RESEARCH COMMUNICATION

Beliefs and Perceptions about Cancers among Patients Attending Radiotherapy OPD in Delhi, India

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Abstract

The prevalence of beliefs and myths amongst cancer patients is a reflection of the level of knowledge in the community regarding cancer. Such beliefs influence the health seeking behaviour of patients and may lead to delay in seeking medical care. The present study revealed that myths and misconceptions are widely prevalent among cancer patients in India. The perception regarding causation of cancer among cancer patients varied from curses, evil eye and spirits to past sins. Only one third of the patients believed that cancer can be detected in its early stages and that it can be cured. The average time taken by patients to report to a doctor after suspecting their disease was 2 years. The majority of patients held fatalistic views about the outcome of cancer. Most (60%) were being discriminated against by their family and society. All these findings highlight that despite considerable medical knowledge of risk factors and treatment modalities, possible social-behavioral strategies for the prevention and control of cancer have not been adequately addressed, especially among South Asian patients.

Key Words: Cancer - beliefs - misconceptions - India

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Introduction

It is estimated that around 11 million cancer cases occur globally each year. In fact, more than 12% of all deaths every year are caused by cancer. That's more than AIDS, tuberculosis, and malaria put together. In industrialized countries, cancer is the leading cause of premature mortality and similar trends are emerging in developing countries UICC/WHO (2005). Cancer has become one of the ten leading causes of death in India. It is estimated that there are nearly 2-2.5 million cancers at any given point of time. Over 0.7 million new cases and 0.3 million deaths occur annually due to cancer in India. Unfortunately, 75% to 80% patients present in advanced stages of the disease when it becomes difficult to treat (Govt. of India, 2007).

Cultural beliefs affect both the risk factors for cancer as well as the meaning of the disease by establishing norms of behavior and providing guidance for its members to respond emotionally, cognitively, and socially to this disease. These beliefs mostly lead to delay in seeking medical treatment, thereby prolonging the interval between the first appearance of symptoms and the first visit to doctor. Thus, cultural beliefs and practices affect cancer care along the entire disease continuum: from prevention and early detection, treatment choices and adherence rates, management of side effects such as pain and its control, to appropriate psychosocial support, rehabilitation efforts, survivorship issues, hospice and effective end of life care (Kagawa-Singer, 2000).

Though it is evident that differences exist on many levels regarding different types of cancer, a general understanding of the mindset of cancer patients and the most basic myths affecting cancer in general is of utmost importance to the physician. It is with this intent that the investigators took up this study, conducted in one of the biggest government-run hospitals in Delhi, the capital city of India, which draws patients not only from Delhi, but also from other areas of Northern India.

Materials and Methods

The study was conducted among cancer patients attending the Out Patient Department (OPD) of Oncology and Radiotherapy of a teaching hospital of Delhi. A total of 95 patients were included in the study. A face-to-face interview was conducted using a pre-tested questionnaire containing 42 items. Information was obtained regarding beliefs, perceptions and myths about cancer among these patients and their outlook towards its treatment.

Only new cancer patients were interviewed before their consultation with the oncologist in the OPD on the first 3 days of the week. This was done so that the patient's views about his/her disease did not get altered. For the purpose of the study, a new patient implied a patient diagnosed within 1 month in any clinical specialty, with no history of previous malignancy or any suspicion of malignancy, which was investigated into. The patients

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included had to be 15 years or more of age, conscious, oriented and be able to understand either Hindi (the national language of India) or English.

Participation was optional and a written informed consent was taken from all the participants. The interviewees were assured of confidentiality of the data and that this would have no impact on their treatment by their respective doctor. The data were analyzed with the help of Epi-info software package.

Results

Equal numbers of male and female patients were included. Mean age of respondents was 52 years. The majority of the study subjects were semi-skilled (54.7%) and skilled workers (20%) with average income per month of whole group as Rs. 3217 (US$64). Majority of them were Hindu (80%) and married (91.6%). More than 60% of the patients were illiterate and belonged to Eastern and Northern regions of India.

Table 1. Myths and Misconceptions about Cancer

Questions	% age of patients N=95
Do you know what illness you have?	
(Yes/No) Positive Response	75.8
Did you go for treatment on suspicious of your illness?(Yes/No)	97.9
If YES then where?	
Allopathic medicine practitioner/hospital	48.4
Alternative medicine practitioner	30.1
Faith healer	21.5
If YES then how long were you treated? (Months)	
0-6 months	74
6-12 months	21
>12 months	5
Do you believe cancer is contagious?	
Yes	27.4
No	42.1
Don't know	30.5
If YES then why?	
Contact with CA patients/infectious secretions	57.7
After close contact from family members who have cancer	42.3
If YES, from where did you get this information?	
Peers	100
If NO then where did you get this information?	
School	5.3
Peers	26.3
Media	68.4
What kinds of people get cancer?	
People with bad habits (smoking/alcohol/drugs)	50.5
People who anger god/don't believe in god	26.3
People with injuries	2.1
Anyone	21.1
Do you believe that cancer can be caused by-	
Ill wishes	57.9
Spirits	48.4
Gods curse	58.9
Evil eye	60
Past or present sins	37.7
Immoral behavior	34
Do you believe that tobacco use causes cancer?	
Yes	44.2
No	42.1
Don't know	13.7

Awareness about the Disease

According to Table 1, the majority (75.8%) of patients were aware that they were suffering from cancer. There was a significant relationship with literacy (p=0.001).

Beliefs Regarding Causes of Cancer

Majority of the patients believed that cancer is caused by God's curse (59%), evil eye (60%), past or present sins (37%). 27.4% of the patients believed that cancer is infectious and more than half (57%) of these patients believed that since they had close contact with a cancer patient, it might be the reason for their present illness. Amongst those who believed that cancer is contagious, 78.3% were illiterate, 65.2% were women and 82.6% were in semi-skilled/unskilled occupational class. 42.1% of the patients believed that cancer is not contagious. A significant relationship was found between literacy and knowledge of the fact that cancer is not contagious (p=0.01).

Mass media were the source of information in majority (68.4%) of cases, while in 26.3% peers were the source . As far as awareness regarding risk factors is concerned, nearly half of the patients were aware that cancer is more common in people with risk factors. However, 21% of the participants were of the opinion that any one could get cancer. Only 44% patients believed that smoking or tobacco use could cause cancer, where as 42.1% did not perceive tobacco use as a risk factor for cancer.

Beliefs Regarding Treatment and Cure of Cancer

As seen in Table 2, only one third of the patients believed that cancer can be detected in its early stages and that it can be cured. Although the majority (65%) believed that cancer couldn't be cured by exorcism/ repenting for one's sins, the rationale behind it was distorted. Significantly more men as compared to women believed that it could be cured by exorcism or repenting for one's sins (p=0.06). Such patients had a significantly less chance of visiting an allopathic practitioner on development of symptoms (p=0.008).

Treatment Seeking Behavior

Regarding treatment seeking behavior, less than half (48%) of the patients went to an allopathic doctor or hospital for treatment after first appearance of symptoms. However, the average time taken by the patients to report to a doctor after suspecting their disease was 2 years. This delay could be attributed to the fact that nearly half (51.6%) of these patients first went to faith healers and practitioners of alternate medicine for approximately 6 months. This was decisive in their late presentation to an allopathic doctor. Some 60.7% of such patients were men, the usual decision makers in the family and community.

Misconceptions amongst Family Members

When asked about the social stigmas faced by cancer patients in their own families, it was found that majority (87%) of these patients were discriminated against in some

Table 2. Stigma, Perception and Health Seeking Behavior of Cancer Patients

Questions	% age of patients N=95
Do you believe cancer can be cured?	
Yes	37
No	63
Do you believe that performing rituals/worshipping/ exorcism/repenting for sins can cure cancer?	
Yes	34.7
No	65.3
If YES then why have you come here?	
Referred by well wisher	6
Forced to come here	21
You weren't cured by these methods	73
If NO then what is the rationale behind your belief?	
These methods have become ineffective recently	24.1
This curse has no remedy	75.9
Do you believe cancer can be prevented?	
Yes	14.7
No	20.0
Don't know	65.3
If YES then how?	
No bad habits (smoking/drinking/illicit sex)	92.9
Praying to god/rituals/exorcism	5
Avoiding contact with other cancer patients	2.1
If NO then where did you get this information?	
School	11.8
Peers	88.2
Media	0
Does someone else in your family have cancer?	
Yes	16.8
No	78.9
Don't know	16.3
If YES then do you believe that it was inevitable you had to get it too because he/she had it too?	
Yes	75
No	12.5
Don't know	12.5
Do you think that the behavior of other members of the family is different in any ways towards you?	
Yes	87.5
No	12.5
If YES, then in what way?	
Isolated completely	60
Separate clothes/food/utensils	40
Do you believe that people with cancer are incapable of leading a productive life?	
Yes	61.1
No	38.9
Do you believe that everyone who has cancer eventually dies?	
Yes	48.4
No	40.0
Don't know	11.6
Do you believe that you will be all right?	
Yes	47.4
No	10.5
Don't know	42.1

way or the other. In 60% of the cases, the patients were isolated completely.

Perceptions Regarding Outcome of Cancer

As far as self-appraisal of cancer patients is concerned, majority (61%) of the patients believed that cancer patients were incapable of leading productive lives. Nearly half (48%) of them held fatalistic views about the outcome of cancer. This group of patients needs to be the focus of counseling and rehabilitation services to improve their quality of life.

Discussion

The present study highlights that myths and misconceptions are widely prevalent among cancer patients. This is an indicator of literacy as well as social factors prevalent in the society. Although 75.8% of the patients were aware of the diagnosis, they had not undergone any sort of counseling, either by a professional counselor or a doctor. However, in a study conducted by Brokalaki et al (2004) among Greek patients with diagnoses of malignancies, over half of the patients evaluated were not aware of their diagnosis.

Here, the causes of cancer cited by patients were frequently curses, evil eye, spirits and past sin. In another study conducted among cancer patients in New Delhi, it was reported by Pahwa et al (2005) that many patients viewed their disease to be due to bad 'karma' (action). More than half of the respondents in the present study believed that cancer is contagious. This belief was also highlighted in the study conducted in West Bengal, India by Ray and Mandal (2004) where it was reported that about 21% of people thought that cancer is an infectious disease.

In our study, only 44% patients believed that smoking or tobacco use could cause cancer. Similarly Ray and Mandal (2004) reported that 44.67% of THE general population was aware of the major risk factors (like smoking and tobacco chewing).

It has been observed that there was a substantial delay in seeking medical treatment for cancer, here around 2 years. Rather than believing that allopathic medicine can provide palliation or even cure, they believed that there is no cure for this 'curse' and henceforth are also 'trying' allopathic therapy. This misconception needs to be addressed adequately. Mandal et al (2001) also reported that nearly 97% of cancer patients in their study appeared at hospital after several months, contributing to a moderate to advanced stage of the disease at first contact. Late reporting by the patients was attributed to lack of awareness about the symptoms of cancer.

Another important fact that came into light is that most of the cancer patients were being discriminated by their family and society. Almost 60% of the patients were facing complete isolation. The significance of this finding lies in the fact that behavior-modifying communication needs to be focused on society at large to convey the message that cancer is not contagious and that it is based on an individual's risk factors, which can be modified. It has also been noted that considerable stigma is attached to this disease. Ray and Mandal (2004) reported that over 11% of the respondents in their study suggested that a cancer diagnosis should be kept secret from neighbors due to some social stigma like problems with daughters' marriage.

A diagnosis of cancer may invoke uncertainty, fear, and loss. In our study, nearly all the patients responded with a feeling of hopelessness when asked what disease they have and a few patients were even afraid to mention the word 'cancer'. Similarly, in a study conducted amongst Tanzanian patients, Kazaura et al (2007) reported that only half of all patients showed their willingness to disclose their disease and a freedom to talk about the disease.5 Alexander et al (1993) in their study conducted among cancer patients in Manipal, India, also reported that major depression was seen in 13% of the patients.

A fatalistic view regarding cancer is an important force that discourages a patient from leading a productive life and propagates a sense of fear about cancer because he/she is a very important source of information in the community. This sense of fear coupled with inadequate knowledge leads to adoption of a negative attitude towards healthcare in general.

There is a major difference in cancer mortality among patients in developing countries as compared to developed countries. In a multi-national collaborative study conducted at breast cancer centers in India, Malaysia and Hong Kong, Agarwal et al (2007) emphasized that cancer mortality is significantly higher in developing Asian countries. This could be attributed to the inadequacies of health care infrastructures and standards and socio cultural barriers.

Pal and Mittal (2004) also concluded similar facts in their study. Studies have highlighted a constantly widening gap in quality of care in cancer patients in developed and developing countries. The research information and knowledge generated in the west may be of limited application in developing countries, due to differences in social and cultural attitudes, lifestyles and lack of sophisticated technologies. Since the death rates from cancer in the developing countries are set to rise at least 3-fold by the year 2025 largely due to the increased life expectancy, containment of infectious diseases and changing lifestyles, the biggest challenge before the clinicians now is the management of the rising incidence of cancer in developing countries, with little prospect of more resources becoming available to fight the disease. Cancer awareness and screening programs for early detection thus should continue to be given utmost attention

Sheikh and Ogden (1998) also reported that although the subjects knew which symptoms were indicative of cancer, this knowledge was not entirely predictive of their help seeking behavior. Their study provided insights into the beliefs which may explain the knowledge/behavior gap. It was emphasized that there is an important role of beliefs in mediating the association between knowledge and behavior, which have possible implications for developing educational programs. Practitioners and community-based organization leaders know the specific problems that exist in their communities, and can develop creative and effective means to address these needs. (Kagawa-Singer , 2000). Thus, beliefs and myths have an important role in cancer prevention and early help seeking.

However, the study had some limitations. These were: a) *Hawthorne effect* - Views expressed by the patients might be influenced by their knowledge of being observed under study. It is likely the patients had answered the questions in a manner, which might not be their true beliefs. b) *Pygmalion Effect* - Since the interview technique involved interaction between a doctor and a patient, a bias might exist in extracting answers relevant to the study. As blinding of subjects or observer was not possible in the study, the interview was kept on the basis of structured questionnaire.

In conclusion, the authors are of the opinion that in view of the rising incidence of cancer, health awareness campaign needs to be modified to address the issues pertaining to cancer patients. Also it is imperative that interventions targeted to improve health care seeking behavior among cancer patients need to include health education and sensitization specifically of cancer disease, and to establish strong referral mechanisms at primary health level. Local practitioners and community-based organizations can be of considerable help in this regard. The cancer prevention programs also need to adopt a protocol which provides counseling to cancer patients and their family members and rehabilitative efforts to improve their social status. More effort is also needed on the part of increasing awareness of screening tests and risk factors.

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