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Exploring the Psychosocial needs of Tongan Families in Hospice Care

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Abstract

Caring for a loved one with a life-threatening illness has a great impact on the carers psychosocial wellbeing. In Aotearoa-New Zealand, Tongan families are accessing hospice care; however, limited to no research has been conducted on their experiences of hospice care particularly regarding their psychosocial needs. Therefore, this qualitative study explores the psychosocial needs of Tongan families in hospice care to identify strategies that can help improve palliative care and support for Tongan family carers. This study employs the Tongan *Kakala* methodological framework as a methodology within the growing suite of Pacific methodologies. Within the *Kakala* framework, the *talanoa* (Tongan way of dialogue) is a tool utilized to gather data. Five participants are involved in this study who were primary family carers of Tongan heritage who accessed hospice care and resided in Auckland. A total of five family-based *talanoa* sessions were completed, transcribed and analysed through thematic analysis. As a result, five psychosocial needs linked to caregiving were identified: **limited knowledge and information regarding hospice care, ineffective communication by health professionals, lack of engagement by health professionals, dissatisfaction with spiritual support provided by hospice care, and lack of discussion and shared planning for future health care**. Recognizing the Tongan family carers' psychosocial needs led to identifying strategies that would help provide optimal palliative care support for Tongan families in hospice care. This includes hospice service providing care in a way that is culturally sensitive and competent for the family carers, delivering culturally appropriate education about hospice care, employing Tongan health professionals, and increasing engagement by health professionals. Implementing these strategies would help reduce the psychosocial burden of caregiving and lead to better health outcomes for both the Tongan family carers and patients.

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Glossary

Term	Meaning
anga-fakatonga	Tongan tradition or culture
fahu	highest-ranking female within the kāinga
faifatongia	fulfilling obligations
faifekau	church pastor
faka‘apa‘apa	respect
fakatōkilalo	humility
fetokoni‘aki	the reciprocal obligation of helping one another in everything
feveitokai‘aki	genuine respect and regard for the feelings or thoughts of others
hosipesiō	hospice
kāinga	extended family
koloa	goods
lotu	faith/religion/spirituality
me‘a‘ofa	gift
ngatae	tropical coral tree
talanoa	to talk or to tell stories
tauhi vā	nurturing relationships
Taula tevolo	ancestral spirits
ulumotu‘a	highest-ranking male within the kāinga

Chapter one: Introduction

The motivation of this thesis is based on my life journey and experiences

Koe taumu'a 'oe fakakaukauni, makatu'unga 'ihe mahu'inga'ia moe a'usia, he na'e fou mai ai e mo'ui

I was born and raised in a Christian home by parents who have strong faith in God. My father is a church pastor for the Seventh-Day Adventist Church, so we, as a family, often moved from one place to another. Growing up, I remember having different people from all walks of life live with us. Despite the daily struggles my parents encountered, they welcomed people to our home with open arms. They were always willing to reach out to the community and help others who were in need. I am a female of Tongan and Fijian descent. My father is from Tongoleleka, Ha'apai, Tonga, and my mother is from the Island of Mualevu, Vanuabalavu, Fiji. My parents met in Fulton College (a Seventh Day Adventist Missionary College in Fiji) while my father was studying Theology and my mother was teaching at tertiary level. I was born in Fiji, and by the age of two, my father was called to work as a church pastor in Tonga so we moved to Tonga. My life revolved around the church and at a young age I took part in community outreach programs such as donating food and clothes for the less fortunate, cleaning up the yards of the elderly and widows in our neighbourhood as well as visiting and delivering food to hospital patients. My parents were often busy with church meetings or volunteering in the community, and as the eldest child, my responsibility was to care for my younger siblings and the people who were shelter-deprived living with us.

In 2006, my family was granted New Zealand residency visas through the Pacific Access category ballot. My parents saw this as a window of opportunity for my siblings and I to

further our education; therefore, they decided to migrate to New Zealand. Immigrating to New Zealand was a challenging experience; mainly having to adapt to a new environment and acculturate. Fortunately, my parents were very supportive and always encouraged us to be persistent. They would remind us of the reason why we migrated to New Zealand and the significance of focusing on our goals. The Christian values my parents have instilled in me have shaped me into the person I am today. I was taught to always put God first in everything I do, to value hard work and education, to be humble and respectful. My upbringing also taught me to have a strong sense of responsibility towards my community. Therefore, I have volunteered for victim support services, was involved in boxing for charities and helped to facilitate Pacific suicide prevention workshops in the community.

In 2016, I took a Pacific health postgraduate course that paved the way to being involved in a Pacific research project. The project focused on exploring and identifying areas to improve the delivery, access, and the use of specialist and primary palliative care among Pacific people in New Zealand. As a research assistant, my role involved collaborating with hospice staff members, recruiting and interviewing participants, as well as networking with the Pacific community. Being involved in this project broadened my knowledge of health and palliative care. Subsequently, I decided to base my research specifically on Tongan families in hospice care.

As a female of Tongan and Fijian heritage I chose to focus on the Tongan population because I identify more with the inside knowledge of Tongan culture and community. Within the Tongan culture, the family is the central unit of life and each family must uphold values and traditions that are passed down from past generations. When a family does not maintain their responsibility, they are frowned upon by the Tongan community (Lee, 2003; Lee, 1996).

Given the collectivist nature of Tongan people I became interested in exploring family views on psychosocial needs, especially as my experience of Tongan families has been how the needs of others supersede their own needs. Kavaliku (2007) and Mulitalo-Lauta (2001) emphasized that Christianity is intricately linked with Pasifika cultures. For Tongan people, Christianity is an important part of their identity and values system. This is evident in how they perceive themselves as members of a group and the central role of *kāinga* (extended family). The Tongan peoples' concept of self is in terms of their connection or relationship with others; a philosophy that is grounded on Christian principles of living. These Christian principles predicate *kāinga* (extended family) values; therefore, putting others before their own needs is part of Tonga's cultural milieu (Havea, 2011).

Research Objectives

The principal aim of this study is to identify strategies that would help improve palliative support for Tongan families. The specific objectives were to explore the:

- the psychosocial needs of Tongan families in hospice care
- the determinants of psychosocial distress in family hospice clients
- the family carers' experience of hospice care

This research has utilized data gathered from a larger study that I participated in: 'Pacific meets West in advance palliative care for Pacific populations; HRC ref id:16/464'. As a research assistant in the larger study, I recruited and interviewed Pacific hospice clients, their families, key informants in the Pacific community and hospice staff members. The larger study was implemented by Massey University to assess the utilization of palliative care services among Pacific populations and to explore the perspectives of Pacific people on challenges and experiences in such services. The study was funded by the New Zealand

Health Research Council and led by Principal Investigator, Dr. Sunia Foliaki. My involvement in the larger study prompted an interest in the psychosocial needs of Tongan family members in hospice care services and led to this area of research for my thesis.

Chapter two: Literature Review

Palliative care services

The diagnosis of a serious life-threatening illness can have profound effects on an individual's wellbeing: psychological, (Hudson et al., 2015; Thomas, Rajaram, & Nalini, 2014), physical (Girgis, Lambert, Johnson, Waller, & Currow, 2012; Schulz & Sherwood, 2008), spiritual (Hampton, Hollis, Lloyd, Taylor, & McMillan, 2007; Young, Nadarajah, Skeath, & Berger, 2015) and social (Girgis et al., 2012; Otis-Green & Juarez, 2012). People with life-threatening illnesses are faced with the challenge of living with uncertainty, while still wanting to maintain meaningful control over their lives. As their illness progresses many choose palliative care as the paramount goal of care (Lo, Quill, & Tulsky, 1999).

The World Health Organization (2018) defines palliative care as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

The need for palliative care has never been greater and is increasing at a fast pace due to an increase in the world's older population and life-limiting illnesses (Alliance & Organization, 2014). Palliative care is delivered at three different levels: the health professional level, the general palliative care level, and the specialist palliative care level. The health professional level refers to providing palliative care through an approach adopted by all health care professionals who are educated, skilled and trained in this field. The general palliative level refers to palliative care provided by primary care professionals

(e.g., General practitioners, nurses) who have a basic knowledge of palliative care.

Specialist palliative care refers to a service provided by specialized teams (e.g., hospice services) for patients with complex problems (Alliance & Organization, 2014).

At various palliative care levels, caregiving can be done by health professionals, friends or family members. However, this is dependent on the progression of the illness and the setting in which the patient would like to access palliative care services whether it is at a nursing home, assisted-living facility, inpatient hospital or at home. The requirement for provision at three different levels differs across countries, varying according to the proportion of death from palliative care diagnoses, the models of healthcare implemented and the nature and extent of integration of palliative care within these models (Alliance & Organization, 2014). This research focuses on specialist palliative care, specifically hospice care experiences of Tongan families.

Palliative care provides relief from pain and other distressing symptoms, integrates psychological and spiritual aspects of patient care, affirms life, and regards dying as a normal process as opposed to hastening death (World Health Organization, 2018). The palliative care service also provides a support system to help both patients and family carers cope during the end of life stages by enhancing their quality of life and addressing their physical, psychological, and social needs. Additionally, palliative care services can include bereavement counselling and other therapies intended to prolong life such as chemotherapy or radiation therapy (World Health Organization, 2018). Patients with life-threatening illnesses can access palliative care at any time while continuing active treatment through different phases of their life-limiting condition. They can access palliative care while still receiving treatment for their disease, when no further treatment is available or when the

treatment's side effects, pain, and suffering are overwhelming. In cases where a patient's treatment is no longer curative, they have the option to access specialized palliative services such as hospice care (MedlinePlus, 2016). Hospice care service is a specific kind of palliative care for patients approaching the end-of-life. This service is provided by health professionals and volunteers with the goal of helping patients who are dying to have peace, comfort, and dignity. The hospice care services offer medical, psychological and spiritual support to patients as well as for their families. Hospice services focus on caring not curing, and in most cases, care is offered in the patient's home. Hospice care can be provided in any setting depending on the patient's choice of place of care. It can be provided in freestanding hospice centers, nursing homes and other long-term care facilities (Alliance & Organization, 2014; National Hospice and Palliative Care Organization, 2017).

Hospice care in Aotearoa-New Zealand

The New Zealand hospice care services adopt a holistic approach to care that has an affinity with the Maori Health model, '*Te Whare Tapa Wha*' (a four-sided house). The *whare* has four walls which represent *whanau* (family), *tinana* (physical), *hinengaro* (mental health) and *wairua* (spiritual health) (Hospice New Zealand, 2012). Each wall represents a different dimension of health; all four walls are essential elements necessary to sustain health and wellbeing. For a terminally ill patient to have a quality end-of-life care, the physical, social, spiritual and psychological needs are addressed (Hospice New Zealand, 2012; Ministry of Health, 2017a). The hospice care supports not only the patient but also their friends and family members. Family participation in caregiving is an integral part of New Zealand's hospice care service since many patients prefer to receive hospice care at home. The patient's ability to be cared for and to die at home is dependent on the caregivers' situation, capacity,

ability and choice. Therefore, hospice programs consider the patient and family together as a unit of care (Hospice New Zealand, 2012). The hospice care service is available to both New Zealand residents and citizens of all ages, religion, and ethnic/cultural groups (Hospice New Zealand, 2012; Palliative Care Council of New Zealand, 2014). The services offered by the hospice care include medical and nursing care; pain and symptom control; rehabilitation therapies including physiotherapy and complementary therapies; spiritual support; practical and financial advice; as well as bereavement care. These services vary across hospices; however, the ultimate goal of all hospices is to meet the patients' and families' needs (Hospice New Zealand, 2012).

Caring for a loved one with a life-threatening illness is embedded in cultural beliefs and processes. This means that the cultural values and norms of a family influence the way they define caregiving particularly their perception of their own caregiving experiences and their roles as caregivers. Therefore, the family dynamics and wider cultural practices in and around kinship and caregiving are specific to different cultures (Fang, Sixsmith, Sinclair, & Horst, 2016). Understanding people's culture is central to understanding their relationships, how they operate and do things, their norms, values and beliefs (Thaman, 1999). The way in which people socialize is based on their culture. Thus, different cultural groups have unique systems of perceiving and organizing the world around them. The importance of understanding various cultures is significant to hospice care in order to provide appropriate support for patients and families (Thaman, 1999, 2009). Given that New Zealand is an ethnically diverse nation, the delivery of hospice service considers the unique needs of various ethnicities/cultures. For instance, health frameworks such as the '*Te Whare Tapa Wha*' model (a Maori health model) and the '*Ala Mo'ui*': Pathways to Pacific Health and Wellbeing 2010-2014 (a document that sets out the strategic direction to address health needs

of Pacific peoples) have been implemented in hospice to provide care to people of different Pacific ethnicities. These health models are designed not to limit people's choices but rather to assist services in delivering quality care (Hospice New Zealand, 2012).

Pacific people and family carers in Aotearoa-New Zealand

In New Zealand, the 2013 census highlighted that the majority of people identify as New Zealander European (74.0%), followed by Maori (14.9%), Asian (11.8%), Pacific people (7.4%), Middle Eastern, Latin American, African (1.2%) and other (1.7%) (Statistics New Zealand, 2013b). According to the population projections released by Statistics New Zealand, one of the fast-growing ethnic groups is the Pacific group. By 2038 it is projected that those identifying with a Pacific ethnicity would grow from 9 percent in the mid-2020s to 11 percent (Statistics New Zealand, 2013c). The term 'Pacific' refers to individuals who have Pacific heritage or who identify with at least one of the ethnic groups originating from the Pacific Islands of Polynesia, Melanesia, and Micronesia. There are 12 nations that are represented in New Zealand's Pacific community. The majority of the Pacific population identify with one or more of the four main ethnic groups; Samoan, Tongan, Cook Island and Niuean. These various Pacific ethnic groups have different languages, customs, and culture; however, they have similarities which identify them as one group, including having collectivist and holistic cultural values (Tukuitonga & Finau, 1997). Most Pacific people live in the Auckland region (65.9%) while others live in Wellington (12.2%), Waikato (5.0 %), Canterbury (4.3%), Bay of Plenty (2.6 %), Manawatu-Whanganui (2.5%) and Hawke's Bay (2.1%) (Ministry of Health, 2014).

Compared to other ethnic groups, Pacific people suffer the highest incidence of chronic illness and have higher cancer mortality rates. The overall incidence of cancer is lower in

Pacific people compared to Europeans, yet cancer mortality rates are higher among Pacific people. This difference is attributed to various factors including late presentations, lack of cultural competence by health professionals and difficulties in accessing care (Ministry of Health, 2014). Pacific people place a strong emphasis on the group as opposed to individual needs thereby they identify themselves within the context of their families and the wider community (Social Policy Evaluation and Research Unit, 2017). Pacific people are interdependent and extended families rely on each other for the care of children, friendship and support (Medical Council of New Zealand, 2010; Social Policy Evaluation and Research Unit, 2017). The family is central to the Pacific culture and community. It is also a support structure and the way of life for Pacific people (Medical Council of New Zealand, 2010; Tiatia & Foliaki, 2005). The traditional Pacific family unit is responsible for the welfare and wellbeing of its members. Therefore, care for family members who are ill is often informally provided within the family (Medical Council of New Zealand, 2010). The patients' preference for family members to be primary carers is common across various Pacific ethnic groups; however, each Pacific ethnic group has its own cultural beliefs and protocols regarding end-of-life care.

Tongan people living in Aotearoa-New Zealand

Among the New Zealand Pacific population, 1 in every 5 are of Tongan ethnicity. The Tongan population is the third largest New Zealand Pacific ethnic group, with just over half being born in New Zealand and the majority living in Auckland (Statistics New Zealand, 2013a). A large number of Tongans arrived in New Zealand to take up work opportunities in the 1960s and 1970s. They arrived on temporary permits via a short-term contract agreement between Tonga and New Zealand; however, many Tongans remained in New Zealand

illegally. There was a downturn in the New Zealand economy and so the government took a tougher stance on Pacific people, including Tongans who were illegal immigrants. The police conducted random street checks and raided Pacific homes in search of overstayers. In 1976, the New Zealand government gave amnesty to the Pacific overstayers and many Tongans were able to live legally in the country. Tongans continue to migrate to New Zealand till this day through the help of their family members and the Pacific access category which grants 250 Tongans permanent residence each year (Taumoefolau, 2015).

When Tongans migrated to New Zealand they took with them their children, *anga-fakatonga*, *lotu* and established a community that valued collectivism. The term *anga-fakatonga* refers to the Tongan tradition or culture. *Anga-fakatonga* continues to exist in New Zealand (Kalavite, 2010; Manu'atu, 2000); nonetheless, some aspects of the *anga-fakatonga* have changed due to Tongans integrating Western ways to allow adaptation, survival, and a degree of flexibility. For instance, following the burial of a loved one, Tongans would mourn for 10 days. This practice no longer exists because families need to work to cover expenses. The older and younger generations have an incongruent view of *anga-fakatonga*. While the older generation holds on to traditional *anga-fakatonga* in which Tongan values are significant in maintaining identity and success, the younger generation are exposed to greater material wealth, and are less traditional and more flexible, adapting both Western and Tongan culture. Although aspects of the *anga-fakatonga* have adapted and changed over the years Tongans continue to take pride in it through their identity (Tānaki, 2015).

A central feature of the *anga-fakatonga* is *lotu*. For Tongans, *lotu* encapsulates faith, religion, church and spirituality based on Christianity. *Lotu* refers to both the institutionalized church and to a personal relationship with God (Havea, 2011). Prior to Christianity arriving in Tonga

in the early 18th century, the Tongans practiced their own *lotu*. This form of *lotu* was known by the missionaries as heathenism. The arrival of missionaries was based on political interest; however, the *lotu* was introduced and now it has become part of the Tongan identity and values systems (Latukeyu, 1974, 1996; Latu, 2011; Niemeitolu, 2007). Although Tongans are far from their ancestral home, the communities are still connected to their *lotu* and still embrace the Tongan motto, ‘*Ko e ‘Otua mo Tonga ko hoku tofi ‘a*’ (God and Tonga are my inheritance) which highlights the importance of *lotu* to Tongans. The significance of *lotu* is strongly advocated by the leaders in the church, community and family as it provides people with a sense of security, identity and wellbeing. Additionally, Tongans saw *lotu* as a source of strong support and sustenance. Many Tongans considered *lotu* as a safe haven where relationships, cultural values and practices are established and maintained. It is also a place where friendships and relational networks are encouraged and nurtured through reciprocal fulfillment of obligations and responsibilities. Above all, *lotu* is a community home where spirituality is fostered and encouraged through interpersonal relationships (Havea 2011; Latu, 2009; Tānaki, 2015).

For Tongans, the concept of self is grounded in the notion of including their *lotu*, *kāinga* and the community. *Kāinga* refers to the extended family or people who are connected through blood or kinship (Tau’akipulu, 2000). Tongan people have a concept of family that includes both the nuclear and extended family organized via the *kāinga* system (Vahefonua Tonga O Aotearoa, 2012; Teisina, 2011). However, this study will use both family and *kāinga*, with family referring to the nuclear family. The *kāinga* system is hierarchal and it determines how people interact and behave in a particular setting and function. An individual’s age, sex, and birth order in their family dictates their rank, role and authority within the *kāinga*. For instance, the older members are ranked higher and respected by the younger members. The

younger members often turn to the older members to seek advice and wisdom. Men are ranked higher than women but ranked lower in the family because of their obligation to care for the needs of their sisters and their children. The paternal side of the family are ranked higher than the maternal side. So the eldest paternal male is the highest-ranking male within the *kāinga*. He is known as the *ulumotu 'a*. While the *ulumotu 'a* is considered lower in ranking within the family, they have the authority and power to direct family events and funerals. His role includes organizing the collection and distribution of products given by the *kāinga* and other lineage (Havea, 1996). On the other hand, the eldest female from the paternal side of the *kāinga* is known as the *fahu*. The *fahu* is the highest-ranking female of the *kāinga* who has superior social status over her brother(s) and their children. Her presence at family functions is acknowledged by being presented with *koloa* or goods (Teisina, 2011). Tongans recognize this hierarchy but place more emphasis on the cultural reciprocal role of *faifatongia* (fulfilling obligations).

Fundamental to the survival of kinship is the notion of *tauhi vā*. The term *tauhi vā* derives from the word *tauhi vaha 'angatae*. During the pre-Christian era, Tongans planted the *ngatae* or tropical coral tree as a living fence post to mark their land properties. The land properties were separated by the *ngatae* tree and so there was a mutual understanding amongst Tongans that individuals will care for their portion of the *ngatae* fence post by keeping it beautiful and free of weed (Ka'ili, 2017). It was an approach that people used to make sense of what was considered right and wrong in their interactions. The concept of *tauhi vaha 'angatae* evolved beyond marking of one's property to include the performance of social duties. This was reflected in the Tongan proverb “*takitaha tauhi hono vaha 'angatae*” (each one tends his space of *ngatae* trees) which emphasized the association between *tauhi vā* and social duties (Māhina 2004, p. 141). When boundaries were created and managed there was order within

the Tongan people. Tongans knew their role and what was expected of them and therefore maintained peace and stability within the community. The relationships between Tongans were taken care of, through the mutual performance of social duties which contributed to maintaining and nurturing relationships (Ka‘ili, 2017).

According to Mafile‘o (2005), *tauhi vā* refers to maintaining or nurturing relationships, with *tauhi* meaning to ‘take care of’ or ‘keep safe’, and *vā* referring to the intervening space. *Tauhi vā* encapsulates more than just the relationships between people; it also refers to space that relates and denotes the unity of separate entities (Wendt, 1996). Relationships are important to Tongans and the maintaining or nurturing of relationships is highly valued. *Tauhi vā* is one of the cornerstones of the *anga-fakatonga* (Ketu‘u, 2014). It is strengthened through *faifatongia* (fulfilling obligation) and built on values including *faka‘apa‘apa* (respect), *feveitokai‘aki* (genuine respect and regard for the feelings or thoughts of others), *fakatōkilalo* (humility) and *fetokoni‘aki* (the reciprocal obligation of helping one another in everything). *Faka‘apa‘apa* literally means respect. It is an attribute deeply embedded in the *anga-fakatonga* which influences how a person should behave, act and dress. Children are taught at a young age to respect the elderly, the *ulumotu‘a*, the *fahu*, their parents and the women. Further, male cousins and brothers are expected to show the highest form of *faka‘apa‘apa* towards their female cousins and sisters. These relationships have certain aspects of taboo that are recognized and must be respected; for instance, brothers or male cousins do not watch TV programs containing sex scenes or profane language with their sisters or female cousins.

Feveitokai‘aki is a byproduct of *faka‘apa‘apa* which emphasizes selflessness through having concern for the interest and feeling of others. In the *kāinga* circle, people have well defined roles and obligations to fulfill. The *kāinga* members show acts of *feveitokai‘aki* by

welcoming and acknowledging the presence of other members despite their rank.

Fakatōkilalo refers to being humble or lowering of oneself to serve others. Tongans display *fakatōkilalo* verbally and non-verbally. Examples include allowing others to speak, the language a person uses to articulate a message and taking shoes off at the door when entering a house (Mafile‘o, 2005). People who display *fakatōkilalo* are admired by their *kāinga*. The act of *fakatōkilalo* stimulates respect and a willingness to reciprocate cultural obligations. *Fetokoni‘aki* refers to the acts of kindness. This concept highlights the communal acts that occurs within members of the *kāinga*. The *fetokoni‘aki* that Tongans show towards others is reflected in the cultural reciprocal role of *faifatongia*. Tongans believe that committing to these values (*faka‘apa‘apa*, *feveitokai‘aki*, *fakatōkilalo* and *fetokoni‘aki*) will benefit their *kāinga*. (Mafile‘o 2005; Manu O‘Uiha, 2018)

The *tauhi vā* that occurs within the *kāinga* is translated into the Tongan peoples’ everyday lives. Tongans continue to *tauhi vā* to their ancestral land; for instance, providing remittances for their *kāinga* in Tonga while they *tauhi vā* to their new environment through acculturation. *Tauhi vā* is important to the wellbeing of Tongans as it creates a sense of belonging, ownership and a greater sense of purpose. As Tongans cope and adjust to life in New Zealand, the *anga-fakatonga* is maintained through *tauhi vā* within the *kāinga*. Central to *tauhi vā* is the concept of *faifatongia*. This cultural reciprocal role of *faifatongia* is expected within the family and therefore when a loved one is diagnosed with a life-limiting illness it is the families’ obligation to care for their loved one.

The Tongan cultural roles and norms play a role in how Tongans perceive caregiving. Many Pacific patients, including Tongans, felt that their role was to receive treatment while their family support them and negotiate with authority figures (Medical Council of New Zealand,

2010). Additionally, Tongans viewed caring for a family member as an expected moral and social duty which explains why families preferred to be primary caregivers. Tongans also preferred to care for their loved ones because they mistrusted the health care system. They felt that the health care system lacked cultural competence and skills in cross-cultural communication (Bassett & Holt, 2002). For many Tongan families, caring for a loved one can be an opportunity for re-connection, healing, and a demonstration of love and affection through daily acts of caregiving. Caring and supporting a loved one with a life-threatening illness can be rewarding yet challenging.

The Impact of Caregiving

Caring for a loved one has many benefits such as reducing the social costs linked to health services and institutionalization, bringing family members together and providing a better quality of life for the patient. Nevertheless, the responsibilities placed upon family carers can be confronting and demanding. While family carers focus on providing care for the patient they often experience substantial social, physical and psychological consequences. The social consequences of caregiving include having a financial burden, lack of social support, and social isolation (Otis-Green & Juarez, 2012; Stenberg, Ruland, & Miaskowski, 2010). The physical consequences of caregiving include fatigue, pain, weight loss, loss of physical strength, and poor sleep quality (Brummett et al., 2006; Gallagher-Thompson et al., 2006; Stenberg et al., 2010). The psychological consequences of caregiving include having higher levels of depressive symptoms, stress, anxiety and other mental health effects (Dumont et al., 2006; Hudson, Remedios, & Thomas, 2010; Hudson et al., 2015).

Psychosocial consequences of caregiving have the greatest impact amongst family carers (Deshields et al., 2012; Hudson & Payne, 2011). Most family carers experience fatigue, sleep problems, depression, burnout and disruption of social connectedness (Deshields et al., 2012; Northouse, Williams, Given, & McCorkle, 2012; Page & Adler, 2008). Since the psychosocial aspect of caregiving has the greatest impact on family carers, it is essential to explore the psychosocial needs of Tongan families in hospice care. Understanding the psychosocial needs of Tongan families will help hospice care deliver optimal psychosocial support. Provision of good support during caregiving can help improve the family carers' psychosocial outcomes and lead to better care health outcomes for both the carer and patient.

The psychosocial impact of caregiving

A substantial body of literature has asserted that family carers in need of palliative services are often prone to negative, physical, social, and psychological consequences (Brännström, Ekman, Boman, & Strandberg, 2007; De Korte-Verhoef et al., 2014; Hudson, Aranda, & Kristjanson, 2004; Hudson & Payne, 2011; Hudson et al., 2010; Hudson et al., 2015; Sklenarova et al., 2015; Stajduhar, 2013; Stajduhar et al., 2010). Caregiving affects the quality of life of family members in many ways but takes its greatest toll on their psychosocial wellbeing (Aoun, Kristjanson, Currow, & Hudson, 2005; Brännström et al., 2007; Caruso, Nanni, Riba, Sabato, & Grassi, 2017; De Korte-Verhoef et al., 2014; Sklenarova et al., 2015; Surbone et al., 2010). For instance, Sklenarova et al. (2015) reported that carers were more distressed and anxious compared to patients. Moreover, Grunfeld et al. (2004) emphasized that their depression levels were similar to patients' and greater than the general population. The most commonly reported disruptions to caregiver's lives were feelings of tiredness, resentment, and isolation (Aoun et al., 2005; Brännström et al., 2007).

A number of studies found that family carers have psychosocial needs including knowledge and honest information needs (Docherty et al., 2008; Schmid-Büchi, Halfens, Dassen, & Van Den Borne, 2008), spirituality needs (Lalani, Duggleby, & Olson, 2018), emotional needs, (Schmid-Büchi et al., 2008), improved communication with providers and better co-ordination of care (MacKenzie, Meghani, Buck, & Riegel, 2015; McMillan, Small, Haley, Zambroski, & Buck, 2013), the need for interdisciplinary support (e.g., including social workers, psychologists, physical therapists, and chaplains on the palliative care team) (Bekelman et al., 2011; O'leary, Murphy, O'loughlin, Tiernan, & McDonald, 2009) and the need for frequent visits by health care professionals (Lecouturier, Jacoby, Bradshaw, Lovel, & Eccles, 1999). As a result, psychosocial support interventions have emerged to help support carers who utilize hospice care services (Cagle et al., 2017; Caruso et al., 2017; Deshields et al., 2012; Engen, 2017; Girgis et al., 2012; Hudson et al., 2010; Northouse et al., 2012; Soothill et al., 2001).

Various psychosocial interventions differ in their approach and focus on key aspects associated with psychosocial functioning such as perception of quality of life, stress, carers' burden and competence. For example, some interventions focus on offering emotional support and ways to manage caregiving-related stress via counselling services (Flanagan-Kaminsky, 2013; Leow, Chan, & Chan, 2015) while others focus on psychoeducation programs (Hudson & Aranda, 2013; Leow et al., 2015) and coping skills (McMillan et al., 2006) to help reduce stress and anxiety, and increase a sense of competency and quality of life for the carers. Studies have consistently reported gains in relation to psychosocial well-being among participants who received the interventions (Cagle et al., 2017; Engen, 2017; Hudson et al., 2010; McMillan et al., 2013; McMillan et al., 2006).

Family carers as a healthcare priority

Many patients with life-threatening illnesses prefer homecare; therefore, there has been a shift from accessing palliative care at hospitals to the home environment. For patients, homecare attempts to provide a sense of normalcy and an environment that can sustain a relationship without the hospital technological stressors (Milberg & Strang, 2007; Sherman, 1998; Wong & Ussher, 2009). The family carers' support is crucial in facilitating homecare and patient care. When an individual is diagnosed with a life-threatening illness, there is an expectation that family members will accept the responsibility of being direct carers (Caruso et al., 2017; Hughes, 2008; Otis-Green & Juarez, 2012). Often carers do not want to appear incompetent or selfish which results in carers' reluctance to express their own needs (Arber, Hutson, de Vries, & Guerrero, 2013; Arber et al., 2010; Grande et al., 2009). Nevertheless, several studies have tried to gain insight regarding the family carers' concerns and preferences. Therefore, there has been increasing recognition of the unmet psychosocial needs of family carers in hospice care.

When family carers have unmet needs, this leads to inadequate provision of care which negatively affects both the patient and carer. The World Health Organization (2017) emphasizes the importance of family carers in the context of hospice care. Hospice care has extended support to the family of hospice patients, and health professionals now realize that family carers are "secondary patients" who also need care and support (Hudson et al., 2015; Hughes, 2008; Stajduhar, 2013). For patients to continue to live at home and experience a good quality of life until death, supporting family carers should be a healthcare priority. Providing optimal support for family members will not only benefit the patient but also enable family members to be effective in their role without compromising their own health

and wellbeing (Hudson & Aranda, 2013; Hudson et al., 2015; Northouse et al., 2012; Otis-Green & Juarez, 2012; Stajduhar, 2013).

Although previous studies have explored the psychosocial needs of family carers in hospice care (Agren, Stromberg, Jaarsma, & Luttik, 2015; Deshields et al., 2012; Northouse et al., 2012; Shaw et al., 2016; Surbone et al., 2010) and the rapid expansion of hospice services (Hudson et al., 2004), the research continues to lack focus on the support provided for family carers, particularly for ethnic minorities. The majority of the studies have largely focused on Western cultures. Therefore, exploring the psychosocial needs of family carers in other cultures and contexts deserves further investigation.

Health outcomes of Pacific people in Aotearoa-New Zealand

In New Zealand, the Pacific population experiences poorer health outcomes compared to other ethnic groups. According to the Ministry of Health (2014), these outcomes are reflected in the higher rates of chronic disease, premature disability, and lower life expectancy. For example, Pacific people have higher rates of both lung and breast cancer compared to the total population. They also have a life expectancy that is four years less than the average population. Moreover, they have disproportionately high morbidity and mortality rates resulting from chronic diseases such as diabetes, cancer, and respiratory illnesses (Ministry of Health, 2014; Statistics New Zealand and Ministry of Pacific Island Affairs, 2011). The latter report by Statistics New Zealand and Ministry of Pacific Island Affairs (2011) recommended that implementing preventative measures and treatment tailored to Pacific people can help reduce these mortality and morbidity rates. Considering the health outcomes and costs carried

by Pacific people, one way to relieve their burdens and improve quality of life is through hospice care.

One of the visions of the New Zealand hospice care services is to support all people who are dying and ensure that their families have timely access to culturally appropriate and quality palliative care services. The hospice care professionals are also encouraged to provide care free of assumptions via consultation and collaboration with Pacific people to ensure access to appropriate cultural support and advocacy (Hospice New Zealand, 2012). They have also developed culturally appropriate palliative and end-of-life care for patients and their families. For example, Pacific frameworks of health care such as the “*Ala Mou’i*” have been used as a guideline to facilitate the delivery of high-quality health services that meet the needs of Pacific people. Additionally, the hospice care services have undertaken a holistic approach to care which encompasses physical, social, mental and spiritual needs (Hospice New Zealand, 2012).

Pacific peoples’ hospice care needs

Robson and Harris (2007) stated that Pacific and Maori populations in New Zealand experience the greatest levels of unmet health needs compared to other population groups due to the differential distribution of deprivation, living standard, and employment status.

Previous palliative care research also noted that since the hospice philosophy represents the core values of the dominant Western culture, ethnic minorities including Pacific people often encounter cultural and language barriers when accessing hospice care services (Bray & Goodyear-Smith, 2013; Frey et al., 2013; Ministry of Health, 2014; Statistics New Zealand and Ministry of Pacific Island Affairs, 2011). The hospice care services have put forward

action plans that emphasize meeting the needs of Pacific people; however, there is limited knowledge regarding the needs and preferences of the Pacific population (Ministry of Health, 2017b). The 2007/2008 Hospice records (Bray & Goodyear-Smith, 2013) highlighted that Pacific people are utilizing palliative care services. That does not necessarily mean that the needs of patients and their families are being met.

The Ministry of Health (2001) reported that Pacific people prefer to care for their dying family members at home. As a result, they are referred to hospice home care services given that they are the main providers of care available to the community. The cultural differences encompass values and ways of approaching end-of-life care; therefore, it is vital that the hospice care services are aware of the patient's specific cultural preferences as well as how their culture influences their needs, to achieve the best possible outcome. This could have been achieved through consultation and collaboration with Pacific people (Statistics New Zealand and Ministry of Pacific Island Affairs, 2011). To date, limited research has been conducted on Pacific peoples' perspectives of hospice care.

Pacific ethnic-specific focus

Pacific people are culturally and socially diverse; thus, it is important to exercise caution in grouping all Pacific people together and making assumptions about Pacific preference (Medical Council of New Zealand, 2015). As mentioned previously each Pacific ethnic group has its own language, history, cultural beliefs, social structure, values, traditions and health needs (Ministry of Health, 2008). However, many Pacific health studies are presented from a pan-pacific approach. The lack of differentiation among Pacific people can be problematic

when researching Pacific health issues. Consequently, it is imperative that hospice care research considers the varying needs of different Pacific cultures.

Of the main 12 Pacific ethnic groups in New Zealand the Tongan population is the third largest Pacific ethnic group, with the majority living in the Auckland region. The Tongan cultural practices are part of the Tongan peoples' lives; therefore, their worldviews and health beliefs are greatly influenced by their cultural values. Research shows that Tongan people have a holistic view of health in which the physical, spiritual, mental and social dimensions of wellness are interrelated. They also view health as the ability to function normally rather than being ill (Bassett & Holt, 2002). The most common form of healthcare used among Tongans was the Western orthodox medicine. Bassett and Holt (2002) reported that majority of the Tongan people were satisfied with the health services. They often resorted to traditional healing if they were not satisfied with the health services or if Western medicine is unable to relieve the person's symptoms (Bassett & Holt, 2002).

The Tongan New Zealand community and Hospice care services

The New Zealand hospice care service considers the ethnic diversity among patients and their families. This is evident in the 'Hospice New Zealand Standards for Palliative care quality review program and guide 2012' in which it highlights the importance of applying hospice standards to all populations. As a result, hospice care has implemented frameworks: '*Ala Moui; Te Whare Tapa Wha* model, that are useful in providing care to people of different ethnicities (Hospice New Zealand, 2012). However, very little is known regarding the needs and experiences of Tongan families in hospice care. While there is no data available on the

national hospice usage by ethnicity (Slater et al., 2015); previous studies showed that Tongan people are accessing hospice services (Frey et al., 2013; Slater et al., 2015).

While Tongans access hospice services, there is no Tongan word that translates to ‘hospice’. Communicating the concept of hospice is just as important as communicating the vocabulary. Consequently, it is important that there is a Tongan word for hospice so people can use it for quick identification. Considering the origin of the word ‘hospice’, the social implications of the word, with the help of a language practitioner, Ika Tameifuna, the term ‘hosipesiō’ was coined. The term ‘hospice’ comes from the Latin word ‘hospes’ meaning “double duty in referring both to guest and hosts” (Joy, 1983, p.138). The term ‘hospes’ is transliterated to ‘hosipesi’ combined with ‘io’ derived from one of the conventions.

Drawing from previous data on the experience of family carers and the psychosocial challenges they face when caring for their loved ones with chronic illness, it is apparent that further research is warranted to explore the psychosocial needs of Tongan families in hospice care. Knowing the psychosocial needs of Tongan families can help health professionals provide the best support for them which, in turn, will benefit patients. Additionally, this knowledge can be used to inform policy and help implement systematic approaches to assessment and care planning.

According to Small and Dixon (2004), the majority of Tongans in the world reside abroad. The Central Intelligence Agency (2010) also provided an estimation of the Tongan diaspora;

approximately 55 percent of migrant Tongans live in New Zealand and Australia, 36 percent reside in North America, 5 percent in Asia, 2 percent in Europe and 1 percent each in Africa, Latin America and Caribbean. Since there is limited international research on Tongan families' utilizing hospice care services, the knowledge gathered from the current research can be applied to Tongans overseas. Given the above, this research aims to explore the psychosocial needs of Tongan families in hospice care. While there is growing recognition of the central role that family carers play, knowledge gaps remain around identifying the psychosocial needs of Tongan families using hospice services.

Chapter three: Methodology (Toli)

Qualitative Methodology

A research methodology determines how research is to be carried out particularly the procedures by which researchers go about their work of describing, explaining, predicting phenomena and how the researchers position themselves when engaging with participants and generating knowledge. Additionally, a research methodology aims to give the work plan of research and also define the methods by which knowledge is gained (Mills & Birks, 2014). As part of a larger project; ‘Pacific meets West in advancing palliative care for Pacific populations’, the current study adopted a qualitative methodology. There is no single, accepted way of carrying out qualitative research but rather dependent on the researcher’s view of the nature of reality, ‘*ontology*’ (Ormston, Spencer, Barnard, & Snape, 2014), what constitutes acceptable knowledge, ‘*epistemology*’ (Cohen, Manion, & Morrison, 2007), the purpose of the research, the characteristics of research participants, the funders as well as the position of the researcher (Ormston et al., 2014; Ritchie, Lewis, Nicholls, & Ormston, 2013).

Ontology and epistemology are important elements of the philosophy of knowledge.

Ontology is defined as “the study of reality.” It is concerned with the nature of reality and how we can understand existence. It is also concerned with what entities exist and the kind of relationships that occur among basic categories of being. A researcher needs to take a position regarding their perception of what constitutes reality; either they accept reality independently of the human mind or accept reality as being subjective (Crotty, 1998).

Epistemology, on the other hand, “is the study of knowledge.” It is concerned with the nature of knowledge and various methods of gaining knowledge. It essentially deals with how

people can learn about reality and what forms the basis of our knowledge (Cohen, 2007). According to Guba and Lincoln (1994), epistemology asks questions such as ‘What is the nature of the relationship between the inquirer and inquired?’. In research, epistemology is the way in which the researcher chooses to investigate the world or topic of interest. Therefore, epistemology reflects how a researcher's worldview influences how knowledge is articulated and communicated to others (Cohen, 2007; Guba & Lincoln, 1994).

Qualitative research has an ontological view asserting that reality (Hampton et al., 2007) is subjective and dependent on peoples' mental structure activity. Thus, there is no single reality but rather multiple realities that are based on how people construct and interpret reality. The epistemological view that underpins qualitative research is rooted in access to social reality that is mind-dependent and socially constructed. Consequently, the best way to understand any phenomenon is for the researcher to interact with that being researched and to view things in its context (Cohen, 2007; Cohen et al., 2007). Undertaking a qualitative approach means that I agree with the underlying ontological and epistemological assumptions that underpin qualitative research.

Considering the broader range of qualitative approaches, I can employ an approach that is closer to the Pacific ways. The qualitative approach embraces diversity and emphasizes the importance of meaning and interpretation of people's lives within their cultural context (Broom & Willis, 2007; Fossey, Harvey, McDermott, & Davidson, 2002). Furthermore, qualitative approaches study people in their natural environment rather than in clinical settings. Participants can provide data in their own words and in their own way which further adds authenticity to the data gathered. Given that there is limited research on the psychosocial needs of Tongan families in hospice care, the qualitative approach can provide rich, in-depth

information regarding their emotions, needs, desires, and experiences in hospice care (Mays & Pope, 2000; Pope & Mays, 1999). Although qualitative approaches lack statistical representation and cannot be generalized to the wider public, this type of approach can simulate the Tongan family's individual experiences in hospice care as well as generate theories (Maxwell, 2012).

Pacific methodologies

When conducting Pacific research, the research design, methodology, methods, and approaches are informed from within a continuum of Pacific worldviews. Generating and understanding Pacific knowledge through research leads to solutions for Pacific issues. Working within a Pacific framework will also help empower Pacific researchers to contribute to the development of a strong Pacific knowledge base via enriching their intellectual and professional expertise. To make meaningful contributions to Pacific societies the approaches to research should be responsive to the changing Pacific context and also be in accordance with Pacific cultural values, beliefs, ethical standards and aspirations (Health Research Council of New Zealand, 2014). Moreover, to create a more authentic knowledge, appropriate researchers are needed to make interactions with Pacific participants (Vaiioleti, 2016) as well as a public context through which information from the research is made available (Thaman, 2002). In this way, Pacific peoples' perspectives are represented in culturally appropriate ways (McFall-McCaffery, 2010).

Pacific people originate from diverse cultures; however, Pacific methodologies draw on their similarities in philosophies and working principles. All Pacific methodologies follow the principles of relative autonomy, cultural aspirations, culturally preferred pedagogy, mediation

of socio-economic and home difficulties, extended family structure and a collective vision philosophy (Anae, Coxon, Mara, Wendt-Samu, & Finau, 2001). Pacific research methodologies work within an extended family framework; for example, the Tongan *kāinga* (extended family) framework. This framework emphasizes the significance of the trust embedded in the researcher-participant relationship as a symbol of being part of a *kāinga* (extended family). The participants trust the researcher will make good use of the information to benefit the community or *kāinga* (extended family) (Fairbairn-Dunlop & Coxon, 2014).

Pacific research methodologies have emerged from the work of some Pacific researchers such as the *Fa'afaletui* model from Samoa (Tamasese, Peteru, Waldegrave, & Bush, 2005), the *Tivaevae* model from the Cook Islands (MaUa-Hodges, 2000), the *Te Vaka Atafanga* model from Tokelau (Kupa, 2009) and the *Vanua* model from Fiji (Nabobo-Baba, 2006). Each methodology refers to a metaphor or term that Pacific people are familiar with (Fa'afai, Parkhill, & Fletcher, 2006). According to Vaiioleti (2006), there is a need for both researcher and participants to connect at a cultural level; therefore, it is important that an insider-researcher is involved. If research is conducted in the Tongan community, a Tongan researcher should conduct the research as well as implement a Tongan methodology to allow the researcher and participants to connect spiritually and intellectually. This connection will enable the researcher to genuinely represent the voices of the Tongan people in a culturally appropriate way and context (Vaiioleti, 2006).

Tongan methodologies

Various Tongan research methodologies have been developed; however, significant ones include Thaman's model of *Kakala* (Thaman, 2002); Vaiioleti's model of *Talanoa* (Vaiioleti,

2003, 2016); Manu'atu's model of *Mālie-māfana* (Manu'atu, 2000); and Māhina's model of *Tauhi vā* (Māhina, 2008). The *Kakala* model draws on the process of fragrant garland making. It was developed to illustrate the process of gathering knowledge, organizing information, and the dissemination of knowledge and information. The *Kakala* model involves three processes: the gathering of flowers (*toli*), the making of the garlands (*tui*), and presentation of the kakala (*luva*). Each *Kakala* process highlights the stages of research where information relevant for the research is gathered (*toli*), written up in the report (*tui*), and presented to the public for everyone to benefit from (*luva*) (Thaman, 2002).

Another research model that has been used increasingly by Tongan and other Pacific researchers is known as Vaioleti's *Talanoa* model. This model emphasizes the notion of a personal or group encounter in which space is created for people to *talanoa* (story) their past, their issues, their realities and aspirations to produce a culturally appropriate authentic Pacific knowledge (Vaioleti, 2003, 2016). The *Talanoa* framework is a methodology that is ecological, oral and an interactive form of communication that is parallel to interviewing which addresses the challenges of race, culture, beliefs, and society. When researchers and participants engage in *talanoa* it requires deep, interpersonal relationship and emotional sharing between both parties. It will enable the researcher and participant's emotions, knowledge, experiences, and spirits to holistically intermingle (Vaioleti, 2016). For a *talanoa* to take place, the researcher needs to be a person of the same culture as the participants. Through *talanoa*, a cultural connection is established between the researcher and participants in which they can reach a state of understanding regarding the research topic.

The *Mālie-māfana* model developed by Manu'atu emphasizes the process and energies present in the context of *faiva* (performing arts). The *mālie* and *māfana* concepts are

inseparable in which *māfana* refers to the movement of warm currents that energizes the process of *mālie*. With practice, the *māfana* and *mālie* are achieved. The *mālie* adopts a philosophy of process, energy, and transformation of cultural productions that provide access to cultural knowledge which contributes to Tongan student's success. This model emphasizes that Tongan teaching and learning are both processes and outcomes similar to the Tongan *faiva* (performing arts). When conducting research, the notion *mālie-māfana* relates to the researcher and participants performing their task effectively to produce a research outcome in which all those who are involved experience the feeling of *mālie* and *māfana*. Once a good relationship is established between the researcher and participant, *mālie* is achieved, followed by the generation of *māfana* to produce excellent outcomes. In research, the process of *faiva* reflects how the research is carried out. Therefore, the presence of *māfana* and *mālie* highlights the product of the relationship between participants and researchers. The absence of *māfana* and *mālie* can produce very little internal passion within the researcher and participants to mobilize themselves to perform and achieve in the research. The above scenario often occurs when people are not the subjects in the contexts in which they live. Hence the reason why they must critically and actively pursue the relationships in these contexts to produce and to experience *mālie* and *māfana* (Manu'atu, 2000).

The *Tauhi vā* model is another model that stems from the notion of Tongan performing arts. During a performance, *mālie* is created through the symmetrically marks time (*tā*) in space (*vā*) (Māhina, 2005a; 2008). The beauty achieved stimulates powerful Tongan emotions including warmth (*māfana*), elation (*hākailangitau*), or honor (*lāngilangi*) among the performers of *tauhi vā*. This model is linked to the *tā-vā* (time-space) theory. For the performance (research or achievement) to be *mālie* and *māfana*, it must be performed at a particular interface of *tā* (time) and *vā* (space) (Māhina, 2005, 2008).

The Kakala Framework

For the purpose of this study, I adopted the *Kakala* framework to guide my research. The term *kakala* refers to a collection of fragrant flowers or garlands woven together as a garland for a special person or occasion. Konai Helu-Thaman developed the *Kakala* framework to highlight the issue of imposing Western educational worldviews on Tongan people. She further criticized the application of Western values, aims and methods on Tongan worldview, processes, and values (Thaman, 1997). The *Kakala* framework provides a philosophy and methodology of research that is rooted in Tongan culture; therefore, it is culturally appropriated and relevant for this study. It is based on Tongan values and principles of reciprocity, sharing, respect, collectivism and context-specific skills and knowledge (Thaman, 2003). Although this framework is sourced from Tongan valued contexts of thinking, it can be adapted to other cultures and contexts (Townsend & Bates, 2007). Since this research focuses on Tongan families in hospice care, it is considered culturally appropriate to adopt the *Kakala* framework as it is rooted in Tongan epistemologies, protocol, and practices. Furthermore, the *Kakala* framework allows me to use the knowledge that is sourced locally and globally to produce a garland that is meaningful and can be passed on to the Tongan community and others. The *Kakala* framework is also an alternative process that most researchers follow when conducting a study based on Western research framework. So, the processes involved in the making of *kakala* is an illustration of how my research was conducted. As mentioned previously, these processes are known as *toli*, *tui*, and *luva*.

The *toli* stage signifies the gathering and selection of flowers and other plant materials required for making a *kakala*. This process is dependent on the occasion, the materials available and the person for whom the *kakala* is being made. Thus, it is important that the

Tongan women carefully pick and select the most appropriate flowers (Thaman, 1997, 2002). In my research, the *tolu* stage involved the selection of the research approach, participants and data collection. At this stage of the *kakala* process, the Tongan research tool of *Talanoa* was utilized as a method to interact with the Tongan families and to gather data.

The *tui* stage highlights the process involved in the making or weaving of a *kakala*. In Tonga, the flowers are ranked according to their cultural importance with the *heilala* (*Garcinia sessilis*) ranked highly due to the mythology associated with it. The time taken to *tui* the *kakala* is dependent on the type of *kakala* made and the complexity and intricacies of the flowers (Thaman, 1997). In my research, the *tui* stage involves explaining how my data was analyzed and presented. The final stage of *kakala* making process is known as *luva*. This stage is about giving the *kakala* to someone as a sign of appreciation, love, peace, and respect. The main purpose of *luva* in this research is to honor those who have given their knowledge and helped with the research (Thaman, 1997). The *luva* stage of my research reflects the discussion of my findings, acknowledging people who were part of the research and the process of giving back my thesis to the Tongan community.

Using Talanoa within a framework of Kakala

For my research, I employed the *Kakala* framework as the research methodology and incorporated the *Talanoa* method as the process of gathering data. Anae et al. (2001) stated that the concept of *talanoa* validates a qualitative approach and is considered the most appropriate method to use in this research, as it adopts an oral interactive approach. The use of *talanoa* within a *Kakala* framework helped to make my research process explicit by placing a strong emphasis on seeking and voicing the perspectives of Tongan families in

hospice care. Throughout the Pacific peoples' histories, they have always relied upon the *talanoa* process to build better understanding and co-operation within and across human relationships (Halapua, 2000).

According to Vaioleti (2006), the term *talanoa* means 'talking about nothing in particular.' It also refers to a personal encounter where individuals tell stories or discuss any topic that comes to mind. The *talanoa* concept is recognized by many Pacific nations including Fiji, Samoa, Solomon Islands, Niue, Cook Islands, Tonga and Hawai'i (S. M. Prescott, 2008). Pacific researchers describe the *talanoa* process as holistic and incorporating the amalgamation of emotions, knowledge, interests, and experiences of the researcher and participants (Farrelly & Nabobo-Baba, 2014). Often Tongan people gather to *talanoa* about their issues, their realities, their aspirations and exchange ideas or thinking in an informal or formal manner. The *talanoa* process has no framework; therefore, there is no set structure or set agenda and time constraints to limit people's *talanoa* but rather promote open discussion and respect among people. Additionally, the process of *talanoa* becomes the mediator between people's worldviews where they can hear, learn, and consider their position amongst others in the community. Moreover, people can embrace their worldviews, work together collectively and relate to one another as a member of society (Vaioleti, 2003, 2016).

In research, the *talanoa* process establishes a setting in which both the researcher and participants can connect and talk spontaneously about any topic that arises. It helps to remove the power of the researcher to control the communication process and allow the conversation to flow freely without the intrusion of a formal structure (Fletcher, Parkhill, Fa'afoi, & Morton, 2006). Moreover, the *talanoa* process provides a familiar environment in which both parties can discuss things freely and safely as well as encourage conversations regarding past

and present experiences. For the *talanoa* to be effective, the researcher needs to observe and practice the basic principles of respect, humility, love, compassion, caring, and generosity. These principles will guide the researcher and allow the participants to set the parameters for their discussion, namely, their inclusions, reconciliation, and mutual respect (Fua, 2014). Furthermore, the *talanoa* process is effective when the researcher and participants have a mutual understanding that it is a culturally and emotionally embedded reciprocal exchange between both parties. Therefore, it requires a deep, interpersonal relationship and emotional sharing to occur between the researcher and participants (Halapua, 2000). Overall, employing a *Talanoa* method to gather data allows me to form a relationship with the participants as well as enable in-depth meaningful exchange of information based on trust and respect.

Procedures/Method

The project ‘Pacific meets West in advancing palliative care for Pacific populations’ was hosted by Massey University and led by Dr. Sunia Foliaki. The project was undertaken in collaboration with Palliative Care Providers in Auckland and Wellington, the Pacific Palliative Care Network, Pacific health care providers, the Capital Coast and Hutt Valley (District Health Board) DHB, and Pacific community groups involved in Pacific palliative care as well as other Pacific community groups. As a research assistant, my role involved collaborating with hospice staff members, recruiting participants and conducting face-to-face *talanoa* sessions in the Auckland region.

The overall objective of the project was to identify strategies to improve provision, access and use of specialist and primary care among Pacific people in New Zealand. However, the present study focused on exploring the psychosocial needs of Tongan families in hospice care

and identifying strategies that would help improve palliative support for Tongan families. The present study was granted ethical approval by the Massey University Human Ethics Committee. The data used for the present study was drawn from the larger project; 'Pacific meets West in advancing palliative care for Pacific populations.' As an insider-researcher, I focused solely on exploring Tongan families' experiences in the palliative care context while keeping the participants' identity anonymous.

Participants

The participants were primary family carers of Tongan heritage who cared for a loved one with a life-threatening illness and accessed hospice care. They were carers between the ages of 30 and 60 who resided in the Auckland region. In total, five participants gave consent to be part of the research. The Tongan family carers were recruited through collaborating with Totara and Mercy hospice, networking with the community and reaching out to churches through my cultural advisor (a pastor for the Tongan Seventh-day Adventist church). Prior to recruiting participants, Dr. Sunia Foliaki and I scheduled a meeting with both Totara and Mercy hospices. The purpose of the meeting was to engage with the hospice staff to discuss the research and ways of recruiting participants. Both hospices agreed that they would assist with recruiting participants and ensured that other staff members were aware of the research. Each hospice had a main person of contact who would liaise between myself and potential participants. Their role involved sending information sheets to potential clients, approaching Pacific families and patients who were using in-patient hospice facilities, and informing both the community and in-patient hospice staff members about the objective and processes involved in the research.

Another process for recruiting participants was through networking with people in the community. I informed my community that I was conducting a study based on Pacific people's experiences in palliative care and further explained the purpose and process of the study. I also approached my church members and informed them about the study. Additionally, my cultural advisor reached out to other pastors from the Seventh-day Adventist church as well as other denominations and informed them of the study and the benefits of conducting such research. Individuals that were interested in participating were then contacted to schedule a time and place to conduct the *talanoa*.

Talanoa

A total of five family-based *talanoa* sessions were undertaken. The *talanoa* process was held in a location where participants felt comfortable and secure as well as a place that was accessible to them, such as their homes, or within the service provider's office, or any other places they preferred. Most participants preferred to conduct the *talanoa* in their own homes or workplace while others chose to do the *talanoa* in my abode. Before conducting the *talanoa*, it was important to consider one's social status, and their position in the community as this will determine how I will approach them and what cultural protocols to follow (Otunuku, 2011). In the Tongan society, a hierarchy exists from monarchy, nobility to commoners. There is also a hierarchy that is reflected in the church and family. For instance, Tongan people have the utmost respect for the church pastors and church leaders as well as for parents and the elderly in the community (Aselson, Hunsicker, Schneider, & Quast, 2011). Most Tongan people emphasize spiritual dimensions to a situation and see the church and the *faifekau* (church pastor) as significant aspects (Völkel, 2010). Consequently, when approaching one of the participants who was a *faifekau* (church pastor), a *kato meakai* (a

basket containing the best foods in my household) was given to show my respect. The cultural protocol involved in approaching the *faifekau* differed from the approach to other participants, which highlights the significance of the church and spirituality in the Tongan community.

Once written informed consent was obtained from each participant, I informed participants about the process of the research, from how the data is collected to how it will be disseminated. Participants were also told that the *talanoa* would be recorded using a digital recorder as well as how information regarding their identity and input is stored or disposed of. Furthermore, I notified participants that they could withdraw from the research at any time without penalty. The *talanoa* sessions were undertaken in the language of their choice (Tongan or English language). During the initial phases of the *talanoa*, the participant and I engaged in an informal *talanoa* process where we established a connection. Once a connection was established between the researcher and participant the formal process of *talanoa* was introduced in which the discussion focused on the research topic. In cases where participants go off-track when engaging in *talanoa*, I used open-ended questions to guide the *talanoa*. Upon completing the *talanoa*, a *me'a'ofa* (gift) was provided to acknowledge participants' time and effort. Moreover, the presentation of a gift was also an essential part of the *talanoa* process as it reflects an expression of respect. All in all, five *talanoa* sessions were completed and transcribed, of which two were conducted in the Tongan language and translated to English.

Ethical considerations

The current study is part of a larger project (Pacific meets West in Advancing palliative care for Pacific populations). As a research assistant for the larger project I was given permission by the principal investigator, Dr. Sunia Foliaki for the use of de-identified data from the wider study, specifically Tongan family carers accessing hospice services. The ethical issues have been considered in the aforementioned project together with my supervisors, Dr. Sunia Foliaki and Dr. Siautu Alefaio and the cultural advisor, Pastor Taufu Pulu. The ethical issues that were considered encompassed culturally appropriate ways of approaching Tongan people. A person's status, and rank in society determines how one should culturally engage with them. For instance, I was advised by my cultural advisor to provide a *kato meakai* (a basket filled with the best food in the household) to the *faifekau* (church pastor) to show our respect.

Chapter four: Data analysis (Tui)

A thematic analysis approach was fitting for the study given that the research question relates to people's experience, views, and perceptions of phenomena. The thematic analysis is also theoretically-flexible and can be used within different frameworks (Braun, 2014). The *talanoa* recordings were gathered, translated from Tongan to the English language (two *talanoa* sessions), and transcribed. I re-read the transcripts to be familiar with all aspects of the data and to gain an understanding of the content of the interaction. Subsequently, I identified preliminary codes which are the feature of the data that appeared interesting and meaningful. Generating the codes indicated the context of the conversation. The codes and collated data were examined to identify significant broader patterns of meaning or potential themes. Once themes were identified, I reviewed them again to see that they answered the research question and checked the candidate themes against the dataset to see if they tell a convincing story of the data. Upon reviewing the themes, a process of refining and defining of the themes was involved. The function of this process was to determine the story and scope of each theme. It also involved deciding on an informative name for each theme.

Results

A total of five participants agreed to be part of the research and *talanoa*. A family-focused *talanoa* was conducted, based on the experiences of primary carers in hospice care. In this study, the family carers refer to any relative, friend or partner who is the primary carer and has a significant relationship with and provides various forms of assistance to an individual with a life-threatening illness (Hudson & Payne, 2009). Overall, five *talanoa* sessions were completed and transcribed, of which two were conducted in the Tongan language and translated into English. The participants (three females and two males) involved in the *talanoa* were primary family carers of Tongan heritage who accessed hospice care services and resided in the Auckland region. They were between the ages of 30 and 60.

This study employed a widely-used qualitative data analysis method known as thematic analysis. Researchers use thematic analysis as a means to gain insight and knowledge from data gathered (Nowell, Norris, White, & Moules, 2017). The current study employed thematic analysis in the analysis of *talanoa* to identify, analyze, organize, describe and report themes (patterns) within the data. Given that the study focused on the experiences of Tongan families in hospice care, thematic analysis is a useful method to examine each participant's experiences in hospice care as well as highlight differences and similarities across the dataset.

The family carers were introduced to hospice care through their family general practitioners, social worker, district nurse and hospital doctors. They had no prior knowledge of hospice care and experienced hospice services for the first time. During end-of-life care, patients and families are prone to negative physical, social, psychological and financial consequences. Therefore, the role of hospice care services is to provide support for both patients and

families, as well as optimizing their quality of life by addressing their psychosocial, spiritual, and physical needs. The hospice care philosophy considers families as an integral support system and promotes the patient together with family as a unit of care. Within the Tongan community, health care decisions are usually a family affair in which patients often consult their *kāinga* (extended family). Thus, it is important that health professionals include family members in decision making regarding the care of loved ones. Although families in hospice care have various needs, the present study chose to focus on their psychosocial needs. The *talanoa* sessions highlighted that four of the five family carers were satisfied with the hospice services; however, there were various aspects of hospice care that psychosocially impacted the families. From the results of data analysis, five psychosocial needs relating to family carers were identified, as shown on figure 1 below:

- limited knowledge and information regarding hospice care
- ineffective communication by health professionals
- lack of engagement by health professionals
- dissatisfaction with spiritual support provided by hospice care
- lack of discussion and shared planning for future health care.

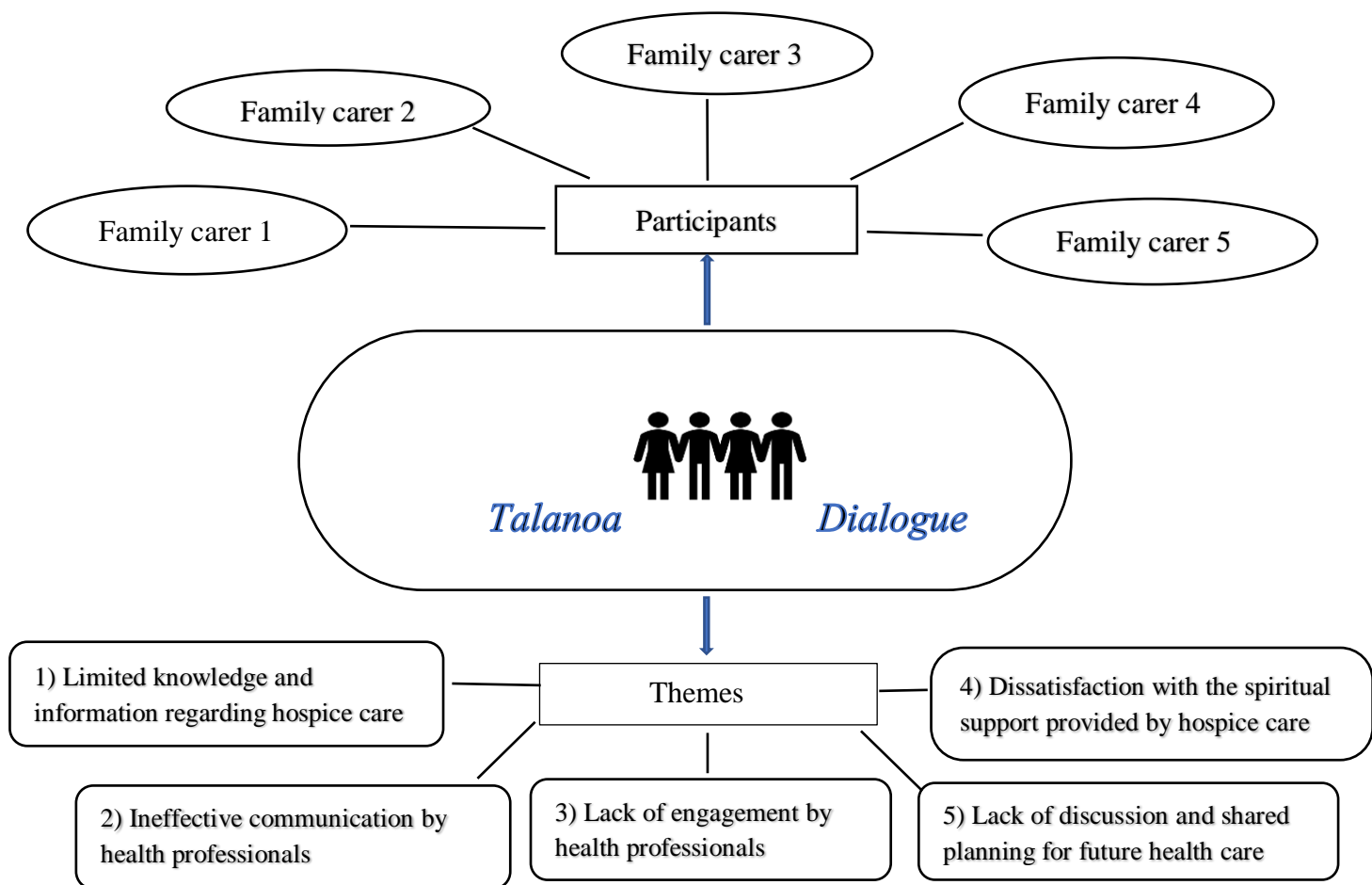


Figure 1: Summary of themes and participants.

1) Limited knowledge and information regarding hospice care.

The majority of the Family Carers (FC) 1, 2, 4 and 5 were aware that people are referred to hospice care when their illness is incurable. They also had some knowledge of the services that hospice care provided including medical and nursing care, pain and symptom control, therapies incorporating physiotherapy and complementary therapies, as well as spiritual support. Nonetheless, there were other aspects of hospice care that the family carers did not fully understand or had no knowledge of. This indicates that family carers have limited knowledge and information concerning hospice care. Many family carers including FC 2, 4 and 5 perceived hospice care as a dedicated care facility for the elderly only as opposed to a

philosophy of care that can be provided anywhere and to anyone with a life-limiting illness regardless of their age. For instance, FC 4 described hospice as a “hospital that looks after the elderly.” Furthermore, most of the family carers (FC 1, 2, 4 and 5) had no or little knowledge regarding the services they are entitled to. For instance, some family carers were not aware that hospice care provided home nursing equipment. This lack of knowledge about their entitlements was illustrated in FC 4’s *talanoa* regarding his initial contact with hospice care:

The beds and wheelchairs came in late even after requesting for it. It took a while to receive this equipment. We didn’t have it initially when accessing hospice care. At first, I had to carry my mother to the toilet. Just realized that there’s a toilet urine seat equipment where my mother can urinate in...I just recently knew that this equipment were available and telling them (hospice staffs) about it. I think they (hospice staffs) should be the ones offering instead of me enquiring because it’s not like I have knowledge of these things. They should have seen the state my mother was in and gave the equipment. It’s not like I knew that they have this equipment. It would have been good if they brought the equipment in the beginning to make the work easier.

FC 4 also noted that things would have been different if he had prior knowledge and information regarding the home nursing equipment, bariatric toilets.

Additionally, many family carers (FC 1, 2, 4, 5) reported having no or limited knowledge regarding respite care. This service provides short-term breaks for the carers in which someone comes over and cares for their loved one while the family carers are able to go to shopping or have a break. Alternatively, family carers could admit their loved ones to hospice as inpatients while they go for a short break (Hospice New Zealand, 2018). Some family carers (FC 4 and 5) had no knowledge of respite care; however, their *kāinga* (extended

family) took turns caring for their loved one. On the other hand, FC 1 and FC 2 knew that respite care was available for family support; however, they were not aware that respite care can be offered to family carers irrespective of where they are. It appears that both family carers (FC 1 and FC 2) viewed respite care as a service offered only when their loved one is admitted to a hospice care facility.

2) Ineffective communication by health professionals.

The persistent gap between the carers' expectations of hospice care and what was actually provided is an indication of ineffective communication occurring between the healthcare team and family carers. Of the five family carers, four (FC 1, 2, 4 and 5) reported situations which reflected ineffective communication occurring between them and the healthcare professionals at each phase of hospice care. The family carers had different communication experiences with their GP during the referral phase. While some family carers were happy with their GP, others were disappointed. For example, FC 5 was happy with their GP and how she communicated with her family while FC 4 noted that:

I had asked my GP to refer my mother to hospice If the GP had referred us earlier we wouldn't have to go through having to carry my mother without the proper equipment.. The hospice people were the ones who came and asked whether we needed government fund. The GP was just slow to provide information even after reporting our care.

When accessing hospice services, the family carers had contradicting views regarding communicating with the hospice care team. FC 4 was satisfied with the way the hospice care team communicated with him; however, FC 5 felt that:

There wasn't really any sort of conversation with my mother-in-law (she was the one who mostly did the coordinating of their family members hospice care) it was more of just a hear it from the doctor sort of thing to go on to hospice and then we kind of spoke.

Furthermore, FC 5 emphasized that the hospice care team did not thoroughly explain to them what they do: "There wasn't any information from hospice...There's not enough information like, we see like advertising and stuff about hospice and that, but there is no sort of like structure as to what they actually do." Moreover, FC 1 and FC 2 reported incidents that reflected the impact of ineffective communications occurring between the healthcare team and family carers. The family carers had expectations of the hospice team and were disappointed that these expectations were not fulfilled. This ineffective communication occurring in hospice care was illustrated in FC 2's experience with the hospice nurse:

Just to be there all the time for the dying patient. Because there were...sometimes dad needed a massage, you know. So I have to massage while they could have done it. They leave the patient too long before they come and see him next time. I advise that they should always check on him, like half an hour.

3) Lack of engagement by health professionals.

Another prominent theme in the data was the perception of carers that some or all health professionals had low levels of engagement with them. Most of the family carers (FC 1, 2, 4, and 5) reported having no follow-up contact with their GP once their loved one was referred to hospice care or having limited engagement with hospice staff. For instance, FC 4 explained that "Once referred to hospice we didn't deal or contact with any doctors. Hospice did everything when we got referred to them." On the other hand, other family carers' had more positive perceptions of GPs such as FC 5 who stated: "We feel more connected to our GP,

you know, than to the hospice. We wouldn't even think of going to hospice...After my sister passed away it was like that was it. There was no continuous care."

While FC 5 felt connected with her GP she mentioned having limited engagement with the hospice staff:

It was like therapy you know like a ..just come in and talk to them how your life is and what you're doing. It wasn't so much with the family it was just to come and visit her (referring to the patient).

For FC 5, "there was no connection at all" with the hospice staffs. Other family carers (FC 1 and FC 4) also reported incidents in which family carers felt that the hospice staff did not engage with them. For example, FC 1 stated: "I think they needed to communicate with the rest of the family... it was only them with my late wife and not with me."

4) Dissatisfaction with the spiritual support provided by hospice care.

Many family carers (FC 1, 2 and 5) were dissatisfied with the spiritual support provided by hospice care because they felt that it did not meet their spiritual needs or that they were not informed about the spiritual support offered in hospice care. This dissatisfaction with the hospice spiritual support was illustrated in FC 2's statement: "Something that I want to see happen in the hospice is the fact that they allow for spiritual like groups to come in and talk to the patient." He further added:

Ever since we were at the hospice, ummmm besides their spiritual program which only the able were allowed to... could make it to. The rest that were static, there were no people to come in...you know like just for comfort..... It would be really good too because the person next to us died with no one there... It would be really great, this is from a Christian perspective or any other religion. It would be good to see someone, to have someone beside them while they're taking their last breath.

Another family carer (FC 1) highlighted that despite hospice care allowing his family to practice their spiritual beliefs, they did not provide a pastor. In addition, FC 5, who was not aware that hospice care provided spiritual support, mentioned the following:

Well, spiritual needs we did through church you know. It was all like a church sort of thing and then pastor would come over and even from my church she would come and visit us and do a prayer and that sort of thing. So we kind of helped ourselves with that but we didn't know that there was something..... that hospice could provide that.

5) Lack of discussion and shared planning for future health care.

The family carers reported having limited discussions regarding advance care planning. Three family carers (FC 2, 4 and 5) reported having no discussion on advance care planning whereas two family carers, FC 1 and FC 3 underwent the advance care planning process. The advance care planning process is about a patient's wishes and preference for the time when they lose the capacity to make decisions. FC 2, 4, and 5 emphasized having no advance care plan put in place for their loved one to direct future medical treatments and procedures. This lack of advance care planning by health professionals was evident in FC 5's statement:

No not through hospice (referring to the discussion of advance care planning). It was more like of a research thing that my sister-in-law did and what we are doing at the moment before anything happens. So wasn't any sort of information from hospice at all.

On the other hand, while FC 3 reported being satisfied with the advance care planning process FC 1 noted that it "didn't really work". His wife had informed the health professionals of her wishes and yet they were not fulfilled. FC 1 mentioned that it would be good if the health professionals had informed the rest of the family so that they could cooperate in fulfilling their loved one's wishes.

Given that majority of the family carers (FC 2, 4 and 5) had no advance care planning with hospice care, the family carers suggested areas in hospice care that need improvement. There was a general consensus that hospice care should be recommended to others. However, the family carers suggested educating Pacific people about hospice care and employing Tongan health professionals in hospice care. The family carers (FC 1-5) had no prior knowledge of hospice care, and some found it challenging to navigate hospice care. For instance, FC 5 mentioned:

To be honest there's a lot out there for the palangi side cause I'm married to a Maori and we've just had his sister-in-law pass away and that was the only time I found out about hospice care and the fact that they can go from the hospital to the hospice in order to help with the family and the grieving and the letting go and all that sort of thing. But even before that, there wasn't a lot of information out there to like, here's care for you and here's the opportunity to do this and that with it. No options really, especially for the Pacific people.

She further suggested the following:

Mostly making sure that there's enough information out there just to help everyone and for them to actually know what they are doing, and you know and there are steps to going to the hospital, and there are options of where to go and stuff. I would love to use hospice if it was there for me grab on to but yeah, unfortunately, it wasn't. Enough information would have been good to me (FC 5).

Other family carers (FC 3 and FC 4) suggested that hospice care should employ Tongan health professionals due to communication reasons and a better understanding of family needs. This desire for hospice care to employ Tongan health professionals was reflected in FC 3's statement: "It would be good to get Tongan staff because it will be easier for families

to communicate with them (hospice staffs).” Another family carer (FC 4) agreed and mentioned the following:

It would be good to have Tongan nurses work in hospice. They would help patients and families in many ways by explaining the services available in hospice. Many elderlies that use the hospice services are unable to speak English; therefore, the presence of Tongan nurses will enable them to share directly what their needs are.

Chapter five: Discussion (Luva)

Psychosocial needs of Tongan families in hospice care

Family carers are the greatest source of support for patients with life-limiting illnesses who wish to be cared for at home. Without the support of family carers, terminally ill people would not be able to continue living out their last days at home. There is an increasing acknowledgment of the significance of family carers in hospice both as supporters of patients and people with psychosocial, physical, spiritual and cultural needs (Otis-Green & Juarez, 2012; Girgis et al, 2012; Hudson et al., 2015). Part of the hospice care philosophy is to promote the patient and families as a unit of care (Hospice New Zealand, 2012). This means that hospice services are provided to both the patient and their families. Although family carers are recipients of palliative care, caregiving literature shows that family carers have consistently reported unmet needs (Bekelman et al., 2011; Cagle et al., 2017; Docherty et al., 2008; Lalani et al., 2018; Lecouturier et al., 1999; MacKenzie et al., 2015; McMillan et al., 2013). As the population ages with increasingly complex morbidities, there will be an increased need for palliative and end-of-life care. Family support will be in great need as patients continue to prefer home care; therefore, hospice care should prioritize finding the best ways to support family carers.

The New Zealand hospice care services acknowledge the cultural diversity amongst patients and families and have incorporated frameworks such as the ‘*Whare tapa wha model*’ and the ‘*Ala Mo’ui*’ to guide their approach to palliative care. Research reveals that Pacific people are accessing hospice care (Hospice New Zealand, 2012); however, limited information is available regarding their experiences in hospice care. Caregiving has the greatest impact on

the carers' psychosocial wellbeing. We are not aware of any research with a focus on the psychosocial needs of Pacific family carers. As a woman of Tongan and Fijian heritage I chose to focus on the Tongan family carers in hospice care. I was interested in their caregiving experiences as well as being passionate about giving back to the community through identifying strategies that would improve hospice support. Provision of optimal support for Tongan family carers will help improve the families' health outcomes and in turn enable them to provide adequate care for their loved ones.

Recognizing and understanding the needs and experiences of carers is important for the provision of appropriate support. Therefore, this study explored the psychosocial needs of Tongan families in hospice care, the determinants of psychosocial distress in family carers, and the family carers' experience of hospice services with the ultimate goal of identifying strategies that would help improve palliative support for Tongan families. Key findings of this study identified five psychosocial needs relating to caregiving: limited knowledge and information regarding hospice care; ineffective communication by health professionals; lack of engagement by health professionals; dissatisfaction with the spiritual support provided by hospice care; and lack of discussions and shared planning for future health care.

Subsequently, these psychosocial needs will be discussed in relation to the overall objective of this study with psychosocial strategies indicating the significance of meeting these needs for Tongan families. In addition, the psychosocial strategies providing optimal support for Tongan families in hospice care will be highlighted and finally, the limitations and future recommendations of this study will be discussed.

Psychosocial strategies for Tongan family carers

By identifying the importance of psychosocial needs for Tongan family carers, strategies to meet these needs also become more evident. This discussion highlights psychosocial strategies that are explained through Tongan cultural metaphors. Each psychosocial strategy is a direct response to the psychosocial need identified.

1) *Fakamatala 'i ke mahino ki he ngaahi fāmili' ke hoko ia koe maama takiloa ki he hosipesiō.*

To explain the information in a way families can understand and use it as a guiding light to navigate hospice care.

Firstly, a psychosocial need identified by Tongan family carers in hospice care which they reflected on was having *limited knowledge and information about hospice care* particularly regarding the objectives and services of hospice care. The majority of the family carers (FC 1, 2, 4 & 5) had perceptions of hospice care that were inconsistent with the objectives of hospice. They believed that hospice care only takes place in a dedicated facility and only elderly with life-limiting illnesses are admitted to hospice care. However, hospice care is a philosophy of care that is provided to anyone with a life-limiting illness regardless of their age. It is also a service that provides support preferably at any location preferred by the patient whether this is at home or an alternative facility. (Hospice New Zealand, 2012). The Tongan phrase '*Fakamatala 'i ke mahino ki he ngaahi fāmili' ke hoko ia koe maama takiloa ki he hosipesiō*' is translated as 'To explain the information in a way families can understand and use it as a guiding light to navigate hospice care'. It highlights the significance of Tongan family carers understanding the information provided by health professionals. When families understand the information provided to them they are able to utilize the services available and have a better

understanding of what hospice care is about. Therefore, it is important that health professionals check that family carers understand the information delivered to them.

Tongan families prefer to care for their loved ones at home and in a familiar environment surrounded by family members. Since families perceive hospice care as a dedicated facility to which their loved ones have to be admitted, it discourages them from accessing any services provided by hospice, because it means having to separate them from their loved ones. Some family carers (FC 4 & 5) were unaware of the support services that were available to them, which led to families not accessing any support services from hospice. The limited information and knowledge Tongans have regarding hospice care ‘keeps them in the dark’ and prevents them from navigating and accessing hospice services. Receiving adequate information and knowledge is a reflection of a light that can guide families in their palliative journey.

Limited knowledge and information about hospice care services identified by family carers is attributed to various factors including health literacy skills, the mode of information delivery being culturally inappropriate and, the time and place of information delivery being inconducive to information exchange. Health literacy refers to the “degree in which individuals have the capacity to obtain, process and understand basic health information and services needed to make informed and appropriate health decisions” (Ministry of Health, 2010). The Ministry of Health (2015) noted that Pacific adults were significantly less likely to have good health literacy skills compared to non-Pacific adults. Ethnic minorities and people who speak English as a second language also have low health literacy (Minister of Health and the Minister of Pacific Island affairs (2010). This inferred that Tongan families

have low health literacy skills. The lower socio-economic status of Tongans living in New Zealand often leads to them having limited education which impacts on their health literacy.

The mode of information delivery adopted by health professionals also contributes to families having limited information and knowledge. The way health professionals convey information to the family carers may not be culturally appropriate. For instance, the health professionals use of medical jargons and incorporation of 'Western' values may not align with the Tongan worldview. The mode of information delivery may have been in the traditional written form as opposed to face-to-face information sessions. In the *anga-fakatonga*, people engage in *talanoa* with their *kāinga* to discuss issues. Therefore, Tongans often prefer oral dissemination of information and discussion over written information. Through face-to-face interaction, Tongans are able to connect with health professionals and better understand the information provided to them.

The time and place in which the information is delivered by health professionals is another factor that impacted families receiving adequate information and knowledge on hospice. The health professionals may have informed families during times when families are exhausted after long hours at work. Additionally, the information may have been delivered to families in a busy environment where families are unable to digest and absorb information. Taken together, the information provided by health professionals should be delivered in a simple quality of care manner and tailored to the Tongan families' needs. When dealing with Tongan families, health professionals should consider the families' health literacy levels and cultural values, the appropriate process and method of information delivery, and the time and place suitable to deliver hospice information. Health professionals should also discuss with family carers an appropriate place and time for information exchange.

2) *Kāfataha moe femahino‘aki ‘ihe fakahoko ngaue’.*

Unity in understanding each other and working together.

Another psychosocial need that the Tongan family carers emphasized was *ineffective communication by health professionals*. Although effective communication lies at the heart of hospice care, many family carers (FC 1, 2, 4 & 5) were dissatisfied with the way the health professionals communicated with them. The Tongan phrase ‘*Kāfataha moe femahino‘aki ‘ihe fakahoko ngaue*’ means ‘Unity in understanding each other and working together’. It emphasizes the importance of team work. Both the health professionals and Tongan family carers need to work together for the patients’ benefit. This shared goal can be achieved when both parties communicate, understand each other and work together in unity.

Through effective communication Tongan families and health professionals can exchange information regarding what hospice care is, what to expect, the role of the health professionals and the services available to family carers. Further, they are able to unify through understanding each other and work together for the overall benefit of the patient. However, this was not the case with the family carers. They felt the need to be informed about hospice care, to be understood and be part of the communication process involving their loved one. Thus, ineffective communication by health professionals slowed the referral processes from primary care to hospice care, and led family carers to having expectations of hospice care that were inconsistent with what hospice delivered.

The communication by health professionals was influenced by factors including the cultural expectations of communication, the communication process being culturally irrelevant and health professionals not understanding the Tongan family dynamics. Culture influences the way people think, act, and interact (Fang et al., 2016); therefore, it can profoundly affect the

way people communicate in a cross-cultural context. This study found that hospice care is dominated by health professionals from Western cultures and therefore sought to discuss the impact of cultural expectations regarding communication. Given that the health professionals and family carers were of different cultures, their expectations of communication were dissimilar. Tongan families expected the health professionals to initiate a family discussion regarding end-of-life care. For instance, a Tongan male primary carer (FC 4) noted that “they should be the ones offering (referring to knowledge about home-based equipment) instead of me enquiring”. Research also shows that health professionals expect the family carers to speak up and communicate their needs (Medical Council of New Zealand, 2010; Ministry of Social Development, 2016). This is difficult for Tongan families as they are less likely to question health professionals, speak about their pain and demand effective services because of the traditional respect for authority figures. Similar to previous research on primary care for Pacific people, cultural expectations continue to be a barrier to effective communication in health care.(Medical Council of New Zealand, 2010; Southwick, Kenealy, & Ryan, 2012).

Moreover, Tongan families do not feel the need to question health professionals due to the expectation that caregiving support is shared and provided within the family or *kāinga*. For example, a Tongan female carer (FC 5) reported that respite care and advance care planning was done by her family and not by hospice care. In the *anga-fakatonga*, the end-of-life care journey is a collective one in which all family members have a responsibility. End-of-life care is a journey sacred to Tongan families and they believe that it is important to create a space which their loved one is familiar with, to follow cultural protocols, and ensure that their loved one’s wishes are fulfilled. Adhering to cultural protocols means that it is the family’s responsibility to ensure that any end-of-life care affair that arises is dealt with within the family.

The way health professionals communicated with the family carers also contributed to ineffective communication especially when the communication style utilized is culturally irrelevant. The health professionals may have communicated in ways that reflected attitudes, awareness, knowledge and skills that were culturally incompetent and inappropriate. It appears that the health professionals did not take time during the initial meeting to engage and learn about the families' cultural preferences or ask about the families' heritage and *kāinga* to develop a connection. For instance, a female Tongan primary carer (FC 4) mentioned that

“there wasn't any sort of conversation with my mother-in-law (who mostly coordinated their loved one's hospice care) it was more of just a hear it from the doctor sort of thing to go on hospice and then we kind of spoke”.

The communication by health professionals seemed brief and hurried which did not allow families to ask questions and inform them about their preference or needs. Part of being culturally relevant is understanding the non-verbal cues displayed by Tongan families. For example, often Tongans do not look directly at someone of high status and authority, and therefore rest their gaze elsewhere. This may be interpreted by health professionals as families being uninterested in health discussions or being impolite. However, health professionals should understand that families behave in such manner out of respect for people of authority and high status. Tongans also tend to raise their eyebrows when communicating with people. The 'eyebrows raising' does not necessarily mean that they understand the information. It means that they are present in the communication. Therefore, it is important that health professionals check in with families to see if they fully understood the information delivered to them.

The lack of knowledge regarding the Tongan family dynamics by health professionals also influence the communication by health professionals. In the *anga-fakatonga*, the relationship between a brother and sister is treated with *faka 'apa 'apa* in which certain aspects of taboo must be respected; for example, brothers and sisters cannot be in the same room if health discussions encompass descriptions of private body parts or demonstrations of bathroom equipment use. When it comes to hospice discussions health, professionals should be mindful of the family dynamics and the appropriateness of the message to avoid families feeling uncomfortable and withdrawn. Considering the factors that impact effective communication, it is apparent that the health professionals in hospice care lack cultural competency skills. Consequently, cultural competency training for health professionals is greatly needed. Another solution that hospice should consider is employing Tongan health professionals into the workforce, given that they have the cultural understanding and skills to work with Tongan family carers.

3) *Tauhi e vaa' ke 'aonga fakalukufua 'i he mala'e 'o e hosipesiō.*

Nurturing relationships will holistically benefit Tongan families and health professionals in hospice care.

The *lack of engagement by health professionals* was another psychosocial need highlighted by Tongan families in hospice. Although some family carers (FC 4 & 5) had positive relational engagement with specific health professionals, the majority (FC 1, 2, 4, 5) felt that most of the health professionals in palliative care had low levels of engagement with them. The Tongan phrase '*Tauhi e vaa' ke 'aonga fakalukufua 'i he mala'e 'o e hosipesiō*' is translated as 'Nurturing relationships will holistically benefit Tongan families and health professionals in hospice care'. It highlights the significance of *tauhi vā* (nurturing relationships) in the hospice context. The *tauhi vā* concept is the essence of relational engagement for Tongan families. When health professionals have an understanding of how

Tongans perceive relational engagement, this will help positively shape the family carers' experiences in hospice care.

Tongans value nurturing interdependent relationships because it contributes toward the process of building collective success. The process of *tauhi vā* should be understood within the *kāinga* system. One of the fundamental cornerstones of Tongan society is the *kāinga* system. The *kāinga* system is of hierarchical with clear rankings that Tongans support and respect. The people's role, status and rank indicate how members of the *kāinga* are related to one another. It also determines how an individual should behave in a particular function and setting. To maintain peace and stability within the *kāinga* there is emphasis on *tauhi vā*, underpinned by four core values: *faka'apa'apa* (respect), *feveitokai'aki* (genuine respect and regard for the feelings or thoughts of others), *fakatōkilalo* (humility) and *fetokoni'aki* (the reciprocal obligation of helping one another in everything) (Mafileo 2005; Manu O'Uiha, 2018). Incorporating these values in *tauhi vā* reinforces reciprocity and mutualism amongst Tongans. The *tauhi vā* occurring within the *kāinga* is strengthened through *lotu* and family events where people gather together and *faifatongia* (fulfilling obligations). The *tauhi vā* that occurs within the *kāinga* is translated into people's everyday lives. By means of *tauhi vā* a harmonious space is cultivated in which people can relate to one another in various ways (Thaman, 2003; Ka'ili, 2017; Vaioleti, 2011). When Tongans migrated to New Zealand, *tauhi vā* was a platform in which assimilation to new customs took place while preserving their *anga-fakatonga*. It was also a support system which enabled Tongan emigrants to adapt and survive in a new environment (Havea, 2011; Tānaki, 2015).

There are processes of *tauhi vā* that health professionals are yet to understand.

These processes will unfold as I discuss the families' expectations of hospice care. Tongan families expect health professionals to be present at all times; for instance, a Tongan male primary carer (FC 3) wanted the health professionals "just to be there all the time for the dying patient." He further noted that "it would be good to see someone (from hospice care), to have someone beside them (referring to their loved one) while they're taking their last breath." However, this may contradict the Western healthcare system that focuses on efficient business management and costed health practices resulting in shorter assessment appointments (Medical Council of New Zealand, 2010; Southwick et al., 2012). This expectation of *tauhi vā* occurs within Tongan families. When loved ones are terminally sick, they expect to be surrounded by their family or *kāinga*, at all times.

Tongans prefer to interact with people they know and feel comfortable with; therefore, they place high value in establishing and maintaining long-term positive relationships with health professionals. They also like to take their time building rapport with the health professionals (J. Prescott & Hooper, 2007). This expectation of establishing relationships differs from the health professionals' approach in which establishing relationship is viewed as a brief and quick interaction (Southwick et al., 2012). Initial processes of forming relationships should provide a lasting impression of the hospice. Therefore, forming positive relationships enables Tongan families to trust a system that represents core values of Western culture. If the initial process of forming relationships is unsuccessful this impacts the utilization of hospice services among Tongan families.

Pacific people, including Tongans, viewed relationship outside the consultation and within a consultation as equally important; nevertheless, this may not be the case for many health

professionals (Southwick et al., 2012). Health professionals conform to the Western values of hospice care in which personal autonomy and individualism is emphasized. However, this contradicts with the Tongan culture that focuses on dependence and collectivism. The Tongan culture values the needs and goals of the group as a whole; therefore, maintaining relationships and interconnectedness is of utmost importance, whether it is outside or within their consultation schedule. It appears that the health professionals' conceptualization of relationships and what they perceived to be of value does not align with Tongans' concept of *tauhi vā*. The lack of cultural awareness by health professionals and the way the hospice care system operates contribute to misunderstanding of the concept of *tauhi vā*. Thus, it is important that health professionals understand Tongan values and their expectation regarding relational engagement.

4) *Koe lotu fakatonga moe tokanga'i fakalaumālie 'o e hosipesiō.*

Tongan Lotu and realities of spiritual support in hospice care.

Another finding that Tongan families reported was being *dissatisfied with the spiritual support provided by hospice care*. The majority of the family carers (FC 1, 2 & 5) felt that their spiritual needs were not met and they had no knowledge of the spiritual care provided by hospice services. For the families that were aware of the spiritual support delivered by hospice care, they felt that it did not quite align with their perception of spiritual care. For instance, some family carers desired to have a pastor present. Another Tongan primary carer (FC 2) reported wanting spiritual support at all times for their loved ones. He also voiced the idea of having spiritual programs conducted in their loved one's ward, given that he was not mobile. As for those who had no knowledge of the spiritual care provided in hospice care, they turned to their church/religion for spiritual support. The Tongan phrase '*Koe lotu fakatonga moe tokanga'i fakalaumālie 'o e hosipesiō*' is translated as the 'Tongan lotu and

realities of spiritual support in hospice care'. It highlights the importance of *lotu* to the Tongan people and their perception of spiritual care. When health professionals understand what *lotu* means to the Tongan people they will be able to provide spiritual care that aligns with the Tongan culture.

Spiritual care is important to Tongan families particularly during end-of-life care. Tongans associate spiritual care with *lotu*. *Lotu* encompasses more than just spirituality; it also refers to peoples' relationship with God, their faith, religion and the institutionalized church that is based on Christianity. When *lotu* arrived in Tonga, it influenced the lives of Tongan people and became an essential feature of the *anga-fakatonga* (Tānaki, 2015). The Tongans in New Zealand built their communities around their faith and continue to practise *lotu*. This is evident in the 98% of Tongans who associate themselves with a Christian denomination (Statistics, New Zealand, 2014). *Lotu* is considered a safe haven for many Tongans because it provided them support, sustenance, identity, wellbeing and a sense of security. Many Tongans viewed *lotu* as a village away from their ancestral homes where cultural values and practices are maintained and relational networks are nurtured through reciprocal cultural *faifatongia*. Above all, *lotu* is a community home where spirituality is fostered and encouraged through *tauhi vā* amongst people (Havea, 2011; Tānaki, 2015).

It appears that the spiritual care provided by hospice care was inconsistent with the spiritual care or *lotu* that the Tongan families were familiar with. The spiritual support offered in hospice care reflects the predominantly Western culture, which was dissimilar to the Tongan families' perception of *lotu*. While prayers and songs were common in hospice care (Angelo & Wilson, 2014) the Tongan people interpreted *lotu* within the confines of their culture, religion and Christian beliefs (Havea, 2011). For Tongans, end-of-life care is viewed as a time to draw on their cultural beliefs, protocols, religious practices, and traditions to enhance

spirituality. This explains why the Tongan families in hospice care saw the church and pastor as fundamental aspects of spiritual care. When a person is nearing the end-of-life, the church provides spiritual care by visiting the individual's home to conduct *failotu*. A Tongan male primary caregiver (FC 2) reflected that hospice care did quite the opposite. Instead of conducting the *lotu* in each ward they wanted the patients to attend a spiritual care program within hospice. Attending the spiritual program was impossible for those who were physically unable. Tongans have a perspective of *lotu* that incorporates their cultural beliefs, protocols, religious practices. As a result, hospice should take into consideration the significance of *lotu* to Tongans and what it means to them.

5) *Tala ke i Kapa telia na'a tō ki Mala.*

A Tongan proverb of warning or advice to act wisely before it's too late.

The final findings of psychosocial needs highlighted by Tongan family carers reflected was the *lack of discussion and shared planning for future health care*. The majority (FC 2, 4, & 5) of the family carers reported having no discussions on advance care planning. The purpose of advance care planning is for the patient to communicate their end-of-life wishes when they lose capacity to make decisions. However, factors such as family carers having lack of information and knowledge about hospice care, ineffective communication and lack of engagement by health professionals, all contribute to the lack of discussion and shared planning for future health care. One of the family carers (FC 1) that experienced advance care planning mentioned that the health professionals need to inform the rest of the family so that they can work together to fulfill their loved one's wishes.

There is a Tongan proverb known as '*Tala ke i Kapa telia na'a tō ki Mala*' which emphasizes the significance of future planning. This proverb originated from ancient Tongans travelling

to Vava'u through the neighboring Islands of Kapa and Mala. Both Kapa and Mala were occupied by the *Taula tevolo* who relayed messages to each other regarding the travelers. All travelers were expected to stop at Kapa to inform the *Taula tevolo* of the purpose of their journey. Those who informed the *Taula tevolo* of Kapa travelled smoothly to Vava'u. Those who did not inform the *Taula tevolo* of Kapa were dealt with by the *Taula tevolo* of Mala. The travelers who did not stop at Kapa were assumed to provoke war in Vava'u and therefore the *Taula tevolo* at Mala would create rough seas to stop travelers from arriving in Vava'u. If people are prepared or inform Kapa before passing Mala then their journey to Vava'u will be a smooth one. This proverb conveys the significance of being prepared and acting wisely before it is too late. The concept of this proverb applies to hospice care. If families are well-informed from the beginning of their palliative journey regarding advance care planning, then they are guaranteed to have a smooth journey. Not only will it benefit their loved ones, but it will also avoid any disputes occurring within the family or *kāinga*. When advance care planning is put in place and health professionals inform families of their loved ones' wishes they are able to work together and better prepare for any future issues that surface. Consequently, hospice should consider introducing advance care planning during the initial process of palliative care to guide families and help them prepare for times when their loved one is unable to make decisions on their own.

Even though FC 2, 4 & 5 had no future health discussions with the health professionals there were aspects of hospice care that they wanted to see improved. Many family carers highlighted the desire to employ Tongan health professionals in hospice care. This suggested that Tongan families preferred health professionals that they are able to connect with at an individual and cultural level. Accessing a service dominated by foreign people (Western cultures) can be an overwhelming experience. Therefore, having someone of the same culture

brings familiarity to the Tongan families as well as help them understand more about hospice care. Moreover, a Tongan female primary caregiver (FC 5) expressed the need to provide the Pacific community information about hospice care, so that families have prior knowledge before accessing the services. It appears that the health professionals expected families to have some knowledge of hospice services. However, all the family carers (FC 1-5) were introduced for the first time with no prior knowledge of hospice care. Hospice care should consider employing Tongan health professionals and ensure that there is hospice information in the community to inform people.

These psychosocial needs relating to the family carers are interconnected. When a particular psychosocial need is unmet it affects other areas of the families' palliative care journey. Family carers are recipients of hospice care and therefore identifying these psychosocial needs of Tongan families demands action. Finding the best ways to support the family carers is a healthcare priority; therefore, formulating strategies to address these psychosocial needs is of paramount importance. These strategies will counteract the unmet psychosocial needs mentioned above and provide optimal support for the carers. Additionally, they will help provide a systematic approach to assessment and care planning. On the other hand, inaction will result in dissatisfaction and a persistence of unmet needs. It will also lead to family carers experiencing poor health outcomes that consequently result in a reduced chance of providing optimal care for their loved ones. By determining the factors that underlie the unmet psychosocial needs of Tongan families, I am able to formulate strategies that will improve palliative support for Tongans.

Strategies addressing the psychosocial needs of Tongan families in hospice care

The exploration of psychosocial needs of Tongan families in hospice care has led to a number of psychosocial strategies that would help improve palliative support for family carers. This includes hospice services providing care in a way that is culturally sensitive and competent for the family carers, delivering culturally appropriate education about hospice care, employing Tongan health professionals, and health professionals' engaging more with family carers. Tongan peoples' experience of health care is influenced by their cultural worldviews, beliefs and values. Therefore, cultural competence of the health workforce is considered an important component of health service quality. It is important that health professionals provide culturally competent care to enhance communication and further address cultural expectations that prevent Tongan families from accessing information and support services in hospice care. As health professionals develop an understanding and sensitivity to the Tongan culture, there will be an increase in knowledge regarding the Tongan family carers' needs and preference.

The provision of culturally-appropriate health education by health professionals will also help Tongan families access adequate information and support services. Health professionals should ensure that hospice information is available in the communities, by way of invitation and letting Tongans know that they are available and that they are welcomed to their services. Many Tongans do not know about hospice care until they are referred to it. Therefore, the initial process is a challenge because families are overwhelmed by a new concept and having no idea of what to expect. During the initial process of palliative care, information delivered to Tongans should incorporate the services available to family carers as well as advance care planning. The information delivered to Tongan families should be delivered in appropriated

modes tailored to the Tongan family's needs. This means that the Tongan families understand and accept the information provided. It is best to always confirm that family carers understand the information by having them explain the information in their own words rather than making assumptions (Medical Council of New Zealand, 2010). It is also important that health professionals consider an environment that is conducive to information exchange: one that Tongan family carers feel comfortable in, where they have privacy and minimal interruptions for optimal communication (Southwick et al., 2012). When family carers acquire concrete care information they are able to better manage their caregiving situation and navigate hospice care.

Another area that hospice should consider is employing Tongan health professionals. Consistent with previous research (Mitikulena & Smith, 1996; Southwick et al., 2012), the family carers (FC 3 and 4) reported a desire to have Tongan health professionals in hospice care. Cohen et al. (2002) emphasized that having a workforce that reflects the population it serves improves the delivery of culturally competent care. Employing Tongan health professionals in hospice care will provide a more culturally appropriate service to family carers because of the shared cultural values and beliefs. Additionally, it will promote better communication and interpersonal interaction with family carers, which, in turn, contributes to improved health outcomes. The family carers (FC 1-5) did not report any language barriers between them and hospice care. However, one family carer (FC 4) suggested that given that the majority of the Tongan elderly who are accessing hospice care are unable to speak English, the presence of Tongan health professionals will help overcome barriers to receiving optimal psychosocial support from hospice care.

Increasing health professionals' engagement with hospice is a prerequisite for creating and maintaining relationships. However, the timeframe for assessment appointments prevents both family carers and health professionals from taking time to build rapport. Therefore, hospice care should consider flexibility with the timeframes allocated for the engagement and assessment process. This will help build trust between the family carers and health professionals and further enable exchange of information that may lead to advance care planning, continuity and coordination of care. Overall, hospice should ensure that these strategies are delivered during all phases of palliative care.

This study revealed the cultural influences that hinder effective hospice service delivery. The cultural misunderstandings between the health professionals and Tongan families play a role in families' lack of palliative support from hospice. Figure 2 depicts the primary cultural principles that should inform hospice care when dealing with Tongan families.

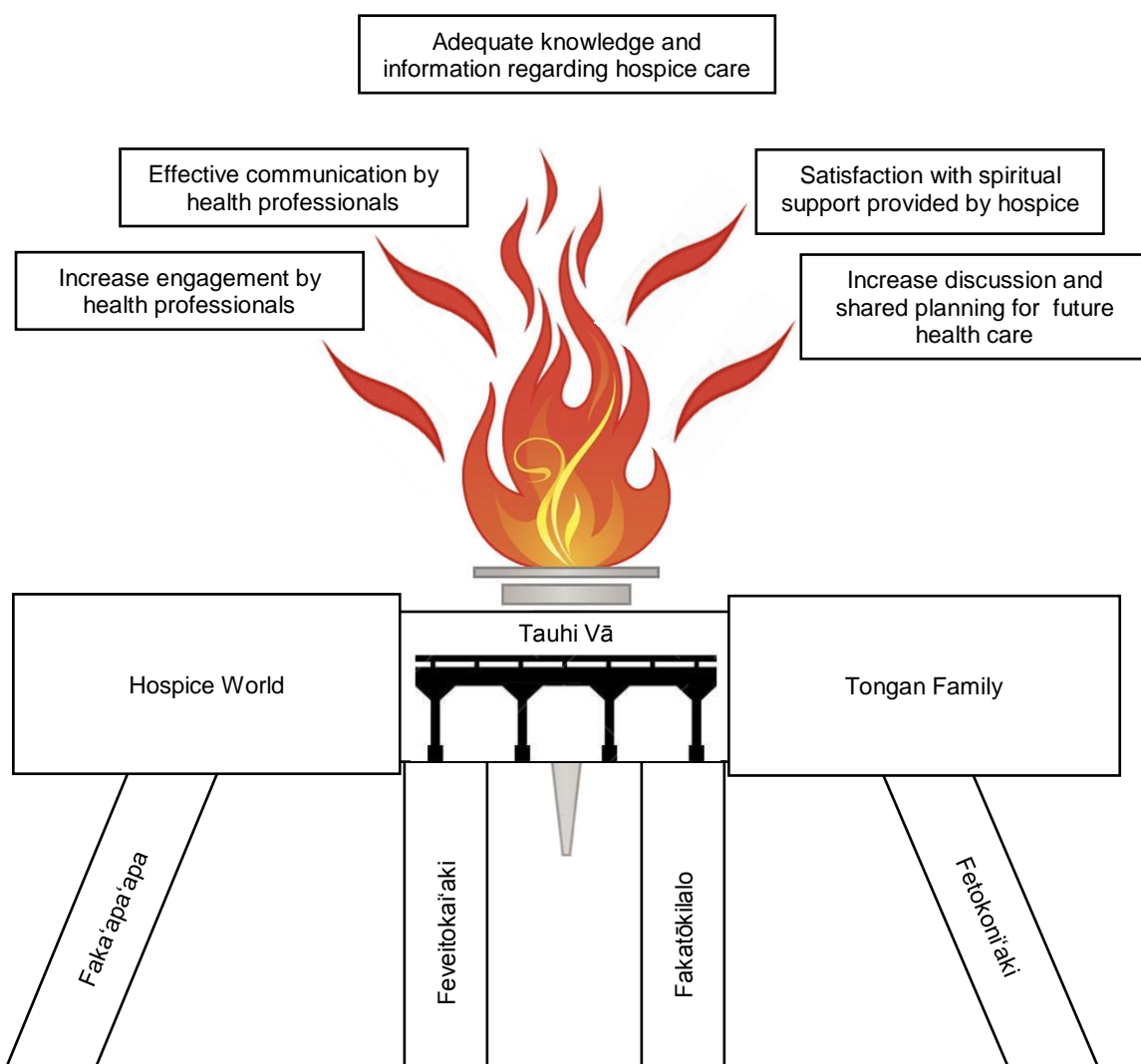


Figure 2: Summary of Tongan values that underpin effective service delivery.

Given the cultural differences between the Tongans and hospice world, *tauhi vā* acts as a bridge to help connect both worlds. All interactions between health professionals and Tongan family carers should be grounded on the following values *faka'apa'apa* (respect), *feveitokai'aki* (genuine respect and regard for the feelings or thoughts of others), *fakatōkilalo* (humility) and *fetokoni'aki* (the reciprocal obligation of helping one another in everything) to strengthen the *tauhi vā*. The presence of *tauhi vā* is symbolized as the effect of a light torch. When *tauhi vā* is intact, aspects including engagement by health professionals,

communication by health professionals, spiritual support and share planning for future health care falls into place. In other words, *tauhi vā* is the key component to connecting Tongans and hospice care that would lead to Tongans having adequate information and knowledge regarding hospice care, effective communication and increased engagement by health professionals, satisfaction with spiritual support and increased discussion and shared planning for future health care.

Limitations

Although this study provides insight into Tongan family carers' experience of hospice care, it is not without limitations. A limitation of this study includes having a small number of participants who live in one geographic area; therefore, these results cannot be generalized to the wider population. A further limitation of the study was the method of sampling utilized in this study. This sampling method may introduce the potential for bias. Additionally, being an insider researcher also leads to a loss of objectivity and bias when researching Tongan families. The results of this study have implications for hospice care service delivery at an individual and organizational level. At an individual level, given that health professionals are the experts, they should guide the process when engaging with family carers. They should also be culturally sensitive when collaborating with the family carers. At an organizational level, health professionals in hospice care need skill-building in cultural competence. Working as culturally competent health professionals will help reduce ineffective communication and lack of interpersonal interaction in hospice care. It will also help health professionals to understand the Tongan family carers' perspectives on end-of-life care and further provide optimal palliative support. Future studies should explore the health-care providers' perceptions about family carers' role in end-of-life care. Furthermore, extending

this research to other ethnicities would provide additional inquiry that should deepen and expand these findings.

Conclusion

This study has identified specific psychosocial needs relating to caregiving for Tongan families in hospice care. These are: limited knowledge and information regarding hospice care, ineffective communication by health professionals, lack of engagement by health professionals, dissatisfaction with the spiritual support provided by hospice care, and lack of discussions and shared planning for future health care. Greater recognition and understanding of the needs of Tongan family carers' will help identify ways hospice care can best support them at end-of-life care. This study has discussed and shown how hospice services can provide care in a way that is culturally sensitive and competent for Tongan family carers. This can be achieved through delivering culturally appropriate education about hospice care, employing Tongan health professionals, and health professionals engaging more with family carers. The provision of optimal palliative support by hospice care will help improve psychosocial outcomes for Tongan families and lead to adequate patient care, which in turn leads to better health outcomes for both carers and patients. From what this research has established, the health professionals and the Tongan community can direct policymakers to areas that need improvements in the hospice care arena by implementing strategies that would meet the Tongan families' psychosocial needs. When Tongans are satisfied with the health services, they often share their experiences with their community and encourage others to consider accessing hospice care.

Future research on the current topic should consider ethnic specific-studies given that New Zealand is a multicultural country. Different ethnic groups have their own language, culture, customs, health status, family dynamics, beliefs and values concerning end-of-life care. Therefore, hospice care needs to understand these cultural variations to help break cultural barriers and bring benefits to all family carers and health professionals. Ignoring the ethnic differences in hospice care can lead to inferior quality of care for ethnic minorities. This study specifically focused on Tongan families and their experiences of hospice care. Their culture shapes their perception of end-of-life care. Nevertheless, the strategy suggestions emphasized in this study are only specific to Tongan families and may not apply to other ethnic groups.

As an insider researcher, I had no problems connecting with the Tongan community given that we shared an identity, language, and culture. I knew people in the Tongan community, and therefore networking was not an issue. I was also familiar with the cultural protocols involved in approaching people of various statuses. For instance, the cultural protocol involved in approaching a *faifekau* differed from that for approaching a health professional. Being an insider gave ease of access to the Tongan people and information which helped speed up the research process. On the other hand, it can prevent the gathering of accurate information due to making judgments based on my personal opinions and interpretations as opposed to being objective. I believe that an outsider researcher would not achieve the same results because as an insider I am in a unique position to study this particular topic in depth, with special knowledge about the Tongan culture and end-of-life care. Furthermore, Tongan participants prefer to work with people they are familiar with. Sharing the same culture with the participants establishes a level of trust and openness which leads to a greater depth of the data gathered. I also have the cultural competency to deal with any cultural issues that arise

as well as understanding unspoken signs or body language that an outsider may not recognize.

To conclude, this study emphasizes the significance of exploring the psychosocial needs for Tongan families in hospice care. By identifying the psychosocial strategies for Tongan families in hospice care, I have strengthened my *tauhi vā* with my *kāinga* and community. I was raised to *faifatongia*, hence the reason why I have a sense of responsibility to give back to the community. This thesis is a special *me'a ofa* to my *kāinga* and community thanking them for their love and support.

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