Respecting the autonomy of cancer patients when talking with their families: qualitative analysis of semistructured interviews with patients

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Abstract

Objectives—To discover cancer patients' views about disclosure of information to their family, their family's influence over the information given them, and their preferences for doctors' behaviour if they and their family disagree, as a complement to applied ethical theory.

Design—Semistructured interviews followed by qualitative content analysis.

Setting—Mainly urban British general practice.

Subjects—30 patients in whom cancer, excluding basal and squamous cell skin carcinomas, was diagnosed 1–7 years earlier.

Results—All subjects wished doctors to respect their views rather than those of their family, should they differ. With their consent, subjects favoured close family receiving information about their illness, all but one mentioning advantage to their family. Without such consent, six unconditionally favoured disclosure of information to their family while seven unconditionally opposed disclosure. Seventeen participants restricted their approval for such disclosure to specific circumstances. Only two participants approved of their family influencing the information that they received about their illness; all but seven wished to receive full information, the exceptions relating to information about bad prognosis.

Conclusions—Subjects favoured openness with their family but most rejected unconditional disclosure of information without their consent and their family influencing what information they would be given. They valued respect for their autonomy more highly than beneficence and considered that their own needs took priority over those of their family.

Introduction

The families of patients with cancer sometimes ask doctors to provide information to the family without the patient's knowledge or to modify the information given to the patient. In the first of these two situations the doctor is asked to breach confidentiality and in the second to tell a patient less than the truth. If such requests came from someone unconnected with the patient there would be no difficulty in deciding how to respond, but when they come from family members who have the patient's best interests at heart the situation is less clear.

Doctors' duty to maintain their patients' confidences and tell them the whole truth is not absolute. The Access to Health Records Act permits doctors unilaterally to withhold information that they think would be harmful for their patients to know.¹ The BMA² and the General Medical Council³ approve five and eight circumstances respectively in which unconsented disclosure of information is regarded as acceptable. Gilson reiterates a widely used framework by which such

ethical problems may be analysed: the principles of respect for autonomy, beneficence, non-maleficence, and justice are used to determine what course of action should be followed.⁴ In the two situations mentioned above should doctors maintain their patients' confidentiality and tell them the whole truth—respecting their autonomy above all else—or should the beneficent views of a caring family, who may have known the patient far longer than the doctor, be taken into account? Perhaps family members affected by their relatives' illness should justly have the right to access to information about it too.

The need to apportion weight to conflicting ethical principles—the problem of indeterminacy⁵—raises the issue of how such weighting should be done. Doctors seem to vary in the way that they solve ethical problems^{6–11} and possibly make judgments on a case by case basis.^{12–14} In addition, doctors and patients may have different views about appropriate standards of providing information^{15, 16} and confidentiality.¹⁷

It is therefore important to know how patients would have their doctors behave when facing problems such as these. We interviewed a group of patients with cancer in order to determine their views on what was acceptable disclosure of information to their family, whether their family should influence the information that they received, and how their doctor should behave if their views conflicted with those of their family, and to determine the reasons underlying their preferences.

Subjects and methods

After the study was approved by the local ethics committee, we searched the computerised records of a general practice covering 9000 patients to identify patients in whom malignant disease other than basal or squamous cell skin carcinoma had been diagnosed between one and seven years previously. Of the 71 patients identified, any who were too physically or psychologically ill for interview or for whom there was doubt whether they knew that they had cancer were excluded. Decisions about exclusion were left to the patients' general practitioners. We invited the remaining 51 patients to participate in our study, and 33 agreed. Two of these became ill and one could not be contacted, leaving 30 to be interviewed. The patients who participated were similar to the non-participants with respect to mean age, mean time since diagnosis of cancer, sex, marital or cohabiting status, and type of cancer.

In order to explore the patients' views in depth and to examine the reasons for these views without unwarranted prior assumptions, we used qualitative methods.¹⁸ All interviews were performed by JB, and the patients were encouraged to reply fully to questions based on the study's aims. The interviews were audiotaped, transcribed, and analysed with the "framework" system of qualitative data analysis.¹⁹ JB studied the tapes and transcripts repeatedly in order to identify

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Table 1—Main views of 30 patients with diagnosis of cancer regarding disclosure of information about their illness and predominant underlying explanatory themes

Patients' views	No of patients	Predominant explanatory themes
Disclosure of information to family with patient's consent		
Approval	30	Advantage to family
Disclosure of information to family without patient's consent		
Approval	6	Closeness of family relationships Advantage to self or family
Disapproval	7	Notions of ownership
Conditional approval	17	Disclosure to particular relatives and closeness of family or doctor relationships Advantage to self or family Type of information disclosed Personal prior cognisance of information disclosed Personal incapacity Notions of ownership
Family influencing the information given to patient		
Disapproval	28	Notions of ownership Personal need for information, either to cope psychologically or for practical purposes
Approval	2	Closeness of family relationships Thought that family would know truth anyway
Patient's views conflict with those of family		
Patient's views take priority	30	Statement or implication that such should be the case

themes in the patients' statements and their underlying reasoning. These themes generated an index, which was applied systematically to the transcripts to permit their reorganisation by category while maintaining the ability to attribute statements to individual patients. The reorganised data were then examined in order to discover how they illuminated the study's questions. This process was monitored by NB, including the examination of three transcripts in detail to check for selective use of data.

Results

Although the patients' views varied, particular preferences were supported by several internally consistent explanatory themes. These are summarised in table 1 and considered below.

DISCLOSURE OF INFORMATION WITH CONSENT

All 30 patients thought that their close family should, with their consent, receive information about their illness. Ten extended this to their relatives in general. All but one reasoned this on the basis of advantage to their family. Ten mentioned advantage to self, but in every case these considerations were closely related to advantage to family—"If your close family know, you can talk about it, which makes things easier than if you've just got to bottle everything up and are too frightened to ... say something in case you're going to upset somebody if they don't know. But if they know ... it's more open and you can discuss it better then."

However, only six participants went so far as to suggest that, even with their consent, their family had rights to information. These rights were, moreover, granted only conditionally—"I think they have a right to know, subject to my ... right to say no, if I so wish."

DISCLOSURE OF INFORMATION WITHOUT CONSENT

Three groups of opinion emerged, regarding disclosure of information to their family without their consent.

Six patients were in favour of such disclosure, mentioning closeness of family relations and advantage to self or family—"They've got to know sometime, and I've always, I suppose, got on with my children very well.... We don't really have any secrets."

"I think they should tell them, definitely tell them, and then they can know what they are going to cope with."

Seven patients were opposed to such disclosure, mentioning notions of ownership of their body, illness, or information—"I think that if I have any major problems with my body then I feel I'm the first that should be told."

The remaining 17 patients generally opposed such disclosure but mentioned circumstances when it would become acceptable. These circumstances were divisible into six non-mutually exclusive categories (see table 1).

Ten patients mentioned the closeness of the relative receiving information as being relevant, and all 10 also mentioned the closeness of family or doctor relationships—"I see [my doctor] every month, so I've got a good relationship and I would not mind him talking to [my wife] any more than she would mind if he spoke to me."

Six patients mentioned advantage to self or family—"I mean it could be affecting [my husband] so badly that he really needs to know."

Seven mentioned the type of information disclosed—"I think the doctors are only justified in talking about management and treatment without the patient's permission actually."

Eight mentioned personal prior cognisance of the information disclosed—"I don't know. But I wouldn't like it if they told him things that they hadn't told me."

Seven mentioned personal incapacity—"Well, if I was unconscious, of course, ... or very nearly unconscious."

Seven mentioned notions of ownership of body, illness, or information, all stipulating either prior cognisance or personal incapacity as preconditions for disclosure—"If it concerns my own health, after all I'm number one as far as that is concerned. So, it shouldn't be done behind my back. On the other hand, I would say, 'Yes, he'll tell you the details,' or whatever."

FAMILY INFLUENCE OVER INFORMATION

Of the 30 patients, 28 opposed their family influencing the information that was provided to themselves. Twenty mentioned notions of ownership of body, illness, or information—"No, I think I'm entitled to know everything, and it's me that it affects. I mean it does affect my family, but ultimately I'm the one that's, you know, going to be told what treatment I'm going to have, whether I'm going to get better or not."

Twenty two mentioned a personal need for information, some in order to cope emotionally—"I like to stare a nasty thing in the eye. I just find it easier to cope with and I know what I'm doing with it, whereas ... if it's all shaded over it's sort of more frightening I think."

Others wished to be able to make practical arrangements—"With my particular case, with being responsible for a daughter and for some property and things like that, I wanted, if you like, to get my house in order and I wanted to face up to the fact and know exactly how I could plan out."

Among the 28 patients who opposed their family influencing provision of information there was a concomitant desire for full information about their illness, generally for similar reasons, although three participants mentioned the impracticability of concealment. Again, personal need for information was in order to be able to cope psychologically or for practical purposes. One exception to this general desire for full information was with regard to poor prognosis: both of those who approved of family influence and five of those who opposed it wished to remain uninformed—"I like to know what it is, but no way would I ever want to know how long I've got."

The two patients who approved of their family influencing provision of information both felt that they would know the truth in any case and mentioned the closeness of family relationships.

CONFLICT OF VIEWS

All the patients made statements which implied that doctors should respect their views rather than those of their family in the event of disagreement: 11 patients made specific statements about disclosure of information, and 18 made statements about family influence over information. Statements regarding family influence over information were notable for their vehemence.

Interviewer: "Does your family have any right to control what you know on the basis they know you better than the doctor?"

Patient: "Well they might say that, ... but I mean in that, in this kind of a situation, which is a very unique situation, if you have got a background illness, then I don't think they do know you better, so, I don't think that's valid."

Discussion

The patients were unanimous in their view that their own opinions about truth telling and confidentiality should take precedence over those of their family. Likewise, all favoured information being given to at least close family, but only with their consent, all but one mentioning its benefit to relatives. Meanwhile, all but two patients rejected their family's right to influence the information that they received, mentioning notions of ownership or personal need for information. Most patients expressed a desire for full information for the same reasons, although some did not want to be told of a bad prognosis. Patients therefore wished their autonomy to be respected over and above any beneficent views of their relatives and considered that their needs should take priority over those of their family.

Patients' views were less homogeneous concerning disclosure of information to their family without their consent. Those opposed to such disclosure mentioned notions of ownership, while those in favour mentioned closeness of family relationships and advantage to self or family. For more than half the patients, however, their view about the acceptability of such unconsented disclosure depended on the particular circumstances of a situation.

Our findings offer an insight into the views of patients who knew that they had cancer in a mainly urban general practice. These can complement, but never replace, careful communication with similar patients about their wishes. We found that when patients considered that they had sufficient personal control of information, they spoke of advantage to self or others and closeness of relationships with others—that is, they looked outward. However, when they considered their loss of autonomy to be unacceptable, they spoke of ownership and advantage to self—that is, they looked inward. It remains to be seen whether these findings are representative of patients with other types of disease or patients unaware that they have cancer, or whether cancer patients' opinions alter during the course of their illness.

The principles of applied ethical theory can clarify choices but cannot offer a prescriptive solution to the question of how those choices should be made.^{20 21} Meanwhile, ethical choices are never made outside social and political contexts. Hoffmaster proposes, as one solution, a collaboration between the fields of philosophical medical ethics and ethnography, and our findings contribute to this.²² Our results show that patients' views about appropriate disclosure and provision of information may depend on details of circumstance. We found various explanatory themes underpinning those views, with differences not only between individuals for the same issue under consideration, but sometimes also between different issues for the same person. The study suggests that assumptions

Key messages

- The families of patients with cancer sometimes ask doctors to provide information to the family without the patient's knowledge or to modify the information given to the patient
- We interviewed 30 patients with a diagnosis of cancer to find their views about these issues
- While the patients favoured their family receiving information about their illness with their consent, most were opposed to their family receiving information without their consent except under specific circumstances
- Almost all the patients were opposed to their family influencing the information that they would receive about their illness
- The patients therefore wished their autonomy to be respected over and above any beneficent views of their relatives and considered that their needs should take priority over those of their family

tions about patients' views may be inappropriate, offers an insight into exploring such views, and begins to address the indeterminacy of applied medical ethics in a difficult but important area of doctor-patient communication.

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