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‘Letting it be’: a grounded theory about dementia care in Fiji

Karen Johnston^a , Sefanaia Qaloewai^b, Taniela Rasavuka^c, Robyn Preston^d , Edward Strivens^e  and Sarah Larkins^a 

^aCollege of Medicine and Dentistry, James Cook University, Townsville, Australia; ^bCollege of Medicine, Nursing and Health Sciences, Fiji National University, Suva, Fiji; ^cSaint Giles Hospital, Fiji Ministry of Health and Medical Services, Suva, Fiji; ^dSchool of Health, Medical and Applied Sciences, CQUniversity, Townsville, Australia; ^eCollege of Medicine and Dentistry, James Cook University, Cairns, Australia

ABSTRACT

Objectives: This research study aimed to discover how dementia affecting older people was perceived, experienced, and managed by stakeholders in the Pacific Island country of Fiji.

Method: A transformational grounded theory approach was used. Semi-structured interviews and focus groups with key stakeholders in the major towns of Suva, Lautoka, and Nadi were carried out. Transcripts were analysed in line with transformational grounded theory methods.

Results: A total of 50 participants (40 service providers, eight family caregivers, one person with dementia, and one village elder) shared their views and experiences about dementia. A grounded theory about dementia care management was constructed. ‘Letting it be’ is the grounding socio-cultural construct that interweaves and binds together the processes of dementia care management. It expresses a compassionate approach to caring for older people with dementia that involves searching for knowledge and support, and application of traditional care practices within the strength of family and community networks.

Conclusion: In Fiji, support for dementia centres on the integration of community understandings, and promotion of cultural values of wellbeing and care, with service provision. It also focuses on support for families and communities through social welfare, community networks, and education.

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Dementia; low and middle income countries; older adults; Pacific peoples’ health; caregiving

Introduction


Dementia is a growing global public health issue with disproportionately higher numbers of people living with dementia in low-and-middle-income countries (LMICs) (Prince et al., 2015) and higher prevalence amongst indigenous populations (Russell et al., 2020; Warren et al., 2015). Increasing numbers of people living with dementia is driven by longer life expectancy and high levels of modifiable risk factors for dementia. Potentially modifiable risk factors include less 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).

The number of older people residing in the Pacific Island Countries (PICs) is forecast to increase rapidly, reaching a peak in 2025 with continued growth to 2050 (UNFPA, 2014). However, historically, health and social concerns for an older population and associated health system implications have been low on health agendas in the Pacific Islands region (Anderson & Irava, 2017). Most PICs have developing economies and smaller populations. PICs here refers to Cook Islands, Federated States of Micronesia, Fiji, Kiribati, Marshall Islands, Nauru, Niue, Palau, PNG, Samoa, Solomon Islands, Tokelau, Tonga, Tuvalu, and Vanuatu. High prevalence of non-communicable diseases (NCDs) and high levels of risk factors for NCDs, many of which are shared with risk factors for dementia, add further significant emerging challenges for well-being and health economies in the Pacific Islands region (Hou et al., 2022; Reeve et al., 2022).

Fiji is a Pacific Island country with an upper-middle-income economy. Prevalence studies about dementia in Fiji (and other small PICs) are currently missing from the academic literature. Importantly, an adapted 10/66 dementia protocol for population-based prevalence studies was found to be adequate for use with Fijians of Indian descent living in New Zealand, with possible application for Fiji (Martinez-Ruiz et al., 2021). Based on estimates of age-standardised prevalence of dementia in Fiji and other PICs (Nichols et al., 2019), the estimated number of people living with dementia in Fiji in 2020 was between 6250 and 7150 people (Johnston, 2021). However, accessing formal care for dementia is uncommon in Fiji. For example, just 72 patients were reportedly admitted to main hospitals in Fiji for a primary diagnosis of dementia between 2002 and 2019 (Johnston, 2021).

Care for older people living with dementia in LMICs and for indigenous populations is typically characterised by poor access to diagnostic and support services, and high levels of informal care (Prince et al., 2016; Racine et al., 2022). Likewise, smaller PICs have few formal support services for issues related to older age, including dementia, with families and communities providing the vast majority of care and support for older people in line with traditional cultural caring practices across the Pacific Island region (UNFPA, 2014). Moreover, in these settings, help-seeking behaviours may be shaped by conceptualisations of dementia within constructs of normal ageing, mental illness, cultural beliefs, or colonisation (Dudley, 2019; Jacklin & Walker, 2020; Johnston et al., 2020). In Fiji, limited care for dementia is available through already stretched general and mental health

CONTACT Karen Johnston  karen.johnston@jcu.edu.au

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services (Johnston, 2021) and further impediments to care exist due to low knowledge of dementia, pluralistic help-seeking behaviours, and stigma around mental illness and use of mental health services (Aghanwa, 2004; Chang, 2011; Leung et al., 2019).

The Global Dementia Action Plan recommends the development of a coordinated care pathway that is integrated within social care and health systems to support people living with dementia, caregivers, and families (WHO, 2017). This requires context-specific knowledge about perceptions and experiences of dementia, health services and systems, and management and impacts of dementia. The transformational grounded theory study described in this manuscript aimed to discover how dementia affecting older people was perceived, experienced, and managed by stakeholders in Fiji.

Methods

Setting

Fiji is an archipelago of 332 islands (110 of which are inhabited) in the South Pacific Ocean (Figure 1). The population of 890,000 people is geographically distributed with 81% of the population residing on the main island Viti Levu and 15% of the population on the second most populous island Vanua Levu. The remaining 4% of the population are dispersed across the smaller islands. Modern day Fiji is home to two main cultural groups: iTaukei (Indigenous Fijians) constitute 57% of the population, Fijians of Indian descent constitute 37%, Rotumans constitute 1% and a mixture of other ethnicities make up the remaining 5% of the population (Fiji Bureau of Statistics; FBS, 2014).

Context of dementia care in Fiji

Formal dementia care mainly occurs within Fiji's public mental health care services. These services are delivered through special outpatient clinics at health centres, sub-divisional hospitals (secondary care facilities), divisional hospitals (tertiary care facilities), and Saint Giles Hospital for psychiatric care. Inpatient services are delivered in Stress Management Wards at the three

divisional hospitals and at Saint Giles Hospital. Domiciliary nursing services are provided by mental health nurses for patients living with dementia who are unable to present at local health centres. There are private general practitioners and counsellors who may also provide care for people living with dementia. People living with dementia may reside at one of three public residential aged care facilities where the majority of care is provided by qualified caregivers. There are also two church affiliated residential facilities that may provide care for people living with dementia.

Approach

A transformational grounded theory (Redman-McLaren & Mills, 2015) approach was used. Transformational grounded theory has ontological underpinnings in critical realism and a methodological basis in grounded theory and participatory action research that is shaped by decolonising frameworks (Redman-McLaren & Mills, 2015). The Fijian Vanua Research Framework (Nabobo-Baba, 2008) is a decolonising framework established in '... indigenous Fijian world views, knowledge systems, lived experience, representations, cultures and values' (Nabobo-Baba, 2008, p.143) and guided research and thought processes. This approach supported the investigation of disparities and inequities experienced in Fijian society, a lens through which to consider and understand knowledge shared through the research process and a focus on research outcomes for positive change.

Sites

The three study sites, Suva, Lautoka, and Nadi, were all major urban towns on the main island (Viti Levu) where health services supported residents of the township as well as surrounding settlements and villages. Factors considered in selecting sites included consideration of the range of health facilities available and the level of health service accessibility for the population (Table 1). The logistical ability to meet with participants, a local awareness of receptiveness to participation in the study, and the presence of mental health services in the areas where the

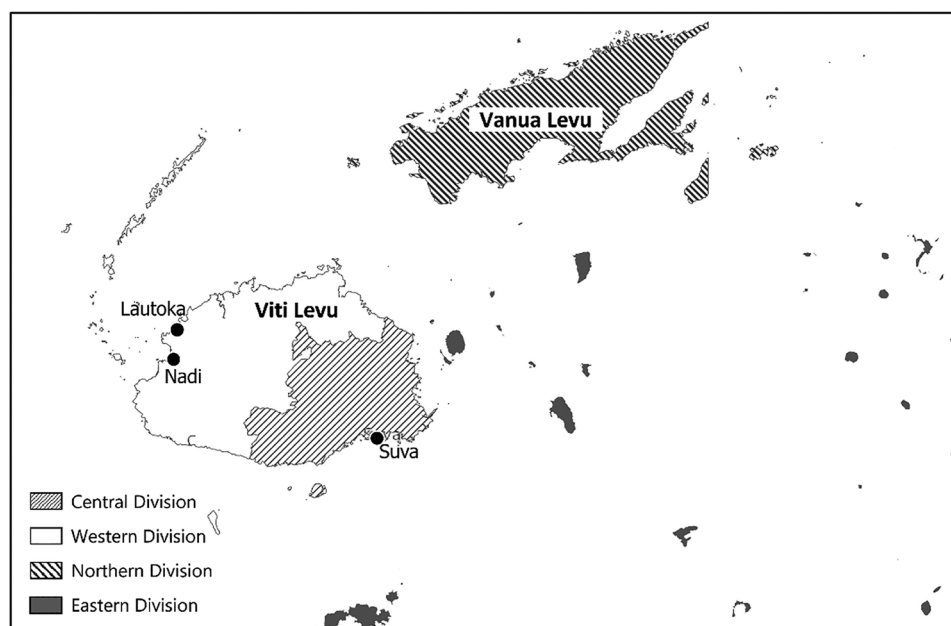


Figure 1. The Fiji Islands with health administrative boundaries and study sites (map created with ESRI, 2018; FBS, 2009).

Table 1. Description of the study sites with a focus on services for older people and mental health issues.

Characteristic	Suva	Lautoka	Nadi
Health administration	Central division	Western division	Western division
District hospital (public)	Colonial War Memorial Hospital (8 beds in mental health unit; outpatient clinics for mental health)	Lautoka Hospital (9 beds in mental health unit; outpatient clinics for mental health)	Nadi Hospital (sub-divisional hospital; outpatient clinics for mental health)
Specialist hospital (public)	Saint Giles Hospital (inpatient and outpatient services)	None	None
Health centres (public)	7	5	3
Private health services	Hospital, general practice, counselling	General practice, counselling	General practice, counselling
Residential aged care	Public (1) Small private or charity run facilities that serve older people (4)	Public (1)	None

researchers had strong existing connections were also important considerations.

Suva is the capital city of Fiji and is a major metropolitan area. The Greater Urban Suva Area (including Suva and the nearby towns of Lami, Nasinu, and Nausori) has a population of almost 270,000 people (FBS, 2019). Major public health services include Saint Giles Hospital (the country's only specialist psychiatric hospital) and the Colonial War Memorial Hospital (the major referral hospital in Fiji with comprehensive specialist, emergency, and outpatient services; FMHMS, 2016). Lautoka is located about 220 km by road from Suva, and 30 km north of Nadi (Figure 1). The public hospital is the referral centre for the Western division. Nadi is a major seaport to popular tourism destinations and has the country's main international airport. The Nadi locality is served by a sub-divisional public hospital (fewer specialist services; FMHMS, 2016).

Sampling and recruitment

Purposive sampling allows the recruitment of people who can offer the most relevant background and contextual information about a topic (Emmel, 2013). People living with dementia and family caregivers were recruited through mental health service providers and through 'word of mouth' as news of the study was shared in the community. Fiji Ministry of Health and Medical Services (MHMS) health care providers (doctors, nurses, and aged care workers) with experience working at the study sites were recruited during site visits. 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, charitable aged care facility and community organisations identified during a service mapping exercise were also invited to participate during site visits. In keeping with grounded theory methods, theoretical sampling (the process of seeking further data based on emergent ideas or concepts) occurred as data collection and analysis progressed (Charmaz, 2006).

Informed consent was collected from all participants. A process for consent for people living with dementia involved written third party consent from the family caregiver and verbal assent from the person living with dementia.

Data collection

Semi-structured interviews with stakeholders were carried out by the first author over a series of three field trips to Fiji in the year 2019 (January, June, and September), each of two weeks in duration. Due to international travel restrictions imposed in response to the COVID-19 pandemic, a Fiji-based researcher (mental health nurse; TR) carried out final data collection over three days in August 2020.

The interview schedules (Supplementary Material 1) were informed by the aim of the study and literature about understandings and experiences of dementia. 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 community members in Australia 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 participants had difficulty interpreting the questions, two vignettes (adapted from a study conducted in Goa, India; Patel & Prince, 2001) were used to assist with a shared understanding of the topic. One vignette described a person in the early stages of dementia and the other described a person in the later stages of dementia. Vignettes have been successfully used in other studies in situations where there is low awareness of dementia (Blay et al., 2008; Patel & Prince, 2001).

Data processing

Interviews and focus groups were recorded (with consent) and transcribed verbatim and supplemented with field notes. Where consent to record was not obtained ($n = 1$), detailed notes were taken during and immediately after the interview. All interviews were conducted in English except for one which was conducted in Fijian language. During this interview, a Fiji-based researcher (TR) translated the discussion in real-time so that the first author (a non-Fijian speaker) could be involved. A Fiji-based research officer proficient in Fijian and English transcribed the interview in Fijian and then translated it to English. In keeping with best practice (Chen & Boore, 2010), the transcript was translated back to Fijian by another local Fijian-English speaker, and key concepts were compared. An error was identified and amended in the original translation to English through this process. The translation omitted the word 'no' and changed the meaning intended by the participant—'[...] when we look at them we immediately know that there is *no* problem.'

Analysis

Transcripts were analysed in line with transformational grounded theory methods (Redman-McLaren & Mills, 2015). The

process was facilitated with QSR NVivo computer software for qualitative analysis (QSR International Pty Ltd, 2018). Open coding using the line-by-line technique was employed initially (for the first few transcripts) to sensitise the researcher to emerging patterns in the data. Analysis progressed to coding according to emergent processes and concepts. Focussed codes, sub-categories, and categories were constructed and reconstructed as decisions about the fit of constructs in explaining the data were made. The technique of constant comparison was used throughout the analysis processes with codes, sub-categories, and categories being constantly compared with each other. The grounded theory method of storyline, whereby the developing theory is written in narrative form (Birks & Mills, 2015), was central in drafting and eventually finalising the theory. After the grounded theory was constructed, an emergent theoretical code that tied the grounded theory together was considered to extend the explanatory power of the theory (Birks & Mills, 2015).

Trustworthiness

The majority of the analysis was carried out by the first author. At the beginning of the analysis phase, two transcripts were coded independently by three Australian-based researchers and compared with agreement on emerging concepts. As analysis progressed, input and guidance from all researchers was obtained during meetings where coding and interpretations were discussed. Grounded theory techniques of memoing, diagramming, and storyline were used throughout the research process to strengthen rigour and trustworthiness. The final theory was presented to Fijian service providers with positive feedback and importantly, the theory resonated with the Fiji-based researchers on the team both of whom provided mental health care for people living with dementia in Fiji.

Importantly, Fiji-based researchers (Fijian researchers with qualifications and extensive experience in mental health; authors SQ and TR) provided and negotiated guidance in organisation and cultural protocols, access to stakeholders, advised on next steps, and discussed findings and interpretations, and were central in gaining and understanding the knowledge shared for this research.

Ethics

This doctoral research was approved by the Fiji National Health Research and Ethics Review Committee (2017.2.NW) and [removed for anonymous review] Ethics Committee (H6798). The

research was conducted with the necessary research governance approvals as required by various national and institutional bodies in Fiji.

Findings

A total of 50 participants (40 service providers, eight family caregivers, one person with dementia, and one village elder) shared their views and experiences about dementia through 37 semi-structured interviews and three focus groups. Eight family caregivers and one person living with dementia from seven family units shared their views (Table 2). Six family units lived in Suva and one lived in Lautoka. All family caregivers cared for an older person living with dementia in the advanced stages of the condition (the older person living with dementia had died before the time of interview in two family units) and all except one resided with an older person who had been diagnosed with dementia.

Other participants were health service providers ($n=30$), aged care providers ($n=6$), providers in the community sector ($n=4$) and one village elder (Table 3). Service providers worked in hospitals, mental health outpatient and community services, health centres, private general practice, and aged care homes, and 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 for many years.

The majority of interviews and all focus groups were carried out by the first author, with Fiji-based researchers (SQ and TR) also involved in some interviews. Interviews with family caregivers and a person living with dementia occurred face-to-face at homes or in private spaces at a health facility or workplace, or online. Three interviews with family caregivers 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. A person living with dementia shared some experiences of living with their condition however mostly offered remarks confirming their family member's experiences of dementia. Three interviews ranged in length from 10 to 15 min due to time constraints. The remaining four interviews ranged in length from 40 to 85 min with an average of 55 min.

All interviews with service providers were conducted in private spaces at places of work. Interviews ranged from 10 to 54 min in duration, with an average duration of 23 min. Two focus groups ($n=4$ and $n=3$) consisted of mental health nurses and one focus group ($n=3$) consisted of nurses providing aged care services, with an average duration of 25 min.

Table 2. Characteristics of participants within family units.

Family unit (interview reference)	Participant type	Age participant (years)	Relationship to person living with dementia	Age person living with dementia (years)	Living arrangements
Unit 1 (I-4)	Family caregiver	40–49	Son	80–89*	Residing together
Unit 2 (I-10)	Family caregiver	50–59	Son	80–89	Residing together
	Family caregiver	20–29	Grand-daughter		
Unit 3 (I-11)	Family caregiver	40–49	Daughter-in-law	60–69	Residing together***
Unit 4 (I-12)	Family caregiver	20–29	Daughter	60–69	Residing together
Unit 5 (I-14)	Family caregiver	40–49	Niece	70–79	Residing separately
	Person living with dementia	70–79	N/A	N/A	Residing with other family members
Unit 6 (I-35)	Family caregiver	70–79	Spouse	80–89	Residing together
Unit 7 (I-37)	Family caregiver	70–79	Daughter	90–99**	Residing together

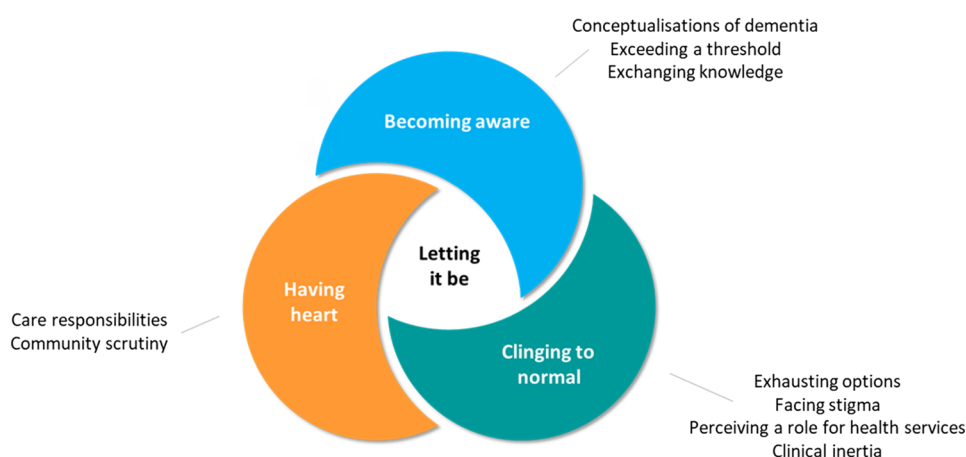
*Deceased for 1 year at time of interview. Alive during study period.

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

***Residing together until just prior to interview.

Table 3. Characteristics of service providers, community providers and leaders who participated in semi-structured interviews and focus groups.

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

**Figure 2.** A diagram depicting the key processes (and main themes) of the grounded theory.

'Letting it be': a grounded theory about managing dementia care

The grounded theory developed through this research centred on the sociocultural construct 'letting it be' as the core process in the management of dementia care. Contrary to the passive connotations evoked by the terminology (that emerged from participants' own words), the construct 'letting it be' expresses a compassionate approach to caring for older people with cognitive decline or dementia that involves searching for knowledge and support, and application of traditional care practices within the strength of family and community networks.

'Letting it be' is the grounding construct that interweaves and binds together the three key processes of dementia care management: 'becoming aware', 'clinging to normal', and 'having heart' (Figure 2). These processes are influenced by two main mechanisms to shape the dementia care experience: (i) 'knowing' which manifests in social norms, professional training, experiences, awareness, and stigma, and (ii) the 'capacity to manage care' which is inclusive of family support, community support and resources. The dementia care experience ranges from 'being forgotten somehow'—a phrase used by a mental health nurse (I-6) that captures the mystery of how neglect of older people could happen in a society with strong social norms around family responsibility—and 'trying our best' (family caregivers, I-10). In this section, each key process is summarised, then described by main themes with supporting evidence. The two main influencing mechanisms of the theory are integrated throughout this section and exemplified in [Supplementary Material 2](#).

The process of becoming aware

In considering the wellness of older people with signs of cognitive decline, family and service provider caregivers engage with a process of 'becoming aware'. Caregivers draw on existing knowledge and beliefs to explain changes associated with cognitive decline and to make judgements about the seriousness of these changes. Awareness of an issue affecting an older person may develop gradually over a period of time or abruptly due to a crisis event. 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.

Conceptualisations of dementia

Ageing within social norms—'getting to that stage'

Signs of cognitive decline and dementia in older age were readily explained within social norms for ageing and therefore were 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). There was a high tolerance for changed behaviours in older age, as clearly captured in a story from a village elder (I-36): 'He [village elder] 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 [piece of clothing that wraps around the waist] again and take him into the house.'

Becoming forgetful, acting immaturely, and being grumpy at times was expected in older age, by both main cultural groups, as a mental health nurse (I-13) explained: '...the thoughts are that when we get old we will become forgetful. That's what they know.' This was particularly true in relation to those aged over 80 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 [referring to members of the community], 83, 84 and 86' (community health worker, I-23). On the contrary, such changes in a younger person were seen to be an important issue. Some service providers reported sharing this expectation of older age until learning about dementia during their health profession studies. Participants often associated the development of dementia with other potentially causative or associated factors including older age, such as loneliness, lack of purpose, a busy or stressful life, having many children, experiencing a stressful life event, and poor lifestyle behaviours.

Associations with mental illness and cultural beliefs

Both main cultural groups also associated signs of dementia with mental illness, with stigmatising terms reportedly used by the community to describe the condition: 'pagala' (Fijian Hindi; mad) and 'lialia' (iTaukei; mad). Perceptions of dementia overlapped with mental illness and cultural understandings of psychosis in the iTaukei concept 'cavuka' which describes a disconnection from reality or a sudden loss of sound mind. A counsellor (I-3) with personal experience of caring for a person living with dementia explained: 'Cavuka means you have been disconnected somehow. Disconnection can also happen to women and also to elderly. And then they [community members] say "O koya sa cavuka buti koya tuga. [The person cavuka. Just leave them]."'

Unusual, disruptive, or concerning behaviours observed in older people were also reportedly conceptualised within magico-religious beliefs, as a mental health nurse (I-13) 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...' Similarly, the behaviours of an older person showing signs of dementia could be explained by an ancestral curse or connected with suspicion of performing witchcraft or being related to someone who was suspected of performing witchcraft. Some participants thought that such beliefs were applied more commonly when a younger person was observed as showing signs of dementia.

Exceeding a threshold

Family caregivers talked about noticing changes in their older family members before a diagnosis of dementia. They 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. These changed behaviours shifted over time (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. Participants described changes in behaviour that were 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, as especially concerning.

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. Crisis events that were experienced by family caregivers required immediate intervention from a health service or emergency services. A further crisis was reported to sometimes occur due to misinterpretation of changed behaviours associated with dementia which resulted in conflict and the breakdown of family relationships, 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).

Exchanging knowledge

Family caregivers who became concerned about changes they observed in an older family member drew on their own experiences and compared them with others in an effort to make judgements about the well-being of their family member. They accessed their knowledge networks which most commonly included family, friends, neighbours, and the internet. Service providers, as community members with a role in the health sector, provided a connection between community members and health services as a mental health nurse (I-6) explained: '... 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?"'

Service providers were aware of dementia and could explain it in simple terms to a patient however confidence in talking about dementia was lacking. 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. 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 (I-21) explained: 'Dementia, [...] 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 [...]' However, it was reported that few people diagnosed with dementia attended services at health care centres and mental health clinics. Service providers in the areas of general health and mental health recognised the need for more education and training on dementia and management of dementia for themselves.

The 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. They consider possible causes for the unwellness of their older family member, the role of health services in addressing the wellbeing of their older family member, implications related to stigma as well as their capacity to manage care within their own resources.

Exhausting options

Participants reported pluralistic help-seeking behaviours for concerns with signs of dementia. Causal beliefs associated with curse, witchcraft, or perceived problems with a person's faith prompted spiritual healing through prayer and ceremony. This involved prayer at Hindu temples and Christian churches, performing traditional customs for forgiveness ('*bulubulu*'), and/or visiting with church leaders, church groups, and traditional healers. Traditional medicine was also reported to be a likely remedy sought out.

Accessing help at a health service was described most commonly as a final option resulting in presentation at health services at more advanced stages of the condition. Service providers 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. Barriers to accessing a health service included 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. Once diagnosed with dementia, additional costs reported by family caregivers were medication and payment for caregivers or housekeepers.

Facing stigma

Mental illness was reported to be strongly stigmatised and to pose a significant barrier to seeking help from mental health services, particularly services offered by Saint Giles Hospital, as clearly described by a doctor (I-17): '*...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 Saint 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.*' Participants shared that there was low awareness of available mental health services outside the main psychiatric hospital and providers working at these services also spoke of stigma as presenting a barrier to the use of their services (though noted stigma as lessening in more recent times). Stigmatised responses to mental illness described included neglect, ridicule, and disconnection from community life. Older people with signs of dementia or diagnosed with dementia could also be blamed for their condition through attributions of magico-religious beliefs involving witchcraft, curse, and ancestral curse, and would also face stigmatising responses from others in their community.

Perceiving a role for health services

Participants described a role for health services in dementia care and care for older people with cognitive decline as being associated with the possibilities of treatment—the need for, and effectiveness of, treatment—particularly when care was considered to be well managed without health sector involvement. The pervasive view of expected cognitive decline in older

age was thought to prevent help-seeking from health services for older people in general, as a doctor (I-22) described: '*They just think [...], "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.*' Likewise, there was an expectation that health services could relieve conditions with medicine, as a mental health nurse (I-19) explained: '*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.*' Indeed, this was the primary reason for one family caregiver (I-11) of a person living with dementia to attend a mental health service: '*That is why we take him to Saint Giles, give the tablets and he's fine eh.*' The family caregivers that participated in this study maintained regular contact with health services through clinic and domiciliary visits however service providers noted that maintaining contact with patients was challenging.

Family caregivers shared various strategies they used to manage the care of their older family member who was living with dementia. These included stopping their older family member from doing certain things 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. Moreover, there were examples in experiences that family caregivers shared that demonstrated a desire as well as action to support the personhood of their older family member, as seen in a story from a daughter of a person living with dementia (I-37): '*Ma [person living with dementia] always invite Aunty Helen to 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].*' However, some family caregivers shared that they had been forceful, though rarely, in some interactions with their older family members.

Some service providers were confident that dementia was managed, or could be managed, appropriately within family support networks. Mental health providers 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. They promoted '*tender loving care*' and acceptance as the most important strategies for looking after family members with dementia.

Clinical inertia

Service providers at health services, particularly general health services, demonstrated clinical inertia towards older people with cognitive decline and possible dementia, as described by a nurse at a primary health care centre (I-28): '*... like chronic cases when they come with that, it's, we don't, like that is maybe secondary, maybe fourth, fifth thing down, six, seventh down the line and then we you know diagnose. But we usually just diagnose you know, the thing they present with.*' This phenomenon was clearly evidenced in the experiences of one family caregiver (I-4) whose concerns about his mother's memory were dismissed by providers at a primary health care centre and again during a subsequent dementia-related emergency hospital admission until he advocated for his mother to be reviewed by a mental health doctor: '*...before she was discharged and everything, all the scan was done, then I mentioned it to her [the doctor], "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.*'

Possible explanations for clinical inertia were evident in participants' 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. These options included the belief that an older person was being adequately cared for within the family, and a burdensome and long pathway to diagnosis for patients including travel to mental health services at main centres and delays in laboratory results. Service providers shared concerns that there were undiagnosed people living with dementia in the community and that some of these older people were ridiculed or neglected.

The process of 'having heart'

There is a strong preference, driven by cultural and social norms, to care for older people within family and community networks thereby sustaining connectedness into older age. However, the realities of care responsibilities in particularly demanding times, as is the case with dementia, can be challenging for caregivers to negotiate.

Care responsibilities

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'. A village elder (I-36) explained that in the village setting, when an older person is no longer able to do things for themselves, the titoko (a 'walking stick and guide' that is a role of honour) 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.'

Similarly, other participants 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.

Fijians of Indian descent were also reported to practice traditional ways of caring for older people whereby care for older people remained within the extended family network and care responsibilities often fell to the son (and the daughter-in-law). Participants shared that there was high emigration of younger generations of Fijians of Indian descent in recent times leaving fewer people available to provide care for an older person.

Contemporary lifestyle was reported by some participants to be changing with more nuclear family units, increased busyness, and a loosening of family and community bonds, with no change in expectations of family responsibilities. Qualified caregivers were considered expensive and their potential role in dementia care in the home was largely unrealised. Housekeepers (who were usually connected to the family in some way) were more often brought into the family home to help if finances allowed.

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 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, as a son (I-10) caring for a family member with dementia described: 'Yeah, only us would know eh. When people ask "How is your mum and all?" Just really... hard work nearly every day. Just... yeah.'

Community scrutiny

Caring for a person living with dementia could be associated with disapproval from community members with families feeling judged as being burdensome or socially stigmatised for not meeting their obligations in caring for their older family member. In particular, aged care homes were commonly viewed as places for neglected older people whose family no longer cared about them. Similarly, some participants shared that families may expect that their care responsibilities to a person with a mental illness or dementia shifted to health providers once a family member was admitted to an institution (aged care home or mental health facility) and there was a risk that such people would be abandoned at services, as reflected in the words of a mental health nurse (I-19): '[...] 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].'

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 shared that earlier in their experience of dementia her family advocated unsuccessfully for her father, who had advanced dementia, to be admitted to the local hospital for a long period of time. Her father had since become bedridden, her mother gave up her job and became his primary caregiver and she was now the primary source of income for the family.

Extending the grounded theory with an ecological perspective of health

The grounded theory constructed describes actors, processes, and contexts that interlink to shape understandings and management of dementia care. A theoretical code that tied together the central construct 'letting it be' and the three key processes of dementia care management emerged through the data analysis process. A socioecological perspective on health was explored to extend the explanatory power of the grounded theory. McLeroy et al. (1988) proposed that determinants of health behaviour may be influenced by intrapersonal factors, interpersonal processes and primary groups, institutional factors, community factors, and public policy. The factors that influenced the management of dementia care identified in the constructed grounded theory were relatable within this model. The constructed grounded theory was integrated with existing socioecological theory by drawing on health and caregiving literature in Fiji on views of ageing and wellbeing, sociocultural meanings of illness, circumstances of the older person, older woman and family, and actions of policy levers. This has been incorporated into the discussion section to a small extent with full reporting available elsewhere (Johnston, 2021).

Discussion

This is the first in-depth study about dementia in Fiji, and in the smaller PICs, to the authors' knowledge. The grounded theory constructed provides insight into factors that influence caregiving and service provision for older people living with dementia in Fiji, and highlights the interplay of culture, tradition, biomedicine, and modern lifestyles in shaping understandings and experiences of dementia.

Similar to other LMIC settings and indigenous populations (Jacklin & Walker, 2020; Johnston et al., 2020), understandings of dementia in Fiji were heterogenous and viewed within constructs of normal ageing, mental illness, and spiritual or magico-religious beliefs. Further, cognitive decline and dementia in older age was experienced through a lens of deeply established cultural and societal norms that prioritised family networks and community values in the care and well-being of older people. This fits within existing descriptions of Pacific Islander views where the idea of well-being is experienced within the group self and is understood within constructs of social order, spirituality, reciprocity, and obligation (Capstick et al., 2009; Groth-Marnat et al., 1996; Ravuvu, 1983). The centrality of supporting spiritual well-being through cultural practices and collective obligations for Māori (indigenous New Zealanders) family caregivers of people living with dementia has also been reported (Dudley, 2019). Critically, and as also reported in some other LMICs and indigenous populations (Chan, 2010; Lanting et al., 2011; Ugargol et al., 2016), realities of living with and caring for an older family member in contemporary times challenged ingrained caregiving values.

Of crucial importance, the implicit role of families in caring for older people in Fiji facilitates care in place in the community and amongst family. While this is driven by cultural and societal norms, other determinants include economic dependence of older adults on others due to limited government social welfare, lack of income security (just 40% of the workforce contribute to the national superannuation fund), and reliance on unpaid subsistence activities (Asian Development Bank, 2015). Women, widows, and older people with disabilities are particularly at risk of living in poverty and alone (Fiji Women's Rights Movement, 2017; Panapasa, 2002). High expectations of families in terms of care responsibilities for older people can be unattainable for some families, particularly those with smaller, exhausted, or fragile kinship networks or those with low resources, and places older people (particularly those with health needs, such as dementia) at risk of neglect. This has implications for stronger income security policy that supports planning for the needs of an older adult, stronger policy around social security to support older adults as well as tangible financial support for those providing care for older adults at times of need.

Strong family caregiving values together with high acceptance of memory loss and changed behaviours in older age masks the true impact of dementia on families and communities. This contributes to slow evolution of policy and health and social system responses to dementia in Fiji. Indeed, the Fiji National Policy on Ageing (2011–2015) includes a statement supporting the need to train providers in care for older people living with dementia. However, as with other policies that attempt to address the needs of older adults in Fiji, there is a lack of detailed strategies, monitoring, and resources for implementation (Palagyi et al., 2022). A lack of policy and strategy

contributes to dementia being perceived by health stakeholders as low priority which in turn perpetuates low awareness of dementia, late help-seeking, clinical inertia, and inadequate systems responses towards older people with cognitive decline and dementia.

The findings of this study point to the need to strengthen referral and diagnostic pathways, and post-diagnostic care for older people living with dementia. The benefits of an early diagnosis of dementia include providing an explanation for signs and symptoms, access to support, and time to adjust and prepare for changes associated with dementia (Rasmussen & Langerman, 2019). Currently, diagnoses of dementia are usually made by public psychiatrists or doctors with special skills in mental health (of which there are few), or much less commonly by general practitioners with confidence and special skills in mental health. Diagnoses involve the Mini-Mental State Exam with adaptations made by doctors as needed and in conjunction with other tests to rule out other conditions. The role of primary health care in early diagnosis and post-diagnostic management of dementia in Fiji is minimal and obscured in large part by low awareness of dementia amongst the general community and service providers, and seemingly high capacity of family networks to care for older people. In Fiji, there is an absence of specialised services to support older people, particularly older people living with dementia and their families. Integrating dementia care with chronic disease management within primary care and community-based services is recommended for countries with constrained resources (Prince et al., 2009). This would be a beneficial and realistic first step in Fiji's health system response to dementia.

Future approaches to dementia care in Fiji should focus on the integration of sociocultural understandings of dementia, and promotion of cultural values of wellbeing and care, with service provision across health and social sectors. In the clinical space, this is already occurring to an extent with health professionals integrating Fijian values around care for older people with biomedical management of dementia care through education about strategies that show 'tender loving care'. Training for all health service providers on recognition of dementia and dementia care management (particularly evidence-based non-pharmacological strategies adapted for the Fijian context), diagnosis of dementia including disclosing a diagnosis, communication, and planning for the future is important in supporting service providers, people living with dementia and family caregivers (Prince et al., 2009). Further, knowledge of dementia has been associated with changing service providers' attitudes and more positive attitudes towards caring for people living with dementia in other settings (Schneider et al., 2020; Surr et al., 2016).

Crucially, awareness campaigns need to harness Fijian ways of knowing and include Fijian understandings of dementia with special attention to the cultural and social meanings of dementia, vocabulary, language, and de-stigmatisation. In Canada, for example, health promotion materials that combined Indigenous and biomedical knowledge about dementia were developed for First Nations peoples using the 'two-eyed seeing' approach (Webkamigad et al., 2020). Family, friends, spiritual healers, and the broader community are the usual sources of support for dementia care therefore education about dementia for the general community is a fundamental strategy to support knowledge sharing throughout Fiji.

In addition, support for informal care through community networks and education is particularly important in Fiji. Education for families and communities about caregiving for older people in general, with cultural considerations, may provide the tools needed to support care for older people within family and community networks and reinforce the ability of families to provide appropriate care. Informal care networks form a strong foundation for dementia care in Fiji. Purposeful, tangible support for these networks, such as through strengthening of financial support and care pathways, could deliver important lessons for the optimal management of care for people living with dementia.

Strengths and limitations

The grounded theory was constructed using robust, theoretically informed methods and analysis with input and guidance from a team of researchers including local Fijian and Australian practitioners and researchers with experience in dementia. Critically, the grounded theory had 'grab' in Fiji.

There are several important limitations. This research set out to include the voices of people living with dementia however only one person living with dementia shared experiences of living with their condition mostly offering remarks confirming their caregiver's experiences and views on dementia. The processes of 'letting it be' are grounded in the experiences of dementia and dementia care as told by family caregivers and service providers. A further limitation was that all family caregivers described caring for a person living with dementia that we surmised to be experiencing moderate to advanced dementia. Low awareness of dementia, low diagnosis of dementia, and high acceptance of cognitive decline in older age prevented thorough exploration of the experiences of people living with dementia explicitly related to early, moderate, and advanced dementia.

Another limitation was that the involvement of participants in the analysis was limited to discussions with the Fiji-based team and *ad-hoc* with other service provider participants during field trips. These people also represented the stakeholder groups with the most experience in dementia care, aside from family caregivers. Further, the need to work in cycles of data collection in Fiji and analysis outside Fiji limited theoretical sampling (in terms of recruitment of new stakeholder types based on emerging concepts). Finally, the grounded theory was constructed through a lens of 'common ground' given the broader societal and political changes that have been happening in Fiji since independence from colonial rule in 1970 as the two main ethnic groups, iTaukei and Fijians of Indian descent, continue to forge a path forward 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 have not been captured in this research.

Conclusion

Dementia is an emerging health and social issue for older people, families, communities, and the health and social system in Fiji. 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. In Fiji, support for dementia centres on the

integration of community understandings, and promotion of cultural values of well-being and care, with service provision. It also focuses on support for families and communities through social welfare, community networks, and education.

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ORCID

Karen Johnston  <http://orcid.org/0000-0002-0477-4666>
 Robyn Preston  <http://orcid.org/0000-0003-4700-1521>
 Edward Strivens  <http://orcid.org/0000-0002-7260-508X>
 Sarah Larkins  <http://orcid.org/0000-0002-7561-3202>

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