

Examining patients' preferences for participation in clinical decision making: the experience in a Latin American COPD and cancer outpatient population.

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Abstract:

Purpose: Our primary objective was to determine what patients wanted to be told about their illness, and whether there might be differences between patients with either cancer or advanced COPD. A second objective was to determine how these patients envisioned their participation, or lack thereof, in the treatment decision-making process.

Methods: Subjects were eligible for this prospective study if they were attending the oncology or pulmonary outpatient consultation services at the British Hospital or the Sanatorio Güemes Private Hospital in Buenos Aires, Argentina between June 2009 and May 2010. Patients have a diagnosis of a primary malignancy or severe COPD (Gold III—IV).

Results: 99 patients were recruited. 44 had a diagnosis of COPD and 55 patients had cancer. Seventeen of the patients expected their health to improve in the future, but a significantly higher proportion of patients with malignant disorders expected to get better in the near future as compared to those with COPD (98.2% vs. 62.8%, $p < 0.001$). Most study participants expressed a desire to receive all the information available about their condition, including potential side effects of treatment and chance for cure.

A majority of the participants expressed a preference for making treatment decisions in collaboration with their physician (40.4%)

Conclusions: While they considered the role of their families relevant, and wanted information to be shared so that family members might participate in decision-making, they did not want their families to have a right to withhold information, make final decisions.

Introduction:

It is generally accepted that patients prefer to be told the truth by their physicians regardless of the patient's gender, ethnicity and place of residence. In some hospitals, however, the practice of partial truth-telling is frequent with an existing 'norm of nondisclosure' practiced by many physicians, particularly those caring for the elderly or for patients with ultimately fatal disease.^(1,2) Furthermore, results from several studies reveal that many physicians avoid the enumeration of statistics or the declaration of chances for decreased survival when describing disease processes or during discussions of prognosis.⁽³⁾

There may be several reasons for variations in physician truth-telling behaviors, probably related to differences in ethics and values regarding principles of autonomy, obligation, duty, *primum non nocere*, and recognition of one's social responsibility to avoid deceptive practices. Variations in patients' desires for truthful disclosure may depend on patient age, medical history, disease type, severity of illness, likelihood of disease-related death, influence of family members and social behavioral expectations

Ethnicity, especially in culturally diverse health care environments such as the United States, may also contribute to patients' perceptions of truthfulness. Results from at least one study revealed that elderly Korean-Americans and Mexican-Americans were less likely to believe they should be told the truth about diagnosis and prognosis in case of serious illness than their European-American and African-American counterparts.^(4,5)

In Japan, investigators found that only 40% of physicians usually told patients about a cancer diagnosis.⁽⁶⁾ In a survey of the International Psycho-Oncology Society, oncologists

estimated that less than 40% of their colleagues used the word cancer in African countries.⁽⁷⁾ Similar practices have been described in France, Hungary, Italy, Japan, Panama, Portugal, and Spain.^(8,9) In Latin America, a study among Brazilian physicians showed that in cases of fatal prognosis, 63.1% of physicians told the truth only to families while 31.6% preferred informing only patients.⁽¹⁰⁾ A study from Argentina identified similar behaviors.⁽¹¹⁾

Family member influence and societal expectations might also impact practices of truthful disclosure. In some countries, health is considered a family affair rather than an individual struggle; the family often makes medical decisions when one of its members is ill without always disclosing the whole truth to their loved one.⁽¹²⁾ In Saudi Arabia, for example, 49% of patients preferred that their families, rather than themselves, be informed of their diagnosis.⁽¹³⁾ In other regions where societies are traditionally averse to the idea of individual, autonomous decision-making, there is weaker evidence, however, that patients support less than fully truthful disclosures from their physicians, or that patients want to be excluded from family-based decisions regarding their medical care.⁽¹⁴⁾ In one study of 382 patients and 482 families in China, a large majority of cancer patients were more likely than their families to believe they should be informed of their diagnosis, stating also that the physician-in-charge was the appropriate person to disclose diagnosis.⁽¹⁵⁾ Similar results were reported from surveys of patients in Taiwan and Japan.⁽¹⁶⁾

Using the terms patient preferences, truth-telling, and disclosure, we found no studies regarding patient preferences from the traditionally family-oriented decision-making cultures of Latin America. The purpose of this study, therefore, was to examine physician

truth-telling practices and patient preferences regarding truthful disclosure and participation in medical decision-making in Buenos Aires City, a large metropolitan area of Argentina; where physicians have historically been reluctant to first share diagnosis and prognosis with patients rather than with family members. Our primary objective was to determine what patients wanted to be told about their illness, and whether there might be differences between patients with either cancer or advanced COPD. A second objective was to determine how these patients envisioned their participation, or lack thereof, in the treatment decision-making process, and what role, if any, they preferred be conferred onto their families and physicians.

Methods:

Subjects were eligible for this prospective study if they were attending the oncology or pulmonary outpatient consultation services at the British Hospital (BABH) or the Sanatorio Güemes Private Hospital (SGPH) in Buenos Aires, Argentina between June 2009 and May 2010. Patients needed to be 18 years or older, have a diagnosis of a primary malignancy or severe COPD (Gold III—IV), present with normal cognition, and be able to communicate fluently in Spanish. The study was approved by Institutional Review Boards for both institutions. Written informed consent was obtained from each patient enrolled in the study prior to completion of any of the survey instruments.

Patients were randomly approached by one of the investigators (NR), who in no instance was a treating physician at the time of the patient's clinic visits. Patients were asked to complete a 30-item survey instrument that had been pilot tested in 15 patients. Each survey consisted of a questionnaire and cover letter explaining the project and the participant's role

in its completion. The cover letter explicitly stated that the survey was in no way connected to the patient's diagnosis or reason for seeing a physician. Patients were informed verbally and in writing of their right to refuse to participate in any portion of the survey. They were also informed that their refusal would be without consequences. Surveys were done face-to-face with nontreating physician-investigators so that all responses were recorded by the interviewer. In addition to asking participants to complete the questionnaire about their preferences regarding truth-telling participation in the decision making process, and desire for information regarding their illness, data were collected pertaining to the patient's age, ethnicity, level of education, occupation, marital status, living situation, household income, self-perception regarding seriousness of their current disease, time since diagnosis, and performance status were collected. This study was approved by the institutional review board of the Buenos Aires British Hospital and the Sanatorio Güemes Private Hospital.

Statistical analysis:

All values were described as mean \pm standard deviation. Chi-square statistics test or Fisher's exact test was used for categorical data and an unpaired Student's t test for continuous data. In order to examine the effects of independent variables on the odds of wanting to be told about near death a univariate logistic regression analysis was conducted. All items were treated as categorical variables in the analysis. In a second step, only the subscales significant in the univariate analyses were tested in a multivariate model. Statistical significance was set at $p = 0.05$. All data were analyzed using SPSS version 13.0 (SPSS, Inc., Chicago, IL).

Results:

Ninety-nine patients were recruited (47 male, 52 female). Mean age was 60 ± 13.9 years). Forty-four had a diagnosis of COPD and 55 patients had cancer¹. Overall, the demographic, social and clinical characteristics of patients with COPD and cancer were similar (Table 1). All but 7 of the respondents lived with family or friends. Most (69%) had a secondary school or higher education, and 92% considered their condition serious or very serious. Only 6 patients felt their illness was not serious. Seventeen of the patients expected their health to improve in the future, but a significantly higher proportion of patients with malignant disorders expected to get better in the near future as compared to those with COPD (98.2% vs. 62.8%, $p < 0.001$).

Most study participants expressed a desire to receive all the information available about their condition, including potential side effects of treatment, chance for cure, likelihood of disease-related pain or disability, whether the disease had an eventual risk of death or if there was a possibility of dying in the near future, and explanations of treatment alternatives including what might occur should treatment be refused (Table 2). Almost all patients wanted to receive all information about their disease, including bad news, and 94% of patients wanted to receive bad news even if their families requested that the physician withhold such information (Table 3).

Less than half of the participants wanted their families to remain uninformed about the seriousness of their condition, if they had one. Logistic regression analysis failed to reveal

factors that could predict what patients would not want to be told about a near death, nor who would not want to have bad news shared with their families. A majority of the participants expressed a preference for making treatment decisions in collaboration with their physician (40.4%) or involving both their family members and their treating physician (33.3%) Only 4 patients wanted their doctors to make decisions on their own, and only 1 patient preferred that the family and the physician together make therapy-related decisions for them (Table 4). Overall, only 5% of patients wanted to refrain from engaging in the medical decision-making process. In case of a disagreement between physicians and family members regarding treatment choices, most patients (76.6%) preferred to follow the physician's recommendation, with only 5% considering the family's choice more relevant (Table 5). Regarding preferences for information provided by their doctor, statistically significant differences between patients with COPD and cancer were noted only for news of potential imminent death (preferred by patients with cancer, Table 5), and treatments that had not been effective in other patients (preferred by patients with advanced COPD, Table 6).

Discussion:

Most patients expect and desire truthfulness from physicians who, by practicing honest and truthful disclosure of diagnosis and prognosis respect a patient's right to receive information about their illness.⁽¹⁷⁾ To refrain from truth-telling, therefore, can severely strain a physician-patient relationship normally based on trust. Truth-telling also honors patient autonomy and allows patients to participate knowingly in the informed consent and medical decision-making process. Several studies suggest that regardless of cultural

context, informed patients are more satisfied, less anxious, more likely to comply with treatment, and have improved outcomes.^(18,19,20,21)

Current opinions and practices regarding the importance of truth-telling, however, are mostly derived from studies of Anglo-Saxon or migrant patient populations in the United States, and may not always take into consideration that truth-telling practices and preferences are a cultural artifact that cannot necessarily be extrapolated to diverse cultural contexts. Truth-telling, however, has been shown to contribute to patient distress, anguish, depression, hopelessness, pain, , anger and does not necessarily result in improved quality of life.^(22,23,24,25) Furthermore, patients with irreversible or ultimately fatal disease such as cancer or advanced COPD are particularly vulnerable to physician behaviors.^(26,27) Health care providers striving to balance their obligation to tell the truth with the do no harm imperative of the Hippocratic oath, may, therefore, practice paternalistic, selective nondisclosure.

In predominantly Anglo-Saxon countries, however, studies show that patients with cancer want to know the nature of their terminal illness, a desire that has also been documented in patients with chronic life-altering diseases such as multiple sclerosis and Alzheimer's.^(28, 29, 30)

Our study demonstrates a similar desire for physician truth-telling practices among patients with advanced COPD (GOLD stage III/IV) and cancer, finding that that 98% of all patients wanted to be told the truth regardless of their illness, even if it meant being told there was a high risk of death.

For those patients aware of their diagnosis, results from studies in the United States, Canada and Japan suggest that preferences regarding the patient's role in treatment-related decision-making vary. ^(31, 32, 33)

Blanchard et al,⁽³⁴⁾ reported that 92% of hospitalized cancer patients preferred receiving all the information necessary to decision-making, but only 69% elected to participate in the process, and of those wanting full disclosure, 24.9% preferred that their physician make therapeutic choices. Elkin, et al, ⁽³⁵⁾ showed that 52% patients age 70 years and older with a recent diagnosis of metastatic colorectal cancer preferred assuming a passive role in treatment-related decision-making, whereas Benbassat⁽³⁶⁾ noted that while patients may not want to assume an active role in the doctor-patient relationship, they do not want to be entirely passive either. Patients may actively seek information to satisfy an aspect of psychological autonomy that does not necessarily include participation in decision making. Strull et al, and Katz J, et al suggesting that one's motivation to become informed in order to exercise or not decision-making power, illustrates one's right to self determination. ^(37, 38)

We found that almost all respondents sought information and wanted to be knowledgeably engaged. These findings illustrate that our patients want families to support their decisions, rather than provide opinions independent from their own or from those of their physicians. This runs contrary to the relatively widespread assumption throughout Latin America that families should make medical decisions when one of its members is ill. ^(12, 39)

Our study also found that patients want to abide by their physician's recommendations in case of disagreement between family and physician. If supported by studies in other Latin American countries, this finding could drastically alter physician behaviors because it has

been common for many physicians to prefer informing families of diagnosis and bad news prior to speaking with patients, but also to abide by family (rather than patient) preferences because family is traditionally presumed to occupy the role of information-gate-keeper and primary decision-maker.

Motivated by the paucity of literature pertaining to truth-telling practices and patient preferences regarding participation in the treatment decision-making process in Latin America, we designed our study to explore these issues, in addition to potential differences among patients with life-altering disease such as advanced COPD and cancer in patients residing in Buenos Aires, a large, metropolitan region in Argentina. The strong family-oriented culture of Latin America was only modestly apparent. Limiting the generalizability of results, however, is that Buenos Aires is a large city that may not be representative of smaller towns and rural areas of Latin America. In addition, Argentina is a culturally diverse country with descendants from immigrants who may not be representative of the rest of Latin America.⁽⁴⁰⁾ Thirdly, the interpretations of quantitative research findings from questionnaires may fail to capture social and psychological phenomena that reflect the true nature of human social behavior. This is because results often rely on what people say rather than what on they do; seeking to reduce meaning to what is plainly observable.⁽⁴¹⁾ This variance might be explained by different settings in which studies are performed, patient populations, disease processes, whether or not patients are hospitalized, whether there exists a preponderance of falsely optimistic views of one's disease, severity of symptoms, and other factors including age, gender, ethnicity and cultural environment.⁽⁴²⁾

Studies incorporating ethnographic and other qualitative research methodologies are warranted to better understand the health care-related preferences and practices of various groups of people throughout the South and Central American continent.

In summary, The Latin American patients in our study wanted to be thoroughly informed about their diagnosis and their disease. Regardless of whether they had advanced COPD or cancer, they also wanted to be actively engaged in the medical decision-making process. While they considered the role of their families relevant, and wanted information to be shared so that family members might participate in decision-making, they did not want their families to have a right to withhold information, make final decisions, or override their physician's recommendation in case of disagreements regarding treatment. Our patients wanted to be told the truth, even if their condition entailed a serious risk of death. These findings can have a profound impact on changing physician-patient communication styles and medical decision-making behaviors in Latin America.

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Table 1: Characteristics of patients with cancer (n=55) and COPD (n=44)

Characteristics	COPD patients (n=44)	Cancer patients (n=55)
Age (years)	60 yrs \pm 14 months	58 yrs \pm 13 months
Male	25	21
Unemployed	6(14%)	10(18.2%)
Completed primary school	29(67.4%)	40(74.1%)
Lives alone	3 (7%)	4 (7.3%)
Time since diagnosis (months)*	69 \pm 117	24 \pm 35
ECOG Performance Status 0	33(78.6%)	47 (83.9%)
ECOG Performance Status 3	1 (2.4%)	1 (1.8%)

*Differences statistically significant (p<0.05)

Table 2: Patient preferences regarding information desired from their doctors. (n=99)

Question	I absolutely want this information	I would like this information	I do not want this information
What are all possible side effects of treatment?	80 (80.8%)	16 (16.2%)	3(3%)
What effect can I expect from this treatment?	85 (85.9%)	9 (9.1%)	4 (4%)
Is my disease cancer or not?	85 (85.9%)	9 (9.1%)	3 (3%)
Is there any chance for cure?	86 (86.9%)	12(12.1%)	1 (1%)
What will the treatment exactly do?	78(78.8%)	14 (14.1%)	6 (6.1%)
What is the medical name of my disease?	79 (79.8%)	11 (11.1%)	8 (8.1%)
Is this a hereditary or contagious disease?	85 (85.9%)	13(13.1%)	1 (1%)
Can I die from this disease?	82 (82.8%)	10 (10.1%)	5 (5.1%)
What are the chances of dying from this disease?	76 (76.8%)	15 (15.2%)	8 (8.1%)
If I may die: how much time will I live?	75 (75.8%)	11(11.1%)	10(10.1%)
Can I become disabled from this disease?	76 (76.8%)	13(13.1%)	9 (9.1%)

Can this disease cause me pain that treatment does not control completely?	83 (83.8%)	9 (9.1%)	7 (7.1%)
How effective is treatment in other patients?	74 (74.7%)	18 (18.2%)	7 (7.1%)
Can you give me examples of treatment effectiveness in other patients	73 (73.7%)	20 (20.2%)	6 (6.1%)
Can you give me examples of when this treatment was not effective in other patients?	67 (67.7%)	18 (18.2%)	14 (14.1%)
What will happen if I do not undergo treatment for this disease?	86 (86.9%)	9 (9.1%)	4 (4%)
What other treatment options exist and what are their advantages and disadvantages?	86 (86.9%)	9 (9.1%)	4 (4%)
Who is the most recognized specialist in this disease to provide a second opinion?	68 (68.7%)	17 (17.2%)	14 (14.1%)

Table 3: Patient preferences (Yes/No questionnaire) regarding information desired from their doctors. (n=99)

Questions	Yes	No
I want my doctor to give me all information, good or bad, about my disease	97(98 %)	2(2%)
If something goes wrong I want my doctor to tell me.	97(98 %)	2(2%)
If my disease is incurable I want my doctor to tell me	92(92%)	7(8%)
If there is bad news I want my doctor to tell my family first	29(29.3%)	70 (70.7%)
If I have a severe illness I want to know, even if my family does not want to give me that information	94(94.9%)	5(5.1%)
If there is a risk I might die, I want my doctor to tell me	95(96%)	5(4%)
If I may die in short time, I want my doctor to tell me.	89(89.9%)	10(10.2%)
If I have a serious illness I want my doctor to tell me and not tell my family	45(45.5%)	51(51.5%)

Table 4: Patient preferences regarding treatment-related decision-making (n=99)

Treatment decisions should be made by:	n
The doctor alone	4 (4%)
Myself alone	10 (10.1%)
Myself and the doctor together	40 (40.4%)
The doctor, myself and my family equally	33 (33.3%)
The doctor and my family together	1 (1.0%)
Myself and my family together	11 (11.1%)

Table 5: Patient preferences regarding information provided by their doctor: patients with COPD (n=44) and cancer (n=55)

Question	COPD	Cancer	p
I want my doctor to give me all information good or bad about my disease	95.3%	100.0%	0.211
If something goes wrong I want my doctor to tell me.	95.3%	100.0%	0.211
If my disease is incurable I want my doctor to tell me	90.7%	96.0%	0.410
If there is bad news I want my doctor to tell my family first	18.6%	30.0%	0.235
If I have a severe disease, I want to receive all the information even if my family does not want me to know about it.	90.7%	98.0%	0.178
If I am at risk of dying I want my doctor to tell me *	90.7%	100.0%	0.042
If I may die in a short time I want my doctor to tell me.*	88.4%	100.0%	0.019
If I have a serious condition I want my doctor to tell me and not to tell my family	51.2%	44.0%	0.536

*Differences statistically significant ($p < 0.05$)

Table 6: Magnitude of need for different sort of information in patients with COPD and cancer.

Question	COPD (mode)	COPD (mean± SD)	Cancer (mode)	CANCER (mean ± SD)	P value
What are all possible adverse effects of treatment?	3	2.84 ± 0.374	3	2.73 ± 0.556	0.304
What can I expect from this treatment?	3	2.88 ± 0.32	3	2.78 ± 0.567	0.218
Is it my disease cancer or not?	3	2.77 ± 0.52	3	2.88± 0.38	0.500
Is any chance of cure?	3	2.84± 0.43	3	2.88± 0.34	0.516
What will the treatment exactly do?	3	2.72 0.59	3	2.75 0.54	0.694
What is the specific medical name of my disease?	3	2.72± 0.63	3	2.73± 0.59	0.763
Is it a hereditary or contagious disease?	3	2.88± 0.32	3	2.82 ±0.43	0.620
Can I die of this disease?	3	2.80± 0.55	3	2.79 ± 0.94	0.144
What are the chances of dying from this disease?	3	2.74 ± 0.58	3	2.64 ± 0.64	0.622
If I can die: how much time will I live?	3	2.74 ± 0.58	3	2.62± 0.71	0.337

Can I be disabled with this disease?	3	2.67 ± 0.68	3	2.69 ± 0.60	0.531
Does this disease cause me pain that the treatment does not control completely?	3	2.81 ± 0.50	3	2.73 ± 0.61	0.713
How effective was the treatment in other patients?	3	2.81 ± 0.45	3	2.57 ± 0.68	0.136
Examples in which the treatment has been effective in other patients	3	2.59 ± 0.62	3	2.79 ± 0.51	0.132
Examples in which the treatment has not been effective in other patients*	3	2.81 ± 0.50	3	2.32 ± 0.81	0.003*
What happens if I do not do the treatment?	3	2.93 ± 0.25	3	2.75 ± 0.58	0.151
What other treatment options exist and what their advantages and disadvantages?	3	2.91 ± 0.29	3	2.77 ± 0.57	0.202
Who is the most recognized specialist in this disease to make a second consultation?	3	2.63 ± 0.69	3	2.48 ± 0.76	0.550

*Differences statistically significant ($p < 0.05$)

****Score using 3 point scale.**