

Original Research Article

Assessment of cancer stigma level among the healthy population in Western Maharashtra: a cross-sectional study

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ABSTRACT

Background: Cancer stigma in India is a major hurdle for patients and families due to inadequate awareness and education. It results in misconceptions, fear, and avoidance of treatment. It brings social, emotional, and economic challenges for the caregivers, as well as isolation and discrimination among the patients. This study aims to assess the level of cancer stigma among the healthy population who may become caregivers or face cancer themselves in the future.

Methods: A cross-sectional study conducted among 267 healthy individuals visiting tertiary care hospital in Western Maharashtra, India, from March 2023 to August 2023. Data was collected through a self-administered questionnaire, using the validated cancer stigma scale (CASS). Microsoft Excel and statistical package for the social sciences (SPSS) version 26 used for statistical analysis and median, mean and standard deviation was calculated.

Results: Levels of cancer stigma were moderate but varied across the six subdomains in our study. The attitudes of respondents were reflected through their agreement with various statements, where 35% of people agreeing on “cancer patient being liable and accountable for their condition”, approximately 15% believed that “once you’ve had cancer you’re never normal again”, while 9% of respondent felt that “cancer devastates the life of those it touches”. Furthermore 45% of healthy individuals expressed that “It is not acceptable to refuse the bank loan for the cancer patient”. About 43% people strongly agree on “policy opposition” i.e. “more government funding should be spent on care and treatment of those with cancer”. People strongly disagree on any kind of awkwardness or avoidance related to cancer patient. Significant differences in policy opposition are observed among participants with distinct employment status (p value <0.05).

Conclusions: The study indicates the enduring presence of cancer stigma among healthy population in Western Maharashtra, with the observed highest stigma related to severity of the disease and policy opposition. This study establishes a fundamental reference for comprehending the existing levels of stigma among healthy individuals who may serve as caregivers in the future.

Keywords: Cancer, Social stigma, Caregivers, Health policy

INTRODUCTION

As per the global cancer observatory (GLOBOCAN) estimates, the global incidence of cancer reached 19.3 million cases in 2020. Projections indicate a significant increase in cancer cases in India, reaching 2.08 million by 2040, representing a 57.5% rise from 2020.¹ Cancer patients face an array of not just health issues but also various psychological pressures from within and the

environment, one such issue being stigma. Stigma is social phenomenon involving exclusion, rejection, blame, or devaluation due to the anticipation or experience of negative social judgment towards individuals or groups.² The fear of stigmatization, rejection, or blame adds emotional stress to those already grappling with a cancer diagnosis.¹ Myths and stigma surrounding cancer can influence behavior, affecting actions from diagnosis through treatment and end-of-life care.³ It is not only the

individuals who are suffering from cancer but, also the caregivers who face stigma. Caregivers may at times have to sacrifice personal opportunities, contributing to self-stigma and feelings of inadequacy.⁵

Stigma can be either perceived where there is shame associated with having a condition, presence of fear of discrimination or facing social exclusion or actual stigma, which refers to obvious discrimination, that may lead to feelings of guilt, shame that can threaten one's own identity.^{6,7} This stigma, coupled with myths related to diagnosis, death and associated pain can have a negative impact on health outcomes among cancer survivors.⁸

This study aims at assessing the level of cancer stigma amongst healthy population in Western Maharashtra and determining the sociodemographic factors that influences it as the secondary objective of the study.

METHODS

General settings

The study was conducted in a tertiary care hospital among the healthy individuals who were visiting the hospital as attendants or visitors of non-cancerous patients.

Place of study

The study was conducted in a tertiary care hospital in Western Maharashtra, India.

Timeline

The data collection was done for the period of three months i.e. from March 2023 to May 2023, followed by the data analysis and report making till August 2023.

Study design

A cross-sectional study design was employed.

Reference and study population

The reference population for the study comprised of healthy individuals who may potentially serve as caregivers for cancer patients. The study population is the healthy individuals of age 18 to 45 years who were visiting the hospital as attendants or visitors of non-cancerous patients.

Sample size

Estimated percentage of healthy caregivers facing cancer-related stigma was taken as 50% and the sample size was calculated by taking $p=50\%$, $q=1-p=50\%$, $d=$ precision at 6%, and $Z=1.96$ at 95% confidence interval.

Sample size, $n = Z^2pq/d^2 = 267$

Sampling method

Convenience sampling method was employed.

Exclusion criteria

Individual suffering from any type of disease was excluded.

Instruments

Data was collected through a self-administered questionnaire which included demographic characteristics and the validated CASS.¹¹ CASS has 25 items assessing six domains: awkwardness, severity, avoidance, personal responsibility, policy opposition and financial discrimination. The participants' responses were recorded on a 6-point Likert scale ('dis-agree strongly' to 'agree strongly'), higher score indicating higher stigma.¹⁴

Issues of analysis

After the data collection, data was entered, coded, and cleaned using MS Excel. Microsoft excel sheet was subsequently converted into statistical package for social sciences (SPSS) version 26 for statistical analysis. Median, mean and standard deviation was calculated.

RESULTS

The study included 267 participants, with 65.5% being male and 34.5% female. The majority fell in the 30–39 age group (50.9%), and those with professional degrees/postgraduate qualifications constituted the largest educational category (28.1%) (Table 1). Findings indicated nuanced perceptions in various domains of cancer stigma (Table 2 and Figure 1).

There were diverse opinions on severity and notable consensus on the belief that individuals diagnosed with cancer may never fully return to normalcy. This perception extends to the view that cancer has the potential to disrupt a person's career and profoundly devastate the lives of those it affects.

People strongly disagree with any form of awkwardness or avoidance related to cancer patients. There is a widespread agreement among people that cancer patients bear personal responsibility for their condition and should be held accountable for it.

Table 3 illustrates a spectrum of responses regarding discomfort associated with cancer, highlighting varied perceptions across different domains of cancer-related stigma."

Male participants demonstrated notably higher composite scores in personal responsibility, avoidance, and financial discrimination compared to females, indicating a higher level of agreement within these domains (Figure 2).

Individuals aged 30 and above show significant agreement on matters related to personal responsibility and financial discrimination. Significant differences in policy opposition are observed among participants with distinct employment status (p value<0.05).

Specifically, the median composite score of policy opposition is notably higher in the group of participants with professional/self-employed employment status compared to the group with other employment statuses (p value <0.05).

Table 1: Characteristics of study participants (n=267).

Characteristics	No. of participants	Percentage of participants (%)
Sex		
Male	175	65.5
Female	92	34.5
Age group (years)		
18–29	114	42.7
30–39	136	50.9
40–49	15	5.6
>50	2	0.7
Marital status		
Married	197	73.8
Never married	70	26.2
Employment status		
Home maker	16	6.0
Self employed	48	18.0
Skilled worker	1	0.4
Unskilled worker	5	1.9
Student	10	3.7
Professional	81	30.3
Unemployed	3	1.1
Other	103	38.6
Education status		
Illiterate	3	1.1
Up to primary school	5	1.9
Secondary school	47	17.6
Senior secondary school	64	24.0
Graduate	73	27.3
Professional degree/post graduate	75	28.1

Table 2: Median scores of various domains of cancer stigma among the study participants.

Domain	Median score	Range (min–max)
Severity	3.00	1–6
Personal responsibility	2.00	1–6
Awkwardness	1.75	1–5.25
Avoidance	1.40	1–5.20
Policy opposition	2.00	1–6
Financial discrimination	2.67	1–6

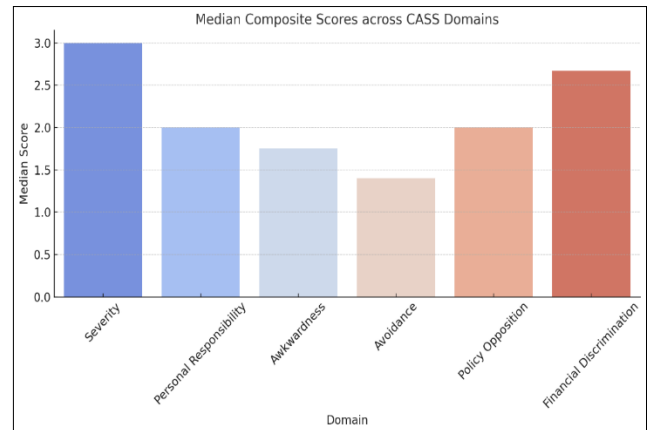


Figure 1: Median composite scores across CASS domains.

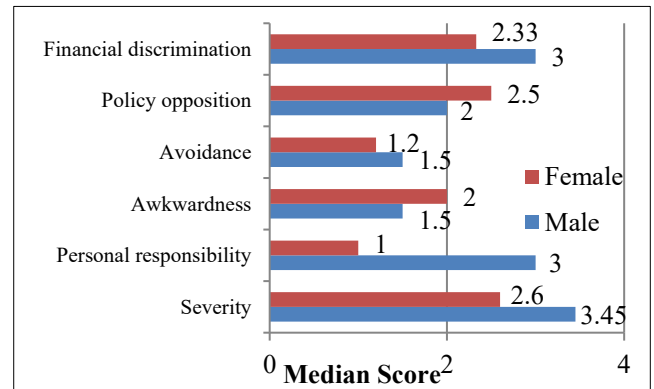


Figure 2: Distribution of median scores of various domains of cancer stigma according to gender of study participants

Table 3: Summary of key findings on cancer stigma among healthy participants.

Parameters	Key findings
Personal responsibility	35% believed cancer patients are liable and accountable for their condition
Severity perception	15% agreed that "once you've had cancer, you're never normal again"
	9% agreed that "cancer devastates the lives of those it touches"
Financial discrimination	45% felt it is unacceptable to deny a bank loan to a cancer patient
Policy opposition	43% strongly agreed that more government funding should be allocated for cancer care
	43% strongly agreed that cancer patients should be given priority in healthcare
Awkwardness and avoidance	Majority strongly disagreed with discomfort or avoidance of cancer patients

Continued.

Parameters	Key findings
Insurance discrimination	General agreement that reviewing insurance policy post cancer diagnosis is acceptable
Gender differences	Males scored higher in Personal responsibility, avoidance, and financial discrimination domains
Age group differences	Participants aged ≥ 30 years showed significantly higher stigma in personal responsibility and financial discrimination domains ($p < 0.05$)
Employment status differences	Policy opposition scores were significantly higher among professionals/self-employed participants compared to others ($p < 0.05$)

DISCUSSION

In our study, we observed a low level of avoidance towards cancer patients. However, study done by Kita et al found that the cancer survivors themselves perceived cancer as a highly stigmatized illness in the workplace, this situation often prompts avoidance behaviors.¹² Shim et al also found in their study that survivors with cancer stigma were more likely to lose their jobs than survivors without cancer stigma.¹³

According to the study done by Paneru et al, women who express perceptions of cancer as a terminal disease and believe they will never return to normal are less inclined to undergo cervical cancer screening.¹⁴ However, in our study we found that males exhibit a higher insight towards the severity of cancer, whereas females tend to have a lower perception of cancer severity and hence it can be a barrier towards the screening of cancer among the healthy males. However, some studies found higher stigmatization towards cancer in men.¹⁵

Notably, the highest median score was observed in the domain of financial discrimination, that indicates widespread agreement on perceiving financial discrimination linked to cancer. A study done by Moffatt et al, titled “work or welfare after cancer” found that patients after being confronted with the shock and fear of a cancer diagnosis, the immediate worries revolved around treatment and prognosis, intertwined with anxiety about their family responsibilities and the impact of the illness on their finances.⁴

Our study also indicates a heightened agreement on policy opposition, signifying a collective stance favoring increased government funding for cancer patients, ensuring the best possible care, and prioritizing them as a top concern. Similar finding was seen in the study where a prevalent perception surfaced that the system was seen as unfair and unhelpful, particularly when it seemed to endorse deceptive claims.⁴

In a study done by Weiss et al it was found that there was a close association among perceived stigma, self blame and depressive symptoms.¹⁶ This study highlights a general agreement in attributing personal responsibility in certain situations, where individuals are considered accountable for their circumstances.

Stigmatization is primarily linked to the behavioral and interactional dimensions of quality of life.¹⁷ Gender differences in personal responsibility, avoidance behaviors, policy opposition, and financial discrimination emphasize the diverse ways individuals experience the challenges associated with cancer stigma.

Limitations

This study, while offering valuable insights, was conducted at a single tertiary care centre using a convenience sampling approach. Although this method is practical in clinical settings, it may affect the generalizability of the findings beyond similar environments. The participants, being healthy individuals with potential exposure to hospital settings, may exhibit heightened health awareness, which could influence their stigma-related perceptions. Efforts were made to minimize such effects by ensuring a diverse participant profile within the study context.

Finally, given the cross-sectional design, causal relationships between sociodemographic factors and cancer stigma cannot be established. Future longitudinal or multi-centre studies employing probabilistic sampling are encouraged to build upon these findings and enhance their applicability across broader populations.

CONCLUSION

The results of this study indicate the enduring presence of cancer stigma among healthy population in Western Maharashtra, with the observed highest stigma related to severity of the disease and policy opposition towards the cancer patients. This study establishes a fundamental reference for comprehending the existing levels of stigma among healthy individuals who may serve as caregivers or may face a cancer diagnosis in the future. The study reveals supportive sentiments and areas where awareness could be improved.

This underscores the necessity for increased investment in diverse public campaigns for broader reach and stronger impact through enhanced IEC materials. It provides valuable insights for future research and interventions addressing cancer-related stigma. Implementing interventions to reduce stigma has the potential to alleviate the burden of cancer stigma and enhance participation in cancer screening and care of the cancer patients.

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