The Views of Informal Carers' Evaluation of Services (VOICES): Toward an adaptation for the New Zealand bicultural context

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ABSTRACT

Objective: The Views of Informal Carers Experiences of Services (VOICES) instrument is a postal questionnaire that has been utilized internationally to capture the experiences of end-of-life care during the last months of life. Aotearoa/New Zealand, traditionally a bicultural society, reflects both the European worldview and that of the indigenous Māori. The Māori collectivist worldview considers whānau (extended family) support as key at the end of life and privileges "kanohi ki te kanohi" (face-to-face) meetings. In such a context, how will VOICES be received? Our pilot study was designed to test the effectiveness of an adaptation of the VOICES questionnaire in the New Zealand social setting for both Māori and non-Māori.

Method: Cognitive interviews were conducted with 20 bereaved whānau and family members whose relative died between January 1 and April 4, 2014, in one urban New Zealand hospital. Thematic analysis was conducted on the resulting transcripts.

Results: We found that, although the questionnaire provides valuable information, administration of the current questionnaire within a bicultural context is problematic. These problems are related to its scope, cultural acceptability, structure, and content. Distribution of the VOICES questionnaire, either through the post or online, without prior consultation, also risks engaging Māori in a culturally inappropriate manner.

Significance of results: These findings will prompt revisions to both the content and research approach to implementing VOICES in a bicultural context. Recommendations include prior consultation with local indigenous communities as well as utilization of a mixed-methods approach to utilizing VOICES in a bicultural context. The cognitive interview procedures employed (adjusted for a collectivist worldview) in this study may also prove useful to indigenous groups seeking to develop or adapt questionnaires within a bicultural or multicultural context.

KEYWORDS: Palliative care, Ethnicity, Bicultural, Informal carers, Questionnaire

INTRODUCTION

When evaluating services for patients at the end of life and their families, researchers are faced with a number of methodological challenges. In the first instance, there is difficulty ascertaining the views and experiences of terminally ill patients. Prospective studies experience high attrition rates, small sample sizes, and issues associated with predicting survival rates (McWhinney et al., 1994; Tang & McCorkle, 2002; Rinck et al., 1997). To respond to these challenges, researchers have relied increasingly on a retrospective "after-death" study design. Proxies (usually family, friends, or health professionals

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directly involved in patient care) are utilized to gather information on the quality of patient care. Proxies are significant and frequently the only available source of information for patients at the end of life (Teno et al., 2004). A systematic review of the literature by McPherson and Addington-Hall (2004) found that proxies can reliably report on the quality of services. This alternate approach has been utilized in studies of the dying in the United States (Teno et al., 2001), Europe (Beccaro et al., 2010), and, pertinent to this study, in the United Kingdom (Seale & Cartwright, 1994; Addington-Hall & McCarthy, 1995). The instrument utilized to collect data in a number of prominent studies was the Views of Informal Carers' Evaluation of Services (VOICES). outlined below.

"VOICES" is a postal questionnaire concerning experiences of end-of-life care during the last months of life, with a specific focus on the quality of care and services received. The VOICES questionnaire (using the post-bereavement method) collects information from bereaved relatives, friends, or carers acting as patient proxies. The survey method utilized in VOICES is informed by earlier research (Cartwright et al., 1973; Seale & Cartwright, 1994). Development of the earliest VOICES version arose from face-to-face interview studies and postal surveys undertaken by Addington-Hall (Addington-Hall & McCarthy, 1995; Addington-Hall et al., 1998; Burt et al., 2010). The VOICES questionnaire has been used extensively in the UK and internationally (Hunt et al., 2011). Six versions have been adapted for and used in specific populations based on disease process or location (Hunt et al., 2011). The standard 144-item VOICES questionnaire was revised and shortened to the 58-item VOICES Short Form for the IMPROVE Survey (Aspinal et al., 2006) to ensure that it met the needs of the UK Department of Health End-of-Life Care Strategy (Department of Health, 2008) as well as current practice and policy priorities. Over the years, a number of issues concerning recruitment (Ingleton et al., 2004) and under-representation of minority groups (Hughes et al., 2005) have been reported. Given its development within the UK, it is important to compile evidence regarding the acceptability of VOICES in exploring end-of-life quality of care in the New Zealand context.

The New Zealand Context

Like many other countries worldwide, New Zealand has an ageing population. The number of people aged 65+ has doubled since 1980, exceeding 600,000 in 2012. This number is predicted to double again by 2036 (Statistics New Zealand, 2013). Escalating ageing and a concurrent rise in chronic conditions translate into a greater need for palliative care services (Davey & Gee, 2002). Also similar to other Western nations, the increased demand and rising costs for healthcare services have led to a shift away from institutional care (World Health Organization, 2007). New Zealand's Positive Ageing Strategy is one such initiative designed to meet more effectively the care and support needs within the community (Dalziel, 2001). However, greater provision of healthcare delivery in the community also translates into greater informal caregiver burden. Stressors can be financial (Gott et al., 2015), physical, and emotional (Angelo & Egan, 2014). International research has demonstrated that service delivery for informal caregivers of persons with palliative care needs is often insufficient (Bee et al., 2009). New Zealand's healthcare is driven by a national strategy, which seeks to support palliative care for all New Zealanders at the end of their lives (Ministry of Health, 2001). The gathering of meaningful information to understand patient and caregiver needs is essential to support both effective and quality care delivery.

Aotearoa/New Zealand is a bicultural society and reflects both the European worldview and that of the indigenous Māori, partners to te Tiri o Waitangi (the Treaty of Waitangi). Māori comprise approximately 15% of the country's population of 4.4 million (Statistics New Zealand, 2013). Inhabitants who identify as European (including NZ European) remain the largest ethnic group (70%), (Statistics New Zealand, 2013). In common with other indigenous groups (Marrone, 2007), disparities exist between Māori and non-Māori in terms of morbidity and mortality as well as in the standard of healthcare services (Robson & Harris, 2007). Pertinent to the current discussion, palliative care services nationally may not adequately meet the needs of Māori patients and their whānau (extended family) (Penney et al., 2009). The identified challenges include: a cultural preference for home care at the end of life (Mann et al., 2004; Lawrenson et al., 2010); the use of traditional medicines (Lawrenson et al., 2010); and communication issues (language barriers) (Ministry of Health, 2003; Lawrenson et al., 2010).

Preparation of the spirit for death is a shared practice among indigenous peoples (Duggleby et al., 2015). By extension, culture and spirituality are inextricably linked to health and well-being (including bereavement) (Duggleby et al., 2015). Māori share this with other indigenous groups (Ngata, 2005). Also, in common with other indigenous groups is the recognition that the Māori patient is not the only one who takes the end-of-life journey (Hampton et al., 2010; O'Brien, 2012). The Māori "whare tapa whā" (four-sided house) model of Māori health has

four dimensions: wairua (spiritual health), hinengaro (emotional and mental health), tinana (physical health), and "taha whānau" (family health) (Durie, 1985). The model emphasizes holistic care and esteems the role of whānau support (Johnston et al., 2014). Whānau comprise all family, including extended family, and the wider society (Durie, 1985). Similarly, Kaupapa Māori health research (research based in a Māori worldview and principles) is rooted in face-to-face or personal contact within the context of the wider whānau (Smith, 1999). Given the salient role of whānau support and a preference for in-person interviews, will a postal questionnaire such as VOICES adequately represent Māori end of life needs? In answering this question, the results may also provide insights that are applicable to other indigenous or minority ethnic groups.

A key factor limiting the development of palliative care services in New Zealand is the lack of available information about the patient and whānau/family regarding end-of-life care. Such data are essential to planning and development. Understanding the acceptability of the VOICES questionnaire is central to the ability to adequately assess the needs of all patients and carers at the end of life within diverse cultural contexts.

Aim

This study was designed to test the effectiveness of an adaptation of the VOICES end-of-life questionnaire in the New Zealand context for Māori and non-Māori.

METHODS

A qualitative design, with its focus on meaning and subjective interpretation, was considered appropriate to establish crosscultural understanding (Denzin & Lincoln, 2008). A qualitative design has also been effectively utilized in questionnaire development, specifically for ensuring content coverage (Doward et al., 2004). Ethics approval for the project was obtained from the University of Auckland Human Participants Ethics Committee.

Sampling and Recruitment Procedure

A palliative care nurse practitioner carried out a purposive sampling of the database of one New Zealand urban hospital. The next of kin of all individuals who had died between January 1 and April 4 of 2014 were sampled. Some 134 potential participants were eligible for inclusion. Telephone contact was achieved with 66 individuals. A total of 41 potential participants requested further information. Agreeing participants indicated their preference for the
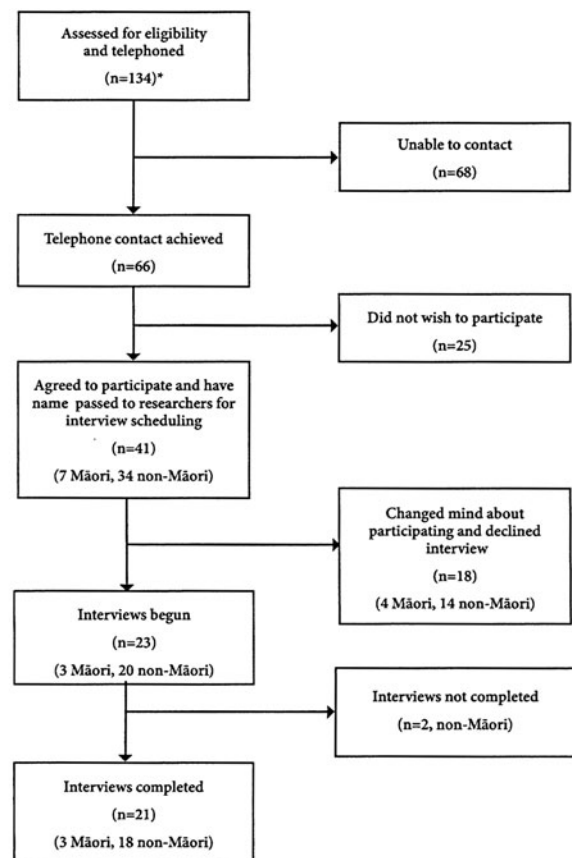
Fig. 1. Flow diagram of the recruitment, consent, and participation process.

interviewer's cultural group (Māori/non-Māori). This was considered a culturally appropriate and culturally safe method of data collection (Wilson & Neville, 2008). Based on this preference, the names of Māori (7) and non-Māori (34) participants were transferred to the preferred interviewer. Some 21 interviews (3 Māori, 18 non-Māori[1]) were completed and included for analysis[2] (Figure 1).

Interview Procedure

The cognitive interview method is a recognized means of ensuring the quality and accuracy of survey instruments (Willis, 2005). It has become an important tool for developing or adapting questionnaires to best fit the range of possible responses within a

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[1]This group included participants ($n = 3$) who were of Māori descent but who did not culturally identify themselves as Māori (Statistics New Zealand, 2015).

[2]One participant could not give informed consent due to cognitive impairment. One participant wished to discuss recent family trauma rather than VOICES questions.

bicultural or multicultural context (Ryan et al., 2012). The verbal probing method designed to elicit further information regarding specific responses was employed. In particular, "emergent" or "spontaneous" probes that were not scripted in advance were utilized (Daugherty et al., 2001). This technique allowed for increased flexibility in adjusting to participants' verbal and nonverbal responses. With participant consent, interviews were digitally recorded and transcribed verbatim. Māori participants were offered the opportunity to have the interview conducted in Te Reo. All declined.

Two of the three Māori interviews involved other whānau members and kaumatua.[3] One of these included seven members of the wider whānau (for a total of 10 contributors). In the whānau interviews, the collection of data about the questionnaire from multiple perspectives necessitated using a "kotahitanga" process (reaching consensus) through unity. This involved lengthy korero (discussions) until participant silence conveyed agreement. The interview process was adapted to incorporate a collectivist worldview in that it has acknowledged the centrality of whānau, rather than the individual, to the creation of knowledge. In all interviews (non-Māori and Māori), the qualitative design was kept flexible to encourage participation by bereaved family. The goal of the cognitive interviews was to provide an understanding of the point of view of the participants in a manner that was not entirely predetermined or restricted.

Data Analysis and Presentation

A thematic analysis was undertaken to provide insight into the ways in which VOICES could be adapted. Thematic analysis can provide a more detailed and nuanced account of one particular area of interest within the data (Braun & Clarke, 2006). The cultural group of the participant and researcher were matched for the data analysis (Wilson & Neville, 2009). Within a bicultural framework, the goal was to achieve an understanding that parallels each culture's particular views and beliefs (Kellehear, 1993). The coding framework was developed through consultations among the researchers. Common themes linking data were identified. Quotations presented illustrate the themes raised by participants and are indicative both of typical responses and of the diversity of views obtained. "Letters" (Māori) and "interview numbers" (non-Māori) have been used to identify participants.

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[3]"Kaumatua" is a term of respect for an elder spouse or relative.

Table 1. *Participant characteristics*

Interview	Gender	Age group	Ethnicity	Relationship
1	Male	60–69	Māori	Child
2	Male	70–79	European	Spouse
3	Female	50–59	Indian	Child
4	Male	30–39	European	Friend
5	Female	70–79	European	Spouse
6	Female	40–49	European	Child
7	Female	70–79	NZ European	Spouse
8	Male	80+	European	Sibling
9	Male	80+	Māori	Spouse
10	Male	40–49	NZ European	Child
11	Female	70–79	NZ European	Spouse
12*	Male	30–39	Māori	Child
13	Male	50–59	Māori	Friend
14	Female	80+	European	Spouse
15	Female	60–69	European	Spouse
16	Male	60–69	European	Spouse
17	Female	50–59	Indian	Child
18	Male	60–69	European	Child
19	Male	70–79	European	Spouse
20*	Female	70–79	Māori	Spouse
21*	Female	40–49	Māori	Sibling

* Interviews include whānau other than the participant listed.

RESULTS

Demographic Overview

Participants most frequently were European/NZ European (61%), nearly equally divided between male (52%) and female (48%), and most often in the 70–79 years age group (29%). Carers were most frequently the spouse or adult child of the deceased (34% each) (Table 1 and Appendix A).

Some 14% of participants self-identified as Māori. Table 2 lists Māori interviewees by relationship to kaumātua (elected elders).

Deceased relatives were also most often male (52%), of European/NZ European ethnicity (76%), and in the 70–79 age group at their last birthday (38%). A majority (76%) had spent some time at home during the last three months of life (Table 3).

The three findings identified from the data related to the scope, cultural acceptability, and content of the VOICES questionnaire. What follows is a further elaboration of these predominant findings.

Scope of the Questionnaire

This theme concerned views about the ability of a questionnaire to completely represent the deceased's last three months of life. Some participants found the

Table 2. *Deceased characteristics*

	Frequency	Percentage
Gender		
Male	10	50
Female	10	50
Age		
50−59	2	10
60−69	3	15
70−79	9	45
80+	6	30
Ethnicity		
New Zealand European/ European	15	75
Māori/Māori and European	3	15
Indian	2	10
Illness Duration		
Not ill, died suddenly	1	5
<24 Hours	1	5
1 day or more, less than one month	4	20
1 month or more, less than 6 months	3	15
6 months or more, less than 1 year	1	10
Longer than one year	9	45
Time spent at home during the last 3 months of life		
Some time	16	80
No time	4	20

Table 3. *Māori interview participants and relationships*

Interview	Whānau members+	Relationship	Kamātua*
12	K	Wife	Matua** T
	A	Son	N
20	I	Son	J
21	T	Daughter	
	W	Daughter	
	S	Sister	
	H	Partner of S	
	E	Cousin	
	L	Cousin	
	Aunty J	Aunty to J and S, Mother of E and L	

+ Letters are pseudonyms for participants.
* Elder.
** Kamātua is a term of respect for an older person in Māori society. It is important to use the culturally appropriate term 'kamātua' because it references the respect Māori hold for older people.

questions to be too generic, lacking the capacity for recording individual differences in experience. For example:

> 'Cos that's [the questionnaire] just general. Do you know what I mean? But there're so many different scenarios of people's passings . . . or death and how those families cope. (Interview 10)

One participant expressed uncertainty that the overall quality of services provided for his mother could be adequately described by ticking a box:

> [Interviewer] And taking all services into account, how would you rate her care in the last three months of life at the hospital, rest home?
> [Participant] Again, you know, we have two different places where she has been, and we've described the difference between these two places. So I don't know how to answer by one box. (Interview 18)

Participants felt that some experiences were not captured by a format limited to multiple-choice and short-answer questions. For example, a Māori whānau discussion about access to their GP in the last three months of life (Q15) deepened the understand-

ing of the deceased's experience (see Appendix B: VOICES Questionnaire). A bereaved wife stated that her husband only saw the family doctor:

> He's Chinese or something like that. He's a real good doctor. (Interview 20)

VOICES also provided little opportunity for documenting the contributions of informal carers. Question 3 refers only to outside services that were contracted to help with these tasks. Yet friends and family provided a diverse range of help that included such tasks as personal care, household help, and transportation:

> So I did his shopping and made sure he had good, you know, soups in blister packs . . . had those in the fridge, and I'd go there, and they'd still be sitting there . . . because he didn't have to cook for anyone, he actually didn't cook. (Interview 1)

Cultural Considerations

Given the sensitive nature of the topic, Māori participants felt that information should be collected through "kanohi-ki-te-kanohi" (face-to-face) contacts. As participant A elaborated,

> It's good because when you're koreroing [talking/ discussing] like you're koreroing to us you can say it how it is, you know, ka pai [not sure how to define this but think it should have an English word for it].

And with the writing it down, I wouldn't know what to write for a start. I'd be too busy looking for all the right words, especially if it's in Pākehā [English]. That's even worse. So I like the korero bit. (Interview 12-A)

Participant 20-K cited a whakatauki (proverb) to explain the importance of face-to-face conversations:

Yeah, and that's a Māori ahua. It's always been like that, korero. That's all like just going back to my granddad and all that. And he always said, "kei a hoki ki te waha niahangia, ki a korero" [it's your responsibility to speak]. And not only that, as far as Papa was concerned, especially when it came to business sort of things, you know, "ka puta te korero oti" [talk until the issue is complete]. (Interview 12-K)

VOICES also does not account for Māori methods for engaging with grief and bereavement through rituals such as tangihanga (a three-day grieving process), ukaipo (returning the body to the homeland), kawemate (returning the spirit), or hura kōhatu (unveiling). The restriction of questions only to participant engagement with formal services overlooks the opportunity to gather useful information for strengthening Māori whānau as they grieve. Question 52 for example, asked whether participants used health, social, or bereavement services. One Māori participant's response indicates indifference:

Someone sent me a letter, bereavement service. I can't remember who, if it was the hospice or if it was the hospital. I think the hospital automatically send you a pack outlining all, well, if you need counseling and that sort of stuff [in a letter]. (Interview 20-I)

Similar to other collectivist societies, Māori worldview emphasizes the well-being of the group (Harrington & Liu, 2002). One's individual identity and rights derive from membership in whānau, hapū (subtribe), and iwi (tribe) (Bishop, 2005). Questions that solicit the opinion of an individual obscure the importance of whānau group decision making:

[Interviewer] How appropriate do you think that kind of question is for whānau? Is it a question that you can just ask one whānau member, or is actually something that's more?
[Whānau] No, ask everyone.
[Interviewer] Do you think there will be different answers given your different roles?
[Whānau] Yes, Yes, absolutely. (Interview 21–T, W, S, H, E, L, Aunty J)

Structure and Content Gaps

The structure of the questionnaire, which incorporates filter or contingency questions, proved hard to follow for both non-Māori and Māori participants. For example, it was not clear whether "Care from the GP" was a subset of "Care at Home" or a stand-alone topic. This had implications for whether or not participants should answer Q15 about whether or not the deceased had seen their preferred GP during the last three months of life. In terms of question clarity, interviewers sometimes offered comments to help with comprehension when requested.

Turning to content, the UK version of the VOICES questionnaire omitted a question concerning the cause of death. It is unnecessary because the UK Office for National Statistics maintains a database documenting all registered deaths, the cause of death, and the name of the informant providing the information (Office for National Statistics, 2015). New Zealand lacks such a resource. The cause of death must be gathered ad hoc, such as from local hospitals.

Regarding ethnicity questions, non-Māori requested "NZ European" rather than "European." Similarly, participants wished to record decedents' ethnicity, as "Kiwi," "New Zealander," or "New Zealand European." A significant issue for Māori participants was the inclusion of the term "whānau" whenever references to the family were made, such as in Question 5: "Overall, do you feel that you and your family/whānau got as much help and support from health and community as you needed when caring for her?"

DISCUSSION

The VOICES questionnaire has been extensively utilized internationally (Addington-Hall & McCarthy, 1995; Elkington et al., 2005; Hughes et al., 2005; Addington-Hall & O'Callaghan, 2009; Burt et al., 2010). The current study is unique, however, because of its bicultural emphasis on Māori and non-Māori. As such it highlights important issues for future adaptations of the VOICES questionnaire. In particular, the results bring into question both the ability of a closed questionnaire format alone to provide depth of information about caregiver experience as well as the suitability of a postal administration method in a bicultural context. Each of these issues will be addressed in turn.

Structure and Content

Self-report questionnaires, although widely used with older adults (Nordhus, 2008), have some notable disadvantages. Included among these are the requirement for good vision, manual dexterity, and

adequate reading comprehension (Bowling, 2005; Nordhus, 2008). Deficiencies in either function or ability can impact upon the validity and reliability of the data obtained (Hughes et al., 2005; Nordhus, 2008). Moreover, in comparison to face-to-face interviews, self-report questionnaires impose greater cognitive burden (Bowling, 2005). Health-related topics are also less adaptable to self-report questionnaire formats, requiring respondents to follow complex routing involving skips of questions, as witnessed in the issue surrounding whether "Care from the GP" was a subset of "Care at Home." Results suggest the need for a revision of the layout to minimize respondent confusion.

The use of face-to-face interviews can also pose challenges. Most commonly cited are the cost and time required for this mode of administration, both of which may be prohibitive in a nationwide study (Sim & Wright, 2002). Additionally, the lack of anonymity may present difficulties when dealing with sensitive topics. However, evidence indicates that caregiver views can be effectively explored in this manner (Addington-Hall & McCarthy, 1995; McCarthy et al., 1997).

Scope

While VOICES supports the collection of much-needed aggregate information on patient and caregiver need, both Māori and Māori participants felt that the questionnaire lacked scope for exploring individual's experiences of specific services. Closed questions may miss valuable information or potentially bias responses by limiting answers to the questions posed (Nordhus, 2008; Bowling, 2014). One possible solution is the use of open-ended questions. This would allow respondents the opportunity to add their views on the care their relative or friend received at the end of life.

Cultural Inclusiveness

Developing a questionnaire that achieves cultural equivalence is no small challenge (Bowling, 2014). It is essential that questionnaires adopted from another context contain appropriate vocabulary as well as common and culturally equivalent[4] meanings. Māori participants commented, for example, on the need to include the word "whānau" when references to the family are made. Likewise, non-Māori often did not identify with European as an ethnicity (in some cases conflating nationality with ethnicity).

This shift in identity may be a result of diverse ancestry, possibly including Māori; Asian, or other non-European ethnicities, or ancestors traceable to Europe several generations in the past (Callister et al., 2009).

Cultural values, expressions, expectations, ceremonies, and rituals give meaning to loss (Hooyman & Kramer, 2006). Account must therefore be taken of Māori participation in tangihanga or other grieving rituals presently not included as an option. Merely listing health and social services precludes the gathering of data about Māori cultural practices useful for expressing and dealing with grief and bereavement.

LIMITATIONS

Difficulties in the sourcing of cause of death in New Zealand from a central database limited this pilot to the next of kin of people who died in one urban hospital. In addition, the small number of Māori interviews meant information relevant to adapting VOICES for use with Māori could be incomplete. Low Māori participation is frequently reported in New Zealand health research (Crengle et al., 2004). This is often attributed to factors associated with socioeconomic deprivation (e.g., lack of a landline) (Fink et al., 2011). The use of Kaupapa Māori methods rather than a reliance on Western methodologies may increase recruitment success. Due to the small sample size, and in keeping with the bicultural nature of this pilot study, the responses of Indian participants ($n = 2$) were not analyzed separately from non-Māori. Future research with a larger sample would permit an exploration of cultural differences between Indian and NZ European participants.

New Zealand is ethnically diverse, and the views of representatives of other cultures and nationalities would add depth and perspective to the ways in which VOICES might be modified.

RECOMMENDATIONS: THE WAY FORWARD

Kaupapa Māori research embraces a Māori worldview that assumes collective decision making. Therefore, simply administering a questionnaire either through the post or online risks engaging Māori in a culturally inappropriate way. Māori culture is also an oral culture (Marshall & Peters, 1989). Use of paper-based questionnaires alone run counter to the tikanga (customs) within Māori oral tradition. Cram and Pipi (2000) reported that" "kanohi ki te kanohi (face-to-face) is regarded within Māori communities as critical when one has an important 'take' or purpose" (p. 14). Māori, like other indigenous cultures, varies in terms of their acceptance of or participation in Western methods of research (Duggleby et al.,

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[4]According to Hughes et al. (2005) "Cultural equivalence requires an understanding of the ways people from ethnic and cultural communities conceptualize lay beliefs about health and illness, and death and dying" (p. 122).

2015). However, it is important to emphasize the necessity of a collaborative approach. Doing so promotes cultural safety and improves the quality of data generated. Similar to recommendations by Hughes et al. (2005) in the Bengali adaptation, the VOICES questionnaire should be developed as a joint project with local indigenous communities to ensure a sensitive and culturally appropriate approach to the research.

The Regional Study of the Care for the Dying (Addington-Hall & McCarthy, 1995), which formed the basis of the VOICES survey, utilized moderators to administer the survey. A later revision employed a postal questionnaire, which, although yielding acceptable response rates, also produced less reliable responses to some questions (Addington-Hall et al., 1998). The results of this pilot suggest the use of a mixed-methods design. VOICES should be constructed as a two-part project and ask participants who have completed the questionnaire to provide their contact details if they would be interested in participating in a telephone or face-to-face interview. In this manner, the strengths of both approaches can be utilized. A self-report survey offers the ability to generalize results to larger populations (Steptoe et al., 2010). Follow-up interviews can provide more in-depth understanding of groups who may be inadequately represented in the questionnaire results (Creswell et al., 2002). The results of this study indicate that mixed methods can be a useful tool to ask complex end-of-life questions without imposing a Western worldview and ignoring contextual factors. In terms of application to other indigenous groups, a mixed-methods design for VOICES administration can potentially provide cultural understandings of end-of-life needs that help researchers develop culturally sensitive palliative care services while also measuring the effectiveness of these service interventions internationally. This is a key point for researchers, policymakers, and practitioners in that culture is an essential component of any interventions to be implemented and assessed. Indeed, as De-Courtney, Branch and Morgan (2010) indicate, incorporating cultural beliefs and practices regarding the end of life may be essential to developing effective palliative care programs for indigenous communities, especially those in remote locations.

Gesink et al. (2010) demonstrated the applicability of cognitive interviewing for indigenous groups in their development of a sexual health survey tool, noting the importance of adapting questions according to the context of a collective society. Similarly, the cognitive interview procedures utilized within this study may also prove useful to indigenous groups seeking to develop or adapt palliative care-related questionnaires within a bicultural or multicultural context.

The issues outlined herein are demanding methodologically but are not insurmountable. If knowledge is to be gained about the needs of people disadvantaged in palliative care access, new approaches are required. The VOICES questionnaire offers a valuable means of gathering data about existing palliative care services as well as gaps in service provision. However, successful use of the instrument must be framed within a broader research approach that incorporates the needs, views and cultural understandings of all participating groups.

ACKNOWLEDGMENTS

SUPPLEMENTARY MATERIALS AND METHODS

To view supplementary material for this article, please visit http://dx.doi.org/10.1017/S1478951516000146.

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