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Profile of Caregivers of Cancer patients: A Sociological Interpretation

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Abstract: This paper explores the diverse profiles of caregivers of cancer patients, focusing on the sociological dimensions that shape their experiences, roles, and identities. Studying the profile of caregivers of cancer patients from a sociological perspective is vital to understanding the multifaceted roles they play in the caregiving process and the broader social dynamics that influence their experiences. Caregivers are often the backbone of patient care, navigating emotional, financial, and physical challenges while managing their personal responsibilities. A sociological interpretation sheds light on how factors like gender, socioeconomic status, cultural norms, and social support systems shape their caregiving roles. Additionally, it provides insight into the inequalities caregivers face, such as the disproportionate burden on those from economically disadvantaged backgrounds. This understanding also helps society acknowledge the invisible labour of caregivers and its profound impact on health outcomes and social well-being.

Keywords: Caregivers, Caregiver burden, Gender, Socioeconomic status, Cultural norms.

1. INTRODUCTION:

Caregiving has become increasingly significant over the past decade, particularly in supporting individuals with serious illnesses like cancer. Providing care to cancer patients is a complex and demanding responsibility, often beginning as soon as the diagnosis is made. The nature and extent of caregiving required vary widely depending on factors such as the cancer type, the stage of the disease, and the treatment approach being pursued. This caregiving journey can be lengthy, sometimes stretching over several years, and it continues through various stages—whether toward recovery or, in some cases, until the end of life. Each phase requires unique forms of support, encompassing both practical assistance and emotional resilience from caregivers. The present paper focuses on profile of cancer caregivers.

Before discussing further, it is essential to explain basic terms;

Care

Cambridge dictionary defines care as "the process of protecting someone or something and providing what that person or thing needs".

According to Knijn & Kremer, (1997:p 330), Care includes the provision of daily social, psychological, emotional, and physical attention for people. This can be provided by paid or unpaid work, on the basis of an agreement or voluntarily, and it can also be given professionally or on the basis of moral obligation.

Caregiver

Merriam Dictionary defines caregiver as, "a person who provides direct care (as for children, elderly people, or the chronically ill)".

According to Collins Dictionary, "A caregiver is someone who is responsible for looking after another person, for example, a person who has a disability, or is ill or very young."



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Caregivers are those who provide routine or regular care to individuals who demand some level of ongoing support with daily duties. The people who get care can live in residential or institutional settings, and they can be youngsters or older adults with chronic illnesses or disabilities. Thus, a person who provides care to people who need help for taking care of themselves, for example, children, the elderly, or patients suffering from chronic illnesses or having disability.

TYPES OF CAREGIVERS: There are two types of caregivers: -

Informal Caregiver:

Informal care is the assistance a person in need of care or support receives from his/her spouse, children, other relatives, friends or neighbors (Jegermalm and Grassman, 2009; Lewinter, 1999; Sand, 2005). Informal caregivers or family caregivers are the peoples who are not paid for care provided by them. The most common example of informal caregiving relationship is an adult child caring for an elderly parent. Other type of caregiving relationships includes: -

- Adult caring for other relatives, such as grandparents, siblings, aunts, and uncles
- spouses caring for elderly husbands or wives
- middle- aged parents caring for adult children having disabilities.
- The care provided by children for a disabled parent or elderly grandparent.

Formal Caregiver: According to National Cancer Institute (2021), a formal caregiver, such as a nurse, is paid and trained to care for a patient. Institutions, Home Help workers, and other extra service providers provide formal care. It is normally carried out in accordance with rules and regulations, and the care receivers or the state and municipalities are usually liable for the cost. (Lewinter, 2003).

In the present study, the term informal care has been used. Most informal care takes place in the home of the care recipient or caregiver. The support provided to a cancer patient by relatives, both with formal and informal personal daily activities. The concept "family care" is integrated in the term "informal care".

Informal caregivers for cancer patients face a multitude of challenges that can significantly impact their physical, emotional, and financial well-being. The demands of caregiving often require them to balance intensive medical tasks, such as managing medications, monitoring symptoms, and assisting with personal care, alongside their regular responsibilities. The emotional toll of watching a loved one suffer can lead to anxiety, depression, and feelings of helplessness, especially as they navigate the uncertainty of the illness's progression. Financial strain is also common, as caregivers may reduce their working hours or leave their jobs to provide full-time care, while simultaneously shouldering medical costs and other expenses. Additionally, the physical demands of caregiving, including lifting or moving the patient and managing daily routines, can lead to exhaustion and burnout. Many caregivers struggle with isolation, as the focus on their loved one's needs often limits their social interactions and personal time. Together, these challenges underscore the need for greater support systems and resources to help informal caregivers manage the immense demands of cancer care.

2. LITERATURE REVIEW:

Palos & Hare (2011) in a study of cancer caregivers in the minority category found that caregivers were predominantly females and mostly younger than patients and living with patients. According to a study that described the sole experience of a 53-year-old woman of caregiving for her husband, who is 56 years old and undergoing a stem cell transplant for leukemia. The women told the caregiving journey full of depression, anxiety, and uncertainty (Bevans & Sternberg, 2012). In a study conducted by Ketcher et al. (2019) focusing on caregivers of individuals with advanced cancer, it was reported that women constituted the majority of the caregiving population. Specifically, 71.6% of the caregivers in the sample were female, highlighting the significant role women play in providing care in such contexts. Dhandapani et al., (2015) in a study of caregivers of patients with intracranial tumors found that 56% caregivers are in the age group of 18-40 years and in the age group of more than 40 years, there were 44 %, caregivers and 40%, females were caregivers and, 60% males were caregivers. In another study on children with Cancer The study conducted by Zhukovsky et al. in 2015 highlighted several key demographic characteristics of caregivers. It found that the average age of caregivers was 39 years, indicating that caregiving responsibilities were most commonly undertaken by individuals in their late 30s. Additionally, a significant proportion of these caregivers—90%—were married, suggesting a prevalence of family-based caregiving arrangements. Furthermore, the majority of these individuals had attained an education level up to graduation, reflecting a moderate to high level of educational attainment among caregivers in the

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sample. A study conducted in the Republic of Ireland, which explored the challenges faced by caregivers of individuals with head and neck cancers, provided significant insights into the demographic profile of these caregivers. The research found that the average age of caregivers was 60 years, indicating that older adults often take on this role. Additionally, the majority of caregivers were women, comprising 77% of the sample, while men represented a smaller proportion at 23%. These findings underline the predominant role of women in caregiving responsibilities within this context (Balfe et al., 2016).

A longitudinal study conducted in the United States on the burden faced by cancer caregivers revealed that a significant portion of caregivers, specifically 69.5%, had an education level of high school or lower (Guadalupe et al., 2011).

A study of PGIMER Chandigarh in which the burden of caregivers of patients with intracranial tumors presented Dhandapani et al., (2015) revealed that the 20% caregivers had education above graduation level, 49% caregivers were educated up to high school and secondary level and 49% caregivers were illiterate and 31% caregivers had education up to primary level. Further it was pointed out 41% caregivers were unemployed. Similarly, Balfe et al., (2016) reported that 51% of caregivers were unemployed, 25% had paid employment.

Vashistha et al., (2019) in a study of quality of life among cancer caregivers of low income analysed that low income caregivers suffers loss in quality of life. Poor caregivers whose health status was poor, who were married, who provided care for a long time, who cared for patients with poor performance status, and who paid high medical expenses were more likely to lose their family savings (Yun et al., 2005).

3. OBJECTIVE:

To examine the demographic profiles of cancer caregivers, including age, gender, socio-economic status, and religious backgrounds.

4. METHODOLOGY:

Caregivers in the present study included those individuals who were living with Cancer patients and providing them full time care at home. Thus, persons who bear the main responsibility of the care recipient and provide care most of the time were treated as care givers. Further they were non-professionals and unpaid caregivers.

Study was done by taking in-depth interviews of 40 caregivers who were providing care to cancer patients. These caregivers were selected from different hospitals in Chandigarh. They were interviewed. The study encompassed caregivers of different ages, genders, socio-economic statuses, religion and parts of the country. Meanwhile, the qualitative sample was intentionally chosen to reflect a wide array of experiences.

5. ANALYSIS & RESULTS:

Age of caregivers

The age of a cancer caregiver is an important factor in cancer caregiving and can vary widely. It depends on various factors, including the relationship with the patient (e.g., spouse, child, parent, sibling), cultural and societal norms, and the specific circumstances of the caregiving situation. The first notable characteristic of cancer caregivers is their age, which varies from patient to patient.

 Age (in years)
 No. of Caregivers

 18-30
 12

 30-45
 20

 45-60
 06

 60-75
 2

 Total
 40

Table 1 Showing Age of the Informal Care givers

The results of our study revealed a notable concentration of cancer caregivers in the younger age groups. Specifically, 20 caregivers fell within the age range of 30 to 45 years, indicating that a significant proportion of individuals providing care are in the prime working and family-raising years. Additionally, 12 caregivers were in the age group of 18 to 30 years, suggesting that young adults are also actively involved in caregiving, possibly as part of their familial or personal responsibilities. Only 6 caregivers were in the age group of 45 to 60 years, a smaller proportion, while just 2 caregivers were aged between 60 and 75 years. These findings suggest that the majority of caregivers tend to be younger, with individuals in their 30s and 40s being the most prominent age group in providing care for cancer



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patients. This trend may reflect the physical stamina and flexibility required to manage the demanding nature of caregiving, as well as the likelihood that younger individuals are more likely to be in close proximity to their ill family members, especially if they are parents or spouses. The relative scarcity of older caregivers could also point to potential challenges older individuals might face, such as health issues, physical limitations, or competing life responsibilities that may make it more difficult for them to take on caregiving roles.

Gender of the Caregivers

Gender of caregivers is also a very important factor in caregiving. Historically, caregiving has often been associated with women due to traditional gender roles that designate women as primary caregivers within families.

GenderNo. of CaregiversMale27Female13Total40

Table 2 Showing Gender of the Informal Care givers

Out of the 40 cancer caregivers, 27 were male and 13 were female. Interestingly, we also observed that in 10 additional cases, female caregivers were involved in caring for their child, alongside their male spouse. This suggests that when the patient is a child, there is a 100% likelihood that both the mother and father are actively engaged in caregiving. If we include these 10 cases of joint caregiving in the count of female caregivers, the number of women providing care increases to 23. This finding highlights the significant involvement of women in caregiving, especially in family-centered caregiving situations, where both parents are equally invested in supporting their child's health. The data also underscores the importance of considering both male and female caregivers in caregiving research, as gender dynamics may influence the distribution of caregiving responsibilities, particularly when the patient is a child.

Education qualification of caregivers

Education plays an important role in the development of human beings. It provides overall growth to a person, whether male or female. Providing care to a loved one who is suffering from a deadly disease like cancer is a very difficult task. Men and women who are illiterate or have limited education face greater challenges in understanding the problem and its treatment. They find it very difficult to communicate with their physicians and healthcare providers.

Education qualification	No. of Caregivers
Illiterate	04
Primary to Middle	07
Matriculation	08
Senior Secondary	09
Graduation	09
Post Graduation	03

Table 3 Showing Educational Qualification of the Informal Care givers.

Education plays a crucial role in shaping the caregiving experience, as it can influence a caregiver's ability to navigate the complex medical and logistical aspects of cancer care. In the present study, a range of educational backgrounds was found among the 40 cancer caregivers, highlighting the diversity in their levels of formal education. Four caregivers were illiterate, which could limit their ability to access and understand health information, manage medical appointments, or seek out support resources effectively. Seven caregivers had completed only primary or middle school education, which may also present challenges in handling more complex caregiving tasks and accessing information related to the patient's care. Eight caregivers were matriculates, meaning they had completed their secondary education, and another eight had completed senior secondary education, providing them with a better foundation for understanding healthcare instructions and managing care responsibilities. Nine caregivers were graduates, possessing a higher level of education that may have equipped them with greater confidence in navigating healthcare systems, understanding medical terminologies, and making informed decisions. Additionally, three caregivers held postgraduate degrees, and one had a professional degree, indicating that higher educational attainment can potentially offer caregivers enhanced problem-solving skills, critical thinking, and the ability to advocate for the patient. The educational diversity

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within the study emphasizes the need for tailored support and educational materials to ensure that all caregivers, regardless of their educational background, can access the resources and information necessary for effective caregiving.

Occupation of the Caregivers

Occupation of caregivers greatly impacts their caregiving role. The caregivers in temporary or private jobs face more challenges than those in stable income and government jobs. High-stress or demanding jobs can intensify the difficulties of caregiving. The pressure from work can hinder a caregiver's ability to handle their duties efficiently and may negatively affect their overall health. The physical and emotional demands of a job can also affect caregiving. Jobs involving physical labour or long hours may drain caregivers' energy, making it harder to manage caregiving tasks, while emotionally demanding jobs can increase their stress levels.

Table 4 Showing Occupational status of the Informal Care givers

Occupation of Caregivers	No. of Caregivers
Housewives	05
Unskilled Labourer	09
Skilled Labourer	06
Agriculture	04
Own Business	03
Professionals	05
Private jobs	07
Retiree	01
Total	40

In the present study, it was observed a wide range of occupations among the 40 cancer caregivers, highlighting the different type of challenges with different occupation in caregiving. Five caregivers were housewives, nine caregivers were unskilled labourers facing different facing the job security issue and risk from owner, six caregivers were skilled labourers posing the same risk and challenges in the job, four caregivers were doing the agriculture, three caregivers had their own business, five caregivers were doing the Professional job, seven caregivers were doing the Private jobs,1 caregiver was retired from Government job. The caregivers especially in occupation like unskilled labourers, skilled labourers and in private job faces more occupational challenges in caregiving than of other occupational groups.

Income of the Caregivers

Income is an important variable to analyse the socio-economic status of a caregiver. Family caregivers are mainly unpaid caregivers. They not receive any direct financial compensation for their caregiving duties. Their income would be determined by their primary occupation, if they have one. The income of cancer caregivers can significantly affect their ability to provide care.

The income level directly correlates with caregivers' ability to afford necessary medical supplies, professional assistance and other crucial resources effective for caregiving. Financial stability can enhance access to quality healthcare services for both the caregiver and the patient, thereby improving the overall standard of care provided. Financial strain can contribute to stress and affect emotional well-being.

Table 5 Showing Income of the Informal Care givers

Income (per month)	No. of Caregivers
Less than 10,000	10
10,000-20,000	13
20,000-30,000	06
30,000-40,000	02
More than 40,000	04
No Income	05
Total	40

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In the present study, a wide range of income levels were observed among the 40 cancer caregivers, highlighting the economic diversity within this group. Ten caregivers reported an income of less than 10,000 rupees per month, while thirteen earned between 10,000 and 20,000 rupees monthly. Six caregivers had monthly incomes between 20,000 and 30,000 rupees, and two reported earnings in the range of 30,000 to 40,000 rupees. Four caregivers had monthly incomes exceeding 40,000 rupees, and notably, five caregivers had no income at all. This variation in income reflects the diverse economic backgrounds of caregivers, which may impact their ability to provide care and access necessary resources. Lower-income caregivers, especially those with little or no income, may face additional financial burdens, as they may struggle to afford medical supplies, transportation, and other caregiving expenses. These findings underscore the need for financial support programs and resources to assist caregivers who may already be financially vulnerable while managing the demanding responsibilities of cancer care.

Marital status of the Caregivers

Marriage is a significant aspect of an individual's life course. In Indian society, the institution of marriage is closely tied to a woman's perceived worth, as well as financial stability and security. The marital status of respondents has been considered an important factor in evaluating their family and social life. Spouses play a crucial role in caregiving. Generally, married individuals have more social support compared to those who are unmarried, divorced, or separated. Information on the marital status of respondents has been taken as a key factor in assessing their family and social life.

Marital StatusNo. of CaregiversMarried33Unmarried05Divorced01Separated01Total40

Table 6 Showing Marital Status of the Informal Care givers.

Out of the 40 cancer caregivers, 33 were married, 5 were unmarried, 1 was divorced, and 1 was separated. The marital status of caregivers can play a significant role in shaping their caregiving experience, as well as the support they receive and the challenges they face. Married caregivers may have the advantage of emotional and logistical support from their spouses, which can help alleviate some of the burdens associated with caregiving. Unmarried caregivers, on the other hand, may rely more heavily on extended family or social networks, potentially feeling a greater sense of isolation or stress if they lack such support. Those who are divorced or separated may face unique emotional challenges, as the absence of a partner could intensify feelings of loneliness or add to the complexity of balancing caregiving responsibilities with other aspects of life. Understanding these dynamics is crucial for developing targeted resources and support systems that consider the caregiver's personal circumstances and social support networks.

Religious affiliation of Caregivers

Religion often has deep roots in culture, and the two are closely intertwined. Culture encompasses the values, beliefs, practices, and norms that shape a society, and religion frequently arises from and reflects these cultural contexts. In Islam, women's roles in family and community life are viewed as integral to their spiritual development. Islam places great importance on family values, and women's contributions to family and community are recognized as spiritually significant. In Hinduism, the concept of "dharma" refers to one's duty or righteousness. Caring for family members, especially elders, is considered a significant aspect of one's dharma. This duty is often seen as both a moral and spiritual obligation.

Table 7 Showing Religion of the Informal Care givers.

Religion	No. of Caregivers
Hindu	29
Muslim	03
Sikh	08
Total	40



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Among the group of 40 cancer caregivers, 29 identified as Hindu, 3 as Muslim, and 8 as Sikh. This demographic distribution highlights the diverse religious backgrounds of individuals providing informal care to cancer patients. Each caregiver's cultural and religious beliefs may influence their approach to caregiving, including their views on health, coping mechanisms, and rituals surrounding illness and healing. Understanding the caregivers' religious and cultural perspectives can play an important role in tailoring support systems to meet their unique emotional and spiritual needs, fostering a more inclusive environment that respects each individual's belief system. Such diversity also reflects the varying social norms and expectations that may affect caregivers' willingness to seek outside assistance, their resilience in the face of caregiving challenges, and the kinds of community support they may rely on.

6. DISCUSSION:

The study revealed that demographic factors significantly influence the caregiving experience. Results reveal that the respondents were of different age categories, however, where the parents were taking care of their younger children, the age of caregiver was more than the care receiver, thus findings don't endorse Bevans & Sternberg, (2012). Findings on the other hand agree with Dhandapani et al., (2015) who reported that 56% caregivers were in the age group of 18-40 years. In the present study, 27 were male and 13 were female. In 10 cases, female caregivers were involved in caring for their child, alongside their male spouse. If we include these 10 cases of joint caregiving in the count of female caregivers, the number of women providing care increases to 23. Results don't endorse Palos & Hare,(2011) who reported that caregivers were predominantly females.

In the present study, out of 40 cancer caregivers, Four caregivers were illiterate, Seven caregivers had completed only primary or middle school education, Eight caregivers were matriculates, another eight had completed senior secondary education and Nine caregivers were graduates, This finding highlights a concerning trend, suggesting that many caregivers may not have access to higher educational opportunities, which could affect their ability to navigate the complex demands of caregiving. Furthermore, lower educational levels may contribute to challenges in understanding medical information, accessing resources, and managing the emotional and physical stress associated with caregiving. Similar results were presented by Dhandapani et al., (2015) who revealed that the 20% caregivers had education above graduation level, 49% caregivers were educated up to high school and secondary level and 49% caregivers were illiterate and 31% caregivers had education up to primary level. Further it was pointed out 41% caregivers were unemployed. Similarly, Pandey et al. 31 (25%) of caregivers were graduate, 186 (35%) passed secondary school, while only 25 (4.8%) were illiterate.

With regard to occupation it was found 5 caregivers were housewives, 19 caregivers were labourers that included skilled, unskilled and agricultural labourers. 3 caregivers were small shopkeepers. 5 caregivers were in professional jobs.7 caregivers worked in private-sector jobs. One caregiver was retired from a government job. Results thus are not in congruence with Balfe et al., (2016) who reported that 51% of caregivers were unemployed, 25% had paid employment.

Results show that out of 40 cancer caregivers, 10 caregivers reported an income of less than 10,000 rupees per month, while 13 earned between 10,000 and 20,000 rupees monthly. Vashistha et al., (2019) in a study of quality of life among cancer caregivers of low income analysed that low income caregivers suffers loss in quality of life.

7. CONCLUSION:

This study aimed to explore the diverse profiles of cancer caregivers through a sociological lens, focusing on their demographic characteristics, religious affiliation and social contexts. The research revealed that factors such as gender and socio-economic status significantly shape caregivers experiences.

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