

The right to information for the terminally ill patient

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Abstract

Objectives—*To analyse the attitudes of medical personnel towards terminally ill patients and their right to be fully informed.*

Design—*Self-administered questionnaire composed of 56 closed questions.*

Setting—*Three general hospitals and eleven health centres in Granada (Spain). The sample comprised 168 doctors and 207 nurses.*

Results—*A high percentage of medical personnel (24.1%) do not think that informing the terminally ill would help them face their illness with greater serenity. Eighty-four per cent think the patient's own home is the best place to die: 8.9% of the subjects questioned state that they would not like to be informed of an incurable illness.*

Conclusion—*In our opinion any information given should depend on the patient's personality, the stage of the illness and family circumstances. Our study confirms that a hospital is not the ideal environment for attending to the needs of the terminally ill and their families.*

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Keywords: Attitude; information; physician; nurse; terminal care

The right to information is a basic right which helps define a person's freedom and dignity. It is an ethical imperative which in some countries has been enshrined in law. Within the doctor-patient relationship, the need to provide suitable information can be summarised as follows: information is a necessary element for receiving the patient's full consent and information is regarded as a therapeutic tool. The lack of information can lead both patients and relatives to unsuitable behaviour and unnecessary concern, which may generate stress in the therapeutic interaction between doctor and patient.¹

A terminally ill patient may be defined as a critically ill patient whose death is considered inevitable within a short period of time. The reason for informing terminally ill patients of their illness is to provide them with the information

necessary for internal mechanisms (psychological and emotional) to influence their adaptation to reality. Communication with the patient is not only an important part of the therapy but, in many cases, the only component.

However, the old dilemma soon arises: has a patient a "right to information" because of any uncertainty he might feel when confronted with the unknown or has he a "right not to know" because of the anxiety which such knowledge might provoke? Patients only need to be informed of what they want to know and their mechanisms of defence or denial should be respected. Sometimes, withholding information can do less harm than giving the information badly.

As Stuart and Byron² point out, the information should be transmitted by the person who has it, normally the doctor, although other members of the health care team or even family members may be better at giving it.

The purpose of this study was to analyse the attitudes of medical personnel (doctors and nurses) in primary and secondary health care towards terminally ill patients and their right to be fully informed.

Material and methods

Of the 810 doctors and 1,280 nurses comprising the total population of health care professionals in Granada (Spain) a proportional random sample of 375 (168 doctors and 207 nurses) were asked their opinion on their attitudes to the treatment given to the terminally ill. The sample comprised 165 males and 210 females aged between 20 and 64 (mean age 34.96, SD 7.83 years). Of these, 250 worked in hospitals and 125 in primary care centres. The subjects had worked for an average of 11.09 years (SD 7.44), varying from 1 to 37 years.

The study consisted of a self-administered questionnaire composed of closed questions: 56 items were structured into two parts: personal and sociodemographic variables, and attitudes towards the terminally ill.

Statistical treatment of the data was performed using the following BMDP (biomedical computer

Table 1 Replies concerning attitudes about working with terminal patients and concerning the information which should be given to the terminally ill patient

	Strongly agree N (%)	Agree N (%)	Disagree N (%)	Don't know N (%)
I would not mind working with the terminally ill	44 (11.8)	136 (36.5)	160 (42.9)	35 (8.8)
I feel personally prepared for caring for the terminally ill	56 (15.1)	165 (44.3)	65 (17.5)	89 (23.1)
I feel professionally prepared for caring for the terminally ill	74 (19.8)	207 (55.5)	33 (8.9)	61 (15.8)
If I had an incurable illness I would prefer to know	184 (49.3)	88 (23.6)	33 (8.9)	70 (18.2)
The truth helps the terminally ill accept their illness	48 (12.9)	116 (31.3)	90 (24.1)	121 (31.9)

Table 2 Who should give information to a terminally ill patient?

	N (%)
Doctor	128 (34.1)
Health care team	62 (16.5)
Family	3 (0.8)
Both health care team and family	176 (46.9)
Don't know	6 (1.6)

Table 3 Information on prognosis should be given to the terminally ill

	N (%)
In all cases	35 (9.3)
Only if the patient will understand and accept the situation	301 (80.3)
Depends on family responsibilities	26 (6.9)
Never	8 (2.1)
Don't know	5 (1.4)

programs): simple analysis of frequencies (number and percentage) and association between variables using a Person's statistic (χ^2) and probability ratios. Association was considered to be significant when $P \leq 0.05$.

Results

Table 1 shows the sample distribution of frequency responses for those variables which were most informative about people's attitudes towards the terminally ill and also summarises the findings for the variables related to whether the terminally ill should be informed of their illness. The results show that 72.9% of the subjects interviewed would like to be informed if they had an incurable illness, 8.9% would not like to be informed and 18.2% do not know. A high percentage (24.1%) do not think that informing the terminally ill would help them face their illness with greater serenity. Although 59.4% think they are person-

ally prepared to treat and help the terminally ill and 75.3% think they are professionally prepared for caring for the terminally ill, 46.9% think the information should be given to a terminally ill patient by the health care team in conjunction with the family (Table 2).

Most (80.3%) think that information should be given only if the patient will understand and accept the situation (Table 3). Eighty-four per cent think the patient's own home is the best place to die, 6.5% think that hospital is the best place, 1.1% a rest home, and 8.6% do not know. Our study showed that 96.5% of all health care personnel think they should receive special training in caring for the terminally ill, while 1.9% disagree; 1.6% did not answer this question.

Table 4 shows some of the statistically significant associations between variables. A greater percentage of doctors than nurses consider that the information given to the patient will help him or her face up to the situation (52.7% compared with 36.9%). Finally, although there is a large majority which considers that home is the best place to die, more nurses than doctors (9.2% compared with 3.0%) think that hospital is best.

Discussion

Palliative care is not just a matter of symptom control but also of good communication, and this skill is fundamental to the effective development of the doctor-patient relationship.³ Information concerning diagnosis appears to be beneficial in establishing satisfactory relationships and communication between patients, relatives and staff.⁴ In a study of cancer patients, Kelly and Friesen⁵ showed that 89% would prefer to know the exact truth. Blumenfeld *et al*⁶ obtained similar results. However, many doctors feel the truth may do

Table 4 Some statistically significant associations between the variables sex, age and profession and other variables in the study

	χ^2	df	P
Profession- I feel professionally prepared to care for the terminally ill	13.14	2	0.0014
Profession- The truth helps the terminally ill patient	12.17	2	0.0022
Sex- The truth helps the terminally ill patient	20.77	2	0.0000
Age- I feel professionally prepared to care for the terminally ill patient	11.41	2	0.0033
Profession- What do you think is the most suitable place for a terminally ill patient	9.61	3	0.0221

more harm than good if the patient's emotional state or wishes are not known exactly. They feel that if a patient does not wish to know his diagnosis he will not ask about it and that information should only be provided if the patient asks for it specifically and has good reason to know it. Data collected by Centeno and Nuñez⁴ showed that 68% of patients had not been informed of their diagnosis; 60% of this group had a high degree of suspicion of their diagnosis, although 42% of non-informed patients did not want to receive more detailed information.

Central question

It is our opinion that any information given should depend on the patient's personality, the stage of the illness and family circumstances. It should be revealed slowly and should maintain some level of hope. The central question is not whether the patient should or should not be told the truth, but rather how much information he should be given, based on the knowledge he has of his illness, his degree of understanding and his probable response to the information. In Spain, Health Law (Ley General de Sanidad) establishes the obligation to provide information to relatives. However, we interpret this to mean that except in very specific circumstances (for example, the patient does not wish to know his prognosis), it is the patient who is the arbiter as to what should be known about his pathological process and who should be given this information.

Doctors prefer to channel information through the family who, since they know the patient better, can adapt or withhold any information. However, care should also be taken when informing the family since they too frequently go through phases similar to those that the patient himself undergoes, ranging from denial of the circumstances to anger at the medical staff. Blackhall *et al*⁵ suggested that doctors should first ascertain whether the patient prefers to make decisions for himself or whether he would prefer his family to accept such responsibility. However, there is controversy about how much information should be provided concerning prognosis and treatment. It is very important for family members to receive unambiguous information about the patient's condition, prognosis and comfort. Informing relatives demands much skill and sensitivity and care must be taken to balance the patient's right to confidentiality and the family's need for information.⁸

Pfeifer *et al*⁶ studied the views of 43 primary care doctors and 47 outpatients to ascertain their beliefs, attitudes, preferences and expectations regarding discussions on terminal care. They found

that the patients preferred frank and honest discussion and were less preoccupied with maintaining hope than their doctors. The patients wanted the doctor to play a central role in the discussions and both parties noted the impact on the patient-physician relationship of these discussions.

Teaching about death, dying, bereavement, and the issues surrounding terminal care is regarded as inadequate in several countries.¹⁰⁻¹³ Doctors have some training in the pharmacology of symptom control, but little in the art of communicating with the seriously ill or dying¹⁰⁻¹⁴ despite the fact that such skills can be taught.¹⁵

The highest percentage of medical personnel prepared to work with the terminally ill belonged to oncology (63.0%) and primary care personnel (53.6%), while only 39.6% of those working in surgical specialties felt the same. Nurses felt themselves more capable and showed less distress than doctors in this respect. Among doctors, those working in specialist fields felt more adequately prepared than general doctors. Pijnenborg *et al*¹⁶ found that general practitioners took fewer decisions about the end of life than hospital doctors and doctors in nursing homes. Differences in the work situation among the group of general practitioners contributed to differences in the number and type of decisions taken concerning the end of life, as well as in the decision-making process.

Palliative care

The professionals who considered that the terminally ill should be kept informed were precisely those who had had more experience in providing palliative care; Rea *et al*¹⁷ obtaining the same results for oncologists. It is clear that direct contact with the terminally ill encourages the idea that they should be told the truth although it seems there is a risk of excessive paternalism on the part of the doctor.

Society in general does not think that the home is the most suitable place for caring for the terminally ill and associates hospitalization with safety and better care. Davidson¹⁸ stated that 90% of deaths occur in hospital, while a recent study by Eve *et al*¹⁹ found that 46% of deaths occurred at home, 26% in a palliative care unit and 23% in a hospital. The fact that death frequently takes place in hospital reflects the opinion that hospitals are better equipped to cope with death.

In our opinion a hospital environment is not the ideal for attending to the needs of the terminally ill and their families, both the medical staff and the families feeling the frustration of the situation. This is in agreement with the results of the questionnaire which demonstrates that most doctors

think that patients would be better off dying at home. Indeed, home care for the terminally ill is increasingly becoming the model because of the advantages it offers.

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