

COMMUNITY ATTITUDES TO PALLIATIVE CARE ISSUES

Prepared by Quantum Market Research for the
Australian Department of Health and Ageing.

THE NATIONAL
PALLIATIVE CARE
PROGRAM 

Palliative care – quality of life for people with a life-limiting illness, their families and carers.

COMMUNITY ATTITUDES TO PALLIATIVE CARE ISSUES



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Community Attitudes to Palliative Care Issues

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Appendix 1

The Questionnaire

1. BACKGROUND

This report provides findings from both a quantitative and qualitative research perspective conducted on the awareness and understanding of palliative care in the community. Quantum Market Research undertook the study and prepared the report for the Australian Department of Health and Ageing.

This report provides important benchmark data and information on what Australian people know and understand about palliative care.

The research found that only one in three of those surveyed had a working knowledge of palliative care. Therefore it is important for work under the National Palliative Care Strategy to improve awareness and understanding of this area of the health care system. To assist with this process and provide a context for the current report some information about palliative care in Australia is included below.

Palliative care in Australia

The *National Palliative Care Strategy* defines palliative care as the specialised care of people who are dying. A person receiving palliative care will have an active, progressive and far-advanced disease, with little or no prospect of cure.

The aim of palliative care is to achieve the best possible quality of life, for both the person who is dying and for their families and carers. Palliative care:

- affirms life and regards dying as a normal process
- neither hastens nor postpones death
- provides relief from pain and other distressing symptoms
- combines the physical, psychological, social, emotional and spiritual aspects of care in a coordinated approach
- helps people have a good quality of life for as long as possible until their death, and
- offers a support system to help the family cope during the person's illness, and in their own bereavement.

Who receives palliative care?

Palliative care is provided to people of all ages who are dying - from children to the elderly. The need for palliative care does not depend on any specific medical diagnosis, but on the person's needs. Some of the common medical conditions of people requiring palliative care include: cancer, HIV/AIDS, motor neuron disease, muscular dystrophy, multiple sclerosis and end-stage dementia.

Families and carers also receive the benefits of palliative care services. These people provide much of the care for patients who are dying, so practical and emotional support for them is critical.

Where are palliative care services provided?

Palliative care services can be provided in the home, community-based settings like nursing homes, palliative care units, and in hospitals. People who are dying need to be able to move freely between these places, in response to their medical care and support needs. The pattern of care will be different for every individual, and may depend on factors like: geography, services in the area, and the needs and desires of the person, their family members and friends. In general, palliative care is best provided within close proximity to the person's local environment and community.

Who provides palliative care services?

The needs of people who are dying and their families cross the physical, emotional and spiritual domains. Care and support is required which coordinates the skills and disciplines of many service providers. People involved in palliative care may include:

- medical practitioners, including general practitioners, palliative care specialists, and other specialist physicians with a related interest
- nurses, including generalist and specialist nurses in the community, hospital and inpatient palliative care settings, and independent nurse practitioners
- allied health professionals, including social workers, physiotherapists, occupational therapists, psychologists, pharmacists, dietitians and speech pathologists
- Aboriginal health workers
- volunteers
- support workers, including nurse assistants, personal care attendants and diversional therapists
- bereavement counsellors
- spiritual carers from a range of pastoral, spiritual and cultural backgrounds
- professionals with language skills and cultural knowledge of ethnic groups
- therapists skilled in music, massage, aromatherapy, or colour.

Administrators or business managers provide essential support to the team. Beyond the palliative care team, a number of other services may help to support people who are dying and their families in, for example, areas such as financial planning, legal issues, and funerals.

Families, as well as receiving care from the palliative care team, are themselves critical members of the team. In particular, where a person is cared for at home, the family usually provides a large proportion of the hands-on care.

2. RESEARCH OBJECTIVES

The overall objective of this research is to provide a benchmark evaluation of the understanding of palliative care amongst the community.

More specifically, we wished to establish the following:

Community awareness of palliative care issues

- What do people understand about palliative care? (spontaneous and prompted)
- What do they think palliative care aims to achieve?
- What services exist for palliative care?
- How are palliative care services accessed?
- What does the community want to know about palliative care?

Community attitudes to palliative care issues

- How does the community perceive palliative care?
- What process does the community expect would occur if palliative care were required?
- How important is palliative care to the community?
- What are the more important aspects of palliative care?

Factors affecting community awareness of palliative care

- What are the influences on awareness? What are the strongest and most important factors? Why these? What role do they play?

Awareness of information available on palliative care issues

- Where do people obtain information about palliative care?
- Are there areas of greater information? Or alternatively where there is not enough information?
- How and where should the community be informed?

Level of community awareness of National Palliative Care Week

- How many people are aware of this event?
- How did they become aware?
- What did they hear or see (specifically) about palliative care at that time?

The stakeholders

- What are the key information needs of stakeholder groups?
- What are the information priorities of stakeholder groups? How are these best met?
- What do stakeholders see as being the key issues for palliative care currently?
- What do stakeholders believe needs to occur in the area of palliative care?
- What are the key strengths, weaknesses and areas for improvement in palliative care?

3. RESEARCH METHODOLOGY

A two stage research approach was used to allow us to explore and understand the issues using a qualitative stage, and then measure the extent to which the issues impact on the community using a quantitative stage.

3.1 Target audience for this research

We spoke to the following groups as part of the research process:

Stakeholder groups:

- Palliative care workers (e.g. palliative care nurses)
- Palliative care association (e.g. Palliative Care Australia) representatives
- Health providers (e.g. hospitals and hospices)
- Palliative care patients / Families within the palliative care system
- Members of the general public/community.

3.2 Qualitative

3.2.1 Groups

A total of nine groups were conducted, two with young singles, two with young families, three with older families and two with empty nesters, structured as follows:

	Victoria			Western Australia			Queensland		
	Inner Metro	Outer Metro	Regional/Rural	Inner Metro	Outer Metro	Regional/Rural	Inner Metro	Outer Metro	Regional/Rural
Young Singles				Group 4				Group 8	
Young Families		Group 2							Group 9
Older Families			Group 3		Group 5		Group 7		
Empty Nesters	Group 1					Group 6			

We also ensured:

- A spread of age within the lifestages
- A spread of socio-economic status
- A mix of males and females

3.2.2 Depths

We achieved 14 depth interviews in total, structured as follows:

	Victoria		Western Australia		Queensland	
	Metro	Regional	Metro	Regional	Metro	Regional
Palliative care workers	Depths 1 & 2			Depth 10	Depth 11	Depth 14
Health providers		Depth 6			Depth 12	
Palliative care associations	Depth 3 Depth 4 (phone to ACT)		Depth 8		Depth 13 (phone)	
Patients/families	Depth 5	Depth 7	Depth 9			

3.3 Quantitative

A total of 750 interviews were conducted among the general community in the five main states of Australia. The achieved sample structure was as follows:

Total Number of Interviews N=750	Number of Interviews per Location				
	NSW/N=270	VIC/N=210	QLD/N=135	WA/N=60	SA/N=75
Metropolitan locations	188	142	90	40	53
Non Metropolitan locations	82	68	45	20	22

A total of 100 interviews were also conducted among patients and families around Australia. These are reported on under separate cover.

4. EXECUTIVE SUMMARY

4.1 Key findings

Three quarters of Australians have heard of the term palliative care. Of these, only 41% claim they know enough to explain what it means. This equates to 31% or one in three Australians having a working knowledge of palliative care. This knowledge is higher among three key groups – older people or empty nesters, females, and white collar workers. This higher level of knowledge is demonstrated consistently throughout the quantitative research. Understanding of palliative care generally comes from experience (37%) or the media (19%), although many can't recall where their knowledge originated (26%).

This low level of understanding is demonstrated throughout the research across most questions. When asked for a description of palliative care, the most frequently mentioned responses are care of the terminally ill, care of the ill or care of people who are dying. The primary aim of palliative care is seen as comfort for the patient, or specifically pain relief. The ability to articulate a description and aims of palliative care was higher among empty nesters and families (rather than singles).

At an unprompted level, there is little awareness of the services that would exist for palliative care, with nursing care the most likely mentioned. Upon prompting however, there is a high expectation that a large number of services exist.

If consumers were put in the situation where they required information about palliative care, they would be most likely to go to their local doctor (51%) or a hospital (33%). They wouldn't however, search for information unless they felt they actually needed palliative care, or somebody had informed them that it was an alternative they should consider.

As experienced in the qualitative research, those who have actually been exposed to palliative care in some form (42%) are affected positively by the experience (86%).

There is a low awareness of National Palliative Care Week (9%), particularly among those who have not been exposed to palliative care (6%) compared to those who have (12%).

4.1.1 Service providers

These findings are further supported by the service providers, who claim that there is relatively limited patient knowledge and understanding of palliative care when patients are first referred to them, with one in two service providers claiming that their patients only having partial knowledge and 12% saying that their patients have never heard of the term.

When patients are provided with more information however, service providers claim that there is quite a high acceptance rate of palliative care, with only 18% of service providers claiming that their patients initially decide to wait a while. Reasons for deciding to wait tend to revolve around more emotional rather than rational reasons, with the primary reason relating to patients associating palliative care with death or giving up.

Service providers also state that their patients see the key aim of palliative care as pain relief and comfort for the patient, holistic support and medical assistance are also seen as key aims according to the service providers.

Patient satisfaction levels of palliative care are perceived as extremely high amongst the service providers, with no levels of dissatisfaction recorded. Suggested improvements of palliative care however, principally relate to resource development and enhancement, with the top improvement recommended by the service providers being increased funding.

Not surprisingly, awareness of National Palliative Care Week amongst the service providers is extremely high, with only 2% not aware. Of those who were aware, 33% of these providers were in some way or another involved in the event.

4.1.2 Community attitudes and implications

Attitudes towards palliative care however, while positive, are generally consistent across the various sub groups. They do however highlight the need for increased awareness and education, as well as planning for the future.

Statement	Implication
97% agree everybody who needs and wants palliative care should be able to access it.	The aim of palliative care to have equality of access has been validated.
96% agree the community needs to learn that the option of palliative care exists.	Greater awareness is required.
95% agree palliative care is about the emotional support as well as the medical side of care.	Communication should emphasise the already recognised holistic nature of palliative care.
94% agree it is a doctors' obligation to inform all patients with a life threatening illness about the option of palliative care. 67% agree to obtain palliative care you need to be referred by a doctor or hospital.	Doctors are key gatekeepers and must be educated and encouraged to inform patients regarding palliative care. It is not possible to access without a referral so importance is reinforced.
96% agree with an ageing population the need for palliative care is going to increase.	Planning for the future is required.
91% agree palliative care provides support and assistance to the patient and the carer.	The role of the carer should be brought to light in communications due to recognition of the importance of carers in the process.
81% agree palliative care helps people die with dignity.	Dying with dignity is aligned with palliative care and one of its key aims. This could be used as potentially a descriptor or a tagline for palliative care.
74% agree palliative care allows the patient to choose how they live the remainder of their life.	Choice is an important part of palliative care.
73% agree euthanasia gives people choice about dying. 36% agree euthanasia is the opposite of palliative care.	Confusion exists in the community about the difference between euthanasia and palliative care, while both relate to choices, opinion is divided as to whether they are similar or different choices.
61% agree they want to know more about palliative care.	Opportunity for targeted communications to improve understanding.
29% agree palliative care doesn't cost the patient anything.	Communication must include that it is free because cost may discourage consideration.
23% agree palliative care is mostly for older people. 83% disagree palliative care is only available for cancer patients.	Don't perceive as limited relevance (not just older or cancer) so free accessibility to all who require. Assumption that available to all, so if it's not, there is potential to disappoint.
23% agree they don't want to know anything about palliative care unless someone I know needs it.	Opportunity for targeted communications to improve understanding.

4.2 Conclusions

The key is that the community should know that palliative care services exist. The problem is they don't want to know too much about it.

Palliative care as a term, may have been heard of by many of those in the community, but is not necessarily understood. Palliative care is not a term people can easily relate to. Language which simplifies what palliative care is, is needed – palliative care needs a tagline which people can easily understand.

The community needs to have a basic understanding of palliative care in order to be able to consider it as an option, when they themselves or their loved ones experience the need. The community needs to understand:

- What palliative care is
- What types of services exist
- What its availability is and what the cost is to them

Most perceive the value of the palliative care service to those who need it.

However, there are fundamental blocks to the community engaging in the message about palliative care. As one professional put it, 'people are just too busy living'. So despite the recognition of a need for understanding, Quantum recommends against a mainstream communications campaign to promote awareness of the availability of palliative care and the specific services it provides.

However, when the need arises and members of the community are open to the message, it is very important that information about palliative care is easily available. While the community consider their doctor to be the first port of call for such information, the qualitative research revealed that doctors are in fact not necessarily as pro-active in providing information in this area as they could be. This is possibly linked to their strong mindset of seeking to cure. In some areas, the problem of late referral impacted heavily on palliative care professionals' belief in the quality of service they could provide. They believed that because they were referred so close to the death of the patient, that they were not able to help as much as they would have liked.

Quantum recommends that as gatekeepers, doctors and other health professionals be made more aware of the value that the community place in palliative care and the very positive regard that the community have for the service. Quantum also considers that information resources should be made easily available through channels such as GPs and specialists.

Quantum believes that information should be made freely available through a range of sources so that those engaged with the topic can choose to better inform themselves. These sources would include, doctors surgeries, hospitals, health care centres, local councils, aged care facilities and over the Internet. In this study, personal involvement through a family member or friend was found to be the key to increased understanding of palliative care. Quantum believes that personal stories are more likely to be engaged with by the community, than other forms of communication around this topic. Using mediums such as papers (including local) or radio, which can communicate these stories will be vital in helping to develop awareness and understanding. This tact should also be used during National Palliative Care Week to improve awareness and involvement.

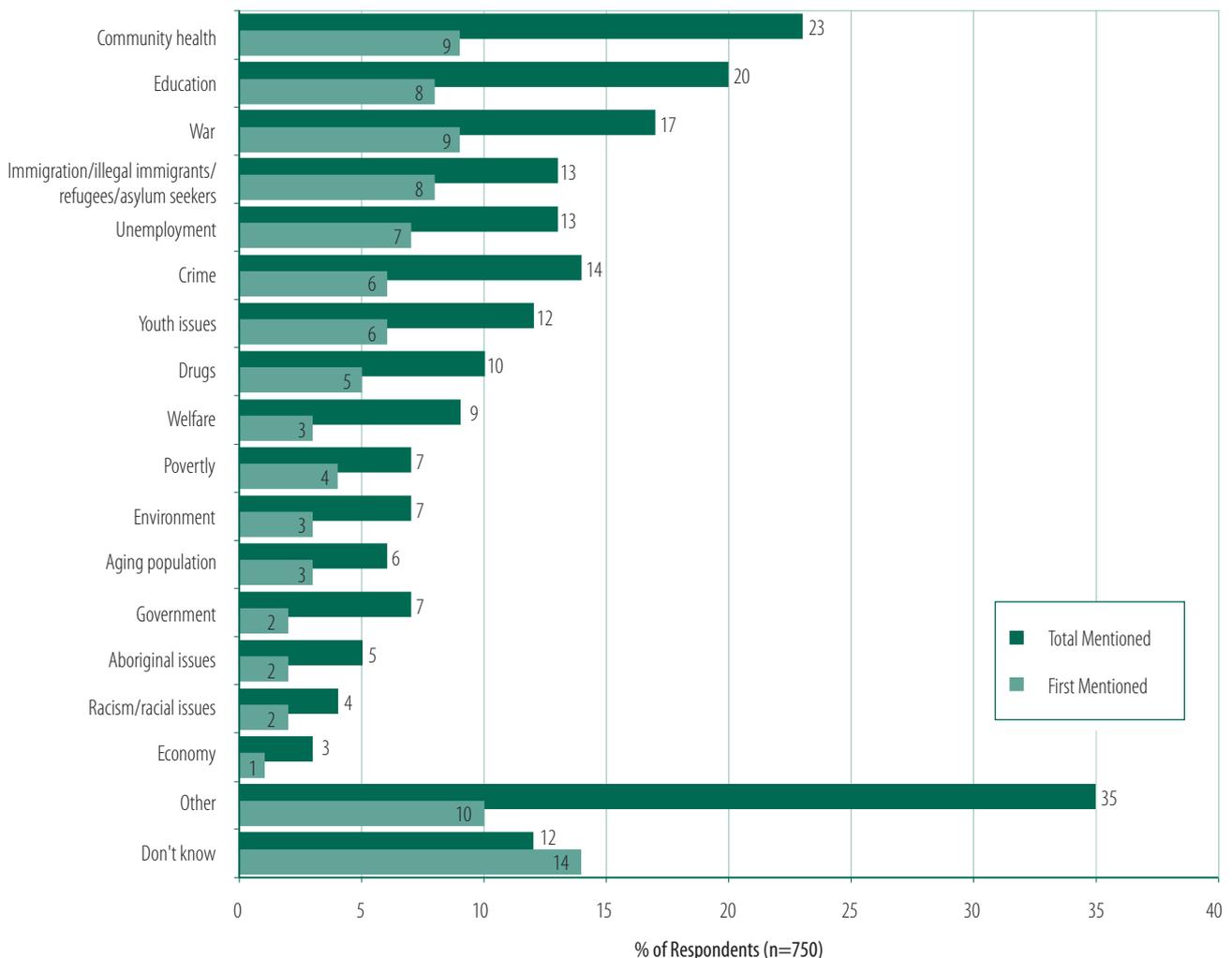
Finally, fund raising, particularly where it involves family and friends of those who have died, was found to be a very positive vehicle for communication and raised awareness with the community. This type of activity (as evidenced in Bunbury) should be actively fostered throughout Australia.

5. MAIN FINDINGS

5.1 Putting palliative care into a context

Australia's social issues are heavily driven by media coverage, as well as local and international events. This makes them highly variable, and therefore different at any given point in time. The key issues spontaneously nominated in September 2002 were community health, education and war. This was followed closely by immigration, unemployment, crime and youth issues. Palliative care was mentioned by less than 1% of Australians.

The qualitative research showed us that when probed on how palliative care fits into the context of current health issues, it was thought of as one of the specialised services which form part of the current health care system. For most it was perceived that it would only be an issue to those who needed the service and therefore not have as much priority as some of the other issues raised. It is not an issue which is spontaneously thought of for many reasons – not wanting to think about it, not having been exposed to it, not understanding it, not knowing anybody who has needed it. Even among those who have previously been exposed to palliative care, only 1% raise it as an issue which deserves our attention. This may be because those who have experienced it consider it to be excellent, and therefore perhaps not requiring attention.



As we saw in the qualitative research, this varies based on location, with different states having different priorities, or strength of conviction. Community health is the number one issue seen to deserve our attention in four out of five states. The state which stands out here is Queensland, which has unemployment as the top issue, with community health at fifth spot.

Personal experience and lifestage were also found to drive what the community see as the issues of most concern in the qualitative research. Examples of this might be aged care for the empty nesters whose parents are ageing, or doctors insurance and obstetricians for those young people having babies. This is evidenced in the quantitative research where the following can be seen:

- Community health is much more important to families (24%) and empty nesters (26%) than to young singles and couples (11%)
- Education is most important to families (30%) compared to young singles/couples (14%) or empty nesters (16%)
- Unemployment is most important to families (17%) rather than young singles/couples (10%) or empty nesters (11%)

SOCIAL ISSUES THAT DESERVE OUT ATTENTION (TOTAL MENTIONS)	Location							Lifestage		
	NSW %	VIC %	QLD %	WA %	SA %	Metro %	Regional %	Young Single/ Couple %	Family %	Empty Nester %
Community Health	28	19	12	28	32	24	21	11	24	26
Education	25	16	17	17	24	21	19	14	30	16
War	16	17	19	15	16	18	15	18	18	16
Crime	18	5	15	22	12	14	12	16	9	16
Unemployment	10	12	21	5	16	13	13	10	17	11
Immigration/illegal immigrants/ refugees/asylum seekers	13	13	11	18	8	14	8	15	16	10
Youth Issues	13	11	11	5	17	10	17	10	15	10
Drugs	8	12	10	10	15	10	11	12	10	10
Welfare	9	9	12	7	4	9	8	8	9	9
Poverty	7	10	7	2	11	7	8	8	9	6
Environment	6	10	5	8	7	7	8	7	8	8

5.2 Awareness and understanding of palliative care

Having experienced very low awareness in the qualitative research, awareness of the term palliative care seems high at 75%, but it does vary significantly by lifestage, socio-economic status and gender:

- Younger singles/couples (51%) vs Families (78%) vs Empty Nesters (82%)
- Males (67%) vs Females (82%)
- Blue collar (58%) vs White collar (84%)

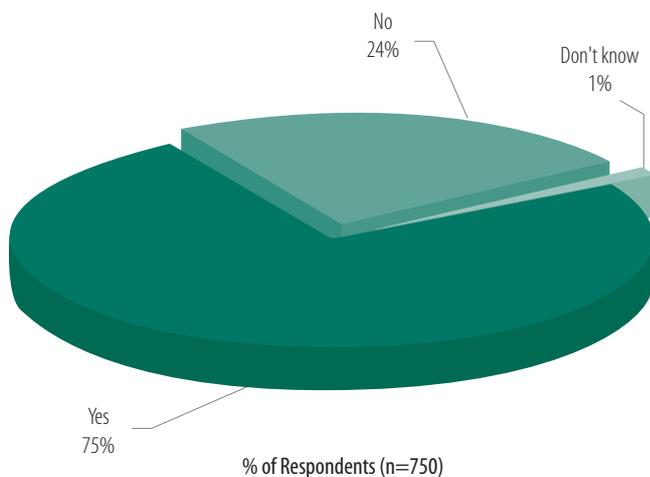
“I’ve heard of the word – what is it?”

“What does the word ‘palliative’ mean?”

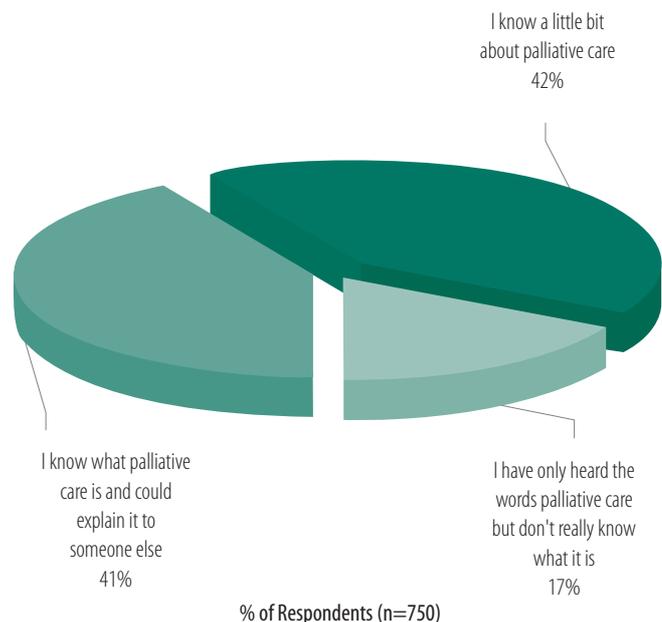
“It’s associated with disease - it’s not a healthy 90 year old in palliative care.”

A lack of clarity is evidenced by the fact that around one in six (17%) of those people who claimed they were aware of palliative care had only heard the words and didn’t really know what it was. If we take a birdseye view, around 3 in 10 Australians (31%) claim they are aware of palliative care and could explain it to someone else. While there is also a significant proportion who claim to know a little bit about palliative care, there is clearly room for improvement.

Q3. Have you heard of palliative care?



Q4. And how would you describe your level of knowledge about palliative care?



As with awareness, lifestage and/or age influence the level of knowledge about palliative care, with empty nesters having a greater level of knowledge and young singles and couples having relatively less knowledge. Gender and socio-economic status also demonstrate variation, with females and white collar consumers having greater knowledge.

LEVEL OF KNOWLEDGE ABOUT PALLIATIVE CARE	Male %	Female %	Young Single/ Couple %	Family %	Empty Nester %	Blue Collar %	White Collar %
I know what palliative care is and could explain it to someone else	33	49	25	40	46	27	46
I know a little bit about palliative care	46	38	45	44	40	45	41
I have only heard the words palliative care, but don't really know what it is	21	13	30	16	14	27	13

Essentially, part of the difficulty in developing an understanding of palliative care is that the word does not relate to anything people experience in their day to day lives. 'Palliate' is not a word in common usage and therefore the community has no way of connecting to the concept.

"You don't read about it."

"Not something that is discussed that much."

Although not everyone knew what palliative care was about, all trusted that the doctor (whether it be the GP or the specialist) would help make the decision to palliate when necessary. Qualitative respondents expressed that there was no strong need for information other than "knowing that it is there" and at a basic level "what is involved".

"We don't pay attention until it affects us."

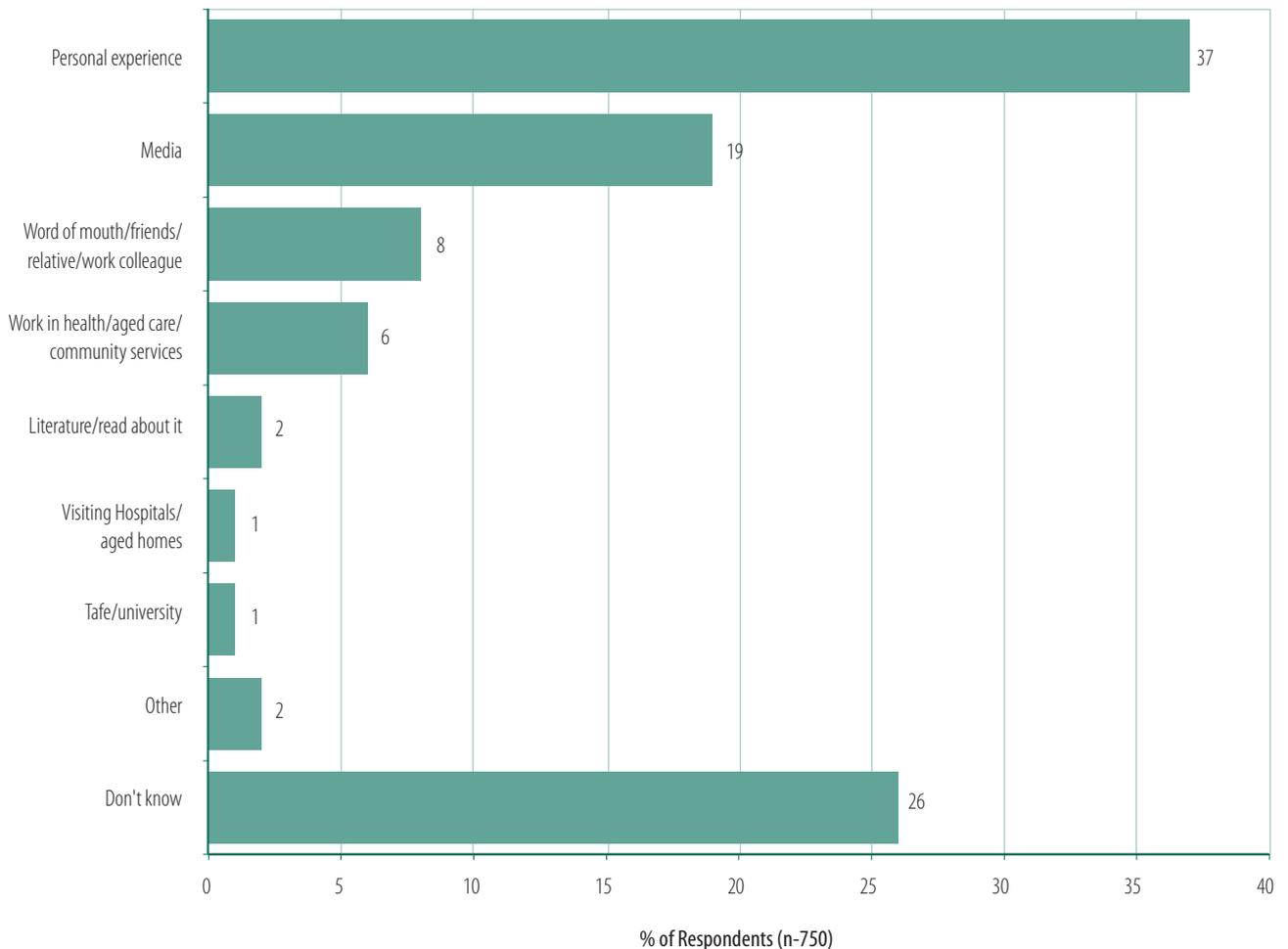
In one case in this study (in Bunbury), there was an awareness throughout the community. Here, palliative care appeared to have become integrated into the community rather than being outside the general sphere of day to day living, as was the case in other areas. This was the case in Bunbury, WA where the Australia Day BBQ/sausage sizzle, held to celebrate the lives of those who had died, was a community event.

5.2.1 Where gained understanding

While one in four (26%) don't know how they obtained their understanding of palliative care, most claim it was through personal experience (37%). The media also plays a strong role (19%), as we found in the qualitative research.

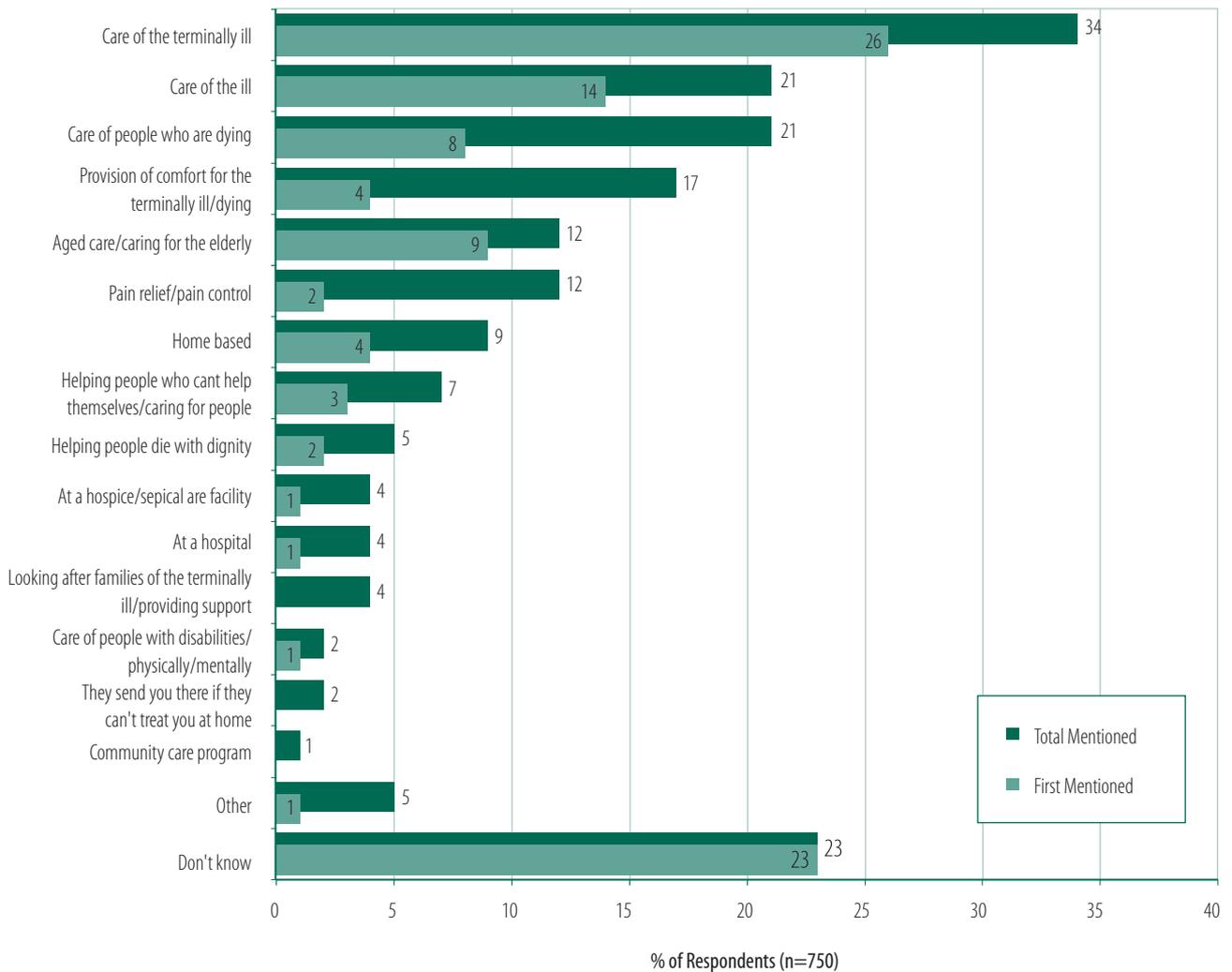
The qualitative research showed us that palliative care tended to be seen in a more positive light when understanding was developed in the context of personal experience. When awareness came via the media - the associations were less positive. We found that particularly in Queensland, where the Nancy Crick case received considerable coverage, that the associations with palliative care were quite negative. In addition media reference to palliative care often placed the service in juxtaposition to the concept of euthanasia, which in this study was found to have a degree of community sympathy.

“Nancy Crick was on TV. Palliative care had a really nasty stigma - a place you go to die.”



5.3 Description of palliative care

When asked over the phone to describe what palliative care is, the most frequently mentioned response was care of the terminally ill or care of the ill. Amongst those amongst the broader community that were able to provide a definition however, the descriptions of palliative care suggested were various:



There was greater ability to spontaneously verbalise a description of what palliative care involved by empty nesters (and families) and white collar workers, generally with a greater number of responses overall among these groups.

5.3.1 Information gaps (Qualitative)

Respondents (particularly those who acknowledged a lower level of understanding) were asked what questions they had about palliative care. The areas requiring clarification were as follows:

- What is it?
 - Where is it delivered?
 - Who provides it?
 - What types of services are involved?
 - Who specialises it?
 - Who staffs it?
 - How do you get it?
 - How do you qualify for it?
 - Does it include counselling?
 - What does it cost?
 - How long does it last?
 - How are staff trained?
 - Are all the staff specialists?
 - Where does the funding come from?
 - Is this to prolong life?
 - How many people require palliative care?
 - Is there private health care that covers it?
- Is it beyond normal care for the aged?
- Is it caring for people who are really ill?
- Is it publicly funded?
- Who offers it?
- Is it attached to a hospital?
- Can I have it at home?
- Do you have to be on a certain kind of pension?
- Are there strings attached?
- Can it be free?
- It might be asset tested?

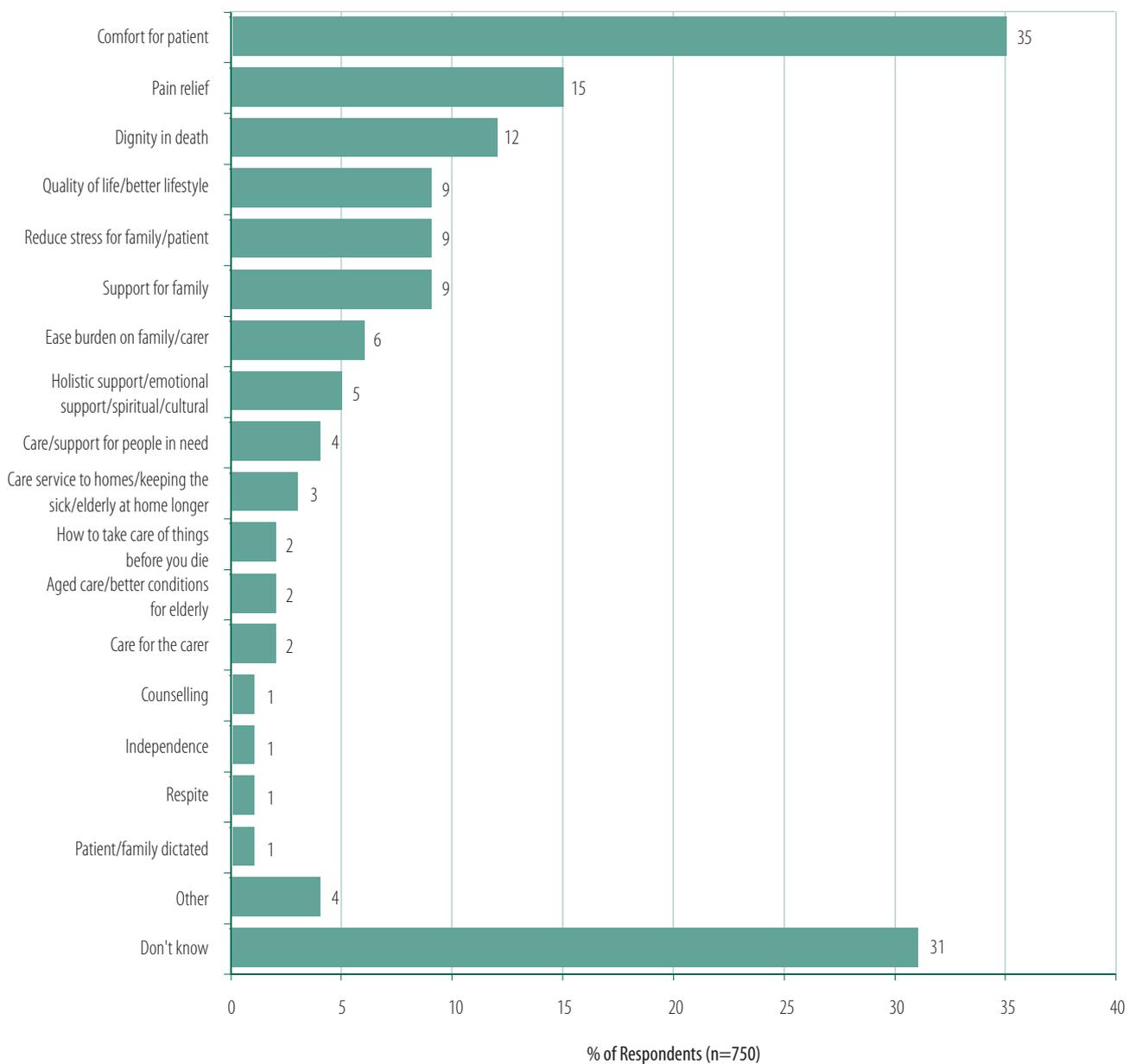
Apart from the recognition of key hospitals that provide palliative care (Mt Olivet and Gandarra) there was not a clear understanding of who would provide palliative care services. Some respondents suggested that nursing or health services such as Silver Chain and/or Blue Nurses might be responsible.

Clearly, palliative care is not as well understood as it should be.
This precludes some people from considering it as an option.

5.4 The perceived aims of palliative care

Palliative care aims to achieve a number of objectives, and this variety of tasks is reflected in the responses given by respondents. While a lack of knowledge continues to be present, the main aim of palliative care is seen to be comfort for the patient and more specifically pain relief.

The theme we have seen throughout this research of older and later lifestage respondents being more *au fait* with palliative care continues here, with 51% of young singles and couples not knowing what palliative care aims to achieve, and 29% and 25% of family and empty nesters respectively not knowing. The ability to articulate the aims of palliative care is higher for the family and empty nester groups than for the singles.

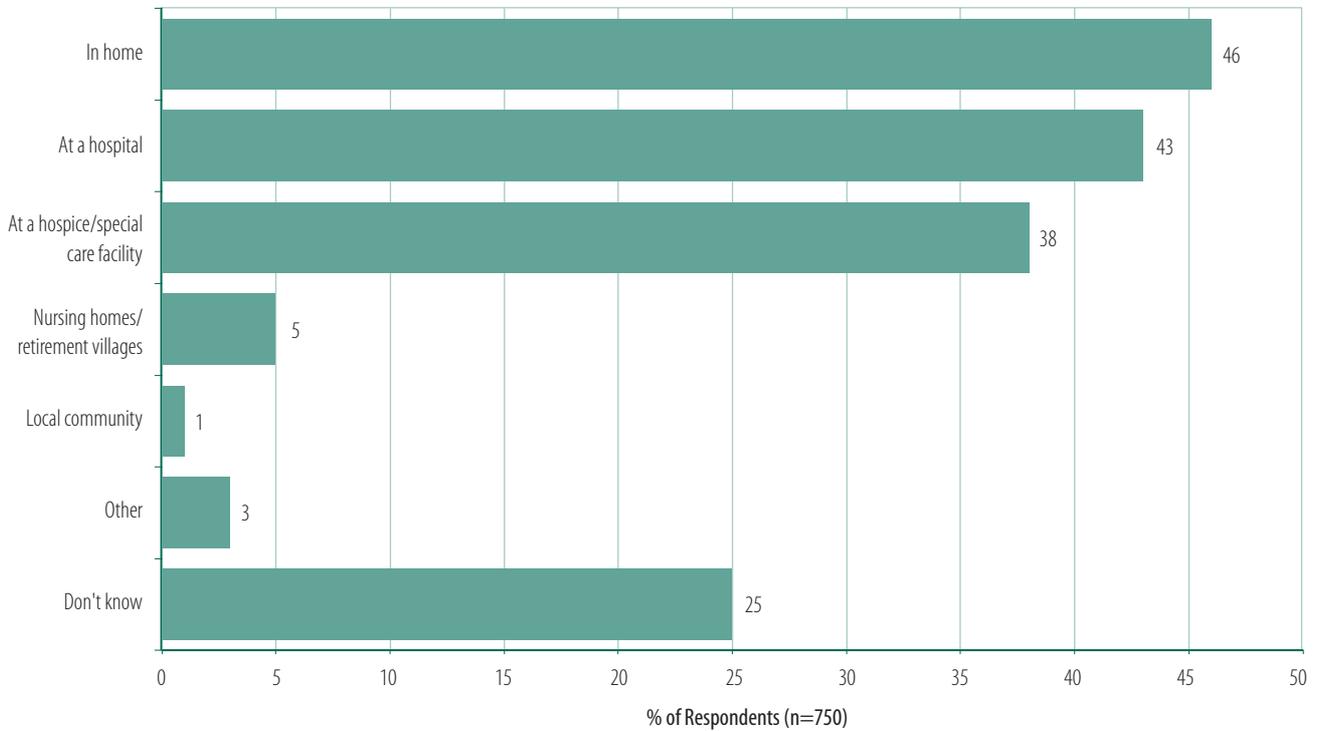


Among those who have been exposed to palliative care in some form there is clearly a higher degree of understanding of a variety of aims of palliative care.

WHAT PALLIATIVE CARE AIMS TO ACHIEVE	Palliative care				Lifestage		
	Aware		Exposure to		Young Single/ Couple %	Family %	Empty Nester %
	Yes %	No/DK %	Yes %	No/DK %			
Comfort for patient	45	6	46	28	22	38	38
Pain relief	20	2	21	11	7	15	18
Dignity in death	16	1	19	7	5	15	11
Quality of life/better lifestyle	12	2	11	9	9	11	9
Reduce stress for family/ patient	12	1	13	7	5	8	12
Support for family	12	1	13	6	4	9	11
Easier burden on family/carer	8	1	8	4	4	6	6
Holistic support/emotional support/ spiritual/cultural	7	-	7	3	3	4	6
Care/support for people in need	4	3	3	4	5	4	3
Care service to homes/keeping the sick/ elderly at home longer	4	1	3	3	2	3	4
How to take care of things before you die	3	1	3	2	-	2	3
Aged care/better conditions for elderly	2	2	2	2	1	3	2
Care for the carer	2	1	3	1	-	2	2
Counselling	2	-	3	1	1	1	2
Independence	1	-	1	1	1	2	1
Respite	1	-	2	1	-	1	2
Patient/family dictated	1	-	1	0	-	0	1
Other	4	3	5	3	4	4	3
Don't know	14	82	15	42	51	29	25

5.5 Perceived location of palliative care

Palliative care is seen to take place either in home, in a hospital or in a hospice. A continued proportion of the sample, do not know enough to answer the question, and these are most likely those who were not aware of palliative care at the start of the survey.



WHERE DO YOU THINK PALLIATIVE CARE TAKES PLACE	Exposure to palliative care		Lifestage			Socio-economic	
	Yes %	No/DK %	Yes %	No/DK %	Young Single/ Couple %	Family %	Empty Nester %
In home	59	37	32	51	48	37	58
At a hospital	55	34	33	44	46	33	49
At a hospice/special care facility	47	31	29	40	39	22	45
Nursing homes/retirement village	7	3	3	7	4	5	5
Local community	0	1	1	1	0	1	1
Other	3	3	6	2	2	1	2
Don't know	10	36	43	21	21	38	17

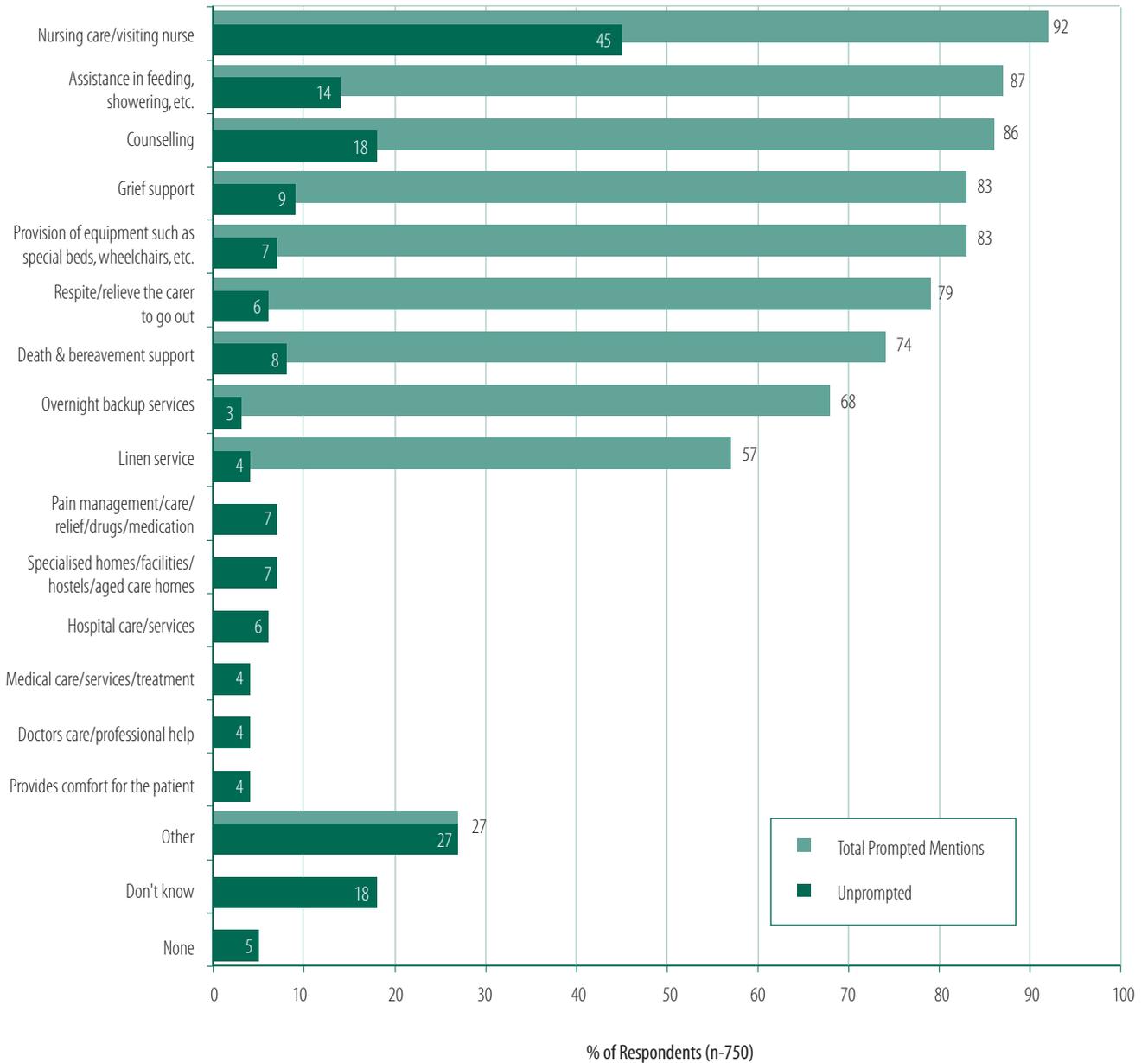
As we have seen throughout the research, the knowledge base of the older age groups or later lifestages and white collar workers is stronger than for their respective peer groups.

However, there is also further evidence here that having been in contact with someone who has used palliative care, while it does ensure a higher level of understanding, it does not necessarily translate into a complete understanding of the issue.

5.6 Provision of services

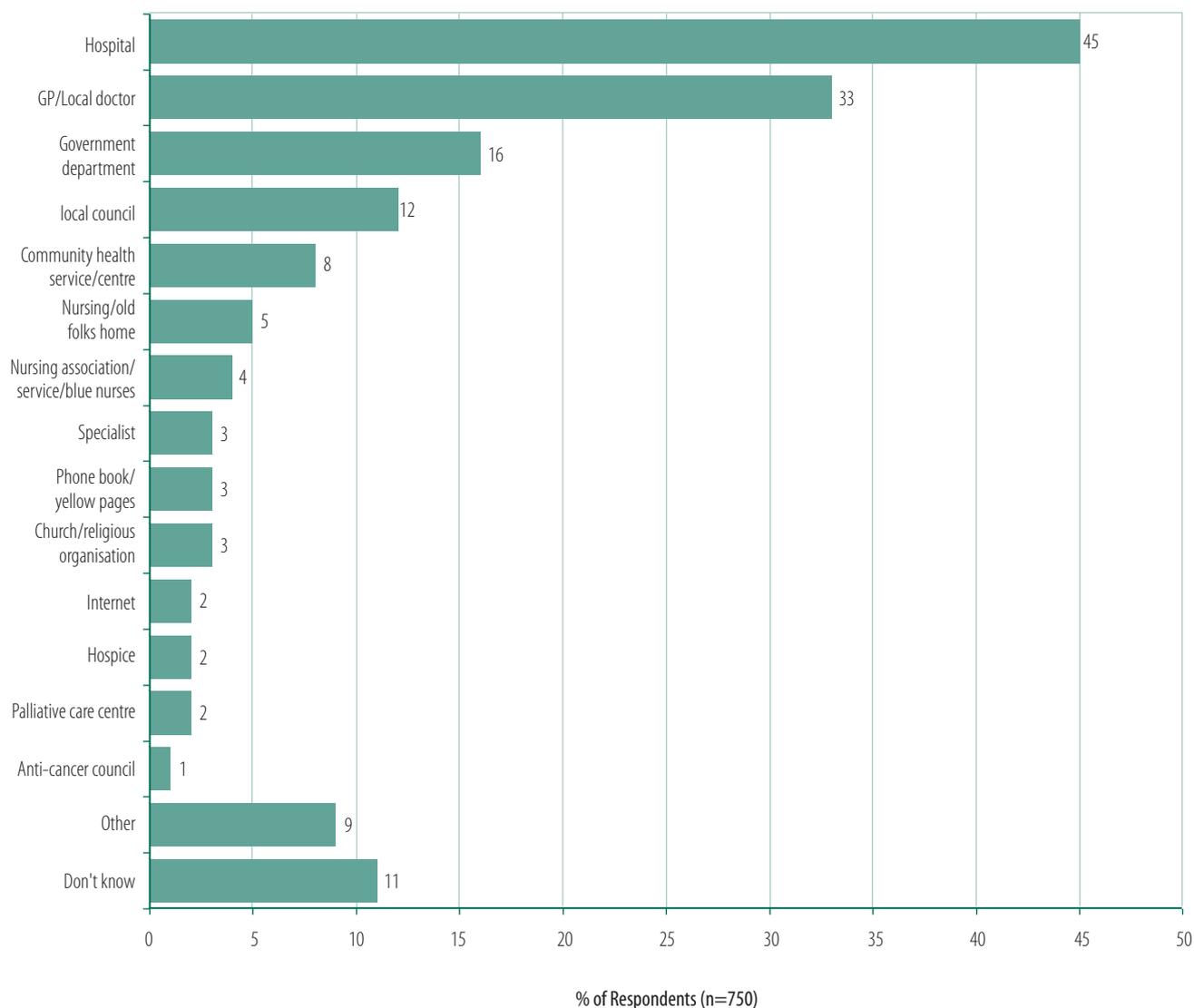
At an unprompted level, there is little awareness of the services that would exist for palliative care, with nursing care or a visiting nurse the most frequently mentioned. This low level of response is driven by the lack of detailed knowledge of palliative care that we have seen during this research.

Upon prompting, there is an expectation that most of the services listed would be provided.



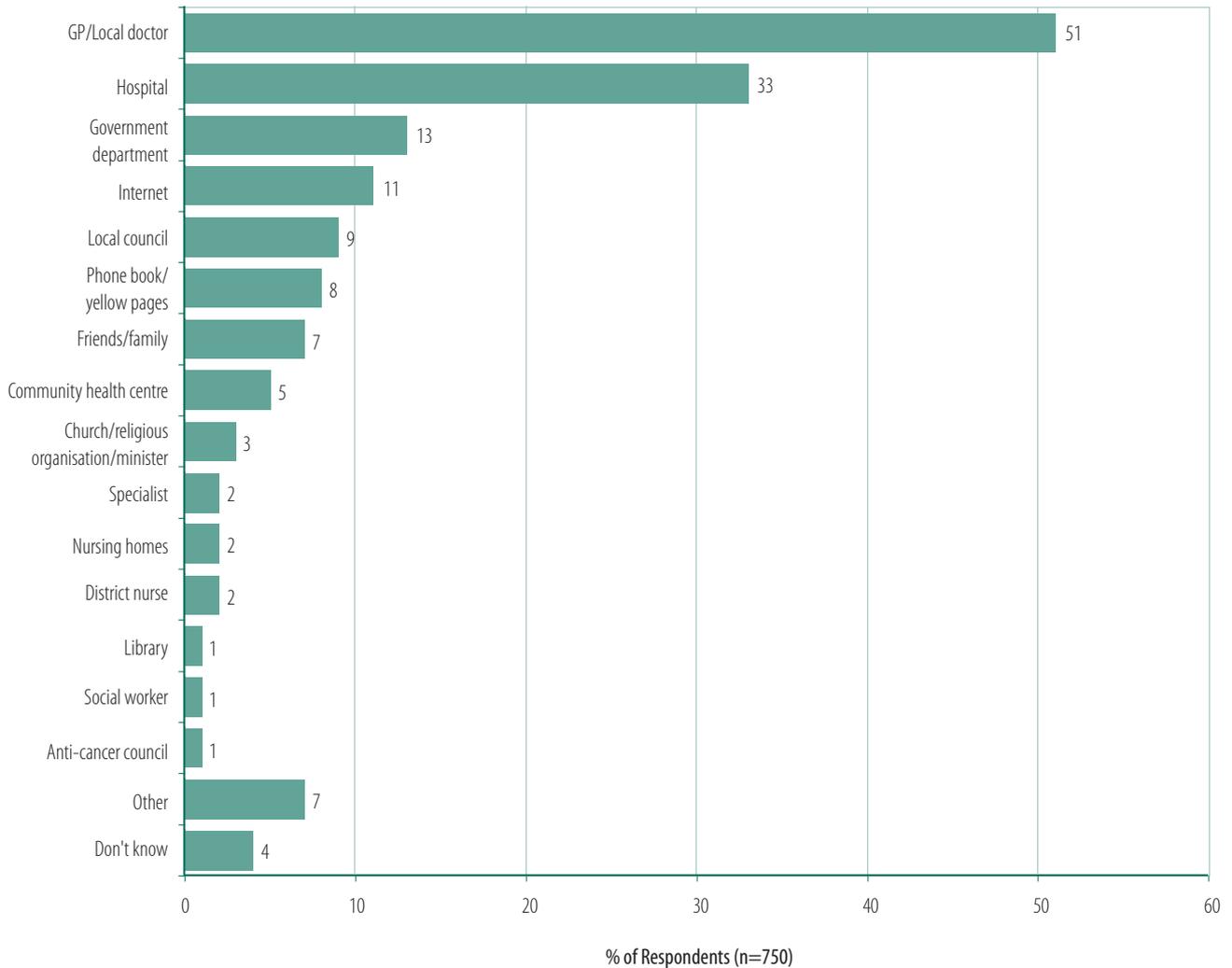
5.6.1 Access to services

It is important to remember that there is limited knowledge of palliative care, as we have seen, so where people might go to access the services (they have just been prompted on) will involve a degree of guesswork. This said, the hospital and local doctor are seen as the main places to go to access palliative care services. There are, however a number of resources that people may go to in order to access these specific health services.



5.7 Information sources

If Australians needed to find out about palliative care, most would turn to their local doctor. The hospital is next on the list, most likely because as we saw in the qualitative research consumers will only look for information if they are in need of it personally, and the hospital is seen as a likely destination if palliative care is needed personally. This confirms the importance of GPs and hospitals as gatekeepers to palliative care services.

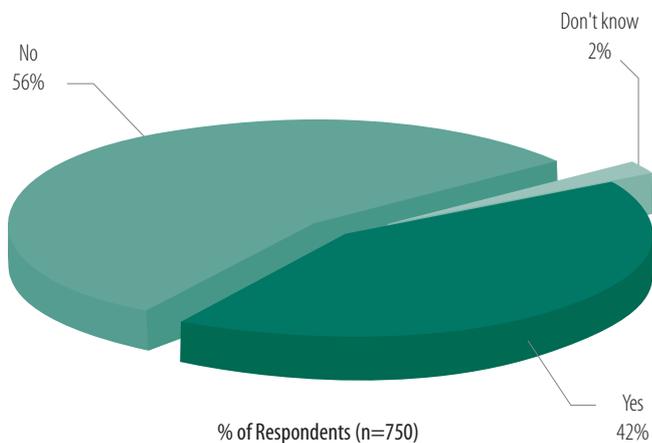


5.8 Exposure to palliative care

Two in every five Australians have had someone close to them require or have access to palliative care. Again this is higher among the older age groups and white collar workers:

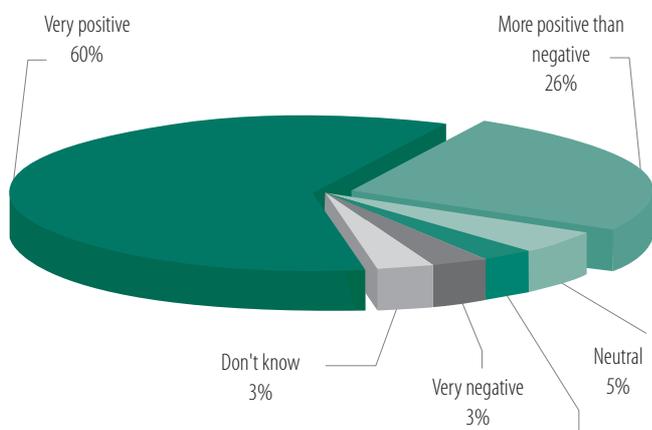
- 18-34 year olds - 26%
- 35-54 year olds – 42%
- 55+ year olds – 54%
- blue collar – 32%
- white collar – 46%

Q13. Have you had someone close to you require or have access to palliative care?



Q14. How do you feel about palliative care as a result of that experience?

As seen in the qualitative research, those who have encountered palliative care in some form or another are touched positively by the experience. The clear majority of Australians in our sample (86%) felt positive as a result of that experience. Only 6% had any negative experiences with palliative care.



5.9 Positive perceptions of palliative care (Qualitative only)

Palliative care's reputation among the community was found to be extremely good. Those who had had direct experience said that it was patient, caring, supportive and definitely delivered on its goals.

Those that hadn't had direct experience also felt very positively about the potential of the service - understanding that those who were going through the experience of death would need support. There was a high level of empathy with how difficult the situation would be for those experiencing it. There was also a sense in which palliative care fitted in with society's value for human life. (This was apart from the small minority of staunch euthanasia supporters, who actually planned to end their lives before the need arose).

"Dying with dignity."

"Care and attention."

"Serenity."

"Contending with the relatives, talk them through."

"Sympathy for the people that go through that."

"They are somebody's mother and father."

"We don't just discard people."

"They deserve it."

Most respondents felt that palliative care 'probably' delivered to its aims. There was also a perception that if palliative care services were poor they would have been exposed in the media.

"You hear about nursing homes!"

"You imagine it achieves its goals."

Those with personal experience of palliative care were unequivocal in their description of the service as excellent. In Quantum's experience of conducting more than 30 research projects in the health care sector over the last few years, this type of positive appraisal of a health care service is incredibly rare. Palliative care services as they are provided across the nation are an outstanding success.

The elements most praised by those with personal experience were:

- The apparently seamless co-ordination of many different types of service providers
- The holistic nature of the service - an emotional support in addition to the physical/clinical management of pain and other nursing duties
- The people who provide the service - particularly their empathy and understanding
- 24 hour service - the reassurance of having someone to call on any time of the day or night.

Universally, respondents perceived that those who worked in palliative care are exceptional people - doing a job that they could not conceive of doing.

"Special people, incredible patience and understanding."

"They wouldn't do it for the money."

"Compassionate."

5.10 Negative perceptions of palliative care (Qualitative only)

There was a stigma associated with palliative care, which appeared to be especially prevalent in Brisbane. In many cases this negative stigma often tied itself to a particular hospice or hospital. In Brisbane, for example, the hospital was Mt Olivet whilst in Ballarat the hospital was Gandarra. Community perceptions of these institutions as negative, harms the message of palliative care and also heightens fears of dying.

“You go there to die.”

“Terrified - it’s a scary thought.”

“Not a happy sort of place.”

In Brisbane, there were associations with palliative care as a place which was one step from the morgue. Some of these negative associations were dispelled when respondents who were less familiar with palliative care understood that it could be provided in the home.

“A place where it’s kind of the end of the care - a waiting room.”

“The end of the road.”

“Where dead people go - you go and you don’t come out.”

Some of the least informed respondents envisaged that palliative care might only be an option given when someone was too ‘out of it’ to make their own decision. There was little understanding that the service was tailored to the needs and requests of the patients. Respondents were concerned at the thought of being terminally ill and losing your ability to make decisions for yourself. When they understood that the patient had active involvement and that palliative care was about ‘choices’ they felt much more positive.

5.11 Making palliative care closer to the ideal (Qualitative only)

In the ideal palliative care scenario that respondents imagined, every individual that wanted or needed palliative care would be able to get palliative care.

As with most types of health care services, respondents wanted to know that it was there should they need it - it would be easily accessible. Respondents wanted to know that they would be able to have the choice to use the service when required.

“Everyone needs to be aware of it - everyone here knows what euthanasia is.”

Also respondents wanted palliative care to be freely available to anyone who needed it, that there was no discrimination in who could avail themselves of the services.

“They need to know it’s not going to cost them anything.”

“Equitable availability.”

Also many felt that the negative stigma would be removed - that dying (and therefore palliative care) wouldn’t be as frightening or morbid as it was currently perceived to be.

“More like a trip to daydream island or ‘Make a wish.’”

“Like the Patch Adams hospital.”

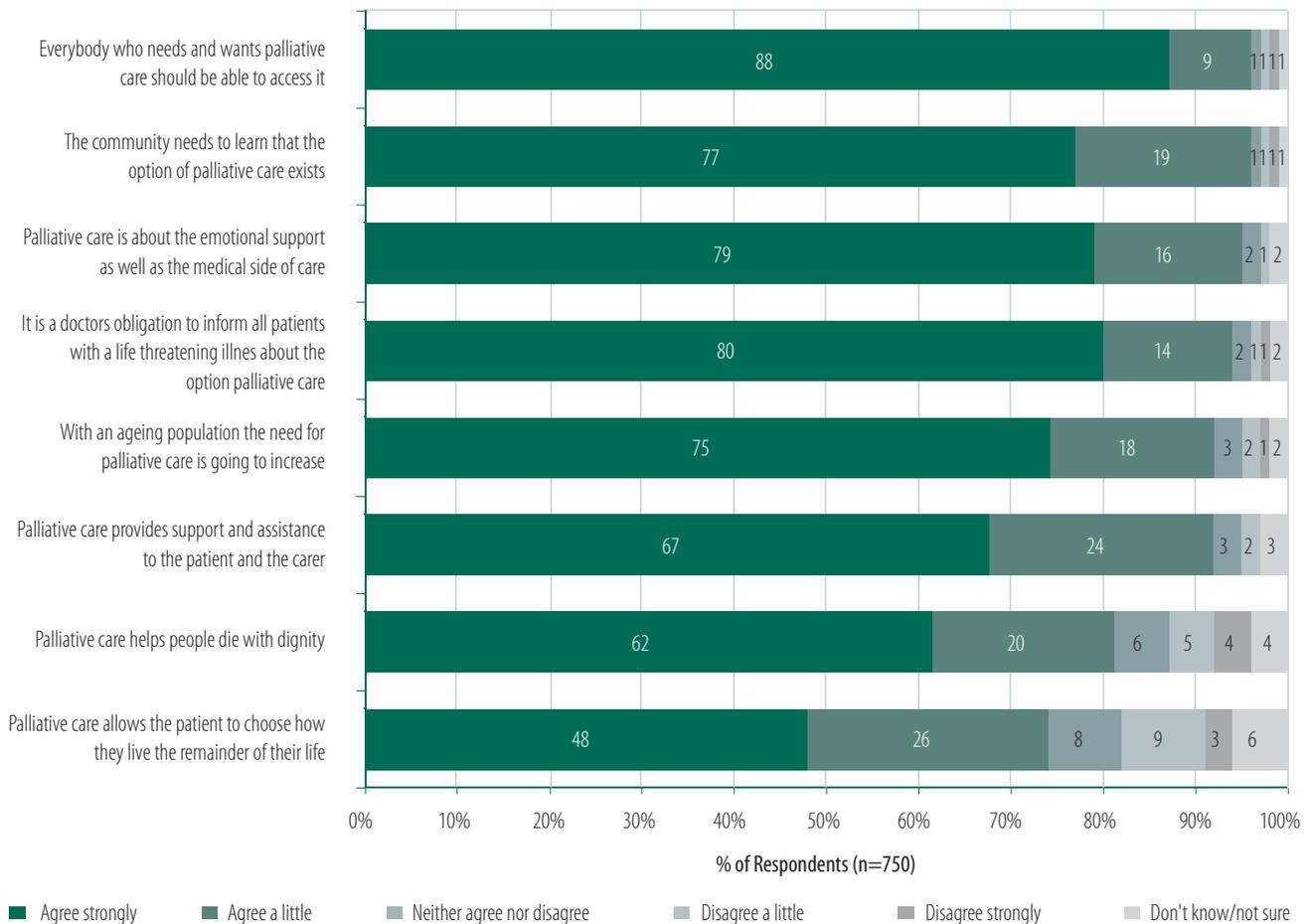
However, in terms of what it is perceived to currently deliver, palliative care, the respect it gives to those who are dying and the support it provides to the families is very close to the ideal.

At present we would say that palliative care awareness does not live up to the ideal because many in the community do not know it exists and therefore have no choice in taking it up as an option when the need arises.

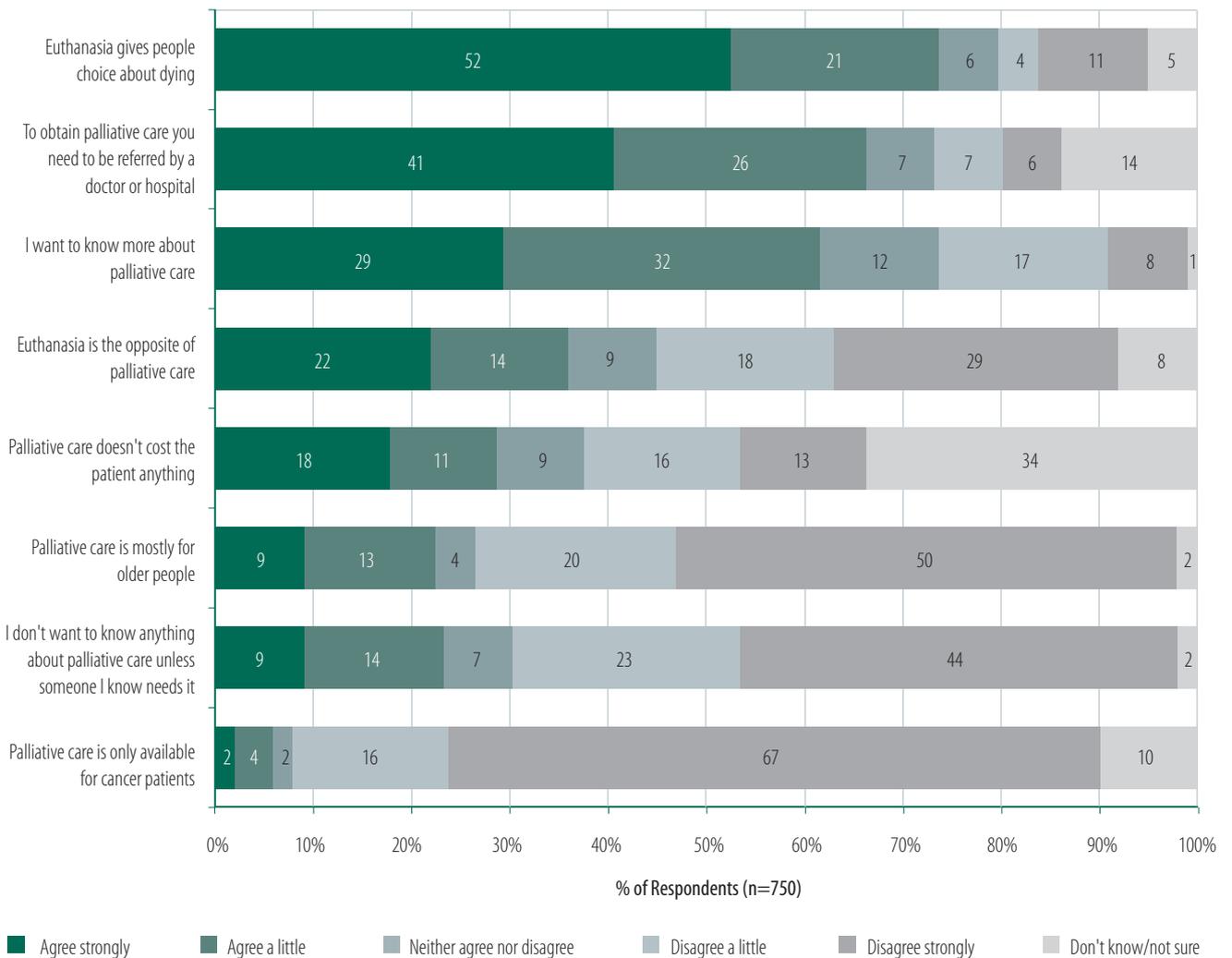
The experience of those who use the service is very close to the ideal.

5.12 Attitudes towards palliative care

There is little doubt in the community's mind that everybody who needs and wants palliative care should be able to access it, with unanimous agreement from the different states, age groups, genders and different levels of exposure to palliative care. There is essentially a very strong level of endorsement on many of the statements and a focus on the increasing requirements of the community in terms of awareness, education and future needs.

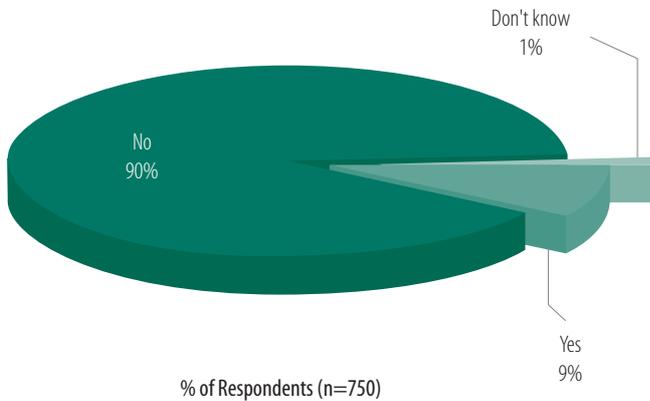


While the strength of conviction varies between the different sub groups, the overall levels of endorsement for any of the statements are fairly similar. The only exception to this is the variation in agreement that palliative care helps people die with dignity. This sentiment is more likely to be believed by older respondents (35-54 and 55+ years) than those 18-34 years old.



5.13 Awareness of National Palliative Care Week

As we experienced in the qualitative research, few people were aware of National Palliative Care Week.



As might be expected, those who are aware of palliative care or those who have been exposed to palliative care are more likely to have heard of National Palliative Care Week.

HEARD OF NATIONAL PALLIATIVE CARE WEEK	Palliative care			
	Aware		Exposure to	
	Yes %	No/DK %	Yes %	No/DK %
Yes	11	2	12	6
No	88	98	86	94
Don't know	1	1	2	0

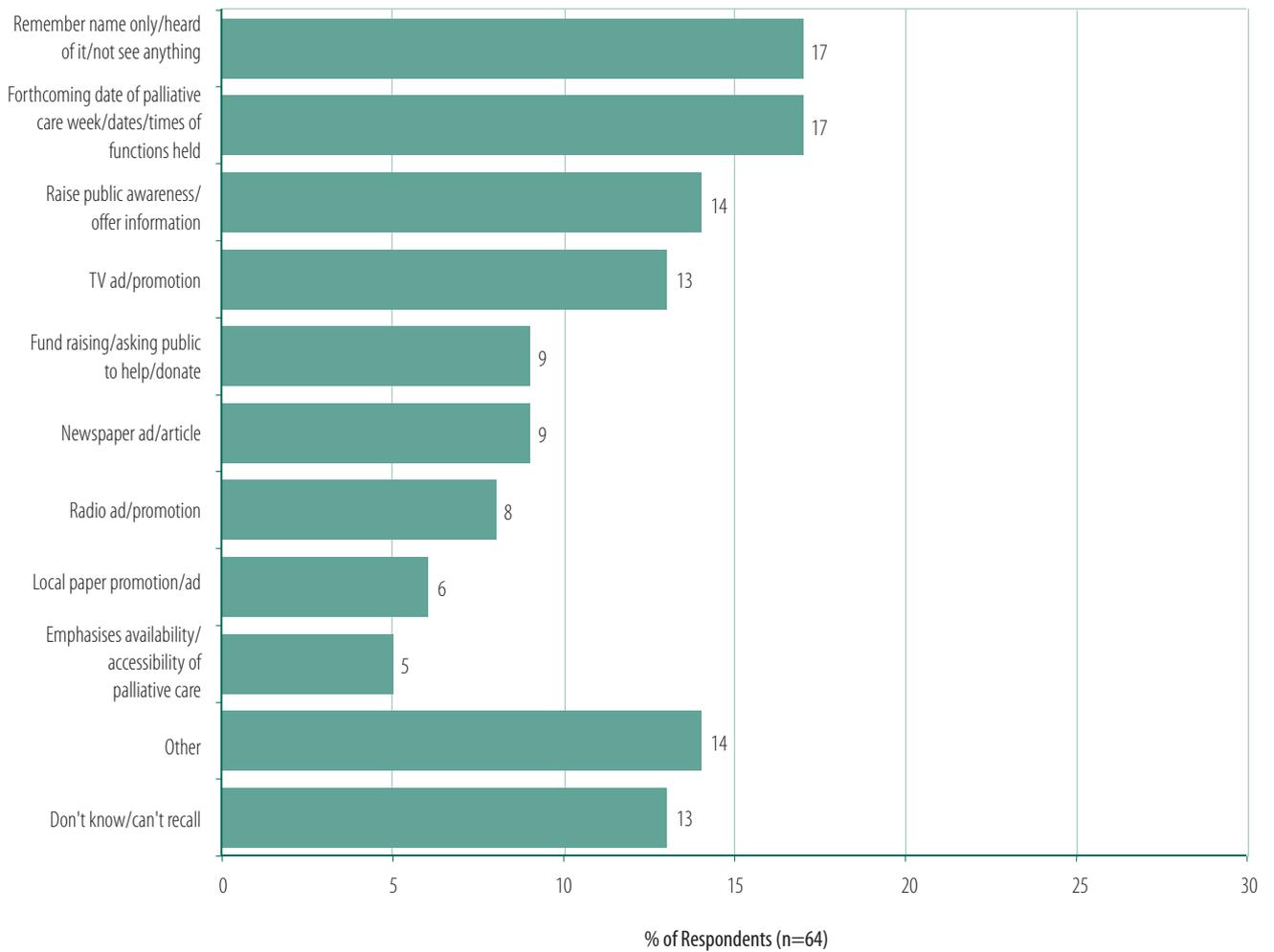
There were no real state differences, and while not statistically significant there seemed to be a slightly higher awareness in regional areas (11%) than metropolitan areas (7%).

In the qualitative research, when asked to imagine what this event might involve (when they weren't aware of it already) respondents generally thought of fund raising. This suggests that the most effective way to communicate to the community is through fund raising. For example, Bunbury residents had a high level of awareness of palliative care and the people involved, through their fund raising initiatives. In this town, there was a community event, an Australia Day BBQ/sausage sizzle, held each year, to celebrate the lives of those who had died.

In addition, many of those with personal experience of the service were so grateful for what it provided that they wanted to contribute. They themselves often made donations, but they could also be mobilised to build community awareness.

5.13.1 Detailed recall

For those few who had heard of National Palliative Care Week, few had any further knowledge of the event than the name, the fact that it had been promoted, or the dates.



6. MAIN FINDINGS — SERVICE PROVIDERS (QUANTITATIVE ONLY)

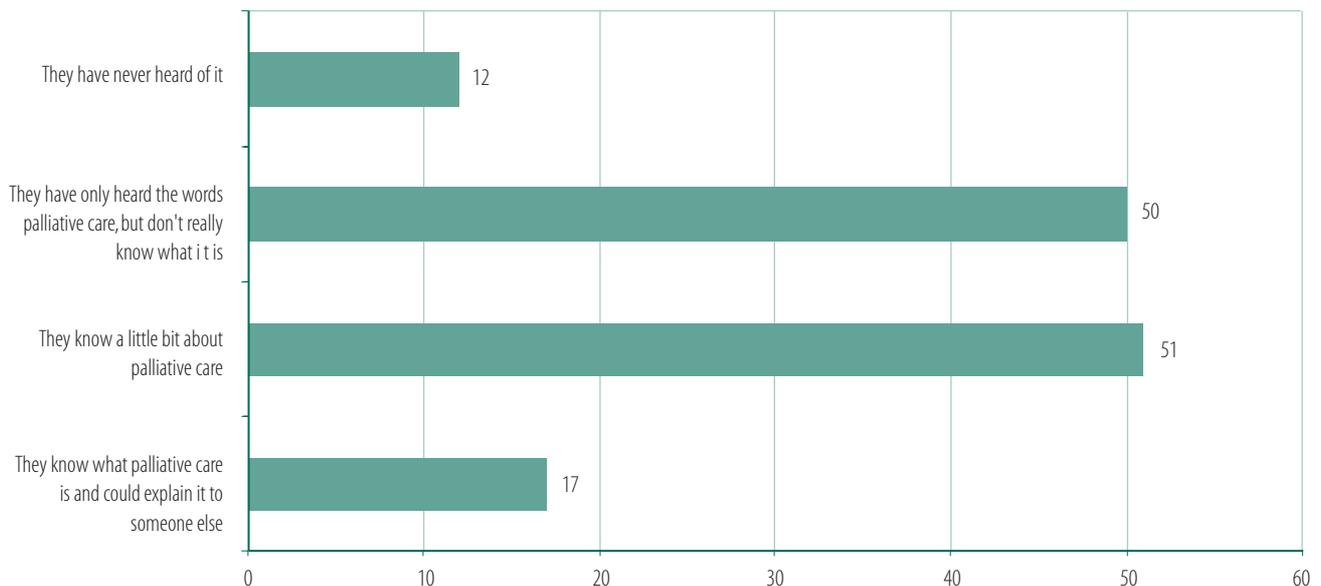
6.1 Patient awareness & understanding

As we saw in the community research, there is variation in different people's level of understanding. While one might expect that those who have been referred to a palliative care facility would have greater than average knowledge of palliative care, this is not always the case. Many of the service providers claimed some of their patients had more knowledge than others. There seemed to be a sense from service providers that the level of knowledge varied depending on where the patients were referred from.

Overall, from the service providers' viewpoint, there appeared to be relatively limited patient knowledge and understanding about the notion of palliative care when they were first referred.

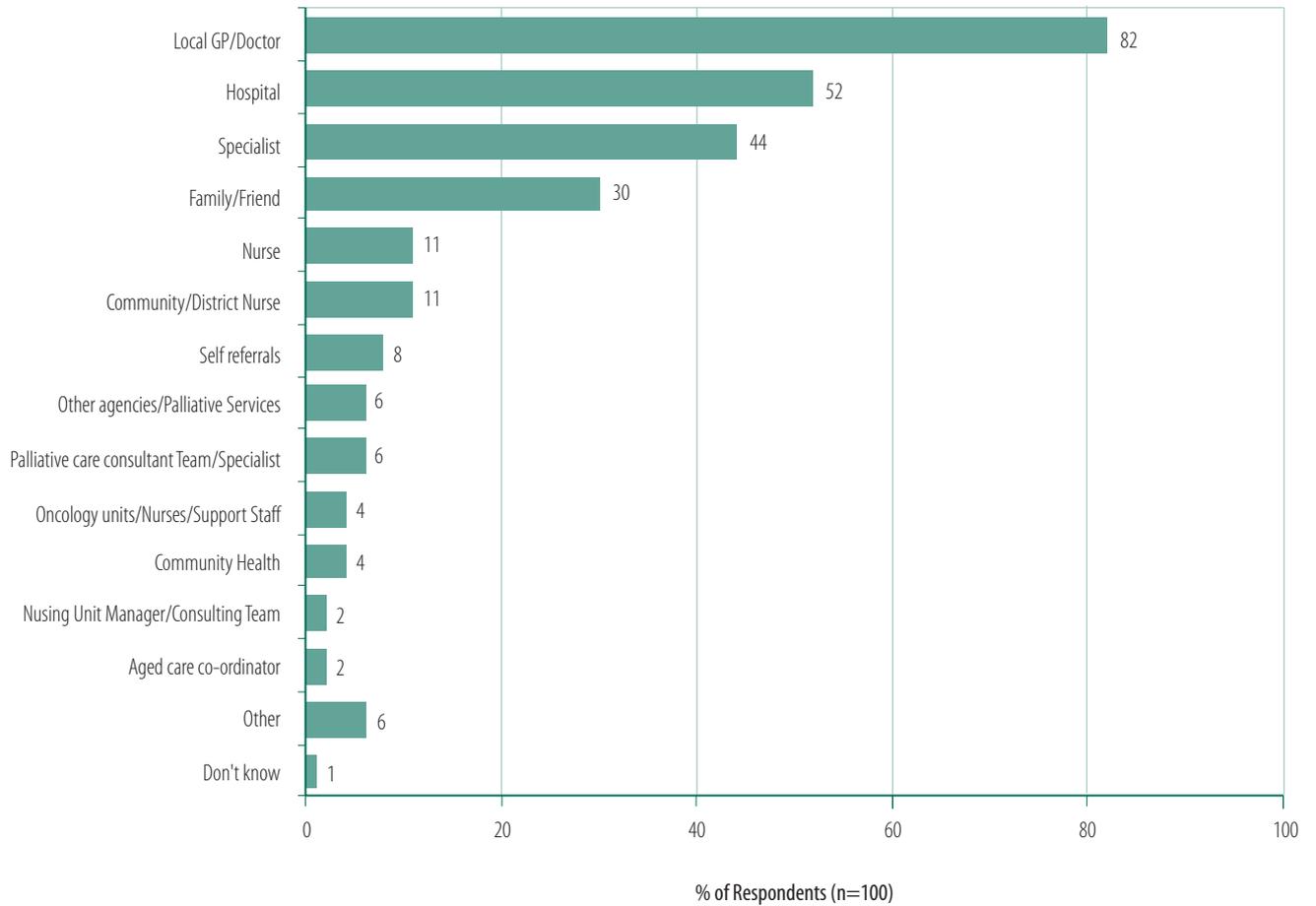
Half the service providers claimed that their patients had only partial knowledge and didn't really understand what it was, compared with 17% who claimed that their patients had a good understanding.

Comparing awareness and understanding of palliative care across regional and metropolitan areas, there seemed to be relatively limited variance.



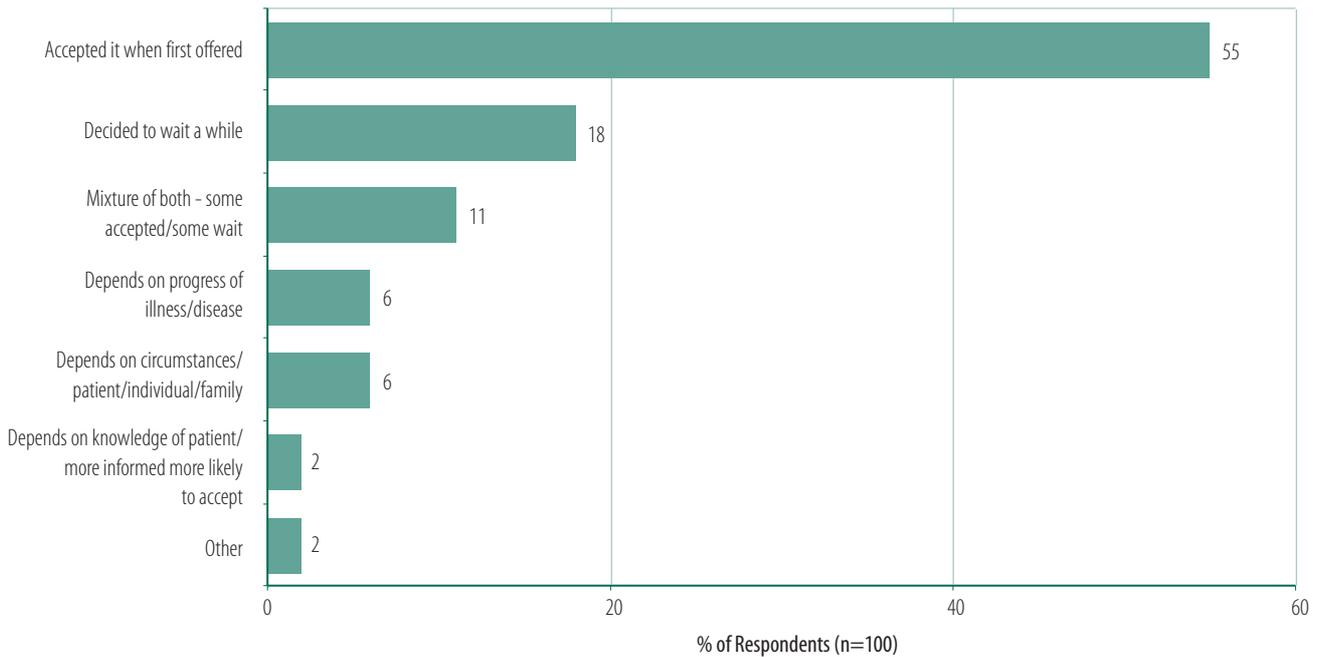
The overwhelming majority of service providers (82%) claimed that their patients were first recommended palliative care by their local GP or doctor.

Hospitals, specialists and even family and friends were often catalysts in recommending palliative care while only 8% of referrals were viewed as self referrals by service providers.



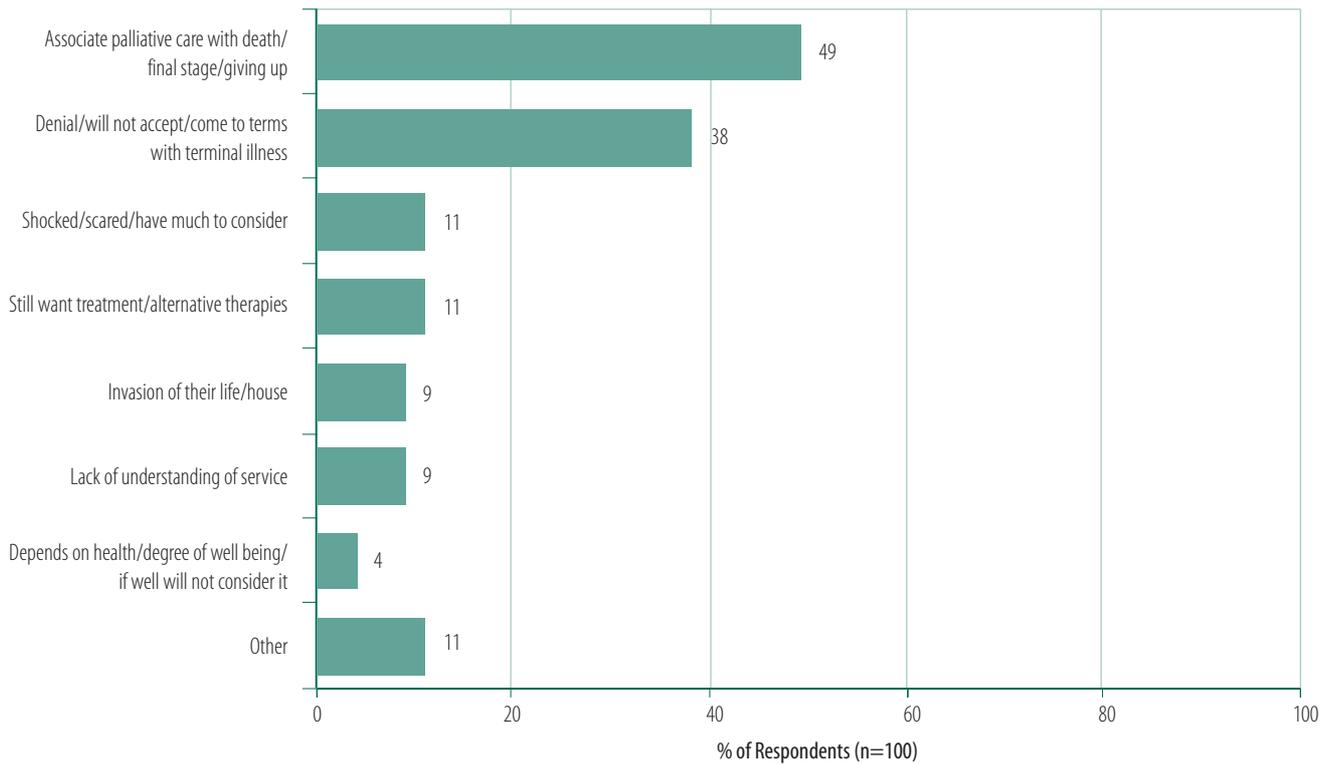
6.2 Patient reactions to palliative care

By and large, there appeared to be quite a significant acceptance rate of palliative care when it was first offered to patients. More than one in two (55%) service providers claimed that patients generally accepted palliative care when it was first offered to them, compared with 18% of service providers who stated that patients initially decided to wait a while.



Service providers believed that one of the primary reasons for patients deciding to wait before accepting palliative care was that patients associated it with death or giving up. Another major reason for patients not initially accepting the care was believed to be the patients' denial and struggle to come to terms with their terminal illness.

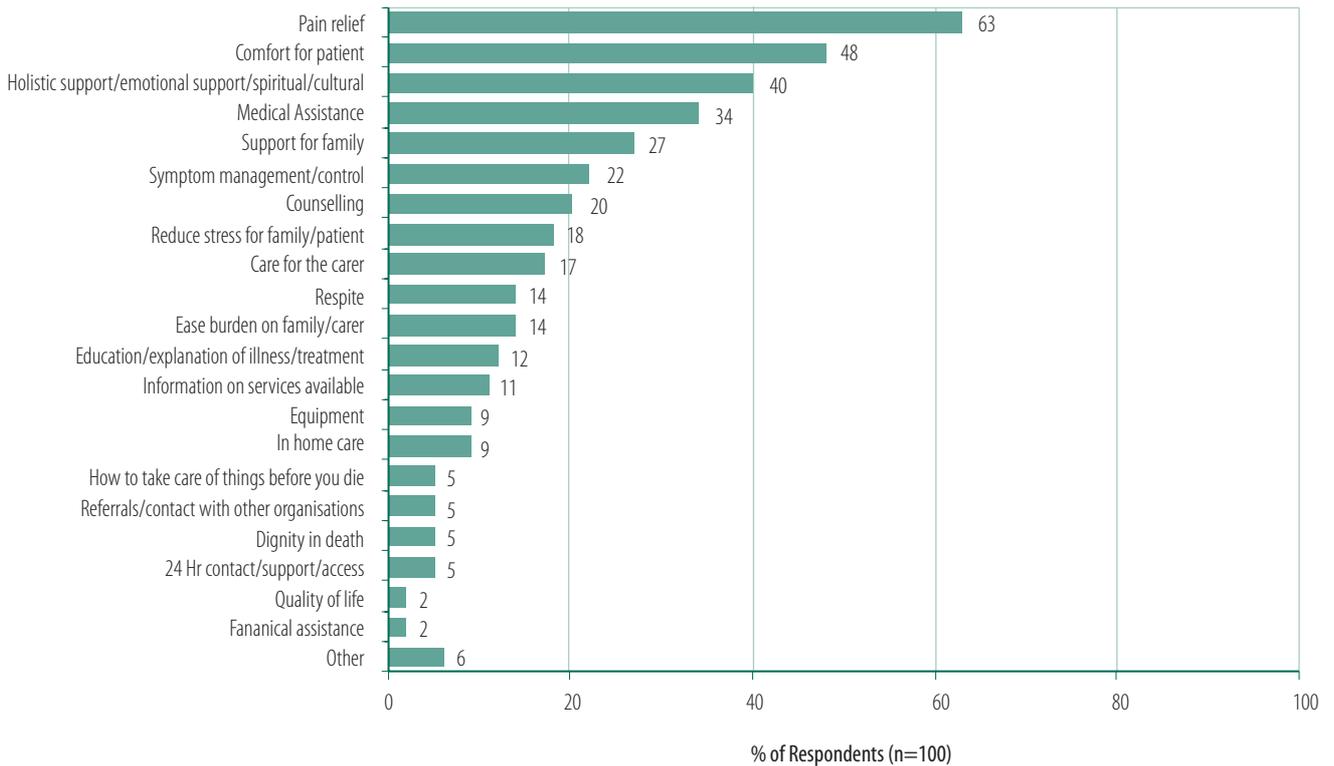
Overall, a large majority of the reasons for postponing palliative care appeared to be more emotional, rather than rational in the eyes of the service providers. Palliative care is viewed by many as the final stage before death, which a lot of patients had trouble coming to terms with. This perception of palliative care is widespread, and people are unwilling to accept it until they feel there is no hope left for them.



A change in perceptions of palliative care is required in order to assist greater use of the service.

6.3 Key needs of palliative care

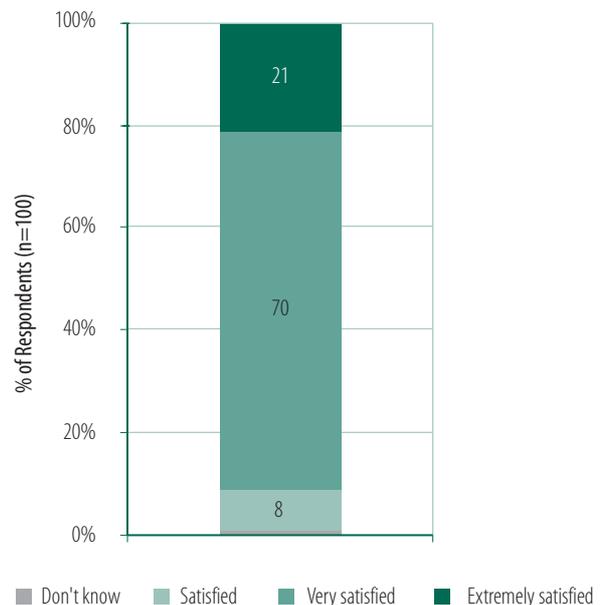
Service providers believed that palliative care serves a large number of purposes and as such, they supplied a huge variance of responses. Principally however, they believed that the key aim, as seen by their patients, was pain relief (63%), followed by comfort for the patient (48%) and holistic support (40%). This is in line with key objectives of palliative care.



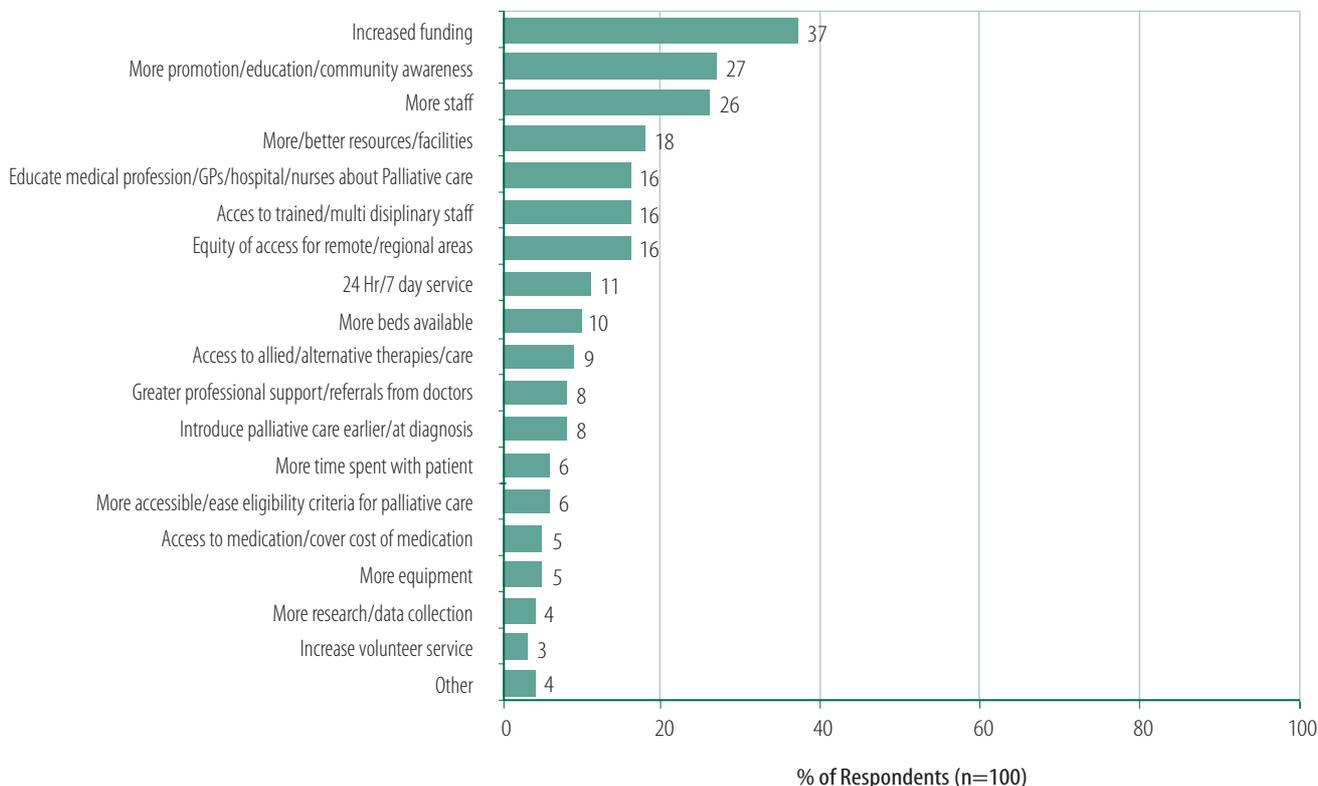
6.4 Palliative care satisfaction and improvement

Overall, satisfaction levels for palliative care were perceived as exceptionally high amongst service providers, with 9 out of 10 believing that their patients were at least ‘very satisfied’ with the service they offered.

Service providers did not perceive any levels of dissatisfaction amongst their palliative care patients.

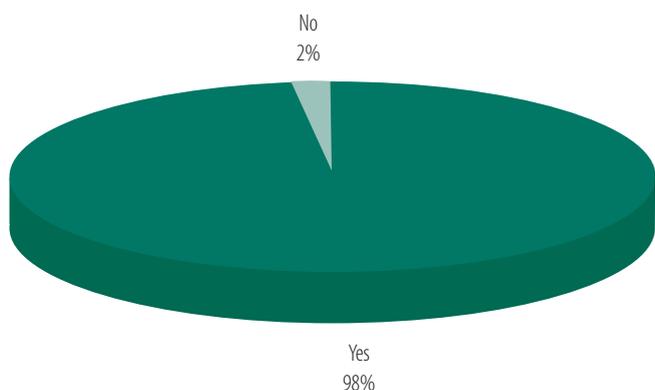


Suggested improvements for palliative care were chiefly based around resource development with the most significant improvement being related to increased funding. 'More promotion and greater community awareness' and more staff were also a significant responses.



6.5 Awareness of National Palliative Care Week

As might be expected, there was extremely high awareness of National Palliative Care Week amongst the service providers. Of those who were aware of National Palliative Care Week, 33% were in some way or another involved in the event. Service providers generally heard about National Palliative Care Week through a range of events and functions as well as through general public awareness campaigns.

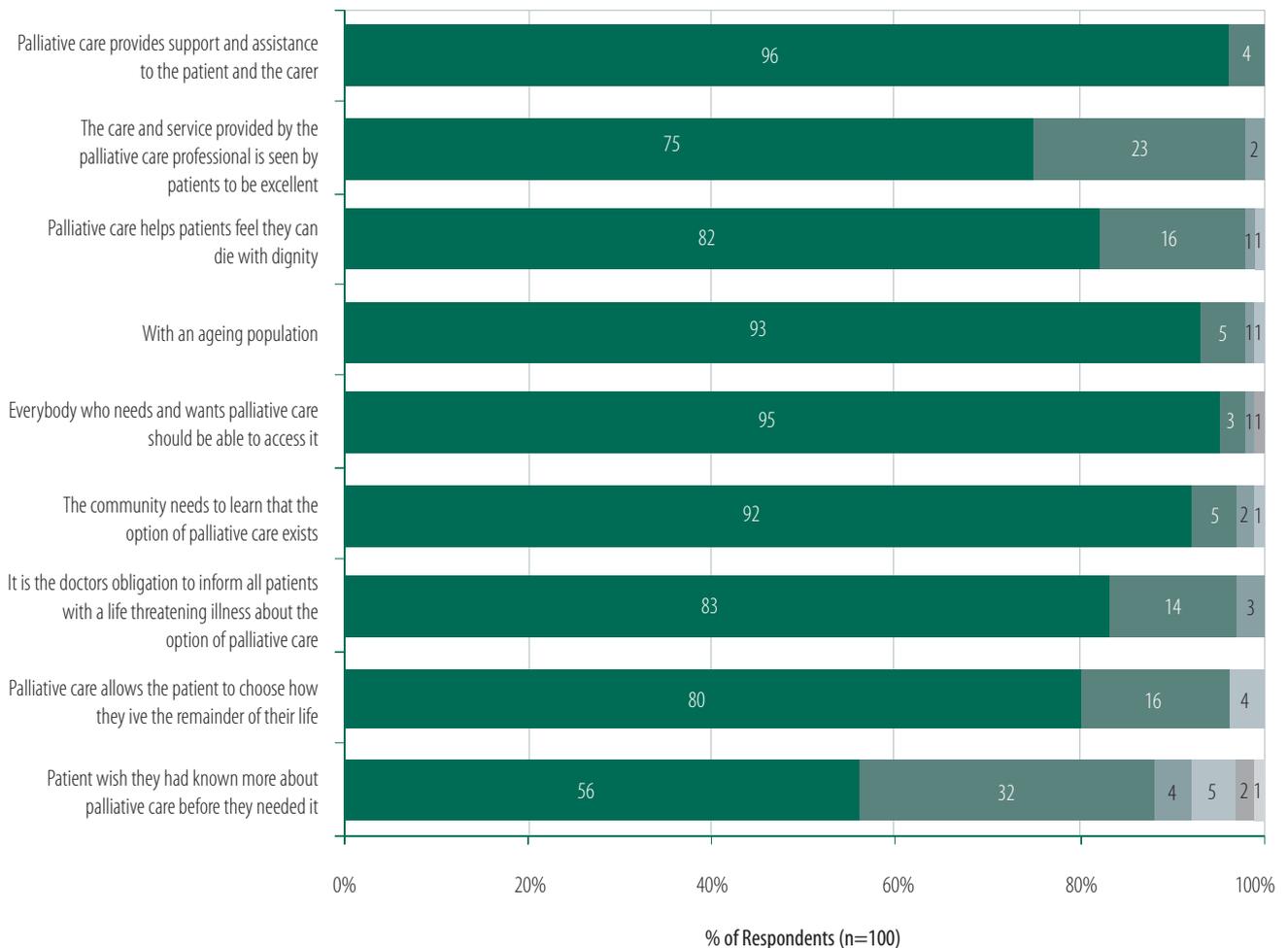


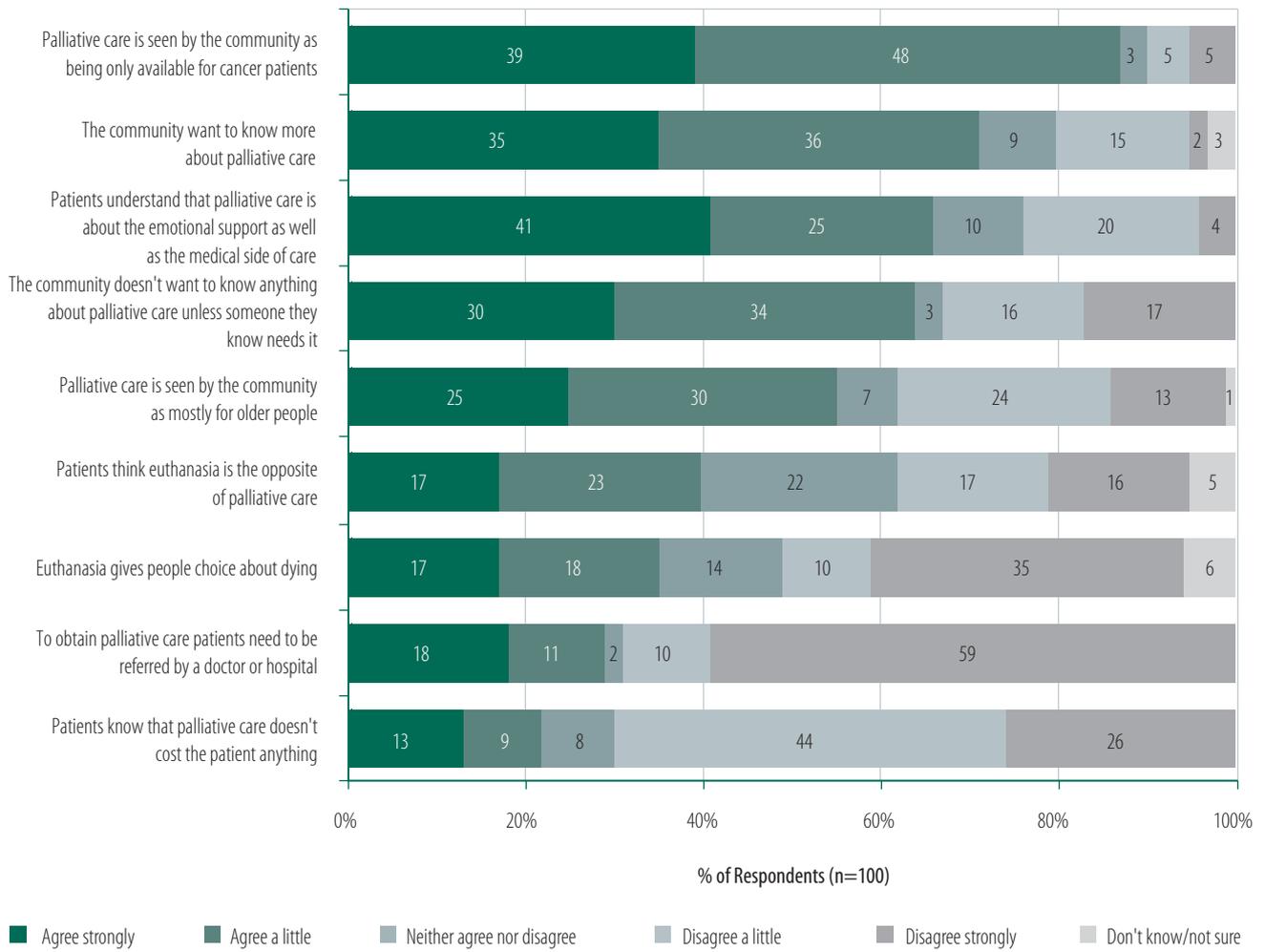
6.6 Overall perceptions of palliative care

Not surprisingly overall, service providers had very positive feelings towards palliative care and had widespread appreciation for its worth. Overall, their major concerns seemed to be related to the lack of patient and community awareness and understanding.

Endorsement was high across most statements, particularly for the fact that ‘palliative care provides support and assistance for both the patient and the carer’, gaining 100% agreement.

Service providers also strongly believed that ‘palliative care should be able to be accessed by everybody who needs it’, and that it ‘helps patients feel they can die with dignity’. They also supported the notion that ‘the need for palliative care is going to increase with our ageing population’, perhaps making the need for resource improvement even more crucial.





Remaining consistent with previous findings, service providers also strongly agreed with the statement that ‘it is a doctor’s obligation to inform all patients with a life threatening illness about the option of palliative care’ as well as that ‘the community needs to learn that the option of palliative care exists’.

The strongest disagreement expressed by the service providers was regarding the cost of palliative care, with 70% of providers disagreeing with the statement that ‘patients know that palliative care doesn’t cost the patient anything’. There was also quite significant disagreement with regard to ‘patients need to be referred by a doctor or hospital to obtain palliative care’.

7. DETAILED FINDINGS — HEALTH PROFESSIONALS (QUALITATIVE FINDINGS ONLY)

7.1 Differences in emphasis from the general community

It was very interesting to understand the different perspective that professionals working in the palliative care area took when compared with the general community.

Many professionals (especially nurses) had come to be involved in palliative care through experiences in their own lives. Most interestingly, for the palliative professionals we spoke to (not doctors) death had no fear/stigma attached to it, which was quite different to general community attitudes.

“I lost my sister through bowel cancer and she was asking questions that I couldn’t answer.”

Most importantly, professionals spent a lot more time talking about their carer focus - not purely the patient who was dying. This once again was quite the opposite of discussions with those in the community (with the exception of current patients and families and those who had had the experience of palliative care at first hand).

“The patient and the family are the unit of care.”

Unlike in the community, where palliative care was most closely linked with older people, within the industry, palliative care was most often associated with cancer patients. Some professionals suggested that this was because cancer organisations had been instrumental in the establishment of palliative care services.

7.2 Key areas for improvement

Essentially, funding is an issue which affects most health service providers, and professionals in the palliative care area are well aware of this. Nevertheless, many of the palliative care services are constantly being stretched to keep up with the demand. Some have even found that in an effort to prevent their staff suffering ‘burn out’, they have needed to carefully plan and manage their case loads. It is important to note however, that palliative care providers in their need for funding always placed the need for the service to continue and the needs of the patients over and above their own needs. (e.g. the desire for more equipment to provide to patients in need came over and above extra staff.) In all the interviews conducted with professionals it was apparent that those involved in palliative care work were very selfless in their application to their work and took on a high degree of personal responsibility for the care they provided. We found the high expectations that they placed upon themselves helped deliver the best possible level of care they could which was outstanding. There was no blaming of funding or other factors for the standard of care or service delivered.

However, within this study different levels of funding were clearly noticeable. In some states incontinence pads had to be purchased by patients, in others not for profit organisations had to actively fund raise to continue providing some essential equipment and services. In other areas it was apparent that state governments were more supportive.

Lack of funding flexibility and strict funding criteria were thought to be limiting the availability of the service for those in need. The difficulty of getting funding approved was of concern in some states. For example, some providers noticed that unless secondary cancers were stated in the referral documentation that funding might not be approved (even if the patient was terminally ill). In addition, funding of long term illness was thought to be problematic. There was thought to be an opportunity for those with other degenerative illnesses such as motor neurone disease and cystic fibrosis to also benefit from palliative care services but the prolonged nature of their illness generally precluded them from the palliative care system.

Interestingly, despite most providers feeling that their resources were currently stretched, some felt they were under pressure to extend the areas in which they provided services – for example into juvenile palliative care. This was an issue because most were concerned that they meet what they considered a minimum standard within their current service areas, before they attempted expansion or refocus.

Location also had an impact on the levels of service which could be provided. This is particularly the case in rural areas where long distances meant that staff could not provide care for as many patients as they might be expected to or wish to. This led to an unequal level of accessibility of palliative care services in more remote areas.

Most health professionals were very concerned about the future of palliative care funding. They perceived that with an aging population the demands on their services would be increasing and yet their budgets might not be. They also envisaged a shortage of specialised staff. Many acknowledged that the current palliative care staff tended to be older and would therefore be retiring in the not too distant future, therefore they were concerned that there was no succession planning in place and that younger staff were not being attracted to come into this specialist area.

Late referral was also thought to be a major issue which affected the quality of palliative care provided. When patients were referred to palliative care providers very close to the time of their death, there was less potential for the patients to get to know and feel comfortable with the palliative care staff. This limited the emotional support side of the service which could be provided. Providers considered that this emotional support was much more able to be provided when the patient was more conscious of their environment, able to be involved in the decision making and could feel comfortable with the new faces caring for them. Many believed that late referral was connected to the fact that doctors, patients and families were not willing to give up hope – that the acceptance of death was fatalistic. There was also some link between late referral and extensions to oncology nursing in some locations, which included in-home patient visits – so that the presence of the palliative care nurse was perceived to be less necessary.

“We don’t get to know a lot of the really sick patients coming out.”

“Their reluctance revolves around the often unconscious decisions not to face the fact that the curative treatment is no longer appropriate and in fact in some cases is harmful.”

7.3 Information sources and distribution

As palliative care services and funding varied widely across the country so too did awareness of palliative care associations. Their profile varied in the different states involved in the study. This had a strong impact on key information sources. Where the palliative care associations had a high level of awareness they were seen to be instrumental in distributing information within the profession. However, in other areas (regional in particular) there seemed to be little formal networking amongst professionals – although there was considerable sharing of resources in other ways (through the fact that due to the smaller number of providers staff were more familiar with them and could call them personally if they felt there was an opportunity to share resources).

“We are part of a network, doctors, hospitals and carers.”

The key type of information that professionals sought was some kind of understanding of government policy and strategic direction in regard to palliative care. Given providers concerns about the aging population outlined above it is not surprising that they were seeking reassurance of governments future plans for palliative care.

However, other than an understanding of government planning and priorities there was thought to be little need for additional information. Most practitioners felt that their on-going training journals and on the job experience provided them with adequate information.

One key suggestion which many thought would be helpful was some way of centralising the accessibility of resources for palliative care. For example, if a particular service provider could not offer a wheelchair that there might be a central database where they could locate one. Given the multiple providers of palliative care services it was hoped that ways could be developed to work together rather than constantly competing for additional resources.

“Lists of equipment that we can hire. We really need more equipment.”

“A single database of what is available and who’s eligible.”

Another suggestion made by those in regional areas was that there could be some kind of job exchange between city and country areas so that those working in city areas could have an idea of what the barriers were to working in country areas.

7.4 Awareness in the community and amongst other health professionals

Health professionals were well aware that the community generally had low levels of awareness. Understandably given their own strong interest in the area they felt that a much stronger community understanding would be very beneficial. Many of them had tried to effect change in community understanding of palliative care, but had not been as successful in their attempts as they would have liked.

“A lot of them don’t know much about it until we go out and meet them.”

“In a nutshell community awareness of palliative care is poor.”

They also understood the barriers behind community reluctance to engage with palliative care. It was thought to reflect the overriding fear of death in western society.

“People are not comfortable – they go into denial.”

“We’ve got a difficult message.”

“The community shuts down.”

It was believed that lack of interest in the topic in the media was a major stumbling block to gaining a better understanding of what palliative care is.

“The media have no interest in promoting it.”

Professionals were keen to see the level of understanding increased and the terminology used to describe palliative care simplified.

“Care for the dying and their families.”

However, it was the poor level of awareness and understanding amongst other health professionals which palliative care providers were most concerned about since they well understood that they relied on other health professionals for referrals.

“Health professionals awareness is on a parallel to that of the community.”

“At the moment because patients are not fully aware of palliative care the choice and power over treatment is left in the hands of medical staff (namely surgeons).”

“In private hospitals especially, where there are no health care specialists on staff, eg social workers, pain management – how would the patient have access to pall care unless they asked?”

Palliative care professionals suggested that the poor understanding on the part of other health professionals precluded some in need within the community from receiving the service.

“Often doctors (GPs, surgeons and consultants) don’t have a good appreciation for palliation (they don’t know exactly what it is, don’t understand its aims) and may be reticent to refer patients”

Quantum suggests that considerable effort should be expended to make other health professionals more familiar with the benefits of palliative care. One suggestion would be that trainee doctors be encouraged to accompany palliative care workers on in-home visits to really understand the service provided.

7.5 National Palliative Care Week

Professionals within the palliative care industry had very varied associations with National Palliative Care Week. These varied from absolutely no involvement in any activities nor any understanding of what was involved to major public relations and fund raising efforts on their behalf as well as attendance at a number of industry related events. Some professionals believed that National Palliative Care Week was just as important for those within the industry as for the community, as it was an opportunity for the hard working palliative care staff to congratulate themselves on what they had been able to achieve (not that they seemed to need or search for such recognition).

7.6 Making palliative care closer to the ideal

Palliative care providers were naturally interested in overcoming funding hurdles, however they saw increased awareness and understanding of what palliative care could offer as central to improving what palliative care can provide to the community. The primary audience for this message was health professionals with a trickle down to the harder to reach audience - the community.

“It’s not about drugging someone to the eyeballs it’s about comfort and quality of life.”

“It’s about caring for somebody right through to the end of their life.”

8. EXPERT INTERVIEW SUMMARY

Interviewee: Professor and Director of a palliative care unit

Key issues:

- Clinicians do not really understand community, and have no real commitment to community. Bureaucrats have a better understanding of community than the clinicians, but they are constrained by the federal versus state split between funding and provision. Federal Government doesn't supply provisional health services, so all they can do is provide guidelines and hope to be able to influence policy using inter-departmental relations.
 - Clinicians and bureaucrats think they have common understanding that palliative care is the clinical, professional provision of care, and they feel that the community exists to do two things. The first of these is to locate clinical services among them (community based palliative care) and secondly to have a "paternal, patronising attitude to educate the community" about the services that are there.
 - There are many people who believe palliative care is only terminal care, specifically the last few weeks of life. In the palliative care community itself, there are a lot of people that resist this image of palliative care. They see palliative care as care of people who live with a life limiting illness, for which there is no cure. This means palliative care can be care of people some years before they die. However, the Federal Government doesn't want to hear that.
- There is significant variation in referral patterns, essentially because of a type of inter-occupational territory dispute or more simply put, a "culture clash".
 - Oncologists think the palliative care people are coming in too early. Furthermore, oncologists think the palliative care people are the "death people", so they don't want to give them up to palliative care, because they think it's sending the wrong message to the patient, that they're giving up hope on them.
 - The palliative care people think oncologists are letting their patients go too late, and believe that the Oncologists tend to be in death denial.
- Another key issue is how palliative care defines itself, and the fact that there isn't even agreement within the palliative care area.
- Inequality of service provision.
 - Currently palliative care is fine if you know a good doctor and a good palliative care service. For those who live in the outer suburbs or regional areas there's not much (good) palliative care, so it's more elitist. Community can be active, and this is necessary. The history of Public Health in the last thirty years has shown that people are interested in their own health, and given half a chance they would be interested in their own death and loss as well.

Priorities for improvement in palliative care:

- The development of a public health approach to palliative care should be funded immediately. There should be priority funding given to community development, policy development, social research, and death education. And this should occur, not only in patient populations, but should be part of the in-service training, and curriculum design in medicine, nursing, social work, pastoral care.
 - Palliative care needs to understand the community, which can only be achieved through a public health approach. palliative care needs to stop patronising the community, and will then go a long way to developing a good, strong system that supports death, dying and loss.

- Barriers need to be broken down. The first barrier is between the bereavement care sector and the palliative care sector. They're often not connected. It needs to be seamless around the issues of death, dying and loss.
- Break down bereavement care. People who do counselling and group work and such would have nothing to do with palliative care. Get them to work with palliative care, and vice versa. Secondly, break down the barriers of public health practitioners and palliative care. This country has a Public Health Association and Health Promotion Association in every State. palliative care has no relationship with them, so without the partnership between Public Health and palliative care, forward advances cannot be made.
- It requires commitment, and getting the Federal Government (through it's bureaucrats) to understand how important it is to have this dimension of palliative care. All the other major health fields have this - maternal health has health promotion and public health, cancer has Slip, Slop, Slap, a dimension of cancer care.

Key things that affect community's awareness of palliative care?

- The reticence of the key media outlets to carry stories regularly about palliative care is a real problem. The respondent did an interview for Channel 9 but they didn't run it because they found it too sad. There was also an interview for Channel 10, which was aired. However in order to get Channel 10 to show it, a lot of effort and talking was required. The TV Channels are scared of showing anything that's not really entertaining, because entertaining is what they do.

What does the community know about palliative care, do you think?

- The community does not know very much. People that do know think it's about care of older people, sometimes people with cancer. And some know that it's the care of people at the end of life. Often people think of Hospices, but they won't necessarily think of community based palliative care services. Most people who actually know about palliative care have a very simple, skeletal understanding. There are a few people who are informed because they've had a member of the family or a friend who has received palliative care.

What do you think the community needs to know?

- The community needs to know that palliative care is care of people who have a life threatening illness for which there is no cure, and that it can provide whole person care - social care, psychological care and spiritual care. People who receive palliative care may not die for a long time, and the main aim is to improve or maintain quality of life of people with serious illness. By serious illness, it may be cancer, or it may be motor neuron disease, or even heart disease.
- But it is not medical care at the end of life, nor is it institutional care, nor just doctors and nurses. It is social work and pastoral care and community workers. People like that are important members of the team, or a palliative approach to care.
- After the person has died, palliative care can supply care to friends and family as they experience the loss, and you find that's important.
- It's not necessary to know about all the different techniques that can be used to help them with their pain or their breathing. It is important to know that there are specialists in the area to rely on.

National Palliative Care Week

- There were only fifteen people at the launch of National Palliative Care Week, and not one of them was a journalist. Simply unbelievable. So there are some serious institutional barriers to get over. It is not just palliative care not marketing itself.

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- It is really important to note that clinicians and bureaucrats can't and shouldn't market a national programme themselves. Palliative care people are palliative care people, not people who hustle the media. It needs community development people who are trained and experienced at liaison and lobbying journalists. Palliative care should pay for some of this expertise in order to get in front of the TV and the microphone.
 - Palliative care also needs to be smarter with the money they do have. Give Palliative Care Australia public relations personnel. Give the key bodies' public relations people and the Minister will roll up with a crowd of journalists next time. Staff are too busy with their day-to-day business to try and organise that sort of event.

Case Study:

- "I don't expect that, for some people palliative care will make the difference. Because the euthanasia debate is not about symptom control. It's about quality of life. And the people who run around and equate the two are the ones who put euthanasia and palliative care end to end. We can do symptom control, but make no mistake, I would say over 90% of your troubles we can deal with. But whether or not you want them dealt with and still feel you want to live, a totally separate issue. I was speaking to a woman the other day who is 86 and she wants to die. She has lost her home, lost her cat, and her friends can't visit her because she's in a nursing home. She's grown fat because she's a vegetarian, and they don't have a service chef in the nursing home. She's had two hip replacements, but her hips have collapsed under the weight of the new prosthesis, and it cannot be replaced so she gets around in a wheelchair. She can only do one thing, she can wipe her own bum, and she's not sure how long she can do that for."

"She wants to die. What can we do for her in palliative care? The answer is, nothing. But even if we could, she would still want to die. You see, it isn't about making her physically healthy. It's about whether or not she thinks she's the person she was, and whether she wants to live whilst being that person. 'Oh you should stay alive, chin up', I'm sure that's a really good answer, but it's not the one she wants to hear. A lot of the issues around euthanasia don't come back to palliative care. That's the point. If you walk into a voluntary euthanasia society, the average age is probably seventy. Those people don't care about, they're not fundamentally concerned about whether or not they're going to get dying, they're concerned about whether they're going to lose their dignity, their homes, people they love, whether or not they feel life is worth living under those conditions, but that is too big for us. This is about how we should live and how we should die. We are only a bloody health service."

APPENDIX 1

The Questionnaire

September 2002

Community Attitudes to Palliative Care
Revised Final - 26 September – 3pm

Job No.: 22104

Introduction:

Hello, I'm..... and I'm calling from Quantum Market Research, the national market research company. Today we are talking to people about general issues of importance to the community. We are not trying to sell anything, we are just collecting information.

We are contacting people randomly. All the answers you give will be strictly confidential. The survey takes around 15 minutes to complete and we'd really appreciate your involvement. Is now a good time or would it be more convenient if I make an appointment to speak to you at another time?

Client identity and source of sample:

I'm sorry I'm not permitted to tell you until the end of the interview. . . . Would you still like to participate?

Screening Questions:

First let me check that you are one of the people who we need to talk to (ASK SCREENING QUESTIONS S1 below)

If individual does not fit specifications or is not interested:

Is there anyone else who might be interested in participating?

If collecting sensitive information:

But please be assured that the information and opinions you provide will be used only for research purposes. While we'd prefer that you answered all the questions, if there is anything that you'd prefer not to answer, that's fine, just let me know.

Security Screener:

S1	Do you or any members of your household work in: (READ OUT – MULTIPLE RESPONSE)	
	Market research industry	1 TERMINATE
	Advertising industry	2 TERMINATE
	Federal government.....	3 TERMINATE
	None of these.....	4

Q.1. Just to ensure we get a good cross section of the community, can you please tell me into which of these age groups you fall? (READ OUT – SINGLE RESPONSE)

- 18-24 years1
- 25-34 years2
- 35-54 years3
- 55-64 years4
- 65+ years5

Q.2. Other people have told us about the important social issues facing the Australian Community today. Which social issues do you think deserve our attention? (DO NOT READ OUT – MULTIPLE RESPONSE. PROBE: WHICH OTHERS?)

	Q.2 Spontaneous Awareness	
	First Mentioned	Others mentioned
Drugs	1	1
Mental illness	2	2
Unemployment	3	3
Child abuse	4	4
Environment	5	5
Work safety	6	6
Education	7	7
Poverty	8	8
Crime	9	9
Community health	10	10
Aging population	11	11
Youth Issues	12	12
Welfare	13	13
Government	14	14
War	15	15
Aboriginal issues	16	16
Palliative Care	17	17
Other (specify)	18	18
Don't know	19	19

Q.3. Have you heard of palliative care?

Yes	1	Continue
No	2	Go to Q.5
Don't know	3	Go to Q.5

Q.4. And how would you describe your level of knowledge about palliative care? (READ OUT)

I know what palliative care is and could explain it to someone else.....	1
I know a little bit about palliative care	2
I have only heard the words palliative care, but don't really know what it is	3
I've never heard of it	4

**Q.5. Where do you think you gain your understanding of palliative care?
(DO NOT READ OUT. MULTIPLE RESPONSE)**

Personal experience	1
Media	2
Other (specify)	3
Don't know	4

**Q.6. Could you please describe for me what you think palliative care is?
(DO NOT READ OUT. MULTIPLE RESPONSE)**

	(First Mention)	(Other Mention)
Care of the ill	1	1
Care of the terminally ill.....	2	2
Helping people die with dignity	3	3
Care of people who are dying	4	4
Pain relief/pain control	5	5
Provision of comfort for the terminally ill/dying	6	6
They send you there if they can't treat you at home	7	7
Home based	8	8
At a hospital	9	9
At a hospice/special care facility	10	10
Other (specify)	11	11
Don't know	12	12

Q.7. What does palliative care aim to achieve? (DO NOT READ OUT. MULTIPLE RESPONSE)

Comfort for patient	1
Support for family	2
Dignity in death	3
Pain relief	4
Care for the carer	5
Respite	6
Reduce stress for family/patient	7
Easier burden on family/carer	8
Patient/family dictated	9
Holistic support/emotional support/spiritual/cultural	10
Counselling	11
How to take care of things before you die	12
Other (specify)	13
Don't know	14

Q.8. Where do you think palliative care takes place? (DO NOT READ OUT. MULTIPLE RESPONSE)

In home	1
At a hospital	2
At a hospice/special care facility	3
Other (specify)	4
Don't know	5

Read out Definition:

Palliative care is the specialised care of people who are dying. A person receiving palliative care will have an active, progressive and far-advanced disease, with little or no prospect of cure.

Q.9. What services do you think would exist for palliative care? (DO NOT READ OUT. MULTIPLE RESPONSE)

**Q.10. And which of these services do you think might exist?
(READ OUT. MULTIPLE RESPONSE)**

	Q.9	Q.10
Provision of equipment such as special beds, wheelchairs, etc	1	1
Nursing care/visiting nurse	2	2
Overnight backup services.....	3	3
Counselling.....	4	4
Grief support	5	5
Death & bereavement support	6	6
Respite/relieve the carer to go out	7	7
Linen service	8	8
Assistance in feeding, showering, etc	9	9
Other (specify)	10	10
Don't know	11	11
None	12	12

**Q.11. Where do you think you would go to access these services?
(DO NOT READ OUT. MULTIPLE RESPONSE)**

GP/Local doctor	1
Specialist	2
Local council.....	3
Internet.....	4
Hospital	5
Anti-cancer council	6
Government department.....	7
Other (please specify)	8
Don't know.....	9

**Q.12. If you needed information about palliative care, where would look for it/who would you ask?
(DO NOT READ OUT. MULTIPLE RESPONSE)**

GP/Local doctor	1
Specialist	2
Local council.....	3
Internet.....	4
Hospital	5
Anti-cancer council	6
Friends/family	7
Government department.....	8
Other (please specify)	9
Don't know	10

Q.13. Has anyone close to you, such as a friend or family member, required or had access to palliative care?

Yes	1	Continue
No	2	Go to Q.15
Don't know.....	3	Go to Q.15

**Q.14. How do you feel about palliative care as a result of that experience?
(READ OUT. SINGLE RESPONSE)**

Very positive.....	1
More positive than negative	2
Neutral	3
More negative than positive	4
Very negative	5
Don't know.....	6

Q.15. Have you heard of National Palliative Care Week?

- Yes1 Continue
No2 Go to Q.17
Don't know3 Go to Q.17
-

**Q.16. Can you please describe to me what you have seen or heard in relation to National Palliative Care Week?
What else? PROBE FULLY**

Q.17. Here are statements that other people have used when discussing palliative care and I'd like to know how strongly you agree or disagree with each. I'd like to stress that there are no right or wrong answers – it's just your opinion that matters. For each statement, please tell me if you agree strongly, agree a little, neither agree nor disagree, disagree a little or disagree strongly. (READ OUT. ROTATE) First of all:

	Agree strongly	Agree a little	Neither agree nor disagree	Disagree a little	Disagree strongly	Don't know/not sure
1 Palliative care is mostly for older people	1	2	3	4	5	6
2 Everybody who needs and wants palliative care should be able to access it	1	2	3	4	5	6
3 I don't want to know anything about palliative care unless someone I know needs it	1	2	3	4	5	6
4 Palliative care doesn't cost the patient anything	1	2	3	4	5	6
5 I want to know more about palliative care	1	2	3	4	5	6
6 Euthanasia is the opposite of palliative care	1	2	3	4	5	6
7 Palliative care allows the patient to choose how they live the remainder of their life	1	2	3	4	5	6
8 Euthanasia gives people choice about dying	1	2	3	4	5	6
9 With an ageing population, the need for palliative care is going to increase	1	2	3	4	5	6
10 Palliative care provides support and assistance to the patient and the carer	1	2	3	4	5	6
11 It is a doctors obligation to inform all patients with a life threatening illness about the option of palliative care	1	2	3	4	5	6
12 Palliative care is only available for cancer patients	1	2	3	4	5	6
13 To obtain palliative care, you need to be referred by a doctor or hospital	1	2	3	4	5	6
14 The community needs to learn that the option of palliative care exists	1	2	3	4	5	6
15 Palliative care is about the emotional support as well as the medical side of care	1	2	3	4	5	6
16 Palliative care helps people die with dignity	1	2	3	4	5	6

And finally, just a couple more questions about you, so that we can understand how different people have answered these questions.

Q.18. RECORD GENDER

- Male1
- Female2

Q.19. RECORD LOCATION:

- Sydney1
- Other NSW2
- Melbourne3
- Other VIC4
- Brisbane5
- Other QLD.....6
- Perth7
- Other WA8
- Adelaide9
- Other SA10

Q.20. Which of the following best describes your household situation? READ OUT

- A young single person with no children1 YS
- A young couple without children2 YC
- A family with most of your children under 13 years3 YF
- A family with most of your children 13 years or older.....4 MF
- A mature couple with no/independent/children left home5 MC
- A mature single with no/independent/children left home6 MS
- None of these describe my situation.....7

Q.21. PRESENCE OF CHILDREN IN HOUSEHOLD:

- 0-4 years1
- 5-9 years2
- 10-16 years3
- 17-18 years4
- No children in household5

Q.22. What is your work situation?

Full time	1	Continue
Part time/casual.....	2	Continue
Self employed	3	Continue
Retired	4	Go to Q.24
Unemployed.....	5	Go to Q.24
Home duties.....	6	Go to Q.24
Student.....	7	Go to Q.24
Volunteer	8	Go to Q.24
Other.....	9	Go to Q.24

Q.23. What is your occupation?

CODERS TO CODE: _____

Lower blue collar	1
Upper blue collar	2
Lower white collar	3
Upper white collar	4

Q.24. And what is the approximate pre-tax income of your entire household per year?

Less than \$20 000	1
\$20 000 - \$29 999.....	2
\$30 000 - \$39 999.....	3
\$40 000 - \$49 999.....	4
\$50 000 - \$74 999.....	5
\$75 000 - \$99 999.....	6
\$100 000 +	7
Don't know.....	8
Refused.....	9

Q.25. What is the highest level of education you achieved?

- Completed Primary School1
- Some Secondary2
- Completed Secondary3
- Some TAFE4
- Completed TAFE or equivalent.....5
- Some Tertiary6
- Completed Tertiary.....7

If contact details are needed for validation:

As part of quality control procedures, someone from our project team may wish to re-contact you to ask a couple of questions, verifying some of the information we just collected.

Terminate with thanks:

Thank you for your time. Just to remind you, I'm calling from Quantum Market Research. If you have any queries, you can call our free line on: 1800 995 688.

NAME:

ADDRESS:

.....

SUBURB:

POSTCODE:

PHONE:

I declare that the information obtained is true and correct and I have obeyed the ICC/ESOMAR Code of Marketing and Social Research Practice.

INTERVIEWER:

Start	Finish	Min

Ref: 22104_Community Attitudes to Palliative Care_ Questionnaire_TH

COMMUNITY ATTITUDES TO PALLIATIVE CARE ISSUES

1800 020 787

www.palliativecare.gov.au