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ORIGINAL ARTICLE

Experience of dying: concerns of dying patients and of carers

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palliative care, dying, terminal illness, ethics, physician-assisted suicide.

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Abstract

Background: Terminally ill patients frequently express concerns about what dying will be like: how their bodies may change as disease progresses, how medication may alter the effect of these changes and whether and how their preferences will be respected as they become more ill.

Methods: Thirty-six patients admitted to a hospice were interviewed and 18 carers of patients of the Palliative Care service, who had died participated in focus groups. Thirty-three patients had advanced malignant disease, 13 were women; their mean age was 68 years (range 44–92 years).

Results: The areas of concern consistently identified by patients were (i) privacy and autonomy, principally in regard to families, (ii) a lack of information about physical changes and medication use as death approached and (iii) the desire to shorten life, which was expressed by all patients. Carers recalled problems accessing services and support and had needed more help with practical issues such as medication timing and dose. They believed that not enough information about the patients' illnesses had been given to them and they were insistent that carers should have information against the wishes of patients.

Conclusion: Some of the patients' and carers' concerns can be readily addressed. Others, particularly access to confidential information, cannot be addressed without a realignment of professional ethical standards and community expectations. The patients' discussions of their desire to shorten life may have implications for the debate on euthanasia and physician-assisted suicide.

Introduction

The purpose of this study was to describe the concerns of dying patients about the problems they would face as death approached. The goal of palliative care is to relieve suffering and to improve quality of life of dying patients.^{1,2} However, the detailed priorities for care are based only to a limited extent on research with dying patients. Our clinical contact with terminally ill patients suggested that

they had important concerns incompletely addressed by routine palliative care and we therefore set out to investigate these concerns systematically. We sought information on the physical and emotional concerns patients had, what information would have lessened these concerns, the values that guided the decisions they made at the end of life and how they thought professional and personal carers could best ease the process of dying.

Patients often suggested that their perspective differed from that of their families and some alluded to conflict between their families' wishes and theirs. We therefore conducted focus group discussions with people who had looked after terminally ill patients in order to compare their reflections on the process of dying with the concerns of the dying patients we had interviewed. We wished also to see how carers felt their particular needs could best be addressed.

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Methods

Setting

The Newcastle Mercy Hospice is a 20-bed hospice, part of the public hospital system but administered by The Sisters of Mercy, Singleton, NSW, Australia. The Hospice is the major source of inpatient palliative care services to the Hunter region and in addition to its 20 inpatient beds, the Hospice serves patients throughout the Hunter Area, a population of about 500 000, through outreach and home care. Acceptance onto the service requires an assessment by the Palliative Care Service medical staff. Patients are admitted to the Hospice for respite, symptom management or terminal care. Criteria for admission to the Service include awareness of the diagnosis and prognosis and undergoing no active oncological treatment.

Ethical considerations

The project was approved by the University of Newcastle Human Research Ethics Committee and the Hunter Area Health Service Research Ethics Committee. All patients and focus group participants gave informed consent, which included consent to publication of their comments.

Patient interview procedures

A total of 36 patients of the Newcastle Palliative Care service were interviewed of which 23 patients were men and 13 were women. Their mean age was 68 years, with an age range of 44–92 years. Thirty-three patients had advanced malignant disease. The diagnoses of the others have been withheld to reduce the risk of identification of patients.

Patients were approached systematically about their participation in the interview study after their medical admission was complete. All patients admitted to the hospice and judged well enough to participate were invited to do so. Patients determined whether or not they would like relatives present at the interview. They were initially asked predetermined open-ended questions and the responses and subsequent discussions were recorded with an MP3 player. Similar questions were posed at several points during the interview to confirm the interpretation of the concept put forward by the patient. Initially, open-ended questions were asked about the things that worried them: "Can you tell me what things are worrying you?", "Are there any other concerns you have?" and "What helps you to cope with that?". Concerns raised by the patients were then investigated specifically, for example, by asking: "Why was that so important?", "What did you think would happen?", "Was there anything that would have made that easier?". When a request for information

was part of their response, we asked who could help them by giving that information and how they would like that help given. When patients raised the issue of suicide, this was investigated with questions about why they had considered suicide and why they had not gone ahead, with questions such as "When did you think about that?" and "Why didn't you?".

The interviews lasted between 20 and 74 min (median 38 min). To ensure the accuracy of their statements as responses to the questions, all the patients had the opportunity to review their interviews and give additional or clarifying views. They also had the opportunity to delete comments. The interval between interview and death was short: in most cases less than 5 days and not longer than 3 weeks.

Focus group procedures

The focus group participants were members of the Hospice bereavement programme, attendance at which is offered to relatives and carers of patients who have died while being treated by the Palliative Care service (but not necessarily as Hospice inpatients); invitations to attend are not made until at least 3 months after the death of the patient. For focus group participants, the time since the patient they had cared for had died was between 6 months and 4 years. No participant of this study had cared for a patient interviewed for our study of dying patients' concerns.

Three focus groups were conducted by experienced facilitators. A total of 18 carers participated, 2 men and 16 women. Groups were scheduled to run for 90 min and all were conducted within a 1-month period. The focus groups did not have the same membership as did the bereavement groups so that the focus groups were not simply recorded instances of the bereavement groups' meetings.³

A focus group guide was prepared following discussion among the researchers. A copy of the guide can be obtained by application to the corresponding author. Open-ended questions were used. The discussions were recorded and written notes on nonverbal communication were taken during the sessions.^{4,5,6} Immediately following the focus groups, the researchers met to debrief and clarify the issues related to conduct of the next focus group. Issues related to suicide and euthanasia were not raised in the focus groups.

Analysis

Interviews and focus group discussions were transcribed verbatim and the raw data archived after it was reviewed for accuracy. The researchers read all transcripts to gain an overall understanding of the narrative descriptions and experiences. A constant comparison method of data analysis was used. All researchers read the transcripts and then searched systematically for similarities and differences,

annotating individual copies of the transcripts.^{7,8} Statements from the individual analysis of transcripts considered by the researchers to be similar were selected and compared to ensure agreement before they were grouped together into categories.^{7,8,9} All transcripts were again reviewed and coded by the researchers on the basis of these categories. The analysis was an iterative process involving several meetings of the researchers who coded the transcripts independently and then reviewed and discussed the significant statements, their memos and coding notes.^{9,10,11} Categories were discussed and modifications made if necessary. Final categories were compared to ensure that there was no overlap and that the themes are supported by direct quotes from the original transcripts.

Results

The areas of concern consistently identified by patients were categorized as (i) privacy and autonomy, (ii) the difficulty of getting timely and relevant information and (iii) dealing with the desire to shorten life. Areas of concern identified by carers were categorized as (i) lack of information about the patient's illness, linked to (ii) lack of recognition of the carer's role, (iii) difficulty interpreting the physical and emotional changes associated with dying and (iv) difficulty obtaining practical assistance.

Privacy and autonomy

The privacy concerns of patients related mainly to sharing information with their families and the risk of families usurping decision-making. The respect of patients' preferences by hospice staff was not perceived to be at issue. Some patients, however, expressed concern about the forced intimacy that some hospice staff appeared to promote and which the patients found distasteful.

Factual privacy and unauthorized disclosure

Concerns about factual privacy related to active and thoughtful decisions by patients to keep details of their illness or their emotions from their families. Although some patients chose to have relatives present at the interview, stating that they felt able to discuss things freely, many wished to exclude relatives from the discussion. Many patients expressed a preference to have information routinely presented to them alone, with families involved later. They expressed concern about explicit information about them and their illness being sought by others or relatives having information or results about them they had not had a chance to censor.

Patients' preferences about privacy did not, in most cases, appear to be new and related to their illness but were styles of behaviour established over many years.

Patients were aware of the possibility of families seeking information about them without their consent but emphasized that they disapproved of this and that they felt protected by the professional standard of confidentiality. Some patients confirmed that the hospice model of 'the family as the unit of care'^{12,13} created tension about information sharing, without, as they saw it, offering them as a patient any compensatory advantage.

Carers' concerns in this area were in direct conflict with those of many patients and implied strong support for the model of the family as the unit of care. Carers believed that they should be provided with complete information about the patient's illness, even when the patient explicitly refused to share the information with them. Although it was often clear that long-established habits of privacy and reticence were involved, many carers felt that terminal illness required these habits to be set aside.

Many carers recalled that they had been the most reliable source of information about the patient and that the patients could not have been cared for effectively without their input. Carers believed also that they needed information to fulfil their caring role and insisted that they, rather than the patient, were the proper judges of how that role should be fulfilled. Carers demanded recognition of their role and access to information about the patient was valued as confirming recognition of the carer's role by health professionals.

Others, spouses in particular, expressed a view of themselves as stakeholders in their own right in decisions about management and believed that for this reason they were entitled to receive information regardless of the patients' wishes.

Patients' comments relating to information and privacy:

You don't want to talk about it in front of everyone, some things you don't want to bring up.

Once you know it is okay, you know your question's answered honestly, then you can talk about it, but you don't want to bring everything up in front of them, in case.

Sometimes it is hard to talk to family, I need to know some more and then if I think we can manage ...

Well, you tell me and then I'll decide, not too much, and then I'll get my girls here so they can get it too, then that would be OK.

You can't tell them though without telling me, can you?

I think they will say something to my wife, but I never even talk to her.

Well, sometimes I don't know what to say, my family want to sack me as a patient. But there are things you don't want to tell anyone.

...and sometimes even with a strong marriage, you need to talk about things outside of this, and know it will always be outside.

I told her not to do that again, not to go and have a yarn to the doctor...

Carers' comments relating to information and privacy:

I was treated really well. I was shown everything, all his results, his pathology and his x-rays. The doctors all would talk to me and I knew everything. And that was good, I used to be busy.

Well, I would have liked to be informed all the way, not just once. And every step of the way. So, unbeknown to the doctor I got hold of copies of these and the reports ...

Well, I don't think enough respect is given to carers.

... because you want to be in charge, but you can't if they won't tell you.

You don't have an input. But part of it is the patient doesn't tell the truth, in fact sometimes everything bar the truth, in fact they go to the doctor's and say I'm fine.

... I think they need to take the carer away and tell them everything separately.

The doctor is important because he is the lynchpin between the husband and wife, and he has to tell you about what is going to happen. It should be between the patient, the carer and the doctor, not anyone else. My husband probably knew more than I did, and that might be his right but ...

I needed to be in charge, and it is the purpose when you are stopping with your relative. And I think that they need to respect that.

The only thing I can see is to separate the patient and the carer. There were some things I couldn't talk about in front of him, serious problems I had to go and talk to the doctor separately.

Information is the most important thing. It really is the most important. If any one is going to tell you then get the husband and the wife together, both of you. It's not just them you know. It's both of us.

Decisional autonomy

Patients often expressed a need to feel they were still in control of decisions about themselves and the management of their illness. Many were concerned that their families would usurp decision-making and even those who were confident that their families would respect their preferences insisted on being actively involved in decision-making. They stated that they wished to treat their health-care decisions as their own responsibility even if that required isolating themselves from their intimate carers. Even those who were happy for information to be shared with their families were anxious that professional staff recognize that their own interests and concerns were distinctly separate from family interests.

The need to make independent decisions was sometimes linked to a concern about a lack of information about their management and patients consistently requested that professional carers took time to explain carefully and repeat-

edly the options for management. However, no patient expressed concern that hospice staff might, on their own initiative, ignore a patient's preferences.

Patients' comments relating to decisional autonomy:

I would like to die like I lived, so even if I'm pretty much gone, I don't want them to decide for me.

...years ago I had chemo and everything, and looking back I would never have it again, so now looking forward if I don't want something, it is up to me, not my daughters. Sometimes they say you have to try everything, but no.

...it should be a joint effort, you can't ask them if I didn't know about it.

I get to say. If I can't be participating any more, get me out of here. At the end I want to be able to make decisions...

Emotional privacy

Most patients felt that their feelings and concerns, although properly things to be shared with those close to them, were deeply personal. Some patients expressed a view that the patient and the family had quite distinct tasks. Some of these tasks related to family relationships but others were the exclusive focus of the dying patient. Attempts by others – whether family members or hospice staff – to involve themselves in those aspects of dying that the patient saw as personal were regarded as intrusive.

Several patients observed that although they knew that families and professional staff would try to understand, and may have thought they did understand, the experience of dying, someone not yet dying cannot encompass the experience of the one who is. Some also expressed the view that the hospice enforced an intimacy they would not have chosen. This resulted in some patients finding themselves under pressure to discuss matters they would prefer to keep private.

Patients requested recognition that meaningful communication resources beyond their families and professional staff were important. Some patients clearly expressed a desire for off-the-record conversations, in which ideas could be tried out without commitments or fear of initiating actions they might regret. They were clear that these interactions needed to be confidential so that there could be no interpretations that might limit their autonomy when making future decisions. Many patients expressed disquiet that on the one hand they needed the hospice support because they wouldn't be able to cope at home but on the other they needed not to have private thoughts dealt with 'medically'.

Some of our patients identified the ghosts of dead family or friends as important sources of counselling and support that met their need for privacy. This support seemed important to these patients and our impression is that it is relatively common.

Patients' comments relating to emotional privacy:

This is all my story. Nobody else knows what is going on inside or outside.

You have to be careful, 'cause no one really knows what dying is and not even my family is where I am.

You can't ask everything, some things you have to keep to yourself.

I won't talk to the kids about dying. I have written letters, and they can't have them till after I go. I don't want a reply. That's the way it has always been.

Some of them offer too much, way beyond what you would want to talk about in front of people.

...but believe me, when it counts, like talking about dying, the ones in here who think they can do it are the last ones I want to talk to.

... no sooner do you talk with one and the next one comes, and you feel all you do is talk about losses.

No, I don't want that, I have talked to people about it, but in the privacy of having a yarn, like down at the hotel.

...but not for someone to deliberately come and want to talk to me about it.

I've been talking to my father, he has been dead for years. He comes and stays and chats to me, and I tell him things I don't tell anyone else.

Getting information

The process of dying

Patients often requested information about how they might die. In particular, they were concerned that they might in their final moments behave in a way that was out of character or bizarre and they were anxious to be told if this was likely. Their behaviour was important to them to maintain their self-image and also to spare their families distress. Patients often expressed concern that they would be unable to reassure their families about any out of character behaviour or damaging remarks made in the moments before they died.

Many patients anticipated some worsening of the physical changes that accompanied their disease but were anxious to have a clearer idea about what was likely to happen. In many cases, this seemed to be mainly a desire to be able to identify changes that would be reliable indicators of impending death.

Carers also frequently stated that they wanted more information about the physical changes associated with disease progression and death. Like the patients, they were particularly interested in events that might indicate impending death, although rather because of the implications that had for telling other family members.

Another concern for carers was a desire to understand the patient's moods and anger. In some cases, it was recalled that the carer had been physically and emotionally

exhausted and being able to attribute the patient's behaviour to the disease process was helpful in maintaining the caring relationship.

Patients' comments relating to the process of dying:

I think: will I be like anyone else, will I disgrace myself?

I will be sad if things went wrong for the last time, and I will be somewhere else, it will be worse for them.

I might die ranting and raving, and my family would not think that was good.

Well, I am going to be frightened, and not knowing how to do it right when the time comes.

...no-one exactly knows, but when there is little else to think about, couldn't someone say this might happen, or that...

Sometimes when you are in pain, you think just get me out of this, and then you need someone to ask about the what-ifs. Then you want to know how will this end, will I die in pain like this? What will it be like?

...but God, I don't want to die screaming in pain, do people die like that? You would have seen a few?

Carers' comments relating to the process of dying:

I didn't know what stages he would go through I didn't know the mood swings. If I had known this was part and parcel of his dying I would have coped a lot better.

They should have said what might happen, like how he was very drowsy. I thought he was sitting and sleeping too much, but if someone had said that's part of the cancer, it would have made things easier.

I tell you the thing that is hard though is the moods. The abuse, I used to cop the abuse, but I don't think it was the real person. They don't understand, and then they lash out.

And he was angry, and he didn't mean it to be at you, he was frustrated and angry and he was that sick, and he didn't understand what was going on in his body.

Well, I didn't know why he was so clingy. Even to the last few days before he died, I couldn't see it for what it was, and everyone I have spoken with seems to have the same experience. I wish someone had said.

Well, physically, pain wise, he didn't seem like he was too bad, I couldn't see why he was just sitting there. And now I've been reading afterwards, but I think it should have been brought to my attention, that is a stage leave him alone, leave him sit there, if that's what he wants to do, that's fine.

Medication

All the patients raised the need to understand how to use medication to control pain, even those not so far troubled by pain. For a few patients, the taking of a large number of medications or the uncertainty of changes to medications was distressing. Some patients felt they, as against their carers, did not have enough information about their pills and they needed someone to talk to them so that they could keep control over that part of their care.

Most patients said that information would best be provided by a knowledgeable person. They emphasized the importance of 24 h access to support because problems often arose at night but needed an immediate solution; for example, if they woke at night with pain and could not remember whether they had already had a dose of breakthrough medication, would it be dangerous to have another?

Importantly, pamphlets and other written information resources were not favoured by patients. Many said that fatigue made reading difficult and some were concerned that they would not be able to control their carers' access to written information.

Carers also had detailed and practical concerns about medication. In many cases, responsibility for medication timing and dose fell wholly on the carer and as disease progressed, rapid changes of drug and dose could be required. This made medication error a major concern. Titrating doses to treat increased symptoms was a source of particular anxiety. An important issue raised was that changes in the appearance of medications caused by brand substitution caused anxiety and were perceived as a potential cause of medication error.

Carers were able to suggest realistic solutions for some of these problems. Establishing simple and robust routines that would not break down under fatigue and emotional stress was felt to be the most important area where help could be offered. In contrast to patients, carers thought that written information would be most useful. They thought this information should cover the appearance of each type of medication and be accompanied by clearly written instructions with an algorithmic approach to common situations. Versions of ward medication charts had been devised by some carers and these carers thought that similar charts should be routinely provided.

Patients' comments relating to medication:

Well, I have to know my pills, I think you have to learn 'cause no-one tells you things.

They put me on medication, but it made me like a zombie, can I cut that one out? I would like someone to talk to me, if I can cut down.

Yes, if someone could tell me who to ask, do I ask that doctor when we first came in, do I ask the other doctor, who do I ask, I don't know if it's him I should be asking. They aren't much help if they can't talk to you.

No, not reading about it. Talking about it is the way to go, it is the only way to go.

Carers' comments relating to medication:

I wish someone had told me at the beginning, here is a standard chart, do it like this, keep the record. But a standard form. I had to devise my own chart to keep my brain organised, because if you give breakthrough...

When you are tired and drained, it is hard. You look at the clock and think, 'Oh gosh, what time was that?' If they had said, keep the chart like this ...

Sometimes he was having such big doses my hands shook giving it to him, but I used to keep notes and all in the exercise book.

I think it is better to go through it all with the drug lady. And then you can go, the colours, the dose and so on.

...and sometimes they use different tablets in hospital and then they get confused. They want the 'big white ones' they are used to.

Practical and emotional support

Carers said that now they were able to look back it was clear that they would have benefited from more support. Many said they should have had support 'forced upon them' because they were tired and not able to assess their own needs. A frequently voiced complaint was that the mechanisms for obtaining information about resources and support were not visible or explained. Contact numbers and locations were obscure and the process of moving through layers of allied health and nursing staff was seen as unfriendly.

Carers' comments relating to support:

No, we left the hospital and I thought where do I turn, so I rang the switch and the lady on the switch she helped me.

I looked in the phone book and I got on the phone. It was a neighbour who told me who to ask for.

Well, we had a lot of information, about support groups and this and that, but I think there is a certain amount of denial, at first you think fine. We are right, we are coping, and by the time you realise there is a problem it is too late.

... because of the strain, because you have to be the one that supports everybody. I wish there was a group, like our bereavement group, but as you are going through it.

I didn't have support I needed. I did have to lift him physically, I had to lift him and get him in the shower. It was a lot to be lifting him, and his skin was like paper after the radiation.

Well, we did go fairly well. He was shuffling on a walker up until he died. I was getting tired and more tired, but they sent help and an electric bed.

The desire to shorten life

All of the patients we interviewed expressed thoughts that included the desire to shorten life. This ranged from fleeting thoughts that life was not worth living, or had gone on long enough, through the expressed wish that they were dead or an isolating preoccupation with death to communicating a plan or a well-reasoned course of action for suicide. Other patients expressed carefully thought-out reasons not to take their own lives. This is consistent with other studies about desire for hastened death.¹⁴⁻¹⁷

When discussion around suicide was investigated, patients were explicit about their concerns. Initially in the discussions we used terms like 'ending it', but the patients commonly replied "You mean killing myself?". None of the patients we interviewed had, however, as far as was known, attempted suicide.

The majority of patients who expressed clear ideas about the desirability of killing themselves were asked 'Why didn't you?'. Few patients expressed concerns about the rightness of suicide and those who did gave their religious faith as a reason for this view. The most frequently stated reason for not acting on the desire to hasten death was not a sense that this was wrong but uncertainty about their ability to end their life without increased suffering or without implicating others in illegalities. A second group of reasons not to commit suicide centred on the reactions of others to their act. These patients were not concerned about the justifiability of suicide in their own minds. Their decisive concerns were about how the people they would leave behind would interpret their actions.

Patients' comments relating to the desire to shorten life:

...of course you do, I'm sure everyone, well everyone like this, does.

Yes. I think everyone who has a chance to think about dying does. Well, I don't believe people who say they don't.

I doubt there would be too many people with this kind of disease who don't think about helping it on.

...when the things you dream of are done, and you have said goodbye, yes, because I worry that I won't die.

God will take me when it is right, but gosh I wish he would take me sooner. I pray, 'Today, could it please be today'.

...but I think the main reason I'm not strong enough is I don't know the best means, and without knowing the means you just might do more harm. Or get someone else in trouble, that would be a bad ending.

Although I have bad days, I think someone else would have to do it, and that would be bad for them.

Well, I think I will if it gets worse. I hope I can manage to do it, before things get too bad. Its one thing you wouldn't have anyone else do for you, that would be awful. And I would not really have anyone euthanase me, although I believe in it, because you see on the tele all the publicity, that would be awful.

No, I don't think it is wrong, it is a very personal choice, but it would be so distressing to mess it up. And to get it right I would have to ask someone, that might be the wrong thing for them. I don't want to die and not be able to check it was the right thing for them.

So I wouldn't do it because it would be terrible for them. I don't think anyone in my family would expect me to commit suicide. They would be shocked.

I thought the kids would feel dreadful, my son I thought about, that's what has made me change my mind. My

youngest he is a very sensitive sort of a bloke, and I think he would think I was a coward. And he would be pretty upset, so that did it.

Discussion

We interviewed hospice patients and conducted focus groups with carers to see what concerns these groups had about the medical and ethical issues raised by the approach of death. We found that many patients did not share the values that underlie the prevailing family centred model of palliative care, which, however, was strongly supported by carers. Patients placed a higher value on their privacy and autonomy than is implied by current Australian palliative care practice. We found also that some patients did not share the value prevailing hospice practice gives to discussing the psychosocial aspects of dying.

Thoughts of shortening life were universal in our sample. An important finding was that patients commonly reported that they had thought about killing themselves but that they had been deterred by uncertainty about the best means to choose and by possible adverse consequences for their families. This implies that systems that removed these barriers, along the lines of that operating in Oregon,¹⁸ might result in more patients acting on their desire to shorten their lives.

We recognize as a limitation of this study that it reflects the views of only 36 patients and 18 carers. Furthermore, the samples were drawn from patients and carers associated with the Newcastle Palliative Care Service and therefore underrepresent the cultural diversity of the community. Patients dying of illnesses other than cancer were underrepresented. The patients were also closer to death than the subjects of most studies of 'terminally ill' patients. For these reasons, other patients and other carers are likely to have different views from those reported here.

The results we present are important, however, particularly in relation to the involvement of patients very close to death. First, because these individuals are entitled to be heard. Second, dying patients, as a group, are entitled to a larger role in the debate about the care of the dying than they have so far been granted. Many studies of the problems of dying report mainly or even only the point of view of professional carers and family members.¹⁹⁻²¹ Our results suggest that this may be misleading. Third, the issues that are important to the dying are not likely to be the same at all stages of their illness: the problems of patients very close to death need to be dealt with on the basis of evidence obtained in patients very close to death.

In relation to the carers' focus groups, it is important to acknowledge the possible distortions imposed by retrospectivity. The stories the carers told and the views they expressed represent edited and reorganized memories. This is particularly so in relation to emotionally demanding or challenging

aspects of their stories.^{22,23} However, retrospective data collection has the countervailing advantage that discussion was not dominated by short-term pressures.

Some of the problems with obtaining practical information and support raised by both patients and carers could be addressed relatively simply by changes in routine procedure. Other issues, such as the belief that there may be reliable indicators of impending death, could be dealt with readily by frank discussion. Patients were also deeply concerned about the very last moments of their lives, especially the possibility of bizarre or undignified behaviour and of unsightly physical change that might distress their families. Detailed discussion with patients of the usual events surrounding death might be helpful.

Two problematic issues raised by our results are the appropriateness of a family centred model of palliative care and the appropriateness of the emphasis in the hospice on psychosocial aspects of dying. It is clear from the data we have presented that some, at least, of the patients we interviewed viewed these matters differently from the professional consensus in Palliative Care. We do not know how many patients share the views of those we interviewed and even if similar views are widely held, patients are not the only stakeholders. We suggest, however, that it is clear that it cannot simply be assumed that all patients want their families to be the unit of care or that all patients regard their most intimate hopes and fears as suitable topics of conversation.

It is important that the patients' choices about privacy and autonomy arose from clearly expressed and coherent personal values. Nothing suggested that patients' expressed views were the result of fear, desperation or unrealistic hopes. In some cases, the values patients expressed are societal norms and the patients merely could not see how their being close to death could make a difference. For example, the desire to control access to personal information and to make independent decisions is normal in our community and the emphasis on privacy and autonomy in contemporary ethics and law reflects this. That is, the preference for strictly observed privacy and autonomy expressed by our patients requires no justification or support. Any practice of communicating with families contrary to patients' wishes, however natural it seemed to those who suggested or adopted it, would require rather careful justification.

The carers' appeal to family authority over patients seemed sometimes to be based on a claim to predict accurately the patients' wishes. This is an empirical claim, which our interviews with dying patients show is, at least for some patients, implausible. There seemed also, however, to be deeper claims about family versus individual rights and about duties arising from the existence of intimate relationships that outweigh individual rights to privacy and autonomy.^{24,25}

Pending a major shift in legal and ethical opinion, health professionals may need to be more open with carers about what information can and cannot be provided. It may help also for carers to have their own doctors and other health professionals for whom they are the primary patient to alleviate the sense of being an afterthought to which carers seemed to be reacting.

One area in which the perspective of patients very close to death is especially valuable is that of suicide. Most research on the attitudes of the terminally ill to suicide has studied patients with an expectation of life of several months, for whom suicide was, predominantly, a matter for the future. Our patients, in contrast, could discuss the reasons they had not, in fact, killed themselves. These reasons were rather different from the factors identified in prospective studies as associated with suicidal planning – predominantly disease burden.²⁶ Of course, we could elicit only reasons not to commit suicide. However, it is important that the commonest reasons patients gave for not acting on their desire to shorten their lives were practical and that concerns about the morality of suicide were infrequently expressed.

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