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ORIGINAL ARTICLE

Hospice patients' views on research in palliative care

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Abstract

Background: This project was conducted to investigate whether the concerns that researchers have about including terminally ill patients in research were shared by a sample of terminally ill patients.

Methods: Twenty-two patients admitted to a hospice participated in semistructured interviews; 18 patients had advanced malignant disease and 13 were women; their ages ranged from 28 to 93 years. The interview transcripts were analysed for common themes and particular attention was paid to the reasons patients gave for their views.

Results: All the patients wanted to participate in research. Patients advanced one or more of several reasons for participation, the commonest being altruism, enhancement of a sense of personal value, the assertion of persisting autonomy and the value they placed on a commitment by doctors to optimising care by research. They rejected the view that their consent might be non-autonomous and put forward consistent views about what they considered relevant to consent.

Conclusions: Our patients did not share the concerns of ethicists about the difficulties and hazards of research with the terminally ill. These patients' views are not reflected in the professional consensus.

Introduction

This article presents a descriptive qualitative analysis of the views of some dying patients about research. Palliative care research is widely perceived to be ethically problematic.[1–6] This would itself raise ethical concerns if the difficulties of including terminally ill patients in research impaired their treatment.[7] We undertook this study because some of the perceived problems of research with terminally ill subjects arise from what the terminally ill are believed by others to think and feel and we thought that the terminally ill themselves might have contributions to make to this debate.

The ethical problems with including terminally ill patients in research include their supposed vulnerability to unrealistic expectations of benefit, their need to spend undisturbed time with their families, and impairment by disease or drug treatment of their capacity to comprehend or consent to research.[8–11] George Annas[12] has gone so far as to say that

> Terminally ill subjects with less than 6 months to live should be disqualified from human subjects research. Desperate, and, therefore, too vulnerable, they are unable to distinguish research from treatment.

This assertion makes or implies a number of claims about the terminally ill: that they are desperate, that they cannot distinguish research from treatment and that they do not value outcomes other than recovery from their illness. These claims justify an ethical conclusion: the terminally ill cannot benefit from participation in research and, therefore, should not to be invited to participate.

These are empirical claims about the thoughts and values of the terminally ill but there is remarkably little evidence to support them. Much of the debate about the concerns of dying patients has been defined by, and filtered through, the views of family, carers and health-care

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professionals or has involved patients who have chronic illnesses but are not close to death.[13–15] We wished, therefore, to investigate Annas' empirical claim to see whether terminally ill patients were indeed desperate for cure, whether cure was the only outcome of research they valued and whether they did have difficulty distinguishing research from treatment.

Methods

This study was a descriptive qualitative analysis of the views of hospice patients on the problems of carrying out research with dying patients.

Setting

The Mercy Hospice is a 20-bed hospice, part of the New South Wales 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, serving a population of approximately 500 000. In addition to its 20 inpatient beds, the Mercy Hospice provides outreach and home care.

Newcastle is a coastal city located 160 km north of Sydney. The majority of the population is Anglo-Celtic in origin. There are important indigenous and non-English speaking communities but they are underrepresented among Hospice patients.

Ethical considerations

This project was approved by the Hunter Area Research Ethics Committee and Newcastle University Human Research Ethics Committee (02/04/10/3.11 and H-324-0502). All subjects gave informed consent, either written or recorded.

Subjects and interviews

The data we present are derived from interviews with 9 male and 13 female patients of the palliative care service. Their ages ranged from 28 to 90 years. During the period of the study, all patients admitted to the hospice who were judged as being able to give informed consent to participate were invited to do so. Patients were approached about their participation in the interview study after their medical admission was complete. They were approached on a single occasion, by a member of the palliative care team other than the researchers or treating physician, and given an information sheet and time to ask any questions about the study. Patients were offered at least 24 hours to consider their participation. None of the patients approached declined to participate and none chose to make use of the opportunity to delay a decision. We did not ask the patients whether they had participated, or had been invited to participate, in research studies before their admission to the hospice.

The recorded interviews lasted between 19 and 74 min (median 40 min). All the patients interviewed are now dead. The interview and death were separated by less than 24 hours for five people, less than 48 hours for a further nine people, and between 1 and 5 weeks for the others. Eighteen of the patients had advanced malignant disease. The diagnoses of the others, and the dates between which data were collected, have been withheld to avoid the possibility of identification of patients.

All the interviews were conducted by one of the authors (W. T.). Patients determined whether or not they would like relatives present at the interview. The interviewer asked open-ended, predetermined questions, structured beforehand by the investigators to cover broad areas commonly considered to be concerns about palliative care research.[16,17] The responses and subsequent discussions were recorded. Variants of these questions were introduced several times during the interview to allow confirmation of the concept initially put forward by the patient. For example, "If we were doing research into hospice or palliative care, what do you think we should do?" was followed later by "What problems do we need to do research into?". When this lead to responses about quality of life, patients were asked specifically "What does quality or quality of life mean for you?". When patients expressed a desire or willingness to participate in research, we asked about practical details such as "Who would you prefer to ask you about being in research?" and "Do you think your own doctor could ask you to be in research?", then "Who else do you think could ask you?". The patients were asked "Do you think you could say no to being in research?", "If your doctor asked you, could you say no?" and "Do you think you could say no if your nurse asked you?".

Patients were also asked questions about how they would like information presented or results of research given, such as "How much information do you think you would need to be in research?" and "How would it be best to give you that information?".

Although patients were asked about the problems that research in the hospice should address, they were not asked about particular research designs, with one exception. All patients were asked if randomized controlled trials were an appropriate design for research in the hospice. This question was later followed up by asking "If we had two treatments and we did not know which was better, would it be OK to give half the patients one and half the other?". The possibility of Phase I drug trials was not specifically raised.

To ensure the accuracy of their statements as responses to the questions, all patients had the opportunity to review their interviews and give additional or clarifying statements and to delete comments.

Recruitment of patients continued until no new patterns of response were observed in the most recent interviews.

Analysis

Interviews were transcribed verbatim. All of the researchers read all transcripts to gain an overall understanding of the narrative descriptions and the patients' experiences. The transcripts were then searched systematically for conforming data by each researcher.[18,19] The selected statements from the transcripts were compared to ensure agreement between researchers before the next step, the development of categories.[20] Data from interviews were then cross-checked between researchers as a means of confirming the categories that emerged. All transcripts were then coded on the basis of these categories. The analysis was an iterative process involving several meetings of the researchers who reviewed transcripts independently and then met to integrate their analyses and to resolve any disputes by extended discussion. Categories were reviewed and modifications were made only once agreement had been reached.[19,21] Final categories were compared to ensure that there was no overlap and that the themes are supported by direct quotes.[22]

Results

Two key areas were identified from the categories and are illustrated here by quotation from the patients' narratives. The areas were (i) the value of research and the value to the patients of research participation and (ii) practical aspects of research. Practical aspects of research included the way in which patients would prefer to be approached about participation in research and the information they believed they would need to make an informed decision about participating in a proposed research.

The value of research and the value of participation

Patients advanced a number of reasons for their wish to be involved in research. We have grouped these reasons in the categories Utility, Self-validation and Assurance. Comments classified under Utility related primarily to the idea of giving something back. Comments classified under Self-validation related primarily to the idea that participating in research allowed patients to see themselves and to be seen by others as more than 'a dying person'. Assurance related to the value of knowing that health-care workers and the community were willing to make an effort to optimize the care of dying patients.

Utility

Some patients said that when they had little time left, it was important that they could use that time to do something of enduring value. They felt that participation in research enabled them to give something back to their families and carers and to the community. Others expressed the view that participation in research when they were in the unique position of knowing they were dying gave them a special gift to give others. Some expressed this view in narrowly technical terms – their intimacy with pain, for example – others in terms of the ability to make decisions without worrying about long-term consequences. Comments illustrating this category are given below.

> Not everyone gets the chance to know when they are dying, so I say yes let me help.

> I don't want people to think I have nothing to give back, nothing to offer…

> Here you could give something back, something to help other people…

> It would be a way to give something back now before I die, I would have done something good for the future.

> Some days it seems important to give something back, other days you might just want to leave something of yourself behind.

> I do feel I'm a bit of an expert in pain, in a way that someone who is not dying might not be.

Validation

Many patients expressed a wish to continue to participate in a range of meaningful activities and not just be the dying person. Their weakness and fatigue made some research activities impossible but most patients were enthusiastic about engaging in research to the limit of their capacity. Comments illustrating this category are given below.

> It is good to research, especially when you are dying, you don't want to be forgotten …

> Taking part in research would help lift that feeling that once you cross the hospice threshold you are not worthy of taking part in ordinary things.

> I want still to be a part of something, and not just someone who has to make their will …

> I think people forget we are still people, with lives outside of being the dying person.

> … if I'm part of a research I am still real, and if you doctors are doing research I know you think of me as real too.

Assurance

Because most of the hospice patients have a primary diagnosis of cancer, many had attended oncology clinics and had observed or been offered participation in radiotherapy or chemotherapy trials. They were aware that teaching hospitals customarily do research and understood this as the pursuit of new knowledge to improve care. They were aware also that a commitment to research is normally perceived as an essential part of the profile of a health institution. Some patients explicitly drew from this the conclusion that not doing research in palliative care was equivalent to not being committed to optimizing care for the terminally ill. Many understood that the knowledge that guided their treatment had been gained through research and stated that they would want others to benefit as they had. These patients did not support the idea that it could be more 'ethical' for doctors to guess about treatment than to confront the difficulties that arise in involving dying patients in research. Comments illustrating this category are shown below.

> …and plus if you do the experiments, it is better than only a guess.
>
> How do they know what to give dying people for pain? That must have been the subject of research.
>
> I suppose we think that you already have the best pain killers, but that might not be true might it?
>
> … if we do experiments for all these things, then other people might die with better quality …
>
> I think it is a good place, and part of this place should be research.
>
> … when you get this far you need things to be proper, and if there is no research here it could be terrible.
>
> You should do it because that professor-man-doctor still needs to learn a thing or two.
>
> You see to me research is the only way you get down to the real issues and get any knowledge of them, be able to make new moves and have different ways.

How research should be carried out

What research should be undertaken in the hospice

Some patients said they would consider participating in any kind of research but most were interested only in research on the "disease that got me here" and a few only in research in palliative care problems. When asked to specify the most worthwhile research areas, however, most nominated problems in palliative care. Comments illustrating these views are shown below.

> The disease, cancer especially …
>
> You could do anything as long as it is not cruel …
>
> I couldn't be bothered to do research in cancer, I'm dying now there is nothing to get from that.
>
> It's too late to worry about cancer …
>
> The drugs to stop the vomiting …
>
> … how to cope and manage the depression.
>
> How things are going to end up …
>
> The pain.
>
> Dying – talk about dying and death in our society. Because if people don't know what to say they should research those things.

How the request to participate should be made

Patients expressed a decided preference to be approached about research participation and consent by a doctor or nurse involved in their care. The most commonly given reason for this was the effort involved in explaining their problems to a new and unknown person. Patients were clear that at a stage in their illness when they had accepted dying, the involvement of a new person who might not understand their situation was a larger concern than any issue of possible coercion. Patients felt they had an established relationship with their doctors and for this reason did not have to explain again all their circumstances and decisions to be able to participate in research. They expressed unwillingness to deal with independent research staff who might not cope with the issues of dying. Comments illustrating these views are shown below.

> I am too tired to explain dying to someone new.
>
> Trust - the one who knows you, knows what you've been through.
>
> … you get faith in your doctor, they have been through it with you, and you don't need to tell them you are dying.
>
> … there isn't time or energy to talk with people who have hang-ups about dying.
>
> They would have to be in it with you, not someone who doesn't have a clue about dying.
>
> The doctor. Well, let me clarify that: a doctor you know should ask you.
>
> … because you have to have someone who knows, who you don't have to go through all the adolescent stuff with, and your doctor is the best one.

Consent

There is a commonly expressed view that terminally ill patients may be distressed, or in pain, or frightened and that this makes them more vulnerable than other patients. The argument is that their vulnerability casts doubt on the voluntariness or the autonomy of their consent. The converse argument was put forward by our patients, who said that there is a 'freedom' in being close to death so that they felt they could say precisely what they wished and had nothing at all to lose by voicing

their own opinion. Comments illustrating this point are shown below.

> I wouldn't feel obliged. If they could talk to you they wouldn't be worried that you couldn't say no.
>
> When you go to the emergency they ask you things, they don't think you have stopped thinking. Why would you not know what to say just because you are dying in the hospice.
>
> We can just say what we think, there is nothing to lose.
>
> … can you imagine the point of not being truthful now, now, when I'm like this?
>
> I would just say no. Sure I would just say no – nothing to lose now.
>
> When you are dying you can think and say anything, you wait you'll know what I mean.

Perhaps the most frequently expressed concern about research with terminally ill patients is that they may imagine that participation offers a chance of prolonging their lives and consent only for this reason. In contrast, many of our patients stated that they would participate in research only if there were no possibility of it delaying their deaths. Death was what they and their families had prepared for and although a chance of cure of their disease would, of course, be attractive, minor prolongation of life was seen as a hazard and not as a benefit. Comments illustrating this point are shown below.

> I need the spare time, but if it was going to keep me alive I would want to know that, because we are all here together for my death to happen.
>
> Well if you were going to last longer, that would be important, 'cause it is such hard work getting to the point you know you are for it, and if you turned that around, well, oh no ….
>
> … well if you are in an experiment it might make you live longer, that would be hard, 'cause … whoever is doing the research would need to tell you that.
>
> … and if the drugs did work then we would all have to try again, and keep going, and that would be hard.

Impacts on families

Another reason for concern about research in the terminally ill is that research may consume some of the time patients have to be with their friends and families. Sometimes the possibility is also raised of relatives being distressed at a trial of new treatment at a late stage. In the interviews, patients offered information regarding both these areas. They regarded the opportunity to make a decision to take part in research independently of their families as an important affirmation of their autonomy. Research participation was also valued as a way of helping their families to understand that they were still valuable people and still making responsible decisions. Patients did not see research participation as a hazard to relationships but as a source of enrichment. Comments illustrating this point are shown below.

> …then my family could see that I gave something back.
>
> … sometimes your family find it hard for you to be the person they knew when you are dying, at least we could talk about my day being in research.
>
> … it would give us something else to talk about, now that we have arranged the funeral.
>
> It would be good for the family, when the kids come in. We can say, well, the doctor said this and that, then I asked would it hurt, and he said 'No' … you know, I can tell them.
>
> At least something else than talking about dying.
>
> It is something else to talk about, my wife and I, at home, we could talk about it.
>
> Like today, I was thinking about things before you came, what you might ask, what we might talk about. That helps.

The patients also made clear statements about the importance of their own doctors and nurses taking responsibility for explaining the research process to families. Patients were aware that their wish to be involved in research could worry their families but this was regarded as having the countervailing value of obliging family members to recognize the patient's persisting autonomy and individuality. Comments illustrating this point are shown below.

> It is important for your family to know, but if I decide, I should decide.
>
> … but if I did, I would like to take part, it would have great meaning for me, and I think you should help my daughter to cope with that.
>
> It might be difficult, they are already upset, but if you tell them it is my wish …
>
> The final say is with the patient not the family.

A key concern to patients in the area of effects on families was the possibility that experimental treatments might provoke abnormal behaviour. Although the patients did not believe that such a risk would make the research unacceptable, they considered that behavioural side-effects would be the most important issue for discussion. Again, patients were clear that the role of doctors was to discuss the possibility of behavioural side-effects with the their family in order that the family be comfortable with the patient's decision to participate. Comments related to this concern are shown below.

> It would be only fair to know if you were going to turn blue or become strange, so the kids would know before.
>
> … as long as I didn't die doing something weird, then my family might not think it was good.
>
> … if research would make you different, or seem different to your family, then it would be best to know that.

… it would have to not make you too tired, too mixed up or forget, or say things you didn't want to say.

Randomized controlled trials

Patients did not want to participate in placebo-controlled randomized controlled trials. However, their negative view of placebo-controlled trials seemed to be based on the assumption that it is known in advance that patients in the placebo arm of a trial will suffer worse outcomes. Some patients appeared to believe that patients in the placebo arm of a randomized controlled trial receive no active treatment. Active comparator randomized controlled trials appeared likely to be generally acceptable. Comments related to randomized controlled trials are shown below.

I don't believe in dummy pills, leading people on is not the way.

… about placebo drugs, sometimes they know they work the same as other drugs, so that's not a good idea to know.

I could not just be a guinea pig. I don't know how you experiment for things like that.

Well you could try both and see which is better, but not one that doesn't work …

The delivery of information

Our patients, almost exclusively, wanted verbal information. They felt that this promoted patient-focussed discussion. Fatigue and some physical changes that accompany terminal stage of illness also featured in this preference for verbal over written information. Several commented that because they had accepted that they were dying, they did not want anything that was similar to the information pamphlets they had received when they were in the phase of active treatment for their disease. Comments illustrating these points are shown below.

Do you see anyone writing here? Reading things is so hard. No long boring pamphlets or pages …

Not more forms …

Talking about things is important, talk it out but not have to sign bits of paper …

… how tired you get reading, how it is much more straightforward to talk about these things.

I don't want to have to read it, reading is really too much.

I just want someone I trust to tell it to me straight. I would let you know if I needed anything else.

I do not want too much information, but I would want to be able to ask questions.

Do not hand out a one and a half page brochure. There is a lot more to be done than that.

I don't think even my daughter would read that. No, really, sit with you and tell you.

Discussion

Palliative care research faces obstacles arising from the perceived practical and ethical difficulties of including terminally ill patients in research. As with other controversial aspects of palliative care, these obstacles have been framed largely in terms of what others thought patients experienced or would feel when participating in research. We wanted to see whether the concerns that are said to distinguish palliative care as a special case, and so limit participation, were shared by a sample of terminally ill patients. We found that they were not. We suggest that current guidelines have over-stated the difficulties of research with the dying and have not taken sufficient account of the value the terminally ill may place on research participation.

The patients we interviewed did not agree that there are serious practical or ethical difficulties in the face of research with the terminally ill. They flatly rejected George Annas' view, both as regards the claim that their autonomy was compromised and as regards the assumption that they gain no direct benefit from research. These patients identified interests in research, which have not been part of previous discussions of this issue. They believed that research participation offered what they regarded as important, immediate benefits. Certainly, they valued the benefits to others that research offers. However, they also identified in research participation a source of what we have called Self-Validation: the knowledge that they could make a useful contribution despite their terminal illness. That is, research participation was perceived by our patients to confer on them benefits they valued because of, and not despite, their terminal illness.

It is important that patients had for the values and preferences they expressed reasons that were both cogent and relevant. For example, one reason advanced to value the opportunity to take part in research was that it would provide a topic of conversation with visitors. This may seem a small hope but it cannot be argued that it is unrealistic or desperate and its importance is for patients alone to judge.

Our conclusions may be objected to on the grounds that they reflect the views of only 22 people, all of whom were close – some very close – to death. It is certainly possible that the views of patients terminally ill but not close to death might differ from those of the patients we interviewed. However, we believe that these particular people are entitled to a say, each one no less than any other individual commentator. The voices of these people bring a perspective to the debate on research in the terminally ill not offered by the views of less sick patients, ethicists, hospice staff or family members. Furthermore, patients who will die very soon have problems that patients who are terminally ill but will die in months do not have. Those

problems deserve research and that research must involve patients similar to ours.

Some of the views our patients expressed deserve consideration not because a dying person held them but in their own right. The clearest example is the suggestion that research in palliative care is important because the dying may justly regard it as the most convincing evidence that the community thinks that their problems are important. The patients particularly valued research on palliative care problems but not because they expected that they themselves might benefit. Some patients had purely altruistic motivations for taking part in research but others were influenced by their awareness of what doing research in palliative care implies about attitudes to the care of the dying. The patients understood that research implies approaching knowledge in an objective and humble way and saw this as a characteristic that their professional carers needed to express. The patients understood also that research is and is seen by the community as the key to improved care. They understood clearly, that is, that the alternative to research is guessing and that if we do not do research in palliative care, it may be because we think that for the dying guessing is good enough. We suggest that this issue has received much less consideration than it deserves in developing guidelines for ethical research.

Of course, patients now terminally ill are not the only stakeholders in this discussion. However, our patients expressed deep concern over the usurpation of their autonomy by others – about being treated as already dead. We suggest that for this reason it is ethically problematical for stakeholders other than patients to base their objections to palliative care research on the ground of patients' feelings and concern as if the patients were incapable of speaking for themselves. This is especially the case if not all patients have these feelings and concerns (such as a desperate desire for any chance of cure).

A related issue is that some 'ethical concerns' about research with the dying may arise from the feelings not of patients but of researchers. For example, a National Institutes of Health consensus conference report has raised "… an ethical question about the *decency or propriety* [our italics] of intruding on patients at a particularly important time in their lives".[23] These feelings of shame are, we suggest, those of the researchers. This is the language of taboo and we do not know of any other area of medical research that has, in recent years at least, provoked it. This is unfortunate because one reason to value the opportunity to participate in research commonly expressed by our patients was that it would confirm that they were still, and were regarded as, real people: not taboo.

Many of the ideas that underlie current views about what makes research ethical or not derive from Hans Jonas.[24] In particular, Jonas articulated the notion that altruism is an implausible reason to take part in research and that, therefore, research would be ethically defensible if, and only if, the subjects shared the goals and values of the researchers. On this basis, he drew up a hierarchy of possible research subjects, from 'ideal' – the researchers themselves – to 'unacceptable' – the dying. We do not have space to argue the issue in detail and wish now only to point out that Jonas' claim leads to the exclusion of the dying from research without their being consulted and that our patients regarded this as unfair.

Our patients had clear and reasonable views about practical aspects of information and consent. In particular, they preferred to be approached about research by their own physician. Research on disclosure of cancer diagnoses gives similar results: dealing with someone you trust is the most important aspect of communication.[25] Provisions in current guidelines restricting the involvement in the consent process of a physician–investigator (e.g., Declaration of Helsinki, Part 1, Paragraph 10[26]) are intended as safeguards but make direct communication about the research between the patient and someone they know and trust impossible.

One surprising result, also not reflected in current guidelines, was that our patients regarded the possibility of an unexpected prolongation of life as an adverse event rather than as a benefit. This is, perhaps, the point on which our patients' opinions might be most plausibly supposed to differ from those of patients less close to death. However, the result is sufficient to show that it is simply not true that all terminally ill patients will grasp at unrealistic hopes of prolonging their lives. It is important in this context that many terminally ill patients wish to shorten their lives and some of the patients we interviewed had expressed this desire. They, at least, are entitled to be believed when they said that prolongation of their lives would be, for them, an adverse effect of treatment.

The patients' unwillingness to enrol in placebo-controlled randomized controlled trials is troubling. If treatment of symptoms such as pain, nausea and dyspnoea is to advance securely, randomized controlled trials are indispensable. Because the reasons patients gave for disliking the idea of randomized controlled trials were sometimes confused or contradictory, it is possible that they did not understand this experimental design well enough to judge its acceptability. In that case, careful explanation might make placebo-controlled randomized controlled trials acceptable to dying patients. Active comparator trials appeared more acceptable to our patients and may need to be the normal design for trials in this setting. If randomized controlled trials cannot be made acceptable to the dying, a major challenge for researchers will be to design robust methods that are acceptable.

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