
Truth-telling and patient diagnoses

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Abstract

How do physicians handle informing patients of their diagnoses and how much information do patients really want? How do registered nurses view both sides of this question?

Three questionnaires were constructed and administered in a mid-size hospital in New York state. Physicians and nurses underestimate the number of patients who want detailed information. Patients who earn more than average, have a college education, and who are under age 60 are more likely to want information, and state that their physician should give it to them. Only 42% of physicians state that patients want a detailed description of their diagnosis and treatment options. Physicians educated outside the USA appeared to be more likely to change their criteria for informing patients and, along with American-educated nurses, were more willing to participate in formal discussions of the issue.

Physicians should comply with the wishes of patients for information and include them in the team deciding on diagnosis and treatment.

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Introduction

Truth-telling in medicine is a broad area and often encompasses several ethical issues. These issues include the right of patients or their families to receive information about their diagnosis and illness. The physician, on the other hand, must balance his or her obligation to tell the truth against the imperative of "do no harm". Questions often arise concerning how much truth to tell. When, if ever, is a physician justified in withholding information? Can too much information be harmful? These conflicts between benevolent paternalism on the part of the physician and an increasing interest on the part of the patient to preserve autonomy are not easily resolved.

This paper describes our research into the area of truth-telling. Our goals were to gather information about what patients want to be told about their illnesses. We were also interested in exploring the standards used by physicians when making decisions about information given to patients. Our third goal was to investigate the opinions and observations of nurses on these topics. Previous studies indicate that the majority of patients want information about their diagnoses.¹ Data are also available concerning the attitudes and policies of physicians.^{2,3} These studies were done several years ago and need to be updated.

Methods

Three research questions were used in this project. They were:

1. How much information do patients want to know concerning their diagnosis and treatment?
2. What individual policies are used by physicians when deciding to inform patients of their diagnosis and treatment options?
3. Do registered nurses feel that the situation is handled adequately?

Three populations were examined in this study, patients, physicians and nurses. The administration of an acute care hospital agreed to assist us. This gave us access to the three groups in the same facility. The hospital is a 295-bed, acute-care facility located in the mid-Hudson valley of New York state.

The surveys consisted of three sets of questionnaires with covering letters explaining the project and the participant's part in it. One set was made available to patients visiting the same day-outpatient facility or arriving for pre-admission workup at the hospital. Ten thousand and seventy-seven patients came through this department during this period. Questionnaires were available at the clerk's desk to adult patients over a three-month period. Participation was voluntary. No attempt was made to identify any patient. It was made clear in the covering letter that the survey was not connected to the patient's reason for visiting the hospital or to his or her own diagnosis. Surveys were used in the study only if they had been completely filled out.

A second questionnaire was given to physicians with admitting privileges to the hospital. The surveys were distributed and collected at medical division meetings over the course of a year. As with patients, no attempt was made to identify individual physicians. The physicians were asked to address the problem of informing a patient with a poor prognosis.

The third questionnaire was given to the registered nurses on the staff of the hospital. As with the other two components of the project, this survey was voluntary and anonymous. Participation of the professional nursing staff was judged vital to the project. Nurses must deal with the consequences of physician policies concerning this topic, with both the patient and with his family. The nursing questionnaire was used as a control on the patient and physician data. Were nurses seeing consistencies or inconsistencies between what

patients wanted and what policies physicians were following?

Data was examined statistically for consensus within each group and for similarities in consensus between the three sets of questionnaires. Data were also examined for possible correlations between demographic information on each population and the possible consensus determined for each group.

Results

Results are presented in tabular format, listing common questions for patients, physicians and nurses. Descriptive percentages are given along with some relationships between demographics and opinion responses. Statistical significance of these relationships was tested by the χ -squared statistic and logistic regression analysis. The answers to selected questions for the three groups were then compared to each other (z-tests for the difference between two proportions).

PATIENTS

Results for those patients choosing to participate can be seen in table 1. The vast majority of patients stated that they want to know about their condition (99%). They also thought that physicians had an obligation to inform patients of their condition (99%), and they would want to be told if they had a life-threatening illness (97%).

Most of the participating patients (95%) also agreed that if patients are informed of their illness and are active in their treatment, the course of the disease is easier and the outcome is better. However, only 72% personally would want to be told all of the details themselves. A higher percentage (85%) would want their family members to be informed of their exact condition.

There was a statistically significant relationship between age, income and amount of education, when compared with the amount of information a patient wants to be told by physicians. A higher percentage of those with higher income want to be told details. Of those participating patients making \$41,000 or more per year, 81% wanted details, compared to a range of from only 62% to 71% of those in the smaller income categories, ($p = .06$).

If patients were over 60 years of age, only 61% wanted to be told all details, compared to a range of from 73% to 82% of younger age groups ($p = .02$). Those with a college education or more had a higher percentage (84%) wanting to be told details compared to 62% of those with high school or less ($p = .00007$).

The above relationship between age and wanting to be told may be due to the patient's education rather than to age as such because age and education were highly related to each other ($p = .00001$). As one might expect, a higher percentage (range

Table 1 Responses for patients (and on similar questions for physicians, and nurses)

Question	Answer	Patient	Physician	Nurse
Patients have right to know about their condition	Yes	99%		99%
Physicians have obligation to inform patients of condition	Yes	99%		100%
I want to be told of serious, life-threatening diagnosis	Yes	97%		
Told how much on illness and treatments	All details	62%	39%	29%
	General terms	28	57	60
	Both (= details)	10	3	11
Want family informed of exact condition	Yes	85%	58%	33%
	Sometimes		40	67
If patient is informed and active participant, better outcome results	Yes	95%	76%	83%
	Sometimes		23	17
Patient age	18-30	11%		
	31-40	16		
	41-50	23		
	51-60	17		
	Over 60	33		
Patient income	Below \$20 000	17%		
	\$21 000-40 000	35		
	\$41 000-60 000	18		
	Over 60 000	18		
	No answer	12		
Patient education	Grade school	4%		
	High school	50		
	College	32		
	Postgraduate	11		
	No answer	3		

N=337 patients with percentages calculated on 326 to 331 who answered any given question.

N=72 physicians with percentages calculated on 66 to 71.

N=66 nurses with percentages calculated on 60 to 66.

from 67% to 69%) of the various older age categories had only a high school education or less, compared to a range of from 39% to 45% for the younger age categories with only a high school education. However, when the relationship between education and wanting to be told details was examined for each age category (multivariate cross tabulation), the same trend appeared for each age, that is: those with more education want to be told more. The role of education was confirmed by a logistic regression analysis. Education level was the first variable entered into the prediction equation ($p < .001$) and resulted in an estimated odds ratio of 3.1. Knowing a patient's educational level increases the odds of knowing whether a patient wants details about the illness by 3.1 times. Adding a patient's age or income category did not increase prediction at the $p < .05$ level, and thus they were not added to the regression equation.

There was no significant relationship between the number of physician contacts in the last year and wanting to be told all details. There was a statistically significant relationship ($p = .0001$) between wanting family members to know one's exact condition and patient age. Of those over 60 years old, 94% want family to know details, compared to only 68% of those aged 18 to 30. Intermediate ages had intermediate results ranging from 73% to 88%. Logistic regression analysis confirmed that neither education nor income were related (not significant at $p < .05$) to this variable.

PHYSICIANS

Approximately 90% of the physicians attending department meetings completed the questionnaire. This represents 75% of the physicians at the facility. Results for questions asked of both physicians and nurses are in tables 1 and 2. Most physicians reported that they inform patients of the major implications of their diagnosis and treatment; 24% said they inform patients 50 to 90% of the time; 39% said 95 to 99% of the time, and 37% said they inform 100% of the time. There was no relationship between the answer to this question and physician age or country of medical school.

Only 42% of physicians said patients want to be told all details about a serious illness. Fifty-seven per cent said patients want to be told only in general terms and one per cent said patients want no information. There was no relationship between the answer to this question and the physician's age or country of medical school. On a related question, 58% of physicians stated that patients wanted their family informed of the details compared to 40% who said that this was true only sometimes. Thus, both physicians and patients indicated a higher percentage of patients wanted family informed than wanted to be informed themselves.

There was a difference among the specialties in the belief that patients want to be told all details. The groups that were more likely to say that patients want details explained to them (over half in each group) were from surgery, pulmonary medicine, gastroenterology and neuropsychology. For

the other physician specialty groups, half or less thought patients want all details.

Younger physicians were significantly more likely ($p = .07$) to have had formal training in ethics compared to those who are older. Of those aged 29 to 39, 67% said they had formal training in ethics, compared to 34% of those aged 40 to 49, and 32% if age 50 and above.

A relationship was found between graduating from a US versus a non-US medical school in respect of the answers to three questions. Of those graduating from US medical schools, 74% agreed that an informed patient is a better patient, compared to 96% of those from non-US schools ($p = .04$). Only 22% of US school graduates said their strategy about informing patients is probably or certainly likely to change, compared to 52% of non-US school graduates ($p = .02$).

Only 42% of US school graduates were interested in participating in structured discussions of this subject compared to 79% of non-US graduates ($p = .01$).

REGISTERED NURSES

Responses to questions for nurses are in tables 1, 2 and 3. An adequate number of responses were obtained from nurses to evaluate the research questions of the study. Nurses also thought that patients have a right to be told everything concerning their illness (99%) and that physicians have an obligation to inform the patient (100%). However, 60% believed that patients only expect general explanations of their problems. Only 46% of nurses said they had received formal training in medical ethics, and 79% were interested in participating in structured discussions of medical ethics. There was a relationship ($p = .02$) between the age of a nurse and interest in participating in such discussions. Only 63% of nurses age 21 to 40 want discussion compared to 90% of nurses age 41 to 57.

Differences in views among groups

There was a statistically significant difference ($p < .0001$) between the percentage of patients who want to be told all details (72%) and of nurses who said patients want to be told all details (40%) (z-test for the difference between two proportions). There was also a difference between patients (72%) and physicians (42%) concerning details ($p < .0001$). There was no difference between nurses and physicians on this question.

Nurses and physicians did not agree on whether patients want family notified of details of their illness. Whereas only 33% of nurses said this was always true, 58% of physicians thought it was always true ($p < .001$). On this question, more nurses stated that patients sometimes wanted family informed (67%) compared to physicians (40%). Very few of either group said patients did not want their family told.

When asked if they would be interested in participating in structured discussions of this subject, 79% of nurses answered "Yes" compared to only 52% of physicians, $p < .001$.

Table 2 Additional responses of physicians (and on similar questions for nurses)

Question	Answer	Physician	Nurse		
Informs patients of major implications of diagnosis and treatment	50–85% of time	8.5%			
	90%	15.5			
	95%	19.7			
	97–99%	19.7			
	100% of time	36.6			
How often make exceptions to rule on informing	0% (never)	36.8%			
	1% of time	14.7			
	2–5%	22.0			
	10%	17.6			
	15–95% of time	8.8			
Factors most commonly included in top 5 which may influence decision to inform patient	Emotional stability	Top 5/ 51%	First 11%	Top 5/ 74%	First 30%
	Improve compliance	44	4	53	6
	Age	33	24	30	15
	Patient requests diagnosis	33	8	62	20
	Prognosis	28	3	45	2
	Acceptance of therapy	24	6	47	5
	Medical sophistication	24	4	9	2
	Harmful to outcome	19	3	18	2
	Length of survival	14	1	26	3
How did you acquire strategy for dealing with informing patients (% ranking in top 7)	Other	45.8%			
	Clinical training	13.9			
	Medical school	12.5			
	Personal factors	8.3			
	Experience	8.3			
	Family, friends	2.8			
	Commonly accepted	1.4			
Received formal training in medical ethics	Yes	41%		46%	
How likely is strategy of informing patients to change	No possibility	9%			
	Very unlikely	30			
	Unlikely	30			
	Probably	26			
	Certainly	6			
Interested in participating in structured discussion of this topic	Yes	52%		79%	
If you were a patient, would you want to be fully informed	Yes	100%		100%	
When patient's death is expected outcome, you feel that (ranked first)	Best therapeutic alternatives have been followed	86%			
	Medical profession has failed this patient	2			
	This is a personal failure	4			
	None ranked	8			
Medical specialty (percentage of sample)	Internal medicine	19.4%			
	Surgery	18.1			
	Neuropsychology	9.7			
	Family practice	8.3			
	Plastic surgery	5.6			
	Cardiology	4.2			
	Physical medicine	4.2			
	Gastroenterology	2.8			
	Pulmonary	1.4			
	Unknown	26.4			
Country of medical school	USA	62%			
	Other	38			
Physician age	29–40	31%			
	41–50	39			
	51–60	19			
	Over 60	3			
	No answer	8			

Note: N=72 physicians. Percentages usually calculated based on number answering question, ranging from 66 to 71 for opinion (non-demographic) questions.

Table 3 *Additional responses of nurses only*

Question	Answer	Nurses
Do nurses favour patients with poor prognosis being informed	Yes	97%
	No opinion	3
If prognosis is poor have you found physicians	Inform	31%
	Do not inform	2
	No consistent policy	67
If prognosis is poor, how often are you in conflict with physician re: informing patient	Frequently	8%
	Sometimes	79
	Never	13
Nurse's specialty area	Medical	22%
	Surgical	25
	Critical care	33
	Emergency	20
Nurse's education	Diploma	29%
	AS	43
	BSN	22
	Masters	6
Nurse's age	21-30	7%
	31-40	35
	41-50	32
	51-57	12
	No answer	14

Note: N=66 nurses. Percentages usually calculated based on number of nurses answering question, ranging from 60 to 66.

There was not a significant difference between the percentage of nurses (83%) compared to physicians (76%) who thought that patients as active participants produce an easier course of treatment and better outcome.

Discussion

The percentage of patients participating in the study is low and may not represent the patient population as a whole. Patients who participated consistently responded that they have a right to know their condition, that they expect physicians to inform them and that they want to be informed if they have a life-threatening illness. Similar results have been reported for patients with serious illness⁴ and, specifically, in patients with ovarian cancer.⁵ In every age group, the more education patients have, the more they wish to be told. This description applies whether the patients see their doctor infrequently or have a chronic illness necessitating frequent physician visits. The older patients are, the more they want their family to know details of their condition. A recent study in Japan also found education to be a determining factor.⁶

About a quarter of the physicians state that they inform their patients between 50% and 90% of the time. Over half of the physicians inform their patients in general terms of their illnesses but not in detail. Less than half of the physician participants in the study feel that patients want to be told all the details of their condition. These findings are in contrast to two studies that found 98% and 90% of physicians gave cancer patients specific information about their condition.^{7,8} All physicians participating in this study wished to be informed of a

life-threatening illness if they were the patient. A similar study of Alzheimer's disease found that 71% of those physicians wanted to be informed.⁹ The physicians in that study informed their patients about 40% of the time. In the current study, internal medicine and family practice are two specialties which were also in the earlier study.

Somewhat more than half of the physicians say that patients want their families informed of the details of their condition. Physicians and nurses both comment that this depends on the patients and their intrafamily relationships. One physician commented that he communicates to families "a majority of the time when (the patient is) married, less often when young, single, divorced, or separated". It should be noted that patients appear to want someone to know the details of their illness, even when they decline details themselves.

One physician noted that he found it difficult to rank-order any factors that would affect his policy of informing patients. Several others commented that their deciding factor was the patient's request not to be told. Other factors mentioned were the golden rule and intuition. One nurse commented that "some physicians have a difficult time telling a patient with a poor prognosis information concerning their condition". More non-US than US-educated physicians indicated a willingness to change their policies and to participate in structured discussions of this aspect of medical ethics. A doctor commented that "ethically I must inform all patients, legally I would be insane not to"; another said that "regardless of the factors mentioned, patients deserve to know as much as they want".

Physicians and registered nurses generally agreed on the items of the survey. They did, however,

greatly underestimate the number of patients who want to be fully informed of their illness. Also, fewer nurses than physicians felt that patients wanted their family informed. In general, nurses were more willing to participate in formal ethical discussions than physicians.

We have demonstrated statistically significant data through this study, but what does the data imply for patient care? Greater efforts should be made to consult with patients about their condition and medical options available to them. This is supported by several other studies.^{6 10 11} Patients should be informed of their right to information and invited to decide about the amount of information they require in order to give a free and informed consent. Health care providers regularly underestimate the information that patients want concerning their condition. In general, the more educated a patient, the more details he requires. If the patient's family relationships allow, the physician should make a specific effort to involve the family in discussions of the patient's condition, especially if the patient is elderly. Physicians' and nurses' participation in formal discussions of these subjects may facilitate changes in physicians' policies.

We recognise that the physician has an obligation to avoid harming the patient. If the physician believes that informing the patient can cause harm, he will have a moral dilemma involving patient autonomy and possible harm. We feel that violating patient autonomy is a serious matter and should be done cautiously and rarely. Paternalistic decisions made by a physician must be justified and made on medical grounds only. Decisions made to avoid possible social or psychological harm to the patient are beyond the scope of medical expertise.

Perhaps the comment of one physician sums up the feelings of many participants in this study: "I'm not the God of this patient, just a technician with an education, despite society's view of doctors' compassion, who does the best he can".

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