ISSN: 2582-7162

Original Research Article

Perceived Psychological Burden of the Family Caregivers of Advanced Stage Cancer Patients- A Qualitative Study

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How to cite this article: Sood A, Shruti, Ghoshal S, Arora M, Kaur M. Perceived psychological burden of the family caregivers of advanced stage cancer patients- a qualitative study.GFNPSS-IJMR 2024; 5:6: 2629-2633

Submitted:30-May-2024: **Accepted:** 05-July-2024: **Published:** 07-July -2024

Abstract

Introduction: The family caregivers play a very crucial role in the delivery of care to the cancer patients in hospice. They have to do more things than they could handle, and providing comprehensive of care to their loved one at the end of life can lead to increased stress, physical and psychological health issues, and decreased quality of life among caregivers.

Objective: The study aimed to explore the psychological concerns of care givers of patients with cancer receiving palliative care.

Materials & Methods: This phenomenological study was conducted on 15 caregivers who were selected by purposive sampling method, at hospice centre, Chandigarh. The data was collected using a semi-structured interview schedule. The experiences were recorded by an audio-recorder following consent of the participants.

Results: Based on the participants'response, the psychological concerns were described in two main themes; the psychological impact and adaptation to role of caregiverwhich werefurther categorized into meaningful sub-themes to understand the information more appropriately.

Conclusions: It is concluded from the documented data in present study that there are various psychological aspects of the caregivers of the cancer patients during care-giving process at terminal stage which needs to be supported. There should be proper and frequent communication with the participants to explore their feelings and to make them feel that along with the patients they are also being supported in our health care setting.

Key words: Cancer, Caregiving, Challenges, Hospice, Palliative Care.

Introduction:

Among all the chronic diseases, cancer is the major leading causes of death in all over the world in this century. The Greek word “Karakinos” derived the term cancer which means non-communicable disease marked by growth of abnormal cells in any part of the human body.

The data from year 2022 suggests that approximately one in five men or women develop cancer in a lifetime, whereas around one in nine men and one in

12 women die from it. Cancer is a major social, public health and economic problem in the 21st century, accountable for about one in six deaths (16.8%) worldwide. India ranked third after China and the United states of America. According to Global Cancer Observatory (GLOBOCAN) prediction, cancer cases in India would increase to 2.08 million, holding rise of 57.5% in 2040 from 2020.

In Punjab, at every 1 Lac population there are at least 90 patients diagnosed with cancer. According to survey by Punjab government it is revealed that the cancer incidence is higher in the Punjab than the national average of 79 per 100,000 populations. As per Indian Council of Medical Research's cancer registry data, the estimated incidence of cancer during 2017 is 33781 in Punjab, 1335 in Chandigarh and 32049 in Haryana. The government is emphasizing on providing high quality of palliative care to cancer patients along with strengthening the early detection and treatment facilities for cancer in the Punjab.

The patients diagnosed with cancer have "family" caregivers which often involves family members, relatives and partners who provide care to their patients with lot of effort, time and commitment. They play a very essential and crucial role in the provision of care to the cancer patients in hospice. Levels of involvement in the care rely on the extent of symptoms, treatments required, stage of illness, or closeness to death. The common and direct care activities for primary caregivers include assessing symptoms and side effects, monitoring condition of patient for adverse effects from treatment, wound care, external feedings, or stoma care. Caregivers look after their patients with their own unmet needs and demands that reflect lack of confidence, incapability, stress and guilt, financial issues, and problems with communication due to inadequate information. This care-giving process has impact on the on the quality of life of the caregivers including physical, emotional, and social health.

Caregiving activities undertaken for people who are at terminal stage of cancer include self care, assistance with physical mobility, communication, household work, psychological support, feeding, managing financial issues, medical care such as management of patients with pain, administration of medications and therapies such as chest physiotherapy, range of motion exercises and managing infusion lines, Caregivers have to adapt more changes than they could handle, and providing comprehensive care to their loved one at the end of life can contribute to increased stress, various health issues, and decreased quality of life.

Materials & Methods:

Qualitative research approach was used in the study with phenomenological research design to explore the lived experiences of caregivers of cancer patients. The study setting was Hospice Center, Sector-43, Chandigarh. Permission was obtained from In charge of the hospice for conducting study and Ethical approval was taken from the Institute Ethics Committee, PGIMER, Chandigarh. Fifteen caregivers of cancer patients were selected by purposive sampling and data was collected by semi-structured interview schedule which consisted of questions related to psychological aspects of caregivers. The tools were developed by intensive literature review and validated by experts of medical and nursing oncology field, consisting of socio-demographic profile of the patients and caregivers, in-depth semi-structured interview guide and audio recorder. Pilot study was conducted on 3 caregivers who were not included in final study and feasibility to conduct the research study was obtained through pilot study.

Data was collected for 2 months i.e. from July to August 2019. After taking written consent, interviews were recorded from caregivers in their convenient time in a private room at hospice centre.Researcher had established rapport and recorded the interviews by using audio recorder. The average duration for each interview was 45 minutes to 1 hour. The recorded interviews were later transcribed into verbatim.

Collected data was analyzed into two sections. The first section consisted of descriptive statistics to describe the socio-demographic profile of caregivers and secondly, recorded interviews from caregivers were transcribed into verbatim and analyzed by Colaizzi's method of data analysis. Meanings of verbatim were obtained by reading and re-reading the caregivers information, remarkable statements were developed and the main themes were extracted.

Results:

Socio-demographic profile of caregivers of cancer patients:

https://doi.org/10.46376/ijmr/05.06.2024:2629-2633

The majority of patients were males and most of them were labourers by occupation before illness. The patients who were admitted were mostly diagnosed as the advanced stage of cancer of hypo pharynx, cervix and oral cavity. All the patients were having primary informal caregivers from their family. Table 1 depicts the socio-demographic data of study participants (caregivers of cancer patients). 33.3% of the participants were in the age group 40-49 with mean age ± S.D (43.93 ± 13.43); and range of 21-68 years. Majority of the participants i.e. 44.4% were female, 55.6% belong to Hindu religion and 61.1% were married. 33.3% of participants were educated upto primary level and 22.2% of participants were labourer and had private jobs out of which 33.3% were from lower middle class socio-economic status. The participants were related to the patient as spouse, children, parents and siblings, mostly the spouse i.e. 22.2%wives werelooking after their patients. 55.6% of the participants were taking care of their patients from more than 1 year of duration.

Table 1(a): Socio-demographic profile of the caregivers

(N=15)

S.No.	Characteristics	Frequency (%)
1.	**Age (in years)***	
	18-28	03 (16.70)
	29-39	01 (05.60)
	40-49	06 (33.30)
	50-59	03 (16.70)
	60-69	02 (11.10)
2.	**Gender**	
	Male	07 (38.90)
	Female	08 (44.40)
3.	**Religion**	
	Hindu	10 (55.60)
	Muslim	01 (05.60)
	Sikh	04 (22.20)
4.	**Marital status**	
	Married	11 (61.10)
	Unmarried	03 (16.70)
	Widow/widower	01 (05.60)

Table 1(b): Socio-demographic profile of the caregivers

(N=15)

S.No.	Characteristics	Frequency (%)
1.	**Education**	
	Illiterate	02 (11.10)
	Primary	06 (33.30)
	Secondary	02 (11.10)
	Intermediate	01 (05.60)
	Graduate or above	04 (22.20)
2.	**Occupation**	
	Government	02 (11.10)
	Private	04 (22.20)
	Labourer	04(22.20)
	Housewife	03 (16.70)
	None	02 (11.10)
3.	**Per capita income**	
	< 1000	04 (22.20)
	1001-2500	08 (38.90)
	2501-5000	02 (33.30)
	>10000	01 (05.60)

https://doi.org/10.46376/ijmr/05.06.2024:2629-2633

Table 1(c): Socio-demographic profile of the caregivers

(N=15)

S.No.	Characteristics	Frequency (%)
1.	**Socio-economic status**	
	Upper class	01 (05.60)
	Upper middle class	01 (05.60)
	Middle class	03 (16.70)
	Lower middle class	06 (33.30)
	Lower class	04 (22.20)
2.	**Relationship with patient**	
	Husband	02 (11.10)
	Wife	04 (22.20)
	Son	02 (11.10)
	Daughter	02 (11.10)
	Sister	02 (11.10)
	Brother	01 (05.60)
	Father	02 (11.10)
3.	**Duration of care giving**	
	3-6 months	02 (11.10)
	7-12 months	03 (16.70)
	More than 1 year	10 (55.60)

***Mean ± SD: 43.93 ± 13.43, Range 21-68 years**

Thematic Analysis:Colaizzi's technique was incorporated to analyze the data. The in-depth interviews of 15 participants were recordedin audio-recorder. Each interview was transcribed into verbatim. Out of caregiversinformation, the psychological responses were extracted.

Themes with frequencies of caregiver's responses:Table 2 depicts the themes with frequencies of caregiver's responses. Out of completedescription, adaptation to role of caregiver and psychological impact of care giving were extracted as main themes. 73.3% responses were of guilt and helplessness among caregivers and 26.6% responses indicated that the caregivers were not able to manage other roles.

Description of themes:

Theme I: Psychological impact: It was found that the care giving had an impact on the psychological health of the caregivers. They described their emotional feelings under subthemes: fear of losing patient, Anxiety related to pain of patient, Guilt & Helplessness, Outburst of emotions and stress. The caregivers' responses revealed that they were emotionally upset due to patient's pain, inability to save patient, and fear of losing patient.

Theme II: Adaptation to role of caregiver: Cancer care giving is stressful as caregivers have to play different roles along with the role of caregiver. They felt unsupported and alone in the caring role and some of them had problems in adjustment with multiple roles at a time. They found themselves to failing in meeting others family member's needs along with the care of patient because their focus was on patients care only. As a spouse the caregivers could not look after their children. The subthemes emerged were: adjustment with added responsibilities, loss of personal interests, overcoming many challenges in life at a time, inability to fulfill other roles. As per the caregivers' responses many of them were experiencing role strain.

Table 2:Cluster of caregiver's themes with frequency and percentage of formulated responses

S. No.	Themes Emerged	Sub-themes	f (%)
1.	**Adaptation to role of caregiver**	A. Adjustment with added responsibilities.	3(20.0)
		B. Loss of personal interests.	2(13.3)
		C. Overcoming many challenges in life at a time.	2(13.3)
		D. Inability to fulfill other roles.	**4(26.6)**
2.	**Psychological impact**	A. Fear of losing patient	8(53.3)
		B. Anxiety	4(26.6)
		C. Guilt & Helplessness	**11(73.3)**
		D. Outburst of emotions	6(40.0)
		E. Stress	6(40.0)

https://doi.org/10.46376/ijmr/05.06.2024:2629-2633

Discussion:

The present qualitative study has attempted tobring the feelings of caregivers associated with their care giving role, and the result shows that caring for an advanced stage cancer patients is challenging for them. Care giving is associated with significant impact on the physical and psychological aspects of caregiver's lives.

In present study the participants have also expressed their emotions regarding pain of the patients. It is painful for them to see the patient screaming in pain anytime. Some feels that its better patient would die than tolerating such pain while somebody has said "I was in such pain in place of mamma, I would have committed suicide rather than tolerating this horrible pain." These findings are consistent with the study in which the participants described feeling about the pain felt by their patient and about their own felt painthat they experience because of the sufferings of their patient. One participant in his study said about this issue.

Conclusions:

The study was about exploring the psychological issues encountered by caregivers of terminal stage cancer patients. The findings emerged under two themes: Adaptation to role of caregiver and the psychological impact. The family caregivers lived experiences illuminated a number of psychological concerns. In this study, the participants mentioned what they expect from health care professionals related to challenges they face: they should be provided with full fledged information, they should be provided with adequate psychological support along with patients.

Implication of the study: This study sheds the light on the necessity of availability of trained specialized oncology nurses in palliative care setting to play a critical role in meeting the psychological needs of caregivers in the care-giving process. The specialized oncology nurse can assess and identify the problems experiencing such as role strain, burden of care, disappointment, anxiety and fear, because of their professional knowledge &training and close interaction during patient care.

Limitation of the study: Data collection was limited to only one and half month period due to the time constraints, gives limited information and the findings could not be generalized to the whole population because of the research design of the study being qualitative with a small sample size.

Financial support and sponsorship: Nil

Conflicts of interests: The authors declare that they have no conflict of interest with regard to the content of the report.

Author's contributions: All authors made considerable contribution to conception and design, analysis and interpretation of data, and critical review of the manuscript. All authors read and approved the final manuscript.

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ISSN: 2582-7162

Orginal Article

A Comparative Study to Assess the Obesity Prevention Behavior among Adolescent Girls in Selected Engineering and Nursing Colleges Sri Ganganagar

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How to cite this article: : Farroda M.A comparative study to assess the obesity prevention behavior among adolescent girls in selected engineering and nursing colleges Sri Ganganagar. GFNPSS-IJMR 2024; 5:6: 2634-2640

Submitted:31-May-2024: **Accepted:**04-July-2024: **Published:** 07-July -2024

Abstract

Introduction: This comparative study aims to assess obesity prevention behavior among adolescent girls in selected engineering and nursing colleges in Chennai, India. The prevalence of overweight/obesity, the association between obesity and college type, the evaluation of obesity prevention behavior, the comparison of behaviors between engineering and nursing students, and the exploration of associations with demographic variables are key objectives of this research.

Materials and Methods: Data was collected using a survey method, which included bio physiological measurements and self-administered assessments. The study targeted adolescent girls aged 18 to 20 years, with total enumerative sampling. Results: The study's major findings revealed no significant differences in overall obesity prevention behavior scores between engineering and nursing students. However, associations were found with demographic factors such as family type, area of residence, and monthly family income.

Results: The findings indicate that while there were no significant disparities in overall obesity prevention behavior scores between engineering and nursing students, there were notable differences in certain demographic factors such as types of family, area of residence, and monthly family income. These variations suggest that socio-economic and environmental contexts may influence the adoption of obesity prevention behaviors.

Conclusions: This study emphasizes the importance of targeted interventions that consider socio-economic and environmental contexts in adolescent obesity prevention. It underscores the need for multifaceted approaches, encompassing education and structural changes, to promote healthier behaviors among adolescent girls. These findings provide valuable insights for policymakers, educators, and healthcare practitioners, facilitating the development of strategies that enhance the well-being of adolescent girls and address the complexities of obesity prevention behaviors.

Keyword;Obesity , Prevention Behavior, Adolescent Girls , Engineering And Nursing

Objectives of the study:

1. To determine the prevalence of overweight /obesity among adolescent girls in selected engineering and nursing colleges.

https://doi.org/10.46376/ijmr/05.06.2024:2634-2640