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Methodological considerations for researching the financial costs of family caregiving within a palliative care context.

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## **Abstract**

The financial impact of family caregiving in a palliative care context has been identified as an issue which requires further research. However, little is known about how research should be conducted in this area. The aim of this study was to explore the opinions of family caregivers in New Zealand regarding the need to conduct research relating to the financial costs of family caregiving and to explore their perspectives on acceptable and feasible methods of data collection. A qualitative study design was adopted. Semi-structured interviews were conducted with 30 family caregivers who were either currently caring for a person with palliative care needs, or had done so in the past year. All participants felt that research relating to the costs of family caregiving within a palliative care context was important. There was little consensus regarding the most appropriate methods of data collection and administration. On-line methods were preferred by many participants, although face to face methods were particularly favoured by Māori participants. Both questionnaires and cost diaries were felt to have strengths and weaknesses. Prospective longitudinal designs are likely to be most appropriate for future research, in order to capture variations in costs over time. The lack of consensus for a single preferred method makes it difficult to formulate specific recommendations regarding methods of data collection; providing participants with options for methods of completion may therefore be appropriate.

## **Background**

Recent evidence from the United Kingdom (UK) suggests that the proportion of people dying in their own homes is increasing, a trend that is reflected in the USA and Canada and is generally accepted as being in line with patient preference.[1] A key policy drive in many developed countries, including the UK[2] and New Zealand,[3] is to support discharge from hospital and avoid unnecessary hospitalisations at the end of life, again in line with the preferences of the majority of patients to remain at home. One consequence of these demographic shifts and policy directives is that an increasing proportion of palliative care provision is being shifted from in-patient facilities to communities and family caregivers. The expertise offered by family carers and wider communities is increasingly being acknowledged,[4] and the financial costs of informal caregiving are well recognised.[5] However, little is known about the financial impact of informal caregiving specifically within a palliative care context.[6]

A recent systematic review exploring literature relating to the financial costs of caregiving within a palliative care context identified a weak evidence base.[6, 7] Nonetheless, findings suggested that the financial impact on caregivers was likely to be significant, with costs identified in a range of domains including work related costs, out of pocket expenses and carer time costs. Evidence also suggests that financial burden can have a considerable negative impact on a range of outcomes including caregiver strain, family conflict, difficulties coping and the need for major life changes such as moving house or giving up work.[6, 7, 8]

Existing evidence therefore suggests an urgent need for further research to explore the financial impact of family caregiving within a palliative care context. However, little is known about acceptable and appropriate methodological approaches for research in this area. One of the challenges identified in conducting palliative care research is selecting appropriate and ethically sensitive methods for undertaking research.[9] Indeed research in palliative care has been criticised for failing to meet the physical, psychological and emotional needs of the end user, and there is a recognised need to improve research methods.[10] The aim of the current study was therefore to explore the opinions of family caregivers in New Zealand regarding the appropriateness of research relating to the financial costs of family caregiving in palliative care, and to explore their perspectives with regard to acceptable and feasible methods of data collection.

## Methods

In order to capture experiential data in an exploratory area, the study was conducted using a qualitative design. Māori are the indigenous people of New Zealand, however a Māori perspective has often been neglected within traditional medically oriented discourse in New Zealand.[11, 12] Therefore a central aim of the study was to ensure adequate representation of Māori views.

Participants in the study comprised family caregivers who were either currently caring for a person with palliative care needs, or had done so in the past year. Participants were recruited using convenience sampling methods from a large city in New Zealand via two sources. Firstly, participants were recruited from a specialist palliative care service in a city hospital catering to a large tertiary catchment area, both urban and rural. Hospital recruitment occurred over one month of palliative care service intake in 2013. Over one month hospital palliative care staff identified and invited next of kin to participate in the research; 20 agreed to participate and 17 took part (drop-outs were due to changes in potential interviewees' availability/location).

A second recruitment strategy was adopted to ensure appropriate representation of Māori whanau<sup>a</sup> caregivers. Previous research has identified that targeting Māori community media is a successful recruitment strategy,[13] therefore advertisements about the study were published in local community media (newspapers, newsletters etc). Following media publicity 13 additional participants were recruited, resulting in a total sample of 30. The study aimed to achieve a sample size of 25-30 as this is recognised as an adequate sample size for an in-depth, exploratory study of this type.[14] All 30 participants were interviewed over six months from November 2012. Participant details are summarised in Table 1, these details are intended to provide context to the qualitative data and were not used as part of the analyses.

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<sup>a</sup> Whānau is most often translated as 'family', but its meaning also encompasses physical, emotional and spiritual dimensions (<http://www.teara.govt.nz/en/whanau-māori-and-family/page-1>)

<b>Characteristic</b>	<b>n</b>
Age Range	22-79yrs
Gender:	
Male	7
Female	23
Self-identified ethnicity :	
Māori	12
European New Zealander	13
Other (Cook Island, Samoan, Tongan)	5
Caring for:	
Mother	14
Father	5
Spouse/Partner	5
Other relative (e.g., sibling, great-uncle)	4
Friend/Client	2
Length of time caring:	
Less than 1 month	2
1 month – 6 months	6
> 6 month – 1 year	4
> 1 year – 2 years	8
> 2 years – 4 years	6
More than 4 years	4
Household income in New Zealand Dollars, and Great British Pounds equivalent as of Nov 2012:	17
< \$50,000 (<£22,500) Low	10
\$50,001-\$100,000 (£22,501-£45,000) Medium	2
>\$100,000 (>£45,000) High	

**Table 1: Participant characteristics (n=30)**

Participants took part in semi-structured interviews at a place of their choosing, including at participants' homes or a relative's home (n = 25), by telephone (n = 2), at the hospital (n = 1), or in a café (n = 2). Interviews lasted between 30 and 90 minutes and were conducted by RA and TMM. In line with culturally appropriate 'kaupapa' Māori methodology,[13] Māori

participants were offered the option of having others of their choosing present at the interviews. Six Māori participants elected to have another whānau member present, and two Māori participants elected to have the person they were caring for present. All other participants were interviewed alone. Interviews began with a short interviewer administered demographic questionnaire. Information about income was also collected and a self-completed questionnaire with envelope was used specifically for this information, to avoid any potential embarrassment to participants. Participants were offered a \$50 petrol voucher to acknowledge their contribution to the research. The interview guide (Table 2) was developed following a review of the literature. [6, 7] Interviews were digitally recorded with participants' consent and transcribed in full. Summaries of interview data were presented back to participants for their feedback and further comment as part of ensuring methodological rigour and confirmability. [15] Ethical approval was provided by the Northern X Regional Ethics Committee.

- A “typical day” in terms of caregiving tasks and associated costs
- Emergency or crisis costs
- How they felt about talking about costs in their current situation
- Who else was involved in caring or supporting them financially; and any financial assistance sought or received (e.g. insurance, statutory agencies, loans, credit, family).
- Thoughts and ideas regarding further research in this area, including the acceptability of surveys/questionnaires, diaries, and interviews.

**Table 2: Topics covered in the interview guide**

### **Data analysis**

Qualitative data software (NVivo 9) was used as the filing system for the initial categorising and analysis of participant data. To ensure rigour and trustworthiness transcripts were read by two authors (RA and TMM) and core themes were identified. “Experience-centred narratives”, [16] such as present and future stories about self and others in relation to care, contradictions and gaps within narratives, and links with larger cultural narratives/storylines about care and costs, [16, 17] were explored using narrative analysis [16] and thematic analysis techniques. [18] Themes and narratives were brought to the research team meetings

for further discussion and review and a coding framework was developed by consensus. Themes and sub-themes were reviewed in relation to coded extracts and themes were refined by consensus. Demographic and socio-economic data about participants were collected and are presented in table 1, this data is displayed to provide context to the qualitative data and was not analysed as part of this study.

## **Findings**

All participants felt that research relating to the costs of caring for family and whānau within a palliative care context was important. However, several key challenges in conducting research in this area were identified, including sensitivities relating to the disclosure of financial information, issues relating to methods of data collection, and the practical difficulties in engaging people in research during a very unpredictable and emotionally difficult time. Findings are summarised in table 3.

### **Participant views regarding the need for, and scope of, further research in this area**

All participants felt financial costs were an important area for research. When asked to consider the value of research in this area one Māori participant reported:

*“ It’s so important because how can society understand the needs..., if [they’re] not looked into, and researched in a way so you could understand... what they firstly go through; let alone how to survive in today’s society and today’s life when it comes to costs? ”*

Whilst the topic was seen as important, some participants did acknowledge that there were difficulties in research of this nature because *“people don’t like to talk about money”*. However, the majority of participants reported no issues relating to the disclosure of financial information.

*“No I, no, no objection to talking about it.”*

Participants had differing views on the scope of research in this area. There was wide variation in perceptions of when the “caring” role first began, and therefore on when would be an appropriate time to begin capturing financial costs. For example, one participant spoke of costs incurred across the final year of his wife’s illness, and not just during the months when she was being treated under the palliative care team and was “considered palliative”.

The financial impact of “caring” was not consistent across the illness trajectory and did not necessarily follow a pattern of increasing expense. For example the purchase of expensive care aides often occurred early on in the illness trajectory.

Participant (P): “We did buy a wheelchair, which was several hundred dollars ”

Researcher (R): “So when did you buy the wheelchair, was that some time before?”

Participant (P): “Yeah, about, well actually got it before she was diagnosed as terminal ”

### **Methods of data collection: questionnaires**

Participants were asked about the acceptability of using structured questionnaire surveys to gather information regarding the financial costs of caring. Most agreed that this would be feasible, however concerns were raised as to whether a survey could adequately capture diverse experiences. As one participant pointed out: *“The only thing is, it’s like, if you don’t fit exactly the boxes, that’s a bit of a hard one.”* Other difficulties that participants mentioned in relation to questionnaires related to a lack of time for completion and the burden of completing a questionnaire at an emotionally difficult time. One participant highlighted the importance of a sensitive approach to recruitment and data collection, and described how she would have rejected a questionnaire if it had been thrust upon her without adequate discussion and explanation.

P: “But a questionnaire I probably would have screwed up straightaway if you had *passed it to me anyway, .....well, at the time I would have thought, ‘Oh, everybody’s against me.’”*

R: *“So in the midst of all that if you’d had another piece of paper to do something with, it would just have been too...”*

P: *“It would have got torn up probably, screwed up and chucked.... I mean, it really wouldn’t have meant nothing to me.”*

Questionnaire methods were less popular with Māori. Only one Māori participant initially thought this method would be appropriate, but later changed their mind in favour of face to face interview methods.

### **Methods of data collection: cost diaries**

Participants were also asked the acceptability of using cost diaries, either noting specific costs (e.g. a medication cost), or keeping a record of activities and events so that costs could be extrapolated retrospectively (e.g. a visit to hospital noting travel time, parking fee, leave from work). There was a mixed response to the idea of a diary. A number of participants said they already had to keep a daily medication and care record, and this could be expanded to include costs. Others clearly stated that having to do any additional routine tasks whilst caring would not be acceptable or feasible at such a difficult time, especially given the sensitivities inherent in discussing finances.

*“I guess I’d have to be more involved in understanding the research project and the outcomes, (...) to have a commitment to be able to note something down on a daily basis that would be outside of my normal daily activities, when my constant primary concern is the care for my parent. And it would be just like, this is someone else intruding into my life and my personal finance which is normally very personal, and I really don’t have the time for that....That would be my thought.”*

Another participant noted *“The diary would be good”* but conversely stated that *“When you’re looking after someone it’s pretty hard to write down... it’s the last thing to be worrying about.”* One participant, whilst enthusiastic about record-keeping with diaries, pointed out that individual preferences would play a role in how acceptable the method was to carers.

*“I probably would have [filled in a diary] because I’m that way inclined because I know [from work] how important these things are to move forward with stuff. But I don’t know whether other people would.”*

### **Methods of administration**

Participants were asked to comment on the most acceptable methods of administration for data collection tools. On-line methods of administration were favoured by most, regardless of age or gender. The technology was perceived to provide greater flexibility, which was seen as important for carers who were very busy: *“I can do things on-line; I usually wait until everyone’s in bed and then do all my things like that.”* Another participant described how recording financial data on-line would give her valuable time to think, ensuring that costs were accurately captured.

*“I actually think on-line is not bad. Because it means you have time to think about it, and time to go and, I don’t know, look up your bank card statements or whatever that might be helpful.”*

Whilst most were positive about on-line methods of administration, it was not a feasible or favoured option for some participants, for example those who were unemployed, on low income, or in rural areas without internet connection. Māori participants were also less in favour of on-line methods of data collection, preferring face to face (kanohi-ki-te-kanohi) methods. One participant described how face-to-face interviews would be valuable because it would help people to express themselves more fully.

*“You could probably express it more [kanohi ki te kanohi]. Whereas, there might be questions that you might want to [answer in a survey/written format], but there might be something that you might want to say in amongst these questions that you may get asked in the questionnaire or survey or something. So I kind of, this personal touch is... I prefer. Yeah, I prefer this”*

**Table 3: Summary of findings**

<b>Key themes</b>	<b>Participant views</b>
Need for research in this area	<ul style="list-style-type: none"> <li>• Agreement that this is an important area for research</li> <li>• Some sensitivities around discussing personal finances</li> <li>• Some complexity around when financial burden begins</li> </ul>
Data collection tools: <ul style="list-style-type: none"> <li>• Questionnaires</li> <li>• Cost Diaries</li> </ul>	<ul style="list-style-type: none"> <li>• Most agreed questionnaires would be feasible</li> <li>• Some concerns about lack of time, emotional burden, comprehensiveness of questionnaires</li> <li>• Less favoured by Māori</li> <li>• Mixed response to diaries</li> <li>• Could be incorporated into existing daily record keeping on medication and care</li> <li>• Concerns around time burden of a daily record</li> <li>• Emphasis on meeting individual preferences</li> </ul>
Methods of Administration <ul style="list-style-type: none"> <li>• On-line</li> <li>•</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• Favoured by the majority, flexibility an advantage</li> <li>• Not necessarily feasible for those on low income, unemployed, those without internet connection</li> </ul>

<ul style="list-style-type: none"> <li>•</li> <li>•</li> <li>• Face to Face</li> </ul>	<ul style="list-style-type: none"> <li>• Less favoured by Māori</li> <li>• Preferred by Māori</li> <li>• Enables people to express themselves fully</li> </ul>
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## Discussion

Findings from this study indicate that research on the financial impact of caregiving within a palliative care context is an important topic for future research. Participants' reflections on the costs of caring confirm a growing body of evidence which highlights the significant financial burden faced by carers of people at the end of life. [5,6] Our finding also reflect evidence on the financial contribution made by carers of those with disabilities or serious illness, a recent report by Carers UK identified the economic value of the contribution made by all carers in the UK is now £132 billion per year, almost double its 2001 value. [19] However, key methodological and practical challenges in conducting research in this area were identified.

Research exploring the financial impact of caregiving in palliative care raises two key concerns. Firstly, the disclosure of personal financial information is recognised as a topic which is likely to be perceived as threatening or intrusive. [20] This issue is compounded in the context of palliative care research by the second concern; the potential burden or distress related to being involved in research at an emotionally difficult time. Given these challenges it is unsurprising that there is a recognised deficit in research on the economic and financial aspects of palliative care. [21] Participants in the current study confirmed the challenges of conducting research in this area, but emphasised that these challenges could be overcome through a sensitive approach to the collection of financial data and the continued involvement of carers and family.

The findings indicate considerable fluctuation in care costs over time. The perceived onset of 'caring' also varies according to the interpretation of family and patient. It is important that the scope of research in this area is sufficiently wide to be able to capture these changing costs across the illness trajectory. For this reason retrospective designs are not recommended, as they may fail to adequately capture variations over time and are subject to significant recall bias. Prospective longitudinal designs are most appropriate for capturing variations over time and are recommended as the first choice for research of this kind, however such

methods are underutilised in palliative care. [22] Challenges for longitudinal research include low recruitment and high rates of attrition, [23] however research has shown these challenges can be addressed with carefully planned and appropriately resourced research methods. For example a recent study exploring resource utilisation during the ‘palliative phase’ utilised a prospective repeat measures design, and successfully collected questionnaire data from a sizeable sample of patients enrolled in a palliative care programme, for a median of 11±9 weeks before death. [24]

Findings regarding methods of administration were mixed. Whilst the majority of participants were positive about on-line methods, access to the internet is not universal. In the UK approximately 83% of the population have access to the internet, [25] in New Zealand while 80% of the population have access to the internet, those who do not have access are more likely to be older people, resident in rural areas, or have lower incomes. [26] This indicates that whilst internet methods may be acceptable to the majority, a study solely utilising these methods would be likely to result in significant sample bias. Internet methods may offer an economical and acceptable option for studies, but should be offered alongside other methods to ensure equity.

Face to face methods were most often favoured by Māori participants, and were reported to provide greatest cultural safety in the context of potentially sensitive discussions around money and caring. A systematic review exploring approaches to capturing the financial costs of caregiving identified that the vast majority of research in this area has to date been conducted using face to face methods of administration. [7] Nevertheless, the increasingly rapid development of the internet and associated technologies over recent years does raise questions about the rise of on-line methods and their place in palliative care research. In the face of rapidly advancing technologies, and in response to findings from this study indicating no single method is the ‘preferred’ option for all, the most appropriate solution for future research in this area may be to offer participants a choice of method of administration. This allows for responsiveness to the preferences of individuals. However the potential bias that may be introduced by the use of varying self-selected methods should also be acknowledged.

Participants had mixed responses about the use of structured questionnaires and cost diaries. Existing evidence on the costs of informal caregiving in palliative care has largely been derived from studies using structured questionnaire formats delivered face to face. [7] However, combined approaches have also been successfully used and studies have collected data using structured questionnaires alongside other methods including qualitative interviews and focus groups [27] and structured quantitative interviews. [28] Again, the lack of consensus over a single preferred method makes it difficult to formulate specific recommendations regarding methods of data collection. Whatever method of data collection is chosen, a key consideration for participants in this study was that it be delivered in a sensitive way which appropriately engages participants. Researchers should be mindful of the sensitive nature of discussions involving finances, [20] and of the practical challenges of involving active caregivers in research. An initial face to face interview to build participant confidence and engagement could be followed up by options for recording cost data either on-line, face to face or over the telephone. A similar approach has been used successfully in research from Canada, where cost data were collected using an initial face to face interview with follow-up interviews conducted by telephone. [24]

A final consideration for methods of data collection is that they need to be responsive to cross-country variations in health care funding. Whilst some countries such as the UK have free comprehensive health care, others including New Zealand and Australia operate a mixed public-private healthcare system. In countries such as the USA the health care system is largely privatised and there are very few state funded health services. Thus, the costs borne by family carers would be expected to differ significantly depending on the nature of the national funding model for healthcare. The content and design of any data collection tool therefore needs to be tailored to the context of the country where the research takes place. Further to the collection of cost data, data collection tools could also consider the potential relationship between income level and costs borne by family caregivers. This data would provide important information on equity of financial burden.

## **Conclusion**

The findings from this study provide valuable evidence from bereaved carers on the importance and appropriateness of collecting financial cost data at the end of life. Whilst

participants agreed that this is an important area of research, opinions differed as to the most appropriate method of data collection. Considerations for research in this area include methodological rigour, cultural safety, managing sensitivities around personal finances and attrition and retention of participants. Further work is required to develop common guidance for research methods in the area of palliative and end of life care costs.

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### **Competing interests**

None declared.

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