

ARTICLES

Patients’ perspectives on medical information: results of an informal survey

KAVITHA RAJA

Department of physiotherapy, Manipal College Of Allied Health Sciences, Manipal Academy of Higher Education, Manipal 576 104 INDIA
 e-mail: kavitha.raja@manipal.edu

Abstract

The autonomy of patients in making medical decisions is increasingly recognised globally, but is not fully adhered to in India. Information is the first step for a patient to be able to make a decision on his or her health care. The objective of this survey was to ascertain patients’ perspectives on the amount of information given to them by health professionals. The results of interviews with 222 patients show that perspectives vary, often according to the diagnosis. The amount of information given and the manner in which it is given are often not acceptable to the patient.

It is commonly accepted that patients have a right to the unbiased opinion of the health care professional. Based on this information, they have the right to choose treatment, refuse treatment, or seek another opinion. This is the principle of autonomy championed by Beauchamp (1). There is, however, the question of too much or confusing detail, which may be counterproductive or harmful to the patient (2). In such a context, it may arguably be necessary for the health provider to withhold information in the best interests of the patient.

However, are providers justified in withholding information only because it is too painful and they are unable or unwilling to handle the situation?

This study’s objective was to evaluate if providers gave patients adequate information regarding their health status, treatment options and prognosis. The study was done by means of informal interviews. This method was chosen in order to eliminate or alleviate the anxiety that respondents might experience about reporting the perceived faults of their providers and if this would adversely affect their continued care.

The subjects were selected by non-random sampling if they met the following two criteria: a chronic or debilitating condition for less than six months, and prolonged contact with two or more health providers. Patients who were unwilling to answer questions or were belligerent towards their health providers were excluded. The sample size was 250. The study was done during 2003-2006 in 14 towns and cities in southern India.

The identified subjects were informed that they would be asked several questions, their responses would be used for academic purposes, and their identities would not be revealed. Of the 250,

28 subjects withdrew before completing the interview. They were excluded from the study. A total of 222 patients or parents were eventually interviewed. Responses were obtained on 1,255 professionals (see table).

The questions in the interview explored the following: Did the patients know their diagnosis? How had they been informed, and who had told them? What did they know of the long-term prognosis? Were treatment options outlined and their relative merits explained? Were they offered a second opinion? If they mentioned a second opinion to the provider, were they encouraged to pursue it without malice? Did the provider sit with them and discuss the details in an unhurried manner in language they understood? Who were the professionals who gave them the most information? Were they empathetic but professional, or brusque?

Characteristics of patients and their providers

Diagnosis	Number of patients	Providers’ professional status						
		Dr*	Nrs†	PT‡	OT§	MSW_	RT¶	Psy**
CP	35	35	-	35	35	7	-	1
SCI	76	76	15	76	10	-	-	-
Cancer	125	125	75	-	-	27	30	-
Multiple trauma	6	13	-	-	-	-	-	-
Autism	2	2	-	2	2	-	-	2
Learning disabilities	15	15	-	-	10	-	-	15
Down’s syndrome	9	9	-	1	-	-	-	-
HSMN	2	2	-	1	-	-	-	-
HIV+	156	156	120	-	-	19	-	4
DMD	7	14	-	2	-	-	-	-
MS	15	15	-	4	5	-	-	-
DM	85	102	80	-	-	4	-	-
CVA	50	50	-	27	9	10	-	-
LBA	29	45	-	29	-	-	-	-
Neck pain	23	37	-	23	-	-	-	-
OBPP	8	8	-	8	-	-	-	-
Total	222	704	290	208	71	67	30	22

NOTE: * physician; † nursing staff; ‡ physiotherapist; § occupational therapist; _ medical social worker; ¶ respiratory therapist; ** psychologist

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Fifty-seven patients had not sought a second opinion because the diagnosis was straightforward and they did not think another opinion was necessary. This included 20 patients with diabetes mellitus, 10 patients with cerebro-vascular accident, all the subjects with AIDS, and the parents of one child with cerebral palsy.

Several patients with diabetes mellitus, cerebro-vascular accident, cerebral palsy and all patients with an HIV positive status were attending specialised centres. They were, without exception, satisfied with the information they were given and said their interaction with multiple providers, including medical social workers, was adequate. These centres used group sessions for educational matters.

Parents of the children who were identified for this survey said, without exception, that the primary physician told them that "Something is wrong with your child" and they were referred to a specialised centre. When this was done parents generally assumed that facilities for a cure were available at the referral centre. Some of the centres had adequate facilities for educational material whereas others sent the parents from pillar to post in search of clear answers. They often had difficulty pinning down a professional to a definite opinion. Some of the typical responses were: "I am not God" and "Who knows how much he/she can improve." Parents perceived these as evasive or insulting responses. One parent of a child with cerebral palsy felt that she was being blamed for her child's condition when one professional told her, "This is what happens when you marry your relatives."

Subjects with chronic pain syndrome felt that they were never given a clear answer about their diagnosis or prognosis. The doctor frequently referred them to a physiotherapist, often with comments like, "Now the ball is in their court." The patients also felt that though they spent an inordinate amount of time with physiotherapists, these professionals were not forthcoming with their opinions. Often the response to questions was, "You must ask your doctor," or "What has your doctor said?" The patients felt this was a ploy to avoid telling them the truth, or the professionals were afraid of the repercussions if their opinion turned out to be not similar to that of the doctor. Most patients had a similar opinion about nurses and said they knew more than they were willing to tell.

Patients with cancer said that more often than not the diagnosis and prognosis were conveyed to the relatives. The relatives were told in hushed tones, in the presence of the patient, to meet the physician later. This indicated to the patient that something was seriously wrong and it caused a lot of anxiety. The same was the case with HIV positive subjects. In terms of a second opinion and clear information about treatment options, the patients felt they were rarely spoken to on an equal basis. The physician's attitude was one of superiority and this made the patients hesitant to ask questions.

Inadequate interaction

The paradigm shift in medical decision-making from the patient as a beneficiary to the patient as an equal partner is

fairly well established in the West. Although the trend appears to be growing in India, we have a long way to go. Involving the patient as one of the primary decision makers involves informed consent. This is often a hurdle in India due to language and literacy barriers.

In this study, the largest number of professionals, after doctors and nurses, was physiotherapists. This is due to the nature of the diagnoses. Five of the patient groups spent the larger part of their inpatient stay with the rehabilitation services of physiotherapists and occupational therapists.

One reason for the inadequate interaction between health care providers and patients, according to the patients, was that doctors handled more patients than was reasonable, which made them harried and overstressed. The ideal situation would be multidisciplinary teams with a designated case manager who would be responsible for a large part of the interaction with patients and families. Would nurses be able to fill this role in India?

Often providers other than doctors are reluctant to talk due to an assumed hierarchy, which implies that only the senior consultant has the right to communicate information. "You have to ask Dr. ..." is a common refrain in our hospitals. Why is this so? Other professionals often have a better rapport and more time to spend with the patients than the senior consultant. Besides, the patient is reluctant to ask questions to the senior doctors due to the professional and social "distance" between them. So even a well meaning senior doctor ends up not giving enough information to the patient. Can't this important part of treatment be delegated?

Professionals dealing with patients are also uneasy when the details of the condition have not been conveyed to the patient. So when they are asked questions, they may say, "I am not sure, you must ask your doctor." Patients often perceive these responses as evasive and think the evasion is due to a dire prognosis. They may also develop a negative attitude about these professionals' level of knowledge. Patients who were able to speak English or the doctor's mother tongue and were well educated were given more information and were happier with the interaction than others. Patients were wary of suggesting that they should get a second opinion in case this insulted their primary physician. It is necessary for the doctor to suggest this option. The patient may or may not take it up. It is absolutely necessary for a patient to be considered as an equal partner for him/her to be empowered in making decisions about treatment options. It is the duty of all professionals to ensure that the patient is thus enabled. Autonomy in health care decisions is a right and not a privilege.

References

1. Gillon R. Ethics needs principles -- four can encompass the rest-- and respect for autonomy should be "first among equals". *J Med Ethics* 2003; 29:307-312.
2. Francis CM. *Medical ethics*. New Delhi: Jaypee; 1993.