

## RESEARCH COMMUNICATION

# A Study on Community Perceptions of Common Cancers, Determinants of Community Behaviour and Program Implementation in New Delhi, India

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### Abstract

Assessment of perceptions of the community, the determinants and development of their behavior regarding common malignancies, helps in establishing evidence-based activities for prevention and early diagnosis of cancer. However information on this important aspect is lacking in our country. Qualitative methods were here used to obtain information through in depth interviews and Focus Group Discussions (FGDs) with all categories of identified stakeholders. Most were unaware of the activities of the cancer control program. Even the providers were not fully conversant. All respondents mentioned lack of diagnostic and treatment facilities in government, primary and secondary level facilities. Perceptions of different categories of stakeholders regarding why many community members did not attend screening camps and other services reflect the determinants of community behavior, acting independently as well as in combination. The cancer control program was thought to be restricted only to some private facilities and overcrowded government tertiary care facilities where the visits were time consuming. Almost all the facilities were considered curative oriented. Issues of supervision, monitoring and feedback were inadequately addressed by providers who were inadequately trained in many program activities. The program lacked effective planning, coordination and appropriate implementation at the grass roots level in Delhi. Social mobilization was grossly inadequate, as most of the community members were unaware of the existence of the program. Misconceptions about the risk factors, signs and symptoms, diagnosis, and treatment were common amongst community members as well as many of the providers. Thus the national cancer control program in our country needs further community participation and social mobilization. Accessibility, availability, acceptability and affordability of various preventive, curative and rehabilitative activities, as well as intersectoral coordination, training, supervision and monitoring of program activities, all need to be addressed to ensure the success of this important public health program.

**Keywords:** Cancers - perceptions - behaviour determinants - programme implementation - India

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### Introduction

The WHO estimates that by the year 2020, the number of cases of cancer will double in developing countries. It is estimated that there are 2-2.5 million cancer patients in India with 0.7-0.9 million new cases in a year (MoHFW, 2008). Cancer is the third major cause of death with 0.4 million deaths per annum. Many of these cases are preventable by simple and cost effective measures focused on primary and secondary levels of prevention. In India, Non Communicable Diseases (NCDs) especially Cardiovascular, diabetes, cancer and stroke have emerged as major public health problems. As per NCMH (2005), it is estimated that in 2005 NCDs accounted for 53% of all the deaths in India. There is evidence based information that NCDs are preventable through integrated and

comprehensive interventions

The analysis of Indian National Cancer Control Program (NCCP) documents reveals lack of community participation and social mobilization (MoHFW, 2002; MoHFW, 2005). Cancer is a disease viewed with fear and foreboding, as seen by many studies from different cultures and many societies have a fatalistic outlook to cancer (Niederdeppe and Levy, 2007; Consedine et al., 2008; Duran, 2011). In India, it evokes a strong emotional response as seen in our day to day practice even amongst many health professionals. Lack of appropriate knowledge, a sense of fear and alienation, financial barriers, prevalent attitudes in the community, inadequate penetration/ poor reach of program activities and socio-cultural factors have been shown to influence the attitudes of the community regarding cancers and affect the cancer control activities

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adversely (Moore and Spiegel, 2004; Smith et al., 2005).

Behavioral research plays an important role in cancer prevention and control. Behavioral aspects influence adherence to preventive activities, screening programs and treatment modalities. The assessment of perceptions of the community, the determinants of their behavior regarding common cancers, assists in establishing evidence based activities for prevention and early diagnosis of cancer. This is a pre-requisite for an effective cancer control program (Green and Kreuter, 1991) However, information on these important aspects is lacking in our country. There is a paucity of community studies regarding cancer and also insufficient number of community based evaluation of cancer therapy and needs of cancer patient studies, as NCCP evaluations have till date largely focused on healthcare facilities (NIHFW, 2002). Though a plethora of qualitative studies on various aspects of cancer are available in other countries (Villafuerte et al., 2007; Allen et al., 2007; Francis et al., 2011), in India, community based studies on cancer have looked at the issue mostly in a quantitative manner (Ray and Mandal, 2004; Seth et al., 2005) and there is a dearth and also a need for qualitative, in-depth studies in this area.

This study primarily evaluated a cross section of community members as well as other stake holders e.g. health professionals like social workers, nurses and para- medical staff, in order to understand: perceptions regarding common cancers; quality and reach of information, education and communication (IEC) by understanding the awareness; and key determinants which were influencing the utilization behavior); Social Mobilization (Process of awareness and demand creation, channels of communication, IEC issues, community participation); and Community Behavior (Socio-cultural beliefs/practices, perceived benefits, client conveniences and role of facilitators).

The qualitative findings from this study build on the quantitative work of the parent study (Seth, et al., 2005). The use of qualitative methods in formative research is becoming more accepted as a mode of scientific inquiry. It may be viewed as a vital precursor to a discussion of evidence-based research in the future. Krieger (1999) has shown that qualitative assessment makes it possible to uncover perceptions and beliefs at a micro-level. As Akpınar et al. (2011) have shown that knowledge level and attitude of health professionals are important factors in the control of breast cancer and health will improve in a society in which health personnel play an active role in health education and are a good role model in the society, the healthcare workers were also included in the study to assess their perceptions for their behaviour and also regarding community behaviours.

## Materials and Methods

This study was conducted in New Delhi, capital of India from the year 2005-2007. Qualitative methods were used to obtain this information. A methodology based on Rapid assessment procedure (RAP) was used as it permits quick and systematic data collection. This approach helped us to synthesize information from multiple sources and to

rationalize and objectively balance the evidence. Data was collected through in depth interviews and Focus Group Discussions (FGDs) with all categories of stakeholders identified for the study. Assent for taping the interviews and FGDs was obtained from all the participants. The interviews and FGDs were taped, transcribed and translated. Other methods of RAP were not used as it was felt that reasonable amount of information will be gathered by these two methods and some information will be available in a country which is woefully lacking in any qualitative information on this aspect. Though many models have been used by researchers worldwide to understand various aspects of community behavior towards cancers, we deliberately did not restrict ourselves to a specific model but in addition to other models we studied in-depth three models, the health belief model (Kirscht, 1998), the theory of reasoned action (Ajzen and Fishbein, 1980) and self-efficacy theory by Bandura (1997). The research framework was then developed to fulfill the objectives.

State of Delhi was the sampling frame, a district was the sampling unit and two districts of Delhi were studied to obtain the information relevant to the study objectives. A list of all the districts of Delhi was prepared and two districts were selected by draw of lots. The same method was used to select one non-slum and one slum cluster from each district. . The variation of slum and non slum was deliberately done in order to find out that to what extent the economic status of the people of both the economic and social category is contingent upon disease etiology (if at all there is any impact). There is always a tradeoff between research duration, quantity and accuracy of data collected. In qualitative methodology, the principles of optimal ignorance and appropriate imprecision are acceptable and necessary. Purposive sampling was preferred as the patients who were interviewed had a feeling of stigma, a fear of unknown (very disclosure may bring ostracisation of self and family). The individuals who could overcome such a mental blockage were part of the study. It was thought to be important to talk to all stakeholders including community members, those involved in national cancer control program policy, planning and implementation, health care workers of all strata and facilitators. A total of 140 in depth interviews and 6 FGDs (4 community, 2 health workers) were conducted; details have been shown in Table 1.

A multidisciplinary team comprising of clinicians, social scientists, public health specialist and epidemiologist did several hours of brainstorming and formulated the study instruments. The instruments had open-ended questions and were pre tested on a few other stakeholders to check for its validity and reliability. Strict quality assurance measures were implemented. Method and data triangulation was carried out to ensure a high quality of data. The data obtained was screened on the basis of transcribed text. The responses were free listed and grouped into domains that emerged from free listed responses. Thereafter the free listed responses were coded into domains. Coded responses were entered into the computer and data analyzed in consonance with stated objectives of the study. Our use of multiple qualitative

methods within the framework of community-based participatory research increased our confidence that our results have validity within the confines of our study sample. Assessing its generalizability would be an appropriate focus for future research.

#### Health setting of metropolis

In the context of cancers, efforts towards prevention, health promotion and early diagnosis, provision of affordable diagnostic and treatment facilities and rehabilitation seem to be non-comprehensive with various uncoordinated efforts in all directions and by various agencies. As India is in a phase of epidemiological transition, the focus of public health sector is still largely towards communicable diseases. The primary health care system with its network of sub centers, primary health

centers (PHCs) and community health centers (CHCs) is not as yet geared up for early diagnosis and management of cancers. In the cities too, the existing urban health centers (UHCs) and various dispensaries lack basic infrastructure for carrying out any cancer related activities.

#### Community setting

Increasing urbanization due to various social pull and push factors has led to a large number of people staying in urban areas and working in its unorganized sector. The appropriate health care facilities are generally available only to the organized sector workers. Others are forced to utilize private sector with its attendant problems of huge cost leading to indebtedness and its focus on curative services only. Thus, the poor, marginalized and unorganized sector workers are denied any preventive and promotive activities towards prevention of cancers.

The number of urban slum-dwellers in India rose from 27.9 million in 1981 to 46.2 million in 1991 and 61.8 million in 2001 (MoHUPA, 2011). The country's financial capital, Mumbai, houses the largest number of urban slums and some 6.5 million people live in them. New Delhi follows, with 1.8 million people living in squalor, bereft of even the basic necessities of sanitation and clean drinking water. With more than 70,000 slums in our country, 15.5% of the population living in urban slums and the fact that 33% of the population of major cities reside in the slums, it was felt important to assess the community perceptions specifically for the slum as well as non slum population. Demographic details of the community members have been shown in Table 2.

**Table 1. Profile of the Interviews Conducted in Each Study District**

Stakeholders	No. to be interviewed per District		Total*	Total**	Focus Group Discussions (FGDs)
	Non Slum	Slum			
1 Program Planners & Managers					
		2	2	4	
2 Doctors, Allopathic (Minimum MBBS)					
Government	2	2	4	8	
Private	2	2	4	8	
3 Doctors (Other systems)					
Government	2	-	2	4	
Private	2	2	4	8	
4 Nurses/Compounders					
Government	2	2	4	8	2
Private	2	2	4	8	
				88	
5 MSW	2	2	4	8	
6 Facilitators					
NGO's&Leaders	1	1	2	4	
7 Community Members					
20-60 yrs.	20	20	40	80	4
TOTAL			70	140	6

\* Total interviews in each district of Delhi, \*\* Total interviews in two districts of Delhi (Total study sample)

## Results

In-depth interviews with open ended questions and FGDs helped us in bringing out the perceptions of the community as well as other stakeholders in great detail in comparison to a quantitative study approach. Qualifiers have been used to explain the results to convey approximate proportion of participants' responses. The qualifiers have been shown in Table 3. The category of respondent whose responses have been used as quotable quotes have been shown in parenthesis: CNS-Community participant from

**Table 2. Demographic Details of the Study Participants**

	SLUM		NON SLUM	
	District 1	District 2	District 1	District 2
1 State of origin	South Indian-75%, U.P & Bihar- 25%	U.P & Bihar-60%, Haryana-15%, Muslim-25%	U.P & Bihar-50%, Haryana & Delhi-50%	Population represent- ing almost all States
2 Sector of service	Majority working at private sector	Government & Private sector, Government- 10- 15%, Private- 85%	30% in government ser- vice, 70-80% in private sector	100% government employees
3 Income pattern	Salaried and daily wagers	Salaried and daily wagers	Salaried and daily wagers	All salaried
4 Occupation sites	Petrol pump, restaurants, shops, catering agencies. The ladies were mostly domestic help in neighbor- ing government flats.	Municipal corporation Schools. Private- Shops, Restaurants, Small scale business, dairy etc.	Small scale entrepre- neurs – blue collar jobs.	White collar jobs

**Table 3. Qualifiers used for Results**

Qualifier Used	Percentage of respondents
1 Almost all	> 90%
2 Majority	70 – 90%
3 Many	40 – 69%
4 Few / Some	11 - 39%
5 Very few	< 10%

non slum area; CS-Community participant from slum area; M-male; F-female; HCW-health care worker.

#### *Knowledge regarding Etiology and Vulnerability to Cancers*

Most of the respondents felt that cancer was a very dangerous/ frightening disease and was fatal if not treated. However a few of them desired additional information about cancer to enable them in taking preventive actions. Only some of them were aware that early treatment was more affective in achieving better cure of cancer. *“It is dangerous, we need to know more about how it occurs”* (CNS-M)

The majority of community members, in slums as well as non slum localities, felt that cancer could happen to anyone. A few felt it happened more to those taking addictive substances (Tobacco products, alcohol and drugs). Some felt it happened only to adults, more in women or in the elderly population. A few felt it was a common entity and any disease (illness) not treated properly could become cancerous. *“Cancer can happen to ordinary people. Those who smoke get it, but I have seen a person who does not even drink tea but got cancer”* (CNS-M).

The doctors of allopathic system of medicine felt that community members are scared of cancer and their ideas about the community’s perceptions matched with what community members mentioned. However, doctors from other systems of medicine (traditional systems of medicine common in India- Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homeopathy [AYUSH]) said that community members thought cancers to be due to sins of past life and negative thoughts. *“Long term resentments, suppressed emotions, negative thoughts and past sins can cause cancers”* (Doctor, AYUSH)

#### *Common Cancer Sites*

The common sites of cancer in men as per community were mouth, neck (throat), lung, teeth, chest and stomach. Other listed were blood cancer, cancers of tongue, esophagus, kidney, prostate and intestines. Very few listed all the correct responses, even they too listed teeth, kidney and intestinal cancers (which are rare), these may reflect other perceived health needs, especially for dental disorders, unrelated to cancer.

Few of the health care workers (HCWs) were aware of common cancers in men, the rest had either no knowledge or incorrect knowledge e.g. kidney, prostate, etc. The order of importance as provided by Non government (NGO) HCWs was different from the community response. The doctors were able to correctly enumerate all the common cancers in males as well as females. However few of them

additionally mentioned few of the uncommon cancers as common cancers.

#### *Risk Factors*

Smoking and chewing tobacco, *gutkha* (pouch containing shredded and dried tobacco leaves and essence of rose water etc.), pan parag (flavoured areca nut pieces with or without tobacco) and alcohol were listed as the common risk factors by the community. Dirt, unhygienic conditions, carelessness, pollution, dietary habits, not breast feeding children and genetic factors were also mentioned by a few. Also, not getting health check ups, lack of awareness regarding the risk factors for cancer, wrong or improper treatment and lack of money were the other reasons stated. Few perceived reduced risk of cancer in women, as they do not smoke or use *gutkha*. Not having correct information and carelessness regarding one’s health was seen as risk factors by a few of the respondents in slum areas. In men, smoking and taking addictive substances; and in women, “internal problems” and having too many children were implicated as major risk factors by the community. Some community participants also mentioned the lack of complete information about risk factors. However, there were some misconceptions, it was felt that any lump could be cancerous, inappropriate medicines and negligence could lead to cancer and “*bad blood*” could also lead to cancer.

The responses of majority of the HCWs were similar to those of the community members, in addition they also mentioned *Bidi* (a locally made cigarette made from tendu leaves and tobacco), cigarette, *Paan* (betel leaf stuffed with areca nut, with or without tobacco and other flavoring agents), tobacco, lack of adequate nutrition and multi parity. However some of them mentioned unrelated factors like consumption of mutton and fish (though consumption of red meat and its association with cancers has been well documented especially in western world- it is unclear whether the respondents really knew about this or this was due to belief that non vegetarian food is bad). The HCWs also brought out the issue of social class having an impact on type or risk of cancer. *“In the lower class there is more mouth cancer in those who consume tobacco. Those who do not have good diet have hereditary cause. Upper class also has some cancers. Sunrays, UV rays can cause cancer”* (HCW, FGD)

Though the NGO supervisors and HCWs mentioned many factors like, tobacco in all its forms, alcohol, drug addiction, early marriage, repeated abortions, home deliveries, sexually transmitted diseases (STDs), internal injuries and accidents, the overall situation was summed up by one of the participants, shown in quote below. *“We ourselves do not know about cancer”* (HCW-M).

#### *Signs and Symptoms and Spread*

All commonly known signs and symptoms were known to the community members. The community mentioned lack of awareness, not taking treatment early in the disease and not completing all the courses of therapy as modalities of spread of cancer within the body.

The HCWs mentioned lack of routine health checkups, lack of knowledge, repeated deliveries, tobacco and all



other addictive substances as modalities of spread of Cancer and thought that any untreated disease has the potential of transforming into cancer. However a few observed that the incidence of Cancer was not increasing so much but that cancer patients are living longer than before. Moreover because of the increased life expectancy the chance of getting cancer are increased as it is found in older people.

#### *Knowledge about Therapy*

In non-slums, surgery and medicines were the commonly known modalities of treatment with few of the community members listing Radiotherapy. Many said that treatment modality depends on the doctor and they would do what the doctor or hospital would tell them to do. Few stated that *jhar-phuk* (an alternative traditional system of medicine-[faith healing]) does not cure cancer. Majority of the HCWs stated that if the treatment is provided in the “*first stage, then only it works*” and every cancer patient must take treatment, even though the treatment is costly.

#### *Health Care Seeking Behavior*

A few of the study participants knew someone close who suffered from cancer. These patients were evaluated in a primary hospital but diagnosis could not be made and finally referred to a bigger hospital (tertiary care) for treatment.

When asked about a hypothetical situation of the respondents themselves suffering from a lump, majority stated they would go to a doctor/hospital immediately for a checkup and treatment. The responses were similar in slum and non slum areas. However, very few of them felt the need to go for medical treatment for each and every lump and would first see if it (lump/lesion) is “*ordinary*” (non cancer) or increasing or if there was pain, and then only go to a doctor. The type of health facility also varied as some of them mentioned nearby hospitals or local doctors, few mentioned names of tertiary care hospitals in the city. “*We may be afraid at first. Then we will get a checkup and treatment. We should see if this is something ordinary or something else*” (CNS- F) “*I found a lump, put soda on it, now it has occurred again but I have not gone to a doctor*” (CNS-F).

#### *Reasons for Delayed Treatment*

In slums as well as non slums, the reasons given for some cancer patients not reaching the health facilities on time ranged from lack of finances, carelessness, lack of knowledge and wasting time with unqualified health personnel. Many of them felt that paucity of knowledge was an important factor resultant in delays, people are unaware of the early signs and symptoms of cancer and do not know where to go for consultation. Both in slums as well as non-slums, respondents perceived inadequacies in the primary health care system and doctors’ inability to diagnose cancer in early stages leading to delay in reaching correct place. Depression and helplessness were other factors implicated in preventing patients from reaching the correct place at the right time. “*First they go to an ordinary doctor who does not know. Then when they go to a big hospital, it is too late*” (CNS-F) “*People do not*

*have time, don’t admit they are very sick. They feel it is not worth it to go to a doctor. That is why the delay*”(CS-M)

In contrast, the majority of health care workers and doctors thought that the main reason for delay in treatment was lack of knowledge. Other factors mentioned were issues pertaining to accessibility, conveniences and opportunity cost.

#### *Factors affecting Completion of Treatment*

The main issues mentioned were of financial problems, lack of appropriate information and acceptability of Public Health Care as reasons for not completing treatment. Some also mentioned negative attitude of doctors while dealing with patients from slums, leading to delay/wrong diagnosis and also non availability of medicines at public health facilities. “*Do not have faith in the public dispensaries/hospitals. Cancer is a big disease, No treatment for us people from the government. Those with government jobs, get free treatment. Poor people hang in the middle with no money. How are we to be saved from this disease?*”(CS- F)

The majority of respondents felt that a lot of money is required for cancer treatment and even more so in private hospitals. The high cost of care is due to expensive tests and costly medications. There is lack of uniform insurance coverage; a minority of people has insurance from employment and purchase of private insurance policies. The respondents also highlighted the disparity based on financial status. Though the treatment was perceived to be costly in private hospitals but the majority opinion was that whether government or private, it costs money and as many people do not have money they die due to the untreated disease. “*Cancer ruins the home, you have to admit the patient, the treatment is very expensive, you have to spend money on checkups and medicine even if you do not have money for food. Only those with money can get treatment*” (CS- FGD)

#### *Gender and Socio-Economic Discrimination*

Existence of gender bias was mentioned by many. Need for a study on the reasons for less seriousness related to women’s health was also mentioned. It was felt by the majority that another very serious form of discrimination was due to financial disparity and even Government hospitals were involved in discrimination of poor and uneducated patients. Similar opinions were voiced by NGO staff. “*Many people do not show a wife or daughter (to the doctor), they say let them die, money will be saved*” (CNS-FGD)

The doctors were divided in their opinion regarding gender discrimination with some (especially female doctors) feeling prevalent gender discrimination. However few of them said there is no gender discrimination in private sector. All of them thought that socio economic discrimination did exist due to cost factor.

#### *Perceived benefits*

The majority of community members thought that it would feel good to attend a camp as they would receive some information about cancer. However most of them had never attended any camp even when one was organized in their locality as they perceived them to be

having inadequate facilities. The community members felt that treatment taken appropriately and in a timely fashion is beneficial and very effective. However they also voiced their concerns about the prohibitive cost of treatment. A few from the non-slum areas who had prior experience with cancer treatment were not very enthusiastic about therapy as they perceived it was not effective.

#### *Social Mobilization Channels*

Television, Doctors, hospitals, posters, banners, friends, radio and media were listed as the important sources of information, education and communication (IEC). However it was felt that TV was not providing the amount of information required on various types of cancers. Doctors and health workers, especially from NGOs, came occasionally and held camps but with little follow up. *“A lot of work is being done for TB but none for cancer”* (CS- M)

Most of the HCWs also held similar views regarding cancer related activities. The cancer related work by the non government organizations (NGOs) however varied in scope in relation to the aims of the NGO. However they themselves felt that there was a lot of knowledge about tuberculosis (TB) and AIDS and the level of knowledge regarding cancer should be scaled up. Few NGOs were actively working in this field. However, all HCWs were unanimous about non-existence of any diagnostic and treatment facilities close by, thus affecting the social mobilization adversely.

#### *Suggestions*

As per community members, the Government should increase facilities, waiting time at hospitals needed to be reduced and treatment cost decreased with provision of free treatment for the poor. Legislation/ control on tobacco and alcohol were mentioned by many of the respondents. Increasing the number of hospitals was another suggestion. Various IEC activities, in the form of camps, *nukkad natak* (street plays), etc should be organized and the program should have the same visibility as the Pulse Polio (universal oral polio immunization program in India) program. *“Government should ban tobacco as passive smoking is a reason for getting cancer”* (CS-F) *“Cancer should be removed from its root. The government should take some action. Like polio, the government must get after cancer”* (CNS-M)

All the HCWs workers felt that regular checkups especially after the age of 40 yrs were an important preventive step. Avoidance of tobacco products and alcohol was also thought to be important. Receiving treatment for minor problems, eating healthy food, exercising regularly were other strategies for reducing the chances of getting cancer. Patients require moral support. Some stressed the need of Cancer related knowledge which should be imparted by all the hospitals. *“Should increase number of cancer hospitals. Patients should complete treatment and not leave in the middle”* (HCW-F).

The NGOs wanted to do more on cancer detection but felt that it was difficult due to the lack of facilities and the need of technical assistance from a higher center. They stressed the need for a uniform policy for the whole

country.

The doctors thought that improved levels of education, increased awareness by behavioral change communication (BCC), outreach activities and health insurance would lead to better services. They also suggested involvement of alternate systems of medicine and provision of emotional support during terminal care.

## **Discussion**

Our past experience with close-ended questions informed us only about the prevalent knowledge, attitudes, and practices but we did not succeed in assessing the determinants of these prevalent attitudes and practices. This qualitative study data has complemented the already available knowledge about the study community obtained from prior quantitative research (Seth et al., 2005).

Published reports show that little research has been carried out into the community's perceptions of cancer except in areas related to the value of screening procedures, or in people who have the disease, have a close relative with the disease, or are health professionals. There is little or no information about the knowledge or concerns of the general public about the relative importance of various risk factors or of their perception of survival rates or trends in cancer morbidity and mortality (Baghurst et al., 1992; Moore and Spiegel, 2004).

In our study, majority of the participants mentioned that anyone could get cancer and any part of the body may be affected but that some sites in the body are commonly afflicted. However a very rare cancer in teeth was also listed as a common cancer, this has not been described in studies from other countries this could reflect an error in identifying oral cancer or point to their need for dental care, if teeth problems were a high health priority for the individual. They may have confused dental decay, and periodontitis with some form of cancer.

Compared to the knowledge regarding male cancers, the awareness of female cancers was limited in both sexes. This is despite more emphasis on breast and cervical cancer by the government and NGOs. This may reflect the gender bias, social inhibitions or the importance of cervical and breast cancers being subsumed by the male dominant tobacco related activities. This is an important issue to be dealt with as this may be one of the important reasons for delayed health care seeking in females. In our society, the woman is mostly on the receiving end. Her sickness due to cancer is not a matter to be empathized with and treated at the earliest rather it is too awful an issue to be brought out in open as it may be perceived as a loss of femininity and existential value of womanhood. It also incorporates embarrassment, fear, shame and shyness to divulge problems regarding two taboo subjects cancer and the female organs. Anwar et al. (2012) in their narrative review of existing literature on health seeking behavior in Pakistan also mentioned the issues of women autonomy and other beliefs regarding illnesses in women. However, this situation may be due to women's own attitudes as Duran, (2011) has shown in Turkey that despite being aware of the necessity of preventive practices for cervical cancer, the women did not have positive health behavior.

Maree and Wright (2010), have shown that women's knowledge and understanding of cancer and health seeking behavior related to cancer do not facilitate early detection and the fundamental strategy of primary and secondary prevention of cancer remains a challenge. This complex interplay of societal pressures, role of women in society, their empowerment and on the other hand their own perceptions, attitude and behaviours need to be addressed for the success of any health programme.

Though a wide range of signs, symptoms and causes were mentioned by the community members, many prevalent misconceptions similar to the findings of the quantitative studies conducted in different states of India were also brought out (Ray and Mandal, 2004; Seth et al., 2005). This is important as a review by Smith et al. (2005) has shown that the way the individuals recognized abnormalities, attributed body changes and assessed the seriousness of their condition affected the time taken to seek help. However, despite incomplete knowledge and misconceptions regarding causes of cancers, a positive finding in our study is the lack of emphasis on superstitions which is at variance with findings in other developing countries as shown by Anwar et al. (2012).

Other studies have corroborated our finding of a differing perception of the major risk factors for cancer of various sites and Stress was also rated highly as a risk factor. However alcohol consumption was rated high in our study as compared to being rated low in some studies from the developed world (Baghurst et al., 1992). In a study in UK, the most widely known risk factor was smoking, followed by having many sexual partners, older age was a little known risk factor along with awareness that family history may pose a threat, but most considered that stress might be a risk factor (Wardle et al., 2001). Alcohol has been rated high in our study probably as alcohol consumption is not taken as an acceptable behavior by the community. Like our findings of differing risk perceptions among slum and non slum community members, other studies have shown that perception of risk factors depend on various other factors like personal risk taking behavior, socio-economic status, etc. (Donati et al., 2012).

Cancer had an ominous connotation in the minds of majority of study participants of our study. They almost uniformly felt it was a dangerous disease with an invariably fatal outcome and were apprehensive about getting the disease. Allen et al. (2007) also found similar fear of cancer among African men with many perceiving cancer as a death sentence. These findings bring out a felt need of information education and communication (IEC) as also highlighted by other studies (Seth et al., 2005; Aswathy et al., 2006). These findings, in our study, were found in all strata of the society irrespective of the education, place of living, income and occupation in stark contrast with similar findings being found only amongst the marginalized in the developed countries (Kwok and Sullivan, 2006; Lyttle and Stadelman, 2006; Allen et al., 2007).

A survey in European countries found that despite raised awareness of the need for the public to be well informed about cancer, and for patients to be educated

about their disease and treatment, there were still shortcomings in the delivery of information. Opinion surveys have long demonstrated the public as having ignorance about cancer and one of the greatest fears is often that they may not be given sufficient information to cope with their disease and its treatment (Serin et al., 1998). Most information was being passed on by 'word of mouth' from family and friends whose understanding was restricted. This may result in misinformation, with unfounded fears and prejudices being promulgated and negative attitudes to cancer reinforced. Other common sources of information were TV, radio, magazines and newspapers. Again, these are sources that have a variable degree of accuracy, and which may be motivated to highlight the more dramatic aspects of cancer and its treatment (Veronesi et al., 1999). In fact, Duran, (2011) has shown that little trust is placed by many women in television and radio. In our study too, various sources of information were listed by the respondents and misinformation has been demonstrated in the results. Bredart et al. (1999) found that insufficient quality of health care provision may constitute an additional burden on patients. Besides, dissatisfaction with care may alter an already challenged compliance which in turn may undermine treatment effectiveness. This has also been shown by our study as per responses by all categories of participants.

Our study also shows considerable gaps in patient education and a degree of dissatisfaction with the scant information received. Rao et al. (2005) have clearly demonstrated the inability of IEC efforts to penetrate into the community by a study done in southern part of India. On the other hand, studies have shown that there was a need for detailed health education for early diagnosis and information from health care workers was more effective in not only changing the knowledge and attitudes but also the practices like early reporting to health care facilities and taking part in screening programmes (Ruth et al., 2010; Duran, 2011). In this regard, the knowledge level and attitude of HCWs being of importance has been shown by Akpınar (2011). The implications of these findings are very ominous for our country as majority of HCWs in our study were themselves in dark about cancers, the national cancer control programme and effective methods of communication.

Barriers to healthcare have been studied by many researchers all over the world. In our study we were interested in seeing if the responses in the community would reflect the dichotomy between communities and reflect the hurdles and hindrances to care. Though the world is now moving towards sequencing of the human genome assuming it to have major impact on the prevention, diagnosis, treatment, monitoring and outcome of cancer, scenario on ground, as also shown by our study and also many other studies is different. A synthesis of qualitative research by Smith et al. (2005) has clearly shown that patients with different types of cancer and from different countries had similar help-seeking experiences. Recognition and interpretation of symptoms and fear of consultation (embarrassment and cancer itself) were identified as main themes in delay in presentation. The



patient's gender and the sanctioning of help seeking also affected the health care seeking behavior. Unger-Saldaña and Infante-Castañeda (2011) have shown that delay is a result of the interplay between the patient's socio-cultural context, individual characteristics that influence symptom interpretation and decision-making, interaction with the social network and types of support obtained, and aspects of the local health services. Socio-economic differences in cancer burden and care have also been shown in other South Asian countries (Kurkure and Yeole, 2006). The health care programmes thus need to go beyond the provisioning of services and integrate with the other aspects of health care seeking behavior to be effective. Meanwhile, Cancer awareness and screening programs for early detection thus should be continued to prevent further widening of the divide of cancer care to the rich and poor (Pal and Mittal, 2004).

Beliefs and practices about cancer prevention are influenced by cognitive social factors (Kurkure and Yeole, 2006). As per Ersin and Bahar (2011), most frequently used models towards breast cancer early diagnosis behaviors are Health Belief Model, Planned Behavior Theory, Transtheoretical model, Precede-Proceed Model, Social Learning Theory and Health Promotion Model. In our study, cancer knowledge and corresponding appropriate behavior were independent of each other. The community members clearly mentioned that factors other than knowledge affect access to health care utilization, whereas in contrast, the health workers and doctors only looked at improved knowledge as a means of increasing the health care utilization. This is important because it runs contrary to the assumption (as also shown by knowledge and perceptions of HCWs in our study) that if people are adequately informed about cancer, they will automatically take appropriate action. While knowledge may be necessary in this regard, it is not always sufficient to instill new habits (Champion, 1988). This is consistent with, health belief model (Rosentock, 1994), which assumes that perceived susceptibility to cancer is one variable that mediates protective action. It is also consistent with self-efficacy theory by Bandura (1997), the core of which is that individuals' beliefs about their ability to perform a behavior (efficacy expectations) and its associated consequences (outcome expectations) are of primary importance in determining whether the amount of effort that goes into it, and whether they face difficulties. Our study, just like Yousuff et al. (2011) in their study using various models have shown important aspects as: addressing health system shortcoming, especially at the level of health policy and implementation level; need of information to community regarding not only about screening practices but also the signs and symptoms of cancers; and need of integrative strategies for effective action for healthcare seeking behavior by the community.

In recommendations, the cancer control program in our country needs to incorporate issues of community participation, social mobilization, accessibility and affordability of its various preventive, curative and rehabilitative activities. Inter-sectoral coordination, training, supervision and monitoring of the activities need to be addressed to ensure the success of this important

public health program. Private and community sponsored, need based programs must be conducted. Without a comprehensive grassroots effort, significant progress in preventing cancers and ensuring early diagnosis and treatment will remain elusive. However, as Kurkure and Yeole (2006) have mentioned that prevention and early detection programs will be effective only when associated with programs for elimination of poverty, illiteracy and restoring social inequity.

Different target groups will require different approaches and the problem of hard to reach groups can be overcome by stakeholder participation. Multi-sectoral interventions for providing an enabling environment will have maximum effectiveness in primary prevention which will reduce the disease burden and the available resources then could be effectively utilized for the early detection and management of the residual cases. Based on the results of present study, we have launched a community intervention trial for assessing various communication strategies for cancers. However, it is just a small effort and more studies and interventions are required as mentioned in preceding paragraphs.

## References

- Ajzen I, Fishbein M (1980). Understanding attitudes and predicting behavior. Englewood Cliffs, NJ: Prentice Hall.
- Allen J D, Kennedy M, Wilson-Glover A, Gilligan T D (2007). African-American men's perceptions about prostate cancer: implications for designing educational interventions. *Social Science & Medicine*, **64**, 2189-0.
- Akpınar YY, Baykan Z, Naçar M, Gün I, Çetinkaya F (2011). Knowledge, Attitude about breast cancer and practice of breast cancer screening among female health care professionals: A study from Turkey. *Asian Pacific J Cancer Prev*, **12**, 3063-8.
- Anwar M, Green J, Norris P (2012). Health-seeking behaviour in Pakistan: A narrative review of the existing literature. *Public Health*, doi:10.1016/j.puhe.2012.02.006
- Aswathy S, Sumithra S, Valsala L S, et al (2006). Self reported morbidity and awareness regarding common cancers in elderly women. *J Communicable Dis*, **38**, 106-1.
- Baghurst KI, Baghurst PA, Record SJ (1992). Public perceptions of the role of dietary and other environmental factors in cancer causation or prevention. *J Epidemiol Community Health*, **46**, 120-6.
- Bandura A (1997). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review*, **84**, 191-5.
- Bredart A, Razavi D, Robertson C, et al (1999). A comprehensive assessment of satisfaction with care: preliminary psychometric analysis in an oncology institute in Italy. *Ann Oncol*, **10**, 839-6.
- Champion VL (1988). Attitudinal variables related to intention, frequency and proficiency of breast self-examination in women 35 and over. *Res Nursing Health*, **11**, 283-1.
- Consedine NS, Adjei BA, Ramirez PM, Mckiernan JM (2008). An object lesson: source determines the relations that trait anxiety, prostate cancer worry, and screening fear hold with prostate screening frequency. *Cancer Epidemiol Biomarkers Prev*, **17**, 1631-9.
- Donati S, Giambi C, Declich S, et al (2012). Knowledge, attitude and practice in primary and secondary cervical cancer prevention among young adult Italian women. *Vaccine*, **30**, 2075-2.



- Duran ET (2011). Examination with the health belief model of women's attitudes to cervical cancer and early diagnosis in Turkey: A qualitative study. *Asian Pacific J Cancer Prev*, **12**, 1179-4.
- Ersin F, Bahar Z (2011). Effect of health belief model and health promotion model on breast cancer early diagnosis behavior: A systematic review. *Asian Pacific J Cancer Prev*, **12**, 2555-2.
- Francis SA, Battle-Fisher M, Liverpool J, et al (2011). A qualitative analysis of South African women's knowledge, attitudes, and beliefs about HPV and cervical cancer prevention, vaccine awareness and acceptance, and maternal-child communication about sexual health. *Vaccine*, **29**, 8760-5.
- Green LW, Kreuter MW (1991). Health promotion planning: an educational and environmental approach. 2nd ed. Mountain View, CA: Mayfield Publishing.
- Kirscht J (1998). The health belief model and predictions of health actions. In D. Gochman (Ed.), Health behavior: emerging research perspectives, (pp. 27-42). New York, USA: Plenum Press.
- Krieger N (1999). Embodying inequality: a review of concepts, measures, and methods for studying health consequences of discrimination. *Int J Health Serv*, **29**, 295-2.
- Kurkure AP, Yeole BB (2006). Social inequalities in cancer with special reference to South Asian countries. *Asian Pacific J Cancer Prev*, **7**, 36-0.
- Kwok C, Sullivan G (2006). Chinese-Australian women's beliefs about cancer: implications for health promotion. *Cancer Nursing*, **29**, 14-1.
- Lyttle NL, Stadelman K (2006). Assessing awareness and knowledge of breast and cervical cancer among Appalachian women. *Preventing Chronic Disease*, **3**, 125.
- Maree JE, Wright SCD (2010). How would early detection be possible? An enquiry into cancer related knowledge, understanding and health seeking behavior of urban black women in Tshwane, South Africa. *Eur J Oncol Nur*, **14**, 190-6.
- Ministry of Health and Family Welfare (MoHFW) (2002). Fifty years of cancer control in India. National Cancer Control Programme, DGHS, Government of India. (2002). New Delhi.
- Ministry of Health and Family Welfare (MoHFW) (2005). National Cancer Control Programme Guidelines, 2005, Government of India, New Delhi.
- Ministry of Health and Family Welfare (MoHFW), Government of India (2008). Annual Report 2007-08, New Delhi.
- Ministry of Housing and Urban Poverty Alleviation (MoHUPA) (2011). Strategy paper (in 7 Steps). Government of India. Available at [mhupa.gov.in/PDF/RFD/MHUPA-STRATEGY\\_PAPER.pdf](http://mhupa.gov.in/PDF/RFD/MHUPA-STRATEGY_PAPER.pdf). Accessed on 11 Mar 2011.
- Moore RJ, Spiegel D (2004). Cancer culture and communication. New York, USA: Kluwer Academic/Plenum publishers.
- National Commission on Macroeconomics and Health (NCMH) 2005: Background Papers (2005). Available at [http://whoindia.org/en/Section102/Section201\\_888.htm](http://whoindia.org/en/Section102/Section201_888.htm). Accessed on 02 Jan 2010.
- National Institute of Health & Family Welfare (NIHFW) (2002). Report on Evaluation of implementation status of national cancer control programme in India, New Delhi.
- Niederdeppe J, Levy AG (2007). Fatalistic beliefs about cancer prevention and three prevention behaviors. *Cancer Epidemiol Biomarkers Prev*, **16**, 998-3.
- Pal SK, Mittal B (2004). Fight against cancer in countries with limited resources: the post-genomic era scenario. *Asian Pacific J Cancer Prev*, **5**, 328-3.
- Rao RS, Nair S, Nair NS, Kamath VG (2005). Acceptability and effectiveness of a breast health awareness programme for rural women in India. *Indian J Med Sci*, **59**, 398-2.
- Ray K, Mandal S (2004). Knowledge about cancer in West Bengal - a pilot survey. *Asian Pacific J Cancer Prev*, **5**, 205-2.
- Rosentock IM (1994). The health belief model: origins and correlates. *Health Education Monographs*, **2**, 336-3.
- Ruth EC, Evans AE, Simon JW (2010). Public perceptions of the harms and benefits of testicular cancer education: A qualitative study. *Cancer Epidemiology*, **34**, 212-9.
- Serin D, Pujol H, Schraub S, Chevalier H (1998). Opinion survey carried out among women treated for gynecologic and breast cancers and their medical care teams. *Bull Cancer*, **85**, 578-8.
- Seth T, Kotwal A, Thakur R, Singh P, Kochupillai V (2005). Common cancers in India: knowledge, attitudes and behaviours of urban slum dwellers in New Delhi. *Public Health*, **119**, 87-6.
- Smith LK, Pope C, Botha JL (2005). Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. *Lancet*, **366**, 825-1.
- Veronesi U, Von Kleist S, Redmond KG, et al (1999). Caring About Women and Cancer (CAWAC): a European survey of the perspectives and experiences of women with female cancers. *Eur J Cancer*, **35**, 1667-5.
- Unger-Saldana K, Infante-Castañeda CB (2011). Breast cancer delay: A grounded model of help-seeking behavior. *Social Sci & Med*, **72**, 1096-4.
- Villafuerte BE, Gomez LL, Betancourt AM, Cervantes ML (2007). Cervical cancer: a qualitative study on subjectivity, family, gender and health services. *Reproductive Health*, **4**, 2.
- Wardle J, Waller J, Brunswick N, Jarvis MJ (2001). Awareness of risk factors for cancer among British adults. *Public Health*, **115**, 173-4.
- Yusoff N, Mohd Taib NA, Ahmad A (2011). The health seeking trajectories of Malaysian women and their husbands in delay cases of breast cancer: a qualitative study. *Asian Pacific J Cancer Prev*, **12**, 2563-0.