

VOICES



South Island Pilot Survey of Bereaved People 2017



Statistical Bulletin

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1. Main Points

This pilot survey was undertaken in the South Island of New Zealand (NZ) in 2017/18. Respondents reported their views on the quality of care provided by health services to their partner, relative or friend in the last three months, and the last two days, of their life.

The majority (93.7%) of the deceased were reported to be aged 60 years and over at the time of death, with 60.7% aged 80 years and over. Their main illnesses were reported as cancer (29.8%) and heart disease (20.0%). Nearly half of the deceased (45.9%) had been ill for more than a year however, 17.3% had been unwell for one week or less (Section 14).

Many (37.5%) people had lived in an Aged Residential Care (ARC) facility for the whole three months prior to their death however, 63.3% had stayed in an ARC facility for at least some of that time. Most (63.3%) had stayed in hospital, while only 19.5% had stayed in a hospice. Most had used an after-hours service (77.5%) and the District/community nursing service (74%) (Section 14).

Only 17.5% of people died at home, with nearly half (42.6%) dying in ARC, 28.7% in hospital (excluding Accident and Emergency) and 8.3% in hospice (Section 13).

Most (88.6%) respondents rated the overall quality of care provided in the last three months of life as good, excellent or outstanding (Section 3). The overall rating was highest for those who died in hospice (90.5%), closely followed by ARC (90%) (Section 4). Respondents were more likely to rate the overall quality of care as outstanding for those diagnosed with cancer (28.4%) (Section 5) and hospice as the highest rated provider of good or excellent care overall (94.8%) (Section 7).

In the last three months of life, most respondents reported that pain was relieved completely (all, or some of the time) by hospice (71%), hospital services (69%) and ARC facilities (61%) but for those at home, only 17.5% of respondents reported this and a further 26% reported that pain was only partially relieved at home (Section 10). However, in the last two days of life, 79% of all respondents agreed or strongly agreed that their partner, relative or friends' pain was relieved (Section 11).

Respondents reported that clinicians treated the person with dignity and respect all, or most, of the time in the majority of cases, ranging from 88% for GPs to 99% for hospice doctors (Section 8). However, 8.8% of respondents did not think that care services worked well together overall (Section 9).

In general, only a small number of respondents (2-7%) disagreed or strongly disagreed that health professionals supported them and communicated well in the last two days of their partner, relative or friend's life (Section 12), and that the person received the necessary practical and emotional care (Section 11).

Most (66%) respondents reported that their partner, relative or friend was involved in decisions about their care and 86.4% reported that the person died in the right place (despite the actual place of death being different to many peoples' preferred place of death) (Section 13).

The results provide reassurance that most of the important tasks in caring for the dying are being provided appropriately by health services in the South Island of NZ.

2. Background

The original VOICES (Views of Informal Carers Evaluation of Services) survey was commissioned by the Department of Health in the United Kingdom (UK) as part of a commitment made in the End-of-life Care Strategy (2008) to survey bereaved partners, relatives or friends about their perception of care provided at the end-of-life.

The VOICES questionnaire collects detailed information about the circumstances of the last three months, and the last two days of life, focusing on the nature and perceived quality of health and social care services provided. It has been shown to be acceptable to bereaved people, without causing them undue distress or harm.

The comprehensive nature of data generated led to VOICES being implemented by the UK Department of Health as a routine quality improvement measure between 2011 and 2016.

New Zealand context

Permission was granted from the UK Department of Health to modify and undertake the VOICES survey in NZ. In 2017, the University of Auckland's Te Arai Research Group made minor changes to the survey, to ensure its effectiveness for Māori and non-Māori, and trialled it in one NZ District Health Board (DHB). The modifications included an additional 16 questions (including experiences with the use of emergency services) and space for open-ended answers for those wishing to offer further comment. Their researchers concluded that the information gained from the NZ VOICES survey would be helpful for DHBs, hospices, other health care providers, and consumers in reviewing and planning end-of-life care in NZ. The research team also noted challenges in terms of cultural acceptability, the timing of survey distribution following the death, and whether prior consultation is required in respect to cultural norms (Frey et al., 2017).

South Island VOICES pilot survey of bereaved people

The South Island VOICES pilot survey was undertaken in 2017/18 to further test the effectiveness of the adapted survey in a wider geographical area (five DHBs). It was undertaken by the School of Health Sciences at the University of Canterbury (UC) on behalf of the South Island Alliance Programme Office (SIAPO) and supported by the South Island Alliance Palliative Care Workstream (PCW). The Te Arai Research Group also supported the South Island VOICES project team to further explore the questionnaire's use.

NoticeMATCH, a company specialising in the collection of publicly available death data in NZ, was engaged to provide summary information for those who died within the pilot timeframe (September, October, and November 2017). The summaries were grouped into five areas; Otago, Southland, West Coast, Nelson/Marlborough and Canterbury (note these areas differ from the five DHB boundaries but cover the same South Island region). In total 1,813 summaries (for people aged over 18 years who had died in the South Island and were eligible to be included) were received in December 2017. As NoticeMatch does not have access to National Health Index (NHI) numbers, no NHI information was collected for this pilot.

Permission was granted by the NZ Electoral Commission to use the General Electoral Roll to locate postal addresses for those identified in the summaries as

partners, relatives or friends of the deceased. Contact details for 272 potential respondents were unable to be located.

Surveys were posted out once to each potential respondent in batches from March 2018. Respondents could complete the questionnaire on paper, online, over the phone, via video conference or face-to-face.

Presentation of statistical results

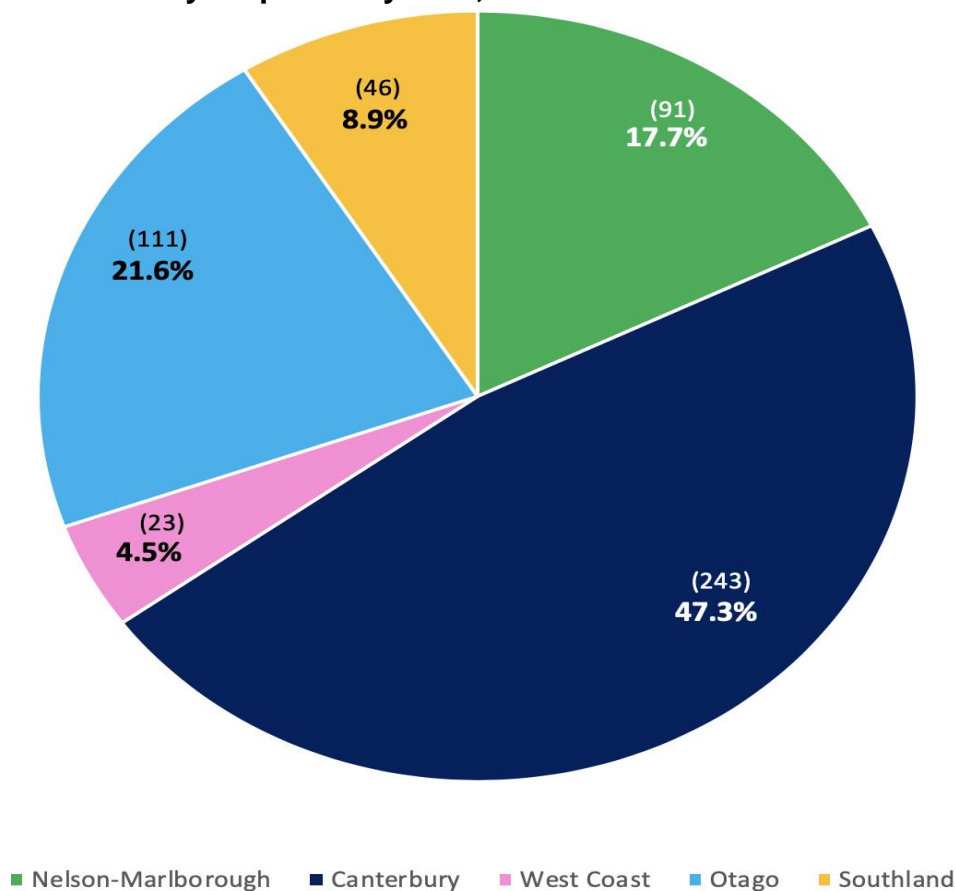
The format of this bulletin follows that of the UK National Survey of Bereaved People (VOICES): England, (Office for National Statistics, 2015). The results from a three-month pilot survey are subject to variability and are not comparable to the well-established UK statistical data.

Of the 1,541 surveys sent out, 514 (33.4%) were completed. Responses were received from all areas in the South Island, in similar proportions to population spread (Fig. 1).

Results are based on the opinions of partners, relatives or friends who rated the care provided. Not all survey questions were relevant to, or answered by, all respondents. Responses (number = 30) from those whose partner, relative or friend died suddenly (e.g. from a road traffic accident, suicide or cardiac arrest) are excluded from this bulletin as the survey questions were inappropriate in these circumstances.

The dataset supporting these findings is held by the University of Canterbury.

Figure 1: Survey response by area, South Island 2017

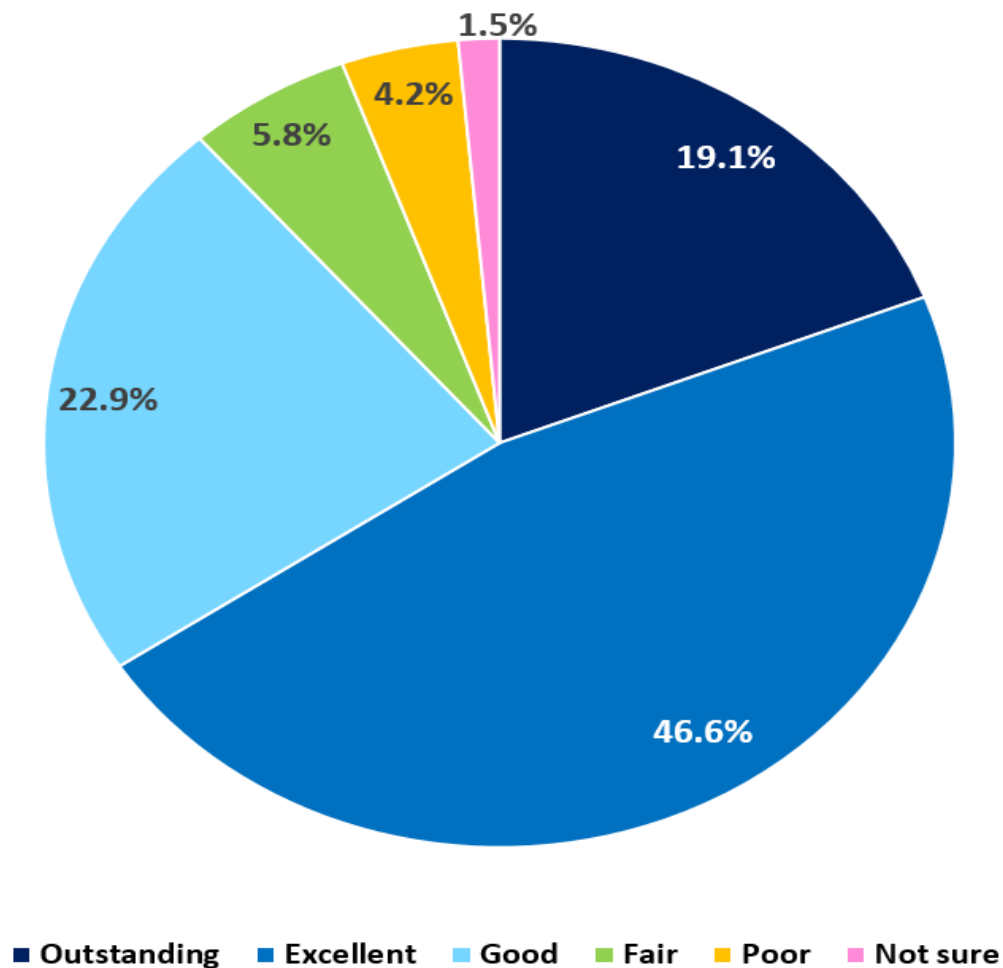


Note: These areas differ from the South Island DHB boundaries due to NoticeMATCH data collection groupings

3. Quality of care in the last three months of life

The majority (88.6%) of respondents rated the overall quality of care provided in the last three months of life across all services (hospitals, hospices, aged residential care and home) as good, excellent or outstanding. Only 10% of respondents rated the quality of care as fair or poor and 1.5% reported they were unsure as they lived away from their partner, relative or friend, and/or were on the periphery of care during this time.

Figure 2: Overall quality of care in the last three months of life, South Island 2017



4. Overall quality of care by place of death

For the 42 people who died in hospices, 90.5% of respondents rated the overall quality of care in the last three months of life as good, excellent or outstanding. This was followed by ARC (90% for 211 deaths) and hospital wards (88.6% for 105 deaths).

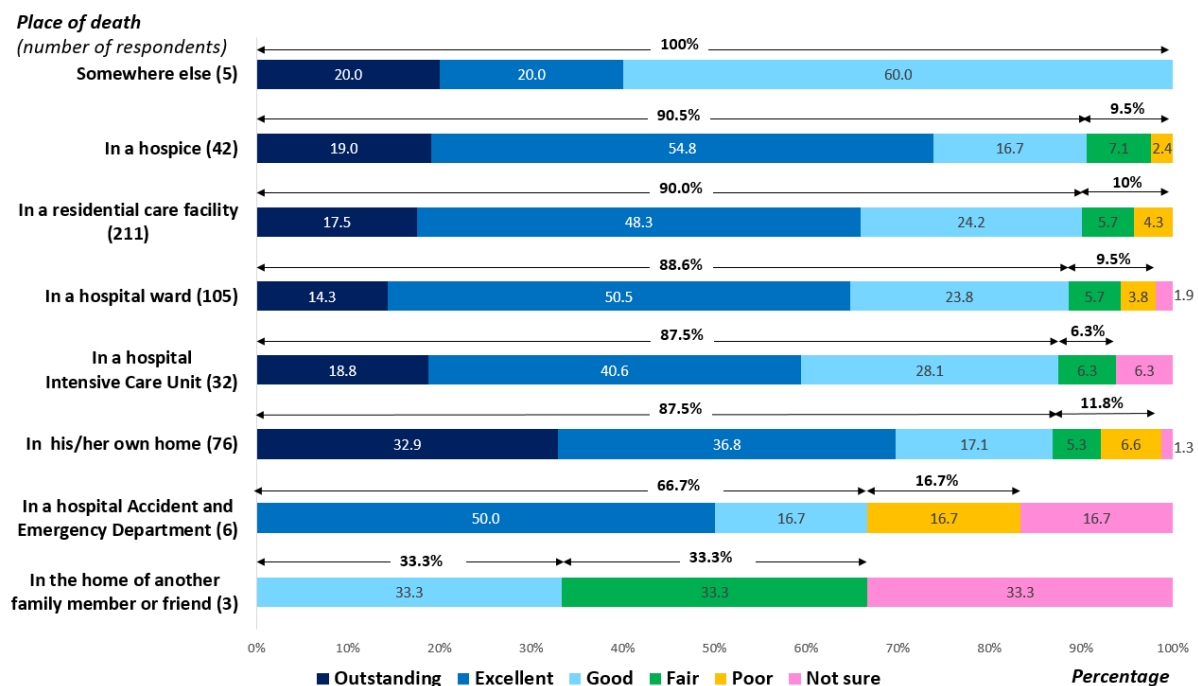
Respondents whose partner, relative or friend died in ICU or their own home rated the overall quality of care similarly with 87.5% reporting the care as good, excellent or outstanding.

The overall quality of care in two settings (A&E and home of another relative or friend) was rated more poorly by respondents however, the number of people who died in these settings is small (6 and 3 respectively). These settings also had a higher proportion of respondents who were unsure of the overall quality of care provided in the last three months of life.

Deaths that occurred elsewhere included people who died in an ambulance on their way to hospital.

It was evident that some respondents were confused about the definitions of home and hospital, therefore this data should be interpreted with caution.

Figure 3: Overall quality of care by place of death in the last three months of life, South Island 2017

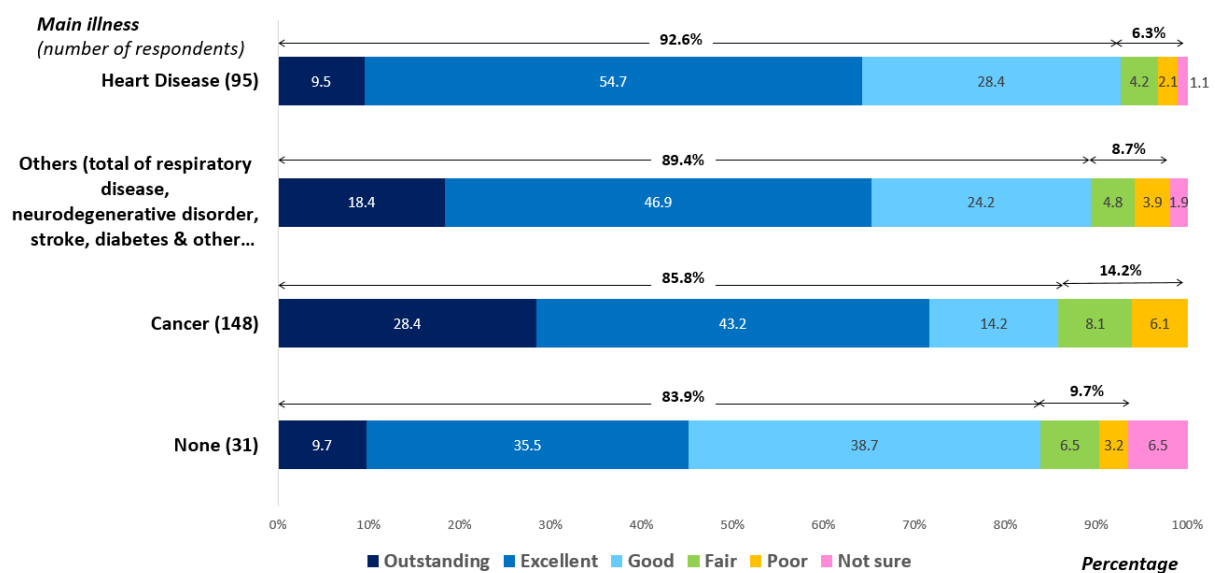


5. Overall quality of care by main illness in the last three months of life

Respondents were more likely to rate the overall quality of care as ‘outstanding’ for those who had cancer in the last three months of life. For these patients, 28.4% of respondents rated the overall quality of care as outstanding, compared with 9.5% for heart disease and 18.4% for other diseases. However, respondents whose partner, friend or relative had cancer also reported the highest rate for poor or fair overall quality of care (14.2%) as compared to those who had heart disease (6.3%) and other diseases (8.7%).

The ‘none’ category includes those who did not have an underlying illness in the three months prior to their death.

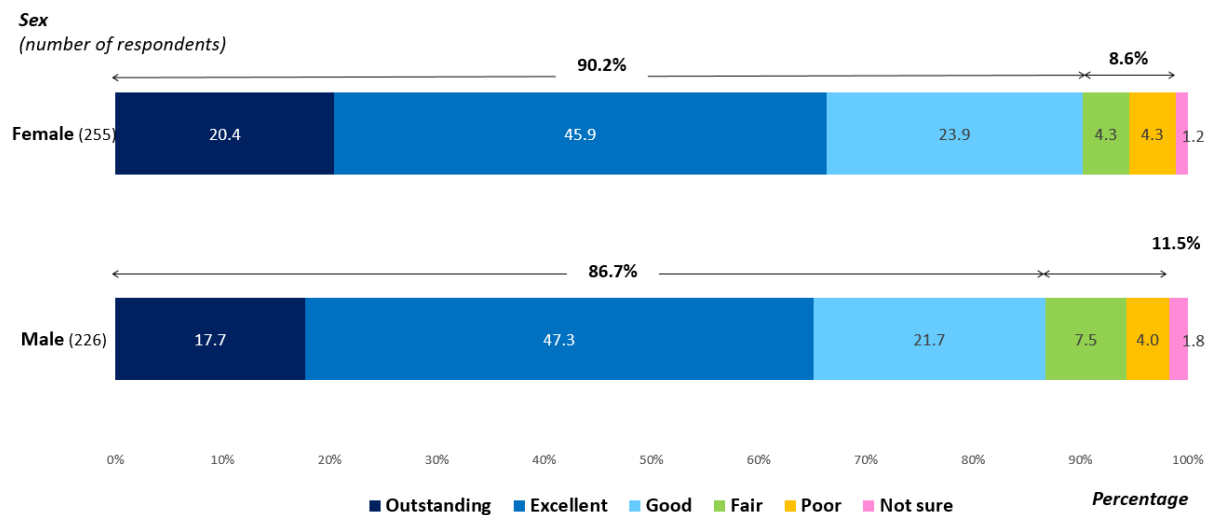
Figure 4: Overall quality of care by main illness in the last three months of life, South Island 2017



6. Overall quality of care by sex

The majority of respondents (90.2%) reported good, excellent, or outstanding quality of care of their female partners, relatives or friends, while 86.7% reported good, excellent, or outstanding quality of care of their male partners, relatives or friends.

Figure 5: Overall quality of care by sex in the last three months of life, South Island 2017

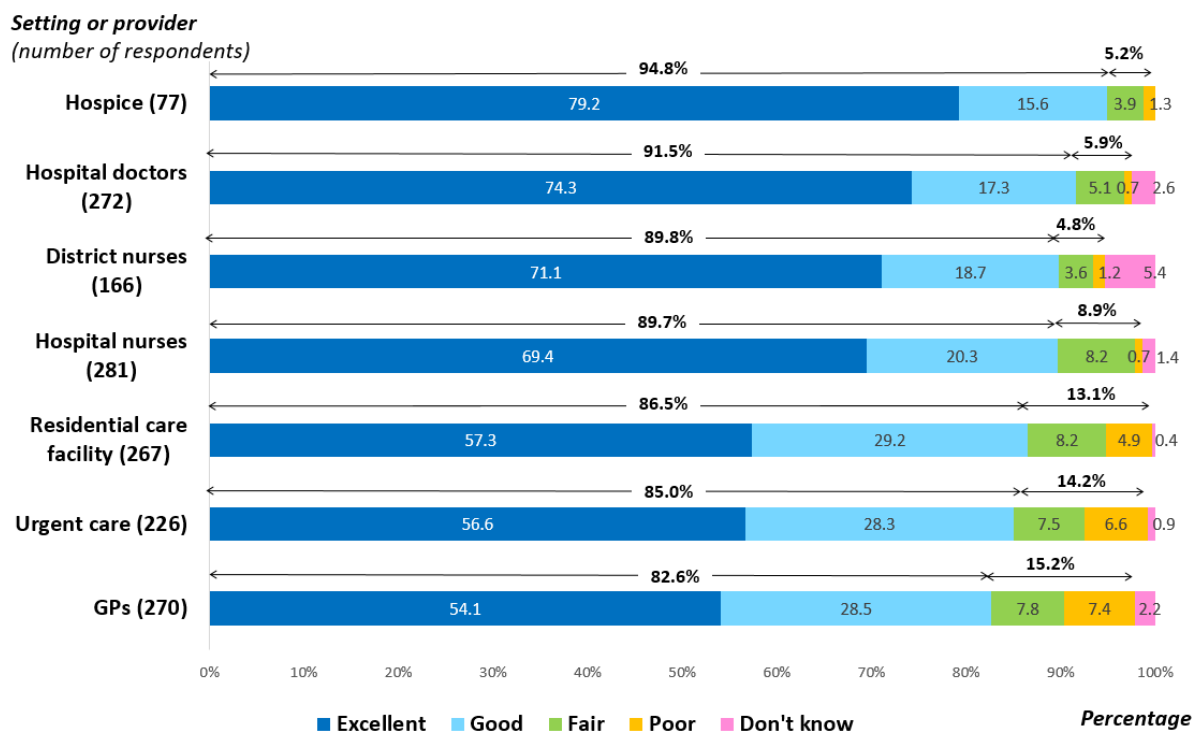


7. Overall quality of care by setting or service provider

The highest proportion of respondents rated the overall quality of care provided by hospices as excellent or good (94.8%), followed by hospital doctors (91.5%), district nurses (89.8%), hospital nurses (89.7%), ARC facilities (86.5%), urgent care (85%), and GPs (82.6%).

The three services that respondents rated poorly with the greatest frequency were GPs (7.4%), urgent care (6.6%) and ARC (4.9%).

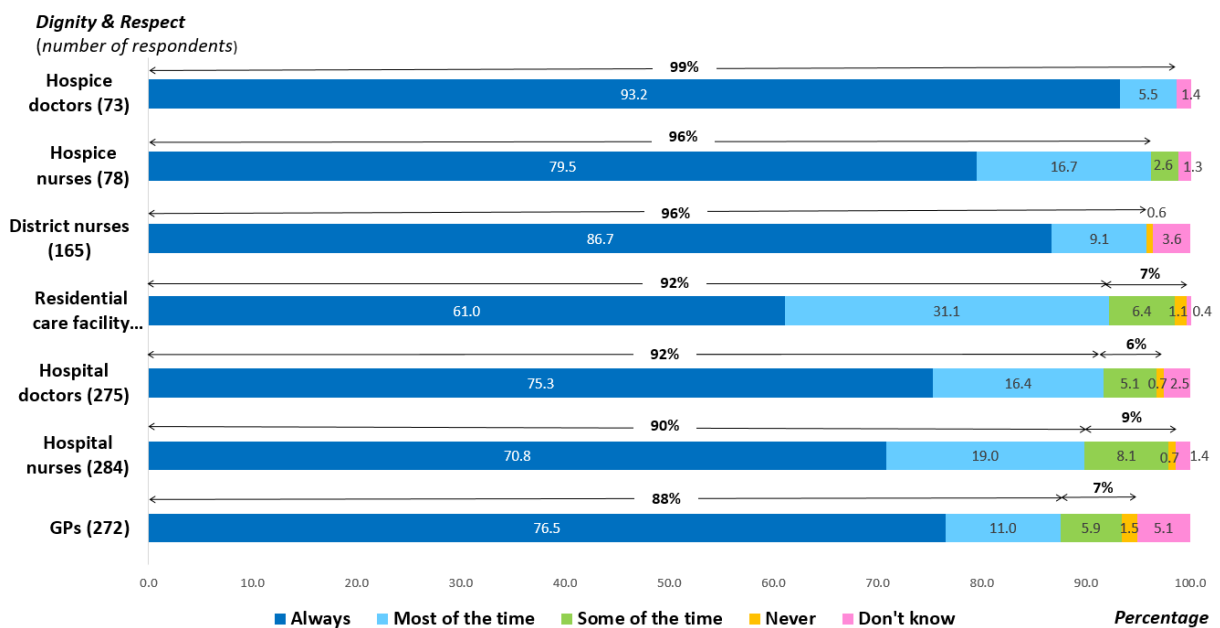
Figure 6: Overall quality of care by setting or service provider, South Island 2017



8. Dignity and respect in the last three months of life

The highest proportion of respondents reported that their partner, relative or friend was always treated with dignity and respect by hospice doctors (93.2%), followed by district nurses (86.7%), hospice nurses (79.5%), GPs (76.5%), hospital doctors (75.3%), hospital nurses (70.8%), and ARC facilities (61.0%).

Figure 7: Dignity and respect in the last three months of life, South Island 2017

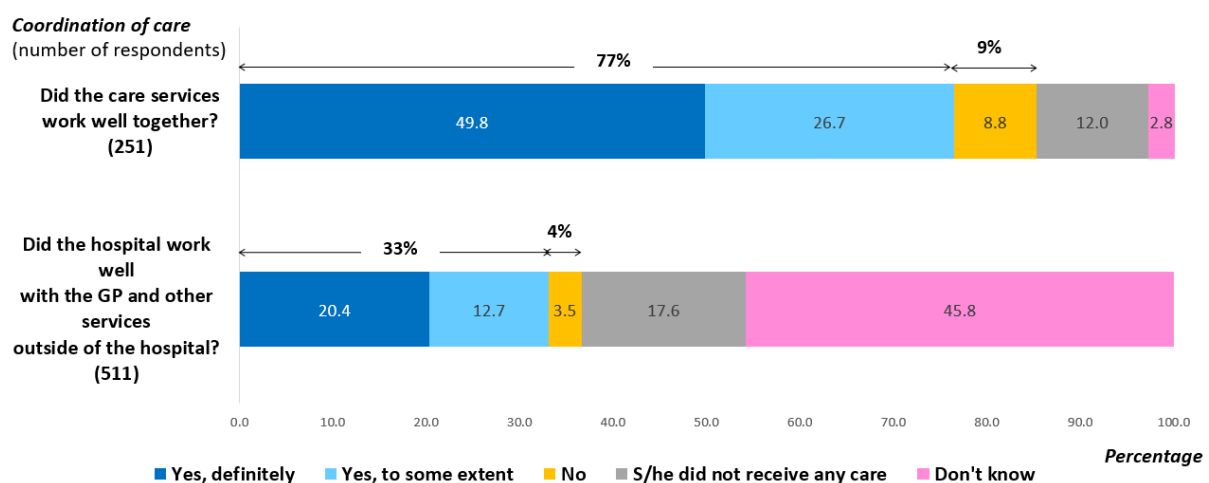


9. Coordination of care in the last three months of life

Overall, 77% of respondents reported that care services worked well together definitely or to some extent however, 8.8% did not think that care services worked well together (note that another 12% of people were reported as not receiving any care during this time).

More specifically, 33% of respondents reported that the hospital worked well with the GP and other services outside the hospital definitely, or to some extent. It is important to note that 17.6% of people did not receive care and 45.8% of respondents did not know, this leaves only 3.5% of respondents who reported that hospitals did not work well with GPs and other services outside of the hospital.

Figure 8: Coordination of care between care services in the last three months of life, South Island 2017



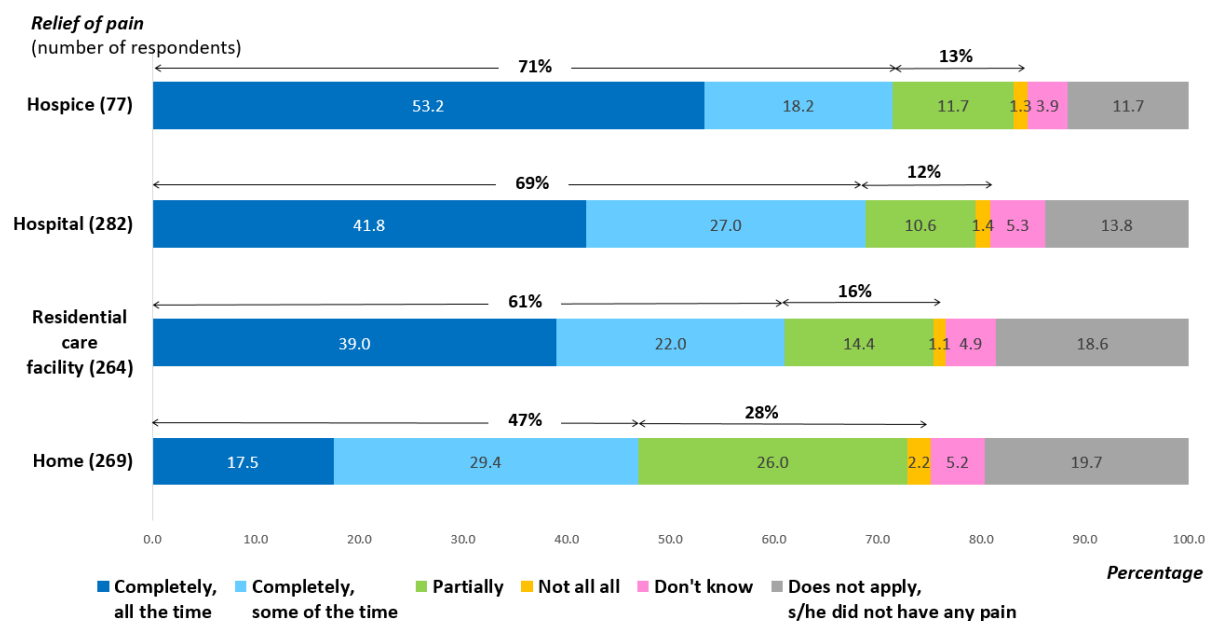
10. Relief of pain in the last three months of life

The highest proportion of respondents reported that their partner, relative or friend experienced complete relief of pain, all of the time, while receiving hospice care (53.2%), followed by hospital care (41.8%), care in an ARC facility (39.0%), and care at home (17.5%). However, some of those who died did not have pain in the three months prior to death; this ranged from 11.7% of those receiving hospice care, to 19.7% of those receiving care at home.

It is noted that 26% of respondents reported that pain was only partially relieved when their partner, relative or friend was cared for at home.

A small number of respondents reported that their partner, relative or friend's pain was not at all relieved. This ranged from 1.1% of those receiving care in an ARC facility to 2.2% of those receiving care at home.

Figure 9: Relief of pain by care setting in the last three months of life, South Island 2017



11. Overall level of care in the last two days of life

This includes overall practical care and overall emotional care.

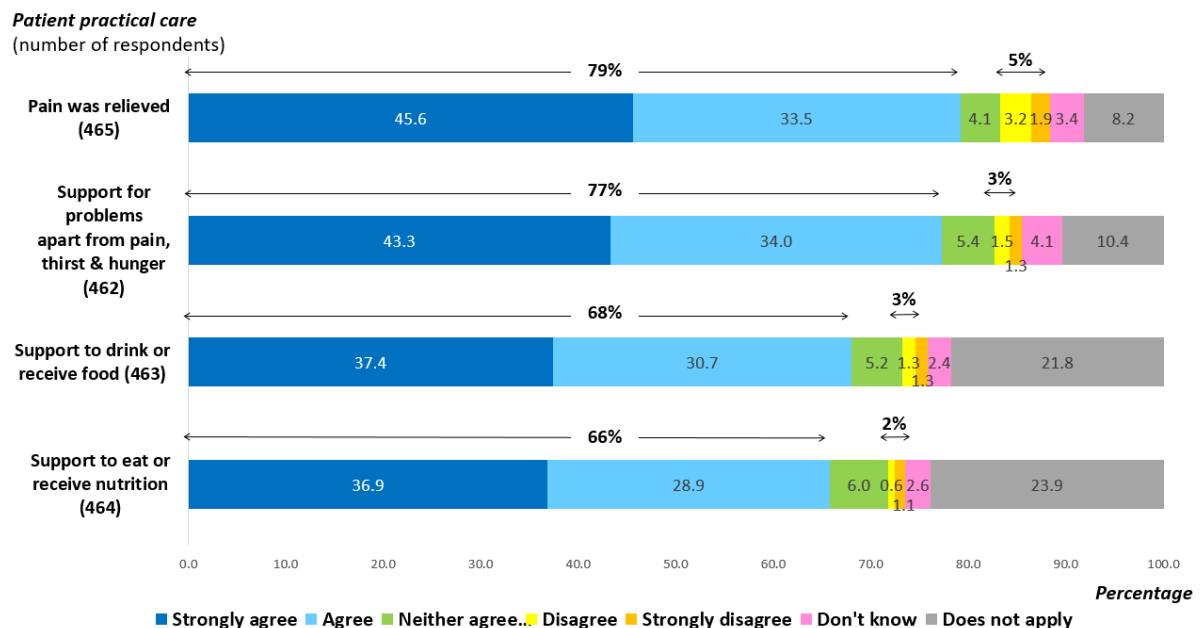
Practical care

In general, respondents reported that pain was the best managed practical care need in the last two days of life with 79% of respondents agreeing or strongly agreeing that their partner, relative or friends' pain was relieved. This was closely followed by 77% agreeing or strongly agreeing that support was provided for problems other than pain, thirst and hunger.

Fewer respondents agreed or strongly agreed that their partner, relative or friend was supported to drink or receive food¹ (68%) and eat or receive nutrition (66%). However, these questions did not apply to many people (21.8% and 23.9% respectively) so the differences are negligible.

Notably, only 2-5% of respondents disagreed or strongly disagreed that these aspects of practical care were provided in the last two days of life.

Figure 10: Overall level of practical care provided by health professionals in the last two days of life, South Island 2017



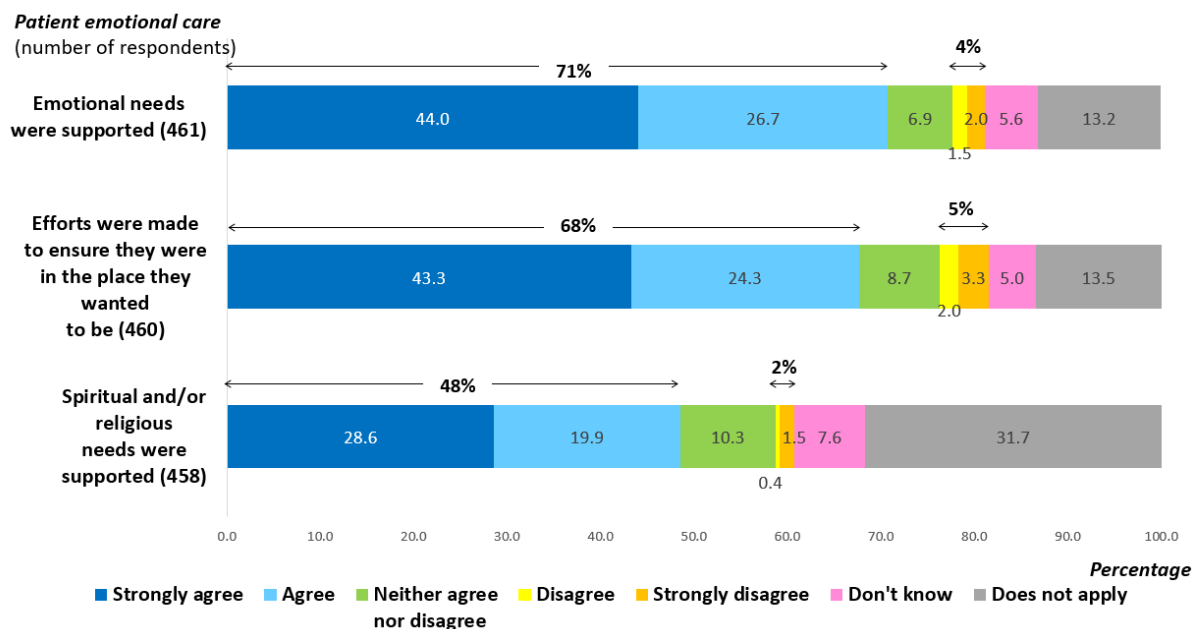
¹ Note that an error in question 48c of the questionnaire may have confused respondents and influenced these results. The question used the word “food” instead of “fluids”, and asked: “In the last two days of life s/he had support to drink and receive food if s/he wished”

Emotional care

The highest proportion (71%) of respondents agreed or strongly agreed that their partner, relative or friend's emotional needs were supported in the last two days of life. Followed closely by 68% agreeing or strongly agreeing that efforts were made to ensure their partner, relative or friend was in the place they wanted to be. While only 48% of respondents agreed or strongly agreed that spiritual and/or religious needs were supported, many respondents (31.7%) reported that this question did not apply.

Notably, only 2-5% of respondents disagreed or strongly disagreed that emotional care was provided in the last two days of life.

Figure 11: Overall level of emotional care provided by health professionals in the last two days of life, South Island 2017

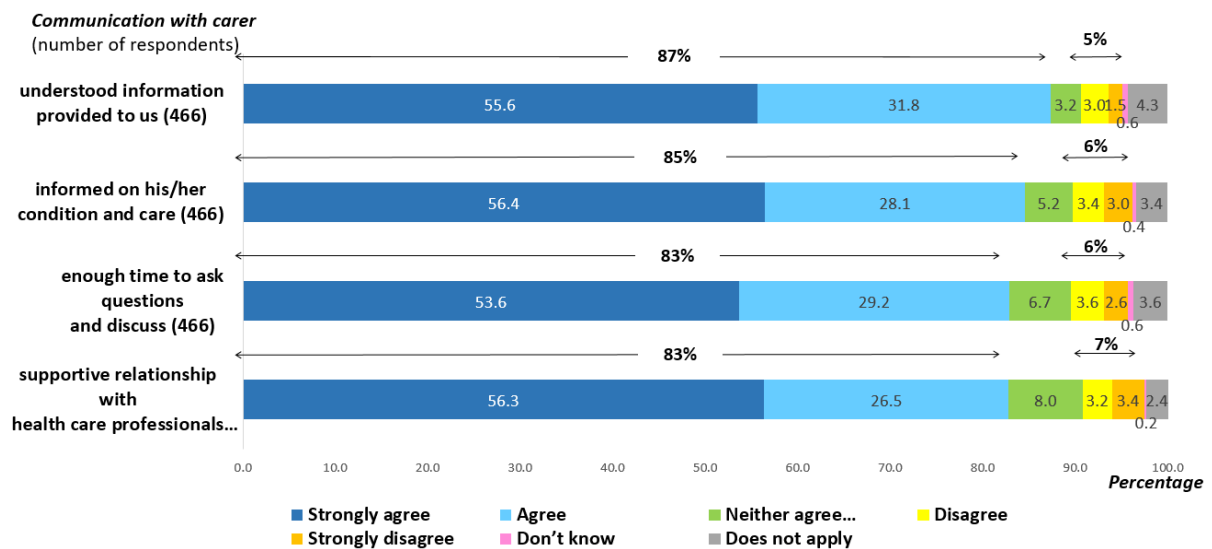


12. Support for partners, relatives or friends in the last two days of life

The majority of respondents agreed or strongly agreed that they understood the information provided to them (87%), were informed about their partner, friend or relative's condition and care (85%), had enough time to ask questions and discuss issues (83%), and had supportive relationships with health care professionals (83%).

In contrast, 5-7% disagreed or strongly disagreed with these statements.

Figure 12: Quality of communication with health care professionals in the last two days of life, South Island 2017



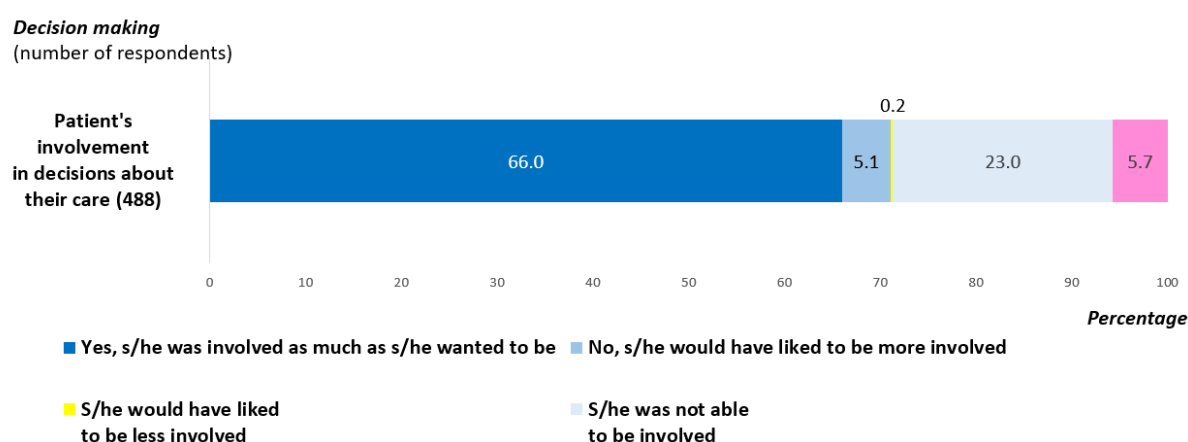
13. Decision making at the end of life

This includes the patient's involvement in care decisions, and dying in the right place.

Patient's involvement in decisions

Sixty six percent of respondents reported that their partner, relative or friend was involved as much as s/he wanted to be in decisions about their care, with 23% reporting they were not able to be involved, and only 5.1% reporting that the person would have wanted to be more involved.

Figure 13: Patient's involvement in decisions about their care, South Island 2017



Dying in the right place

Among those who had stated where they wished to die, 60.9% had expressed the wish to die at home, 12.4% in ARC, 7.9% in hospice, and 12.9% had said they did not mind where they died (Table 1).

Table 1: Preferred place of death

Where did he/she say that he/she would like to die?	Frequency	Percent
At home	123	60.9
In a hospice	16	7.9
In a hospital	4	2.0
In a care home	25	12.4
Somewhere else	5	2.5
Did not mind (26)	26	12.9
Changed mind (3)	3	1.5
Total	202	100.1

Respondents reported that healthcare staff were aware of the person's preferred place of death for 41% of people (Table 2).

Table 2: Staff knowledge of preferred place of death

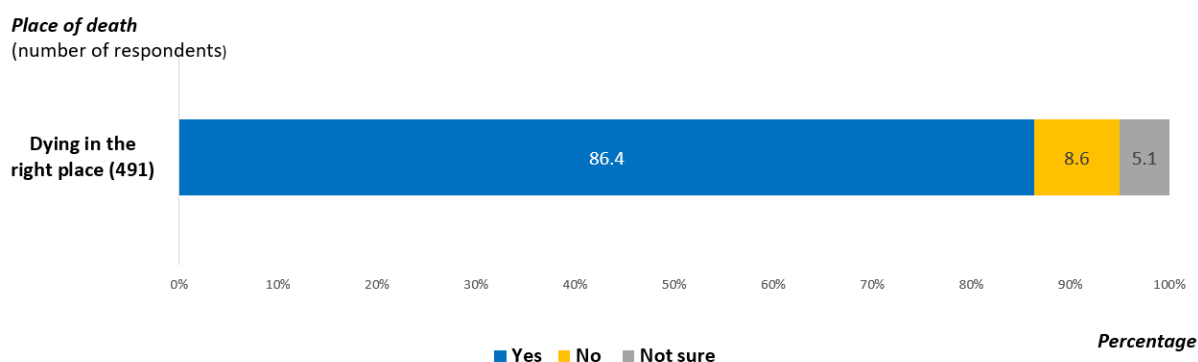
Did the health care staff have a record of this?	Frequency	Percent
Yes	89	41.0
No	55	25.3
Not sure	73	33.6
Total	217	99.9

Despite differences between peoples' expressed preference and their actual place of death (Tab. 3), most respondents (86.4%) felt that their partner, relative or friend died in the right place (Fig. 14).

Table 3: Place of death

	Frequency	Percent
Own home or with another family member or friend	89	17.5
Aged 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

Figure 14: Dying in the right place, South Island 2017



14. Sample information

Of the 514 respondents, 40% were either the spouse or partner of the deceased, 50% were a son or daughter, and 10% were a parent, friend, son/daughter in law or other relative of the deceased.

Almost two-thirds (65%) of respondents were female, 34% were male, with the remainder (1%) not identified. New Zealand European/Pākehā was their dominant ethnicity (85%) with 3.5% identifying as Māori.

Of the deceased, 48.6% were male and 51.4% female.

Further information about respondents and the deceased are detailed in the following tables:

- Table 4: Age of respondents
- Table 5: Age of deceased at time of death
- Table 6: Ethnicity of deceased
- Table 7: Religious affiliation of deceased
- Table 8: Main illness of deceased
- Table 9: Length of illness prior to death
- Table 10: Health services used in the last three months of life

Table 4: Age of respondents

Age group in years	Frequency	Percent
20-49	39	7.7
50-59	108	21.3
60-69	172	33.9
70-79	126	24.8
80 plus	63	12.4
Total	508	100.0

Note: six respondents did not provide their age.

Table 5: Age of deceased at time of death

	Frequency	Percent
Under 60 years	32	6.3
60-69	53	10.5
70-79	114	22.5
80 plus	308	60.7
Total	507	100.0

Note: seven respondents did not provide the age of the deceased.

The majority (93.7%) of deceased were aged 60 years and over with 60.7% aged 80 years and over at the time of death.

Table 6: Ethnicity of deceased

	Frequency	Percent
New Zealand European/Pakeha	424	82.5
Māori	17	3.3
United Kingdom	36	7
European	28	5.4
Australian	3	0.6
Chinese	3	0.6
Lebanese	1	0.2
Unknown	2	0.4
Total	514	100.0

The majority (82.5%) of deceased were reported as NZ European/Pākehā with 3.3% reported as Māori. Other ethnicities (14.2%) reflected NZ Census categories and included UK, European, Australian, Chinese, and Lebanese. No Pasifika deaths were reported in this survey.

Table 7: Religious affiliation of deceased

	Frequency	Percent
Christian	349	69.1
Māori/Christian	3	0.6
Spiritualism/New Age religions	4	0.8
Buddhist	2	0.4
Other/don't know	3	0.6
No religion	144	28.5
Total	505	100.0

Note: nine respondents did not provide the religious affiliation of the deceased.

Table 8: 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 two main causes of death; cancer and heart disease, are reported at percentages similar to recent New Zealand national mortality data (Ministry of Health, 2018) and represent nearly half of all deaths in this sample.

Table 9: Length of illness prior to death

	Frequency	Percent
Not ill at all or for only 24 hours before death.	54	10.5
One day or more but less than one week	35	6.8
Between one week but less than one month	66	12.8
One month or more but less than six months	73	14.2
Between six months and one year	50	9.7
More than one year	236	45.9
Total	514	100.0

Nearly one-fifth (17.3%) 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 one week to six months. The majority (55.6%) had been ill for at least six months to over a year.

Table 10: Health services used in the last three months of life

	Frequency	Percent
Stayed in hospital	281	63.3
Stayed in hospice	78	19.5
Stayed in Aged Residential Care facility	269	63.3
Lived in care for the whole three months	172	37.5
District/community nurse	159	74.0
An After-hours service	172	77.5
Spent time at home in the last three months	259	56.4

Although 37.5% of people lived in care for the whole three months prior to death, 63.3% had been admitted to an ARC facility at some time. The same percentage (63.3%) had stayed in hospital, while only 19.5% had stayed in a hospice. Most had used an after-hours service (77.5%) and the District/community nursing service (74%).

Respondents reported that 56.4% of people had spent some time at home however, another 10.7% did not respond to this question.

15. Acknowledgements

The Principal Researcher would like to acknowledge the South Island Alliance Programme Office (SIAPO) and the South Island Alliance Palliative Care Workstream (PCW) for commissioning, funding and supporting this research.

Support from the Te Arai Research Group, University of Auckland, was also appreciated.

Special thanks must go to the survey respondents. This project would not have been possible without you. The gift of your time to complete the survey, your gratitude for the care offered during this personal family time of caring for a loved one who is dying, and the courage to offer critique when you felt let down by the system, are very much appreciated as we strive to maintain and improve end-of-life experiences in our community.

The Principal Researcher would like to acknowledge the support and advice for the project provided by staff of the School of Health Sciences.

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