Cancer Stigma in Non-patient Population Visiting B&B Hospital, Lalitpur, Nepal: A Descriptive Cross-sectional Study

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Introduction: Research on various aspects of cancer, including stigma among cancer patients have received considerable interest in the recent years, but very few studies have studied cancer related stigma in healthy population. This study aimed to assess the situation of cancer stigma among the non-patient population.

Methods: This cross-sectional study included 330 purposively selected non-patient population of age 18-45 years visiting B&B Hospital, Lalitpur, Nepal from March 2019 to August 2019. The data was collected from self-administered questionnaires. Caner stigma was measured with the validated Cancer Stigma Scale, which assesses six sub domains viz. severity, personal responsibility, awkwardness, avoidance, policy opposition and financial discrimination.

Results: The highest score in Cancer Stigma Scale was found in the "severity", while the lowest in the "policy opposition". The policy opposition statements "More government funding should be spent on care and treatment of those with cancer" and "cancer patients should be given top priority" attracted the highest level of agreement (75.4 - 81.6%) followed by the statement about their comfort with cancer patients (59.5%), the acceptability for insurance companies to reconsider a policy once diagnosed with cancer (54.5%). A similar proportion felt getting cancer is to be prepared for death (38.5%) and a cancer patient is to be blamed for its condition (33.7%).

Conclusions: Cancer stigma persists in Nepal with varying level in different domains of stigma.

Introduction

Cancer is a leading cause of mortality and disease burden globally [1]. Approximately 28,000 new carcinoma cases are diagnosed every year in Nepal with mortality at 20,000, both at an increasing rate as per the Global Cancer Observatory estimates [2]. With the advent of new technologies, a large number of cancer related mortalities are preventable; but social stigma related to the disease is one of the major barriers influencing cancer prevention, early diagnosis and treatment [3].

Delay in health seeking behaviour is very common among cancer patients because of the stigma of cancer, and many patients opt alternative medicines and traditional healers for the treatment [4]. Various studies have found that negative beliefs about cancer are indeed associated with lower screening uptake, lower rates of self-examination for skin cancer, and higher healthcare avoidance for fear of having the illness [5]. Cancer patients seek support and care, not only from their family members, but also from the society. Studies have shown that people fear to disclose their diagnosis or to participate in screening programs to avoid rejection from family, society, or workplace [6,7].

There is a very limited study to assess the stigma related to a disease in Nepal. This study aims to

assess the cancer related stigma in an apparently healthy young and middle-aged population.

Materials and Methods

This was a cross-sectional study conducted among 330 purposively selected non-patient population visiting B&B Hospital, Lalitpur, Nepal from March 2019 to August 2019. The inclusion criteria for this study were hospital visitors of non-cancerous patients of age 18 to 45 years. Data was collected through a self-administered questionnaire form which included demographic characteristics and the validated Cancer Stigma Scale (CASS) to measure the stigma related to cancer. Participants unable to read and write Nepali language were excluded from the study. The sample size was calculated supposing 50% of the population has some type of stigma on cancer. Taking p=50%, q=1-p=50%, l= precision at 6%, and Z=1.96 at 95% confidence interval, the final sample size $n=Z^2pq/l^2=267$.

CASS is a validated six-point Likert scale with 25 items to assesses six sub domains of cancer stigma viz. severity, personal responsibility, awkwardness, avoidance, policy opposition and financial discrimination [8]. Score ranged from 1 to 6 with higher score indicating more stigma. There was positive as well as negative statements. The positive statements were marked as 6,5, 4,3,2,1 for strongly agree, moderately agree, slightly agree, slightly disagree, moderately disagree, and strongly disagree, respectively. Similarly, reverse markings were done for negative statements. The possible score range for CASS is from 6 to 150. Later, the responses of CASS items in this study were dichotomized into two; agree and disagree. The CASS scale was translated into Nepali language and back translated. Both the original and the translated version were examined by the experts. A pilot study among 20 participants who were not the part of this study was conducted and the necessary amendments were made before rolling out to the study participants. The CASS score showed a good internal validity (Cronbach's alpha=0.81) in this study.

After the data collection, data was entered, coded, and cleaned using MS Excel. Microsoft excel sheet was subsequently converted into Statistical Packages for Social Sciences (SPSS) version 16 for statistical analysis. Frequency, percentage, mean, standard deviation (S.D.) was calculated.

This study was approved by the Ethical Review Board of Nepal Health Research Council, Kathmandu, Nepal (Reg no. 616/2019). The study objective was explained to the participants and self-administered questions were administered only after obtaining the written consent.

Results

A total of 330 participants were included in this study with majority (88.5%) of the participants below 30 years of age and the mean age was 23.9 years. More than half (53.9%) participants were males. Similarly, majority (89.4%) were students, followed by professionals, semi-skilled workers, and homemakers. Almost all (99.7%) study participants were educated, with majority of them (84.2%) with a bachelor's degree and 5.2% with a master's or above qualification. Only one participant had no formal education (Table 1).

Characteristics	Category	n	(%)
Age in years	18-30	292	(88.5)
	31-45	38	(11.4)
Gender	Male	178	(53.9)
	Female	152	(46.1)
Occupation	Student	295	(89.4)
	Professionals	25	(7.6)
	Semi-skilled	6	(1.8)
	Homemakers	4	(1.2)

Education	No formal education	1	(0.3)
	Up to Class 10	5	(1.5)
	Intermediate	29	(8.8)
	Bachelors	278	(84.2)
	Masters and above	17	(5.2)

Table 1. Sociodemographic Characteristics of Participants (n= 330).

The level of stigma varied across the six sub domains, with highest score seen in the "severity", while the lowest in the "policy opposition". While measuring severity, most (72.2%) of the respondents disagreed to the concept that we can never return to normalcy with cancer. Likewise, three-fourth (75.5%) believed that cancer can be cured, and the survivor can establish a successful career. Similarly, nearly two third disagreed that cancer ruins personal relationships and devastates the lives of people suffering from it. In the domain "Personal Responsibility", only 24.5% believed that a person with cancer should be blamed for their condition. Similarly, more than half of the respondents disagreed to the statements that a person with cancer is liable or accountable for their condition. Regarding awkwardness, only 14% and 10.8% reported of finding it difficult to be around someone with cancer and to talk to someone with cancer, respectively. More than half of the respondents said they would be at ease and feel comfortable around someone with cancer.

A high majority of respondents (more than 90%) disagreed that they would avoid or get angered and irritated by someone with cancer. Likewise, more than 80% of the respondents believe that people and the government should work towards providing better care and treatment to the cancer patients. In financial discrimination, more than half of the respondents supported banks and insurance companies in refusing or reconsidering loans and insurance policies to someone with cancer. However, 88% and 67% of the respondents were against the idea of refusing loans to cancer patients and mortgage applications for cancer related reasons, respectively (Table 2).

S.N	CASS description	Disagree n (%)	Agree n (%)	Missing n (%)	Mean (SD)
Severity					12.4 (5.4)
1	Once you've had cancer, you're never normal again	213 (72.2)	82 (27.8)	35 (10.6)	
2	Getting cancer means having to mentally prepare oneself for death	241 (75.5)	78 (24.5)	11 (3.3)	
3	Having cancer usually ruins a person's career	192 (61.5)	120 (38.5)	18 (5.5)	
4	Cancer usually ruins close personal relationships	229 (72.5)	87 (27.5)	14 (4.2)	
5	Cancer devastates the lives of those it touches	193 (61.1)	123 (38.9)	14 (4.2)	
Personal Responsibility					9.3 (4.8)
6	A person with cancer is to blame for their condition	243 (75.5)	79 (24.5)	8 (2.4)	
7	A person with cancer is accountable for their condition	209 (66.3)	106 (33.7)	15 (4.5)	
8	A person with cancer is liable for their condition	223 (70.8)	92 (29.2)	15 (4.5)	

9	If a person had cancer, it's probably their fault	244 (77.5)	71 (22.5)	15 (4.5)	
Awkwardness					11.2 (5.0)
10	I would feel at ease around someone with cancer (R)*	124 (40.5)	182 (59.5)	24 (7.3)	
11	I would feel comfortable around someone with cancer (R)	126 (41.0)	181 (59.0)	23 (7.0)	
12	I would find it difficult being around someone with cancer	278 (86.0)	42 (14.0)	10 (3.0)	
13	I would find it hard to talk to someone with cancer	289 (89.2)	35 (10.8)	6 (1.8)	
14	I would feel embarrassed discussing cancer with someone who had it	279 (88.6)	36 (11.4)	15 (4.5)	
Avoidance					7.9 (4.1)
15	I would try to avoid a person with cancer	299 (92.3)	25 (7.7)	6 (1.8)	
16	I would feel angered by someone with cancer	303 (93.5)	21 (6.5)	6 (1.8)	
17	I would feel irritated by someone with cancer	295 (91.9)	26 (8.1)	9 (2.7)	
18	I would distance myself physically from someone with cancer	288 (90.9)	29 (9.1)	13 (3.9)	
19	If a colleague had cancer, I would try to avoid them	301 (93.8)	20 (6.2)	9 (2.7)	
Policy Opposition					6.6 (4.5)
20	The needs of people with cancer should be given top priority	79 (24.6)	242 (75.4)	9 (2.7)	
21	More government funding should be spent on the care and treatment of those with cancer (R)	61 (19.4)	254 (80.6)	15 (4.5)	
22	We have a responsibility to provide the best possible care for people with cancer (R)	59 (18.4)	261 (81.6)	10 (3.0)	
Financial Discrimination					7.1 (3.7)
23	It is acceptable for banks to refuse to	254 (87.9)	35 (12.1)	41 (12.4)	

	make loans to peoplewith cancer (R)				
24	Banks should be allowed to refuse mortgage applications for cancer related reasons	197 (66.8)	98 (33.2)	35 (10.6)	
25	It is acceptable for insurance companies to reconsider a policy if someone has cancer	133 (45.5)	159 (54.5)	38 (11.5)	
Total Stigma Score		54.6 (17.4)			

Table 2. Agreement in Each Cancer Stigma Items Among the Participants.

Discussion

To the best of our knowledge, this paper is the first study using the CASS to report the level of stigmatization towards cancer in Nepal. While, even globally, a lot of studies have focused on various aspects of cancer, very few studies deal with stigma related to cancer. Findings from this current study shows that the highest mean score is on perceived severity followed by awkwardness and personal responsibility. Similarly, lowest was seen in policy opposition, discrimination, and avoidance sub scales. This result shows that the non-patient population is less likely to have avoidance attitudes towards cancer patients.

Severity factor included items relating to how severe the consequences of a cancer diagnosis were expected to be and the likelihood of recovery from cancer [8]. Despite advances in understanding the causes, treatments, and outcomes of cancer, it remains one of the most feared illnesses [9]. Cancer patients worry about how their life may change following diagnosis including changes in appearance, and the threat of recurrence [10,11]. Besides, cancer fatalism also has the role to play in hindering general population's participation in cancer screening and prevention programs [12]. The main reason for higher score on this subdomain may be attributed to the belief that cancer is incurable and will lead inevitably to death. Most people are oblivious of the recent advances in the cancer treatments. Besides, out of pocket expenditure and financial constraints that can hinder cancer treatment might have resulted in pessimistic view towards cancer. Responses on the severity sub scale can be intervened by increasing knowledge about cancer screening, raising awareness on the success of cancer treatments, and addressing fatalistic beliefs.

The CASS also assesses Awkwardness i.e., whether people feel comfortable around someone with cancer. In our study, rate of feeling awkwardness was slightly higher.

Studies show that cancer patients' social interaction is greatly impacted by treatment related physical changes like, alopecia, anemic and weak appearance, surgical scars, mastectomy, colostomy, which can make them feel different and excluded [13]. Visibility is taken as an important predictor of stigmatization [14]. This can make people prone to depression, which is a commonly found psychiatric disorder in patients with cancer, with prevalence rate ranging from 21%-71% [15].

Personal responsibility, which relates to how much a person's actions are considered to have contributed to their cancer, has consistently been identified in stigma theory.8 Unhealthy lifestyle such as tobacco consumption, alcohol intake, fatty diet, obesity, and physical inactivity have been closely linked with cancer incidents [16]. So, most of the cancers are increasingly seen as self-inflicted. Lung cancer patients with smoking history may be seen as responsible for and even

deserving of this devastating illness [17]. Score on the Personal responsibility is increased as public becomes aware of the lifestyle risk factors for cancer.

Financial worries are always an additional stress following a cancer diagnosis with loss of employment and high spending due to treatment [18]. They also had to face discrimination from employers or colleagues on return to work [19]. Although the Government of Nepal has been providing financial support of 100,000 Nepalese rupees to cancer patients [20], it is not sufficient and thus most of the medical expenses fall on the shoulders of patients and their families. Almost everyone relies on out-of- pocket payment for cancer treatment, which is managed through loans and selling their properties [21]. There are many new treatment options for people with cancer, like immunotherapy or targeted therapy, but they are either not available or are unaffordable. Many people in Nepal do not complete their cancer treatment, often because of poor access to health care, and the high cost of diagnosis and treatment [20]. The government should take initiative regarding mass health education and reduce cancer stigma in the public by disrupting the misconceptions and changing the perceptions towards cancer.

There are some limitations to this study. It has employed purposive sampling technique and the participants were the visitors of non-cancerous patients from one hospital. Hence this study cannot be generalized. There can be social desirability bias in this study.

In conclusions, the findings of this study showed that the cancer stigma persists in Nepal with highest in severity domain and lowest in the policy opposition domain. This study serves as the benchmark for the stigma level in Nepal and helps in future research and intervention related to cancer stigma.

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