Research Paper

Caregiver Burden, Resilience and Optimism-A Prospective Study in Caregivers of Cancer Patients in Mumbai, India

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ABSTRACT

Caregivers assist with daily activities, including transportation, bathing, and shopping, as well as providing emotional support and company to the patient. Caregiver stress is a phenomenon that arises as a result of caregivers taking upon these duties. This study investigates the adult caregiver community of cancer patients in Mumbai, India and explores how caregiver resilience, optimism and burden levels differ among them. The impact of factors such as gender, age and relationship status of the caregiver and the patient cancer stage have been examined. The sample comprises 40 caregivers of cancer patients, including 20 male and 20 female caregivers. A demographic information survey as well as three standard psychological tests - the revised Life orientation test, the 4 item Zarit Burden Interview and the Brief Resilience Scale were used to evaluate optimism, caregiver burden and resilience levels among the population. The results indicate that despite high perceived levels of burden, the optimism and resilience of caregivers remained moderate instead of being low. Hence more emotional and physical support for the caregiver is required Furthermore, this study found that optimism was significantly affected by stage of cancer, while resilience was significantly affected by age, and caregiver burden was significantly affected by age and stage of cancer. These findings emphasize the need for a support system for caregivers, including therapies similar to cognitive behavioural therapy to further uplift their optimism and resilience levels. This support system should be targeted towards the psychologically vulnerable demographics identified in this study.

Keywords: *Optimism, Caregivers, Resilience, Spouse, Child*

Cancer is described as 'a generic term for a large group of diseases that can affect any part of the body' (World Health Organization, 2022). More specifically, cancer occurs when genes mutate to create cancerous cells (Cleveland Clinic., 2024). Globally, cancer's incidence has been increasing, accounting today for nearly 1 in 6 deaths.

This increase has been attributed to an ageing population, improper dietary habits, the taking on of unhealthy lifestyles, among a variety of other risk factors (Bahrami et al., 2023). Cancer incidence nationally is expected to further increase by 12.8% from 2020 to 2025, reinforcing

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the idea that it is a healthcare issue of growing prevalence, both nationally and globally (Mathur et al., 2023).

Dealing with a diagnosis of cancer and subsequent treatment has a significant effect on the physical and mental health of the patient. In addition, it takes a considerable toll on their loved ones, since the majority of the immediate caregivers are family members. A caregiver is defined as 'a person who has taken on the responsibility of looking after someone who is unable to care for himself or herself fully due to illness, frailty, disability or a mental health problem' (Agency for Integrated Care, 2024b).

Most research suggests a negative impact of caregiving on the mental health of the caregivers, with Indian caregivers being 15 times more susceptible to depression compared to the general Indian population especially when the patient is inflicted with a disease like cancer. (Times of India, 2018). The impact is similar globally, as a meta-analysis of 35 studies with over 11,000 participants found that 42% of cancer caregivers experienced depression (Bedaso et al., 2022).

Caregiver stress and burden can cause depression in caregivers (Moghaddam et al., 2023). Depending on the family's financial status, cancer stage and general family and patient health, caregiving could include a myriad of tasks from mundane tasks of housekeeping, meal preparation, medication reminders, errands, hospital transport to more evolved activities like decision-making, accompanying for doctor visits or hospital stays, financial assistance, communication to extended family and emotional support. An important point to be noted is that the caregivers themselves are individuals with their own life roles and social responsibilities and do not provide caregiving in isolation. In addition, they sacrifice their social participation to focus on the challenges of caregiving.

Caregiver burden can be divided into objective and subjective burden. Subjective burden involves the personal feelings of carers, while objective burden is defined as events related to negative caring experiences (Liu et al, 2020). Burden results when caregivers are in a state of physical, emotional, and mental exhaustion. It is a consequence of excessive workload, lack of privacy, and emotional demands by the patients. These factors lead to feelings of decreased mastery, autonomy and ambition in caregivers, manifesting themselves as depression and helplessness. Thus, the consequences of caregiver burden can be severe, and can lead to caregiver depression.

It is important to note, however, that optimism and resilience are protective factors against caregiver burden and depression. (De Oliveira et al., 2020; Fang et al., 2022). Resilience refers to the ability to maintain psychological wellbeing in the face of adversity. A resilient person is able to move through *and* grow through difficult times. Resilience has been shown by research to increase as a result of caregiving, if caregivers gain positive experiences from caregiving and indulge in self-care and have a lower caregiver burden (Manzari et al, 2023). Increased resilience leads to decreased levels of caregiver burden, and so, it is important for caregivers to develop it in order to prevent caregiver depression. There is a paucity of studies on resilience and optimism in cancer caregivers in India. Research in this area is important as high optimism and resilience levels in caregivers can lead to better physical and mental health outcomes for patients. This is significant especially in cases where patient optimism could positively impact quality of life and disease outcomes. (Allison et al., 2003). Thus, factors which affect high optimism, resilience, and caregiver burden are necessary to review.

METHODOLOGY

Research Design

The aim of this study is to understand the levels of the optimism, resilience, and caregiver burden of cancer caregivers in Mumbai, India, using a quantitative approach.

Sample

A total of 40 caregivers were surveyed: 20 male, and 20 females in the Outpatient Oncology Clinic and Chemotherapy Ward of Wockhardt Hospital, a tertiary care hospital in Mumbai. Purposive sampling was carried out, with all of the participants being caregivers of patients suffering from a cancer-related illness. The cancers included breast, lung, cervical, and oral cancers with breast cancer being the most common. Inclusion criteria for the caregivers were as follows: 1) a willingness to participate, 2) aged 18 years old or older, 3) being able to communicate, 4) being the primary caregiver, 5) not being paid for the care provided.

Table 1: Demographic distribution of the sample group (N=40)

Age	Number
20-29	3
30-39	12
40-49	5
50-59	9
60-69	10
70-79	1
Gender	**Number**
M	20
F	20
Religion	**Number**
Hindu	27
Muslim	10
Other	3
Cancer stage of relative (Cancer Research UK)	**Number**
1: very early cancers	4
2: cancer spreading to nearby tissue	12
3: cancer spreading to local lymph nodes	15
4: distant spread	9
Relationship with patient	**Number**
Child	17
Spouse	15
Sibling	3
Parent	5

Ethical Consent

Informed verbal consent either in English or Hindi language was received from all 40 participants. While obtaining consent, the purpose of the survey, how the gathered data would be used and the benefit of the study was explained. They were assured that caregiver and patient confidentiality would be maintained. There was minimal potential for harm in the data collection process as questions were short and objective. Effort was taken during the survey to create a trusting environment so participants would answer honestly.

Tools Used

In this study, three variables were investigated: resilience, optimism, and caregiver burden, along with demographic information. The demographic survey includes questions like "What is your age?", and "What is your relationship with the patient?". Demographic information was collected as a means of identifying any potential data trends. Questions related to caregivers' religion, educational qualifications, length and type of caregiving were also included in the demographic survey.

- *Brief Resilience Scale*: (Smith et al., 2008) For resilience, the *Brief Resilience Scale* was used, a 6-item questionnaire that measures an individual's 'ability to bounce back' and 'recover from stress'. The scale ranging from 1-6 consists of "strongly agreeing" to "strongly disagreeing" to questions including, "I tend to bounce back quickly after hard times", and "I tend to take a long time to get over set-backs in my life". The scale is 'negatively related' to several mental health illnesses. According to the creators of the scale, the scores can be interpreted through the following norms:
  - 1.00-2.99: Low Resilience
  - 3.00-4.30: Normal Resilience
  - 4.31-5.00: High Resilience
- *Revised Life Orientation Test*: (Scheier et al., 1994) To test optimism levels, the Revised Life Orientation Test[17] was used, a 10-item questionnaire that measures 'how optimistic or pessimistic people feel about the future'. It consists of statements like "In uncertain times I usually expect the best" and "I rarely count on good things happening to me". The scores can be interpreted as follows:
  - 0-13: Low Optimism
  - 14-18: Moderate Optimism
  - 19-24: High Optimism
- *Zarit Burden Interview*: (Bédard et al., 2001) The 4-item screening version of the Zarit Burden Interview was used to test caregiver burden. It measures the 'level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time'. It consists of questions like: "Do you feel you don't have enough time for yourself? Do you feel uncertain about what to do about your relative?", and "Do you feel stressed when you are around your relative?". The total score range is 0-16. Scores greater than or equal to 8 on the scale indicate high levels of caregiver burden.

Data Collection procedure

While obtaining verbal consent, the purpose of the survey, how the gathered data would be used and the benefits of the study were explained. After informed consent, a printed version of the questionnaire was handed to the participant. The author then translated each of the questions for those who could not understand English and helped them tick the appropriate option using a pen. The data was then entered into a google form, a digital version of the questionnaire and the data was saved onto a google sheets file. Scores for optimism levels, resilience and caregiver burden were calculated as per the described scales above. Select questions were reverse scored, as per recommendations by the respective scales. Those caregivers who were comfortable reading and writing in English filled out a digital google form instead. The caregiver data and scores calculated were then analysed.

Data analysis

T-test was carried out for the three variables- optimism, resilience and caregiver burden were tabulated with relation to gender, age, relationship and stage of cancer. Descriptive statistics

including mean and standard deviation were used to analyse the 3 variables related to the demographic status of the caregiver.

Other demographics that were included in the questionnaire were religion, length of caregiving, educational qualifications of the caregiver, incidence of similar occurrences of severe diseases in the family, length of caregiving and number of earning members in the family. However, as the sample size was small, there was not sufficient distribution among different choices in these categories and hence these factors were discarded from the analysis.

RESULTS

In this section, the results have been presented including the scores of the three variables: optimism, resilience and caregiver burden collected from the data as mentioned in the methodology. Statistical tools have been used to look for significant differences in these three variables across different categories with descriptive and inferential statistics. to interpret the data collected.

Table 2: Data table showing the demographic distribution of the sample continued (N=40)

Previous occurrences of severe illness in family such as stroke, other cancers, Parkinson's etc	Number
Y	15
N	25
Length of caregiving	Number
<1 year	26
2-5 years	8
5+ years	6

Table 2 depicts that most of the sample (62.5%) has not experienced a previous occurrence of severe illness in their family, indicating that most of the sample is inexperienced caregivers. This is buttressed by the fact that most of the caregivers had a length of caregiving that is less than a year (65%).

Table 3: Independent t-test analysis of optimism levels based on gender, relationship status, age and stage of cancer (N=40)

Source	M	n	SD	t	p
Male	18.15	20	3.9	-0.87	.39
Female	16.9	20	5.11		
Child	18	17	3.89	-0.23	.821
Spouse	18.33	15	4.3		
age ≥50	17.4	20	5.08	0.38	.708
age < 50	17.95	20	3.91		
Stage 2	16	12	5.24	-1.76	.092
Stage 3	19.33	15	4.39		

*Note:p<.010**

Table 3 denotes that gender t(40) = -0.87, p>0.05, relationship t(32) = -0.23, p>0.05 and age t (39) = 0.38, p>0.1 showed no significant impact on the optimism levels of caregivers. There was, however, a significant difference in optimism levels between caregivers of patients with

stage 2 cancer and stage 3 cancers, t (27) = -1.76, p<0.1, and hence stage of cancer influences caregiver optimism.

Table 4: Independent t-test analysis of resilience levels based on gender, relationship status, age and stage of cancer (N=40):

Source	M	n	SD	t	p
Male	3.275	20	0.957	-0.64	.527
Female	3.075	20	1.023		
Child	3.215	17	0.687	-0.14	.888
Spouse	3.267	15	1.225		
age ≥50	2.76	20	0.75	1.86	.073
age < 50	3.38	20	1.3		
Stage 2	3.18	12	0.78	-0.52	.607
Stage 3	3.38	15	1.18		

Note:p<.010*

From **Table 4**, it can be inferred that there is no significant difference in resilience levels between male and female caregivers t(40)=-0.64, p>0.05 or between child and spouse caregivers of the cancer patients t(32)=-0.14, p>0.05 Similarly, there was no significant difference in resilience levels of caregivers of patients with stage 2 or stage 3 cancers t(27) =-0.52, p>0.1. There was however a significant difference in resilience levels between caregivers of patients below the age of 50 and older caregivers t(39)=1.86, p<0.1.

Table 5: Independent t-test analysis of caregiver burden levels based on gender, relationship status, age and stage of cancer (N=40)

Source	M	n	SD	t	p
Male	6.75	20	4.23	-0.97	.336
Female	8.05	20	4.21		
Child	6.65	17	4.94	-1.09	.284
Spouse	8.33	15	3.79		
stage 2	7	12	3.67	-2.63	.015
stage 3	10.67	15	3.52		
age ≥50	8.7	20	3.77	-2.03	.05
age<50	7.3	19	4.13		

Note:p<.010*

It can be inferred that there is no significant difference in caregiver burden levels between male and female caregivers t (40) = -0.97, p>0.05 or between child and spouse caregivers t (32) = -1.09, p>0.05 .There was, however a significant difference in caregiver burden levels between caregivers of patients with stage 2 and stage 3 cancers, t (27) = -2.63, p<0.1. Caregiver age above 50 years also negatively impacted burden levels t (39) = -2.03, p<0.1 (Table 5)
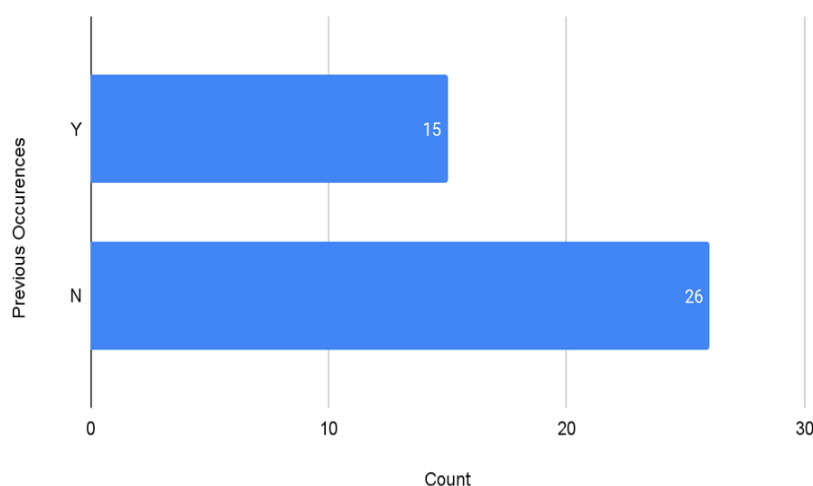
Figure 1: Graphical representation of caregivers having previous occurrences of serious illness like cancer, stroke, Parkinsons in the family(N=40)

In figure 1, 63.4% of the respondents do not have a family member who has encountered a similar disease before. Hence, for the majority of the sample, caregiving may be an unexplored realm, which could impact their levels of caregiver burden.

DISCUSSION
This section discusses the results, providing the interpretation of the same for each of the variables: optimism, resilience, and caregiver burden.

● **Optimism**

From the results section, it can be seen that the mean optimism score as measured by the LOT-R in both men and women was in the range of 16-19 which was moderate optimism as opposed to low or high levels of optimism. In addition, the optimism level was unaffected by the gender of the caregiver. Opposing results were obtained by Schnedier et al. (2011), who show that female caregivers have lower optimism levels when compared to their male counterparts. This is consistent with research for non-caregivers as well; in the realm of economics, employment, and in general risk-taking attitudes (Dawson, 2023). The reason this study did not yield the same results is likely because the sample size of this study was lower i.e. 40 respondents.

The second variable studied under optimism was age and no significant results were found when analysing the two variables. It is important to note that higher caregiver burden is linked to lower optimism levels (Sardella et al., 2021). Since older people generally experience higher caregiver burden while caregiving due to higher physical strain, it is likely that older caregivers will be less optimistic. There is, on the other hand, research that suggests that caregivers that are grandparents have better psychological health than other types of relationships (De Oliveira et al., 2017). Putting the conflicting research aside, there are many other factors that affect caregiver optimism, and hence the aforementioned logic cannot be relied upon without more concrete scientific research to support it. Hence, the findings of this study are supported, though more research needs to be done specifically analysing caregiver age and optimism before conclusions can be drawn.

Significant results were found when exploring the link between stage of cancer and optimism levels in caregivers. It is a somewhat counter-intuitive finding, as the optimism of caregivers of patients with stage 3 cancer was higher than that of stage 2 cancer. This finding suggests that the increased workload and burden that comes with caregiving for a patient with a higher stage of cancer actually results in higher optimism. However, since higher caregiver burden is linked to lower optimism (Sardella et al., 2021), and caregivers of stage 3 cancer patients have increased duties and burden, it is more likely that advanced cancers would actually lead to lower optimism levels, contrary to this study's finding. This is supported by research that shows that caregivers of higher cancer stage patients have worse psychological outcomes (Ketcher et al., 2020).

- **Resilience**

The study showed no significant changes in resilience levels among caregivers of stage 2 versus stage 3 cancers. A previous article (Cui et al., 2023) showed that patients undergoing fewer than two types of treatment and a lower symptom burden of patients predicted higher caregiver family resilience. Though there is not a very explicit link between treatments and cancer stage, the fact that higher stage cancers typically necessitate more treatments and have higher symptom burden makes the study relevant. However, their study was restricted only to patients with advanced cancers and may not be representative of cancer holistically-especially when making comparisons between stages. Though Thakur et al. (2024) did show that there is a link between duration of treatment and resilience, the relationship between stage of cancer and treatment duration is not perfect, and hence the conclusion made by our study is supported.

The current study also showed no differences in resilience levels between both genders. An opposing viewpoint is held by Dias et al., (2015), showing that resilience is higher for females. This is contrasted with research that suggests males have higher resilience by Whitten et al., (2022), and research by Dias et al. (2016), which suggests that there is no relationship between the two. Since there are contrasting results regarding the resilience of both the genders in a caregiving context, the conclusion made by this paper is supported- that there is no difference in resilience levels between genders. Similarly, no difference was found on caregiver resilience on the basis of relationship (adult-child or spousal).

Evidence derived from research by Donnellan et al., (2021) shows that spousal relationships often result in higher caregiver resilience, with the motivation of marital duty being a driving factor for the same. The reason for this is that spouses are already accustomed to taking care of each other, hence caregiving is merely seen as an "extension of marriage" Though researchers like Ott et al. (2007) show that adult-child caregivers draw more positive experiences from caregiving than their spousal counterparts, and experience more personal growth, adult-child caregivers do experience more guilt and view caregiving as more of an obligation (Donnellan et al., 2021).

Hence, the conclusion being made here is that spousal relationships do elicit higher levels of caregiver resilience than adult-child relationships, which is also supported by Thakur et al. (2024). The reason this study did not reach the same conclusion is likely because of the limited sample size. Though the study being used here, conducted by Donnellan et al, only had a sample size of 13 people the reason their conclusion is being supported is because it is logically sound, theoretically backed, and supported by another conducted research. Another variable measured was resilience of the caregivers which was tested among those less than

and greater than the age of 50. A significant difference was found in resilience levels between those two groups, with older caregivers having higher levels of caregiver resilience. This finding is supported with a study carried out by Thakur et al. (2024). There is also theoretical reasoning that supports this. According to Yashasvi. (2021), resilience is a learned ability and is not innate. It is something that develops with experience with handling trauma or adversity. Hence, older people, in essence, have more opportunities to "learn" this ability of resilience, which usually strengthens it, just as active recall would for a student learning history.

- **Caregiver Burden:**

The study also found that caregiver burden level was not affected by gender of the caregiver or their relationship with the patient. The reason the results may not indicate any significant results is likely because the sample size is too small. Though this may not be the strongest argument, considering caregiver burden also has a subjective facet, and females tend to be less optimistic than males, it would seem more likely for females to have a higher caregiver burden. Looking at more concrete reasoning, there are also multiple research papers that buttress this view. Moghaddam et al. (2023) and Thakur et al. (2024) showed that females have higher caregiver burden than males. As for the type of relationship, research by Reed et al., 2014 does indicate that adult-child caregivers experience greater caregiver burden than spousal caregivers. The reasoning for this result is likely that adult-child caregivers have to balance more commitments with caregiving, on average. Considering Reed's study had a data set of 1,497 participants which is significantly more than that of this study, it can be concluded that the reason significant results were not obtained regarding the relationship type and the associated caregiver burden likely boils down, again, to the sample size of the study.

The finding that caregiver burden is higher in older caregivers is supported by Tuttle et al., 2022 who found, nearly half of the 69 caregivers surveyed were over sixty years old, and age was significantly associated with caregiver burden, as was found by our study. The conclusion that there is a positive relationship between caregiver burden and age is also to be supported because there is very clear logical reasoning as to why this relationship should exist. As put by Tuttle, this could arise due to the physical difficulties experienced by caregivers as they age, experiencing reduction in stamina and strength. It is important, however, to discuss some differences between the studies that need to be considered before drawing such conclusions. In their study, the caregivers cared for older people with physical disabilities while this study focussed on cancer caregivers. Also, this was an urban setting in a tertiary hospital, while their study was a rural setting. There are, however, multiple other studies that support our finding. Mukhtar et al. (2019) shows that older caregivers generally experience higher caregiver burden, with the 60-79 age range encountering the most. This finding is supported due to the reasoning and numerous studies that support it.

Caregiver burden was also similarly higher among caregivers of Stage 3 cancers when compared to stage 2. Since a higher stage cancer usually warrants a patient that has worse physical and mental health, a caregiver would, naturally, need to assist them with daily tasks more, increasing caregiver burden. This reasoning is supported by research from Thakur et al. (2024).

CONCLUSION

The aim of the study is to explore how resilience, optimism and caregiver burden differ amongst the caregivers of cancer patients in Mumbai, Maharashtra, India. The study explored how the aforementioned variables differed by caregiver age, caregiver gender, the

relationship between the patient and the caregiver, and the patient's stage of cancer. By doing so, it has identified demographics that are potentially vulnerable to mental health issues and presents a target group for healthcare providers to act on. It can also be used to inform mental health services that can be catered towards ameliorating the mental health and depressive symptoms of these caregivers. Furthermore, interventions can be executed by doctors for these caregivers, creating workshops to educate caregivers on how to deal with caregiver burden, as well as strategies to increase their optimism and resilience. These workshops could be catered towards the vulnerable demographics. Further studies must be done in order to investigate optimal strategies to target caregiver depressive symptoms.

A major limitation of the study is the sample size. Further studies must be done with larger samples to ensure proper representation of the Mumbai population. There also was a potential language barrier, as many of the participants did not use English as their first language and so the meaning of the questions may have been lost in translation. The researcher, as a result, often also had to explain the meaning of the questions to the caregivers. This means biases like the framing bias could influence the results, especially since the data is self-reported. Lastly, a potent limitation is that some of the studies' findings are not conclusive because there is a lack of research surrounding it. Meta-analyses thus must be done in order to yield conclusive findings.

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Conflict of Interest
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