

How family caregivers help older relatives navigate statutory services at the end of life: A descriptive qualitative study

Lisa Ann Williams¹, Tess Moeke-Maxwell¹, Janine Wiles², Stella Black¹, Gabriella Trussardi¹, Ngaire Kerse² and Merryn Gott¹

Abstract

Background: A key challenge in meeting the palliative care needs of people in advanced age is the multiple healthcare and social service agencies typically involved in their care. The ‘patient navigator’ model, originally developed in cancer care, is the professional solution most often recommended to address this challenge. However, little attention has been paid, or is known, about the role that family carers play in enabling their dying relatives to negotiate service gaps.

Aim: To explore the role family caregivers play in helping people dying in advanced old age navigate health services at the end of life.

Design: Qualitative study using semi-structured interviews and analysed via thematic analysis.

Setting/participants: A total of 58 interviews were conducted in New Zealand with the family caregivers of 52 deceased older relatives who had been participants in *Life and Living in Advanced Age: a Cohort Study in New Zealand*.

Results: Fragmentation of services was the key concern, causing distress both for the older person and their family caregivers. Carers identified and engaged with appropriate services in order to facilitate care and treatment. Their involvement was not always met by healthcare professionals with respect or regard to their knowledge of the older person’s needs.

Conclusion: Family caregivers are trying to help their older relatives overcome the limitations of fragmented health systems at the end of life. They are doing so at times by stepping in to perform patient navigator tasks usually conceptualised as a role for statutory services to carry out. Programmes and services need to be implemented that will better support family carers who are acting as care navigators.

Keywords

Palliative care, end-of-life care, family caregiving, informal care, older adults, elderly, patient navigation

What is already known about the topic?

- Multiple healthcare and social service agencies are often involved in the healthcare of adults of advanced age nearing the end of life, which may contribute to fragmented care.
- The professional patient navigator is a professional solution for negotiating the gaps and inconsistencies that patients experience.
- In contrast, Health Promoting Palliative Care (HPPC) recognises the expertise of family caregivers and looks for solutions centred in the community.

What this paper adds?

- Evidence that families noted the gaps in services or lack of coordination between services and how they affected their family members and themselves.

¹School of Nursing, Faculty of Medical and Health Sciences, The University of Auckland, Auckland, New Zealand

²School of Population Health, Faculty of Medical and Health Sciences, The University of Auckland, Auckland, New Zealand

Corresponding author:

Lisa Ann Williams, School of Nursing, Faculty of Medical and Health Sciences, The University of Auckland, Private Bag 92019, Auckland 1142, New Zealand.

Email: la.williams@auckland.ac.nz

- Evidence that inadequacies in healthcare services led carers to step in to perform patient navigator tasks.
- Evidence that family caregivers experienced barriers to acting effectively as navigators; their knowledge and experience regarding their relative's health was discounted or ignored by health professionals, and as a result, the relative suffered unnecessarily.

Implications for practice, theory or policy

- Healthcare providers need to acknowledge the crucial role that family caregivers play in navigating health services at end of life.
- HPPC approaches could be developed that partner healthcare providers with community groups or recruited volunteers to assist family caregivers with aspects of patient navigation.
- Research is needed to identify the extent to which such models can better avoid or bridge gaps in end-of-life care service provision.

Background

Previous research has identified that a particular challenge in meeting the palliative care needs of people in advanced age relates to the multiple healthcare and social service agencies typically involved in their care. For example, a recent UK study reported on the numerous professionals – from the Marie Curie nurse to the house cleaner – that advanced heart failure patients interacted with in order to access services and complete daily tasks.¹ Although it is not necessarily a given that dealing with many individuals or agencies will result in poor care, the patients and carers in this study were ‘unnecessarily burdened by poorly co-ordinated, fragmented, and discontinuous care’. Similar findings have been reported in relation to older people with advanced chronic obstructive pulmonary disease (COPD); their care has been described as ‘fragmented, episodic, and reactive’² and inadequate to meet palliative care needs on a day-to-day basis. Even within cancer care where, overall, services are regarded as being more integrated,³ health professionals have indicated the challenges patients with advanced cancer encounter towards the end of their lives, particularly in rural areas, due to the complexities of coordinating palliative care services with other treatment-related visits.⁴ Finally, research centred on medical complexities of care for those with comorbidities found that care from multiple clinicians could lead to uncoordinated prescription regimes and recommendations that resulted in polypharmacy, escalating treatment costs, side effects and unforeseen drug interactions.⁵

These findings indicate that, for older people at least, the current situation may be a long way from the seamless, patient-centred care espoused in policy. England's *End of Life Care Strategy*, for example, lists the ‘delivery of high quality services in all locations’⁶ among the steps in its care pathway, while the vision for the New Zealand strategy is to provide all people with ‘timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way’.⁷

Originally developed for cancer patients, one common solution for negotiating the gaps and inconsistencies patients experience in accessing health and social care services is the professional ‘patient navigator’.⁸ Initially created to help improve the survival rate of disadvantaged African-American breast cancer survivors,⁹ patient navigators help people negotiate their cancer care and treatment. They may also, depending on how their role is conceptualised, work to remove barriers to care faced by patients and to provide psychosocial support.¹⁰ Typically, navigators enable timely access to services and resources,¹¹ assess need, coordinate care among services, advocate for patients and evaluate whether the services provided meet the needs of those under care and their families.¹⁰ Furthermore, patient navigation has now spread to other disciplines. Nurse navigators help COPD patients,¹² Family Community Navigation Specialists (F-CNS) assist individuals in the community with serious mental illness¹³ and Emergency Department-based patient navigators connect ED community-based primary care providers.¹⁴ Although their exact duties may vary, similar to cancer patient navigators, their purpose is to help people better negotiate health systems and cope with their illness.

In contrast to these professional solutions, little is known about the role families play in providing patient navigation services for their dying relatives. This is a significant oversight for two reasons. First, governments have been calling for the development of programmes and policies that provide for palliative care in the community,^{6,7,15} which can equate to services provided by families.¹⁶ This suggests that navigation of services and supports may be among the myriad ways families help at end of life. Second, at present, the philosophy underpinning the role of patient navigators is the conviction that assistance originates in the statutory sector. However, public health approaches to palliative care and, in particular, Health Promoting Palliative Care (HPPC) suggest solutions might be found in a broader context that includes, or originates in, communities.¹⁷ Yet, while ways in which family caregivers have been involved in palliative care provision

Table 1. Family carer characteristics by gender, age, ethnicity, employment status and relationship to deceased older person.

Variable	Frequency	
Gender		
Male	13	
Female	45	
	Male	Female
Age		
20–29	1	0
30–39	0	1
40–49	3	1
50–59	4	8
60–69	2	28
70–79	1	3
80–89	2	4
Ethnicity		
NZ European	9	30
Māori	4	15
Employment status		
Fulltime	6	16
Part time	1	9
Retired	4	16
Not in paid employment	2	4
Relationship to deceased		
Spouse/partner	3	8
Son/daughter	5	28
Son-in-law/daughter-in-law	0	4
Other family	2	1
Friend/neighbour	1	2
Grandchild	2	0
Other	0	2

have been highlighted,^{18–21} the means by which they navigate health systems to support family members dying in advanced age has not been previously explored.

Aim

To explore the role family caregivers play in supporting their relatives aged 80 and over to navigate health services at the end of life care.

Design

Because of its exploratory nature, a qualitative study design was used for this bi-cultural (Māori and non-Māori) research. Social constructionism informed the design, supported by a Kaupapa Māori research framework. Kaupapa Māori research is an indigenous approach developed to counter the effects of colonialisation perpetuated in Western research designs.²² Neither a methodology in itself nor an established set of methods, it is an approach that at its most fundamental level involves making Māori

central in all aspects to the research process.²² A Kaupapa Māori research framework emphasises respect, care and safety for all participants, which also includes the analysis and use of their data, and informed our approach with all participants, in line with the bi-cultural framework which underpins the work of our research group.²³ Participants provided very positive experiences of participation, supporting this decision.

Study population

This research study aligns with *Life and Living in Advanced Age: a Cohort Study in New Zealand* (LILACS NZ).²⁴ In 2010, LILACS NZ recruited 421 Māori aged over 80 years and 516 older non-Māori men and women aged 85 years to participate in a longitudinal study examining predictors of successful aging amongst people of advanced age. Differential markers of advanced age were adopted due to marked differences in life expectancy between Māori and non-Māori people in Aotearoa, New Zealand. Six successive waves of yearly interviews were completed from 2010 through 2016. LILACS NZ is a population-based sample which is representative of the underlying population, except non-Māori men were slightly oversampled. The sample for this research was drawn from Wave 3 onwards. It comprised those who (1) said yes to asking a carer about them after they died and (2) nominated a carer and then died. These individuals did not differ from the wider LILACS NZ sample on key sociodemographic factors but were more likely to have lower function and higher comorbidities and depression than non-participant survivors, as would be expected due to their proximity to death.

The participants referred to in this paper are comprised of individuals, usually family caregivers, who had either been nominated by the older person enrolled in the LILACS NZ study before their death to be interviewed, or were referred by the nominated individual to the research team via the local LILACS NZ team recruiters. Carers were selected by their older relatives to be their nominated spokesperson before they entered into the last weeks of life. Therefore, they would not have known ahead of time whether their experiences would be positive or negative. Local recruiters contacted *all* potential participants after the death of the older relative.

A total of 58 interviews were conducted concerning 52 participants in the LILACS NZ study. As would be expected, in the instances when more than one person was interviewed regarding their care for the same older relative, their roles and experiences differed. However, in relation to the topic of this paper, they expressed no divergent opinions. Participants received information sheets and completed signed consent forms. See Table 1 for a breakdown of participant characteristics. Table 2 offers information on the deceased LILACS NZ participants. Interviews took place on the North Island in New Zealand.

Table 2. Deceased family member characteristics.

	Number
Gender of deceased	
Male	24
Female	28
Total	52
Ethnicity	
Māori	20
NZ European	32
Total	52
Deceased age at death	
82	1
83	2
84	3
85	4
86	1
87	12
88	12
89	12
90	4
91	0
92	2
Total	52
Who deceased lived with before death	
Alone	13
Spouse/partner	13
Spouse/partner + other relative	2
W/child (not spouse)	7
W/others (not spouse or children)	17
Total	52
Description of deceased's home	
Private dwelling/stand-alone house	26
Private unit/apartment – independent	1
Retirement village – villa or own unit	9
Rest home	11
Private hospital (own or shared room)	4
Other	1
Total	52
Cause of death	
Heart disease	21
Stroke	1
Pneumonia	3
Cancer	13
COPD	3
Sudden death	1
Other	10
Total	52
Where did deceased die	
At own home	11
In whānau/family room in public hospital	7
In another part of a public hospital, for example, ED or ward	14
In a hospice	2
In a rest home/private hospital	18
Total	52

Table 2. (Continued)

	Number
Presence of significant long-term memory problem or dementia before death	
Yes	17
No	35
Total	52

COPD: chronic obstructive pulmonary disease; ED: Emergency Department.

It should be noted that for the purposes of this research, the definition of 'family caregiver' also includes those other than blood relatives who had a significant relationship with an older person and who provide the person with assistance regarding their healthcare needs. This definition is also in keeping with the bi-cultural nature of the study; the Māori term 'whānau' includes extended family and can also refer to those not related by blood.

Data collection

Face-to-face interviews of 1–2.5 h conducted between September 2013 and September 2015 took place in the participants' homes or other place of their choosing. They followed an in-depth guided conversation format and also included a questionnaire soliciting detailed information about the relative's circumstances at the end of life. Five interviewees chose only to complete the questionnaire because of time limitations. Even so, it should be noted that the questionnaire was still administered by the interviewer face to face; participants were able to make any additional comments they chose about the end-of-life period; the interview was audio-recorded with the participant's permission and they signed a written consent form. These interviews based solely on the questionnaire usually took approximately 1 h to complete and therefore, captured a significant quantity of information about end-of-life circumstances.

Kaupapa Māori research principles designed to promote participant and researcher safety informed the protocol for the interviews.²⁵ Interviews with Māori were conducted by Māori researchers, T.M.-M. and S.B. For the most part, interviews with non-Māori were conducted by T.M.-M. and L.W., although due to scheduling conflicts S.B. at times accompanied T.M.-M. for non-Māori participant interviews. Participants were encouraged to invite other people to their interviews for support should they wish to do so. Researchers kept field notes about interactions with participants.

Data analysis

Interviews were audio-recorded and transcribed verbatim by a transcriptionist, who signed a confidentiality agreement.

Participants were given the opportunity to collaborate with the researchers to create a summary report based on their transcripts. Those that did so (41 participants of the 52 deceased LILACS participants) reviewed, modified and approved the content. Changes were minor and reflected participants' wishes to clarify content.

As a group, over an 8-month time period, the research team discussed and coded line by line a representative sample of transcripts, an inductive approach that drew upon the data to construct a coding framework.²⁶ Codes relating specifically to Māori culture were developed by T.M.-M. and S.B.

Subsequently, all transcripts were coded according to these categories and into any new ones identified during the coding of subsequent interviews. The data were stored in NVivo 10 for purposes of data management. L.A.W. and M.G. reviewed the data stored within the NVivo codes and categories relevant to the statutory healthcare provided to the deceased LILACS participants and, by working iteratively with the original transcripts, developed the themes addressed here. The study was approved by the University of Auckland Human Ethics Committee (Reference 9186).

Findings

Positive experiences regarding many aspects of care were reported. However, none were reported by participants in relation to the topic of this paper. Indeed, the findings revealed the challenging circumstances older people encountered when interacting with the health system and the distress their family caregivers felt on their behalf. Carers felt compelled to identify and engage with appropriate services in order to facilitate care and treatment. Yet their involvement was not always met by healthcare professionals with respect or regard to their knowledge of the older person's needs. As a result, the older person could suffer, which further heightened their carer's distress. Both Māori and non-Māori experienced similar challenges, as the findings indicate.

In the following section, the findings have been divided into three themes, with associated quotations from the interview data cited. These provide not just examples to support the themes developed, but also serve to highlight the emotional distress that insufficient care generated. All names used are pseudonyms.

Families noted the gaps in services or lack of coordination between services and how they affected their family members and themselves

Overall, participants identified service fragmentation, poorly coordinated care and the failure of health professionals to recognise the wider social and health context within which their older relative lived as their main sources of dissatisfaction with end-of-life care. Lana, for example,

mentioned how an absence of round-the-clock hospice care impacted her father's last 24 h. She described how he was being cared for in her home and was experiencing great distress at two o'clock in the morning. She said, 'I was becoming increasingly alarmed at the difficulty he was clearly in'. She rang hospice and discovered they could not send anyone to help. Instead, they coached her over the telephone on how to give an injection, although she had no experience or training. She said, 'I was terrified that I would mix the mix wrong and do something wrong' (Lana, a non-Māori daughter of a non-Māori father).

Families indicated gaps in services happened due to a lack of attention by professional health services to contextual factors. David commenting about his mother, did not dispute the quality of the care given. Rather, his complaint was that the general practitioner (GP) and district nurse failed to take into account her dementia or the fact she lived rurally. He said,

If she managed to make her way into town, this is say three to six months before she passed away, then yeah, the care and attention was fine. But it was the, as I say, the coordination between them and the public nurse, and how does she get into town to, and who reminds her? (Māori son of Māori mother)

In a similar vein, Lenua expressed dissatisfaction with the hospital for releasing her mother-in-law 2 days before she died without inquiring appropriately into what care would be available at home for her. She said,

As far as we know, they never knew what she was going home to. They sent her home from a severe, serious illness to a home where she was caring for a man with Alzheimer's. To me, that's completely wrong. They probably asked her, 'Will there be somebody to look after you?' And she probably said, 'Yes, my husband'. But they don't know what's wrong with her husband, and to me that whole thing is wrong, that shouldn't be allowed to happen ...

To me, the medical profession do need to be a little bit more wide ranging in their assessment of whether somebody is okay to go home. (Non-Māori daughter-in-law of Māori mother-in-law)

Inadequacies in healthcare services led carers to step in

The observed deficiencies in care noted above motivated carers to intervene in diverse ways to source the help their relative needed. Sometimes urgent, direct action was required while in other cases, intervention took place over time. For example, Molly reacted to negligent care at an Age Residential Care (ARC) facility by personally transporting her older friend, Major, to see a specialist regarding his gangrenous toe that the staff ignored. She said,

I took it upon myself at the last time to wheel him out of there without informing the staff where I was going, down to the doctor's to get something done about a toe that was so obvious to me – who is not a nurse but work in the field – gangrene. (Non-Māori friend of older non-Māori man)

Family carer support and advocacy roles grew and evolved as the need arose. Frances helped coordinate her mother Elvira's primary care, which had become inconsistent due to the turnover of GPs within the primary care practice. At first, she merely accompanied her mother on visits, but upon learning she had blood in her urine her role grew to include appointment scheduler. She said, 'Well, the first thing you do when that happens is you're supposed to go to the doctor, so off we went to the doctor ...'. This role expanded again to include advocacy, 'I followed Mum into the toilet one day and there were clots in the toilet, so we went back to the doctor and I said to Mum, "Look, I'm talking today" and she said, "Oh, good"' (Māori daughter of a Māori mother).

Despite Frances' oversight, Elvira was still subject to differences in types of care offered depending on which GP she saw. One remarked that Elvira had a lot of blood in her urine but added, 'I'm not going to refer you to anyone because she's an old lady and they won't do anything about it'. Conversely, when Frances took Elvira again to primary care because of her extreme pain, a different GP sent her for tests, which confirmed that Elvira had bladder cancer.

Gaining knowledge about how to access care and services could require family caregivers to learn by trial and error. David, recalling his mother's interaction with the health services involved in her care said, 'it took a little while to actually ... see who had records for what and what they were doing'. He also indicated that gaining the knowledge required often came from hard-won or painful experience. He said,

I was the main point of contact and as a result of that just sort of, yeah it's, yeah it's quite stressful when you don't know what's to be expected. (Māori son of Māori mother)

Family caregivers experienced barriers to acting effectively as care navigators

Despite their willingness to take on the role of patient navigator (where they had the time to do so), family caregivers were at times not listened to by professional healthcare staff, which they found upsetting. Their disquietude was not so much for their own sake but because by dismissing their voices, services missed an opportunity to provide appropriate care for their relative. Molly, mentioned above, was angry with the ARC staff; her distress was evident in her tone of voice throughout the interview. Her statement that, 'they turned their noses up at me, but tough!' reflected her resentment that ARC staff did not take seriously her

concerns about Major's health. She noted that some of the difficulty may have been because she was not related to Major. However, she asserted the staff was aware of her ties to him. She said,

I probably wasn't listed in the front of their folders, but they knew from years of me being there who I was and they knew the bond and the care, that we did everything for Major. (Non-Māori friend of older non-Māori man)

Because she was James' wife, Ann, a retired nurse, did not face the same problem as Molly, regarding her legitimacy as an advocate for her husband. Nonetheless, she felt her expertise as James' caregiver was ignored by health-care professionals. James, who had Alzheimer's, continually scratched himself; the hospital staff concluded he had scabies. When Ann visited, she found him 'gowned up' from 'head to foot' with rubber gloves on. Dry skin, rather than scabies was the culprit, but the staff would not credit Ann's experience. She said,

He's scratched for the last 40 years, he's always scratched. They wouldn't take my opinion of that and that upset me greatly. That really did upset me because it was subjecting somebody of nearly 90 to sit there with rubber gloves on and gowned up itching. (Non-Māori wife of non-Māori husband)

Similar to Ann, Donald and his siblings were not taken seriously by hospital staff during their mother, Ruth's, final stay. Ruth experienced bouts of hallucination, one to the degree that she was out of her hospital bed 'whacking into a security guard' with her walking stick. Despite her lack of coherence, the medical staff secured her consent for a surgical procedure, the insertion of a pacemaker. Donald indicated his dissatisfaction with the specialist's failure to check in with the family. He and the family had many years of experience caring for their mother. He said,

(The cardiologist rang) to tell us that this was being done, but the cardiologists, they see the world from the cardiology but we're seeing the world from Mum who's got to cope with her failing body, and it could have been a wonderful operation for the heart, fine. But hang on, we're the ones, and she's the one, that's got to cope with what's happening now.

Recovering from the pacemaker operation, Donald felt, involved unnecessary pain and suffering for their mother at the end of her life: 'it was a trauma that Mum went through, like she was black from here to here' (Non-Māori son of non-Māori mother).

Discussion

The literature has indicated there are gaps in health services, lack of care continuity and poorly coordinated services for older people seeking palliative care.^{27–29} Our findings add insight into how family caregivers are attempting to

fill these gaps or coordinate care by undertaking tasks often fulfilled by professional patient navigators. In other words, they are taking action rather than waiting for professionals to step in. The fact that they assert healthcare professionals are not always paying attention to contextual factors – the ‘bigger picture’ of older people’s lives that may include issues such as dementia, living rurally, lacking home help or caring for an ill partner – suggests that carers are aware of the need for care navigation. Interestingly, health professionals may at times, at least on an implicit level, be cognisant of how family caregivers do serve as care navigators. For example, in one study concerning older patients, whether or not a nominated carer was involved had an impact on if hospital staff organised patient health and support services.³⁰

A closer look at the extensive role family carers have played in providing care for older relatives has revealed some similarities to those completed by a professional patient navigator. Just as navigators do,³¹ family carers carried out patient management and advocacy tasks such as accompanying relatives to medical appointments, maintaining health diaries and overseeing medications. Furthermore, regarding plans for care after discharge for heart failure patients, researchers found that a benefit of keeping carers informed was their usefulness as advocates, ‘particularly for those patients who experienced difficulties in their communication with clinical teams’.³¹

This research is valuable in that it explicitly identifies the ways in which family caregivers act as patient navigators for their older relatives. However, we are not suggesting that family caregivers should necessarily adopt the role of patient navigators; rather, we are pointing out that this is occurring whether or not it is acknowledged within the palliative care sector. Furthermore, by disregarding family caregivers’ knowledge about the older person’s healthcare, professionals are at times preventing them from performing this role effectively. This means not only that the older person suffers but that the caregiver experiences additional stress. This is not a small consideration, given the ill health that family carers, especially older spouses, may experience while being called upon to care.^{31,32}

Cultural considerations

Aspects in this study that relate specifically to Māori participants and their deceased relatives resonate with findings reported about other indigenous communities. For example, David, the Māori son who spoke about his Māori mother, mentioned that for his mother simply getting into town was a problem. Many Māori still dwell on rural, ancestral lands, which can make access to care and treatment more difficult.³³ Similarly, McGrath et al.,³² reporting about Aboriginal Australians and Finke et al.³⁴ reporting about Pueblo Zuni, discussed issues related to rural living and proximity to palliative care. Economic

disadvantage can also be an issue for Māori regarding unmet need for healthcare,³⁵ as it is for other indigenous groups.³⁶ Therefore, David’s statement about his mother’s access to town may relate not just to physical inaccessibility but to monetary as well. For Māori the costs associated with transport and other palliative care expenses can be an added burden.^{33,37}

Implications for practice and further research

In congruence with an HPPC approach,³⁸ healthcare organisations could partner either with community groups or recruit volunteers in the community directly to assist and support family caregivers with aspects of patient navigation. The value of volunteer assistance for family carers has already been documented;^{39–41} extending the remit to include patient navigation guidance or advice could be useful for families. Because of the involvement of families in the care of older relatives at the end of life, assisting and training them could be quite beneficial. In addition to providing navigation assistance, the volunteer or community group member could also serve as a contact for support, an important function given the isolation that family caregivers can experience whilst caring.^{42,43} Furthermore, as the above examples related to Māori suggest, programmes would need to take into account the particular needs and circumstances of indigenous groups to ensure they operated in a culturally safe manner.⁴⁴

The HPPC approach also reframes carers as experts, and this was evident in this study. Given the expertise evidenced by family caregivers about the particular history and concerns of their older relative, the flow of information should not be one way. As these findings demonstrate, their knowledge of contextual factors would be invaluable for informing care and treatment. Further research would be useful to develop methods for strengthening partnerships between healthcare professionals responsible for care and treatment decisions and family members in ways that are also supportive of the older person’s preferred level of involvement in decision-making.

Working more closely with family caregivers who are willing and able to perform care navigation may enable reduced hospitalisations, where this is preferred by the older person themselves. Research on people with COPD revealed that they experienced a lack of ‘a clear coordinated pathway’ for ‘obtaining support and advice’.² As a result, the reactive, episodic care COPD patients received often led to hospitalisations in a crisis. These findings are consistent with data demonstrating that having a family carer increases the likelihood of dying at home.^{45,46} Further research could explore whether enhancing family caregivers’ interaction with healthcare professionals by supporting the work they do as patient navigators could reduce such crises and the resultant implications for the older person, caregiver and the health system. However, this is not

to advocate an indiscriminate change in policy or practice that fails to take into consideration family caregiver capacity. Attempting to reduce costs by placing care burdens onto families, assuming that they can and will take on the role, can in itself create distress and suffering,⁴⁷ and it is important to acknowledge the gendered nature of caring places disproportionate responsibility onto women.^{48,49}

Strengths and limitations

This study is valuable for exploring how family caregivers are helping their older relatives navigate healthcare services to receive care at the end of life. The qualitative approach offered participants the opportunity to speak in-depth about their experiences, thereby creating scope for detailed, considered accounts of their involvement in their older relative's end-of-life journey. The bi-cultural nature of the study allowed unique information to be gathered regarding end-of-life experience for Māori, and the Kaupapa Māori research protocols promoted participant safety. A limitation, however, is that the retrospective nature of the study meant relying exclusively on data supplied by family caregivers. It is possible that their views about the end-of-life experience diverge from those the older person would have reported.

Conclusion

Family caregivers are trying to help their older relatives overcome the limitations of fragmented health systems at the end of life. They are doing so at times by stepping in to perform patient navigator tasks usually conceptualised as a role for statutory services to carry out. A barrier they encounter to their effectiveness is health professionals' lack of regard for their expertise. This barrier also contributes to suffering for the older person and frustration for their caregivers. Programmes and services need to be implemented that will better support family carers who are acting as care navigators, especially as governments move to shift responsibility for such care into the community.

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