

## RESEARCH ARTICLE

# Multiple Stakeholder Perspectives on Cancer Stigma in North India

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### Abstract

**Background:** Cancer is a leading cause of death worldwide. A large proportion of cancer deaths are preventable through early detection but there are a range of social, emotional, cultural and financial dimensions that hinder the effectiveness of cancer prevention and treatment efforts. Cancer stigma is one such barrier and is increasingly recognized as an important factor influencing health awareness and promotion, and hence, disease prevention and control. The impact and extent of stigma on the cancer early detection and care continuum is poorly understood in India. **Objectives:** To evaluate cancer awareness and stigma from multiple stakeholder perspectives in North India, including men and women from the general population, health care professionals and educators, and cancer survivors. **Materials and Methods:** A qualitative study was conducted with in-depth interviews (IDIs) and focus group discussions (FGDs) among 39 individuals over a period of 3 months in 2014. Three groups of participants were chosen purposively - 1) men and women who attended cancer screening camps held by the Indian Cancer Society, Delhi; 2) health care providers and 3) cancer survivors. **Results:** Most participants were unaware of what cancers are in general, their causes and ways of prevention. Attitudes of families towards cancer patients were observed to be positive and caring. Nevertheless, stigma and its impact emerged as a cross cutting theme across all groups. Cost of treatment, lack of awareness and beliefs in alternate medicines were identified as some of the major barriers to seeking care. **Conclusions:** This study suggests a need for spreading awareness, knowledge about cancers and assessing associated impact among the people. Also Future research is recommended to help eradicate stigma from the society and reduce cancer-related stigma in the Indian context.

**Keywords:** Stigma - cancer - qualitative study - stakeholders - India

*Asian Pac J Cancer Prev*, 16 (14), 6141-6147

### Introduction

Cancers are among the leading causes of death around the globe (Globocan, 2012) and are estimated to affect about 20 million individuals worldwide by 2030 (WHO, 2008). In India, approximately 1 million new cancer cases are detected every year with an annual toll of 0.63 million deaths (WHO, 2008; Globocan, 2012). In India, the most common cancer sites are lung and oral cancer in men and breast and cervical cancer in women (Dikshit et al., 2012). Low and middle-income countries (LMICs) such as India face the double burden of communicable diseases and increasing chronic, non-communicable conditions (NCD's) (Boutayeb, 2006), which are attributed to the combined effects of risk factors like high tobacco and alcohol consumption, low fruit and vegetable intake, environmental exposures including urban air pollution, and indoor smoke from household use of solid fuels, and

patterns of physical activity (WHO, 2009; Mathur et al., 2014). To address this disease burden, there is a growing advocacy for public health interventions focused on NCD prevention and control as illustrated by the United Nations High Level meeting and the inclusion of NCD's in the post-2015 sustainable development agenda (Sustainable Development Solutions Network, 2014).

A large proportion of cancers can be prevented with an increase in the adoption of healthy lifestyles through intensive and sustained efforts by governments and health practitioners to offer prevention and control services (WHO, 2008). Research suggests that key global risk factors for cancer such as tobacco use can be modified with effective health promotion and policy interventions (Mackay, 2012; Lane and Carter, 2012; Hammond et al., 2013; Aldrich et al., 2014). Evidence from around the world suggests that there is range of social, emotional, and financial dimensions that pose a challenge to the

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effectiveness of cancer prevention and treatment efforts (Halpin, 2010), including cancer stigma (Keusch et al., 2006a; Hatzenbuehler et al., 2013; Cho et al., 2013). Health-related stigma is increasingly recognized as a factor influencing health promotion, disease prevention and control (Daher, 2012). Stigma may occur in two forms, (Goss et al., 2014) perceived and actual. Perceived stigma refers to the shame associated with having a condition and to the fear of being discriminated and denied basic welfare rights leading to social exclusion (Scambler, 1984; Moffatt et al., 2010; Ehrmann-Feldmann et al., 1987). On the other hand, actual stigma refers to obvious discrimination, which may lead to feelings of guilt, shame and threatens one's own identity (Scambler, 1984; Chapple et al., 2004). Several myths including fear of diagnosis, death, pain from treatment (Daher, 2012) and stigma per se can have a negative impact on health outcomes among cancer survivors (Chambers et al., 2012; Cataldo et al., 2012; Link and Phelan, 2006).

The extent and impact of stigma on the cancer prevention, detection and care continuum are poorly understood in India. Several studies have documented the low levels of awareness of cancers in general and their risk factors among people (Robb et al., 2009; Karbani et al., 2011; Kumar et al., 2011; Hvidberg et al., 2014). However, none have evaluated the level of awareness, role of stigma and underlying belief systems in shaping perceptions of cancer and the pathways to care. In India, delays in diagnosis are a major contributor to high rates of cancer mortality (Chintamani et al., 2011). A recent study found that cancer patients waited 271 days, on average, before consulting friends or family members about signs and symptoms (Pati et al., 2013).

Research on stigma and its influence on the cancer care continuum is required for effective cancer prevention, service delivery and improved survivorship (Daher, 2012; Nayar et al., 2014). A UK-based study showed that education on the role of sexually transmitted infections in cervical cancer led to higher levels of stigma and shame (Waller et al., 2007), which suggests that cancer education messaging needs to be carefully framed in order to avoid reinforcing stigma. We carried out a qualitative study to explore awareness and the perceptions of cancer stigma among women and men health care providers and cancer survivors residing in urban communities of New Delhi.

## Materials and Methods

Thirty nine men and women who attended a cancer screening centre in New Delhi, India in 2014 were purposively recruited for this qualitative study (Strauss, 1990). We conducted individual face-to-face in-depth interviews (IDIs) and focus group discussions (FGDs) through purposive sampling of three different types of stakeholders. The first group comprised of men and women aged 18 years and older, who attended cancer screening camps held by the Indian Cancer Society (ICS), Delhi. The second group consisted of health care providers who were responsible for cancer detection and management at ICS, and were approached for IDIs. The third group included cancer survivors who volunteered with ICS as educators

and counsellors, who had completed their treatment and were cancer-free during the previous year.

IDIs offered cancer survivors an opportunity to discuss their cancer-related experiences in a confidential manner. The lead author facilitated the IDIs and FGDs using a guide that included sensitive and supportive probes to encourage dialogue.

Four FGDs were conducted with men and women attending the camps, with 8-10 volunteers in each group to explore broader societal perceptions related to cancer and stigma. Four IDIs with cancer survivors were conducted exploring their personal feelings, opinions, and experiences with family and the community, before and after the diagnosis of cancer. Three IDIs with health care providers (n=3 IDIs) elicited experiences and observations on awareness, perceptions and behaviour of screening participants, as well as their own attitudes and practices on early detection and referral care in the screening camps. Semi-structured topic guides were used to conduct the IDIs and FGDs. The guides included the major themes of interest: understanding and beliefs about cancer and its causes; knowledge and attitudes towards cancer patients; level of awareness and perceptions of cancer stigma as well as the impact of cancer-related stigma on seeking care and treatment; and dynamics of family relationships. The FGDs and IDIs with the general population and cancer survivors were carried out in the native language i.e. Hindi, while IDIs with health care providers were conducted in English. All interviews were tape-recorded, translated from Hindi language to English and further transcribed by two authors. The accuracy of the then translated transcripts was cross checked by another co-author.

Participation was voluntary and written informed consent (in Hindi or English, according to native language of participant) was obtained from all participants. Individuals who were contacted were assured that their decision to participate would have no impact on their current or future access to services provided by the ICS. The study protocol was reviewed and approved by the institutional review board of the Public Health Foundation of India, New Delhi.

### Data analysis

The thematic framework theory (Ritchie and Spencer, 1994) guided the analysis, in which transcripts were read by the lead author several times and a deductive approach was employed to develop an analytic framework describing cancer stigma and its impact on cancer prevention and treatment from the data. The data was coded using the qualitative data management and analysis software, Atlas-ti. Coded transcripts were reviewed to identify key themes and in developing a framework encasing varied experiences of each group of the participants. Network diagrams were then used to compare, contrast and synthesize the views of the three groups.

## Results

We conducted two focus group discussions with men and women each (n=32) and a total of seven in-depth interviews. The demographics are presented in Table 1.

**Table 1. Demographic Characteristics of the Study Sample (n=32)**

	n (%)
Age	
40-59	22 (69)
60-80	10 (31)
Education	
Primary level	2 (6)
Secondary level (diploma level)	22 (69)
Tertiary/Higher Education (degree level)	8 (25)
Occupation	
Housework	0 (0)
Skilled worker	29 (91)
Professional	3 (9.4)
Marital Status	
Married	31 (97)
Divorced/Separated	1 (3)
Unmarried	0 (0)

**Table 2. Major Themes that Broadly Emerged**

1. Awareness and perception about cancer, its causes and prevention
2. Attitudes of self and family towards cancer patients
3. Stigma and its manifestations
4. Barriers to seeking care
5. Suggested actions to combat stigma

Participants were 40- years of age and mostly married. Majority of the men and women in the FGs were graduates (with bachelor degrees). The survivors were highly educated (had completed their Master level degrees) and the health care providers were all specialists in the field of medicine. Thus, all the participants were employed in their respective fields.

Five broad themes as shown in Table 2 emerged from the analysis and are described as follows.

#### *Awareness and perception about cancer, its causes and prevention*

Cancer survivors described a significant change in their awareness and perceptions of cancer, before and after their diagnosis. Prior to diagnosis, they perceived cancer to be the end of life like a death sentence, "*Cancer means death*" as stated by them. It was the last thing that they imagined could happen to them, they stated, "*I had never thought of cancer. That was the last thing that came in my mind*". But after the diagnosis, they became more aware of treatment, prognosis and other aspects of cancer. One survivor emphasized the importance of awareness about causes, prevention and management of cancers in order to be in a better state of mind to make the right decision and live a healthy life. For another survivor, "*suffering from cancer was an opportunity to become an inspiration for others, by fighting the disease in good spirit*".

Health care providers over-estimated the level of awareness of cancer among people and assumed that people are highly aware and proactive in current times. Care providers thought that people's perception of cancer had changed over time, from being an untreatable deadly disease to a disease that can be now treated with advanced drugs. Two of the health care providers assumed people

from rural communities to be equally aware as the people from urban communities about the benefits of screening and attributed this to public health efforts, "*Cancer awareness is increasing in both communities because of government efforts, NGO's efforts and general public and people are also becoming conscious of their health*". On the contrary there was some disagreement among the providers regarding the awareness levels. One of them mentioned that awareness levels in rural regions of the country continued to remain low. He pointed out disparities in knowledge stating, "*Poor people living in lower socioeconomic groups have no awareness. Middle class and high income groups are aware of cancer*".

Both men and women thought of cancer as a consequence of fate/destiny, leading to a condition that is incurable and shortens one's life expectancy. Participants feared that death was the ultimate consequence of cancer. "*It's because of destiny,*" said one man, while a woman used the following phrases to describe her reaction to the word "*cancer*": "*feeling of fear*" and "*fear of death*". The majority of men were aware that cancer is not a contagious disease and could be caused by the use of tobacco. "*It's not contagious and can happen to anyone,*" noted one male participant.

#### *Attitudes of self and family towards cancer patients*

To understand the cancer survivor's reaction after the news of diagnosis was broken to them, they were asked to recall their experiences. All the cancer survivors mentioned that they underwent a series of emotions like being anxious, apprehensive, self-conscious, embarrassed, uncomfortable, upset, scared, and worried for their children's future and family well being. They were in a state of shock for some period of time before they could accept the diagnosis and prepare themselves mentally. One of them mentioned that: "*I did not believe what happened and felt so embarrassed and bad*".

To understand and facilitate reflection of individual's attitudes (protective or negative) towards cancer patients, similar scenario-based questions were posed in the FGDs. The participants were asked to describe what would be their attitude and reaction if they found out someone close to them or they themselves were suffering from cancer. To this, both men and women displayed a highly positive attitude. They used adjectives like being courteous, helpful, caring and cooperative to describe their attitudes towards people with cancer. For example, one described his reaction as: "*I will cooperate with that person and will help him/her too*". Another, mentioned that she would be "*courteous towards [people with cancer] and give more love to these people*".

On enquiring about the dynamics of family relationships among men and women from the general population and cancer survivors, mixed opinions emerged. On one hand, men and women believed that their family would become more loving and caring in the event if they were diagnosed with cancer. Two cancer survivors reported receiving similar love and support from their close family. However, another two mentioned that they faced negative reactions like being shunned and distanced by family members and friends. One of them said, "*My family became much more*

*caring and everybody was very conscious not to tell me anything hurting” and the other survivor said, “My in laws disowned me”.*

### *Stigma and its manifestations*

Cancer survivors claimed that stigma continued to prevail in society. They described perceived stigma - their own and others' beliefs that cancer is the result of 'sins of the past life:’ *“The first myth is that you have done something wrong that is why god is making you suffer.”* Some also experienced stigma in terms of social and family rejection due to a false perception of cancer being an infectious disease. Stigma was also internalized as guilt and embarrassment about their condition, resulting in self- isolation post-diagnosis.

Cancer stigma emerged as a consistent theme across all interviews. Men and women from the community sample observed that they would feel highly stigmatized if they were to be diagnosed with cancer and that stigma would manifest as rejection by the society leading to social exclusion. For example, one participant felt that *“society may neglect such people and may shun them”*. Another noted that these actions would lead to internalization of stigma: *“Society may not accept these people and the patient starts to dislike or blame himself as a result of this”*. Others also spoke of internalized stigma, noting that they would feel embarrassed about their condition and would not disclose their diagnosis.

Two health care providers felt that stigma was a problem primarily in rural communities that lacked knowledge, *“It is in backward classes, means those who don't have knowledge about this disease”*. They believed that as people became more educated, cancer stigma declined; this was seen to be the case in cities. In contrast, one health care provider considered stigma as a normal reaction as he felt it was highly prevalent, *“Stigma is normal”*. This provider did not differ in background and experience with that of the other two health providers.

### *Barriers to seeking care*

The most common barrier identified by all three respondent groups was the cost of treatment. One cancer survivor stated, *“[The treatment] it is so expensive, that [it] is very traumatizing for patients from poorer sections of society”*. Another survivor recalled, *“My first reaction was that I am not going to survive because I don't have the money for treatment”*. The health provider shared from their experience that, *“If people knew they are suffering from cancer, the treatment is very expensive, drugs are quite expensive and that is why some of the people do not get proper treatment”*.

A few other challenges that were highlighted by health care providers were a reliance on alternative medicines and practices like witch craft and black magic to get rid of the disease. One of them mentioned, *“In villages they try witch craft”*. They also mentioned, *“Phobia of getting diagnosed”*, i.e. fear of the unknown or fear of getting diagnosed as a potential barrier to timely diagnosis. Another barrier was the common practice of visiting a health professional only when there is pain, which can often indicate more advanced stages of disease. Apart from

the above stated challenges, women in focus groups also highlighted lack of awareness and knowledge as a barrier, which led to delays in diagnosis and treatment seeking. The health care providers also raised similar concerns. One of the health providers recalled their patient's words as, *“Even if I go for treatment I will die so why go through all that process”*.

### *Suggested actions to combat stigma*

Cancer survivors suggested various methods for instance, *“Lot of lectures, free screening”* increasing cancer awareness of cancer across the different socio-economic groups. Others mentioned, *“Institutions that give small scale loans should come forward and give loans to cancer patients to rehabilitate themselves”*. Some of the cancer survivors urged the need for counselling for both the patients and their family to get rid of myths and taboos, *“When the patient comes we should counsel not only the patients but the family also, specially the husband and in-laws”*.

Health care providers suggested that people should get health check-ups done at regular intervals of time to track their own health. They quoted, *“We can show them motivating videos or audios as these are more effective”*. Another health provider emphasised on other ways like, *“We can spread awareness through posters, media, health talks in schools, colleges and social events”* finding them highly effective and engaging.

## **Discussion**

The study explored the current state of cancer stigma in India from the perspectives of cancer survivors, health care providers and general population including men and women. Low levels of awareness about cancer is increasingly considered to be a serious public health issue, because it prevents a broader recognition of the disease and leads to delays in diagnosis and treatment and poor outcomes (Sullivan et al., 2014; Sankaranarayanan, 2014; Pramesh et al., 2014; Mallath et al., 2014; Goss et al., 2014). In our study, we found that majority of the general population was unaware of cancer in general, its causes, risk factors and symptoms and factors contributing to cancer stigma. Their responses were consistent with cancer survivors' pre-diagnosis understandings of cancer as well as with other published studies from India (Kumar et al., 2011; Sharma et al., 2013). Studies conducted in metropolitan cities like Delhi, Chandigarh and Mumbai reported similar findings on awareness levels (Nair et al., 2004) (Seth et al., 2005; Puri et al., 2010; Kumar et al., 2011).

Attitudes of the general population participants in our study were highly positive on providing help and care to those with cancer. Cancer survivor responses' did not suggest an overwhelming response from families, despite answers from the general population (which was a hypothetical question being asked to potential providers, which is quite different than the reality being asked from the actual patients). It must be acknowledged that the emotional and mental impact on the individual of having diagnosed with cancer is far greater than what

the prevalence of cancer alone would suggest (Dinshaw et al., 2005). Just the initial diagnosis of cancer is perceived as a life-threatening event with a feeling of uncertainty, fear and loss, regardless of their prognosis, which also are potential drivers of stigma. Similar findings were also found in other studies (Kazaura et al., 2007; Kishore et al., 2008). Approximately, one third of these diagnosed patients experience repeated episodes of anxiety and depression (Alexander et al., 1993). A study in West Bengal reported that over 11% of the respondents thought of keeping cancer diagnosis as a secret from neighbours to avoid social stigma and associated problems, for instance, problems with daughters' marriage (Ray and Mandal, 2004). On exploring the family dynamics and their attitudes towards cancer diagnosis, both positive and negative attitudes arose.

Our study revealed that certain myths and misconceptions about cancer exist among the general population; cancer survivors and even health care providers who think that awareness in rural areas are similar to urban ones. A study also found that stigma often leads to restricted access to supportive care within the community for many (Broom and Doron, 2012). Also, beliefs and myths silently influence cancer prevention and early help seeking. This was also explained by a similar study conducted in India, which found negative influence of local belief systems and socioeconomic structures on access to cancer care and help-seeking behaviours (Broom and Doron, 2012; Daher, 2012). Further research is required to better understand how these myths and misconceptions, and low levels of awareness, drive stigma and health seeking behaviours and outcomes, including disclosure of a cancer diagnosis, psychosocial status, and treatment adherence.

Multiple barriers emerged that affected people's health care seeking behaviour. With the rising cost of cancer care, treatment related cost was found to be the most common barrier that emerged across all three groups with an emphasis on the poorer sections of the society. They were considered to be the most vulnerable group as suggested by the health providers. Other studies have found cost to be a major concern not just across the poor sections but also across a heterogeneous group of people and their families who may be underinsured or under the burden of additional cost of travel, medications and therapy (Stump et al., 2013; Wagner and Lacey, 2004; Meropol and Schulman, 2007).

Similar to other studies, we found that knowledge and awareness of signs and symptoms of cancer among the groups was general in nature and that most participants lacked a comprehensive understanding of the disease (Chattoo et al., 2002; Randhawa and Owens, 2004; Scanlon et al., 2006; Khakbazan et al., 2014). Closely associated with poor knowledge and lack of awareness of the signs and symptoms of cancers, there was a general confusion and uncertainty about causation followed by fear of diagnosis that was raised as a concern. A consequence of this general fear of cancer was related to delay in seeking care and treatment. This was in resonance with other studies that considered fear of the unknown to

be a major detrimental factor in early diagnosis (Lagnado, 2008; Daher, 2012; Khakbazan et al., 2014). This fear was also recognised as a triggering factor for several myths, misconceptions and stigma (Link and Phelan, 2006; Keusch et al., 2006b; Daher, 2012).

Faith in traditional, complementary, and alternative medicine (TCAM) is widespread in Asia, particularly India and is very popular with Indian cancer patients (Broom, 2009a; Broom, 2009b; Broom and Doron, 2012; Broom and Doron, 2013). Homoeopathy is one of most commonly accepted as a very effective form of medicine by people (Prasad, 2007), although findings from a large comparative study (Shang et al., 2005) showed that the effects of homoeopathy are consistent with a placebo effect. Additionally, due to immense religious faith of people in healers who rely on chants, pujas (religious worship), and sacred powders to cure patients with disease, they often deceive vulnerable people (Goss et al., 2014). These strong faith in healers reduce the credibility of modern scientific medicine and evidence based research in rural areas in India (Goss et al., 2014).

There is a strong need to address the drivers and manifestation of stigma. The study participants suggested several ways to enhance awareness levels and to remove misconceptions around cancer such as media, campaigns, health talks, posters, audio and video presentations, counselling, detection camps and centres. A significant amount of work is yet to be done to improve the degree to which people feel informed about cancer through training (Daher, 2012). Spread of awareness is the foremost important strategy to improve cancer prevention and control. People need to be provided with guidance in understanding several aspects related to cancer from screening and early detection; to several treatment options; palliative care; cancer survivorship; government efforts in cancer prevention and control; new research or funding devoted to cancer; and cancer-related activism (Daher, 2012; Anand et al., 2008).

The strength of this study lies in the triangulation of perspectives on cancer prevention and treatment among individuals eligible for cancer screening, health care providers and cancer survivors in a developing country with a high cancer burden. The study has several limitations, including a small sample size and the use of a purposive sampling technique. Also views expressed by the patients might have been influenced by their knowledge of being a part of the study and their responses may have been shaped by perceptions of social desirability. Our findings provide insights on the nature and potential impacts of cancer stigma on cancer prevention and treatment, which can be explored further through a larger quantitative study and an expanded qualitative study on key themes that have emerged from this work.

In conclusion, this study attempts to address the gap in understanding economic and socio-cultural concerns around cancer in contemporary India by evaluating social, economic and cultural determinants related to awareness and stigma from multiple stakeholders in the cancer detection and care continuum. Future research should focus on drivers, manifestations and impacts on outcomes of cancer stigma and low awareness, with an

emphasis towards driving policies on health promotion, early detection and treatment services.

## Acknowledgements

The authors thank the participants and for their participation, time and cooperation. Also, the authors thank Ms. Smriti Gulati from Public Health Foundation of India for assisting in transcriptions of the recorded interviews.

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