Title: What is the role of community at the end-of-life for people dying in advanced

age? A qualitative study with bereaved family carers

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What is already known about this topic:

- New public health approaches to palliative care prioritise the role of community in end-of-life care.
- There is evidence from previous studies that social networks can provide good support, and even be strengthened, during the end-of-life period.

What this paper adds:

- Beyond family support, we found limited evidence of end-of-life support for people in advanced age, or their family carers, provided by communities of place, interest or identity.
- In particular there was evidence of barriers to network development and no evidence of new social networks being formed at end-of-life

Implications for practice, theory or policy

- In order to be effective, public health approaches that foreground the role of community as support for people in advanced age and their families must acknowledge diversity in access to this resource and develop strategies to strengthen social networks in ways sensitive to the unique circumstances of people of advanced age.
- There is an urgent need for further theoretical, practical and research integration between gerontology and palliative care.

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Abstract

Background: New public health approaches to palliative care prioritise the role of community at end-of-life. However, little is known about community support for the increasing numbers of people dying in advanced age.

Aim: To explore the role of community at end-of-life for people dying in advanced age from the perspective of their bereaved family caregivers.

Design: A constructionist framework underpinned a qualitative research design. Data were analysed using critical thematic analysis.

Setting/Participants: 58 participants (19 Māori and 39 non-Māori) who cared for 52 family members who died aged >80 years participated in semi-structured interviews.

Results: A reduction in the social networks and community engagement of the older person was identified in the end-of-life period. Numerous barriers to community engagement in advanced age were identified, including poor health (notably dementia), moving into an aged care facility, and lack of access due to transport difficulties. An active withdrawal from community at end-of-life was also noted. Carers felt limited support from community currently, but identified that communities could play a particular role in reducing social isolation and loneliness amongst people of advanced age prior to death.

Conclusions: Our study provides strong support for public health approaches to palliative care that advocate building social networks around people who are dying and their family carers. However, it also indicates that strategies to do so must be flexible enough to be responsive to the unique end of life circumstances of people in advanced age.

Key words: Community Networks; Aged, 80 and over; Oldest Old; End-of-life Care; Palliative Care; Public Health; Caregivers; Family caregivers; Social Support; Indigenous.

Background

The recent shift to address palliative care from a public health perspective is underpinned by ideological concerns about the nature of societal responses to ageing and dying. In particular, what is perceived as an increasingly 'professionalised management' of end-of-life care, has led to calls for health services 'to hand back ownership of dying to communities'.[1] This way of thinking recognises that it is not health professionals, but rather family and friends, who provide the vast majority of palliative care when someone is dying.[2,3] The support they require to do is argued to be best found within 'compassionate communities' which act as a repository of palliative care knowledge and skills.[4]

Palliative care policy which affords centrality to the role of community is increasingly being adopted internationally.[5,6] However, the evidence base to underpin such developments remains limited. Indeed, a recent review identified only six studies examining the outcomes resulting from community engagement in end-of-life care.[7] These evaluative studies concluded that community engagement in end-of-life care increased social capital; influencing professional activities, promoted the creation of community activists, and embedded social change. Leonard et al. concluded that carers can successfully mobilise complex social networks to support their caring work and that caring can, in itself, grow and strengthen these networks.[8] However, half of their participants were recruited from a community-based hospice organisation providing mentoring advice to family carers and findings may therefore not be generalizable to all groups.

Kellehear's 'Compassionate Cities Charter' recognises that 'diversity shapes the experience of ageing, dying, death, loss and care' which requires attention is paid to understanding the unique circumstances of different social groups.[3] It has already been established that older people, and those in advanced age in particular, have unique requirements for support and care at the end-of-life[9] and are disadvantaged in access to specialist palliative care services, particularly if they have a life limiting condition other than cancer.[9, 10] However, research exploring how their needs can be better met using a public health approach remains limited, a key gap in current understanding given that demand for palliative care is increasingly concentrated within this age group.[10]

In this context we explored the role community played at the end-of-life for people dying in advanced age in Aotearoa, New Zealand.

Study Design

The study protocol explaining the genesis of the study and providing a detailed overview of the research design has previously been published.[11] In brief, the research drew participants from a New Zealand based longitudinal study examining predictors of successful ageing: *Te Puāwaitanga O Ngā Tapuwae Kia Ora Tonu, Life and Living in Advanced Age: a Cohort Study in New Zealand (LiLACS NZ).*[12] LiLACS NZ participants constituted 421 Māori >80 years and 516 non-Māori >85 years originally recruited in 2010. Different age cut-offs were used due to the approximately seven year difference in life expectancy for Māori when compared with NZ Europeans. In Waves 3 and 4 of the study, participants were invited to nominate a family or whānau member to be interviewed about their end of life care after their death (whānau is a

Māori term encompassing extended family and friends who contribute a functionary role).[13] The participants referred to in this paper therefore comprise those nominated individuals and additional family/whānau and friends they nominated to participate due to their extensive caring role. In total, 58 interviews were conducted for 52 older people. See Tables 1 and 2 for socio-demographic information.

Data collection

Face-to-face interviews were conducted with 58 participants between 2013 and 2015 in a place of their choosing – typically their home and lasted 1-2.5 hours. One interview was conducted by telephone and one using Facetime. An interview guide informed by relevant literature was developed to explore: the older person's life, with a focus upon their experience of advanced age, key aspects of the older person's end-of-life circumstances, and the participants' experiences of caring and bereavement. A structured questionnaire was used to gather more detailed information about the period immediately preceding death. Five interviewees chose only to complete the questionnaire because of time limitations; however, they still discussed the end of life period, including themes relevant to this paper. Research with Māori participants adhered to the principles of the Treaty of Waitangi - partnership, participation and protection. Te Ārai Kaumātua (respected elders) Advisory Group provided input into study design and analysis,[14] and Māori community researchers facilitated fieldwork. Cultural protocols (mihimihi/formal introductions; karakia/prayer and sharing of kai/food) were adopted to promote an environment of safety.[15] Three dissemination meetings were held with participants to ensure they could inform the final presentation of findings.[16] Forty one participants also chose to receive a summary report constructed from their interview which served as a member-

checking device. Ethics approval for the study was obtained from the University

of Auckland Human Participant Ethics Committee (UAHPEC 9686).

Data analysis

Interviews were audio-recorded and transcribed verbatim. Analysis first involved

line-by-line discussion and iterative development of coding categories in selected

transcripts by all members of the disciplinarily-diverse research team during bi-

weekly meetings over a six month period. N-Vivo 10 software was used for purposes

of data management. This critical thematic analysis[17] was informed by social

constructionist, Kaupapa Māori and feminist frameworks and also drew on narrative

methods, paying attention not just to what was said, but how it was said.[18] Careful

consideration was paid to the diversity of experience and 'silences' in the data, as well

as divergent cases. The following techniques to promote data rigour were adopted: 1)

prolonged engagement in the field; 2) peer review and debriefing; 3) negative case

analysis; 4) clarifying researcher bias; 5) member checking; and 6) rich, thick

description.

Analyses discussed here sought to identify three commonly differentiated forms of

community: communities of place, of interest and of identity. We conceptualised

community as: 'A group or network of persons who are connected (objectively) to

each other by relatively durable social relations that extend beyond immediate

genealogical ties and who mutually define that relationship (subjectively) as

important to their social identity and social practice'.[19] This way of conceptualising

community is congruent with the central role afforded to relationships in Māori

understandings of community. Māori define community in two inter-related ways:

hapori (section of kinship group) and hapori whānui (the public and wider community).[20] We also drew upon Abel et al's Circles of Care model[21] to inform both our analyses and recommendations. This model identifies the following 'circles' of support available to a person with a life limiting illness: inner network (close family members and friends who have direct contact with the patient), outer network (less close family members, friends and neighbours), community, service delivery, and policy.

Findings

Participants described undertaking a very wide range of caring tasks; notably, these extended beyond physical caring tasks to include, for example, domestic care (such as shopping and cooking), emotional support, service navigation, 'accompanying' (for example, providing companionship), and financial management. They reported that the vast majority of these caring tasks were undertaken by immediate family/whānau (inner network) and, with a few notable exceptions, there was only limited involvement of either an 'outer network' (comprised of friends and neighbours), or wider community involvement during the end-of-life period. Indeed, by the time the older person had died, their social networks were much diminished and there was no evidence either of network 'activation' or the development of new networks prior to their death. Reasons for this related to barriers to community engagement in advanced age, and active withdrawal from community at end-of-life. Carers also reported little support themselves from either 'outer network' or other community members. A potential role for community members was identified by participants in terms of addressing social isolation amongst people of advanced age at end-of-life.

Diminished social networks at time of death

It was evident that there was variety in the extent to which the older people had been engaged in communities of place, interest and identity throughout their long lives. Some had been central figures in their communities, occupying leadership roles for various political, social and cultural groups. Others were described as 'not sociable' and throughout their lives had social networks that did not appear to extend beyond their immediate family or whānau group. Amongst all the older people participants were describing, social networks were much diminished in advanced age and, during the end of life period, were limited for most people. This was most poignantly described in accounts of funeral attendance, where the death of friends and peers meant attendance was low, or had led the older person to decide they did not want a funeral, as in this example of an older non-Māori woman:

> Yes [Dad] died at 67 and he was very well known around town and it was a huge funeral, but as Mum got older her views changed. So many people have died, all of her friends and relatives. They'd either died or [were] too old to go to a funeral anyway, and why would you do that to all these old people. The need wasn't there.

Barriers to community engagement in advanced age

Several barriers to community engagement, which had resulted in diminished social networks at the time of death, were mentioned. *Communities of place* were disrupted by migration of the older person in later life, either for retirement, and/or to live closer to, or with, family and whānau. Access to transport was also very difficult for many, particularly in rural areas, as this grandson who had been caring for his Māori grandmother described:

> P: She always wanted to go to church, yeah, Anglican. And yeah she really liked it, but not very often.
> I: She didn't get to go very often?

> P: No.
> I: Do you know why that was?
> P: Just transport, yeah. Because I only had a motorbike when I was staying there, I couldn't take her around, yeah.

Twenty six older people were living an aged residential care facility at the time of death and little evidence was provided that these older people were well integrated into wider place based communities whilst living in these settings. Experiences in retirement villages appeared more mixed. Some participants felt these facilities had enabled existing social connections to be maintained, particularly when facilities were geographically in the same area as the older person had previously lived, as this non-Māori daughter recounted:

> [My mother had a steady stream of visitors]… from the village, from the church, from the Catholic Women's League which she belonged to. She had a brother and sister-in-law living over there just over the next street. They would pop in and their children would pop in, her ex-daughter in law would pop in. She did have a lot of visitors and a lot of friends. Because she was a very social woman, relatives would drop in or stay, visit or whatever.

However, participants also provided accounts where they felt there was little evidence of social interaction within the facility, which interestingly ran counter to their expectations of what a 'village' would provide in terms of social support:

> She was very lonely there although it was a village, when I say village she had like independent little units and the units were all lined up but they didn't tend to go and visit each other.

Engagement with *communities of interest* was also reported to wane for most as people reached advanced age, typically as a result of deteriorating health, mobility and the onset of sensory impairment such as hearing and vision loss. As one daughter remarked in relation to her non-Māori mother:

> P: The social group there, the craft group there, she played cards on a Tuesday night, all of that stopped.
> I: So she more or less became?
> P: Housebound.

11

Ill-health disrupted all types of community engagement; this was especially marked

for participants with dementia who were typically lacking in social networks at the

time of death and rarely engaging with people beyond family/whānau and

professional carers. An interesting exception was provided in an example of a kuia

(older Māori woman) who was included in tribal meetings despite her dementia as she

was considered an integral part of the community as her son recounted:

> I: Any church or religious leaders or tohunga [involved?]…
> P: Yeah, well there were the local kaumātua, if you like.
> I: And they would visit her at home?
> P: Yes, oh regularly and they would also transport her to any of the significant sort of events at the marae constantly.
> I: Oh how lovely.
> P: Yeah and then return her. It was, yeah it was almost pre-empted or planned, because it is a standard ritual, if you like, as to what protocols to follow, how they shall be followed. So it's, they're very professional at it.

This provided a good example of how *communities of identity* could facilitate support

for the older person. This was most evident in the accounts of Māori participants who

identified strong whanau and tribal connections'. Engagement with Māori networks

was seen to facilitate access to both direct, and more indirect, resources. However,

being Māori did not necessarily guarantee a well resourced hapori or hapori whānui

and, in some cases, much of the end-of-life care was carried out by a spouse or one or

two whānau members.

Active withdrawal from community in advanced age and at end-of-life

Many of the older people were described as playing an active role in determining their

own engagement with the wider community or, in many cases, disengagement. An

active withdrawal from people outside of the immediate family/whānau in the period

preceding death was frequently reported. As one daughter recounted, her non-Māori

mother 'wasn't allowing people near her' towards the end of her life '…there was just

me'. Reasons given for this included the older person preferring care and support to

be provided by whānau and family, as well as concerns, and possible shame, about

physical decline, as in the following account – 'he didn't want to see anybody…he

said 'I don't want visitors - I don't want them seeing me like this'.

A general reluctance to seek, and accept, help was also noted due to concerns about

being a 'burden', and an inability to reciprocate. When asked if anything more could

have been done to support her non-Māori mother in her last months of life, her

daughter said:

> Well it's really hard to say because she's also the type of person that didn't like to bother anyone. You knew there was a need; she had a need there, but she wouldn't tell you what it was because she didn't like you to run around after her, she doesn't like to bother nobody. …She had the odd person who would ring her and talk to her [but] she didn't go out anywhere after Dad died. I offered to take her to cards and I did a couple of times and people from the card club; she goes up to the RSA which is only 200 metres away. People offered to drop her off or whatever else, but she really didn't like to be owing to people. 'That's fine, I'm quite happy to stay home'.

For Māori participants reciprocity assumed particular importance given the centrality

of manaakitanga (the act of shared hospitality, generosity and care) in the formation

and maintenance of healthy relationships. Providing kai (food) is an integral part of

manaakitanga. Not being able to provide this form of cultural care is apt to cause

whakamā (sense of embarrassment or shame). In this example, a daughter discusses

how visitors invoked their manaakitanga when her Māori mother could not afford to:

> Sometimes it was really hard that Mum had no money at all … that the people would come down and she wanted to be able to [manaaki them]… and in the end they'd buy the fish and chips and pay for everything whereas she would like to pay her way. That was very difficult.

Input from community at end-of-life

Overall, input from non-whānau and family community members into the provision of care and support at the end-of-life was described as limited. Community-based support groups such as the Alzheimer's Society were mentioned in a minority of cases, however these were seen as information providers earlier in an illness trajectory, rather than active supports during the end-of-life period. Neighbours were identified as helpful in terms of 'keeping an eye' on the older person by a small number of participants:

> The neighbours were all good and if I was worried I would ring the neighbours and they'd say no, he's out in the garden or we can see him from here, he's up a ladder or on the roof, or something.

However, the movement of the older person in later life and resident changes in a neighbourhood meant this degree of connection with neighbours was not always evident. As one wife who had cared for her non-Māori husband noted:

> It's not like it used to be, when we first came here you'd have neighbours around here all the time, but there's only about three families still on this road who were here when we came, this guy down the road, he's over 90.

Support from churches was mentioned as important only in very few cases; this typically constituted religious leaders visiting the older person in the period immediately preceding their death. In one notable exception the support provided was very extensive due to the Māori older person's estrangement from their wider whānau. The (non-Māori) pastor was the main carer and organised rotas of volunteers from the church to provide meals, company, and other supports needed. He discussed this support as follows:

> When you receive the Holy Spirit you are adopted into God's family, and so therefore we are truly and I don't use the term loosely but truly brothers and

14

> sisters because we've all been adopted into the same family…. and my belief
> is that if somebody in the family needs something, well then the family
> provide that.

Finally, whilst caring has been identified in research with younger people as extending social networks[21] there as little evidence that this had been the case amongst our participants. Indeed, several felt that the opposite had occurred, namely that caring had had a negative impact upon their networks. As one non-Māori daughter caring for her non-Māori mother noted: 'We've cut ourselves off from a lot of friends and social activities because of Mum'.

Potential role for community members

When asked to reflect on what additional community supports would have been helpful, several participants discussed the potential role for community members to spend time with older people, either as a mechanism to alleviate loneliness and/or as a means of enabling family/whānau caregivers to undertake vital tasks such as shopping. As one wife caring for her non-Māori husband reported:

> Various local people said, you know, "We'll come in and sit with him, for an
> hour," but, it didn't sort of work out - people are busy in the middle of the day.

Discussion

This study provides unique new insights regarding the role of community for people dying in advanced age and their family and whānau. In contrast to previous studies,[22] we found limited evidence of end-of-life care or support provided by communities of place, interest or identity – where community is defined as relationships that extend beyond genealogical ties.[19] This is unsurprising given that many of the sources of community support identified in previous work – for example workplace and school-based networks – are not available to most people of advanced age. Whilst for some people already existent strong networks could be drawn on in advanced age, there was no evidence of new networks being established to draw on, either by the older person, or by the family and whanau carers and, indeed, significant barriers to network development were identified.

Our findings support previous research demonstrating that people in advanced age are often not integrated into the geographical communities in which they live, particularly if living in institutional settings,[23,24] and can become alienated from communities of interest due to ill-health and the onset of ill-health and disability.[25] We also heard accounts of older people actively resisting community support, with reasons related to shame about bodily decline, concerns about being a burden, an inability to reciprocate, and difficulties maintaining engagement in the face of deteriorating health (most notably dementia). Whilst these issues have been reported in previous gerontological research,[26] they have not been considered in relation to later life community engagement within a palliative care context. However, they provide important context as to why people dying in advanced age may have unique needs in terms of support required to enhance social networks when adopting a public health

approach to improving palliative care. Indeed, Horsfall et al concluded that the person at end of life had to 'do the work' to enhance such networks, noting that it was most successful when 'the dying person took control and did the work of keeping the social connections alive'.[22] The issues we identify above make it clear why those in advanced age may often not be well positioned to 'take control' in this way.

Our study provides strong support for public health approaches to palliative care which advocate building social networks around people who are dying and their family carers.[21, 22] . However, it indicates that strategies to do so must be flexible enough to be responsive to the unique circumstances of people dying in advanced age. For example, our findings indicate that this group may be resistant to 'outer network' and community support for reasons described above. Furthermore, providing such supports to family and whanau carers is complicated by the fact that many are not geographically co-located and therefore not aware of potential community resources. Indeed, our findings are consistent with previous research in demonstrating that caring can be an isolating experience,[27] leading to disengagement from the carer's own 'outer network' and community. Again, this indicates the potential value of new public health approaches to palliative care.

Overall it is apparent that further integration between research, practice and policy related to ageing well, and to palliative care would be helpful in reflecting upon how these approaches can best address the needs of the rapidly growing numbers of people dying in advanced age. For example, there have been calls for further theorisation around key concepts, including 'community' and 'social capital' .[28] and such work could helpfully draw upon previous gerontology research. For example, ,

research has shown that when definitions of social networks and community are broadened to include physical, imaginative, social and symbolic connections *across time*, the connections for people in advanced age can actually expand, rather than contract.[29] This would be something worth exploring in a policy context to help strengthen ways of promoting support systems for people in advanced age.

Strengths and limitations

We interviewed family members identified by the older person themselves as most critical to their care prior to death. However, for obvious reasons, the older person themselves could not be interviewed. Future research would helpfully explore the attitudes of people of advanced age towards community support within an end-of-life context and explore their perspectives on how social networks could be strengthened at end-of-life.

Conclusion

Community is a 'potent symbol and aspiration' which, in the absence of adequate evidence, risks being viewed as a universal panacea.[8] This study highlights the need to address diversity in access to community resource and, in particular, for community based support for people with palliative care needs to be tailored to the unique needs of people dying in advanced age.

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Declaration of Conflicting Interests

The Authors declare that there is no conflict of interest.

Data access

Any reasonable requests to review the datasets from this study would need to be reviewed and approved by the LiLACs NZ Te Rōpū Kaitiaki o Ngā Tikanga Māori and Te Ārai Palliative Care and End of Life Māori advisory group, as well as the research participants themselves. This is in accordance with New Zealand's Treaty of Waitangi under which Māori assert their cultural and intellectual property (IP) rights to the protection of taonga (resources/treasure), which includes research data.

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