

Original Article

Family Caregivers' Experiences of Caring for Cancer Patients In Tertiary Care Hospitals, Islamabad Pakistan

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Abstract

Background: Cancer gravely affects the physical, psychological, emotional, and economic conditions of not only the patient who has been afflicted but also the friends and loved ones, especially those who are involved in caregiving. Extended hospital stays place greater demands on caregivers, highlighting the crucial role of family caregivers (FCGs) as primary patient support.

Purpose: This study aimed to explore the experiences of FCG of cancer patients who are admitted to the tertiary care hospitals of Islamabad, Pakistan.

Methods: A qualitative exploratory descriptive study design was used. The sample size was 16 FCGs of cancer patients from public and private hospitals. Data collection involved face-to-face interviews. Data was analyzed by using the following sequential process of data analysis.

Result: FCGs experience significant physical and emotional challenges while caring for critically ill cancer patients. They endure hardships of caregiving by providing physical care and a few of the imposed tasks like drawing blood and intravenous infusions. The emotional toll is profound, leading to psychological distress and neglect of their well-being. The financial strain impacted the education of children of FCGs, the loss of jobs, and the selling of property to manage cancer treatment. To cope with these challenges, FCGs relied on the teachings of their faith, offering religious prayers, and diverting minds using social media. FCGs emphasized the need for improved communication and attitudes of healthcare staff.

Conclusion: This study highlighted the physical, emotional, and financial hardships endured while providing care. However, their personal needs often go unnoticed and may become ineffective in supporting patients. Therefore, healthcare professionals must develop targeted support programs for FCGs.

Keywords: cancer patients, experiences, family caregivers, informal caregivers, oncology patients, perspectives

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Background

Cancer affects the physical, psychological, emotional, and economic conditions of not only the patient who has been afflicted but also the friends and loved ones, especially those who are involved in caregiving. The caregivers around the cancer patients provide care to the patient in a variety of ways, some help with activities of daily life (such as bathing, clothing, grooming, feeding, toileting, bed and chair transfers, etc.), while others in everyday living responsibilities that are essential (such as transportation and finance), and in providing nursing duties such as giving medication, providing mouth and back care, etc. Others deliver care remotely while continuing to be deeply devoted to and perhaps worried about their care.¹

Anyone who provides emotional and physical support for a sick family member at home or in a hospital setting is referred to as a "family caregiver" including parents, adult children, spouses, etc. As a result, the family caregiver (FCG) of a cancer patient might be regarded as an integral part of the healthcare team. Many people who become caregivers take on a new role that they may not be prepared for. They may feel anxious or overwhelmed by the demands of the role and may also find themselves doing new and unexpected tasks, such as providing medications, helping with meals, and performing medical and nursing tasks. This can lead to a variety of conflicting emotions, such as worry, anger, and despair.²

There is strong evidence to support the claim that FCGs manage numerous, complex symptoms and health issues on behalf of their loved ones. Additionally, because of prolonged hospital stays there is an increase in caregiver responsibilities, which emphasizes the FCGs' role as a patient support system. However, the challenges of caring for cancer patients seem to be complex and can affect the caregiver's communication styles, work output, and social roles.³ Therefore, it is increasingly important to acknowledge the FCGs as an integral element of the process of care.⁴

Clinical care tasks that were previously carried out by licensed healthcare professionals are now more frequently asked of FCGs. For instance, they are required to carry out a variety of duties like managing medications, providing physical care, managing finances, and providing emotional support. But without the proper assistance, these daily responsibilities leave FCGs with their own needs for help, which, if unmet, can result in a lower quality of life and more distress.⁵ Existing qualitative research on the topic revealed that the FCGs need help to prepare for their role, being seen and heard by healthcare professionals, getting clear information about the condition of their patients, and finding emotional support.³ Through appropriate training, education, and support, it may be possible to lessen the burden on caregivers. It is possible that many caregivers are not receiving the training they require.⁶ Additional studies have revealed high levels of stress and annoyance experienced by FCGs, as well as their desire to receive counseling and support. Due to their increasing responsibilities, FCGs frequently exhibit greater psychological discomfort, stress, as well as risky behaviors when it comes to their health.⁷

In Asian cultures, family members prioritize making sure the patient has the maximum possible care. They felt they had not provided the patient with enough care after witnessing the patient's suffering. It is crucial to inform the patients' caretakers about the course of their sickness so that they would understand that the patient's decline was a natural component of the disease.⁸ According to the International Agency for Research on Cancer (IARC), Pakistan has 0.18 million recent incidences of cancer, 0.11 million cancer mortalities, and 0.32 million prevalence cases. There is no systematic strategy to combat cancer. There are presently no

integrated healthcare education programs for cancer prevention and control in Pakistan. Due to this inadequacy and uncertainty, the family's stress and burden have increased.⁹

Currently, the experience of FCGs of cancer patients is not considered by healthcare staff for comprehensive and effective care. This can have many negative consequences for both patients and caregiving families. Secondly, most of the studies have measured the phenomenon of anxiety and depression of the caregivers but not the overall experiences. Therefore, a qualitative study needed to be done. The study findings provide valuable insights into the challenges faced by family caregivers of cancer patients in Islamabad, Pakistan, enhancing our understanding of their experiences and coping mechanisms. The purpose of this research was to investigate and comprehend the experiences of family caregivers who provide care to cancer patients admitted to tertiary care hospitals in Islamabad, Pakistan. The primary research question addressed in this study was: "What are the experiences of family caregivers of cancer patients while providing care to their patients?" To gather relevant literature on this topic, the researchers utilized electronic databases such as PubMed, Wiley Online Library, PakMediNet, CINAHL, and also explored grey literature through Google Scholar. This comprehensive search strategy ensured a thorough review of existing knowledge related to caregivers of cancer patients, enriching the study's foundation and potential implications.

Methods

A qualitative exploratory descriptive design was employed in this study to elicit the experiences of FCGs of cancer patients. The FCGs of cancer patients were the population of the study. The study sample was collected from one Public Sector and one Private Sector tertiary hospital in Islamabad to ensure the collection of diverse and rich data. The study duration was from February 2023 to July 2023. The data was collected from 16 FCGs of cancer patients. To ensure authenticity, a purposive sampling method was selected so that the participants could provide in-depth information about their experiences. FCGs of admitted cancer patients were engaged in this study who met the following inclusion criteria: Caregivers who were involved in caring for the cancer patients for at least three months after diagnosis, Participants who were above 18 years of age, Participants were able to express their feelings in English or Urdu languages comfortably.

After approval of the Institutional Review Board (IRB), permission from the management of included hospitals was taken through a permission letter Registered nurses and team leaders were approached with the help of Head Nurses and Managers of the Oncology Unit. The researcher discussed the purpose of the study, potential risks, and benefits with the participants before obtaining the informed consent. The data was collected using a demographic information sheet and the interview guide. Before collecting actual data, two mock interviews were conducted. The demographic sheet consisted of FCGs' age, gender, marital status, relationship with the patient, occupation, educational status, job status, monthly income of the family, and source of financial burden like Panel, loan, self, etc. Moreover, the type and stage of cancer of their patients, the kind of treatment of cancer, the duration of the diagnosis, and the patient's ability to self-care were confirmed by the patients' files as well. Once the demographic data sheet was filled, the interviews were taken face-to-face using an open-ended interview guide. Field notes were also taken to note the participants' nonverbal cues and emotional responses. 16 interviews were taken among which eight were from the public sector and eight from the private sector hospitals. The steps for qualitative data analysis specified by Creswell and Creswell (2018, pp. 268-270) were followed. Data was analyzed by using the following sequential process of data analysis.

Approval was sought from the Shifa Tameer-e-Millat University Review Board (IRB) (IRB #097-23). Moreover, approvals were obtained from the management of both hospitals (Appendix E) from where the data was collected. Participants were informed of the purpose of the research and its advantages before the data collection process. In addition, the participants were explained that they had the right to withdraw from the study whenever they wanted without affecting the treatment of their patient in any way. Every participant's privacy was preserved, and confidentiality was guaranteed. After their willingness to participate in the study, written informed consent was obtained from the participants.

Results

A total of 16 FCGs of cancer patients were interviewed; among them, eight were recruited from a private hospital and eight from a public hospital. Their age ranged between 19 to 58 years with a mean of 36 years. Their monthly income (Pakistan Rupees/Month) ranged from 10,000 to 200,000. Most of the participants were from a low socioeconomic family background. The majority (69%) of the participants were married and among them, 44% were females who were homemakers. Regarding education, approximately 38% of FCGs had a university-level education, and 25% had completed secondary education. All of the participants were Muslims. The detailed demographic information of FCGs is provided in Table 1.

Table 1. Demographic information on family caregivers

Demographics (FCG)		N	%
Type of hospital	Private	8	50
	Public	8	50
Gender	Male	7	44
	Female	9	56
Marital status	Married	11	69
	Unmarried	5	31
Relationship with Patient	Spouse	4	25
	Father	3	19
	Mother	2	13
	Brother	4	25
	Sister	2	13
	Daughter	1	6
Education	Nil	3	19
	Primary	2	13
	Secondary	4	25
	High school	1	6
	University	6	38
Occupation	Business	1	6

	Government job	1	6
	Housewife	7	44
	Labor	1	6
	Nursing	1	6
	Private job	1	6
	Student	2	13
	Teacher	1	6
	Unemployed	1	6
Source of finance	Panel	4	25
	Self	1	6
	Loan	9	56
	Bait-ul-Maal	2	12.5
	Sehat Card	0	0
	NGO Help	0	0

Various types of cancers were reported by FGC including Acute Lymphoblastic Leukemia (ALL), Chronic Myeloid Leukemia (CML), and different types of blood cancers. In addition, the different stages of cancer as reported by FCGs were stage 2 (n=3), stage 3 (n=1), and stage 4 (n=3). For ALL and CML, participants mentioned that their family members were in acute (n=4) and chronic stages (n=5). When the participants were asked about the patient’s ability for self-care, they reported some being independent 12% (n=2), 44% were partially dependent (n=7) and 44% were dependent (n=7) on the caregivers.

Table 2. Categories, sub-categories, and codes of the study findings

Codes	Subcategories	Categories
<ul style="list-style-type: none"> Feeding and changing clothes Bathing and toileting 	Acceptable Tasks	
<ul style="list-style-type: none"> Medicine administration and drawing blood Arranging blood & labs 	Imposed Tasks	Caregiving Responsibilities
<ul style="list-style-type: none"> Aches and pains Sleeping disturbances Maintaining hygiene 	Physical Hardships of Caregiving	
<ul style="list-style-type: none"> Fear and anxiety Crying Neglecting self 	Psychological Distress	Grief & Sorrow
<ul style="list-style-type: none"> Suffering Providing false hope 	Emotional Burden	
<ul style="list-style-type: none"> House chores and social activities Compromised education and work-life 	Disruption of Family Functions	Socio-economic Burden

<ul style="list-style-type: none"> • Difficulty affording treatment & less Income • Selling the property and taking loans 	Financial Burden	
<ul style="list-style-type: none"> • Patience and understanding • Acceptance of mortality 	Faith in Allah	
<ul style="list-style-type: none"> • Offering prayers • Reading Quranic verses 	Religious Practices	Coping Mechanisms
<ul style="list-style-type: none"> • Mobile use and social media • Going out for a walk 	Mind diversional Activities	
<ul style="list-style-type: none"> • Staff attitude • Need for a communication forum 	Communication Issues	Healthcare Management Challenges
<ul style="list-style-type: none"> • Limited resources & lack of cleanliness • Inadequate healthcare facility 	Facility Management Issues	

Caregiving responsibilities encompass the diverse tasks and duties undertaken by FCGs in their unwavering commitment to supporting their loved ones battling cancer. FCGs expressed that caregiving is their responsibility. Therefore, they have to help their sick family member as they are culturally bound to take care of them. They shared about the activities performed for their loved ones.

Feeding and Changing Clothes.

A family caregiver (FCG) stated *“I change my brother's clothes, wash his hands and face, massage him, give him water, take him to the washroom, and feed him”* [FCG 15]. Similarly, another FCG expressed that, *“He (The patient) has to be looked after all day long, fed, and given medicine. My husband has also been treated like a child”* [FCG 1].

Bathing and Toileting.

Bathing and toileting the patient with increased dependency becomes challenging and requires the support of more people. As one of the FCGs narrated, *“I change my brother's clothes, wash his hands and face, massage him, give him water, and feed him. I take him in a wheelchair to the washroom”* [FCG 15].

Imposed Tasks

The imposed tasks refer to the tasks that are related to healthcare professionals or nursing care, whereas, such tasks were performed by the FCGs which they thought were not their responsibility. These tasks included medication administration, drawing blood, and arranging for blood and labs.

Medication Administration and Drawing Blood

About the medication administration and drawing of blood, an FCG asserted:

A family member who is the brother of the patient expressed that; *“I help in giving medication. I do a lot of things. I prepare the injections and inject them. The nurses just asked, me if I had given him the medicine. They [hospital staff] also asked me to sign the medication chart by myself.”* [FCG 3]

Arranging Blood and Labs.

The FCGs are involved in the arrangement of blood for their patients. Particularly in the public sector hospitals, FCGs were facing many challenges with blood arrangements. Regarding the lab tests, some lab tests are not available inside the hospital therefore, patients or FCGs were expected to explore and arrange for the lab tests of their patients. An FCG who is the wife of a patient, narrated:

“I have a lot of problems with arranging blood because my husband needs eight or nine bottles of blood every month. The problem is for those who cannot arrange blood, it should be the job of the doctors or nurses of the hospital to make arrangements for blood rather than sending the patient to the blood banks to continuously beg for blood.... A cancer patient should not be told to first get a donor and then he will be given blood.” [FCG 2]

Physical Hardships of Caregiving

FCGs expressed numerous physical hardships that they experienced while taking care of their loved ones while in the hospital, like aches and pains, sleeping disturbances, and maintaining hygiene.

Aches and Pains

The FCGs were having aches and pains in different parts of their body as a result of caregiving. One of the FCGs said, *“I have migraine headaches. When I got the news [diagnosis of cancer], I got the attack of this disease [migraine] instantly. I suffer a lot from this thing”* [FCG 1]. This problem was commonly experienced by many participants because of sitting next to their patients for long periods.

Sleep Disturbance

In addition to aches and pains in different parts of the body, FCGs complained about sleep disturbances as well. An FCG who is the patient’s wife, expressed that:

“I can’t sleep at all in the hospital. Because he [patient] is in pain all day, I just stand all day. At midnight, if the chemo room is empty, then I go there and sleep. Otherwise, if someone finds a bench [for me], then I lie on it and sleep at night... It is very difficult to sleep on a bench.” [FCG 2]

Similarly, another FCG stated, *“Sometimes I have body aches due to tiredness. At night, my mother doesn’t let me sleep. So, I get disturbed. I cannot sleep enough. I have headaches due to sleeplessness”* [FCG 5]. This disturbance is also evident in another son's narrative as he said:

Maintaining Hygiene

Many of the FCGs expressed that maintaining hygiene for themselves added to the physical hardships of caregiving. An FCG alluded to the fact: *“It’s difficult to stay clean here [in the hospital]. I go home once in two weeks to change my clothes and take a bath. Before this, I used to go home three or four times a week to change my clothes”* [FCG 3]. Another participant expressed, *“I can’t even wash my face, change my clothes, and take a bath here. It is very hard to spare time...”* [FCG 5].

Grief and Sorrow

The grief and sorrow category emerged from the psychological distress and emotional burden sub-category and related codes.

Psychological Distress

The psychological distress emerged from stress, fear and anxiety, depression, and neglecting self when providing care to their loved ones with cancer. Emotional burden emerged from the suffering endured by FCGs and providing false hope to self and the patient with the cancer.

Fear and Anxiety

The diagnosis of cancer and the deteriorating health conditions of the loved ones caused fear and anxiety in FCGs.

"I can't bear it. Now my heart becomes weak.... I can't bear it anymore [sickness of her sister]. ... I don't know what's happening to me these days. I have a lot of burden on my mind. I get anxious about her whether she will be fine or not." [FCG 6]

Another FCG said: *"I get worried to see deaths...the mind is heavily burdened and affected. Our mind goes numb when we see these events. I worry a lot. Not only worried, too much worried"* [FCG 15].

Crying

"Crying" seems to hold a significant emotional weight. Crying often serves as an outlet for the complex and overwhelming emotions that caregivers grapple with daily. Crying was common in all participants' narrations. One of the FCGs who is the father of a patient father, narrated that;

"The word cancer is daunting. So, when I found out that my daughter had cancer, my feet were falling off the ground. I would go outside and cry. It had a strange feeling. Whenever I talk about it, tears start falling from my eyes" (started crying)" [FCG 10].

Neglecting Self

Furthermore, FCGs neglect themselves, they often prioritize their patient's well-being over their own, even if it means enduring pain or discomfort. One FCG whose brother is the patient expressed:

"If you ask me personally, the truth is that I am not bothered about myself in these troubled times [cancer treatment]. I don't care. Even if it hurts.... If my brother is in pain, I forget about the pain that I have. I don't know if I'm hungry or thirsty.... I am not thinking about my children. I only worry about my brother." [FCG 15]

Emotional Burden

The emotional burden subcategory emerged from suffering and the provision of false hope to the FCGs.

Suffering

The expression of suffering is reflected as an FCG narrated:

"It is very difficult as a wife [pause and deep breath], very difficult [started crying]. So, getting a blow of such a big disease [cancer] makes it very difficult.... See, the patient is already suffering, but the family is suffering more than him" [FCG 1].

The quote also affirms increased distress due to enduring criticism from doctors for not being able to perform certain tasks.

Providing False Hope

The FCGs provide false hope to their children, other family members, and sometimes to patients by hiding the disease and its prognosis to keep them away from stress and anxiety. A FCG whose sister is admitted, stated, *“She (The patient’s mother) keeps on crying every time. I told her that she would be all right why do you take tension?... I don’t even cry in front of my sister. I just tell her that all the tests are clear and that she can go home”* [FCG 6].

Few FCGs explained their approach when dealing with the patient's cancer diagnosis in front of their children. They choose not to disclose the word "cancer" and instead focus on describing the patient as unwell or weak.

Socio-Economic Burden

The socio-economic burden included subcategories such as disruption of family functions and financial burden.

Disruption of Family Functions

Caring for a loved one with cancer can significantly disrupt family dynamics and functioning. As the caregivers become primary sources of support, other familial relationships may be strained, and the overall family equilibrium can be destabilized.

House Chores and Social Life

Regarding disruption in house chores and social activities, an FCG who is the patient’s son, elucidated:

“My personal life is nothing nowadays, which means it has been compromised. Nowadays, I am only doing patient care. I don’t have time to do anything else. I am not able to balance life. I don’t go to a gym or participate in any activity; nothing is like that. I stay here with my mother all the time (in the hospital).” [FCG 12]

The FCG described how his personal life has been disrupted due to providing care for his mother.

Compromised Education and Work-Life

In addition to the social life, the education and work life of the FCGs were also affected as expressed by an FCG: *“We stopped our son’s studies. At first, he [husband] worked for six years despite cancer, but since the chemo began, he has been completely bedridden. So now he doesn’t work so I can’t afford the fee”* [FCG 2]

Financial Burden

The financial burden of caregiving developed as a result of selling properties, taking loans, and difficulties in affording treatment.

Selling Properties and Taking Loans

Selling properties and taking loans can be critical decisions for cancer caregivers, often driven by the need to ensure quality care for their loved ones.

An FCG whose son is admitted, stated:

“We sold one or two buffalos...Then a sister of mine had some gold in the bank. She took out that gold and sold it.... I have taken out all the money from the relatives and the house and given it to them [hospital]. You can go to my house and see that my house is falling, my

house is completely damaged. There is no lie, no fraud. It is like that; we are left only with one room in the home. But we say 'O God bless our son'. We have sold our land." [FCG 11]

Another participant said, "The biggest difficulty was financial. Its (cancer) treatment is so expensive and difficult. We have struggled a lot, sold many household things, and took loans from the people" [FCG 16].

Difficulty Affording Treatment & Low Income

Most of the FCGs belonged to low socio-economic backgrounds. Therefore, it was difficult for them to afford the expensive medication and chemotherapy. Further exploration revealed acute financial distress faced by the FCGs. As one of the FCGs said; *The hospital discharged us today. We don't even have money [to pay bills] and... take him home... Then I called a boy (a relative) and he gave me some money and he said, I should pay him back* [FCG 11]. The FCG expresses the helpless situation that she experiences for not being able to afford the treatment of their loved ones.

Coping Mechanisms

The FCGs used numerous coping mechanisms namely faith in Allah, religious practices, and mind-diversion activities.

Faith in Allah

All the FCGs who participated in the study were Muslims. They expressed a strong belief and faith in Allah as the Creator and can do miracles. FCGs of cancer patients frequently place a high value on their faith in Allah. It gives them the resilience to handle the difficulties of caregiving with patience and understanding

Patience and Understanding

FCGs of cancer patients demonstrate exceptional patience and unwavering understanding as they navigate the complex and emotionally challenging journey alongside their loved ones. An FCG whose daughter is the patient narrated:

"You have to keep patience. Because, you see, despondency is a sin in our religion. I pray to Allah Almighty that I have fallen into a well right now and may Allah Almighty take me out of it like (Hazrat) Yousef (Peace Be Upon Him)." [FCG 10]

The FCGs showed profound reliance on faith and trust in God. The FCG draws a parallel with the story of Yusuf (Peace Be upon Him) and hopes that God will similarly rescue him from his current difficulties.

Acceptance of Mortality

The FCGs' perspective is centered on the belief that everything happens for a reason and that ultimately, challenges and hardships are meant to lead to something better. This interpretation highlights the FCGs' reliance on faith to find meaning and resilience in the face of difficulties. An FCG who is the patient's wife, expressed:

"Life and death are side by side. We should be ready for that. Life is in Allah's control; doctors treat and we try. It is Allah who gives life and He also gives death...Allah has passed me through this phase and I have more faith in Allah. I say that if something happens to him or my children or me, it is God's will we have to accept it." [FCG 16]

In the above quote, the FCG expressed strong belief in accepting God's will, whether it pertains to their husband, children, or themselves, and their deep trust in their faith.

Religious Practices

FCGs of cancer patients often draw upon their religious beliefs and practices to find solace, strength, and hope during the challenging journey of caregiving. For coping, some of the FCGs expressed that offering prayers and reading Quranic verses helped them in their caregiving journey.

Offering Prayers

The FCGs follow religious practices to cope with difficult times by offering prayers. An FCG said offering prayers helps them relax and achieve a sense of inner peace. He said:

"I say that the peace you get from praying you don't get from anything else. Prayers help you get rid of your tiredness, you get relaxed, and you get rid of your tension. You get a lot of peace from praying. I feel very peaceful when I pray." [FCG 3]

Reading Quranic Verses

Among the religious practices, the FCGs were also involved in reciting the Holy Quran. An FCG who is the patient's mother explained *"I have faith in God. I read the Quran. I just recite Surat-ul Baqara and then offer my prayer. His father's teacher told me to recite Surat-ul-Kousar 121 times, and I recite it"* [FCG 11]

In addition to the recitation of the holy verses, the FCGs used the digital device to hear the Holy Scripture.

Mind Diversion Activities

FCGs of cancer patients often engage in diversional activities to provide a much-needed respite from their caregiving responsibilities. The FCGs stated that the use of mobile phones, social media, and going out for a walk helps them divert their minds.

Use of Mobile Phones and Social Media

FCGs use social media as a mind-diversional activity for coping with distressing situations. *"To divert my mind, I use social media. I do have a friends' circle. But since the cancer was diagnosed, I have not been able to meet or attend a party and hang out with my friends"* [FCG 12]. The FCGs acknowledged that they use the mobile phone as a coping mechanism and a source of comfort. This highlights how the FCG relies on their faith and modern technology.

Going Out for a Walk

Besides using social media and mobile phones, the FCGs also used mind diversion activities like going for a walk.

An FCG said, *"When my patience runs out, I go out. I don't say anything to her otherwise she will get more upset."* [FCG 6] The quote highlights the FCG's attempt to manage their emotional response by disengaging to avoid the exacerbating issue. Similarly, another FCG said, *"When she becomes irritable, I control it a lot. If I cannot bear it anymore, I go outside."* [FCG 9].

Healthcare Management Challenges

A specialized healthcare management system for FCGs of cancer patients would provide essential support, resources, and guidance to help them navigate the challenges of caregiving. FCGs made a few suggestions for healthcare management including addressing staff attitude, having a forum for communication, improvement of resources and lack of cleanliness, and inadequate facilities.

Communication Issues

The FCGs highlighted many communication issues that added to the difficulties in caregiving. They struggled to effectively convey their own needs and emotions to the healthcare professionals while trying to understand the disease and their patient's wishes and concerns. FCGs mentioned the staff attitude while dealing with them and they also highlighted that there should be a communication forum to facilitate them.

Staff Attitude

Clear and effective communication between health care professionals and FCGs of cancer patients is essential for providing high-quality care. Because caregivers play a vital role in patient care, healthcare professionals need to actively involve them in the patient's care plan, communicate clearly with them, and offer emotional support. The FCGs pointed out the inappropriate attitude of staff as a disturbing experience with caregiving. The FCG said that this issue is more prevalent in government hospitals. Similarly, another FCG reiterated:

“If we ask a nurse to change the drip, she would come on her own time. I will speak the truth...It is the choice of nurses. We must call them three to four times to change the drip. If the patient is in pain, still, they do what they want.” [FCG 15]

Furthermore, an FCG who is the patient's father, expressed that, “The people in government hospitals treated us in a very harsh manner...” [FCG 8].

On the other hand, FCGs appraised the attitude of staff in private sector hospitals. An FCG said: *“Regarding private hospitals, the behavior of the staff is very nice. But in government hospitals, we don't find this thing”* [FCG 16].

Need for Communication Forum

The FCGs expressed the need for a communication forum that could provide them with information for numerous purposes. An FCG who is the mother of the patient, expressed that: *“The people who have this issue and problem. If some NGOs help and listen to us in this regard, then it will be very good”* [FCG 10].

The FCGs suggested providing FCGs with a support network and connecting them with other caregivers who voluntarily offer guidance. They stressed the importance of a dedicated team to provide guidance, consultancy, and counseling to ease FCGs' worries.

Facility Management Issues

Facility management is essential for providing a supportive and compassionate environment for FCGs of cancer patients. This category included limited resources lack of cleanliness, and inadequate health care facilities.

Limited Resources and Lack of Cleanliness

Limited resources in the hospital can pose several challenges for FCGs of cancer patients. Caregivers had difficulty finding comfortable and private spaces to rest and recharge, unavailability of sitting places, and getting the support they needed from hospital staff. These challenges had a *significant* impact on the well-being of caregivers, leading to caregiving burden. An FCG expressed her feelings by stating;

“No one considers this ward as critical though there are critical patients here. There is a total space of 18 beds here but 30 or 40 patients are admitted here. So what to do? Most of the time 8 or 9 stretchers are put in the corridor and outside the rooms. In chemo rooms, there are only two stretchers. Patients receive chemotherapy while sitting.” [FCG 2]

One more FCG who is the wife of the patient showed her dismay: *“I went to the (Public Sector) hospital. The hospital was in bad condition. There was so much dirt, heaps of dirt that I couldn't tell you. There was blood on the bed. The smell of filth was everywhere... There is no check and balance. There is no justice here.”* [FCG 16]

Inadequate Healthcare Facility

The FCGs suggested the desire for improvement in the cancer care facilities. An FCG said that;

“If it was up to me, I would have made it a full cancer ward. And the chemotherapy room should be big enough so that everyone can lie down and get chemo, and the attendants who came along could also sit.” [FCG 2]

The FCGs suggested transforming the entire ward into a dedicated cancer ward.

Another FCG highlighted the unavailability of the sitting place: *“There is no bench to sit on. I just stand all day and at 11-midnight, if the Chemo room is empty, then go there and sleep. Otherwise, if someone finds a bench for me, then lie on it and sleep at night”* [FCG 2]. The FCG reflected her aspiration for better cancer care infrastructure that can enhance the comfort and well-being of both patients and themselves.

Discussion

Caregiving Responsibilities

The study explores the caregiving responsibilities of FCGs who support their cancer patients. FCGs have a cultural obligation to care for sick family members, including tasks like feeding, changing clothes, bathing, and toileting. Disruptions of these practices can impact the quality of life for both caregivers and patients. The complex role of FCGs requires knowledge, expertise, and dedication.¹⁰ In line with the findings of a study done by Ismael (2023), most of the participants shared that they were involved in caregiving tasks, such as feeding, changing clothes, bathing, and toileting.¹⁰

The study revealed that FCGs were sometimes required to perform tasks such as blood and transfusion arrangements, laboratory tests, medication administration, and diagnostic blood drawing. They were not prepared for these technical tasks but sometimes they were expected to perform them. According to a study conducted by Muhammad et al. (2023), Pakistan's healthcare system faces numerous infrastructural challenges, including a lack of hospitals, clinics, and diagnostic centers. Pakistan's healthcare system is suffering from a significant shortage of nurses, with only 5% holding a BSc. or higher education, which is a critical issue, given the importance of nurses and paramedical staff in the country's healthcare workforce.¹¹

Consistent with the previous research (LeSeure & Chongkham 2015), the study highlights the physical suffering faced by FCGs in providing care to cancer patients, including aches, pains, sleep disturbances, and hygiene concerns. Limited time and energy for self-care and access to hygienic facilities in public sector hospitals further complicate the situation. The findings call for increased resources and support mechanisms in hospitals to alleviate the strain on FCGs. A strong family bond with their patients could be another reason for FCGs to do most of the patients' tasks.¹² In a study conducted by Jeong et al. (2017), Korean cancer patients were seen as heavily dependent on their FCGs to meet their psychological and physical needs.¹³

Grief and Sorrow

As has been mentioned by Caruso et al., (2017) and Chan & Ng, (2022), the present study found that most participants experienced grief and sorrow due to the cancer diagnosis in their loved ones, leading to significant psychological distress and emotional trauma. Fear and anxiety about the potential loss made them cry and neglect themselves. This emotional toll on mental health is a significant challenge for FCGs.^{14,15}

Socio-Economic Burden

The study highlights the emotional and socioeconomic burdens faced by FCGs, with financial constraints exacerbated by the high costs of cancer treatment and advanced cancer patients' symptom burden. Their study also highlighted the financial constraints faced by FCGs, who were forced to sell their homes and take loans to cover the exorbitant costs of cancer treatment.¹⁶ The disruption in family functions caused by caregiving responsibilities adds to the socioeconomic burden. LeSeure and Chongkham (2015), found in their study that a significant number of caregivers faced a huge burden that affected both their psychological well-being and their financial circumstances.¹²

Pakistan urgently needs policies and support structures to address the financial hardships faced by Family and Community Groups (FCGs) due to inadequate financial protection in healthcare systems. According to Muhammad et al., (2023), Pakistan also faces challenges such as inadequate healthcare infrastructure, underfunding (0.4% of GDP), corruption, political instability, and resource distribution disparities, which result in unequal access to healthcare, particularly in rural and low-income areas.¹¹

Coping Mechanisms

The coping mechanisms used by FCGs reveal their resilience and resourcefulness. Faith in Allah, religious practices, and mind-altering or diverting activities emerged as prominent coping mechanisms used by FCGs. During difficult times, they relied on Allah for comfort and strength. Rajabi et al. (2018), also discovered that caregivers' religious coping styles play a significant role in their experiences of caring for end-stage cancer patients in their study. In the present research, FCGs are believed to have found solace and mental relief in religious practices like prayer and Quranic recitation. Additionally, mind-distracting activities like using a phone or social media platform helped them with stress management and mental health. These results provide insights into the adaptive techniques FCGs use to deal with the difficulties of providing care.¹⁷

Health Care Management Challenges

The participants of the current study offered few recommendations for improving healthcare-related challenges. They emphasized the critical need to have open lines of

communication between patients, caregivers, and healthcare professionals. Effective communication between patients and healthcare providers is critical for patient care and recovery. According to Kwame and Petrucka (2021), patient-centered communication is critical to achieving optimal health outcomes, reflecting long-held nursing values that care must be personalized and responsive to patient's health concerns, beliefs, and contextual variables.¹⁸

FCGs highlighted the concerns related to staff attitudes, particularly in public-sector hospitals adding to their problems. This can be attributed to several factors, including the carelessness of staff, overwhelming patient load, limited resources, and high levels of stress within the healthcare system. According to Yusuf, A. (2013), there is a shortage of medical physicists, radiation therapy technologists, and oncologists. The number of patients per oncologist has increased, hence, additional infrastructure is required to accommodate the growing number of patients, which is expected to increase further in the coming decades. There is little undergraduate oncology training, leading to a lack of knowledge among physicians about cancer screening, diagnosis, and referral.¹⁹

Additionally, FCGs suggested improving hospital resources like having more than one chemotherapy room and special cancer wards to accommodate the increasing number of cancer patients' needs. Muhammad et al. (2023), suggested that Pakistan urgently needs to increase its healthcare budget, prioritize the construction and upgrading of healthcare facilities, particularly in rural areas, and explore innovative financing models such as public-private partnerships (PPPs) to address these infrastructure and workforce challenges.¹¹

Conclusion

In conclusion, this study provides a comprehensive understanding of the challenges faced by FCGs of cancer patients in Pakistani tertiary care facilities in Islamabad. It highlights the physical, mental, and financial burdens these caregivers encounter and suggests practical solutions to alleviate their struggles. By implementing specialized areas for deceased patients, caregiver training programs, psychological support initiatives, and collaboration with NGOs, the well-being of both caregivers and patients can be greatly improved. Ultimately, by providing caregivers with the necessary tools, resources, and support, and fostering a compassionate healthcare environment, the quality of care for cancer patients can be significantly enhanced.

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