/postal address for meaalofa, transcript, final summary, and/or final research report:

____

APPENDIX C: TALANOA QUESTION SCHEDULE

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2nd Floor, Room 236
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TALANOA QUESTION SCHEDULE

Research Title: Behind closed doors: Using talanoa to understand the experiences of Samoan caregivers taking care of loved ones with dementia

Researcher: Malia Tagatanuu

Supervisors: Dr Makarena Dudley, Associate Professor Vili Nosa.

Theme:	**Topics covered:**	**Estimated time:**
Welcoming/Purpose of Talanoa	● Opening Prayer ● Verbal consent	~5 minutes
Introductions	● Reminder to focus on YOUR experiences ● No right or wrong answers - share as much as you are comfortable sharing. ● Safe space to openly share - not formal	~10 minutes
Formalities	● Participant rights ○ Right to withdraw ○ Break(s) if needed ● Vouchers + T-shirt ● Housekeeping (if in-person)	~10 minutes
Guiding Questions	● Talanoa	±60 minutes
Final remarks	● Final questions/concerns ● Closing Prayer	~5 minutes

Guiding Questions:

1. Understanding of Dementia: Objective 1

a. Tell me about the person you care/cared for.
b. How did you feel after learning about the diagnosis?

2. Family Dynamics: Objectives 1 & 2

a. How did you come about becoming the main caregiver for your loved one?
b. What were the impacts on your family after becoming the main caregiver?
c. What influenced you to provide care within the home setting rather than receiving formal care?

3. Caregiver Experience: Objective 1

a. Tell me about your experiences as a caregiver.
b. How do you describe to other people what it means to care for someone with dementia?

c. Challenges/Stressors: Objective 1
   i. Tell me about the challenges/stressors you have faced as a caregiver.
   ii. How has your mental or emotional well-being been impacted?

d. Coping Mechanisms: Objective 1
   i. What types of coping mechanisms do you have in place in times of stress?

4. Samoan Perspective of Care: Objectives 1, 2 & 3

a. How do you think being Samoan (your culture) influences (or influenced) the way you have taken on the responsibility as the primary caregiver for your loved one?
b. What ways has *fa'a Samoa* influenced your understanding of care?
c. What are cultural practices that have been helpful in your journey as a caregiver?

5. Support Services for Caregivers: Objectives 2 & 3

a. Tell me about any of the support services you are aware of and your experience with accessing any support services.
b. What sort of expectations do (or did) you have as a caregiver in terms of receiving support?
c. What would you like to see differently when it comes to the current dementia-related services?
d. What would the best support look like for you as a caregiver?

6. Access to Healthcare Resources: Objectives 2 & 3

a. Tell me about any resources you are aware of and your experience with accessing healthcare resources.
b. What are some of the challenges you have faced in accessing resources or support in your community?
c. What do you believe would have been a better approach for you to access healthcare resources?

7. The Positives: Objective 1

a. Tell me about some of the positive outcomes you can think of as caregivers?

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