

VOICES: South Island pilot survey of bereaved people

Kate Reid, Ray Kirk, Pauline Barnett, Ann Richardson, Annabel Ahuriri-Driscoll

ABSTRACT

AIMS: To test the feasibility of surveying bereaved next-of-kin in the South Island about their perceptions of end-of-life care for people over 18 years of age; to report results; and to identify issues for future research.

METHOD: The study used the VOICES (Views of Informal Carers Evaluation of Services) questionnaire from the UK, adapted for use in Aotearoa New Zealand. Identification of next-of-kin for all South Island deaths September–November 2017 was undertaken by a commercial firm specialising in such work. Addresses of next-of-kin were sought from the Electoral Roll, with 1,813 eligible people identified and 272 (15.0%) next-of-kin unable to be traced. Surveys were posted out once only, with options to complete by mail, online, by telephone or with a face-to-face interview.

RESULTS: Of the 1,541 surveys distributed, 514 (33.4%) were completed. Results confirmed the suitability of the locally modified VOICES instrument and research process. The quality of care overall was rated most highly in hospice or own home, but only a minority were able to die in these settings. Nevertheless, relatives indicated that most people died ‘in the best place’.

CONCLUSIONS: The VOICES questionnaire is acceptable to respondents and there are viable methods for seeking a population sample. Aspects of the questionnaire require modification before wider use. The information obtained can help district health boards, hospices other healthcare providers, and consumers in planning for end-of-life care.

From 2016–2038, the number of people dying in New Zealand is predicted to increase by almost 50%.¹ These projections indicate that palliative care requirements will increase by 37.5% in public hospitals, 84.2% in aged residential care (ARC) and 51.8% in hospice care. Palliative care is provided either by specialists or usual care providers such as general practice teams, ARC, district nurses and hospital services.

A 2017 Ministry of Health review noted that “the overarching goal for adult palliative care ... is to provide high-quality care, in all settings and geographical locations, enabling someone to die in an environment that feels, and is, safe and comfortable (p. 2)”.² The review confirmed support for family/whānau to be a core aspect of care. Consistent with this philosophy, the VOICES (Views of Informal Carers Evaluation of Services) questionnaire was identified as a research instrument that could contribute to the development of policy and evaluation of performance.

The original VOICES study was commissioned by the Department of Health, UK to survey bereaved relatives about the experience of end-of-life care.³ The questionnaire collects data from two time periods; the last three months of life and the last two days of life. The VOICES questionnaire proved acceptable to bereaved people and generated comprehensive data for policy and monitoring.⁴ Versions of the questionnaire have been used successfully in Canada and Sweden.^{5,6}

The questionnaire was adapted, with permission, by the Te Arai Palliative Care and End-of-life Research Group (University of Auckland) to accommodate the bi-cultural circumstances of Aotearoa New Zealand. A pilot study of deaths at one Auckland hospital evaluated the appropriateness of the questionnaire and revealed areas requiring amendment, for example including whānau/family, clarifying some questions to take into consideration bereavement practice, enabling face-to-face

Table 1: Regional distribution of the sample.

NoticeMATCH Region	Number of deaths	Next-of-kin unable to be traced	Number of questionnaires mailed to next-of-kin
Nelson-Marlborough	237	12 (5.1%)	225
Canterbury	946	207 (21.9%)	739
West Coast	76	6 (7.9%)	70
Otago	334	34 (10.2%)	300
Southland	220	13 (5.9%)	207
	1,813	272 (15.0%)	1541

or telephone completion of the questionnaire rather than relying solely on postal responses and adding room for expanded narrative.⁷ The recruitment of respondents had limitations as it included only those who died in hospital but not elsewhere. In New Zealand only 34% of all adult deaths are in DHB facilities, requiring an alternative approach to the target population and recruitment.¹

The South Island VOICES survey was undertaken by the School of Health Sciences, University of Canterbury on behalf of the South Island Alliance (SIA) of five district health boards (Canterbury, Otago-Southland, South Canterbury, Nelson-Marlborough, West Coast).

This study had three aims: (i) to develop a population-based method of recruiting next-of-kin; (ii) to test the appropriateness of the modified VOICES questionnaire; and (iii) to report on bereaved persons' views on end-of-life care.

Methods

The target population was all next-of-kin/preferred contacts of people over 18 years of age who died in the South Island during September–November 2017. The term 'next-of-kin' is used for consistency. Next-of-kin data are available from the National Health Index (NHI) database via DHBs, although there are doubts about its accuracy. The Canterbury District Health Board approved access to this information, but the time scale for this project meant that it was not possible to obtain approvals across all five South Island DHBs.

An alternative approach involved engaging NoticeMATCH, a death data collection and notification service, to

identify and report on people who died during September–November 2017. Their report was categorised into regional groupings, with boundaries slightly different from those of DHBs. The report included information about people who had died in all settings, including sudden deaths, regardless of whether there had been prior contact with a DHB service. In total, 1,813 summaries for people aged over 18 years were prepared during December 2017. Permission was granted by the Electoral Commission to use the electoral roll to locate postal addresses for next-of-kin identified by NoticeMATCH. There were 272 (15.0%) next-of-kin unable to be traced, resulting in a sample of 1,541 people eligible to be contacted.

The regional distribution of the sample for the three months September–November 2017 is set out in Table 1.

Surveys were posted out with a prepaid return envelope, invitation letter, information sheet and reply slip. Options for respondents were to complete the survey online (via Qualtrics), or by a telephone, skype or face-to-face interview, or to return the completed questionnaire by mail. As this was a pilot survey, only one mail-out was sent.

Modifications to the questionnaire were made with the agreement of the Auckland research group. Ethnicity designation was made consistent with the New Zealand Census. The appearance of the questionnaire, and its bicultural representation, were enhanced by inserting a kowhaiwhai (cultural image) banner across the top of each page. The CDHB Māori Health Team generously wrote a mihimihi and provided a karakia to be included in the invitation letter.

Table 2: Main illness of deceased.

	Frequency	Percent
Cancer	153	29.8
Heart disease	103	20.0
Neurodegenerative disorder	81	15.8
Respiratory disease	35	6.8
Stroke	30	5.8
Other	73	14.2
None	39	7.6
Total	514	100.0

The questionnaire, gender specific to the deceased, was sent to the next-of-kin. Brief demographic and personal information was sought for both the deceased and next-of-kin, but most of the questions addressed the experience with the health system of the deceased in the last three months of life and the last two days of life. Questions addressed respect, communication, pain management and overall care, as assessed by the next-of-kin. Sudden unexpected deaths had been an exclusion criteria with the VOICES survey in UK and the Auckland pilot but were included for this pilot study as NoticeMATCH do not hold details on how the person died, therefore all deaths were surveyed. There were a large number of questions (83) but only a proportion applied to any particular respondent. Pre-testing indicated that the questionnaire would take 30 minutes to complete; this was indicated on the information sheet for respondents.

The Statistical Package for Social Sciences (SPSS) was used to calculate descriptive statistics. For open-ended questions, some responses consisted of a few sentences while others consisted of entire paragraphs or more. Given this, a manifest content analysis was conducted, following Graneheim and Lundman (2004).⁸ These findings are not reported here, but referred to as necessary to clarify results.

Results

Of the 1,541 surveys sent out, 514 (33.4%) were completed. The large majority of deceased were reported as NZ European/Pākehā (82.5%) with 3.3% reported as Māori. Other ethnicities (14.2%) reflected New Zealand Census categories and included UK, European, Australian, Chinese and Lebanese. No Pasifika deaths were reported.

The two main causes of death, cancer and heart disease, are reported as percentages similar to the most recent New Zealand national mortality data⁹ and represent half of all deaths in this sample (Table 2).

Nearly one-fifth of people had little or no warning of impending death as they had been unwell for less than one week, or not at all. A further 27% had been ill for up to six months, suggesting some time for them and their families to adjust to a different health and living scenario. A majority (55.6%) had been ill for at least six months to over a year, indicating a long-term adjustment for themselves and their families and the formation of long-term relationships with the healthcare system.

The largest group of deceased (42.6%) were reported as dying in a residential care facility, with 28.7% dying in hospital, 17.5% at home and only 8.3% in hospice (Table 3).

Table 3: Place of death.

	Frequency	Percent
Own home or with another family member or friend	89	17.5
Residential care facility	217	42.6
Hospital ward	110	21.6
Hospice	42	8.3
Hospital ICU	36	7.1
Hospital A&E unit or ambulance	9	1.8
Elsewhere	6	1.2
Total	509	100.0

The last three months of life

Of the 259 people (50.4%) who spent some time at home during that period, the majority received district or community nursing services (60%), care either from a GP or other doctor (58.7%) or services from a home care worker (51.3%). A smaller number received social work/support worker care (13%), occupational therapy (13%), help from a religious leader (10.8%) or meals-on-wheels (8.9%). Some people clearly received more than one service and 33 (12.7%) did not receive any services at home.

Regarding particular settings and providers of care in the last three months of life (Figure 1), the highest proportion of next-of-kin reported the quality of care as excellent for hospices (79.2%), followed by hospital doctors (74.3%), district nurses (71.1%) and hospital nurses (69.4%). Residential care facilities (57.3%), urgent care (56.6%) and GPs (54.1%) were rated somewhat lower. ‘Urgent care’ reflects the challenge of obtaining assistance after hours (including calling the ambulance, fire brigade or Healthline). Respondents

Figure 1: Last three months of life. Overall quality of care by setting or service provider, South Island 2017.

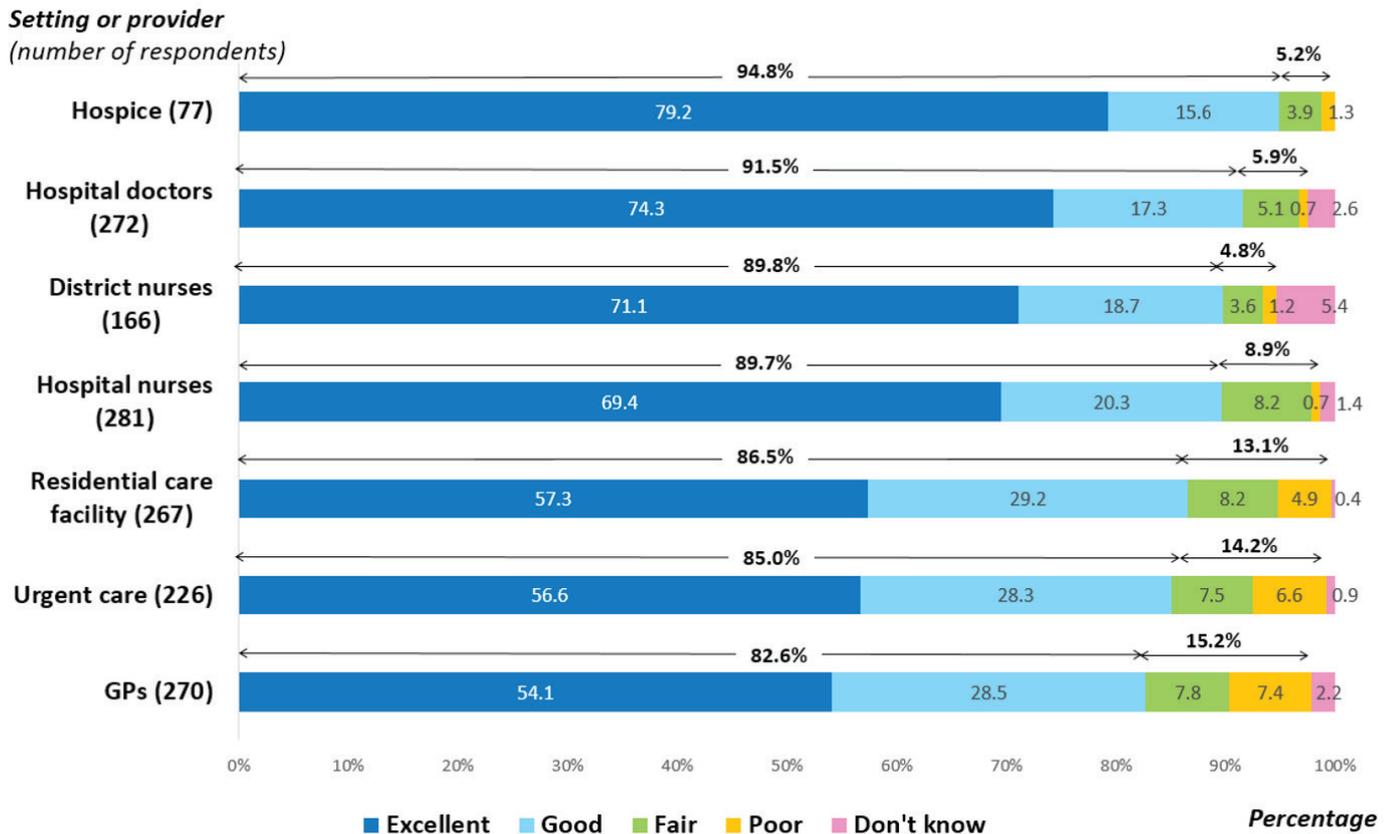
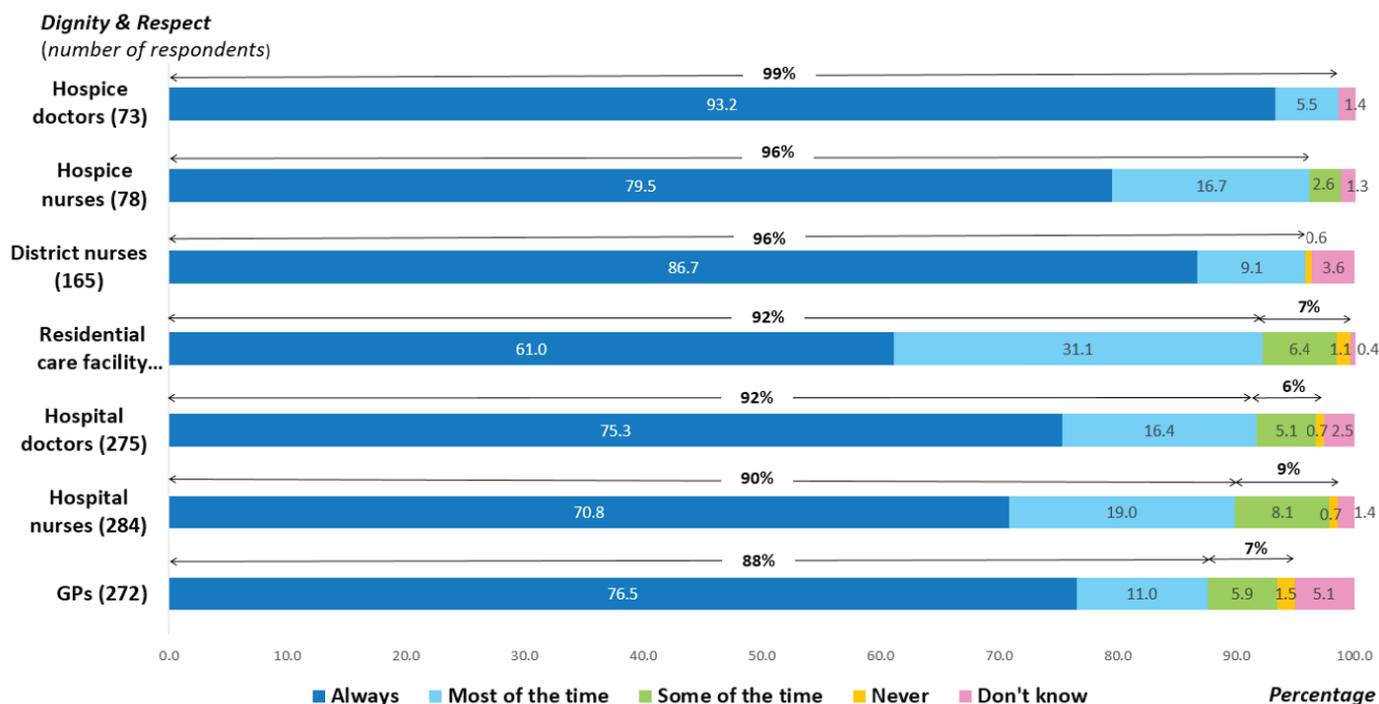


Figure 2: Last three months of life. Dignity and respect in the last three months of life, by setting or provider, South Island 2017.



commented on the short-staffing, high workload, low pay and high turnover of staff in ARC facilities. GPs were seen as having complex co-ordination roles as well as time pressures that made home visiting difficult.

As in the UK VOICES survey, next-of-kin were more likely to rate the overall quality of care as ‘outstanding’ for relatives who had cancer (28.4%) compared with those who had died of heart disease (9.5%) or other named conditions (18.4%).

Besides quality of care, respect and dignity are important components of end-of-life care. Figure 2 reports levels of dignity and respect experienced in the last three months of life, by setting or provider.

Next-of-kin reported that their relative was ‘always’ treated with dignity and respect by hospice doctors (93.2%), district nurses (86.7%), hospice nurses (79.5%), GPs (76.5%), hospital doctors (75.3%), hospital nurses (70.8%) and residential care facilities (61.0%).

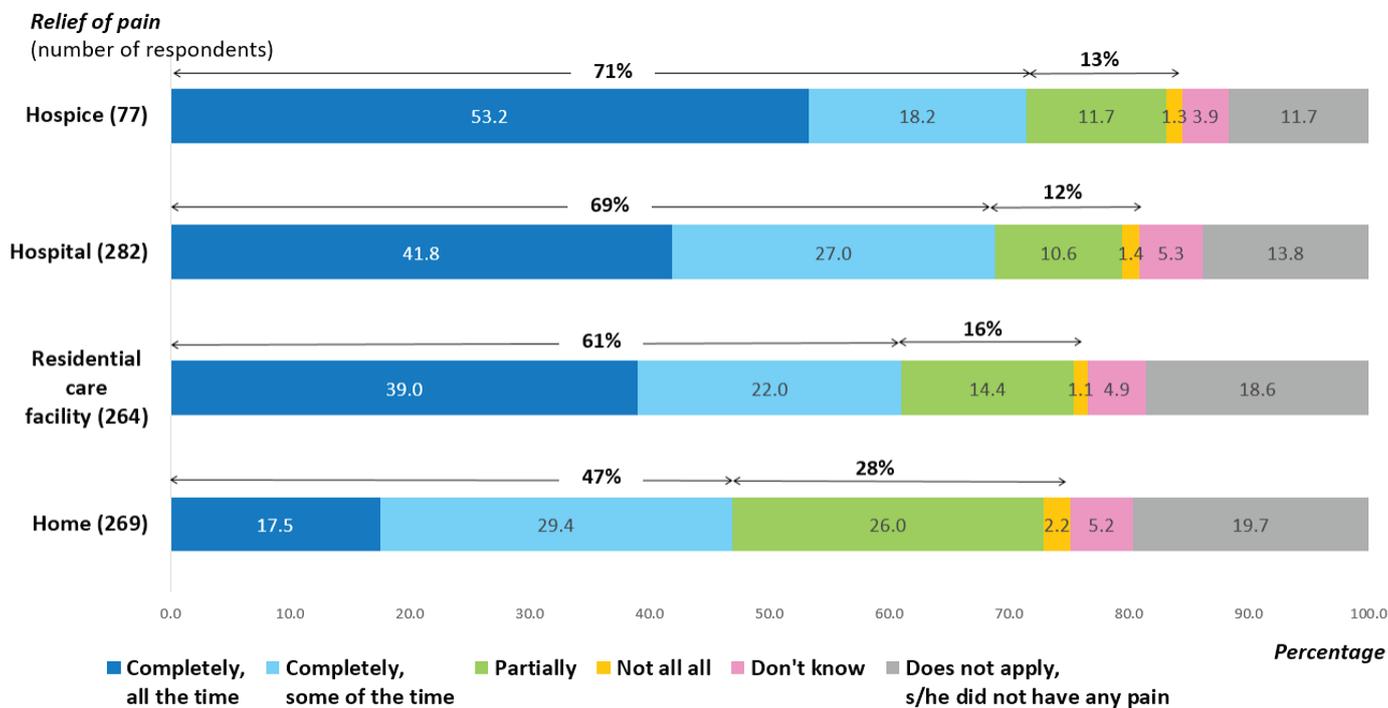
With respect to perceptions of coordination of care between care services in the last three months of their relative’s life, 77% of respondents reported that care services

worked well together ‘definitely or to some extent’ (even though 12.0% of people had not received care). With respect to coordination between hospital and other services, only 33% of respondents reported that the hospital worked well with the GP and other services outside the hospital ‘definitely or to some extent,’ but 17.6% of people had not received care, and 45.8% of respondents did not know. Clearly there are difficulties in assessing the extent of effective coordination.

Pain relief is often critical at the end of life. Figure 3 reports the respondents’ perception of pain relief according to care settings in the last three months of life.

More than half of next-of-kin reported that their relative had complete pain relief all of the time in hospice care (53.2%), with less complete pain relief in hospital care (41%), residential care facilities (39.0%) and home care (17.5%). These percentages may seem low, but some patients did not have pain (ranging from 11.7% in hospice care to 19.7% receiving home care). Respondents reported between 5.2% and 7.4% of patients having their pain ‘not at all’ or only ‘partially’ relieved.

Figure 3: Last three months of life. Relief of pain by care setting, South Island 2017.

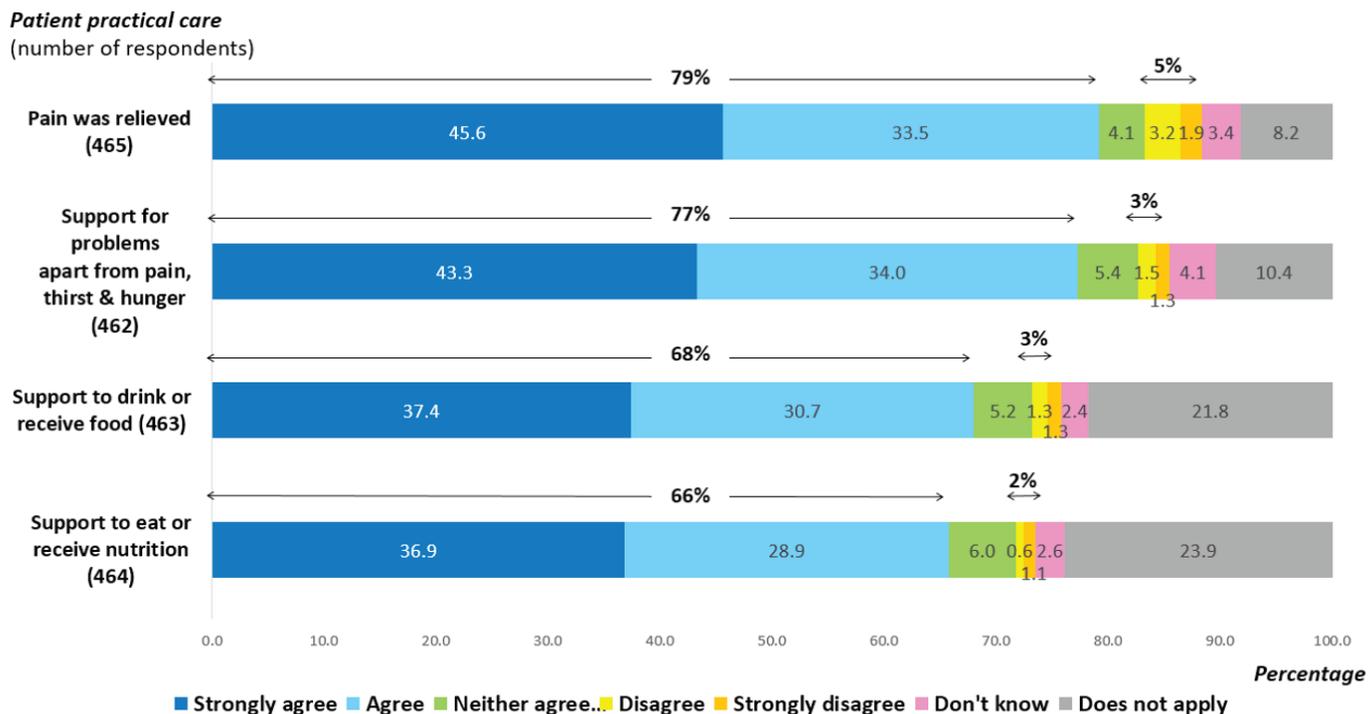


The last two days of life

This is a trying time for patients and families. Figure 4 presents respondents' perception of practical care provided by health professionals at this time.

There was agreement or strong agreement that their relative's pain was relieved (79%), that support was provided for problems apart from pain, thirst and hunger (77%), that their relative was supported to drink

Figure 4: Last two days of life. Overall level of practical care provided by health professionals, South Island 2017.



or receive food (68%), and supported to eat or receive nutrition (66%). The differences in responses to these questions about practical care are negligible, given that the questions did not apply to some patients; ranging from 8.2% for pain relief, 10.4% for support for problems apart from pain, thirst and hunger, to 23.9% for support to eat or receive nutrition.

Emotional care is increasingly recognised as important in end-of-life care. The highest proportion of next-of-kin agreed or strongly agreed that their relative's emotional needs were supported (71%) and that efforts were made to ensure that their relative was in the place they wanted to be (68%). Almost half of the respondents agreed or strongly agreed that their relative's spiritual and/or religious needs were supported (48%). Some respondents felt that the questions did not apply to their relatives; this ranged from 13.2% for emotional needs to 31.7% for religious and/or spiritual needs.

With respect to communication, over 80% of next-of-kin agreed or strongly agreed that they understood information provided to them, were informed about their relative's condition and care, had enough time to ask questions and discuss issues, and had supportive relationships with healthcare professionals. Respondents reported (66%) that their relative was involved as much as s/he wanted to be in decisions about their care, while 23% reported that their relative would have liked to have been more involved.

Many people express a preference for place of death as they approach end-of-life. Of the 202 people who had stated where they wished to die, 61% had expressed the wish to die at home, but in fact only 17.5% did so. A higher proportion died in residential care (42%) compared with an expressed preference of 12%. Some (13%) did not mind where they died. Healthcare staff had a record of the person's preference for only 41% of people, but nevertheless 86.4% of respondents believed that their relative died in 'the right place'.

Other issues emerged. Advance Care Planning (ACP) is new to many people in the community and only 26% of respondents relative had completed the ACP with 51% reporting that this had benefited their relative. In addition, 30 respondents reported their bereavement as a 'sudden

death'. The questionnaire was not suited to these circumstances and they were not included in the analysis. Nevertheless, next-of-kin shared their frustration and despair, with the hope of making changes for service improvement. These findings will be reported elsewhere.

Discussion

This study aimed to test the feasibility of surveying the next-of-kin of deceased. A method of population recruitment proved successful, although further examination of alternatives using DHB/NHI data is necessary. The questionnaire proved acceptable and practical although greater clarity in the definition of 'home' and 'hospital' is needed. Modification of the questionnaire to accommodate 'sudden deaths' is suggested so that next-of-kin could comment on issues such as availability of support and coronial services. The response rate (33.4%), was highly satisfactory from one mail out and compared favourably with similar surveys. The first UK national VOICES survey, for example, used three mail outs to achieve a response rate of 45.7% (2012).⁴ The Swedish survey (response rate 37.9%) used a single mail out but was not a population survey and was assisted by a follow-up phone call.¹⁰

The results confirmed that to die at home is the preference of most people, but this is not a reality for many, influenced by the gap between availability of services and the ability of family to care for them at home. Furthermore, only a small minority receive hospice care. Most people receive end-of-life care from primary healthcare teams, GPs, district nurses, ARC, acute hospitals, and home and community services. People were treated with dignity and respect and received both practical and emotional support, a critical combination¹¹ of community palliative care.

Palliative care philosophy was present across all settings and practitioners. Families were pleased with the care and attention given by all parts of the health system, but noted that coordination could be improved. Comfort-focused end-of-life care is increasingly understood by whānau/family/friends and is consistent with the fundamental components of palliative care. The importance of whānau/family/friends was shown in

the personal reports of the final three months of life from some next-of-kin of people who spent part of those final months at home.

Conclusion

Dying is not merely a medical event but a family and social event that is supported by health services and community support agencies working in partnership with families. This strengthens the notion that end-of-life-care is the responsibility of all of society, based on the philosophy and principles of palliative care. Effective symptom management, and psychological and social support can only be achieved when service providers are partners in providing care in an inter-professional way.

Future research will require refinement to the VOICES questionnaire to include

provision for sudden deaths, widening its scope to acknowledge allied health professionals, and others (eg, lawyers) who support families with end-of-life care. Greater consideration of cultural needs will ensure better engagement of potential participants. A small comparative study to compare the effectiveness of NoticeMATCH data with DHB/NHI data for locating next-of-kin is essential before considering a national survey.

Based on the findings from this survey, there are a number of priorities for service development including: improve access to and better co-ordination of home care services; strengthening the ARC workforce based on palliative care principles; and supporting community capability and willingness for informal care-giving at end of life.

Competing interests:

Kate Reid and Ann Richardson report grants from South Island Alliance during the conduct of the study.

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Author information:

Kate Reid, Senior Lecturer Palliative Care, School of Health Sciences, University of Canterbury, Christchurch; Ray Kirk, Professor, School of Health Sciences, University of Canterbury, Christchurch; Pauline Barnett, Adjunct Associate Professor, School of Health Sciences, University of Canterbury, Christchurch; Ann Richardson, Professor of Cancer Epidemiology, Wayne Francis Cancer Epidemiology Research Group, School of Health Sciences, University of Canterbury, Christchurch; Annabel Ahuriri-Driscoll, Lecturer School of Health Sciences, University of Canterbury, Christchurch.

Corresponding author:

Kate Reid, Senior Lecturer Palliative Care, School of Health Sciences, University of Canterbury. Private Bag 4800, Christchurch 8140.
kate.reid@canterbury.ac.nz

URL:

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