

Cultural Beliefs, Cancer and Stigma: Experiences of Patients from Punjab (India)

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ABSTRACT Stigma is defined as a negative evaluation linked to characteristics of a person, which places the person on the outskirts of some socially acceptable standards of human attributes and performance. The present study was conducted among 230 rural cancer patients to understand the interrelationship between cancer and the stigma related to it. The respondents were chosen from five villages each from three districts namely, Sri Muktsar Sahib, Faridkot and Bathinda in the state of Punjab, India. The widespread stigma was prevalent in the villages under study. The two major causes of stigma were found to be the bodily changes that happen due to cancer and its treatment and related body image concerns, and the beliefs related to cancer and its treatment. There were various ways through which this stigma manifested including, preferable use of local terminology for describing cancer, social non-disclosure of cancer and discrimination against cancer patients. From the careful analysis of data, it can be concluded there is a need to create awareness about cancer in the study area as a number of myths about cancer prevail. These myths about cancer not only create stigma for the cancer patients and their families, but also affect the health seeking behavior of the cancer patients.

INTRODUCTION

Stigma has been a topic of interest for social scientists since Goffman (1963) published his seminal work. Goffman distinguished three different varieties of stigma or stigmatizing conditions including, “abominations of the body” (for example, physical deformities), “blemishes of individual character” (for example, mental illness, addictions, unemployment), and “tribal identities” (for example, race, sex, religion, or nation). Since then a number of researchers have attempted to categorize stigma. Jones et al. (1984) identified six dimensions of stigmatizing conditions: (a) concealability, which involves the extent to which the stigmatizing characteristic is clearly visible; (b) course of mark relating to whether the mark may become salient or progressively debilitating over time; (c) disruptiveness, which refers to the degree to which the stigmatizing characteristic interferes with the flow of interpersonal interactions; (d) aesthetics which relate to subjective reactions to the unattractive-

ness of the stigma; (e) origin of the stigmatizing mark, which can also involve the person’s responsibility for creating the mark; and (f) peril, which involves the perceived danger of the stigmatizing conditions to others. Link and Phelan (2001), however proposed that the stigma exists when four specific components are covered. These are, (a) individuals differentiate and label human variations; (b) prevailing cultural beliefs tie those labeled to adverse attributes; (c) labeled individuals are placed in distinguished groups that serve to establish a sense of disconnection between “us” and “them”; (d) labeled individuals experience “status loss and discrimination that leads to unequal circumstances”. Research since Goffman’s seminal essays has been incredibly productive, leading to elaborations, conceptual refinement, and repeated demonstrations of the negative impact of stigma on the lives of the stigmatized. The concept of stigma is applied to a number of circumstances ranging from urinary incontinence (Sheldon and Caldwell 1994) to exotic dancing (Lewis 1998) to leprosy (Opala and Boillot 1996), cancer (Fife and Wright 2000; Chapple et al. 2004; Rosman 2004; Lebel et al. 2006; Ploug 2007; Frith et al. 2007; Lebel and Devins 2008), and mental illness (Angermeyer and Matschinger 1994).

Stigma is one of the hindrances in the way of effective healthcare for cancer patients. Under-

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standing the nature, causes and manifestations of stigma is crucial in order to provide effective healthcare. The present study attempts to understand the interrelationship between cancer and stigma in the Malwa region of Punjab where the occurrence of cancer is an epidemic. The previous researches on interrelationship between cancer and stigma suggest that cancer is regarded as a highly stigmatized disease (Fife and Wright 2000; Chapple et al. 2004; Rosman 2004; Lebel et al. 2006; Frith et al. 2007; Ploug 2007; Lebel and Devins 2008).

The work of Fife and Wright (2000) suggest that stigma has differential negative impacts on particular elements of the self, regardless of illness type. Chapple et al. (2004) found that certain types of cancer such as lung cancer are more stigmatized, as individuals are held responsible for its occurrence. As a result the interaction of patient with family, friends and doctors often gets affected and many patients, particularly those who had stopped smoking years ago or never smoked, felt unjustly blamed for their illness. A few patients were worried that diagnosis, access to care, and that research into lung cancer might be adversely affected by the stigma attached to the disease and those who smoke.

Rosman (2004) examined how patients react to hair loss caused by chemotherapy, for women in particular. The reaction involved a confrontation with the lethal nature of cancer, whilst for men it was a normal and an inevitable consequence of the treatment. The women used strategies such as camouflaging, hiding and wearing wigs in an attempt to partially or completely hide their hair loss. Similar findings have been made by Ploug (2007) who reported social stigma among the women undergoing chemotherapy in Denmark and Frith et al. (2007) who described how the women try to hide their hair loss in order to save themselves from the stigma. The other scholars such as Cataldo et al. (2012), Lebel et al. (2013), Brown and Cataldo (2013), Shephard and Gerend (2014), and Lehto (2014) also made significant contributions in understanding interrelationship between cancer and stigma.

METHODOLOGY

The present study was conducted in three districts namely, Sri Muktsar Sahib, Faridkot and Bathinda of Punjab with an aim to understand the interrelationship between cancer and stigma. These districts fall in the Malwa region and report highest number of cancer cases in Pun-

jab. A total of 230 rural cancer patients (118 female and 112 male) were included in the study. These patients were first identified from Guru Gobind Singh Medical College, Faridkot (Punjab) using purposive sampling. The hospital was selected because this was the only government hospital in the vicinity of the study area where all the facilities of cancer diagnosis and treatment were available. The reason for using purposive sampling was to get the sample according to the requirement of objective of the study. From the records of Guru Gobind Singh Medical College, Faridkot, five villages from each of the three districts were identified based on the highest number of cancer patients recorded. These villages were then visited and key respondents were identified from among the caregivers of cancer patients who were previously interviewed or the person introduced by them or a village head contacted them on the first visit to the village. The other cancer patients were identified using snowball sampling. The cancer patients were also interviewed at the regional cancer center that is, Postgraduate Institute of Medical Education and Research, Chandigarh.

For the present study, the ethical clearance was obtained from Punjab University Institutional Ethics Committee. The written informed consent was also obtained from the respondents or at least one of their caregivers after explaining the research objectives clearly. While interviewing, it was made sure that the respondents do not get disturbed or emotionally distressed. The formal interviews were not conducted rather the researcher accompanied the cancer patient and their family members during the treatment. During this time period, informal interviews were taken and observations were made.

RESULTS

The mean age of all respondents in the present study was 46.88 years (45.88 for males and 47.84 for females). The differences between the mean ages of males and females were non-significant. The ages of the respondents ranged between 22 to 78 years. The socio-demographic characteristics of patients included in study are given in Table 1.

Figure 1 based on the researcher's own fieldwork shows the interrelationship between stigma, its manifestations, body image concerns and beliefs related to cancer and its treatment. It can be concluded that there are two main causes of

Table 1: Socio-demographic characteristics of patients

| Variables | Gender | | Total (N=230) |
|----------------------------|--------------|----------------|---------------|
| | Male (N=112) | Female (N=118) | |
| <i>Age (in years)</i> | | | |
| 21-30 | 18 (16.1) | 13 (11.0) | 31 (13.5) |
| 31-40 | 29 (25.9) | 28 (23.7) | 57 (24.8) |
| 41-50 | 22 (19.6) | 31 (26.3) | 53 (23.0) |
| 51-60 | 25 (22.3) | 19 (16.1) | 44 (19.1) |
| 61-70 | 14 (12.5) | 17 (14.4) | 31 (13.5) |
| 71-80 | 4 (3.6) | 10 (8.5) | 14 (6.1) |
| <i>Caste</i> | | | |
| Jatt Sikh | 73 (65.2) | 73 (61.9) | 146 (63.5) |
| Majhabi Sikh | 32 (28.5) | 38 (32.2) | 70 (30.4) |
| Ramgarhia Sikh | 7 (6.3) | 7 (5.9) | 14 (6.1) |
| <i>Marital Status</i> | | | |
| Unmarried | 5 (4.5) | 3 (2.5) | 8 (3.5) |
| Married | 101 (90.2) | 101 (85.6) | 202 (87.8) |
| Others | 6 (5.3) | 14 (11.9) | 20 (8.7) |
| <i>Educational Status</i> | | | |
| Illiterate | 8 (7.1) | 12 (10.2) | 20 (8.7) |
| Upto middle | 23 (20.5) | 13 (11.0) | 36 (15.7) |
| Upto senior secondary | 49 (43.8) | 56 (47.4) | 105 (45.6) |
| Graduation and above | 32 (28.6) | 37 (31.4) | 69 (30.0) |
| <i>Occupational Status</i> | | | |
| Housewife | - | 72 (61.0) | 72 (31.3) |
| Farming | 63 (56.3) | - | 63 (27.4) |
| Labour | 36 (32.1) | 31 (26.3) | 67 (29.1) |
| Government employees | 8 (7.2) | 11 (9.3) | 19 (8.3) |
| Others | 5 (4.5) | 4 (3.4) | 9 (3.9) |

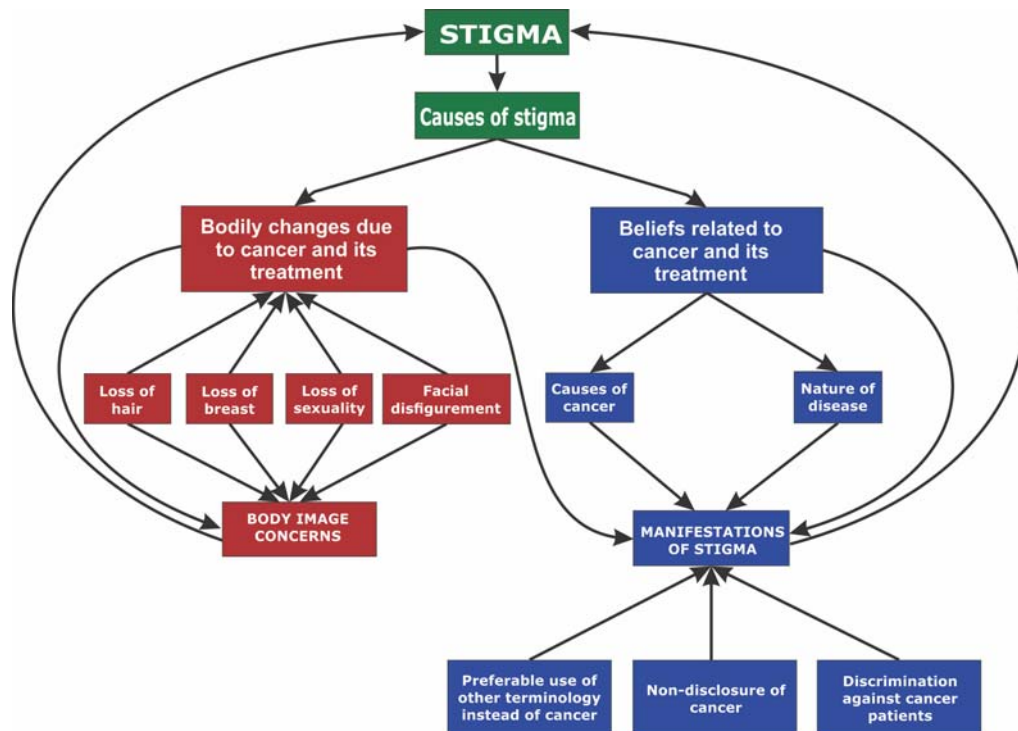


Fig. 1. Interrelationships between cancer and stigma in Punjab
 Source: Author

stigma; firstly, bodily changes due to cancer and its treatment and secondly, beliefs related to cancer and its treatment. The bodily changes due to cancer and its treatment (in the form of loss of hair, loss of breast, loss of sexuality and facial disfigurement) lead to body image concerns, which further lead to stigma. The body image concerns among cancer patients are because of two reasons; firstly, due to bodily changes and secondly due to stigma. The beliefs related to cancer can be subdivided into: beliefs related to causes of cancer (*karma*, *kismet* and contagion), and beliefs related to the nature of the disease (cancer fatalism and incurability of cancer). These beliefs lead to manifestations of stigma in terms of preferable use of other terminology instead of cancer, non-disclosure of cancer and discrimination against cancer patients.

Causes of Cancer

In the present study, two major causes of stigma were found: bodily changes due to cancer and its treatment, and related body image concerns and beliefs related to cancer and its treatment.

Bodily Changes and Body Image Concerns

In the present study, an attempt has been made to understand the hair loss as a consequence of cancer treatments. This process included preparing for hair loss, experiencing hair falling out, realizing the altered sense of self and minimizing effects. It was found that the respondents prepared themselves for hair loss by gathering information from three sources, which include, healthcare providers (doctors and nurses), other cancer patients undergoing treatment and information material in form of posters and pamphlets. It was observed that talking and discussing with fellow patients was the most important source of information seeking. This is known as social comparison. Social comparisons help gain information about the treatment, side effects, and ways of coping. The respondents were asked whether they tried to contact or meet other cancer patients. 67.40 percent respondents agreed that they contacted or met other cancer patients to compare their own health conditions and course of treatment with others, while 32.60 percent respondents did not contact or meet any other cancer patient. The respondents who contacted or met other cancer patients were asked

whether they made an upward comparison or a downward comparison. The findings of the present study are in contrast with the findings of Van der Zee et al. (2000), as majority (53.54%) of the cancer patients tend to compare themselves with those who were doing better.

In Punjab, the women wear *salwar kameez* and the women residing in the villages usually cover their head with a *dupatta* wrapping it around their upper body. This practice saved the women who underwent breast removal surgery from public stigma but the perceived stigma was more among these women. The women said that the scars of surgery remind them of their irreparable loss and the queries extended by other women either within their families or among their social network makes them uncomfortable and consider it as intrusion in their privacy.

Similarly, the women suffering from gynecological cancers reported difficulties in their interpersonal relationships especially with their spouses. These women felt that due to lack of communication with their doctors on gynecological or sexual issues, most of their queries are left unanswered. The factors that affected the doctor-patient communication include time constraints, focus on treatment rather than on communication, age and gender differences between doctor and the patient, lack of rapport establishment, and cultural insensitivity. The women with gynecological cancers had fears relating to resuming sex after treatment, spread of disease or recurrence of disease after sexual intercourse.

It was found that cancer patients either faced social stigma or perceived stigma. The social stigma was more among the cancer patients where bodily changes were evident (such as hair loss) and self-stigma was more among the cancer patients where the bodily changes led to altered sexuality or difficulties in interrelationships with their spouses.

Beliefs Related to Cancer

The beliefs related to cancer can be subdivided into those related to causes of cancer and those related to the nature of disease.

Beliefs Related to Causes of Cancer

A majority, 53.5 percent (39.3% males and 66.9% females) of the respondents believed *kar-*

ma to be the cause of cancer followed by contamination of underground water 20.9 percent (34.8% males and 7.7% females), contagion 9.6 percent (12.5% males and 6.8% females), hereditary 5.2 percent (3.6% males and 6.8% females), stress 4.3 percent (4.5% males and 4.2% females), *kismet* 3.9 percent (2.7% males and 5.1% females), injury 0.9 percent (0.9% males and 0.9% females), and the remaining 1.7 percent of the respondents did not mention any cause of cancer. There were highly significant differences in the causes of cancer mentioned by the respondents with respect to gender.

After the diagnosis with cancer, the cancer patients tried to search meanings behind their illness and attributed causes to their illness. The attribution of cancer to *karma* by the respondents and search for meaning behind the disease may be termed as “religious purification”, which means confession of sins and asking for forgiveness. In their study, Pargament et al. (1988) also confirmed the role of *karma* in attribution of meanings to the disease. The narrative of *kismet* and a lesson from God appeared in some of the cases. Some of the respondents asserted that the cancer experience leads to a renewed and enhanced faith in God. The respondents drew strength from their religious belief that their *kismet* is in God’s hands. They also believed that through *ardas* (individual prayer) and *sewa* (service of God), the disease could be cured. Through the narratives of *karma* and *kismet*, the individuals held themselves responsible for their illness. Their caregivers held a similar view. Contagion was considered to be one of the possible causes of cancer by the respondents and their families. This created fear of contracting cancer among those who were not affected and those who were affected attributed it to contagion from a cancer patient.

Beliefs Related to Nature of Disease

Cultural beliefs establish the meaning of a disease by establishing norms of behavior and providing guidance for its members to respond emotionally, cognitively and socially to this disease. These beliefs may also lead to delay in help seeking and may prolong the interval between the first appearance of symptoms and the first visit to the doctor (Kishore et al. 2007). In the present study, beliefs such as fatalism and incurability were found to be associated with cancer.

Cancer fatalism is the belief that death is inevitable when cancer is present. Fatalism is traditionally conceived as the perception that events and/or health issues are out of an individual’s control. The fatalistic individual assumes that the outcome of the disease will be negative. Cancer fatalism is a multidimensional construct, which is guided by a number of factors such as awareness, perceptions and beliefs about the disease. According to Powe and Johnson (1995), cancer fatalism is a “categorical surrender of the human being to the external forces of life, which destroy human personality, potential, hope and even life itself”. A number of studies report that cancer fatalism leads to delay in cancer treatment (Conrad, 1996; Mayo et al. 2001; Powe and Johnson, 1995; Phillips et al. 1999). It has been identified as a barrier in help seeking for cancer screening, detection, and treatment, and may affect the decision-making regarding cancer (Beekan et al. 2011). Some of the important narratives in relation to cancer fatalism are: “*Es bimari da koi ilaj nahi*” (This disease is not curable), “*Mainu tan maut di saja hogi*” (I have got the death sentence), and “*Cancer da matlab maut hai*” (Cancer means death). In these narratives, cancer has been equated to death.

Another belief that the cancerous growth increases after the surgery at a faster pace than before was also prevalent. A similar belief was also held by the *desi* healers (quacks) in the area. This belief prevented a large number of cancer patients from undergoing surgeries even if prescribed by their doctors.

Manifestations of Stigma

The manifestations of stigma were found in the form of preferable use of other terminology, social non-disclosure of cancer and discrimination against cancer patients.

Preferable Use of Local Terminology for Cancer

During the interviews, most of the respondents and their family members avoided the use of the term ‘cancer’ as they considered ‘cancer’ to be a dreaded word. The respondents described cancer as a disease, which spreads very fast and develops its tentacles all over the vital organs of the human body and ultimately leads to

death. The other terms like *pinna* (rounded mass), *gath/gand* (dense mass), *rasauli* (tumour) and ulcer were used to describe the disease. The other prevalent terms for cancer include *mari bimari* (bad disease), *chandari bimari* (dreaded disease), *bhairi bimari* (worst disease), *opri bimari* (unknown disease), *jar wala phora* (rooted sore), *mare karma wali bimari* (disease caused due to bad *karma*) and *Bikaner wali bimari* (disease treated at Bikaner, Rajasthan).

Non-disclosure of Cancer

Due to the stigma associated with cancer, the families of cancer patients tend to hide the diagnosis of cancer from others outside the family for four reasons: firstly, it is believed that cancer is caused due to *karma* and *kismet*, and individuals are held responsible for their illness; secondly, cancer is considered as a contagious disease and that it spreads from one person to other; thirdly, to save the patient from stigma; fourthly, cancer is considered to be an incurable disease and is often equated to death. Similar kind of observations have been made by other researchers who found that stigma associated with cancer often precludes cancer patients from openly discussing their experiences with individuals outside their family units (Bottorff et al. 1998; Choudhry et al. 1998).

Discrimination Against Cancer Patients

There are a number of ways by which cancer patients are discriminated against. These include keeping their utensils and other things of necessity separate, washing utensils and clothes of the cancer patients separately, giving food to cancer patients separately, and keeping the cancer patients in isolated places.

Two of the important case studies in relation to discrimination against cancer patients observed during fieldwork are given here. Case 1 suggests that some of the families seclude cancer patients due to their belief that cancer is contagious.

Case 1: A female respondent (aged 33 years, suffering from breast cancer, from Faridkot) was undergoing treatment at PGIMER, Chandigarh. Every time, she came to Chandigarh, she stayed with her brother's family. She said that she is

given food in separate utensils, her utensils are washed separately and kept at a separate place after washing. She is also told to sit and sleep separately from her brother's family, and as a result she felt isolated and secluded.

On enquiring about this seclusion, the respondent's brother said that to save other family members from the disease, they have secluded her. Her brother believed that cancer is a contagious disease and spreads from one person to another. For him, seclusion of the patient is the precaution taken to save other family members.

Case 2 suggests that in some cases, it is believed that cancer is due to *karma* and thus, individuals are held responsible for their illness.

Case 2: A male respondent (aged 40 years, suffering from cancer of larynx) told that the people from his village believe that his cancer is due to his past sins and look upon at him with a feeling of hatred. He had two daughters and was afraid that the stigma towards his disease would prove bad, especially for his daughters and they might not get a good life partner.

The stigma experienced by cancer patients often leads to their social isolation. Given these circumstances, the stigma of cancer diagnosis sets patients apart from others, results in perception of the self as being different, and results in isolation and alienation.

Some of the common observations in relation to stigma associated with cancer include: covering face with a cloth only leaving eyes uncovered by family members and visitors; the young women and children are advised not to go near cancer patients as it is believed that these two categories of individuals are more prone to infections (and cancer is considered as a contagious illness). Further, it is believed that the elderly men and women have already lived most of their lives and do not catch the infections much easily.

DISCUSSION

The specific nature of stigma associated with a serious illness may be dependent on whether the individual can be blamed or held responsible for its occurrence, whether the illness has potentially serious consequences for others, the illness, and/ or whether it results in a decreased level of competence. Once a stigma becomes evident to others, persons are labeled as an out-

sider, and expectations and assumptions are associated with the individual from which patterns of response from others emerge during interaction. As the person internalizes the label, it becomes a part of his/her identity and thereby, a part of the self that generates behavior. In the present study, it was found that a stigma is associated with cancer because of the following reasons: Firstly, it is believed that cancer is caused due to *karma* and the individuals are held responsible for their illness. This leads to labeling of the individuals with cancer as 'cancer patients' and the labeling results in stigma. Secondly, the bodily changes that occur as a result of cancer and its treatment, gives them a new identity that is, a 'cancer patient' to the sufferer and this identity is different from the previous gender or religious identity. This change in identity not only leads to public stigma but also leads to perceived stigma. Thirdly, it is believed that cancer is contagious and spreads from one person to others. This belief leads to stigma, seclusion and social isolation of cancer patients. Fourthly, it is believed that cancer will increase debilitation and lead to eventual death. This belief also leads to cancer related stigma. The findings of the study suggest that stigma exists where there are five components: (a) prevailing cultural beliefs about illness; (b) visible changes in bodily attributes take place or illness leads to physical or mental disability; (c) individuals are held responsible for their illness; (d) fear is associated with illness; and (e) illness with long-term treatment.

CONCLUSION

The present study suggests that cancer is a highly stigmatized disease in the study area. A number of myths and misconceptions about cancer exist and these myths and misconceptions about cancer not only create stigma for the cancer patients and their families but also affect their health seeking behavior. There is need to create awareness about symptoms, causes and treatments of cancer at different levels: one within the family, so that stigma can be reduced within the family setting, and at the level of society, so that stigmatizing behavior towards the patients and their families could be reduced. Awareness could be generated by the treating doctors, other healthcare providers, health experts, survivors and non-governmental organizations.

RECOMMENDATIONS

The following recommendations are made based on the present study:

- ♦ Efforts to create public awareness and dispel myths about cancer must be made.
- ♦ Community based programs must be launched to involve the community in the care of cancer patients.
- ♦ Prosthetics to hide hair loss and breast loss must be provided to the patients.
- ♦ Collaboration with non-governmental organizations may prove useful.

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