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Discussing end-of-life issues with terminally ill cancer patients and their carers: a qualitative study

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Abstract *Goals of work:* Discussing end-of-life issues is of key importance to terminally ill cancer patients and their families, and a challenging topic for both health professionals and patients/carers. There is a lack of research evidence in the literature to guide clinical practice. The objective of this study was to explore the optimal content and phrasing of information when discussing the dying process and end-of-life issues with terminally ill cancer patients and their carers. *Subjects and methods:* We conducted focus groups and individual interviews with 19 palliative care patients and 24 carers from three palliative care services in Sydney, and 22 palliative care health professionals from around Australia. The focus groups and individual interviews were audiotaped and fully transcribed. Further focus groups and/or individual interviews were conducted until no additional topics were raised. Participants' narratives were analysed using qualitative methodology. *Main results:* Distinct content areas emerged for discussing end-of-life issues: treatment decisions at the end-of-life; potential future symptoms; preferences for place of death; the process of dying; what needs to be done immediately after death; and existential issues. When discussing the process of dying participants recommended: exploring the persons' fears about dying and dispelling myths; describing the final days and the likely unconscious period; and the reduced need for food and fluids. Many participants identified the dilemma regarding whether to discuss potential complications around the time of death. *Conclusions:* This paper provides strategies, words and phrases which may inform discussions about the process of dying and end-of-life issues. Further research is needed to determine the generalizability of these findings.

Keywords Terminally ill · Advanced cancer · Palliative care · Communication · End-of-life issues

Introduction

Most of the literature regarding communication between health professionals and patients at the end of life has focused on specific topics, for example breaking bad news and discussing treatment decisions such as cardiopulmonary resuscitation and advanced directives. While discussing end-of-life (EOL) issues can be construed as bad news and is in some ways similar to disclosing a diagnosis of cancer, the context and content are very different. Conversations about EOL issues often take place over time rather than as a single discussion. In addition, EOL discussions may have a different psychological impact to other types of bad news as they pertain to a certain, final outcome. These conversations are very difficult for both health professionals and patients. Yet, having a doctor who is willing to discuss dying has been identified as one of the most important needs at the end of life [17]. There are some recommendations in the literature regarding how to initiate EOL discussions [6, 12]. However, very little empirical data exist concerning the optimal content of these discussions or of terminally ill cancer patients' and their carers' information needs regarding the dying process and EOL issues.

Palliative care health professionals have particular interest and experience in this arena, in part due to the centrality of these issues to their clinical practice. Furthermore, they may be a self-selected group of people who have innate skills in this area, although there is no objective evidence to support this assumption. The views of these health professionals may have particular value not only for their own setting, but also for oncology and general medical practice. The views of patients and carers, who are the target of such discussions, should arguably have the greatest influence on clinical practice. To our knowledge no previous studies have systematically examined terminally ill cancer patients', their carers' and palliative care health professionals' views on the optimal content of EOL discussions and the dying process. In the current study we aimed to explore the views of these stakeholders regarding these topics. Australia is an ideal setting in which to conduct such a study due to the established nature of palliative care practice in this country [8].

Subjects and methods

Sample

Specialist palliative care services in Australia are composed of teams with a range of medical, nursing, and allied health professionals and volunteers. Each service commonly provides consultations across a variety of settings including tertiary referral and district hospitals, inpatient palliative care units, and the community in homes, hostels and nursing homes. Patients are referred any time from diagnosis and many are still receiving antineoplastic treatment with palliative intent [2]. The mean length of time that patients are referred prior to death varies in different services; for the services participating in the current study this figure was approximately 8 to 12 weeks.

Three groups felt to have important input were sampled: a) palliative care patients, b) carers of palliative care patients, and c) health professionals working in palliative care. Patients and carers were eligible to take part if they were: (1) over 18 years of age, (2) English speaking, (3) well enough to take part in a focus group or interview, (4) able to give informed consent, and (5) referred to a specialist palliative care service and diagnosed with an incurable and progressive illness, or the carer of such a patient. Sampling was aimed at achieving a diverse group of participants from different socioeconomic and cultural backgrounds; hence three palliative care services in Sydney with different population bases were approached to participate. Patients and carers were recruited from these services via hospitals, palliative care units and the community.

Palliative care doctors and community nurses identified suitable patients and carers and sought their approval to be contacted by a researcher. Patients and carers were then telephoned and invited to participate in the study. The health professional participants were all currently working in palliative care and had at least 2 years experience in this area. Participants were selected across a range of disciplines and from various palliative care centres to ensure that relevant views were represented. A snowballing technique was used [13]. Eligible health professionals were contacted by an investigator and invited to participate. All participants received an information sheet and gave written consent.

Data collection and analysis

Focus groups of four to eight participants, supplemented by individual interviews with those unable to attend a focus group, were held separately with patients and carers and conducted by a palliative care physician (J.C.) and a clinical psychologist (P.B.) experienced in qualitative research methods. Health professionals were given a semistructured individual interview either face to face or over the telephone, conducted by the first author (J.C.). The discussion format for the interviews and focus groups is outlined in Appendix 1. In this paper we are reporting participants' views regarding the optimal content and phrasing of information given about the dying process and EOL issues. Results of the other discussion items outlined in Appendix 1 will be reported elsewhere. Sociodemographic data about participants were collected via a brief questionnaire at the end of the interview or focus group.

The focus groups and telephone interviews were audiotaped and fully transcribed. Data analysis was informed by qualitative methodology [10]. The transcripts were read and individual points identified by the facilitators, using the participants' own language where possible. These were discussed by both facilitators to ensure consistency of interpretation and were organized into mutually exclusive categories. Further focus groups and/or telephone interviews were conducted until no additional topics were raised. The final categories were reviewed by all investigators and any discrepancies were resolved.

The study was approved by the ethics committees of participating institutions.

Participants

A total of 24 carers took part in three focus groups (21 participants) and three individual telephone interviews. Three additional carers declined to participate in either an interview or a focus group (all said they were too busy). Nineteen patients took part in three focus groups (14 participants) and five individual telephone interviews. Four additional patients declined to participate in either an interview or a focus group (either too unwell or unstated reasons). The demographic characteristics of patients and

Table 1 Demographic and disease characteristics of patient and carer participants

Characteristic	Carers participating in focus group/individual interviews (*n*=24)	Patients participating in focus group/individual interviews (*n*=19)
Age (years)		
Median	53	68
Range	23–71	36–83
Sex		
Male	8	8
Female	16	11
Education		
School certificate or below	9	3
Completed high school but not tertiary	1	5
Tertiary education	14	11
Underlying diagnosis of patient		
Advanced cancer	24[a]	19
Primary site of malignancy		
Lung	4	7
Gastrointestinal	7	2
Breast	2	4
Melanoma	3	0
Prostate	0	2
Other	8	4
Time since referral of patient to palliative care		
Median	14 weeks	12 weeks
Range	2 weeks to 2.5 years	3 weeks to 2 years
Current residence of patient		
Home or home of family/friends	18	16
Hostel	0	1
Inpatient palliative care unit	5	2
Other hospital	1	0
Carer's relationship to patient		
Spouse/defacto	11	
Son/daughter	9	
Same sex partner	2	
Grandchild	1	
Friend	1	

[a] The underlying diagnosis of the patient for one of the carers was both advanced cancer and motor neurone disease

carer participants are shown in Table 1 (the demographic details of the patients and carers who refused participation are unavailable, because consent for this information was not obtained).

Interviews were conducted with 22 palliative care health professionals including 13 doctors (7 specialist physicians and 6 senior registrars in training), 4 nurses and 5 allied health staff (an occupational therapist, physiotherapist, social worker, bereavement counsellor, and pastoral care worker). One additional palliative care health professional (a specialist physician) was invited to participate, but declined for unstated reasons. The health professionals worked at ten different palliative care services in two States of Australia in a variety of settings including teaching hospital, community and inpatient palliative care units (many mixed). All health professional participants were working full time in clinical palliative care practice. There was a range of palliative care experience amongst the health professionals with seven (32%) having more than 10 years experience (mean 8.3, SD 4.9 years). Their ages ranged from 31 to 70 years (mean 41.5, SD 10.4 years). Only five participants (23%) were male (all doctors), but this is representative of the sex distribution of palliative care health professionals in Australia.

Results

Distinct content areas emerged for discussing EOL issues, including: treatment decisions at the end of life, potential future symptoms, preferences for place of death, the process of dying, what needs to be done immediately after death, and existential issues. Summaries of these content areas are outlined below; participant quotes are shown in Appendix 2.

Discussing treatment decisions at the end of life

Many physician participants said patients often ask them to give a second opinion about antineoplastic treatments that are being recommended by oncologists. Patients and carers said it was helpful to go over the pros and cons of treatment decisions with a doctor from palliative care who would not actually be giving the treatment. Some health professionals said it was important to ask patients about the sort of treatments that they may want in the future when they are no longer able to speak for themselves. In addition, some health professionals said that patients value being involved in decisions about their EOL care such as whether to give antibiotics in the case of pneumonia. One carer said there needs to be more explanation when decisions are being made about life-prolonging treatments in hospital. Patients did not mention this. Surprisingly the issue of discussing formal written advanced directives and cardiopulmonary resuscitation orders was raised by only one doctor; no other health professionals, patients or carers mentioned these particular topics, although we did not specifically ask about them.

Discussing future symptoms

Most health professionals said that it is important for terminally ill patients to be warned that there is likely to be a gradual deterioration, so that they do not have the misconception that they will be well for a period and then die suddenly. Several doctors and nurses said that they would emphasize that as people get sicker the predominant symptoms they are likely to experience are due to the general effects of their cancer on the body (for example, fatigue, general weakness, reduced appetite and weight loss). They would explain that with time the person is likely to gradually have less energy to do things and need to spend more time resting but would reassure patients that other symptoms such as pain, which may or may not occur, can be controlled. Patients and carers in particular wanted to know that pain could be controlled in the future. Many patients said they did not want detailed information about future symptoms but they wanted a broad picture of what to expect and to know that they would be supported through whatever problems may arise. On the other hand carers seemed to want to want more details about what to expect so that they could be prepared and know what to do, especially if the person was to be cared for at home.

Preferences for place of death

Many heath professionals said that it is helpful to have early discussions with patients and their carers about their preferences for where they wanted to die, despite the fact that patients often change their minds. They would explore the practical issues that need to be sorted out if the patient wants to die at home and reassure patients and carers that most of the care that can be provided at hospital can also be given in the home. Some doctors said they talk about likely determinants of being able to die at home, such as the person's illness, their physical size and mobility, the family support and facilities available at home and the services which can be provided in their local area. To avoid carers feeling guilty, some health professionals warn families that despite best intentions sometimes it is not possible for the person to die at home. Health professionals noted that many patients were reluctant to discuss this issue directly.

Many carers wanted to know whether it was realistic for them to care for the person at home. The patients did not discuss place of death or the information they would like on this topic, although we did not specifically probe them about this.

Discussing the terminal phase/dying

Patients emphasized the importance of reassurance that pain will be controlled when they die, that they will maintain their dignity, have plenty of support and that their health professionals will be there with them through the process. They did not specifically say how they wanted health professionals to describe dying, although we did not ask them this question. Some patients said it was comforting when they saw other patients in the ward dying because it was handled delicately and the person seemed to die peacefully.

In general, carers wanted more detail about what to expect during the terminal phase than the patients, particularly if they would be caring for the person at home. They wanted practical information about looking after a very sick person and whether they would be able to physically manage and what support and help is obtainable. They also wanted to know that they would not be left alone to make decisions about the person's care. Some carers did not want to know too many details as they thought it could be overwhelming, but valued knowing that they could discuss it with the palliative care team when they wanted. One carer said it was good that he was not pushed to discuss dying until it was imminent, because he thought it would be too much information to contend with earlier on.

Most health professionals said that although patients and carers are often afraid to talk about the process of dying, they are relieved when the topic is finally discussed. The doctor and nurse participants all said that they frequently discuss the process of dying with palliative care patients and their families. Some allied health professionals, on the other hand, felt it was not really their place to describe the actual dying. The health professional participants had many specific suggestions regarding optimal ways to discuss the dying process, and these are outlined below. Where patients and/or carers also raised these issues is indicated.

Exploring fears about dying and dispelling myths

When discussing dying most health professionals said that it is important to explore people's fears about it first and to dispel any myths. For example, patients may think that they will die the same way as someone else they know who had their type of cancer or that they may have a lot of pain. Some health professionals also said that patients may be worried about being a burden on others during the terminal phase and about loosing control over their bodily functions. Allowing the patient to voice their concerns about this was seen as important.

Describing the final days and unconscious period

Many health professionals said they would describe the terminal phase in terms of the person gradually becoming weaker and needing to spend longer periods resting and eventually becoming less conscious of what is happening around them. Some doctors said that they would talk about the unconscious period and describe it as a sleep-like state, at the same time reassuring patients that it is not the same as night-time sleep so they do not become fearful of going to bed at night. Many doctors and nurses said that it is important to warn families that dying can be a slow process, because families often expect the person to die very quickly once they are confined to bed. Nevertheless, it was felt important to warn patients and their carers that things can also happen suddenly and unexpectedly.

Dilemma of discussing potential complications around the time of death

The dilemma of whether or not to discuss potential complications around the time of death, such as massive haemorrhage, seizures and suffocation, was raised by several health professionals. When asked by patients or their families about this, most health professionals would say that these complications are extremely rare but, if in the unlikely event that they did occur, the patient could be sedated and therefore would not suffer. In the circumstance where a patient with a higher risk of one of these complications (such as tumour adjacent to trachea or major blood vessel) wanted to die at home, then doctors and nurses felt that it was important to at least raise this possibility with their family and to ensure that appropriate medications were available. Health professionals said these conversations have to be handled very delicately so as not to frighten people. Several doctors said that people with lung cancer for example are often worried about struggling to breathe at the end of life. They would explain to these patients that the most common way for people to die from cancer is from its general effects on the body, such as fatigue and weight loss, and that people tend to "fade away" and that nothing "dramatic" is likely to happen. They would also reassure patients that medications to relieve breathlessness/suffocation are available.

Some carers, particularly those caring for dying patients at home, wanted to be warned about potential complications during the terminal phase, so they would not be surprised or be left in a situation not knowing what to do. These carers felt it was not necessary to tell patients about such potential complications for fear of frightening them. Patients did not raise this issue.

Food and fluids for the dying person

Several doctors and nurses said it is important to allay families' anxiety about the person dying of starvation or dehydration once they are no longer able to eat or drink. They commented that it is not routine practice to administer parenteral fluids for the dying person and they would reassure families that this does not result in discomfort for the patient. On the other hand, where it was very important to the family for specific cultural or religious reasons some doctors said that they would give the dying patient parenteral fluids purely to give comfort to the family.

Some carers raised concerns about the person not eating as they got sicker and needed reassurance that they would not be failing in their duties as a carer if the person did not eat. Patients did not mention this issue.

Discussing what needs to be done immediately after death/funerals

Health professionals and some carers said that it can be helpful to discuss what happens to the body after the person dies as well as practical issues such as funeral arrangements, how families can tell when the person has died, and who to call. Health professionals said these topics would usually only be discussed in response to carer or patient questions, although they would initiate a discussion about this with the carer of a person who was imminently dying at home so they were prepared. Patients did not mention this.

Existential issues

Some health professionals said that patients sometimes asked them about existential issues in the context of a conversation about dying. Most, aside from the pastoral care worker, felt that it was not their role to discuss these issues in depth with patients but that it was important to be open to such conversations and to be able to listen to people's spiritual concerns. Patients and carers did not raise this issue, but some noted the availability of staff to discuss this with.

Discussion

This is the first study to explore in detail how terminally ill cancer patients, their caregivers and health professionals with special expertise believe EOL topics should be discussed. Another unique contribution of this study is that it allows comparison of patients', carers' and palliative care health professionals' views regarding these matters.

In general the patient participants wanted to know less detailed information than carers about potential future symptoms and the dying process. The main things patients wanted to know were that they would not be in pain, they would retain their dignity and they would be well supported by their health-care team. Many carers, on the other hand, expressed a need for detailed information about what to expect regarding future symptoms, the terminal phase and what to do after the person dies, so they could be prepared. Patients and carers did not say how they would like the dying process explained to them, perhaps because we did not probe about it specifically. Our sample of patients, while all terminally ill, were well enough to take part in an interview or focus group. Perhaps detailed discussions about the dying process are more likely to take place when the patient is closer to death.

The health professional participants said they often have detailed and specific discussions about the dying process and that such discussions are frequently a source of relief and comfort for terminally ill cancer patients and their families. Health professionals had fairly uniform views and useful suggestions regarding ways to discuss and phrase information about likely future symptoms, preferences for place of death, the dying process, and the potential for complications in the terminal phase. One of the few areas where there was some difference of opinion was regarding the use of the phrase a “sleep-like state” to describe the common unconscious period in the terminal phase. Some health professionals were concerned that this may make patients frightened about going to sleep, but others said it was a helpful analogy so long as it is explained carefully.

The importance of reassuring terminally ill patients about pain and symptom control has been identified in previous research [3, 14, 16]. Likewise a survey of the views of 360 seriously ill patients about EOL care conducted by Steinhauser et al. [15] in the USA showed that 96% of patients wanted to know what to expect about their physical condition and 86% wanted to know that their physician was comfortable talking about death and dying. In one of the few studies examining the information needs of patients along the trajectory of a terminal illness, only 20% of the 56 patients surveyed were afraid of death but almost 40% were afraid of the dying process [5]. However, we could find no other studies regarding the optimal content and phrasing of discussions about future symptoms and the process of dying with terminally ill cancer patients.

Our finding that some patient and carer participants valued being involved in discussions about treatment decisions is similar to previous empirical literature regarding important components of quality EOL care [14, 16]. It is interesting, however, that only one health professional participant mentioned advance directives or cardiopulmonary resuscitation orders when asked what is important when discussing the future with palliative care patients and their families. Both of these issues have dominated the theoretical and empirical literature regarding doctor/patient communication at the end of life. While we did not specifically probe for the participants views on discussing advanced directives and not-for-resuscitation orders, and therefore it is difficult to make any definite conclusions, it may be that once patients are referred to palliative care, formal written advanced directives are no longer relevant. In many palliative care units in Australia cardiopulmonary resuscitation is routinely NOT performed. However, a number of the health professional participants also worked in acute hospitals where cardiopulmonary resuscitation is performed unless documented otherwise. Perhaps the health professional participants do not think it necessary or ethical to give patients a choice about cardiopulmonary resuscitation when it is a futile intervention in the context of a progressive and terminal illness. Alternatively, the health professional participants may feel it is possible to elicit the patient's general preferences for medical care, without having to describe potentially distressing details about cardiopulmonary resuscitation. For example, the patient may express a clear preference for treatment aimed at comfort rather than prolonging their life. In contrast, Bruera et al. [1] surveyed palliative care physicians from Europe, South America and Canada and all physicians agreed that "do not resuscitate" orders should be discussed and documented with all patients. Future studies should explicitly explore this issue [4, 9].

The health professional participants' view that it is important to be comfortable to at least listen to terminally ill patients' spiritual concerns is consistent with recent recommendations in the literature [7, 11]. In the survey of seriously ill patients by Steinhauser et al. [15], 50% of patients agreed that it was important to be able to discuss spiritual beliefs with one's physician. The fact that few patients or carers mentioned existential issues is therefore interesting. However, because we did not probe specifically for patients' and carers' views about discussing existential issues with health professionals, it is difficult to make any conclusions about this.

Limitations and applicability of findings

Qualitative methodology dictates small sample sizes. The use of qualitative methods such as those used in the current study is common in exploratory studies and can generate hypotheses and provide rich descriptive information about a phenomenon. However, it is difficult to make assumptions about the generalizability of data obtained using such methodology.

The sample in this study was limited to English-speaking patients and carers (some of the carers were caring for patients from non-English-speaking backgrounds) from three different palliative care services in an urban setting in Sydney with an underlying illness of advanced cancer. The patient and carer participants may therefore not have been representative of Australia's culturally diverse population. The educational background of the carer group was higher than the general population. All patients and carers were receiving ongoing follow-up from a palliative care service. The fact that their primary doctors referred them to this service, their willingness to be seen by the palliative care team and the relatively long time (median 12–14 weeks, range 2 weeks to 2.5 years) they had been in contact with the palliative care team make this population somewhat unique. Thus participants may have been more accepting of a palliative approach to their illness and therefore have different views on discussing EOL issues than those patients with incurable cancer outside a palliative care setting. Furthermore, patients and carers in our sample may also have had different experiences and expectations than patients seeing their general physician or oncologist, because "palliative care" may symbolize death and dying for some people.

The health professional participants came from various disciplines and from several different palliative care centres in Australia servicing culturally diverse populations in mainly urban settings. However, the views of palliative care health professionals may differ from those providers caring for terminal patients in other settings.

Future research and implications

A larger sample of patients and carers would be required to explore whether the views expressed by participants in the current study are held by a majority of dying patients and their carers. However, it may be ethically difficult to survey palliative care patients regarding their views on participants' suggestions for describing the dying process. Future studies of the views of bereaved carers may obtain useful data, although sufficient time would need to be allowed for them to recover from the acute bereavement period. It is also possible to audiotape a series of palliative care consultations to see how EOL issues are currently discussed and whether this is associated with patient outcomes and satisfaction with the consultation. Our group plans to conduct this research, and data collection is underway.

The results of this study provide some practical suggestions for clinicians regarding ways of explaining and phrasing information about the dying process and EOL issues with terminally ill cancer patients and their families. The more detailed information needs of carers about the dying process were also highlighted. These results may inform the development of communication training interventions for health professionals in discussing these difficult topics. However, further research is needed to determine the generalizability of these findings, before firm recommendations can be given to inform clinical practice.

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Appendix 1: Focus group and individual interview discussion format

Discussion format for health professionals

Discussions about the future in a palliative care setting are often difficult. I am referring not only to discussions about life expectancy but also the likely symptoms that a patient may face in the future and the likely mode of death.

- How do you tend to approach questions about the future from palliative care patients?
- How do you tend to approach questions about the future from carers of palliative care patients?
- How do you think information about the future should be portrayed during a palliative care consultation?
- Do you ever initiate discussion about the future during a palliative care consultation? In what circumstances do you think this is appropriate?
- When discussing the future with a palliative care patient or the carer, is there any way of communicating hope?
- If a palliative care patient (or carer) asked about life expectancy:
  - What words would you use?
  - What sort of time frames would you give (if any)?
  - Would you give any statistics?
  - Would you draw survival graphs or use any other aids?
- What advice would you give to palliative care trainees regarding discussion of the future?

Discussion format for patients and carers

Prognosis refers to likely future developments and life expectancy.

- What information do you think is important for your palliative care doctor to tell you (or the person you care for) about your (their) prognosis? (not necessarily during the first consultation)
- What information do you think is important for a palliative care doctor to tell carers about the prognosis of the person they care for?
- How do you think information about prognosis should be portrayed during a palliative care consultation?
- Who should initiate discussion about prognosis during a palliative care consultation?
- Should palliative care doctors offer to discuss prognosis with you (or, for carers, the person you care for or with you the carer) at certain times?

Appendix 2: Participant quotes

Discussing treatment decisions at the end of life

“Have you discussed with the person who’s most important in your life, the following issues? ... Your wishes ... if you’re unable to make decisions for yourself about potentially life-prolonging treatment. Have you sorted out ... your power of attorney, your advance directive, whatever it is. Have you sorted out those issues, have you talked to your family about what you want, because I think one of the things that people don’t realize is that we will be asking families, what would the patient want under these circumstances, and they go no idea, never talked about it. So I think something around those issues is helpful ... But ... you’ve got some real challenges in getting the wording right and sorting out how it’s introduced.” (doctor 10)

“Discussions about ... whether we’d treat or not treat ... we’re different from a lot of other teams who seem to make decisions and then tell the patients what their decision’s been ... People that we see ... like the fact that we will sit down and go through the pros and cons, and it’s not necessarily a medical decision, it’s often a decision that we all make together ... We’d often say ... each time a problem occurs, we will sit down with you and discuss what’s happening and what ... are your options and what are the consequences from the ... options ... and people seem to like the fact that they ... have some choices ... Most people that talk to me, that’s the biggest thing they find in palliative care, that they’ve been provided with information, that you’re available if they want more ... and they haven’t had that before. In fact they’re often more impressed with that than the complicated pain control stuff.” (nurse 2)

Discussing future symptoms

“What’s going to happen to me and it’s sometimes about very concrete things like am I going to lose bladder or bowel control. Am I going to be confused or incoherent, but often it’s also at a more global level. Am I going to have to have someone come and turn me in bed? ... If so how am I going to cope with that because I don’t have anyone around to help? I think there are comments frequently around change in role, particularly ... loss of control is a theme I hear coming through very frequently ... From leading a fully independent life to actually saying to people I need your help ... or that they’re particularly concerned about ... the ... fact that at some stage they may not have the control that they currently have. So people are very frightened by that. I think sometimes you need to put it on the table. It must be really hard having people help you, and just leave some silence, and people turn around and say ... the most unbelievably confronting thing that I can imagine, or whatever they say." (doctor 10)

"I would often say that I believe their condition could continue to deteriorate ... that they would become weaker and be not able to move around as much, not able to get out of bed, lose their appetite, become less involved with people around them, perhaps wanting more privacy, perhaps wanting more time to themselves and that eventually if there is some sort of an infection that might interfere with that gradually their condition will gradually get worse and they will eventually not be able to continue to communicate with people." (nurse 1)

"Hopefully by my experience I can allay fears and say ... you're more likely to just get sleepier and sleepier ... and ... you ... may not get ... pain at all, and that you lose your appetite, and that's all quite normal, just sort of normalizing what's going to happen and reassuring them that that's how it usually is." (nurse 3)

"I think it is important to help the people who are taking care of these patients, to understand the different stages because sometimes it is very confusing, ... what happens to the patient ... maybe he becomes confused and a little bit lost, just give a general idea." (carer from focus group 6)

"It would be good to know what to expect. No one tells you at all. So even the oncologists they don't say anything about the future, the symptoms and so as soon as something new comes I freak out." (carer from focus group 6)

Preferences for place of death

"They ... find it hard to ask about terminal care and where that will happen. I think that's a thing that people would ... sometimes benefit from thinking about a little bit earlier, so that we can set up things at home more and we wouldn't end up having to admit people to palliative care wards for terminal care when they've ... been going ... along okay at home and the family have always wanted to keep them at home ... If we'd had a little bit more insight, or a little bit more warning about how much they wanted to look after them at home, maybe we could have ... got ... in earlier and allowed them to stay at home. So also thinking about where people die. But then a lot of that comes into the denial part of things and not really wanting to bring that up, because that would sort of mean acknowledging how seriously things are going." (doctor 13)

"Often a question comes up from the carers, can the person be looked after at home ... and my response to that is ... it's not black and white but there are essentially three things that determine whether a person can be at home, the first thing is what's actually wrong with them, the second thing is what sort of care they've got at home and the third thing is what sort of services can be provided ... There are certain medical things that families don't seem to be able to cope with if the patient's very big and immobile and the carers are small then there's just the physical problem with lifting when the person's dependent ... Then the other two things that seem to freak families out are seizures and bleeding and if I don't think the person's likely to have either of them I would say to the wife look, the main two things that freak people out are if the patient's going to start bleeding or start having seizures, and I don't think that's very likely to happen in your husband and I think he'll just get weaker and sicker and with help you'll be able to manage but it could be that right at the end he might need to come into hospital." (doctor 11)

Discussing the terminal phase/dying—general quotes

"That's a discussion I actually look forward to having because I know deep down that most people do want to talk about that (dying) and I do feel very comfortable about talking about it, rather than creating a concern it more often than not creates relief, not only because the subject has been brought to the surface, but some of the things that they've been worried about have been dealt with." (doctor 9)

"People don't often ask what happens when I die, but when I ask do you want to know, a lot of people say actually yes. That's a big one, yes, what actually happens, what physically happens ... they're quite interested in some of the more minute details." (nurse 2)

"It's very good to know that there is a place like this (palliative care unit) where you can be received and ... you retain your dignity. You have love and care surrounding you, and brave compassion and if ... the cards fall against you you are somewhere where you can ... be let down ... softly softly with great dignity and loving care ... So they give you back your human identity rather than a bed number." (patient from focus group 1)

"I just find that they are not pushing the fact of ... having to talk about dying, that has not ever been pushed at all." (carer from focus group 6)

"That was ... most important ... that I wouldn't have to be making decisions ... that I would not be left trying to work out what to do, that the responsibility would not fall onto me to decide what happens next, because obviously I'm not skilled to do that. I wanted to know just what sort of support I would be given, because I always intended that it would be done at home ... I didn't know how I would go being able to handle the physical part of things, like the showering and that sort of thing ... but knowing that somebody will help or ... do it ... for you ... was good." (carer individual interview 2)

Discussing the terminal phase/dying

Exploring fears about dying and dispelling myths

“The first thing is dispelling myths ... people assume that it’s going to be a terrible horrible death and that ... cancer equals a person racked in pain, and so I’ll say things like ... one-third of patients who die of cancer may not have had any pain in the course of their illness and it depends where the cancer is and what it’s doing, but even if they have pain, 90% we should be able to get on top of really easily with relatively simple medications. The other 10% it’s a challenge, but that’s what we’re there for and that’s what we’re trying to sort out.” (doctor 12)

“I think basically they want to know if their death’s going to be pain-free and they’re going to be comfortable and dignified. Most of the patients would have a story to tell about a situation they’ve seen in their family or at any other stage of their life where they’ve seen people being really undignified and ... I think most people want reassurance that that’s not going to happen to them ... I think that’s the overwhelming fear, of pain and confusion and loss of dignity. They’re not that concerned about becoming a bit anorexic or losing their appetite, it’s really the pain and the loss of dignity that I tend to focus on.” (nurse 1)

Describing the final days and unconscious period

“The one that I talk about a lot ... is about unconsciousness at the time they’re dying ... I go through what I think happens ... The language that I use, it’s a deep sleep, I’ll say it’s very similar to sleep ... you’ll eventually reach a time where you’ll sleep more and more and you’ll wake less and less until eventually you’re sleeping all the time until you die ... But ... again you’ve got to do it carefully because if you do it badly they’ll think ‘oh, if I go to sleep tonight, I might not wake up’, so I’ve got to spend a lot of time and check with them that they’ve understood and that they see it as going into a state which is like a sleep. It’s not the same as the sleep they have at night. So I do like to spend a fair bit of time talking about that ... what we do to care for them ... why we need to continue treatment for pain relief, even while they’re asleep and unconscious.” (doctor 9)

Dilemma of discussing potential complications around the time of death

“With lung cancer, a lot of people are terrified that they’re going to suffocate to death and to reassure on that point is ... really important and ... even giving the worst scenario that if ... you really ... couldn’t get your breath then we can actually give you medications that will help you sleep so that you’re not aware of what’s happening. ... but that’s the worst scenario and I’ve hardly ever had to do that and chances are that that won’t happen ... basically even in the worst situation we can still manage it and we’re not going to let you ... be gasping for air.” (doctor 12)

“You have to be careful once you start talking about prognosis exactly what things you talk about and how much you highlight those possibilities ... You find sometimes that you can give a little bit too much information about what could happen and unfortunately we sometimes see people very very anxious once possibilities have been discussed with them, such as massive haemorrhage and things like that.” (doctor 13)

“I don’t think it would be a good idea to tell the patient whether you might have this terrible problem ... but on the other hand ... the carer ... may well benefit from that ... ‘look watch out for this ... these sorts of things ... if you observe this happening call us’, you might not tell the patient because then they are a bit inclined to go looking for it.” (carer from focus group 6)

Food and fluids for the dying person

“I always spend a lot of time talking about food and fluids because family are concerned that they might die of starvation or die of thirst, so I spend a lot of time trying to allay those anxieties, and for the patient concerned when they’re hearing that it at least is a relief that they don’t have to eat. Sometimes they eat only because family bring food in, or in hospitals we have this ridiculous idea that we bring food trays around three times a day, in other words continuing what is normal, what is perceived to be normal in our society but which is particularly abnormal for people who’ve got cancer or dying of cancer, so I talk about those things too.” (doctor 9)

“She (wife of patient) just breaks down and she’s finding it hard to go into the room now. She’ll go in to give him a couple of spoonfuls of food ... he’ll take ... a bit in his mouth, just a taste and it just breaks her heart.” (carer individual interview 3)

Discussing what needs to be done immediately after death/funerals

“What to do after someone dies. That is asked a lot of me. You know, how to arrange a funeral, what happens, where the body goes, who looks after the body, is it treated well, where’s the morgue, are they put into a bag, all those questions I get asked. How the body feels after a couple of days, is it stiff and cold.”(nurse 1)

“Somewhere along the line ... we need to talk to people about funerals.” (pastoral care)

“Information about particular things like funerals, and procedures of contacting ... for some people that point doesn’t come, because it’s just something they don’t talk about, it's taboo and maybe culturally it's taboo, or the family's protecting the patient and doesn't want anything said to them ... that's why we go in fairly carefully and fairly gently to begin with, and don't bring up those issues early on until we've done a general sort of assessment." (social worker)

"They sat there and explained things, that because he was on the breathing machine, he could pass away and the machine would still be going, so they sort of told us what to look out for, and how we should call a doctor, for a certificate and then we could call the funeral parlour and all of this. They said we can ... call our family doctor so that they can come and write an initial certificate." (carer individual interview 3)

Existential issues

"When the patient talks about their ... life after death ... their religious beliefs throughout life, or that they've been a strong believer of this, or a strong believer of that, to actually just feel comfortable in being in that discussion in the first place, being a part of that discussion rather than saying oh this is not my area. To actually be quite comfortable in letting them express things they want to say, and sometimes in relatives, if they have expressed various issues about that, I feel quite comfortable talking to them about other people's experiences that I've heard, of them feeling the presence of the person around after they've gone, and actually just exploring some of those issues." (doctor 4)

"I suppose it's an existential thing what's it like to die. It must be forefront in their mind but ... it's not asked very much so I will talk about that, I will say look I don't know what it's like to die because I've never done it but I've looked after a lot of people ... Finally they might come up with the really difficult questions, what happens after I die ... they ask a lot of questions for which I can't and should not answer, but just allow them to talk about it is important." (doctor 9)

"But ah you know, as far as myself, ah I am at peace with myself and the world and I don't have any great fears about up there. Now we do have pastoral care here. Which is quite good, I mean we have a variety of people who are approachable and you can discuss with them anything you like. Ah but they don't push you. That's a very good point, that they don't impose their thoughts." (patient from focus group 1)

"They talk about the healing process, and they don't just talk about that in terms of making any progress physically but also spiritually ... which is great." (carer from focus group 6)

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