

Talking about dying

Where and
how we choose
to die



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Talking about dying: Where and how we choose to die

Research Report

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Table of Contents

Summary	4
Background literature	6
Method	9
Findings	11
Talking about dying	11
Communicating with each other	11
Talking honestly	14
Sharing information	15
Dying with dignity	16
Indignities	16
Taking control of the dying process	18
Choice and control	18
Advocacy	19
Advanced Directives	19
Euthanasia.....	20
Access to appropriate services	21
Place to live while dying	22
Home	22
Hospice	23
Hospital.....	24
Nursing home	24
Communities in action	24
The business of dying	25
Conclusion	26
References	27

In this report, all text in “*italics and quotation marks*” is a direct quote from a participant. Participants are not identified. The names of all health care professionals, hospitals, hospices, and nursing homes referred to by participants have been removed. In addition, the term family is defined as “those closest to the patient in knowledge, care and affection. This includes the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (not related biologically by marriage/contract)” (Canadian Palliative Care Association 1988).

1

Summary

This research project invited people to think and talk about dying. We are grateful to the individuals, families and communities who participated. Thank you for allowing us to share your knowledge and experiences with a wider audience.

One hundred individuals from many different walks of life accepted a public invitation¹ to tell us about where and how they wanted to die. Many also shared their experiences of loved ones dying in different places (home, hospice, hospital and nursing home). Participants welcomed the opportunity to talk with us about dying. This suggests that issues around death and dying may no longer be considered taboo in Australian culture.

This report provides feedback to all those who participated in the research. It may also provide new insights for health care professionals and policy makers. By discussing the process of dying from the consumer and carer perspective, the research identified a gap between health care rhetoric and current realities. The data indicates that participants' choices were often not respected. Many also described loved ones dying without dignity.

Those participants with terminal illnesses described dying as a life experience - they wanted to live while they were dying. Participants without terminal illnesses also welcomed the opportunity to talk about their experience of a loved one dying. Some described the dying process as a "*good death*", others did not. These positive and negative experiences influenced the way participants thought about their own death, and what they wanted for themselves.

A few participants had not experienced a loved one dying nor given any thought to their own death. They too welcomed the opportunity to consider the issue of death and dying.

The article in the HeraldSun really awakened something in me that I never gave much thought to. I believed that someone other than myself would make the decision when the time came.

Most participants did not want "*someone other than themselves*" making decisions about their death. Although professional expertise was valued, most participants did not want health care professionals making decisions on their behalf. They wanted to have choices and control of their, and their loved one's, "*dying experience*". At the very least, participants wanted to have an influence on end of life decisions.

Participants made it clear that people who were dying and their loved ones wanted honest communication. They appreciated health care professionals who were compassionate and truthful. They also wanted health care professionals to communicate using appropriate language. They did not want health care professionals to use euphemisms. Most did not want to be bamboozled with medical jargon. Instead, they wanted a genuine conversation in which information was shared.

Participants described how the flow of information affected how a person died. This flow of information depended on communication and cooperation between health care professionals. This cooperation benefited families because they received consistently reliable information. On the other hand, poor communication between health care professionals added stress to people who were dying and their loved ones. Participants described this poor communication as both systemic and interpersonal. For example, participants described being asked the same "*litany of questions*" from different health care professionals.

Participants said that better access to information would have enabled them and their loved one to have more control during the dying process. They needed information about the specific illness and what to expect. Participants needed this information so that they and their loved one could make informed choices about where they died, and with whom. Feeling informed was important to having a sense of control when things felt "*uncontrollable*".

¹ HeraldSun Healthwatch published Fay Burstin "*Terminal Solutions*" February 25th 2004 (Appendix 1); ABC radio (Lynne Haultain and Madeleine Randall)

Many participants said that health care professionals did not provide sufficient information, particularly about the range of support services that were available. Without knowledge of the health care system, or knowing what specific questions to ask, many participants were denied access to support services. Participants said that support services should be more readily available. When participants were having difficulties “*coping*”, the options were limited to respite, hospice or hospital. Additional support to help family to solve the difficulties at home was rarely offered as an option.

Rather than respond to their individual circumstances, health care professionals often relied on professional assumptions about what participants needed, and when they needed it. The data indicates that these assumptions were often misplaced. As a result, many participants were angry that their control and choice were taken away from them. This anger was reflected in a number of letters of complaint to health care professionals, health ombudsman, and coroners. Anger about the inadequacies within the health care system impeded the grieving process for some participants.

Participants considered the place of death important because it often determined how people died. Most participants wanted to die at home, preferably in their own bed. However, many reasons were given to explain why this might not be possible. In many instances, participants did not want to become a “*burden*” to loved ones. They also thought that home support would be too expensive, particularly home nursing care. A few participants stated that dying at home would tarnish the home for those who continued to live there.

If dying at home was not possible, many participants would choose to die in a hospice, preferably one that was “*homely*” and located close to home. Driving long distances to a hospice was identified as a major obstacle, particularly for people living outside metropolitan Melbourne.

A few participants would prefer to die in a hospital. They would feel safe knowing that professional care was readily available. They envisaged compassionate professionals taking control of the physical aspects of care. This would enable family and friends to provide emotional, psychological and spiritual care. Some participants, however, said that hospitals were “*too clinical*” and focused on treatment, not care.

Participants would not choose to die in a nursing home. Nursing homes were described as “*not a nice place to die, and not a nice way to die*”, particularly if you were a younger person. Those who had experienced a loved one’s death in a nursing home described a need for better palliative care in nursing homes.

Some participants joined the voluntary euthanasia society after experiencing a loved one’s death, and witnessing their process of dying. Their reasons for joining the euthanasia society were to gain more autonomy and control over their own death. Many had witnessed loved ones enduring uncontrolled symptoms such as physical pain, nausea, incontinence, and severe emotional distress. They described the medical treatment of these symptoms as often inadequate.

A few participants acknowledged that their loved one’s death, and their process of dying, had motivated them to document their own advanced directive and nominate a medical power of attorney. These advanced directives were discussed with their loved ones. Although participants hoped health care professionals would respect their documented wishes, many worried that they would receive medical intervention against their wishes. There was a perception in the community that health care professionals often disregarded advanced directives. Participants wanted health care professionals to respect their right to make their own decisions.

A few participants described consumer driven action in their local communities. People within these communities wanted the option of dying in a home-like environment in their own communities, surrounded by people they loved. However, current economic priorities within health care made it difficult for these communities to attract resources to support small facilities for people who are dying. The two community based units discussed in this report have not yet received any government operational funding. With the current priorities in the health care system, resources were more likely to be allocated to large, clinical hospices, than small home-like facilities run with the assistance of local volunteers and community involvement. This raises the question of whether resources are allocated on the basis of clinical and economic considerations, not consumer wishes.

This research demonstrates that there is an urgent need for health care professionals and policy makers to be more responsive to individual circumstances and changing needs from the consumer perspective. They need to really listen to what people have to say. There is also a need for decision makers to focus more on human values such as respect, dignity, kindness and compassion. These non-economic values need to be inserted into the debate about what people need while they are dying.

The researchers acknowledge that the data collected often provided a critical perspective of the health care system and professional behaviour. Our responsibility as researchers is to provide as accurate and honest account of this data as possible. ❖

2

Background literature

People in the community want to be involved in making decisions about their own lives. This includes decisions about their own care and treatment when they are dying. However, people in the general community are often excluded from participation in research about dying (Small & Rhodes 2000). Instead, the literature is overflowing with commentary from health care professionals, academics, policy makers and service providers. Until recently, the consumer perspective was largely absent from this literature. As a result, palliative care services have historically been built on 'expert' decisions about what the community needs.

In recent years, the definition of 'to palliate' has shifted from meaning 'to alleviate disease without curing it' to "*specialised care of the dying*" (Department of Health and Ageing Australia 2003). According to policy makers, only a few people have an understanding of '*palliative care*' (Department of Human Services 2004). This 'specialisation' of dying has had implications for where and how people die.

According to Kristjanson and Aoun (2004), families cannot adequately care for their family member without 'specialised' palliative care support. Research has also shown that families, partners and friends may need professional support from a palliative care service when a person is dying (Hudson et al 2004, Kristjanson & Aoun 2004). This view underestimates the knowledge, skills and expertise that are often found within families. Although there is a need to raise awareness of options available and to offer support services to help people who are dying (Department of Human Services 2004), there is also a need to recognise the value and expertise of non-professional care. Many families understand how to love and care for someone who is dying.

The literature frequently refers to 'a good death', indicating that a 'good death' can be achieved within our contemporary health care system. The choices of people who are dying and their families about the place of dying,

and the type of care, are said to have central importance to a 'good death' (National Palliative Care Strategy 2000). However, Masson (2002) explains that dying is a dynamic process - the process is rarely all good, or all bad.

In Australia, most people die in hospitals (Field 1996). However, much of the dying takes place at home where families and friends provide most of the care with varying degrees of support from professionals (Field 1996). Health care professionals and policy makers believe that people in the community want to die at home (Rhodes, Holland et al. 1991; Tang & McCorkle, 2001). Yet research indicates that people in the community were not certain about where they would prefer to die - hospital, hospice or home (Steinberg et al 1997). Although people were often of two minds about where they wanted to die, they were decisive about their choice to die surrounded by people they loved. Generally, people prefer to die with the support of family and friends, either in their own home or as an inpatient within their local community (National Palliative Care Strategy 2000).

Kristjanson and Aoun (2004) believe that decisions related to families play a major role in the decision about where to die. Dying at home is thought to provide high-quality interactions with loved ones. Home also provides physical and emotional comfort and a sense of belonging. Dying at home also has a greater chance for controlling environment, privacy, and a sense of autonomy and normality (Tang & McCorkle 2001).

Although hospice care is described as more clinical than home, it provides care, comfort, control of symptoms and maintenance of quality of life at the optimal level possible (Tang & McCorkle 2001). However, the original ideals of the hospice movement have been replaced by a focus on the medical management of physical symptoms (McNamara 2004). It has been noted that referrals to palliative care services were most often made for pain management, not emotional, social or psychological support (Garrett 2004). However, researchers have found that depression and fear were also important symptoms (Agrawal & Ezekiel 2002, Craib 2003).

Dying in a hospital is described as clinical (Glare et al 2003). According to the literature, the principles of support for a person who is dying and their family have not yet been incorporated into acute-care settings (Pincombe et al 2003). Patients who are dying may still be subjected to invasive treatments immediately prior to death. This may occur even when a prognosis is poor (Seymour 2000).

Worldwide research shows that there is often a difference between preferred and actual place of death (Tang & McCorkle 2001). This raises many questions such as:

- What factors make so many people from many different cultures change their minds about dying at home?
- Do other people decide on their behalf?
- Is a messy, painful death the reason why people seek a more medical environment?
- Do health care professionals insist that hospitals or hospices offer more support than a home death?

The literature frequently refers to the notion of “*dying with dignity*”. It is recognised that dignity is not something that can be given. Dignity belongs to an individual - they bring their own dignity to death. Although health care professionals can not confer dignity, they can ensure that someone dies without “*indignity*” (Allmark 2002). An increased reliance on others should not result in decreased participation in decision making related to care and other personal issues (McClement et al 2004). Also, an increased reliance on others should not result in a loss of dignity.

Integrating death with dignity can provide complex difficulties for health care professionals, particularly those who are cure-oriented (Ciesla 2000). The notion of dying with dignity in the literature raises a number of questions such as:

- How can palliative care practitioners support the dignity of both those who are dying and their loved ones?
- What does dignity and indignity mean to the person who is dying and their loved ones?
- How are people included in decisions that may impact on their sense of dignity?
- How can indignities be avoided when death is inevitable?

When a loved one is dying, the demands placed on a family are immense. Health care professionals need to ask family members how they can best be supported (Johnson & Bourgeois 2003). Families were found to feel guilt and remorse if they considered their family

member received less than the ‘best’ care (Kristjanson & Aoun 2004).

There is a need for health care professionals to understand the choices of different groups depending on age, gender, culture, sexual preference, education, place of residence, and occupation (Lickiss 2003). In addition, health care professionals need a better understanding of the specific cultural needs of indigenous Australians (McGrath et al 2004). The literature highlights the importance of not assuming cultural needs and treating people as individuals. The palliative care multicultural guidelines also talk about the need to understand a person’s decisions within their family context (Taylor & Box 1999).

Patients’ families require information that will help them to understand the patients’ illness (Zarit 2004). When people did not receive adequate information about their illness and plan of care, they experienced distress (McClement et al 2004). Health care professionals needed to ensure that patients received information, and be prepared to discuss concerns and answer questions as the illness progressed.

When giving information to people, the process was as important as the content (Kirk et al 2004). Process mattered at every stage of the illness. All participants wanted information about their illness and wanted it fully shared with their relatives, regardless of cultural background. The attitude of practitioners in giving information, timing, management and delivery made a difference to how information was received (Kirk et al 2004).

In America, it has been shown that those who prepare living wills, advance directives, and do-not-resuscitate orders received the same medical treatment as those who took no such measures (Wolfson 1998). Both groups were equally likely to receive life saving interventions. Wolfson concluded that the most realistic goal for people with terminal illnesses was high quality palliative care (i.e. no technical intervention and no doctor-assisted death). However, Wolfson did not consider the option of health care professionals listening to patients’ wishes and respecting patients’ choices.

Wolfson’s conclusions raise questions about who should make our end-of-life decisions. Should people who are dying make these decisions about their own lives? Or should health care professionals, family members, priests, policy makers, or hospital managers make decisions on behalf of those who are dying? Patients are often encouraged to ‘negotiate’ their care with health care professionals. This implies that people who are dying and their families have voices that will

be heard by health care professionals. Unfortunately, this is often not the case.

In Australia, advanced directives are topical. Special projects have recently been funded to encourage health care professionals to respect patients' choices (Austin Health 2003). The 'Respecting Patient Choices' project will "set up systems and processes, policies and procedures to ensure that the Respecting Patient Choices program becomes part of routine clinical practices and embedded into the culture of the organisation" (p5). It is also necessary for governments and policy makers to "set up systems and processes, policies and procedures" to listen to consumer wishes. Our research is an essential step in including the voices of individuals and communities in talking about dying. ❖

3

Method

A qualitative research design was used to collect information about where and how people in the community preferred to die.

Recruitment

A media release was circulated to ABC radio and The Herald Sun. This resulted in an interview on ABC radio with Lynne Haultain and Madeleine Randall and the publication of an article ‘Terminal Solutions’ by Fay Burstin in the Herald Sun. The following list of questions was prepared for the article in the Herald Sun.

- Do you know anyone who died recently at home or in hospital?
- Was that person given choices about where he/she died?
- Have you thought about your own death?
- What does “dying with dignity” mean to you?
- What could be done in your community to improve the quality of life of people who are dying?
- Where would you prefer to be cared for if you were dying?
- Who would you prefer to provide care for you while you were dying?
- What services need to be provided in your community for people who are dying?
- How can the community best meet different cultural/spiritual needs of people who are dying?
- What specific services could be provided for young people who are dying?
- What information is needed to assist people who are dying?
- What could palliative care facilities do to provide fun and recreation for people who are dying?

These twelve (12) questions became the basis for an open-ended questionnaire. Friends and colleagues were asked to circulate the questionnaire to other potential participants. The aim was to collect views from one hundred participants.

Ethics

The day-to-day research process was conducted in an ethical and reflective manner. The research project received ethical approval from Deakin University’s Human Research and Ethics Committee. Ethical considerations were adhered to in the storage of data and in the communication with participants at all times.

Sample

In response to our recruitment methods, we received emails, letters and phone calls from over 100 people willing to share their views about dying. The data included in this report are limited to the first 100 participants. Unfortunately, these methods did not recruit any Indigenous Australians, young people (under the age of 25), or people from diverse cultural and linguistic backgrounds. As a consequence, the research data did not include information about how the community could best meet the needs of people from different cultures who were dying. To answer this question appropriately, views from people from different cultures were required.

The sample included 69 women, 27 men (4 participants were anonymous). The average age was 61 years (range 25 - 85 years). Without recruiting anyone under the age of 25, the question “What specific services could be provided for young people who are dying?” was unable to be explored from the perspective of a young person. However, the sample included the views of parents of young people who had died.

Using information from the preliminary data collection, we selected 20 people to interview. The 20 interviewees were chosen to explore a range of issues,

views and experiences in more depth. In particular, the notion of “dying with dignity” was further explored. We selected people who described a “good death” and those who did not. The sample included people who:

- were diagnosed with a terminal illness;
- had experienced the death of a loved one
- at home
- in a hospice
- in hospital
- in a nursing home
- had experienced the death of a young person (under 20 years old);
- disclosed religious views;
- supported or opposed euthanasia;
- lived alone, with partner, or with family.

During the data collection, we learnt about two community based facilities for people who are dying. We decided to take a detour to one of these facilities where we explored the community facility in more depth. We interviewed a family who had recently used this facility and conducted two (2) focus groups with people who supported this facility. We also discussed the facility with local health care professionals and a local politician.

Although our recruitment methods explicitly targeted only community views, several health care professionals contacted us, wanting to share their views and experiences. Given that professional views are well documented elsewhere, we talked briefly with only a small sample of eight (8) health care professionals. This data provided useful background information, though it has not been used extensively in this report.

Analysis

All interviews with people in the community were tape-recorded and transcribed. Conversations with health care professionals were recorded in field notes. To facilitate a detailed examination of this project’s data, transcripts, field notes and preliminary data were entered into a computer software package designed for qualitative research (NVivo). This computer package was used to store and manage the data. Using NVivo, the transcripts were coded according to categories and sub-categories. The main categories were primarily determined by the questionnaire, though some new sub-categories were also identified. The main purpose of the analysis was to generate general themes from the data. ❖

4

Findings

This section quotes extensively from the interview data. It uses participants' own words to describe their individual experiences. This provides powerful and sometimes emotional descriptions of the consumer and carers' perspective. It also highlights some of the gaps between lay and professional views.

The data are presented under the following main headings:

- Talking about dying
- Dying with dignity
- Taking control of the dying process
- Access to appropriate services
- Places to live while dying
- Communities in action

Talking about dying

Participants were grateful for the opportunity to think and talk about their own death and the death of a loved one. In some cases, the topic created more questions than answers. Some participants found the questions challenging. It was not until their own mortality was confronted, or someone close to them, that they examined their own thoughts and feelings about dying.

Several participants took the opportunity to debrief about the way their loved one had died. Some wanted to share their loved one's 'good death' - peaceful, pain free, and surrounded by love. Others were angry at their loved one's dying process. They described poor communication, lack of effective pain relief, and inadequate health care and support services. Many had written letters of complaint to hospital administrators, health ombudsman and the coroner. One participant attributed her recent heart attack to "the stress of writing all those letters".

Communicating with each other

Data provides many examples of poor communication. People who were dying, families, friends, health care professionals and other service providers were not always effective communicators. Participants described how the quality of communication, and the flow of information, played an important part in determining whether an individual died with, or without, dignity. This section discusses the data under the following headings:

- Listening to what individuals want for their own death
- Listening to families
- Listening to each other
- Listening to spiritual choices

Listening to what individuals want for their own death

Participants described the importance of listening to what individuals want for their own death. Some participants were able to support loved ones in the way that was wanted.

My father-in-law wanted to stay at home. We found a young, compassionate general practitioner who promised to do all he could to keep him at home. We began our journey together.

My son pleaded with me to die at home. I promised him that we would do our best. We kept him at home, but it was hard with so little support.

Even though participants wanted to respect their loved one's wishes, some found it physically and emotionally difficult to keep their loved one at home. It was often difficult for families to provide the level of support that a person who was dying required. In particular, participants described difficulties managing their loved one's "uncontrollable pain". Some participants also described difficulties managing vomiting, incontinence, anxiety and confusion.

Although a home nurse or a general practitioner visited for an hour or so each day, the remaining twenty

three hours of care giving work was provided by the family, friends and people in the community. Without adequate support, this was extremely difficult for many carers.

We kept her at home for as long as was physically possible for us. It was beyond our capabilities to keep the pain under control.

He really wanted to come home, but the decision was taken out of our hands. The doctor decided he could not be discharged because I would not have been able to care for him at home on my own. There needs to be more in-home nurses. He was fearful of dying in hospital.

My brother wanted to be at home. His wife wanted to care for him at home. But she was not able bodied and had no medical training. She became exhausted. He was admitted to the hospice for palliative care. We all felt disappointed that we could not give him what he wanted.

By not keeping their loved ones at home, several participants described feeling guilty because they had not “honoured” their loved ones’ final wishes. Some said that they had not “tried hard enough”. They described “failing” their loved one “in the end”.

I feel that I did not try hard enough to keep him at home with me. It is a burden that I carry. I feel I should have done more.

Listening to families

Participants described some instances when different views were respected by health care professionals. Participants were grateful when health care professionals listened and respected their loved one’s choices.

We let every doctor know that she did not want to be kept alive by mechanical means. That choice was respected.

Several participants described health care professionals making assumptions about what individuals needed. These assumptions were based on professional knowledge and their own past experiences. Data indicates that these assumptions were often misplaced.

I think they are trying to do their best, but they can only see the medical side of it. The medical side is only one side.

Participants described health care professionals as “well meaning” but often not good at “really listening”. Participants suggested that it would be better if health care professionals asked people who were dying and their loved ones what they wanted and needed. They also recommended listening to the responses, and respecting different choices.

Things definitely need to improve. Doctors and nurses need to listen to both the patient and their family. We could not get through to the doctors. They just would not listen. We were

not happy with his medical care, particularly during the last month. We did not want him to have any more active treatment. They knew he was dying, yet they continued to prescribe invasive treatments. Right up until the end, they gave him enemas. He needed peace when the end was near, not enemas.

Participants described feeling devalued when health care professionals did not listen to them. The following seventy two year old participant had slept with her husband throughout their adult lives. She felt qualified to recommend his preferred sleeping positions.

I told them he can not sleep on his back - he had a very bad curvature of the spine. But nobody listened to me. They put him on his back and he got terrible ulcers on his bottom. It was dreadful. I did not feel as though they were listening to me. They did not even ask me any questions when he was admitted to hospital.

One participant believed that health care professionals were more likely to listen to her if she presented as well dressed and intelligent.

It is very important to get across to the medical profession that you are intelligent. If you can do that, they will respect you more. They may even listen to what you have to say. I would make sure I wore a business suit when I spoke with them. I wanted them to listen to me.

Without listening to consumers and their carers, health care professionals sometimes provided support that was neither needed nor wanted.

Whether you want it or not, the palliative care nurses think you want the whole package - nursing, aids and equipment, counselling and religious support. There is not an awful lot of consideration as to whether these are the things you want. We told them that we just wanted nursing, but they did not listen. They assume everyone wants the same. They insisted on sending all these people anyway. It was certainly invasive and not appropriate.

Listening to each other

1. Communication between family members

A few participants described “tensions” and poor communication within families. In some cases, members of the family had different understandings of what their loved one would like.

The surgeon in charge would only talk with my step mum. But my step mum could not recall anything he said. She did not accept that my father was dying. So the rest of the family was kept in the dark. His six kids did not even know the type of tumour. Also, my step mum wanted dad in a private room, but he wanted company. In his private room, dad just looked at a blank wall - the shelves for his cards and photos were all behind the bed head. Towards the end, he told me his wishes for his wake. I wrote these down but my step mum did not follow these because they were different from the instructions in his will.

2. Communication between health care professionals

Some participants described experiencing good communication between different health care professionals. Cooperation between health care professionals was beneficial because families received consistently reliable information.

There was also great cooperation between our GP and the hospice. Once the hospice was involved, I did not feel alone about it. I had no medical experience but I felt safe that they knew what was happening and could advise me properly. They were great, just wonderful. He died peacefully at home with those who loved him at his bedside.

Other participants described poor communication between health care professionals. In particular, participants described being asked to repeat the same information over and over again.

With home palliative care, there was a lack of continuity. There was a different nurse on each visit. Each nurse wanted a full history. I had to try to remember things. I found this stressful because I was not a good historian. I am not medically trained and I am not good at remembering things.

The last thing I needed was to be endlessly answering the litany of questions. Each different health care professional asked the same questions - his medical history, current medications, smoker? drinker? Over and over again. I ended up printing out a detailed list of answers to spare dad's dwindling patience.

Participants also described a poor flow of information between the different professionals (e.g. doctor, nurse, social worker, psychologist, occupational therapist). This poor communication between professionals added stress to people who were dying and their loved ones. According to the data, better communication between health care professionals would have improved the care that was provided to both people who were dying and their loved ones.

I expected different health care professionals to talk to each other, to transfer information. There was no flow of information.

Someone should have brought it together. Someone should have taken a little bit of time out, and said: "OK, what can we do for you? What would you like to know? What do you need?"

One participant described receiving different information from various health care professionals. Some told her that she could nurse her husband at home; others insisted that she "could not manage him at home".

I was getting two messages here. The nurses told me that they were going to help me in the home. But the doctor told my husband that I could not manage him at home. That really

upset me because what woman can not manage her husband, even a sick husband? How could they give me these mixed messages? They built my hopes up and then took them away. There was no teamwork.

3. Communication between health care professionals and families

Participants would have preferred more communication between the health care professionals and the family. They described a need for kindness and politeness. One participant wanted health care professionals to do more than just look at the medical and nursing charts. She wanted health care professionals to acknowledge that family members were present at the bedside.

Once he was in the hospice, we hardly spoke with our doctor. She would come round in the morning for about one minute. She would look at his charts and that was it. She did not say one word to us.

There's just not enough discussion with the family. This one doctor, the oncologist, was so abrupt. He talked down to us. He was patronizing. He was just lacking in so many areas of relationships - the things that are needed when someone you love is dying.

Listening to spiritual choices

Participants acknowledged the importance of having respect for an individual's belief systems. Several participants described the importance of being able to "keep their faith". This respect was taken as "a given" for people with a Christian faith. It was more difficult for people with diverse faiths to have their needs respected.

Data indicates that the health care system was sometimes ill equipped to meet the specific religious and cultural requirements of diverse faiths. A participant described the difficulties for a Muslim woman, her family and others in the shared ward.

There was an old Muslim lady who was dying in Dad's ward. It was an 8-bed room with both female and male patients. Given the Muslim views on women covering heads/faces when in the company of strange men, it seemed cruel for her to spend her last days in such inappropriate surroundings. Sometimes her curtains were closed, but more often she was exposed to the view of everyone in the ward, male or female, in her full misery, groaning and vomiting with her gown falling open. Part of this family's ritual surrounding impending death involved having relatives present round the clock chanting prayers. While it was good that the hospital allowed her this comfort, it was very disturbing to the other seven patients in the ward, who could not sleep for the noise.

A participant described hospices as "facilities designed to meet the spiritual and religious needs of people who are dying". However, he would be reluctant to put himself in the hands of hospice staff. He expressed fear that they

would overrule his “*autonomy by their moral and/or religious pre-suppositions*”.

When people were dying, pastoral visits and religious ministry were often considered to be helpful. Many participants welcomed visits from religious people. However, some participants with no religious beliefs did not.

People with no religious beliefs sometimes had difficulty having their views accepted. Some participants without a religion described hospital and hospice staff failing to respect their religious and spiritual needs. For example, those without a religion did not like having a crucifix above their hospice bed. One participant attempted to remove the crucifix, but discovered that it was screwed on. Other participants were visited by religious strangers, even though they had indicated that they had no religion. This lack of respect caused some people considerable distress.

Health care professionals need to pay attention to what people say about their religious and spiritual needs. My dad indicated that he had no religion - he had a deep resentment of the church, especially Catholicism. Yet the Catholic priest visited him every day. It really upset him.

The first person they sent was this pastoral care worker when what they needed was practical support. They didn't even check whether he was religious.

For religious and spiritual rites to be imposed on those who did not have a faith was considered inappropriate and disrespectful to their wishes. Participants wanted pastoral visits to be offered as a choice.

Talking honestly

Most participants said that they wanted health care professionals to tell them the truth. One participant described truthful information as “*empowering*”. He believed that hiding information from people who were dying was “*abhorrent*”. Yet it was also acknowledged that some people may not want to hear the truth.

The person who is dying should be told as much or as little as he or she wants to hear, in suitable language.

Several participants said that “*most doctors do not want to discuss dying*”. However, it was not only health care professionals who were reluctant to talk honestly about dying. Some families also chose to avoid talking about the possibility of death.

Friends and family were reluctant to actually talk about the possibilities of him dying.

Participants valued conversations in which health care professionals, family members and friends spoke honestly. They also valued courtesy, compassion

and sensitivity. They did not appreciate health care professionals using “*horrible language*”. Participants also commented on the need for health care professionals to improve their “*bedside manner*”.

The doctor wanted to stop his steroids. I'll never forget the words he used. He said: “To facilitate things”. What horrible language. I just replied “You mean to kill him”.

Getting a diagnosis of terminal disease in the words “Your kidneys are cactus,” is honest, but it is hardly appropriate.

There is a trend these days for doctors just to lay it on the line and just tell you the truth there and then, but maybe it's the way they do it that needs looking at. He was very abrupt and matter of fact. I just think there needs to be more caring and more compassion.

Sorry old man, this disease has finally got you.

I told the consultant that I thought my daughter was in pain. And the doctor said, “Well, she is dying isn't she.” I think she had spent so long working in a hospice with people who are dying that she had lost her compassion.

Participants said that information should not only be truthful but also clear and comprehensible. Participants did not consider it helpful when health care professionals used euphemisms to describe death. Participants wanted “*some plain speaking*”.

The doctors were very reluctant to talk about the possibility that he might die. They would talk about dying using euphemisms. It was simply not possible to get a direct and truthful response from them.

They (health care professionals) should give us information in appropriate language. They should also respond honestly to the types of questions that we ask. An obviously intelligent person who wants to make informed choices should not be given half truths in baby talk, while a frightened person with limited understanding should not be bamboozled with medical jargon.

The doctors were very reluctant to talk about the possibility that my husband would die. Right up until the end, they used euphemisms. I needed to hear that he was dying.

Information about diagnosis, prognosis and treatment is critical at all stages of disease from diagnosis onwards. It is still unfortunately true that doctors are often not good at giving this information in a manner which is appropriate in both its timing and in non-technical language.

Many participants were not told that their loved one was dying. They described needing this information to prepare better for their loved one's death. Some said that if they had known their loved one was dying, they would have done “*a lot more*”.

At no stage was anyone told that he was dying. He was

having active treatment right up until the end. My husband's family thought he was going to survive. I looked up the type of cancer on the internet, so I knew he was dying. The others did not have a clue. The doctors had not mentioned "dying". My husband's family was not at all prepared for his death. We deserved honest communication.

I don't know whether it was because they didn't know the right questions to ask, but at no stage did either of them really believe that he was going to die. His specialist should have been up front and said "You are going to die. Do you want to try to prolong your life with chemotherapy?"

We need to teach our doctors differently. Just because they can not cure somebody does not mean that they have failed.

According to the data, health care professionals sometimes made assumptions about the capacity of people to be told the truth. The following participant's teenage son needed to be told the truth. She told him "everything" that health care professionals told her.

He said to me: "Always tell me the truth. I need the truth." I repeated to him everything that the doctor said to me. I made sure there was no whispering in front of him, no hiding information. He hated whispering and hiding. He wanted to know everything that was going on. It did not make him afraid.

Many participants described "struggling to get to see specialists", then "struggling" to get responses to their questions. Some participants described health care professionals who avoided answering questions.

I was not able to talk to the doctors directly. All communication with doctors had to be done via the district nurses. The nurses spoke with the doctors, not me. It was like I was just "the mother", not someone in the medical field. I would have liked to be able to talk to the doctors directly - to ask them what else we could do to relieve his pain. But the doctors were not available. I was too passive. I was a mother whose son was dying. I was too nice. I should have made them listen to me. My son was in agony until the day he died.

I had questions around taking time off work - should I take time now or do I wait another month? Really practical stuff around how we would manage his care. Like do we need to get a special bed in? They did not give us nearly enough information. They did not even tell us that he was dying.

Many participants needed specific information so they could plan the management of their loved one's care. Some also wanted health care professionals to tell them when someone will die. Although most health care professionals were reluctant to even give an informed estimation, several participants said having "some idea" was better than "no idea".

Participants wanted information about possible eventualities. The following participant would have liked information about various scenarios for people

as the level of urea in their blood increased. Although "fading away peacefully" was the preferred option, it was certainly not the only option.

Doctors had advised him that, when his quality of life deteriorated, he could opt to cease dialysis. They told him that uraemia would cause him to slip into a coma and fade away peacefully. Unfortunately, the doctors had failed to fully inform him about how unpredictable the effects of uraemia could be. He grew more wretched and remained painfully conscious. We had to watch helplessly day after day as he pleaded for it all to be over. The promised coma refused to come.

Participants said that they did not appreciate health care professionals being "jolly" around the person who was dying and their loved ones. The following participant would want her own death dealt with honestly and respectfully. She would not want to be "jollied" out of it.

It would be a great comfort to have health care professionals around who have come to terms with the thought of death. It would be comforting to be able to talk to them honestly about how I felt, rather than have people trying to deny the fact that I was dying and try and to 'jolly' me out of it.

Participants described feelings of anger and betrayal when health care professionals made promises that were not kept.

The doctors promised my son that he would not be in any pain when the time came. Some doctors told him that he would just fall asleep. It was nothing like they told him it would be. He was in absolute agony most of the time that he was dying. We needed to be prepared for this.

Participants were also disappointed that health care professionals changed their minds. In the following example, a family was told that their loved was being admitted to hospital only for tests, not treatment. He commenced chemotherapy and remained in hospital until his death.

On entering hospital, staff reassured us about the availability of home nursing and the support and equipment available for his return home. All these discussions were forgotten. He was subjected to all these tests. They immediately started chemotherapy, without telling us about its effects. From that day on, he was unable to communicate with us. We were unable to say our good-byes.

Sharing information

Participants required information about a range of issues. This included information about:

- their illnesses
- the potential symptoms associated with their illness
- what usually happens
- treatment options

- possible adverse effects of treatment
- what to expect
- approximate life expectancy
- various types of support services
- entitlements (e.g. carers' pensions)
- legal information (final wills and testament, medical power of attorney, advanced directive)

Several participants would prefer to receive information when they were healthy, so that they could make well informed decisions. They accepted that these decisions may need to change depending on the circumstances.

People need to be given a range of options. There is no wrong or right way to do it. In order to have options, we need information and we need communication from health care professionals.

Many participants described inadequate information to help them support their loved one. Participants often described “*working it out for themselves*”. Many participants were not told how the illness would progress or what to expect. Participants also described instances in which health care professionals made incorrect assumptions about their access to information.

It would have been good to have something informing me of the different sort of services that I could call if I needed. Even a handbook would have helped. But they did not have anything like that. I got a sheet from the doctor about what to expect. But it was for an older person dying. It was not for a child. And that was all I was given. There needs to be something more for children who are dying.

The specialist's attitude was that if we wanted to know anything about this disease, or the medication, we needed to look it up on the internet.

Health care professionals assume that people will ask questions if they want to know. But we don't always know what to ask.

The following participant believes health care professionals need to be proactive about informing people of their options. It is often difficult for people to find this information without help from people within the health care system. When health care professionals did not provide this information, participants were not given the opportunity to make the “*best decisions*” based on their own circumstances. The following participant wanted to take her husband and young children on a holiday in Queensland before her husband died.

I needed to know what might happen so that I could make decisions for my family based on the correct information. I wanted to know when to take him on a holiday with our children. We really needed the medical profession to be proactive in somehow spelling out our options. The doctor denied us the information so that we could make the best decisions for ourselves. He replied that if he had told us that my husband was

dying, we would have given up hope. They should not assume that we would have given up hope. By denying the possibility of death, they denied us so much else. By the time we took the family trip to Queensland he was so ill.

Dying with dignity

When discussing death and dying, the term “*dying with dignity*” is often used. Participants often said: “*I want to die with dignity*”. But what does “*dying with dignity*” actually mean? Participants gave many different meanings of what “*dying with dignity*” meant to them. The data indicates that people value different things both in their lives and when they are dying.

There is more to dying with dignity than a comfortable bed. There is a whole mental, emotional and spiritual side to it as well.

Participants said that people who were dying were at their “*most vulnerable*”. Maintaining an individual's ‘dignity’ depended, to some extent, on how others treated them. Some participants achieved this by maintaining as normal a relationship as possible with the person who was dying.

If you can't get past the fact that they are dying, then you are unable to have some sort of normal relationship with them. Dignity is caring for them as the person they were. Respecting the type of things they enjoyed before. Not allowing them to become the illness.

Health care professionals need to be responsive to the needs expressed by the patients. Some want to be entertained while others want quiet time with their loved ones and time to contemplate. Some are eager to embrace what is left of their lives while others feel so wretched they are beyond caring. It is important not to try to make one size fit all. People are as individual in death as they are in life. Once you cease to be treated as an individual, you lose your dignity.

Indignities

When participants were asked to explain what dying with dignity meant to them, participants often described a health care professional treating their loved one without concern for their dignity. Participants talked about various “*indignities*” that occurred during their loved one's dying process. Pain was the most often cause of a person's loss of dignity. Participants were often told that the pain would be “*treatable*”. However, many participants described pain being poorly treated.

One participant said that people “*turn on the compassion*” far too late. Her mother was cared for in a shared room in a hospice, with little privacy. It was not until death was imminent that she was transferred to a single room.

The room change did not happen during the time when she was alert to the humiliation of her circumstances. It did not occur until she was virtually unconscious. While it may have given comfort to her loved ones, she was barely aware of it. Why do they wait until the patient is beyond caring before turning on the compassion? It is when people are still alert enough to care that dignity matters most to them.

The following table provides examples of how dignity was both maintained and taken away. There are three columns. First, a list of what “dying with dignity” meant to participants. Column two contains an example of how that type of dignity was maintained. Column three describes how that type of dignity was taken away or an indignity experienced.

What does dying with dignity mean to you?	Example of dignity	Example of an indignity
To maintain a sense of self.	When we first found out the news, I said to my husband “What can I do?” He said “just be with me”. And so I kept that in my mind. And a nurse in palliative care said “just love him”. So that’s what I did.	The hospital sent a letter to my mum to say how sorry they were to hear about Peter’s death. His name was John.
Pain and symptom management.	Drugs are so sophisticated these days that no one need suffer unnecessarily. I have nothing but praise and gratitude for his excellent care. He died peacefully without any pain.	He was old and very, very sick and in incredible pain. I expected them to help him control his pain. I met with the pain management team. They could not help. They said that he could linger in this condition for months. How was it possible for them to tell me that my father would go on in pain for months? In a civilized society one expects that people will act with care and compassion. I thought I would go insane watching him in such terrible pain and distress. It was the most horrific thing I have ever seen.
To die without being a burden on loved ones	Although it was very hard, unremitting work, I found my sister a joy to look after at home.	I did not know that he would need to be turned for bedsores. I did not know that I would have to give the medications myself. When he was in too much pain, I had to put a needle into his line to give him more morphine. It was my responsibility. If he got too anxious, I had to put medication under his tongue. I had to bath him myself. A sixteen year old boy is big – he was nearly six foot tall. He also became very constipated. I had to lift him into a warm bath so he could just do it into the bath. He just could not sit on a toilet. These are things you are never told about.
To have loved ones around	I had flexible work commitments, so I was able to spend a lot of time with mum at the end.	I had expected the hospital to phone to say that my father was “dying”, not that he was “dead”. I was very disappointed because he died alone. It was very important for me to hold his hand while he died.
To not be kept alive with mechanical interventions	She did not want to be kept alive by mechanical means. That choice was respected.	We were kept out of ICU being told they would let us in shortly. At 8pm I asked what was going on and they said a few minutes more. At 9pm I asked again and they said a few minutes more. They let us in at 9.10pm and she died at 9.20pm. We were so lucky to be there when she passed away. But if we had not kept asking, we would not have been allowed in. I worry that we missed being with her those last few hours. I really did not want her to be alone when she died. We can only hope she was treated with dignity for those final hours but had we been privy to her last hours we may have been able to save her some of the procedures by saying “halt”.
To have control over the environment	He died peacefully at home in our lounge room surrounded by our five beautiful children and myself.	Dying should be among familiar faces, not an audience of strangers.

What does dying with dignity mean to you?	Example of dignity	Example of an indignity
To maintain self respect	I would like to die in a manner which minimised the suffering for those left behind as well	The nurses insisted on calling her by her first name. My mother hated this. It was terrible.
To maintain self determination	Before he was dying, it was important for him to be shaved and cleaned. I made sure he was shaved and cleaned every day.	You're in charge of your life throughout your life. It is soul destroying when you lose that at the end.
To maintain control	It was dignifying – he had some control at the end. I helped him to achieve that. He did not have crowds of people around him. He hated that sort of thing.	You are in control of your life, and then when you get sick at the end and you lose all that control. You lose your dignity. You lose your sense of you.
To be able to make choices	My father was in a nursing home with alzheimers. When he got pneumonia, we were given the choice to send him to hospital or keep him in the nursing home. We did not want him taken to hospital and treated.	I know he would have hated the inability to control his own life and the return to the dependency of babyhood. Yet, when he contracted an infection and I and my adult children asked that no antibiotics be given, the hospital refused.
To have my basic needs met	When it comes to dealing with the really yucky details, I don't think I'd want to inflict that on the ones I love most. That's not how I want them to remember me. I would want a professional carer.	We had to take turns standing guard in the hospital to make sure his basic needs were attended to. The nurses would sit at their desk ignoring patients' buzzers.
To be able to feed myself and take myself to the toilet.	Factors such as incontinence would bother me, but I would have to be ready to use the supports that are available for this condition.	She could not get to the toilet easily. They had to take her in a wheelchair. So the nurse put her in a nappy. It made things more convenient for the nurses. But for the person in the nappy, and her family, it was not dignified.
To be spiritually prepared	Health care professionals need to pay attention to what people say about their religious and spiritual needs.	It was downright offensive to have the hospital's Catholic chaplain bouncing into his room every couple of days on the off-chance of a deathbed conversion.
Privacy	My mother was moved to a single room when she was near death.	My mother died in an 8-bed ward with nothing but a curtain between her and a roomful of strangers.
To maintain a sense of humour	Even though I am dying, it is important to feel alive. Just because I am dying does not mean I can not have fun. I want to die laughing.	There can be no fun or recreation for people who are dying.
To be treated with respect	It is acknowledging and respecting that we have an individual here and responding appropriately.	He had dignity when I was there, but not when all these different nurses came and prodded and pushed. They did not even explain what they were doing. They talked over him. They did not treat him like a person.

Taking control of the dying process

Choice and control

Most participants described 'choice and control' throughout the dying process as "very important".

To me it's a matter of control. If I go to a doctor, I don't expect him to decide whether I should be treated any particular way. I expect him to tell me what's wrong with me and what my options are for healing. I make the decisions as to whether I will be treated or not.

However, many participants were aware that choice and control were often taken away from people who were dying and their loved ones. They described health care professionals as "trained" to take control.

Choice and control are very important. The medical profession is not good at giving you control. They assume that you are not going to be able to cope. They feel they have to take that choice and control from you.

It is very rare to have a doctor who gives advice. They are trained to be prescriptive.

Participants said that it was possible for people who were dying and their loved ones to take more control over the dying process when the person who was dying stayed at home. Participants were aware that they would have less control if they were cared for in institutions (hospices, hospitals and nursing homes).

If you're in an institution of any sort, whether it is hospital, hospice or a nursing home, you have other people making the decisions for you. To some extent you are at the mercy of whatever they choose to do.

Several participants related cases in which loved ones in hospitals had been treated against their wishes.

Even though he was dying, they treated him with chemotherapy against the family's wishes.

Participants said that the 'health care system' should listen to what people want for their own death. The data indicates, however, that decisions were often taken out of their hands.

People's wishes should be respected. We should be able to decide what type of medical support we want. It should not be left up to doctors to decide what they think should be done.

Advocacy

Many participants were advised not to care for their loved one at home. Some described instances when their loved one was "not allowed to die at home". They were forced to fight for the right to care for their loved one at home. Some people won the battle, others lost.

Many well meaning people, professionals as well as family, felt it would be better if he was in a hospice. Even our local doctor told us that we could not keep him at home. He felt keeping him at home was not good for me or our children. I felt I was battling against people and their fear of death. Everyone was really scared that my husband's death would have some dreadful effect on the children. But the children were really involved in the dying process. They helped bath their dad. They also bathed him after he died. They were not frightened of him. He died peacefully at home in our lounge room surrounded by our five beautiful children and myself. But it was a battle to get there.

We wanted to bring him home, but the doctors would not let us bring him home. We had a meeting with the social workers and doctors. They would not let him come home. They kept telling us, his family, that we could not look after him at home. They told us that the bed was not the right height. I loved him. I would have nursed him on the floor.

One participant was told that she and her partner could not take her brother home without receiving training from the hospital staff. They had to prove their ability to care for him at home.

Staff at the hospital told us that we needed to come into the hospital to take sole care of my brother for forty-eight hours.

They wanted us to do all duties. We were told not to expect the nurses to do anything. Apparently they had to verify that we were able to care for him 'properly'. It was just the most bizarre thing. So we decided to just take him home. When we arrived, the nurse said "You've come, for your forty-eight hours shift" and we said, "No we've come to take him home". They had to get the doctor. It was just so bizarre. And then he had a fit. He was unconscious. And they said "Well, you can't take him now". We asked if these fits were likely to keep happening. They said "yes". We told them that we would take him home. It was quite a battle.

In another "battle", a woman flew inter-state to "fight" for the right for her father to die at home.

My father's very clear wish was to die at home. The family supported his decision. Then two weeks before he died, his care needs had become extreme. My mother was extremely tired, so we placed him in a hospice so mum could have a rest. One day one of the doctors just walked up to mum and said that she was not able to take him home. The doctor said that he has to go into a nursing home. My mother was shattered. Our family had worked for two years to keep him home. I wound up having to fly interstate, convene a meeting of all the medical specialists and reinforce what the family wanted. He was subsequently brought home with the most excellent palliative care imaginable and did indeed die at home. But it took a full-scale fight.

Advanced Directives

Participants discussed the preparation of their last will and testament. They described talking with loved ones about funerals, burials, cremation and where they wanted their ashes scattered. Few, however, had documented an advanced directive or appointed a medical power of attorney.

There was confusion among participants about the legalities of a 'living will'. Some participants who had prepared an advanced directive expressed concern that their "piece of paper" would be disregarded by health care professionals. Others described it as a "legally binding document". Those who had appointed a medical power of attorney expressed an expectation that their wishes would be respected.

At this time in Australia - no matter how many forms are filled in, witnessed, placed with doctors and children in good faith that my wishes will be carried out - it is unlikely that I will be allowed to die quickly and quietly as a hospital patient.

The 'living will' is a legally binding document. It clarifies one's choices and life values. It takes the burden off family members to guess at what one's wishes might be. This should not be left until one is already hopelessly ill. It should be undertaken at the same time that a financial will is done.

My eldest son is a surgeon. He told me that the living will was not worth the paper it was written on. He told me that doctors

ignored it. So I have not written instructions in a living will. Instead I have appointed my daughter as my medical power of attorney.

Data indicates that few hospitals or health care professionals are aware of the Medical Treatment Act. Data indicates that it was “*very easy*” for advanced directive to become buried by bureaucracy. One hospital has introduced colour-coded administrative processes for advanced directive. These colour coded documents were not a replacement for verbal communication between participants and health care professionals. When these documents were used to replace verbal communication, problems arose.

There is a hospital procedure that these forms have to be in a green sleeve in the front of our medical histories. My pink piece of paper had not been placed in a green sleeve. So the doctor did not respect my wishes because he did not read the pink piece of paper.

According to participants, some health care professionals were unaware that they were required to concede to the wishes of the patient - health care professionals were described as being “*aghast*” at the notion that patients could make decisions for themselves. In one instance, when a participant gave the doctor her ‘living will’, he immediately referred her to a psychiatrist.

The surgeon made me see the psychiatrist because I had written an advanced directive form prior to my knee surgery. He thought I must be depressed.

I do not feel confident that my advance directives would be adhered to. It would depend on the doctor. Most would be aghast. Their professional training does not give much allowance for patient autonomy.

A palliative care nurse said that advanced directives were not required in the palliative care setting if the team was updating family and patient constantly. However, data indicates that patients and families sometimes had difficulties updating the palliative care team.

Euthanasia

Some participants said that most health care professionals believe in “*extending misery*”, rather than voluntary euthanasia. Others believed that voluntary euthanasia was widely practiced by health care professionals, though this was rarely acknowledged publicly.

My mum died quite a few years ago in a bush nursing hospital. She had cancer of many organs. She had known the doctors and nursing staff for many years. She was given 100% choice over when and how she died. When the pain after many months got too bad, we all said our goodbyes and left the hospital. She just said “now Johnny!” and our GP gave her a fatal dose of morphine and she died a few minutes later.

I hope to have the same choice when I die, but this is very unlikely.

Several participants wished that they could have done more to help their loved one to die.

He asked me to help him die. He wanted to be put out of his misery. He said that dogs get better treatment than we do. If it was legal, I would have helped him. I wanted to decrease the amount of suffering he had to endure. One night, the doctors said that every time he coughed, I could give him morphine. I told my husband that I would give him morphine every time he coughed. He knew what I meant. He was aware that I was trying to do something to help him die. I gave him morphine, on the hour, every hour, all night. But he was still alive in the morning.

I have always regretted that I failed to end his suffering. I wouldn't let my dog suffer like we let him suffer. In the nursing home, he got pneumonia. They insisted on giving him antibiotics.

Several participants were members of the voluntary euthanasia society. Many had joined the society after witnessing a loved one die.

After witnessing the agony that my son endured while he was dying, I fully support euthanasia.

Participants who were members of the voluntary euthanasia society described joining because they wanted “*autonomy and control*”. They wanted to have a good death, with adequate pain relief. They also wanted control of where and when they died.

As I near my 78th birthday and my body is starting to succumb to the ravages of old age I feel that the availability of the means to end one's own life quietly and peacefully at a time of one's own choosing should be everyone's right. I personally do not wish to endure a long period of degradation before I eventually get free of a body that is no longer of any use to me. Neither do I wish to end my days in a hospice, nursing home or aged care facility. I personally see no value in life under these circumstances. Having visited a friend in these places I find it all very depressing.

One participant with a terminal illness has decided to kill herself rather than spend the end of her life in a nursing home. She regards the process of ending her life as quite straight forward. However, it was difficult to know when to end her life.

Anyone can just take an overdose and die. All you have to do is get your scripts filled and take all the pills that you need to take. But as I lose my independence, my ideas about when to

euthenase change. As I get closer to death, I hang on to life. I find there is something for me to live for.

Access to appropriate services

Some participants identified a range of services in their community to support people who are dying and their loved ones. However, most participants were unaware of any support services apart from their local GP. To find out about the existence and availability of support services, they needed someone to tell them about the service. In some cases, participants found out about support services via social networks (e.g. friends, family, 'contacts' and support groups). One participant found out when it was too late.

There are services out there that I just did not know about.

There are all these services out there. But no one tells you about them. How can you use the service if you don't know about it?

According to the data, the types of services that people accessed while caring for a person who was dying at home included:

- Daily nursing care (district nursing, palliative care nursing)
- 24 hour on call nursing care
- GPs
- Allied health care (occupational therapists, physiotherapists, music therapists)
- Complementary therapists (e.g. massage therapists, naturopaths, aromatherapy)
- Personal care attendants (showering, dressing)
- Housekeeping (cleaning, cooking)
- Child minding
- Animal minders
- Support groups
- Family support
- Respite
- Advocacy (e.g. patient representatives in hospital)
- Counsellors

Despite a range of support services being available, many participants relied only on their local GP to provide support. Although most participants described GPs as "caring", several participants described their GP as reluctant to administer adequate pain relief. Participants described a fear among some GPs that high levels of opiates (e.g. morphine) would "kill" the person who was dying.

Our GP refused to give her morphine because it would further depress her respiratory system. He said that he was not going to be the one who killed her. Instead, she died in pain.

A few participants were given brochures about the types of support services available in their local community. One participant appreciated a brochure that spoke openly about sexual difference.

As a lesbian couple, we were nervous with people coming into our home. We felt exposed and vulnerable. The palliative care brochure said their service was open to all people, including other sexualities. That was really nice.

While some participants spoke about the compassionate palliative care nurses, the food parcels from people in the community, the helpful housekeepers, dog walkers and the comfort of being able to call for advice and assistance day or night, 24 hour a day, other participants struggled with minimal support. They had not been informed about the range of support services.

My mother needed support in the house, council support, anything. When eventually they did offer care, they would come twice a week for a few hours at a time. It was grossly inadequate for what they needed.

Participants believe that more community support services would allow people to have more choice about where they died. In addition, information about the existence of these services needs to be more widely available to people who are dying and those who care for them. Participants described informing people about the support services as a GP's responsibility. Several participants described the importance of "knowing the system" and "getting into the system".

People have to know that there is a system to get into it. The information needs to be readily available at the beginning. Your GP would be your first port of call. They should be aware that these are things they offer. Even if it's just getting into the system so you get personal care from the council. You've got to get in there. Someone should be giving you information about the Medical Treatment Act and all that sort of thing. But it is just not talked about. And I mean most doctors never talk about this sort of thing.

One participant described herself as "lucky" because she knew people who worked in the health care system. Without these "contacts", she would not have known about the support that was available. Without this support, she would not have been able to care for her brother at home.

People need to be told the kind of supports that can and can not be provided. We had to find out from our own contacts that there were options. We had to orchestrate the whole thing. I think we got a bit of a reputation of being difficult people at the hospital.

Although those with contacts and connections in the health care system accessed support services, those without connections did not.

And I just think it is terrible for families who have not got connections in the health care system or have not got the money. What do they do? I just think that care for people who are dying needs a huge overhaul.

Participants made several suggestions for ways to overhaul the system. One suggestion was 24 hour home nursing. Although participants described round the clock nursing as “a blessing”, they invariably described home nursing as “too expensive”.

I would have preferred a nurse to be with us constantly during that final week. As I said to the hospital, if they could have allowed a nurse for those few days to be in my home, live there, free board or even if I paid her, whatever, to administer the drugs and things like that, it would have relieved me of the pressure. And I would have had more time to just be with my son. As it was, I still had to run a house.

24 hr home nursing would greatly enhance the quality of life for someone dying at home. It would also provide relief to family and friends from the strain of being constantly on call. I suspect this type of service would be almost impossible to fund. But if it were available, it would be a blessing.

A few participants accessed complementary therapies. They reported mixed results.

We got into different things like Gawler, juice, diets, meditation and all that sort of thing. It was trying to give him hope. But I do think there is a lot of charlatanism about. I think there is a tendency for sick people to be preyed upon.

After the marijuana cookies, he went for walks and he could drive the car. He was obviously dying but it was a better quality of life. He could laugh again. Instead of being dead within a week, as we were told, he lived another six months. Once he was on the cannabis, the home nurse did not need to come. He was perfectly capable of bathing himself. Nobody recovers but it gives them much better quality of life. The morphine was hopeless.

Place to live while dying

Participants made it clear that the choice about where one dies should be made in consultation with loved ones and include “advice” from health care professionals. According to the data, such decisions should be thought, planned and discussed in advance, preferably when they were in good health. However, the decision about where a person wanted to die often changed as their circumstances changed. Without regular consultation with the individual who was dying and their support networks (partner, family, friends), health care professionals relied on their own assumptions about where people wanted to die. The data suggests that professional assumptions were often mistaken.

Home

Many participants preferred to die in a place that reminded them of their life. They wanted to “live at home” while dying. They wanted not only to sleep in their own bed (rather than in “a sterile hospital bed”) but also to be surrounded by people who loved them and things that were familiar.

I want to die at home. I want to be able to look out the window, see the flowers see the trees. I would feel safer and I would feel loved. It is not clinical. Also you are not just a number in a hospital.

Having people I love close by, hearing their voices, enjoying the warmth of my home and its familiarity would be a great comfort to me. However, it would depend on their ability and willingness to care for me at home.

Although many participants would prefer to die at home, they acknowledged the difficulties that this would impose on family and friends. They did not want to be a burden on people.

There are many barriers to dying at home. Sometimes it is ignorance about the support that is out there. A lot of people do not know that there is palliative care support at home. They do not know about it. They think they have to go a hospice, hospital or nursing home to die because there is no other option.

Those participants who lived alone described having fewer options - they said that it would be difficult for them to die at home.

Once you have lost your partner, you are in the hands of other people. If you have a partner, you can make the choice to stay at home. But you can not lay down the law and tell your children what to do. It is more complicated when you live alone.

Many of those who accessed home palliative care were grateful for the support.

The community nurse sat down at our kitchen table and said: “What are your concerns? What are your questions? What do you need?” No-one at the hospital had spoken to us like this. In hospital, they simply told us what we needed. Her approach made a huge difference to us feeling like we can do this. Then she told us what their service provided. The only down side was they did not have enough staff. If they had been better resourced, it would have just been brilliant.

According to a community palliative care nurse, it was possible to have “a really good death in a home environment”.

Good palliative care allows people to die in the way they choose. It means that people are able to have the best quality of life possible while they are dying. They can be comfortable. In most cases they should not have uncontrolled pain. They should not have uncontrolled nausea. They should have holistic support - emotionally, psychologically, spiritually. They should have the support that they want.

Another palliative care nurse consultant thought it was important to ensure that the home was set up “properly”. In addition, dying at home often involves “training inexperienced family members” to undertake major dressings, medications, injections (including pain relief). However, many participants found the intensive medical and nursing aspects of care “too physically and emotionally draining”. Some would prefer nurses to undertake the ‘physical and nursing care’ and doctors to undertake the medical aspects of care. This delegation of tasks would enable family and friends to concentrate on the emotional and spiritual support.

Caring for a dying person can be an enormously taxing task, especially with minimal support.

There was no way I could have cared for him at home. It would not have been fair on him.

A palliative care nurse said that it was a “great tragedy” that many people are not able to remain at home.

It is a great tragedy when it is not possible to remain at home. People are unable to stay at home because of the carer’s inability to cope, or the home itself being unsuitable for the patient’s needs or a myriad of other reasons.

One participant was determined to put on a brave face whenever she met with health care professionals. She did not want them to think she was “not coping”. She was afraid that if health care professionals decided that she was not coping, her husband would be placed in a hospice or hospital.

I was conscious that, as a woman, I had to be controlled and not cry, not get upset. I did not want them to look at me and say: “she’s not coping”.

When participants were having difficulties “coping”, the options were often limited to only respite, hospice or hospital. Additional support to help family to solve the difficulties at home was rarely offered as an option. Some participants described being “talked out” of caring for their loved one at home.

Although Dad had wanted to die at home, the palliative care people at the hospital talked us out of it. I can understand why. I now appreciate the care that was needed to look after him. With only a single visit per day from a qualified nurse, we would have been very alone, confused and vulnerable.

On some occasions, the only home support being offered was a visit from a GP and a nurse each day. For some participants, this was a frightening prospect so they decided to admit their loved one to a hospital or hospice. This was not their preferred option. The data suggests that the situation may have been different if health care professionals had mentioned the possibility of a range of support services (e.g. personal care attendants, housekeepers, child minders, pet carers, support groups,

community helpers, volunteers, respite, counsellors). The following elderly participant was offered a range of services to help her husband die at home. In particular, she felt secure being able to call for advice and assistance on a 24 hour day-or-night number.

It was absolutely wonderful having him at home. I could not have done it without all the support from the hospice. I felt totally safe because I could ring if I was anxious. The nurse would advise me about whether she needed to come or whether what was happening was normal. Someone could be here within 10 minutes - day and night, 24 hours. It was a wonderful experience. All sorts of support were provided by the hospice. Someone would come so that I could have an afternoon to do just what I wanted. Things like that.

Hospice

Not every participant would want to die at home. Some believed that dying at home would change the feeling within the family home with memories of death.

My mother felt that if someone died at home, it tainted the home. She felt that the room would become ‘the room where mum died’.

Other participants would prefer to die in a hospice because they said that their family may not be able to care for them at home. They would not want to become a burden on their family and friends.

I would prefer to die in a hospice only because I think my husband or family would find it difficult to have me die at home.

He was very aware of becoming a burden. He had been very independent all of his life. One thing that he did not want to be at the end of his life was a burden.

Most participants described hospices as more accepting of death than hospitals. They described their loved ones being “safe and secure” in a “caring environment”. One participant hoped she would be as “lucky” as her brother.

My brother had wonderful care in a hospice. I hope I am lucky to be sent there.

Hospices have “up to date” palliative care nurses who are not afraid of death and using drugs.

In contrast, some participants did not like the thought of being in a hospice, surrounded only by people who were all dying.

When you are in a hospice, you know that you are going to die. You are surrounded by death.

Participants described the personal and family contexts for their decision to move themselves or their loved ones into public care. Many participants put the

needs of others first. Many described care in a hospice as necessary because their partner or children would be unable to care for them at home. If admitted to a hospice, many would prefer a “homely” environment rather than a clinical hospital/hospice setting.

Hospital

Some participants would feel safer dying in the hospital system. They would prefer to die in a clinical surrounding where pain relief was available at very short notice. These participants believed there were insufficient services in the community.

If you are relying on community palliative care nurses, they mostly visit only daily. If you have pain in the middle of the night, it becomes an issue if your carers are not able to administer the morphine.

However, data indicates that people who were dying did not always receive good pain relief in hospitals. According to a palliative care nurse, it will take some time before there are good palliative care services in hospitals.

My one experience of palliative care in hospitals was bad. I found that nurses do not like patients who are not going to get better. I decided not to trust my dying sister to the care of these callous people. So I asked for an ambulance to take her home. They told me “we are not treating your sister. We are giving her palliative care”. I thought “so this is palliative care.”

The nurses broke my mother’s arm lifting her out of bed. Then the resident would not give her morphine for her broken arm because he thought it might kill her. She had a cancer that was killing her! I can still hear her screams. You would not let an animal suffer like my mum did.

Consistent with previous research (Seymour, 2000; Webb, 1996), participants said that general hospitals were more interested in treating and curing people, than caring for the needs of people who were dying. They felt that “long-stay or terminally-ill patients are not well-served in a hospital”. They felt the emphasis in hospital was on “basic bodily needs” - hygiene, food, fluids and daily vital signs. A participant described it as “a clinical approach to dying”.

He was treated reasonably well in hospital. But it was left to us as his family to do any more than the basic care. There was no sense of dying as a sacred time, that we were journeying with a person towards death. It seemed more like they were waiting for the bed for their next patient.

My husband’s final admission to hospital was dreadful, simply because the emphasis was on treatment, not care. The hospital employed agency nurses. They had no knowledge of my husband as a person, his illness or our family.

Nursing home

Participants described staff working in nursing homes as “frantically busy all the time”. Nurses often did not have time to sit with people who were dying or to really listen to them. However, the care was considered “as good as could be expected”.

He didn’t have a good death. He was ill for a long time. He died in a nursing home, in a four bed ward, in a curtained off corner. It was not a nice place to die, or a nice way to die. But the care was kind. It was probably a bit rough and ready because the nurses and all the other staff were overworked. But they did care about what they were doing. He was kept clean. We never went in and found him sort of in a state of distress due to lack of care or anything like that. The care was as good as could be expected under the circumstances which were far from ideal.

Several participants would have preferred there to be better palliative care in nursing homes. In particular, they felt there needed to be better education about the “proper administration” of pain relief.

Several participants received phone calls from staff in the nursing home after their loved one had died. They would have preferred to have been informed when death was imminent. Having loved ones present at the moment of death was considered very important to many participants. Those in nursing homes were often denied this.

Some participants had witnessed young people being cared for in nursing homes. They did not consider it an appropriate place for a young person to die. Also, participants said that it was “unfortunate” that some older people received medical treatments that prolonged their life in a nursing home. Nursing homes were described as places where people “waited to die”.

In old days, old people got pneumonia then died. It was our friend. Now you get pneumonia and doctors keep you alive so you can go to a nursing home. These are often miserable places with people waiting to die.

Communities in action

Data identified an urban and a rural community in which people have worked hard to provide local facilities for people who are dying. The following vignette illustrates one community’s commitment to building a facility for people who were dying and their families. It also illustrates some of the obstacles that this community has faced, and continues to face.

Building a place to die in the local community

People in this small rural community knew exactly where they wanted to die - they wanted to die in their local community surrounded by family and friends. They did not want to be transferred to hospitals in Melbourne or hospices in Bendigo, Mildura or Ballarat. They wanted to die where they lived.

People in this rural town wanted people to have the choice to die in their own environment while being supported professionally. They wrote numerous letters to health bureaucrats and politicians about providing such a facility. These letters were largely ignored. They were told that it was "more economical" to operate large, clinical hospices with twenty or so beds. Unfortunately, health bureaucrat's economic perspective limited their vision. They did not see the value in supporting a small community facility that would help people to die in a familiar, homely environment.

Rather than feeling deterred by this lack of government support, local women began to fundraise. The fundraising began with a raffle for a hobbitex table cloth. Later there were lamington drives, cake stalls and many other raffles. Their local politician supported their fund raising efforts. He even made a promise to them - if they raised \$25,000, the government would provide \$75,000. This offer is yet to be honoured.

Rather than wait a life-time for the government's financial support that had been promised, a local woman began writing letters to managing directors of Australian companies. She found their addresses on the backs of tins, jars and packets in her pantry. On the back of each envelope she wrote: "Dreams really do come true, especially when it comes to people who are dying".

Unlike her letters to health bureaucrats and politicians, these letters received overwhelming support from senior executives in private industry. They not only replied promptly and courteously to her letters, they also gave generous donations.

The letters began a long period of successful fundraising in the local area. With energy, commitment and vision, this rural community raised \$180,000. Together with a large workforce of voluntary tradesmen, and heavily discounted supplies, they began to build a community facility for people who were dying and their families.

The community facility was opened in August 2001. It looks and feels just like a home. It is furnished beautifully and there is a lovely garden area. It has two bedrooms, both with state-of-the-art hospital beds (both donated). There is an open plan living area with comfortable couches and a large dining table. There is also a well equipped kitchen with a life-time supply of tea and coffee (also donated).

The community facility was intentionally attached to the local hospital so that patients could receive professional care while living in a homely environment. Unfortunately, workplace issues have made it difficult for some nurses to care for patients in the community facility. While these workplace issues remain unresolved, health care professionals rarely offer the community facility to people who are dying, though families are sometimes offered the facility. Instead, the District Health Care Service uses the 'Palliative Care Suite' as a venue for their meetings.

Without operational funding for nursing services, the state of the art hospital beds (and other equipment that was kindly donated) remain unused. For all those who worked hard to make dreams come true, and all those who donated money in good faith, it is disappointing the community facility is currently not being used for the purposes for which it was built.

The business of dying

Those participants trying to establish alternative, community based, home-like facilities said they were "battering their heads against a brick wall". For them, the economics of health care was a major obstacle.

Had we wanted a facility for sixty patients, the government might have thought it was viable. But a large facility would not provide the home-like atmosphere that we want to provide. It would be adopting their clinical model. We want people to feel that this is the next best thing to home.

Although participants recognised that most palliative care beds were located in large, clinical environments, they questioned whether a clinical model was more cost effective. In one community, a property has been donated so that people who are dying can be supported while remaining in the surroundings that they love. Many people have also offered to volunteer their time for such things as cleaning, gardening, personal care, massage, and aromatherapy. However, without government support to fund the nursing care and ongoing operational costs, dying in their beloved local environment was not yet an option for many people.

If participants were unable to die at home, many would prefer to be able to die in a "homelike environment" within their own community. One participant who was trying to establish a community facility remained optimistic about the future.

The palliative care models in Victoria are fairly clinical. Policy makers are not listening to what people want. I think that will change over the next fifty years, especially as the baby boomers get old. ❖

5

Conclusion

Participants were very clear about how they would like to die. They would like to:

- spend their last days with their loved ones
- remain in control of their decisions
- be treated with respect
- have their spiritual views respected
- be treated with compassion and kindness
- die with dignity

Participants' last wishes may seem simple, but the findings indicate that participants' last wishes were often difficult to achieve. The quality of our health care system, and the behaviour of individual health care professionals working within it, often influenced the way people and their loved ones experienced death and dying. The data indicates that the quality of medical, nursing and allied care varied enormously. Some participants described kind, competent nurses and compassionate, communicative doctors. Other participants "*fought battles*" with officious, interfering nurses and described doctors as abrupt and directive.

According to the data, it is important for the health care system to consider the needs of the whole family, not just the person who was dying. Given that "*all families are different*", health care services need to be flexible and responsive. Currently, this was not always the case. With limited resources (time, staff, money), it was difficult to be flexible and responsive. Instead, patients and families were expected to fit in with health care routines, not vice versa.

Many participants described the contemporary Australian health care system as not respectful to the process of dying. They said that the health care system should support people to play an active role in their end-of-life decisions. This requires the provision of information about options. Without being aware of options, people living with a terminal illness and their families have no choice but to accept the health care professionals' expert opinion.

According to the data, many important decisions around dying were made by health care professionals without sufficient consultation or respect for people's wishes. Although most health care professionals acted in the best interest of the person who was dying and their loved ones, their perception of "*best interest*" was often from the professionals' perspective, not the consumer or carer's perspective. While health care professionals may have expertise in medical care, people who are dying and their loved ones are experts about their own lives. Most participants knew what they wanted, and what they did not want.

This project shows that consumer participation and community engagement processes are an effective way for people to talk about death and dying. It also shows that engaging communities in discussions about palliative care services provides information that can assist more responsive and appropriate services. The findings can be used to improve processes that support people when they are dying. Given that people who are dying are being cared for within communities, it is essential that communities become involved in the design and implementation of palliative care programs. ❖

6

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