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# Assessing the caregiving burden of the family members of patients receiving palliative care in a tertiary care setting in Karachi, Pakistan: A mixed method approach

by Parveen Chagani, Salma Rattani, Khairunnisa Mansoor, Salima Shams, and Atif Waqar

## ABSTRACT

**Background:** A family caregiver is a person from a patient's family who is looking after the sick individual and helps to fulfill the needs related to activities of daily living and overall well-being of the patient. This may impact the life of the family caregiver. This study aimed to assess the caregiving burden of the family members of patients receiving palliative care.

**Methods:** A convergent parallel mixed methodology design was employed to achieve the study objectives. Quantitative data were collected from 323 family caregivers using the Zarit Burden Interview (ZBI) tool. Participants from the quantitative phase were also invited to participate in individual qualitative interviews, which continued until data saturation was achieved. A semi-structured interview guide, including probing questions, was used to explore the burden experienced by family caregivers ( $n = 15$ ).

**Results:** The overall mean burden score of 29.22 depicted a high burden in the study cohort. The domains of burden in relationship and emotional well-being were mainly affected by the caregiving task. Three themes were extracted from the interview transcript analysis: care providers' burden, factors that add to their burden, and factors that relieve the burden.

**Conclusion:** Family caregivers of terminally ill patients receiving palliative care are highly burdened and stressed, impacting their own physical and emotional wellbeing. The impact ultimately affects the sick individual who needs care. Interventions, focusing on the caregiver's physical and psychological concerns, that offer support in lessening the caregivers' burden and improving patient care-related outcomes are of utmost importance.

**Keywords:** care providers burden, oncology nursing, palliative care, low- and middle-income countries (LMICs)

## BACKGROUND

Family caregivers are family members who fulfil the needs of an ill person (Cruz-Oliver et al., 2017). Performing this role burdens the caregivers physically, psychologically, socially, and financially (Ehsan et al., 2018; Shah et al., 2017). However, these caregivers are often neglected or receive little attention from the healthcare provider, as the focus of care is on the person suffering from the disease (Mashayekhi, 2015). As the patient progresses through the stages of terminal illness and their health condition gradually deteriorates, there is a resulting increase in caregiving requirements. Subsequently, the change can alter normal family functioning with disruption in family members' routine, and their health and employment (O' Hara et al., 2010).

The severity of the issue means the assessment of a family caregiver's burden and determination of the domains affected by providing care to ill individuals is extremely vital. Moreover, studies conducted in Pakistan have focused primarily on caregiver burden of patients with mental illnesses or other chronic disease. Little research has focused on family caregivers caring for their family members suffering from any of the terminal illnesses and receiving palliative care. Therefore, the objective of this research project was to assess the burden of family caregivers caring for palliative care patients in Pakistan. Understanding the burden of family caregivers potentially can help in designing interventions and policies to minimize their burden.

## METHODS

### Research design

To assess the caregiving burden of the family members of patients receiving palliative care, a convergent parallel mixed-method study design was used. Quantitative and qualitative data were collected and analyzed independently, and then were compared, related, and followed by interpretation (Creswell, 2021; see Figure 1).

## AUTHOR NOTES



Parveen Chagani, School of Nursing and Midwifery, Aga Khan University, Karachi, Pakistan  
Email: [parvin.badrudin@gmail.com](mailto:parvin.badrudin@gmail.com)



Dr. Salma Rattani, School of Nursing and Midwifery, Aga Khan University, Karachi, Pakistan  
Email: [salma.rattani@aku.edu](mailto:salma.rattani@aku.edu)



Khairunnisa Mansoor, School of Nursing and Midwifery, Aga Khan University, Karachi, Pakistan  
Email: [khairunnisa.mansoor@aku.edu](mailto:khairunnisa.mansoor@aku.edu)



Salima Shams, School of Nursing and Midwifery, Aga Khan University, Karachi, Pakistan  
Email: [salima.shams@aku.edu](mailto:salima.shams@aku.edu)

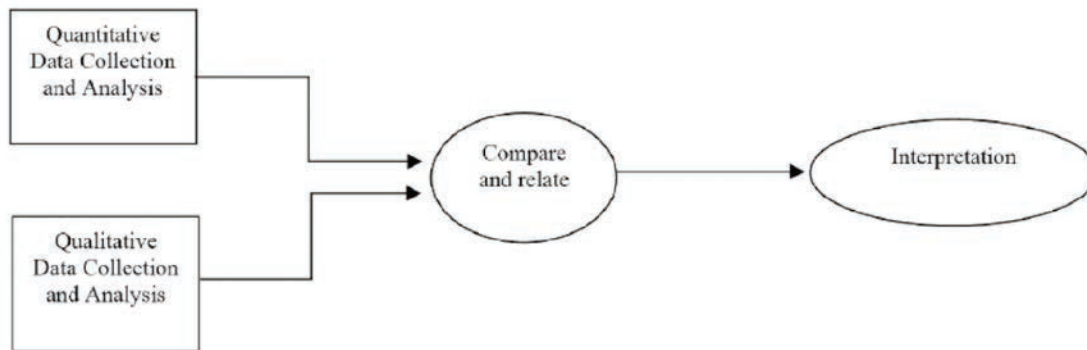


Dr. Atif Waqar, Department of Palliative Medicine, Aga Khan University, Karachi, Pakistan  
Email: [atif.waqar@aku.edu](mailto:atif.waqar@aku.edu)

Corresponding author: Khairunnisa Mansoor, School of Nursing and Midwifery, Aga Khan University, Karachi, Pakistan  
Email: [khairunnisa.mansoor@aku.edu](mailto:khairunnisa.mansoor@aku.edu)

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Figure 1



### Research setting and patient accrual process

For quantitative and qualitative data collection, the participants selected were individuals who were family caregivers aged more than 18 years, who were taking care of adult patients suffering through any of the terminal illnesses, and were registered at palliative care outpatient clinics and/or admitted to an inpatient palliative care unit at a tertiary care hospital in Karachi, Pakistan. The list of these patients was provided by the palliative care nurse navigator to the principal investigator. Participants involved in quantitative data collection were also invited to take part in the qualitative phase of the study. Those who agreed to participate were individually interviewed. Participants who spoke languages other than English or Urdu, or those who were not willing to consent, were excluded from the study.

A total of 323 caregivers were recruited via the universal sampling technique for quantitative data collection and 15 participants enrolled via purposive sampling techniques for qualitative data collection. Sample size for the quantitative study was calculated using the Open Epi sample size calculator. Based on the expert opinion from one of the palliative care consultants, the majority of the family caregivers experience persistent moderate to severe burden in our study setting. Therefore, we anticipated a 70% caregiver burden level with 95% confidence level and 5% bound on error of estimation, giving a sample of 323 family caregivers to be obtained. For the qualitative data collection, participants from the quantitative phase were invited to join the study, and those who agreed were individually interviewed. Fifteen family caregivers were interviewed to explore the burden of caregiving experience, while providing care to their patients. The interviews were conducted until the point of data saturation or no new ideas were shared.

Written informed consent was obtained from all participants. Confidentiality and anonymity were maintained. The study was approved by the institutional ethical review board of the study setting (ERC Reference # 2020-5070-14545).

### Data collection instruments

**Socio-demographic variables:** A questionnaire was developed by the investigator to collect data regarding the socio-demographic characteristics of the study participants. The

questionnaire was structured and included questions taken from previous studies investigating similar concepts to this study. The structured questionnaire asked about age, gender, marital status, literacy status, employment, and financial stability.

The qualitative sample participants came from the same group who completed the survey, and their sociodemographic data were gathered in the same structured questionnaire. Additionally, information about the participants' relationship with the patient, participants' gender, patients' gender, and patients' level of activity (dependent or independent) was collected and is presented in Table 1.

**Quantitative caregiver burden:** The Zarit Burden Interview (ZBI) is the most widely used instrument for measuring the perception of burden experienced by family caregivers. With permission from the original authors, an Urdu version of the ZBI tool was used to measure the caregivers' burden (Schreiner et al., 2006). The tool was reviewed by a committee of experts, including four medical doctors and two nurses working in a palliative care setting, for both relevance for this country and clarity. The content validity was calculated as described by Polit & Beck (2012). The experts were requested to rate all the questions on a four-point Likert scale (0 = not relevant and 4 = very relevant) for relevancy and clarity. Changes to the questions were made as suggested by the experts and the questionnaire was given back to the experts to rate all the questions again. The content validity index was calculated to be 0.87 based on the experts' final remarks for both relevance and clarity. The reliability coefficient (Cronbach's alpha) for the total scale was 0.85.

This ZBI instrument consists of 22 items scored on a Likert-type scale with five response options: never (0 points), rarely (1 point), sometimes (2 points), quite often (3 points), and almost always (4 points) with a maximum score of 88. Higher scores indicate a greater caregiver burden. Caregivers with a score of  $\geq 24$  are categorically defined as being in a clinically 'high burden group' (Burke et al., 2015). This study utilized the statistically driven scores of  $> 24$  for burden-level analysis. To complete the adapted ZBI, participants were interviewed by the trained research assistants for 25 to 30 minutes in a private space.

**Table 1***Description of Participants Interviewed (n = 15)*

Interview Number code	Relationship with patient (gender)	Patient's gender	Level of activity of sick patient
No. 1	Sister (female)	Male	Completely dependent
No. 2	Daughter (female)	Male	Completely dependent
No. 3	Wife (female)	Male	Completely dependent
No. 4	Sister (female)	Male	Partially dependent
No. 5	Son (male)	Male	Completely dependent
No. 6	Wife (female)	Male	Completely dependent
No. 7	Son (male)	Female	Completely dependent
No. 8	Son (male)	Male	Completely dependent
No. 9	Wife (female)	Male	Partially dependent
No. 10	Sister (female)	Female	Completely dependent
No. 11	Brother (male)	Male	Completely dependent
No. 12	Daughter (female)	Female	Completely dependent
No. 13	Wife (female)	Male	Partially dependent
No. 14	Daughter (female)	Male	Partially dependent
No. 15	Wife (female)	Male	Completely dependent

*Qualitative caregiver burden:* For qualitative data collection, a semi-structured interview guide with probes was developed to explore the phenomenon of family caregivers' burden, while providing care to their sick family members receiving palliative care. The in-depth qualitative data were gathered using the guide in face-to-face interviews held in a private space. The date and time of the interview was negotiated with the family caregiver ahead of time and generally lasted 45–60 minutes. All interviews were audio recorded and transcribed verbatim. The transcript was translated from Urdu to the English language by the investigator.

Two data collectors/research assistants, with a minimum of 1-years' experience of collecting data previously in health sciences research and fluent in English/Urdu, were recruited. Training sessions for data collectors were arranged by the principal investigator with briefing regarding the study objectives, study design, and sampling strategy. The data collectors were continuously guided and supervised by the principal investigator during the data collection process.

### Analysis

Statistical Package for the Social Sciences (SPSS) version 19 was used for statistical analysis. The demographic and clinical variables were analyzed through descriptive statistics. The continuous and normally distributed variables were analyzed through calculating mean and standard deviations (SDs). For categorical variables, frequencies and proportions were used. The ZBI scores were reported as means and SDs.

The transcripts of the qualitative data were independently analyzed by each of the three researchers (the first, second, and third authors) to ensure a comprehensive understanding and to reduce individual biases in interpretation. During this process, each researcher identified key patterns, concepts, and preliminary themes based on their individual analyses. After completing this step, the researchers convened as a group to compare their findings, discuss any differences in interpretation, and refine the identified themes. Through in-depth discussions and collaborative deliberation, they synthesized their insights and reached a consensus on the final set of themes, ensuring the results were robust and reflective of the data. Themes are presented in Figure 2.

The quantitative and qualitative data were initially entered, analyzed, and compiled individually. Results from both the approaches were then compared to identify similarities and discrepancies in the participant's perspectives. The goal was to gain a better understanding of the concept of caregiving burden experienced by informal family caregivers while caring for their terminally ill loved one.

## RESULTS

### Demographic characteristics

Among the participants ( $n = 323$ ) 55% were male and 45% were female and the mean age was 39.2 years. Most caregivers (63%) were either sons or daughters taking care of their parents. Seventy-four percent of the participants cared for their loved ones for a year or more. Many (47%) of the

**Figure 2***Themes and Subthemes*

Burden on Care Providers	Factors that added to burden	Strategies for relieving burden
<ul style="list-style-type: none"> <li>Physical and emotional burden</li> </ul>	<ul style="list-style-type: none"> <li>Sequel of disease</li> <li>Finance</li> <li>Participant's own health</li> <li>Fear of the future</li> <li>Inability to fulfill social responsibilities</li> <li>Burdened with added responsibilities</li> </ul>	<ul style="list-style-type: none"> <li>Turning to family for support</li> <li>Self-prescribed medications</li> <li>Seeking divine support</li> </ul>

family caregivers spent >10 hours/day providing care to their patients. A few of the family caregivers (18%) themselves were hypertensive, diabetic, or had other health issues. Table 2 provides a detailed description of the participants' demographic characteristics.

For the qualitative interviews, the 15 participants were among those who participated in quantitative data and, thus, shared the same demographic characteristics (see Table 1).

**Quantitative results: Caregiver burden**

The overall mean caregiver burden score was 29.22, with a SD of  $\pm 16.20$ . With respect to individual domains, the participants reported a great burden in their relationship with a mean score of 10.15 (SD +5.08). In addition to this, caregivers also experienced emotional tolls depicted in the mean score for emotional wellbeing of 8.23 (SD  $\pm 6.74$ ). The other domains, loss of control over one's life and social and family life, had low means of 5.50 (SD +3.52) and 4.8 (SD +3.82) respectively. A mean score of 1.0 (SD +1.43) was observed by family caregivers regarding finance (See Table 3).

High mean scores were reported for the items of feelings 'should do more for sick relative' ( $X = 2.62$ ), 'dependency on caregiver' ( $X = 2.34$ ), 'fear of future' ( $X = 2.17$ ), 'uncertainty' ( $X = 1.40$ ), 'expectation of care from sick relative' ( $X = 2.16$ ), 'stress of balancing self-time' ( $X = 1.38$ ), and 'other responsibilities with the care tasks' ( $X = 1.73$ ). Low scores were evident for the items 'wish of leaving the care of relatives' ( $X = 0.34$ ), feeling of anger' ( $X = 0.45$ ) and 'embarrassment over relative's behaviour' ( $X = 0.40$ ). When asked how frequently family caregivers attended social gatherings or participated in such activities (Z12), 45 % of the participants said they rarely attended due to care responsibilities. When asked about overall burden (Z22), 41% of the family caregivers responded that the burden they felt was "moderate to extremely high." Individual item scores from the ZBI tool are presented in Table 4.

**Qualitative results: Themes from interviews**

Family caregivers who were interviewed in-depth about their caregiving burden offered additional insights with their

**Table 2***Demographic Characteristics*

Characteristics	n (%)
Age	
Mean	39.20
Gender	
Male	178 (55)
Female	145 (45)
Marital Status	
Married	259 (80)
Unmarried	64 (20)
Employment Status	
Employed	191 (59)
Unemployed	132 (41)
Family Members	
1-4	154 (48)
5-10	149 (46)
> 10	20 (6)
Relationship with Patient	
Spouse	55 (17)
Parents	10 (03)
Children	202 (63)
Siblings	33 (10)
Other Relatives	23 (07)
Caregiver's Children Taken Care of By	
No Children	99 (31)
Self	145 (45)
Spouse	62 (19)
Others	17 (05)
Previous Experience of Caregiving	
Yes	118 (37)
No	205 (63)
Professional Training Received	
Yes	32 (10)
No	291 (90)
Nature of Training Received	
Physical Skills	13 (04)
Stress Relieving Techniques	03 (01)
Doing Task Without Training	292 (90)
Others	15 (05)
Comorbid for Caregivers	
Yes	59 (18)
No	264 (82)
Duration of Care	
$\leq 6$ Months	56 (17)
> 6 Months-1 Year	29 (09)
1 Year and Above	238 (74)
Caring Hours/Day	
1-5 Hours	61 (19)
5-10 Hours	109 (34)
> 10 hours	153 (47)

**Table 3***Burden Scores in Five Domains of the Zarit Burden Interview (ZBI)*

Domains	N	Mean	SD
Burden in Relationship	323	10.15	5.08
Emotional Wellbeing	323	8.23	6.74
Loss of Control Over One's Life	323	5.50	3.52
Social and Family Life	323	4.80	3.85
Finances	323	1.09	1.43
Overall, Burden	323	29.22	16.20

descriptions (See Table 1). Three overall themes and relevant sub-themes for each were extracted from their interview transcripts (Figure 2).

### Theme 1: Burden on care providers

Participants described how their family members' sickness had affected them personally. The burdens were felt physically, mentally, emotionally, and financially.

#### *Physical and emotional burden*

Physically, caregivers found their sleep and rest patterns were affected, as they needed to take care of the patients' needs at various times of the day and night. The care included changing the patient's position in bed and checking IV (intravenous) sites when the patients were on continuous fluids. Family caregivers described the burden they felt as follows:

*"If the father's condition is stable then at night, 4, 5 hours are easy to sleep. But if the condition is not stable then 2 to 3 hours (of sleep) a day" (#08).*

*"Everything whatever, it's a matter of lifting him up or laying him down or feeding him. I need to do everything" (#06).*

The participants felt, when a family member is sick, it is the family's social responsibility to care for the sick member. A female participant said, *"he is my elder brother. I must be with him" (#02)*. Another said, *"I wanted to work (be employed to earn) but I could not work to fulfill the role as the care provider. I needed to prioritize my life" (#01)*.

All the participants shared that they were stressed mentally and were exhausted emotionally. For example, two caregivers shared, *"...there is a tension and stress" (#02)*, and *"I get stressed out when I feel his condition worsens. But, when I see his improvement, I feel relaxed" (#04)*. Describing the impact on self, a participant said, *"I just have a heavy burden on my mind, have severe headache due to tension, but what can I do, I just have to endure this" (#06)*. Emotional burden was also evident when the care providers witnessed their family members in pain and agony due to disease process.

Explaining the severity of distress, a participant said, *"When I am under stress then my brain stops working, like restlessness, then thoughts came into my mind that my brain will*

*burst if I overthink" (#09)*. Caregivers experienced extreme sadness when they were watching their loved ones deteriorating, *"Sometimes at night when I lie down, and my eyes are open, and my tears are flowing, and I cannot speak, I only cry" (#09)*. Based on the participants' descriptions physical and emotional burden could not be separated all the time but overlapped.

Being sick, a few of the patients were very irritable, aggressive, and sometimes abusive toward their family caregivers (#06, #09). Both these participants were wives of the patient. Both of these participants had young families (participant #06 had four children and participant #09 had one child 4 years of age). Such conditions resulted in caregivers feeling drained physically, mentally, and emotionally.

### Theme 2: Factors that add to the burden

Family caregivers reported multiple factors that they thought contributed to their burden level. These factors are described in six subthemes: sequels of disease, finance, caregivers' own health, fear of future, inability in fulfilling social responsibilities, and burdened with added responsibilities. Sub-themes are supported with verbatim quotes from caregivers.

#### *Sequel of disease*

The duration of the patients' illnesses varied between 2–5 years. For compensatory care, this ranged from 2 months to 1 year with an average of 6 months when the patients were completely dependent on their caregivers. For example, one participant (#07) reported that the initial diagnosis was ovarian cancer and with treatment the patient (participant's mother) was managing her life. This process continued for 2 years. However, as the disease progressed, cancer metastasized to other organs including the brain. The mother's condition deteriorated and within 15 days the patient was completely dependent on the family members. Another participant said, *"Conditions deteriorated extremely fast, within 3 months" (#06)*. Patients' sequela of the disease impacted on the caregivers, leading them to feel they were involved in an endless process.

#### *Finance*

The financial burden was due to the heavy cost of treatment, repeated hospitalizations, and lab investigations. A

**Table 4***Individual ZBI item score*

ZBI item #	Item description	N	Never	Rarely	Sometimes	Quite frequently	Nearly always	Item mean
1.	Do you feel that your relative asks for more help than they need?	323	162	29	57	26	49	1.29
2.	Do you feel that because of the time you spend with your relative, you don't have enough time for yourself?	323	142	35	61	52	33	1.38
3.	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	323	103	22	93	68	37	1.73
4.	Do you feel embarrassed about your relative's behaviour?	323	249	31	32	11	0	0.40
5.	Do you feel angry when you are around your relative?	323	236	36	44	7	0	0.45
6.	Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	323	164	36	66	31	26	1.13
7.	Are you afraid what the future holds for your relative?	323	95	15	57	53	103	2.17
8.	Do you feel your relative is dependent upon you?	323	90	17	41	43	132	2.34
9.	Do you feel strained when you are around your relative?	323	162	41	66	30	24	1.11
10.	Do you feel your health has suffered because of your involvement with your relative?	323	166	38	67	39	13	1.30
11.	Do you feel that you don't have as much privacy as you would like, because of your relative?	323	145	39	76	40	23	1.25
12.	Do you feel that your social life has suffered because you are caring for your relative?	323	140	39	72	39	33	1.34
13.	Do you feel uncomfortable about having friends over, because of your relative?	323	245	18	38	17	5	0.51
14.	Do you feel that your relative seems to expect you to take care of them, as if you were the only one they could depend on?	323	107	21	29	46	120	2.16
15.	Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?	323	183	33	38	35	34	1.08
16.	Do you feel that you will be unable to take care of your relative much longer?	323	218	36	42	15	12	0.66
17.	Do you feel you have lost control of your life since your relative's illness?	323	183	31	43	32	34	1.08
18.	Do you wish you could just leave the care of your relative to someone else?	323	262	20	33	7	1	0.34
19.	Do you feel uncertain about what to do about your relative?	33	128	34	76	51	34	1.4
20.	Do you feel you should be doing more for your relative?	323	67	13	42	55	146	2.62
21.	Do you feel you could do a better job in caring for your relative?	323	97	24	60	47	95	2.06
22.	Overall, how burdened do you feel in caring for your relative?	323	125	66	58	40	34	1.36

caregiver said, “The cost is heavy, and the family members find it difficult to bear the cost” (#05). The cost also increased due to over-medicalization when the need was to palliate, but the healthcare team focused on treatment. A participant said:

*“One of my colleagues suggested me not to continue with oncology (treatment) and see doctor for palliative care, since further treatment was not needed for my father but to keep him comfortable.... Oncology people (team/doctors) only talk about cancer and gastro people (team/doctors) only talk about stomach. If I knew earlier, I would have changed the service earlier. Nobody guided me earlier...” (#05).*

For a few of the participants, the financial burden, in addition to the cost of treatment, was also related to unaffordability for the living expenses of the family. One of the participants described that as her husband was sick, he could not provide money for the family. Hence the family survived on support from the members of the extended families, and the social support in the community (#06). For others, their extended families were not able to support them due to their own financial constraints and caregivers needed to make other arrangements. One participant said that the support obtained through social support was not sufficient. She was required to borrow money with a promise that she would pay it back; but so far, she was not able to keep her promise and was feeling bad about it. She said, “People are asking that I had promised to return their money, so I said that I’ll pay it back to you, but I don’t know from where to get the money and pay” (#09). Participants described how the cost of repeated hospitalizations had added to their financial burden. A son described the disease journey of his father saying, “The thing is, his [father’s] condition gets better, and he comes home, but again at home we put him on oxygen and arrange machines, look after everything; so, yes, this all gets tiring” (#08).

#### *Caregivers’ own health*

Constant caregiving task was a challenge for the participants that primarily affected their own health. As one of the caregivers verbalized, “I have to come to hospital twice every day, all morning, and evening (night stay). I get very tired it impacts on my health” (#02). Selfcare time was very minimal for the caregivers, and all their concentration was on the sick individual. One female spouse said, “I am with him [husband] for 24 hours. I just take out some time at night to sleep if he is well. I sleep for 2 to 3 hours” (#06).

#### *Fear for the future*

One female participant, who was the wife of the patient and a mother of four children, in describing her fear about the future said, “Sometimes I think that, what will happen to me if something happens to him [die]?” (#06). Participants described their fear and anxieties related to the outcomes of the disease, and the future of their families. Simultaneously, there were expressions of emotional drain, crying out that these problems should end, and the need for relief. One participant said, “...that he may take any step-in anger or tension that will harm himself because he thinks, he can neither do anything nor have any life” (#04).

The other fear caregivers expressed was related to emergencies that happened as conditions deteriorated. One female participant, who was the patient’s wife, indicated her husband with oral cancer could not spit out and choked due to secretions in his mouth, became suddenly breathless, and was rushed to the hospital. Participants described their uncertainties and emotions including feeling guilt, anger, and helplessness.

#### *Inability to fulfill social responsibilities*

The participants described that, in being busy with providing care, they were not able to attend to their other social responsibilities. As a participant said, “there were four to five weddings, but I have been with him [husband] all the time in the last three months, taking his care” (#06). The majority of the caregivers expressed that their social activities were reduced greatly compared to the time they previously spent. One of the caregivers showed his discomfort in going out frequently to avoid any uncertain situation and said, “...if we talk about socializing, it’s become lesser than before, as we know, if there will be any emergency, we have to rush. So better as a precaution we avoid socializing more” (#08).

#### *Burdened with added responsibilities*

Participants were fearful about the added responsibilities that occurred due to sickness of the family member. One of the participants shared that, “He [father] manages everything like filling a water tank, taking care of generator oil, etc., so suddenly all these things are now on us. This becomes hectic...” (#08). This means, all the work that the participant’s father used to do was now added to the responsibilities of the son. He shared, “Things before this [illness], were totally different. I was used to the gym in the morning. I was used to go for a birthday party or dinner, watched TV.” (#08). With added responsibilities, social life and leisure activities were not possible.

### **Theme 3: Strategies for relieving burden**

#### *Turning to family for support*

Having a good family support system shared the caregiver burden (01). Describing strategies for relieving their burden, a participant said, “Having a good family support system shared the burden” (#01). Among those who received support through paid services said, “We have an attendant...” (#08), “It (providing care to her father (patient)) would have been very difficult for me if we did not have support from our helpers and maids” (#02). Similarly, families were relieved when the cost of treatment was covered by the companies. One participant said, “He (patient) is an employee in the hospital (patient/family did not need to pay the cost of treatment)” (#01).

Based on the support system available, responsibilities were allocated. For example, one of the participants shared that during the hospitalization of her husband, she requested her sister to stay at her home and take care of children and other household responsibilities. One of the participants reported that, “...my younger brother is a mental health counselor, I get motivation [counselling] from him, divert my mind, sometimes for a very short time got out of the house” (#08).

### Self-prescribed medication

Caring tasks were time-consuming, prolonged, and required the full attention from individuals. Therefore, caregivers often ignored their own physical health and wellness. Some tried to deal with their health through selecting medications on their own. This was evident from the comment of one of the participants who said, “Sometimes I use to take Panadol [to manage her aches and pain], what else I can do?” (#06).

### Seeking divine support

All the participants described that religion was the main support system that helped them recover from trauma and they were able to continue their role as caregivers. A female family caregiver said, “I only prayed to Allah [God] and nothing else” (#13), while another said, “I just pray to Allah that He may fix or remove our troubles” (#15). Similarly, other participants said, “I just pray to Allah [God] that my mother doesn’t get pain... I don’t have words to describe” (#07).

Participants verbalized that it was not easy for them to see the day to day deterioration in the health of their loved ones, despite lots of efforts in caregiving; however, the strength they received from their regular religious practices strengthened them to deal with these extreme uncertainties of life. A female caring for her sick sister verbalized that, “When I feel depressed about my sister’s condition getting worse, I cannot do anything, I hand it over to Allah, then it feels that all the tension from head to toe is gone” (#10). Few caregivers also express their misery that they do not have any support system they focus on divine help. A participant said: “There is no one except Allah to care for us” (#06).

### Integrating findings

Integration of the findings occurred through data management and analysis of quantitative data ( $n = 323$ ) and qualitative data ( $n = 15$ ). This process identified similarities and differences in what was reported and is presented in Table 5. The high overall burden score mean of 29.22 ( $\pm 16.20$ , SD) was reflected in the individual interviews regarding the experiences of the participants’ burden. As one of the participants said, “...my tears are flowing, and I cannot speak, I only cry” (#09).

The burden scores in all five domains of the ZBI (Table 3), were reflected in the interviews. The high mean burden scores were in relationship ( $X = 10.15$ ) followed by emotional wellbeing ( $X = 8.23$ ), loss of control over one’s life ( $X = 5.50$ ), social and family life ( $X = 4.80$ ), and finances ( $X = 1.09$ ). All of these aspects were described in detail in the interviews. Corroborating quantitative data (ZBI) and qualitative data (themes and sub-themes), ‘burden in relationship’ in ZBI corresponded to theme one ‘burden on care providers’ in the qualitative data. The ZBI domain of ‘emotional wellbeing’ corroborated to ‘physical and emotional burden’, a sub-theme under the theme one. Domain ‘loss of control over one’s life’ corresponded to a sub-theme ‘caregivers’ own health’. This sub-theme is under the theme of two titled ‘factors that add to the burden’. Domain ‘social and family life’ corresponded to ‘inability in fulfilling social responsibilities’, which is a sub-theme under theme two. The ZBI domain ‘finances’ linked to a sub-theme ‘finance’. This sub-theme is also under theme two, titled ‘factors that add to the burden’. Thus, all the domains of the ZBI corresponded to the themes and sub-themes in the qualitative data.

**Table 5**

Quantitative Data and Qualitative Data

Quantitative data	Qualitative data
Domains of the Zarit Burden Interview (ZBI)	Themes and sub-themes
Burden in Relationship	<b>Themes 1:</b> Burden on Care Providers
Emotional Wellbeing	Physical and Emotional Burden
Finances	<b>Themes 2:</b> Factors that Add to the Burden
Loss of Control Over One’s Life	Sequel of Disease
Social and Family Life	Finance
Overall, Burden	Caregivers’ Own Health
	Fear of Future
	Inability in Fulfilling Social Responsibilities
	Burdened with Added Responsibilities
	<b>Themes 3:</b> Strategies for Relieving Burden
	Turning to Family for Support
	Self-Prescribed Medication
	Seeking Divine Support

However, analysis of qualitative data identified themes and sub-themes that were not in any of the five domains of ZBI (Table 3). These were 'sequel of disease', fear of future', and 'burdened with added responsibilities'. All these three are sub-themes under theme two, 'factors that add to the burden'. Similarly, theme three, 'strategies for relieving burden', and its sub-themes; turning to family for support', 'self-prescribed medication', and 'seeking divine support' were not in any of the five domains of the ZBI.

## DISCUSSION

Liu, Heffernan, and Tan (2020) define caregiver burden as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member. Traditionally in Pakistan, the family bonding is very tight where family members take care of each other. In any unexpected circumstances like illness, the expectations rise and taking care of family members is considered as their highest responsibility. Failure to fulfill these obligations creates a sense of guilt and shame in individuals. Therefore, most of the family caregivers in this study were continuing their act of caregiving. This is congruent with the findings from Martín-Martín et al., (2022) where the caregivers were taking care of the elders with disabilities. That study was conducted in Spain and stated that when the dying process moved into the home environment, the responsibility for care falls largely on the family, thereby challenging and testing the stability of the family. As Spain has moved from middle-income to high-income status (Chislett, n.d.), is different from Pakistan, which is a lower-middle income country (Iqbal, 2023). However, culturally, regarding the burden of caregivers in Spain, as asserted by Martín-Martín et al., (2022), it is similar to the culture in Pakistan where family members are the caregivers (Noreen et al., 2021).

The caregiver participants described themselves as being burdened physically and emotionally, impacting their well-being. These findings correspond to the findings of Ahmad Zubaidi et al. (2020), Martín-Martín et al. (2022), Kilic & Oz (2019), and Khan (2020). Additionally, Semere et al. (2021) reported that compared to caregivers for patients with other medical conditions, caregivers for patients with cancer reported a higher number of total hours spent on providing care, and more hours spent assisting them with activities of daily living. Among caregivers of patients with cancer, those caring for patients with advanced cancer experienced worse physical and mental health issues (Govina et al., 2015).

The caregivers in this research reported experiencing health issues. Likewise, Lewandowska et al. (2021) assert the caregivers, in their research, reported illnesses of hypertension, insomnia, arrhythmia, asthma, and rheumatic disease. In the present research, the participants also asserted that their caregiving role influenced their health, social life, and employment. These findings are also in line with those of Saimaldaher & Wazqar (2020) who reported that caring for their family members with cancer can affect caregivers' social roles, work performance, and communication patterns.

Looking at employment from the perspective of presenteeism, which refers to reduced productivity while at work, Xiang et al. (2022) asserts from population-based research that cancer caregivers are 1.54 times more likely than non-caregivers to experience presenteeism attributed to caregivers' fatigue, worry, and time spent during the workday discussing patient care with family and healthcare providers and attending to patient medical needs. This presenteeism may result in receiving warnings from their employers about their performance and missing the opportunity for career promotion (Xiang et al., 2022).

Financial burden was illustrated in the caregivers' subjective responses; however, it was not rated highly in the ZBI item (Z15), which asked about the expenses utilized in the care of sick relatives. Financial burden or distress is described in the literature as financial toxicity (Hussaini et al., 2022). It also described as the harmful effect of high cost of treatment on a person's quality of life (Sadigh et al., 2022) and can vary based on the healthcare system and private insurance availability.

### Limitations

All the caregivers were caring for patients with oncological diseases and were enrolled from a single private health care organization. Hence, the results have limited generalizability and are relevant only to similar clinical settings and populations.

### Recommendations

Based on the findings from this research on family caregivers, it is recommended that approaches like support groups or counselling with caregivers in similar situations be made available. This could help in sharing their feelings and potentially can minimize mental exhaustion. Also, psychological screening for family caregivers as a part of the treatment can identify those at risk and possibly help decrease emotional distress. Additionally, it is suggested that hospital inpatient/outpatient units arrange family counselling sessions to educate families on the significance of sharing caregiving responsibilities. It could help to educate them especially on distributing the workload for the daily living activities and encourage them to seek spiritual care for their own internal peace and comfort. Furthermore, formal training for the family caregivers in the psychomotor skills they need to take care of patients and education sessions about coping strategies to deal with the situation are recommended to facilitate family caregiving.

## CONCLUSION

The current study indicated a high caregiving burden among family caregivers of terminally ill patients on palliative care in Pakistan. The results offer significant insight into the need to initiate certain strategies for family caregivers, which could help alleviate their physical and psychological sufferings.

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