

# END-OF-LIFE CARE AND MĀORI WHĀNAU RESILIENCE

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## Abstract

This article focuses on the cultural resources that made Māori carers resilient when providing care to an ill family member at the end of life. Caring often took place against a backdrop of poverty, personal factors, racism and a lack of health literacy affecting access to resources. The action values of aroha and manaakitanga, compassionate giving, caring, receiving and sharing established a resilient foundation upon which whānau engaged in the illness-to-death trajectory. It served to fortify the dying and their whānau and provided a sense of belonging and a meaningful way of engaging with illness, dying, death and bereavement.

## Keywords

caregiving, culture, palliative care, resilience, whānau

## Introduction

Providing care to a whānau member at the end of life is an important contribution whānau make to each other, their communities and the nation. In New Zealand, the recent shift in

palliative care from acute to community settings places a huge responsibility on whānau to provide end-of-life care in the home setting (Gott, Williams, & Moeke-Maxwell, 2014; Ministry of Health, 2001). High incidences of chronic and degenerative diseases among Māori and

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palliative care treatments that prolong life mean whānau are increasingly being called upon to provide end-of-life care for months or years. According to the New Zealand Carers' Strategy,

Anyone can find themselves caring for another person, usually a family, whānau or aiga member, at any time. Often this can happen unexpectedly, e.g. sometimes as the result of an accident or sudden illness. Most carers see themselves not as carers but as relatives or close friends of the person who needs support. (Ministry of Social Development, 2008, p. 4)

Caring requires families to “balance their paid work, their caring responsibilities and other aspects of their lives” (Ministry of Social Development, 2008, p. 4). Risk factors compound when carers are unwell themselves, are financially challenged or have other stressors. Māori whānau carers potentially face high risk factors due to socio-economic and environmental factors which can become exacerbated at the end of life and affect, for example, home death preferences (Gott et al., 2014). This requires an ecological approach (Bronfenbrenner, 1994) to understand the pressures carers face and to understand people in interaction with, and influenced by, the physical, social and economic environments in which they live (Windle, 2011).

### Whānau resilience

The resilience and capacity of whānau to provide care and support to its members, particularly during times of adversity, has been the focus of the New Zealand Carers' Strategy (Ministry of Social Development, 2008). Windle (2011) describes resilience within the end-of-life context as

the process of negotiating, managing and adapting to significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate

this capacity for adaptation and “bouncing back” in the face of adversity. Across the life course, the experience of resilience will vary (p. 152).

Resilience studies tend to explore negative social processes like homelessness, poor health, recessions, discrimination, limited education, and their consequences, such as at-risk children and youth, and diminished mental health (Steven et al., 2011). Research on carer resiliency provides some insight into protective factors during an often critical and difficult time for families. A study by Giesbrecht, Wolse, Crooks, and Stajduhar (2014) investigated the socio-environmental factors that facilitated resilience among Canadian palliative caregivers. Six factors played a role in shaping family carer resilience: access to social networks; education/knowledge/awareness; employment status; housing status; geographic location; and the life course stage. Giesbrecht et al. (2014) assert there is an increasing responsibility on families to provide palliative care in the home, “resulting in some caregivers experiencing high levels of stress and burden that may ultimately surpass their ability to cope” (p. 1). They conclude that resilience is multi-dimensional; it is a complex process influenced by numerous related variables that intersect to create positive and negative experiences (p. 1). In another study on resilience and family carers of people with dementia, researchers identified positive factors that increased resiliency, reducing the risk of higher rates of depression, anxiety and hopelessness; these were the use of coping strategies, faith, social support and personal characteristics (O'Dwyer, Moyle, & van Wyks, 2013).

While the above studies highlight the fluid nature of resilience, we must remain aware that most overlook the cultural foundation and meaning-making experience of participants. Writing about end-of-life care practices amongst Māori, Paratene Ngata (2005) highlights elements that make up a cultural framework of care which support the well-being of the

individual and the broader whānau, thereby enhancing resiliency. Whakapapa, shared cultural and familial values, and a commitment to the process of caring for a loved person and their whānau as a whole both strengthen and encourage a way forward. He draws attention to the strength of the whānau as a collective, a unified group, where individuals carry the responsibility of ensuring the well-being of the group is maintained. He demonstrates that these cultural processes seek to reduce individual suffering as this negatively impacts and weakens the whānau as a whole. The cultural imperative to release overwhelming emotions, for example, is important to reduce risk of depression and anxiety associated with loss and grief. For Ngata, dying and death are a familiar terrain and ancient tikanga are in place to manage this part of the life cycle. A profound belief in wairuatanga, the deeply flowing beliefs and cultural practices involving the spiritual realm, permeate all aspects of life and govern all stages of living and dying (Pere, 1991).

The definition of the term “whānau” employed throughout this paper is “a collective of people connected through a common ancestor (whakapapa) or as the result of a common purpose (kaupapa)” (Families Commission, 2010, p. 9). Whānau resilience is defined as the processes which support whānau in caring for a member following news of a life-limiting illness. It is the capacity to respond productively to the challenges that arise through the process of caring for an ill family member throughout the living, dying and bereavement phases. Whānau resilience is therefore inherently relational and is conceptualised as a capacity born out of the interrelatedness and associated cultural and social capital of a collective such as whānau (Houkamau & Sibley, 2010).

In a whānau-centred resilience framework the family is viewed as somewhat fluid as new members are included through birth, relationship, marriage and evolving social networks. Whānau well-being and that of its individual members are mutually inter-dependent.

However, all whānau are different and members may or may not share the same whakapapa and cultural values, beliefs and practices. Each whānau is made up of individuals who contribute to the overall resilience of the family as a whole. Individual life histories reflect highly specific gendered and ethnic subjectivities and life experiences (Moeke-Maxwell, 2005, 2008) which shape coping thresholds and capabilities. Individuals exhibit varying coping abilities, so that some are able to manage adversity and stress more effectively; for example, the presence of early childhood attachment or trauma may affect personal resiliency (Steven et al., 2011).

In this paper we present an aspect of the findings of the broader Kia Ngāwari study (2010–2012) funded by the Health Research Council of New Zealand. The aims of Kia Ngāwari were to investigate the end-of-life experiences of Māori and their whānau to understand their palliative care needs, cultural requirements and bereavement. Below, we present and discuss those findings related to resilience and whānau capacity to care for their ill and dying whānau member with dignity (Moeke-Maxwell, Nikora, & Te Awekotuku, 2013a, 2013b).

### **The Kia Ngāwari study, 2010–2012**

The study employed a Māori-centred ethnographic research design which included face-to-face interviews with whānau, journaling, photo elicitation, case studies and autoethnography (Denzin & Lincoln, 2005; Moeke-Maxwell et al., 2013a, 2013b). Twenty-seven adult men and women and their whānau situated predominantly in the Waikato and South Auckland engaged in the study. Most were over the age of 50 and the group was divided into two cohorts: those who were caring for someone with a life-limiting illness and those with historic caregiving experiences. Fifteen whānau had a family member with a current life-limiting illness while the remaining

provided information about their historical experience of providing care to a family member. Most participants lived in urban areas; however, just under a third lived rurally. The majority identified strongly as Māori and most were familiar with tribal customs. Many were fluent in te reo Māori. Older people generally grew up rurally and moved into urban settings as young adults. A small group were deeply knowledgeable about traditional customs and rituals while others were comfortable modifying traditional customs to suit contemporary circumstances or occasions and the needs of the whānau, reflecting a more hybridised lifestyle (Moeke-Maxwell, 2003, 2012). Co-morbidities, including mental health issues, were common. Only a few participants identified less with their taha Māori. Most participants were dependent on Government-assisted incomes, worked part-time or were low-income earners.

In the majority of cases the person with a life-limiting illness was supported by other whānau members in an interview which lasted up to 2 hours. Sometimes, interviews were spread over two separate days to accommodate the health needs of the ill person. From the main cohort six adults were invited to participate in a case study to capture information about their ongoing needs and experiences of engaging with generalist and specialist palliative care services. Selection was based on a range of chronic and acute illnesses, gender and a mix of geographical locations. Although repeat interviews were conducted with all case study participants, several participants opted to augment data collection with photo essays and journals which were discussed during the interviews.

All participants received a Warehouse voucher to acknowledge their participation and contribution, and their journeying was recorded into a narrative presented to them as koha. Each whānau had the opportunity to comment, change or delete content to suit. Pseudonyms assured confidentiality.

For this paper we purposefully, critically and repeatedly interrogated participant narratives

to discover patterns related to the meanings and practices whānau associated with experiences of living with dying and with whānau capacity to care for the dying (Denzin & Lincoln, 2005; Wiles, Rosenberg, & Kearns, 2005). More importantly, we tried to reflect the experience of participants by drawing on those cultural frameworks they themselves used in their narratives and ways of seeing the world consistent with kaupapa Māori research principles (Pūtaiora Writing Group, 2010).

## Findings

This section considers activities and routines that Kia Ngāwari study participants developed to care for the ill or dying whānau member. Attention is first given to the contextual difficulties that whānau shouldered. For example, a daughter carer described how she coped dealing with her own health issues. She recalled:

To be honest I'd have to say Dad's illness was my biggest stress, really from the time he took sick I was already wavering then, way back then ... Now I'm just starting to get hair returning ... well little random bits ... I've dealt with it, slapped my wig on and tattooed some [eyebrow] lines on ... At the end of the day even when it [my hair] fell out I barely spent anytime feeling sorry for myself 'cause my dad was dying; my mum's a cancer survivor, and I just thought "Oh well, you know I'm alive, I'm not dying," so that put things into perspective pretty fast.

Providing care that gave "quality to life" and "dignity to death" (World Health Organization's Quality of Life Group, 1997) was made more difficult depending on illness type and duration (some illnesses require specific care over a longer period of time); the social and economic positioning of whānau; co-morbidity of person with illness, their primary carer or other dependent whānau; whānau carer sustainability

(small families or only one primary carer); living arrangements; low palliative care health literacy (Ministry of Health, 2010); and high financial costs associated with end-of-life care.

Each of the following sections addresses a specific strength, approach, or area which positively contributed to increasing whānau carer resilience: rangatiratanga; whānau kotahitanga; aroha and manaakitanga; making meaning from illness and death; tangihanga; and spiritual and religious beliefs.

### Rangatiratanga

Participants with a life-limiting condition were usually able to maintain their own rangatiratanga until their illness progressed and prevented them from continuing. They took care of their own affairs and liaised with medical and health services and administered medications for as long as they could. For example, Kelly highly valued her independence:

Yeah I like to be independent ... I don't like asking for help, I'd rather do it myself. I mean I actually drive myself to chemo and back, to radiation and back ... Yeah, so my husband says, "I'll take you." I says, "No you won't, I'll drive."

Kaumātua continued to honour their obligations in their communities, contributing to whānau and community life for as long as they could. Nat, a kaumātua with a serious heart condition, continued to provide his expertise on waka to students. Other kaumātua engaged with iwi and marae business participated in familial and community matters, and officiated at formal gatherings like tangihanga. Whānau felt it was important to support kaumātua to continue their cultural obligations for as long as possible. Eventually, the illness progressed and life became challenging with fewer and fewer excursions as capacities diminished and care and support became more central. At these

times the ill person relied on the rangatiratanga of the whānau to make good end-of-life care decisions on their behalf. Tia's whānau put a care management plan in place for their mother. While her brothers provided financial support,

Ariana [sister] was in charge of making sure that her medication was [taken care of] ... she was in charge of taking Mum to the doctor to her appointments and what have you. Moana's [midwife] role was everything; it was making sure that the house was well looked after for our mother's comfort ... I was sort of like a floater, I would sort of float, but if it was anything to do with her medication ... anything to do with that it was primarily Ariana. (Tia)

Many whānau carers who supported the ill and dying, particularly those with chronic health conditions, appeared to link the origin of illness to Māori disenfranchisement and poverty associated with colonisation and socioeconomic status; historical trauma; alcoholism; obesity; and inadequate housing. A lack of financial and material resources prevented easy access to medical support and procurement of medication for some people. Financial factors placed a huge burden on the sick but their love for their whānau made them determined to live. Ripeka described what fortified her when she struggled with debt:

So I helped her out [financially] but now I'm suffering and I feel sorry for my family, because they're suffering too because I'm paying their [other family's] loan off which is quite a lot. So I'm still paying that back and I think that's what the determination is, "Don't let me die tonight 'cause I still need to carry on working for a wee while yet 'cause I don't want to leave that debt with my kids." I need to get myself out of that debt with my family; my kids shouldn't be taking on that burden. So I motivate myself to keep going. Some days I could be in such pain but I push myself, yeah.

Racism within the health system thwarted the rangatiratanga of several participants. Allan was diagnosed with cancer prior to joining the case study. A self-diagnosed alcoholic and former drug user, Allan felt this was the reason staff in an urban hospital withheld pain medication from him. He believed they “stereotyped” him as a current drug user. He reported experiencing severe pain and the memory of this stayed with him throughout his illness trajectory, causing him to have ongoing anxiety about his end-of-life pain and symptom management. Allan feared that pain relief would be withheld from him at the time of his death.

Whānau carers strove to make life as normal as possible for as long as possible. Whānau empowered themselves by planning future goals, attending anticipated social events and fulfilling cultural obligations. They planned and celebrated important milestones. They did not give in easily to death.

### Whānau kotahitanga

Whānau came together to support each other when news of a life-limiting illness emerged. Several whānau provided detailed accounts of how they prioritised the needs of the ill person; they described their whānau being united in their efforts to shoulder the care burden. This not only benefited the ill person but also supported the primary carer. Unified families shared the spectrum of care responsibilities. When having to negotiate geographic distances, sometimes bridging this distance was a challenge to overcome.

Many whānau who provided support to the ill or dying often had strong positive tribal engagement. They confronted the illness adversity by confidently drawing on Māori world values, beliefs and relationality to guide, sustain and give meaning to their experiences. Strong unification and a common goal provided the best possible care and brought positive outcomes through and beyond the illness journey.

Successful caregiving relationships were those with a strong sense of connectedness and commitment within the immediate and extended whānau and broader care community.

### Aroha and manaakitanga

Aroha and manaakitanga were two dominant action values present in whānau carer narratives. Aroha was witnessed in compassionate care and patience within the physical and social environments, which enriched, affirmed and bolstered trust and encouraged whānau to care for each other. Healing and sustenance came through the close emotional, spiritual and physical engagement that whānau provided. Participants often reported an ill person’s wairua being uplifted by children and mokopuna. Children “warmed a home” with their gaiety and laughter. Seeing a familiar ancestral landscape—a maunga, an urupā, a marae—had a similar healing affect.

Pursuing the value of manaakitanga (see also Ritchie, 1992) meant it was everyone’s responsibility to share resources to support a caring environment for the dying as well as each whānau member. Cultural and family values influenced the way practical caregiving tasks were carried out; it ensured the needs of the unwell/dying person and their broader whānau were catered for. A dedicated daughter recalled:

I have to stop everything; Mum goes into hospital—I stop. These fellows [my children] get palmed off to whoever [family] will have them, and I do Mum. When Mum’s finished and I come home, do my dinner and then I take off back to Mum ... When Mum gets really bad, I’ll bath her. I’ll make her get out of her bed so I can bath her ... like she’s been sick this week so she’s been in bed most of the weekend. Yesterday I forced her to get out of bed to have her shower, and I could quickly just change her sheets.

A sense of connectedness and relatedness

built upon reciprocity between immediate and extended whānau and community provided a sense of belonging and emotional healing and supported resources being shared.

### **Kaitiakitanga—Leadership**

Not all people who were ill or dying had a large whānau to support them. The care and leadership of a sole family carer demonstrated whānau resilience in an otherwise bleak situation. Often, the provision of daily care typically fell to one main caregiver (see also Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000), usually a close family member, and they too were sometimes unwell. One female carer who had her own health issues recalled how hard she found it to make the decision to involve hospice in her husband's care:

It was brave [to go to hospice]. Boy I cried. It made me think as if I didn't want him [husband], I didn't love him, but I told him ... I said, "Gee I'm tired." He said, "Tired of what?" I said, "I'm tired, there's too much going on. Your family's coming 'round, I've got to feed them, plus feed our kids and then—we've got nothing to feed them on."

Primary carers tended to have a big picture view of their whānau members' illnesses and needs because they tended to intimate care, feeding, checking on hygiene, pain and comfort. They also took responsibility for the day-to-day practical living needs associated with running the household. If tasks were delegated to other whānau members, the primary carer became the overseer coordinating domestic chores such as cooking, cleaning, paying bills, mowing lawns and gardening, and caring for family members including tamariki/mokopuna, the elderly and others who were unwell. They also helped to access health care and support. They arranged medical and health-related appointments and Work and Income (WINZ) appointments,

provided travel, organised and administered medications, facilitated social encounters, assisted discussions about preferences for end-of-life care and supported their implementation.

Carers supported the ill in the cultural transference of taonga and kaitiakitanga. They arranged and attended hui with immediate or extended whānau to oversee succession planning of responsibilities concerning whenua, personal taonga and the transference of kaumātua and kaitiaki roles. The care needs of the dying person became the central focus around which daily living, the household and whānau were organised; the "primary" carer made it happen.

### **Making meaning from illness and death**

Whānau appeared to develop a sense of meaning or purpose related to the illness or death experience. With each successful medical intervention whānau gained renewed hope for longevity but, similarly, with every setback came disappointment and emotional turmoil. Participants with life-limiting illnesses expressed anxiety related to leaving their whānau behind when they died. Some expressed their fears of the unknown and several people spoke about their fear of physical pain at the time of death. Open communication skills were essential to ensure everyone was informed about new developments, care needs and personal preferences for end of life. Kelly, who had inoperable cancer, commented that her whānau communicated a lot: "We sit down as a family ... like they've always been involved with my [colostomy] bag, and they're telling me [things] and every night we'll sit around the table and we talk about things."

Whānau who could make meaning from their experiences appeared to cope better than those who felt overwhelmed by what was happening. Enacting spiritual rituals like karakia supported the ill or dying in overcoming painful or intrusive medical procedures, and whānau

were more likely, in the face of adversity, to maintain a positive outlook and hope for the future following death. For example, a kaumātua whose wife died found a way of being with her through prayer, which he found comforted his grief. He commented:

But it was hard the first two months, it was hard for me because we were so close and I didn't think I'd ever let her go, because man ... 'cause I got a son and [daughter] living here. When they've both gone to work, oh I feel it, but not now, I don't. Because I think it's because I talk to her every night; it's just looking at her photo, something for me with her, while they're all sleeping. [Daughter] starts work at 11 o'clock at night ... and then I say, "I'm going to have my pray" so I have a pray with her [wife], so I think that's one way I'm getting over it.

As stated earlier, planning ahead and goal setting helped whānau prepare. Whānau discussed their hopes for their futures. Moving to a new location, planning new career pathways or encouraging children and mokopuna to follow their dreams helped to ease suffering. Self-care plans included whānau taking time out to participate in other activities that gave meaning to life; for example, engaging in sport. Often it was the little things like celebrating Christmas or birthdays that people looked forward to and provided the incentive to stay positive and united. Accessing appropriate palliative care support and resources to assist whānau carers was an essential component that strengthened their resilience. Caring often took place over many months or years. Whānau familiar with palliative care services (Ministry of Health, 2010) or who had prior experience of caring could identify and access support and resources as needed. Knowing when and where to ask for help, and who to ask help from, reduced stress on whānau. Good problem-solving skills ensured whānau could access support and resources as required. A participant who had

a previous positive experience of using hospice services reflected on why she chose hospice to help her and her whānau care for her dying husband:

I didn't have the facilities here [at home] either, and I know that's what [he], I know he would have been thinking that ... "I don't want to die at home." ... Not that he said it, not that he said it. But I know, knowing [him], he wouldn't have wanted to die at home.

Occasionally, when the illness progressed beyond the capability of the whānau to provide care at home, important decisions had to be made. Sharon, who was aware of hospice, recalled supporting her adult nephew. He had managed to maintain his personal independence for a long time with support from his dedicated and caring whānau. But the time came when he needed more intense support and eventually his need for 24-hour care became difficult for the whānau to continue to balance alongside work and other commitments. Although home was the preferred place of death, Sharon prompted her nephew to reconsider accessing hospice in-patient support when she recognised that they could no longer manage home-based care. Meaning-making is not just about finding purpose and hope in the end-of-life process, but also about the dying considering the stress and needs of those around them.

### Tangihanga

Most whānau had sufficient cultural knowledge and engagement with their hapū that they could plan tangihanga, burials or cremation, and unveilings. This was a major strength as it increased resilience both prior to death and post-death as families knew what was expected of them. Whānau drew from Māori death customs to bring dignity to the dying and their family. The majority of individuals discussed and planned tangihanga and memorialising

preferences in advance with whānau soon after diagnosis. Tangihanga was familiar; most knew what had to be done and how to go about it (Nikora, Masters-Awatere, & Te Awekotuku, 2012). A daughter relied on cultural customs after her mother died unexpectedly:

I wanted her [at the homestead] because her brothers and sisters didn't have the chance to spend any time with [her] plus we've got a huge whānau ... The following morning we took her to [name of marae] before moving over to [name of marae] where the rest of the tangi was held.

Pre-death discussions included where people wanted to lie in state; this was a sensitive topic if the person belonged to more than one tribal group or affiliated with more than one marae. Some whānau did not meticulously plan the details of their funerals prior to the person dying as their customary rituals were so firmly embedded they had confidence their broader family would organise their tangi appropriately. Sometimes affiliations were stronger with one side of a person's whakapapa or with a spouse's whānau. For some, the desire to lie in state at a spouse's marae or to be buried in their urupā to be closer to the deceased spouse and their tamariki or mokopuna was stronger than the desire to return to their tribal homelands. The expense of tangihanga and negotiating long distances prevented some people pursuing this option. The families in our study were more likely to shoulder all or the majority of the costs, making tangihanga unaffordable for some unless they had funeral insurance. Satisfying death rituals appeared to provide a sense of healing for whānau pani. When death came, despite some whānau having more urban inspired tangihanga, whānau still observed a range of tikanga and kawa reflecting the iwi-specific customs and rituals of the deceased and their whānau.

Tangihanga outcomes were satisfactory for participants when planning had been fully

discussed prior to death and where agreement had been made between the dying person and their whānau. However, not all participants desired traditional tangihanga or unveilings. Returning to Allan's story, Allan did not have a strong sense of being Māori, nor did he indicate attachment to his tribal family or land. He wanted to be cremated and his ashes placed with his maternal Pākehā grandparents in an urban cemetery because they "had been good to him". Individuals who did not have a strong emotional attachment to being Māori, and those who had strong religious beliefs opted for more Christian or Westernised funeral observances. When the values and beliefs of the individual differed to those of their whānau, the individual's funeral preferences tended to be upheld.

### Spiritual and religious beliefs

Wairuatanga was a key cultural strength that most individuals and their whānau drew from to bolster and guide them through this difficult time in life. Wairuatanga took the form of traditional cultural beliefs, religious practices or more secular new age spiritual variations, or occasionally, a mixture of all of these. Whānau placed great importance on spiritual life and it was a central component in whānau-centred care. Spirituality appeared to be a critical factor in coping with the challenges associated with diagnosis, ongoing and often numerous treatment cycles, the dying process, tangihanga, unveilings and bereavement. Spiritual belief systems bolstered whānau resilience by fortifying relationships, increasing morale, influencing meaning-making, strengthening identity and uplifting the mauri of ill and dying individuals and whānau. Spiritual practices were used to guide, protect, cleanse, clear, fortify, console and heal. Engaging in spiritual practices provided solutions to pressing issues and eased depression and anxiety.

Karakia appeared most helpful in

strengthening families. Karakia accompanied daily and customary rituals and were employed as a normal part of whānau life, particularly among kaumātua participants. Karakia were used to assist whānau at challenging times. They were considered healing and helped to ease suffering as an illness progressed. They supported whānau's ability to cope, especially with receiving bad news or during a death and through bereavement. Karakia carried hope for the future, which was an essential element that helped to uplift the mauri of individuals and whānau.

Tohu or symbolic occurrences varied significantly and whānau attached profound meaning to these experiences. A participant said her father's behaviour presented a helpful tohu which prepared the whānau for his death: "Well I thought a week before he died I didn't think it was a good sign like for Māori anyway, he was talking to a couple of his dead mates ... We knew then ..." Tohu provided symbolic evidence of the metaphysical realm and helped whānau contextualise what was happening in their lives. Critical life changes and transitions often brought new tohu which had to be analysed and contextualised. Tohu were relational—they provided a means of communication between God(s), tūpuna and in some cases, the deceased.

## Discussion

The study aims were to investigate the end-of-life experiences of Māori and their whānau to understand their palliative care needs, cultural requirements and bereavement. This study is unique in that it provides a window on an intimate stage in life usually reserved for close whānau, health professionals, and spiritual or religious advisers. These were private and sometimes trying moments demanding personal and collective resilience. Some whānau carers were alone and without others to share the burden of care. Without knowledge or familiarity of

health and palliative care services, some felt isolated and drained by the increasing physical, financial and emotional demands that the approach of death brings. Hospital admission or the involvement of hospice or other services were sometimes viewed as failing the ill or dying person. Compassion fatigue was clearly apparent in their narratives. In contrast and consistent with the work of Ngata (2005) and Hutcherson, Seppala, and Gross (2008), those carers with the support of immediate and broader whānau members had a deeper and wider well of resource to draw from and their care was clearly patterned by Māori cultural action values of rangatiratanga, aroha, manaakitanga, kotahitanga, kaitiakitanga and wairuatanga. When situated in a cultural web of support, these whānau carers and the dying person faced adversity with the strength of whānau leadership; open communication; prior knowledge and planning; a willingness to work together and take complementary roles; a unity of purpose; and a connectedness to each other and the universe through strong beliefs about spirituality and the afterlife. Being driven by the action values of aroha and manaakitanga means compassionate giving, caring, receiving and sharing are set to prevail. Culture provided whānau with a sense of belonging and a way of engaging with illness, dying, death and bereavement (Dein, 2006).

Reid (2005, p. 47) asserts that Māori live in a changing world, illuminating that it is our right to evolve and to change. She asserts the Māori way or perspective of dying, death and bereavement is "plural, it's diverse, it's multiple, it's flexible, and it's changeable". Our study revealed diversity between and within whānau. Some whānau closely observed kawa and more traditional cultural customs, while others were less observant in this regard. However, cultural values, beliefs or customs prevailed to some extent within all whānau and fortified their ability to provide care.

Colonialism has been linked to lower levels of cultural efficacy (Houkamau & Sibley,

2010), yet carers and whānau in this study strove for autonomy and self-determination in the face of adversity (Moeke-Maxwell et al., 2013a, 2013b). Whānau coped *despite* the myriad of medical, economic, social, structural and systemic issues faced. Social inequity, racism, low palliative care health literacy (Ministry of Health, 2010), whānau demographics (smaller families to provide care) and structural barriers increased carer burden and the risk of depression and anxiety. Our study shows that the economic and material ramifications of colonialism impact on Māori hugely at the end of life, directly influencing the ability of whānau to identify and access much needed resources and palliative care support. Generally, only whānau who had a family member with a tertiary qualification or employment within a health or related field were well placed to identify and access much needed statutory support, palliative care and resources. Knowledge of the health system, or previous use of specialist palliative care services, increased the likelihood of some whānau accessing palliative care support and resources. When combined, these things strengthened whānau to provide the best care, frequently under difficult circumstances.

New Zealand's health care system could strengthen resilience among whānau carers by developing equitable end-of-life and palliative care services and improving their palliative care information dissemination and communication competencies to improve Māori palliative care health literacy (Kidd et al., 2014; Ministry of Health, 2010; Rauawaawa Kaumātua Charitable Trust Research Project Team, 2014). Conducting further research to identify the risks and resilience factors associated with end-of-life caregiving could positively influence end-of-life care. Cherry et al. (2013) state that "factors associated with carers' resilience are not yet fully understood" (p. 251). This study involved 27 whānau and used a broad lens of enquiry into Māori end-of-life experiences: therefore, a larger study dedicated to traditional caregiving customs would provide a greater depth of

understanding of resiliency to inform policy and structural developments.

This paper contributes to an understanding of resilience associated with Māori whānau providing end-of-life care. Rangatiratanga, aroha, manaakitanga, kotahitanga, kaitiakitanga and wairuatanga highlighted Māori values and customs underpinning agency and perseverance during a critical part of the life phase. Culture plays a vital role in guiding, strengthening and sustaining whānau during the illness-to-dying journey (Dein, 2006). However, further exploration of risks and cultural strength factors are needed to ensure Māori have equitable access to end-of-life and palliative care resources and support to strengthen resilience among whānau carers. This is likely to support whānau with increasing carer demands in the future.

The whānau who participated in this study remind us that it is *how* we care that ultimately matters at the end of life. Culturally informed care practices bring quality of life to the dying and dignity to death. But whānau resilience would be helped exponentially by having equitable access to palliative health care services, psychosocial resources and statutory entitlements, highlighting that resilience is multi-dimensional, contextual and relational.

## Glossary

aiga	Samoan term for family
aroha	love, care, concern, compassion
hui	gathering or meeting
iwi	tribe
kaitiaki	spiritual guardian
kaitiakitanga	practice of spiritual guardianship
karakia	prayers, invocations, incantations, chants
kaumātua	older men and women
kaupapa Māori	Māori ideology
kawa	protocols, ceremony

koha	gift, donation
kotahitanga	unity through consensus
manaakitanga	hospitality, kindness, generosity
marae	ancestral home/site
maunga	mountain
mauri	energy life force or essence
mokopuna	grandchild/ren
Pākehā	non-Māori New Zealander/ colonial descendant
rangatiratanga	autonomy and self-determination
taha Māori	Māori side
tamariki	children
tangi	shortened form of the word “tangihanga”
tangihanga	funerary customs
taonga	artefacts
tapu	sanctity
te reo	Māori language
tikanga	traditional tribal practices
tohu	signs/messages from the metaphysical realm
tūpuna	ancestors
urupā	graveyard
wairua	spirit
wairuatanga	spiritual domain
waka	canoe
whakapapa	genealogical descent lines
whānau	family, including extended family
whānau pani	bereaved family
whenua	land

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