

Doing what it takes: a qualitative study of New Zealand carers' experiences of giving home-based palliative care to loved ones

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ABSTRACT

AIM: The study explored the views of New Zealand home carers providing home-based palliative care, as little is known about this in the New Zealand context.

METHODS: A qualitative interview study involving nine bereaved carers whose loved ones had received a combination of hospice, district health board, home-support and general practitioner care. Inductive thematic analysis was undertaken.

RESULTS: Two main themes emerged, both with subthemes: (1) Home—a place of safety and self-determination. (2) Doing what it takes.

CONCLUSIONS: The study shows that New Zealand carers' experiences of providing home-based palliative care are similar to those in international studies; country-context, ethnicity and health systems likely influence the differences. While carers are grateful for professionals and family/whānau/friend support, they experience challenges that could be addressed by the following recommendations: undertake a regular review with carers regarding the decision to provide care at home; support carers to take on a leadership role if this is what they want; ensure carers have information regarding which professional and which agency does what and who to contact for help; provide post-bereavement support to carers for longer than it is currently being given.

People at the end of life who wish to die in their own home typically need the support of a home-based carer. This is defined as a person within the family/whānau/friend group who takes on the key role in caring, often with support from others including health and social-care professionals.¹

Internationally, it has been shown that people prefer to die at home.^{2,3} In New Zealand, this is assumed to be the same, and 23% of deaths in New Zealand occurred at home in 2013.⁴ Dying at home has particular importance for certain groups (eg, Māori, who are 15% of the

New Zealand population)⁵ and Pacific Peoples.⁶ Being able to offer care is seen as giving aroha and respect; it is a form of reciprocity.⁷

Considerable international research has been undertaken regarding home-based carers' experiences (eg, Morris et al⁸, Martin et al⁹, Jack et al¹⁰, Horsfall et al¹¹). Carers provide normality and ensure their loved ones' comfort needs are met. However, this often impacts on carers' own prior personal roles. They need practical and professional support, especially frail carers, and when this support is not available they rely on family/whānau/

friends. Towards the end, carers find the home becomes an institutional space with extra equipment and professionals visiting and carers can lose their privacy and became isolated from friends and community. Recent literature reviews have drawn together the key barriers and facilitators to providing home-based palliative care.^{12–16} These do not always take account of different health delivery systems or cultural differences within and between countries.^{17–19}

New Zealand research on carers giving home-based palliative care has specifically focused on the following topics: home-care of the aged,^{20,21} culturally appropriate care including information and care delivery,^{7,22–28} financial cost,^{13,29,30} educational need³¹ and the priorities and feasibility for carer research.^{32,33} One study focused more generally on carers' experiences of giving palliative care at home.³⁴ It revealed the following themes: physical demands, emotional and spiritual distress, preparing for the future, securing help, medication management, navigating agencies and relationships.

This study explored the experience of carers giving home based palliative care with interagency and interprofessional support.

Context and setting

In New Zealand, patients receive no-charge hospital and hospice care with part-charge general practice services.^{35,36} Hospices provide inpatient and community-based care for those most at need, usually in collaboration with district health board (DHB) district nurses, general practitioners (GPs) and DHB or privately funded home-based support workers.

This summer student research project was undertaken in an urban region with a population of just over 300,000 people. It involved interviews with bereaved carers of loved ones (the term used by carers) who died at home. Carers had been supported by hospices, DHB district nursing, GPs and home-support services. The hospice service included a recently introduced, extended-hours, hospice-at-home nursing service (2pm–10pm).

Methods

A qualitative methodology was chosen because it gives insight when little is known about a topic, or when research comes from another country or context.³⁷ The semi-structured interview method enabled researchers to respond to the varying levels of engagement by bereaved carer participants (see the Appendix for the interview schedule).³⁸ In line with the principles of naturalistic enquiry,³⁹ audio-recorded interviews were undertaken in each carer's home, the setting where the loved one had been cared for. Field-notes of observations were also kept. Ethical approval was granted by the University of Otago Health Ethics Committee (H19/129). A maximum variation sampling framework was developed to help select the participants (Figure 1)⁴⁰ with inclusion/exclusion criteria (Table 1).

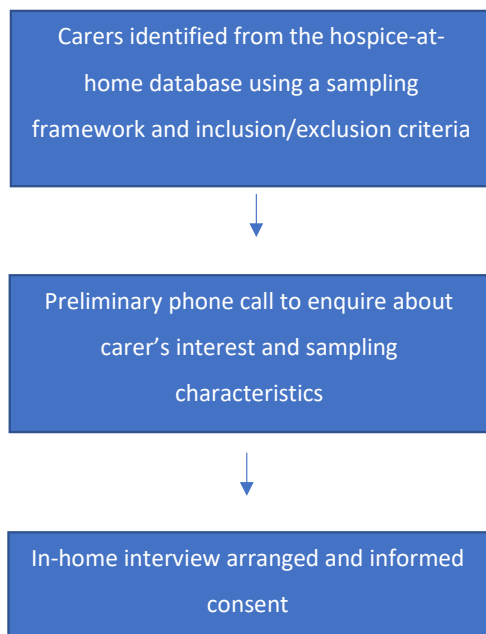
Figure 1: Sampling framework.

- Gender (F/M/GD)
- Age: older (>60yrs) and younger (<60yrs)
- Employed and retired
- Number of visits by the hospice-at-home team (many and few)
- Sole and multiple carers
- Prior experience in palliative care (experience and no experience)
- Māori
- Pacific

Potential carer participants were contacted between November 2019 and January 2020.

Results

We approached 13 carers who had been bereaved for between 6–18 months: two declined or did not respond, one agreed to take part then became uncontactable and one responded after recruitment ended (Figure 2). Nine carers were interviewed, including two pairs of two carers: each pair cared for one person. The loved ones had cancer diagnoses (some with comorbidities), and most were cared for by the hospice-at-home service from days to up to six weeks (Table 2).

Figure 2: Carer recruitment.

Audio recordings were transcribed verbatim by KV, and qualitative inductive thematic analysis of the qualitative data and field-notes was undertaken. Broad topic categories were established by KV & EM. Interview data were coded to these categories and then the themes were determined after a full and robust discussion with the entire research team.^{41–43} Field-notes were analysed according to common significant observations (the response of the carers to questions; observing the place where the loved one died; the artefacts of caring shown to interviewers, such as notes and equipment; the layout and accessibility of the home).

Two main themes emerged, each with subthemes:

- Theme one: Home—a place of safety and self-determination
 - Honouring the promise
 - Supporting the care at home
- Theme two: Doing what it takes
 - Day-to-day caring activities
 - Leading and coordinating care
 - Regrets

Theme one: Home—a place of safety and self-determination

Carers repeatedly described the importance of the loved one being cared for at home. In their minds, there was no doubt

that this was what the loved one had wanted. The carers emphasised that they could not have undertaken care at home without the support of others and the use of practical resources and equipment. Health professionals, family/whānau, friends and community supporters were mentioned.

Subtheme: Honouring the promise

Carers spoke of their resolve to take loved ones home from hospital or hospice, even though sometimes this had not been initially endorsed by professionals.

They [hospice staff] were very strongly suggestive that she should go into a [aged residential care] home—that it was going to be too hard [for the carer]... I said, “You’re going home”... we knew that that’s really what she wanted to do.

(Interview 7)

They described providing care at home as the fulfilment of a spoken or unspoken promise and knowing the loved one would have reciprocated.

[they] would have done exactly the same for me... I don’t have any doubts about that...

(Interview 2)

Towards the end, it became very difficult for some. A few had considered transfer to a care facility or hospice.

[being admitted to die in the hospice] was mentioned reasonably early on as an option and she [the loved one] didn’t want to do that... Had that situation lasted for a longer time, then eventually we would’ve had to.

(Interview 6)

Subtheme: Supporting the care at home

Carers supported their loved ones to die in their home and in the manner they chose:

It was our [dying] process... So, to be doing that in your home means that you retain that personal focus on the person. When you’re [the loved one] dying, you want to die where you want to die. You want to say: “This is how I want it.” You don’t want that control to be taken out of your hands.

(Interview 4)

Carers commended the interagency and interprofessional care given and recognised these services required complex coordination. Carers recalled memorable acts, typically undertaken by specific hospice or district nurses. They highlighted the nurses' skilful interpersonal approaches, which conveyed respect, sincerity, calm, problem solving, flexibility, information, education, watchfulness and cultural appropriateness.

There was a lot of flexibility in their approach... They all had their own skill sets... Great problem solvers, and assessors of a situation. They were adaptable... They didn't just pull the rug out. They were very respectful of the situation they were walking into... (Interview 4)

[the loved one, who was of Pacific ethnicity, did not want] people touching him. He's very independent and the culture [influences this]... With [the hospice nurse], she's just come in and met Dad, but he obviously felt comfortable enough with her that he allowed her [to admin-

ister care]. She asked him first—you know, if it's okay for her to do what she was going to do—and he said yes... he gave her permission to look after him.

(Interview 5)

The support of doctors (hospice doctors and GPs) was also recognised, particularly for advising about medications and acting as advocates.

...there must be a very good doctor at the hospice.... They [the nurses] were on the phone to her and they just—I could hear how they could rationalise things and work things out—and it just made good sense.

(Interview 4)

However, not all experiences with professionals and agencies were positive. Some professionals arrived late or did not come at all. Public holidays and weekends were a particular problem. At times, care was reactive and lacked continuity.

a [health professional said she] couldn't come until half seven, [and then she didn't] come [until] half past

Table 1: Inclusion/exclusion criteria.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> Registered on the hospice-at-home database At least six months post bereavement Primary/main carer over 18 years old 	<ul style="list-style-type: none"> Carers with cognitive impairment Carers deemed to be at bereavement risk (complex grief) Carers who were providing palliative care again

Table 2: Participant demographics.

Gender	Age	Ethnicity	Relationship	Employed/retired	Length of time providing palliative care	Previous/no experience in palliative care
8 women	8x <60yrs	7x Pākehā	3x partner/spouse	7x employed or self employed	6x <1yr	4x previous experience
1 man	1x >60yrs	1x Māori 1x Pacific peoples	5x daughter 1x mother-in-law	1x not employed 1x retired	3x 1–2 yrs*	5x no experience

* Two had lived in multigenerational homes for many years preceding the end-of-life stage.

eight. She did not look neat and tidy and I just felt cross... [Then there] was a very nice young man, but I could tell he didn't have the experience.

(Interview 1)

There was difficulty in 'knowing who is who' and 'who to contact'. As a result, sometimes carers took their loved ones to the local hospital emergency department (ED) or called the ambulance.

Sometimes... you don't know who you should ring. I wasn't sure whether [hospice] people were the main contact, but then... it was like no, "the GP is still the overall person"... "who do I ring out of district nurses, or, you know, the doctor or the [hospice]."

(Interview 3)

Carers highlighted the support of family/whānau, friends and neighbours. Some formed wider networks to share the caring including 24-hour rosters.

... We all had our roster... you know we have whānau [family], and... his aunty is a very close friend of Mum's, so she came from [Australia] to help. Her son came down from [up north] to be the cook and the cleaner and all that kind of stuff.

(Interview 7)

Supporters provided moments of respite and help with unexpected events. Yet there were challenges in achieving this, particularly for those who had smaller support networks.

We were just us.... we are just a small family.

(Interview 3)

It was important to have appropriate equipment, such as lie-back chairs, pressure-relieving mattresses, hoists and commodes, and their arrival charted pivotal moments in the final illness.

We had a hoist... We had a hospital bed and by that time [we] had a good mattress and everything.

(Interview 1)

Although carers described core equipment being supplied by the health agencies, often carers searched the internet for equipment suppliers and purchased or rented other items.

We wanted to get her out of the bed because she didn't want to sit there all day. We got her one of those recline lift chairs—we found a cheapie on [a trading site].

(Interview 7)

Theme two: Doing what it takes

As time went on and the loved one declined, 'doing what it takes' was fully assumed by the carer, usually with support from professionals, family/whānau and others. The home environment setup posed potential challenges for some.

Subtheme: Day-to-day care

Carers with previous experience of giving end-of-life care talked about anticipating what was required. Caring was complicated by home layouts with stairs and difficult-to-access bathrooms.

Access to the house was up a very steep driveway, plus 15 concrete steps

(Field-notes, Interview 1)

Physically moving the loved one was hard work, especially for solo carers.

...it was really hard to get him up to the bedroom. It was really hard to manoeuvre him and hold him... and getting to the toilet and things.

(Interview 1)

Others spoke of not leaving the house because the loved one did not want them to go.

[The loved one] was never settled if I wasn't there...

(Interview 2)

Toileting problems were frequently mentioned, often in relation to the location of the bathroom, the loved one not wanting a commode, the use of urinals or incontinence products and catheters. Bowels and/or the need for enemas were often an issue.

...he got up around midnight, to go to the bathroom and he had a fall. Lucky the window of the bathroom downstairs was open because my son had to jump through...

(Interview 5)

Carers talked extensively about how they judged symptoms and when to give medicines. Although instructed by the nurses on how to do this, some never felt comfortable about medicines, particularly increasing doses.

Myself and I think my brother... were shown how to give him more, increase the syringe. They showed us and they watched us do one... we were just nervous.

(Interview 3)

Near death, each caring activity became more difficult, time consuming, complicated and frequent (comfort, mobility, pressure relief, washing, toileting, giving medicines). All carers talked about the strain of giving care overnight and the relief of having a night-nurse.

[We] had one [nurse] come for a night, which was really good, it allowed... me to sleep... [and] you thought, "I don't have to worry, he's got somebody sitting with him"... [But you only] have so many [funded] hours... so we were trying to then weigh up [when to use them].

(Interview 3)

Subtheme: Leading the care

Carers talked of their role in leading the overall care: giving direction; co-ordination; record keeping, judging; anticipating; seeking out information and resources and calculating the financial costs. Family/whānau and friends looked to them for guidance.

If I was calm, they [the family/whānau] were calm they looked to me and if I was okay and understood it, they would just go with it.

(Interview 5)

Carers described using logs and notebooks and kept records of vital signs (temperature), symptoms (pain) and bodily activity (urine and bowels). They recalled past medical information and reminded loved ones of what had been said to them.

The carer was super organised. She showed us clear files for notes, plastic baskets for medicines and still has these items in ready access. Described recording everything: bowels and body temperature.

(Field-notes, Interview 2)

... it took a bit of work [coordinating]... So [it took] quite a bit of time to get everyone on the same page.

(Interview 7)

Carers talked of constantly weighing up, anticipating, worrying and preparing. Even

though coached by professionals coming into the home, there were times when they simply did not know what to do. They described often looking up information they were worried about and emphasised the amount of time this took.

I was constantly [trying to work out what to do], but it's hard if you don't know... You don't know what you don't know.

(Interview 2)

Financial circumstances were different for each carer. Some carers struggled with maintaining income from regular or self-employment and some gave up working. Some self-funded additional daytime or night care, but this was a strain.

... my business took a huge hit... and I had a good business.

(Interview 2)

Subtheme: Regrets

Although time had passed since the death of the loved one and when the interviews took place (6–18 months post bereavement), the detail was fresh for all of the carers. In most interviews, there were moments of pleasure and humour; but carers expressed regret—even remorse.

He was initially contained and reserved but became tearful talking about regrets halfway through the interview.

(Field-notes, Interview 4)

Carers recalled things not done well by professionals or themselves.

Dad was on no pain relief [for many months] until [the hospice nurse] came in [in the last week]. That's where I feel the GP could have helped us a little... They could have given us a little pain relief... It makes me angry when I think back on it...

(Interview 5)

... he kept getting up one night and he just kept going "oh I have to go to the loo... He just was dying to go to the toilet and I look back and I think how could I not [have noticed he was in urinary retention]—I think I was just so tired.

(Interview 2)

Discussion

This study builds on existing New Zealand research on home-based carers giving palliative care, echoing and expanding the findings.³⁴ It is similar to international studies,⁴⁴ where carers emphasised their loved ones wanted to die at home and knew that this drove them to undertake the care. This has been described as ‘enabled determination’⁴⁵ and the carers in this study acknowledged the enablement came from health and social care professionals and family/whānau/friends and the wider community. It also came from having the right (medical and other) equipment in the home. Even with enabled determination, providing care right through to the end was difficult, suggesting more services at the last stage of life are particularly needed.^{46,47}

For some carers, ‘the promise to care’ seemed to have been made early on in the dying process or when the loved one was still receiving active treatment and this sometimes made it difficult for carers to change their mind if they became overwhelmed. Similarly, some carers initially restricted professionals providing support in the home, changing their mind later on. This aligns with Fanueli’s New Zealand research with Pacific carers of the dying who described caring as a ‘family affair’. A recent meta-ethnography of UK carer studies⁴⁸ has associated ‘late help seeking’ with having few family/whānau or community supporters, complex symptom management and limited funded overnight care.

Each carer in this study actively assumed leadership and responsibility for their loved one’s care. This contrasts with a Canadian study where home-carers providing palliative care felt ‘thrust’ into being in charge.⁴⁹ A carer-led approach is at odds with some national and international policy that endorses health services leading the delivery of palliative care.^{50,51,4,52} More recent New Zealand policies support people to pro-actively engage in advance care planning⁵³ and self-initiate end-of-life conversations and decisions.⁵⁴ This more engaged, person-empowered approach is important^{55,56} if New Zealand is to create compassionate communities⁵⁷ where friends, neighbours and family/whānau, along with health and social care professionals, support carers and loved

ones. Carers taking on leadership roles could enhance the sustainability of palliative care delivery in the home.⁵⁸ In this study, however, information needs about symptom recognition were not being met, and despite the involvement of several agencies, there were lapses and gaps in care.

Home-based palliative care is a complex intervention and strategies are needed to ensure clear communication between all parties about actions being undertaken.^{59,60} Carers in this study, as in others, were uncertain about who to call for help, particularly after hours and when many agencies were involved.⁶¹ This was a particular issue when symptoms changed and medicines needed adjustment. Similar to a German study,⁶² the New Zealand carers appreciated the skills of palliative care nurses and district nurses. These nurses did not ‘take-over’ but sensitively acknowledged the home was the domain of the loved one and the carers.⁶³ Māori and Pacific carers described culturally safe approaches, including the nurses not automatically assuming they would give ‘hands-on’ care, coming promptly when asked and supporting the carers’ privacy and decision-making. All these aspects have previously reported as problematic in the delivery of culturally appropriate palliative care in New Zealand.²⁸

Carers, even though they were bereaved for some time, vividly described what they perceived as their own or others’ deficiencies, and expressed sadness, regret and remorse, possibly signalling unresolved grief.⁶⁴ This contrasts with Wong and Usshers’ Australian study that found bereaved carers often accentuated the positive aspects of the caring process.⁶⁵ This study showed three groups of carers were under increased stress: carers of loved ones who had received active cancer treatment almost up until the time of death; carers simultaneously looking after a loved one while trying to maintain employment or being self-employed; carers in multigenerational family/whānau arrangements without other family/whānau or community support, where the carer cared for their own children as well as elderly parent(s) with palliative care needs.

This study has limitations. The loved ones had received ‘specialist’ palliative care by a

local hospice (including a hospice-at-home service), in combination with DHB district nursing, GP care and other DHB-contracted or privately funded home-care services. Their experience may be different from carers *not* receiving the support of these agencies. It was undertaken in an urban setting and the findings may not apply to carers in rural settings where services are more limited. Not all carers approached agreed to be interviewed and their views may be different. Strengths of the study include: interviewing carers in their homes, having two researchers undertaking each interview and ensuring there were Māori and Pacific research processes for Māori and Pacific carer interviews.

Recommendations for practice and policy and for further research include:

Practice:

1. Options for the site of palliative care (home, hospice, aged residential care, hospital) should be explicitly and regularly discussed with loved ones and carers.
2. The key agency involved should consider offering home-visit check-ins to those who initially restrict professional support when phoned, giving a greater chance for care to be accepted.
3. Revalidate the international bereavement assessment tool to the New Zealand cultural context to identify carers with risk factors for poor psychological wellbeing. Consider a longer period of follow-up by bereavement counsellors or establish community-based support.

Policy:

1. Provide increased carer funding for practical support including over-night nursing and equipment if not able to be supplied.

2. Enable secure technology enabled pathways between agencies providing support to carers. Shared electronic records and care plans (including with carers and key whanau/family and community supporters) would clarify which agencies are involved, staff by name and who to call and when.

Research:

1. Further research is needed to better understand how to provide more effective support, education and mentoring for carers. This includes how best to support carers to judge, anticipate and feel confident about giving physical and psychosocial care, such as when to give or increase medicines to relieve symptoms; which symptoms need health professional assessment and how to quickly access and receive this help; how to recognise impending death. It is possible a uniform national package of resources could be developed that is able to be tailored to regional differences.

Conclusion

This New Zealand-based study of home-based carers' experiences of providing home-based end-of-life care for loved ones revealed similarities and differences to international studies. It commended some aspects and revealed ways carers could be better supported to provide care.

Appendix: interview questions

- To start with, how did you first become connected with the hospice?
- Involvement: General
 - I understand you were the main carer for X when s/he was at home in her/his final illness. Can you tell me about who supported you to look after X?
 - (If more than one person noted) Can you tell me the organisations these people came from?
 - It sounds like people from several organisations were involved. Can you tell who came from where?
 - Do you know if the different people and organisations were coordinated?
- Hospice-at-home: Specific
 - You mentioned staff from the hospice-at-home team. Can you tell me what you know about this service?
 - You may have been told it operates from 2–10pm. Did you use the service specifically (and when and how)?
 - What do the hospice-at-home service do that differed from the care and support provided by the district nurses and palliative care coordinators?
- Education/knowledge
 - Have you cared for someone else at end of life in the past?
 - How prepared did you feel for the role?
 - Did you have any questions for the professionals helping you? How were they answered?
 - Were you left with further questions after a visits/first contact?
 - Can you recall receiving any information and training about specific tasks such as moving X, providing hygiene or continence care, giving fluids/food and giving medicines?
- Care and support
 - Do you recall X being assessed when in their final illness for the care they needed?
 - Where you asked what support you needed?
 - What aspects of care did you need support with?
 - Was this written down in a care plan? (Was it in your home?)
 - Can you give examples of when support was given and what for?
 - Can you give examples of when support was *not* given when you needed it?
 - What were the most difficult aspects of giving care at home?
 - What was the most difficult thing that happened? What did you do?
 - Did you call for help in the evening or weekend? If yes, can you recall what this was for and who you called. How was the call resolved?
 - Did you use the hospice-at-home afterhours phonenumber?
- Sum-up
 - Overall, what went well with the care/support given?
 - Can you think of any areas for improvement?
 - What made caring at home preferable to ARC, in-patient hospice unit or hospital care?
 - Were you given options and support for where X could pass away?
 - How were you supported after X passed away?

Competing interests:

Nil.

Acknowledgements:

We are deeply grateful to the carers who took part in this study. We also acknowledge the help and support of Louise Forsyth and Vanessa Eldridge.

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