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Patient-Caregiver Relationship and Psychological Distress among the Caregivers of Cancer Patients

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ABSTRACT

Despite efforts to strengthen long-term hospital-based care, informal caregivers continue to provide substantial support to individuals diagnosed with cancer. The emotional and psychological health of these caregivers is heavily influenced by their relationship to the cancer patient. A limited amount of research exists on how the specific nature of the patient–caregiver relationship (e.g., parent–child, sibling, spousal) affects psychological well being of the caregiver caring for a cancer patient. This study aims to explore the relationship between caregiving roles and psychological distress among caregivers of cancer patients in India. The cross-sectional study involved 80 caregivers who consented to participate in the study from various hospitals in New Delhi, India using purposive sampling. Data was collected through face-to-face interviews. Psychological distress was measured using the General Health Questionnaire (GHQ-28), a widely validated tool for assessing psychological well-being. Descriptive statistics was used to summarize demographic and caregiving role information. Regression analyses were conducted to explore the extent to which the type of caregiver relationship predicted psychological distress outcomes. The findings indicated that caregivers who were parents of a child suffering from cancer and spouse (wife) caring for her husband suffering from cancer experienced higher levels of psychological distress, including significant worry and uncertainty in comparison to caregivers attending to their parents or siblings with cancer. Regression analysis also showed that the caregiver role significantly predicted psychological distress scores ($p < 0.05$), with parental caregivers caring for their children suffering from cancer showing the greatest vulnerability

Keywords: *Patient - Caregiver relationship, Psychological Distress , Cancer caregivers*

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1. INTRODUCTION

Worldwide, a major predominant reason for mortality and morbidity is cancer, placing considerable burden on the patient and caregiver (World Health Organization, 2022). With the advancement of disease, cancer patients often need the comprehensive medical and emotional support for which informal relationships come into picture including- spouses, parents, children, relatives and friends. These informal caregivers aid the long-term hospital care, providing the daily routines assistance which are very crucial for the patient to be taken care of. Routine physical activity, symptoms management, psychological care and medical treatment intricacies are taken care of by the caregiver with selfless intentions (Northouse et al., 2017). The extended caregiving obligations often result in substantial emotional turmoil, caregiver psychological and physical well-being, thus affecting overall quality of life (Geng et al., 2018). The caregiver experiences are shaped due to multiple reasons including patient-caregiver relationship, emotionally fluctuating situations and the availability of social support. These factors are interrelated and comprehending their impact will be helpful in development of intervention for the well-being of caregivers and to support those thus enhancing the patient's outcome.

1.1 The Role of Informal Caregivers in Cancer Care:

Caregiving is an act of compassion and dedication and its association with distress leads the caregiver’s loss of interest in their own overall well-being. Caregivers tend to be psychologically distressed due to the burden of emotions and practical exposure of medical reality. Caregiver helps in maintaining the duties related to medical treatment and involved in daily routine necessities. In contrast to informal caregivers, professional caregivers know how to handle the situation and provide care to the patient in a systematic way but informal caregivers genuinely take care out of concerns and try to do their best leading them to loading themselves with stress (Bevans & Sternberg, 2017). The caregivers are involved in assisting the patient and are available for different timelines depending on the stage and the condition of the patient. Research showed that the caregiver of cancer patients experienced heightened psychological well-being drop down in comparison to the general population, often showing the signs of anxiety, depression and sleep deprivation (Priego-Cubero et al., 2023)..

1.2 Psychological Distress among Cancer Caregivers:

Cancer patients' caregivers tend to unknowingly get psychologically distressed due to various unavoidable factors such as caregiving responsibilities, patient’s physical and mental conditions, financial strain and individual stress coping strategy (Geng et al., 2018). Caregivers may encounter grief for the condition, sadness, sense of powerlessness and fear of losing their loved ones. The ambiguity relative to cancer prognosis exacerbates the stress and makes their emotions complicated, neglecting their own well-being (Northouse et al., 2017). Multiple physical issues such as cardiovascular problems, weak immunity, physical health issues and tiredness, etc. can be experienced by the caregivers (Priego-Cubero et al., 2023).

The healthcare industry is expected to be a source of support, satisfaction and thus a guarantee that both the patient and the caregiver are satisfied and their wellbeing supported but from the cancer perspective, the fact that healthcare institutions are focusing on the patient rather than the caregiver reflects the fragile and uncoordinated system of oncology care today.

1.3 Patient-Caregiver Relationship and Psychological Distress among Caregivers of Cancer Patients — A Research Need:

The relation between the patient and caregiver is an important factor for influencing the caregiver's well-being. Young and Kahana (1989) investigated the involvement of gender and caregiver-recipient relationships in the occurrence of stress during care provision. According to their research, the most affected groups were the female caregivers, especially spouses and daughters as they experienced the most emotional and physical strain in comparison to the male caregivers. Spousal caregivers were found to be under the highest degree of burden because of the care’s intensity and continuity, while children caregiver’s burden was associated with care balance. The study thus showed that the effects of caregiving were contingent not merely on the gender of the caregiver but the relationship between the caregiver and the care recipient. Pinquart & Sörensen (2011) confirmed that the impact of caregiving on psychological well-being is correlated with the nature of caregivers’ relationships to their care receivers. Girgis et al. (2013) in their study stated that the nature of the patient-caregiver relationship may influence the level of distress experienced. Spouses and parents, due to their emotional proximity and extended caregiving hours, may experience greater psychological strain than more distant relatives or friends. Litwin, Stoeckel, & Roll (2014) found that the type caregiver-patient relationship is associated with psychological well being, with spousal and child caregivers showing lower well-being compared to those caring for parents or siblings. Kim et al. (2015) investigated the chronic effects of caregiving stress on cancer caregivers’ physical health, particularly spousal caregivers. The long-term study depicted a different picture as chronic stress from the experience of providing care was associated with caregivers’ physical health issues. It was also stressed that the healthcare and well-being of caregivers have an important impact on the patients’ recovery and general healthcare of their family members. A study by Penning and Wu (2016) focused on caregiving ties and gender inferences for caregiver stress and mental health. Their study proved that the main reason for the overload and depression in caregivers was the fact that spouse caregivers were too emotional and had more demands in the marriage than those of the children. Also, the gender difference was found, where females had more stress and psychological issues than males. This has been attributed both to stereotyped female roles, as well as to the commonly assumed view that a woman should be the one to take care of a family member. It became clear that the level of caregiving burden was not comparable across all of the caregivers.

Caregiving burden is getting attention and recognition for its heavy duty and imposed stress on caregivers but still more research work is needed to identify the inter-connective effects of interaction of psychological distress and patient-caregiver relationship. These interactions are crucial to be observed for the development of targeted interventions with the objective of mitigating the caregiving burden and holistic well-being of caregivers. Family-centred care models help in reducing distress by strengthening patient-caregiver relationship with the open communication and their emotional support to each other (Li et al., 2021). For instance, social support programs can be integrated into health care service centers to support the family or caregiver of a patient and guide them for effective caregiving so as to avoid distress. Caregiving for the cancer patient imparts a significant impact on the mindset, as cancer is life-altering disease and its diagnosis affects both patient and caregiver, directing them to turmoil of emotions and psychological burden. Informal caregivers including family members, provide utmost care in terms of emotional support, medical care, physical help, etc. This study aims to identify and examine the relationship of patient-caregivers and psychological distress among caregivers of cancer patients and also whether the patient-caregiver relationship and demographic factors are a predictor of psychological distress among cancer caregivers. A cross-sectional survey mixed design and standardized measurement tool for the justification with the empirical evidence on how different relationships of caregiver and patient can affect the psychological well-being of caregivers is used. This study will give a good contribution to better understanding of the needs of caregivers and interventions needed to improve their psychological health and provide support systems to mitigate stress.

2. OBJECTIVES OF THE STUDY:

To investigate the role of patient-caregiver relationship in predicting psychological distress among caregivers of cancer patients.

3. HYPOTHESIS:

Distribution of psychological distress scores is the same across all caregiver groups caring for cancer patients.

4. METHODS AND MATERIAL

A cross-sectional study was conducted using a mixed method approach and was carried out at different hospitals in Delhi, India. Purposive sampling was used to collect data. About 140 numbers of caregivers of cancer patients were approached out of which 80 numbers of caregivers agreed to participate. Caregivers of cancer patients who volunteered to provide information were given the details about the study. Informed consent was received to use this data for research purposes only and they were assured of confidentiality of data. Demographic details such as age, gender, education level, monthly income, work status, type of family and length of caring were gathered in person using standard questionnaires. Five categories were used to classify the patient-caregiver relationship: spouse, parent, sibling, children, daughter-in-law/son-in-law. To measure psychological distress, the General Health Questionnaire-28 (GHQ-28), a validated tool for measuring psychological discomfort across four domains—Somatic Symptoms, Insomnia, Social Dysfunction, and Severe Depression—was used. Likert scales with four points, from 0 ("Not at all") to 3 ("Much more than usual"), were used to score each item. The sum of the scores from the four subscales was used to determine the overall psychological distress score, which could range from 0 to 84. Higher scores denoted more psychological discomfort. The scores were divided into three categories based on established guidelines: 0–23 (No/Mild Distress), 24–35 (Moderate Distress), and 36–84 (Severe Distress). Data was compiled, tabulated in Microsoft Excel sheet and analyzed with the help of SPSS software (version 27). The normality of data distribution, which was evaluated during preliminary analysis, provided the basis for choosing the non-parametric test given the existence of ordinal and nominal variables. To summarize the individuals' demographics and GHQ-28 scores, descriptive analyses were used. For both categorical and ordinal variables, measures included frequency distributions, median and interquartile range (IQR). Psychological distress levels across relationship types were compared using a Kruskal-Wallis Test (non-parametric) in which the GHQ-28 total score (ordinal) was the dependent variable, while the patient-caregiver relationship (nominal) was the independent variable. The combined effects of the patient-caregiver relationship and demographic characteristics (e.g., education level, income, age, gender) on psychological distress were investigated using a Regression model. Both category (nominal) and ordinal predictors were independent variables, whereas the GHQ-28 psychological distress score (categorized ordinally) was the dependent variable.

5. RESULTS

5.1 Demographic Profiles: The data on family income distribution reveals that the majority of respondents (42.5%) fall into the highest income category of above 5 lakhs. This is followed by 21.3% of families earning between 3 to 5 lakhs, while 17.5% earn between 1 to 3 lakhs. The data on education level indicates that a majority of the respondents (62.5%) have attained higher education, reflecting a well-educated population. A smaller percentage, 23.8%, have completed secondary education, while 11.3% have only primary education. Notably, only 2.5% of the respondents have no formal education at all. The age group data shows that the majority of respondents fall into the Middle Age category (45%), followed closely by young individuals (41.3%). A smaller portion, 13.8%, are classified as Elder.

Among the 80 caregivers included in the study, the majority were employed, accounting for 67.5% of the sample. A smaller proportion, 28.8%, were economically weaker, while only 3.8% were unemployed. In terms of family structure, the sample was nearly evenly split, with 52.5% of caregivers living in joint families and 47.5% in nuclear families.

5.2 Statistical Analysis: The descriptive statistics provided insights into the psychological distress levels among the 80 respondents. The psychological distress scores range from 5 to 74, with a mean score of 37.96 and a relatively high standard deviation of 17.60, indicating considerable variability in distress levels among participants is given in Table 1.

Table 1:Psychological Distress Score among participants

	N	Range	Minimum	Maximum	Mean	Std. Deviation
Total score psychological distress	80	69.00	5.00	74.00	37.9625	17.59995

Table 2 gives psychological distress scores of participants in various categories – mild distress, moderate distress and severe distress. 20 number of participants undergo mild distress with a mean of 16.3 and standard deviation of 5.371, 19 number of participants suffered from moderate distress with a mean of 29.36 and standard deviation 4.044 and 41 number of participants have severe distress with a mean of 52.51 and standard deviation 10.198.

Table 2: Psychological Distress Score in different categories of distress

Psychological distress Category	N	Range	Minimum	Maximum	Mean	Std. Deviation
Mild distress	20	18.00	5.00	23.00	16.3000	5.37146
Moderate distress	19	11.00	24.00	35.00	29.3684	4.04434
Severe distress	41	38.00	36.00	74.00	52.5122	10.19834

For comparing the psychological distress across patient-caregiver relationship categories, Kruskal-Wallis's Test was used , summary of which is given in Table 3. Since the p-value is 0.000, which is less than the standard alpha level of 0.05, the result is statistically significant. Therefore, we reject the null hypothesis, which stated that the distribution of psychological distress scores is the same across all caregiver groups caring for cancer patients.

Table 3: Independent-Samples Kruskal-Wallis Test Summary

Total N	80
Test Statistic	32.302
Degree Of Freedom	8
Asymptotic Sig. (2-sided test)	0.000

Psychological distress score of different caregiver groups is given in Table 4. The highest psychological distress is reported when the mother is the caregiver (57.18) followed by the father caring for their child suffering from cancer and the spouse (wife) caring for her husband suffering from cancer. The lowest distress is seen with sister (14.00) and brother (18.50) as caregivers for their siblings having cancer. Parental caregivers (mother/father) of children suffering from cancer and spouse caregivers (especially wife) are associated with higher psychological distress. Sibling caregivers appear to be linked with lower distress levels.

Table 4: Psychological Distress Score of Caregivers– Groupwise

Care giver group		Mean (Psychological Distress)	Mean(Psychological Distress) Caregivers categories
Father	Parents	46.5	51.84
Mother		57.18	
Spouse (Husband)	Spouse	36.72	40.98
Spouse(Wife)		45.25	
Brother	Siblings	18.5	16.25
Sister		14	
Daughter	Children	33.58	30.2
Son		26.8	
Daughter in law		19.5	19.5

To determine whether the patient-caregiver relationship and demographic factors influence the level of psychological distress among the cancer caregivers, the Regression model is used, as given in Table 5. The regression model significantly predicts psychological distress among caregivers, with approximately 48% of the variance in distress scores explained by demographic characteristics and the caregiver's relationship to the patient. The result is statistically significant ($p < 0.001$), indicating that these variables collectively provide a meaningful understanding of the psychological burden experienced by informal caregivers of cancer patients.

Table 5: Relation between Patient-Caregiver relationship and Demographic factors with Psychological Distress

Coefficients						
Regression model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	63.358	12.812		4.945	0.000
	Family Income	-0.441	2.241	-0.029	-0.197	0.844
	Family Type	-0.012	4.199	0.000	-0.003	0.998
	Education level	2.306	2.913	0.104	0.792	0.431
	Age group	-2.333	3.077	-0.092	-0.758	0.451
	Relation Type Brother_Sister	-30.260	8.624	-0.419	-3.509	0.001
	Relation Type Daughter	-16.598	6.759	-0.339	-2.456	0.017
	Relation Type Son	-21.794	7.340	-0.412	-2.969	0.004

	Relation Type Daughter_in_law	-27.123	9.351	-0.338	-2.900	0.005
	Relation Type Father	-2.858	9.065	-0.036	-0.315	0.754
	Relation Type Mother	7.792	7.192	0.153	1.083	0.283
	Relation Type Spouse_Husband	-11.358	5.550	-0.271	-2.046	0.045
	Economically weaker or Unemployed	-1.850	4.334	-0.050	-0.427	0.671

The purpose of this regression model is to evaluate how demographic variables and caregiver-patient relationship types influence psychological distress among caregivers of cancer patients. Scores were compared to the reference group 'spouse wife' being the strongest predictor among relationships. It is found that psychological distress scores were 30.26 points lower for caregivers who were siblings, suggesting they experience significantly less psychological burden. As for children, sons reported significantly lower distress than the spouse and daughters also experienced less psychological distress, though to a lesser extent than sons or siblings. For daughters-in-law, there is a strong negative effect, indicating daughters-in-law reported substantially lower psychological distress. Spouses (husbands) reported less distress, though to a higher degree than children or siblings.

Nonsignificant predictors are (i) Family Income: Income level does not significantly predict psychological distress (ii) Family Type (B = -0.012, *p* = 0.998): Living in a joint or nuclear family does not significantly affect distress levels (iii)Education Level (B = 2.306, *p* = 0.431): Education had a positive but non-significant association with distress.(iv)Age Group (B = -2.333, *p* = 0.451): No significant difference in distress across age groups (v)Relation Type: Father, Mother: Not significant. For example, mothers had a positive coefficient (B = 7.792), suggesting they reported slightly higher distress, but not statistically significant (*p* = 0.283) (vi) Economically weaker/Unemployed (B = -1.850, *p* = 0.671): Employment status was not significantly related to psychological distress. Findings suggest that the type of caregiver relationship is a strong predictor of psychological distress. Caregivers who are siblings, sons, daughters, daughters-in-law, or husbands experienced significantly lower distress than the reference group and demographic factors (income, education, age, employment, family type) did not show significant impact on psychological distress in this model.

6. CONCLUSION:

This study highlights the crucial influence of patient-caregiver relationship on psychological distress among caregivers of cancer patients. The highest psychological distress is reported when the mother is the caregiver (57.18), followed by the father caring for their child with cancer and spouse (wife) caring for her husband suffering from cancer. The lowest distress is seen with sister (14.00) and brother (18.50) as caregivers of cancer patients. The findings highlight that spouses (especially wives) caring for their spouse having cancer and parental caregivers (particularly mothers) caring for their children suffering from cancer experience the highest levels of psychological distress, while sibling caregivers, particularly sisters, report the lowest levels of distress. This suggests that the nature of the caregiving relationship has a profound impact on the caregiver's psychological well-being, with more involved or primary caregivers tending to experience greater psychological strain. Based on the findings, the null hypothesis that distribution of psychological distress scores is the same across all caregiver groups caring for cancer patients is rejected**.** Our findings are in consonance with the findings of Litwin, Stoeckel, & Roll (2014) and Penning and Wu (2016) that caregivers providing care for spouses and children are more likely to experience decreased psychological well-being than those caring for parents or siblings.

Demographic factors such as family income, education level, age, and employment status were found to have no significant impact on psychological distress, suggesting that the caregiving relationship plays crucial roles in determining psychological well-being than traditional demographic factors.

Overall, the study emphasizes the need for targeted support programs for caregivers, especially for spouse and parental caregivers, who face higher distress levels. Programs that enhance social support and offer emotional relief can significantly reduce the psychological burden on caregivers, improving their quality of life and caregiving effectiveness. Future research with larger and more diverse samples is recommended to further explore the long-term impact of caregiving and the role of support programs in diverse cultural contexts.

Ethics Statement: This study was approved by the Institute (K.R. Mangalam University, Sohna Road, Gurugram,Haryana ,India) ethics committee vide letter no: KRMU/RDC/CER/2024-25/0121.

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