

New Zealanders' knowledge of palliative care and hospice services

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Abstract

Aim This project investigated New Zealanders' views about palliative care and local hospice services.

Method A representative population-based sample of 1011 New Zealanders completed an online survey.

Results The age, gender, and geographic region of the 1011 participants were broadly representative of the New Zealand population. Varying awareness of hospice services and palliative care were displayed among respondents, with age and gender influencing awareness.

Conclusions There was a reasonably good understanding of the concept of palliative care. However, participants could not always identify local hospices, with younger people and males more unaware of accessible hospice services. Low levels of understanding point to the need for continued public education so that the holistic nature of palliative care is understood and accessible hospice services are sought when required.

There were 28,964 deaths registered in New Zealand in 2009, with 14,480 male and 14,484 female deaths according to Statistics New Zealand.¹

The number of deaths will rise rapidly in the years ahead with population aging and population growth, so it can be anticipated that many more people will personally need to use hospice/palliative care services to assist them when dying and many more people will have family or friends needing hospice/palliative care services.

Hospice New Zealand is a national organisation that exists to support member hospices in their work of caring for people who are dying and their families. Their primary goal is to give voice to the interests, views and concerns of member hospices. Their work is in keeping with the 2001 New Zealand Palliative Care Strategy.² The aim of this Strategy was to further a systematic and informed approach to the provision and funding of palliative care services through the implementation of the following vision:

All people who are dying and their family/whānau who could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way.

Strategy 6 of that document relates to informing the public about palliative care services. In particular, it states “Public information specific to each District Health Board area is necessary to:

- Outline the public’s rights/entitlement to palliative care services.
- Describe the services offered by palliative care providers.
- Provide information on what the public should expect from a palliative care service.”

Nearly one decade later, it is of concern that New Zealanders’ knowledge of palliative care and hospice services has not yet been researched. In New Zealand, hospices are independent charitable organisations providing care and support free of charge for all who are dying. This care extends beyond the physical – as it includes social, emotional and spiritual aspects of each unique person’s life. For the purposes of this survey the terms hospice and palliative care have been used interchangeably.

The New Zealand definition of palliative care identifies a similar aim and includes (as hospice does) the support of the individual’s family, whānau and other caregivers into bereavement.³ Awareness of hospice services and the nature of palliative care may still be low, even among health professions.

For many, hospice is still perceived as a ‘place to die’ rather than as a philosophy of care and so people may not seek support from hospices until near the very end of their life. We also do not know much about public attitudes to death and dying, and the anxiety associated with them.

Tomas-Sabado and Limonero claim that ‘our attitudes to death and dying are shaped by many things such as cultural perspectives of illness and the religious and spiritual beliefs of our family and community.’⁴ We do know, from the recent Australian National Community Education Initiative, that ‘talking about dying and death is not something that comes naturally to Australians.’⁵

Palliative Care Australia, the national peak body for palliative care has, over the last 13 years, held a National Palliative Care Awareness Week in an attempt to address a perceived lack of understanding and preparedness for death in Australia. In the UK, the Dying Matters coalition (www.dyingmatters.org) encourages people to talk death in general about their wishes towards the end of life in particular. No similar initiatives are yet available in New Zealand.

Method

Under the auspices of Hospice New Zealand, the researchers approached The Nielsen Company, an international market research company, to conduct a survey. The questions asked were identical to those asked in similar studies conducted in a number of other countries (with minor modification for our on-line methodology), as there is a plan to compare research findings. Ethics approval was obtained from the Northern X Regional Ethics Committee of the New Zealand Health and Disabilities Ethics Committee (MEC/10/27/EXP).

The survey components reported here comprised:

- A. 17 items on the purpose and practice of palliative care and hospice services. Response to these questions were sought using a 5-point Likert scale from *strongly disagree* to *strongly agree*.
- B. 16 items on the participants, 12 on socio-demographics (e.g. gender, age, marital status, education, state of health, strength of connection with family, importance of religion and

spirituality to them, and personal experience with palliative care and death) C. 15 items on attitudes on dying and death, again on a 5-point Likert scale.

C. 1 open-ended question to gauge awareness of their nearest hospice.

Data were collected via an online survey using the Nielsen *Your Voice* panel, an online community designed to provide members with a forum to voice their opinions on a number of matters (www.yourvoice.net.nz).

The survey commenced on 27 July 2010 and continued until 2 August 2010 when the online tool was taken down off the Internet. The survey was expected to take under 11 minutes to complete, and a representative population-based sample of 1011 was anticipated and obtained. Invitations to panellists (18 or over) were sent via e-mail which contained a link to the survey. A sampling matrix was used to ensure that the number of surveys sent to different age groups, regions, and gender was in line with the makeup of the New Zealand (18+) population.

The results were also weighted by age, gender and region to account for any minor imbalances the sampling matrix was unable to account for.

Results

Respondents were distributed throughout the country; 48% were male and 52% female. The age and gender of participants broadly represent New Zealand's population (Table 1) with an over-representation of NZ European responders.

Table 1. Population sample characteristics

Age (years)	Survey %	Ethnicity	Survey%	New Zealand population %*
18–20	4	NZ European	85	77
20–29	18	Māori	6	15
30–39	19	Pacific	–	7
40–49	20	Chinese	3	10
50–59	17	Indian	2	
60–69	15	All Other	9	
70+	7	Total	105 †	†

* www.socialreport.msd.govt.nz; † Some identified 2 nationalities.

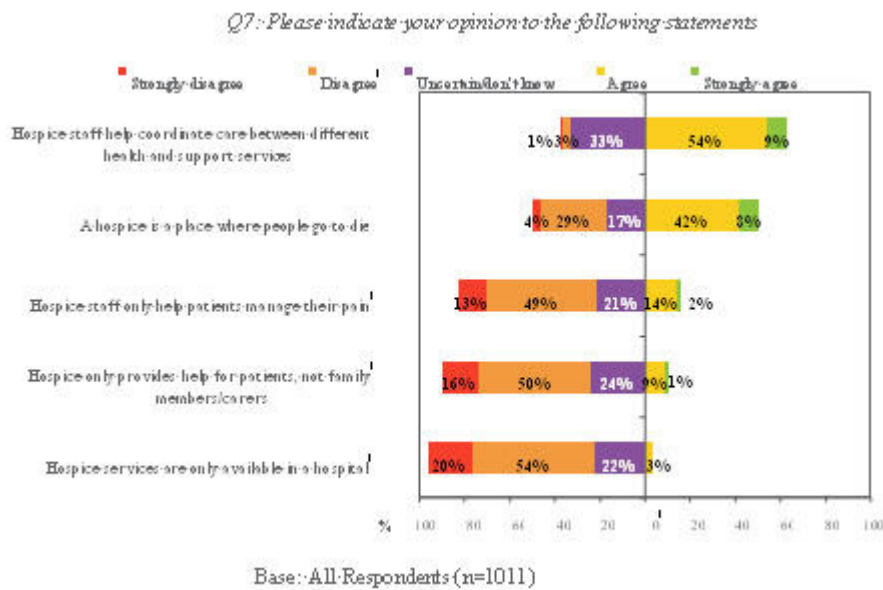
Awareness of hospice activities

Where differences between subgroups and the total sample are identified here these are all statistically different at 95% level.

Figure 1 demonstrates the New Zealand public's awareness of hospice and hospice activities. Only half of the respondents agreed that a hospice is a place where people go to die, while two-thirds agreed or strongly agreed that hospice staff help coordinate care across health and support services.

Just over a third of respondents (35%) correctly named their local hospice. Many respondents simply assumed that their local hospital was where their local hospice was located, but others thought it was in retirement villages or even at the Ronald McDonald House.

Figure 1. Differences by age



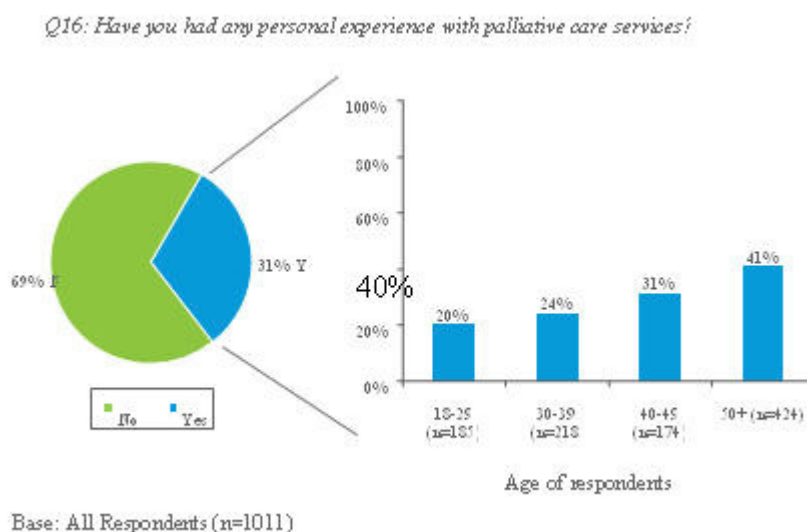
People aged 50 and over had greater confidence that hospice staff coordinate care between a number of different health and support services (71% agreeing cf. 63% average for all respondents). Respondents aged 50 and older also illustrated more accurate perceptions of hospices, as they were more likely to *strongly disagree* with the following statements:

- Staff only help patients manage their pain (19% cf. 13% average for all respondents).
- Hospices only provide help for patients, not family members/carers (20% cf. 16% average for all respondents).
- Hospice services are only available in hospitals (27% cf. 20% average for all respondents).

In comparison, people under the age of 30 were the least likely to be accurate in their responses to the above three statements.

Experience of palliative care—Figure 2 illustrates that around three in ten respondents indicated they had had personal experience with palliative care services. Experience increased with age, with people aged 50 or older twice as likely as those under the age of 30 to have had experience.

Figure 2. Personal experience of palliative care services



Of the two main types of community palliative or hospice care services available, inpatient care was the most likely service that New Zealanders reported experience with. However, 1 in 10 respondents did not know what type of palliative care service they had been exposed to, and this gap was more likely to be the case for those under the age of 30 (24% cf. 9% average for all respondents).

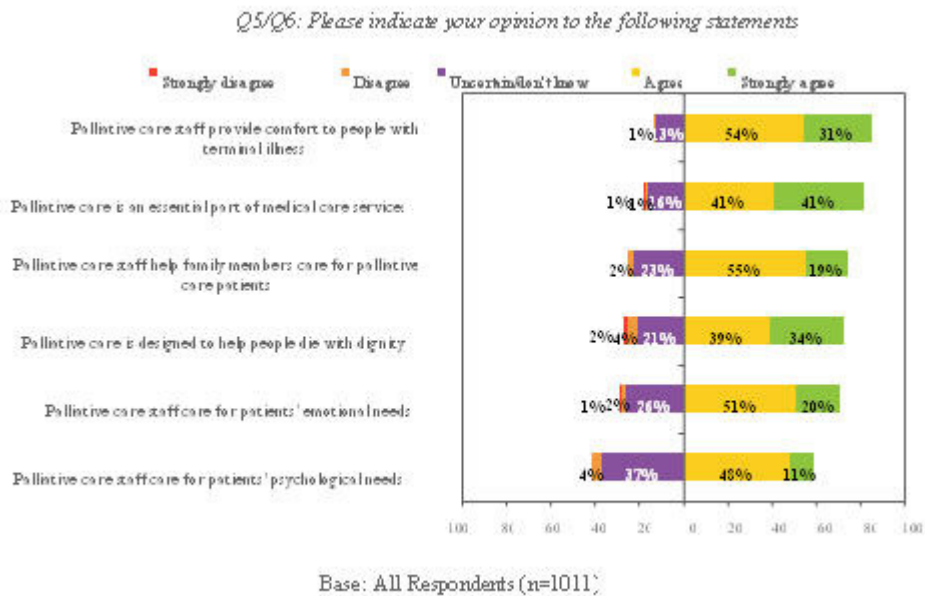
Understanding of palliative care

Figure 3 reveals that the respondents as a whole were most in agreement with the statement “palliative care staff provide comfort to people with terminal illness,” followed closely by “palliative care is an essential part of medical care services” and “palliative care staff help family members care for palliative care patients.”

Differences by age—Age was again found to be a factor in public support for palliative care, as people aged 50 or over placed more value on palliative care, with half (51%) strongly agreeing that it is an essential part of medical care services as compared to 41% for all respondents. This older age group also had more accurate perceptions of palliative care as evidenced by higher *strongly agree* scores for the following statements:

- Palliative care staff provide comfort to people with terminal illness (43% cf. 31% average for all respondents)
- Palliative care is designed to help people die with dignity (50% cf. 34% average for all respondents)
- Palliative care staff care for patients’ emotional needs (27% cf. 20% average for all respondents)
- Palliative care staff care for patients’ psychological needs (17% cf. 11% average for all respondents).

Figure 3. Opinions about palliative care statements (part 1)



Opinions about palliative care

The majority of respondents recognised accurate inaccurate statements about palliative care (see Figure 4), but more than half were unsure about spiritual care services being provided in hospices.

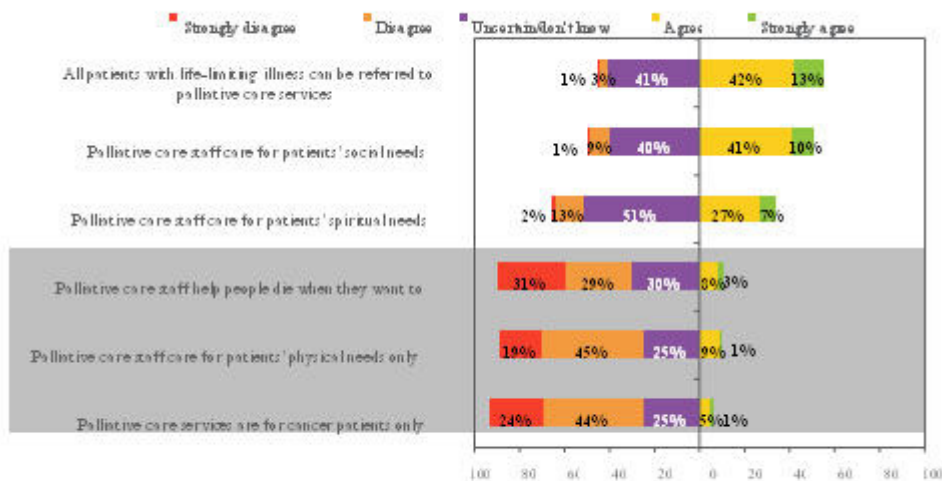
Differences by age—Age was a factor in knowledge of palliative care services, as people aged 50 or over were more likely to know that palliative care staff care for patients' social needs (15% cf. 10% average for all respondents). In addition, people aged 50 or over were more likely to disagree or strongly disagree with three inaccurate statements:

- Palliative care staff care for patients' physical needs only (74% cf. 64% average for all respondents).
- Palliative care staff help people die when they want to (e.g. physician assisted suicide – 66% cf. 59% average for all respondents).
- Palliative care services are for cancer patients only (76% cf. 68% average for all respondents).

Those under the age of 30 were again more likely to be uncertain or not have an opinion about any of the statements about palliative care.

Figure 4. Opinions about palliative care statements (part 2)

Q5/Q6: Please indicate your opinion to the following statements



Base: All Respondents (n=1011)
 Note: Inaccurate statements have been highlighted

Differences by gender—Females were revealed as more informed about hospice, as shown by three key findings:

- Females were more likely to strongly disagree that hospices only provide help for patients, not family members/carers and that hospice services are only available in hospitals (21% and 23% respectively cf. 10% and 17% for males).
- Females were also more likely to strongly agree that hospice staff help coordinate care between different health and support services (12% cf. 6% for males).

There was also a clear gender difference in perceptions of palliative care with females more likely than males to agree or disagree with all statements depending on their accuracy.

Personal experience with death of a family member or close friend

To provide context for this section we evaluated respondents' personal experience with death, their current state of health, importance of religion and religious group they identify with, importance of spirituality, and level of connection with family.

Around 8 in every 10 respondents have personally experienced the death of a close friend or family member (we take this to mean have been bereaved rather than a more literal experience of being at the bedside). Irrespective of age, personal experience of death is very high, with seven in every ten respondents under the age of 30 also having personally experienced the death of a close friend or relative.

Figure 5. Personal experiences of death (part 1)

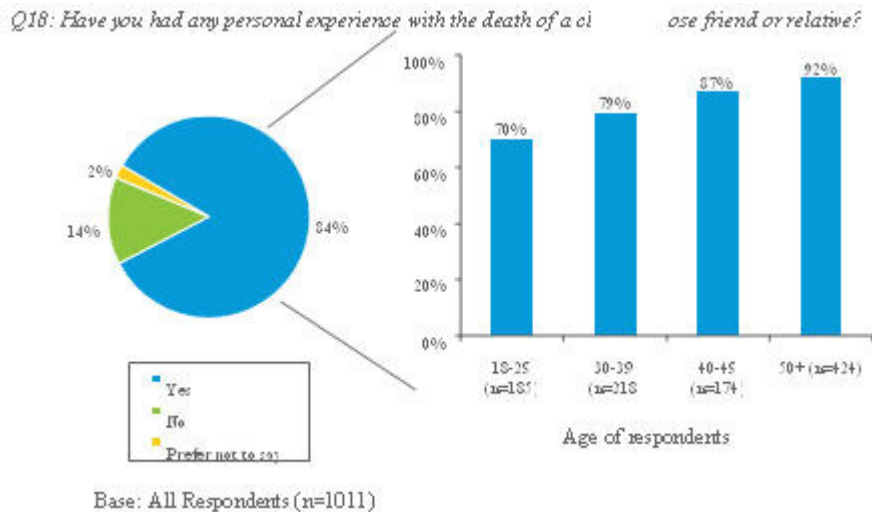
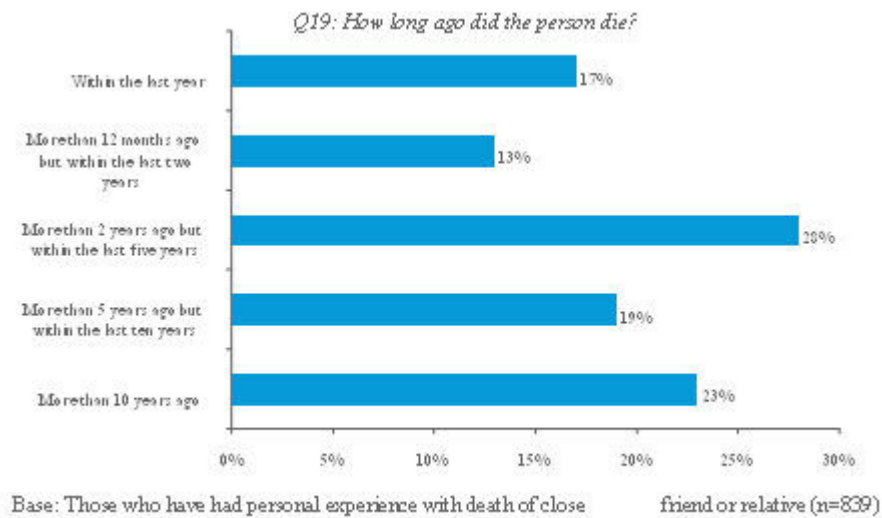


Figure 6 illustrates that for the majority of respondents the death of a close friend or relative occurred more than 2 years ago.

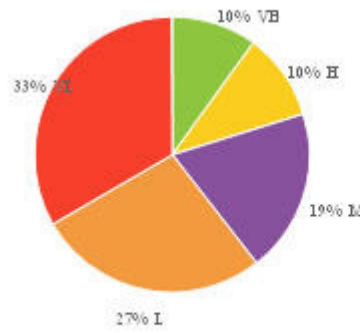
Figure 6. Personal experiences of death (part 2)



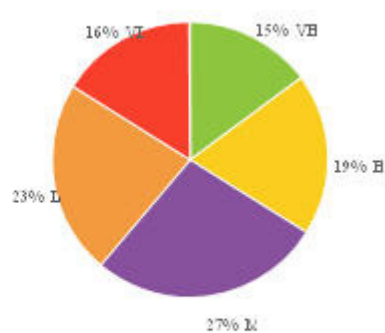
Religion was considered important (both high and very high importance) by only two in every 10 respondents (Figure 7). In comparison, one third of respondents (34%) considered spirituality to be of high or very high importance in their life.

Figure 7. Importance of religion and spirituality

Q12: How important is religion in your life?



Q13: How important is spirituality in your life?



Base: All Respondents (n=1011)

Differences by age—Although people aged in their thirties were more likely to say religion was of *very low* importance (41% cf. 33%), the importance of spirituality was consistent across age groups.

Differences by gender—The only difference in importance of spirituality was the greater likelihood for females to say it was of high or very high importance in their life (40% cf. 28% for males). In terms of strength of connection with family, just over three quarters believe they have a strong or very strong connection with their own family.

Discussion

This research revealed that although New Zealanders generally understand the concept of palliative care, 65% of respondents were unable to name their local hospice. Despite high levels of awareness that hospice support is designed for both patients and families, there were lower levels of understanding of the psychosocial and spiritual services available in hospices. Not surprisingly, people under the age of 30 were commonly the most unaware of hospice services. However, 82% of all respondents believe palliative care is an essential health service.

These findings reflect the experiences and expectations of a society where palliative care has been a part of some districts' health services for over 30 years. It is possible that some respondents had experience of hospice that did not include all the services that could be available, so skewing their responses. For example, not all hospices have care coordination or spiritual care available specifically.

One of the other findings that needs further attention is that a significant number (34%) of New Zealanders consider spirituality to be of high or very high importance in their life. Given that the survey also identifies that a majority of people do not think, or were uncertain, that palliative care staff address spiritual needs, this is something that providers of care may need to attend to.

It is important for the achievement of Strategic goal 6 of the NZ Palliative Care Strategy that education of the public continues so that the true nature of hospice and palliative care services is understood and sought when required.²

Competing interests: None declared.

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