

Patients' attitude towards concept of right to know

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Abstract

Objective: To ascertain patients' attitude towards concept of right to know about Terminal cancer

Materials and methods: Questionnaire was constructed that included demographic and clinical information distributed to 500 OPD patients and interviewed them at Patan Hospital in Kathmandu, Nepal.

Results: 500 OPD patients completed questionnaire along with interview. 63.4% of patients wanted to know diagnosis, 41.2% wanted to know about prognosis and 13% wanted to make own end of life decision-making about the terminal cancer. Similarly, 89% of patients wanted to tell diagnosis to their family members and 83% wanted to tell prognosis. The view for disclosure rate is different when one is as patient and as family member (63.4% versus 34.4%). Elderly people are more likely to know the prognosis and educated and Brahmin people are more likely to make their own end of life decision-making.

Conclusion: Findings of the study indicated that most patients want to be informed about their terminal illness. Physicians should realize that patients and family units might differ in their attitude therefore; truth telling should depend on what the patients want to know and are prepared to know.

Key words: attitude, patient, right to know (autonomy), terminal illness

The principle¹ of a patient's right to know (autonomy) asserts the rights of individuals to make informed decisions about their medical care status. Thus, patients should be told the truth regarding their diagnosis, prognosis, the possible treatments, as well as the risks and benefits of proposed treatments and should be allowed to make choices (choose or refuse life prolonging medical care in case of terminal illness) based on this information. At present, medical treatment is patient centred and information to the patient is a key element in the decision-making for appropriate management. Moreover, the ethical principle often focuses on respect for patient's autonomy, do well and do not harm.

Terminal cancer² is a condition when there is no response and rather deterioration with definitive treatment. The lack of knowledge about deteriorating illness, increasing pain and suffering without sharing may lead to suicide³, unplanned death and increase demand for euthanasia. Similarly there may be increasing demand from family members for vigorous medical intervention, life prolonging technology and futile treatment³.

The best solution in such case will be true information about illness and freedom for patient's own decision making. This helps in providing more appropriate care⁴ (avoid aggressive treatment,

decrease financial burden and provide comfort to the patient and family members). The informed palliative care² decrease suffering and increase quality without unnecessarily hastening and prolonging life. But, this all is easier if patients want to know about their illness.

The amount of information received by terminal cancer patients about their illness varies between person to person and countries. In USA, The idea of patient autonomy is so powerful that attempts have been made to extend patients control over medical decision making through advance care directives. So, the majority of the doctors (97% by 1979) indicated a preference for telling the truth⁵. Approach differs in many other countries; like in China where disclosure is perceived as a harmful act and autonomy as isolation⁶. In such culture, most patients with the terminal cancer die without being informed when treatment changes from curative to palliative. So, it is always difficult for the physician to maintain a balance between cultural sensitivities, family pressure, medical ethics and patient's right to know (autonomy).

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Like in China, the actual practice in our country is to tell the patient's family about such illness and not to inform the patient. It is important to know patient's attitude towards autonomy for possible solution of such problem regarding terminal illness in our setting.

Materials and methods

This was a descriptive study. Data was collected by questionnaire and interview from OPD patients of age group 18 years and above who were randomly selected. It was carried out at Patan Hospital, over 6 months (June to November 2004) after taking ethical consideration from hospital committee. This Hospital is one of the major hospitals in the Kathmandu valley of Nepal, which is located in the city of Lalitpur District (Lagankhel). Patients who were very sick and refused to participate were excluded from the study.

Statistical analysis

After completion of data collection, the collected data was edited, coded and plotted in frequency tables to be put on computer for statistical analysis and the required analytical interpretation and description were done. The package of SPSS X² test was used to analyse the data according to the objectives of the study. Differences in the dependent and independent variables across groups were assessed with the use of analysis of variance or X² procedure. Estimation of

the odds ratio (OR) was calculated for each independent variable with the use of univariate logistic regression analysis. OR>1 represent how much more likely it was for the subject in a specific category to believe that a patient should have autonomy with regard to knowing their diagnosis. In addition stepwise multiple regression analysis was performed for each dependent variable to assess which of the dependent variables best predicted attitude toward truth telling and medical decision-making.

Results

Out of 500 OPD patients, almost half of them were of different gender. The ages were between 18 to 65 years. Majority of the patients (51.4%) were of below 40 years of age, and minority of them (21%) were above 60 years of age. Patients were grouped into different cast systems as Brahmin, Chhetri, Newar and Others with almost equitable distribution. Based on education, they were grouped into Illiterate, secondary level, intermediate level and above intermediate level. Majority of them (around 60%) were of below seven-class level. The sample characteristics are shown in Table 1.

Table 1: Sample characteristics (n=500)

Character	Number	Percentage
Gender		
Male	252	50.4
Female	248	49.6
Age		
<39 Years	257	51.4
40-59 Years	138	27.6
>60 Years	105	21
Ethnicity		
Bramhin	126	25.2
Chhetri	123	24.6
Newar	127	25.4
Other	124	24.8
Schooling		
Illiterate	98	19.6
1 to 7 Class	193	38.6
8 to 12 Class	126	25.2
> 12 Class	83	16.6

Fig 1: Attitude towards patient's autonomy, diagnosis and prognosis

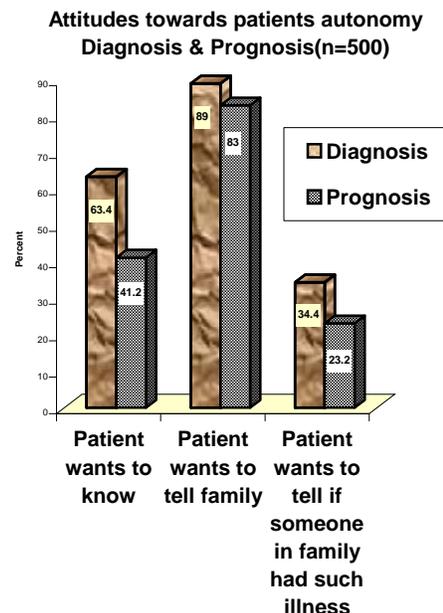


Fig 2: Attitudes towards disclosure of end of life decision making

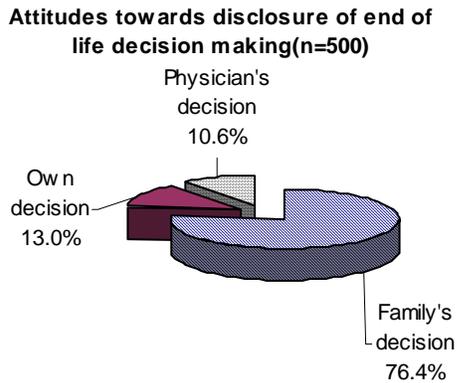
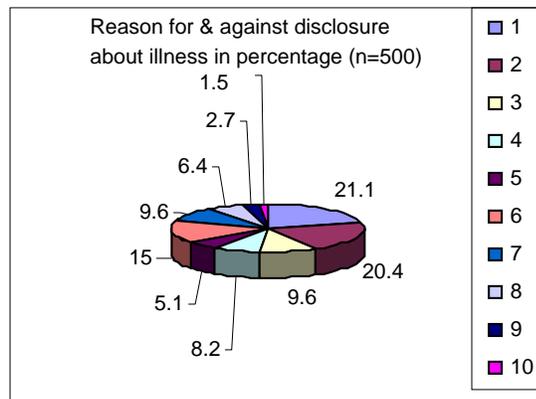


Fig 3: Reasons for and against disclosure



1. Getting Things in Order
2. I know it anyway
3. Tell me the Truth
4. It's my right (Autonomy)
5. For religious rituals
6. Telling truth is harmful
7. To give Hope
8. Anyway No Difference
9. I don't want to know (Autonomy)
10. I can't take it

Attitude towards patient's right to know

Out of 500 patients 63.4% of patients wanted to know the diagnosis, 41.2% wanted to know about prognosis (Fig 1) and 13% wanted to make own end of life decision-making (Fig 2) about the terminal cancer. Similarly, 89% of patients wanted to tell diagnosis to their family members and 83% wanted to tell prognosis. The view for disclosure rate is different when one is as patient and as family member (63.4% versus 34.4%).

Other findings

on Logistic Regression analysis-People >60 years want to know more about the prognosis than younger people ($p < 0.01$). *On stepwise multiple logistic*

regression- Brahmin and educated people are more likely to take their own decision ($p < 0.01$). The reason given why they want and don't want to know about their illness is shown Fig 3 with numbering 1-10 and discussed below.

Discussion

Doctors should never lie to his/her patient. It is difficult, however to decide what, how much and when to tell them⁴. In the other hand, breaking bad news for patients having terminal cancer is probably one of the most distressing problems. So, it should be assessed during consultation of individuals. In our country, it is customary not to inform patients about their illness. The most important finding in this study was most (63.4%) of the patients wanted to know, majority of the patients (89%) wanted to tell family members and most of the family members (65.6%) did not want to tell to the patient about their illness which is different from the study of Ranjan Singh and Majhi PC *et al*^{8,9}. This data showed that there is discrepancy towards the attitude of the individual in different situation as mentioned by Tse CY *et al*¹⁰ (when he is as a patient and as family members).

Comparison between studies

Baile *et al*¹¹ provided preliminary data regarding cultural differences in disclosing cancer diagnosis and prognosis. Similarly ethnicity plays the major role in the attitude towards patient autonomy¹. In our study, Brahmins were more likely to take their own decision regarding end of life decision-making. Robert JS *et al*¹² and Hasui *et al*¹³ have suggested that education plays a significant role in patient's attitude towards autonomy, in this study also they wanted to take their own decision. But there was no significant difference regarding diagnosis and prognosis by caste and education. Study done by Robert *et al*¹² showed that people older than 60 years wanted to know less about their illness than younger people. In contrast, in this study older people (Majority of them are the head of the household) want to know more about their illness. This may be due to older people being the more responsible member (household) in the family. This query was put forward by Blackhall *et al*¹ "Is the interaction between patient and family different when the patient is the head of the household?"

Reasons why patients want to know about their illness

1. **Getting Things in Order** (21.1%) – Patients want to know their prognosis so that they can plan the things in order¹⁴ like resolve unfinished business, meet friends, and want to stay with family members.
2. **I know it anyway** (20.4%) – I will ultimately know the truth sooner or later. Patients who repeatedly visit

cancer hospital might obviously guess he has cancer¹⁴.

3. **Tell me the Truth** (9.6%) - Most of the elderly people want the truth^{12, 14}.

4. **It's my right (Autonomy)** (8.2%) – Some patients would like to know the worst prognosis also because “it’s me; It is my right.” I would have to face it¹⁴.

5. **For religious rituals** (5.1%) – It’s ok if I got cancer, God is there for us¹⁴.

Reasons why patients don't want to know about their illness

6. **Telling truth is harmful** (15%)- Receiving a diagnosis of the terminal illness is traumatic. So, patients may die faster¹⁵.

7. **To give Hope** (9.6%) – “Give me hope....” So, I can always have hope that I will get better¹⁵.

8. **Anyway No Difference** (6.4%) – What does it make difference if I know or not? Anyway I might have had disease.

9. **I don't want to know (Autonomy)** (2.7%) – I don't want to know about bad things. As there is right to know about the illness, there is equal right not to know also¹⁶.

10. **I can't take it** (1.5%) – I can't take it. Some people just are not able, for whatever reason, to deal with unpleasant facts¹⁴.

Further research

1. Do patients who are not told about the diagnosis usually know it anyway (by verbal or non-verbal means)?

2. What is the perceived harm when the medical community violates cultural conventions and insists on telling the truth to the patients (Do they really die early /have emotional problem)?

Limitations of the study

First, the family members sitting in the OPD might not have been representative of all family members. Second, this study did not allow the participants to complete the questionnaire and deliver it in a sealed envelope, so it may have been biased toward positive outcomes. The researcher however, did not allow the patients to share information, which should minimize the bias caused, by patients answering according to others' expectation. Third, there is no equal distribution in education and age group. Finally, Sample size couldn't be worked out to show significant difference.

Conclusion

My findings suggest that most of the patients (around 2/3) want to know the diagnosis; around half of the patients (around 1/2) want to know the prognosis and

only few (around 1/7) want to take end of life decision-making. There is difference in attitude toward disclosure of illness when one is as patients (around double) and as family member. Culture, cast, education and age may play a role towards attitude of patients' towards their terminal illness. It is important to avoid stereotyping during disclosure.

Recommendations

Doctor- patient relationship should be for the benefit of patients. The right of both who want or do not want should be respected (patient's Autonomy). We should try to find out whether they want to know or not about their illness. During consultation we should try to address different issues by ideas, concerns & expectations about their problems.

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