The value of taking an ‘ethics history’

Gwen M Sayers, David Barratt, Catherine Gothard, Clive Onnie, Sunimalee Perera and Daniel Schulman
Northwick Park Hospital, London

Abstract

Objectives—To study the value of taking an ethics history as a means of assessing patients’ preferences for decision making and for their relatives’ involvement.

Design—Questionnaire administered by six junior doctors to 56 mentally competent patients, admitted into general and geriatric medical beds.

Setting—A large district general hospital in the United Kingdom.

Main measures—To establish whether patients were adequately informed about their illness and whether they minded the information being communicated to their relatives. To establish their preference regarding truthful disclosure and participation in decision making with risk attached. To establish whether they wished to be involved in CPR decision making, and if not, who should make the decision. To establish whether they knew of living wills and whether they had any advance directives.

Results—Twenty-four (43%) were inadequately informed of their illness. Forty-six (82%) said they would want to know were something serious to be found. Twenty-eight (50%) wanted to make their own decision if requiring risky treatment and 11 (20%) wanted family members involved. Thirty-one (55%) wanted to make a cardiopulmonary resuscitation (CPR) decision and five of these decisions differed from those made by the doctors. Twenty-five (45%) preferred the doctors to decide. Eleven (20%) of the patients had heard of living wills but only one had executed such a will. Seventeen (31%) of the patients wished to provide advance directives. Three (5%) did not find the history taking helpful but none were discomforted.

Conclusion—Taking an ethics history is a simple means of obtaining useful information about patients’ preferences.

Keywords: Autonomy; confidentiality; CPR decision-making; advance directives

Introduction

Patient autonomy has for some time occupied a central position in the medical-ethical arena. In recognising the importance of autonomy it is acknowledged that patients have a right to self determination in matters involving their health care and that their wishes and values ought to be respected. However, complying with the principle of autonomy has always been tempered by the recognition that some patients may prefer not to make health care choices, some do not want to hear the truth about their health, and some might prefer others to act as their proxy.

In arguing the case for respecting patient variety, Brewin’ suggested that “What we need is better communication; more explanation for those who need it, less for those who don’t; and greater empathy and understanding of the patient’s real needs, fears, and aspirations”.

This paper proposes that a simple means of addressing the issue can be found in extending the medical history to incorporate an ethics history. Such a history would inquire as to whether the patient required further information regarding his/her condition. It would inform clinicians regarding the patient’s attitude towards disclosure of information. It would explore his/her feelings as regards truth-telling and decision making, and inquire into whether he/she had any desire to participate in cardiopulmonary (CPR) decision making. Finally, it would establish whether he/she was in possession of a living will or had preference for any other form of advance directive.

Perhaps it is particularly opportune at this time to have such a measure of patient preference available, in the light of the recent adverse publicity centred on “not for resuscitation” orders in older patients. Not all elderly patients wish to make such decisions, and relatives in the UK cannot legally act as proxy decision makers. More importantly, not all elderly patients would wish their relatives to do so, and proxy predictions do not always accord with the patients’ preferences.

In America the federal government brought the patient Self-Determination Act into effect in 1991. This makes it obligatory for patients to be informed of their right to make decisions about their medical care. Nevertheless, the percentage of patients who execute advance directives is low. One of the reasons given is that patients prefer their doctors to initiate the discussion, but physicians appear reluctant to do so, although it is known that when such discussions do take place patients have benefited psychologically. Markson has suggested that the single most important barrier to such discussion is the doctor’s lack of experience. Whatever the reasons, it is felt that all patients should at least be given the chance to have such conversations.

Methods

Patients with a mental test score of >8 on an Abbreviated Mental Test were eligible for the study.
There were no age limits to entry and ages ranged from 36 to 93, with a mean of 77. However, only three patients under the age of 65 were included. Fifty-six patients (22 males and 34 females) were approached, and all consented to participate in the study. The histories were obtained by five senior house officers and one house officer, admitting the patients into either general medicine, or geriatric medicine, beds.

The patients were asked the following questions:

1. Do you know much about your illness?
2. Would you like further information?
3. If a member of your family approached us to find out what was wrong with you would you like us to tell them?
4. Do you think we should ask you first?
5. If something serious was wrong with you, would you want us to tell you (or someone else) or would you prefer not to know?
6. If you needed treatment or an operation, which was risky, would you want to know everything about it and decide what to do by yourself? If not who should decide?
7. Very occasionally patients have what is called a cardiac arrest. This means their heart stops beating. Usually we try to restart it using artificial respiration, drugs and sometimes an electric shock. Usually doctors decide what to do, but some patients prefer to decide for themselves. Would you like to make this decision? Would you like us or a family member to decide? Do you need more information before answering?
8. Some people make advance directives or living wills. Have you heard of this?
9. If so, are there any such directives that you would want us to know about?
10. Thank you for answering these questions. Do you think that discussing these issues has been helpful to you?

Results
Questioning the patients took about ten minutes and no difficulties were encountered.

Responses to the Questionnaire

Questions 1 and 2
Twenty-four (43%) patients thought they were inadequately informed of their illness and requested further information, which was provided.

Question 3
Fifty (89%) were happy with their doctor discussing their illness with relatives without prior consultation with the patient.

One patient (suffering from cancer) said her illness should not be discussed with her relatives.

Question 4
Five patients said their relatives could be told, but that they would like to be asked first.

Question 5
Forty-six (82%) of the patients said they would want to know the truth about their illness if something serious were to occur.

Four (7%) patients said they would not want to be told.

One patient would not want to be told if there was no cure.

One patient said it depended. If he had “galloping cancer” he would not want to know.

One was unsure.

Three said they would want to be told together with a family member.

Question 6
Twenty-eight (50%) of the patients said they would want to make their own decision if faced with the need for risky treatment. One of these patients stipulated that if incapacitated he would want his son to decide.

Seven (12.5%) would want to make the decision together with family members.

Two (3.5%) would want family members to decide.

Five (9%) would want to make the decision together with the doctor.

Ten (18%) would want the doctor to decide, one of whom requested his son be informed.

Two (3.5%) would want the doctor to decide in conjunction with family members.

Two (3.5%) were unsure.

Question 7
Thirty-one (55%) patients said they would prefer to make their own CPR decision. One of these said he would want a doctor to decide only if he was unable to.

Five of the decisions made by the patients differed from those made by their doctors.

Twenty-five (45%) said they would prefer the doctor to decide. None wanted their relatives to be involved.

Questions 8 and 9
Eleven (20%) patients said they had heard of living wills.

One patient said she had made such a will and the general practitioner held a copy. It stipulated that she did not want to be kept alive if there was no prospect of her recovering with a good quality of life.

Three of the patients who had heard of advance directives provided such directives in response to question 9: “If I’m ever a cabbage and on a life-support machine I would want it turned off”;

“Not for resuscitation. I don’t want to be kept going. I have been a member of the Euthanasia Society for the last six years. One has a right to decide when one wants to finish”;

and “I would not want to have active medical management if my brain was not functioning. I would not want to live if my leg was amputated as a result of gangrene.”

Four of the patients who said they had not heard of advance directives provided directives after
The value of taking an ‘ethics history’

...patients, and clinicians when faced with difficult choices, particularly those involving value judgments. It allows for a rational approach to autonomy, by taking into account the understanding that not all patients want to make decisions for themselves. After all, making a choice that a doctor, or a family member decide in place of the patient, is an alternative expression of autonomy, far removed from the paternalism that still dogs the practice of medicine.

www.jme.bmj.com
Gwen M Sayers is Consultant Physician in Geriatric and General Medicine at Northwick Park Hospital, London.
David Barratt, Clive Onnie, Sunimalee Perera and Daniel Schulman were all Senior House Officers, and Catherine Gothard was House Officer, at Northwick Park Hospital, London at the time of the study.

References
1 Angell M. Respecting the autonomy of competent patients. New England Journal of Medicine 1984; 310:1115-16.
23 Luttrell S. Living wills do have legal effect provided certain criteria are met. British Medical Journal 1996;313:1148.

News and notes
International Guidelines on Bioethics

The Council for International Organizations of Medical Sciences (CIOMS) has published a booklet, International Guidelines on Bioethics, which provides an informal listing of selected international codes, declarations, guidelines, etc on medical ethics, bioethics, health care ethics and human rights aspects of health.

The listing is published as a supplement to The EFGCP News, Autumn 2000.
For copies and other information on EFGCP publications contact: F P Crawley, Editor, The EFGCP News, Schoolbergenstraat 47, B-3010 Kessel-Lo, Belgium; fax: +32 16 35 03 69; email: fpc@pandora.be
The value of taking an 'ethics history'

Gwen M Sayers, David Barratt, Catherine Gothard, Clive Onnie, Sunimalee Perera and Daniel Schulman

*J Med Ethics* 2001 27: 114-117
doi: 10.1136/jme.27.2.114

Updated information and services can be found at:
http://jme.bmj.com/content/27/2/114

These include:

**References**
This article cites 19 articles, 7 of which you can access for free at:
http://jme.bmj.com/content/27/2/114#BIBL

**Email alerting service**
Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

**Topic Collections**
Articles on similar topics can be found in the following collections
Research and publication ethics (490)
Long term care (8)

To request permissions go to:
http://group.bmj.com/group/rights-licensing/permissions

To order reprints go to:
http://journals.bmj.com/cgi/reprintform

To subscribe to BMJ go to:
http://group.bmj.com/subscribe/