



ORIGINAL RESEARCH PAPER

Oncology

DISCLOSURE OF DIAGNOSIS IN PATIENTS WITH HAEMATOLOGICAL CANCERS- EXPERIENCE FROM A TERTIARY CENTRE IN INDIA

KEY WORDS: Hematology, Oncology, India, Disclosure

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ABSTRACT

Background: Disclosure of diagnosis is a challenge for health care providers in India. There is preference towards a family centred decision making in favour of a patient-centred process. Various socio-cultural factors are then at play in a doctor-patient interaction in India. With family playing a significant role in healthcare decisions, there is often collusion between the doctor and the family to withhold information from the patient. **Aims:** To to assess and answer the decision making process and depth of diagnosis disclosure in patients with haematological cancers. **Methods: Study setting:** This study was conducted at a tertiary level teaching hospital, the Christian Medical College & Hospital, Ludhiana. Ethics approval was obtained from the Institutional research committee. **Study period:** 01 August 2016 through 30 Jun 2017. **Results:** A total of 100 consecutive patients were interviewed. The mean age in patients who sought to know about their disease compared to those who did not wish to know about it were 42.6 ± 16.7 and 52.7 ± 12.5 respectively, P=0.011. In our study we noted that family-centric decision making is a common practice. We observed that the spouse was the most influential member in our patients' treatment decision (35%). Forty one percent of patients did not want to know if they had cancer, 59 (59%) patients wanted to know some details of their illness. **Conclusions:** In our analysis, we noted that two factors that influenced the patients' preference for disclosure of diagnosis were age and education. Younger and higher educated patients had more information needs regarding their disease.

INTRODUCTION

Disclosure of diagnosis is a challenge for health care providers in India. (1) There is preference towards a family centred decision making in favour of a patient-centred process. Various socio-cultural factors are then at play in a doctor-patient interaction in India. With family playing a significant role in healthcare decisions, there is often collusion between the doctor and the family to withhold information from the patient. (2)

Specific details of the disease are not uncommonly undisclosed to the patient; with relatives requesting the provider to withhold such information. This is however in good intent and stems from the societal belief that the patient would be better served by ignorance rather than the knowledge which would drive him to disappointment and isolation. (3,4) An added factor to the prevalence of such practice is possibly the paternalistic doctor-patient relation in India fuelled by the faith in the beneficence of the doctor with acceptance to his choice of treatment. (5)

The fear of discrimination and stigma which are further accentuated when the diagnosis is cancer adds to this challenge. It is a disease with multiple treatment modalities requiring continuous surveillance associated with differing patterns of relapse, treatment effects and a pervading sense of inevitability. The diagnosis of cancer is often perceived with helplessness and could affect one's quality of life. (6,7)

The benefits in withholding the diagnosis disclosure and the paternalistic doctor patient relation in India possibly relates to the hierarchal pattern and illiteracy in the community. (5) It is a practice which does not appear to be supported by evidence. It is now known that diagnostic disclosure to the patient does not appear to worsen any dimension of quality of life in general and emotional state in particular (8).

Instead, honest disclosure establishes a satisfactory relationship between the doctor, patient and family members (9). It is being increasingly advocated that the patient has a 'right' and not a 'duty' to know about the diagnosis. It entirely relies on the patient's will to whether he or she should possess such knowledge regarding him or her

respectively (10). The choice of whether the patient wants to know the diagnosis is affected by the desire to protect his family and himself (11).

This contrast with evidence and practice in India requires a scientific analysis. In identifying with this goal we undertook a prospective descriptive study to assess and answer the decision making process and depth of diagnosis disclosure in patients with haematological cancers.

METHODS

This prospective study involved a questionnaire-based interview that assessed patient demographics, the information provided about cancer, patient preference about the diagnosis disclosure, and the roles of family and finances in treatment planning. Consecutive inpatients beginning August 2016 through June 2017 were interviewed in the absence of their relatives with the intent to derive genuine patient responses. The questionnaire was derived and modified from an extensive literature search, and its components had been validated elsewhere in the country. Informed consent was obtained prior to the interview.

Patients admitted for therapy were chosen as participants and were interviewed face to face in the absence of any relative. It was anticipated that admitted patients were best reflective of the cohort with most knowledge on their condition; and the intent of interviewing in the absence of relative was to derive genuine patient responses minimising reporter bias.

Statistical Analysis:

This was a descriptive non-interventional study. Descriptive statistics summarised the demographic characteristics of the population studied. The comparisons were made using a χ^2 or t-test or Mann-Whitney-U test as appropriate using the SPSS. The χ^2 or fisher exact test was used to compare differences between those who were aware and those unaware of their diagnosis.

RESULTS

Demographics

100 consecutive patients were interviewed. The patient demographics are detailed in table 1. The majority, 93 were

from within the state. Fifty-four patients had completed their secondary education. The majority (80%) had been to other treatment centers before the current admission.

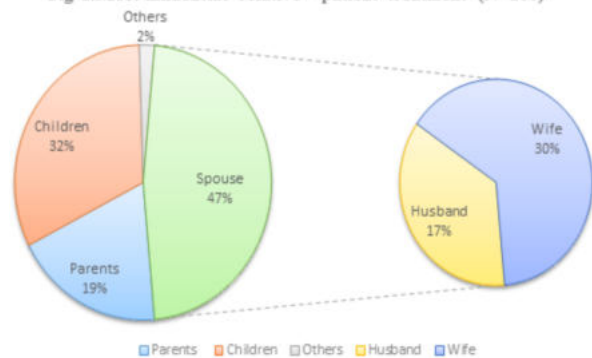
Table 1: Patient Demographics

Variable	Patients (N=100) n (%) Median (Range)/Mean ±SD
Age	46 (17-83)
Gender (Male)	59 (59)
Monthly family Income (\$)	410 (137 – 2048)
Family history of Malignancy (Yes)	5 (5)
Satisfaction with diagnosis discussion (Yes)	97(97)
Aware of disease as a malignancy (Yes)	73 (73)

Diagnosis Disclosure – Patient features

The current centre was the first centre where 42 (42%) patients had reached out for treatment. 90 (90%) patients responded as being aware of their disease, and 35 (35%) were clear that they were admitted with cancer. Eight (8%) patients had doubts about their disease. The spouse was the most critical member in 47(47%) patients in making decisions on their treatment, **Fig 1**. Twenty six (26 %) patients preferred having their consent taken prior to the physician discussing their illness with others. **Table 2** lists the additional details on the patients, nature, and delivery relating to disclosure of diagnosis.

Fig 1. Most influential relative - patient treatment (N=100)



Variable	Patients (N=100) n (%) Median (Range)/Mean ±SD
Monthly family Income (₹)	30000 (10000 – 150,000)
Patient present at diagnosis discussion (Yes)	73 (73)
Patient has some idea of disease (Yes)	90 (90)
Patient aware that disease is cancer (Yes)	73 (73)
Duration of diagnosis discussion (mins)	15 (2-30)
Discussion all present (Yes)	94 (94)
Deciding member on treatment (Spouse)	47(47)

Table 3: Comparison of patients according to need of diagnosis disclosure (N = 100)

Variable	Want to Know (N=59) n (%) Median (Range)/Mean ±SD	Don't want to know (N=41) n (%) Median (Range)/Mea n ±SD	P value
Age (years)	42.6 ±16.7	52.7 ±12.5	.011
Monthly family income (₹)	38000 (10000-150000)	35000 (10000-50000)	.241
Education (graduate)	20 (33.8)	4 (9.7)	.000

Prior treatment centers	1 (0-2)	1 (0-2)	.554
Duration of discussion (min)	16.5 ± 5.4	15.8 ±5.1	.736
Financial insecurity (No)	40 (67.7)	21 (51.2)	.480
Treatment decision (Spouse)	10 (41.7)	15 (51.7)	.012
Side effect information	49 (83)	17 (41.4)	<.001
Type of therapy information	41 (69.4)	4 (9.7)	<.001

Diagnosis Disclosure – Factors influencing patient preference

Of the 100 patients, 59 (59%) wanted to know about their disease. We compared their characteristics with those who did not want to know about their disease, table 3. The patients who wanted to know about their disease were significantly younger and more likely had graduate education, P<0.05.

DISCUSSION

This prospective study illustrates our center's attitudes and preferences towards diagnosis disclosure. This research aimed to understand the current Pattern in patients with hematological cancers in a contemporary setting in India. A more extensive study from multiple centers in India is required to conclusively state that the results of this study are truly representative of the country. Despite these limitations, there are interesting observations from our research.

This cohort's median age of 46 years (range: 15–83) is different from that routinely reported on haematological malignancies in the literature from developed countries (12). However, it is in continuation with the trend in India of patients presenting at a younger age (13)

From our experience, it is clear that family-centric decision-making is a common practice. This conforms with cultural practice in India of not burdening the patient with the details of therapy and treatment mentioned, which have been earlier reported (14,15). We observed that the spouse was the most influential member in our patients' treatment decision (47%).

Though there is a belief that patients adopt a less active role in information needs on their cancer, reports from cancer centers in India have suggested that this cannot be generalized. We observed that patients tend to seek information on their disease, but not all patients wanted extensive information.

Though forty one percent of patients did not want to know if they had cancer, 59 (59%) patients wanted to know some details of their illness. This is different from earlier reports from India which (7,16) have suggested a higher proportion of patients who sought to know about their disease in detail. This is possibly since our patients had a lower educational background, and more patients from such backgrounds have access to treatment at specialized centers. Our finding that not all patients wanted to uncover their disease details has been reported earlier (17).

In our research, we noted that two factors that influenced the patients' preference for disclosure of diagnosis were age and education. Younger and higher educated patients had more information needs regarding their disease. The mean age in patients who sought to know about their disease compared to those who did not wish to know about it were 42.6 ±16.7 and 52.7 ±12.5 respectively, P=0.011. This is similar to earlier observations reported from the west and India (7,18). It has been postulated that elderly patients hesitate to seek out more information from doctors, reflective of their upbringing that asking too many questions would be seen as rude (19). It

is also likely that there could be a feeling of inevitability among the elderly.

Thirty-three percent of our patients who wanted to know about their disease pursued graduation or had a higher qualification. This was significant compared to the 9% in the group who did not want to know about their disease, $P < 0.001$. This subset of patients is likely to be more informed about the medical advances in diseases and seek out more information from alternate sources, reflective of their need for diagnosis disclosure.

The group wanting to know about their disease also expectedly preferred to be active in other decision-making areas of their disease, as reflected by the higher number of patients seeking out information on their treatment (69.4%) and possible side effects (83%).

CONCLUSION

In conclusion, the majority of patients did not want to uncover information about their cancer though they wanted some information on their disease. The patient's spouse was the most influential member in deciding on their treatment. There also exists a group of patients who prefer diagnosis disclosure. This group was significantly younger in age and had a higher level of education.

Our study though limited by patient numbers and the single-centered data collection reveals some valuable insights. There is a tendency in patients to seek some information regarding their illness, but the majority preferred not to know if their disease is cancer. Age and education influence patient preference to know about their disease. These observations must be tested in a larger setting and can guide future doctor-patient interactions in India.

REFERENCES

1. Thilakavathi S, Manickam P, Mehendale SM. Disclosure of leprosy by health care providers in south-India: patients' perception and relevance to leprosy control. *Tamil Nadu. Indian J Lepr.* 2015;87(3):155-60.
2. Jeba J, Jacob A, Kandasamy R, George R. The patient who 'must not be told': demographic factors associated with collusion in a retrospective study in South India. *Postgrad Med J.* 2016;92(1093):659-62.
3. Kalantri SP. Informed consent in public hospitals. *Issues Med Ethics.* 2000;8(4):116-7.
4. Madhiwalla N. The ethics of truth telling. *South Asian J Cancer.* 2013;2(2):53.
5. Malik AY, Foster C. From informed consent to informed request: strengthening shared decision-making. *Indian J Med Ethics.* 2014;11(1):53-4.
6. Zebrack BJ. Cancer survivor identity and quality of life. *Cancer Pract.* 2000;8(5):238-42.
7. Laxmi S, Khan JA. Does the cancer patient want to know? Results from a study in an Indian tertiary cancer center. *South Asian J Cancer.* 2013;2(2):57.
8. Bozcuk H, Erdoğlan V, Eken C, Çıplak E, Samur M, Özdoğan M, et al. Does awareness of diagnosis make any difference to quality of life? *Support Care Cancer.* 2002;10(1):51-7.
9. Centeno-Cortés C, Núñez-Olarte JM. Questioning diagnosis disclosure in terminal cancer patients: a prospective study evaluating patients' responses. *Palliat Med.* 1994;8(1):39-44.
10. Fried TR. Shared Decision Making—Finding the Sweet Spot. *N Engl J Med.* 2016;374(2):104-6.
11. Thomsen O, Wulff HR, Martin A, Singer P. What do gastroenterologists in Europe tell cancer patients? *The Lancet.* 1993;341(8843):473-6.
12. Smith A, Howell D, Patmore R, Jack A, Roman E. Incidence of haematological malignancy by sub-type: a report from the Haematological Malignancy Research Network. *Br J Cancer.* 2011;105(11):1684-92.
13. Philip C, George B, Ganapule A, Korula A, Jain P, Alex AA, et al. Acute myeloid leukaemia: challenges and real world data from India. *Br J Haematol.* 2015;170(1):110-7.
14. Chaturvedi SK, Loiselle CG, Chandra PS. Communication with relatives and collusion in palliative care: A cross-cultural perspective. *Indian J Palliat Care.* 2009;15(1):2.
15. Seth T. Communication to pediatric cancer patients and their families: A cultural perspective. *Indian J Palliat Care.* 2010;16(1):26.
16. Sriram TG, Kumar KK, Jayaprakash MR, Sriram R, Shanmugham V. Informed consent: A study of experiences and opinion of utilizers of health services from India. *Soc Sci Med.* 1991;32(12):1389-92.
17. Leydon GM, Boulton M, Moynihan C, Jones A, Mossman J, Boudioni M, et al. Cancer patients' information needs and information seeking behaviour: in depth interview study. *Bmj.* 2000;320(7239):909-13.
18. Sutherland HJ, Llewellyn-Thomas HA, Lockwood GA, Trichter DL, Till JE. Cancer patients: their desire for information and participation in treatment decisions. *JR Soc Med.* 1989;82(5):260-3.
19. Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centres. *Br J Cancer.* 2001;84(1):48-51.