



“PSYCHOSOCIAL BURDEN AMONG CAREGIVERS OF CANCER PATIENTS”

Oncology

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ABSTRACT

Introduction: Chronic illness from advanced disease affects all family members. The stress of knowing about a limited lifespan changes the patient's relationship with their world and their family/caregivers. Caring for a person with cancer is demanding and overwhelming and can affect the caregiver's physical and psychological health. It's important to identify burdened family caregivers to prevent negative outcomes associated with caregiving. **Aims and Objectives:** To assess the psychosocial burden on caregivers of cancer patients and its association with various socio-demographic factors. **Methods:** The study included caregivers of 100 cancer patients. Information was collected about their socio-demographic characteristics, the patient's disease details, and the caregivers' psychosocial burden using the reliable and validated Zarit Burden Interview (ZBI scale). **Results:** The assessment using the Zarit Burden Interview Scale showed that 50% of caregivers experienced no or minimal burden, 34% had mild to moderate burden, 14% had moderate to severe burden, and 2% faced severe burden. **Conclusion:** These findings highlight the need for targeted interventions and support systems to alleviate the burden on caregivers, regardless of their individual characteristics or circumstances.

KEYWORDS

Physical, psychosocial burden, Zarit Burden Interview Scale (ZBI scale).

INTRODUCTION

Webster Dictionary defines a caregiver as a person who provides direct care, such as to two children, elderly people, or a chronically ill person. A caregiver can be an informal family member or a trained paid professional. We are primarily focusing on the roles and concerns of an informal family caregiver. When a person suffers from a chronic debilitating ailment, like cancer, it affects not only the patient but also their family. The responsibility falls on the family members of the patient who have to assume new roles as caregivers and decision makers for the patient without training, in addition to carrying out their own individual duties and responsibilities. This can lead to a lot of caregiver stress. Caring for the caregivers is an important aspect of holistic health and the health of society at large. Empowered caregivers can better care for their loved ones as well as themselves and are a valuable asset to the healthcare team and the community. Caring for a sick family member with a chronic illness presents a multitude of problems. As the severity of the disease increases over time, the problems tend to increase as well. It is imperative to proactively address the caregivers' needs along with the patient's so that effective long-term care can be delivered.⁽¹⁾ Factors such as the age and gender of the caregiver, socio-economic status, personal health, family dynamics, and the available healthcare facilities all impact the problems faced by the caregiver. Below are some of the problems faced by caregivers in providing care:

1. Mental health concerns

- **Depression:** persistent feelings of sadness, hopelessness, and disinterest in activities
- **Anxiety:** constant worry, fear, and physical symptoms such as increased heart rate and sweating
- **Subclinical stress:** experiencing high levels of stress that may not meet the criteria for a clinical diagnosis
- **High rates of negative affect including guilt, sadness, dread, and worry:** feeling overwhelming negative emotions
- **Ambivalence about care:** feeling uncertain or conflicted about receiving assistance or treatment
- **Witnessing the suffering of relatives:** observing the pain and distress of loved ones
- **Becoming easily irritated or upset:** feeling quick to anger or experiencing heightened emotional responses
- **Feeling isolated or abandoned by others:** experiencing loneliness, disconnection, or perceived lack of support
- **Anticipatory grief:** grieving or mourning in advance of an anticipated loss

2. Physical health concerns

- Experiencing fatigue can lead to sleep issues, increased risk of illness, injury, and mortality, and a weakened immune system. It can also result in lower self-rated physical health compared to others of the same age and sex, adverse changes in health status, increased use of health services and medication, and dysregulation of stress hormones.

3. Functional and cognitive impairment

- Greater need for help with IADL assistance (especially among dementia caregivers)
- Difficulty with memory and concentration

4. Secondary strains

- Work-related issues such as reduced work hours, difficulty balancing family and work responsibilities, and the impact of work on family life.
- Financial pressures and strains.
- Stress within personal relationships.
- Lack of time for self-care, including insufficient sleep, poor diet, and inadequate exercise.
- Decreased overall quality of life.

5. Care decisions

- “When is it time” for various services?
- Residential placement
- End of life care planning

6. Resources and eligibility for services

- Housing
- Healthcare
- Community services
- Respite

7. Family challenges

- Conflict about care
- Lack of support for caregiver
- Balancing needs of healthy and sick family members
- Behavioral issues
- Interpersonal conflicts
- Lack of cooperation by care recipient

8. Advocacy for care

- Interface with service systems

- Coordinating systems^[2]

Aims And Objectives

- To assess the psychosocial burden on the caregivers of cancer patients.
- To find out the association of various socio demographic characteristics with the level of burden amongst care givers.

MATERIAL AND METHODS

Sure, here is the revised text:

The study was a hospital-based prospective observational study conducted in Jaipur, approved by the institutional ethical committee. 100 caregivers of cancer patients in the palliative department were interviewed, both indoors and outdoors.

Data Collection Tool: A pretested and prevalidated semi-structured questionnaire, the Zarit Burden Interview (ZBI) scale, was used to assess the psychosocial burden. The questionnaire consisted of the following sections:

- 1) Socio-demographic details
- 2) Disease details
- 3) Burden of the caregiver of cancer patients using the ZBI scale

ZBI Scale: This is a 22-item tool with excellent psychometric properties. Each item's response is recorded using a 5-point Likert type scale, ranging from 0-4. The level of burden is assessed by cumulative score:

- 0-21: little or no burden
- 21-40: mild to moderate burden
- 41-60: moderate to severe burden
- 61-88: severe burden

Inclusion Criteria

- Caregiver is a family member.
- Caregiver must be in good physical and mental health.
- Consent is required.

Exclusion Criteria

- Under 18 years of age.
- Mental illness.

RESULTS

Socio demographic characteristics of caregivers	No to mild burden (N)	Moderate to severe burden (N)	p value
Age			
Less than 20	1	0	>0.05
21 to 50	28	16	>0.05
More than 50	24	31	>0.05
Gender			
Male	31	23	>0.05
Female	20	26	>0.05
Marital status			
Married	40	36	>0.05
Others	12	12	>0.05
Type of family			
Joint	25	27	>0.05
Nuclear	25	23	>0.05
Place			
Urban	17	13	>0.05
Semi urban	11	9	>0.05
Rural	23	27	>0.05
Education			
Illiterate	8	7	>0.05
Up to high school	32	23	>0.05
Above high school	18	22	>0.05
Occupation			
Unemployed	10	15	>0.05
Employed	41	34	>0.05
Number of family members			
Less than or equal to 4	28	27	>0.05
More than 4	23	22	>0.05
Kuppuswamy scale			
Upper lower and lower	25	22	>0.05
Middle and above	25	28	>0.05
Relation to patient			

Spouse	18	14	>0.05
Children	18	21	>0.05
Others	15	14	>0.05

Table 2 :-

Characteristics of Cancer Patients and Their Disease Details.	
Characteristics	Total No
Age of cancer patients	
Less than 20	1
21 to 50	44
More than 50	55
Gender of cancer patients	
Male	36
Female	64
Stage of cancer	
Initial stage	45
Advanced stage	55
Type of treatment	
Surgery	3
Chemotherapy	40
Radiotherapy	16
R + C	12
R + S	7
S + C	9
R + S + C	7
Only palliative care	6
Duration since diagnosis	
Less than or equal to 6 months	52
7 to 12 months	18
1 to 5 years	25
More than 5 years	5
Duration of help by caregiver	
Less than or equal to 6 months	52
7 to 12 months	19
1 to 5 years	22
More than 5 years	7
Type of facility	
OPD	55
IPD	36
Day care	9

Note. OPD = outpatient department; IPD = inpatient department.

Table 3 :-

Caregiver's Burden According to Zarit Burden Interview Scale.	
Level of burden (total score)	N= 100
No or minimal burden (0-20)	51
Mild to moderate burden (21-40)	33
Moderate to severe burden (41-60)	14
Severe burden (61-88)	2

In this study, the majority of caregivers (55%) were above 50 years of age, and a significant proportion (44%) were between 21 and 50 years old. Most caregivers were married (76%) and lived in joint families (52%). The educational background of caregivers varied, with 15% being illiterate, 55% having completed up to high school, and 40% having education beyond high school. Notably, 75% of caregivers were employed. The socioeconomic status distribution was relatively balanced, with 47% falling into the upper lower and lower categories and 53% in the middle and above categories. Regarding their relationship with the patient, 32% were spouses, 39% were children, and 29% were other relatives.

The cancer patients being cared for were predominantly over 50 years old (55%), with 44% between 21 and 50 years old. Females constituted the majority of patients (64%). The disease was in an advanced stage for 55% of patients, while 45% were in the initial stage. Treatment modalities varied, with chemotherapy being the most common (40%), followed by radiotherapy (16%), combined radio- and chemotherapy (12%), and surgery (3%). The duration since diagnosis was less than or equal to 6 months for 52% of patients, with 25% having been diagnosed between 1 and 5 years prior. Caregivers had been providing help for a similar duration, with 52% doing so for 6 months or less.

The assessment of caregiver burden using the Zarit Burden Interview Scale revealed that 50% of caregivers experienced no or minimal burden, 34% had mild to moderate burden, 14% had moderate to

severe burden, and 2% faced severe burden.

Statistical analysis

Statistical analysis using chi-square tests for categorical variables revealed no significant association between caregiver burden and age ($p > 0.05$), gender ($p > 0.05$), marital status ($p > 0.05$), family type ($p > 0.05$), residence ($p > 0.05$), education ($p > 0.05$), employment status ($p > 0.05$), number of family members ($p > 0.05$), socioeconomic status ($p > 0.05$), or relationship with the patient ($p > 0.05$).

DISCUSSION

The psychosocial burden on caregivers of cancer patients can be significant and often underestimated. Caregivers may experience emotional distress, anxiety, depression, and feelings of helplessness and isolation as they navigate the challenges of caring for a loved one with cancer.

The stress of providing physical and emotional support, managing medical appointments and treatments, and balancing their own personal and professional responsibilities can take a toll on caregivers. They may also feel a sense of grief and loss as they witness the physical and emotional impact of cancer on their loved ones. Furthermore, caregivers may face financial strain, disruption of their daily routines, and a lack of social support, which can further exacerbate their burden.

It is essential for caregivers to prioritize self-care and seek support from healthcare professionals, support groups, and other caregivers. Providing resources and education on coping strategies, mental health support, and practical assistance can help alleviate the psychosocial burden on caregivers of cancer patients. Additionally, promoting open communication and understanding within the caregiving relationship can also help address these challenges.^[3]

Caring for a loved one with cancer can be an emotionally and physically demanding experience, and caregivers often face a significant psychosocial burden. Here are some common challenges and burdens that caregivers of cancer patients may experience:

- 1. Emotional Distress:** Caregivers often experience a range of emotions such as fear, anxiety, depression, guilt, sadness, and grief. Witnessing a loved one go through the physical and emotional challenges of cancer can take a toll on the caregiver's mental well-being.
- 2. Social Isolation:** Caregivers may find themselves isolated from their social support networks as they devote much of their time and energy to caring for the cancer patient. This social isolation can lead to feelings of loneliness and a lack of support.
- 3. Financial Strain:** The cost of cancer treatment, medications, and caregiving responsibilities can place a significant financial burden on caregivers. This can lead to financial stress, worry, and even impact the caregiver's own health and well-being.
- 4. Physical Health Issues:** Caregivers often neglect their own physical health as they prioritize the needs of the cancer patient. This neglect can lead to increased stress, fatigue, sleep disturbances, and other physical health issues.
- 5. Role Strain:** Balancing caregiving responsibilities with work, family, and personal life can be challenging for caregivers. Many caregivers may feel overwhelmed by the multiple roles they are expected to fulfill, leading to feelings of inadequacy and burnout.
- 6. Loss of Identity:** Caregivers may feel that their identity becomes defined solely by their role as a caregiver, leading to a loss of personal identity and a sense of self.
- 7. Grief and Anticipatory Grief:** Caregivers often experience grief not only for the changes in the cancer patient's health but also for the future losses that may occur. Anticipatory grief can be emotionally draining and challenging to cope with.
- 8. Communication Challenges:** Caregivers may struggle with communicating effectively with the cancer patient, healthcare providers, and other family members. Misunderstandings and conflicts can arise, adding to the caregiver's stress and burden.

It's important for caregivers to prioritize self-care, seek support from healthcare professionals, support groups, and loved ones, and practice coping strategies to help manage the psychosocial burden associated with caregiving for a cancer patient. Taking care of one's own physical, emotional, and mental well-being is crucial in order to provide effective care and support to the cancer patients. [4]

CONCLUSION

Based on the assessment of the psychosocial burden experienced by cancer caregivers, the key conclusions could be:

1. Emotional and psychological impact:

- Increased levels of anxiety, depression, and stress among caregivers
- Feelings of grief, loss, and emotional exhaustion related to the patient's illness
- Difficulty in maintaining a sense of balance and well-being

2. Physical and practical burden:

- Caregiver fatigue, sleep disturbances, and neglect of self care.
- Challenges in managing the practical aspects of caregiving, such as coordinating medical appointments, administering treatments, and providing daily assistance

3. Social and relational impact:

- Strain on personal and family relationships due to the demands of caregiving
- Isolation and reduced social engagement as a result of the time and energy devoted to caregiving
- Difficulties in maintaining a work-life balance or continuing employment

4. Financial and economic burden:

- Increased financial strain due to medical expenses, lost income, and reduced work productivity
- Concerns about the long-term financial implications of the patient's illness and caregiving responsibilities

5. Unmet support needs:

- Inadequate access to resources, information, and support services for caregivers
- Limited availability of respite care, counseling, or support groups to address the caregiver's emotional and practical needs

6. Resilience and coping strategies:

- Some caregivers demonstrate remarkable resilience and adaptive coping mechanisms
- Factors such as social support, self-care practices, and access to resources can enhance caregiver well-being

The overall conclusion should highlight the multifaceted nature of the psychosocial burden experienced by cancer caregivers and the need for a comprehensive, multidisciplinary approach to address their diverse needs. Recommendations for interventions, support services, and policy changes may also be included to alleviate the burden and improve the well-being of cancer caregivers.

Here are some strategies and interventions that can help caregivers cope with the challenges they face:

- 1. Education and Information:** Providing caregivers with information about the cancer diagnosis, treatment options, and what to expect can help reduce anxiety and uncertainty. Education can empower caregivers to better understand and navigate the caregiving role.
- 2. Emotional Support:** Encouraging caregivers to express their feelings and providing a safe space for them to talk about their emotions can help alleviate emotional distress. Counseling, support groups, and therapy can offer valuable emotional support.
- 3. Respite Care:** It's important for caregivers to take breaks and prioritize self-care. Respite care services can provide temporary relief for caregivers, allowing them to rest, recharge, and take care of their own needs.
- 4. Social Support:** Encouraging caregivers to maintain social connections and seek support from friends, family, and support groups can help reduce feelings of isolation and provide a sense of community and understanding.
- 5. Stress Management Techniques:** Teaching caregivers stress management techniques such as mindfulness, relaxation exercises, deep breathing, and physical activity can help reduce stress levels and improve overall well-being.
- 6. Setting Boundaries:** Helping caregivers establish boundaries and prioritize their own needs can prevent burnout and promote a healthier caregiving experience. It's important for caregivers to recognize their limits and seek help when needed.
- 7. Seeking Professional Help:** Caregivers experiencing significant emotional distress, anxiety, or depression should seek help from mental health professionals such as therapists, psychologists, or

counselors. Professional support can provide tools and strategies to manage psychosocial challenges effectively.

8. **Encouraging Self-Care:** Caregivers should prioritize their own physical and mental health by engaging in activities they enjoy, maintaining a healthy lifestyle, getting regular exercise, eating well, and getting enough rest.
9. **Communication Skills Training:** Helping caregivers improve their communication skills can enhance their ability to communicate effectively with the cancer patient, healthcare providers, and other family members, reducing misunderstandings and conflicts.
10. **Cognitive Behavioral Therapy (CBT):** CBT can be effective in helping caregivers manage negative emotions, develop coping strategies, and challenge unhelpful thoughts and beliefs related to caregiving stress.

By implementing these strategies and interventions, caregivers can better manage the psychosocial burden associated with caring for a loved one with cancer. Encouraging caregivers to prioritize their own well-being is essential to ensuring they can continue to provide quality care and support to the cancer patient while maintaining their own health and resilience.

In summary, this study emphasizes the widespread psychosocial burden experienced by caregivers of cancer patients, with a significant number facing mild to severe burden. Interestingly, the burden does not seem to be significantly influenced by socio-demographic factors or the caregiver-patient relationship. These findings highlight the importance of tailored interventions and support systems to relieve the burden on caregivers, regardless of their specific characteristics or situations.

Ethical Consideration

Ethical Committee of Mahatma Gandhi Medical College and Hospital Jaipur, Rajasthan reviewed and approved the study vide letter No/MGMC & H/IEC/JPR/2024/1923.

Funding :-

No Funding.

Consent

Informed consent was taken from all Participants.

Acknowledgement

We would like to thank all the participants for their valuable contribution to this study.

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