‘O le toe Fa’amoemoe ‘o le ‘Aiga - A Family’s Last Hope

Understanding of Hospice and Palliative Care among Samoan Women Family Caregivers

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Abstract

Introduction: In general, populations worldwide are aging with non-communicable diseases more likely to affect the elderly; and this group is prone to suffer from more than one chronic condition often resulting in complex clinical and psychosocial situations. As a result, the need for hospice and palliative care services will increase. However, Pacific people prefer to be cared for at home by their family, and they are therefore less likely to access and use hospice and palliative care services. There is limited evidence as to why there is less use of hospice and palliative care services, and there is a gap in strategies aimed at improving access within a Pacific context. This aligns with a poor understanding of the availability of health services more generally within a Pacific context. This research explores the understanding of these services by Samoan female family caregivers who cared for an elderly relative diagnosed with a life limiting condition, in Auckland, New Zealand.

Methods: Qualitative methodology was used, and was underpinned by two approaches: Talanoa, and Constructivist Grounded Theory. Participants were interviewed and the data subjected to thematic analysis.

Results: Findings from the research acknowledge the importance of understanding cultural beliefs and values, and the relationship between these and the understanding and utilization of, hospice and palliative care services.

Conclusion: Several opportunities are identified to enhance engagement by Samoan families with these services.

Keywords: Samoan, culture, hospice, palliative care, caregiver

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Pacific Health, vol 7, 2024, DOI:10.24135/pacifichealth.v7i.79

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Introduction

The purpose of palliative care is to relieve pain and suffering and improve the quality of life of the patient who has been diagnosed with a life limiting or life-threatening illness. This requires the early identification, assessment and treatment of pain and other issues, and all within the physical, psychological, and spiritual domains (New Zealand Palliative Care Strategy, 2001). Despite this stated strategy, providers and users of palliative care services still report difficulties in gaining access and that referral typically occurs later than is recommended (Lowe & Liversage, 2013). There is an additional challenge: although palliative care was initially provided for patients diagnosed with a cancer, palliative care services are increasingly caring for those diagnosed with non-malignant diseases such as dementia and cardiovascular disease (World Health Organisation, 2022).

Recent research by Gurney et al (2022) has explored patients' choice in relation to place of death. This research specifically focused on patients dying of cancer, and the majority of patients were elderly. Data indicated that, while slightly more than half of people with cancer would prefer to die at home, about one third will die away from their preferred place of death. In New Zealand, findings from this study also showed that Pacific patients are much more likely to die in a private home (41%), or in a hospital (34%), rather than in a hospice (15%) or an aged residential care facility (10%). From their research, it was not clear if these were choices that represented a preference for place of death, or, the place of death is a consequence of differences in access to palliative care.

Therefore, towards the end of one's life, and particularly during their active dying process, older people are often spending that time in an unfamiliar location, and one that is institutionally and not home care focused. This does potentially mean a higher level of expert care, but not being in one's home can add an additional emotional burden to both patient and their family.

New Zealand’s population is aging, is ethnically and culturally diverse, and is expected to double by 2040. Additionally, the aging experience differs across ethnic groups (Parr-Brownlie, et. Al., 2020). This has implications across all aspects of home and institution-based health care delivery. In the next 10 – 15 years, this ethnically diverse population is predicted to increase. Specifically, the Pacific population – 0.41 million in 2018 - is expected to increase to between 11.6 – 12.0 per cent in 2028, and to between 13.9 – 17.8 percent in 2043 (Statistics New Zealand, 2021). These statistics speak to a need to ensure Pacific peoples, along with all culturally and ethnically diverse groups, have a knowledge of what palliative care services are available and what this type of care means for both patients and their families.

The joint publication by The Palliative Care Council of New Zealand and Cancer Control New Zealand, aims at defining a strategy for the delivery and the measurement of effectiveness, of palliative care services across all populations within New Zealand. This will be done through ensuring sufficient capacity of services, appropriate referral processes, continuity and coordination of care, that best practice is followed, and that the needs of patients and their families are met (Cancer Control New Zealand, 2012).

Importantly, and because of the diversity of Pacific cultures, palliative care services need to take into account the unique cultures and values of Pacific peoples as these views do not correlate with the dominant Western perspective (Bellamy & Gott, 2013; Foliaki et al, 2020). In addition, it is known that when Pacific people are diagnosed with a life limiting condition, most Pacific peoples prefer to be cared for at home by family members. These authors also report that when Pacific elders are nearing the end of life, family members are the main providers of care. Hospice based palliative care providers do collaborate with many community services in supporting and enabling Pacific families to care for their dying loved ones at home. However, hospice services are less likely to be used and accessed by Pacific people in New Zealand (Bray & Goodyear-Smith, 2013; Foliaki et al., 2020). Specific cultural values and beliefs guide practice. Le Va in the Fa’a Samoa way refers to respecting the sacred space between males and females. Daughters cannot change or shower their fathers; sons cannot change or shower their mothers. But again, this is subject to each family.

Death is an inevitable event and different cultures and religions understand and conceptualise death, dying and bereavement in different ways (Pentaris, 2011). Although Pacific people in New Zealand are grouped under the term ‘Pacific’, each island has their own experiences, traditions and beliefs regarding death, dying and bereavement (Medical Council of New Zealand, 2012), and this is true within the Samoan culture. To understand the experiences and needs of individuals around death and dying it is important to first understand the uniqueness of their culture and faith which shapes their values, beliefs and perceptions. Faith in Samoan culture is also an important aspect to understand when looking at death and dying as both culture and faith shape the conceptualization, and therefore the rituals and practices of death, dying and bereavement among Samoan people (Schwass, 2005). Samoan people are part of a community and collective group who are multi-connected and belong to a very wide network of *aiga* or family and communities and when *fa'alavelave* (crisis or unfortunate events) happen, such connections and networks are vital during times of sadness as it is through the loving care and support of others. Values such as aiga, alofa (love), tautua (service) and respect (fa'aaloalo) underpin and govern decisions regarding the care of parents, grandparents and family members especially when a life-limiting diagnosis is made. It is these values which help families get through difficult and stressful times (Seiuli, 2013).

When families and communities are notified of someone approaching death, that person is never left alone. Many visitors come to pay tribute and say their farewells to the dying person as well as to support the family. Ministers or priests are also present in order to comfort the dying as well as to lead prayer meetings, and church choirs and groups will arrive to pray and sing. The terminally ill elderly relative will always be surrounded by people and activity whether they are cared for in the home or in the hospital or hospice. Within Samoan culture, it is an honour to care for elderly or dying parents and those who do care become richly blessed and privileged as a result. From a Pacific point of view, having family members in institutional care is culturally inappropriate (Cullum et al, 2020). Fa'a Samoa values are preserved when care is provided within the home setting (Fernandes et al, 2021). There is an expectation that close family members will assist in caring for the dying as well extended families providing financial and emotional support and assisting with work such as cleaning, laundry and preparing meals for visitors. Carers may use this time to reconcile with the dying person and ask for their forgiveness for any wrong doing or any offence caused. At the time of death, the last people to embrace and cover the head of the dying family member are those closest to the person (Schwass, 2005). It is important that health professionals involved in the care of the terminally ill, have a knowledge of these cultural norms, or a willingness to learn. Acquisition of such knowledge could be obtained through an education programme provided by a Pacific peoples' health provider. Employing a culturally appropriate approach, and with specific regard for participant levels of health literacy, is essential as, despite such strongly embedded values of caring for family members, research by Taueetia Su'a (2017) reported that nearly 90% of Pacific peoples aged 15 years and over, did not have an adequate level of health literacy.

To enable health professionals to engage in best practice when providing palliative care for Samoan people, the current study was undertaken. Samoan women caregivers were recruited as participants as, in Samoan culture, the norm is for elderly Samoan to live their last years with one of their children, and often the eldest daughter (Fernandes & Allen, 2024). The intention was that the voices of these female caregivers are heard.

Methodology

The key objectives of the study were: to identify barriers to accessing palliative care services; to identify ways in which information and support services about palliative care can best be provided; and to gain an understanding of the views held by Samoan women family carers regarding palliative care services.

An ethics application was submitted to and approved by the University of Auckland Human Participants Ethics Committee (Approval Number 014940).

A qualitative research design was used for this study as it provides a clear and in-depth understanding of how people interpret their experiences and the meaning they assign to their experiences. This type of research design also involves emerging procedures and questions, as well as the collection of data in the setting of the participant. This should take place where participants can give voice, report and interpret their experiences and understanding. It includes an inductive approach to data analysis where emerging themes are constructed from the bottom up and the researcher can interpret the comments made by the participants (Merriam & Tisdell, 2015). The theoretical paradigms chosen for the study were the Constructivist Grounded Theory (CGT) approach of Charmaz (Charmaz, 2006), and the Pacific research methodology Talanoa framework introduced by Vaioleti (2006).

While these two methodologies remained separate, and with CGT being the main approach, Talanoa allowed a fuller understanding of the worldviews and values which maintain the integrity of the participants as Pacific cultural beings, and provided a culturally appropriate method for the Samoan female participants. Utilising these two methodologies together provided a rich and holistic view of the experiences of the participants.

Recruiting through personal networks, and using a purposive sampling approach, Samoan female caregivers 18 years or over and who resided in the Auckland region, were selected. These caregivers were caring for or have cared for an elderly family member aged 60 years and over, and with a life limiting condition where death is inevitable. Face to face semi-structured interviews conducted in both Samoan and English language, were recorded and analysed. Following the CGT methodology, memo writing, data analysis using initial coding, focused-coding and theoretical-coding, were undertaken. Data themes, with verbatim participant statements, were finally reported.

The research is strengthened by being undertaken by a researcher of Samoan descent with fluency in Samoan language, and one who had seen the confusion about these services from within their own family. These factors enhanced the mutual understanding between the researcher and participants and allowed for the building of rapport and trust, both of which are important Samoan and Pacific concepts.

Results

Sample Characteristics

Twelve participants (numbered P1 to P12) took part and with ages ranging from 23-80 years. Five participants were born in Samoa with the remaining born in New Zealand. Half of the participants were single at the time of the interview, one indicated they were in a relationship, three specified they were married and two were widowed. Eight were employed at the time, three unemployed and one retired. Eight had attended tertiary education. Six identified as belonging to a Congregational Christian church, three as members of a Protestant church, two identified as Catholic and one was a member of the Church of the Latter-Day Saints.

Six of the participants cared for their mother, two participants for both parents, one cared for her father, one participant cared for her grandmother, one participant cared for her aunt and one participant cared for her husband. All the participants lived with their elderly relative.

After their relative was diagnosed with a life limiting medical condition, one participant cared for their elderly relative for five months, five participants cared for their elderly for a year after diagnosis, three participants cared for their elderly for between 2-5 years, and three participants cared for their elderly for 10 years or more. Samoan language was the main language of communication for seven of the participants, and five used both Samoan and English to communicate with their elderly relative. Half of the people being cared for died in a hospital, with the rest occurring in a hospice, in an aged residential care facility, and at home.

Thematic Analysis

With respect to hospice and palliative care services, data were analysed grouped into four main themes:

- Participant understanding
- Participant experiences
- Challenges in using services
- Strategies to increase utilisation of services

Data were analysed under each of these themes in order to address the three key study objectives. Within each of these themes were several sub-themes. Examples are given for each theme.

Theme One: Participant Understanding

Participants were asked what they understood about palliative care and participants recognised palliative care as a type of care provided for loved ones who are dying.

> *"Palliative care is comfort care just to get you comfortable, manage pain, and make sure you're at peace and you have family and you can have anything that you want."* ***(P12)***

> *"To me it's like she's going to go and die so I said no, I can take care of her she can stay at home and we'll look after her, but that place (hospice) is a sad place."* ***(P7)***

Theme Two: Participant Experiences

Only four participants used palliative and hospice services. Two had their relative die in a hospice, and two were provided with palliative care services at home by the hospice. When asked about their hospice experiences, the two participants shared how they had been cared for by the staff at the hospice. These participants also indicated how caring and understanding the hospice staff were towards them and their terminally ill relative, and overall had a positive experience.

> *"From that day, cause we were cared for, the nurses came in, they asked how was dad how am I, it was awesome! The nurses, they came and checked on me and him all the time, they didn't come and check in a medical way, it was*

> *like, are you alright, is there anything you want to do kind of thing.”* ***(P5)***

Samoan women must only be changed or showered by female health professionals only.

> *“They were changing my mum but there was a Palagi (European) man there and the island lady was doing the changing but I was really angry. That’s the thing I didn’t like (cries) cause I was thinking this is so terrible I felt so sorry cause I thought there we are and I know my mum doesn’t like anyone else to [change her] I’m so sorry to my mum that we even took her there.”* ***(P1)***

In being offered palliative care services participants were asked if they had used respite care. Some participants noted that caring for their mother was not a chore and did not use respite care services because they felt they did not need a break.

> *If our family needed a break from looking after Mum, we had 3 weeks every 3 months that mum could go into a rest home/ hospice. We didn’t take it. The reasons for not taking it is we don’t look at looking after my mum as a job. What do you mean have a rest? Did my mum have a rest when we were growing up? I don’t think so, and could she go for three weeks and not look after us?”* ***(P12)***

Most participants expressed that, if their mother would have to stay overnight at either the hospital or hospice, they never left their mothers alone by themselves.

> *“I always feel like there has always got to be a girl with my mum like she can’t be - even if our brothers are there, they can’t do the stuff that needs to be done. That’s what I learnt from my mum – you never leave someone alone. I didn’t trust the hospice care enough to leave her on her own. My trust wasn’t in the hospice it was in my family. Like I just needed to know that*

> *someone from my family was with mum."* ***(P1)***

Some participants expressed a lack of understanding of pain management.

> *"I wish I had known all that cause I was just like she's in pain, we're not doing anything about it so all I can do is just fofo (massage) her, and that's all I was doing, was just massaging her breast and I'd do it for hours and then she'd be like 'ia lava ga' (that's enough) I think she thought I was doing it for 5 minutes not knowing it had been 4 hours later. I knew it was just sore. Pain meds were just Panadol and those other meds. It was so hard."* ***(P4)***

When participants were asked about services they needed, but were not available when they were going through palliative care, many participants acknowledged their need for a spiritual counsellor - someone who can talk to their family and loved one before they pass away. Participants also mentioned how their spiritual wellbeing as caregivers was provided by their own local church.

> *"I talked to my mum and she said just leave it – kuu ai faapea, po'o le a le finagalo a le Atua. (Leave it as it is, whatever the will of God is)"* ***(P8)***

Theme Three: Challenges Using Services

It is a cultural belief that it is the duty of family members to look after their own family members. Particularly in the Fa'a Samoa way, it is the role of the daughter or granddaughter to care for the parents especially their mothers.

> *"They offered that, they encouraged me to do that but I wouldn't. I think it's my cultural thing as well, like I'll feel more guilty putting her in there. I knew she'd be more comfortable at home, I didn't want her to get more upset if I took her there."* ***(P11)***

Participants shared experiences with other family members. Extended family members had certain opinions and the challenges participants experienced were from the opinions of these other family members.

> *"We didn't experience challenges in hospice just from our family. I think it was cause we were the first to ever have done something like this, to ever even consider this option (hospice) like for those who had been in our family and been terminal it's just the challenge were the expectations of like what is the best care for our Samoan parents and it could've been seen as disrespectful, that was their values but I'm new generation and thank God for education and thank God that dad was able to be humbled in a way to accept the fact that he needed this time for himself. Not worry what his sister thinks."* ***(P6)***

Another challenge revealed by participants was the need to fight to be heard and have doctors explain everything going on with their loved one.

> *"If my siblings weren't pushy, mum wouldn't have got there. If we're here and we keep questioning and it took how long to get her there – Pacific people always have to fight. We were thinking if we weren't asking questions "oh our mums just going to die." If we never pushed, that's what I mean.* ***(P1)***

Theme Four: Strategies to Increase Utilisation of Services

Participants were asked about ways in which to improve the means information about palliative and hospice care is shared with the Samoan community. Many ideas were offered, in particular; having a Pacific Advisor/Support Person available, as well as establishing Pacific caregivers training and using church networks. Such a role exists within some hospices within New Zealand.

Having a Pacific support person was suggested by many participants, who said they would have liked to have had someone whom they could relate to. They felt such a person could explain the exact situation their loved one is in or what to expect as well as the options available for the family. Someone in this role can understand specific cultural aspects of a Samoan person and their family. Samoan values and traditions affect the attitudes and perceptions Samoan people hold and have an effect how caregivers carry out their caregiving duties.

> *"Our culture is that we are very private. But you need to understand our culture first, when our family comes first, when someone is sick or dying, the last thing you want to do is put them in another place."* ***(P12)***

> *"Also, if professionals are not islander be culturally aware there is stuff you can do, I don't remember being asked if we would like an island person."* ***(P1)***

It was also felt that a Pacific support person was needed to be present in family meetings at the hospital so they are able to explain medical procedures for their loved one.

Most participants emphasised the importance of informing the Samoan community about the purpose of palliative and hospice care services. They said that the Samoan community does not understand the support available to help them when they are caring for a loved who is going to die. Education, in culturally appropriate ways, and particularly in relation to the way the education is delivered and respect for what may be discussions about intimate issues, used, is key to this.

> *"You know what would be good is if there is some whanau workshop or somewhere in Pacific health where you invite people who are caregivers for their elderly who are still alive and even though it's a tough topic, but it's good to hear what is offered. Rather than at a really emotional time, when you're just told at the hospital, "she's going to pass away what do you want to do, this is palliative care?" You're not thinking straight cause you've just caught up with the worst news of your life."* ***(P3)***

> *"I think go through the church, just places where they might mostly see as a safe place or who they see as authoritative cause they're really like that. You know our people, they really respect those high up like the pastors, leaders…* ***(P5)***

Several participants talked about how they found the term 'hospice' confusing, and that perhaps another term might be used. One participant talked of the difficulty of trying to translate the term 'hospice' in Samoan and how the description in the Samoan language made the 'hospice' sound like a scary place.

> *"What I remember is me trying to explain what was hospice because I think all of us kids we all loved our Dad and had his best interests at heart. But he was still not happy with the idea of the hospice because when I actually explained it to him in simple terms in Samoan it was a scary place for him because I said something like 'o le fale lea o le fale e foigale e, e maua ai lou malologa but e le o se fale e maguia ai sesi. (It's a place where you rest it's not a place where you get better) It was hard to explain it."* ***(P6)***

Discussion

Understanding of Hospice and Palliative Care Services

Most participants said they understood palliative care as caring for someone who is dying where there is the provision of pain medication but no more hospital care. Most perceived hospice as a 'death house' where loved ones were sent to die or where there is nothing more to do except wait to die. This is a common perception held within the Samoan community. These long-term beliefs have previously identified as a barrier to accessing palliative care (Bray & Goodyear-Smith, 2013). This lack of understanding of palliative and hospice care will shape community response to the provision of services to patients, caregivers, and the family of dying relatives. The understanding of hospice as a place for respite care was also not appreciated by participants. For some, hospice is seen as being similar to a rest home and, similar to placing relatives in rest homes, this ignores the Fa'a Samoa values of a child caring for their parents.

Experiences of Hospice and Palliative Care Services

Those participants who used inpatient hospice services or had hospice services provide palliative care at home, appreciated the care that was shown to them. Although caring for a relative at home can be demanding, Samoan belief systems value the caring of loved ones especially parents at the end of life and children who care for parents are known to be blessed (fa'amanuiaga). At this time, children are able to reciprocate the love and care back to their parents for the time spent nurturing when they were born. The support provided by hospice complimented family caring roles.

One particular aspect of hospice support was to explain to family caregivers what death looks like as this allowed the participant to be aware of what was happening with their dying relative. This helped them to come to terms with the reality that their loved ones will pass. This knowledge is important for organizing the appropriate care that dying relatives may need as well as the support needed for family members. The importance of being with their dying relative at all times, and in all places, was a fundamental issue with participants in this study.

Samoan families, and particularly the older members, are likely to belong to a faith community. Having access to those providing their spiritual support throughout all stages of the palliative care journey, is important for both the dying, as well as family members.

Challenges in Using Hospice and Palliative Care Services

Samoan cultural beliefs and values may, at times, prevent families from accessing and engaging with hospice and palliative care services. The values of aiga (family), alofa (love), tautua (service) and respect (fa’aaloalo) underpin and govern decisions regarding the care of parents, grandparents and family members especially when a life-limiting diagnosis is made. However, for many Samoan families and caregivers, hospice is unfamiliar and based on a Western framework of care that is perceived to go against Samoan values and beliefs. Health and social services professionals need to acknowledge this and be able to provide culturally appropriate information to Samoan families in order to help them understand what services can be provided, both inpatient and in the community.

When grandparents or parents are diagnosed with a life-limiting condition grandchildren or children who are younger are less likely to have a say because in the Samoan culture there is a cultural concept named Le va fealoaloa’i. Le va fealoaloa’i is the relational space between people. The relationships between people are informed by principles which determine appropriate conduct and language between people. This is to protect the relationships within the family as well as maintain safe limits for those outside the family. At times, younger children or grandchildren are less likely to be heard regarding the decisions of care or treatment for parents or grandparents; with the oldest child being more likely to make the final decision in terms of treatment or care. As a sign of respect grandchildren cannot force their opinion or decisions to be heard as this will be a sign of disrespect and the Samoan expression of ‘teu le va’ which means to take care of the relational space within the aiga, will not be followed which can lead to a falling out in family relationships.

These important cultural beliefs and values, as well as the need for both families and professionals to establish a trusting relationship, underpin many of the challenges faced by families in their interactions with health professionals when caring for their dying relative.

Strategies to Increase Utilisation of Services

A central theme in the findings from this research is the need for further education. This need is a bi-directional dialogue involving both families and caregivers as well as health professionals working in hospice and palliative care. For families, the education is about the roles – medical, nursing, and psychosocial - that hospice and palliative care services can provide. For health professionals, the education is about deeply held values and beliefs by Samoan peoples about their place in caring for their dying relatives, and the ways in which these values and beliefs guide who does the caring, how this caring happens, and where. Such sensitive and open dialogue may be best facilitated by a Pacific support person. In addition to this reciprocity of learning, other specific strategies such community engagement with Pacific groups; such as community groups, church groups, Pacific-focused activity groups; for education purposes, have all been identified as opportunities for enhancing Samoan peoples understanding and increased utilization of, hospice and palliative care services. An example of a successful engagement over several years by a health provider (Counties Manukau District Health Board) and Pacific churches, is the LotoMoui programme, which engaged with Pacific church communities across South Auckland (Counties Manukau District Health Board, 2005). Findings from this research could be used to influence policy relating to Pacific peoples and their utilization of palliative care, the development of training programmes for non-Pacifika health professionals, and the development of Pacific appropriate both in-patient and out-patient palliative care services.

Additionally, while this study specifically related to hospice and palliative care, the recommendations may appropriately be extended into other health and social services utilized by Pacific peoples in order to address identifiable needs.

Conclusion

This study aimed to explore the understandings and attitudes of Samoan female caregivers regarding palliative care and hospice care services in Auckland, New Zealand. We wish to acknowledge the generosity of the participants in the gift of their wisdom and their engagement in this research. We also wish to acknowledge those family members who were dying while in their care.

Findings from this study recognise the need for cultural awareness among health and social professionals within hospice and palliative care services and the need for education for caregivers and families about hospice and palliative care services, particularly how these services can provide support for the dying and their families, and in a cultural acceptable way. Specific suggestions have been made that enable this to happen.

Strengths and Limitations

This study is one of the first to look at the understanding of hospice and palliative care services among Samoan female caregivers. The study was qualitative in nature; therefore, it explored the views, attitudes and experiences of the Samoan female caregivers through in-depth interviews, and provided a way in which to understand the caregiver's attitudes and understandings of hospice and palliative care. The use of semi-structured interviews using open-ended questions, allowed participants to freely express their experiences. The methodological frameworks underpinning the study were also a strength. The use of the Pacific methodological framework – Talanoa – and in tandem with the Constructivist Grounded Theory to guide the study, was valuable and important in ensuring the research methods were culturally appropriate. Utilizing these methodological processes throughout the data collection and the data analysis process made certain that the views of the participants were well represented.

A limitation is that the participants are 12 Samoan female caregivers residing in the Auckland. Therefore, results may not be generalizable across all Samoan and Pacific female populations in New Zealand. Also, though interviews were conducted in both the English and Samoan language, at times, the translation into the English language for the analysis may have led to a loss in cultural understanding due to terms used in translation. Having only female caregiver participants limits the perspectives. Future research including male caregivers, should be conducted to better reflect the overall Samoan caregiving perspective. Additionally, future research should be undertaken exploring these perspectives in Pacific peoples other than Samoan.

There is much to do, and this research may inform further development of Samoan in particular, and Pacific peoples in general, support services within hospice and palliative care services in New Zealand.

Competing Interests:

None to declare

Acknowledgements:

We most sincerely thank the participants who generously gave of their wisdom and their experiences.

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