RESEARCH COMMUNICATION

Influence of Patient's Perceptions, Beliefs and Knowledge about Cancer on Treatment Decision Making in Pakistan

Shiyam Kumar[1]*, Asim Jamal Shaikh[2], Sana Khalid[3], Nehal Masood[2]

Abstract

Introduction: Cancer is a cause of major disease burden across the world and Pakistani data suggest that its incidence is increasing. Pakistan's socio-cultural history, social practices, religious beliefs and family systems differ in many ways from rest of the world. These factors make the practice of oncology a challenge. Materials and Methods: A comprehensive questionnaire focusing on socio-cultural and religious aspects was administered to patients with a diagnosis of cancer and receiving chemotherapy at the Aga Khan University Hospital, Karachi, Pakistan. Results: A total of 230 patients agreed to answer the questionnaire, with a mean age of 46 years and 63% were females. Obtaining some formal education was claimed by 87%, 75.2% had received some treatment before seeing an oncologist, including homeopathic physicians and faith healers. Of all 27 % thought that cancer is contagious, a fact observed more so in those who were illiterate, 27 % believed in some myth such as past sins, evil eye or God's curse as to be cause of their cancer, while 39.6% thought that cancer can be prevented by a regular religious activity. Some 30% thought that a meaningful life after diagnosis of cancer was not possible and 28%considered that they did not have proper information about chemotherapy. About 73% wanted to have their treatment related decision made by the treating physician. Conclusions: Patient related beliefs in myths and concerns are unique in the socio-cultural set up of Pakistan. If physicians are better aware of these factors, they may be able to handle patient related issues in a more effective way.

Key Words: Patient beliefs - perceptions - cancer treatment - Pakistan

Asian Pacific J Cancer Prev, **11**, 251-255

Introduction

More people die of cancer than from malaria, tuberculosis and AIDS combined together. The death toll from cancer is equally enormous in developing as well as developed countries (Kishore et al., 2008). Socio-economic and socio-cultural differences are known to contribute to increasing incidence of cancer worldwide by affecting the approach to screening, diagnosis and management of cancers. This socio-cultural impact on outcomes in cancer is observed throughout the world (Kagawa-Singer, 2000; Lukwago et al., 2003; Paskett et al., 2004; Talcott et al., 2007; Kishore et al., 2008). Prevailing beliefs and attitudes have great impact on the practices of a society for the prevention and diagnoses of a disease, decisions regarding its treatment, and care at the end of life (Kagawa-Singer 2000).

Diagnosis of cancer, is often a medical and social dilemma for the patients and their families, the word cancer has been a social stigma, and looked at and spoken with hesitation, therefore an open approach related to screening diagnosis and treatment discussions is not easy, specially when families of patients want to exclude patients from awareness about existence of disease itself. (Brokalaki et al., 2005; Chu et al., 2007; Kishore et al., 2008). Studies have focused on possible association of better outcomes in cancer when patient is part of decision making process, cultural differences in many parts of southeast Asia, do not allow this to happen frequently (Arora and McHorney, 2000; Maly et al., 2006; Watanabe et al., 2008).

Cancer like in the rest of the world is a major disease burden in Pakistan. Unfortunately no valid and authenticated tumor registry exists for the whole country, but hospital based reports and data from Karachi cancer registry (KCR), the most reliable registry with a track record of more than seven years now, do suggest that cancer is a major cause of disease burden in Pakistan and the burden is increasing by the day. The age standardized ratio (ASR) for all cancer combined for Pakistan; per KCR data is estimated to be 19.8/100000 (Bhurgri et al., 2004).

Pakistan has a unique socio-cultural environment; it has cultural and ethnic back ground dating back to years 2800-1800 BC, the era that is considered to be one of the world's first settled people. With this back ground its claim to represent one of the oldest human habitats cannot be denied. The region has formed a distinct cultural unit within the main cultural complex of South Asia, the Middle East and Central Asia from the earliest times. Modern Pakistani society is largely multilingual, multi-

*[1]Sultan Qaboos University Hospital, Muscat, Oman, [2]Section of Hematology/Oncology, Department of Medicine, Aga Khan University Hospital, Karachi, Pakistan, [3]Columbia University, New York *For Correspondence: bhagia1@yahoo.com*

ethnic and multicultural. Increasing globalization has amplified the influence of "Western culture" in Pakistan and currently it stands at rank 46th in the world on the Kearney/FP Globalization index. There are at least six major languages that are spoken here, English remains the official language of communication and Urdu is the national language. Sindhi, Punjabi, Pushto and Balochi are other major regional languages.

Pakistan has four provinces, each representing a different cultural group. Karachi is the largest city of Pakistan and its population is considered to be a representative sample of all Pakistan by having a mix of population groups found throughout the country, including people who migrated to here from neighboring India at the time of its independence from British Rule (Bhurgri, Bhurgri et al. 2002).

The socio-cultural set up of Pakistan is different from rest of western world in many ways therefore it is natural that the attitude, behavior and response of its population can differ from the rest of the world too, especially when it's related to coming to terms with disease.

Believing in myths and trusting traditional medicines has been part and parcel of disease management for the core population here (Nisar et al., 2007; Shafiq et al., 2008). Such differences for cancer in Pakistani population have scarcely been studied and limited to the use of alternative and traditional medicine's only, yet they suggest that such practices are much more common here in Pakistan compared to what are reported from west (Malik, 1997; Malik and Malik, 2000). Literature from the western and developed countries also suggest a great influence of socio-cultural practices, an area of residence (rural vs. urban) and gender differences on decisions regarding disease management (Creel 1995; Carlsson and Carlsson, 1997; Reynaert et al., 2000). With this background in mind we decided to conduct a study on patients coming to our tertiary care facility based in Karachi to see what influence the belief's and knowledge of such patients about cancer has on decisions regarding management.

Materials and Methods

A total of 241 patients, who came to the medical oncology day care clinic for chemotherapy were asked to fill in a questionnaire in Urdu (national language of the country) or English. All the patients included were diagnosed to have cancer and were undergoing some treatment. Patients who were illiterate were helped by the interviewer or the attendant family member. Terminally ill patients and those with other serious medical illness other than cancer were excluded. All patients signed an informed consent. However, 230 patients agreed to participate in the study.

The questionnaire

We designed the questionnaire after thorough review of literature for studies on this theme done in South Asia such as those of Kisore et al (2008) and Elkin et al (2007). Our Questionnaire was unique in itself as it included questions focusing on prevailing cultural practices and religious beliefs, education, and employment status, previous treatment for the disease, knowledge, beliefs and myths regarding risk factors for cancer and its treatment, role in decision making and satisfaction with the provided knowledge and treatment of cancer (Bruera et al., 2001).

We created the questionnaire in Urdu with In page ® software and first ran a pilot project on fifteen patients. Simple categorical variable based response was graded from scale of one to five and likard scale was used to record the response. Data were entered into the MicrosoftExcel ® spread sheet, statistical and social sciences package v. 16 ® was utilized to analyse responses. The study was conducted in accordance of ethical values according to Helinsinki declaration and The Institutional Ethical Review committee approved this study.

Results

A total of 241 patients were asked to fill in the questionnaire and out of those 230 patients consented and filled in the Performa. Mean age of the participants was 46 years (range 13-77 years). Gender distribution showed 63% participant to be females and rest males. Of all 77.4% were married, majority of them were Urdu speaking (64.3%). About 83% of participants claimed to have had some formal education and were able to read and write, one third of them had bachelor degree (33.5%). Among 145 female respondents 111 (76.55%) were housewives (see Table 1). Of all 91.7% of participants were aware of their diagnoses and 75.2% of them were treated previously for their symptoms and ailments by other physicians (non-oncologists), alternative medicines, homeopathic physicians or faith healers. Most reported to oncologists within 6 months (range 1 month to 2 years) of appearance/ suspicion of cancer diagnoses. Literacy level had a significant relation with early suspicion of disease ($p = 0.03$) and disease awareness ($p = 0.05$).

Perception and beliefs about cancer

Table 1. Participant Characteristics and Cancer Knowledge

Education Level	Illiterate	12%
	Primary	1%
	Middle	6%
	Metric	19%
	Intermediate	16%
	Bachelor Degree	34%
	Master Degree	12%
Participant's Occupation	House Wives	49%
	Office or Skilled	29%
	Unemployed	11%
	Retired	7.6%
	Student	3%
	Landowner	0.4%
Is Cancer Contagious?	No	73.5%
	Don't know	16.5%
	Yes	9.1%
	No response	0.9%
Causes of Cancer	Myths	27.4%
	Infection	13.9%
	Don't know	9.6%
	None of these	49.1%

Table 2. Patient's Perceptions for Cancer and Family

	Cancer is curable	Rituals[1]	History[2]	Inevitable[3]	Change[4]	Life[5]	Die soon[6]	Educated[7]
Yes	206 (89.6%)	138 (60.0%)	79 (34.3%)	10 (4.3%)	35 (15.2%)	57 (24.8%)	36 (15.7%)	166 (72.2%)
No	16 (7.0%)	79 (43.3%)	142 (61.7%)	66 (28.7%)	190 (82.6%)	162 (70.4%)	179 (77.8%)	42 (18.3%)
Don't know	8 (3.5%)	13 (5.6%)	9 (3.9%)	14 (6.1%)	5 (2.1%)	11 (4.8%)	3 (1.3%)	
No answer				140 (60.9%)			12 (5.2%)	22 (9.6%)

[1]Rituals can cure cancer?; [2]History of cancer in family; [3]Do you think it was inevitable for you to have cancer because of family history; [4]Change in family's behavior?; [5]Life with cancer is incapable?; [6]Patients with cancer die soon?; [7]Were you educated for your treatment?

Cancer was thought to be a contagious disease by 27.5% of patients. Of the 73.5% who thought cancer to be non contagious, 95% had some education compared to those who had none (p = 0.005). Of all, 63.5% respondents were of the view cancer is not specifically related to any social habits while 37.5% associated cancer to be related to some social habits such as taking alcohol (21.3%), not believing in God (5.7%) or infections, eating non home foods, God's curse, an evil eye and past sins, more females associated with the causes than males (p = 0.03) (see Table 1).

Beliefs and perceptions for cancer treatment

Cancer was thought to be potentially curable by 89.6%, additionally performing some rituals was thought to bring in a positive outcome by 60%. About two third (67.4%) thought that cancer is preventable (Table 2), 39.6% thought that regular religious activity can prevent cancer, 23.5% participants think that by avoiding unhealthy habits (smoking, alcohol) can help in cancer prevention while 34.3% did not answer to this question.

Knowledge and beliefs regarding outcome and treatment:

A meaningful life despite of cancer was thought to be possible by 70.4%. A total of 77.8% did not expect to die soon, Table 2. Female gender has significant association with this belief (p = 0.03). Of all respondents 72.2% thought they have adequate information about chemotherapy side effects. Source of information was primary physician, 45.2%; nurses, 4.8%; printed material and by other patients 23.9% and internet, 7.4%. Of all patients 39.6% were fully informed of their disease, treatment course and associated side effects while rest of patients wanted more information about their disease and treatment (Table 3).

Table 3. Beliefs and Perceptions regarding Decision-making

Decision making	Doctor makes final decision	74 (32.2%)
	Together with the doctor	52 (22.6%)
	Doctor makes the final decision considering my opinion	38 (16.5%)
	Will make final decision after listening to my doctor	23 (10.0%)
	Family makes final decision	21 (9.1%)
	No answer	21 (9.1%)
	Decide on my own	1 (0.4%)
Feel informed	Fully	91 (39.6%)
	Most of it	37 (16.1%)
	To some extent	61 (26.5%)
	Little bit	13 (5.7%)
	Not at all	10 (4.3%)
	No answer	18 (7.8%)

Attitudes towards decision making and being informed:

About 72% patients wanted their doctor to be either main decision maker with or without their own input, regarding their treatment, while 9.1% wanted their family to make decision about them (see Table 3).

Discussion

Cultural values have significant influences on attitudes towards disease process, including response to advice on screening, diagnosis, and strategies to cope with it (Gupta, 1956). A physician's knowledge of cultural patterns in area of practice help him deal with needs of the patient effectively and compassionately (Hausman, 2004). As simple as it may sound, however, differences in cultural patterns within the same geographical location make the physicians knowledge about area of practice all the more important (Kagawa-Singer, 2000).

Our study is an effort to look in to practices and belief of our society towards the diagnoses, treatment, risk factors and decision making behavior for the patients diagnosed with cancer. We find that education and literacy level has a significant impact on factual dealing with cancer and an important factor associated with inverse proportion with taboos and myths associated with cancer diagnosis (p = 0.05). Almost similar trends are seen by Kishore et al (2008) and Brokalaki et al (2005). We found that most of the patients at least visited the alternate healthcare givers or faith healers (33.9%) but only 6.9% were actually being treated by them as well. The trend of visiting alteranive medicine practisioners or faith healers is seen throughout the world albeit with proportions varying according to level of literacy or area of residence. An Indiana university study which surveyed a socioeconomically deprived group of participants but not affected by cancer found that majority of participant thought faith healers, intake of vitamins and alternative medicines have an important role in bringing about cure for cancers (Loehrer et al., 1991).

We tried to analyze prevalence of common fears and association of widely believed factors such as role of religion with regards to cancer diagnosis and treatment in our set up. The stigmas regarding cancer as being contagious were found to affect a significant 25.6% of our patients, more so in patients without any formal education (p = 0.05). Not following religious practices, God's curse, an evil eye, past sins, ill wishes and immoral behavior were some of the factors identified in our population to be related to cancer. Although literacy level were interestingly not found to affect the perception of this, but gender was, with females being more influenced by these factors (p = 0.03). Majority (60%) considered

performing rituals (offering prayers and asking for God's mercy) has an equal and important role in achieving cure for cancer and about one third thought that performing regular religious activities can in fact prevent cancers, this was true for both genders and not affected by literacy level. This fact highlights the importance of treating physician's awareness and sensitivity of this fact. This suggests that respecting religious beliefs and encouraging religious activities can build a positive physician patient bond.

We found a significant population in our study of cancer patients who were on treatment, believe that cancer is curable (89.6%); our finding surpass those observed by Loehrer et al (Loehrer et al., 1991), Phillips at al (1968) and are much higher than the findings reported by Kishore et al (Kishore et al., 2008). The efforts to increase the awareness of tobacco to be cause of cancer seem to have paid off in our society as we found that tobacco smoking is known to be related to cancer by a significant 81.3% of our population. Although this may seem impressive compared to studies from neighboring India (Kishore et al., 2008), results should be read with caution though as it still leaves an important 19.7% of population out. Amazingly females were better aware of smoking hazard fact compared to males ($p = 0.07$).

Although there is thought to be a strong family structure existing for most Pakistani families, we did not find significant number of patients reporting increasing care or loving change in family's attitude for the patient, this finding is subjective and may not be reflective of true family attitude but is being reported as such. Most of the cancer patients are frightened by the diagnosis and question their possible positive role in society; with different responses seen according to the level of education, gender, access to treatment modalities, financial status and family support system. Surprisingly females were more optimistic about their life as compared to males ($p = 0.03$) in our study, this appears in contrast to the findings from a British study (Morris et al., 2008).

Although physicians plays a major role in breaking the news, discussing treatment modalities, toxicities etc decision making remains an important issue. The three approaches described by Charles et al for decision making regarding patient's management range from an authoritative physician only method at every stage of management, to, including patient along from beginning to end (Charles et al.. 2003; Watanabe et al.. 2008).

Families and patients themselves are known to influence physician decision all around the world (Watanabe et al., 2008). Pakistani population, specially the rural population is male dominant and elder males of the family are known to make decisions for patients in a rural family system. Older patients are a special population as they play a less active role in decision making process (Elkin et al., 2007) while some times patients opt for passive role in decision making and leave all his decision making to treating physician (Arora and McHorney 2000). Physicians should specially be considerate for the treatment goals, cost and outcomes of the disease process in this population.

In conclusion our study has highlighted some of the core socio-cultural issues that relate to management of cancer patients. Our aim is not to criticize or comment upon patient's beliefs, perception, religious ideas or state of mind, but to highlight the presence and prevalence of these as such. If the treating physicians has some socio-cultural background of community at hand they may render greater empathy and compassion which is bound to alleviate many of the fears and factors for anxiety associated with cancers.

Acknowledgment

We are thankful to Raja Mahendar Nankani and Miss Erum Ghafoor, medical students from Chandka Mediacl College Larkana and Allama Iqbal Medical College Lahore for their contribution as interviewers in this study.

References

Arora NK, McHorney CA (2000). Patient preferences for medical decision making: who really wants to participate? *Med Care*, **38**, 335-41.

Bhurgri Y (2004). Karachi Cancer Registry Data--implications for the National Cancer Control Program of Pakistan. *Asian Pac J Cancer Prev*, **5**, 77-82.

Bhurgri Y, Bhurgri A, et al (2002). Cancer patterns in Karachi division (1998-1999). *J Pak Med Assoc*, **52**, 244-6.

Brokalaki EI, Sotiropoulos GC, et al (2005). Awareness of diagnosis, and information-seeking behavior of hospitalized cancer patients in Greece. *Support Care Cancer*, **13**, 938-42.

Bruera E, Sweeney C, et al (2001). Patient preferences versus physician perceptions of treatment decisions in cancer care. J Clin Oncol 19(11): 2883-2885.

Carlsson ME, Pm S (1997). Facts, misconceptions, and myths about cancer. What do patients with gynecological cancer and the female public at large know? *Gynecol Oncol*, **65**, 46-53.

Charles CA, Whelan T, et al (2003). Shared treatment decision making: what does it mean to physicians? *J Clin Oncol*, **21**, 932-6.

Chu DT, Kim SW, et al (2007). Patient attitudes towards chemotherapy as assessed by patient versus physician: a prospective observational study in advanced non-small cell lung cancer. *Lung Cancer*, **56**, 433-43.

Creel J (1995). Myths & facts ... about pain in cancer patients. *Nursing*, **25**, 55.

Elkin EB, Kim SH, et al (2007). Desire for information and involvement in treatment decisions: elderly cancer patients' preferences and their physicians' perceptions. *J Clin Oncol*, **25**, 5275-80.

Gupta N (1956). Influence of Hindu culture and social customs on psychosomatic disease in India. *Psychosom Med*, **18**, 506-10.

Hausman AV (2004). Measuring social aspects in the physician/patient relationship. *Health Marketing Quart*, **21**, 3-26.

Kagawa-Singer M (2000). A Socio-cultural perspective on cancer control issues for Asian Americans. *Asian Am Pac Isl J Health*, **8**, 12-17.

Kishore J, Ahmad I, et al (2008). Beliefs and perceptions about cancers among patients attending radiotherapy OPD in Delhi, India. *Asian Pac J Cancer Prev*, **9**, 155-8.

Loehrer, P. J., Sr., H. A. Greger, et al (1991). Knowledge and beliefs about cancer in a socioeconomically disadvantaged population. *Cancer*, **68**, 1665-71.

Lukwago SN, Kreuter MW, et al (2003). Sociocultural correlates of breast cancer knowledge and screening in urban African American women. *Am J Public Health*, **93**, 1271-4.

Malik I (1997). QACwcp, experience in Pakistan. Communication with the cancer patient, information and the truth. A Surbone and M. Zwitter. New York, The New York Academy of Sciences: New York: 300-308.

Malik I KN, Malik KW (2000). Use of unconventional methods of therapy by cancer patients in Pakistan. *Eur J Epidemiol*, **16**, 155-60.

Maly, R. C., Y. Umezawa, et al. (2006). Racial/ethnic group differences in treatment decision-making and treatment received among older breast carcinoma patients. *Cancer*, **106**, 957-65.

Morris AM, Billingsley KG, et al (2008). Residual treatment disparities after oncology referral for rectal cancer. *J Natl Cancer Inst*, **100**, 738-44.

Nisar N, Khan IA, et al. (2007). Myths about diabetes mellitus among non-diabetic individuals attending primary health care centers of Karachi subrubs. *J Coll Physicians Surg Pak*, **17**, 398-401.

Paskett ED, Tatum C, et al (2004). Racial differences in knowledge, attitudes, and cancer screening practices among a triracial rural population. *Cancer*, **101**, 2650-9.

Phillips A J (1968). Knowledge about cancer among Canadian men. *Can Med Assoc J*, **99**, 408-12.

Reynaert C, Libert Y, et al (2000). Psychogenesis of cancer: between myths, misuses and reality. *Bull Cancer*, **87**, 655-64.

Shafiq M, Tanwir M, et al (2008). Myths and fallacies about epilepsy among residents of a Karachi slum area. *Tropical Doctor*, **38**, 32-3.

Talcott JA, Spain P, et al (2007). Hidden barriers between knowledge and behavior: the North Carolina prostate cancer screening and treatment experience. *Cancer*, **109**, 1599-606.

Watanabe, Y., M. Takahashi, et al (2008). Japanese cancer patient participation in and satisfaction with treatment-related decision-making: A qualitative study. *BMC Public Health*, **8**, 77.