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Understandings and experiences of dementia in Fiji

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In loving memory of Bubu

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(2 Timothy 1:7)

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Abstract

Introduction

Fiji is an upper-middle-income-country located in the South Pacific Ocean. It has a population of almost 900,000 people, with the proportion of older people projected to rise from 9% in 2015 to 19% in 2050. In addition to the challenges associated with an older population, Fiji is facing an epidemic of non-communicable diseases. Longer life expectancy and high levels of risk factors for dementia have been associated with a greater increase in the number of people living with dementia in low- and-middle-income countries compared with high-income countries. It is foreseeable that dementia will become an important issue for Fiji and other Pacific Island countries in the next two decades.

There is very little empirical evidence about experiences of dementia in Fiji. Yet, in talking with Fijian community members, it is common to hear about older family or community members being forgetful, grumpy or behaving ‘childishly.’ Moreover, health service providers have noticed that older people living with dementia usually present at health facilities at advanced stages of the condition, and once diagnosed, there is low attendance for follow up appointments. This research aims to uncover the processes that shape experiences of dementia care - describing the strengths, enablers, shortcomings and fragilities, and the conditions in which these are realised.

Methodology and methods

The study uses a transformational grounded theory approach. The transformational aspect of this paradigm emerges from its ontological grounding in critical realism and methodological basis in grounded theory, with participatory action research and decolonising frameworks. In line with the research paradigm, I used multiple methods to conduct a critical realist exploration of the topic. The research consisted of four phases conducted in parallel. In the major component of my research, I used qualitative methods to explore the views and experiences of dementia from the perspectives of multiple stakeholders, and to construct a grounded theory about the processes that caregivers use to manage dementia care. I used quantitative analysis of hospital admissions data to obtain an impression of the scope of dementia in Fiji and possible underlying phenomena that shape dementia care. I also conducted a mapping exercise of services available for older people, and in particular, services that support dementia care.

Findings

Available support for dementia care

There are no specialised dementia care services in the formal health sector or community sector in Fiji. The vast majority of care is informal family care in the community. Formal care for dementia occurs primarily within existing mental health services, and to some extent within primary health care services, hospital in-patient services and residential aged care. Service providers have variable (usually lacking) expertise, experience, confidence and knowledge of dementia and dementia care.

Hospital admissions for a primary diagnosis of dementia

In-patient hospital services were accessed by 72 people with a primary diagnosis of dementia (over 79 admissions), with the majority of admissions being for patients aged over 60 years. These are very low numbers over a period of 16 years. Given the expectation of informal care networks for caring for older family members, and expectations of ageing as inclusive of symptoms of cognitive decline, these admissions likely represent the tip of the iceberg – that is, family crises whereby family members and their support networks are exhausted or a health crisis has occurred.

Transformational grounded theory

The grounded theory, ‘letting it be’, was constructed through interpretation and synthesis of the views and experiences of family caregivers and service providers on dementia. Eight family caregivers from seven family units shared their perceptions and experiences of dementia with myself and my colleagues during face to face interactions in Fiji. One person living with dementia and a village elder also contributed their experiences. A total of 40 service providers discussed their understandings and experiences of dementia – sharing their views as both providers of services and as members of the community.

‘Letting it be’ is a sociocultural construct. It is an approach to caring for older people with cognitive decline or dementia that involves compassion, searching for knowledge and support, and application of traditional care practices, within the strength of family and community networks. It is driven and maintained by the social norms of a society that is traditionally collectivist. The construct, ‘letting it be’, is at the core of processes that caregivers in Fiji use to manage the care of older people living with dementia. It ties together the other categories of the theory, relating to cognitive (“becoming aware”), behavioural (“clinging to normal”) and emotional (“having heart”) processes of dementia care. Together these shape the dementia care experience, and the mechanisms of ‘knowing’ and ‘capacity to manage care’ also influence the dementia care experience.

Conclusions

Sociocultural meanings of dementia and wellbeing in Fiji both produce and influence conditions that affect the management of dementia care. A reliance on informal care, primarily family support, is established in Fijian ways of knowing and doing and is driven by a combination of preference, community expectation, obligation and availability of resources. These factors contribute to delayed help seeking and clinical inertia, and of crucial importance, also facilitate care in place in the community and amongst family. The recommendations stemming from this research aim to draw on the strengths of Fijian ways while recognising that a romantic view of family and community connectedness ignores the realities of a dynamic, contemporary Fijian society. Positive change in dementia care centres on the integration of community understandings, and promotion of cultural values of wellbeing and care, with service provision. It also focuses on tangible, purposeful community-based and community-engaged models of support and care for older people living with dementia and their families.

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List of Abbreviations

ADI	Alzheimer’s Disease International
AIHW	Australian Institute of Health and Welfare
APO	Asia Pacific Observatory on Health Systems and Policies
APTC	Australian-Pacific Training Coalition
CD	Communicable Disease
CHW	Community Health Worker
CSO	Civil Society Organisation
CSR	Colonial Sugar Refining Company
CWM	Colonial War Memorial Hospital
FBS	Fiji Bureau of Statistics
FCOSS	Fiji Council of Social Services
FNPF	Fiji National Provident Fund
FNU	Fiji National University
FVRF	Fijian Vanua Research Framework
FWRM	Fiji Women’s Rights Movement
GDP	Gross Domestic Product
HIC	High-Income-Country
LMIC	Low-and-Middle-Income-Country
mhGAP	World Health Organization Mental Health Gap Action Programme
MHMS	Fiji Ministry of Health and Medical Services
MMSE	Mini-Mental State Exam
MSWWPA	Fiji Ministry of Social Welfare, Women and Poverty Alleviation
MWCPA	Fiji Ministry for Women, Children and Poverty Alleviation
NCD	Non-Communicable Disease
NCOP	National Council for Older Persons
NGO	Non-Government Organisations
PATIS	Patient Information System
PCN	People’s Community Network
PHC	Primary Health Care
PIC	Pacific Island Country
POLHN	World Health Organization Pacific Open Learning Health Net
UMIC	Upper-Middle-Income-Country
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific

UNFPA	United Nations Population Fund Pacific Sub-Regional Office
VHW	Village Health Worker
WHO	World Health Organization
WPRO	World Health Organization Regional Office for the Western Pacific

1. Introduction

Age profiles are changing across the Pacific Island Countries (PICs), with the proportion of older people estimated to increase dramatically over the coming decades to 2050. The PICs are located in the South Pacific Ocean (part of the Western Pacific Region, World Health Organization [WHO]) and are broadly described as located within three ethnogeographic groupings: Melanesia, Micronesia and Polynesia. In Melanesia, PICs include Papua New Guinea, Fiji, Solomon Islands, New Caledonia and Vanuatu. Samoa, Tonga, Cook Islands, Tuvalu, Niue, Wallis and Futana, Tokelau and New Zealand are PICs in the Polynesian region. In Micronesia, PICs include Palau, the Federated States of Micronesia, Kiribati, Marshall Islands, Guam, the Commonwealth of the Northern Mariana Islands and Nauru. Many PICs have developing economies and small populations, with New Zealand being an obvious exception. Fiji has one of the most developed economies of the small PICs and is often referred to as the hub of the South Pacific. In the context of competing priorities in childhood and early life, little attention has been paid to health and social concerns for an older population in this region. Furthermore, the experiences and wellbeing of older people living with dementia, and their caregivers, are unknown and undocumented.

In my research, presented in this thesis, I explore the understandings and experiences of dementia in the PIC of Fiji (an Upper-Middle-Income-Country; UMIC). In initially embarking on this research, I visited Fiji to find out what service providers thought about my proposed study exploring dementia in older people in Fiji. Overall, the service providers that I talked with thought that dementia was an important, yet neglected issue, and one that affected Fijian communities. Some service providers shared stories of older people who seemed to be showing signs of more advanced dementia. They were seen walking around their community "half-naked", talking to themselves or eating out of rubbish bins. Some community members would ridicule them or ignore them. One service provider shared that people tended to look after such people at home, outside of health care services. Other service providers, working in mental health services, noticed that visits from older people living with dementia were usually delayed, with clients presenting at more advanced stages of the dementia. Once a diagnosis of dementia was made, maintaining contact with people living with dementia was particularly challenging.

In this thesis, I endeavour to give an account of dementia in Fiji; one that uncovers the strengths that shape experiences of dementia and is honest about the shortcomings and fragilities. My motivation to do this is to inform practice and policy in Fiji that will support older people living with dementia, those who love and care for them, and those who can support them.

1.1 Chapter One outline

In this chapter, I provide an overview of dementia as a global health priority, with a focus on Low-and-Middle-Income-Countries (LMICs) and indigenous peoples. I describe the rationale for my research study in Fiji, and introduce the study aims, methodology and methods. Finally, I describe the flow of my thesis with reference to each chapter.

1.2 Dementia as an emerging issue for LMICs and indigenous peoples

Dementia is an umbrella term for the syndrome caused by a number of neurodegenerative conditions of the brain. The condition involves progressive impairment of cognitive function and skills, increasingly impacting on daily living as the condition worsens. Though dementia can occur in younger people, age is the greatest risk factor (Coope & Richards, 2014).

In 2015, 46.8 million people globally were estimated to be living with dementia (Prince et al., 2015). An older population worldwide is expected to be associated with an increase in numbers of people living with dementia to 74.7 million people in 2030, and 131.5 million people in 2050 (Prince, Ali, et al., 2016; Prince et al., 2015). The majority of people living with dementia reside in countries classified by the World Bank as LMICs (estimated to be 58%; Prince et al., 2015). This is expected to increase to 68% (Prince et al., 2015) and will likely add to existing disparities in health equity between and within countries. Longer life expectancy and high levels of risk factors for dementia are associated with a greater increase in the number of people living with dementia in LMICs compared with high-income-countries (HICs; Livingston et al., 2020). Potentially modifiable risk factors for dementia include early life education; midlife hypertension, obesity, hearing loss, traumatic brain injury and alcohol misuse; and smoking, depression, physical inactivity, social isolation, diabetes and air pollution in later life (Livingston et al., 2020). Many of these, namely hypertension, obesity, physical inactivity, smoking, alcohol misuse and diabetes, are in common with risk factors for other non-communicable diseases (NCDs) resulting in a growing multi-morbidity amongst the older population.

It has been estimated that under 50% of people living with dementia have been diagnosed in HICs, and even fewer (under 10%) are likely to have been diagnosed in LMICs (Prince, Comas-Herrera, et al., 2016). For indigenous peoples, who already experience significant disparities in health outcomes even when they live in HICs, the issue of dementia is only recently gaining public recognition. Few studies about the prevalence of dementia for indigenous peoples have been conducted, however, emerging evidence indicates that the prevalence of dementia is higher for some indigenous peoples compared with non-indigenous people (Russell et al., 2020; Russell et al., 2016; Warren et al., 2015).

In 2015, 87% of the global economic cost of dementia (estimated to be US$ 818 billion) was generated in HICs (Prince et al., 2015). The greatest proportion of these costs was attributed to direct social sector costs (professional home care, residential home care and nursing home care) in HICs compared to informal, unpaid care in LMICs (Prince et al., 2015). Dementia costs overall, and distribution of costs, reflect a combination of health and social care systems factors, community factors, health services accessibility, severity of the condition and experiences of people living with dementia and their caregivers (Allegri et al., 2007; Dominguez et al., 2021; Wang et al., 2008; Zencir et al., 2005). The costs of dementia extend far beyond economic value and should also be considered in terms of societal and health system impacts.

1.3 Social impacts of dementia

In terms of social impacts, people living with dementia experience changes in family roles, and the ability to work, socialise and participate in hobby and cultural activities often leading to social exclusion (Batsch et al., 2012; Erol et al., 2016). Such reduction in everyday interactions that fundamentally require human connectedness often leads to social isolation. People living with dementia and their caregivers have been found to be the loneliest of people (Alzheimer's Australia, 2016). Support and advocacy groups, such as Dementia Alliance International, together with strategies such as Alzheimer’s Disease International’s Dementia Friendly Communities Program, are successfully raising awareness of dementia (Alzheimer's Disease International [ADI], 2017). However, there is still much to learn about how to address the rights of people living with dementia, especially in countries where the condition is not yet recognised as a health priority. Similarly, the experiences of informal caregivers (often family, friends and community) are of increasing relevance in the face of rapid growth of dementia cases, especially in countries with constrained health resources.

Caregiver ‘burden’ in association with caring for people living with dementia is common. The task of caring entails extraordinary amounts of time supporting people living with dementia to complete daily tasks such as dressing and eating. Caring for people living with dementia has been associated with increased levels of stress and depression, loss of income, and increased financial burden (Lindeza et al., 2020). In LMICs, the majority of care is provided by informal caregivers (and may include unregistered, untrained paid workers). However, a lack of health infrastructure and government policy leaves such caregivers unsupported, under-educated about dementia and undervalued, and places people living with dementia at risk of inappropriate, though well intended, care. Certainly, educational programs for caregivers of people living with dementia have a protective effect on caregiver burden and may also reduce caregiver depression (Jensen et al., 2015).

1.4 Services for dementia

In common with people with other intellectual disabilities, people living with dementia have unmet health care needs and experience disparities in health outcomes (Krahn & Fox, 2014). Formal care aims to promote early dementia diagnosis, maintain wellness and reduce the risk of comorbidities for people living with dementia and their caregivers. Generally, a mixture of primary health care (PHC), specialist care, in-home and residential care, and supportive services may be available through private and government organisations. PHC provided by physicians has been shown to be as effective as that provided by specialists, though diagnosis and care provision for dementia through the PHC sector is deficient globally (Prince, Comas-Herrera, et al., 2016). Prevention of dementia through risk factor reduction is emerging as a cost-effective solution that is forecast to lower future dementia prevalence (Mukadam et al., 2020). With costs for dementia care expected to increase over the coming years the role of the PHC sector in provision of care for people living with dementia is increasingly important. Additionally, the importance of service integration to meet health needs of people living with dementia and their caregivers is crucial, not only to cater for growing demand for services, but also to ensure quality of care (Prince, Comas-Herrera, et al., 2016).

1.5 Dementia research

Worldwide, there is increasing recognition of dementia as a major public health concern. Following the release of the first global report on dementia from ADI and the WHO (2012), the G8 Summit of 2013 formed the Global Action Against Dementia. This was the first tangible step towards addressing dementia as a global health priority. In 2015, the WHO facilitated a global forum on dementia encouraging shared commitment and collaboration between stakeholders. In 2017, the first Global Action Plan on the Public Health Response to Dementia was released (WHO, 2017). In addition to increased global discourse on dementia, it is evident from the increase in numbers of countries with national dementia plans and strategies that global recognition of dementia as a priority health need is increasing. However, a substantial number of countries are yet to engage in discussions about dementia (ADI, 2018). Furthermore, although dementia research in LMICs is increasing (Prince et al., 2015) with the help of global funding initiatives and partnerships, local funding for dementia research in many LMICs is inadequate.

In addition to symptomatic or disease modifying pharmacotherapies, the focus of dementia research should encompass and focus on prevention (Livingston et al., 2020), social determinants, quality of life and care, and cost-effective models of care (Prince et al., 2015; The Lancet, 2014). Such areas of research are especially relevant in countries with constrained resources where the highest burden of current and projected dementia is experienced. In the absence of capacity for strong, coordinated health and community system responses, the following two preliminary dementia research priorities proposed at the WHO Ministerial Conference on Global Action Against Dementia are of particular importance.

- Priority 4 - Determine the most effective interventions for educating, training and supporting formal and informal carer(s) of people with dementia.
- Priority 9 - Evaluate the relative effectiveness and identify the optimal models of care and support for people with dementia and their carers in the community (e.g. collaborative care, integrated health and social care, case management) across the disease course.
  (Prince et al., 2015, p. 77).

For PICs, where population ageing is occurring at a rapid rate, these dementia research priorities are especially pertinent.

1.6 Ageing and dementia in Fiji and PICs

Age profiles are changing rapidly amongst PICs and an older population will be associated with higher dependency ratios and lower support ratios (United Nations Population Fund Pacific Sub-Regional Office [UNFPA], 2014). The health of older people has been a relatively low priority for PICs given their younger age demographic and lower life expectancy in the past. In Fiji, the proportion of older people is expected to increase from 9% in 2015 to 19% in 2050 (UNFPA, 2014). Thus, issues related to health and diseases in older age, such as dementia, will become more important within the next 20 years.

The prevalence of dementia in PICs is unknown. The Global Burden of Diseases Study estimated an age-standardised prevalence of dementia of 700-799 people per 100,000 for Fiji, and for other PICs including the Marshall Islands, Solomon Islands, Kiribati, the Federated States of Micronesia, Vanuatu, Samoa and Tonga (Nichols et al., 2019). Based on this estimate, in 2020, the number of people living with dementia in Fiji is likely to be between 6,265 and 7,151 people (see Section 6.4). In comparison, Australia and New Zealand were each reported to have a prevalence of 500-599 people per 100,000 people living with dementia. It is foreseeable that with a changing demographic that will see less people of working age per older person (UNFPA, 2014) together with high levels of NCDs and risk factors for dementia (Snowdon et al., 2011), dementia will become an important issue for the Fijian health system. Moreover, Pacific Islander worldviews encompass cultural constructs of social order, spirituality, reciprocity and obligation informing decisions about health and healing, and promoting care through kinship ties (Capstick et al., 2009; Groth-Marnat et al., 1996; Ravuvu, 1983), Higher prevalence of dementia is of critical importance for families and communities who traditionally provide the majority of care and support for older people across the Pacific Island region (United Nations Population Fund Pacific Sub-Regional Office, 2014).

Fiji is addressing ageing and mental health through national and regional policies. Mental health is included in the Fiji Ministry of Health and Medical Services (MHMS) National Strategic Plan 2020-2025 (MHMS, 2020) and the Fiji National Mental Health and Suicide Prevention Strategic Plan 2015 (MHMS, 2015b). A national policy specifically addressing dementia is yet to be developed. Additionally, the National Policy on Ageing 2011-2015, embodies a national approach and commitment to the wellness of older people (Fiji Ministry of Social Welfare, Women and Poverty Alleviation [MSWWPA] & UNFPA, 2011). In line with this policy, the creation of the National Council for Older Persons (NCOP) in 2013 facilitated advocacy and policy input from the perspectives of older people. Of particular relevance for this study, the National Ageing Policy specifically identifies that, *“Older persons suffering dementia should not be treated as mental patients suffering psychotic or neurotic illnesses. Other maladies affecting the elderly such as Alzheimer’s disease also require specialised care for which health personnel need to be appropriately trained”* (MSWWPA & UNFPA, 2011, p. 20). Research into the wellbeing of older people living with dementia in Fiji is timely and can inform future directions in policy and practice.

There is very little research on dementia in Fiji. Leung et al. (2019) investigated community knowledge and attitudes to dementia in Fiji, Cambodia, and the Philippines with the Alzheimer’s Disease Knowledge Scale, Dementia Attitude Scale and through focus group methods. The authors found low knowledge of dementia in the Fijian community. Health professionals were reportedly the most common source of help (89.3% of survey participants) followed by family (34.7%) and religious figures (27.3%). Importantly, the study also found that positive attitudes towards dementia were associated with knowledge about the life impact of dementia. Qualitative findings of the study supported the presence of low knowledge about dementia, the importance of religious activities for management of dementia, and the presence of stigma that resulted in people living with dementia being hidden from the community. It is known that mental illness in Fiji is associated with stigma and that this may affect help seeking behaviour (Aghanwa, 2004; Chang, 2011), though health care staff have been found to have positive attitudes towards people with mental illness (Aghanwa, 2004; Foster et al., 2008). The implications of stigmatising attitudes towards help seeking for dementia care and provision of dementia care, for instance, are unknown in Fiji. There are likely other important phenomena that influence responses to dementia in Fiji.

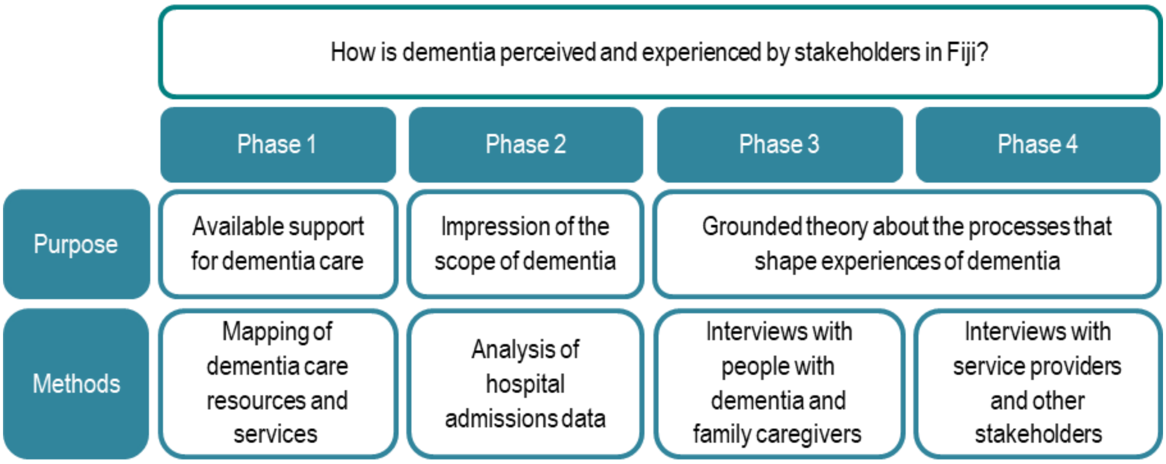
1.7 Research question and aims

This research draws on qualitative and quantitative sources to answer the primary research question: How is dementia perceived and experienced by stakeholders in Fiji?

This research aimed to:

- Describe the understandings and experiences of dementia from the perspectives of people living with dementia, family caregivers (informal caregivers) and service providers, including how they are shaped.
- Construct a grounded theory about the processes that shape experiences of dementia.
- Explicate how knowledge and theory generated through this research may benefit people living with dementia, caregivers, the wider community and the Fijian health system.

This research consisted of four phases, conducted in parallel (Figure 1.1). In Phase 1, a mapping exercise of services available to support people living with dementia and their families was conducted. In Phase 2, hospital admissions data for patients with a primary diagnosis of dementia were analysed to provide a foundational impression of the scope of dementia in Fiji. Phase 3 and Phase 4 constitute the major component of this research. In these phases, a transformational grounded theory approach (Redman-MacLaren & Mills, 2015) was used to explore the understandings and experiences of dementia from the perspectives of people living with dementia, family caregivers, service providers in health, ageing and community services, and community leaders. Knowledge was shared through semi-structured interviews and focus groups. A grounded theory about the processes that caregivers in Fiji use to manage care for older people living with dementia was constructed.



How is dementia perceived and experienced by stakeholders in Fiji?

	Phase 1	Phase 2	Phase 3	Phase 4
Purpose	Available support for dementia care	Impression of the scope of dementia	Grounded theory about the processes that shape experiences of dementia	
Methods	Mapping of dementia care resources and services	Analysis of hospital admissions data	Interviews with people with dementia and family caregivers	Interviews with service providers and other stakeholders

Figure 1.1. Diagram depicting the research question, the purpose of each phase and the methods used.

1.8 Thesis structure

The structure for the remainder of this thesis is as follows:

Chapter Two. Situating the researcher

In this chapter, I consider personal reflexivity in order to situate myself within the research study. I reflect on my background and the personal experiences that have shaped my character and worldview. I conclude the chapter with a discussion about how my position has influenced my research.

Chapter Three. Study context

Fiji is a small PIC with a diverse and widely distributed population in terms of geography, a developing economy and an evolving health system. The country has been independent of British rule for only the past 50 years. In this chapter, I position my research within the context of Fiji. I provide an overview of Fiji's geography, economy, colonial history, socio-demographic profile, and health and health care, including the health system.

Chapter Four. Conceptualisations of dementia in older people

Conceptualisations of dementia vary across countries, settings and amongst diverse populations. In this chapter, I provide an analysis and synthesis of the international literature about conceptualisations of dementia in countries with constrained resources and amongst indigenous populations.

Chapter Five. Methodology and methods

The research paradigm that I chose for this study is transformational grounded theory (Redman-MacLaren & Mills, 2015). This methodology permeates all aspects of the study, from design through to interpretation. In this chapter, I describe and explain how I used this methodology for my research. The research consists of four phases and employs qualitative and quantitative methods, that are outlined in detail in this chapter. Qualitative data collection from a person living with dementia, family caregivers, a village elder and service providers occurred at Suva, Nadi and Lautoka. Quantitative hospital admissions data for patients with a primary diagnosis of dementia to MHMS hospital facilities were collected at the national level. I include discussion of reflexivity throughout this chapter and also discuss trustworthiness more broadly. I conclude the chapter with an outline of the ethics approvals and other approvals that I obtained to conduct my research.

Chapter Six. Dementia and dementia care

In this chapter, I describe the findings of a service mapping exercise. I also present the findings of an analysis of hospital admissions data for patients with a primary diagnosis of dementia. I conclude this chapter with a critical reflection on the findings and limitations of the study.

Chapter Seven. A grounded theory about dementia care management

In this chapter, I present the major component of my research. I describe the grounded theory, ‘letting it be’, that was constructed from knowledge that co-researchers shared with me about dementia and dementia care. I describe the layers of dementia care management and the powers that influence the dementia care experience. I also provide a rationale for using socio-ecological theory as a theoretical code to extend the explanatory power of the grounded theory.

Chapter Eight. Discussion

Here I draw on the Fijian literature to extend the explanatory power of the grounded theory, using concepts of socio-ecological theory as a framework. I integrate and discuss the key findings of my research and then consider the scholarly contribution that my research makes to the international literature. I conclude this chapter with a discussion of the strengths and limitations of my research.

Chapter Nine. Implications and recommendations

In this final chapter, I discuss how my research can inform positive change in Fiji. I consider the findings and implications of my research, and link them to recommendations for practice, policy and research.

1.9 Chapter One summary

In this introductory chapter I have:

- Described dementia as an emerging issue.
- Linked this research with recommended and emerging research priorities for dementia.
- Briefly described ageing and dementia in Fiji and PICs.
- Introduced the area of enquiry, aims, methodology and methods for this research.
- Described the structure of this thesis.

In the next chapter I will:

- Situate myself within this research.
- Discuss personal reflexivity and the influence of reflexivity on my research.

2. Situating the researcher

> *"Reflexivity serves as a dual-lensed critical consciousness: the awareness of oneself engaging in experience, like an arrow pointed at both ends or an eye that sees itself while gazing outward at the world."*
>
> (Probst & Berenson, 2014, p. 815)

2.1 Chapter Two outline

In this chapter, I consider personal reflexivity in order to situate myself within the research study. I will reflect on my background and the personal experiences that have shaped my character and worldview. I discuss how my background and worldview have influenced my approaches to this research. I will discuss other modes of reflexivity important to consider in this study, epistemological, ontological, methodological and analytical reflexivity (Longhofer & Floersch, 2012) in Chapter Five.

2.2 Reflexivity

Reflexivity involves critical self-evaluation of the researcher's role in knowledge creation throughout the research process, from study design through to participant recruitment and interpretation of findings (Berger, 2015). Personal reflexivity describes the awareness of a researcher of the influences of their personal worldview and experiences on their research, and the ways in which they themselves are changed by the research (Probst & Berenson, 2014). It is a shifting dynamic requiring active engagement with reflective activities such as blogging or keeping a diary of thoughts about decisions, judgements and reasoning (Berger, 2015; Probst & Berenson, 2014). Credibility and trustworthiness of the researcher and the research study are enhanced through engagement with processes of reflexivity. Being an Australian conducting research in Fiji, consideration around the influences of my background and worldview are particularly important.

2.3 The emic and the etic

In preparing to write this chapter, I have spent a lot of time reflecting on my life, experiences, and my PhD journey so far. In fact, thoughts of my place in this research, as an Australian researching a phenomenon in Fiji, have lingered in my mind since first proposing this study. My concerns have revolved around the acceptability of a 'foreigner' (my etic position; Pike, 1971))[1] conducting research in Fiji, not only from the perspective of the acceptability of the study but also the interpersonal interactions that would need to take place. Would people be open to me? How would they view me? Would we be able to relate with each other? And then leading on to – What if I misunderstand? What if I cause someone offense? If I get it all wrong, what will that mean for my

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[1] Pike (1971) described an etic approach to studies of behaviour as one that views data from a standing point outside of a particular system, and an emic approach as the view from within a system. The etic and the emic approaches to data are valuable for accessing a 'dimensional understanding' of behaviour (p. 41). In relation to my research, my etic view was coloured by events and understandings as an 'outsider' who has spent most of her life in Australia and my emic view was established in experiences and values as a family member with Fijian heritage and family ties.

Fijian family and other Fijians who have invested their efforts in the study? I have entered into this research with a heavy sense of responsibility for my actions and their outcomes.

The term 'foreigner' is perhaps not the correct terminology to describe who I am in this study. I have close and active ties with my extended family in Fiji and I find myself drawn to strengthening these ties further as I grow older (my emic position). My mother was born in a small Fijian village, Visoto, on the island of Ovalau. Her mother was the descendent of an iTaukei (Indigenous Fijian) chiefly clan and her father was a first-generation Chinese immigrant from Canton. My mother and her large family spent most of their lives in Ba, on the mainland of Viti Levu. My mother finished her schooling at the end of primary school and in the absence of a school that my Grandmother thought appropriate, my mother entered the workforce and provided income for her family.

My father was born in England and migrated as a young boy to Sydney, Australia on the SS Ranchi. He finished schooling in Year 10 and after proving himself through work as a tea boy for the Colonial Sugar Refining Company (CSR), embarked on an apprenticeship as a fitter and turner. His employment with CSR took him to Fiji where he worked in the sugar mills of Lautoka, Ba, Raki Raki and Labasa over ten years. My father often shares fond memories of his time working in Fiji and grew to consider Fiji as home. My father met my mother while working in Fiji – theirs is an enchanting love story that will be passed on through our family for generations.

I was born in Australia while my father was completing a short stint of work with CSR having spent the previous ten years working in Fiji. Two weeks after my birth, homesickness drove my parents to accept a position with the Fiji Sugar Corporation and we relocated to Ba, Fiji. We lived in Ba for three years before moving permanently to Australia where my parents believed my sisters and myself would have better educational and life opportunities. We visited Fiji every few years and always spent time with family, living in the 'real' Fiji, as opposed to holidaying at resorts where tourists catch only a glimpse of the Fijian lifestyle and culture. Together with the way my parents raised me, I learned the importance of being with family and the value of sitting and being together without rushing or prioritising other things (something I have come to think of as Fiji time). I learned respect for my elders. I grew familiar with many of the nuanced expressions used during interactions and, on reflection, I realise that we would use them naturally within our family unit in Australia.

I have lived most of my life in Australia and find that I have grown accustomed to the daily freedoms of being Australian – I enjoy reliable access to water, shelter, education, employment and human rights. Perhaps I take these things for granted. As I learn more about Fiji, the inequities in many aspects of life in Fiji, compared with Australia, become apparent (Chapter Three). Reflecting on my life so far and the experiences I have from time spent in Fiji, I know that I have experienced much privilege in my upbringing and life in Australia. In the early years of their life together, my parents built my Grandmother a house to provide a stable, secure shelter for my mother's family to live in. This came at great personal and financial expense to my parents, then a young couple starting out, but this was a necessity for my mother's family and a sacrifice that was willingly made. This need for safe, secure shelter is in stark contrast to my own experience of only ever knowing home to be a safe and very comfortable place.

I have also experienced privilege in my upbringing relative to my parent's upbringing. Privilege that has resulted from my parent's determination to provide the best life for their children. My sisters and myself are the first in our family to finish high school and we have also all completed a university degree. We witnessed our parents' struggle and determination to provide us with this opportunity - my parents raised four children in a capital city and then in a rural town, on a single income. In further testimony to my privileged life in Australia, I'm not sure that my own two children have witnessed such struggle.

In sharing this background, I hope to have conveyed my position in this study as a westerner with a deep connection with the Fijian culture. While not a true 'insider (emic)', I also consider myself not as a true 'outsider (etic)'. I possess cultural knowledge nurtured through a vibrant connection with Fiji - a connection that has been fostered by my parents all my life. I acknowledge the relative privilege that influences my world and life view, while recognising an ingrained value for sacrifice and hard work. In this section, I have also alluded to the values of love and responsibility that were instilled in me through my parent's actions from a very young age.

2.4 Inspiration and motivation

The inspiration and continued motivation to conduct this study on experiences and perceptions of dementia in Fiji is firmly established in my personal values and worldview. My values were nurtured through my parents who raised me to embrace Christianity and who coloured my upbringing with Fijian and traditional western cultural values. I describe the values that I hold most closely as love for family, love for God and love for people, with responsibility and obligation interwoven. I feel this is important to share and acknowledge as this study has great personal meaning. It is very much an expression of my love and sense of responsibility.

My maternal grandmother, whom I affectionately call Bubu, lived with dementia for many years. She passed away early in 2018. Bubu was a seamstress and mother to eleven children. Bubu had a quiet, assured strength that I always admired. The kind of strength that undoubtedly grows out of necessity, resolve and purpose.

I witnessed some of the impacts of dementia on Bubu's life and on the lives of those around her. The confusion and fleeting moments of recognition. The deterioration in her physical health. My Aunty eventually became Bubu's primary caregiver, though I doubt very much that she would refer to herself as a caregiver. The role of caregiving, with all the physical, mental and social challenges was heavy. Support for dementia in Fiji is limited. This is not surprising as there are many other health priorities that concern a greater number of the Fijian population, and efforts fairly focus on these. In Australia, there are still many gaps in care for people living with dementia and caregivers. However, the gaps are far greater in Fiji. I felt compelled to conduct this study in the hope of contributing to the easing of this inequity and to advocate for older people living with dementia, their families and caregivers.

At the time of proposing this study, I had worked as a research project officer for three years. Prior to this, I had worked as a scientist in the field of microbiology. I had also been studying nursing and the more I learned about social and health inequities, the more I wanted to be part of making a difference. The research role was appealing to me as it afforded me the opportunity to join a group of people aiming to improve health inequities for underserved populations. Over the years, my understanding around issues related to health equity has continued to grow and is nurtured by my colleagues and my faith.

2.5 Views on older people living with dementia

My attitude towards older people and older people living with dementia has been greatly influenced through my work as an assistant in nursing in a rural town in Australia. In the first few weeks of beginning in this role, I recall going home and crying after each shift. It was confronting to care for people who appeared to be vacant from their bodies – lying motionless in a bed except to open their mouth for food. It hurt to tell one of the male residents each day that his wife had passed away two years ago; and to see his reaction that could be described as indifference. I remember the fury in one of the resident's eyes when I accidently pulled a slipper off her foot too quickly and gave her a fright. She never reprimanded me, though I deserved it. The flash of anger quickly left her face and returned to her usual impassive expression. I recall one of the residents pacing endlessly around the rooms and hallways, never able to be still to enjoy a moment of quietness.

Over time, the pity that I felt towards the residents transformed to respect and admiration. I admired the tenacity of one of the female residents who would sometimes sit out on the garden bench waiting for her husband to pick her up. She would stay out there until it was dark. I would go out to her and put a cardigan around her shoulders. She would eventually come inside and eat dinner, her husband forgotten about for now. I began to see the resilience that had previously been hidden from me, clouded by feelings of sorrow.

It was during that work that I began to understand that older people living with dementia were not "shells of human beings." They were not "shadows of their former selves." So often we hear this in our communities. They were changed by dementia, yes. But not lost to dementia. People living with dementia continue to be unique individuals with feelings, will and hope. While advanced dementia sees drastic deterioration in abilities, a person's spirit remains so I learned to be present in the moment. I gave hand and foot massages, I sang and sometimes danced with residents, and played music at meal times. I learned to celebrate the spirit.

2.6 Influence of my position

In this section I discuss personal reflexivity and the ways in which I believe I may have influenced this study. I will refrain from discussing other types of reflexivity here (see Chapter Five).

I define myself as who I am in my family. I am a mother, wife, sister, daughter and granddaughter. I think that this view of myself has become ingrained through my values that I have talked about in the previous sections of this chapter. I sometimes found it difficult to balance this view of myself with the need to progress my research and collect data. For example, when talking to people living with dementia and family caregivers, it was challenging to move from a more passive position of quiet respect into the role of a researcher who had an 'agenda' related to my study. In particular, my cultural knowledge of interactions with older people and families in Fiji stipulated that questioning and enquiring should be respectful, and this required a high degree of thoughtfulness. I found that this was particularly demanding, especially considering all the pressures associated with interviewing in any case.

Adding to this challenge, my past experiences in research have involved professionals in the workplace, a very different group. After my second interview with a family caregiver (conducted with my Fiji-based advisor and Fijian colleague), I reframed this sense of making 'demands' to seeing the interview process as a way of sharing knowledge. Throughout this interview, I observed how my colleagues shared their knowledge at times, and gently probed for more information. From this point, if I sensed a shyness or uneasiness during an interview, I tried to work in a little bit of information about what I had been finding since starting the research and used this as a starting place. However, the mixture of our (myself and co-researchers) mutual unease at times (mostly due to my clumsiness in navigating questioning and my position as a researcher, and a foreigner) may have affected the depth or type of knowledge shared with me.

Interviews with service providers were more comfortable for me, as I have more experience with this through my employment and I felt that service providers were mostly at ease with me. However, there were times when my background as an 'outsider' gave me power and influenced the dynamics of an interview. I wrote about one instance of this in a memo at the end of a day, during a field trip to Fiji:

6th February 2019

> *Another thing I noticed was that people assume that Australia is miles ahead and like they are almost trying to excuse the situation in Fiji. I have found that I've been able to say, "Well people still think the same sorts of things in Australia," and I can see a change in demeanour. It really makes me realise that just by being an Aussie, people may be wary of what they say and maybe even how they portray their country. Example, talking with [a doctor] today we were talking about GPs diagnosing dementia and she mentioned that in Fiji doctors are reluctant/not confident to diagnose dementia - it felt almost apologetic, as she then went on to say that in Australia we have good algorithms for doctors to follow. I told her that this is the same in Australia where some doctors are reluctant to diagnose dementia and she seemed surprised. I then followed up and mentioned that we in Australia can learn from Fiji in the way family care for older people. She mentioned that this is the norm but is getting more difficult as children emigrate. So, I think that by levelling the playing field, this might have helped the conversation to continue. […] I need to think about how to put people at ease at the start I think, rather than waiting to see a bit of a problem.*

I became sensitive to the presence of this power dynamic and noticed it several times during field trips. Sometimes I noticed this same 'almost apologetic' attitude when service provider co-researchers interacted with me, and on occasion, this attitude was matched with a passion for wanting change. I recall one interview when a doctor shared with me the challenges that older people, families and service providers faced, and highlighted the very real disparities between Australia and Fiji. It was during this interview that I realised that my affluence had caused me to fail to appreciate the enormity of the impact of financial capacity on help seeking in Fiji. Looking back, this fact seems blaringly obvious. However, as a researcher in training, this was a pivotal moment that really opened my eyes to how important it was to practice reflexivity throughout the research process.

With my 'outsider' background, having lived in Australia for most of my life, it was a very important aspect of decolonising methodology to share my 'insider' position, and my desire to work collaboratively to progress this research. Throughout my interactions, I would try to position myself as the learner and the co-researcher as the expert. I shared my personal familial experiences of dementia and the reasons for conducting my research at the beginning of an interview. I would always work around availabilities of co-researchers in an effort to avoid imposing my agenda as being somehow more important than the daily activities that filled co-researchers lives. On three occasions, I met with co-researchers in their homes. I drew on my ‘insider’ cultural knowledge of etiquette and removed my shoes before entering a home, and I sat on the floor with co-researchers if that is where they were sitting. On one occasion, I was able to be prepared with a gift of fruit for a family, as it is customary to give a food item when visiting (something that I learned from my Mum and Aunties).

Throughout my research, I have tried to draw on my strengths as an ‘outsider’ with some ‘insider’ knowledge. I have tried to be sensitive to the influence of my actions and ways of thinking in approaching and carrying out this work. My position and worldview have also influenced other aspects of this research. I will discuss this further in Chapter Five and Chapter Seven when I consider ontological, epistemological and analytical reflexivity.

2.7 Chapter Two summary

In this chapter I have:

- Discussed my background and worldview, and situated myself within the research study; and,
- Discussed how my background as an ‘outsider’ with ‘insider’ knowledge has influenced some aspects of my research.

In the next chapter I will:

- Position my research within the context of Fiji by discussing the geography, population, history and health system of Fiji.

3. Study context

One of my favourite things to do in Fiji is to take bus trips as much as possible – it happens that this suits a student budget as well. I made many trips between Suva and Nadi on the express bus during field trips. The bus hurtles around the gentle curves in the road giving the feeling that it is not stopping for anything. It's a very comfortable ride but not one that everyone would enjoy – particularly for those who sit down the back and are prone to travel sickness! Once, I made an 11-hour round trip between Suva and one of the study sites (a town on the western side of Fiji) in one day. The purpose of the trip was to conduct a single focus group with health service providers. By the time I returned home it was dark and I was hungry. I had learned to look forward to the scheduled stop at Sigatoka where I could enjoy some locally made curry wrapped in roti. On every trip I would notice something different or learn something more about Fiji and the Fijian people. My favourite kind of bus trip though is riding around town on a "locals" bus, which is typically open air, with no closable windows.

This photo is a still image taken from a short video that I made during one such trip. I had visited a health service on the outskirts of Suva and was now heading back to the university. I wrote my feelings of this particular trip in my field notes. I share this here in the hope of bringing some of the *feeling* of Fiji to this chapter: *The wind coming through the bus openings cools my sweaty face as I watch the coastline disappear behind rows of houses interspersed by trees and greenery. I catch glimpses of people walking along the footpaths headed for bus shelters or some other destination as they go about their day. The ambience is warm. The island reggae dances through the air and intermingles with the smell of coconut oil that is swirling gently around the bus. The sounds of car horns honking disrupt the music fairly often as drivers signal their intention to merge into traffic. There are no exchanges of angry words or flaring of tempers between drivers. As I tuck my hair back behind my ears, I think about how beautiful this country is. Fiji. I love this place.*

3.1 Chapter Three outline

In this chapter, I position my research within the context of Fiji. Fiji is a small PIC with a diverse population, developing economy and an evolving health system. Many such contextual factors are unique to Fiji and the PICs, and are important to reflect on in terms of the study design and interpretation of the findings. This chapter provides an overview of Fiji with a focus on the geography, population, history and the health system.

3.2 Geography

Fiji is an archipelago of 332 islands (110 of which are inhabited) situated in the Melanesian region of Oceania, in the southern Pacific Ocean. Fiji has a population of 884 887 people distributed across 15 provinces (Fiji Bureau of Statistics [FBS], 2018). Approximately 81% of the population reside within eight provinces and are located mostly on the largest island, Viti Levu (FBS, 2018). Fifteen percent of the population reside within three provinces on the second largest island, Vanua Levu (some provinces include populations living on outer islands of Vanua Levu; FBS, 2018; Figure 3.1). The remaining 4% of the population live in the maritime provinces of Lomaiviti, Kadavu and Lau, and in the Fijian dependency of Rotuma (FBS, 2018).

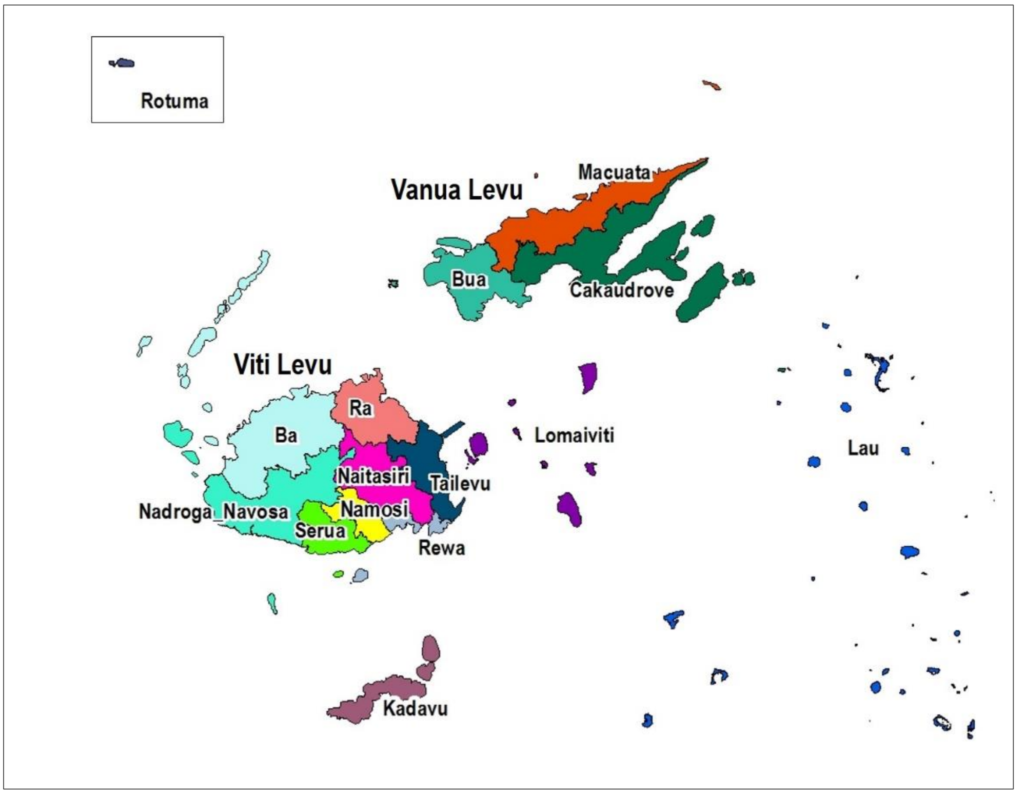

Figure 3.1. Fiji's provinces and the dependency of Rotuma (map modified from FBS, ESRI, 2018; 2009).

3.3 Fijians

iTaukei people are the main Indigenous people of Fiji. Prior to colonisation, iTaukei people lived in a patriarchal society with hierarchical kinship organisation and deep connections with the *vanua* (Ravuvu, 1983). The *vanua* encompasses the Fijian identity and explained the elements of, and connections with, the spiritual world and land (Parke, 2014). The *vanua* continues to be central in Fijian society (Parke, 2014). Between 1879 and 1916, Indian migrants arrived in Fiji under an indentured labour scheme implemented by the British colonial power (see Section 3.4). The majority of Fijians of Indian descent presently residing in Fiji have origins in indentured labour (Trnka, 2005). According to the 2007 Population and Housing Census, iTaukei constitute 56.8% of the population, Fijians of Indian descent constitute 37.5%, Rotumans[2] constitute 1.2% and a mixture of other ethnicities make up the remaining 4.5% (FBS, 2014; 2017 census data relating to ethnicity was not released). Sixty-four percent of the population is Christian, 27.8% are Hindu, 6.3% are Muslim, 0.4% are Sikh and the remaining 1.1% identify with another religion or no religion (FBS, 2018).

3.4 Colonial history

Fiji's colonial history has undeniably shaped modern day Fiji, its politics, people and culture. Modern day Fiji is home to two main cultural groups, with a variety of other smaller cultural groups. Both iTaukei and Fijians of Indian descent experience the legacy of colonisation, most notably through political tensions that have culminated into a series of coups, as both groups strive for self-determination in post-colonial Fiji. This section provides a very brief history, mentioning only key aspects important for contextualising this study.

Europeans began trading goods for sandalwood and bêche-de-mer with Fijians in the early 1800s (Kerr & Donnelly, 1972). From the 1850s, the number of European settlers in Fiji increased. They bought land from Fijian chiefs to run plantations and paid Fijians minimal wages to labour on their plantations (Kerr & Donnelly, 1972). In 1865, a confederation of Fijian chiefs, a European styled group with the King of Fiji Ratu Seru Cakobau of Bau as president, was formed (France, 1969). Fijian and settler discontentment with Cakobau's government grew (Kerr & Donnelly, 1972). Wesleyan Methodist missionary stations had also begun to appear at this time (Kerr & Donnelly, 1972).

Fiji was ceded to the British Crown in 1874 by the confederation of chiefs. Unlike many other British colonies, iTaukei, were not completely dispossessed of their land (though some land was taken as Crown land and some had already passed into the hands of European settlers). To the contrary,

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[2] Rotuma is a Fijian dependency located 500km north of Fiji, with a population of less than 2000 people. Rotumans are considered to be Indigenous Fijians and many Rotumans live in Fiji.

iTaukei communal way of life was protected through paternalistic laws that retained customary land title with village owners and prevented iTaukei people from participating in agricultural labour and urban life (France, 1968). Traditional principles, kinship, and social and territorial organisation were simplified and reconstructed with subsequent changes to roles and traditional life (France, 1968; Macnaught, 1982). The Great Council of Chiefs was established as an advisory group to the government speaking on matters concerning iTaukei (France, 1968). Represented by the chiefly systems, iTaukei commoners only received the right to vote in 1960, more than 30 years after male Fijians of Indian descent (Lawson, 2006). Speculation continues about how best the iTaukei people, as the traditional land owners, may achieve self-determination (O'Sullivan, 2018).

To support growth of the sugar industry as the economic foundation for the country, indentured labourers were brought from India between 1879 and 1916 (Lal, 1983). Aggressive recruitment campaigns were held throughout India with 60,965 labourers ultimately signing the Girmit, the agreement for a fixed period of labour in Fiji in return for money (Lal, 1983; Mayer, 1963). Many indentured labourers became ill and perished from poor health (Sharma, 2017). Following five years of indentured labour, workers could stay in Fiji or choose to return to India at their own expense, or accept free return passage to India after a further five year indentured period (Mayer, 1963). Indentured labourers were unable to communicate with their homeland; their caste system was broken down and connection with their homeland was difficult (Mayer, 1963). Many chose not return to India but took up leases to farm in Fiji, or became wage earners and business owners (Lockwood, 2004; Mayer, 1963). Their struggle for self-determination became active in the 1920s when they fought for the right to vote, earn fair wages and a place at the political table (Lockwood, 2004).

Since achieving Independence from the British Crown in 1970, political tensions between iTaukei leaders and leaders representing the interests of Fijians of Indian descent resulted in a series of coups; two coups occurred in 1987 and others in 2000 and 2006. In the coups of 1987, iTaukei leaders sought acknowledgement of their political right to power as traditional inhabitants of Fiji and Fijians of Indian descent sought recognition of their rights (O'Sullivan, 2018). During this time, violence and personal insecurity resulted in large numbers of skilled Fijians of Indian descent emigrating and unstable growth of the economy (Chand, 2015; Trnka, 2005). The population of Fijians of Indian descent declined from 48.7% of the population in 1986 to 37.5% in 2007 (FBS, 2014). In the 2006 coup, 'the coup to end all coups', military leader Commodore Bainimarama sought to dissolve racial divisions and unite Fiji (Fraenkel & Firth, 2009). The newly elected government that was overthrown had received 80% of the iTaukei vote (Fraenkel & Firth, 2009). Bainimarama (Fiji

First Party) was voted as Prime Minister during the 2014 and 2018 democratic elections and remains as Fiji's leader as of 2021.

3.5 Economy

Fiji is classified as an UMIC (The World Bank, 2021). UMICs are defined as economies with a Gross National Income (GNI) per capita of US$4,046 to US$12,535 (The World Bank, 2021) with Fiji's GNI per capita being towards the lower end at US$5,800 (The World Bank, 2019). The agricultural, tourism, mining and garment industries are important in the Fijian economy (Macdonald & Foster, 2018). Subsistence farming remains important particularly in rural areas (Asian Development Bank, 2015).

The average proportion of Gross Domestic Product (GDP) for health expenditure in middle income countries is 6%, and 12% for HICs (Xu et al., 2018). Fiji's current health expenditure as a proportion of GDP is low in comparison averaging 4.2% between 2011 and 2015 and 8.1% of total government spending (MHMS, 2015a).

Health care in Fiji is mostly provided through the public health system and is free or low cost, being subsidised largely through the taxation system (WHO Regional Office for the Western Pacific [WPRO] & Asia Pacific Observatory on Health Systems and Policies [APO], 2011). In 2015, 63% of total health expenditure was contributed by the government; high in comparison to the average of 48% to 51% in middle income countries (Xu et al., 2018). There is a small but growing private health sector in urban areas of Fiji that includes three general hospitals and private practitioners comprising general practitioners, dentists, pharmacists, optometrists and acupuncturists (Asante et al., 2017; WPRO & APO, 2011). In 2014, 25% percent of health expenditure occurred in the private sector, with household out of pocket expenses making up almost two thirds (73.2%) of private expenditure (MHMS, 2015a).

The wealthiest urban population spends much more than the rural population on health. The wealthiest fifth of the urban population spent FJ$199 per capita on health in 2008/2009 compared with $41 per capita for the rural population (Narsey, 2012). In comparison, the poorest 40% of urban and rural populations spent less than $19 per capita on health (Narsey, 2012). Participation in private health insurance and spending on private medical services was highest for the top two quintiles of the urban population but virtually non-existent for the lower urban quintiles and rural population (Narsey, 2012). A lack of private health services in rural areas combined with relative poverty are possible explanations.

Data about spending on aged care is limited. In 2015, 0.5% of public current health expenditure for health care providers was for residential long-term care facilities, and 5.3% of spending on health services and goods was for rehabilitative and long term care (MHMS, 2015a). To my knowledge there are no other publicly accessible sources describing expenditure on the aged care sector in Fiji.

3.6 Socio-demographic profile

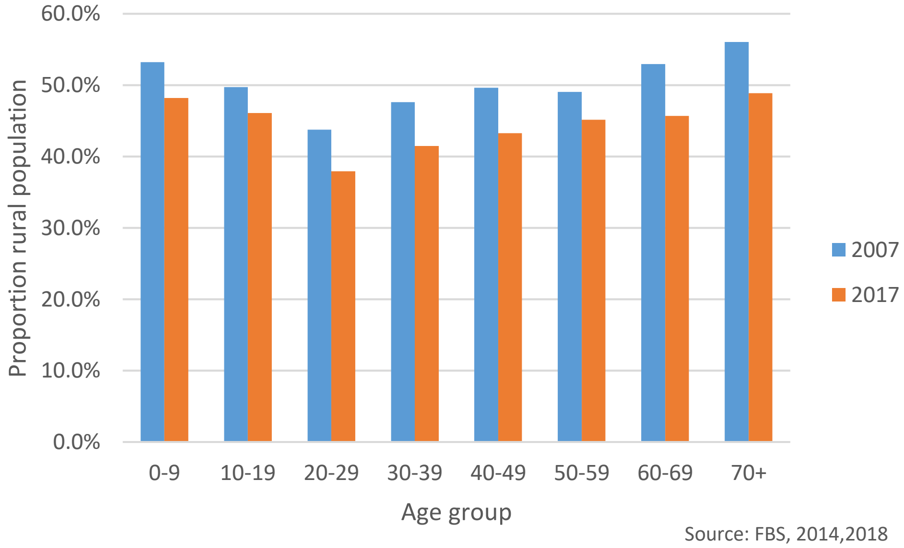
Over half of the population (55.9%) resides in urban areas, the boundaries of which continue to sprawl creating extensive peri-urban areas (FBS, 2018). Rural poverty linked with non-renewal of agricultural leases on customary land and inadequate income generated through agricultural activities contributes to rural-urban migration (Jones, 2012; Mohanty, 2006; Naidu & Matadradra, 2014). 'Squatter' or informal settlements reportedly accommodate up to 15% of the urban population and 7% of the total Fijian population (Fiji Ministry of Local Government Housing Urban Development and Environment, 2011) and continue to grow within Suva and other large towns, and on the urban fringes (Bryant-Tokalau, 2012; Phillips & Keen, 2016). Estimates of the population living in informal settlements vary due to different methods and definitions with estimates as high as 20% of the population (People's Community Network [PCN], 2016; Phillips & Keen, 2016). In 2016, 76,600 people were estimated to live in 171 informal settlements in the Greater Suva Area, Nadi, Lautoka, Ba, Levuka and Labasa (PCN, 2016).

While some settlements have clan and ethnic origins affording the security of kinship support (Jones, 2012), typically people residing in informal settlements are poor, living in overcrowded conditions with poor access to adequate housing, water and electricity (Adelman et al., 2015; Jones, 2012; Mohanty, 2006; Pabon et al., 2012; PCN, 2016). Traditional villages on the fringes of urban areas also experience poverty and poor living conditions (Bryant-Tokalau, 2012; Bryant, 1992). Urban income inequality, as measured by the Gini-coefficient, is slightly higher than rural inequality (FBS, 2021).

Overall, 22.9% of households and 29.9% of the Fijian population lives below the Basic Needs Poverty Line (FBS, 2021). The rural Fijian population, as a proportion of the total population, has decreased from 49.3% in 2007 to 44.1% in 2017 (FBS, 2014, 2018). The incidence of poverty is much higher in rural Fiji (41.5%) than in urban Fiji (20.4%; FBS, 2021) and is associated with high rates of subsistence activities that attract little to no income and a decline in earnings from the sugar industry (Asian Development Bank, 2015; Narsey, 2012). Moreover, households with three children or more have much higher rates of poverty (44.0%) than households without children (19.9%; FBS, 2021). Sixty percent of people participating in the workforce are involved in informal employment, with higher informal employment in rural areas (78.3%) than urban areas (38.6%; Asian Development Bank, 2015).

3.6.1 Ageing in Fiji

The proportion of older Fijians is growing rapidly due to declining fertility rates and improved survival to older age (MSWWPA & UNFPA, Anderson & Irava, 2017; 2011). The iTaukei demographic transition is occurring at a slower rate than that of Fijians of Indian descent who have lower mortality and fertility rates (MSWWPA & UNFPA, 2011; UNFPA, 2014). The median age of Fiji's population has steadily increased from 17.8 years in 1976 to 27.5 years in 2017 (FBS, 2018). The life expectancy for a Fijian at birth is 69 years with a healthy life expectancy of 60 years (WHO, 2015a). The population aged over 60 is expected to increase from 9.1% in 2017 (FBS, 2018) to an estimated 19% in 2050 (UNFPA, 2014). The majority of older people in Fiji are women and this trend is expected to continue (United Nations Economic and Social Commission for Asia and the Pacific [UNESCAP], 2016). The proportion of older people living in rural areas is higher than for younger age groups, with just 36.2% of those aged 20-24 years living in rural areas steadily trending upwards to 49.7% of those aged over 75 years (FBS, 2018). This trend was also apparent in 2007 and one possible explanation is an urban to rural drift as people age (Figure 3.2).



Source: FBS, 2014,2018

Figure 3.2. Proportion of the population residing in rural areas according to the Census of Population and Housing 2007 and 2017.

Traditionally in the Pacific, care for parents in older age is the responsibility of children (UNFPA, 2014). The majority of older people in Fiji co-reside with family and this is more likely for older people in poor health (Seniloli & Tawake, 2014, 2015). Economic factors may drive co-residency with older people having limited financial capacity to reside alone or offspring co-residing with older people due to unaffordable living expenses (Seniloli & Tawake, 2014). There is some speculation that factors such as rural-urban drift, more nuclear family units and emigration may reduce the capacity for children to care for their parents (UNFPA, 2014). An additional pressure for traditional provision of care, is the creation of a ‘sandwich generation’ whereby people find they must care for their own children as well as their dependent parents (MSWWPA & UNFPA, 2011). Together with high rates of poverty, minimal social protection and loss of status within the family, the needs of older people may not be adequately met.

Social welfare, though minimal and with poor coverage, is available through various government initiatives. The Family Assistance Programme and Poverty Benefit Scheme is available for older people, people with chronic illness, permanent disability, death of family breadwinner, dependents of prisoners and single female heads of households, although in practice, older people had poor access to this assistance (UNESCAP, 2016; WHO, 2013). Additionally, the Social Pension Scheme was introduced in 2013 and now provides financial support to people aged over 66 years who have no other source of income or pension (UNESCAP, 2016). For women, low participation in the workforce in general and greater involvement in the informal sector, together with lower education, and less authority and autonomy in the family, place them at greater risk of hardship in older age when compared to men (Asian Development Bank, 2015; MSWWPA & UNFPA, 2011; UNESCAP, 2016).

The Fiji National Provident Fund (FNFP), Fiji’s national superannuation fund, requires compulsory participation for the formal employed workforce. Participation in the fund by the informal workforce and self-employed is extremely minimal, constituting just 1% of members (MSWWPA & UNFPA, 2011). The fund can be accessed at the retirement age of 55 years with the majority of members withdrawing the full amount prior to retirement to pay for housing and education (Seniloli & Tawake, 2015, 2016). Moreover, just 25% of active members have sufficient funds after retirement to remain above the poverty line (Seniloli & Tawake, 2015, 2016). Relatively few older people are members of the FNPF (UNESCAP, 2016).

3.7 Health care in Fiji

The provision of health services by the MHMS occurs through four divisions; the Central, Eastern, Western and Northern division (Figure 3.3). Substantial outreach and rural services facilitate provision of health care.

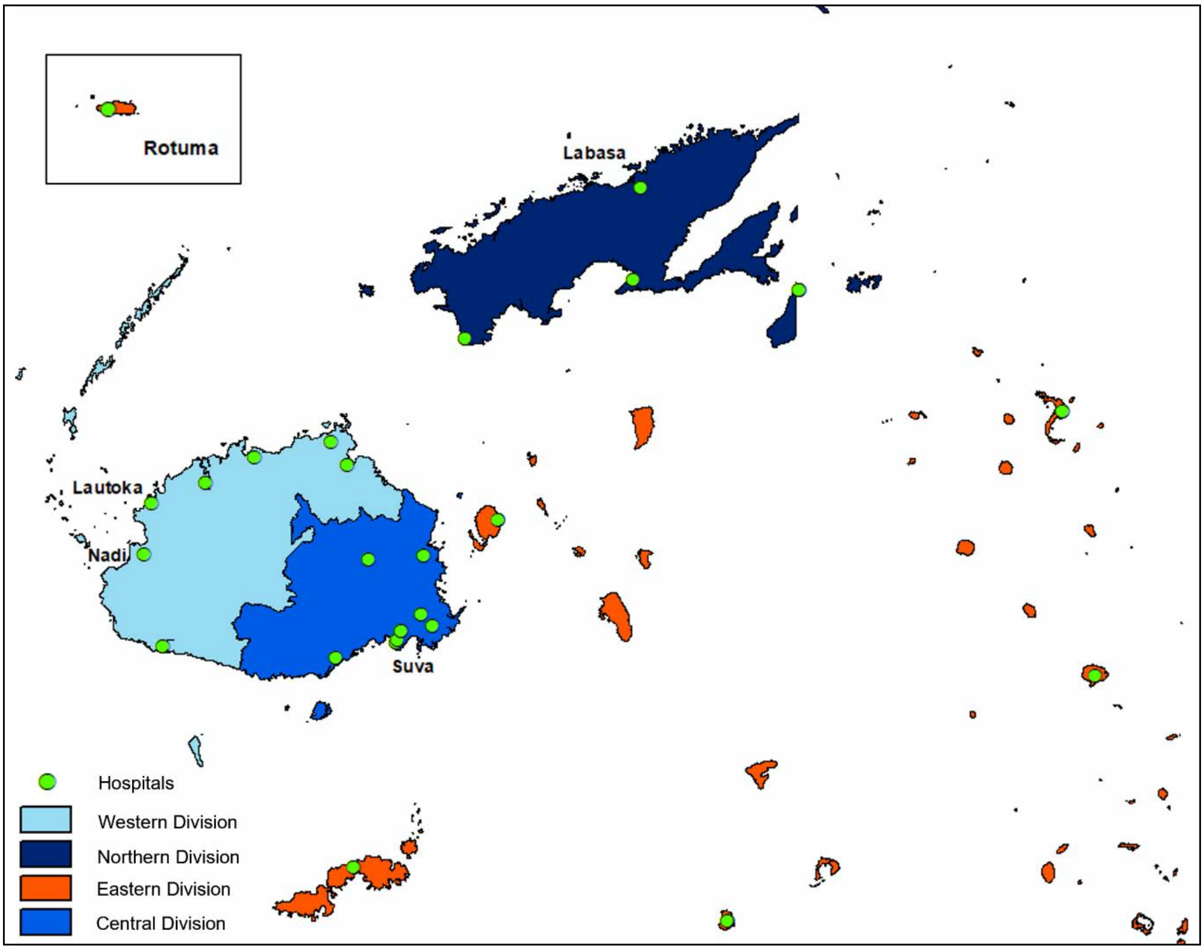


Figure 3.3. Administrative boundaries for health services and hospitals (map modified; ESRI, 2018; FBS, 2009; FBS, n.d.). There are a small number of aged care homes and these are located in Suva, Lautoka and Labasa.

Tertiary level care occurs at the three public divisional hospitals; Colonial War Memorial Hospital (CWM; Central/Eastern Division – central referral hospital), Lautoka Hospital (Western Division) and Labasa Hospital (Northern Division). The administrative boundaries are further broken into geographic sub-divisions. Primary care and limited secondary care occurs at sub-divisional hospitals (17 in total). PHC occurs at health centres (84 in total) and nursing stations (mostly in rural areas, 98 in total; MHMS, 2018) and is provided by general practitioners, medical officers (often very junior newly graduated doctors) and nurses. Village health workers (VHWs) are based in village clinics (900 in total) and treat and refer people to the formal health system (WHO, 2013) while community health workers (CHWs) perform this role in communities predominated by Fijians of Indian descent (WPRO & APO, 2011). VHWs and CHWs receive training from the MHMS and are supported financially by their community.

There are three specialist tertiary hospitals – Tamavua Hospital for rehabilitation, the P.J. Twomey Hospital for tuberculosis, leprosy and dermatological issues and Saint Giles Hospital for psychiatric care. The Oceania Hospitals Pte Limited (formerly known as the MIOT Pacific Hospital and Suva Private Hospital), Pacific Specialist Healthcare and Nasese Private Hospital are the three private general hospitals. There are also two faith-based mission hospitals, the Ra Maternity Hospital (private) and the Ba Mission Hospital (public). Figure 3.4 summarises services for each of the tiers of the Fiji health system. Specialist services for older people, the disabled and chronically ill are limited. The Fiji Ministry for Women, Children and Poverty Alleviation (MWCPA) fund three residential aged care homes and there are four privately funded or charity-based homes that accept older people.

Specialist Hospitals

- Saint Giles Hospital: 136 beds, services other PICs
- Offers occupational therapy and counselling services
- In 2017, inpatient admissions n=575; outpatients n=9078
- In 2013, 1 local consultant psychiatrist, 6 local psychiatric registrars, 3 regional psychiatric registrars
- Tamavua/Twomey Hospital consists of 3 units: Leprosy and Dermatology hospital, Tuberculosis unit, National Rehabilitation Medicine hospital

Divisional Hospitals n=3

- Colonial War Memorial Hospital (CWM; Central/Eastern division), Lautoka Hospital (Western division), Labasa Hospital (Northern division)
- Specialists, medical staff, registered nurses
- Broad range of services: accident and emergency, medical, surgical, orthopaedic. ophthalmology, obstetrics, gynaecology, paediatrics, outpatient clinics.
- Critical care, laboratory services, dental/oral surgery, radiology, acute psychiatric, chemotherapy, palliative care.
- CWM hospital is national referral hospital; Other PICs access this hospital

Mental health: Outpatient, Inpatient through Stress Management Wards, Counselling services at CWM and Lautoka Hospitals.

Sub-divisional Hospitals n=17

- General practitioners, midwives, registered nurses
- Primary health care, acute care
- Accident and emergency, inpatient care, obstetrics, dental, some diagnostic, facilitate outreach
- 300, 000-1,000,000 patients per annum
- Mental health: No allocated beds for mental illness. Containment where necessary occurs at local police station. Doctors may prescribe psychotropic medication which are available at health facilities with pharmacists.

Health Centres n=84

- Headed by medical officer or nurse practitioner and registered nurses (n=2-20)
- 24 hour on call; population health monitoring; maternal/child clinics; school, family, reproductive health; outpatient follow up and domiciliary care
- Urban: may have pharmacy, laboratory, radiology, dental, environmental health officers, dieticians, nurses for school visiting
- Catchment range: 3,500-10,000 people
- 15,000-50,000 patients per annum

Nursing stations n=98

- One registered nurse (on call 24 hours)
- 95% are funded by MHMS. Remaining funded by communities.
- Outreach to catchment area. Population health monitoring; maternal/child clinics; outpatients; school, family, reproductive health; domiciliary services
- Catchment range of 200-5,000 and see 1,500-30,000 patients per annum

Mental health: Open communication with Saint Giles Hospital for management of psychiatric cases through District or Health Centre (Zone) nurse. Outpatient domiciliary and follow up care for mental health patients. Minimal training in mental health.

Village/community health workers

- n=900
- Volunteers selected by the community and supported by the community - not formal MHMS staff.
- Supervised by District Nurse
- Training, pharmaceuticals and equipment funded by MHMS.\

Private health sector

- Oceania Private Hospital (largest private hospital in Fiji), Pacific Specialist Healthcare, Nasese Private Hospital
- Faith-based hospitals: Ba Mission Hospital and Ra Maternity Hospital (staffed by MHMS)
- 130 General Practitioners in private practice
- Cardiology, orthopaedics, urology, gynaecology, nephrology, ophthalmology, dietetics, imaging, physiology, counselling, paediatrics, dermatology, plastic surgery, neurosurgery

Figure 3.4. Tiers of the Fiji health system (Extracted from: MHMS, 2018; WHO, 2013; WHO, 2012; WPRO & APO, 2011; and supplemented with online information about health facilities).

3.8 Health system reform

The Fijian health system has undergone periods of reform since 1999. Health management reform from 1999 saw decentralisation of the health system to the divisional level with some centralised functions retained (Mohammed, Ashton, et al., 2016; WPRO & APO, 2011). However, lack of appropriately skilled managerial staff and the failure of financial management reforms, resulting from impacts of the 1987 and 2000 coups, saw the management reforms not realised in full (Mohammed, Ashton, et al., 2016). Additionally, lack of support from the MHMS inhibited the reform implementation (Mohammed, Ashton, et al., 2016). In 2008 the health system was recentralised to the former structure (Mohammed, Ashton, et al., 2016; WPRO & APO, 2011).

In 2009, decentralisation of the Suva subdivision (within the Central/Eastern division) involved strengthening of peripheral health centres and restriction of accessibility to the CWM Hospital to professional referral only (Mohammed, Ashton, et al., 2016). Resources for health centres were increased in line with substantial increases in hours of operation and clinical services offered. While decentralisation increased development of hospital services, this was not accompanied by changes in health centre autonomy from central management in decision making, possibly limiting the value of decentralisation (Mohammed, North, et al., 2016).

Mental health care is largely restricted to urban areas with Saint Giles Hospital, the only psychiatric hospital in Fiji, being located in Suva. However, decentralisation of mental health services is occurring. Mental health units (known as stress management wards) were opened in 2011 at the three divisional hospitals (Singh et al., 2013). Outreach mental health services have also been provided at nursing stations, health centres and sub-divisional hospitals in some urban areas since 2009, and often involve community mental health teams (Singh et al., 2013). Although local mental health workforce training for graduate nurses and doctors has been successful for Fiji and the PICs, achieving adequate numbers of professionals and retaining health workforce remains an issue (WPRO & APO, 2011). In addition, inadequate training of public health staff at the primary care level challenges further decentralisation of mental health services (MHMS, 2016a). Chapter Six provides further discussion of mental health care services.

3.9 Health workforce

Health workforce challenges in Fiji include rural-urban migration, emigration of skilled workforce and constrained financial resources (Wiseman et al., 2017; WHO & MHMS, 2012; WPRO & APO, 2011). Similar to most PICs, there is a shortage of doctors in Fiji with 0.8 doctors per 1,000 population (Matheson et al., 2017; World Health Organization, 2019b). This is despite Fiji National University College of Medicine, Nursing and Health Sciences (FNU) enrolling approximately 70 doctors per year, and the University of Fiji Umanand Prasad School of Medicine and a partnership program (between PICs and Cuba) adding graduates to the Fiji health workforce. Moreover, six provinces of Fiji have an inadequate density of nurses and doctors, with less than the 2.3 health workers per 1,000 population recommended by the WHO (Wiseman et al., 2017). The majority of medical officers are now located in urban areas, where major hospitals are situated, leaving some health centres in rural areas without medical staff (Wiseman et al., 2017; WPRO & APO, 2011). To counter the shortage of doctors, medical positions at health centres have been filled by international doctors and nurse practitioners may undertake management of health centres (WPRO & APO, 2011). The MHMS have also employed other strategies to address workforce issues including increasing numbers of places at the medical and nursing schools.

Qualified health professionals, particularly specialists, remain in demand in Fiji. Currently, there are no specialist doctors in the care of older people. There are three psychiatrists, several psychiatric registrars, one clinical psychologist and 60 public sector staff with mental health training in Fiji (WHO, 2013). There are no social workers with mental health qualifications working at Saint Giles Hospital or in mental health care (WHO, 2013). A mental health project officer in each division oversees mental health training for public sector staff though time and resources limit opportunities for training (WHO, 2013). Health profession education at FNU includes a two week training block for undergraduate nursing students and a nine week block for medical students (Chang, 2011). Additionally, nurses can undertake a postgraduate certificate or postgraduate diploma in mental health nursing in Fiji (Roberts et al., 2017). Doctors, social workers and counsellors can also undertake a postgraduate diploma in mental health (Roberts et al., 2017; WHO, 2013). Further training for doctors in the Master of Medicine (Psychiatry) is undertaken overseas.

3.10 Social care

The formal social care sector consists of some government services, including social welfare (see Section 3.6.1), and Civil Society Organisations (CSOs; special interest community organisations herein referred to as community organisations) that are mostly located in urban areas. The Fiji Council of Social Services (FCOSS), an umbrella organisation, aims to strengthen and support community organisations through collaboration, advocacy and training. There are more than 500 members and associated members registered with FCOSS (FCOSS, Pacific Islands Association of Non-Governmental Organisations & Humanitarian Advisory Group, 2019). Of particular relevance, the FCOSS HelpAge Centre conducts seminars on healthy ageing and delivers workshops on social protection (Chand & Naidu, 2010; HelpAge International, n.d.) however detailed information and evaluation of the FCOSS HelpAge Centre is not publicly available. There are very few community organisations that provide support for mental health and older people. Discussion about community organisations and their programs may be found in Chapter Six.

3.11 Priority health areas

Fiji is experiencing a crisis of NCDs. NCDs account for over 70% of premature deaths since 2010 (MHMS, 2020) and 72% of the top ten causes of death in 2017 (according to hospital admissions data; MHMS, 2018). Cardiovascular diseases, cancers, diabetes and chronic respiratory diseases are the main causes of death (MHMS, 2020). In 2017, diseases of the circulatory system were responsible for 34.6% of deaths and were amongst the top four causes of morbidity (MHMS, 2018).

There is growing recognition of mental health issues as causes of morbidity and mortality (MHMS, 2016b; Roberts et al., 2017). Improvements in collection of epidemiological data on mental disorders is planned (MHMS, 2015b). However, based on WHO estimates, in their lifetime 3% of adults (about 14,000 people) will have a severe mental disorder and 10% of adults (about 48,000 people) will have a mild-moderate mental disorder (WHO, 2013). In particular, suicide and self-harm are high priority issues (MHMS, 2015b).

Communicable diseases, including leptospirosis, typhoid fever, vector-borne diseases, sexually transmitted diseases, diarrhoea and respiratory infections, and injuries are also important causes of morbidity and mortality (MHMS, 2018; Institute for Health Metrics and Evaluation [IHME], 2016).

3.12 Policy context guiding health and ageing

The Yanuca Island Declaration, a commitment to improving the health of Pacific islanders, was made at the first Pacific Health Ministers Meeting at Yanuca Island in 1995. The Healthy Islands vision emerged as an expression of this declaration and acts as a framework for health development in the Pacific Islands region. This vision continues to inspire PICs to improve health together in partnership with communities and organisations at local, national and regional levels (WPRO, 2015a; WPRO, 2015b). There are several policies, plans and frameworks that guide health in Fiji and the PICs (Box 3.1), and issues of mental health, ageing and disability have also been addressed at the policy level (Box 3.2, Box 3.3, Box 3.4).

Box 3.1. Key general health strategies in Fiji.

General health strategies

Fiji Ministry of Health and Medical Services National Strategic Plan 2020-2025

(MHMS, 2020)

The strategic plan was developed over 12 months and was informed by a national steering committee, a situational analysis, and in consultation with stakeholders. The plan sets out three core priorities to be addressed through a one-system approach: i) reform public health services to provide a population-based approach for diseases and climate crisis; ii) increase access to quality, safe and patient-focused clinical services, and iii) drive efficient and effective management of the health system. The plan focuses on improving the wellbeing of all Fijians.

Fiji Non-Communicable Disease Strategic Plan 2015-2019

(MHMS, 2014)

The strategic plan provides guidance on the prevention, treatment and management of priority NCDs. The plan focuses on the reduction of risk factors that commonly lead to NCDs, with a specific focus on cardiovascular disease, diabetes, stroke and suicide. Strategies incorporate a multi-sectorial approach and aim to reduce the social determinants of the priority NCDs. Health systems' strengthening includes a focus on primary health care in prevention, early diagnosis and treatment.

Fiji National Wellness Policy 2015 (draft)

(MHMS, 2015c)

The policy has been developed to reframe a formerly disease focused approach to health to one that is holistic and population focussed. This policy is multi-sectoral involving formal and informal sectors that can influence wellness through the social determinants of health. It actions the Wellness Fiji Conceptual Framework which aims to incorporate and promote wellbeing into everyday living. The framework approaches this through seven dimensions of wellness, seven domains of influence, seven cohorts and seven settings.

Box 3.2. Mental health strategies in Fiji.

<u>Mental health strategies</u>

Fiji Mental Health Decree 2010

The Decree upholds a human rights approach and provides a framework for the development of mental health services in Fiji that are accessible for all (Chang, 2016).

Fiji National Mental Health and Suicide Prevention Strategic Plan 2015 (draft)

(MHMS, 2015b)

This strategic plan aims to: i) provide a framework for addressing mental health issues; ii) promote strategies to reduce self-harm and suicide; iii) improve mental health service delivery; iv) provide care in the least restrictive environment; v) integrate mental health services into general health services; vi) develop community based mental health services; vii) promote strategies for ongoing training and research; and viii) ensure adequate resources for prevention and management of mental illness.

Box 3.3. Ageing strategies in Fiji and the Pacific Islands regions.

Ageing strategies

Fiji National Policy on Ageing 2011-2015

(MSWWPA & UNFPA, 2011)

The policy provides a framework for multi-sectoral action to address the needs of a growing aged population (aged over 60 years). The policy aims to be inclusive of older people, uphold their human rights and to recognise their contributions to society. It was developed in consultation with government agencies, CSOs, faith-based organisations and communities. There is a particular focus on support for older women and older people living in poverty, and improvement of health through improved community and social support. The National Council for Older Persons Decree 2012 saw the formation of the NCOP as a key guiding body for implementation of the policy. To date the NCOP is active, however a small annual budget has limited activities of the group (Anderson & Irava, 2017).

Fiji Ministry of Women, Children and Poverty Alleviation National Strategic Plan (2018-2022)

(MWCPA, 2018)

This plan focuses on the vision of transformation of communities with empowered women, children, older people, people with disabilities and disadvantaged people. The plan was informed by a SWOT analysis and consultations with stakeholders. There are five objectives: i) promote sustainable and inclusive growth; ii) inclusive socio-economic development; iii) good governance and best practice; iv) integration of climate action into economic growth, environmental protection and social development; and v) empowering women.

Regional framework for action on ageing and health in the Western Pacific (2014-2019)

(WPRO, 2014)

The framework serves to direct further dialogue on ageing and health in the Western Pacific region. The framework is structured around four pillars of action to foster age-friendly environments, promote healthy ageing, reorient health systems for older people and strengthen the evidence base on ageing and health in the Western Pacific.

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The Wellness Fiji Concept, National Policy on Ageing, National Policy on Persons Living with Disability and various mental health and general health strategies are all positive steps towards better health and wellbeing for older people, and older people living with dementia. The inter-sectoral approach across the strategies is encouraging and promotes a holistic outlook for ageing and health. However, transformation of these plans and strategies into actions that will benefit the wellbeing of older people is still lacking. For example, a policy gap analysis of the Fiji National Policy on Ageing (written following the expiration of the policy in 2015) was critical of poor clarity about the inclusion of the views of older people in the policy development, the omission of the issue of disabilities due to NCDs and robust discussion of the human rights of older people, and a lack of measurable indicators (Sharma & Koroivueta, n.d.). The gap analysis also reported a lack of review and reporting, and a lack of evaluation of policy implementation.

3.13 Access to health and social care in Fiji for older people

The dispersed geography of Fiji presents challenges for health service provision and access barriers for people living in the maritime islands and in rural areas on the mainland. The shortage of doctors in rural areas and costs associated with travel likely add to issues of poor access to quality health services for people living rurally or in informal settlements. For older people, there is a reliance on family for care in line with tradition and culture, but this is likely exacerbated by lack of financial independence. Treatment requiring specialist care is only available in urban areas. Additionally, access to mental health care, disability services and aged care is limited by geography and availability of services. This is problematic for both people living with dementia and formal and informal caregivers whose access to support, education and training is also limited. As will be discussed in Chapter Four, knowledge and beliefs are also likely to form barriers to help seeking and provision of quality, appropriate care.

3.14 Chapter Three summary

In this chapter I have:

- Provided an overview of the population of Fiji in relation to the geographic distribution of the population, colonial history, socio-demographics and main aspects of health and social care.
- In doing this, I have situated my study about dementia of older people within the context of modern day Fiji.

In the next chapter I will:

- Review the literature about understandings of dementia in LMICs and amongst indigenous people, and how these shape experiences of dementia.

4. Conceptualisations of dementia in older people

> *"Ah, I don't really understand. Yeah I don't really understand what's the meaning of [dementia], I only come to know that dementia is like forgetting, eh."*
>
> (Niece of person living with dementia, I-14)

4.1 Chapter Four outline

In this chapter, I provide an overview of conceptualisations of dementia in LMICs and amongst indigenous populations. I do this by providing a qualitative meta-synthesis of studies about understandings of dementia in LMICs and indigenous peoples that has been published in a scholarly journal.

4.2 Introduction to the paper: Understandings of dementia in low and middle income countries and amongst indigenous peoples - A systematic review and qualitative meta-synthesis

In conceiving the idea for this research about dementia in Fiji, it was clear to me that, like for other health conditions, provision of dementia care and experiences of dementia must be influenced by context. I thought that there was evidence of this in my own experiences of discussing my grandmother's wellbeing over the years that she lived with dementia, and those of my Aunty, Mum and other family members who were caring for my Grandmother. I had reflected on these discussions, as well as my own experiences working with people living with dementia in a dementia ward at a residential aged care facility in Australia. It also seemed to me that there were obvious differences in resourcing between Australia and Fiji that likely influenced how care for dementia was delivered and the availability of specialised support for people living with dementia and their families.

I was interested in how dementia was conceptualised in Fiji, having heard from my family that my grandmother was just getting old. Further, I was interested in how perceptions of dementia might influence dementia care. Given that Fiji is an UMIC and home to a majority iTaukei population, I decided to conduct a literature review about perceptions of dementia of older people in LMICs and amongst indigenous populations. This literature review also enabled me to investigate how others have explored this issue and to meet institutional requirements for candidature.

The literature review as published forms the remainder of this chapter. It was published in Aging and Mental Health in advance online (Epub) in mid-2019 (Johnston et al., 2020). The article has been cited nine times in scholarly journals (as at 18th August 2021). In addition to the other co-authors of this article, I acknowledge support and expertise from the late Associate Professor Suzanne McKenzie as an advisor on the PhD advisory panel. I also acknowledge the time and expertise of senior librarian Mr Stephen Anderson (James Cook University). This research was supported by an Australian Government Research Training Program Scholarship.

In keeping with the authors' copyright agreement with Taylor & Francis, in the following section I share the 'Accepted Manuscript' version of the literature review that was published by Taylor &

Francis in Aging and Mental Health on 10 May 2019, available online: https://www.tandfonline.com/doi/full/10.1080/13607863.2019.1606891

4.3 Introduction

Dementia is a growing health priority, particularly in less resourced countries and amongst indigenous populations (Arkles et al., 2010; WHO, 2012). The majority (58 per cent) of people with dementia currently reside in countries classified by the World Bank as low and middle income countries (LMIC), and this proportion is likely to increase in the near future (WHO, 2012). Likewise, prevalence studies of dementia in indigenous populations indicate disproportionately higher rates of dementia than those found in non-indigenous populations (Jacklin et al., 2013; Li et al., 2014; Smith et al., 2008; Warren et al., 2015). These populations already experience inequitable access to health services and poor health outcomes.

Conceptualisations of dementia may be embedded within a society's existing cultural and social constructs, rather than within a biomedical framework (Barker, 2009; Cohen, 1995; Henderson & Traphagan, 2005). In Japan, 'boke' is a cultural concept that is characterised by various signs including those typical of Alzheimer's Disease (AD; Traphagan, 2005). The condition of 'boke' refers to when one perceives, or is perceived to be 'spacing out' (Traphagan, 2005, p. 147) or disconnected from social interactions. It is a 'moral concept' (Henderson & Traphagan, 2005, p. 273) whereby it is one's social responsibility to prevent 'boke' through personal endeavor, with consequent implications for those perceived to be 'boke' and the associated burden they present to others. Here, cognitive decline in older age is deeply embedded within social constructions, rather than pathological.

In contrast, within a biomedical framework, dementia is a condition of the brain characterised by progressive decline in cognitive function that increasingly affects a person's ability to participate in daily life. Assuming that services exist, a diagnosis of dementia facilitates access to the health system including public, private and community health, and social services. Support from the health and social system may include advice and education about dementia management, medication, and support with maintaining social contact and community involvement. Dementia care is evolving as recognition of the harms of institutionalisation and complexities of medication for people with dementia increase (Buckley & Salpeter, 2015), and person-centred approaches gain momentum (Fazio et al., 2018). However, beliefs around illness and ageing, low awareness and knowledge of dementia, and stigma prevent help-seeking for dementia care (Batsch et al., 2012; Mukadam et al., 2011; Werner et al., 2014) and negatively impact on the human rights of people with dementia (WHO, 2017).

The first global action plan on public health responses to dementia advocates for the prevention of dementia, and the promotion of care and support that enables the wellbeing of people with dementia and caregivers (WHO, 2017, p. 5). The action plan provides the impetus and framework to drive dementia research and policy change globally. However, health system responses for chronic problems associated with ageing are slow to evolve, especially in LMIC (WHO, 2015b), where high stakes national health priorities compete. In the Pacific Islands, for example, the population aged over 60 years is expected to increase four fold from 2014 to 2050 (UNFPA, 2014). Family and community networks traditionally form the core of care for older people but these networks are threatened due to emigration, urbanisation and increasingly nuclear families (UNFPA, 2014). However, attention to other health priorities including non-communicable diseases, mental health, and maternal and child health compete with the growing challenges associated with ageing. A similar narrative is true for other lower resourced countries. Indigenous populations also experience significant health disparities, often despite residing in high income countries. Health system responses for indigenous populations should center on culturally congruent provision of care which traditionally entails consideration of cultural approaches to wellbeing and caring (Arkles et al., 2010). There is now recognition of the need to understand issues of dementia in indigenous populations and cross national research is needed to inform policy development (Flicker & Logiudice, 2015).

A key action area of the global action plan on dementia focuses on increasing dementia awareness to foster acceptance and understanding, thereby improving the environment and communities in which people with dementia and caregivers live (WHO, 2017). Understanding conceptualisations of dementia is therefore an important aspect of policy development and provision of culturally congruent care and support for people with dementia, their family and the caring professions. The literature on the perceptions and beliefs around dementia and their impact on experiences for immigrant ethnic minority groups is substantial (Kenning et al., 2017; Mukadam et al., 2011; Sayegh & Knight, 2013). However, synthesis of the literature on perceptions and beliefs around dementia and their impacts in the contexts of lower resourced countries or indigenous populations is currently missing. This review aims to investigate the conceptualisations of dementia amongst indigenous populations and populations living in LMIC, both groups who experience relatively low formal dementia care and support relative to higher income countries and non-indigenous populations, and how these shape responses to dementia.

4.4 Methods

4.4.1 Search strategy

A systematic review of empirical literature available online was undertaken to December 2018 (there was no lower date limit applied on the bibliographic databases). The search strategy aimed to capture the following inclusion criteria: study design includes perceptions, attitudes or understandings of dementia; set in LMIC according to the World Bank (2017; High Income Country included if about indigenous population); about indigenous population; empirical; and reported in English. A librarian from the authors' institution educated the first author about the databases that should be used for this specific search and how to search each database comprehensively (Scopus, Medline, PsycINFO, CINAHL and Informit databases), and assisted in developing the initial search strategy. Formation of the search strategy was an iterative process involving several cycles of searching. Search terms were first identified based on the aim of the review and consisted of terms in the categories of 'knowledge, beliefs, attitudes', 'dementia', 'low and middle income countries' and 'indigenous'. Subsequent searches were modified based on keywords in relevant articles of the preceding search. This cycle was repeated several times within a database and then across databases until new terms no longer emerged from the results. Two searches were then performed in each database: one focused on LMIC and the other on indigenous studies. Subject heading terms were used in Medline and CINAHL, and keywords were used in Scopus, PsychInfo and Informit databases. A full description of the final search strategy may be found in Appendix 1. Reference lists of articles chosen for further review were also hand searched for other potentially relevant articles.

4.4.2 Review strategy

The review was conducted in several stages (Figure 4.1). All articles resulting from the search were imported to EndNote (The EndNote Team, 2013). Duplicate records were removed. Titles and abstracts were reviewed for potential relevance for the aim of the review. Remaining publications were reviewed in full and screened according to the inclusion criteria. Articles were excluded for the following reasons: review article; non-empirical; quantitative methodology, research based in high income country according to the World Bank (2017); evaluation of health service or education intervention; mental illness in general; about dementia experiences with no investigation of perceptions of dementia; or focus purely on younger onset dementia (as social, health and care issues differ and warrant a separate review).

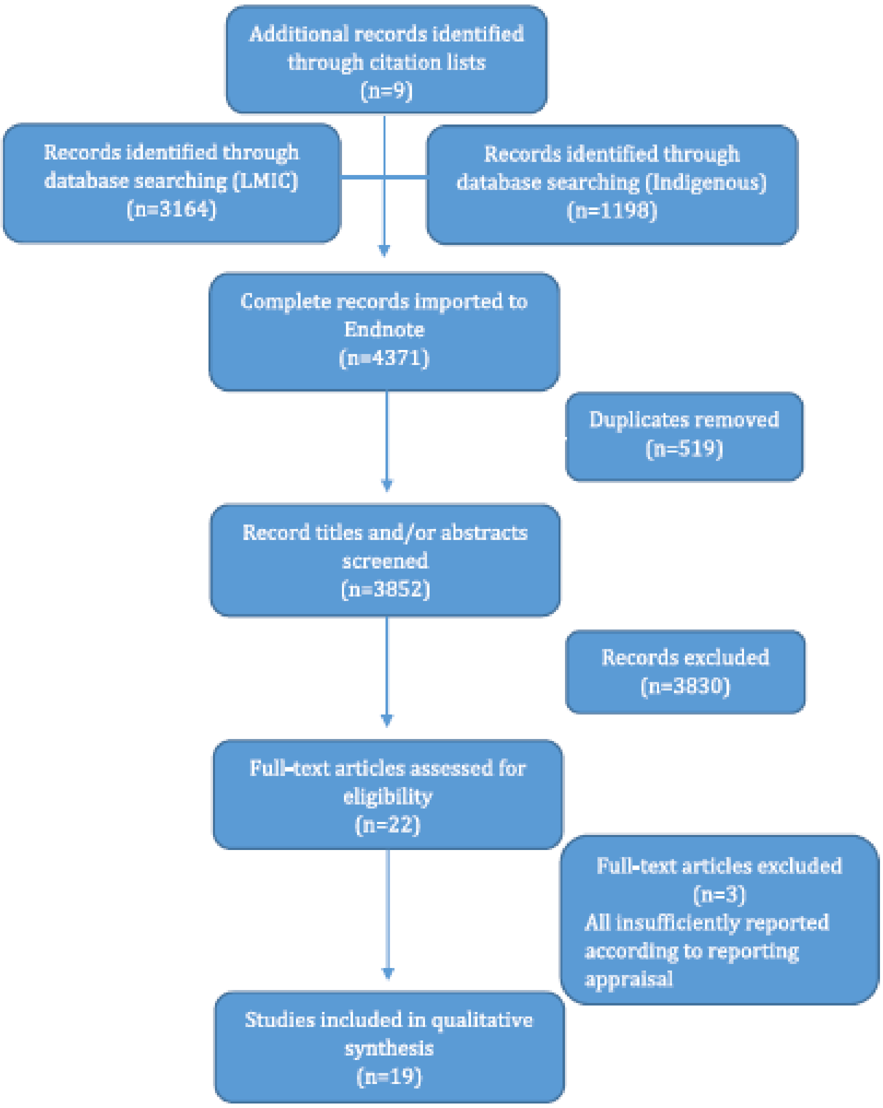


Figure 4.1. PRISMA diagram for review of search results.

The remaining studies were examined using a data extraction template. Information extracted was study aims, study design, participant recruitment, data collection method, analysis, sample and findings relevant to the review's aim. Quality of reporting in studies was assessed through four criteria and used as a basis for decisions about inclusion or exclusion from the review. The criteria required assessment of reporting quality (as satisfactory or unsatisfactory) for the research question and study design, participant selection, data collection methodology, and data analysis methodology (Table 4.1; Carroll et al., 2012). Studies that met at least two of the four criteria were included in the review (Appendix 2). Carroll and others (2012) suggested that studies assessed to be adequately reported contributed to rich thematic synthesis whereas inadequately reported studies could be excluded from the final synthesis without consequence. Reflexivity, evaluative rigor and study relevance were also assessed, summarised and considered in the context of the review findings and limitations (Appendix 2).

Table 4.1. Criteria for inclusion of study in review based on quality of reporting (based on Carroll et al., 2012).

Criteria	Rationale
Question and study design	Research question and study design described
Participant selection	Details provided should include: Sampling method; who, where, how, number recruited
Data collection methodology	Description of formation/piloting of tools, process for data collection, duration, consent
Data analysis methodology	Description of data analysis method. Some specific information should be given about processes used.

4.4.3 Qualitative analysis and synthesis

The qualitative synthesis used techniques for meta-ethnography (Noblit & Hare, 1988) as they offered a structured and rigorous approach to the review. Initially, studies were grouped according to the country setting or indigenous group and analysed in these clusters. As studies were read, concepts were identified from the findings of each study. The authors' words were used as much as possible as a strategy to stay true to the original study and maintain context. Through repeated reading of the studies and constant comparison, key concepts emerged that described how the studies were related. Once these key concepts were identified, studies were re-read multiple times to aid in context specific interpretation of study findings for each concept. This was an iterative process with modification, removal or addition of key concepts and was facilitated by the use of a grid containing the studies and key concepts. These key concepts, or translations, were synthesised to form interpretations of each study. These interpretations were considered and synthesised across all the studies to form second order interpretations. In meta-ethnography, the translation and interpretation of studies may result in a reciprocal, refutational or line-of-argument synthesis (Noblit & Hare, 1988). For this review, the second order interpretations were framed into themes. The first author was primarily responsible for all stages of the review and met regularly with fellow co-authors to discuss the quality and inclusion of studies, analysis and synthesis.

4.5 Findings

Following review of the articles resulting from the literature search, 22 publications were identified for appraisal of reporting quality. Three studies were excluded following appraisal due to insufficient reporting (Cohen, 1995; Henderson & Henderson, 2002; Mbelesso et al., 2016). A total of 19 publications were included for qualitative analysis and synthesis. Fifteen studies were set in LMIC: China (n=3); various areas of India (n=4); Iran (n=3); Mexico (n=1); Pakistan (n=1), South Africa (n=1) and Tanzania (n=2). A further three studies involved First Nations populations in Canada and one involved Aboriginal and Torres Strait Islander populations from Australia (Table 4.2). The studies explored a combination of perspectives from various key stakeholders with personal experience of dementia (including people with dementia, caregivers and service providers), as well as views of community leaders, older people or general community on dementia and ageing (Table 4.2).

The studies reported various aspects of trustworthiness. Nearly all studies reported approval from appropriate bodies and collection of informed consent. The two studies (Patel & Prince, 2001; Shaji et al., 2003) that did not report ethical approval from an institution were early studies from the 10/66 Dementia Research Group. Consent was obtained from participants in both studies though only one study reported a process of informed consent. Both studies were published in reputable journals. Some studies conducted interviews and focus groups in participants' languages however not all of these reported steps taken to increase the dependability of translated transcripts. Member checking and investigator triangulation increased credibility of some studies. Few studies described using audit trails and reflexive practices. The studies from Canada were particularly rigorous due to the decolonising methodologies employed such as consultation with community leaders on research design and inclusion of First Nation peoples throughout analysis and research dissemination (Hulko et al., 2010; Jacklin et al., 2015; Lanting et al., 2011). This review aims to draw out similarities and differences in findings between settings, while acknowledging that transferability of a study's findings across settings is often limited by the ability to interpret and describe contexts in sufficient detail (Finfgeld-Connett, 2010).

Table 4.2. Studies reviewed for qualitative analysis and meta-synthesis (grouped by country for study setting).

Reference and study area	Aims	Study design	Participant recruitment	Data collection method & analysis	Participants	Interpretations
Smith et al. (2011) Kimberley region; Australia	• Investigate health needs for Aboriginal people living with dementia in remote communities	• Semi-structured interviews and focus groups • Steering committee; Aboriginal caregivers, key service providers, Aboriginal community council members	• Purposive sample • 3 phases – phase 2 informed phase 3 • Key service providers interviews • Aboriginal caregivers and community care staff interviews • Focus groups	• Caregiver/care staff interviews 30-60 minutes duration • Audiotaped and transcribed • Aboriginal researcher involved in interviewing, transcribing, analysis • Ongoing thematic analysis	• Key service providers (n=42) • Aboriginal caregivers/care staff (n=32) • 3 focus groups with community care staff and aged care service providers (number of participants not reported)	• Community and caregivers perceive dementia to have various causes - older age, head injury, lack of family visits and brain changes. An older person was valued as a knowledge keeper and important role model who should be cared for within the community, with fear for the wellbeing of those leaving the community for residential aged care. Community want to have knowledge about caring and services, and this could be achieved through genuine community engagement.
Hulko et al (2010) British Columbia, Canada	• Explore perceptions of First Nation peoples on dementia	• Constructivist grounded theory informed by Indigenous perspectives • Sharing circles with Elders; interviews with some • Baskin (2005) storytelling method • Photo elicitation Bastings (2009) • 3rd party questions	• Purposive sampling of 43 communities	• 3 communities participated • 1-2 sharing circles in each community (n=4-9 elders per circle); 1.5-2 hours duration • Interviews similar method; 1.5 hours • Iterative analysis process; grounded theory methods, collaborative	• Secwepemc Nation people • n=21 Elders; 4 with memory loss; 2 family/ community members Majority lived on reserve; spoke native language; majority residential schools; majority knew someone with memory loss (probably same person)	• Meanings for memory loss change over time with the influence of colonization – from conceptualization of memory loss within traditional Indigenous notions of circularity to 'your dementia' being associated with changes in diet, environment and lifestyle following colonization, partnered with a change from acceptance to fear. • Supporting one another involves staying within the community with support from the community.

Reference and study area	Aims	Study design	Participant recruitment	Data collection method & analysis	Participants	Interpretations
Jacklin et al. (2015) Ottawa, Sudbury, Thunder Bay, Six Nations, Wikwemikong Unceded Indian Research, Manitoulin Island, Mosse Cree First Nation Canada	• Investigate family caregiving for dementia in Indigenous communities	• Part of a larger multisite anthropological study • In-depth semi-structured interviews • Observations, field notes	• Convenience sample • Recruited through contact with local health care providers	• Conducted in Indigenous language as appropriate at participant home • 90 minutes duration • Audio-recorded/transcribed • NVivo to facilitate organization • Critical interpretive approach and participatory approaches	• Indigenous informal caregivers of people with dementia (n=34); adult children, spouses, extended family, friends • Most caregivers members of immediate family	• Dementia as a condition, its symptoms and progression were not known to most with later symptoms of dementia triggering realization of a problem. Traditional Indigenous values of family motivated caring by family though obligation was sometimes a factor. Care is best provided within the community in familiar surroundings and surrounded by family and community. Care homes mostly viewed to not provide culturally appropriate services and contradict strong family caregiving values.
Lanting et al. (2011) Saskatchewan, Canada	• Investigate Aboriginal perceptions of aging and dementia for development of assessment procedures	•Constructivist grounded theory •Small group interviews – semi-structured •Conducted with same people over time •Purposive sample •Questions chosen to meet aims of study •Participatory •Culturally sensitive	•Recruited from Grandmothers Group – meet for education, advocacy and social gatherings •Formed partnership with leader of group then asked others to participate	•Informant group interviews monthly for six months. •Researchers active participants – conducted in English with spontaneous use of own language •No consent to record – researcher transcribed •3 hour duration •Shared food •Thematic analysis after second meeting - with participants (during meeting) •Theoretical saturation	•Aboriginal seniors (n=3) – six key informant group interviews monthly •Reflect diverse backgrounds of Aboriginal groups in town. •All rural background	•Dementia symptoms were associated with normal aging and the 'circle of life' (a cultural concept). Dementia was linked with changes in traditional diet, exercise, family structure and increased stress in modern times, and evoked fear. Traditional notions of circularity and aging exist within modern conceptualizations of dementia. Loss of traditional lifestyle contributes to a loss of family and community caregiving.

Reference and study area	Aims	Study design	Participant recruitment	Data collection method & analysis	Participants	Interpretations
Dai et al. (2015) Wuhan & Beijing, China	• Investigate perception of Alzheimer's Disease and caregiving among caregivers of people with mild cognitive impairment and Alzheimer's Disease	Qualitative • Grounded theory methods • Semi-structured interviews • Piloted study • Demographics obtained at survey pre-interview	• Purposive sample • Recruited from memory clinics through another study • Inclusion criteria: Primary family caregiver now or in future; at least 18 years of age	• Conducted by 2 trained interviewers • 60-180 minutes • Audiotaped/transcribed into Mandarin Chinese then compared with recording. Also transcribed to English and back-translated. • "Core variables" (described in more than 60% interviews)	• Caregivers of people with diagnosed cognitive impairment: spouses, children, sibling (n=46) • Zhongnan Hospital, Wuhan (n=21); Peking University Dementia Care and Research Centre (n=25)	• Family caregiving and respect for older people is deeply embedded in Chinese tradition and terminology is important - 'laonian chidae' is perceived as offensive. An expectation that illness and dementia are normal for aging people creates a perception that health care is not necessary.
Hsiao et at (2016) Beijing, China	• Compare knowledge and attitudes of dementia and practices among mental health providers in city versus town settings	• Qualitative • Focus group discussions • Survey for sociodemographic information	• Purposive • Inclusion criteria: full time work in mental health and community psychiatric hospitals	• Two researchers conducted focus groups - facilitator and observer • 90 minutes in duration • Video recorded and transcribed • 4 researchers conducted the analysis • Framework analysis • Analysis included district, themes, notes	• 2 focus groups (n=10/group) per district • Community doctors (n=17; 12 Xicheng) • Hospital physicians (n=11; 2 Xicheng) • Nurses (n=12; 6 Xicheng)	• Early symptoms of dementia are rejected by inexperienced health providers who associate dementia with psychotic illness. Inexperience and lack of training leaves providers to struggle with counseling and information giving. Providers' fatalistic view of dementia prioritizes family as caregivers. Responses from community to dementia are influenced by their perception of the cause of symptoms - normal aging or psychotic illness – delayed help seeking, avoidance and stigma.

Reference and study area	Aims	Study design	Participant recruitment	Data collection method & analysis	Participants	Interpretations
Lian et al (2017) Chongqing, China	• Investigate experiences of engaging in dementia diagnosis	• Interpretative informed by Gadamer's hermeneutic principles • Focus group discussions	• Recruited through memory clinic • Inclusion criteria; diagnosed and caregivers co-resided for at least 6 months	• Collected over 3 months in 2016 • Two researchers conducted focus group-facilitator and observer • Duration: Focus group 120 minutes; Interview 30-45 minutes • Audio recorded/transcribed • Thematic analysis	• 1 focus group (n=14) • 9 individual interviews • 3 people with dementia; rest caregivers	• Responses to dementia are influenced by community perceptions/social networks despite recognition of symptoms of dementia by caregivers. Structural factors also delay help-seeking (financial resources, availability of appropriate service). Education can 'spare' others from stressful experience of late diagnosis.
Brijnath & Manderson (2011) Delhi, India	• Investigate appropriation of dementia diagnosis into meaning and how perceptions of body and self are altered	• Critical ethnography • Semi-structured interviews, observation in home, hospital, community settings in Delhi and some other cities	• Purposive sample and snowballing • Through Indian NGO for people with dementia • Key providers; health and NGO workers, policy makers, attendants, police	• Audiotaped • 1 hour duration • Non-participant observation at outpatient clinics in public hospitals • Transcribed, thematic analysis with inductive and deductive methods	• Family caregivers of people diagnosed with dementia (n=20); All female, most Hindu, mostly middle-class and some upper class • Key service providers (n=21)	• Responses to dementia from community and caregivers differed according to the severity of the symptoms and more advanced symptoms were associated with stigma. Doctors incorporated biological terminology with lay language – meaning understood differently by receivers of the information.
Narayan et al. (2015) Bangalore, India	• Investigate extent that meaning and caregiving same across cultures for Indian context SAAVY Caregiver Program	Qualitative: •Semi-structured interviews. •Program reviewed by Bangalore team for validity for India. •Schedule informed by process of assessing validity of program.	• Purposive sample • Caregivers of Gero-psychiatry Clinic • Interviewed while attending clinic	• Interviewer a clinical psychologist at clinic. • Conducted in appropriate language • Audiotaped/transcripts translated to English • Constant comparative analysis	• Caregivers of people diagnosed with dementia (n=30): most female; most live with care recipient; most middle or low income; most reside in urban areas	• Progressive deterioration of dementia is not well understood by caregivers – rather symptoms of memory loss and forgetfulness describe the condition. Causation beliefs include aging, mental illness, stress, black magic, punishment form God. A lack of prior understanding of dementia leaves caregivers extremely unprepared and with caregiving grounded in duty to family and/or God, overwhelmed perhaps contributing to high caregiver stress, poor coping and violence to person with dementia.

Reference and study area	Aims	Study design	Participant recruitment	Data collection method & analysis	Participants	Interpretations
Patel & Prince (2001) Goa, India	• Investigate understanding of dementia and depression in older age • Investigate views of status, roles and relationships of older people	• Focus groups. Open discussions and using vignettes that describe dementia and depression.	• Purposive sampling • Community dwellers and old age homes • Key informants: Councilors, health workers, caregivers. • Explained study to the group and then invited to participate	• 2 teams (consisting of trained facilitator and observer/recorder) • Audiotaped 45-90 minutes duration • Constant comparison technique • Two researchers coded all separately then compared	• 5 focus groups (FG) with older people (n=37) • 8 FG with key informants (n=51) • 1 FG of primary care center doctors (n=3); 2 FG with multipurpose health workers (n=17); 1 FG village councilors (n=5); 4 focus groups with caregivers (n=26)	• Early and late symptoms of dementia associated with different perceptions of cause. Causation as normal part of aging encourages fatalistic view of dementia and delayed presentation at clinics for early dementia. Various causal attributions for dementia with possible implications for family eg. neglect abuse, lack of love. Advanced dementia requires support. Recognition of a problem facilitates better care.
Shaji et al. (2003) Kerala, India	• Investigate the experiences of caregivers on dementia.	• Semi-structured interviews • Schedule formed in conjunction with Alzheimer's Society • Piloted with caregivers	• Purposive sample. • Identified people with dementia as part of another study. • Invited caregivers to be interviewed by social worker.	• Interviews 30-90 minutes duration. • Detailed field notes – verbatim as much as possible. • Supplemented with information from clinician, nurse and health workers • Constant comparison	• Caregivers (n=17); most females and daughter-in-laws; cared for own young family also.	• Dementia unknown and perceived (not homogenously) to be a disease of aging while other causal attributions place blame on the person exhibiting the symptoms. Caregiving has multiple motivations; duty, family and fate. Knowledge about dementia and its management is important to caregivers, and support from others and better financial capacity enables better coping. Family pressures and conflict cause reduced well-being for caregivers, and deviation from recommended care.

Reference and study area	Aims	Study design	Participant recruitment	Data collection method & analysis	Participants	Interpretations
Mazaheri et al. (2013) Iran	• Describe the experiences of living with dementia in Iran	• Qualitative	• Convenience sample from Alzheimer's Association – until data saturation • Inclusion criteria: diagnosed with dementia; can communicate and willing to participate	• Collected in 2008-2009 • Interviews 23-51 minutes in duration. • Recorded, transcribed • Content analysis	• 15 people with moderate dementia (6 female) • 3 living alone and close to children; 3 living with spouse and children, 2 living with children; 7 living with spouse	• Dementia mostly recognised as a disease that was troublesome and defined by forgetfulness. A loss of status within the family along with changes in the way others treated people with dementia signposts their deterioration. Responses from others mean that people with dementia are unwillingly relieved of decision-making, responsibility, independence, sharing of knowledge, advice and skills.
Navab et al. (2013) Iran	• To report on family stigma among caregivers of people with dementia in Iran	• Qualitative • Hermeneutic phenomenological approach • Semi-structured interviews	• Purposive. • Inclusion criteria- experience caregiving, can communicate verbally, willing • Caregivers registered with Iran Alzheimer Association	• 63-115 minutes duration • Conducted in Persian (language of all involved) • Hermeneutic approach • Collaborative analysis with preliminary findings	• 10 caregivers (8 female) • 13 interviews – 3 people were interviewed twice	• Behavioral symptoms of dementia cause families to feel ashamed and humiliated driving caregivers to socially isolate themselves and their loved one to overcome shame. Caregivers want to protect the identity of their loved one in the community and protect them from humiliation, and fear the effect of community judgement on themselves and their family.
Navab et al. (2012) Tehran, Iran	• Investigate experiences of family caregivers of people with dementia in Iran	• Qualitative • Hermeneutic phenomenological approach • Semi-structured interviews	• Purposive. • Inclusion criteria- experience caregiving, can communicate verbally, willing • Caregivers registered with Iran Alzheimer Association	• 63-115 minutes duration • Conducted in Persian (language of all involved) • Thematic with hermeneutic approach • Collaborative analysis with preliminary findings	• 8 caregivers (7 female) • 11 interviews - some were continued in a separate session	• Reliving the past was doubly painful for caregivers who watched as loved ones' health deteriorated while experiencing past events and being reminded of them before dementia. Caregivers searched for the cause in their own past and their shared past - looking for meaning. Caregiving is an anxious experience and poor knowledge of dementia contributes to fear for a loved one and of the condition.

Reference and study area	Aims	Study design	Participant recruitment	Data collection method & analysis	Participants	Interpretations
Juarez-Cedillo et al. (2014) Mexico city, Mexico	• Investigate caregivers' social representations of dementia and its influences on help seeking	• Part of Study on Ageing and Dementia in Mexico. • Qualitative • Semi-structured interviews	• Random selection from previous cross-sectional study of 100 people. • Caregivers of people diagnosed with dementia in previous year.	• Approximately March 2010 • Interview in home • 45-60 minutes duration • Statement semiotics and thematic analysis	• 8 primary caregivers of people with dementia aged over 60. • All female; most daughters	• Dementia recognised by the effects on behavior with memory loss perceived as unimportant delaying help seeking. Dementia has the stigma of a mental illness with responses from caregivers of denial, normalization and avoidance which results in restrictions on social environment.
Qadir et al. (2013) Pakistan	• Investigate perceptions, understanding and impact of dementia in Pakistan	• Semi structured interviews	• Through psychiatric outpatient departments of 2 urban tertiary care hospitals. • All primary caregivers of people diagnosed with dementia recruited during data collection period.	• Semi-structured interviews in hospital setting • Thematic analysis	• 12 primary caregivers (7 female) • All low to middle income • Aged 19-47 • No spouses – all daughters, sons, daughters-in-law, nephew or grandson • Most in nuclear family units rather than joint	• Ageing is associated with memory loss and behaving like a child and there is no common conceptualization of dementia though there is a term for senility that is associated. Caregivers responses to dementia are driven by religious obligation and sense of reciprocity rending negligence and expression of distress unacceptable and pressure to keep behaviors hidden from public scrutiny. Shared care between other family members enables care.
Mkhonto & Hanssen (2018) Tshwane, South Africa,	• Explore the link between culture and dementia care	• Describes one aspect that emerged from study about dementia care in the nursing home.	• Purposive • 4 nursing homes • Relatives of people with dementia and nurses in a residential care home	• Narrative interview approach • 5 interviewers • 13-63 minutes duration • Hermeneutic approach to theme development	• 18 family members (2 Black African background) • 19 nurses (18 women)	• Witchcraft is a strong traditional belief of the community. Dementia is a white person's disease while people perceived to be behaving strangely or abnormally in the community are thought to be bewitched and are feared. Education and exposure to people with dementia may be a way to approach beliefs about witchcraft and dementia.

Reference and study area	Aims	Study design	Participant recruitment	Data collection method & analysis	Participants	Interpretations
Hindley et al (2016) Hai District, Tanzania	• Explore practice and attitudes to dementia of traditional and faith healers, people with dementia and caregivers	• Semi-structured interviews	• Convenience sample of healers • Purposive sample of people diagnosed with dementia and caregivers through previous study • Sampled until data saturation	• Data collection between March - May 2015 • Interviews conducted by two researchers in English and Swahili • Audio recordings • Translated to English	• 11 traditional healers (all Muslim) • 10 faith healers (all Christian) • 18 people with dementia and 17 caregivers (family or friends)	• Traditional and faith healers recognize symptoms associated with dementia. There is no term for a collective condition as perceived as normal for older people and multiple other causal attributions. Caregivers perceive various causes though are unable to articulate a problem. Beliefs about abilities of healers to help with a problem influence help-seeking.
Mushi et al. (2014) Hai District, Tanzania	• Explore socio-cultural beliefs of dementia and experiences of dementia	• Cross-sectional • Part of larger study • Semi-structured interviews. • Tools developed based on Kleinmann's explanatory model	• Purposive sample from larger available sample. Selected based on certain criteria. • Nine villages • Community-based	• Interviewers were experienced social scientists • Conducted at home • In Kiswahili language • Audiotaped • Duration 45 minutes • Transcribed and translated to English • Content analysis	• N=25 pairs of caregivers and people with dementia • N=16 caregivers • Demographics reported • Most Chagga; followed by Christian; and Muslim • All people with dementia were farmers and most with no primary education	• Dementia recognised and thought to be normal for an older person or a normal disease of aging and not associated with stigma. Various causal attributions including stress, loss of loved ones and thinking deeply, and also an inability to describe a cause. People with dementia require resources to help them maintain their independence while caregivers require education and practical help with care.

The studies were related through six key concepts: (i) recognition or interpretation of symptoms and behavioural expressions; (ii) causal attributions; (iii) dementia associated with stigma; (iv) fear; (v) knowledge needs; and (vi) caring and care expectations. Interpretations for each article were formed around these concepts (interpretations in brief, refer Table 4.2). These interpretations were synthesised into second-order interpretations. The first author framed the interpretations into four themes and these were discussed with the co-authors: (i) conceptualisations of dementia; (ii) meanings for dementia are associated with stage of illness progression and stigma; (iii) conveying and incorporating information about dementia; and (iv) caregiving and care expectations. Each of these is outlined below.

4.5.1 Conceptualisations

Commonly, across the various study contexts, dementia was largely unheard of as a distinct condition. In Tanzania, where dementia is a topic of recent times, some caregivers, people with dementia and, faith and traditional healers were not sure what the problem was (Hindley et al., 2017; Mushi et al., 2014). Likewise, in Pakistan and China, memory loss and ‘child-like’ symptoms of dementia were associated with ageing, a minor concern for which help was unnecessary (Dai et al., 2015; Hsiao et al., 2016; Lian et al., 2017; Qadir et al., 2013). Symptoms of dementia existed within cultural conceptualisations of ageing, perhaps explaining the uncertainty for some in describing a problem. Conceptualisations of ‘normal’ ageing incorporated illness in China, Tanzania and India (Dai et al., 2015; Mushi et al., 2014; Shaji et al., 2003). In contrast, most participants with dementia in Iran attributed dementia as a medical disease, separate from ageing, that impacted enormously on their lives by causing forgetfulness (Mazaheri et al., 2013). Other people with dementia in this study described dementia as part of normal ageing or resulting from a hard life.

Indeed, various causal beliefs and conceptualisations of dementia existed within the same community and included: stress; hard life; death of loved ones; neglect by family; abuse; loneliness; various physiological diseases; malaria; faking or deliberate misbehaviour; weakness; poverty; curses; growing connection with the spiritual world; colonisation; witchcraft; and, punishment from ancestors. Detailed exploration of these various beliefs in the context of the study’s setting was not the focus of most studies. It can be seen that some of these beliefs align with known issues of ageing, including loneliness, abuse, poverty and neglect, perhaps indicating social conditions commonly experienced by older people in some of the study settings. Most commonly though, a conceptualisation of dementia within ageing constructs had biomedical origins in settings where associations with ageing was the predominant view. In First Nation communities in Saskatchewan however, dementia was traditionally conceptualised within ageing constructs that carried a spiritual element.

Traditionally, memory loss was viewed in First Nations communities as becoming closer to the creator and spirit world and was not feared or associated with ‘losing it or something’ (Hulko et al., 2010, p. 329). However, meanings of memory loss changed over time and were now connected with impacts of colonisation and ‘your dementia’ was to be feared (Hulko et al., 2010). It was the consequence of colonisation where cultural change such as environmental, dietary and lifestyle changes had occurred. This association between dementia and sociocultural change was also apparent in Lanting and others’ (2011) study though conceptualisations of dementia appeared to remain within traditional notions of circularity and ageing, rather than as a new illness. A study involving Indigenous Australians in the Kimberley region of Australia, found that dementia was associated with old age, brain changes, head injury and lack of family visits (Smith et al., 2011). However, in depth exploration of these understandings and possible associations with the trauma of colonisation were not reported. Conceptualisations of dementia changed over time as First Nations communities incorporated social, political and environmental impacts of historical trauma into meanings of health and illness.

4.5.2 Meanings for dementia are associated with stage of illness progression and stigma

Symptoms and behavioural expressions of dementia were associated with different meanings in some studies, loosely aligning with progressive changes of the condition. Responses to dementia varied according to perception of the symptoms and behavioural expressions. In India, more advanced dementia was viewed as a physiological issue for which nothing could be done, rather than a psychological issue or ‘weak nerves’ as with earlier stages of dementia (Patel & Prince, 2001). Similarly, disruptive behaviour, aggression, delusions and incontinence was associated with madness, with resultant adverse consequences for the person with dementia and their family (Brijnath & Manderson, 2011). This contrasted with the cultural category ‘sathiyana’ or ‘going sixtyish’, a condition expected with older age and characterised by memory loss, stubbornness, anger and suspicion that was tolerated by the community.

In China, health providers in a rural town with low experience with dementia, associated dementia with psychotic illness while memory loss was perceived as unimportant (Hsiao et al., 2016). Community members were perceived to accept symptoms commonly observed in the earlier stages of dementia as normal ageing, which delayed help seeking, while threatening behavioural expressions were thought to cause them feelings of fear. These responses to dementia were similar for caregivers in Mexico and Iran (Juárez-Cedillo et al., 2014; Navab et al., 2013) where negative attitudes were directed towards behavioural symptoms that violated social norms and resulted in social isolation of people with dementia and caregivers. In South Africa, behavioural expressions considered strange or “abnormal” were ascribed to witchcraft, a strong cultural belief in Black South

African culture that resulted in ‘witches’ being treated with disrespect and violence (Mkhonto & Hanssen, 2018).

Caregiver and community responses of shame, described in many settings, allude to the presence of stigma associated with dementia. This can be seen in the labelling of earlier stages of dementia with terms associated with ageing or childishness and in more advanced dementia with harsh terms similar to those used for mental illness. The former terminology commonly described a state that was better tolerated by the community. The impact of terminology on stigma is well illustrated in China. Popular terminology for AD was discordant with cultural values of caregivers due to its translated meaning that mocked older people (Dai et al., 2015). The terminology has since been officially changed by the government in an effort to reduce stigma associated with cognitive impairment in older people (Dai et al., 2015). Interestingly, in the studies with First Nations participants, dementia was commonly discussed in terms of memory loss and forgetfulness (Hulko et al., 2010; Jacklin et al., 2015) with little reference to behaviours that caregivers commonly report as upsetting in later stages of dementia. Lanting and colleagues (2011) report that participants described similar symptoms to those observed in the majority culture with examples of memory loss, wandering and hoarding given.

The pervading negative attitude of the community caused feelings of humiliation to families and people with dementia (Navab et al., 2013) and fear of community judgement (Lian et al., 2017; Navab et al., 2013; Qadir et al., 2013). In order to protect the identity of their loved one in the community and to protect them from humiliation, caregivers withdrew socially (Navab et al., 2013; Mazaheri et al., 2013). In one study, community shunned families and made accusations of neglect where people with dementia resided due to socially unacceptable behavioural expressions displayed by some people with dementia and unpleasant smells associated with incontinence (Shaji et al., 2003). Experience with people with dementia was proposed to reduce stigma (Mkhonto & Hanssen, 2018), though it also created fear of the condition (Lanting et al., 2011; Navab et al., 2012). Perceptions of symptoms and behavioural expressions of dementia, as well as terminology, were important factors in stigmatisation of dementia and negative responses from communities.

4.5.3 Conveying and incorporating information about dementia

Overall, knowledge of dementia was valuable for caregivers, health providers and communities. Health providers, people with dementia and caregivers sought or saw need for information and training to support them in caring for people with dementia though a lack of support resources or knowledge of available support was commonly reported (Hsiao et al., 2016; Hulko et al., 2010; Jacklin et al., 2015; Juárez-Cedillo et al., 2014; Lian et al., 2017; Mkhonto & Hanssen, 2018; Mushi et al., 2014; Narayan et al., 2015; Navab et al., 2012; Patel & Prince, 2001; Shaji et al., 2003; Smith et al., 2011). The community had little awareness of dementia and this contributed to fear of dementia (Navab et al., 2012). More experience in managing dementia increased confidence of health providers in conveying information and support to caregivers (Hsiao et al., 2016).

Health providers could influence how dementia was perceived by their patients and the community. The use of a term that was offensive to caregivers may have contributed to stigmatisation of MCI and AD in China (Dai et al., 2015). Similarly, fatalistic views of ageing and dementia discouraged caregivers from seeking health care (Hsiao et al., 2016; Patel & Prince, 2001). These views could have been reinforced by other formal care system factors such as in India where a diagnosis of dementia could exclude a person with dementia from residential aged care facilities (Patel & Prince, 2001). In India, doctors integrated dementia into the cultural understandings of their patients by promoting biomedical classification over social meanings (Brijnath & Manderson, 2011). Younger women tended to draw on these biomedical explanations for dementia while older people drew on existing meanings of illness and integrated aspects of modern lifestyle. In this setting, service providers also associated symptoms and expressions of dementia with ageing to discourage stigma related with mental illness. There was a role for service providers in framing dementia, an important finding given that caregivers desired and sought information from professionals.

4.5.4 Caregiving and cultural expectations

In all settings, family was the primary if not only source of care for people with dementia. Despite significant emotional or financial implications, families persisted with providing care. Families provided care: (i) to preserve the role of the person with dementia in keeping family together and pass on traditional knowledge (Hulko et al., 2010, Smith et al., 2011); (ii) to keep a person with dementia living in the community (Hulko et al., 2010, Jacklin et al., 2015; Smith et al., 2011); (iii) to impress on younger generations the traditional value of caring and how to provide care (Dai et al., 2015, Hulko et al., 2010); (iv) out of duty or affection to family (Narayan et al., 2015; Shaji et al., 2003; Navab et al., 2012); and (v) out of religious obligation and reciprocity (Qadir et al., 2013). Despite the caring intentions of family caregivers, people with dementia in Iran found the caring environment confining (Mazaheri et al., 2013). They experienced an unwelcome shift in role from valued provider and advisor to being redundant and dependent on others.

Community perceptions of ageing and dementia, together with stigmatising responses, impacted notably on help-seeking and caregiving as described throughout the preceding sections. Adding to this, the influence of strong cultural expectations of caregiving influenced responses to dementia in some settings. In settings that also described strong values of duty and obligation being linked to caregiving, frustrations of caregiving were reported to result in aggression and violence of caregivers toward people with dementia (Narayan et al., 2015; Qadir et al., 2013). Pressures of providing care that met socially acceptable standards were overwhelming for caregivers and had a detrimental impact on caregivers' health (Qadir et al., 2013; Shaji et al., 2003;). Additionally, support from extended family was sometimes felt to be missing (Shaji et al., 2003; Qadir et al., 2013), or detrimental for a person with dementia (Shaji et al., 2003). Such negative connotations were not associated with the culture of caregiving in indigenous communities though, as in Pakistan (Qadir et al., 2013), disapproving attitudes towards families who used aged care facilities were noted (Jacklin et al., 2015). Studies from indigenous communities found that caregiving within, and engaged with, family and the community was far more desirable than institutional care for caregivers and service providers (Hulko et al., 2010; Jacklin et al., 2015; Lanting et al., 2011; Smith et al., 2011).

4.5.5 Summary

Throughout the studies, dementia was rarely conceptualised as a defined, pathological condition characterised by progressive cognitive decline. Rather, notions of dementia existed within conceptualisations of ageing, mental illness, traditional cultural beliefs or the trauma of colonisation. These understandings were not always homogenous within the populations studied. Conceptualisations of dementia had a temporal aspect accompanied by different responses to dementia. Understandings of dementia influenced help-seeking behaviors, and family and community responses including the presence of stigma and fear. Furthermore, responses to dementia were encompassed within and influenced by culturally defined norms for caregiving.

4.6 Discussion

A synthesis about the perceptions and conceptualisations of dementia amongst indigenous populations and populations living in LMIC has been missing from the literature until now. Indigenous populations and populations living in LMIC experience relatively low formal dementia care and support compared with non-indigenous populations and higher income countries. Understanding how dementia is perceived and conceptualised amongst these populations is a critical first step in comprehending how to foster supportive environments, communities and services that are culturally congruent for people with dementia and their families. Furthermore, in lower resourced settings, sustainable responses to dementia should consider the local context and be sensitive to available resources (Ferri & Jacob, 2017). This review highlights the need to understand conceptualisations of dementia of all stakeholders within a setting, and the dynamic responses that exist between key stakeholders, in approaches to awareness raising and provision of community and health services. It corroborates findings from the ethnic minority literature that have associated social and cultural beliefs, stigma and knowledge with barriers to help-seeking (Mukadam et al., 2011; Werner et al., 2014). This review provides a synthesis that should be useful in countries where the discourse around ageing and dementia are just beginning.

Given the various cultural, social and biomedical understandings of dementia present within and across different contexts the way in which dementia is discussed in low awareness settings (that is settings where there is low awareness of dementia as a health condition that one can live well) is important. The 'Looking out for dementia' initiative is an educational resource developed by the Alzheimer's Australia organisation in the Northern Territory (Australia) that describes dementia, and strategies for the management and risk minimisation of dementia for Aboriginal communities (Taylor et al., 2012). A qualitative evaluation of the resource, consisting of focus groups, interviews and observations of implementation, found that in this low dementia awareness setting, the resource helped people to identify dementia and change their approach to be more supportive and understanding of symptoms of dementia. The success of the resource was attributed to engagement with community during development and implementation, language awareness and skillful facilitation (Taylor et al., 2012). Interestingly, although the development of the DVD in local Aboriginal languages was highly valued and improved engagement, the ability to follow through with discussions in local languages was just as important and allowed for support and alleviation of fears, and importantly a forum to develop a 'health vocabulary' around dementia. Formulating a vocabulary to discuss dementia seems a sensible place to start dialog about dementia. Certainly, there is a risk that awareness campaigns will increase or perpetuate stigma (especially given the lack of evidence based approaches to stigma reduction; Herrmann et al., 2018) having the opposite effect of what is intended (Cahill, 2020).

Finkelstein et al. (2012) identified a knowledge system for dementia care in their study in a First Nations community that enabled the provision of culturally appropriate dementia care. In the knowledge system, people with dementia, family care providers, community and health providers were recognised to hold and need knowledge, and these stakeholder groups shifted between states of knowing and not knowing through sharing, or failure to share, knowledge. By drawing on the cultural knowledge and experiences of dementia within the groups, culturally appropriate resources and care strategies were formed within the formal care health system. If the knowledge system could be applied in other settings and include all stakeholders, it could facilitate meaningful dialogue around appropriate and acceptable health and community care responses to dementia, and approaches to stigma reduction. Furthermore, it is foreseeable that bringing additional stakeholders into the knowledge system, such as policy makers, would strengthen the development and usefulness of solutions.

4.6.1 Future research

Accessible, rigorous research such as that conducted by Hulko and others (2010) is important for informing approaches to dementia care. From their research, Hulko and others (2010) question the assumption that one will seek help when ill, and propose further investigation into the role of community members in supporting First Nations people with dementia and how this can be supported by health systems. In addition, research involving people with dementia as participants and co-researchers was lacking in the settings explored in this review. People with dementia are important owners of knowledge. As advocated by the human rights and dementia advocacy group Dementia Alliance International (https://www.dementiaallianceinternational.org/) and renowned activist, Kate Swaffer, the expertise of people with dementia is imperative in research if the true experience of its impacts and possible solutions are to be learned (Swaffer, 2014). The value of involving people with dementia in research about them is increasingly recognised with useful recommendations for researchers emerging (Cridland et al., 2016; Phillipson & Hammond, 2018).

There could also be important approaches to dementia care that could be learned from indigenous communities. In some studies, such as those from the First Nations communities in Canada, dementia was described in terms of memory loss and forgetfulness. Other signs of dementia, including changes in personality, and communication and mobility problems, may go unrecognised in the indigenous population. Differences between ethnic groups in terms of symptoms and behavioural expressions of dementia have been reported although there is conflicting evidence (Salazar et al., 2016; Shah et al., 2005; Watari & Gatz, 2004). To our knowledge, similar studies about indigenous groups are not yet in the peer reviewed literature. Perhaps symptoms and behavioural expressions of dementia have different meanings or are rarely observed in First Nations people with dementia, or perhaps in First Nations community approaches to elder care limits other behavioural expressions.

4.6.2 Limitations

There were very few qualitative studies exploring understandings of dementia in LMIC and amongst indigenous populations in the peer-reviewed literature. Many of the studies included in this review did not explore understandings of dementia in depth, rather, an overview of common perceptions tended to be reported. The scope of the studies included in the review was limited to peer-reviewed journal articles investigating perceptions of dementia. Such articles represented a very low proportion of low and middle income countries and indigenous populations. The review included two studies from India (Patel & Prince, 2001; Shaji et al., 2003) that were conducted well before global discourse on dementia began in earnest (following WHO's endorsement for dementia to be recognised as a public health priority in the year 2012). With increased advocacy for dementia awareness, and new pathways to diagnosis and strategies for care provision for dementia, it is possible that views have changed in this setting, and also in other settings included in this review. A focus on perceptions of dementia is an important limitation of the review as it may have missed studies investigating care practices for dementia, which may have included sociocultural understandings of ageing and dementia. Grey literature could have added valuable insight on this topic however empirical evidence was appropriate to strengthen confidence in the review findings. The exclusion of book chapters is a limitation of the review with important case study research, such as that conducted by Barker (2009) in her study of the 'decrepit elderly' in Niue being excluded from the synthesis.

Another limitation is the method chosen for reporting quality as a basis for inclusion and exclusion of studies. This method was chosen in an effort to include as many studies as possible from lower resourced settings where research capacity is growing. However, this meant that studies that were reported inadequately but were rich in information, most notably studies by Cohen (1995) and Henderson and Henderson (2002), were excluded. Finally, inclusion of studies only published in English may have meant that studies were missed. Additionally, translations to English occurred in several settings and is accompanied by a risk that complexities may have been lost in interpretation and dissemination in English.

4.7 Conclusion

The global action plan on public health responses to dementia calls for efforts to increase dementia awareness (WHO, 2017) and this is supported by the findings of this review. Notions of dementia exist within established conceptualisations of ageing, mental illness, traditional cultural beliefs and the trauma of colonisation. Responses to dementia are influenced and perpetuated by community and health providers, and cultural norms for caregiving. Community knowledge systems could facilitate understanding about appropriate and acceptable health and community care responses to dementia, and approaches to stigma reduction. Given the wide variability of, and context specific conceptualisations of dementia amongst communities, engaged and inclusive discussions about dementia are essential if awareness campaigns are to improve, not reduce, the wellbeing of people with dementia and caregivers.

4.9 Chapter Four summary

In this chapter I have shared a published manuscript and through this:

- Provided an analysis and synthesis of the international literature about conceptualisations of dementia in lower resourced countries and amongst indigenous populations.

- Emphasised the value of understanding how dementia is perceived and responded to for fostering supportive environments, communities and services.

In the next chapter I will:

- Provide a rationale for the study methodology and methods.
- Describe the phases of the research and the methods used.
- Outline the approvals obtained to conduct this research in Fiji.
- Reflect on the processes of carrying out the research, and how the chosen methodology and methods may have influenced aspects of the research.

5. Methodology & methods

5.1 Chapter Five outline

In this chapter, I provide an overview of the research paradigm that informed the design, methodology and interpretation of this study and provide a rationale for the chosen paradigm. I also explain its use in the context of my research study in Fiji. I then describe the methods employed and how they were applied. I incorporate discussion of reflexivity throughout this chapter and then discuss trustworthiness more broadly. I conclude the chapter with a summary of the approvals required to conduct this research in Fiji.

5.2 Approach

A research paradigm is *"a basic set of beliefs that guides action"* (Guba, 1990, p. 17) and serves as a framework through which researchers can access, explore and interpret phenomena. A paradigm is characterised by four dimensions: axiology (ethics and values), epistemology (the nature of knowledge, and the relationship between a researcher and the world), ontology (the nature of reality) and methodology (ways of gaining knowledge about the world; Denzin & Lincoln, 1994). I chose to place this research study within a transformational grounded theory paradigm. This paradigm was first described by Redman-MacLaren and Mills (2015) and evolved from Redman-McLaren's research in Papua New Guinea that investigated the implications of male circumcision for women.

In the process of proposing this study, it is difficult to identify when and how exactly I came to a decision about transformational grounded theory as the approach that would guide all aspects of this study. From the beginning, I aspired to produce rigorous research that was relevant in the context of Fiji, its people and communities, and the subset of the Fijian population who were the focus of my research. Upon reflection, and after delving into all manner of philosophy about the nature of reality and research paradigms, I realise that my personal worldview, beliefs and experiences (Chapter Two) were central in developing my research proposal and my decision to use a transformational grounded theory approach. In particular, I held (and continue to hold) some core values in relation to the study that I believed were encompassed by transformational grounded theory. These values include that:

(i) much can be learned from people's stories and experiences;

(ii) critical realism can offer valuable insight into society; it can guide exploration and understanding of the world and I can relate to the guiding philosophy;

(iii) creation and interpretation of knowledge should acknowledge the researcher's personal standpoint, and the inevitable impact this has on the interpretation of findings;

(iv) interpretations of knowledge should be explained by the research data as far as possible, and this is only achievable with the involvement of participants of the research; and

(v) research outcomes should be tangible, provide direction for positive change and be entirely relevant for the context of the study setting.

In the next section, I describe transformational grounded theory as I understand it and provide a rationale for its use in the context of my research study in Fiji.

5.3 Rationale

Transformational grounded theory has been proposed as an expanded methodology for grounded theory (Redman-MacLaren & Mills, 2015). The transformational aspect of this paradigm emerges from its ontological grounding in critical realism (Bhaskar, 1975) and methodological basis in grounded theory (Charmaz, 2006), with participatory action research and decolonising frameworks (Redman-MacLaren & Mills, 2015). The paradigm compels a focus on research outcomes for positive change, identified together with those people (termed co-researchers) who participate in the research. The metatheory for transformational grounded theory is described in Table 5.1.

Table 5.1. Metatheory for transformational grounded theory.

Element of metatheory	Characteristics
Axiology (values)	Love, social justice, equality
Ontology (nature of reality)	Critical realism
Epistemology (how knowledge is gained about the nature of reality)	Knowledge is culturally and historically situated
Methodology (principles which inform steps taken to gain this knowledge)	Grounded theory combined with participatory action research, and decolonising methodologies

Table reproduced with permission (Redman-MacLaren & Mills, 2015, p. 3).

In the following sections (5.3.1 to 5.3.3) I describe the metatheory of transformational grounded theory, as I understand it, in relation to my research in Fiji.

5.3.1 What is valuable?

Worldwide, older people experience disparities in health, social and financial wellbeing, and are challenged by attitudes, policies and institutional cultures that discriminate against older age. For people living with dementia, these inequities and challenges are magnified, extending to stigmatisation associated with dementia including labelling and negative assumptions about capabilities. This was an important consideration in the choice of a research paradigm to guide my study.

Transformational grounded theory, with axiological underpinnings of love, social justice and equality, is a compelling choice for the investigation of disparities and inequities experienced within societies. Oliver (2012) explains, *"Critical realism has an explicit emancipatory goal and provides a framework wherein surface appearances may be challenged by examination of the structures that generate them […]"* (p.375). The values of transformational grounded theory are further emphasised through the use of participatory action research and decolonising methodologies. This research paradigm recognises the existence of power inequalities, and historical, social and cultural factors that shape multiple realities for marginalised society. It acknowledges that there is a context dependent connection or mechanism of action, or inaction, between these powers and factors (or social products). Transformational grounded theory guides exploration of reality for marginalised society including reasons for the marginalisation, and demands action for positive change (Mertens, 2009; Redman-MacLaren & Mills, 2015).

5.3.2 Ontology and epistemology: An explanation

Critical realism represents a meta-theoretical, post-positivist philosophy of science and social science (Archer et al., 1998). Critical realism, or transcendental realism as it was originally termed, was first theorised by Bhaskar (1975) and described in his seminal work "A realist theory of science." Critical realists view society as *"…both the ever-present condition (material cause) and the continually reproduced outcome of human agency. And praxis is both work, that is, conscious production, and (normally unconscious) reproduction of the conditions of production, that is society"* (Bhaskar, 1998, p. 34). In other words, society is both the cause and outcome of human action and interaction. Furthermore, human action (conscious or unconscious) is both the product and conditions that produce perceptions, and experiences, of society.

According to Bhaskar (2008), there are three interacting domains, or layers, of reality; the empirical (our experiences), the actual (events that we experience) and the real (the causal mechanisms that give rise to events; Figure 5.1). Bhaskar also described two dimensions of knowledge, the intransitive and transitive. The intransitive objects of knowledge exist independently of human interaction and independently of knowledge of their very existence (Bhaskar, 2008). They are the generative mechanisms, processes, practices and relationships that act, or do not act, to give rise to the actual reality (Bhaskar, 2008). As described by Fletcher (2017), they are *"…social products that can ultimately be understood through – and indeed, that exist within – phenomena at the empirical level (e.g. human actions and ideas that are generated by these mechanisms)"* (p. 183). Critical realists seek to explain the intransitive objects (structures, mechanisms and causal powers) that underlay experiences as well as the conditions under which they are experienced (Archer et al., 1998).

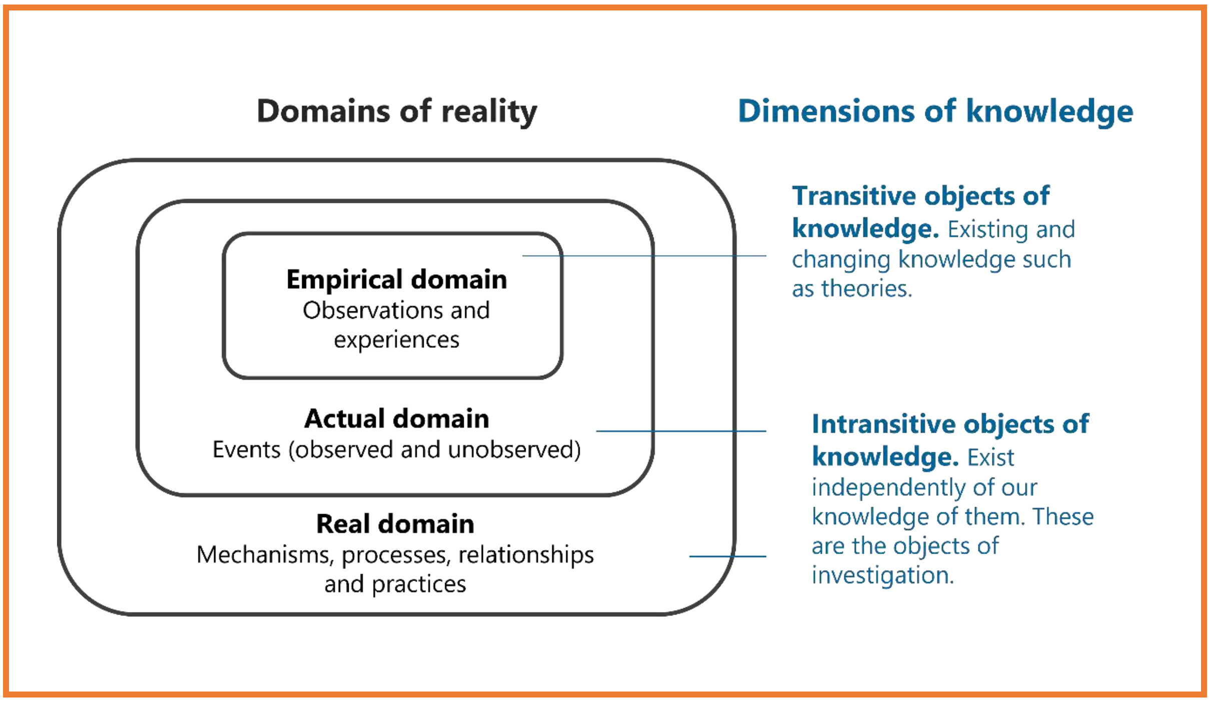


Figure 5.1. Diagrammatic representation showing the stratified ontology of critical realism.

Critical realists understand accounts of the world and the attempts to explain underlying mechanisms as transitive knowledge (Bhaskar, 2008). Transitive knowledge is the *"material cause or antecedently established knowledge which is used to generate the new knowledge"* (Bhaskar, 2008, p. 6). It exists within the domain of experience (the empirical domain) and is therefore situated in historical, social and cultural contexts (Archer et al., 2016). The empirical reality is observable, however can never be described completely due to its contextually dependent nature, and because the underlying events, structures and mechanisms may not be experienced or observed. Moreover, our ability to describe reality is automatically coloured by our own perceptions and experiences and thus reality is never completely and accurately comprehended (Oliver, 2012). Our accounts of reality are therefore fallible (Bhaskar, 2008), thus multiple methodologies are required to thoroughly investigate a phenomenon (Archer et al., 2016).

I incorporated a critical realist line of inquiry in the research questions. Through this study, I sought to understand the perceptions and experiences of dementia in Fiji from multiple viewpoints, through a variety of methods. I sought to investigate not just the outcomes related to these perceptions and experiences, but the drivers of them. What are the events that influence the perceptions and experiences of dementia for people in Fiji, and what are the mechanisms, structures and relationships that give rise to these events? What causal powers do these mechanisms, structures and relationships have, and in what social conditions? In answering these questions, I synthesised extant knowledge, and constructed new knowledge, about the strengths and needs that underlie the care experiences of older people living with dementia and their families. Looking towards the future, I aim to bring this knowledge to the attention of communities, health providers, and policy makers in Fiji. Moreover, an understanding of the mechanisms that shape the perceptions and experiences of dementia in Fiji, and the social conditions in which they act, may also be useful for other PICs.

5.3.3 How knowledge was gained

Transformational grounded theory requires the use of participatory and decolonising methodologies and encourages the consideration of multiple perspectives and sources. In the major component of my research, I used qualitative methods to explore the views and experiences of dementia from the perspectives of multiple stakeholders and to construct a grounded theory about the processes that caregivers use to manage dementia care. I also analysed hospital admissions data and conducted a service mapping activity, to supplement the larger qualitative component of the study. In this section, I continue to provide a rationale for the methodologies used and go on to detail the particular methods.

5.3.3.1 Grounded theory methodology

Grounded theory methodology (Charmaz, 2006), an essential component of transformational grounded theory, was used for sampling, analysis, interpretation and construction of a grounded theory. Various grounded theory methodologies have emerged since the seminal work published by Glaser and Strauss (1967) introduced grounded theory for qualitative enquiry. Charmaz (2006) takes a constructivist approach to grounded theory, emphasising researcher reflexivity and writing in grounded theory methodology. A constructivist foundation has application in other approaches, including critical realism (Charmaz, 2006). Charmaz (2006) also argues for a pragmatist underpinning to *"…preserve an emphasis on language, meaning, and action in grounded theory"* (p. 184). The core analytical methods required to produce a transformational grounded theory include: coding data; categorising data; concurrent data generation and analysis; constant comparison; theoretical sampling, and; construction of a core category (Birks & Mills, 2015; Redman-MacLaren & Mills, 2015). Added to this, ongoing memo processes are crucial in the analytical work, helping to develop, construct and integrate ideas, data and concepts (Birks & Mills, 2015; Charmaz, 2006). Grounded theory methods strengthen the quality of the research by encouraging reflexivity and promoting the ability to collect rich data (Birks & Mills, 2015; Charmaz, 2006; Charmaz & Thornberg, 2020).

5.3.3.2 Decolonising methodology and participatory methods

Transformational grounded theory requires the use of decolonising research methodologies (Redman-MacLaren & Mills, 2015). Importantly, participatory methods are at the core of decolonising research frameworks (see Box 5.1; for examples of how I applied participatory methods).

Box 5.1. Examples of how I applied participatory methods in my research.

In line with transformational grounded theory, I planned to involve co-researchers, family caregivers, service providers and community members, at every step of the research - in the research design, data collection, analysis and dissemination. Early on in my candidature, my Fiji-based advisor took me to visit several health professional stakeholders, the Head Sisters of health facilities, around Suva. The Head Sisters of health facilities are often primarily responsible for the daily management of services, staff and patients. The purpose of our visit was to introduce me, and the idea of the research. It gave me an opportunity to find out about how stakeholders thought that this research should proceed, and the kinds of outcomes that would be of interest. These stakeholders shared that they were interested in raising awareness and finding out about the levels of knowledge and knowledge gaps that health providers had. I made a few minor changes to the questions to ensure that these outcomes of interest would be investigated.

Throughout the research, I employed various participatory methods. During interactions with co-researchers, I ascertained their level of interest in being involved in data analysis to co-produce knowledge. A family caregiver and some service providers were interested. However, given the short bursts of field work this was difficult to achieve. Instead, I shared a research update with preliminary findings through a newsletter, distributed by my cultural mentor, and invited feedback. My Fiji-based advisor also arranged a feedback and discussion session with health service providers using the online platform Zoom. I continued to discuss emerging findings with my Fiji-based advisor and cultural mentor. Furthermore, in an example of reciprocity, I shared information about dementia through a presentation that I delivered to students undertaking a caregiving course in Fiji.

In thinking about decolonising methodologies that I could use to guide my research in Fiji, it was important to consider the meaning of ‘decolonisation’ in the context of Fiji. As described in Chapter Three, there are two main cultural groups in Fiji. iTaukei people faced paternalistic policies imposed by the British colonisers that (amongst other things) resulted in restructuring of kinship and boundaries and the loss of an opportunity to prosper from Fiji’s growing economy, with flow-on effects impacting iTaukei people today. Fijians of Indian descent, relatively new comers to Fiji through indentured labour, also continue to be impacted by Fiji’s colonial history through, for example, a loss of connection with their kinship and caste origins in India (Voigt-Graf, 2004; Chapter Three). Since gaining Independence, racial divisions have played out most obviously in political tensions that have resulted in several coups. Decolonisation in the context of Fiji is a complex matter.

Decolonising research methodologies aim to support the production of knowledge through enacting values of justice and equality in research approaches and methods (Tuhiwai Smith, 2021). The Fijian Vanua Research Framework (FVRF) is a decolonising framework grounded in *“… indigenous Fijian world views, knowledge systems, lived experience, representations, cultures and values”* (Nabobo-Baba, 2008, p. 143). In my work, the framework allowed me to access an approach to research that prioritised iTaukei worldviews. It strengthened my commitment to produce research that would benefit Fijian people and gave me practical ways to conduct my research. It reminded me of the importance of inclusiveness and cultural protocols, in particular, reciprocity. Nabobo-Baba (2008) states that *“The philosophy behind Vanua Framing is one of the interconnectedness of people to their land, environment, cultures, relationships, spirit world, beliefs, knowledge systems, values and God(s)”* (p. 143). By reflecting on the essence of the framework, I gained a deep appreciation of the importance of history, culture and Indigenous knowledge as foundational aspects of iTaukei world views and interactions. This enabled me to think more deeply about the stories and experiences - the knowledge - shared by Fijians. I acknowledge the centrality of my cultural mentor and Fiji-based advisor, and our relationship, in gaining and understanding the knowledge shared for this research.

I was unable to find any frameworks or guidance for research with populations who had been impacted by indentured labour due to historical, British imperial policies. Indentured labour also occurred during colonisation of Australia and affected South Pacific peoples. This is most obvious in the history of Australian South Sea Islanders who were kidnapped from their home countries amongst the South Pacific islands for labour, and later a system of indentured labour. In the absence of specific frameworks, I aimed to apply the broader values of decolonising frameworks in my interactions and thinking. These included reciprocity, respect for all knowledge and practicing reflexivity in relation to my position in this research.

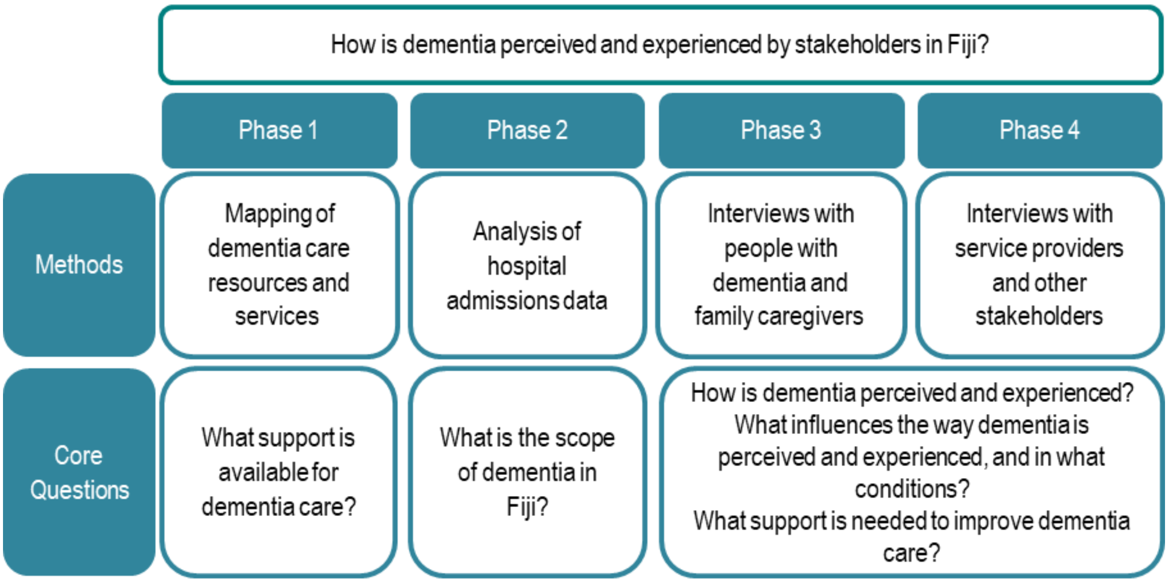
It is important to discuss here the possible influence of the political climate in Fiji throughout the duration of my research. The Fiji First party has been in government since 2014 and remains in power in 2021. This party seeks to dissolve racial tensions and build a multiracial Fiji. During interviews, I asked about cultural differences. I expected that this would be a sensitive topic, given the impacts of Fiji's colonial past, and navigated these questions with care taking my cues about appropriateness from co-researchers' responses. Co-researchers, if they shared responses on cultural differences, spoke of the influences of kinship ties in facilitating care of older people. I had presumed a cultural difference, but it emerged that important drivers of care for older people were related to family's capacity to provide care. This idea can be seen in a statement from a mental health nurse (who I feel that I offended in asking about differences based on culture): *"[…] I'm not saying um that there is a difference between other races and, ah, I won't be racist here, but it's like everything is the same. All the cultures are same now. It's how they [families] see, how they see you know, their loved ones"* (I-27; mental health nurse). Perhaps, in a way, this is a form of decolonisation as Fijians of both major cultural groups seek common ground. The grounded theory that I present in Chapter Seven was constructed through this lens of 'common ground'. I discuss the limitations of this approach in Chapter Eight.

5.3.3.3 Mixed methods

I incorporated a mixed methods approach to conduct a critical realist exploration of the topic. I used an embedded design, whereby quantitative data were embedded within the qualitative study design (Creswell, 2009). Creswell (2009) states that this mixed-methods approach can be useful in gaining a broader perspective of the topic. I used quantitative analysis of hospital admissions data to obtain an impression of the scope of dementia in Fiji (having rapidly established that a prevalence study would be impossible from the data available). I used this data source with the expectation that the findings would be interpreted in light of the grounded theory that I would construct. Also, to better understand the context of dementia care in Fiji, I conducted a mapping exercise of services available for older people, and in particular, services that support dementia care.

5.4 Methods

The research consisted of four phases, correlating with the type of data involved, that proceeded concurrently (Figure 5.2). Phases 1 and 2 aimed to capture information at a national level, and Phases 3 and 4 were conducted at three sites: Suva, Nadi and Lautoka.



How is dementia perceived and experienced by stakeholders in Fiji?

	Phase 1	Phase 2	Phase 3	Phase 4
Methods	Mapping of dementia care resources and services	Analysis of hospital admissions data	Interviews with people with dementia and family caregivers	Interviews with service providers and other stakeholders
Core Questions	What support is available for dementia care?	What is the scope of dementia in Fiji?	How is dementia perceived and experienced? What influences the way dementia is perceived and experienced, and in what conditions? What support is needed to improve dementia care?	

Figure 5.2. Depiction of aims and phases of the study with core questions for each phase.

5.4.1 Partnership

In line with transformational grounded theory, collaboration with local Fijian partners was essential. I was engaged with my Fijian PhD advisor (Dr Sefanaia Qaloewai) from the time of proposing this study. Later in the research, Dr Qaloewai introduced me to a senior mental health nurse, Mr Taniela Rasavuka. These two co-researchers were pivotal in facilitating this research in several ways, including: (i) guiding me in organisational and cultural protocols; (ii) giving me access to service providers; (iii) ‘vouching’ for me during site visits; (iv) advising on next steps, and (v) discussing our findings and my interpretations. I view our relationship as a partnership within which together, we learned about the research topic and learned how to do research. For the remainder of this thesis, I will refer to Dr Qaloewai as my Fiji-based advisor and Mr Rasavuka as my cultural mentor, even though their roles in our partnership were much more than this terminology describes.

5.5 Phase 1: Dementia care resources and services

Mapping of formal and community services available in the public and private sector in Fiji formed Phase 1 of the study. In this phase, I aimed to identify health and community resources for people living with dementia and caregivers. I conducted broad searches of the internet, using variations of the following terms, in combination (“dementia” OR “Alzheimer’s disease” OR “older people” OR “senior citizens”) AND (Fiji OR “Pacific Islands”). I also conducted a search for senior citizen organisations, aged care and dementia services in the Fiji Yellow Pages. While on field trips in Fiji, I looked on walls of health facilities and other community buildings for any event posters or information aimed at older people or people living with dementia. My Fiji-based advisor and cultural mentor who accompanied me on many field trips (both as my cultural advisor and to facilitate approvals as needed) also advised on possible health and community resources that may be useful for a person living with dementia or their families. Other available sources of support for older people and mental health also emerged during interviews and focus groups. This Phase continued throughout the study as further resources and services were discovered. I discuss the findings of this mapping activity in Chapter Six.

5.6 Phase 2: Scope of dementia in Fiji

In this Phase, MHMS hospital admissions data for patients with a primary diagnosis of dementia were reviewed in order to obtain an initial impression of the scope of dementia in Fiji. A retrospective, manual audit of outpatient records at Saint Giles Hospital and a sample of public health centres was considered. However, after discussion with my PhD study advisors and local Fijian service providers, we decided that we did not have the resources to support the required manual searches of patient hard copy records.

5.6.1 Data collection

A Patient Information System (PATIS) has been in place at Saint Giles Hospital and other divisional and sub-divisional hospitals since 2007. Prior to this, records were kept in hard copy format and held at each individual hospital, though some transfer of these records to PATIS has occurred. There are some known issues with PATIS (discussed further in Chapter Six) however data provided from PATIS presented a practical means to gain insight into patient contact with health services for dementia.

A data request was submitted, with the appropriate ethical approval, to staff at the MHMS Health Information Unit. The data request included patient age, gender, ethnicity and residential tikina (residential district); admission date; diagnosing hospital and, any secondary diagnoses relating to other co-morbid NCDs. Upon approval, staff from the Health Information Unit released the data to me in Excel format. The data were sourced from PATIS and non-PATIS records (non-PATIS records originated from the transfer of paper-based records to a central dataset at the Health Information Unit). Data for patients' residential tikina was not provided, as this was not available.

A second data request was submitted to the Health Information Unit for data for patient admission and discharge dates, and for data relating to patients admitted with a secondary diagnosis of dementia. Of the additional requested data, only admission and discharge dates sourced from PATIS were provided with the second dataset. The two datasets were combined however there were missing data for admission and discharge dates in non-PATIS data.

New variables were created for age group, number of admissions per patient and length of admission (days). Binary categorical variables were created for ethnicity (iTaukei and Indian of Fijian descent) and presence of co-morbid NCDs (yes/no).

5.6.2 Quantitative data analysis

Basic descriptive statistics were used to analyse the data. Chi-square tests were used to investigate associations between binary categorical variables where appropriate. Temporal trends in the data were also investigated. Analysis, findings and discussion of this phase of the research is presented in Chapter Six.

5.7 Phase 3 and Phase 4: Understandings and experiences of dementia

Phase 3 and Phase 4 formed the major components of my research and used qualitative methods. Phase 3 explored the understandings and experiences of people living with dementia and family caregivers through semi-structured interviews. Phase 4 explored the topic from the perspective of health and community service providers, and other community leaders, using semi-structured interviews and focus groups. I collected data over a series of three field trips, conducted in January 2019, June 2019 and September 2019. Each field trip was two weeks in duration. I was accompanied by my Fiji-based advisor on many site visits to health facilities and to a family home. My Fiji-based advisor introduced me to service providers and navigated the facility approval processes, which often occurred at the same time as the visit. I was also sometimes accompanied by my cultural mentor on trips when my Fiji-based advisor was unable to attend. In August 2020, I was unable to travel to Fiji to complete data collection due to the COVID-19 pandemic and related travel restrictions. My cultural mentor conducted data collection over three days on my behalf. This was a significant commitment from my cultural mentor who was also involved in the COVID-19 response as a frontline service provider. Not only did he take leave from his job for this research, but he also navigated a changed health system climate with different and restrictive procedures, and changes in personnel at health facilities.

5.7.1 Sites

The qualitative component of my research was conducted at three sites: Suva, Nadi and Lautoka. The sites were all major urban towns where health services are accessed both by Fijians residing in those towns, and in the surrounding areas and villages. In setting out to identify sites, the factors that I considered would be important in site selection included the range of health facilities available, population size of the catchment area and level of health service accessibility for the population. My Fiji-based advisor was central in the final selection of sites and highlighted other important factors. Three additional factors that were important from my advisor’s perspective was the logistical ability to meet with co-researchers, an awareness of receptiveness to participation in the study and the presence of mental health services in the areas where my mentors already had strong connections.

5.7.1.1 Suva

Suva, located in the Central Division, is the capital city of Fiji and has a population of 93,870 people (Figure 5.3; FBS, 2019). It is a major, metropolitan area and the Greater Urban Suva Area, comprising of the nearby towns of Lami, Nasinu and Nausori, has a population of 268,432 people (FBS, 2019). Public health services include Saint Giles Hospital (the country’s only specialist psychiatric hospital), the CWM Hospital (a divisional hospital with comprehensive specialist, emergency, outpatient services and a mental health unit with eight beds), seven health centres, a diabetes centre, reproductive health clinic and a clinic for attention deficit disorder (MHMS, 2016a). There are many private health services (mostly within general practice and private hospital services, but also includes some outpatient specialist services such as ophthalmology) and some counselling services (public and private). A publicly funded aged care home is located in Suva, and all private and charity run facilities that cater for older people are located in Suva.

Figure 5.3. A photo of metropolitan Suva looking out on Suva Harbour.

5.7.1.2 Nadi

Nadi is a busy, major urban town located on the western coast of Fiji (and within the Western Division). The town has a population of 71,048 people (FBS, 2019). Nadi is a major seaport to popular tourism destinations and has the country’s main international airport. There is a sub-divisional hospital, three public health centres and five nursing stations (MHMS, 2016a). There are no aged care homes. Mental health care is primarily provided through a special outpatients department for mental health clients located at the hospital, health centres, and private general practitioners and counsellors.

5.7.1.3 Lautoka

Lautoka is also located in the Western Division and is situated about 30km north of Nadi (Figure 5.4). This town has a population of 71,103 people (FBS, 2019). The sub-divisional hospital has a mental health unit for in-patients (nine beds), and there are also mental health clinics provided for outpatients. There are five public health centres, counselling services and private general practitioners. There is also a publicly funded aged care home.

Figure 5.4. Photo of a main street in Lautoka.

5.7.2 Interview and focus group schedule

The interview/focus group schedules for Phase 3 and Phase 4 (Appendices 3 and 4) were informed by the literature around dementia experiences. For people living with dementia and family caregivers, open questions aimed to learn about the pathway to diagnosis, perceptions of dementia, impact of dementia on daily life, and enablers and barriers to seeking help and support. Questions for service providers aimed to elicit information about understandings and management of dementia, community perceptions of dementia, help seeking behaviours of clients, enablers and barriers to help seeking, and ideas about support for clients, family members and service providers. The schedules were pilot tested with colleagues and my family members resulting in some changes to simplify the questions.

The interview schedule evolved with successive interviews as concepts and processes emerged during data analysis. In the case that co-researchers had difficulty interpreting the questions, two vignettes were used as a basis for discussion. One vignette described a person in early stages of dementia and the other described a person in the later stages of dementia (Appendix 5). Vignettes have been successfully used in other studies in situations where there is low awareness of dementia (Blay et al., 2008; Patel & Prince, 2001). The vignettes used in this study were adapted from a study conducted in Goa, India (Patel & Prince, 2001).

The interview schedules consisted of questions with prompts. However, for some interviews with non-professional co-researchers, I used an approach that was more topic-based, rather than asking specific questions. For example, in the interview with the village elder, I began with an invitation to tell me more about the knowledge that this co-researcher wanted to share. I then shared the vignette and asked how they viewed the older person living with dementia described. From here, I only asked questions when there was a break in the story telling and focussed on theoretical sampling around categories that were taking shape in my analysis. I will describe co-researchers and other details pertaining to the interviews in Chapter Seven.

5.7.3 Consent

The study was described and discussed with co-researchers prior to obtaining written consent to participate in the study (Appendix 6). Information was also provided on an information sheet that was left with the co-researcher (Appendices 7, 8 and 9). Written consent to record the interview was also obtained. This was a straightforward process for interviews involving family caregivers.

I had obtained ethics approval to include people living with dementia in my research and I had a process for obtaining consent that involved third party consent from the family caregiver, and assent from the person living with dementia (Appendix 10). The consent and interviewing processes were informed by recommendations made in the literature (Cridland et al., 2016). One co-researcher had been diagnosed with dementia and was attending an appointment at a health service when I met her. She attended the clinic with her niece who was very willing to talk with me about her experiences. She provided written consent for her Aunty (who had been diagnosed with dementia) to also share her views for the research. The person living with dementia also indicated that she wanted to sit down with me and talk about her experiences. Throughout our conversation, I monitored the expressions of the co-researcher (diagnosed with dementia). I was compelled to end the interview a little prematurely when the person living with dementia expressed frustration: *"You don't have to ask every time, tell you this is what, this is what. That's no good" (I-14).* I interpreted this to mean that this co-researcher was finished participating in the interview. I thanked both co-researchers for sharing their time and knowledge with me and concluded the interview. As we were leaving the table that we were sitting at the co-researcher with dementia was called for her appointment. I took this break in our interaction to ask her niece if she would be interested in talking some more and that perhaps we could organise another time. She said that she would return after the appointment. We talked briefly after the appointment and then they left the facility so that the co-researcher (niece) could return to work.

5.7.4 Phase 3: Understandings and experiences of dementia from the perspectives of people living with dementia and family caregivers

This phase of the study aimed to explore the understandings and experiences of dementia from the perspectives of people living with dementia and their family caregivers, through semi-structured interviews.

5.7.4.1 Sampling and recruitment

A total of seven family units, consisting of eight family caregivers and one person living with dementia, shared their views and experiences for my research (Table 7.1; Chapter Seven). Purposive sampling allows the recruitment of people who can offer the most relevant background and contextual information about dementia (Emmel, 2013). Purposive sampling of people living with dementia and their family caregivers occurred through mental health teams at each of the study sites. Whilst visiting outpatient or hospital services, patients diagnosed with dementia and family caregivers were informed about the study by mental health service providers. An information sheet was available for service providers to pass on to patients and family caregivers, so that patients could consider the study and contact myself or my Fijian based mentors directly. However, caregivers of patients preferred to arrange their initial contact through the mental health provider. I recruited four family caregivers and one person living with dementia in this way.

The remaining four family caregivers were recruited through word of mouth. Two family caregivers were recruited through a mental health provider who had personal connections with an older person who had been diagnosed with dementia. Members of this person’s family expressed that they were very satisfied with being able to share their experiences. A further two family caregivers were recruited through connections that I had made: one family caregiver introduced themselves to me following a workshop that I co-presented during a mental health conference in Fiji, early on in conceiving this research, and the other connection was formed through my personal networks in Fiji.

In keeping with grounded theory methods, theoretical sampling occurred as the study progressed (Birks & Mills, 2015). Theoretical sampling is the strategic sampling of other forms of data, or other stakeholders, based on emergent ideas or concepts (Birks & Mills, 2015). Theoretical sampling continues until categories are developed in full (Birks & Mills, 2015). I discuss theoretical sampling further in the section about qualitative analysis (Section 5.7.6).

5.7.5 Phase 4: Understandings and experiences of dementia from the perspectives of service providers and other community leaders

This phase aimed to investigate the understandings and experiences of dementia for service providers and other community leaders through semi-structured interviews and focus groups.

5.7.5.1 Sampling and recruitment

As in Phase 3, sampling was purposive initially and followed by theoretical sampling. Purposive sampling of MHMS staff with experience working at the identified sites occurred with the guidance of my Fiji-based advisor and my cultural mentor. Public providers were recruited during site visits. These site visits were sometimes prearranged, though mostly they occurred when my advisor was available and at times when service providers would be most available. Health care providers included doctors, nurses, aged care workers, a CHW and a social welfare officer (Table 7.2, Chapter Seven). In the private sector, doctors were invited to participate through the professional networks of a general practitioner working in private practice. Providers at a private aged care facility were also invited to participate during a site visit. A trained caregiver from this organisation consented to participate in an interview, however family circumstances changed and they were no longer able to participate. Community groups identified during the service mapping exercise were also invited to participate. I contacted these groups through email or telephone, and followed up with a personal visit.

I had set out to include religious leaders, village leaders and traditional healers in this research. However, these were difficult stakeholder groups to engage. In relation to village leaders and traditional healers, my ‘outsider’ stance together with the logistics of short field trips, made it challenging to reach these stakeholders. More importantly, I had committed to conducting research in line with the FVRF. I felt that it would be improper to try and engage these stakeholders given that I would not be able to perform the appropriate cultural protocols that have relationship building at their core. It is my view that this work would be best done by a local Fijian researcher who would have the appropriate level of cultural knowledge and standing in the community. As I progressed with my research, a village elder living in Suva (whom I knew through my personal network) approached me to share their knowledge of caring for older people with signs of dementia in the rural village setting. They wanted their knowledge to be recorded and shared through my research.

In relation to religious leaders, I met with a leader of a large faith-based organisation early on in the research (during the consultation stage). They indicated that church leaders had a focus on the holistic wellbeing of older people, rather than particular mental health issues. They were also focussed on providing psychosocial support during times of disaster and in response to trauma. In the time that I conducted my research in Fiji (over the period of 2015 to 2021), Fiji experienced three Category 5 cyclones[3] that caused significant damage and loss of lives. Domestic violence and the COVID-19 pandemic are other major causes of trauma that were affecting Fijians at the time of conducting this research. It was clear that religious leaders were an important stakeholder group. However, given the logistics of obtaining appropriate approvals from faith-based organisations, my limited field trips and the low likelihood of finding a co-researcher with knowledge of dementia, I decided not to actively pursue this group any further. I remained open to being connected with religious leaders however this did not eventuate.

5.7.6 Qualitative data analysis

Critical analysis of transcript content was inductive and involved coding, constant comparison, memoing, diagramming and ultimately formation of a grounded theory (Birks & Mills, 2015; Mertens, 2009; Oliver, 2012). The process was facilitated with QSR NVivo computer software for qualitative analysis (QSR International Pty Ltd, 2018). For the remainder of this chapter, I describe the analysis process and conclude with a discussion of trustworthiness.

5.7.6.1 Transcripts

Interviews and focus groups were recorded (with consent) and transcribed verbatim. Upon returning to Australia, I would transcribe the interviews. I viewed this process as a way of staying close to the data, and this was especially important given the nature of my data collection strategy (see Section 5.7.5.3). One family caregiver co-researcher did not consent to being audio-recorded, and I endeavoured to write detailed notes during and immediately after this interview.

One interview, with a CHW, was mostly conducted in Fijian language. During this interview my cultural mentor interpreted my questions and asked them in Fijian, and then translated the co-researcher's responses to me. A research officer proficient in the Fijian language, located at Fiji National University, transcribed this interview in Fijian and translated it to English. I used this transcript to identify key concepts. Then, in line with best practice, I used the technique of back translation to assure the trustworthiness of the translated transcript. A community member, also proficient in the Fijian language, translated the transcript from English back to Fijian and compared the original Fijian to English translation with the English to Fijian translation to check for the same

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[3] The most severe tropical cyclones are classed as category 5 cyclones. The most intense cyclone to affect Fiji and the South Pacific region was Tropical Cyclone Winston in 2016 with winds exceeding 230km/hr. This cyclone caused widespread damage, mass homelessness, 42 deaths and an extensive, years long, rebuilding effort.

key concepts. The community member confirmed that the key concepts were the same and also identified an error in the original translation, which was amended.

5.7.6.2 Coding

I conducted initial open coding using the line-by-line technique (Charmaz, 2006) for several transcripts. This process forced me to look closely at co-researchers' words and helped me to start seeing emerging patterns. When I had a feel for the data, I used line-by-line coding much less, instead coding according to emergent processes and concepts. Birks and Mills (2015) suggest that line-by-line coding is no longer necessary when a *"researcher gains a sense of conceptual control over the data"* (p. 94). I returned to line-by-line coding when I felt that I needed the focus that this technique offered. I stayed close to the data by coding data as actions and staying open to new or revised codes, as Charmaz (2006) recommends. As coding progressed, I began to conduct focussed coding whereby I made decisions about the fit of codes in explaining the data, and the grouping of codes into sub-categories and categories. I used memoing and diagramming to work through this process (Section 5.7.5.4).

Early on in the coding processes, two of my advisors, both with extensive experience in qualitative research, coded two transcripts. We compared our coding and the overall concepts of the codes were aligned, though one advisor (an experienced general practitioner) picked up on clinical aspects that I had not considered from my perspective as a non-health professional, and my other advisor (a medical anthropologist) picked up on the potential influence of a co-researcher's professional background. This process highlighted the value of my advisors' perspectives in raising my theoretical sensitivity as the analysis continued. I met with all of my advisors regularly to discuss emerging concepts and the developing theory.

5.7.6.3 Concurrent data collection, constant comparison and theoretical sampling

Grounded theory methodology requires concurrent data collection and analysis (Birks & Mills, 2015; Charmaz, 2006). This method is unique to grounded theory and, through constant comparison of codes and concepts, drives theoretical sampling (Birks & Mills, 2015). Theoretical sampling facilitates the collection of rich data to ensure that there is theoretical saturation of the properties and dimensions of categories (Birks & Mills, 2015). In constant comparison analysis the researcher collects data concurrently, following leads emerging in the data, and works iteratively to link and integrate the data into *"high-level conceptually abstract categories [...]"* (Birks & Mills, 2015, p. 90). Using the method of constant comparison, I moved between comparing incidents, comparing incidents with codes, and comparing codes with codes. I used this method to analyse data within a transcript, and then as the data collection and analysis progressed, for data across transcripts. Later in the analysis, I compared codes with sub-categories and categories, and categories with categories.

It is important here to discuss how concurrent data collection and analysis, in its purist form, was challenging in my research. Data collection occurred in blocks of two weeks and there was limited opportunity to carefully analyse data during these trips. I conducted concurrent data collection through two cycles: one beginning during the June 2019 field trip (following analysis of the data collected in the January 2019 field trip), and again in the September 2019 field trip (following analysis of data collected in the June trip). The final field trip in August 2020 (conducted by my cultural mentor) was focussed on including stakeholders we had not reached yet, though there was some opportunity to sample to fill in gaps in the developing theory. In addition to these cycles, at the end of the day, while in the field collecting data, I would review my reflections made immediately after interviewing (although at times these reflections would occur at the end of the day due to travel between sites). I also listened back to audio recordings in preparation for the following day. Sometimes, despite my best efforts, the tiring nature of the field trips prevented me from engaging thoroughly in this process.

In this way, the logistical challenges of living outside of Fiji affected my ability to conduct theoretical sampling. Making contact with further stakeholders, identified through theoretical sampling, was also challenging. For example, during my second field trip, the idea that health professionals ignored cognitive decline began to emerge. In my third field trip, the settings where this seemed to occur more commonly emerged. I would have liked to talk to health providers in the general medical wards and further providers in primary health care. Through my cultural mentor, I was able to gather the views of doctors in an emergency department during this field trip. However, further access to the other stakeholders identified was not possible in the time left in the field. Analysis following this field trip saw the development of a concept called 'clinical inertia'. In the fourth and final field trip (conducted by my cultural mentor), a health system focus on the COVID-19 response meant that recruiting stakeholders from health services was again not possible.

While theoretical sampling was challenging in terms of recruiting further co-researchers, I conducted theoretical sampling through sequential interviews with stakeholders that I had initially identified. Foley et al. (2021) discuss how the course of interviewing can drive theoretical sampling for theory building, and they provide an example from their research whereby: *"Questions followed a line of inquiry based on the data generated and proceeded to tease out the relationship between key concepts and categories. Teasing out the relationship between key concepts and categories in* *interviewing helped to saturate categories […]"* (p. 6). These were the messy realities of my research. I will discuss this further in a section about trustworthiness (Section 5.9).

5.7.6.4 Memoing, diagramming and storyline

Memoing, diagramming and storyline are techniques that strengthen the rigour, trustworthiness and quality of grounded theory research (Birks & Mills, 2015). Memoing is the practice of writing about the research process with a reflective, descriptive or analytical purpose (Birks et al., 2008; Birks & Mills, 2015; Charmaz, 2006). Memos may function as an audit trail whereby the researcher can keep a record of analytical decisions made in constructing the grounded theory. I kept a single, date stamped memo that tracked changes in the big picture of the theory. I also kept memos about how field trips were progressing with descriptions and reflections about research processes.

Memos also serve an analytical function (Birks & Mills, 2015; Charmaz, 2006). I kept memos about the data that was contained within key codes and about each category as they developed. In particular, I continuously referred to Charmaz's process for developing a category from codes whereby I used memoing to work through: defining the category, properties and dimensions; identifying the conditions that affect the category; describing the consequences; and, making associations with other categories (Charmaz, 2006, p. 92). I used diagramming to think about how codes related to categories and how categories related to each other. Diagramming and memoing facilitated the construction and reconstruction of sub-categories and categories. At some point, I felt that I needed to articulate how the categories came together to explain the data in a single piece of work. I needed the clarity that storyline technique could offer.

Storyline is a grounded theory method that may be used to present the developing theory in narrative form. It has *"the intent of constructing, integrating and making visible the final theory"* (Birks et al., 2009, p. 407). My storyline consisted of a series of statements that defined categories, the ways that the categories linked and the consequences of the processes that the categories described. A modified version of the storyline is presented in Chapter Eight where I summarise the grounded theory. I shared the storyline with my advisors for discussion face to face, and with my Fijian advisor using a PowerPoint presentation to guide the discussion on Zoom. There was some discussion about possible gaps in the theory during these rounds of discussion and feedback. I returned to the data to explore these gaps. This process, together with the process of drafting the theory in full, allowed me to finalise the theory. I discuss the strengths and limitations of the grounded theory in Chapter Eight.

5.7.6.5 Theoretical coding

Grounded theory methodology may make use of theoretical codes. Birk and Mills (2015) define theoretical coding as *"the use of advanced abstractions to provide a framework for enhancing the explanatory power of a grounded theory"* (p. 81) but warn against using frameworks in a deductive manner. Theoretical codes show relationships between the substantive codes of the grounded theory and aim to move a grounded theory in a theoretical direction (Charmaz, 2006). The rationale for theoretical coding and how I applied it in my research is discussed further in Chapter Seven and Chapter Eight.

5.8 Integration of findings

I constructed a grounded theory, 'letting it be' (presented in Chapter Seven), through analysis of qualitative data collected from family caregivers and one person living with dementia (Phase 3), and service providers and community leaders (Phase 4). The grounded theory forms the major component of my research, and in terms of mixed methods methodology, carries the most weight. The embedded quantitative analysis of hospital admissions data for patients with a primary diagnosis of dementia (Phase 2) provided an impression of the scope of dementia, the health system and help seeking behaviours for dementia care. I integrated the findings of this analysis in light of the grounded theory (discussed in Chapter Eight). Finally, the mapping activity (Phase 1) provided contextual information about the availability of services for support with dementia, and informed data collection and interpretations.

5.9 Trustworthiness

Throughout this chapter and in Chapter Two, I have discussed matters of reflexivity and rigour. Building on this, I now discuss analytical reflexivity and trustworthiness more broadly. Throughout my research, I actively reflected on the influences of my position as an outsider (etic) with insider (emic) knowledge. I have discussed some pertinent examples earlier in this chapter. My insider stance and motivation for this research granted me a degree of relatability and trust, perhaps allowing me access to knowledge that might not otherwise have been shared. My cultural knowledge helped me to navigate my outsider stance while in the field and informed my ways of thinking and interpreting the data. Indeed, it was reflection on the influence of my insider and outsider stance that inspired the grounded theory (see Chapter Seven).

Charmaz (2006) outlines four criteria of quality in grounded theory: credibility, originality, resonance and usefulness. Credibility relates to procedural rigour in applying grounded theory methods of coding, constant comparison, concurrent data collection, theoretical sampling and saturation, and memoing (with an emphasis on reflexivity throughout; Birks & Mills, 2015; Charmaz, 2006). I experienced challenges in applying theoretical sampling, as discussed in Section 5.7.6.3. Moreover, I found it challenging to manage analysis and interpretation of data at times due to low levels of experiences managing people living with dementia amongst service providers, and low awareness of dementia overall. The techniques of theoretical sampling through adapting my line of questioning during subsequent interviews, constant comparison and memoing were pivotal in working through these challenges. Theoretical saturation was difficult to achieve however the grounded theory represents a significant and valuable starting point for improving and supporting dementia care in Fiji.

Moreover, the grounded theory resonated strongly with my Fiji-based advisor. This 'resonance' is a very important indicator of quality (Charmaz, 2006), or trustworthiness, particularly as indicated by in-country stakeholders. Moreover, my other PhD advisors, two of whom are health professionals with expertise in dementia care, also felt that the grounded theory had 'grab' in line with their experiences of dementia in Australia. Charmaz (2006) further describes resonance as relating to making links *"between larger collectivities or institutions and individual lives, when the data so indicate"* (p. 183). The findings of the quantitative analysis of hospital admissions data reflect low help seeking behaviour and underlying health systems factors that were also revealed in the grounded theory (discussed in Chapter Six and Chapter Eight), indicating resonance and strengthening the credibility of this research.

5.10 Approvals to conduct the research

This research was approved by the James Cook University Human Research Ethics Committee on 7th December 2016 (valid until 31st December 2021; HREC approval number H6798; Appendix 11). Approval was conditional upon approval from the Fiji National Health Research and Ethics Review Committee. This was received on 11th October 2017 (FNHRERC number: 2017.2.NW; Appendix 12). This approval was sufficient for research involving the Fijian community and MHMS service providers, as described in my ethics application. I sought (and obtained) further approval from the Permanent Secretary for MWCPA to interview service providers at public aged care homes. This approval was facilitated by the MWCPA Older Persons Unit.

Being a researcher from outside Fiji, I was also required to obtain official approval to conduct research in Fiji from the Fiji Ministry of Education, Heritage and Arts. The process was vetted by the Fiji Ministry of Education, Heritage and Arts Research and Ethics Council. Approval was granted on 28th February 2018 and was valid until to 28th February 2022 (Appendix 13).

With all ethics and higher-level approvals in place, there were also various processes for obtaining approval from individual health facilities. At one facility, approval required endorsement from an institutional medical advisory committee. At another facility, approval from the doctor-in-charge of the facility was required and could be obtained through their sighting of the ethics approval. At other facilities, verbal approval from the nurse-in-charge or doctor-in-charge was sufficient.

5.11 Chapter Five summary

In this chapter I have:

- Provided a rationale for using transformational grounded theory.
- Discussed the phases of the study, and the methods employed and how they were applied.
- Described how the findings were integrated.
- Described the ethics and other approvals that were obtained to conduct this research.

In the next chapter I will:

- Describe and discuss formal support and resources for dementia care.
- Present and discuss an analysis of hospital admissions data for patients with a primary diagnosis of dementia.

6. Dementia and dementia care

"I called this young boy to the ward. I told him sit down. I told him, 'See, the reason I brought you here [to this consulting room] because like, ahhh, the look that you show us today on your face, it tells me a lot of stories behind you bringing your grandfather to the hospital.' He just sat there and cried. And I let him cry. For about 15 minutes he was crying and then he said, 'You know, I'm the only one looking after my grandfather. And I am a Form 4 [15 year old] student and I have two other younger siblings.' And I ask him, 'Where are your parents?' [He said,] 'My father is working and usually travels a lot abroad.' [And I asked,] 'And your mother?' […pause…] 'Your mother is working and most of the time she comes late.'"

(mental health nurse, I-18)

6.1 Chapter Six outline

In this chapter, I provide an overview of dementia and dementia care services in Fiji. First, I describe the health and social services available in Fiji for dementia care. Data is drawn from a service mapping activity, field work and interviews. Later in the chapter, I present an analysis of hospital admissions data for patients with a primary diagnosis of dementia with a critical reflection on the findings.

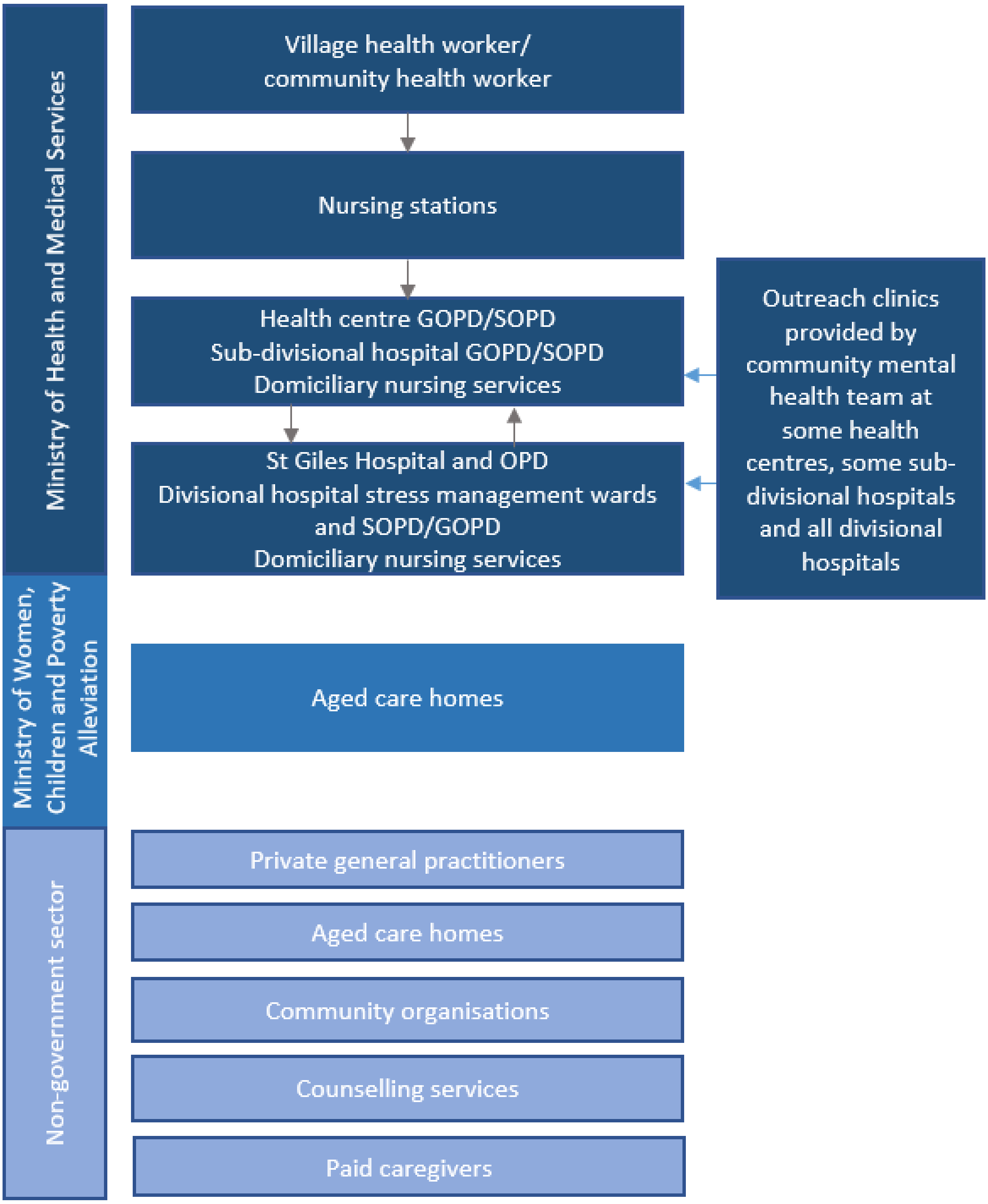
6.2 Services for dementia care

6.2.1 Overview

Over the duration of the study, I conducted a mapping exercise of formal services and community services available in the public and private sector for dementia care, mental health and older people. Broad searches of the internet, with a focus on Fiji and the Pacific Islands, revealed some news articles, documents and blogs about mental health, care of older people and occasionally dementia. Within these sources, I identified few services for mental health and none for older people, people living with dementia or family caregivers other than those offered by aged care homes and within the mental health sector in Fiji. Likewise, observations from the field including discussions with Fijian service providers, my Fijian based advisor and a search of the Fiji Yellow Pages yielded few community services specifically for mental health or older people. There were no specific organisations or programs for dementia support in the health or social sectors.

6.2.2 Management of dementia in the formal health sector

Formal support for people living with dementia and family caregivers occurs through existing organisations and programs that support mental health, older people and vulnerable people, across the MHMS, MWCPA and the non-government sector (Figure 6.1). Additionally, qualified caregivers may work in private residential homes (for those who can afford to pay for this service) and can support older people within their caregiving roles.



(Grey arrows show the typical flow of referral through each level of the health system, with referral back to health centres following diagnosis of dementia, as appropriate. Abbreviations used in figure: OPD, outpatient department; SOPD, special outpatient department; GOPD, general outpatient department)

Figure 6.1. Services involved with supporting mental health, and the health of older people, people living with dementia and family caregivers.

6.2.2.1 Public mental health care services

Formal care for dementia is provided primarily within mental health care services provided by the MHMS (Figure 6.1). Diagnosis and post-diagnostic care for dementia may occur at health centres, at general outpatient departments or special outpatient departments (if available) at sub-divisional and divisional hospitals or during admission at hospital. In addition, the community mental health team provides community outreach clinics at all divisional hospitals, some sub-divisional hospitals and several health centres. Once diagnosed with dementia, patients who are unable to present at their local health centre may access domiciliary nursing services provided by mental health zone nurses. Service providers at all levels of the health system can discuss cases directly with Saint Giles Hospital. Patients may also directly access the outpatient department at Saint Giles Hospital for diagnosis and post-diagnostic care.

People living with dementia may be admitted at Saint Giles Hospital for inpatient management of dementia. Stress management wards established at the three divisional hospitals - the CWM Hospital in Suva, Lautoka Hospital and Labasa Hospital also provide care for people living with dementia. Patients admitted to Saint Giles Hospital may be transferred to these stress wards for further follow up and discharged to their respective sub-divisional hospitals and health centres. Patients may also be admitted to other sub-divisional hospitals where they have presented for care however there are no separate wards for mental health care at these hospitals.

6.2.2.2 General practitioners

General practitioners may be accessed at public health centres, although there is a shortage of doctors in rural areas with one third of health centres headed by nurses (WPRO & APO, 2011). In 2011, there were 125 general practitioners who provide services in the private sector, mostly in Suva and Nadi (WPRO & APO, 2011). Diagnosis and treatment for dementia has been described by a general practitioner as more timely through the private sector however private services are only accessible by those who can afford to pay for a consultation and the associated management, including medications. Geographic access to health centres is especially challenging for people residing in rural areas. Assuming that a referral for a person with possible dementia is given by a nurse at a rural nursing station, it is an average of 1.5 hours (by land or boat) to the nearest health centre (WPRO & APO, 2011). Added to this, health centres are busy places, providing services to between 50 and 2000 patients per day (WPRO & APO, 2011). During fieldwork, I visited several health centres and was struck by the high numbers of people waiting patiently for their consultation. According to the latest statistics, there were just 0.8 medical doctors per 1,000 population in 2015 (WHO, 2019b).

6.2.2.3 Diagnosis of dementia

The Mini-Mental State Exam (MMSE) is usually used to test cognitive function. The MMSE has been reported to be a culturally insensitive tool with ethnicity, educational level, social class and socioeconomic status known factors that affect MMSE scores (Tombaugh & McIntyre, 1992). Doctors adapt the examination for language and culture when necessary, as a doctor explained: *"So a lot of the times we would go MMSE, do as much as we can but like, for example, calculation. If you haven't gone to school, which a lot of our patients have not, they're not going to be able to count 100 minus 7. And they're not going to be able to spell 'world' backwards. So we would start with, 'OK, do you cook?' Yeah. 'So what do you cook and how do you cook?' So then we would see whether they were able to go through the process as well"* (doctor, I-7). However, confidence in diagnosing dementia is lacking (described in the grounded theory; Chapter Seven) and may prompt a recommendation for a patient to attend Saint Giles Hospital, which can present a challenging and drawn-out pathway to diagnosis. In the private sector, a doctor explained that many general practitioners prefer to refer patients to another general practitioner with mental health expertise (of which there are few), or to a public mental health clinic, as they do not have time to provide management and treatment.

6.2.2.4 Counselling

There are professional counselling services available in urban areas across Fiji. People living with dementia and their families may access counselling services directly (private services) or they may be referred by health services or community organisations (though the extent to which this occurs is unknown). Private counselling services tend to be situated within services for family planning or domestic violence. There are also non-professional counselling services available through some faith-based organisations (Australia Department of Foreign Affairs and Trade, 2017). Service providers reported variable use of counselling services by people living with dementia and their families. Counsellors in one town indicated that they had not managed cases of dementia in their experience, while counsellors in another town reported experience providing counselling for people living with dementia and their families. Lifeline Fiji is also available by telephone (24 hours) and online service, and for face-to-face counselling (https://www.lifelinefiji.com/about/).

6.2.3 Aged care services

Specialised services for older people, the disabled and chronically ill are limited. There are no geriatricians or health professionals with specialisation in geriatrics, as of the year 2021. People living with dementia may be cared for in public and private aged care homes, or in charitable facilities that provide residential care for disabled people, older people and those with nowhere else to go. The MWCPA fund three aged care homes located in Suva, Lautoka and Labasa. These homes provided a combined total of 130 places for residents in 2017 (MWCPA, 2017). They are managed by registered nurses and the majority of daily care is provided by qualified caregivers. There are also three privately funded homes for older people and one charity run home in Suva (Chandra, 2017). Not all of these homes have registered nurses on staff and there is a dependence on professional volunteers to visit. Ratios of caregivers per resident are low. A service provider from one aged care home indicated that there was typically a maximum of two caregivers per 30 residents. This was felt to be insufficient when caring for people living with dementia who would sometimes leave the home unexpectedly: *"There are residents, there are a few of them who walked out, like, when there is on [it is a] weekend, we've got only two carers in the shift, so they just walk out. And then we have to go get them back. And there are residents who walk in night time, wandering, so they walk out and then we have to be… so at times, it's very hard. One carer to look after 30 people or two carers* (qualified caregiver, I-31). Added to this, expertise in dementia care is low and may mean that an aged care home will not accept a person with advanced dementia. The first public day respite centre for older people is currently being constructed in Labasa, as part of a new 40 bed aged care home, and was expected to be completed by July 2021 (Bolanavanua, 2019; Turagaiviu, 2019).

Public aged care homes are available at no cost. However, all aged care homes are located in major urban areas, far from rural villages, necessitating a move away from family and local supports to access these services. Moreover, while aged care homes exist, the use of these services by families is strongly stigmatised. In line with values in the Pacific Islands region, family networks are expected to provide care for the health and wellbeing of older family members. This is strongly supported in messages from the Fijian government, often delivered through the media such as newspaper articles, pleading with families to discontinue the culture of 'dumping' parents at aged care homes, and to care for their parents at home. This value is also upheld in the National Ageing Policy that specifically recognises that *"older persons should be supported in their communities and in their homes as long as possible"*(MSWWPA & UNFPA, 2011; p.2).

6.2.4 Qualified caregivers

Qualified caregivers have undertaken training in caregiving and may work in aged care homes or other homes such as those for disabled people, or in private residences. The University of the South Pacific offers a short caregiving course, Caregiver Fundamentals, consisting of 110 hours of theory and 40 hours of practical experience (https://www.usp.ac.fj/index.php?id=cce). The Australian-Pacific Training Coalition (APTC) offers a 22 week Certificate III in Individual Support (ageing, home and community; https://www.aptc.edu.au/courses/courses-info/community-services/individual-support). While families may access qualified caregivers to manage the care of an older family member with dementia, their services are too costly for most families. Added to this, finding a trained caregiver can be challenging given that many leave the country to work where there is a demand for their services. One family caregiver co-researcher, who I stayed in contact with over the course of my research, encountered many challenges in finding daily support to assist with the care of her spouse who had been diagnosed with dementia. Important factors in her choice of paid caregiver included qualifications, trust and her husband's acceptance of the caregiver.

6.2.5 Community organisations

There were several organisations that provided services that could support people living with dementia, their families and service providers (Table 6.1). Most of these organisations were located in Suva or in major towns. They focused on specific, consumer driven issues or mental health more generally. While programs, activities or services available through these organisations may support people living with dementia and family caregivers, the community providers that I talked with indicated that few (if any) such people would access these services.

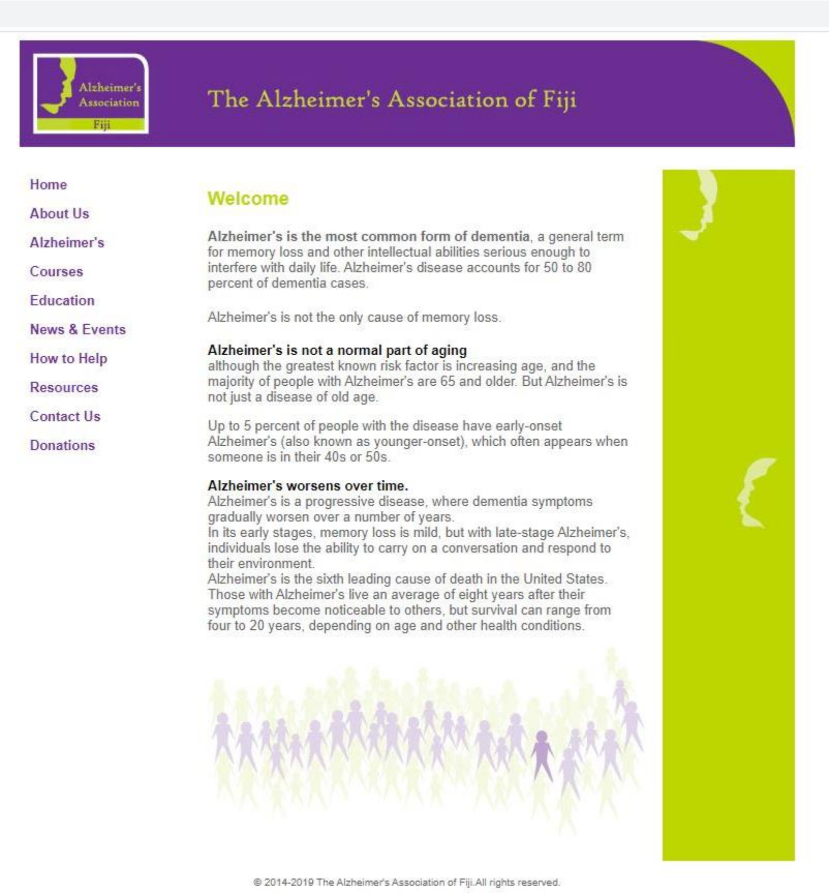
Table 6.1. Organisations that may support people living with dementia and their families.

Organisation	Purpose	Location
Empower Pacific http://empowerpacific.com/	• Offers free professional counselling and social services: 30 counsellors, 7 social workers and 8 support staff (Empower Pacific, 2018). • Work in consultation with government, community organisations and community groups. • Offers local and regional training. • Individuals and their families may be referred to this service by a doctor following diagnosis of dementia. The service is free and there are several locations, at all divisional hospitals and at some sub-divisional hospitals and health centres. In 2018, 12,078 individuals accessed hospital-based antenatal counselling services, and 4,790 accessed therapeutic counselling and social support services (Empower Pacific, 2018). As part of case management, social workers regularly follow up with clients or family members.	Offices at Suva, Lautoka, Nadi, Labasa Satellite Centers: Nausori, Valelevu, Tavua Hospital, Ba Mission Hospital

Faith-based organisations	There are many local churches and temples where people may receive pastoral care, with some organisations offering counselling services.	
Family Support Network in Mental Health (FSNet)	• Established in Suva in 2009 and works in partnership with Saint Giles Hospital and Fiji Alliance for Mental Health. • Support group (through information sharing and education about mental health) for family, caregivers and friends of people with mental illness. (WHO, 2013)	Suva
Fiji Alliance for Mental Health (FAMH) https://fijialliancemh.wixsite.com/famh-homepage	• Peak mental health organisation with a mission to promote and destigmatise mental health through advocacy for equality, education, support for research and service delivery. • Offers training for doctors, nurses, orderlies, counsellors and students of the health professions. Training for survivor and caregivers as peer mental health support.	Suva
Fiji Disabled Peoples Federation https://fdpf.org/	• This community organisation was established by a group of people with disabilities in the late 1970's. The organisation continues to be led and supported by people with disabilities. The mission is to support and promote the equitable inclusion of people with disabilities in services, programs and decision-making on issues that affect their lives. • It has four affiliates: Fiji Association for the Deaf, Psychiatric Survivors Association, Spinal Injury Association and United Blind Persons of Fiji.	Suva
Fiji Red Cross Society https://www.fijiredcross.org/	• Partners and volunteers work together in humanitarian service and advocacy. • Health and care programs aimed at identifying, preventing and addressing the priority health issues of vulnerable communities with a focus on: awareness raising; training; advocacy and support; preventative	Suva and Nadi

	activities for non-communicable diseases; and, designing and disseminating information, education and communication materials for community education.	
Fiji Women's Crisis Centre http://www.fijiwomen.com/	• Working towards ending violence against women in Fiji and the Pacific Region. • Counselling and crisis services for women and children experiencing or at risk of domestic violence, abuse and crime. Also involved in community education to raise awareness on violence against women, and training for service providers working in the areas of violence against women and children. • I talked with a service provider at two offices and both were unaware of women with dementia seeking help from their services.	Suva, Nadi, Ba, Rakiraki, Labasa
Fiji Psychiatric Survivors Association http://psafiji.weebly.com/	• A support group for people who have been diagnosed with mental illness. Many members have accessed care at Saint Giles Hospital. The group organises social gatherings, conducts home visits, provide counselling services, raise community awareness about mental illness, advocate for equality and, organise workshops for members and their families about mental illness and caring for someone with mental illness.	Suva
The Senior Citizens Ba Community Centre https://www.facebook.com/seniorcentreba/?nr	• The centre is a meeting point for older members of the Ba town community. There is a program of activities that runs two or three times a week. There may be other community centres with a focus on activities for older people however I was unable to identify any further centres through internet searches or field work.	Ba

A website for "The Alzheimer's Association of Fiji" appears to have been created in 2014 (Figure 6.2). I asked service providers about the website over the duration of the project but I was unable to find out who the site was created by and for what purpose. It is possible that it was created as part of a web design project or something similar. There is no content other than that displayed on the website Home Page (https://www.byrdinstitute.org/index.html).



Welcome

Alzheimer's is the most common form of dementia, a general term for memory loss and other intellectual abilities serious enough to interfere with daily life. Alzheimer's disease accounts for 50 to 80 percent of dementia cases.

Alzheimer's is not the only cause of memory loss.

Alzheimer's is not a normal part of aging
although the greatest known risk factor is increasing age, and the majority of people with Alzheimer's are 65 and older. But Alzheimer's is not just a disease of old age.

Up to 5 percent of people with the disease have early-onset Alzheimer's (also known as younger-onset), which often appears when someone is in their 40s or 50s.

Alzheimer's worsens over time.
Alzheimer's is a progressive disease, where dementia symptoms gradually worsen over a number of years.
In its early stages, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment.
Alzheimer's is the sixth leading cause of death in the United States. Those with Alzheimer's live an average of eight years after their symptoms become noticeable to others, but survival can range from four to 20 years, depending on age and other health conditions.

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Figure 6.2. Home page for the “Alzheimer’s Association of Fiji”.

6.3 Resources for dementia care

6.3.1 Resources for people living with dementia and caregivers

6.3.1.1 Local information

I found two resources for people living with dementia and informal caregivers. The first resource was a series of pamphlets published by the MHMS that a nurse working in mental health shared with me (Figure 6.3). One pamphlet provides brief information about mental illness and specific mental illnesses, including dementia. The other two pamphlets promote mental wellbeing and destigmatisation of mental illness.

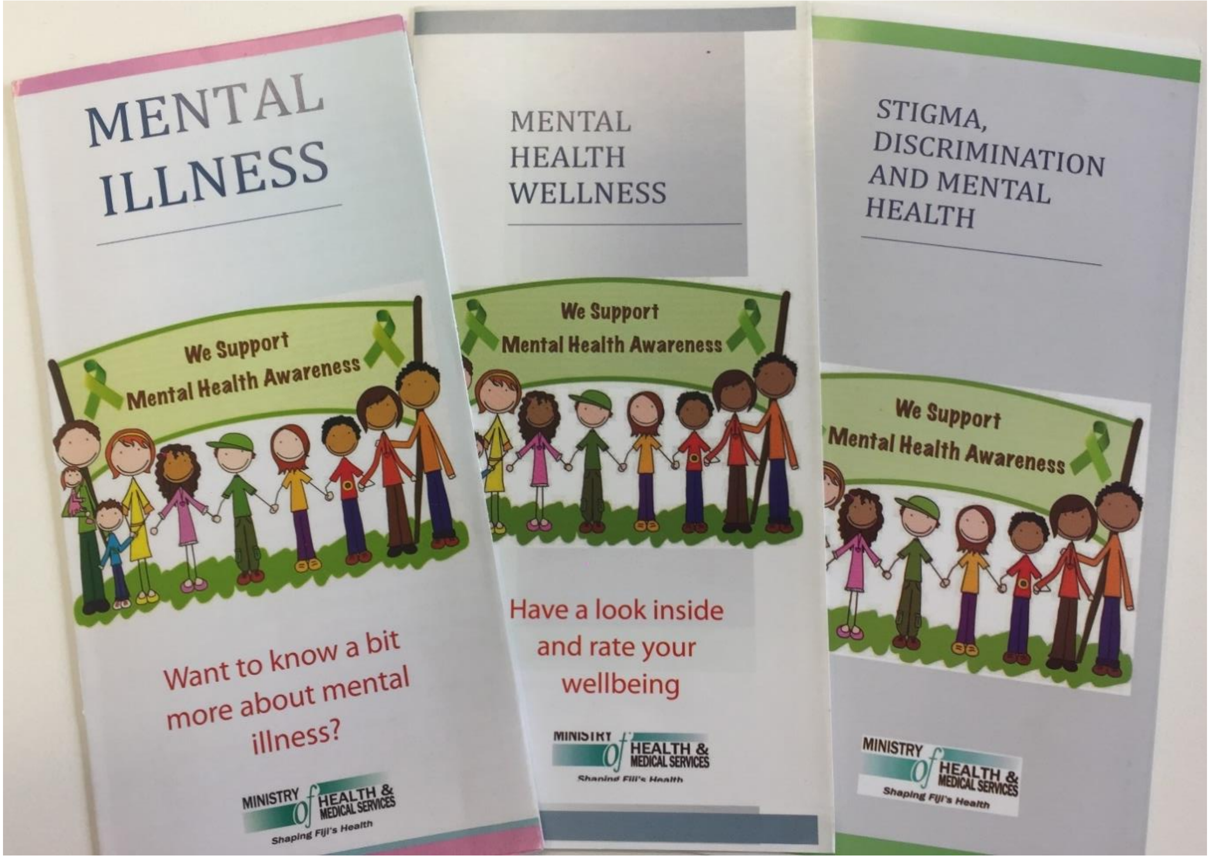

Figure 6.3. Pamphlets about mental health for community members.

Another information pamphlet (Figure 6.4) was available on the website for the Fiji Alliance for Mental Health (see Section 6.2.5). I did not come across this pamphlet while I was in the field. This resource provides information about dementia, early signs of dementia, caring for someone with dementia, self-care and where to find help or information (Fiji Alliance for Mental Health, 2017).

What is dementia?

Dementia can happen when one or more areas of the brain are damaged. It happens sometimes as a person gets older, but most older people do not get dementia. It is not a normal part of ageing. And rarely a person in their 30s or 40s can develop dementia. One type of dementia you may have heard of is Alzheimers.

Some of the effects of dementia can be:

▶Personality and behaviour changes eg easily upset, unusually aggressive, forgetting respect, being suspicious such as accusing others of stealing, being sexually inappropriate, wandering and getting lost in a familiar environment such as the village or street, over-reacting to minor events

▶Communication changes eg getting confused and jumbling words, losing the ability to speak or read, speaking too loudly or softly, repeating the same questions and stories

▶Being restless, pacing, making repetitive movements, trying to go to work or wanting to go home when they are already at home, acting as if they are doing a chore but nothing gets done such as moving dirt around without planting anything

▶Being very forgetful eg forgetting to go to the toilet, how to use household or farming appliances, how to get dressed, how to chew or swallow or even to feed themselves

▶Having trouble with their balance

▶The person may experience changes in seeing, hearing, their feeling of the temperature, and perception of depth.

The effects can depend on the stage of the disease, but they are different for each person. Sometimes a particular time of day or stress can make the symptoms worse. It is important to remember that the person cannot help their behaviour.

How can I tell if my family member or friend has dementia?

Sometimes the symptoms might look like dementia, but they are caused by a vitamin or hormone deficiency, depression, an infection, too much medication, or medications disagreeing with each other. These conditions are able to be fixed.

So it is important to get a checkup from a health worker or your doctor. They might ask your family member some questions, do a blood or urine test, and ask you what changes have been happening.

After tests they will be able to tell you if it is dementia or another problem.

How can I make sure my family member or friend is safe?

Most accidents happen in the person's home or village.

▶Lock away in a safe place all medicines, household cleaners, pesticides, sugar and seasonings, and anything that is poisonous

▶Lock up in a safe place anything that could be dangerous, such as kitchen knives, machetes, matches, whipper snippers, car keys and boats

▶Take the knobs off the gas burner or oven, don't leave the person unsupervised with a fire or flame, try to make sure water, gas and electricity have a shut off mechanism

▶Secure any mats or rugs to the floor, reduce clutter in the house

▶Check the temperature of food and drinks

▶Supervise the person's use of kava "grog" and alcohol which can increase confusion and interact with other medicines

▶Keep the contact details of a health worker, doctor or nurse close to hand, and contact them if you need help.

What can I do to help my family member or friend with dementia?

▶Help them to feel safe, be reassuring, encouraging and positive. The more relaxed and less overwhelmed they feel, the longer they are likely to remain independent

▶Communicate your messages clearly, ask simple questions, break activities into one step at a time, and explain what is happening

▶Make sure the person gets enough exercise which can help reduce anxiety, agitation, restlessness, and wandering

▶Provide opportunities for the person to be involved in structured useful familiar activities throughout the day eg safe food preparation, folding washing, gardening

▶Make sure their basic needs for food, water and toileting are met

▶Avoid busy places and loud noises

▶Don't leave them unsupervised in new surroundings

▶If they are having problems with incontinence, take them to the toilet regularly, try to avoid coffee, tea, coke and beer, and limit drinking before bed

▶Make sure they are eating enough healthy foods

▶As their sleep may be disturbed, try to make sure they are comfortable, that they go to bed at a regular time, explain that it is night time, or ask the doctor for some medication

▶Give the medication prescribed by the doctor to the person in the amount and at the time they suggest.

Is there any treatment?

There is no cure for dementia. However especially in the early stages there are some medications which might help.

Figure 6.4. Information pamphlet for family and friends of people living with dementia (Fiji Alliance for Mental Health, 2017).

6.3.1.2 International community

During my search of the internet for dementia care in Fiji, I found online international sources that could support people living with dementia and family caregivers in Fiji. In the absence of support specifically for dementia in Fiji (at the time of this research), internet resources present an important and accessible source of information. A mental health nurse shared a story of a young boy who was caring for his grandfather who was showing signs of dementia:

> *"Man, like he was telling me the story like it really touched me and I asked him, 'Where did you learn about all this management?' 'I, one of my friend', he said, 'told me that is dementia, from school'. So he went and Google how to take care of people who are going through dementia. So he learn. And in the house, this is what he do. He did to the house. He knows that his grandfather, he loves the red colour. His clothes all red. His eating utensils is all red. His room door is red. The bathroom door and the toilet door. He labelled in red, toilet and the bathroom. And his room, his towel and everything is in red" (I-18).*

I provide a brief summary of three international resources here. There may be other sources of support that Fijians have sought online.

iSupport

iSupport is an online resource designed for informal caregivers of people living with dementia. It incorporates education about dementia, being a caregiver, coping and providing care, and managing changing behaviours. Interactive exercises are linked to lessons. iSupport can also be linked with other platforms, such as Facebook, to enable an interactive experience thereby facilitating social support (Pot et al., 2019). The resource can be adapted for use in different contexts, with adaptation and implementation of iSupport in India, China, Japan, Portugal, Brazil, Australia and the Netherlands (Pot et al., 2019). A hard copy version of iSupport is also available, with an adaptation and implementation guide available for countries that wish to adapt the resource (WHO, 2019a).

Dementia Australia and Dementia New Zealand

Australia and New Zealand are Fiji's close neighbouring countries. Both Australia and New Zealand have national dementia organisations, Dementia Australia and Dementia New Zealand. Both these organisations host websites with resources, including fact sheets and video clips, for people living with dementia and informal caregivers. The resources available on these websites may be useful for information about dementia however consumers from Fiji would need to be wary of the differences in available services for dementia support.

6.3.2 Resources for service providers

Training in mental health for health professionals begins at the undergraduate degree level, with further education available as outlined in Chapter Three (Section 3.9). The education team at Saint Giles Hospital conducts regular needs assessments of mental health staff and provide workshops and training for health providers as needed. In addition, the WHO Mental Health Gap Action Programme (mhGap) was first implemented in Fiji from 2014 as part of scaling up of services for mental, neurological and substance abuse disorders (Charlson et al., 2019). The program consists of training for health providers working in non-specialised settings (nursing stations, health centres and hospitals) in the use of the mhGAP intervention guide for detection and management of mental, neurological and substance use disorders. The mhGap package includes an introduction to dementia, with education about the types, stages and causes of dementia, and management strategies. Training in the mhGap is also available online through the WHO Pacific Open Learning Health Net[4] (POLHN; https://polhn.wpro.who.int/courses/mental-health).

I found few other resources or training about dementia for service providers. Some service provider co-researchers reported that there was a lack of flow charts available to assist them with identifying possible dementia, and many providers reported a need for further education. For aged care service providers, the APTC have worked in collaboration with the Fiji government to provide professional development workshops for staff involved in public aged care services.

6.4 Estimated prevalence of dementia

The experiences and impact of dementia in PICs with constrained resources (LMICs) have not been explored to date. Likewise, prevalence studies have not yet been conducted in any PIC. Major sources of global dementia prevalence estimates are the Global Burden of Diseases, Injuries, and Risk Factors Study 2016 (GBD; Nichols et al., 2019), analyses disseminated in the World Alzheimer Report 2015 (Prince et al., 2015) and a Delphi consensus study (Ferri et al., 2005).

GBD dementia prevalence estimates have been developed through complex methods that synthesise incidence, prevalence, risk factor and mortality data from multiple sources (Nichols et al., 2019). The GBD estimated an age-standardised prevalence for dementia of 700-799 people per 100,000 for Fiji, and for other PICs including the Marshall Islands, Solomon Islands, Kiribati, the Federated States of Micronesia, Vanuatu, Samoa and Tonga. By extrapolating this estimate to the estimated population of Fiji in 2020 of 894,961 people (SPC Statistics for Development Division, 2020), the number of people living with dementia in Fiji is likely to be between 6,265 and 7,151 people. Using predicted population, in 2030, the number of people living with dementia is likely to be between 6,447 and 7,359 people (Appendix 14).

The 2015 World Alzheimer Report presents rigorous (and well accepted) meta-analyses of prevalence studies to estimate the prevalence of dementia in GBD regions (Prince et al., 2015). Prior to these analyses, global prevalence of dementia was estimated through a Delphi consensus study involving 12 experts with experience in dementia prevalence studies and meta-analyses of dementia incidence and prevalence, with synthesis of prevalence studies to guide (Ferri et al., 2005). Published analyses for an economic impact study of dementia in New Zealand extrapolate estimates for dementia in the Australasia region to estimate the prevalence of dementia in New Zealand (Ma'u E et al., 2021). Using the same method, the prevalence of dementia in Fiji can be estimated using the age-standardised prevalence of 6.46% for people aged over 60 years estimated for the Oceania

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[4] The POLHN, established in 2003, develops and sponsors online education courses designed by professional bodies to overcome geographic barriers to education in the Western Pacific region.

GBD region (Ferri et al., 2005; Prince et al., 2015). In 2020 and 2030, the estimated number (and projected number) of people living with dementia in Fiji using this method is 5,888 and 8,080 people respectively.

6.5 An impression of the scope of dementia

In this section, I describe the findings of an analysis of hospital admissions data to provide a foundational impression of the scope of dementia in Fiji. The methods used for this analysis are described in Chapter Five (see Section 5.6).

6.5.1 Hospital admissions data

Between July 2002 and March 2019, there were a total of 79 admissions for patients (aged over 18 years) with a primary diagnosis of dementia at divisional hospitals, sub-divisional hospitals and Saint Giles Hospital. The majority of cases of dementia were coded as unspecified dementia (n=66; 83.5%), and there were seven cases coded as vascular dementia and a further six cases specified as multi-infarct dementia.

6.5.2 Patient characteristics

The admissions related to 72 individuals, five of whom were admitted twice over the time period and another patient who was admitted three times. Looking at the two main cultural groups of Fiji, there was a slightly higher proportion of individuals who were Fijians of Indian descent (n=35; 48.6%) than iTaukei (n=31, 43.1%; Table 6.2). There was an almost equal proportion of females and males who had been admitted (Table 6.2). Of the 41 admissions with data for secondary diagnoses, 17 (41.5%) admissions were for patients with at least one comorbid NCD. NCDs included ischaemic heart disease, diabetes mellitus, cardiovascular disease and chronic kidney disease.

Patient age at admission ranged from 20 years to 92 years. The age of patients at admission was skewed towards older age with the median age being 71 years (Interquartile Range [IQR] 15 years). The vast majority of admissions were for patients aged 60 years or older (n=64, 88.9%; Table 6.2), with 69% of this age group (n=44) being aged over 70 years. There were no statistically significant associations between being aged over 60 years at the time of admission, and gender or belonging to one of the two main cultural groups (χ^2=0.054, df=1, p=0.0.82; χ^2=2.473, df=1, p=0.12, respectively).

Table 6.2. Characteristics of patients with a primary diagnosis of dementia.

Characteristic		**n (%)**
Age group (N=79)	60 years and over	64 (81.0)
	50 to 59 years	8 (10.1)

	20 to 49 years	7 (8.9)
Ethnicity (N=72)	Fijian of Indian descent	35 (48.6)
	iTaukei	31 (43.1)
	Other	6 (8.3)
Gender (N=72)	Female	38 (52.8)

6.5.3 Geographic distribution of admissions

The admissions occurred across all four health administrative divisions, with the majority of admissions in the Central division (Suva and surrounding area; n=44; 55.7%), followed by the Western division (Lautoka, Nadi and surrounding area and islands; n=21; 26.6%), then the Northern division (located on Vanua Levu and surrounding islands; n=13; 16.5%); and finally the Eastern division (the island groups located east of Viti Levu; n=1; 1.3%; Appendix 15). Most admissions occurred at major divisional hospitals however there were some admissions at more rurally located sub-divisional hospitals.

6.5.4 Length of stay

Fifty percent of admissions were for a period of three to thirteen days (IQR 10 days), excluding six outliers that ranged from an admission length of 32 days to 137 days (Figure 6.5). Excluding outliers, patients were admitted for a median of five days.

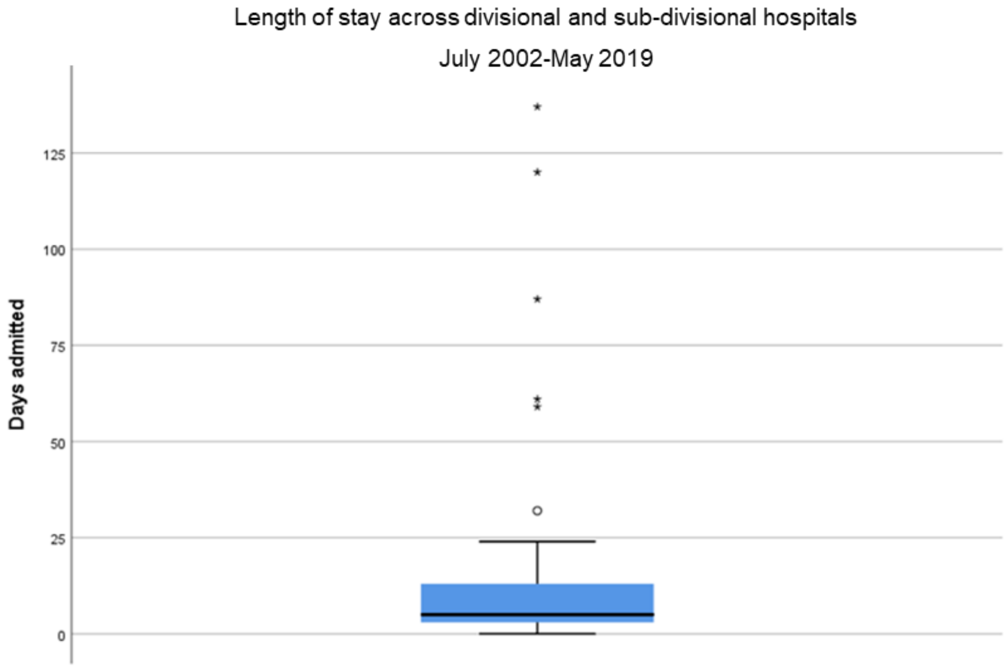

Figure 6.5. Box plot displaying the distribution for length of stay for patients with a primary diagnosis of dementia (N=68; missing data n=11).

6.5.5 Temporal characteristic of admissions

From 2002 until 2016 there were between one and six patients admitted to a hospital with a diagnosis of dementia recorded as the reason for admission each year (Figure 6.6). This increased over the following two years and in 2018 there were fourteen admissions for dementia, more than three times the number of admissions in 2015 (n=4).

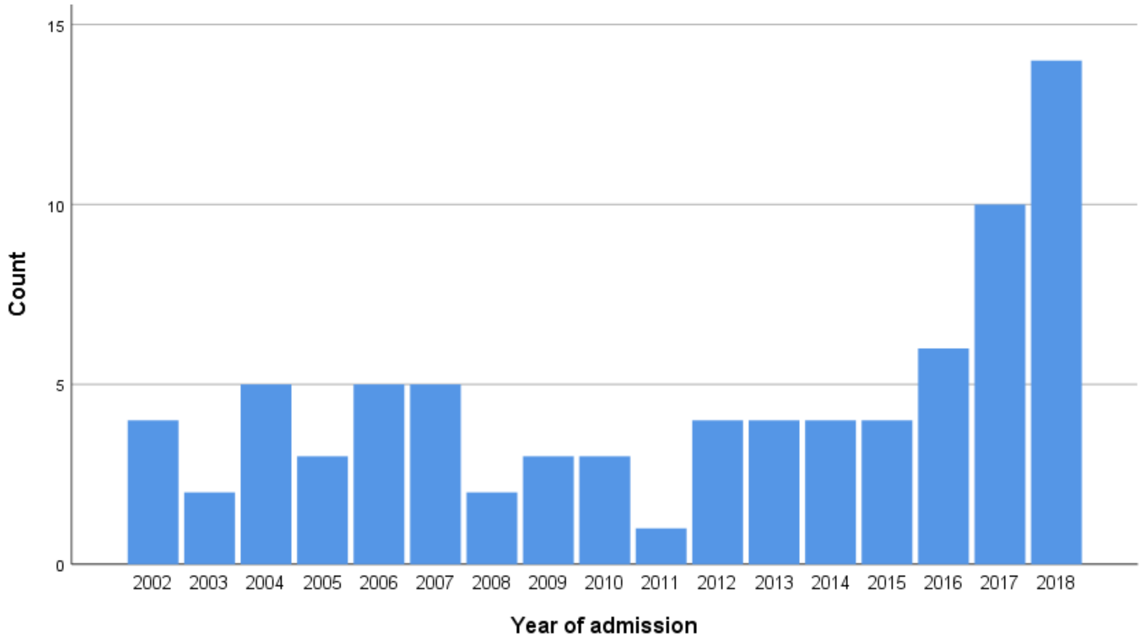

Figure 6.6. Number of admissions for patients with a primary diagnosis of dementia per year (N=79).

6.6 Critical reflection

This analysis represents an initial investigation of dementia in Fiji using readily accessible hospital admissions data. There was a total of 79 admissions (for 72 patients) with a primary diagnosis of dementia at public hospitals across Fiji between July 2002 and early 2019, with most admissions occurring in urban settings on the mainland of Viti Levu. By way of comparison, in 2017 alone there were more than 76,000 hospital admissions overall in Fiji (MHMS, 2018). The number of patient admissions with a primary diagnosis of dementia, though very small in comparison, is significant in terms of the wellbeing of people living with dementia and their families. The findings show a clear upward trend for hospital admissions in more recent years. This could reflect a true increase in need for hospital care for people living with dementia, but more likely reflects improvements in recording and reporting of patient data (including changed practices for recording diagnoses of dementia), and increased awareness of dementia through local and regional mental health initiatives and the presence of this research about dementia in Fiji. For example, the Creating Futures conference (that aims to build capacities for improving the mental health of disadvantaged populations in Australasia and the Western Pacific) was held in Fiji in 2017 and included a workshop about dementia that was led by one of my advisors together with myself and other colleagues. Importantly, the findings of this analysis have implications for the Fijian health system, and indicate the likely presence of underlying health system factors and community factors, such as help seeking behaviours, that hinder contact with health services and limit diagnosis of dementia.

The most frequent diagnosis was ‘dementia not otherwise specified’ (83.5%), with very few patients diagnosed with a subtype of dementia (including dementia of Alzheimer’s type). A prevalence study conducted in Australian Aboriginal communities in the Torres Strait region of Australia, a resource constrained setting, reported dementia not otherwise specified as the most common diagnosis (38.5%) though this was closely followed by dementia of Alzheimer’s type (30.7%) and vascular dementia (20.5%; Russell et al., 2020). The authors attributed the high proportion of dementia not otherwise specified to a lack of access to neuroimaging and clinical information. Similar issues of low access to imaging and patient history, or concurrent vascular changes, may also explain the findings from this analysis in Fiji.

In this study in Fiji, the majority of patients (80%) admitted to hospital with a primary diagnosis of dementia were aged over 60 years at the time of their admission with a median age of 71 years. This suggests that people accessing hospital care for dementia in Fiji are most likely to be older adults. In Australia, in 2016-2017, there were close to 95,000 hospitalisations for people who had at least one diagnosis of dementia, with 22% of admissions being for a principal diagnosis of dementia (Australian Institute of Health and Welfare [AIHW], 2019). The vast majority of these hospitalisations (97%) were for people aged over 65 years (AIHW, 2019). There is strong international evidence that the risk of hospital admission for people living with dementia increases with older age (Shepherd et al., 2019). Moreover, evidence from other parts of the world confirms that people living with dementia: i) are very likely to need acute care in the years following a diagnosis of dementia (Sommerlad et al., 2019); ii) that people living with dementia require hospital admission at a higher rate than people without dementia (Shepherd et al., 2019), and iii) require relatively longer hospital stays (Möllers et al., 2019). This has important implications for a health system that is responsive to the needs of an older population.

In the context of the Pacific Islands, where family networks are integral in providing care for older family members, these hospital admissions likely represent people living with dementia and their families in crisis. Singh (2019) contends that in India the use of hospital services and aged care homes for people living with dementia represents, in part, 'helplessness' of family members in providing care. A reliance on the family support network for the care of older people is challenged by migration, economic issues and lack of space (Singh, 2019). Similarly, issues with migration of the working age population and stretched family networks are emerging challenges for an older population in Fiji (UNFPA, 2014). Moreover, given an estimated number of people living with dementia in 2020 of between 5,888 and 7,151 people, and a projected estimated number in 2030 of between 6,447 and 8,080 people, addressing the issue of dementia and associated impacts on families, communities, the health system and social sector is critical.

For people living with dementia and their families, dementia is physically and emotionally demanding, and has major negative personal, social and financial implications (Brodaty & Donkin, 2009; WHO, 2012). Certainly, evidence from global literature (Johnston et al., 2020) and the qualitative aspects of this study (see Chapter Seven) indicates that dementia is a challenging issue for families and communities. Perceptions of dementia as normal ageing, or stigmatisation of changed behaviours as mental illness or associated with curse and witchcraft prevent or delay help-seeking from health services. Moreover, in Fiji, specialised services for dementia care are non-existent and support services for caregivers of people living with dementia are inadequate. Where services exist (via counsellors, general practitioners, mental health care services and aged care homes), they are located in major urban towns. Added to this, opportunities for training and education in dementia for service providers is limited. This has consequences for timely diagnosis of dementia and the wellbeing of older people living with dementia and their family caregivers.

There are some important study limitations for this part of the thesis. There are challenges with information systems and patient records in Fiji which limit confidence that all admissions with a primary diagnosis of dementia were identified for this study. Data for the years that predated initial establishment of PATIS were retrospectively entered. It is possible that retrospective data entry occurred only at some hospitals and is quite likely incomplete. Additionally, there are undoubtedly issues with accuracy and completeness of records associated with the transfer of records from one system (local, disconnected computer-based systems or paper-based systems) to a single, shared information system. Reyburn et al. (2017), in their audit of PATIS, found that a high proportion of admissions data captured by the electronic system matched manual ward registers, and this was highest at divisional hospitals using PATIS (89.1%) compared with sub-divisional hospitals using manual reporting (where paper-based records are centrally transferred to an electronic database; 57.6%). They also found variation in the completeness of reporting in each year.

Additionally, the information system is available at just 36 out of 200 public health facilities (all divisional hospitals, sub-divisional hospitals and some health centres; Ravindra et al., 2017). There are known issues with the use of the information system, including limited technical support, insufficient numbers of providers trained in the use of the program, procedures for medical coding and designation of codes for diagnoses, and issues with telecommunications and inadequate equipment (Mataitoga et al., 2014; Ravindra et al., 2017; Soar et al., 2012).

Another limitation is that this study only included admissions for a primary diagnosis of dementia. Data for hospitalisation relating to secondary diagnosis of dementia were requested however these data were not provided. In Australia, just 22% of hospital admissions were classified with a principal diagnosis of dementia (AIHW, 2019) suggesting that the scope of dementia in Fiji is higher than the study findings show. A final limitation of this study is that it only included hospital admissions data. Outpatient data would likely reveal more about the impact of dementia however manual chart audits at multiple health facilities would need to be conducted to obtain the necessary data. This was too resource intensive to be included in this study.

In Chapter Eight, I integrate the findings of this analysis with the qualitative component of this research.

6.7 Chapter Six summary

In this chapter I have:

- Described services and resources for dementia care, and their availability for people living with dementia, family caregivers and service providers.
- Presented an impression of the scope of dementia in Fiji using hospital admissions data.
- Provided a critical reflection about the use of in-patient hospital services in the context of low awareness and service availability for dementia care.

In the next chapter I will:

- Describe the grounded theory that I constructed from the views and experiences of stakeholders.
- Reflect on the trustworthiness of the grounded theory, including a discussion about analytical reflexivity.
- Provide a rationale for my choice of theoretical code to extend the grounded theory.

7. A grounded theory about dementia care management

In the Fijian community is that mentality with old age comes forgetfulness so when the old people are manifesting a sense of forgetfulness, so they just, they don't really, how should I say… They think it comes with old age so they don't really, they just let it be.

(P3, mental health nurse, FG-3)

7.1 Chapter Seven outline

In this chapter, I describe the grounded theory that was developed from knowledge that co-researchers shared about dementia and dementia care. First, I describe the co-researchers that contributed to the grounded theory, and how I integrated their knowledge. Next, I outline the core category and how it connects with the other three main categories of the theory. I then explain the three main categories and how they link together to form the grounded theory. Next, I present the layers of dementia care management that exist across the grounded theory. I then discuss trustworthiness. Finally, I provide a rationale for drawing on a socio-ecological perspective of health to extend the explanatory power of the grounded theory.

7.2 Co-researchers

A total of 50 co-researchers contributed their views and experiences about dementia through 37 semi-structured interviews and three focus groups. Co-researchers were family caregivers, a person living with dementia, health and aged care providers, and community providers and leaders.

7.2.1 Family caregivers and people living with dementia

Co-researchers included eight family caregivers and one person living with dementia, from seven family units (Table 7.1). Six families lived in Suva and one family lived in Lautoka. All family caregivers except one lived with an older person who had been diagnosed with dementia. All family caregivers cared for an older person living with dementia in advanced stages of the condition. One person living with dementia was physically unable to leave their bed due to frailty and severe cognitive impairment at the time of interview.

Table 7.1. Characteristics of co-researchers within family units.

Family unit (Interview reference)	Co-researcher				Person living with dementia Age (years)
	Type	Relationship to person living with dementia	Age (years)	Living arrangements	
Family unit 1 (I-4)	Family caregiver	Son	40-49	Living with person with dementia	80-89*
Family unit 2 (I-10)	Family caregiver	Son	50-59	Living with person with dementia	80-89
	Family caregiver	Granddaughter	20-29	Living with person with dementia	
Family unit 3 (I-11)	Family caregiver	Daughter-in-law	40-49	Living with person with dementia until just prior to interview	60-69
Family unit 4 (I-12)	Family caregiver	Daughter	20-29	Living with person with dementia	60-69
Family unit 5 (I-14)	Family caregiver	Niece	40-49	Living separately from person with dementia	Person living with dementia was a co-researcher
	Person living with dementia	N/A	70-79	Living with other family members	N/A
Family unit 6 (I-35)	Family caregiver	Spouse	70-79	Living with person with dementia	80-89
Family unit 7 (I-37)	Family caregiver	Daughter	70-79	Living with person with dementia	90-99**

* Deceased for 1 year at time of interview. Alive during study period.

**Deceased for 18 months at time of interview. Alive during study period.

7.2.2 Service providers, community providers and leaders

Other co-researchers were health service providers, aged care providers, providers in the community sector and one village elder (Table 7.2). I conducted interviews with 40 service provider co-researchers. A mixture of health providers from the public and private sectors participated. They worked in hospitals, mental health outpatient and community services, health centres, private general practice and aged care homes. Service providers were located in Suva (n=21), Lautoka (n=16) and Nadi (n=3). The village elder lived in Suva and maintained close ties with their home village where they grew up and lived in for many years.

Table 7.2. Characteristics of service providers, community providers and leaders who participated in semi-structured interviews and focus groups.

Stakeholder group (total number)	Stakeholder category	Number of co-researchers Total	Site Suva	Nadi	Lautoka
Mental health care providers (n=22)	Counsellor	3	2	0	1
	Nurse	17	8	1	8
	Doctor	2	1	1	0
General health care providers (n=8)	Nurse	2	2	0	0
	Doctor	5	3	0	2
	Community health worker	1	0	1	0
Aged care providers (n=6)	Nurse	4	3	N/A	1
	Qualified caregivers	2	0	N/A	2
Community providers and leaders (n=5)	Community organisation	2	2	0	0
	Training organisation	1	0	0	1
	Social welfare worker	1	0	0	1
	Village elder	1	1	0	0

7.2.3 Conduct of interviews and focus groups

Interviews with co-researchers of family units were conducted in various places, as suited co-researchers. Three interviews were conducted in the family home. Two interviews were conducted using an online communication platform, while I was in Australia. One interview was conducted in a private space at a health facility, and another in a private space at the workplace of the co-researcher. Three interviews were conducted with the family member diagnosed with dementia present, two of whom were experiencing advanced stages of the condition and did not participate in the discussion. Three interviews ranged in length from 10 minutes to 15 minutes. Two of these interviews were constrained by a need to work in with the timelines of my health professional travel companions who were conducting home visits. The co-researchers lived in the outer areas of Suva, accessible only by dirt roads with few road signs, and would have been challenging for me to find on my own. The other short interview occurred at a health facility prior to an appointment. The remaining four interviews ranged in length from 40 minutes to 85 minutes with an average of 55 minutes.

Interviews and focus groups with service providers were conducted in private spaces at their place of work. These interviews were often constrained by time due to other activities that the service provider needed to address. Interviews ranged from 10 to 54 minutes in duration, with an average duration of 23 minutes. Focus groups ran for an average of 25 minutes.

All co-researchers consented to being audio recorded except one. Detailed field notes were taken during this interview, with permission. At times, I noticed some discomfort with the presence of my voice recorder on the table when we were sitting together for an interview. Some co-researchers' eyes would flick between me and the recorder. I noticed this during my first field trip. From then on, after obtaining consent to record, I always mentioned when I was turning the recorder on. Then I would cover it with a light-weight scarf and explain that it helped with reducing background noise. It seemed to make the recording of the interview less distracting and improved the quality of the recording. One interview was conducted in the Fijian language by my cultural mentor who was fluent in this language. This interview was transcribed to English and then back translated (described in Section 5.7.6.1).

7.3 Overview of the grounded theory

The grounded theory developed in this research is about the processes that caregivers use to manage dementia care (Figure 7.1). This grounded theory draws on the knowledge of informal (family caregivers) and formal (service provider) caregivers. It draws on their knowledge, shared with me, through their roles not only as caregivers, but as family members and community members. Family caregivers shared their experiences of their journey towards a diagnosis of dementia and in so doing talked about their concerns and reasons for seeking help to manage the care of their loved one. These views offer insight into the lived experience of caring for an older person who was eventually diagnosed with dementia. In Fiji, according to service providers, diagnosis of dementia in older people is uncommon with many cases of undiagnosed dementia likely to exist in the community. Service providers talked about their experiences with older people diagnosed with dementia, and also about cognitive decline and undiagnosed dementia. These various perspectives offered different views of processes, interactions and outcomes. Thus, the grounded theory presented overlaps in places, as indicated by references to other parts of the theory in parentheses.

The core category of the theory is a socio-cultural construct, 'letting it be'. This category is at the core of processes that caregivers in Fiji use to manage the care of older people living with dementia, as shown in Figure 7.1. 'Letting it be' ties all other elements of the theory together as symbolised by the arms swirling out from the centre, filtering between and connecting the other categories. The categories relate to cognitive, behavioural and emotional aspects of dementia care. They are depicted in a circular manner around the core category to illustrate that the theory describes processes for managing the care of older people living with dementia that are not perfectly sequential or independent of each other but come together to shape the dementia care experience.

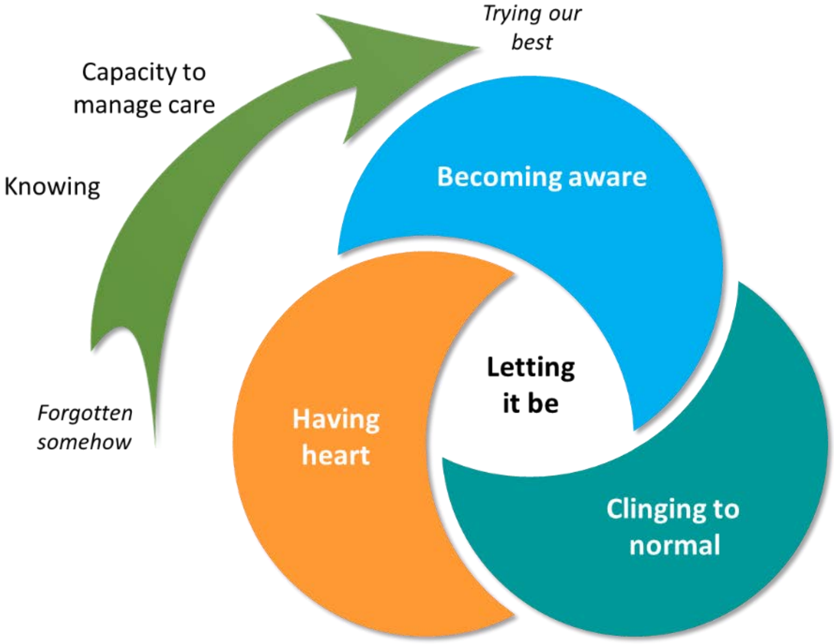

Figure 7.1. A diagram depicting the grounded theory.

The dementia care experience ranges from 'forgotten somehow' to 'trying our best'. The phrase *'forgotten somehow'*, used by a mental health nurse (I-6) in describing their experience of how older people with possible dementia may be treated in the community, captures the mystery of how neglect and abuse of older people can happen in Fiji, a society traditionally known to have collectivist values and strong social norms around family responsibility. In contrast, the phrase *'trying our best'* was used by two family caregivers (I-10) who were caring for their loved one who had been diagnosed with dementia. The phrase encompasses the relational way of caring for an older person that is characteristic of Fijian society, including the desire to support an older family member's wellbeing. The origins of these consequences are explained through the major categories ‘becoming aware’, ‘clinging to normal’ and ‘having heart’. ‘Knowing’ and the ‘capacity to manage care’, have the power to influence the dementia care experience for people living with dementia, family caregivers and service providers. These factors are woven through the processes that caregivers use to manage the care of older people living with dementia and are described in each category as appropriate.

In regards to terminology, throughout the grounded theory, the term ‘caregivers’ is used to denote both family caregivers and service provider caregivers, unless otherwise qualified.

7.4 The core category: Letting it be

The core category is a sociocultural construct called ‘letting it be’. This concept weaves through the other three categories connecting them into a grounded theory about the processes that caregivers in Fiji use to manage dementia care. ‘Letting it be’ is a way of approaching care for older people with cognitive decline and dementia that is consistent with ingrained cultural values for caring for older people (described later in the main category ‘having heart’). The concept 'letting it be' emerged from service provider co-researchers experiences of dementia care, from their perspectives as community members and service providers, where they used phrases like "*they just let it be*", "*they leave them be*" and “*we just leave it*” to describe responses to people with signs of dementia. The concept was also apparent in the caring approaches that family caregiver co-researchers had prior to diagnosis, and for some, after diagnosis as well. The terminology that I chose for this category may insinuate a passive approach to care for older people with cognitive decline and dementia, but this is not the case. Rather, it is an approach that is enacted with equanimity and involves compassion, searching for knowledge and support, and application of traditional care practices, within the strength of family and community networks. It is driven and maintained by the social norms of a society that is traditionally collectivist. The sense of connectedness that characterises Fijian society is maintained in this way of caring for older people with signs and symptoms of dementia or diagnosed with dementia.

However, ‘letting it be’ is accompanied by an assumption that care for older people will be managed appropriately within family and community networks, and that these networks are always available and accessible (in line with cultural values for caring for older people). Caring for an older person living with dementia challenges this assumption and challenges the capacity to provide care. Moreover, deviating from ‘letting it be’ is associated with strain on a family’s capacity to manage care and the threat of disconnection from family and community.

7.5 Becoming aware

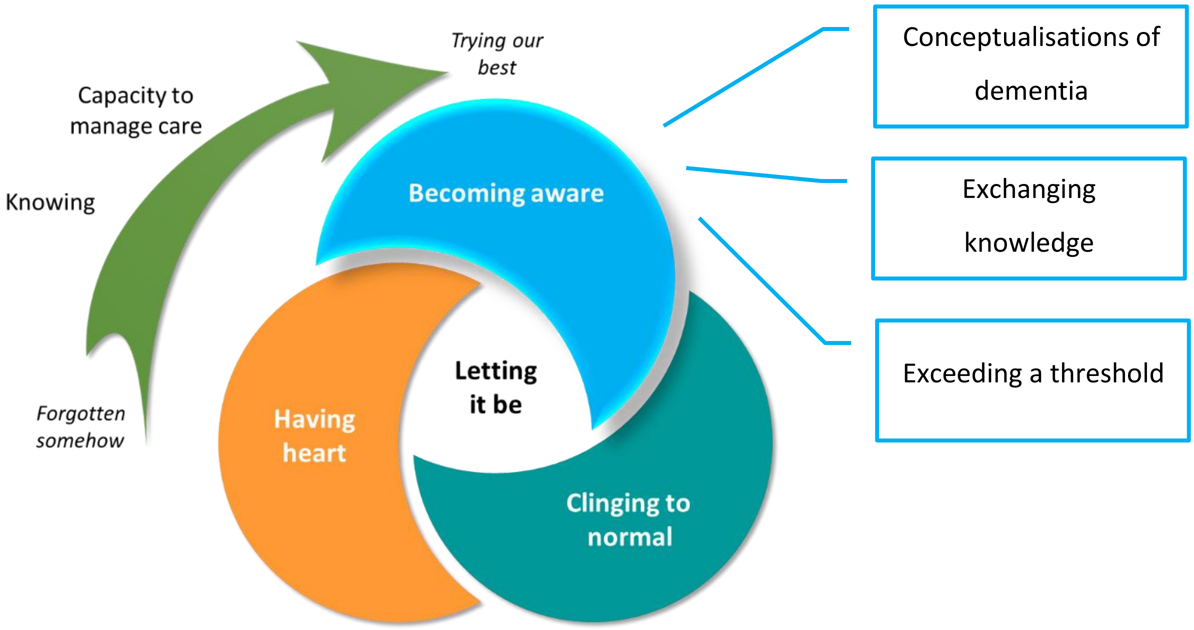

Figure 7.2. Diagram depicting the grounded theory showing the sub-categories for the main category 'becoming aware'.

7.5.1 Conceptualisations of dementia (sub-category)

For most Fijians, dementia in older age is a foreign concept. The general community in Fiji have little, if any, awareness or knowledge of dementia as a defined condition. Family caregivers (who cared for a person diagnosed with dementia) had various understandings of dementia and incorporated a mixture of age and other factors as causative aetiologies. Five family caregivers (four family units) accepted the unwellness of their older family member as attributed to a condition called dementia, though understanding of the condition was low and all except for two caregivers viewed dementia as a normal part of becoming older. Three family caregivers from different family units struggled to connect with the concept of dementia and related the condition to having lived a long life and lifestyle factors. Of these, one family caregiver linked the changed behaviours in an older family member to loneliness, being a widow (with no-one to share daily life with) and lacking purpose; and two family caregivers attributed a variety of other factors including age, worry, poor health behaviour, a busy or stressful life, having many children or experiencing a stressful life event. These understandings, together with views from service provider caregivers, are described in the following properties of this sub-category.

7.5.1.1 Ageing within social norms – 'getting to that stage'

Becoming forgetful, acting immaturely and being grumpy at times is expected in older age, as a spouse of a person living with dementia shared:

> *"… [my son said of his father who had been diagnosed with dementia], 'Oh yeah, my Dad. He's 80. He just doesn't talk to anybody and then he yells and screams,' and I thought, well, I don't think he has a clue what that behaviour was. You know. Just my 80, you know, all these 80 year olds. You know, all the 80 year old behaviour..."* (I-35)

Commonly, service providers expressed that community members viewed signs and symptoms of dementia as a normal part of ageing: *"...the thoughts are that when we get old we will become forgetful. That's what they know"* (mental health nurse, I-13). One family caregiver believed that dementia was not a disease but was caused by biological deterioration over a long life and affected older people in various ways. Some family caregivers viewed dementia as an illness of older age, as a son caring for his mother described, "*I think maybe it was just a year ago now [when he thought there might be a problem]. Before, we thought that it's just something that will pass away, you know, it'll go away but, and then we like, eh, no. Age. It's ageing kinda sickness or something, eh"* (I-10).

Service provider caregivers described the terms that family caregivers used when they visited their services for help with an older family member. Terms from the iTaukei language that were used to describe expected behaviours in older age included '*yatayata*' (unstable, unsettled), '*guiguileca*' (forgetful) and '*yalowai*' (acting immaturely). These terms could be used to describe signs of dementia and they could also be used in a derogatory manner. Hindi terms used to describe signs of dementia were '*bhool ja*' (forget), '*bhoole wala bemari'* (forgetting disease) and '*halka dimag*' (weak brain). A doctor explained how '*halka dimag*' was used by family members to describe their concerns relating to an older family member:

> *Doctor: "...they just say that she is 'halka dimag' so that means like their mind is not what it used to be."*
>
> *Facilitator: "What is…?"*
>
> *Doctor: "'Halka dimag'. Like 'halka' means it's lighter so they said that, and 'dimag' is like the brain and so the brain is lighter kind of thing. That's what they've said. Or they say that she is forgetting things now because of old age, that's how they've explained it to us."*
>
> (I-24)

There is a high tolerance for changed behaviours in older age, as clearly captured in a story from a village elder:

> *"Yeah, I was in the, few weeks ago, was in the village, you know one of our elders went to the hospital, got really sick, was OK but came back. He got to that stage where you know, he walks around in the village and you know, he just want to wee somewhere, he just takes*

> *off his clothes and just you know, just urinate. But it's in the village setting, it's acceptable, you know, they understand what's happening to that old age, and you know, the sons and daughters, they look after him well, you know. They will come and put back his, put on his sulu[5] again and take him into the house."* (I-36)

Moreover, family caregivers commonly described a sudden awareness of a problem with an older family member (see Section 7.5.3; 'exceeding a threshold').

This perception of signs of dementia being part of ageing applied in both main cultural groups (iTaukei and Fijians of Indian descent). Surprisingly, two service providers also shared views that normalised signs of dementia in older age: *"…because when they reach that age, they, you know like how children are, there is children and there's old people. They have the same mentality kinda thing and so you'll have to be patient with them and make them happy and all"* (doctor, I-25). Many service providers admitted to being unaware of dementia and sharing community views about ageing until they began their health studies, though knowledge of dementia was low amongst service providers (see Section 7.5.2; 'exchanging knowledge').

Reflecting the social norm in relation to expectations of ageing, a nurse providing mental health services reflected on presentations of older people with symptoms of forgetfulness and changed behaviours at a mental health service:

> *"I feel that they are not psychotic. It's just that they are, it's to do with age. They are just forgetful. Men [common Fijian expression], at times in our communities, when people are old, ah, they are not given much attention. Like people to listen to them more. Spend time and talk with them. And maybe they are just lonely and seeking attention."* (I-6)

Similarly, a family caregiver of a woman who had been diagnosed with dementia, attributed the worsening of forgetfulness and other changes to loneliness and a lack of purpose. She felt that these things had been brought about because other family members had reduced her Aunty's participation in daily life because she started forgetting things. While this family caregiver associated her Aunty's dementia with older age, when she compared the presentation with other older people she couldn't resolve this as being caused solely due to age.

> *"Ah for me it's, it could be more of lonely and um, the age as well. Her age as well but compared to people with that age, they are not having this problems. But for me, it's more like that she is single and ah, um, and all her life was just staying home."* (niece, I-14)

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[5] The sulu has become known as Fiji's national dress. It is a piece of clothing worn by men and women that wraps around the waist and may be worn in a formal or less formal manner.

7.5.1.2 *Evoking associations with mental illness*

Dementia is sometimes associated with losing one's mind. This is equated with stigmatising views of mental illness, that is, of going 'mad', as a counsellor explained:

> *"…they [families] have lack of understanding about what this condition is. To them it's like, ah, the patient has lost his or her mind. And I think there is a little stigma attached to it because once, when we reach a certain age they usually say that, 'Oh, you know, they're old. They've lost their mind.'"* *(I-26)*

Stigmatising terms for mental illness that also described how older people with signs of dementia could be perceived were '*lialia*' (iTaukei; mad), '*cavuka*' (iTaukei; disconnected) and '*pagala*' (Fijian Hindi; mad). '*Cavuka*' is an iTaukei concept whereby a person is said to be going crazy or their mind has suddenly snapped. The term is used as a figurative way to describe a person who is disconnected from reality and may be applied to anyone who is displaying signs of psychosis. A counsellor with personal experience of caring for a person living with dementia shared the response of community members towards older people with signs of dementia:

> *"They call them names. 'Lialia [mad].' 'Koya sa lia lia tiko [The person is going mad]'. 'O ko sa cavuka tiko [The person has snapped]', you know in Fijian, 'Cavuka'. 'Cavuka yalewa [cavuka woman], cavuka na tagane [cavuka man].' And they will literally say, 'Cavuka'. Cavuka means you have been disconnected somehow. Disconnection can also happen to women and also to elderly. And then they say 'O koya sa cavuka buti koya tuga. [The person cavuka. Just leave them].'"* (I-3)

The use of the term '*cavuka*', with its connotations of 'sudden' disconnection, possibly further demonstrates the high tolerance for forgetfulness and changed behaviours in older age and the crossing of a threshold to a realisation of something being wrong or 'off'.

7.5.1.3 *Having suspicious thoughts*

Curse and witchcraft are common explanations for strange behaviours, unexpected events and unwellness in Fiji, particularly in more rural village settings but also throughout urban areas. Unusual, disruptive or concerning behaviours observed in older people may be conceptualised within magico-religious beliefs, as a mental health nurse described:

> *"[They say] 'That's the devil inside. We have to warfare, pray over the person, or beat the person up' or something. So they don't only consider old age when the behaviour gets aggressive and the patient doesn't sleep, walks around all the time, looking. […] People will think that 'He's looking for that thing.' It's suspicious thoughts that come…"* (I-13)

Similarly, the behaviours of an older person showing signs of dementia could be explained by ancestral curse, connected with suspicion of performing witchcraft or being related to someone who was suspected of performing witchcraft. One co-researcher explained that older age could be seen to make a person more vulnerable to ancestral curse:

> *"The first thing that comes up is age. People say its age. He's old and, ah, now all this. Sometimes they would liken it to family curse and now all because of the age, now, there's more vulnerable layer, more vulnerable to all the curses of the family, some people come up with that."* (mental health nurse, I-19)

While a presentation of dementia in an older person was described as sometimes framed within magico-religious beliefs, these beliefs were thought by some co-researchers to apply more commonly when a younger person was observed as showing signs of dementia.

7.5.1.4 Noticing changes

Family caregivers talked about noticing changes in their loved one prior to a diagnosis of dementia. They talked about changes over a time period that ranged from one to three years and had an undefined beginning as evidenced by estimation references to 'years go by so fast, I don't know', 'started to' and 'about'. Family caregivers described their family member as having memory loss, getting mixed up with activities of daily living, pacing around the house, being grumpy (angry outbursts, aggression), having changed eating and sleeping habits, and going for long walks or trying to go home while already being at home. They described changed behaviours as increasing in type (e.g. forgetfulness, exploring, eating habits) and 'building up' over time, as well as decreasing (e.g. "she's not asking to go home anymore"). Family caregivers showed high levels of tolerance for these changes with monitoring sometimes occurring over a period of years or not occurring at all until the condition was in more advanced stages or a crisis event occurred (see Section 7.5.3).

> *"And even one day, we [mother who has dementia and co-researcher's sisters] were sitting. We were laughing, laughing. She was in the kitchen. She just turned around and said, suddenly she said, 'Eee, you people ever go and visit your people's Father's grave?' Wow, I could have… we all got a shock. And I said, 'Oh Ma, what you talking about? We have been.' 'No, you people think like this but you never go' […] That's when I know that she was getting a bit [purposeful gap]. But to think back now, that's how it started. But not, it wasn't that bad. I don't know what causes it. But I don't know, it just suddenly came up like that."* (daughter, I-37; the person living with dementia in this case was diagnosed after a crisis event occurred).

> *"Oh, they said, like, for example one 88 year old man, the wife and the daughter-in-law came to me and they were saying, my father-in-law, all of a sudden he started forgetting my family members."* (mental health nurse, I-21)

Service providers noticed cognitive decline and possible dementia amongst older people in their own communities, and during the course of their work where they interacted with community members, or patients they consulted for concerns relating to dementia and for other reasons. Service providers described older people living with dementia presenting at health services with the behaviours described above and also disorientation, paranoia and hallucinations. Service providers monitored people living with dementia and supported caregivers through review appointments at private general practices, the Special Outpatient Departments located at some hospitals and health centres, clinics through the stress management wards at some hospitals, through clinics provided at intervals through the community outreach mental health team or through domiciliary visits by mental health providers, as appropriate. Health professionals working in the mental health sector or possessing mental health qualifications are primarily involved in the monitoring and care management of people living with dementia. In contrast, health professionals in the general medical field may notice their older patients as being forgetful but may not investigate beyond the immediate reason for the patient's presentation. These health providers had very few experiences caring for people diagnosed with dementia. Monitoring of cognitive decline in such situations does not appear to regularly go beyond an assessment of a family's ability to manage the forgetfulness or behavioural changes (see Section 7.6.3.2; 'clinical inertia').

7.5.1.5 Perceiving 'serious'

Changed behaviours in older age are explicable within existing worldviews. In relation to perceptions of unwellness, they are therefore commonly *"missed"* (community service provider, I-5), *"watered down to be not so serious"* (counsellor, I-3) or dismissed completely by the general community, as a family caregiver said, *"It is just worry and nothing so serious"* (daughter-in-law, I-11). Some co-researchers explained that dementia, or signs of dementia, were expected in older people aged over 65 to 70 years: *"Io tau au vakabauta ni sa dodonu ga me tauvi ira na qase na mate oya, na guiguileca. [Yes my friend, I believe it is normal for an older age people to be forgetful]. The age, the older one, they should be like that because they were so old, now over here, 83, 84 and 86"* (CHW, I-23). Some co-researchers, in talking about community views of dementia, referred to expectations of forgetfulness in the oldest old: *"You know, [they will say] they're being, too old and that's why they're getting forgetful"* (mental health nurse, I-8). On the contrary, such changes in a younger person are seen to be an important issue.

There appears to be a siloing of mental health and physical health that pervades community attitudes and extends into the health system. In the community, this distinction is seen in the challenge of recognising an issue with wellbeing in the presence of apparent physical health. Family caregivers find it difficult to reconcile unwellness with the presence of good physical health:

> *Son: "We didn't really expect this to happen to her because she always so healthy and active, like the garden, boy, I would come when I was small…"*
>
> *Granddaughter: "She'll keep on working."*
>
> *Son: "…and the garden was just spot on because she's always outside, eh, like always physical, so we really didn't expect anything to happen to her."* (I-10)

Indeed, help seeking from health services for health issues of older people is usually for physical complaints. This siloing of mental and physical health is also seen in the stigmatisation of mental illness and mental health services by the community (see Section 7.6.2; 'facing stigma'), as articulated by a mental health nurse:

> *"[…] we notice that there's a bit more stigma towards this ah dementia and this things, rather than medical problems. Medical problems they are OK. They, like it's easy for the community to accept the medical problems but for problems like this it's a bit hard for them […]"* (I-21)

In the health system, this distinction manifests as clinical inertia towards cognitive decline of older people, particularly in the general health sector (see Section 7.6.3.2; 'clinical inertia'). In general, medical issues are more often recognised as 'serious' and treatable. On the other hand, the idea of mental illness is commonly dismissed or avoided promoting general unawareness of progressive cognitive decline in older people, or an unwillingness to confront mental illness as an important health issue (see Section 7.6; 'clinging to normal').

7.5.2 Exchanging knowledge (sub-category)

Families who become concerned about their older family member (that is, have exceeded a threshold) search for explanations through their knowledge networks. Knowledge networks include family, friends, neighbours, community members and the internet. Family caregivers draw on their own experiences and compare them with others to explain and understand the changes that they are observing in their older family member, as a son explained:

> *"Yeah you know the people get it when you grow old, they forget things, yeah. They keep on question, they keep on asking. Cause when, you know, talking with the family, you know, they say, 'Oh when she gets old, she'll have some [dementia], probably' and, 'Oh yeah,' but we didn't expect it to happen so fast to her.'"* (I-10)

This searching for meaning may continue even after a diagnosis of dementia: "*But ah, I have a grandmother, ah she was 93 years old but she did not have this problems. Yes. Yes. So this is like very new to me and yeah, it's really hard to tell what is, ah, it could, maybe it's not dementia or, maybe it could be something else"* (niece, I-14).

Caregivers may have an awareness of dementia through their knowledge networks and/or their professional lives however the level of awareness and knowledge is restricted by the opportunity to access information, education and experiences. Given the low awareness of dementia amongst the general community in Fiji, traditional knowledge networks (which form the main platform for knowledge exchange about health conditions) likely perpetuate existing conceptualisations of dementia and cognitive decline in older people. This idea is further supported in the positive effect of *"global influence"* (doctor, I-17) on help seeking for dementia in Fiji:

> *"So previously we were seeing lesser numbers. Now it's the relatives are living more abroad, they have better facilities to identify these illnesses in their own country, then they say, 'Oh, something is happening there too. So let's call and tell them to take them to the doctors.'"* (doctor, I-17)

Likewise, experience in the health sector promoted an awareness of dementia and health conditions in general, as a family caregiver said:

> *"Like for me, it was a reason why I took her [to the health centre] because I was working in this medical background, public health. So I tend to have exposure on literature and on mental health issues, I mean like some knowledge, ideas. So it sort of like, it gives me um opportunity to explore. But there are some other people who doesn't, doesn't know. We need a lot of awareness in this."* (son, I-4)

This awareness provided the impetus to search for information about dementia on the internet when he started noticing changes in his mother's behaviour. However, use of the internet for finding out about dementia is restricted to those with internet access and with knowledge to search for appropriate terms relating to dementia.

Service providers are valuable sources of health information in their communities. As community members with a role in the health sector, their presence in a community is recognised as a knowledge source and provides a connection with health services: *"…when I'm out there in the community and people who recognise me as a nurse from here, they would ask, 'Can I bring my mother over [to the mental health service]?' or 'my grandmother over?'"* (mental health nurse, I-6).

Furthermore, service providers notice that following visits to communities to raise awareness about health and health services they will receive information from community members about people in the community who may be experiencing the condition they have talked about, including dementia. There is a role for health providers in raising awareness of dementia and available support. Some health providers recognised their standing in the community and felt responsibility towards the community: *"… we are, like, health professionals. So we can start with awareness. We can educate and inform our families, our friends whom we know and they can pass on the information"* (doctor, I-25). However, formal circulation of information about dementia to community members through health service providers is affected by limited opportunities to provide community education and the low prioritisation of dementia for public health education. This is exacerbated in more rural settings that are relatively isolated from health services and other forms of communication, including access to the internet, and where visiting health teams are particularly important for exchanging knowledge about health.

Service providers are aware of dementia and can explain dementia in simple terms to a patient however confidence in talking about dementia is lacking, and there is some confusion about the use of dementia terminology. Moreover, particularly for health providers outside the area of mental health, an awareness of dementia as a health condition that could affect older people did not appear to be associated with a view of dementia as a 'serious' health condition. Service providers became aware of dementia during their undergraduate studies at university, caregiving training courses, workshops delivered by local health professionals, the WHO mhGap program and through self-directed learning using the internet. They often acknowledged that prior to this training, they shared community views around expectations of ageing. The experience of managing and caring for people living with dementia, and undertaking further studies in mental health promoted better understanding, as a mental health nurse explained:

> *"Dementia, like I learned in school what are the, the theory part I learned from school, but when I started doing the clinic here, then I came to realise. Like, I was able to relate that theory to the symptoms the patients were having. And that enhanced my knowledge, eh, like I was able to relate, like ah, this symptoms are related to this, this and that."* (I-21)

However, few people diagnosed with dementia attend services at health care centres and mental health clinics. Service providers in both the areas of general health and mental health recognised the need for more education and training on dementia and management of dementia for themselves.

7.5.3 Exceeding a threshold (sub-category)

At some point in time, family caregivers of people with possible dementia may exceed a threshold of concern for their older family member or they may exceed a threshold of tolerance for changed behaviours.

7.5.3.1 Accumulating changes

There may be a moment in time, or a collection of moments over time, which trigger a realisation that an older family member is unwell (also see Section 7.5.1.1). Changes in behaviour that are very uncharacteristic for a person, in particular changes in eating, sleeping, and hygiene habits, agitation, an inability to recognise family members, and walking off unexpectedly, are especially concerning.

> *[Forgetfulness is viewed as an issue] "When they (person with cognitive decline) start presenting those peculiar behaviours you know, ah, that was one of my cases, and we used to go and visit her at home. She used to lie down on the bed for whole day, and weeks she would never come out of the bed. She was able to walk and her daughter was always complaining that her Mum is not even doing her bath in the washroom. She used to go to the washroom to open her bowel. It was very difficult and after doing bowel in the washroom, she will just hold her business and roll, rub it on the walls."*
>
> (Nurse involved in aged care, P3; FG1)

Similarly, a service provider shared their personal experience of exceeding a threshold of concern for the wellness of their father-in-law who was eventually diagnosed with dementia:

> *"He'll forget his room in the middle of the night and he will end up in somebody else's room and you know, I think because I am a counsellor I would understand when he would go into my niece's room you know, just imagine if it happened to anybody who didn't understand. What it would have done to that old man, he would have been bashed up. But my nieces because they have, we have an understanding, I usually tell them like he's forgetting and people might think like he is lying. And we'll lead him back to the room. And sometimes you get a shock. He's curled up in somebody else's bed because not only my niece's, it's somebody else's bed, somebody else's room. So we realised that he was going through something that was more serious. And there was actually one time he left the house and he went to the back part of the house and slept there the whole night. And we looked all over the road. Couldn't find him. To me it was serious…"* (Counsellor, I-3)

7.5.3.2 Experiencing a crisis

A crisis event involving an older family member may also prompt or compel a family into action. Of the seven family units that shared their experiences, five families experienced a crisis event that led to their older family member being diagnosed with dementia. Two families experienced a crisis event that required immediate intervention from a health service; one family experienced a suicide attempt by their older family member, and an older person from another family was hit by a car while walking in their neighbourhood. In this latter case, a family member had previously sought help from health services for their older family member for memory concerns but this did not result in a diagnosis of dementia (see Section 7.6.3.2; ‘clinical inertia’). A further two families experienced an emergency situation that triggered help seeking from a health service; an older person in one family left the stove on and set the kitchen on fire compelling the family to act on their concerns that had been accumulating, and an older person in another family became increasingly aggressive prompting the family to call the police on one occasion, who then advised them to seek help from Saint Giles Hospital. Another family had noticed forgetfulness and changed behaviours over two or three years and sought help when there was an issue with constipation.

Co-researchers also described how misinterpretation of changed behaviours associated with dementia could cause misunderstanding and conflict resulting in the breakdown of family relationships, and exposing an older person to abuse and neglect: *“I mean chasing them out of the house, they either hit, they hit them because of all this, ah, odd behaviour […]”* (mental health nurse, I-27).   This could also result in shaming of the family as they tried to control disruptive behaviours in a manner that was viewed as unacceptable by the community (see Section 7.7; ‘having heart’):

> *“Like sometimes we get mixed pictures. One relative come and says something, another will come and say something, you know, ‘This one is being abused.’ The other one will say ‘No, no, no, it’s not abuse. It’s just that we held, because was not listening, so we had to grab and bring inside the house,’ or whatever, yeah.”* (doctor, I-17)

7.6 Clinging to normal

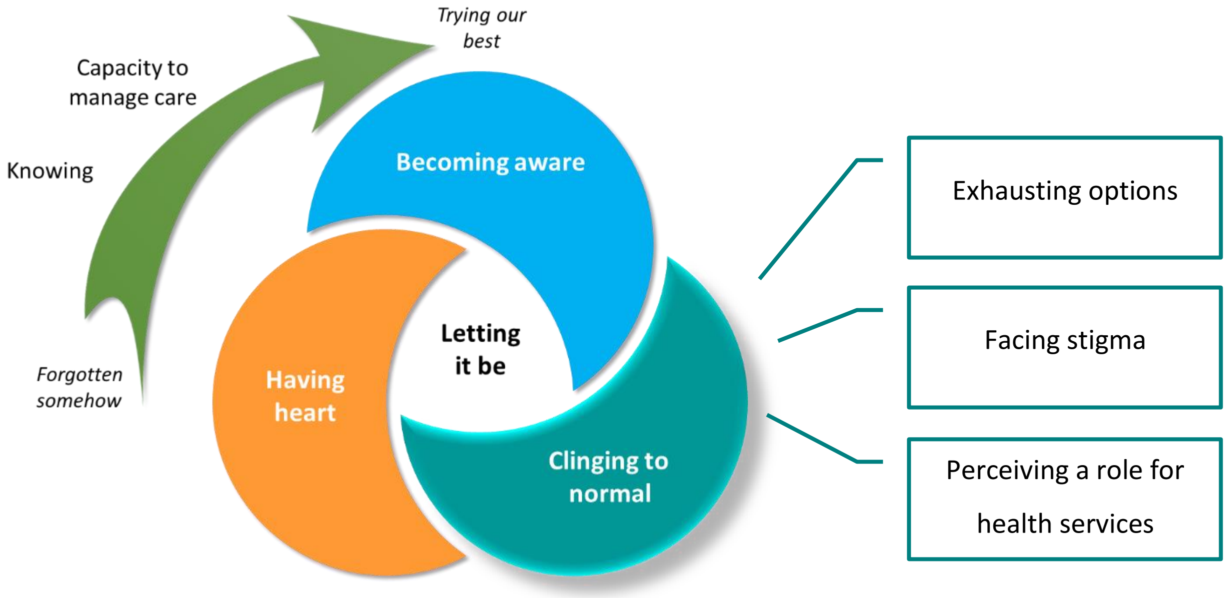

Figure 7.3. Diagram depicting the grounded theory showing the sub-categories for the main category ‘clinging to normal’.

7.6.1 Exhausting options (sub-category)

Fijians seek advice and support for concerns with an older person with cognitive decline from various sources. Because there is a high tolerance for changed behaviours in older age, help seeking usually occurs at more advanced stages of dementia when there is increasing disruption to the family or a crisis event has occurred. Causal beliefs associated with curse, witchcraft or problems with a person's faith prompt spiritual healing through prayer and ceremony. This may involve prayer at Hindi temples and Christian churches, performing traditional customs for forgiveness, and visiting with traditional healers, church leaders and church groups.

Son: *"Because they started doing all sort of ritual, like superstitious, traditional rituals. Like doing some form of ceremonial stuff just to really get the spirit, and also doing like um, 'Oh, it must be the curse from this,' and they started doing this traditional reconciliation type of things which has an added economic cost as well as by buying of whale tooth and other stuff, kava, and all that. Yeah, it sort of like, it's more ritual. And then they believe in also witchcraft. It also is a witchcraft thing and um they start, oh it must be this person here is doing witchcraft that's why he or she is being like this, yeah."*

Karen: *"OK, and so the reconciliation type rituals, is that like a religious…"*

Son: *"We call it iTaukei, bulubulu*[6]*. Yeah. Traditional way of seeking forgiveness and pardon and saying sorry, we are sorry for this here."*

Karen: *"Right. So it's sort of a Christian religious thing or ….?"*

Son: *"No. No, the Christian one is a bit different. But this is more using materialistic stuff like whale tooth, kerosene, food, groceries and all those and kava, it involves kava.* (I-4)

Belief in the power of spiritual healing continues after diagnosis. Families and the community continue to support their family member with their spiritual lives through visitations from church groups and prayer practices.

Son: *"Yeah but we always, I mean, spiritually we always, you know…"*
Granddaughter: *"Yeah we sort a lot of spiritual guide and spiritual help."*
Son: *"People come and pray for her, over her."*

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[6] Bulubulu involves the exchange of a whale tooth with the head of the family whose forgiveness is being sought. A whale tooth is a very expensive item and needs to be purchased if one is not already held by the family seeking forgiveness. Other items are also presented, often including yagona (otherwise known as kava) which forms an important part of traditional iTaukei ceremonies and is also shared routinely amongst family and friends of all ethnicities, across Fiji.

Granddaughter: *"Yeah, but other than that we just knew that we had to live with it."*
Son: *"Yeah, so it's, is a portion in life so… thank the Lord for her."*

(I-10)

Families also seek out traditional medicines: *"I mean, you know, is there any exercise or something that you especially can relieve with it or something? Is there a drink or something that people have? My sister was trying to give her, it didn't work, just tried to give her…….me gunu waiwai nacava tale…. [Drink oil and what else?]"* (son, I-10). Traditional medicines are commonly used to manage health conditions in Fiji and this is also applied for concerns with the health of older people. *"In Fiji, unfortunately, um, people believe a lot in herbal medications. And more often than not, we'll be seeing, and I'm going back to my experience in Ba, where I was a general practitioner, a lot of the times we'd be seeing patients quite late. Like, I would see patients with diabetic foot sepsis when the sepsis is already reaching their calf or their ankle. And they'll come in and say, 'Oh no, we were treating with herbal medication,' and when you tell them she needs an amputation, they'll be like 'No, no, no. We'll take home'. And they'll sign out against medical advice and bring in when the patients are septic"* (doctor, I-7).

Families may also seek help from health services. This tends to be a final option though not always. Service providers described families who seek help from health services in earlier stages of the condition as being attentive, educated and knowledgeable. However, early help seeking from health services may be hindered by clinical inertia and service providers' lack of knowledge and confidence in diagnosing dementia. A counsellor shared their personal experience in caring for an older person living with dementia:

> *"We would bring him [to a health service] for other problems. But there was never any point in time that dementia was mentioned. I actually learnt about dementia when I went to Australia to, I went on holiday for 3 months and I had to stay in a house with a friend of mine who was looking after two elderly people that had dementia. So that's how I learned. When I got back, he was with us. So they were the experiences that actually helped me."*
>
> (I-3)

In addition, in accessing health services, families also consider the potential extra burden that may be involved. This includes transport to the service for an initial consultation and subsequent review appointments, lost ability to work and earn money, other priorities such as raising children, available family support (to accompany an older person to the service), and the financial impacts associated with each of these. Family caregiver co-researchers needed to purchase incontinence pads and medications and some need to provide payment for caregivers/housekeepers. Service provider co-researchers commonly reported that financial capacity for many families was low and even travel to services was a major barrier for presenting at health services for any condition. These things all represent substantial barriers to help seeking from health services and contribute considerably to the preference to manage the care for older people with changed behaviours outside the formal health system, and within family and community networks.

Most commonly, help is only sought from mental health services when the condition of the older person has not improved and has become unmanageable, despite various attempts to reconcile the problem. Some families may be referred to mental health services by general health services or the police. Some families will present at mental health services when they perceive a mental illness: *"Because at first, before we talk to the patient, they just label as patient has gone mental. He's acting like this. He needs to do be admitted. Their first step they think is the patient should be admitted in a specialised unit like Saint Giles [Hospital]"* (mental health nurse -I21). This suggests that an acceptance of mental illness as the issue may be conducive of contact with mental health services but, more pertinently, reflects stigmatising attitudes that associate mental illness with institutionalisation. Stigma surrounding mental illness is a significant deterrent for families in accessing mental health services, as a mental health nurse described:

> *"It's just that stigma of going to the mental, of being referred to the mental hospital, that people just hold back and would rather just, especially when they're not disruptive. Usually the ones that present here are having, are becoming disruptive. They have become quite difficult to handle, and this is mostly the last resort. They've been to the pastor, they've been prayed upon, they've been to the herbal medicine, through all kinds of herbal medicine. And they've been through all kinds of healing that now that the client has gone a little worse, and has become a little disruptive, and doesn't sleep at night and disturbs them at night, that's when they do present here. At that stage."* (I-19)

7.6.2 Facing stigma (sub-category)

7.6.2.1 Mental illness

Mental illness is strongly stigmatised and poses a significant barrier to seeking help from mental health services. In particular, the institution of Saint Giles Hospital has come to represent the mental health system in Fiji. This was most clear in a description provided by a doctor of the high degree of stigma surrounding mental illness and Saint Giles Hospital:

> *"…so they wouldn't want to go to the psychiatric hospital cause of this, the biggest stigma in the country. Some even don't say St Giles hospital. They will say just, you know, the road, that road, Reservoir Road. The hospital in Reservoir Road. So much stigmatised that they'll just say the road."* (I-17)

A poignant example of deeply rooted stigmatisation of the institution of Saint Giles Hospital, and mental illness by association, can be seen in this story from a daughter of a person living with dementia:

> *"You know, the funny thing is when we first went to Saint Giles, you know Ma, it's, she looks, she saw Saint Giles. She said to me, 'Hey, why you bringing me here? I'm not mad!' I said 'Ma, you're not mad. This is where the old people they come and have check up.' […] Just imagine. Man, when I was telling my friend, they couldn't stop laughing. I said, 'Man, this old lady...' With her, like instant thing, she's perfect like that when she saw that sign, eh. Saint Giles yeah. But after that, no, yeah."* (I-37)

In more recent times, mental health services have become decentralised and are now available at various locations other than at Saint Giles Hospital. Co-researchers shared that there was low awareness of available mental health services and co-researchers working at these services also spoke of stigma as presenting a barrier to the use of their services. Stigmatising views of mental illness and mental health services are tied up in, and have been influenced by, the history of Saint Giles Hospital - the national asylum where people were committed and disconnected from their communities during colonial times.

Stigmatisation of mental health services was thought to be lessening in more recent times with co-researchers noting that services were getting busier:

> "*I remember when we used to get paid by cheque so on my pay cheque would be Saint Giles Hospital. And they'd look at me and they'd say, 'What are you? You're working there? Or are you a patient there?' [laughter amongst group] 'Is this cheque good?' [laughter amongst group] So the stigma back then was pretty big. Now we're getting a lot of people, first visits, people who are finally, you know, they want to access the system even for small things, eh."* (P2, mental health nurse; FG3)

There was a tangible pride amongst many mental health providers about their role in caring for people with mental illness, especially in the face of stigmatising views, as best represented in a reflection from a mental health nurse:

> *"I went for my stress, ah, the postgrad certificate in mental health. Like, it's like an added bonus to me so when I came back [to the mental health service], I started to, like, we always been labelled as we are from this [names mental health service] but it seems like we have a thick skin now. When they talk about our patients like we tend to fight because it seems to be they're the vulnerable ones and who else can defend for themselves, so that's why we are here. And we seem to know, like, their behaviour. Like we can really tell whether… to me [names the mental health service] has really helped me in terms of my*

> *relationship, in terms of even myself, to know myself better. I really, I'm proud to be a mental health nurse."* (P2; FG2)

Strong stigmatisation of mental illness and mental health services contributes to an unwillingness of lay community members to talk about mental illness:

> *"Cause you know, mental health issues, this are some of the things that people are so, you know, they are so closed up to, ah, they don't openly talk about until it becomes very obvious that they started, you know, being a problem in the community, in the society, then they started you know going around to look for help. […] Mental health issues, some of the topics, it's kind of like treated in our society like it's kind of taboo that we don't talk about because it brings you know, like ah, the impact of it is bad and people think that way."*
> (mental health nurse, I-2)

This negatively affects the ability to access information about mental health and dementia from formal health services. In terms of dementia, changed behaviours may be perceived as mental illness and families may seek to avoid the stigma (and thereby avoid the perceived threat of social disconnection from community) associated with using mental health services.

7.6.2.2 Being cursed

Older people with signs of dementia or diagnosed with dementia may also be blamed for their condition through attributions of magico-religious beliefs involving witchcraft, curse and ancestral curse. A mental health nurse shared an experience from a village setting:

> *"Then after a few days, then that old man was missing. He just came out of his house and he forgot to go back inside again at night so he walked on the road and went past two other villages. The last village, they found him and brought him back. And you know, this what they said, the village. You know, before, they were, the village was suspicious of them doing witchcraft. Because one of the child is um a bit, mild retard um, one died, the other one fell into the sea and was not found, and they connect all these things and this old man went to that stage of having dementia and that is what they were saying. To the stage that he was urinating in the house, bowel open everywhere in the house. And like no one was coming forward to look after him ey."* (I-18)

In such cases, a person is likely to be subjected to stigmatisation resulting in neglect and ridicule and is essentially disconnected from community life. Such cases were described by one co-researcher as uncommon in relation to older people but described by another as quite common:

> *"When we take trip to the communities, whether we in Lau or we've been to Koro, there is you know, every village there is someone. 'Oh who's that?' 'Oh leave him, he's like that, he*

> *can't, he's old. He can't remember.' And then, 'Shh, you know this people are the drunikau [witchcraft], the demon people, it comes from that family.'"* (counsellor, I-3)

Belief in curse and witchcraft is present in urban and rural settings, and there was some suggestion that these beliefs were more prevalent in the rural village setting - described by two co-researchers as part of the village 'mindset'.

7.6.3 Perceiving a role for health services (sub-category)

7.6.3.1 Possibilities of treatment

Perceiving a role for a health service involves a belief that there is a health issue, that the health issue is serious enough to justify a visit to a health service and is within the family's capacity, and that there is treatment that will improve or cure it. Expectations that normal ageing will include cognitive decline and dementia discourage help seeking from health services. There is no need to treat a natural part of ageing or an expected problem that comes with age, as a doctor explained:

> *"They just think they're getting old. And they think, the main thing I get is, 'Oh, it's probably old age', and they think old age has caused certain symptoms and they relate everything to old age. Like, 'He's just old now,' and then, 'Do you really need medication for this, it's just being old'. People do not believe that anything can be done."* (I-22)

Ageist views, whereby the wellbeing of an older person is ignored due to their being towards the end of their life, may also prevent contact with health services: "*With some [people], it's just, 'Oh, he's, she's old. Just let it be. And after that, ga*[7]*, she will just pass away'"* (aged care nurse, I-32).

The willingness and ability to manage care of older people at home also prevents help seeking from health services. There may be a lower threshold for help seeking from health services due to limited family support as family migrate away from Fiji. A doctor also noted that Fijians of Indian descent may have higher expectations of health services:

> "*I see that the Indo Fijian community has a lot of difficult[y] accepting, but I see that the iTaukei are very easy, they can accept easily. Yeah, that you know, such event has happened and nothing much could be done. Whereas the Indo Fijian community here expects a lot more to be done by the practitioner in terms of probably medications. So, and if they become unmanageable, could they be admitted to a facility where they could be, you know, helped and taken care of."* (I-27)

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[7] *'Ga'* is an adverb in the Fijian language that has various meanings depending on its use in a sentence. In this sentence, the term may equate with 'all the same'. The term is not always translatable to English.

The perceived effectiveness of treatment influences the use of health services. In visiting a health service, there is an expectation that there will be a medicine that will improve a condition: *"And they think that whenever you lose your minds, take them to that hospital. They're supposed to give some form of tablet and cure it"* (mental health nurse, I-19). Similarly, this is evidenced in the reason for visiting a mental health service by a family caregiver: *"So this friend of mine said, 'Why don't you take her to Saint Giles. They have pills.' And I did. I took her there and they check on her, they took her pressure. They explain you know what's happening to her. So they gave that pill. That pill it help her"* (I-37). Most of the family caregivers that participated in this study maintained contact with health services through clinic and domiciliary visits, with one family caregiver stating that: *"That is why we take him to Saint Giles, give the tablets and he's fine eh"* (I-11). The appropriateness of available medication for older people and the types of medicine available in Fiji for dementia was questioned by some service provider co-researchers. Antipsychotic medication, usually Haloperidol, was prescribed if needed. This medication was covered under the government pharmaceutical scheme at a certain dose. Donepezil was available only to those who could afford to pay for medication.

Family caregivers shared various management strategies as they adapted to changes over time ('trying our best'). Some family caregivers spoke of acting on changed behaviours by stopping their older family member from doing certain things in order to keep them safe and let them rest, for example, leaving the house, shopping and chores such as cleaning. They also reminded and re-oriented their older family member as needed, reassured them, and assisted them with daily activities. One family caregiver, who cared for their spouse and stayed in touch with me over a few months via email messages, shared their daily struggles and the various strategies that they would put in place to adapt to progressive changes in their family member's wellbeing. Moreover, there were examples in experiences that family caregivers shared that demonstrated a desire and ability to support the personhood of their older family member:

> *"Ma always invite Aunty Helen come up. She said, 'I like to see Aunty Helen,' so Aunty Helen come. She goes to her room, leave Aunty Helen in the sitting room. [laughing]. Oilei,[8] I tell you, this one here. I remember, 'Ma, Aunty Helen there.' 'Yeah, yeah, yeah.' She goes and lie down and leave her here."* (daughter, I-37)

These approaches, enacted in 'letting it be', are enough for some families to manage the care of their family member, precluding a perception that support from formal services is necessary. Certainly, some service provider co-researchers were confident that dementia was managed, or

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[8] *Oilei* is an expression of sadness or grief in the iTaukei Fijian language. It may also be used to express frustration in which case it is often used light heartedly.

could be managed, appropriately within family support networks. However, some family caregiver co-researchers shared that they had been forceful, though rarely, in managing their older family member:

> *"At times we feel anger. When she doesn't want to listen to us. Yeah, but it's just like a normal child, if the child doesn't listen you get frustrated and going to smack the child. I did smack her, like a child, like take her hand [demonstrating smack, smack on hand]. Naughty. The reason why I did it when she started eating her own poo. [Short silence]. And she was playing with her own poo. That's the time that we did that to her. And we made her clean it. And then she didn't repeat the same thing."* (source withheld for anonymity)

Service provider co-researchers also shared concerns that as a result of 'letting it be' there were undiagnosed cases of dementia in the community, and that some of these older people were ridiculed or neglected (they were 'forgotten somehow').

The value of non-pharmacological strategies for managing dementia care was evident in service providers' attitudes and was seen to enable families to continue to care for their older family members at home: *"I think it's 90% or 75% of the treatment is like the home care management, tender loving treatment from the relatives and from the loved ones who had this cases of dementia at home"* (mental health nurse, I-2). While medication to treat conditions was an important motivator for family caregivers to have contact with health services, the value of non-pharmacological approaches was appreciated by family caregivers and some family caregivers actively sought information and ideas about this from their health providers.

Maintaining contact with health services for support helped to build trust as family caregivers heeded advice about management and saw positive changes in their relationship with their family member who had dementia. A mental health nurse described her experience of providing domiciliary services to people living with dementia:

> *"Actually when they come to me the first time they are really, they are just fed up with them, they don't want to accept them, they just ask me to take him somewhere, 'because my family cannot accept, I have kids.' But when we, like for first visit it will be hard. When we go to the family, talk to them, it will be hard for them to accept but they start trusting us. Know, they have trust when we continuously go and visit them every month and then they notice that whatever we do to the patient, they notice changes in patient, so they do comment that, 'Man, when you people started coming, he's improving. Whatever you taught us we're doing and he's really improving. It's easy now to handle him.'"* (I-21)

However, service provider co-researchers shared that once families learn that dementia is a condition that progressively worsens and for which treatment will not cure, review appointments are perceived as futile and families may not return to health services.

7.6.3.2 Clinical inertia

Clinical inertia towards older people with cognitive decline and possible dementia occurs within the health system, particularly in the general health sector. This is evident in the prioritisation of medical problems when health professionals address only the presenting complaints, despite noticing possible problems with cognitive decline: *"… like chronic cases when they come with that, it's, we don't, like that is maybe secondary, maybe 4th, 5th thing down, 6, 7th down the line and then we you know diagnose. But we usually just diagnose you know, the thing they present with"* (nurse, I-28). A family caregiver sought help for his mother's memory concerns from a health centre however because blood results were normal further investigation did not occur. The mother was later involved in a car accident as a pedestrian and was taken to hospital. It wasn't until the family caregiver advocated for his mother to be reviewed by a mental health doctor that a diagnosis of dementia was made: *"…before she was discharged and everything, all the scan was done, then I mentioned it to her, 'Can you do a referral? Um, she forgotten her name. She forgotten where to stay. She forgotten to know that this is a road that's very dangerous.' And then they did a referral"* (son, I-4).

Possible explanations for clinical inertia were evident in co-researchers' experiences: (i) other health priorities from the viewpoint of the health system and presenting patient, coupled with time constraints; (ii) limited access to mental health expertise; (iii) lack of knowledge and confidence in diagnosing dementia; and, (iv) perceptions about treatment options including: the belief that an older person was being adequately cared for within the family; and, burdensome and long pathway to diagnosis for patients including travel to mental health services at main centres and delays in laboratory results. While care and support may be available for a person living with dementia within the family network, clinical inertia towards older people with cognitive decline prevents early diagnosis, and presents a missed opportunity to educate people living with dementia and families about dementia, care planning and care strategies.

7.6.3.3 Understanding

Co-researchers commonly suggested that raising awareness about dementia in the community would encourage understanding of symptoms of dementia in older people and thereby promote help seeking, and improved wellbeing of the person living with dementia and their family. Raising awareness within the health system and aged care system was also seen to be needed to encourage understanding of the condition and management strategies. Some co-researchers shared that in some institutions, care providers did not have adequate knowledge of dementia and care strategies, leading to people living with dementia being misunderstood and at risk of abuse. Service provider co-researchers commonly shared that training and education for service providers was needed, particularly as they reflected on their own experiences and training in dementia and dementia care.

Most family caregivers who shared their experiences lacked knowledge about dementia. However, they demonstrated an acceptance of unwellness whether perceived to be caused by dementia or other causal attributions that explained changed behaviours and facilitated supportive responses. Understanding the condition, and therefore the symptoms of dementia that frustrate families or cause mistrust and conflict, will help family members to further support their relationships and provide better care.

> *"Because I have seen when I, that maybe you know they get frustrated, you know, at home. 'Cause they stay full time with her and they understand …, but they really need to understand, cause we have explained to everyone at home, like, they have to keep reminding, don't ah scold her and things. Yeah, I think if we do that she'll be, she'll be OK."* (niece, I-14)

However, two family caregiver co-researchers (from different family units) encountered situations at health services where their concerns about their older family member were not understood. In the face of service providers' lack of knowledge about dementia and clinical inertia, family caregivers need to advocate for a diagnosis of dementia.

Service provider co-researchers actively involved in care for older people living with dementia frequently commented about the importance of providing psychoeducation to families to help them understand their role in care management. Service providers promote *'tender loving care'* and acceptance as the most important strategies for looking after family members with dementia. Information provided by health professionals and the internet are important sources of information about dementia and dementia care (see Section 7.5; 'becoming aware'). However, encouraging understanding of the condition is challenging for service providers when faced with families who are unwilling to accept the condition, particularly the idea that the condition will require ongoing care. Some co-researchers shared that the intense nature of care for dementia, requiring constant attention, was too much for some families and they would rather not understand how to manage the condition, as a mental health nurse shared, *"Oh yeah, so that's usually the challenge. To get them to accept that they need to change and not the client"* (I-19).

7.7 'Having heart'

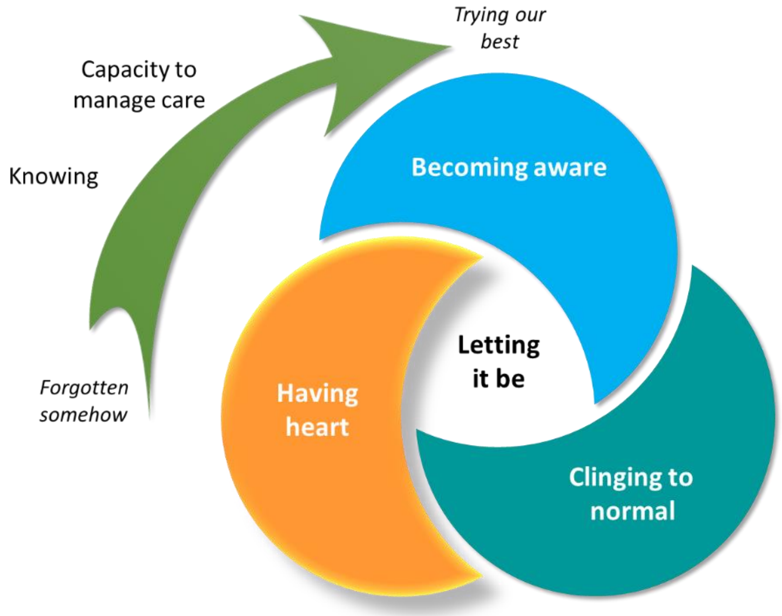

Figure 7.4. Diagram depicting the grounded theory.

7.7.1 Properties of 'having heart'

7.7.1.1 Care responsibilities

There is a strong preference in the Fijian community to care for older people within family and community networks. While there are differences in ways of caring reported by co-researchers, it would be presumptuous to assume that there is a clear delineation in care practices based on cultural group. The factors that influence how individuals define themselves in terms of culture must be complex with the two main cultural groups (iTaukei and Fijians of Indian descent) co-existing in Fiji since colonisation, with blending of cultures through marriage, friendship, business and politics. Certainly, there are differences in traditions and dialects within the iTaukei culture and a blending of Hindi to what is commonly referred to as Fiji Hindi. Moreover, in addition to the two main cultural groups in Fiji, there are also other cultural groups in Fiji including from other Pacific Island countries and Rotuma, China, Europe and America. The main point for this study is that Fijians tend to care for older people within their family and community networks, though how this care occurs may look different based on, for example, care responsibilities and cultural values. These points are important to bear in mind in the following descriptions of care for older people that co-researchers shared.

In the iTaukei culture, the preference to care for older people at home within family and community networks has deep roots in Fijian history and culture, and is captured in the iTaukei cultural concept, '*titoko*', that was described by a village elder co-researcher. In the village setting, when a person ‘gets to that stage’ in older age and is unable to do things for themselves, the *titoko* (a ‘walking stick and guide’) is called upon:

> *“[…] if it’s the father that is, you know, that is being affected with that, the male, the sons look after him. It’s the female, the mother, the grandmother, the daughters look after, you know. And I’ve seen a lot of responsibilities given to grandchildren to be their guide along, you know, where they go to the toilet or go and bath or what, you know, they just tag along with them and make sure that they are OK. Yeah. And the communities are also watching and you know, helping them along.”* *(*village elder, I-36)

The co-researcher who shared this knowledge was a *titoko* for their grandmother and emphasised being a *titoko* as an honour with strong connectedness between the *titoko* and older person, even extending past death.

Similarly, other co-researchers shared that caring for an older person in the iTaukei culture involved all the family: *“So they’ll just manage it [cognitive decline] at home because there’s a lot of people at home that, you know, look after them. Not only one person that looks after them. There’s like a whole family takes turn to look after them”* (nurse, I-28). In urban areas, older people with signs of dementia may be taken back to the village to be cared for by relatives in a safer environment:

> *“Even my Dad, he reached something like dementia. Yeah, I think he got to that stage, oh yeah, he wanders off at times and sometimes he, you know, even though it’s a hot day, he puts on 3 or 4 sets of clothes on [...]. Yeah, he started to roam, when I’m not at home, he roams around in town. And ah, when I get back, he’s back at home and I ask him, ‘Where have you been’. ‘Oh I was just walking down the road’. So it got to a stage where it was quite dangerous you know, because of the traffic and all that, so I have to take him to my sister in the village. And he was looked after well there.”* (village elder, I-36)

In a close knit village setting, such a person would be cared for by all the community: *“Even if one of them wanders around the village, at breakfast, any of the houses they will call, ‘Ey come and eat, come and have breakfast’. He’ll walk in. He wanders around at lunch, they’ll take him in to have lunch and dinner, so there’s no problem, he won’t go hungry”* (village elder, I-36).

The idea of sustaining connectedness with family and community into older age is evident in a tradition described as occurring in a rural island setting. In this setting, the family would build a separate house for a person with signs of dementia when they became too disruptive to live with the family. The family would provide food and water, and the older person would be left to their own devices: *“Instead of bringing them to the main, to the health facility, they think ‘Oh, it’s because he’s, she’s old, so let her stay there’. And they just go provide food, give them food, give them* *whatever they, and it will be totally up to the person, their behaviour, the thing for the day, it's all up to them"* (mental health nurse, I-27).

Fijians of Indian descent also practice traditional ways of caring for older people that are akin to those practiced in India. Care for older people remains within the extended family network and care responsibilities often fall to the son (and the daughter-in-law) who may have resided in the son's parent's home since marriage. Co-researchers shared that there was high immigration of younger generations of Fijians of Indian descent in recent times leaving fewer people available to provide care for an older person. This meant that there was a shift of responsibility for care and more older people living alone*:*

> *"Previously when we had a lot of extended family members living in Fiji then the relative who would get affected would be very well looked after. But now we see a lot of trend of children migrating, grandchildren migrating, you know, so the older relative is usually left mostly alone or with some caregivers, or with some relatives and if it's not your children, and it's some other relatives, then it becomes a little difficult for them to be cared for."*
>
> (doctor, I-17)

The value of family support in caring for a person living with dementia is clear, but for some, this support is inadequate or non-existent. Villages or settlements where people know each other well or are related, in particular in rural areas, tend to have supportive family networks. More urban areas are less likely to have supportive networks due to smaller family networks and family members being formally employed.

Some co-researchers shared that contemporary lifestyle was changing from earlier times and there were now more nuclear family units, increased busyness and a loosening of family and community bonds, with no change in expectations of family responsibilities – a feeling that:

> *"…it's not really like compared to the time that we had in the past where everything is just, like, everything is like slow. We can, ah, keep up with the standard, we can keep up with the changes in time. But now it's like everything are just going fast and you are kind of slow and unable to reach some of the, it's unreachable some of the expectations."*
>
> (mental health nurse, I-27)

Similarly, a doctor working in mental health shared their thoughts on the stresses of contemporary lifestyle in relation to delayed help seeking:

> *"Because now, like in the olden days, a lot of the times the males were working and the females would stay at home look after the males, families and stuff. And so, even if they act out, somebody was looking after them. Now everybody's working. No one's at home so*

> *the, those elderly at home, are supposed to be independent. If they're not independent, they're a burden. And so that's why a lot of, I feel, we're seeing a lot more patients with dementia than we used to. And the only time they come is because they become a burden. Rather than to help them. There are one or two who come in because family is worried. But not so much."* (doctor, I-7)

Due to their reliance on informal support from families and communities, the pressures of modern day lifestyle presents a serious challenge to families caring for a person living with dementia. The need or desire to work adds to the busyness of life leaving little time to care for older people.

In the case of inadequate or unavailable family support, families ask relatives to assist with care. Relatives may be brought from another town, village or settlement and some financial support is generally given:

> "*To them, when they are together in the family, to them it's not a hard work but you know somebody can do it, somebody can just takeover. Not just, you know, if they have people at home, the families, they'll find somebody to be, to look after this member of the family if they don't have anybody, they have to find somebody from the village or something to come."* (caregiver trainer, I-34)

A paid caregiver may be hired but this represents a significant expense for most families. In addition, some co-researchers suggested that qualified caregivers are difficult to find as they leave Fiji to work in other countries. House keepers are more often hired to help with care as they are more affordable and usually connected to the family already in some way.

Members of the community, including police and faith groups, play important roles in supporting dementia care (also see Section 7.5; 'becoming aware'). In particular, neighbours are sources of support for family caregivers and people living with dementia when family caregivers are unavailable. A mental health nurse shared a story of a school age grandchild who had little family support and was the primary carer for his grandfather, and who relied on his neighbour to watch for his grandfather while he attended school:

> *"In the morning he [the grandson] wake up early, get ready his siblings to go to school. Wake his grandfather, bath him. Bath him, prepare his breakfast, then after that, then he prepare himself. He'll cook, he'll take the food to the neighbour, for them to cook his lunch. And he'll lock the house. Lock the house and he'll put his grandfather outside on the verandah. And I ask him, 'How come you put your grandfather outside on the verandah and he can't walk out?' And he said, 'I use the rope. I rope the verandah all around, right up to reach the top of the rim on top so that when he walks around, he touch the rope, he*

> *knows he has to walk around in that area'. And then um, 'Do you have any bed?' 'Yeah, I put a bed outside. A plastic table and a plastic chair. The neighbour just bring his lunch, during the day, and I always put some changes there as well for them to change.'"* (I-18)

In the context of poor family support, community members are especially important sources of support. The boy's teachers were aware of his situation and supported his learning by preparing his notes and homework, and understanding if he was late for class.

Although the community and extended family have active roles and share responsibility for older people, most family caregivers who participated in this study conveyed a sense of aloneness. Family caregivers shared that family support could be low, particularly in relation to fewer visits from family and community members as people struggled to find ways to relate to the person living with dementia or were busy with their own lives. This idea is alluded to in a quote from a son and granddaughter who were caring for a loved one with dementia:

> *Son:* *"We're trying our best, we're trying our best."*
> *Granddaughter:* *"But yeah… it's an experience. It's a journey. "*
> *Son:* *"Yeah, only, only us would know eh. When people ask 'How is your mum and all?' Just really… hard work nearly every day. Just… yeah."* (I-10)

Within family units, the 'real' experience of dementia care is stressful. A son of a person living with dementia described receiving great support from his immediate family:

> *"First was my immediate family members. Those are the ones that gives me a rest in my heart. That is my own family members they're supportive, so why should I look for help outside when they're already giving their time."* (I-4)

This supports the idea that the experience of caring for a person living with dementia usually falls to a few devoted members of a family with other family and community members playing supportive roles but not intimately involved. Isolation from family and the community also occurred as social events were avoided to prevent disrupting the person living with dementia:

> *"…sometime you ask, you know, the Lord in hard times, eh. Why is this happening to her because we like to spend time, old age, talk to her, take her out and do all the good things to her. When she's like that is just stops everything man! We can't have fun with her or go to church. Even go to the family meetings. Oh, Okay, set. We just have to accept it and just. Yeah, so we just change our life style around… Funny thing… [sad tone]"* (son, I-10)

The need to be available to their family member meant that outings for family caregivers needed to be planned so that someone else could be at home, further adding to experiences of aloneness.

7.7.1.2 Community scrutiny

In rural and urban settings, scrutiny from the community is expected as care responsibilities extend to community members. Family caregivers strive to meet cultural and social expectations for care. However, the realities of care responsibilities in particularly demanding times, as with dementia, can be challenging for caregivers to negotiate. Caring for a person living with dementia could garner disapproval from community members as the heaviness of managing care increases. Family and community members may judge families as not meeting their cultural obligations in caring for their older family member. Judgements may be made about the family as they attempt to manage changed behaviours:

> *"In fact, um, we went through a lot of mental torture. Mental torture. Not really mental torture, but we'd been looked down by people. Because people, they believed Mum than us. That we are giving Mum a hard time smacking her. We are tying her up like animal just to confine her in the house and all. So people was like started like saying things to us. But that changed when they came over to see her and then it was totally different to when they hear it from outside. So when they come into the house and they see actually what is happening then they tend to understand the situation."* (son, I-4)

Furthermore, an awareness of the well-established role of community members in supporting another member could create feelings of worry about scrutiny from the community. A community group leader explained that caring for an older person with possible dementia could create fear of becoming a burden:

> *"…one of the lady in the village was saying, 'You know, I am just tired of people keep on coming back and said your father is here, your father is here, your father is here. I have to run around and it's like 24/7 I am just around, running around after my father. And like I know the community are looking at me too you know.' And this one said, 'She's worried about herself and she's worried about what the people are thinking because every now and then it's like, you know, and now we are like a burden to the community.'"* (I-5)

Abandonment of unwell people at mental health services and aged care homes is an unacceptable deviation from cultural values. Some co-researchers shared that families may expect that once admitted to an institution, their care responsibilities to a person with a mental illness or dementia are shifted to the health providers or aged care providers, and there was a risk that such people would be abandoned at services. It is common practice for family members to accompany an unwell person during their stay in hospital to assist them when there are few staff available. This often requires extended family members to be called upon to share in this responsibility but can be difficult to achieve. A family caregiver shared a difficult experience of when an older family member (now diagnosed with dementia) was admitted at a women's ward of a hospital:

> *"[…] she was seeing things, you know, the hospital and things, and all the patients. She woke up all the patients with her... she was really loud. Yeah. And then she, I wanted to go somewhere and I hid and then she said, 'I know he is here somewhere!' This was in the woman's ward, you know, I had to ask permission to look after her at night because nobody else was going to do it yeah, lack of resources, so I had to stay over there… yeah man. I had to try and get away… 'He's here somewhere I know,' and she was just mad today and I was really, really, you know, she was kind of… I had to really smack her on the [makes smack sound with hands] bum, you know, harder [makes smack sound with hands] on the hand or somewhere."* (source withheld to respect anonymity)

The responsibility of accompanying family members to hospital adds to negotiations that family caregivers engage with and are a sign for service providers of a 'good' family, as reflected in a comment from a mental health nurse: *"The case that I come across here, they, when they bring their relative, it's like a big relief to them, away from them, eh, away from home. Ah, some are very supportive, some we have to be running after them, eh, just to have a family conference or something. Planning their discharge planning, you know. Some, they just don't understand, eh. Depends, some are educated but still, ah, family members, eh. Those are, some do understand, very supportive. They'll get a relative to stay with them in the ward, assist us in the ward. Some just come and they just dump. So we do everything, get the patient ready, keep track […]. Some they just show up on the first day, for admission, and then we'll see them later when the patient is ready to go* (I-9).

Aged care homes are commonly viewed as places for neglected older people whose family no longer care about them. They were commonly described by co-researchers as somewhere to 'dump' an older person. A family placing an older person into an aged care home is socially stigmatised, particularly in the iTaukei culture:

> *Facilitator:* *"It's in the Fijian community here, the iTaukei, it's like a shame, like a shame if we children of the elders consider for us take our elderly to put in the home. It's like an embarrassing and shameful thing to do. Can you talk about that?"*
>
> *Village elder:* *"Yeah, it's not ah, it's well they say it's a kai valagi [European] way, you know, way of life, European way of life. Ah and we never, we don't take our elders to the old people's home. Yeah."* (I-36)

Placing an older person in an aged care home usually means that they will become socially disconnected from family and community, as an aged care provider (paid caregiver) described:

> *"Most of the dementia cases are missing their family. They, a moment comes in that time, that they want their grandchildren to come and see them, talk to them, sit with them. They want some like clothes and other stuff, they want it. So here, basically we can't be giving everything, since it's government generated eh. So it's hard, it's hard. Families need to come. They need family support too"* (I-31).

This caregiver and another aged care provider both talked about the way they enacted understanding and love towards residents in their care: *"My experience here like I'm telling you I've been working here for 10 years, eh, so what I only can do is just to love them all. Cause like here, old people's home, most of them are already…. left from the family. They came here. The […] love that the family are supposed to give it to them, so what I did, I just, what I always do from home […] I do love them all. So they can feel that they're at their own family, eh"* (I-30).

Service providers are wary of the potential to disconnect older people from their families and communities through hospital stays and aged care homes, as a mental health nurse explained:

> *"I'm not saying that we're going to entertain all these demented people, to bring their loved ones so that they can have the respite because even with the condition we have, ah, even with us, there's a lot of problem trying to reconnect them back to the community to their loved ones, eh, so that's why we have lots and lots of people are still resting here with us [at a health facility]."* (I-19)

However, the lack of respite, short term and long term care for older people living with dementia leaves family caregivers with very few options when they are no longer able to cope or manage the care of a person living with dementia. A family caregiver co-researcher shared that earlier in their experience of dementia her family advocated strongly for her father, who had advanced dementia, to be admitted at the local hospital for a long period of time. When I talked to her, her father had been back at home for some time and was now bedridden. Her mother was his primary caregiver and had given up her job, and she was now the primary source of income for the family.

7.8 The dementia care experience

7.8.1 Powers that influence the dementia care experience

'Knowing' and the 'capacity to manage care' are mechanisms that influence processes of the grounded theory to shape the dementia care experience. These causal mechanisms exert their influence in the health system and in the community (Figure 7.5).

Figure 7.5. ‘Knowing’ and the ‘capacity to manage care’ have the power to shape the dementia care experience.

As described through the grounded theory, ‘knowing’ (noun) is a mechanism that has causal powers and acts in certain conditions, on and through community members, family caregivers and service provider caregivers. Examples of each of the mechanisms that may be considered as under the umbrella of ‘knowing’ are described below:

(i) Social norms: Practices for caring for older people within family and community networks are ingrained within social values of Fijian society. Families learn about how to care for their older family members through the passing on of traditional knowledge from families and communities. This ‘knowing’, represented as social norms, informs expectations of care. ‘Knowing’ may be a causal power of strong family and community support for a person living with dementia in a close knit community. Alternatively, it may have little or no power when there are few people available to provide support for families, or it may be considered as a liability to families caring for an older family member who has dementia when it gives power to family and community members to judge them. Similarly, changed behaviours are considered to be an expected aspect of ageing, this is a known and accepted phenomenon: *"...the thoughts are that when we* *get old we will become forgetful. That's what they know"* (mental health nurse, I-13). Here, 'knowing' has the power to normalise changed behaviours for those people who are unaware of other possible explanations, causing a delay or preventing family members (and some health providers) from acknowledging changed behaviours as a serious issue.

(ii) Professional training: Health providers become aware of dementia during their studies to become health professionals. Before this, they often share community views about expectations of ageing. 'Knowing', generated through training, has the power to support health providers in providing dementia care in general health and mental health settings. Training in mental health creates expertise in managing dementia and works against clinical inertia. However, 'knowing' through training may have little power without supporting structures of policy and resources.

(iii) Experiences: Families talk about changed behaviours that they observe in older family members with friends, relatives and community members (including service providers who they recognise as knowledgeable and experienced in health matters). They share and compare their experiences. Individuals also draw on their own experiences and 'knowing' of dementia to inform decisions. The power of 'knowing' through experiences can generate awareness of an issue and inform decisions about help-seeking.

(iv) Awareness: 'Knowing' about available services and health issues, through sources such as health provider visits to communities, family and friends, and the internet, has the power to prompt help-seeking from health services for families who have the capacity and confidence to access such services. 'Knowing' may also have little power in connecting families with health services when financial capacity is low or family support is high.

(v) Stigma: Stigmatisation of people perceived to have mental illness or to be cursed, and their families, is a type of 'knowing' that pervades Fijian society. This 'knowing' has the power to facilitate access to mental health services for families who are aware of these services, or can be considered a liability by families who are living with a person with possible dementia through presenting an additional barrier to support from mental health services.

The mechanisms of the 'capacity to manage care' also have causal powers that act in certain conditions. Examples of each of the mechanisms of the 'capacity to manage care' are described below:

(i) Families and community support: Family and community support has the power to influence a family's 'capacity to manage care'. This mechanism has power to cause strong support when there are many family members living in a close knit community, particularly in more rural areas. Alternatively, this mechanism may cause low support for families with few relatives living nearby or available to help, particularly in more urban areas. The actions of this mechanism influences help-seeking behaviour.

(ii) Resources: Financial capacity has the power to influence the dementia care experience in a positive way through enablement of access to public and private health services, transport, medication and qualified caregivers or housekeepers. Availability of family members has the power to support people living with dementia to stay connected within family and community networks by enabling management of care outside the health and aged care sector. In the health sector, availability of mental health providers with expertise to assess lower priority patients has the power to facilitate more timely diagnosis.

(iii) Competing roles: Family members with multiple roles, for example roles as community members, family members and employees, have less capacity to manage care, in the absence of strong family and community support.

7.8.2 Layers of dementia care management

In relation to help-seeking for dementia care, this grounded theory about processes that caregivers use to manage the care of older people transverses three layers of dementia care management: (i) traditional care practices (described in the major category 'having heart'); (ii) knowledge and help seeking when there is an awareness of potential unwellness of an older person (the sociocultural construct 'letting it be'); and, (iii) contact with formal services including the health care sector where diagnosis of dementia may occur, and aged care homes (Figure 7.6).

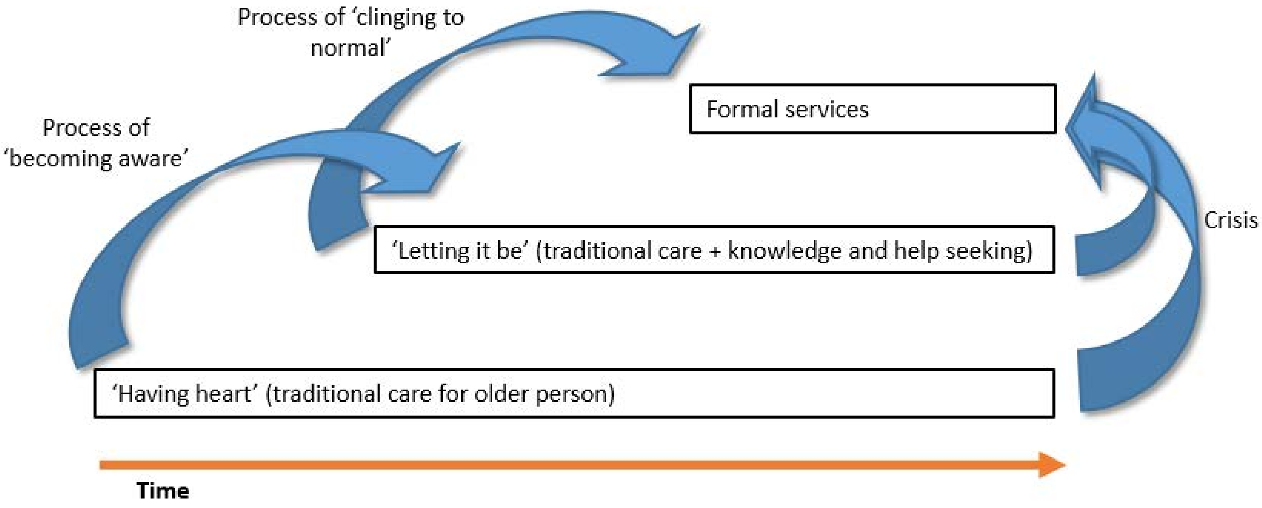

Figure 7.6. Layers of dementia care management.

Given the low awareness of dementia as an issue for older people amongst the lay public in Fiji, most community members begin at the base dementia care management strategy of 'having heart'. Movement from one layer to another occurs over time and is dependent on the processes of 'becoming aware' and 'clinging to normal'. These processes overlap in the temporal dimension. Crisis events may also force families into another layer of dementia care management. The pace with which a person with possible dementia reaches the health sector, and is diagnosed with dementia, is influenced by 'knowing' and the 'capacity to manage care'. Importantly, family caregivers/community members may remain in the base layer or may not proceed to management in the health care or aged care sector.

7.8.3 John's story

John's story can be used to illustrate how a family caregiver may move through the layers of dementia care management. John engaged with the process of 'becoming aware' when he noticed his mother forgetting his name and how to do things such as cook. He became acutely aware of a possible problem when his mother could not remember his name. John worked in the health sector (in a non-clinical role) and had an idea of biomedical causes of unwellness. John understood that a person's brain would start deteriorating with age and that this would variably affect people. He perceived the changes he was observing in his mother as serious, as he described:

> *"She was diagnosed with dementia in 2017 and prior to that we had few lead up episode like when she started forgetting things. Like whenever she does cooking she mistaken white sugar with salt, and then she mix up the spices together, um, with the Indian cooking, she always mix up this milo drink with the masala cause it's both brown. So we had that incident. And then*

> *ah one of the incident like we encountered was when she couldn't remember who I was. That was for the first time that I came to know this is not funny."*

John engaged with the process of 'clinging to normal' when he decided that there was a possible health problem that was serious enough to investigate at a health service. He accompanied his mother to their local health centre to discuss his concerns. A diagnosis of dementia was not made at this time as the blood tests conducted were normal. John's family believed that his mother's condition was associated with a curse. Her sisters had also gone *"through the same thing"*. The family went through the *bulubulu* ceremony to seek forgiveness and pardon for a perceived wrong. Over time, John's mother began to leave the house and she would walk around the neighbourhood, sometimes getting lost. She was hit by a car during her walk one day and entered the health sector again. During this admission, her injuries were addressed but no attention was given to possible dementia. John sought a referral to mental health services where his mother was diagnosed with dementia, as he described:

> *"Then, before she was discharged and everything, all the scan was done, then I mentioned it to her 'can you do a referral. Um, she forgotten her name. She forgotten where to stay. She forgotten to know that this is a road that's very dangerous.' And then they did a referral. We did ah, the stress ward. The first appointment was done at the stress ward."*

John's dementia care experience, as a family caregiver, could be described as in the dimension of 'trying our best' - the powers of 'knowing' and 'capacity to manage care' that influenced the dementia care experience supported him and his family in supporting his mother. John shared that he felt he had a head start on the pathway to a diagnosis of dementia. He worked in the health sector and was familiar with various aspects of health and wellness, and navigating the health system. He also knew people with medical knowledge who he could reach out to and he knew how to use the internet to investigate health concerns. John possessed the knowledge and confidence to advocate for his mother and because of this, his mother was able to access a diagnosis of dementia. John had the capacity to manage expenses related to caring for his mother including incontinence pads, medication and trips around town and to health services. He also had reliable family support and, after explaining his mother's condition on social media and asking his neighbours to look out for her, he also had the support of his neighbourhood (though this support took time to build).

7.9 Rationale for using an ecological perspective of health as a theoretical code

Grounded theory methodology may make use of theoretical codes (Section 5.7.6.5). In line with methodology described by Birks and Mills (2015), I have considered theoretical coding outside of the grounded theory to ensure that there is separation between integration of the grounded theory through a theoretical code, and the theory that is grounded in, and has been inductively derived from, primary empirical data.

The grounded theory describes a network of interlinking actors, processes and contexts that work to influence how people understand dementia and manage dementia care. An ecological approach is useful for understanding the relationships and influences of, and between, personal and contextual factors in health, and could therefore extend the explanatory power of the grounded theory. Bronfenbrenner (1977, 1981) identified four interconnected ecological environments that influence child development. Interactions and processes occur both within these environments, and across them. The microsystem is constituted by activities, roles and interpersonal relations that are experienced by a person in a particular setting. The mesosystem is “a system of microsystems” (Bronfenbrenner, 1981, p. 25) whereby activities, roles and interpersonal relations are experienced across settings. The exosystem environment consists of setting/s that impact on, or are impacted by, the events in a person’s setting. The exosystem exists without active participation of the person. Finally, the macrosystem refers to ‘consistencies’ (Bronfenbrenner, 1981, p. 26) such as culture, belief systems and underlying ideologies. McLeroy et al. (1988) proposed an ecological model for health promotion based on Bronfenbrenner’s model in which the determinants of health behaviour may be influenced by intrapersonal factors, interpersonal processes and primary groups, institutional factors, community factors and public policy. McLeroy et al. (1988, p. 355) describe each of the layers of influence as follows:

1. *Intrapersonal factors – characteristics of the individual such as knowledge, attitudes, behaviour, self-concept, skills, etc. This includes the developmental history of the individual.*
2. *Interpersonal processes and primary groups – formal and informal social network and social support systems, including the family, work group, and friendship networks.*
3. *Institutional factors – social institutions with organisational characteristics, and formal (and informal) rules and regulations for operation.*
4. *Community factors – relationships among organisations, institutions, and informal networks within defined boundaries.*
5. *Public policy – local, state, and national laws and policies.*

7.9.1 The underlying socio-ecological perspective

To demonstrate that a socio-ecological perspective could extend the grounded theory, I identified the factors that influence the management of dementia care (an aspect of health behaviour) present in the grounded theory, and related them to the layers of influence proposed by McLeroy et al.

(1988). Figure 7.7 depicts the socio-ecological model as a series of overlapping circles with the factors listed around the outside. I chose to represent the model in this way to highlight the idea of interactions and processes in one environment influencing and being influenced by those in another, or several other, layers of influence.

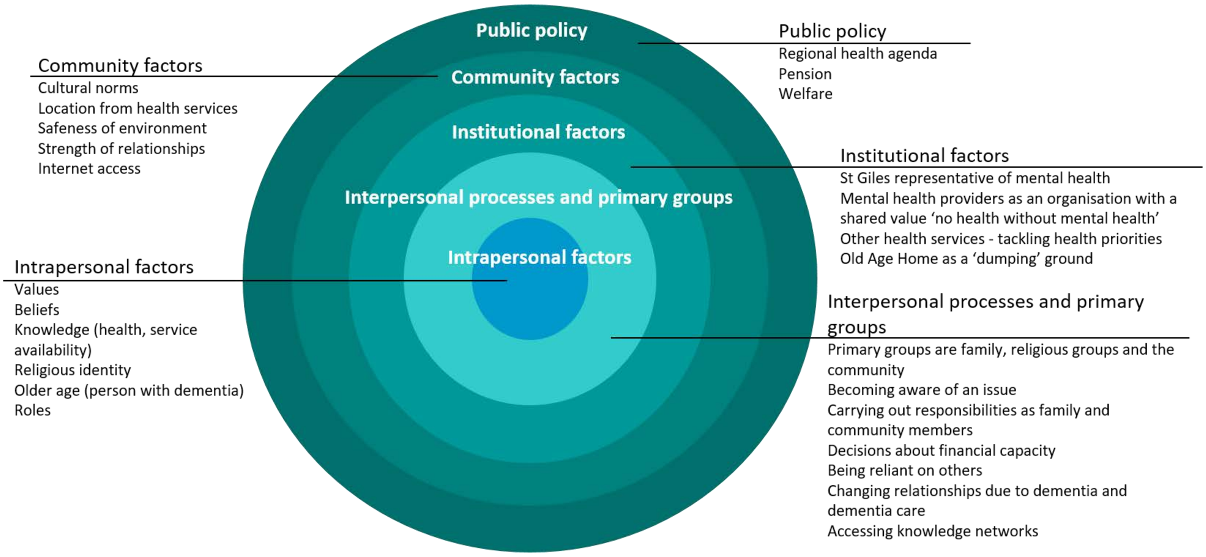

Figure 7.7. Factors influencing dementia care management in relation to cognitive decline and dementia that were identified through the research.

7.9.1.1 Intrapersonal factors

The intrapersonal factors that influence management of dementia care relate to a person's values about health and wellbeing (including spiritual wellbeing), and beliefs about what constitutes a health problem, particularly what constitutes a *'serious'* health problem. If physical health conditions such as diabetes or cardiovascular conditions are present, these may be considered more serious than issues with cognition. A mental health nurse explained how an older person diagnosed with dementia thought about his wellbeing: *"When we told him that he had dementia. He said, 'Oh fancy English. I only know that I forget my remember.' I'm OK"* (P2, FG3). Knowledge about dementia influences the ability to, and the timing of, identifying a problem with cognitive health. Knowledge and beliefs about the use of health services, including fear of stigma, are other intrapersonal factors that influence help seeking behaviour. Religious identity and cultural beliefs relating to the spiritual realm influence how family caregivers approach possible unwellness and dementia of an older person, by informing perceptions of spiritual wellbeing, causal attributions for unwellness and sources of help. Older people in Fiji have few social welfare supports that are independent of family (see Chapter Four). Older age therefore presents issues for people with possible cognitive decline and dementia as it increases their dependence on others to support them in their wellbeing, whether or not that includes seeking help from health services. Other physical health problems and decline in functioning linked with ageing also act to create dependence on others. For family members, roles as parents, offspring, grandchildren, employees and community members compete and influence, and are influenced by, other layers of the model.

It is important to note that I was unable to gather experiences and perceptions about dementia from people living with dementia. The intrapersonal factors identified could only be drawn from formal and informal caregivers' experiences and their accounts of cognitive decline and dementia. In the context of the ecological model, I have considered intrapersonal factors to refer to the dyad consisting of the person living with dementia and their family members. Certainly, from discussions with co-researchers and based on this research, the dyad, rather than the individual, is the effectual unit. That is not to say that the views of people living with dementia do not matter in the context of Fiji. Understanding the experience of older people living with dementia in Fiji, as they themselves describe and think about it, is pivotal in understanding how to support older people living with dementia in living well with dementia.

7.9.1.2 Interpersonal processes and primary groups

The primary groups that have strong influences on dementia care management are family, faith-based groups and the community. These groups influence management of dementia care through their strength and capacity to support family caregivers and family members with possible dementia, and through the creation of opportunities or barriers to help-seeking. For example, a person with possible dementia may interact with a family member in a way that is unexpected or out of character for them. This exchange initiates interpersonal processes that could involve monitoring of the person with possible dementia or restriction of their duties or movements, which in turn influences decisions about what to do next, if anything.

7.9.1.3 Institutional factors

There were three main institutions involved in dementia care: Saint Giles Hospital and mental health services, other health services and aged care homes. Saint Giles Hospital is representative of mental health in Fiji and is strongly stigmatised. However, mental health service provision is emerging as a proud institution espousing the value that 'there is no health without mental health'. 'Other health services' take their mission to tackle national health priorities for older people seriously, but to the detriment of cognitive decline in older people. Aged care homes are considered as a 'dumping ground' for older people – an outsider's way of managing the care of an older person.

7.9.1.4 Community factors

Community factors that influence dementia care management included cultural norms, the safeness of the environment for people living with dementia, the strength of relationships within a community and, structural factors such as location of communities (villages, settlements) from health services and access to the internet.

7.9.1.5 Public policy

Public health policy focuses on the regional health agenda, emphasising NCDs and mental health as priority health issues. Other policies that influence financial capacity, and therefore the degree of dependence that an older person has on their family, are pension and welfare schemes.

In undertaking this exercise of mapping the determinants of dementia care management to the ecological model, I have positioned an ecological perspective of health as an element that underlies the grounded theory. This perspective can be used as a theoretical code to extend the explanatory power of the grounded theory.

7.10 Chapter Seven summary

In this chapter I have:

- Presented a grounded theory about the processes that caregivers use to manage dementia care in Fiji.
- Described the layers of dementia care management that transverse the grounded theory and illustrated how family caregivers move between these layers within the grounded theory.
- Positioned a socio-ecological perspective of health as a theoretical code that extends the explanatory power of the grounded theory.

In the next chapter I will:

- Summarise the findings of the research
- Discuss the grounded theory from an ecological perspective using existing knowledge about Fiji and the Pacific Island countries.
- Discuss the strengths and limitations of my research.

8. Discussion

8.1 Chapter Eight outline

In this chapter, I summarise the grounded theory and extend its explanatory power by drawing on a socio-ecological perspective of health. I do this by reflecting on the processes and underlying mechanisms of the grounded theory and integrating them with existing knowledge in the literature about Fiji. I then integrate the findings from the different phases of the research and link the key findings with the international literature.

8.2 Summary of the grounded theory - 'letting it be'

8.2.1 Methods

The grounded theory was constructed through interpretation and synthesis of the views and experiences of family caregivers, service providers and community leaders on dementia. Eight family caregivers from seven family units, and one village elder, shared their perceptions and experiences of dementia with myself and my colleagues during face-to-face interactions in Fiji. One person living with dementia listened as their niece talked about their experiences of dementia, interjecting at times, usually to confirm what her niece was saying. A total of 40 service providers also discussed their understandings and experiences of dementia – sharing their views as both providers of services and as members of the community. The theory presented in Chapter Seven was constructed using grounded theory methods including open and focused coding, theoretical sampling and constant comparison whilst moving between the analysis and the data. I also drew on my notes, reflections and memos developed during field trips to Fiji and upon returning home. Importantly, my interpretations of the data are coloured by my own experiences and understandings of Fijian life and health related issues gained through my personal and familial connection with Fiji, and my life (personal and work) experiences as an Australian. My advisors (both Fijian and Australian) guided concept development through discussion of my interpretations at intervals during field trips and as the storyline developed.

8.2.2 Managing dementia care

The grounded theory describes a sociocultural construct, 'letting it be', as the central process in the management of dementia care. This process involves knowledge seeking and the application of traditional care practices within family and community networks. The construct, 'letting it be', is at the core of processes that caregivers in Fiji use to manage the care of older people living with dementia. It ties together the other categories of the theory, relating to cognitive ('becoming aware'), behavioural ('clinging to normal') and emotional ('having heart') processes of dementia care. The mechanism of ‘knowing’ manifests in several forms (social norms, professional training, experiences, awareness and stigma) and has power in certain conditions to influence processes of the grounded theory. The mechanisms of the ‘capacity to manage care’ (family and community support, and resources) also have causal power that is enacted in certain conditions. These mechanisms and processes come together to shape dementia care as experienced by family caregivers and service providers.

In relation to help-seeking, the processes of dementia care management can be conceptualised as traversing three layers of dementia care management. In the base layer, care for older people with cognitive decline occurs without conceptualisation of unwellness and is enacted within community norms of kinship responsibility for older members of the family and community.   In the middle layer, ‘letting it be’ is enacted and characterised by knowledge seeking and help seeking. In the top layer, health and aged care services are engaged in the care of a person living with dementia. Family caregivers move within and between layers as influenced by the mechanisms and processes of the grounded theory.

8.2.2.1 The process of ‘becoming aware’

In considering the wellness of older people with cognitive decline, family and service provider caregivers engage with a process of ‘becoming aware’. The process of ‘becoming aware’ may develop gradually over a period of time or abruptly due to a crisis event that requires intervention involving formal health services.   Caregivers notice changes in the behaviour of an older person and may monitor these changes over time. They draw on existing views to explain changes associated with cognitive decline observed in older people. Most commonly, dementia is conceptualised as normal ageing, promoting a general acceptance of deterioration of cognition in older age. Conceptualisations of dementia as mental illness, or connected with curse and witchcraft, is associated with stigmatising responses. Added to this, physical or medical issues are more commonly perceived as serious, in comparison to potential issues related to mental health. These phenomena contribute to a general unawareness of progressive cognitive decline in older people, or an unwillingness to confront mental illness as an important health issue. Caregivers may gain or have an awareness of dementia through their knowledge networks and/or their professional lives however the level of awareness is restricted by their access to information, education and experiences. A trigger event occurs during the process of ‘becoming aware’. This is a crisis event, or a single moment or collection of moments, that signals a deviation from wellness alerting caregivers to an issue. This awareness can feel sudden due to a high threshold of tolerance for changes in older age, such as forgetfulness, grumpiness or behaving immaturely.

Coming to a realisation of a potential issue with the wellness of an older person may prompt families to enact ‘letting it be’. They seek help and advice from their knowledge networks, traditional healers, church leaders and church groups. This may include accessing health services, though usually as a last resort and often prompted by a crisis event. Alternatively, families may take no action, increasing the risk of misunderstanding of symptoms of dementia and the possibility of conflict, and abuse or neglect of an older person. Becoming aware of an issue is not always connected with recognition of dementia as the causal issue, despite a diagnosis being made.

8.2.2.2 The process of ‘clinging to normal’

Throughout the dementia care experience, families and service providers engage in a process of ‘clinging to normal’.   Within this process, caregivers draw on the meaning of cognitive decline or dementia for them and their community to inform any actions they may take, with a visit to a health service usually the final option. Pluralistic help seeking behaviour that characterises care for people living with dementia and cognitive decline in Fiji ultimately results in presentation at health services and mental health services at more advanced stages of dementia: *“So it’s not that as soon as they see there’s signs of something wrong in the behaviour or anything that they reach us, but I’ve noticed they go to traditional healers, witchcraft, they go to other medical places and then they have, they come to know about this mental health very late, and then they come”* (mental health nurse, I-20). Families also cling to social norms in an effort to avoid the perceived threat of disconnection from community through stigmatising responses and social disconnection.

For family caregivers, perceiving a role for health services in dementia care and care for older people with cognitive decline is associated with the possibilities of treatment – the need for, and effectiveness of, treatment - particularly when care is considered to be well managed without health sector involvement. Family caregivers consider these possibilities together with their capacity to manage care within their resources. Clinical inertia at health services suggests that a role for health services for older people with cognitive decline or dementia is largely unrecognised by service providers, particularly for those providers outside the mental health services. Clinical inertia was described by Phillips et al. (2001) as the failure of health professionals to “initiate or intensify therapy when indicated” (p. 825). This concept has been associated with factors of insufficient consultation time, lack of education and patient factors (Byrnes, 2011).   Similarly, in the grounded theory, clinical inertia refers to the failure of health providers to initiate therapeutic management due to time constraints, competing priorities, lack of knowledge and confidence, judgements about adequate care provision in the home and access to expertise. Mental health providers promote the power of understanding the condition in facilitating the provision of dementia care through education for family caregivers. They encourage families to provide *‘tender loving care’* and accept people living with dementia thereby integrating traditional values of family responsibility with biomedical management.

8.2.2.3 The process of ‘having heart’

There is a strong preference in the Fijian community to care for older people within family and community networks, sustaining connectedness into older age. Throughout this category, and through the category ‘clinging to normal’, there is a sense of a need for understanding, love and compassion for people living with dementia that builds on strong traditional values of kinship responsibility and obligation, as also captured in the words of a mental health nurse: *“But, and I’m just hoping that everybody will have that same kind of feelings and thoughts you know, being a member of a family, a member of a community who contributes positively during their times of not being sick, then from there they can understand that there is a need to look after these people. You know, just to reward them on what they have contributed so far. And I’m just hoping that everybody have the same thought and have the same heart”* (I-27).

There is great strength in family and community networks for caring for older people with cognitive decline and dementia. However, the realities of care responsibilities in particularly demanding times, as is the case with dementia, can be challenging for caregivers to negotiate. Scrutiny from the community can threaten the informal care networks that family caregivers depend on for support and places high expectations on families. Caring for an older person living with dementia is a stressful and isolating experience with care falling primarily to the closest family members, and community and other family members offering more peripheral support. Moreover, values and needs have been changing over time with urban living and employment challenging priorities and commitments. The lack of appropriate services for respite, short term and long term care for older people living with dementia leaves family caregivers with very few options when they are no longer able to manage care.

8.3 Extending the grounded theory

In the next section, I seek to extend the explanatory power of the grounded theory. After identifying the main determinants of dementia care management in the grounded theory (Section 7.9), I take a closer look at slices of the ‘ecological pie’ (Figure 8.1). In doing this, I integrate the grounded theory with existing socio-ecological theory that posits that the outcomes of health and health behaviour are determined by interlinking and overlapping settings, processes and relationships (see Section 7.8.1). I draw on knowledge about health and caregiving that is available in the literature about Fiji.

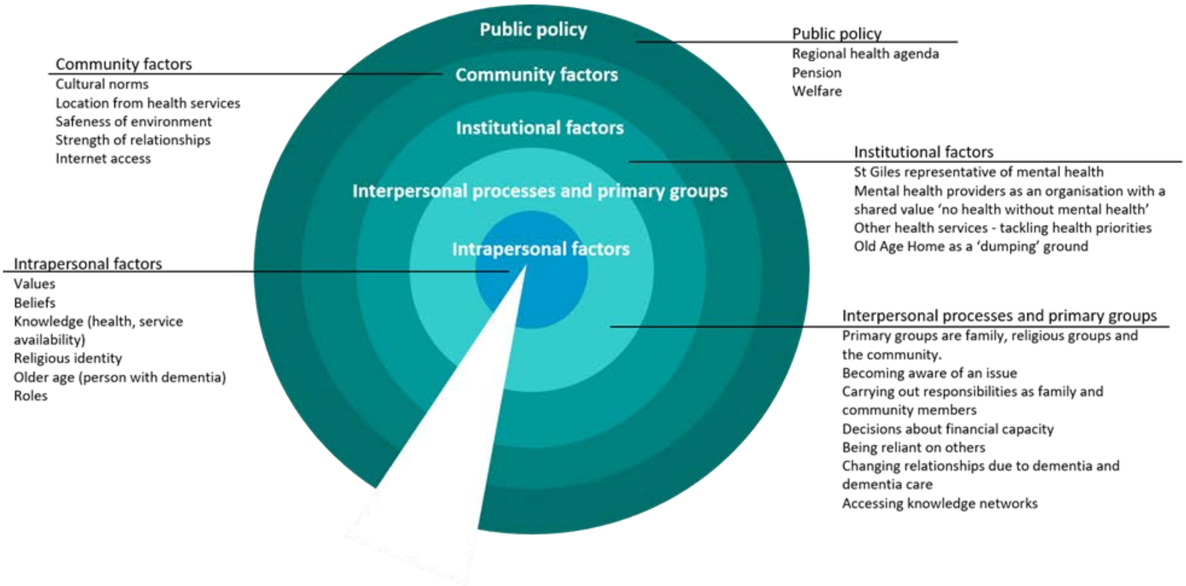

Figure 8.1. Diagram depicting my approach to integrating a socio-ecological perspective of health by taking slices of the 'ecological pie'.

8.4 A relational view of wellbeing

8.4.1 Ageing and wellbeing

While I was constructing the grounded theory, it became clear that the knowledge shared with me by co-researchers positioned older people in a dyad with their family members. This dyad is positioned as a component of a much larger structure with associated roles, responsibilities and expectations. I wanted to know more about how these relational aspects interacted to shape the dementia care experience. In this section, I extend the grounded theory by exploring a slice of the 'ecological pie' constituted of intrapersonal factors of older people and their family members, interpersonal processes and community factors (Figure 8.1).

The grounded theory describes dementia of older people as being experienced within the broader context of relationships with family and community. The most concerning features of dementia, which sparked help-seeking, were the forgetting of family members' names, and experiencing changed behaviours that disrupted family relationships and daily life. Dementia, commonly perceived without reference to biomedical systems of knowing, has sociocultural meaning. It is this that primarily shapes patterns of help-seeking.

8.4.1.1 Experiences of dementia are relational

Pacific Islander conceptualisations of wellbeing have been described as relational, being intertwined with interpersonal and sociocultural processes within the group self (Brison, 2001; Capstick et al., 2009; Groth-Marnat et al., 1996). Wellbeing in Fiji and the PICs is a notion that applies to individuals as members of a larger self, the extended family and community, that is understood within constructs of social order, spirituality, reciprocity and obligation (Capstick et al., 2009; Groth-Marnat et al., 1996; Ravuvu, 1983).

These views on health and wellbeing predominantly stem from the perspectives of indigenous Pacific Islanders. Such views of wellbeing have been described in depth in traditional iTaukei village settings and have deep roots in cultural meaning. Meo-Sewabu (2015) in her study of iTaukei women's views on health in a rural village in the Lau group of Fiji, found that health was defined in terms of women's capacity to be active participants in their community. Five cultural values contributed to wellbeing and failure to fulfil any of the values was associated with being "unhealthy or not fully achieving wellbeing in the village context" (Meo-Sewabu, 2015, p. 112). The values identified were *'dau veiqaravi'* (to be of service), *'taucoko ni qaravi itavi'* (completion and completeness of tasks), *'na veiwekani'* (maintaining harmony within relationships and family), *'kena i rairai'* (physical appearance) and *'bula vakayalo'* (spiritualty and outward reflection of happiness). Vudiniabola (2011) describes a health and wellness model relating to nursing care for iTaukei called *'vale ni bula'* (house of life; usually used in reference to the institution of the hospital). Vudiniabola (2011) uses the concept of a house to describe her theory. Identity is the central concept of the model and refers to the centrality of the '*vanua'* and spirituality, in reference to God or ancestry, in the Indigenous worldview. This is represented by the central beam of the house (the '*bou'*). The four posts (*'duru'*) of physical, spiritual, mental and socio-economic aspects of living emerge from, and support, the construct of identity thereby shaping an individual's status and roles, and thus their traditional obligations and responsibilities. Weakness in any of these aspects is identified as sickness. The four walls (*'lalaga'*) "represent the strength of relationships and responsibilities to families and community which provide protection from outside forces, evil spirits and a barrier to unwelcome intruders" (Vudiniabola, 2011, p. 248). These studies support the relational and spiritual view of wellbeing held by iTaukei Fijians throughout rural and urban Fiji.

Importantly, relationships, customs and traditions exist beyond the traditional iTaukei village, and apply within informal settlements and less rural villages. As iTaukei people have moved to urban areas, their ties with their village homes and cultural values move with them. For example McNamara and Henrich (2016), in their study of kinship structure in the Yasawas (a group of Fijian islands to the west of Viti Levu), explain that even those born in the city and who have never returned to the village of their heritage will still consider themselves as from a particular Yasawan village. Furthermore, Trnka (2004) described a settlement, that she later termed a *'gaon'* (Hindi for village) in line with residents' perceptions of their neighbourhood, on the outskirts of Suva. The *gaon* consisted of households of Fijians of Indian descent that practiced Hindu, Christianity or Islam, as well as iTaukei Christian households. Trnka (2004) describes the cohesiveness of the village as being "*created through every day acts"* (p.144). The community shared values and developed community obligations through participation in religious activities, neighbourhood events such as funerals, and through shared occupations, language and food. Likewise, Khan (2010) describes Jittu Estate, the oldest and largest informal settlement in Suva, as a place where one is *"…obligated to enter into a communal lifestyle which thrives on dependency relations with friends and neighbours in the community"* (p.77).

In the grounded theory, I describe relational experiences of dementia. I have drawn on similar concepts of community, and health and wellbeing that are described in research and commentary about Fiji in this section. It is clear that relational experiences are a central tenet of wellbeing in Fiji and a phenomenon that is shared across geographical and community settings. The centrality and strength of these views of wellbeing confers dementia with sociocultural meaning, shaping help seeking behaviour.

8.4.1.2 Sociocultural meaning, causal attributions and treatment options

The sociocultural meaning of dementia is also evident in Fijians' understandings of dementia which involved ageing, loneliness, mental illness and magico-religious beliefs (ageing will be discussed in Section 8.4.1.3 and 8.4.1.4). Illness, including mental illness, has long been associated with breaches of cultural values, witchcraft, being cursed or demon possession (Chang, 2011; Roberts et al., 2017). Groth-Marnat et al. (1996) explain that iTaukei *"…conceptions of illness are multi-layered in that they might simultaneously be punishment for wrongdoings, the result of a broken tabu*[9]*, the disturbance of sacred forces, or the result of altered physiological changes. It is commonly believed that individual health and illness are closely related to the overall sense of interpersonal harmony in the community"* (p.474). Roberts and others (2017) assert that both iTaukei and Fijians of Indian descent, while having their particular traditions, share belief in the power of prayer and the presence of supernatural powers that may be provoked to influence events in the real world. For instance, iTaukei concepts of witchcraft have been absorbed into the belief systems of Fijians of Indian descent (Roberts et al., 2017). Significantly, views regarding causal attributions of illness and treatment options vary across Fiji, intersecting rural and urban settings, younger and older generations, ethnic groups and occupation groups, for example (Aghanwa, 2004; Phillips, 2020).

Congruent with the grounded theory (Section 7.6.1), pluralistic approaches to treatment options (including spiritual healing, traditional medicine and biomedicine) for a variety of illnesses have been described in other studies (du Toit et al., 2006; Ho et al., 2018; Tomlinson, 2004). Phillips (2020) found that choices for treatment to manage diabetes reported by people living in Ovalau and the

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[9] Tabu implies a forbidden act, prohibition or sanction.

Suva-Nausori area were influenced by perceptions of causal attributions of the illness, perceptions of the safety and effectiveness of options, and importantly, also by accessibility to treatment options. Similarly, du Toit et al. (2006) reported that 82% (66/80) of rural residents would visit their local public health services for eye problems as they perceived this service to be easy to access.

8.4.1.3 Circumstances of the older person

Older people are traditionally well respected and continue to be part of their communities, attending family events and gatherings, ceremonial occasions, church services, group meetings and choir, village steering committees and village clan meetings (Seniloli & Tawake, 2015). They hold a place of honour within families and extended families however, for some, their dependence on family members places them at risk of poor wellbeing and mistreatment.

The ability of an older person to contribute to their families and communities has both real and perceived value (Panapasa, 2002). The majority of older people live in multigenerational homes, either as home owners supporting their children and grandchildren or as dependents living with children or other relatives (Seniloli & Tawake, 2014). A survey of 787 working people aged over 65 years found that 53.8% of participants lived with their spouse and at least one child, and a further 10.5% lived with their spouse and at least one child plus others (Seniloli & Tawake, 2016). Older people are often called upon to assist with household duties such as cleaning and caring for children, while those family members who can work support the household financially, in a reciprocal arrangement (Panapasa, 2002). Co-residency and having a form of disability increase with age (Seniloli & Tawake, 2014). Older people who are disabled are less likely to be able to reciprocate their care, and are at risk of being abandoned or mistreated, and more likely to live in poverty and alone (Panapasa, 2002). Widows in particular are at higher risk of vulnerability due to disability and poverty (Fiji Women's Rights Movement [FWRM], 2017; Panapasa, 2002).

Adding to this, older age is characterised by poverty and economic dependence with limited social welfare available and only a small proportion of the population are able to contribute to the FNPF during their working years (see Section 3.6). It is important to note that older people may continue to work and gain income, mostly in the informal sector, with those aged younger than 70 years more likely to be working (UNESCAP, 2016). Less capacity to contribute to household income threatens the status and position of an older person in a family, and financial decisions rest with working members of the household (Seniloli & Tawake, 2015). Financial capacity is an important consideration in accessing health services and medication. Seniloli and Tawake (2015) report that older people in rural areas and working in the informal sector tend to use traditional medicine for health conditions rather than medication because it is free, while older people who are working in the formal sector are likely to have health insurance and access medication through private pharmacies.

8.4.1.4 Circumstances of the older woman

Older women in Fiji have less economic capacity compared to men having earned and saved less during their lifetimes, particularly as the majority of women work in the informal sector, and due to their inability to secure an income into older age (FWRM, 2020; Seniloli & Tawake, 2015). The traditionally patriarchal society, that applies in both iTaukei and Fijians of Indian descent populations, sees women as 'homemakers' leaving them with less educational and work opportunities, few rights to land and at risk of poor living conditions (FWRM, 2017; Khan, 2010). This is slowly changing and there have been increases in women participating in the paid workforce and completing secondary education (Chattier, 2013; UNESCAP, 2016).

However, working women commonly continue with their cultural and religious roles and responsibilities (which include their place as the primary carer in the family) in addition to managing a working life. Meo-Sewabu (2016) stated that rural village life was becoming more individualistic, causing negative impacts on women's wellbeing as they failed to meet obligations and risked social disconnection from their families and communities. Similarly, Trnka (2004) reported that Hindu Fijians of Indian descent in a village experienced negative impacts on their health as they juggled paid work, household duties and contributing to religious activities. Such duty contributed to the wellbeing of their community by promoting peace ('*shānti'*) and happiness ('*khushi*'; Trnka, 2004). A study about perceptions of ageing for women in Fiji, published by the FWRM (2017), reported that family expectations for older women to continue to care for their family, financially or in a caring role, was perceived as a challenge to their wellbeing in older age. Women were concerned for their health as they aged including concerns about mobility, dementia and lifestyle related diseases. Moreover, women felt stigmatised in their communities due to their older age (FWRM, 2017). Given the status of the older woman, it is likely that the older woman with dementia is particularly at risk of poor wellbeing due to her lack of financial status, decreased ability to contribute to community activities of importance and decreased ability to perform duties for her family.

8.4.1.5 Circumstances of the family

The grounded theory described a change in culture and community values, with adverse impacts on the capacity of families to manage the care of an older person (Section 7.7). The following quotes build on this aspect:

> *"I can just, ah, tell from the experiences, eh, now, like even in our culture, like, ah, maybe because of all this new, this transition, the processes that everyone is going through, like it's*

> *kind of like a new thing to some. Like what we used to experience before, it's not happening now. Ah, like before we used to have this, you know, more closely ah knitted family where you know, where there is a strong bond between the family. Where there is, we, you know, we love one another, even to the extended family, we still have hearts for each other. But now we seem, maybe because of this, I don't know, I really I'm just assuming, maybe the new standard of living, the expectations and what they go through now that ah loosen up all this ah bond that we used to have before. We've seen there's a lot of changes."*
>
> (mental health nurse, I-27)

> *"The rise of individualism, where I entered a community culture and finding it hard to adjust to this change. It's a global cultural change […] but gets tricky as one tends to assume community support. And the public discourse keeps mentioning the sharing and caring value in Fijian culture and this is truly present but where it appears and is in action is the tricky part."*
>
> (family caregiver, I-35)

With a shift to a predominantly cash based society, the need for families to work to meet their expenses has seen younger people moving from rural areas to urban areas in search of work, and women entering the workforce (Panapasa, 2002). Added to this, Brison (2003) describes the Fijian identity as a negotiation of tradition and modernity (manifested as "increased flows of capital, commodities, ideologies and images"; p.355), experienced within local contexts. It can thus be construed that the Fijian identity is dynamic. In nurturing new identities, the demands of tradition (cultural obligations and responsibilities) may be at tension with commitments and values of a changing society. For example, '*sevusevu'* is an official welcoming ceremony that requires the presentation of handmade articles such as woven mats and the sharing of food, all of which are usually prepared by women. However, the burden of the ceremony has been recognised by the government of Fiji which has declared that *sevusevu* is not expected during official government visits (Meo-Sewabu, 2016).

Pacific Islander culture traditionally requires children to care for the wellbeing of their parents as they grow older (Seniloli & Tawake, 2016). However, working family members have care responsibilities towards their own children, as well as their parents and other older members of the extended family. The challenges of raising children have been found to affect the type of work that parents do, their career aspirations, hours of work and decisions about staying in the workforce (International Finance Corporation World Bank Group, 2019). Parents commonly turn to spouses, other family members or unqualified babysitters to care for children while they are at work (International Finance Corporation World Bank Group, 2019). For the majority of families, the wellbeing of younger members of the family and providing basic necessities for all family members is prioritised (neglecting the health needs of older family members; Seniloli & Tawake, 2015).

In participating in paid work, regardless of whether motivation is driven by a need to counter financial pressures or to nurture personal identity and aspirations, the availability of family members to provide care for older people can be low and even more so for older family members who require more attention due to disability or illness. Additionally, migration out of the country, and from rural to urban areas, leaves less extended family to share the care for older, dependent people (Seniloli & Tawake, 2014, 2015).

Yet families must find a way to support older members of their family, with little room to negotiate how they may do this within their ever-watching neighbourhoods and communities (see the grounded theory; Section 7.7.1.2). While usually a protective mechanism for ensuring the wellbeing of older people, social expectations surrounding ageing, care responsibilities and family support can be detrimental for families, particularly those with smaller, exhausted or fragile kinship networks. This has flow on effects for older people, particularly those with health needs such as dementia, who without adequate family support are at high risk of neglect and abandonment.

8.5 Actions of policy levers

8.5.1 Health priorities

I was interested in the power of public policy to influence other layers of the ecological model, particularly after a discussion with my Fiji-based advisor about reasons for the clinical inertia that we had described in the grounded theory. We discussed how a policy focus on NCDs and related activities has strongly influenced the clinical priorities of health service providers. This unintentionally gives rise to clinical inertia towards cognitive decline and dementia of older people, and low levels of dementia diagnoses. There are several health policies that guide the direction and focus of health service delivery. These include the national health strategy, NCD strategy and mental health strategies (Section 3.12). The need to address high morbidity and mortality due to NCDs in Fiji led to the development of the NCD Strategic Plan 2015-2019 (MHMS, 2014). This plan addresses objectives relating to diet, physical activity, obesity, diabetes, tobacco use, alcohol consumption, suicide, and violence and injuries. Actions are aimed at improving health behaviours, service provision across sectors and knowledge about the issues, and creating healthy settings. Activities include awareness campaigns, training for service providers, strengthening of programs, and creating or scaling-up services.

A lack of health policy with actions relating to dementia contributes to low awareness and knowledge of dementia, and late help-seeking from health services by families caring for relatives with dementia. Co-researchers in this study shared that awareness campaigns for the community and for health providers were effective, as a doctor described: *"Like we have community awareness with RHD [Rheumatic Heart Disease} and I have Mums bring their kids to say that, 'Hey look, my child, had this, this, this. Had joint pains and I heard about RHD, could you please have a listen to his heart'"* (I-22). Moreover, co-researchers reported that while attitudes in the health sector towards mental illness and provision of mental health services were becoming more positive, it was still perceived to be primarily the responsibility of mental health care professionals, as described by a doctor: *"…and so, if they're treated at a health centre, they'll be like, 'Oh, the patient is agitated and has no fever. Vitals are all stable. You know, this is your case.' And so they'll transfer over to us and we'll be like, 'Have you done any bloods? Have you done a septic screen, maybe she has a UTI [urinary tract infection]? Have you checked anything?' And a lot of the times they don't, and so we check it here"* (I-7). Certainly, co-researchers shared that mental health services were increasingly busy and that there were a lot of awareness raising activities going on for mental health, particularly about depression and suicide. Many co-researchers talked about the lack of awareness of dementia amongst the general community and the currently untapped value of awareness campaigns about dementia. This is important because, drawing on the ecological model in the Fijian context (Figure 8.1), awareness campaigns may foster understandings of dementia at intrapersonal, interpersonal, institutional and community level thereby having the potential to encourage support for people living with dementia and their families (WHO, 2017).

However, as highlighted in an evaluation of implementation of the WHO mhGAP in Fiji (see Section 6.3.2), a low proportion of non-specialist health providers participated in awareness raising activities and mental health screening (key activities of the mhGAP; Charlson et al., 2019). Charlson et al. (2019) associated a lack of priority for mental health activities amongst non-specialist health providers with time pressures, a lack of confidence and low prioritisation and commitment by organisations and their leaders towards mental health initiatives. Co-researchers in this grounded theory study talked about the way their work was defined by public health priorities, as described by a nurse: *"We are looking at NCDs, we are looking at CDs [Communicable Diseases]. We actually looking now, we are doing RHD, but none of us have actually asked about dementia. We, you know, I think that part of mental health is missing from public health" (I-29).* Service providers are acutely aware and prepared to treat and manage health conditions that they perceive as national priorities. However, the distribution of resources (including formation of new clinics for managing diabetes and training for service providers for instance) is influenced by national health priorities, having the effect of turning attention towards particular issues and population groups, and neglecting other health issues.

8.6 Summary of the scope of dementia and dementia care services

8.6.1 Scope of dementia

I analysed hospital admissions data for patients with a primary diagnosis of dementia between 2002 and early 2019. In-patient hospital services were accessed by 72 people with a primary diagnosis of dementia, the majority being aged over 60 years. These are very low numbers over a period of 16 years. Given the expectation of informal care networks for caring for older family members, and expectations of ageing as inclusive of symptoms of cognitive decline, these admissions likely represent the tip of the iceberg – that is, family crises whereby family members and their support networks are exhausted or a health crisis has occurred. Extremely low numbers of admissions probably represent both a high degree of under-diagnosis in the community and health system, and also a degree of clinical inertia whereby people who are diagnosed are not admitted or brought in for further treatment in the absence of a crisis. Despite this, these data indicate that dementia affects older people in Fijian communities and support to manage the condition is needed by rural and urban residents, regardless of ethnicity.

8.6.2 Dementia care services

I also conducted a mapping exercise of formal services and community services available in the public and private sector that could support people living with dementia, family caregivers and service providers. Through internet searches, discussions with Fijian stakeholders and field observations I found that there are no specialised dementia care services in the formal health sector or community sector in Fiji. Care for dementia occurs primarily within existing mental health services and to some extent within primary health care services, hospital in-patient services and residential aged care with services providers at these services having variable (usually lacking) expertise, experience, confidence and knowledge of dementia and dementia care.

8.7 Integration of key findings

Dementia has sociocultural meaning and is experienced within relational views of wellbeing – it is conceptualised within expectations of ageing and loneliness, ideas of mental illness and the stigmatisation of being ‘mad’, and magico-religious beliefs and the meaning of being cursed. Relational experiences also drive the recognition of dementia whereby, for example, unwellness is suddenly recognised when there is an uncharacteristic interaction with a family member such as the forgetting of a family caregiver’s name. Recognition of unwellness in an older family member initiates a process of ‘letting it be’, a sociocultural phenomenon involving traditional care practices, and knowledge and help seeking. Help-seeking for advice and support with cognitive decline and dementia is pluralistic, being driven by the sociocultural meanings associated with signs of dementia.

Help-seeking involves family and community knowledge networks, and therapeutic management through traditional medicine, spiritual healing and also health services (though less commonly).

The role for health services in cognitive decline and dementia in older people is unclear for both community members and service providers. There is an expectation that health services are for ‘serious’ problems for which there is therapy to improve or cure the problem. Problems with cognition are not ‘serious’. The use of health services for health problems related to signs of dementia is characterised by delayed presentation and often only in response to a crisis. Furthermore, few people living with dementia reportedly require in-patient hospital services for complaints directly related to a diagnosis of dementia, and of those who have needed these services, the majority are aged over 60 years. Given low awareness of dementia, high acceptance of cognitive decline in older age and social expectations to care for older people at home, these admissions likely represent the very tip of the iceberg in relation to families in crisis - where family members and their support networks no longer have the capacity to care for their family member, they are exhausted or a major health crisis has occurred. Furthermore, stigmatising attitudes towards mental illness and mental health services, low awareness of available services and when to use them, and limited health system and family resources add further barriers to support for dementia.

The vast majority of care for older people with cognitive decline or dementia is informal family care in the community, with intimate involvement in care from a small group of family members. While community members provide peripheral support to families caring for an older person with cognitive decline or dementia, community expectations (that direct care for older people living with dementia to occur within family and community networks) leave little room for families to negotiate how they may provide this care. Moreover, the realities of care responsibilities for an older person living with dementia, including financial strain and poor availability of family support, in the context of increased demands and commitments associated with a dynamic Fijian identity challenges the capacity of the informal care sector. Added to this, there is very little social welfare or social services available to support older people and families with caregiving roles.

Formal dementia care occurs primarily within mental health services and to some extent through primary health care services, hospital in-patient services and residential aged care. The process of health assessment in the clinical space is, in part, a balancing of judgements established in cultural and social norms, with competing priorities (patient, family and clinical priorities), inadequate knowledge and lacking confidence tipping clinical decisions in favour of clinical inertia towards people with cognitive decline or dementia (particularly in the general health sector). Mental health providers are typically most involved in formal dementia care for older people. They integrate traditional values of *'tender loving care'* with biomedical therapy by promoting understanding and acceptance of people diagnosed with dementia.

In conclusion, dementia in older people is an issue that is hidden from view by sociocultural meanings for cognitive decline; whereby perceptions of wellbeing centre on relational experiences and sociocultural understandings of cognitive decline and dementia. Strong values and expectations around caregiving also conceal the scale of cognitive decline and dementia affecting older people. Crucially, family and community support is strong but variable, depending on individual and family circumstances. There are a number of significant challenges that families and service providers face, combinations of which place older people living with dementia (particularly women and those with disabilities) at risk of poor health, neglect and abuse, and family caregivers at risk of poor wellbeing. These challenges fall in the areas of awareness and knowledge, health system responses and social support. In Chapter Nine, I will provide recommendations to address these challenges.

8.8 Summary of integration of key findings with the international literature

As outlined in the literature review in Chapter Four, conceptualisations of dementia are associated with ageing, mental illness, spiritual or magico-religious phenomena, or other social factors in LMICs and amongst indigenous populations (Johnston et al., 2020). Further studies published since the literature review was conducted, including findings from Fiji presented in this thesis, discuss similar conceptualisations of dementia that shape responses to dementia (Agyeman et al., 2019; Brooke & Ojo, 2020; Cox et al., 2019; Dudley, 2019; Jacklin & Walker, 2020; Musyimi et al., 2021). Underlying many of these accounts is the notion of the influences of history and place on understandings and experiences of dementia. Of particular importance, as foregrounded in the literature review (Johnston et al., 2020), culturally defined norms for caring for older people in Fiji motivate and compel processes of dementia care management, My research builds on existing knowledge by adding the voice of a small PIC; where views of wellbeing and dementia have embedded sociocultural origins and where contemporary realities of living with and caring for a family member with dementia challenges culturally ingrained values for caring.

Certainly, evidence about other LMICs and indigenous populations report challenges and enablers for fulfilling the traditional values of caregiving in modern society (Chan, 2011; Lanting et al., 2011; Ugargol et al., 2016). My research draws attention to the inadequacies of a health system with colonial origins in supporting older people living with dementia and family caregivers in Fiji. That is, the provision of health care informed by 'western' biomedical frameworks and the assumptions that accompany this, including biomedical definitions of unwellness and help-seeking pathways (see Section 9.3). These findings have important implications for awareness raising, education and training, models of health care delivery and social support which will be outlined further in Chapter Nine.

8.9 Strengths and limitations

8.9.1 Strengths

This is the first in-depth investigation of the understandings and experiences of dementia in Fiji and the first such study amongst the PICs (with small populations and constrained resources). The grounded theory, 'letting it be', was constructed using robust theoretically informed methods and analysis. The use of several sources of data and the inclusion of multiple stakeholders' perspectives and experiences allowed for a broad and deep exploration of the topic. Critically, the grounded theory had 'grab' in Fiji.

A strength of this research stems from my emic position as the granddaughter of a strong, Fijian woman who lived with dementia in her older age. Furthermore, my understanding of Fijian culture, gained through my active family ties to Fiji, my parents and my experiences of Fiji, have allowed me to engage with the knowledge shared with me at a meaningful level. Also, I was advised and guided by my Fiji-based advisor and cultural mentor which nurtured crucial contextual interpretations and understanding. Furthermore, preliminary findings were shared with co-researchers through personal communication during field work, through a newsletter (Appendix 16) and through a Zoom presentation for service providers throughout Fiji. The presentation was hosted by FNU and was well attended. A further strength of this research is that it was supported and guided by a mixture of advisors with backgrounds as leading health professionals and researchers in psychiatry, geriatrics and general practice, and an expert medical anthropologist, all of whose experiences coloured my exploration of the data.

8.9.2 Limitations

The voices of people living with dementia were largely missing from this research. One person living with dementia shared some experiences of living with their condition however this co-researcher mostly offered remarks confirming their niece's experiences and views on dementia. Thus, the processes of 'letting it be' are grounded in the experiences of dementia and dementia care as told by family caregivers and service providers. Another limitation is that during interviews, talking about dementia and undiagnosed dementia was inevitable. While this was challenging to navigate, I think that this ultimately inspired the construction of the processes of 'letting it be'.

A further limitation is that theoretical saturation was difficult to achieve. It was necessary to conduct concurrent data collection and analysis in cycles thereby limiting my ability to conduct theoretical sampling and affecting theoretical saturation of some concepts (also see Section 5.7.6.3).

Also, I think that my approach in constructing the grounded theory through a lens of ‘common ground’ was necessary given the broader, societal changes that were happening in Fiji at the time of my research. My intention in taking this approach was not to trivialise culture but rather to access the key factors that affect Fijians, all of whom live in a postcolonial world with only 50 years’ experience of finding out about who they are together. However, particular views of ageing and specific caring practices would expectedly vary across the diverse settings of Fiji and across cultural groups, and these nuances were not captured in my research. Another limitation is that the involvement of co-researchers in analysis was limited to discussions with my Fiji-based advisor, cultural mentor and ad-hoc with other service provider co-researchers during field trips. Notably, these people represented the stakeholder groups with the most experience in dementia care, aside from family caregivers. Finally, the limitations of the analysis of hospital admissions data are described in Chapter Six (Section 6.6).

8.10 Chapter Eight summary

In this chapter I have:

- Summarised the findings of each phase of the research.
- Extended the grounded theory by drawing on socio-ecological theory.
- Integrated the key findings of the phases of research, and integrated them with the international literature.
- Discussed the strengths and limitations of my research.

In the next chapter I will:

- Discuss the implications and recommendations stemming from my research for practice, policy and future research.

9. Implications & recommendations

When talking about things that might help with dementia and dementia care, service providers used the twelve words in the word cloud above most frequently. The context for these words is best seen in a reflection from a doctor: *"I think ah, maybe, training and education […]. To be able to better appreciate that we do have to deal with dementia and how we can better help them. And I think here the most important thing for them is their relatives. They come, like, it has to be like a partnership with their relatives."* (I-15)

9.1 Chapter Nine outline

In this chapter, I discuss the implications of my research for practice, policy and future research, and link these with recommendations for the future.

9.2 Implications and recommendations for practice, policy and further research

Implications and recommendations for practice

Dementia is an emerging health and social issue for older people, families, communities, and the health and social system in Fiji. Low awareness of dementia, high levels of acceptance for memory loss and changed behaviours in older age, and stigma surrounding mental illness and magico-religious beliefs, prevent older people and family members from accessing health services for support. Structural constraints associated with financial capacity, transport, time, service provider expertise and health system resources add barriers to health care access and provision. The findings of this research point to a critical need to plan for the future health needs of Fiji's older population and the families, communities, service providers and systems that will support them.

The rest of this chapter aims to answer the research question: How may knowledge and theory generated through this research benefit people living with dementia, caregivers, community and the Fijian health system? I discuss the implications and recommendations stemming from this research. The principal goals for dementia management are early diagnosis; optimisation of physical health, cognition, activity and wellbeing; management of changed behaviours; and long-term support for caregivers (Prince et al., 2009). These goals are used as a guiding framework.

Recommendation 1. Provide training for service providers to promote the integration of Fijian ways of supporting people living with dementia and family caregivers with evidence-based management

Throughout this research, family caregivers and service providers in health and social care expressed deep values for caring for older people, and older people living with dementia, within the family setting. Service providers require training and education in dementia so that they can build on the strength of families by facilitating families' understanding of dementia and dementia care. The concept of *'tender loving care'* sees service providers integrating Fijian values around care for older people with biomedical management (see Section 7.6.3.3).

1.1 Provide training and education for service providers

Levels of awareness and knowledge of dementia, and confidence in providing dementia care, were reportedly variable across health and aged care sectors in Fiji. Service providers commonly shared a desire for more training and education in dementia, and dementia care. They perceived that this would help them be aware of dementia as a possible health problem of older people and promote competence and confidence in recognising and managing dementia.

1.1.1 Training and education for service providers in the health sector

Training and education will promote and facilitate awareness, competence and confidence in the diagnosis and management of dementia care. Training and education are important for several reasons. Knowledge of dementia will reduce clinical inertia towards older people with cognitive decline or dementia. Cognitive decline may be explained by other health conditions that may be effectively treated to improve the wellbeing of an older person with cognitive decline. By reducing clinical inertia, the wellbeing of older people can be improved in a timely manner. Moreover, early detection of dementia promotes better outcomes for people living with dementia and their family members.

In addition, knowledge of dementia is associated with changing service providers' attitudes and more positive attitudes towards caring for people living with dementia (Schneider et al., 2020; Surr et al., 2016). Service providers most involved with providing dementia care in Fiji already display positive attitudes towards supporting family caregivers and encourage *'tender loving care'* through the provision of psychoeducation and sharing biomedical management strategies.

1.1.1.1 Provide training and education for professionals in the private and public sector and across disciplines, including doctors, nurses, zone nurses and qualified caregivers working in the areas of general health, general practice, mental health, emergency care and aged care. Training using online methods is highly acceptable in Fiji with service providers routinely using platforms such as Zoom during the COVID-19 pandemic. Development of training materials and conduct of training could be arranged in partnership with FNU and MHMS. The WHO POLHN has a role in providing health professionals, in Fiji and in other PICs, access to education about dementia. This network would be another important partner in this endeavour. Further partnership between the MHMS and MWCPA would facilitate education for providers working in aged care and in social welfare and provide a foundation for working together across sectors to improve and sustain the wellbeing of older people. Collaboration with local and international universities and dementia organisations, such as Dementia Australia and Dementia New Zealand would provide a platform for two-way learning about dementia care and management.

1.1.1.2 Effective training and education will comprise of learning in the areas of recognition of dementia, dementia care management including non-pharmacological and pharmacological interventions, diagnosis of dementia including disclosing a diagnosis, communication and planning for the future. It is also imperative to incorporate learning about context specific factors in particular lay community understandings of dementia, attitudes towards older people living with dementia, social norms for caring for an older person, pathways for dementia care and family caregiver support including learning about coping with dementia and available resources and services for further support.

1.2 Education for other service providers

Family members accessed their informal networks for advice, support and help about their concerns for an older relative. Informal networks included health service providers (in their role as community members), local police and religious establishments. In addition, educators involved in training qualified caregivers, providers of community services, community leaders and CHW/VHW are also well placed to support community members. Education in the recognition of dementia in older people, appropriately adapted for each of these groups, could reduce delays in help seeking from health services by reducing stigma and increasing awareness of available support. Earlier help seeking from health services can rule out other causes of signs and symptoms and determine a diagnosis of dementia, leading to earlier management of the condition.

1.2.1 Provide education for service providers outside the health and aged care sectors, including; police officers, religious leaders, community leaders, qualified caregiver trainers, community service providers, CHWs/VHWs. This education could be delivered through an online course as described in Recommendation 1.

1.2.2 Education that would equip providers in these groups with the knowledge to refer community members to health services requires learning in the area of recognition of signs and symptoms of dementia and available health services.

Recommendation 2. Strengthen health system responses

2.1 Strengthen diagnostic and referral pathways

Undiagnosed dementia places an older person at risk of poor wellbeing associated with factors such as changed ability to manage medication, finances and relationships, and emotional, physical and financial abuse. In Fiji, co-researchers reported that undiagnosed dementia was a problem in the community. Indeed, family caregiver co-researchers sought help from health services at more advanced stages of dementia. The issue was primarily brought about by: social norms associated with ageing and caring for older people that prevent recognition of dementia; beliefs around wellbeing and help-seeking; limited family and health system resources, and clinical inertia towards older people with cognitive decline.

2.1.1 Increase health providers’ confidence in recognising and diagnosing dementia.

This will increase the timeliness of provisional diagnosis providing people living with dementia and families with appropriate care sooner. Certainly, low recognition of dementia in PHC occurs in other settings (Bradley et al., 2020). Importantly, there is good quality evidence that education for general practitioners increases recognition of potential dementia (Mukadam et al., 2015). As part of this, knowledge and confidence in using referral pathways will also increase.

2.1.3 Investigate the potential role for CHWs/VHWs in identifying undiagnosed dementia.

CHWs/VHWs who work closely with community members are well placed to refer people with possible dementia to nursing stations starting them on the pathway to a diagnosis (see Box 9.1).

2.1.4 Develop a standardised culturally-adapted cognitive assessment tool.

This will provide more accurate diagnosis and provide doctors with confidence in their assessment. Box 9.2 describes a validated cognitive assessment tool for use with Australian Aboriginal peoples and Torres Strait Islanders and another tool for use with Fijians of Indian descent living in New Zealand.

Box 9.1. CHWs have a role in identifying dementia in some LMICs.

Studies from LMICs indicate that CHWs trained in identification of dementia in community dwellers have been successful at identifying dementia (Ramos-Cerqueira et al., 2005; Shaji et al., 2002). Although associated with a high false positive rate, the majority of conditions identified that were not diagnosed as dementia by a psychiatrist were other psychiatric conditions (Shaji et al., 2002). Ferri and Jacob (2017) suggest that a tiered system for referral through the health system improves the effectiveness of this strategy.

Box 9.2. A culturally-adapted cognitive assessment tool can facilitate accurate diagnosis of cognitive impairment and dementia.

The Kimberly Indigenous Cognitive Assessment (KICA) tool was developed because existing cognitive screening tools were found to be culturally inappropriate for use with Australian Aboriginal and Torres Strait Islander people. The culturally sensitive tool was adapted from existing assessment instruments through consultation with linguists, health providers and Indigenous Elders (LoGiudice et al., 2006). It facilitates systematic collection of client information and carer reports and assesses memory, comprehension and language abilities. It also includes a simple assessment of executive function. The KICA has been validated in Australian Indigenous communities and is reported to be accurate for diagnosing dementia affecting Australian Indigenous people (Dyer et al., 2017). It is also highly acceptable for health providers, community members and families (Marsh et al., n.d.).

The 10/66 dementia protocol is another instrument that aims to overcome the influences of literacy and culture on dementia assessment scores. The tool has been adapted for use with Fijians of Indian descent living in New Zealand through translation processes involving bicultural translators who were fluent in English, Hindi and Fiji Hindi (Martinez-Ruiz et al., 2021). A small scale validity study has found that the adapted tool has sufficient diagnostic accuracy and has potential for use with Fijians of Indian descent living in New Zealand and Fiji (Martinez-Ruiz et al., 2021).

2.2 Strengthen post-diagnostic care for older people living with dementia

Once an older person has been diagnosed with dementia, review appointments become a crucial aspect of their continuing care. Review appointments are important because the needs of people living with dementia change over time. Importantly, they may develop other health complications that can be managed effectively. PHC delivered through health centres and private general practice is well placed to provide the ongoing care of older people living with dementia and their family members. Continued monitoring of people living with dementia is also essential for supporting palliative care.

Family caregivers and service providers reported that it was challenging for people living with dementia and their families to attend review appointments. Logistical issues related to attending clinics included time constraints, other commitments such as attending work, lack of availability of someone to accompany a person living with dementia and transport to clinics including the financial capacity to pay for transport. Domiciliary services are provided by district nurses, zone nurses and mental health nurses who work out of some health centres and hospitals. Additionally, the community mental health team also provides outreach clinics in various locations at regular intervals. This network of services is vital in the provision of continuous, accessible care and effective management of dementia care involves continued fostering of these services.

Education for family caregivers is another crucial aspect of post-diagnostic care. Family caregivers actively sought out information about dementia and management of care for people living with dementia. Service providers provided such education to family caregivers however access to this information is reliant on attendance at review appointments or service provider visits to the family home. It is important to increase family caregivers' access to contextually relevant information about dementia care.

2.2.1 Promote the role of PHC in dementia care.

Raising the awareness amongst service providers and in the community of the role of PHC in supporting people living with dementia will increase access to services. This needs to be accompanied by training and education for PHC providers.

2.2.2 Continue to nurture outreach services.

In addition to current outreach services, district and zone nurses involved in public health activities and domiciliary services are well placed to both identify issues with wellbeing of older people and provide education.

2.2.3 Improve family caregivers' access to contextually relevant information about dementia.

The WHO iSupport for Dementia education package is a course for informal caregivers involved in the care of people living with dementia. It has been successfully adapted for use in other countries (Pot et al., 2019). The course can be delivered online or as a hard copy manual meaning that it presents an excellent opportunity to provide culturally appropriate, highly accessible and comprehensive education for family caregivers in Fiji.

Recommendation 3. Foster a multi-sectoral approach to dementia care

3.1 Draw on the expertise of all stakeholder groups

There is an absence of specialised services to support older people, particularly older people living with dementia and their families. This absence of specialised support is exacerbated by inequitable access to health and aged care services due to a geographically distributed population and high levels of poverty. Dementia in older people is a topic that crosses sectors requiring expertise in aged care, mental health including counselling, preventative and continuing health care, along with support from social welfare, police and religious groups. It also requires heavy involvement from family caregivers, particularly in Fiji's context where families form the foundation of care for people living with dementia.

3.1.1 Foster a professional network focused on issues for the care of older people more broadly, and people living with dementia, to support development of local and national solutions to strengthen dementia care.

3.1.2 Develop local service provider and community networks to create community-based support groups.

3.2 Form cross-country partnerships

The PICs will all need to address issues associated with an older population in the near future. While each PIC has their own unique culture they share a setting of constrained resources, small populations, issues with the emigration of the working age population, and spiritual and relational views of wellbeing. There is opportunity to build on the strengths of PICs that can be identified through cross-country partnerships and mentoring. In addition, Australia and New Zealand (Fiji's neighbours in the Pacific region) have national dementia organisations and institutions with expertise in dementia and ageing. Of note, there is now research being conducted with Torres Strait islanders living in the Torres Strait region of Australia, and with Māori people and Pacific Islander people living in New Zealand. In particular, a research group in New Zealand have adapted the 10/66 cognitive assessment tool and evaluated its use for Fijians of Indian descent living in New Zealand (Box 9.2; Martinez-Ruiz et al., 2021). Partnership and collaboration with the institutions conducting this work could be valuable for all.

<u>Implications and recommendations for policy</u>

Recommendation 4. Raise awareness of dementia

4.1 Raise awareness of dementia amongst the community, service providers and policy makers with a focus on Fijian ways of knowing and Fijian knowledge

Health providers involved in caring for people living with dementia and their families felt strongly that raising awareness of dementia in the general community and amongst service providers possibly involved in dementia care, would reduce stigma, improve attitudes towards people living with dementia and their families, and reduce delays in help-seeking from health services. Knowledge sources reported to be commonly accessed by family caregivers and community members were those within their informal networks – other family members, friends, neighbours and spiritual healers. These networks also formed an important source of tangible support through sharing of duties and care for an older person living with dementia. With family and community as the customary source of support for dementia care, raising awareness of dementia amongst the general community is a fundamental strategy to support knowledge sharing throughout Fiji. Crucially, awareness campaigns need to harness these Fijian ways of knowing and include Fijian understandings of dementia.

4.1.1 Raise awareness of dementia at national and regional levels.

This will improve understanding of dementia and support for families, as well as increase visibility of dementia to policy makers. Incorporation of dementia into existing policies, such as the National Ageing Policy and National NCD Strategy, will facilitate awareness campaigns, and education and training for stakeholders.

4.1.2 Develop awareness campaigns with special attention to the cultural and social meanings of dementia, vocabulary, language and destigmatisation.

This will promote help-seeking and support for people living with dementia and their families and increase visibility of dementia to policy makers. An example of a contextually and culturally appropriate approach to developing a dementia awareness campaign is found in Box 9.3.

4.1.3 Promote risk factor reduction for dementia as part of prevention activities for other NCDs.

Many of the modifiable risk factors for dementia are shared with those for NCDs. Campaigns that aim to reduce risk factors for NCDs are also relevant for reducing risk factors for dementia.

Box 9.3. An example of designing materials for a dementia awareness campaign that combines traditional and cultural knowledge with biomedical knowledge.

The global action plan on dementia sets out recommendations for programs for dementia awareness. The plan includes recommendations that awareness programs should promote an understanding of dementia, reduce stigmatisation associated with dementia, and increase knowledge of signs of dementia and risk factors (WHO, 2017). In Fiji, a considered approach to the application of awareness campaigns and education is needed. In Canada, health promotion materials about dementia for First Nations peoples that combined Indigenous and biomedical knowledge were developed (Webkamigad et al., 2020). The materials were developed using the 'two-eyed seeing' approach which is a theoretical framework that acknowledges both indigenous and biomedical (western) ways of knowing equally, as Martin (2012, p. 31) explains:

> *"Two-eyed seeing stresses the importance of being mindful of alternative ways of knowing (multiple epistemologies) in order to constantly question and reflect on the partiality of one's perspective. It values difference and contradiction over the integration or melding of diverse perspectives, which can result in the domination of one perspective over the others. As a result, one "eye" is never subsumed or dominated by the other; rather, each eye represents a way to see the world that is always partial. When both eyes are used together, this does not mean that our view is now "complete and whole," but a new way of seeing the world has been created — one that respects the differences that each can offer."*

This approach was applied to develop two culturally appropriate fact sheets for First Nations people about what dementia is, and signs and symptoms of dementia (Webkamigad et al., 2020). Cultural or traditional knowledge, such as that shared by co-researchers involved in this study, can be combined with biomedical knowledge to produce materials that are appropriate and relevant in settings where there is low awareness and knowledge of dementia.

Recommendation 5. Promote social support for people living with dementia and family caregivers

There is a reliance on families to support older people living with dementia in Fiji. Family caregivers show great compassion towards their older family member with dementia but caregiving can be stressful and socially isolating. The motivation for caring for people living with dementia within family networks are complex being a combination of preference, community expectation, obligation and resources. Families experience a spectrum of socioeconomic wellbeing and informal social support. They need financial and social support to care for an older person living with dementia.

5.1 Provide education for families and communities in their roles as caregivers.

Education for families and communities about caregiving, with cultural considerations, can provide the tools needed to care for older people within family and community networks. Box 9.4 describes an example of caregiving education for communities in Fiji.

5.2 Ensure that people living with dementia and their family caregivers are connected with the Social Welfare Department.

This will ensure that people living with dementia and their families are able to access all forms of welfare for which they are eligible.

Box 9.4. A partnership providing education for communities about caregiving.

In 2019, the APTC, in partnership with MWCPA, provided a two day workshop for community members in Fiji (APTC & Australian Aid, 2019). The workshop was conducted with 70 community members and aimed to empower communities in the care of older people. The education provided community members with knowledge and skills to help them care for older people and people living with disabilities.

5.3 Develop local, community-based respite care services.

Long-term aged care services are strongly stigmatised. Respite services for family caregivers situated within communities, rather than health facilities, may be an acceptable form of care that will offer family caregivers rest and offer people living with dementia an opportunity to socialise and connect with their community. If linked with outreach services, these respite services could also be a point for family caregivers and people living with dementia to access health care. Community volunteers and retired health professionals could be included amongst personnel at a respite service.

Implications and recommendations for further research

Recommendation 6. Conduct further research about dementia in Fiji

6.1 Investigate the views of people living with dementia

In Fiji, the views of older people on issues relevant to them are often unheard and were not captured in this research about dementia. The views of people living with dementia about their beliefs, understandings and experiences are essential in informing all aspects of dementia care, particularly considering that many older Fijians are dependent on their families. The value of including people living with dementia in qualitative research is increasingly being recognised (Cridland et al., 2016; Phillipson & Hammond, 2018) reflecting a recent shift in thinking that values their contribution in research. Traditionally, studies have described the views of caregivers only, on the assumption that people living with dementia cannot articulate their own views. However, evidence increasingly indicates that the views of people living with dementia are not only valid, but often differ from the views of caregivers (Murphy et al., 2015).

6.2 Investigate younger onset dementia

As described in the grounded theory, signs and symptoms of cognitive decline observed in older people were commonly attributed to older age. In contrast, such signs observed in a younger person were viewed as a matter of concern. Co-researchers also commented that younger onset dementia was an emerging health issue based on their experiences. Younger onset dementia has various and serious implications on the wellbeing of people living with dementia and family caregivers, and service provision. Given that co-researchers were concerned about observations of increasing numbers of people with younger onset dementia, an investigation into the scope of this issue is recommended. Such a study could be conducted as part of other mental health studies.

Recommendation 7. Conduct research about ageing

To date, very little research has been conducted about ageing in Fiji. This research about dementia in older people in Fiji showed that factors influencing wellbeing were often based in culture. In other settings, evidence shows that wellbeing in older age is influenced by a great variety of factors. For example, important factors of quality of life of older Aboriginal Australians are: connection to community, family, friends, and Country; cultural practices; autonomy in health decisions; respect; the Elder role; safety and security, and meeting basic needs (Smith et al., 2020). The Fiji Wellness Approach identifies social, spiritual, environmental, occupational, psychological, physical and financial dimensions of wellness (MHMS, 2015c). This approach provides a culturally appropriate framework that could guide research about ageing in Fiji. Knowledge about these dimensions in relation to ageing, including gendered experiences and specific cultural beliefs and practices, can inform planning of support and services for the older population that is relevant for the local context.

9.3 Conclusion

Sociocultural meanings of dementia and wellbeing in Fiji both produce and influence conditions that affect the management of dementia care. A reliance on informal care, primarily family support, is established in Fijian ways of knowing and doing and is driven by a combination of preference, community expectation, obligation and availability of resources. These factors contribute to delayed help seeking and clinical inertia, and of crucial importance, also facilitate care in place in the community and amongst family. The recommendations stemming from this research aim to draw on the strengths of Fijian ways while recognising that a romantic view of family and community connectedness ignores the realities of a dynamic, contemporary Fijian society. Positive change in dementia care centres on the integration of community understandings, and promotion of cultural values of wellbeing and care, with service provision. It also focuses on tangible, purposeful community-based and community-engaged models of support and care for older people living with dementia and their families.

10. References

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Appendix 1. Final search strategy for literature review

Two separate searches were conducted for each population group.
"Low and middle income countries" AND "knowledge, beliefs, attitudes" AND "dementia"
"Indigenous" AND "knowledge, beliefs, attitudes" AND "dementia"
The searches are shown in expanded form below.

Scopus, PsychInfo and Informit

Low and middle income countries (Search 1)

((TITLE-ABS-KEY ("low and middle income country" OR "low and middle income countries" OR "upper middle income country" OR "upper middle income countries" OR "LMIC")) OR (TITLE-ABS-KEY ("Low-and-middle-income country" OR "low-and-middle-income countries" OR "lower-income country" OR "lower-income countries" OR "low-income country")) OR (TITLE-ABS-KEY ("low-income countries" OR "middle-income country" OR "middle-income countries" OR "low-middle-income country" OR "low-middle-income countries")) OR (TITLE-ABS-KEY ("lower-middle-income country" OR "lower-middle-income countries" OR "upper-middle-income country" OR "upper-middle-income countries")) OR ((TITLE-ABS-KEY (afghanistan OR benin OR burkina OR faso OR burundi OR chad OR comoros OR congo OR eritrea OR ethiopia OR gambia OR guinea OR guinea-bissau OR haiti OR korea OR liberia OR madagascar OR malawi OR mali OR mozambique)) OR (TITLE-ABS-KEY (nepal OR niger OR rwanda OR senegal OR somalia OR sudan OR tanzania OR togo OR uganda OR zimbabwe OR angola OR armenia OR bangladesh OR bhutan OR bolivia OR cabo OR verde)) OR (TITLE-ABS-KEY (cambodia OR cameroon OR djibouti OR egypt OR georgia OR ghana OR guatemala OR honduras OR india OR indonesia OR jordan OR kenya OR kiribati OR kosovo OR lao OR lesotho OR mauritania OR micronesia OR moldova)) OR (TITLE-ABS-KEY (mongolia OR morocco OR myanmar OR nicaragua OR nigeria OR pakistan OR png OR philippines OR sudan OR swaziland OR syria OR tajikistan OR timor-leste OR tunisia OR ukraine)) OR (TITLE-ABS-KEY (uzbekistan OR vanuatu OR vietnam OR gaza OR yemen OR zambia OR albania OR algeria OR samoa OR argentina OR azerbaijan OR belarus OR belize OR bosnia OR herzegovina OR botswana OR brazil OR bulgaria OR china OR colombia)) OR (TITLE-ABS-KEY (croatia OR cuba OR dominica OR "dominican republic" OR ecuador OR guinea OR fiji OR gabon OR grenada OR guyana OR iran OR iraq OR jamaica OR kazakhstan OR lebanon OR libya)) OR (TITLE-ABS-KEY (macedonia OR malaysia OR maldives OR mauritius OR mexico OR montenegro OR namibia OR nauru OR panama OR paraguay OR peru OR romania OR russia OR samoa OR serbia OR grenadines OR suriname OR thailand OR tonga OR turkey)) OR (TITLE-ABS-KEY (turkmenistan OR tuvalu OR venezuela OR "dominican republic" OR "democratic peoples republic" OR "sierra leone" OR "côte d'ivoire" OR "arab republic" OR "el salvador")) OR (TITLE-ABS-KEY ("kyrgyz republic" OR "papua new guinea" OR "sri lanka" OR "west bank" OR "costa rica" OR "south Africa" OR "st lucia" OR "st Vincent"))) OR ((TITLE-ABS-KEY ("marshall islands" OR "Russian federation" OR "solomon islands" OR "central african republic" OR "sao tome" OR principe)) OR (TITLE-ABS-KEY ("developing countries" OR "developing country" OR "developing nation" OR "developing nations" OR "least developed countries" OR "least developed country" OR "less developed countries" OR "less developed nations" OR "less-developed countries")) OR (TITLE-ABS-KEY ("less-developed country" OR "less-developed nation" OR "less-developed nations" OR "third world countries" OR "third world nations" OR "third-world countries" OR "third-world country")) OR (TITLE-ABS-KEY ("third-world nation" OR "third-world nations" OR "under developed countries" OR "under developed nations")) OR (TITLE-ABS-KEY ("under-developed countries" OR "under-developed country" OR "under-developed nation" OR "under-developed nations" OR "fourth world countries")) OR (TITLE-ABS-KEY ("fourth world nations" OR "fourth-world countries" OR "fourth-world country" OR "fourth-world nation" OR "fourth-world nations")) OR (TITLE-ABS-KEY ("low income country" OR "low income countries" OR "lower income country" OR "lower income countries" OR "middle income country" OR "middle income countries"))))

AND

Knowledge, beliefs and attitudes

(((TITLE-ABS-KEY ("health knowledge" OR "attitudes" OR "practice" OR "knowledge" OR "attitude" OR "practices" OR "health behavior" OR "health behaviors" OR "health behaviour" OR "health behaviours" OR "attitude to health" OR "health attitude" OR "health attitudes")) OR (TITLE-ABS-KEY ("belief" OR "beliefs" OR "cultural background" OR "cultural backgrounds" OR "culture" OR "cultures" OR "custom" OR "customs" OR "cultural anthropology" OR "ethnographies")) OR (TITLE-ABS-KEY ("ethnography" OR "medical anthropology" OR "social stigma" OR "social stigmas" OR "taboo" OR "taboos" OR "superstition" OR "superstitions" OR "ethnomedicine" OR "folk medicine")) OR (TITLE-ABS-KEY ("folk remedies" OR "folk remedy" OR "home remedies" OR "home remedy" OR "indigenous medicine" OR "primitive medicine" OR "traditional medicine" OR "exorcism" OR "exorcisms")) OR (TITLE-ABS-KEY ("spiritual healing" OR "spiritual healings" OR "spiritual therapies" OR "cultural characteristic" OR "cultural characteristics" OR "ceremonial behavior")) OR (TITLE-ABS-KEY ("ceremonial behaviors" OR "ceremonial behaviour" OR "ceremonial behaviours" OR "rituals" OR "ritual" OR "alternative medicine" OR "alternative therapies" OR "complementary medicine" OR "complementary therapies"))) OR (TITLE-ABS-KEY ("Indigenous Healer" OR "Indigenous Healers" OR "Medicine Men" OR "traditional Healer" OR "Witch Doctor" OR "Witch Doctors" OR "Divine Healing" OR "Faith Healing" OR "Attitude to Disease" OR "attitudes to disease")) OR (TITLE-ABS-KEY ("attitudes to sickness" OR "Attitude to Sickness" OR "Attitudes to Illness" OR "attitude to illness" OR "Disease Attitude" OR "Disease Attitudes" OR "Illness Attitude" OR "Illness Attitudes")) OR (TITLE-ABS-KEY ("Illness Beliefs" OR "illness belief" OR "Sickness Attitude" OR "Sickness Attitudes" OR "Access to Health Care" OR "Access to Health Services" OR "Barrier to Care" OR "Barriers to Care" OR "Health Care Accessibility" OR “caregiver” OR “caregivers”)) OR (TITLE-ABS-KEY ("Health Service Access" OR "Health Service Accessibility" OR "Health Services Access" OR "Attitude of Health Employee" OR "Attitude of Health Staff" OR "Attitudes of Health Employees" OR "Attitudes of Health Personnel")) OR (TITLE-ABS-KEY ("attitude of health personnel" OR "Health Personnel Attitude" OR "Health Personnel Attitudes" OR "Health Staff Attitude" OR "Health Staff Attitudes" OR "Help Seeking Behaviors" OR "Help Seeking Behaviour")) OR (TITLE-ABS-KEY ("Help Seeking Behaviours" OR "Treatment Seeking Behavior" OR "Help-Seeking Behaviors" OR "Help-Seeking Behaviour" OR "Help-Seeking Behaviours" OR "Treatment-Seeking Behavior")))

AND

Dementia

((TITLE-ABS-KEY ("amentia" OR "amentias" OR "dementia" OR "dementias" OR "familial dementia" OR "familial dementias" OR "senile" OR "degenerative neurologic disease" OR "degenerative neurologic diseases" OR "degenerative neurologic disorder")) OR (TITLE-ABS-KEY ("degenerative neurologic disorders" OR "nervous system degenerative diseases" OR "neurodegenerative disease" OR "neurodegenerative diseases" OR "neurodegenerative disorder" OR "neurodegenerative disorders")) OR (TITLE-ABS-KEY ("neurologic degenerative condition" OR "neurologic degenerative conditions" OR "neurologic degenerative disease" OR "neurologic degenerative diseases" OR "cognitive disorders" OR "cognitive disorder")) OR (TITLE-ABS-KEY ("neurocognitive disorders" OR "neurocognitive disorder" OR "senile dementia" OR "alzheimer dementia" OR "alzheimer syndrome" OR "alzheimer type dementia" OR "alzheimer type senile dementia" OR "alzheimer's disease")) OR (TITLE-ABS-KEY ("alzheimer's dementia" OR "alzheimer's syndrome" OR "alzheimer's type dementia" OR "alzheimer-type dementia" OR "familial alzheimer disease" OR "vascular dementia" OR "vascular dementias")) OR (TITLE-ABS-KEY ("Frontotemporal dementia" OR "frontotemporal lobar degeneration" OR "lewy body dementia" OR "lewy body disease")))

Indigenous (Search 2 – replace LMIC with indigenous terms)

(TITLE-ABS-KEY ("african continental ancestry group" OR "american native continental ancestry group" OR "asian continental ancestry group" OR "alaska indigenous people" OR "alaska indigenous peoples" OR "alaska native" OR "alaska natives" OR "alaska's indigenous people")) OR (TITLE-ABS-KEY ("alaska's indigenous peoples" OR "alaskas indigenous people" OR "native alaskian" OR "native alaskians" OR "central american amerind" OR "central american amerinds" OR "central american indian" OR "central american indians")) OR (TITLE-ABS-KEY ("south american amerind" OR "south american amerinds" OR "south american indian" OR "south american indians" OR "american indian" OR "aleut" OR "aleuts" OR "eskimo" OR "eskimos" OR "inuit")) OR (TITLE-ABS-KEY ("inuits" OR "inupiat" OR "inupiats" OR "kalaallit" OR "kalaallits" OR "indigenous population*" OR "population* indigenous" OR "native*" OR "indigenous" OR "native born")) OR (TITLE-ABS-KEY ("tribes" OR "native-born" OR "Oceanic ancestry group*" OR "aboriginal*" OR "aborigine*" OR "first nation" OR "first nations"))

CINAHL

Low and middle income countries (Search 1)

MM “low and middle income countries” OR “MM developing countries” OR afghanistan OR benin OR burkina OR faso OR burundi OR chad OR comoros OR congo OR eritrea OR ethiopia OR gambia OR guinea OR guinea-bissau OR haiti OR korea OR liberia OR madagascar OR malawi OR mali OR mozambique OR nepal OR niger OR rwanda OR senegal OR somalia OR sudan OR tanzania OR togo OR uganda OR zimbabwe OR angola OR armenia OR bangladesh OR bhutan OR bolivia OR cabo OR verde OR cambodia OR cameroon OR djibouti OR egypt OR georgia OR ghana OR guatemala OR honduras OR india OR indonesia OR jordan OR kenya OR kiribati OR kosovo OR lao OR lesotho OR mauritania OR micronesia OR moldova OR mongolia OR morocco OR myanmar OR nicaragua OR nigeria OR pakistan OR png OR philippines OR sudan OR swaziland OR syria OR tajikistan OR timor-leste OR tunisia OR ukraine OR uzbekistan OR vanuatu OR vietnam OR gaza OR yemen OR zambia OR albania OR algeria OR samoa OR argentina OR azerbaijan OR belarus OR belize OR bosnia OR herzegovina OR botswana OR brazil OR bulgaria OR china OR colombia croatia OR cuba OR dominica OR "dominican republic" OR ecuador OR guinea OR fiji OR gabon OR grenada OR guyana OR iran OR iraq OR jamaica OR kazakhstan OR lebanon OR libya OR macedonia OR malaysia OR maldives OR mauritius OR mexico OR montenegro OR namibia OR nauru OR panama OR paraguay OR peru OR romania OR russia OR samoa OR serbia OR grenadines OR suriname OR thailand OR tonga OR turkey OR turkmenistan OR tuvalu OR venezuela OR "dominican republic" OR "democratic peoples republic" OR "sierra leone" OR "côte d'ivoire" OR "arab republic" OR "el salvador" OR "kyrgyz republic" OR "papua new guinea" OR "sri lanka" OR "west bank" OR "costa rica" OR "south Africa" OR "st lucia" OR "st Vincent" OR "marshall islands" OR "Russian federation" OR "solomon islands" OR "central african republic" OR "sao tome" OR principe

AND

Knowledge, beliefs, attitudes

MH “Health knowledge” OR “professional knowledge” OR MH “health behaviour” OR MM “help seeking behaviour” OR MM “information seeking behavior” OR MH “attitude to health” OR MH “attitude to illness” OR MM “patient attitudes” OR MH “culture+” OR “organizational culture+” OR MH “anthropology” OR MM “stigma” OR “caregivers”OR MH “medicine, traditional+” OR MH “spiritual healing+” OR MM “traditional healers”

AND

Dementia

MH “dementia” OR MH “neurodegenerative diseases”

Indigenous (Search 2 – replace LMIC with indigenous terms)

MM “indigenous health” OR MM “native americans” OR MM “Maori” OR MM “indigenous peoples+” OR MM “eskimos” OR MM “aborigines+” OR “aboriginal” OR “first people” OR “indigenous”

Medline

Low and middle income countries (Search 1)

Exp MeSH developing countries/ OR MM low and middle income countries OR MM developing countries OR afghanistan OR benin OR burkina OR faso OR burundi OR chad OR comoros OR congo OR eritrea OR ethiopia OR gambia OR guinea OR guinea-bissau OR haiti OR korea OR liberia OR madagascar OR malawi OR mali OR mozambique OR nepal OR niger OR rwanda OR senegal OR somalia OR sudan OR tanzania OR togo OR uganda OR zimbabwe OR angola OR armenia OR bangladesh OR bhutan OR bolivia OR cabo OR verde OR cambodia OR cameroon OR djibouti OR egypt OR georgia OR ghana OR guatemala OR honduras OR india OR indonesia OR jordan OR kenya OR kiribati OR kosovo OR lao OR lesotho OR mauritania OR micronesia OR moldova OR mongolia OR morocco OR myanmar OR nicaragua OR nigeria OR pakistan OR png OR philippines OR sudan OR swaziland OR syria OR tajikistan OR timor-leste OR tunisia OR ukraine OR uzbekistan OR vanuatu OR vietnam OR gaza OR yemen OR zambia OR albania OR algeria OR samoa OR argentina OR azerbaijan OR belarus OR belize OR bosnia OR herzegovina OR botswana OR brazil OR bulgaria OR china OR colombia croatia OR cuba OR dominica OR "dominican republic" OR ecuador OR guinea OR fiji OR gabon OR grenada OR guyana OR iran OR iraq OR jamaica OR kazakhstan OR lebanon OR libya OR macedonia OR malaysia OR maldives OR mauritius OR mexico OR montenegro OR namibia OR nauru OR panama OR paraguay OR peru OR romania OR russia OR samoa OR serbia OR grenadines OR suriname OR thailand OR tonga OR turkey OR turkmenistan OR tuvalu OR venezuela OR "dominican republic" OR "democratic peoples republic" OR "sierra leone" OR "côte d'ivoire" OR "arab republic" OR "el salvador" OR "kyrgyz republic" OR "papua new guinea" OR "sri lanka" OR "west bank" OR "costa rica" OR "south Africa" OR "st lucia" OR "st Vincent" OR "marshall islands" OR "Russian federation" OR "solomon islands" OR "central african republic" OR "sao tome" OR principe

AND

Knowledge, beliefs, attitudes

Exp MeSH “health knowledge, attitudes, practice” OR exp MeSH “attitude to health” OR exp MeSH “health behavior” OR exp MeSH “culture” OR exp MeSH “anthropology, medical” or exp MeSH “anthropology, cultural” OR exp MeSH “social stigma” OR exp MeSH “taboo” OR exp MeSH “superstitions” OR exp MeSH “medicine, traditional” OR exp MeSH “spiritual therapies” OR exp MeSH “cultural characteristics” OR exp MeSH “ceremonial behavior” OR exp MeSH “complementary therapies” OR exp MeSH “health service accessibility” OR exp MeSH “attitude of health personnel” OR exp MeSH “help seeking behavior” OR exp MeSH “caregivers”

AND

Dementia

exp MeSH “dementia” OR exp MeSH “neurodegenerative diseases” OR exp MeSH “neurocognitive disorders”

Indigenous (Search 2 – replace LMIC with indigenous terms)

exp MeSH “continental population groups” OR exp MeSH “african continental ancestry group” OR exp MeSH “american native continental ancestry group” OR exp MeSH “Alaska natives” OR exp MeSH “indians, central american” OR exp MeSH “indians, north American” OR exp MeSH “Indians, south American” OR exp MeSH “inuits” OR exp MeSH “asian continental ancestry group” OR exp MeSH “european continental ancestry group” OR exp MeSH “oceanic ancestry group”

Appendix 2. Literature review: Assessment of reporting quality (S=satisfactory, U=unsatisfactory) and comments on reflexivity, credibility and transferability.

Reference and study area	Question and study design	Participant selection	Data collection method	Data analysis method-ology	Inclusion or exclusion	Reflexivity, credibility, transferability
Smith et al. (2011) Australia	S	U	S	S	Included	Ethics approval from relevant body. Findings described briefly. Large number of participants from key stakeholder groups. Details on recruitment method and numbers and roles of participants lacking. Difficult to separate views of stakeholders according to their role (e.g. informal caregiver v health professional). Inclusive methodology appropriate for study aims. Engagement with steering group and inclusive data analysis lends credibility to study. Feedback to participants through newsletter.
Hulko et al. (2010) Canada	S	S	S	S	Included	Ethics approval from university, health sector and ethics protocols negotiated with community. Informed consent. Study discussed at forums with community leaders. Researchers Indigenous and non-indigenous. Third party questioning strengthened some findings. Inclusive, decolonizing methods for design, analysis and dissemination. Feedback to key stakeholders.
Jacklin et al. (2015) Canada	S	S	S	S	Included	Critical interpretative approach with community participatory and post-colonial approaches forming appropriate approach to research with indigenous peoples. Conducted collaboratively with sites.
Lanting et al. (2011) Canada	S	S	S	S	Included	Ethics approval from university, Grandmother's group and clinic. Although very few participants recruited - participants were Elders in the communities and based on the purpose of their group, the participants were involved and in touch with the population group the study sought to explore. Credibility addressed through involvement of participants, steering group and community members in study design and data analysis processes.

Reference and study area	Question and study design	Participant selection	Data collection method	Data analysis method-ology	Inclusion or exclusion	Reflexivity, credibility, transferability
Mbelesso et al. (2016) Central African Republic and Republic of the Congo	S	S	U	U	Excluded	Ethics approval was not reported. Informed consent was collected. Details for qualitative component including vignette not described. Details on qualitative analysis lacking. Survey instrument was translated into local languages. Transcripts translated to French. Limitations for interpretation noted. Sample inclusive of main stakeholders though unable to differentiate between findings from people with dementia and people with mild cognitive impairment.
Dai et al. (2015) China	S	S	S	S	Included	Study protocol approved by appropriate bodies. Verbal informed consent. Interviews conducted in interviewee's preferred location. Participants were caregivers who had accessed services for help with cognitive impairment. Interviewers understood local dialect. Issues of translation addressed thoroughly. Three coders analyzed interviews.
Lian et al. (2017) China	S	S	S	S	Included	Ethics approval from relevant body and informed consent. Research team contributed to theme development and cross-checked codes. Participants invited to review and revise main points from focus group.
Hsiao et al (2016) China	S	U	S	S	Included	Ethics approval from relevant body and informed consent. Details on recruitment lacking. Rural town, Daxing, is in Beijing and not representative of all rural settings in China.
Brijnath & Manderson, (2011) India	S	S	S	S	Included	Ethics approval and informed consent from participants. Effort made to protect confidentiality. Urban study of relatively wealthy people who had access to private and public diagnostic and dementia care services.
Cohen (1995) India	S	U	U	U	Excluded	Although this study is a rich source of information about dementia in India, the way in which the study has been reported makes it difficult to separate the findings from the authors' interpretations.

Reference and study area	Question and study design	Participant selection	Data collection method	Data analysis method-ology	Inclusion or exclusion	Reflexivity, credibility, transferability
Narayan et al. (2015) India	S	U	S	S	Included	Ethics and consent process not clear. Urban clinic – low representation from rural areas and sample consists of only people who have sought care. Details on recruitment method lacking. Data analysis performed by the US team – concept checking with partners in Bangalore not described.
Patel & Prince (2001) India	S	U –	S	S	Included	Ethics not reported. Findings were relevant for study aims and context. Details on recruitment method lacking. Use of vignettes to elicit views on dementia in a low awareness setting. Inclusiveness of participants considered through study design to include conduct of focus groups in different languages and purposive sampling used. Representation from large range of stakeholders. Limitations not reported.
Shaji et al. (2003) India	S	S	S	U	Included	Ethics review and informed consent not described. Participants were community primary caregivers, most of whom hadn't sought healthcare for dementia. Process for inclusion of information from health professionals not described.
Mazaheri et al. (2013) Iran	S	S	S	S	Included	Ethics approval from relevant body and informed consent. Monitored participants for signs of desire to withdraw from the interview. Validated transcripts by listening back. 2 researchers analyzed interviews and compared – discussed with whole research team. Acknowledgment that authors from different countries and have different world views.
Navab et al. (2013) Iran	S	S	S	S	Included	Ethics approval from relevant body and informed consent. Presented findings to faculty. Member checking of themes. Audit trail.

Reference and study area	Question and study design	Participant selection	Data collection method	Data analysis method-ology	Inclusion or exclusion	Reflexivity, credibility, transferability
Navab et al. (2012) Iran	S	S	S	S	Included	Ethics approval from relevant body and informed consent. Presented findings to faculty. Audit trail and evidence for interpretations' basis presented. Member checking by some participants for theme descriptions
Juarez-Cedillo et al. (2014) Mexico	S	S	S	S	Included	Ethics approval from relevant body and informed consent. Recruitment process not described Term dementia or AD not used unless participant uses word. Two researcher analyzed. Use of statement semiotics unexplained.
Qadir et al. (2013) Pakistan	S	S	S	S	Included	Ethics approval from relevant body and informed consent. Interviews conducted in Urdu and translated to Pubjabi – no details of cross-checking.
Mkhonto & Hanssen (2018) South Africa	S	S	S	S	Included	Ethics approval from relevant body and informed consent. Possible bias in selection of nurse participants using recruitment procedure. Two authors analyzed all interviews. One author had insight into Black South African culture.
Hindley et al (2016) Tanzania	S	S	S	S	Included	Ethics approval from relevant body and informed assent/consent collected. Vignette used as term dementia not well recognised. Built rapport prior to interviews. Random pages of transcription compared to original recordings by one author. Compared with separate random transcription pages translated by professional translator not involved with the study. Thematic analysis by one author.

Reference and study area	Question and study design	Participant selection	Data collection method	Data analysis method-ology	Inclusion or exclusion	Reflexivity, credibility, transferability
Mushi et al. (2014) Tanzania	S	S	S	S	Included	Ethics approval from relevant bodies. Confidentiality and anonymity observed. Informed consent. Hard to distinguish between reporting of findings from people with dementia and caregivers. Participants accessed health care for issues other than dementia but comparisons with understandings of dementia were not reported. Two researchers analyzed independently and discussed. Authors acknowledge that responses given by participants may have been influenced by social acceptability.
Henderson & Henderson (2002) USA	U	S	U	U	Excluded	Case exemplar of one family – convenience sample. Scant information on methodology. No details of informed consent.

Appendix 3. Interview schedule for family caregivers

Topic guide for caregivers/family

Open discussion to allow story telling which supports the oral tradition in Fiji of sharing knowledge and information.

Introduce selves briefly

Introduce purpose of the research

- To learn from people who experience dementia about:
    - what they understand it to be and why
    - what happened in the lead up to diagnosis, how did diagnosis happen and what happened after diagnosis
    - what they experience – impacts on daily life, self, family, community
    - what sort of support would help

1. Share own background. Ask about participant background.

2. What was happening in the lead up to your loved one being diagnosed with dementia?
   Want to know about:
    - What sorts of things did you notice?
    - What sorts of things did others notice?
    - What was worrying?
    - What was not worrying?

   And – Why were things worrying or not?

3. What did you do about the things that you were noticing in your loved one?
    - Who did you talk to about it?
    - Did you go and ask for advice or help from anyone? Who? Why?

4. What happened when your *[family member]* was diagnosed with dementia?
   Want to know about:
    - When and where was [name] diagnosed with dementia?
    - Why did you decide to go to [place]? Were you worried about going there?

5. What happened after *[name]* was diagnosed with dementia?
   Want to know about:
    - Do you attend follow up appointments – why/why not? Where do you attend for these appointments?
    - How have things changed since receiving a diagnosis? (wanting to know about what difference, if any, a diagnosis makes for families and people with dementia)

6. What sorts of things do you do to support your loved one? Who helps you? Is this different to what you did before the diagnosis of dementia?

7. What do you think about this condition [dementia]?
   Want to know about:
    - Have you ever heard of dementia before?
    - What do you think causes dementia?
    - Have you known this kind of thing as something else?

8. Why do think people get this?
    - If ageing mentioned, explore other possible beliefs connected with view of normal ageing.
    - Explore witchcraft and curse if mentioned.

9. How have things changed for you since your *[family member]* has been going through these changes you talked about before? (participant might talk about earlier and more recent times)
   Want to know about:

- Family - role
- Community - role
- Health
- Social
- Work

10. How has life changed for *[family member]*? (participant might talk about earlier and more recent times)
    Want to know about:
    - Family - role
    - Community - role
    - Health
    - Social
    - Work
    - Is this different to what older people generally experience?

11. Do you know of other people in the same situation as you?
    Want to know about:
    - Do you share experiences?
    - What are their experiences like?

12. What sort of help do you and *[family member]* need? Is this different to what might be needed if your loved one did not have dementia?

13. What are your plans for the care of your loved one in the future?

14. Is there anything else that you would like to talk about?

Appendix 4. Interview/focus group schedules for service providers and community leaders

Interview schedule for service providers (adapt for community leaders)

1. Can you tell me about your role here as a *[profession]*?
   Prompts:
   Have you worked/volunteered in this area long?
   How did you come to be interested in this field of work/volunteering?

2. What is your understanding of dementia? What would you tell a patient or family?
   Prompts:
   - How did you find out about dementia?
   - If applies: What do other professionals who don't work in mental health think about it?
   - Before you knew about dementia as a health condition, what did you think about it?

If not very aware of what dementia is, share vignettes.

3. What do you think that people in the general public think about dementia?
   - Can you tell me more about that?
   - Want to know more about:
     - lay person views on expected ageing and how/if dementia presentation differs from expected ageing
     - lay person views on mental illness, curse, witchcraft if mentioned
     - cultural group differences, rural vs urban differences

4. Can you tell us about your work experiences with older people with dementia?
   - Want to know about
     - What is caring for people with dementia like?
     - What sorts of ways do you care for someone with dementia?

5. How do older people with dementia come to be at your health setting?
   - Want to know about
     - Who brings and why?
     - If appropriate, ask about diagnostic and referral process.
     - How often people with dementia come to be at health setting
     - Do you notice older people with cognitive decline in your health setting? If so, what sorts of things do you about this?
     - Are there any cultural group or rural/urban differences?

6. Based on your experiences, what is it like for families who care for someone who is like this?
   - What to know more about:
     - Is this different to what would be experienced in caring for an older person with another health issue or no health issue?

7. What does a diagnosis of dementia mean for patients/family/communities?
   - What are the positives? eg. education, management of care, support
   - What are the negatives? eg. labelling, stigma, burden, care expectations

8. Where do people go and look for help for dementia?
   - Want to know about:
     - Where else do they go to find out more?
     - Where else do they go for support or help?

9. What sorts of things do you think might influence the decision to look for help?
    - What to know about:
        - Possible barriers and enablers of help seeking
          eg. knowledge, available services, family roles, stigma, burden, structural things like cost of travel, don't feel they need support, don't feel that support would be useful….
    - Follow up – do you think the issues are the same for both main cultural groups; in rural and urban settings?

10. If applies: Sometimes after older people have been diagnosed with dementia, they stop attending follow up appointments. Do you have any ideas of why this might happen?

11. What things do you think would help with providing support and care for people with dementia, and those supporting them?

Appendix 5. Vignettes forming part of the interview/focus group schedules

These stories describe a condition called dementia. It is a condition that gets worse over time.

Share vignette for early dementia

> *Mr [common name] is 75 years old. Recently he has begun to be forgetful. He confuses peoples' names, even those he knows well. He often seems not to be able to remember things from one moment to the next. One example was when he went to the market to buy food and came back with nothing, having forgotten what he went out for. He repeats himself in conversation, and always seems to talk about the past. His family first noticed the problem one year ago. Since then it has been getting steadily worse.*

Share vignette for more advanced dementia

> *Mr [common name] is now 78 years old. He has difficulty in recognising his wife and other close family members. He sits in a chair for most of the day. He never starts a conversation but will respond to questions by smiling or saying something, but his answers do not usually make sense. Sometimes he gets restless and agitated, asking over and over again 'When are we going out?' If he wanders out of the house he gets lost and has to be brought back by neighbours. His wandering can be a particular problem at night. Sometimes he gets short-tempered and abusive for no reason. He needs to be reminded to go to the toilet, but is still incontinent of urine.*

Appendix 6. Consent form for family caregivers, service providers and community leaders

This administrative form
has been removed

Appendix 7. Information sheet for person living with dementia

INFORMATION SHEET

PROJECT TITLE: *Dementia in Fiji: Views of people with dementia, caregivers, community leaders and service providers*

You are invited to take part in a research study about what you think about dementia. The study aims to find out what dementia means to you and how it has affected your life. The study is being done by Mrs Karen Johnston, Dr Sefanaia Qaloewai, Dr Robyn Preston, Dr Edward Strivens and Professor Sarah Larkins. The study will contribute to Karen's PhD degree in health at James Cook University.

People who are in this study have been diagnosed with dementia or they are caregivers or family members.

If you want to be in this study, you will be invited to be interviewed. The interview is talk between us where we share our stories. It should only take about 1 hour. We can do this at a place that you choose. If is OK with you, our talk will be audio-taped.

Being in this study is up to you. You can stop being in this study at any time without saying why. There is no problem with pulling out from the study. You will be thanked for your time and we will not trouble you again about this study.

You may become upset while talking about your life with dementia. This is understandable and we can stop talking at any time if you say so. You may like to have a rest or to talk at another time.

No one will know that you have been in this study. The data from this study will be used in reports, and may be talked about at meetings. Your name will not be used at any time.

If you know of other people that might want to be in this study, can you please pass on this information sheet to them? Our contact details are on the next page and they may contact us to volunteer for the study at any time.

This research study has the approval of the Fiji National Research Ethics Review Committee (2017.2.NW) and Human Research Ethics Committee, James Cook University, Australia (H6798).

Should you need counselling services please call toll-free Lifeline Fiji on 132 454.
You may also contact your Community Mental Health team who will arrange services for you. You may also contact the stress management ward at CWM Hospital, Lautoka Hospital or Labasa Hospital where you may be referred on to counselling services.

Central/Eastern Community Mental Health Team
Ph: 3340 421;
After hours 3381 399 and leave a message

Western Community Mental Health Team
Ph: 6660 411;
After hours 3381 399 and leave a message

Northern Community Mental Health Team
Ph: 8812 522;
After hours 3381 399 and leave a message

Colonial War Memorial Hospital
Address: Waimanu Rd, Suva
Phone: 3313 444

Lautoka Hospital
Address: Hospital Rd, Lautoka
Phone: 6660 399

Labasa Hospital
Address: Hospital Rd, Labasa
Phone: 8811 444

Information sheet. Primary. Version 1.0 19/10/2016.

If you have any questions about the study, please contact – Dr Sefanaia Qaloewai.

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Co-Investigator:
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St Giles Hospital, Ministry of Health and Medical Services

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If you have any concerns regarding the ethical conduct of the study, please contact:
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Phone: 3306177/3221424 (Approval No. 2017.2.NW)
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: +61 7 4781 5011 (ethics@jcu.edu.au) (H6798)

Appendix 8. Information sheet for family caregiver

INFORMATION SHEET

PROJECT TITLE: *Dementia in Fiji: Views of people with dementia, caregivers, community leaders and service providers*

You are invited to take part in a research study about what you think about dementia. The study aims to find out what dementia means to you and how it has affected your everyday living. The study is being done by Mrs Karen Johnston, Dr Sefanaia Qaloewai, Dr Robyn Preston, Dr Edward Strivens and Professor Sarah Larkins. The study will contribute to Karen's PhD degree in health at James Cook University.

People who take part in this study have been diagnosed with dementia, or may be caregivers or family members supporting a person who has been diagnosed with dementia.

If you agree to be in this study, you will be invited to be interviewed. The interview is talk between us where we share our stories and experiences. It should only take about 1 hour. We can do this at a place that you choose. If it is OK with you, our talk will be audio-taped.

Taking part in this study is completely up to you. You can stop taking part in the study at any time without saying why. There is no problem with pulling out from the study. You will be thanked for your time and we will not trouble you again to be in this study.

You may become upset while talking about your experiences with dementia. This is understandable and we can stop talking at any time if you want to.

Your responses and contact details will be strictly confidential. This means that your name and any other identifying information will not be shared with anyone. The data from the study will be used in research publications and reports, and may be presented at community meetings and conferences. You will not be identified in any way in these presentations and written materials.

If you know of other people that might be interested in this study, can you please pass on this information sheet to them? Our contact details are on the next page and they may contact us to volunteer for the study at any time.

This research study has the approval of the Fiji National Research Ethics Review Committee (2017.2.NW) and Human Research Ethics Committee, James Cook University, Australia (H6798).

Should you need counselling services please call toll-free Lifeline Fiji on 132 454.
You may also contact your Community Mental Health team who will arrange services for you. You may also contact the stress management ward at CWM Hospital, Lautoka Hospital or Labasa Hospital where you may be referred on to counselling services.

Central/Eastern Community Mental Health Team
Ph: 3340 421;
After hours 3381 399 and leave a message

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Ph: 6660 411;
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Northern Community Mental Health Team
Ph: 8812 522;
After hours 3381 399 and leave a message

Colonial War Memorial Hospital
Address: Waimanu Rd, Suva
Phone: 331 3444

Lautoka Hospital
Address: Hospital Rd, Lautoka
Phone: 666 0399

Labasa Hospital
Address: Hospital Rd, Labasa
Phone: 881 1444

Information sheet. Carers and family. Version 1.0 19/10/2016.

If you have any questions about the study, please contact – Dr Sefanaia Qaloewai.

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If you have any concerns regarding the ethical conduct of the study, please contact:
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Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
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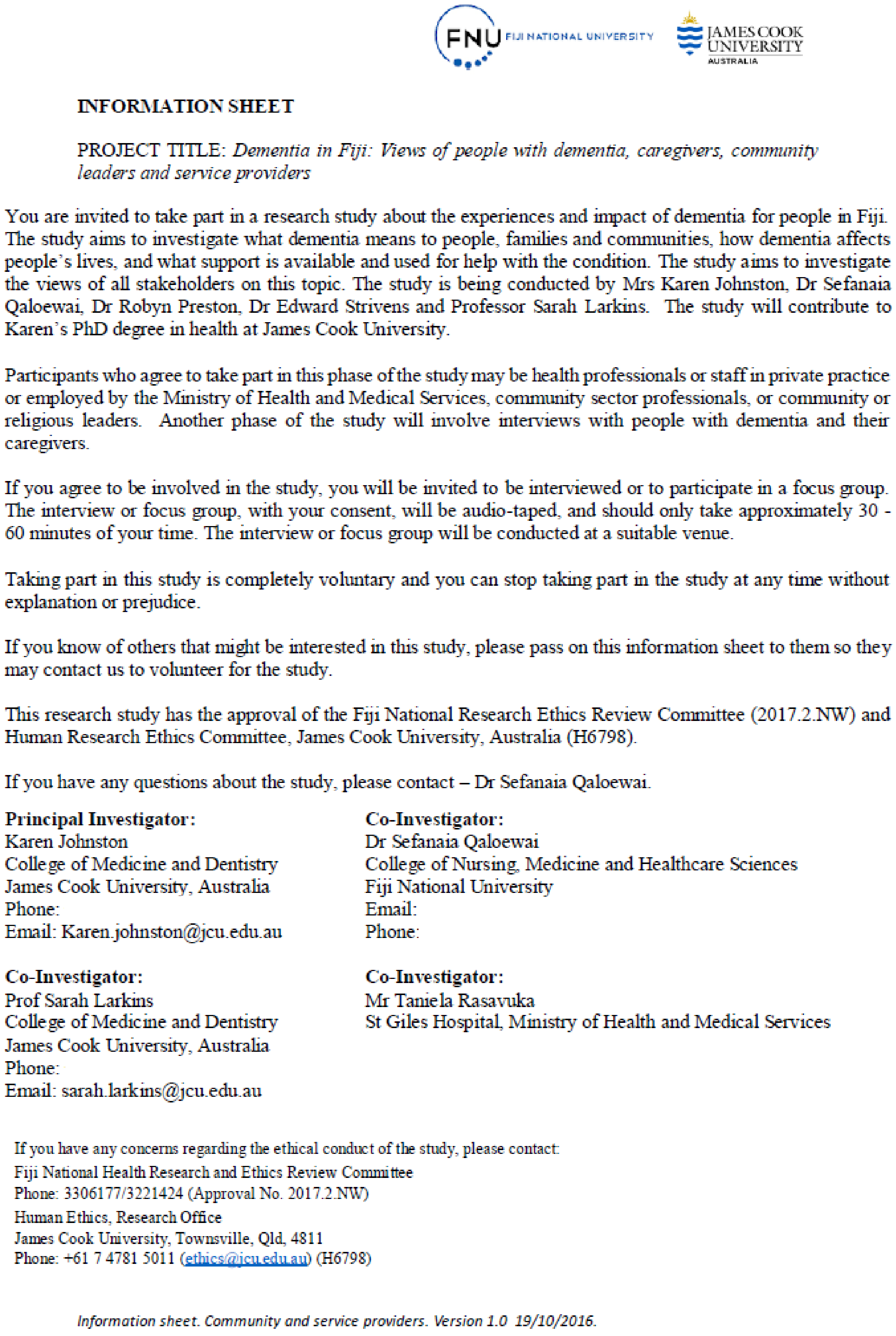
Appendix 9. Information sheet for service providers and community leaders



INFORMATION SHEET

PROJECT TITLE: *Dementia in Fiji: Views of people with dementia, caregivers, community leaders and service providers*

You are invited to take part in a research study about the experiences and impact of dementia for people in Fiji. The study aims to investigate what dementia means to people, families and communities, how dementia affects people's lives, and what support is available and used for help with the condition. The study aims to investigate the views of all stakeholders on this topic. The study is being conducted by Mrs Karen Johnston, Dr Sefanaia Qaloewai, Dr Robyn Preston, Dr Edward Strivens and Professor Sarah Larkins. The study will contribute to Karen's PhD degree in health at James Cook University.

Participants who agree to take part in this phase of the study may be health professionals or staff in private practice or employed by the Ministry of Health and Medical Services, community sector professionals, or community or religious leaders. Another phase of the study will involve interviews with people with dementia and their caregivers.

If you agree to be involved in the study, you will be invited to be interviewed or to participate in a focus group. The interview or focus group, with your consent, will be audio-taped, and should only take approximately 30 - 60 minutes of your time. The interview or focus group will be conducted at a suitable venue.

Taking part in this study is completely voluntary and you can stop taking part in the study at any time without explanation or prejudice.

If you know of others that might be interested in this study, please pass on this information sheet to them so they may contact us to volunteer for the study.

This research study has the approval of the Fiji National Research Ethics Review Committee (2017.2.NW) and Human Research Ethics Committee, James Cook University, Australia (H6798).

If you have any questions about the study, please contact – Dr Sefanaia Qaloewai.

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Mr Taniela Rasavuka
St Giles Hospital, Ministry of Health and Medical Services

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Information sheet. Community and service providers. Version 1.0 19/10/2016.

Appendix 10. Third party consent form for person living with dementia

This administrative form
has been removed

Appendix 11. James Cook University Human Research Ethics Committee approval

A subsequent amendment to extend the duration of this ethics approval was approved.

This administrative form
has been removed

Appendix 12. Fiji National Health Research and Ethics Review Committee approval

This administrative form
has been removed

This administrative form
has been removed

Appendix 13. Fiji Ministry of Education, Heritage and Arts approval

This administrative form
has been removed

Appendix 14. Estimates for the prevalence of dementia in Fiji

The Global Burden of Diseases, Injuries, and Risk Factors Study 2016 (Nichols et al., 2019) estimates an age-standardised prevalence of dementia for Fiji of 700-799 per 100,000 people. Based on this estimate, the number of people living with dementia can be estimated for Fiji. It is important to acknowledge that these estimates do not use prevalence data from Fiji or other PICs.

Year	Estimated population*	Rate (%)	Estimated number of people living with dementia	
2020	894,961	0.7-0.799	6265	7151
2030	920,980	0.7-0.799	6447	7359

*(SPC Statistics for Development Division, 2020)

The World Alzheimer's Report 2015 provides estimates for dementia for the Oceania GBD region. These estimates are based on a consensus study conducted in 2005 (Ferri et al., 2005). The estimates are provided below. Again, it is important to acknowledge that these estimates do not use prevalence data from Fiji or other PICs.

60-64 (%)	65-69 (%)	70-74 (%)	75-79 (%)	80-84 (%)	85+ (%)	Age-standardised prevalence for population aged over 60 years (%)
0.6	1.8	3.7	7.0	14.4	26.2	6.46

Following methodology used in an economic impact study of dementia in New Zealand (Ma'u E et al., 2021), these estimates may be extrapolated to the Fijian population. Data for population aged 80 to 84 years and over 85 years are unavailable for Fiji. Therefore, the age-standardised prevalence for population aged over 60 years (6.46%) must be used, as calculated below.

Year	Estimated population aged over 60 years*	Estimated number of people living with dementia
2020	91,144	5,888
2030	125,083	8,080

*(SPC Statistics for Development Division, 2020)

Appendix 15. Distribution of hospital admissions for patients with a primary diagnosis of dementia across health administrative areas

Health division	Health sub-division	n (%)
Central		44 (55.7)
	Naitasiri	1
	Rewa	6
	Serua/Namosi	1
	Suva	34
	Tailevu	2
Western		21 (26.6)
	Ba	2
	Lautoka/Yasawa	9
	Nadi	2
	Ra	1
	Nadroga/Navosa	5
	Tavua	2
Northern		13 (16.5)
	Bua	2
	Cakaudrove	4
	Macuata	6
	Taveuni	1
Eastern		1 (1.3)
	Lomaiviti	1

Appendix 16. Newsletter project update for stakeholders

Are you caring for an older person who has been diagnosed with dementia?

Are you an older person who has been diagnosed with dementia?

We would love to hear from you!

Please get in touch with us. Our contact details are on the back.

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FNU FIJI NATIONAL UNIVERSITY
JAMES COOK UNIVERSITY AUSTRALIA

Understandings and experiences of dementia in Fiji

A research study by PhD candidate Karen Johnston of James Cook University, Australia.

Conducted with advice and support from Dr Sefanaia Qaloewai (Fiji National University), Professor Sarah Larkins (James Cook University), Dr Robyn Preston (CQU) & Dr Edward Strivens (James Cook University).

And with project support from Charge Nurse Taniela Rasavuka and Sister Salome Nacagilevu of St Giles Hospital.

Project summary

In Fiji, the proportion of older people in the population is expected to double from 6.0% in 2000 to 12.6% in 2025. This rise in older people will most likely be associated with a rise in numbers of people with dementia.

Dementia is a condition of the brain that worsens over time. People with dementia experience changes in their memory, behaviour and thinking. This impacts on the ability to work, socialise, and participate in everyday activities which in turn often leads to social exclusion, financial strain and poor wellbeing.

Caregivers, who are often family members, also experience changes in their lives associated with the demands of caring for their loved one. There may be little access to support services.

By finding out about the experiences of dementia in Fiji, it may be possible to improve support for people with dementia, their families and service providers.

PROJECT PROGRESS

We have conducted interviews with people in Suva and in two towns on the western coast of Fiji. We asked about their thoughts on dementia, their experiences and the kinds of support they need. So far, we have talked with:

- family caregivers from 5 family units, including 1 person with dementia;
- 27 health service providers;
- 5 providers of community services.

We are currently analysing the data that we have collected. So far, we have found that in Fiji:

- There is low awareness of dementia in the general population.
- Forgetfulness, grumpiness and childish behaviour in older age is commonly thought of as an expected part of ageing. Terms that are used to describe changes associated with dementia include: 'gui guileca' (forgetful; Fijian), 'yalowai' (acting childish; Fijian), 'cavuka' (disconnected; Fijian), halka dimag' (the brain is getting lighter; Hindi).
- Witchcraft and 'going mad' are also associated with behaviours that are perceived as strange.
- Families often manage the care of their loved ones with cognitive decline and dementia within their family network.
- Family caregivers find that it is challenging to care for a loved one who has dementia. They want to know more about how to manage the care of their loved one.
- As many signs of dementia are thought to be normal, or explained by witchcraft or madness, families present at health services when dementia is quite advanced. Family and community support, and traditional ways of caring also contribute to late presentation at health services.
- Service providers in the mental health sector are the main support for people with dementia and their families in the health sector in Fiji. Residential aged care providers also provide care for people with dementia.

WHAT'S NEXT?

⇒ Talk with more family caregivers and people with dementia. Please contact Dr Qaloewai (743 3354) or Karen (karen.johnston@jcu.edu.au).

⇒ Continue with data analysis and reporting—lots more interesting and helpful findings in the data!

⇒ Report on how this research project can support people with dementia, caregivers and service providers.