



Original Article



Lived Experiences of Direct Care Givers of Stroke Patients in Khyber Pakhtunkhwa, Pakistan: A Qualitative Study

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ABSTRACT

Each year, approximately 15 million new people are diagnosed with strokes across the globe. Stroke is a profoundly debilitating condition that extends its impact beyond the individual affected, placing a significant burden on the caregivers. **Objectives:** To explore the lived experiences of direct givers of stroke patients in Khyber Pakhtunkhwa, Pakistan. **Methods:** In a qualitative study, purposive sampling technique was used in which the caregivers fulfilling the inclusion criteria of the current study were recruited. After ensuring the ethical considerations, total eight in-depth interviews were conducted, and the data saturation was achieved. Interviews were audiotape recorded, transcribed and then thematic analysis approach was followed. **Results:** The data of eight participants were included in the analysis. Five themes emerged from the data: early disappointment, economic burden, impact on personal life, impact on social life, and coping mechanism. **Conclusions:** Caregivers often face a multitude of challenges when taking on unexpected responsibilities of care of the loved ones. These difficulties encompass physical demands, psychological strain, social isolation, and financial burdens. Healthcare professionals should consistently educate caregivers on patient care and regularly evaluate their need for counseling and psychological support. Providing caregivers with essential knowledge and addressing their emotional and mental health needs are crucial for ensuring effective and compassionate care for patients.

INTRODUCTION

Stroke is a devastating disease that leads to a considerable proportion of deaths worldwide. It is the second major cause of mortality after ischemic heart disease (IHD) globally [1]. Each year, approximately 15 million new people are diagnosed with stroke across the globe [2]. Keeping the risk factors and growing prevalence in view, it is expected that the most common disease after IHD would be stroke worldwide [3]. Pakistan, being a developing country, also has a high burden of stroke. According to a study conducted in 2015, it was estimated that per one lac population, there are about 250 Pakistani patients having stroke [4]. A survey conducted in Khyber Pakhtunkhwa (KP)

in 2017 randomly selected 22500 participants and identified the prevalence of stroke as 1.2%, translated to 1200 per one lac population [5]. The incidence of stroke in the urban population as compared to rural areas is much higher in Pakistan due to a sedentary lifestyle and other habits [6]. Stroke is such a debilitating disease that it does not affect the sufferer only, but it also places a significant burden on the family and especially the caregiver. A stroke patient is entirely dependent on others because he cannot move, clean or feed himself, and he is at a very high risk for falls and injuries. Since the onset of this disease is acute and everything happens suddenly, none of the family



members is ready and aware to bear the load of new responsibilities. Direct caregiver plays a key role in rehabilitating such patients and their adaptation to the disability [7]. The caregiver in the family is usually a spouse, son or daughter. Caregiving is a formal process, but when the family caregivers shoulder this responsibility, they are unaware of how to begin because they are not educated or trained for it. This sometimes stresses out the caregiver and makes them burn out [8]. In addition, the caregivers often provide care without any planning or defined goals, probably due to unawareness; this drains all their attention towards their patient's care, and thus, they ignore their own health [9]. The socio-economic, physical and psychological consequences of stroke extend beyond the patient to the whole family and direct caregivers, especially [10]. It is essential to explore the experiences of direct caregivers of stroke patients. There are many quantitative studies conducted on various aspects of stroke in Pakistan that have identified the prevalence, determinants, associated factors, post-stroke depression, etc. However, the researcher did not find any qualitative study that talked about the caregivers' lived experiences in KP, Pakistan. This study aimed to explore the lived experiences of caregivers directly involved in the care of stroke patients. Although stroke is becoming common, especially in developing countries like Pakistan, little attention has been paid to caregivers' challenges, either emotionally, physically or financially. Quantitative studies have produced information about stroke prevalence, but there is a lack of research on stroke caregiving from the perspective of those directly involved. This study is based on caregivers' views to explore how caregiving affects the health, social life, and economic well-being of the caregiver in depth. Moreover, it stresses the necessity for targeted interventions and support systems to benefit the caregivers' quality of life and, therefore, their ability to provide good care to stroke patients.

The purpose of this study was to explore the lived experiences of direct givers of stroke patients.

METHODS

A qualitative study was conducted from October 2022–March 2023 to explore the lived experiences of direct care givers of stroke patients. An ethical consent (No: 255/BKMC) was provided by the Ethical Committee of Bacha Khan Medical College prior to the study. Nonprobability, purposive sampling technique was used to recruit study sample because this is a method widely used in qualitative research to get deep insights from people with different experiences. Total of eight in-depth interviews were conducted because data saturation achieved at the sixth one and two more were held to verify that there were no more emerging sentiments. Data saturation is one of the basic principles in qualitative research and therefore deciding to include only eight

interviews was based on the concept of data saturation. In terms of participants, this was sufficient to give meaningful insights while staying within the bounds of practical limits of time and resources for in-depth qualitative analysis. Participants in the current study were recruited as having the characteristics of being aged above 18 years, provided care to stroke patient for more than one month, and could speak Pashto, Urdu, or English. Participants were approached in a tertiary care hospital as they brought their patients for follow-up visits. Study purpose was explained and written informed consent was signed by all the participants. They were ensured for data confidentiality and anonymity throughout. Questions were asked through interview guide and probing questions developed by the researcher. A review of the existing literature was done to develop the interview guide; the consultation with the healthcare professionals was also part of such a process. With the problem in mind of exploring the emotional, social and economic challenges for caregivers, the guide was developed. It consisted of open-ended questions that allowed participants to talk about themselves in their own words with regards to their experiences, feelings and coping mechanisms. The interviews were in Pashto and Urdu, the two primary languages spoken in Khyber Pakhtunkhwa, on an individual basis in Urdu for all, other major ethnic groups where Pashto was spoken also being permitted. All the interviews were transcribed and then translated into English by the researcher, who is well versed in the Pashto and Urdu languages. The translation was done very carefully so that meaning of participants' response was not affected. The interview guide included important areas of study such as psychological difficulties, economic difficulties, social life problems, mental and physical wellness and stress management techniques. Firstly, the audio recordings were listened to several times and then translated and transcribed. Each transcript was read and reread while listening to audio recordings. Following the thematic analysis, and open codes were identified by underlying the meaning segments within the transcripts. Axial coding was done by segregating open codes into relevant axis. Themes were developed which had common meaning for all the participants and the pertinent codes were then brought under the relevant themes. Certain irrelevant codes were omitted since those were misfit under any theme. Themes were supported by the participants' quotes.

RESULTS

Table (1) shows the characteristics of direct caregivers of stroke patients who participated in the current study.

Table 1: Characteristics Of Direct Caregivers of Stroke Survivors

Participant	1	2	3	4	5	6	7	8
Age in Years	30	24	31	28	32	34	30	26
Gender	Male	Male	Male	Male	Male	Male	Male	Male
Marital Status	Married	Single	Married	Married	Married	Married	Married	Single
Level of Education	Matric	Middle	Middle	Matric	Inter	Master	Matric	Middle
Profession	Shop-keeper	Labor	Driver	Electrician	Shop-keeper	Teacher	Labor	Shop-keeper
Working Status	Part time	Unemp-loyed	Unemp-loyed	Unemp-loyed	Part time	Full time	Part time	Part time
Ethnicity	Pashtun	Pashtun	Pashtun	Pashtun	Pashtun	Pashtun	Pashtun	Pashtun
Relationship with Patient	Son	Son	Son	Son	Son	Son	Son	Son
Duration of Care in Months	04	06	08	06	06	08	10	12
Diagnosis of Stroke Survivor	Don't know	Ischemic	Ischemic	Ischemic	Ischemic	Ischemic	Don't Know	Ischemic

Thematic analysis was done and total five themes were identified which are: Early-stage disappointment, Economic burden, Impact on personal life, Impact on social life, and Coping mechanism. The theme **"Early-Stage Disappointment"** captured the participants' experiences regarding disappointment due to people's bizarre labeling, prolong nature of disease, and no initial improvement despite provision of care. Some of participants stated that stroke is a dangerous name, and this bizarre labeling would discourage us as one of the participants said: People in the surroundings used to say that Mr. so and so has got stroke. They should pray for his (patient's) peaceful death as he would not come to normal state of health again. The family should not waste their money on his treatment (Participant 6). Similarly, the participants also shared that they were disappointed due to the chronic nature of the disease and said: We have seen stroking patients and heard that stroking patients either die soon or live in a diseased condition for years and never return to normal condition. We were really frightened when we found out that our father had got stroke (Participant 8). Despite the consistent efforts, caregivers did not see any improvement in the condition of their patients as the patients remained dependent as they were on the first day. One participant said: Initially we were hopeless despite the efforts because he was not able to talk, he was not able to take food, he was unable to change his position in the bed, and he was not able to attend the washroom. For long time we cared for him, and we did not see any improvement in his condition which made us unhappy (Participant 1). The second theme of **Economic Burden** talks about three main categories which are taken out from the codes namely reduced income, augmented expenditures, and difficulty managing finances. Leaving the job or making it part time to take care of loved ones decreased their income as one said: I am basically a shopkeeper. I have a small general store, and I used to sit in the store from morning till evening before the disease. When my father got this disease I divided my time

and most of the day time I had to be in the home with my father. Due to this lack of duty, my earnings have been affected badly. (Participant 7). Another participant shared: This disease has affected my financial condition a lot. Before this disease, I used to drive a loading vehicle but as my father got this disease, I had to leave that duty and take care of my father (participant 3). In this category, the participants share their views about the expenses: About the expenses, you know the current situation. Along with my household expenses I must take my father to the big hospital, pay for the doctor, labs and medicines. We live in far-flung areas so we spent a lot on transportation to the hospital because such paralyzed patients cannot be moved in public transport (participant 5). The participants shared grievous concern about financial and resources management. One respondent shared: In the initial days of the disease, I had some of my savings which I have spent on my father. Now there is nothing left and as I told you that income from my shop has been decreased because I cannot give enough time to it. I thought that my wife had some gold for our wedding in her possession, so I will sell it to manage the expenses in intense need (participant 1). All the participants shared that they have taken loans from their relatives or friends to manage the financial crisis. The theme of **"Impact on Social Life"** captured the participants' experiences regarding their social life, focused on two main categories i.e. abandoned social gatherings and restricted to home. The participants shared they had friends' circles with whom they had to spend some time in the day to refresh themselves. After the disease of their patient, they had quit all those activities to spend more time at home as one participant said: This disease of my father has affected my social life a lot. I cannot go for outings with my friends because I must be with my father all the time. We often went to riverside previously but now I cannot. I am unable to attend the friends' functions due to this disease. Mr. ABC is my close friend here in the village; I could not attend his marriage ceremony unfortunately (Participant 3). In taking

care of their loved ones, the participants said that they were compelled to be homebound and that they are unable to attend marriages and other happy events of relatives because such events need spare time. Before the disease, I used to carry my family to the relatives' homes for happy events but now I cannot afford this. In addition, this is the demand of our culture that if someone visits you at the time of different events, you must visit him at the same events as well, due to this disease many of my relatives are not happy with me because I have skipped many of their events (Participant 1). Similarly, the participants also shared a serious concern about their inability to appear at the funerals of people as one person shared: One of my best teachers Mr. ABC died, I heartedly wished to attend his funeral and set for the prayers at home, but I could not manage to spare time and go there since my father needed me at home. There are many such examples of happy and sorrowful events which I wished to attend but due to my father's disease I could not attend any (Participant 3). The fourth theme **"Impact on Personal Life"** emerged by two major categories which included effects on personal health and effects on immediate family. The participants shared: One thing I must say is that due to this disease, I have forgotten myself and my total focus is on my father. I cannot visit a doctor for my own illness which sometimes worsens; thus, my personal health is affected (Participant 4). Similarly, another participant said: Before the disease I would play games regularly, I would go friends for swimming in the river; now after the disease I cannot spare time for such activities. Even if I go out for some tasks my mind is towards my father because of his dependence, so I avoid going out (Participant 5). The caregivers also shared that they have much disturbed sleep. One of the respondents said: I give most of my time to the care of my father. My sleep has been disturbed. I never sleep during the daytime and at night when I fall asleep, I must get up after some time and sit with my father (Participant 1). About personal life, the participants said that being a husband and a father, there are certain responsibilities which one should carry out and due to problems of finances and time, such activities cannot be accomplished which affects the relationship of immediate family even if they don't verbalize. One of the participants said: I am a married man, and I have kids, I cannot give proper time to them. I used to take my wife shopping and kids for short trips once a month or so. After this disease, I cannot afford all these things; however, they still demand such activities because they were used in it (Participant 6). According to the last theme of **"Coping Mechanism"**, caregivers adopted various strategies to deal with liability of care to the loved ones having this devastating disease i.e. stroke. These include awareness, support system, belief system, and time management. They shared that they were instructed about

every aspect of care in each visit which made them confident in care provision as one shared: By visiting the hospital, the doctor and nurses would teach us to take care of him and give him massage, exercise and medicine regularly. They would advise us that he will get better with the passage of time. Such statements from a medical associated person would give us courage and hope (Participant 4). The caregivers shared that they live in joint family system. Living together provides moral support and strength to cope up with shouldered responsibilities. It is difficult to handle everything single handedly, so many of such tasks which someone else can do for me, my family members perform it for me and spare me for the care of my father. Sometimes I discuss care related matters with my close family members, and they provide me with good advice and courage (Participant 1). Religious beliefs and practices were highly highlighted by the caregivers as significant coping strategy. They shared that, being Muslims, it should be the belief that Allah tests individuals through various troubles and He removes the troubles away. They also shared that they increased the regularity of performing prayers and recitation of the Holy Quran which would give them satisfaction and hope. Before the disease, I was not very regular in performing religious activities. Now, I have started offering regular prayers and recitation of the holy Quran. This diversion into religious activities provided more satisfaction and gave me hope that our father will get better (Participant 6). The caregivers also highlighted time management as an effective coping strategy. One participant shared: When this disease came, we changed our life in such a way that we left certain activities of roaming out because now we give most of our time at home to be available to our patient (Participant 5). Some of the caregivers said that their patient is given food, medicine and other required care in the afternoon, after which the patient sleeps peacefully for some time. So, one of the participants shared: Usually in the afternoon my father used to sleep after he is given medicine and care; this is the only best time in which I can go out of my home towards my friends for some time or bringing something from the market (Participant 8).

DISCUSSION

The current study found out that the participants face disappointment in the early phase of their loved ones' disease. They related this stress and hopelessness to prolong nature of disease and no obvious improvement in the first month. These findings are in line with a study which identified that the caregivers are often unaware and untrained when they start care for their patient; this leads to stress and burnout [8]. Another Pakistani study also reported that informal caregivers of chronic patients face negative psychological impact. It also added that family

caregivers are at more risk for developing depression as compared to non-caregiver members of the family [11]. A quantitative study conducted in China in 2020 revealed that frequency of hospitalization of stroke survivors, financial pressures and dependent nature of patients are the primary factors of disappointment and stress among the caregivers [12]. A significant finding in the current study was economic burden on caregivers related to decreased income and increased expenditures. In Pakistani communities and especially in KP province, commonly the bread earners are the men. When such earning members quit their jobs or make it part time, this leads to decreased earnings. The study participants related their heightened expenditures to their patients' disease costs along with household expenses. These findings are similar with other Pakistani studies which identified that more than two third of the participants had to quit their jobs in order to make themselves available for care and transportation of their patient for follow ups [13, 14]. Regarding expenses, another Pakistani study revealed that transportation of patient and paying his hospital and medicine charges increase the expenses of caregivers [11]. Impact on social life due to the disease of the loved one was another finding of the current study. The participants said that they have abandoned social gatherings, friend circle activities, going for outings, and being restricted to homes. These findings are in line with a quantitative study which revealed that majority of participants expressed that their social lives are badly affected due to caregiving process [15]. Similar findings are identified by a South African study which reported that stroke restricts the caregivers' social life and disrupts the whole family system [10]. Likewise, a Chinese study has similar findings of affected the physical, psychological, and social lives of caregivers [16]. The fourth theme in this study was impact on personal life. The participants shared significant concerns about the effects of dedicated caring on their personal health and immediate family relationship. They stated that, after their loved ones' dependence, they are unable to go to doctor for their own checkup in case of any minor illness, unable to play games, cannot go for any mind refreshing activity or even sleep properly. Similar findings are reported by a study conducted in Karachi, Pakistan which stated that the care drags all of the caregiver's attention towards the care of their patient and thus they ignore their own health. The caregivers often feel tired, exhausted, and do not have enough sleep due to constant care provision [9, 17]. Similarly, the findings of disrupted immediate family routines in the current study are supported by a Spanish study which reported that the caregivers face loss of independence, inability to plan normal patterns of life, and loss of autonomy due to burden of care. These lead to

negative psychological experiences of spouses [18]. The findings of the current study showed that caregivers coping mechanism was related to awareness of care and prognosis by healthcare professionals, the support system, belief system, and time management. A study conducted in Ireland stated that it is helpful for the caregivers to seek counseling from the professional healthcare workers. This decreases their anxiety and provides them motivation towards better caring [19]. The findings of increased religious activities as a matter of satisfaction in the current study are also in line with another Pakistani research which revealed that caregivers usually increase religious rituals and prayers in hard times [15]. Due to cultural limitations, female caregivers were not added as a study participant. In current study, the female were approached, and the purpose and process of interview were explained, however, they were reluctant regarding tape recording of their interviews. The future research should focus on data from both genders. Moreover, as the family caregivers of stroke survivors experience altruism and burdens [20], there is a dire need for collaborative efforts and support from communities and occupational therapy.

CONCLUSIONS

Stroke is a debilitating disease, and the caregivers experience various hardships because of the sudden responsibilities of the care of stroke survivors. These include physical, psychological, social, and financial implications. The current study identified specific coping strategies to help them ease the trouble. The healthcare professionals should always teach the caregivers about the care process and assess their counselling and psychological support needs. The hospital administration shall keep instructional pamphlets regarding the care of stroke patients in outpatient departments and stroke units.

Authors Contribution

Conceptualization: DM, SK¹

Methodology: HK, ZA

Formal analysis: HK, SK²

Writing review and editing: HK, DM, SK¹

All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

All the authors declare no conflict of interest.

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