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What people close to death say about euthanasia and assisted suicide: a qualitative study

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Objective: To explore the experiences of people with a "terminal illness", focusing on the patients' perspective of euthanasia and assisted suicide.

Method: A qualitative study using narrative interviews was conducted throughout the UK. The views of the 18 people who discussed euthanasia and assisted suicide were explored. These were drawn from a maximum variation sample, who said that they had a "terminal" illness, malignant or non-malignant.

Results: That UK law should be changed to allow assisted suicide or voluntary euthanasia was felt strongly by most people. Those who had seen others die were particularly convinced that this should be a right. Some had multiple reasons, including pain and anticipated pain, fear of indignity, loss of control and cognitive impairment. Those who did not want to be a burden also had other reasons for wanting euthanasia. Suicide was contemplated by a few, who would have preferred a change in the law to allow them to end their lives with medical help and in the company of family or friends. The few who opposed a change in UK law, or who felt ambivalent, focused on involuntary euthanasia, cited religious reasons or worried that new legislation might be open to abuse.

Conclusion: Qualitative research conducted on people who know they are nearing death is an important addition to the international debate on euthanasia and assisted suicide. Those who had seen others die were particularly convinced that the law should be changed to allow assisted death.

The Netherlands and Belgium permit euthanasia performed by a doctor, and define it as the act, undertaken by a third party, which intentionally ends a person's life at his or her request. Doctor-assisted suicide is legal in The Netherlands, Belgium and Oregon. Assisted suicide, with or without the involvement of a doctor, is legal in Switzerland. In Australia, the Northern Territory approved euthanasia in 1995, but in 1997 this bill was overturned by parliament.

In the UK, the issue of euthanasia has been widely debated since the 1870s,¹ and many argue that the question of the right to die has become one of the most important in contemporary ethics.² A House of Lords select committee recently produced a report on Joel Joffe's Assisted Dying for the Terminally Ill Bill, and recommended that, in future, assisted suicide and voluntary euthanasia be debated separately, allowing the possibility of a change in the law for one but not the other.³ Lord Joffe has since redrafted his bill, which had its formal first reading in November 2005.

Euthanasia in the UK is illegal, but the application of the law is not always clear. For example, although doctors in the UK are not allowed to give treatment that causes death, doctors can withhold artificial nutrition and hydration (defined by the British Medical Association as "life-prolonging treatments") if they believe that this would be in the patient's "best interests". In the absence of consensus, any decision must be authorised by a court, but the meaning of "best interests" can be controversial. Giving food and drink to the sick has long been used to symbolise "compassionate care",⁴ and some may regard the withdrawal of food and water, as in the Tony Bland case,⁵ as a form of involuntary euthanasia or even murder.⁶ Thus, the law seems to be inconsistent.⁷ It forbids doctors to give a patient a lethal injection at his or her request, but permits a court to authorise death by starvation without such a request.

The UK law on assisted suicide has also been described as "contradictory, confusing and opaque".⁸ What counts as assistance in suicide in "mercy-killing cases" seems to be

rather arbitrary. In 1989, a couple were convicted because they sat and watched their daughter (who had motor neurone disease) commit suicide and die of an overdose, but in 2005 Graham Lawson was not prosecuted after he comforted his sister, who had multiple sclerosis, during a 26-h suicide ordeal. She finally killed herself with a plastic bag. The Director of Public Prosecutions continues to consider cases individually. Under the Suicide Act 1961 section 2 (4), no prosecution for the offence of assisted suicide can take place without the consent of the Director of Public Prosecutions. He will exercise his discretion only after a suicide has taken place; therefore, no prospective guidance can be given to people.⁹

Previously, attitudes to euthanasia and assisted suicide were examined mainly from the perspectives of politicians, ethicists, health professionals and the general public.^{10–12} A few studies tried to capture the patients' perspective indirectly—for example, Seale and Addington-Hall¹³ found that a quarter of bereaved respondents would have preferred an earlier death, and examined the reasons, but they did not interview the people who were dying. Little is known about euthanasia or assisted suicide from the patients' point of view.¹⁴ We explore these issues from the perspectives of people who knew they were terminally ill.

METHOD

With the approval of the ethics committee, we invited people living in the UK to participate in a study on the experience of "living with a terminal illness". Interviews were contributed to the website, DIPEX (Personal Experiences of Health and Illness; www.dipex.org).¹⁵ We interviewed 41 people who said that they had a terminal illness. We aimed for a sample with maximum variation, including younger and older people from various social backgrounds, with malignant and non-malignant disease (table 1).¹⁶ The sample included people who had attended a

¹Airedale NHS Trust v Bland (1993) AC 789.

hospice for day care and others who had spent a few weeks in a hospice or nursing home. Some people were recruited through general practitioners, hospice staff and Macmillan nurses. Long discussions (to explain the study) were held with health professionals, who then approached suitable patients with full information. Patients returned a reply slip to the research team if they wished to participate. Other people volunteered after reading about DIPEX in a national newspaper, through support groups or during a conference about palliative care that included patients.

The interviews

Most people were interviewed in their homes during 2003 and 2004 by a sociologist and asked to talk about their recent experience of illness. Some were interviewed twice, usually because of fatigue. All interviews were audiotaped and lasted 1–2 h. Rather than use a structured approach, we conducted narrative interviews, which were led by respondents. A few people themselves raised the subject of suicide, euthanasia or assisted suicide, which became a high profile issue in the media during the fieldwork. It was considered to be unethical to press respondents to talk about the subject, but in some cases the researchers judged that they could invite respondents to comment on the euthanasia debate. In some interviews the subject was initially raised during a break for rest or cup of tea (it is sometimes easier to raise a sensitive subject “off tape” in a more informal atmosphere) and then repeated as part of the taped interview. The subject was not always raised because it became apparent during the interviews that some respondents did not think they were dying (even though they had said they had a terminal illness and had volunteered for the study), and it did not seem appropriate at the time. Eighteen people discussed these topics, some briefly and others at some length.

Analysis

Two members of the research team, both medical sociologists, read and re-read the data and constructed a coding

frame. Data analysis included examining expected themes such as pain and emergent themes, including suicide and assisted death, across the whole dataset and in the context of each person’s interview. The method of constant comparisons was used to ensure that all perspectives were included in the analysis.¹⁷ QSR N5 (a qualitative data-indexing package; QSR International Pty, Melbourne, Australia) facilitated the analysis.¹⁸ AC and SZ regularly discussed coding and interpretation of results (for more details on methods, see www.dipex.org/methodology.aspx).

RESULTS

Arguments supporting voluntary euthanasia or assisted suicide

Pool³ found that “control over the time and manner of death” was a central theme in requests for euthanasia in a Dutch hospital. Some people we interviewed also mentioned a need to control events, but had further reasons for wanting a change in the law. For example, a young woman with chronic obstructive lung disease said that without a change in the law she may commit suicide alone. She was in great pain, and could not find a place in a hospice. Throughout the interview she said she wanted to be in control and emphasised her right to choose:

R: I myself want to be in control as long as I can, I don’t want doctors and nurses controlling me (...) I’m on morphine, I get a lot of breakthrough pain, when I get to the pitch where I really can’t cope with anything any more, where my quality of life is totally gone, I will tell my husband I want a really good day out with the kids which is when he’ll know that when I go to bed that night I won’t wake up the next morning.

I: Because you’re going to take control?

R: Yes.

I: Have you talked to anyone else about that?

R: Yes, I’ve talked to my GP about it. He wishes I lived in another country because that decision would be helped. (...)

I: And if you were in control of legislation what would you say should happen?

R: (...) I think that you have to really look into it seriously, whether this is the right thing for the right person because I think there is the risk it might be abused. But with myself, if the legislation was there then it would be nicer for me, so I’m not on my own, which I know I will be because I don’t want any of the family here when it happens.

I: Why don’t you want anyone with you?

R: Because I don’t want them involved, I don’t want them to get in trouble. (...) In other countries, (...) I believe now, you’re allowed to choose when you die so you’ve still got your dignity. This country we don’t allow it; (...) if anybody helps us they lock them up, which is wrong. You’ve taken away that person’s dignity and nobody should have the right to do that. We should all have the right to choose when we die and how we die (LD25).

She believes that without a change in UK law she would have to die alone to protect her family from prosecution for their involvement in assisted suicide. She also notes the difference made by personal involvement:

I think the government has got to seriously take it on board, and I realise that it’s a very dangerous subject, and it’s a very dangerous area, but in the right situation it’s needed (...). I think if some of these ministers and

Table 1 Characteristics of 18 people who discussed euthanasia or assisted suicide, drawn from a larger sample of 41 people interviewed about terminal illness

Characteristic	No of people
Age at interview (years)	
30–50	3 (5)
51–60	4 (11)
61–70	7 (16)
71–80	3 (7)
81–90	1 (2)
Ethnicity	
White	18 (39)
Indian	0 (1)
Black Caribbean	0 (1)
Main occupation before becoming ill	
Professional or higher managerial	13 (26)
Other non-manual	3 (9)
Skilled manual	2 (3)
Housewife	0 (3)
Type of disease	
Cancer	13 (32)
Non-malignant disease	5 (9)
Recruited through	
Hospice staff (nurses, social worker, consultants)	2 (14)
Article in national newspaper	7 (9)
Community palliative care nurse specialists	2 (4)
General practitioners	1 (4)
Conference on palliative care	2 (2)
Other—for example, via another participant, support group	4 (8)

Numbers in parentheses indicate those in the entire sample.

politicians who are against euthanasia, I sometimes wonder, if it was their life or their wife or mother, how they'd feel then (LD25).

One argument against euthanasia has been that good palliative care should control symptoms, including pain and depression, and therefore people who consider ending their lives may change their minds when symptoms are properly controlled. Although most patients do have a pain-free death, however, a few do not. Sometimes analgesia is insufficient without side effects such as sedation, nausea and confusion.¹⁹ Some respondents mentioned uncontrolled pain:

R: Sometimes I am in that much pain that all I want to do is put myself on my bed and go to sleep but I can't sleep because the pain keeps me awake (...). I feel sad and angry that at the dawn of the 21st century they're able to talk on television about taking photographs and soil samples of Mars but they can't give me something that will keep me awake, lucid and to be a useful member of society and kill the pain at the same time (LD09).

This man had searched the internet to find out how to commit suicide. He said that he would not do this without talking it through with his fiancée. He was against euthanasia but for assisted suicide:

R: The people that have motor neurone disease, the people that have MS and are in excruciating pain, a lot worse than the pain that I have, they should be able, in conjunction with their partner [our emphasis], to decide that enough is enough and that they should be able to take their own life (LD09).

The hospice movement exists to deliver outstanding care to dying patients and does so.²⁰ But research suggests that hospice care does not stem the wishes of a notable minority for euthanasia. Seale and Addington-Hall²¹ interviewed relatives and acquaintances of those who had died and found that respondents for hospice patients were more likely than respondents for those who had not received hospice care to believe that an earlier death would have been better, even after controlling for levels of distress and dependency among those who were dying. The authors suggest that this may be either because hospice care is geared to helping patients express their fears and exercise choice or because people (and their relatives) who accept hospice care may be predisposed to consider the benefits of an earlier death. But other reasons may also contribute. One woman we interviewed said that she would welcome euthanasia or assisted suicide because of what she saw on a shared ward:

R: I spent a month in the hospice, (...) just unfortunately probably nine different ladies came into the ward and died (...). So I have seen what happens at the end and if I could avoid it happening to me I would, simple as that. (...). It was really bad luck because I've seen it first hand whereas in the past I could only guess at I suppose what it could be like at the end, and it's not a pleasant prospect and if I could just take enough of something to put myself to sleep for good, I would happily do it and [um]. If somebody wants, you know wanted to help me, if somebody was brave enough to help me, I'd be grateful to them. It's almost a nonsense we can't decide what to do with our life at the end, isn't it? Why should a judge be able to say, no, I can't kill myself if I want to? (LD02).

In the 1970s Murray Parkes²² interviewed surviving spouses, and asked how their husbands and wives had felt about other people's deaths in St Christopher's Hospice. Of these, 15 (44%) respondents said that their spouse had realised that a death had occurred but most were apparently not upset. More recently, however, Lawton²³ observed patients in a hospice who had unpleasant symptoms that could not be successfully treated or controlled, and who sometimes requested euthanasia or refused food and drink to hasten death. She noted that other patients in the ward, like the woman just quoted, were very distressed by what they saw and smelt.²³

Another woman with metastatic kidney cancer, whom we interviewed, had seen her mother die a painful, undignified death, and hoped that the law would be changed before she died. She too was worried by the possibility of an incontinent, "unbounded" body:²³

R: It would be a comfort to me to think that when I've come to a point where I'm clearly dying, you know there is no further treatment available for me and if I am in lots of discomfort, I would like to be able to say, "Can you get my kids to come and see me," and maybe, I don't know, my friend, that's a minister or whatever and say goodbye. And then [er] you know can you just do what has to be done, give me an overdose of morphine or whatever it is. Because actually my Mum was in hospital for about three months before she died. And she had sort of raging osteoporosis having taken lots of steroids for another condition. And she was in terrible pain and she had made a living will actually. [Um] And they had to give her so much morphine in the last few weeks, to be honest she was talking rubbish and coming up with ideas. She told us there was something she wanted to tell me and that she had murdered twelve children. And I said, "Oh Mum, you know that is your mind playing tricks because of the drugs. You haven't murdered anybody". But she still insisted that she had. And I just wish that she could have gone a month or two earlier before she went through all that indignity that is dying really. [um] And I would feel the same about myself (...). I just think that when you've come to that stage, only you know when that is, how bad that has to be, you don't need to go through the physical indignities of throwing up, being smelly, being incontinent, whatever it might be (LD17).

Others have noted that when death approaches, people still wish to remain physically independent.^{13 24} A man with progressive multiple sclerosis hated being dependent on his wife and wanted the option of euthanasia. He had run a nursing home and had seen others die in great pain. At times he suffered from excruciating pain himself, and he dreaded cognitive impairment:

R: I have a strong opinion about that [euthanasia]. First of all I believe that it is everybody's right to die as it is their right to live (...). Now I would like to think that if something happens to me [so] that I become completely incapable of enjoying life then I would want someone to do to me what they would do to any ordinary animal. They would if it was a dog and it was suffering and in pain and couldn't be a dog anymore, you would say, "Oh pity", and you would take the dog to the vet. I would hope that I could be taken to a doctor or the doctor would come to me, or would be allowed to and would be able to just put me to sleep, because I think life is only tolerable if you're alive (...). What I am saying is for me if I have a stroke that leaves me

paralysed, leaves me brain dead, then I don't want to live like that, I don't and why should I? (...) I've seen people who you could show a mirror and they would say, "Who's that?" and they don't know who it is, but the soul has gone as far as I'm concerned if that's what happens. I don't want to be like that (LD27).

That some people will feel undervalued and obliged to end their lives to reduce the cost to others is a concern. Two people we interviewed said that they did not want to be a burden to others, an important finding, but this was not the only reason they wanted the option of euthanasia. For example, one woman knew a man with dementia. Having seen his wife struggling to cope, she said she did not want to "lumber" herself with anyone or with any institution. But she was also concerned about pain:

If your usefulness has gone out of life I can't see the point in delaying things. And certainly if you are in a vegetative state there is none, I don't know how anyone can justify it (...). I know one lady who is determined to go on looking after her husband, and in the eleven years since he was diagnosed with Alzheimer's, he got to the stage where he was blind, dumb, and she thought deaf, and she was still pushing food in one end and collecting it the other. He wasn't alive he was existing (...) God forbid that I ever got to that (...). I don't want to lumber myself on anyone, or any institution for that matter (...) but if I ever get to the stage of having the pain which I'd had in the past without my husband and without my children really needing me, (...) I think the plastic bag might just come in use. Back to euthanasia, I would much prefer it if someone would say, "Well, we'll just do it for you calmly and quietly". I don't see any point in continuing when there is no purpose in life (LD 22).

A woman with motor neurone disease worried about the cost of care, but also strongly favoured euthanasia because she had seen her husband suffer:

R: I said the same when my lovely husband was ill, if I could have given him a tablet I would have done. But that isn't possible (...). If your GP or someone can't do it [assist with suicide or euthanasia] or wouldn't do it, I respect them but I think somewhere along the line someone should help you. What is the point? You're suffering unnecessarily and the cost is, you can end up with the cost, the costs are astronomical and there's no point because there's no end to it.

I: In some countries, I think in Scandinavia, it's different, isn't it?

R: Yes, and Holland there is. My grandson lives in Holland so I know.

I: Why do you think it's happened in those countries and not in ours?

R: Because we so drag our feet here, that's why. I mean it's all judgement by people who are able-bodied and they don't have a clue.

I: So if the people who are in your situation could be asked their opinion, do you think a lot of people would think like yourself?

R: I don't know, I really don't know. But I'm only speaking for me and I saw my own husband suffer unnecessarily for an end that was inevitable anyway. And to me that is evil or at least cruel (LD34).

Among these interviews with people who were themselves facing death, those who spoke most passionately about the

need for a change in the law were those who had also seen others die.

Arguments against a change in UK law

A few people opposed a change in UK law (or were ambivalent), who represent negative cases in the analysis.²⁵ Apart from three people who appeared to be discussing involuntary euthanasia, one said that people should trust God and that good could come out of suffering, and another was anxious that people might ask for assisted suicide to help carers rather than themselves. Others, who overall were in favour of euthanasia, feared that any new legislation may be misused. For example, a man with oesophageal cancer said that he would welcome euthanasia for himself, but hesitated to recommend it as national policy:

R: I would like an easy death and from that point of view I think I would welcome euthanasia. Having said that I see all the complications of it, and people who are at a stage of illness where they can't speak for themselves, a possibility of somebody wanting to get rid of their relatives, that makes me very nervous, so although on the one hand I would like to see it to help me, I'm very hesitant about it.

I: As a national policy.

R: As a national policy (...). Yet on the other hand there was um, Dianne [Dianne Pretty, who took her case to the European court] isn't it, with motor neurone disease, and that poor women obviously wanted to die and nobody would do anything about it. It's a conflict, I don't know, I can't deal with it, I don't know how you sort it out (LD21).

Others shared concerns about the potential for abuse, but concluded that each case should be judged on its own merit:

The thing that would concern me very much is the abuse of it [euthanasia]. It could be used in the wrong way, and therefore requires a lot of careful thought (...) I think you've got to judge each case on its own merit actually, and the people involved (LD31).

DISCUSSION

Our study is important because it draws on accounts of patients who knew that they would probably die soon of either cancer or non-malignant disease (table 1). Most previous qualitative research designed to understand the dying process has been based on the views of patients with cancer or those of patients dying of AIDS.^{14–26} When examining the views of those with HIV-1 or AIDS, Lavery *et al*²⁶ found that people desired euthanasia or assisted suicide because of disintegration or loss of community. Our participants did not mention loss of community as a reason for desiring euthanasia or assisted suicide, perhaps because they did not have diseases as highly stigmatised as AIDS. But they gave many other reasons for wanting the option of ending their lives. They often had multiple reasons for wanting a change in the law, including the right to choose when to end their own life, pain, anticipated pain, cognitive impairment, fear of indignity, fear of loss of control and concern that they may be a physical or financial burden on others. Some regretted that they may have to die alone if suicide became their only legal option.

Only a few people opposed a change in UK law, mainly it seems because they were discussing involuntary rather than voluntary euthanasia. Some were ambivalent about a change

in the law that would allow voluntary euthanasia because they feared that a new law may be misused. It is important, however, to note that this was not a numerically representative sample and that interviews were led by the patient's story, not by a set of questions from the researcher. The appropriate emphasis for the findings is therefore the range of perspectives and the characteristics and experiences of people who held different views and not the numbers of people who were for or against euthanasia.

The method was appropriate to the aim of the study but it had some limitations. The interviewer did not define exactly what she meant by euthanasia when she introduced the subject herself, which led to confusion in some cases. One person, for example, mentioned Harold Shipman, and evidently thought that the interviewer was talking about involuntary euthanasia or murder. Also, some respondents may have had strong views but felt unable to introduce the topic themselves. Although we aimed for a maximum variation sample, we interviewed few manual workers and the two from minority ethnic groups did not discuss the subject. It is extremely hard to recruit patients who are dying for any type of research. Family members may resent precious time and energy being spent on work that will not give a chance of a cure.²⁷ Health professionals can also be very protective of their patients and may not facilitate recruitment.²⁸ Seale and Addington-Hall¹³ found that social class and religious denomination did not greatly influence people's views about euthanasia, but they interviewed few people of non-Christian faiths. If we had interviewed more people from minority groups with other religious views, we may have heard additional arguments. Numbers of people interviewed in qualitative studies are necessarily small; so entire studies may be needed to explore the subject of euthanasia and assisted suicide from the perspective of the various minority ethnic groups in the UK.²⁹

Most people in our study were interviewed only once. Some of those who expressed strong views, either for or against the option of euthanasia or assisted death, may have changed their views as their illness progressed. Also, the comments some people made about euthanasia or assisted dying, or the lack of comment in other accounts, may have been influenced by a need to project a particular moral stance, by current media debates, or by the palliative care argument that better end of life care would reduce the need for euthanasia.

Of course it is important to provide more resources to help all patients die with dignity in a setting of their choice.³⁰ But, some reason that even with the best palliative care there may be a case for euthanasia or assisted suicide in certain situations,³⁰ and that without new legislation, euthanasia and assisted suicide will simply be driven underground.¹¹

In the UK, the law on euthanasia and assisted suicide certainly needs clarification, and perhaps even change. Our respondents spoke powerfully, some thinking about their own deaths, and others recalling the deaths of other people, which fuelled their criticism of the current UK law. In many parts of the world, the intense controversy about euthanasia and assisted suicide persists.^{31–33} We believe that these accounts of ordinary people who are facing death should inform current debate in the UK and elsewhere, but there is still a need for more research that includes patients' views of these important issues.

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