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Research Paper

Assessing Compassion Fatigue in Family Caregivers of Cancer Patients

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ABSTRACT

Cancer causes significant stress to patients and their families. The family's role as the patient's support system is crucial, but long-term caregiving can lead to compassion fatigue, negatively impacting their quality of life and caregiving ability. This study aims to understand the quality of life of caregivers through the assessment of the compassion fatigue (CF) levels of family caregivers of cancer patients. One hundred family caregivers of cancer patients undergoing treatment at Jawaharlal Nehru Cancer Hospital and Research Centre, Bhopal, were asked to respond to the Professional Quality of Life Scale Version 5. The scale was made available in both Hindi and English for the participant's linguistic comfort. Their Compassion Satisfaction (CS), Burnout (BO), and Secondary Traumatic Stress (STS) were assessed, with focus on BO and STS for analysis as components of CF. The average level of CS was high (M = 43.90, SD = 4.25), BO (M = 23.52, SD = 5.65) and STS (M = 30.00, SD = 8.01) were both moderate (n=100). According to the ProQOL manual's interpretation guidelines, the obtained results were the most positive outcome associated with caregiving. In the given sample, on average, people experienced positive reinforcement from caregiving. Participant interaction during data collection revealed motivations for caregiving were often familial duty and love. Targeted interventions to mitigate CF, enhancing support programs building on the high CS, awareness of the potential aspects of QOL for care providers which allow for recognition of support systems.

Keywords: *Cancer Diagnosis, Family Caregivers, Compassion Fatigue, Quality of Life, ProQOL*

Cancer casts a long shadow over the lives it touches. The diagnosis evokes fear, apprehension, and uncertainty. It transcends physical suffering, imposing a significant emotional, psychological, and financial burden. Consequently, the disease not only profoundly impacts the lives of the patient but also their families. Throughout the diagnosis, treatment, and outcomes, family caregivers of cancer patients play a vital role as primary support systems. Caregivers experience high levels of stress, anxiety, depression, grief, and other negative emotions, which can negatively impact their quality of life and general well-being (Lynch, 2015). This can cause the caregivers to experience a gradual

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lessening of compassion towards the cancer patient, characterised as Compassion Fatigue (CF).

Compassion fatigue is not a moral failing nor a state of emotional, physical, and behavioural selfishness. It is a natural result of cumulative burden due to the unprecedented volume and duration of care required, especially in the context of cancer. Compassion fatigue is the exhaustion and distress experienced due to the emotional demands of caring for others (Leinwand & Vale, 2023). It is known to adversely impact both caregivers' quality of life and the care they provide, and can occur in a variety of professions in which helping is a key factor, like physicians, nurses, etc. (ibid.).

As a negative aspect and outcome of caregiving, it manifests with varied symptoms like headaches, gastrointestinal issues, increased disturbances in sleep, feelings of helplessness, negative effects on work-related satisfaction etc. (*Compassion Fatigue: Signs, Symptoms, and How to Cope*, 2020).

The Professional Quality of Life Scale (ProQOL) understands this cost of caring as constituting two dimensions. The first is burnout, "a syndrome of emotional exhaustion, depersonalization, and reduced personal accomplishment that can occur among individuals who do 'people-work' of some kind" (Maslach, 2003). Burnout is the stress arising from the chronic emotional strain of the social interaction between helpers and those who receive help with its typical symptoms of exhaustion, frustration, anger, and depression (ibid.).

The second is vicarious or secondary traumatic stress. It is the work-related, secondary exposure to exponentially or traumatically stressful events. Developing problems due to exposure to other's trauma is somewhat rare but does happen to many people who care for those who have experienced exceedingly stressful events.

The World Health Organisation intimates an increase in the projected cancer burden by 2050, where over 35 million new cases are predicted (World Health Organization: WHO, 2024). Consequently, there will be a rise in family caregivers who are witnesses to the patients' suffering, emotional and physical demands in times of uncertainty, and neglect of self-care.

Research in this area is relevant because CF directly impacts the caregivers and can have a major indirect effect on the patients. However, almost all of the attention after a diagnosis is given to the cancer patient, overlooking the needs of the family caregiver(s). Research on compassion fatigue in this realm can bring to light the unrecognised and underserved needs of these caregivers, informing future caregiver support strategies guiding the development of evidence-based interventions.

The significance of study lies in its ability to reveal the hidden toll of caring for cancer patients. Given the critical role that family caregivers play in the care and assistance of cancer patients, it is imperative to comprehend the severity of compassion fatigue and how it affects their quality of life. Not only will this study bring attention to the emotional, psychological, and physical challenges faced by the family caregivers, it will also provide insights that can inform support strategies, mechanisms, and targeting interventions for these caregivers- improving their quality of life and ability to provide care.

To provide a comprehensive understanding of the challenges faced by the family caregivers of cancer patients, the research directive the study aims to occupy is multifaceted. The primary objective of this study is to assess the overall quality of life of these caregivers, using the ProQOL questionnaire, a tool designed to measure various dimensions of caregiver well-being.

Additionally, the objective extends to measure levels- in its prevalence and severity- of compassion fatigue which is a subscale of the quality of life in these caregivers.

Compassion Fatigue in Healthcare

Also known as secondary traumatic stress (STS), CF is associated with the "cost of caring" for others in emotional pain; in this study's case, both physical and emotional pain as a cancer patient (Figley, 2002; Jenkins & Baird, 2002). This is experienced perhaps due to the emotional attachment between the sufferer and caregiver, and those with a heightened sense of empathy are often at higher risk for CF (Figley, 1995).

STS is becoming viewed as an occupational hazard of providing direct services to traumatised populations as Bride (2007) mentioned in his examination of the prevalence of the concept in social workers. In a literature review of STS in nurses, Beck (2011) found only seven studies studying STS in nurses within a time frame of 1981-2011. In the 14 years since the publication of the paper, the topic has been examined more closely. A few studies examined STS in healthcare workers during the COVID-19 pandemic and found that exposure to factors like patient death, perceived stress, financial difficulty, and emotional exhaustion predicted STS, along with a female preponderance for severe STS, whereas it was reduced in those healthcare workers engaging in healthy coping strategies like making time for hobbies, reading books etc. (İlhan & Küpeli, 2022; K.N. et al., 2021; Orrù et al., 2021 etc).

In the setting of oncology as well, CF and STS has been studied in detail. Sinclair and Hamill's literature review (2007) on the topic of STS in the UK highlighted how the concept had been examined in mental health professions, but less so in the field of oncology nursing, arguing for the need to review the existence of the concept in oncology. As established earlier, oncology is an incredibly emotionally demanding field to be a professional in. Quinal and colleagues (2009), in an early American study examining the prevalence of STS in oncology staff, found that it ranged from 16-37%, and found that the most common symptoms of STS were intrusive thoughts about patients, sleep issues and irritable mood. A Spanish study, conducted ten years later, examining the same in 297 nurses, using the ProQOL Scale, found that 18.2% presented low compassion satisfaction; 20.2%, high burnout; and 37.4, high STS (Arimon-Pagès et al., 2019). In their study, high levels of burnout and STS were associated with a desire to leave the oncology unit, as a function of the continuous demand of empathy on the nurses.

Compassion Fatigue in Family Caregivers

Compassion fatigue in family caregivers is less documented than in professional settings.
This points to a need for examining the status of family caregivers, especially in the setting of oncology, considering how mentally, physically, emotionally, and financially draining cancer can be for both the patient and caregiver.
Examination of the quality of life of family caregivers is essential, so that interventions and support systems can be designed and implemented for the welfare of those working for others (Lynch, 2017). Compassion fatigue can afflict caregivers across the kind of people

they are caring for, be it cancer patients, the geriatric population, or people with chronic illnesses (Blair & Perry, 2017; Liao et al., 2022; Lynch, 2015). Lynch, Shuster and Lobo (2017) in a cross-sectional descriptive survey, examined compassion fatigue and related concepts in 168 caregivers. They found patients reporting high levels of caregiver burden, but moderate to low levels of compassion fatigue's concepts of STS and BO. In the family caregivers of people with dementia, Day and Anderson (2011), found evidence supporting the idea that such caregivers were at risk for CF.

There are several demographic variables that can influence whether caregivers experience CF. Employment status and number of hours per week caregiving, but not necessarily number of years caregiving, resources of income and caregiver health, all have the potential to affect caregiver burden and CF (Kwon et al., 2013; Lynch, 2015). Gender, although in a limited fashion, also plays a role in the experience of caregiver burden. There is evidence that women experience greater fatigue and caregiver burden, although the literature examining gender differences is not extensive (Lynch, 2015; Schrank et al., 2016). Gender can determine appraisal of the caregiving experience as negatively stressful, as well as perception of self-esteem (Kim et al., 2007).

Although there is once again, limited literature on specific psychological factors affecting CF, in one study, perceived stress and avoidant coping styles predicted BO positively, whereas an emotion-focused coping style and well-being had negatively predicted BO (Asha et al., 2024).

Johansen and colleagues also discovered that caregiver burden was affected, immediately from beginning of treatment, by the mixed effects of observing patient symptoms and difficulties, and recognizing their own symptoms and issues (Johansen et al., 2018).

The need for more studies in the Indian context examining CF in oncology, particularly in central India prompted the authors to examine in greater detail the experience of the phenomenon of CF in family caregivers.

Use of ProQOL in Research

Existing literature on CF regarding family caregivers is limited. Cavanagh et al. (2019) provided a systematic review of CF in healthcare providers, including the frequency of its reporting, the variables impacting compassion fatigue, and the common values reported on the subscales of the tool ProQOL. In 71 articles they analysed meeting inclusion criteria, CF was reported in all studied practitioner groups. However, prevalence was highly variable, and its relationship with other variables like professional, personal, and demographics was inconsistent.

Focusing on CF in caregivers of cancer palliative care, particularly in an Indian setting, Kaur and colleagues (2018) explored the professional quality of life in centres in Bengaluru, India, and examined the relationship between demographic and work-related variables with the experience of compassion satisfaction (CS), BO and STS. They found significant differences in levels of CS, BO, and STS based on additional training taken in palliative care, designation type, and workplace type. However, recent research also shows that CF adversely impacts both the caregivers quality of life as well as the care they provide (Leinwand, 2024).

While the ProQOL is a scale used for professionals, the parallels drawn between family caregivers and professional caregivers in terms of the usage of the concept of CF, shows promise in studying the concept for family caregivers, and therefore, expanding knowledge about the same (Lynch & Lobo, 2012).

METHODOLOGY

This study employed a cross-sectional design for data collection to gather a primarily descriptive representation of the quality of life and compassion fatigue in the population of family caregivers of cancer patients. The data was collected using the Professional Quality of Life Scale Version 5, a questionnaire. It helped us get a broad overview of the population and in identifying trends in quality of life.

This study was conducted in Jawaharlal Nehru Cancer Hospital and Research Centre, Bhopal, Madhya Pradesh. The target population was family caregivers of cancer patients.

Tools Used

A demographic form was used, which collected the demographic variables of name, age, sex, occupation, area of residence (rural/urban), education level, marital status, relationship to patient, and hours of caregiving. Any present complaints such as physical pain were also inquired about. After this, a total of 100 caregivers were asked to respond to the Professional Quality of Life Scale (ProQOL) Version 5, and their responses were recorded by the authors. The participants were selected through purposive sampling based on the inclusion and exclusion criteria mentioned below. This was done to ensure a balance between different confounding variables like demographic particulars, and different wards.

According to the Concise Manual for the Professional Quality of Life Scale, helpers being anyone who offers assistance, have both positive and negative influences on their quality of life (Stamm, 2010). Therefore, professional quality of life comprises two aspects- compassion satisfaction (positive) and compassion fatigue (negative). Compassion fatigue can further be divided into Burnout (BO) and Secondary Traumatic Stress (STS). Scale properties include a t-distribution of the scores on the scale for CS, BO, and STS. Over 200 published papers and 100,000 articles signify its construct validity.

The compassion fatigue scale, among the three constructs the scales measure, is the most distinct. The scoring for ProQOL involved the following steps in order: reversing some items, sum the items by subscale, and converting the raw scores to t-score. ProQOL is not a diagnostic tool, rather it helps identify and can be a guide concerning the balance of the positive and negative aspects of professional caregiving.

The official manual further provides information regarding the scales it explores- compassion satisfaction, compassion fatigue, burnout, and secondary traumatic stress. These scale scores can also be interpreted in combination (a) high compassion satisfaction, moderate to low burnout and secondary traumatic stress (b) high burnout, moderate to low compassion satisfaction and secondary traumatic stress (c) high secondary traumatic stress with low burnout and low compassion satisfaction (d) high secondary traumatic stress and high compassion satisfaction with low burnout (e) high secondary traumatic stress and high burnout with low compassion satisfaction.

Sampling

Purposive sampling was used for the process of data collection.

Inclusion Criteria

The inclusion criteria for the study was the following: the caregiver must have a patient undergoing treatment currently, have ability to speak/read English or Hindi, and voluntarily participate in the study. There were no restrictions on sex, age, education level or marital status.

Exclusion Criteria

The caregivers meeting the following criteria were not considered for study: the patient was in remission, or if there was mental illness present in the caregiver.

Sample Characteristics

Responses for the ProQOL were collected from a total of one hundred people; fifty male, and fifty females. The mean age in the present sample was 36.39 years (SD= 11.58). Most of the population was working in blue- or white-collar jobs (31% each), resided in urban areas (54%), and were married (79%). Caregivers were mostly the patient's children (42%) or spouses (35%), with 86% providing 24-hour care.

Procedure

After setting the criteria for inclusion and exclusion of participants, the procedure to administer ProQOL began with obtaining their informed consent. A short survey of demographic questions followed this, after which the participants were presented with the ProQOL questionnaire in their preferred language, between English and Hindi. These data collection sessions were conducted in the hospital itself, in the ward where their patient was admitted. It was ensured that the participants understood each question and the response format, which was the 5-point Likert scale. Participants were assured of the confidentiality of their responses, as their anonymity was maintained and data was stored securely.

Data was checked for completeness and incomplete responses from the ProQOL Scale were excluded from the study. IBM SPSS Statistics software Version 29 was used to obtain the means and standard deviations of each subscale of CS, BO, and STS.

RESULTS

Table 1 Depiction of the Frequencies and Percentages of Sociodemographic Variables

Variable	**n**	**%**
Age in Years		
10-20	8	8
21-30	25	25
31-40	41	41
41-50	12	12
51-60	9	9
61-70	4	4
Missing	1	1
	Total: 100	
Sex		
Male	50	50
Female	50	50
	Total: 100	
Occupation		
Blue collar jobs	31	31

Variable	n	%
White collar jobs	31	31
Homemaker	26	26
Student	9	9
Unemployed	2	2
Retired	1	1
	Total: 100	
Area of Residence		
Urban	54	54
Rural	46	46
	Total: 100	
Education Level		
No formal education	10	10
Primary school	5	5
Secondary school	23	23
Higher school	19	19
Graduation or higher	42	42
Missing	1	1
	Total: 100	
Marital Status		
Single	20	20
Married	79	79
Divorced	0	0
Separated	0	0
Widowed	0	0
Missing	1	1
	Total: 100	
Relationship to Patient		
Spouse	35	35
Offspring	42	42
In-law	7	7
Sibling	8	8
Parent	2	2
Grandchild	3	3
Nephew	2	2
	Total: 100	
Hours of Caregiving		
0-4	3	3
5-8	4	4
9-12	6	6
13-16	1	1
17-20	0	0
21-24	86	86
	Total: 100	

Analysis of demographic variables revealed that in the present sample, mean age was 36.39 years (SD= 11.58). Both blue-collar and white-collar jobs had 31% of people engaged in each. Most participants lived in urban areas (54%), and had obtained an education of graduation level or higher (42%). A majority of caregivers (79%) were married, but the most common relationship to patients was that of offspring (42%), followed by spouse (35%). 89% of caregivers were with their patients for twenty-four hours of the day.

Table 2 Depiction of Chief Complaints as a Caregiver

Chief Complaints	Instances reported (n)	%*
Tiredness	4	4
Blood Pressure Issues	7	7
Headaches	16	16
Body Pain	3	3
Backaches	8	8
Stomach Pain	6	6
Sugar	3	3
Other (Waist pain, asthma, cardiac issues, sleep issues, leg pain)	9	8
None	53	53

** Total percentage may tally to more than 100% due to more than 1 complaint being reported by the same people.*

When it comes to major complaints (physical), 47 of 100 people reported discomfort of some kind, with the most common complaint being that of headaches. Caregiving has been known to have an adverse impact on physical health, and our results are indicative of the same (Chang et al., 2010; Vitaliano, 1997). The long hours spent with the patient, potential sleepless nights, and overall toll also contribute to complaints of physical discomfort.

Table 3 Depiction of the Results of the ProQOL Subscales of Compassion Satisfaction, Burnout, and Secondary Traumatic Stress

ProQOL Subscale Categories	Mean (n=100)	SD
Compassion Satisfaction (CS)	43.9	4.25
Burnout (BO)	23.52	5.65
Secondary Traumatic Stress (STS)	30	8.01

Finding the mean and standard deviations for responses to each of the three subscales revealed that participants comprising this sample experienced high levels of CS, and moderate levels of BO and STS.

DISCUSSION

According to the ProQOL manual's interpretation guidelines, the obtained results of high CS (Mean= 43.9, SD= 4.25), and moderate BO (Mean= 23.52, SD= 5.65) and STS (Mean= 30, SD= 8.01) were the most positive outcome associated with caregiving (Stamm, 2010). In the given sample, on average, people experienced positive reinforcement from caregiving. There were no significant worries about being "bogged down" or not being efficient in caregiving. There were no striking fears resulting from their caregiving. A study by Lynch (2015) found similar findings, with the 168 family caregivers experiencing moderate BO, and equally divided low and moderate levels of STS. Other studies also confirmed findings of moderate level of burnout, with high level of compassion satisfaction (Asha et al., 2024; Murkute & Veer, 2021).

Although not a quantitative study, during the course of data collection, in response to the items on the ProQOL Version 5, several participants remarked upon how it was their duty as family members to provide care for the patient, and how they are not necessarily ‘happy’ that they are providing care for their family members. This aligns somewhat with what Gupta and colleagues (2024) found in a study in the US, where the primary motivations for caregiving for families with cancer were love and sense of duty. Even in Singapore, an Asian country, filial piety was a major motivator for caregiving (Ng et al., 2016). These could also potentially account for the high levels of CS observed in the sample. Nonetheless, the authors felt that these motivators need to be accounted for in the future when examining compassion fatigue in family caregivers.

Another topic that came up was that caregivers mentioned how their happiness, or positive state of being, was linked to how well the patient was faring in treatment. A Canadian study found that the caregivers’ mental well-being declined as their cancer patient’s state of functioning also declined, which supports the experiences reported by the participants in this study, and could serve as an avenue of further inspection (Grunfeld et al., 2004). Although not in the field of oncology, Boerner & Mock (2012)’s study on caregivers of patients with amyotrophic lateral sclerosis (ALS), a debilitating disease that impacts muscle function, found significant associations between negative caregiver affect and patient distress.

The moderate levels of BO and STS point to the existence of CF in the family caregivers. Therefore, support systems also need to be put in place for mitigating the negative effects of CF. This is especially relevant in a country like India where there are insufficient support systems and where family caregivers shoulder the enormous financial burdens of cancer-treatment out of pocket, as well as face the negative physical and mental health effects of having to constantly care for someone with cancer (Ranganathan et al., 2023; Hiremath et al., 2017).

Counselling, psychotherapy and psychosocial interventions are important mechanisms of support that can improve the well-being of the family caregivers. In terms of interventions specifically, goal-oriented and time-limited interventions seem to have provided the best outcomes for family caregivers, as well as educational interventions teaching them various methods of managing their burdens (Applebaum & Breitbart, 2013; Nayak & George, 2021). A counselling programme for caregivers of cancer patients in Kanyakumari also proved to be effective in improving coping and reducing burden among the primary caregivers (Sam et al., 2019). Such methods thus, have been proven to be effective means of reducing caregiver burden and aiding positive mental health outcomes.

Support programmes need to be established, and if existing, need to be enhanced by building on the high CS scores, and examining the factors that contribute to CS. Awareness for availability of such support must also be increased across family caregivers.

CONCLUSION

This study found that, while family caregivers of cancer patients suffer moderate levels of compassion fatigue, they also report high levels of satisfaction, implying that caregiving is frequently viewed as a worthwhile and meaningful, albeit emotionally demanding, duty. We believe this shows how profoundly caregiving is based in emotional relationships, societal expectations, and a strong sense of familial duty—all of which can provide emotional resilience even in high-stress conditions. However, the prevalence of moderate burnout and secondary traumatic stress should not be underestimated, as they suggest an unmet need for psychosocial and structural support. Caregivers' well-being, we believe, should be considered as a cornerstone of quality cancer care, rather than a secondary concern. Ignoring their distress will only reduce the quality of care they receive. We strongly encourage caregiver-inclusive healthcare policy, particularly in India's resource-constrained public healthcare system. Future treatments should be customized to the requirements of caregivers, including psychoeducation, accessible and stigma-free counseling, and culturally responsive support mechanisms that empower and sustain people who silently help others.

Future Recommendations

Future studies can examine the impact of various demographic factors, as well as factors such as the type of cancer, and duration of illness on compassion fatigue. Researchers can also adopt a paradigm shift in exploring the caregivers' experiences qualitatively through interviews, or focus group discussions.

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Conflict of Interest

The author(s) declared no conflict of interest.

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