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# Cancer stigma among the caregivers of cancer patients, a cross-sectional study from a secondary care hospital in Andhra Pradesh, South India

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## Abstract

**Background**: The burden of cancer is growing globally, with rising rates of incidence and mortality. Given the increasing Cancer rates in India, understanding the burden of cancer on patients and their caregivers is important to improving access to care and social support as it is considered one among the potential barriers to care and support.

**Objective**: The study was intended to assess the cancer stigma among the primary caregivers of patients diagnosed with cancer and to determine the association between the cancer stigma and the selected demographic variables.

**Methodology**: Using quantitative approach, a descriptive study was undertaken for a period of one month. A total of 54 primary caregivers of patients diagnosed with cancer were recruited using total enumeration sampling technique. Data was collected using self-administered questionnaire consisting of demographic profile and cancer stigma scale (CASS) from the primary caregivers of cancer patients.

**Results**: Levels of stigma were low but varied across the six sub scales. Items related to the severity of cancer diagnosis attracted the highest levels of disagreement (mean – 12.9 and SD – 7.0). More number of subjects agreed that getting cancer is not related to personal responsibility (mean – 8.7 and SD – 5.8). Most of them agreed that there should not be financial discrimination for patients diagnosed with cancer and banks, insurance companies should support treatment (mean – 8.5 and SD – 4.7).

**Conclusion**: Caregivers of cancer patients have low levels of stigma however, majority of the subjects agreed for the statements that more government funding should be spent on the care for people with cancer and insurance companies to reconsider a policy if someone has cancer.

**Keywords:** Cancer Stigma; Caregiver's Stigma; Cancer; Primary Caregivers; Stigma

## 1. Introduction

In India, the patients diagnosed with cancer have expressed the belief that people bring cancer upon themselves because of the wrong doings either in this life or in the previous life (i.e., Karma). Lack of awareness or knowledge about the causes of cancer and fear that cancer is communicable have also been identified as one of the reasons for the existence of stigma in India. Stigma Manifests as social isolation within home – separate living space, utensils, clothes etc., or in community, slander or verbal abuse and decreased marriage prospects (1). However, there are limited studies done in India. The main aim of the study is to assess the cancer stigma among the primary caregivers of patients diagnosed with cancer and determine the association between the cancer stigma and the selected demographic variables in a secondary hospital setting in a rural area in Andhra Pradesh.

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## 2. Subjects and Methods

Using quantitative approach, a descriptive study was undertaken for a period of one month in a rural area in Andhra Pradesh. A total of 54 primary caregivers of patients diagnosed with cancer (<1 year) were recruited using total enumeration sampling technique. Data was collected using self-administered questionnaires consisting of demographic profile and cancer stigma scale (CASS) from the primary caregivers of cancer patients. Stigma towards cancer was measured using the Cancer Stigma Scale (CASS) developed by Marlow and Wardle (2014). It has 25 items scored on a 5-point Likert scale ranging from *Strongly Disagree* to *Strongly Agree* with scores ranging from 1 to 6. CASS scale has six subdomains, namely, awkwardness (five items), severity (five items), avoidance (five items), policy opposition (five items), personal responsibility (five items), and financial discrimination (three items) (2). There are positive and negative statements. The negative statements will be marked as 1, 2, 3, 4, 5, 6 and reverse markings will be done for positive statements (5 items). Higher the score, higher the stigma and vice versa.

## 3. Results

Data was analyzed using Statistical Product and Service Solutions (SPSS) version 23. Categorical data was analyzed using frequency and percentage. Descriptive data was analyzed using mean and standard deviation. Chi square test and logistic regression was used to find the association between selected demographic variables and cancer stigma of primary caregivers. Collected data are presented as tables. The findings are presented in the following order.

**Table 1** Distribution of subjects based on the agreement **(N = 54)**

| S.No | Questions | Disagree strongly | Disagree moderately | Disagree slightly | Agree slightly | Agree moderately | Agree strongly | Not sure |
|---|---|---|---|---|---|---|---|---|
| Severity | | | | | | | | |
| 1 | Once you've had cancer you can never be 'normal' again | 19 (35.2%) | 6 (11.1%) | 11 (20.4%) | 3 (5.7%) | 4 (7.4%) | 10 (18.5%) | 1 (1.9%) |
| 2 | Getting cancer means having to mentally prepare oneself for death | 26 (48.1%) | 1 (1.9%) | 5 (9.3%) | 7 (13%) | 7 (13%) | 6 (11.1%) | 2 (3.7%) |
| 3 | Having cancer usually ruins a person's career | 15 (27.8%) | 7 (13%) | 7 (13%) | 8 (14.8%) | 3 (5.6%) | 9 (16.7%) | 5 (9.3%) |
| 4 | Cancer usually ruins close personal relationship | 31 (57.4%) | 4 (7.4%) | 7 (13%) | 5 (9.3%) | 0 (0%) | 5 (9.3%) | 2 (3.7%) |
| 5 | Cancer devastates the lives of those it touches | 26 (48.1%) | 3 (5.6%) | 6 (11.1%) | 5 (9.3%) | 0 (0%) | 11 (20.4%) | 3 (5.6%) |
| Personal responsibility | | | | | | | | |
| 6 | A person with cancer is to blame for their condition | 29 (53.7%) | 5 (9.3%) | 4 (7.4%) | 7 (13%) | 1 (1.9%) | 7 (13%) | 1 (1.9%) |
| 7 | A person with cancer is accountable for their condition | 23 (42.6%) | 8 (14.8%) | 5 (9.3%) | 6 (11.1%) | 6 (11.1%) | 4 (7.4%) | 2 (3.7%) |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 8 | A person with cancer is liable for their condition | 25 (46.3%) | 2 (3.7%) | 7 (13%) | 7 (13%) | 2 (3.7%) | 5 (9.3%) | 6 (11.1%) |
| 9 | If a person has cancer, it's probably their fault | 30 (55.6%) | 4 (7.4%) | 6 (11.1%) | 2 (3.7%) | 0 (0%) | 5 (9.3%) | 7 (13%) |
| Awkwardness | | | | | | | | |
| 10 | I would feel at ease around someone with cancer (R)* | 12 (22.2%) | 3 (5.6%) | 4 (7.4%) | 6 (11.1%) | 1 (1.9%) | 27 (50%) | 1 (1.9%) |
| 11 | I would feel comfortable around someone with cancer (R) | 8 (14.8%) | 3 (5.6%) | 5 (9.3%) | 9 (16.7%) | 7 (13%) | 21 (38.9%) | 1 (1.9%) |
| 12 | I would find it difficult being around someone with cancer | 34 (63%) | 10 (18.5%) | 4 (7.4%) | 2 (3.7%) | 1 (1.9%) | 2 (3.7%) | 1 (1.9%) |
| 13 | I find it hard to talk to someone with cancer | 36 (66.7%) | 10 (18.5%) | 3 (5.6%) | 0 (0%) | 0 (0%) | 3 (5.6%) | 2 (3.7%) |
| 14 | I would feel embarrassed discussing cancer with someone who had it | 41 (75.9%) | 4 (7.4%) | 3 (5.6%) | 1 (1.9%) | 2 (3.7%) | 1 (1.9%) | 2 (3.7%) |
| Avoidance | | | | | | | | |
| 15 | I would try to avoid a person with cancer | 34 (63%) | 7 (13%) | 0 (0%) | 3 (5.6%) | 3 (5.6%) | 4 (7.4%) | 3 (5.6%) |
| 16 | I would feel angered by someone with cancer | 45 (83.3%) | 5 (9.3%) | 1 (1.9%) | 1 (1.9%) | 1 (1.9%) | 0 (0%) | 1 (1.9%) |
| 17 | I would feel irritated by someone with cancer | 43 (79.6%) | 6 (11.1%) | 2 (3.7%) | 0 (0%) | 1 (1.9%) | 0 (0%) | 2 (3.7%) |
| 18 | I would distance myself physically from someone with cancer | 39 (72.2%) | 5 (9.3%) | 3 (5.6%) | 5 (9.3%) | 1 (1.9%) | 0 (0%) | 1 (1.9%) |
| 19 | If a colleague had cancer, I would try to avoid them | 38 (70.4%) | 3 (5.6%) | 4 (7.4%) | 4 (7.4%) | 1 (1.9%) | 3 (5.6%) | 1 (1.9%) |
| Policy Opposition | | | | | | | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 20 | The needs of people with cancer should be given top priority (R) | 37 (13%) | 3 (5.6%) | 0 (0%) | 7 (13%) | 7 (13%) | 27 (50%) | 3 (5.6%) |
| 21 | More government funding should be spent on the care and treatment of those with cancer (R) | 9 (16.7%) | 2 (3.7%) | 0 (0%) | 4 (7.4%) | 8 (14.8%) | 30 (55.6%) | 1 (1.9%) |
| 22 | We have a responsibility to provide the best possible care for people with cancer (R) | 8 (14.8%) | 0 (0%) | 1 (1.9%) | 9 (16.7%) | 4 (7.4%) | 32 (59.3%) | 0 (0%) |
| Financial discrimination | | | | | | | | |
| 23 | It is acceptable for banks to refuse to make loans to people with cancer | 27 (50%) | 4 (7.4%) | 4 (7.4%) | 5 (9.3%) | 2 (3.7%) | 5 (9.3%) | 7 (13%) |
| 24 | Bank should be allowed to refuse mortgage application for cancer related reasons | 24 (44.4%) | 4 (7.4%) | 2 (3.7%) | 5 (9.3%) | 5 (9.3%) | 7 (13%) | 7 (13%) |
| 25 | It is acceptable for insurance companies to reconsider a policy if someone has cancer | 6 (11.1%) | 0 (0%) | 0 (0%) | 10 (18.5%) | 4 (7.4%) | 27 (50%) | 7 (13%) |

* Reverse scoring

**Table 2** Mean score and standard deviation for each domain

| S.no | Domains | Mean score | SD |
|---|---|---|---|
| 1 | Severity (Min: 0, Max: 30) | 12.9 | 7.0 |
| 2 | Personal responsibility (Min: 0, Max: 24) | 8.7 | 5.8 |
| 3 | Awkwardness (Min: 0, Max: 30) | 10.1 | 4.6 |
| 4 | Avoidance (Min: 0, Max: 30) | 7.6 | 3.7 |
| 5 | Policy Opposition (Min: 0, Max: 18) | 6.7 | 4.8 |
| 6 | Financial discrimination (Min: 0, Max: 18) | 8.5 | 4.1 |

**Table 3** Stigma score categories

| **Scores (n=54)** | **Stigma score** | |
|---|---|---|
| | Numbers | % |
| <50% (0 – 74) | 47 | 87.0 |
| ≥50% (75 – 150) | 7 | 13.0 |

**Table 4** Association between demographic profile and stigma score

| **Variables** | | **Stigma score ≥50%** | **Stigma score <50%** | **OR (95% CI)** | **p value** | **AOR (95% CI)** | **p value** |
|---|---|---|---|---|---|---|---|
| Gender of the care giver | Female | 3 (16.7%) | 15 (83.3%) | 1.60 (0.32 – 8.07) | 0.674 | 1.79 (0.22 – 14.54) | 0.587 |
| | Male | 4 (11.1%) | 32 (88.9%) | | | | |
| Age category of the care giver | 20 - 40 years | 4 (15.4%) | 22 (84.6%) | 1.52 (0.31 – 7.53) | 0.699 | 1.91 (0.16 – 23.16) | 0.610 |
| | 40 – 80 years | 3 (10.7%) | 25 (89.3%) | | | | |
| Education of the care giver | Up to High school | 4 (22.2%) | 14 (77.8%) | 3.14 (0.62 – 15.92) | 0.205 | 5.04 (0.73 – 34.88) | 0.102 |
| | Higher secondary, UG & PG | 3 (8.3%) | 33 (91.7%) | | | | |
| Occupation | Unskilled & Unemployed | 5 (15.6%) | 27 (84.4%) | 1.85 (0.33 – 10.54) | 0.687 | 1.49 (0.20 – 10.81) | 0.696 |
| | Skilled & Professional | 2 (9.1%) | 20 (90.9%) | | | | |
| Relation to the patient | First degree | 5 (13.5%) | 32 (86.5%) | 1.17 (0.20 – 6.75) | 1.000 | 0.56 (0.04 – 7.11) | 0.655 |
| | Others | 2 (11.8%) | 15 (88.2%) | | | | |
| Marital status | Married | 4 (10%) | 36 (90%) | 0.41 (0.08 – 2.11) | 0.358 | 0.22 (0.02 – 2.88) | 0.247 |
| | Single | 3 (21.4%) | 11 (78.6%) | | | | |

## 4. Discussion

### 4.1. The first objective of the study was to assess the cancer stigma of caregivers of cancer patients.

Overall, there is low level of stigma but it varied across the six sub scales. Items regarding the severity of a cancer diagnosis attracted the highest levels of disagreement (mean – 12.9 and SD – 7.0). Majority of caregivers disagreed for the statement that they would feel awkward around someone with cancer (mean – 10.1 and SD – 4.6). However, many agreed that getting cancer is not related to personal responsibility (mean – 8.7 and SD – 5.8). This illustrates positive outlook on the disease. In addition, many agreed that there should not be financial discrimination and banks, insurance companies should support treatment (mean – 8.5 and SD – 4.7). Similarly, many agreed for policy opposition statements (mean – 6.7 and SD – 4.8). This reflects that there is more expectation from bank, government, agencies and insurance companies to support cancer treatment financially.

This finding is consistent with the study done in Nepal in 2019 on cancer stigma among non-patient population. They reported that overall, there is low levels of stigma but higher disagreement score in severity domain and higher agreement for policy opposition (3).

Another study done in England on cancer stigma and cancer screening – a population-based survey in England in 2016 reported that there are low levels of stigma but varied across the domains (4).

*The second objective of the study was to find the association between the cancer stigma of caregivers with their selected demographic profile.*

Chi-square analysis was done to estimate the association between the demographic variables with the stigma score. The results were documented as odds ratio with 95% confidence interval and p value. The results suggests that there is no significant association between the levels of stigma and their selected demographic variable.

Similar findings seen in the study cancer stigma and cancer screening – a population-based survey in England in 2016. A total of 2048 adults participated in the study. They reported that stigma is not statistically associated with age or social grade (4).

## 5. Conclusion

Caregivers of cancer patients have low levels of stigma however, majority of the subjects agreed for the statements that more government funding should be spent on the care for people with cancer and insurance companies to reconsider a policy if someone has cancer. They also agreed that it is unacceptable for banks to refuse loans and mortgage application for people with cancer. More than half of the subjects agreed that getting cancer is not their fault.

## Compliance with ethical standards

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### *Disclosure of conflict of interest*

The authors declare no conflicts of interest.

### *Statement of ethical approval*

This study was conducted after approval by the Institutional Review Board on 16/8/23 (minute no: 15660). Informed consent was obtained from all individual participants included in the study.

### *Statement of informed consent*

Informed consent was obtained from all individual participants included in the study.

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