

## Original Article

### Life after stroke: exploring social and psychological consequences of stroke survivors and their caregivers

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#### Abstract

**Aim:** To explore the social and psychological consequences of stroke among stroke survivors and their caregivers in Addis Ababa, Ethiopia.

**Methods:** We conducted in-depth interviews with stroke survivors (n=13) and their caregivers (n=13) in Addis Ababa, Ethiopia. Interviews were conducted in Amharic and were audiotaped. After repeated listening to the records and reading the transcripts, a thematic analysis was conducted.

**Results:** Six themes emerged: explanatory model, new body, living on a bread line, psychological toll, elephant in the room, and finding a silver lining.

Stroke survivors described stroke as a sudden event that changed their life forever.

Some participants attributed it to the devil's doing, spirit possession (“ልክፍግ”) and their sins. Both survivors and their caregivers reported financial crises related to disability, inability to return to work, treatment, and transportation costs. Both survivors and caregivers described the psychological tolls such as emotional ups and downs, anxiety, frustration, sleep problem, and suicidal ideation. Survivors reported distancing themselves from social activities or events whereas; caregivers reported that they did not have enough time to be a part of one. Stroke survivors considered surviving the stroke as a blessing. Caregivers say they have set their minds to be thankful to God that they have their loved ones around despite all the limitations.

**Conclusion:** Stroke survivors and their caregivers suffer from financial crises and emotional up and downs. This warrants the need for compressive social and psychological interventions in addition to the usual physical care provided for such cases in low-income countries.

**Keywords:** social, psychological, stroke, caregivers, LMICs

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#### Background

In Ethiopia, stroke is one of the leading causes of death contributing 1.8% to the Years of Life Lost (YLLs). The statistics increased by a staggering 31% from the year 1990 – 2010 making it into the chart of the leading causes of YLLs (1). Even if the person is lucky and survives, stroke may change the survivors' outlook on life, their ability to participate in daily activities, and their family's financial situation.

The consequences of stroke such as communication and physical disability determine the survivors' ability to return to work. This reduces the quality of life of the stroke survivor and their family for many years post-stroke (2, 3, 4). Returning to work after a stroke

is also associated with improved subjective well-being and life satisfaction (5).

Due to the above consequences most stroke survivors need continuous care from their informal caregivers. The burden on caregivers and the pressure they are under while caring for their loved ones by giving up or putting their own lives on hold is rarely acknowledged (6, 7). They suffer from all the economic, social, and psychological strain that comes along with stroke (8, 9).

However, stroke survivors' and their caregivers life experiences, challenges, and coping practices have not been well explored. In this study, we aimed to get a comprehensive understanding of the after-

math of stroke on survivors and their caregivers in a low-income setting where there is a limited social welfare system and where the epidemiology of stroke is different from high-income countries (10).

## Methods

### Study design and setting

We conducted a qualitative study to explore the lived experience of stroke survivors and their caregivers. The study was conducted in physiotherapy units of public hospitals in Addis Ababa, Ethiopia. The physiotherapy units provide physical rehabilitation to service users with minor and major disabilities caused by stroke, other health conditions, and accidents. Three to seven physiotherapists with bachelor's and master's degrees in physiotherapy work in each clinic and three of the clinics have physiotherapists with doctorate degrees in physiotherapy. Stroke survivors usually get a minimum of six consecutive therapy sessions and additional unspecified sessions based on the level of disability.

Clinics located on the ground floor of the hospital have a ramp to facilitate access to the unit while those located above the ground floor have elevators to the physiotherapy unit. The units are easily accessible for people who use wheelchairs and canes. All of them have an information desk at the front and one or two offices. All the units have up to ten curtain-sectioned rooms for massage and electrical stimulation sessions. They also have waiting areas for caregivers and family members.

### Participants

We employed purposive sampling considering gender, age, time since stroke, and patient health questionnaire (PHQ-9) (11) scores to have a maximum variation in the sample. Stroke survivors with severe aphasia were excluded. A person accompanying a stroke survivor to the physiotherapy unit who lives in the same house, unpaid, and directly implicated in the survivor's care was considered as a caregiver. The number of participants was determined based on theoretical information saturation.

### Data collection procedure

We conducted in-depth interviews using an interview guide with probing questions to capture the experience of survivors and caregivers. After the participants finished their physiotherapy session, the physiotherapist linked them with the principal investigator (SS). SS explained the aim of the study and invited them to take part in the study; Written consent was obtained from all participants. All interviews were conducted in a private room.

The interviewer introduced herself, and her role in the research and served kolo (roasted barley) and water, a traditional snack to build rapport and create a welcoming environment. The interviews were audiotaped. The shortest interview took 50 minutes and the longest took 1:30 hrs. The interviews continued

until there was no additional new information obtained. At the end of the interview, participants' feedback on how they felt about the interview was obtained.

### Data processing and analysis

All recordings were transcribed in Amharic and translated into English by research assistants and the first author. A thematic analysis approach was used to analyse the data (12). Open Code software V4.03 (13) was used to assist with the analysis.

After repeatedly listening to the audio recordings and reading the transcripts, the primary author (SS) developed initial codes on two transcripts. Then, these initial codes and their descriptions were discussed with another co-author (WF) and came up with a refined framework. The rest of the data were coded according to the agreed codes; with new emerging codes identified throughout the data collection process. After the coding, each code was combined to form themes and sub-themes. Finally, illustrative quotes were used to describe each subtheme.

### Data quality measures

A good rapport was built before the interview sessions, and the guide was amended after the first interview. We also tried to involve different types of participants by age, gender, PHQ-9 scores, and duration of the stroke to get different dimensions of survivors and their family's experience after the stroke. We triangulate the experience of stroke survivors' and their caregivers.

### Ethical considerations

We obtained ethical clearance from the Institutional Review Board of the College of Health Sciences, Addis Ababa University in 2020 (Psy protocol number=120/20). Written consent was obtained from all participants after the provision of adequate information about the study. Caregivers signed for participants who were unable to write due to their disability with consent from the survivors.

## Results

### Participant characteristics

We interviewed 26 participants: 13 stroke survivors and 13 caregivers. The stroke survivors' age ranged from 30 to 69 years while caregivers' age ranged from 20 to 83 years. All participants except one, had received formal education. All survivors have hypertension as a comorbidity, and some have diabetes mellitus, cancer, and HIV (Table 1). Ten of the caregivers reported that they spent more than 8 hours a day with survivors giving care as required. Seven of the survivors and five of the caregivers had above 10 scores on PHQ-9 indicating moderate depressive symptoms(14) and they were linked with the psychiatry clinic.

**Table 1:** Characteristics of stroke survivors and caregivers

No.	Stroke survivors					Caregivers			
	Sex	Age	Duration after stroke in months	Comorbidities	PHQ-9 Score	Sex	Age	Relationship with the survivor	PHQ-9 Score
1	F	30	4	HT	>10	F	41	Sister	>10
2	M	55	13	HT, DM	>10	F	40	Wife	>10
3	M	51	9	HT	<10	M	28	Son	>10
4	M	48	14	HT	>10	F	20	Daughter	<10
5	M	37	6	HT	>10	F	34	Wife	<10
6	M	49	11	HT	<10	F	45	Sister	<10
7	M	61	24	HT, DM	<10	M	31	Son	<10
8	M	48	8	HT	<10	F	37	Wife	<10
9	M	57	144	HT	>10	F	83	Mother	>10
10	M	69	12	HT, DM	<10	F	49	Wife	<10
11	F	51	5	HT, Cancer	>10	F	21	Daughter	>10
12	F	47	24	HT, HIV	<10	M	51	Husband	<10
13	F	38	36	HT, Cardiac	>10	F	35	Relative	<10

DM – Diabetes Mellitus, HT – Hypertension, PHQ-9 – Patient Health Questionaries

### Thematic analysis

In the thematic analysis, six themes emerged: explanatory model (perceived cause), new body, living on the bread line, psychological toll, elephant in the room, and finding the silver lining.

### Explanatory Model

Participants reported their insight about stroke, the cause of stroke, and their physiotherapy journey. They described stroke as a sudden event that changed their life forever. It was something they were never prepared or ready for. They explained it as an incident without warning and a near-death experience.

*“I felt like something hit us like an ocean wave, yesterday we were living a normal life going here and there, he works as a daily labourer, but he was very productive, then you see us today. He cannot lift a finger. It is like death. It did not tell us the date.”*

[caregiver\_4]

Some participants reported that it was the devil’s doing, other people’s bad wish upon them, and spirit

possession (“ልክፍት”) as the cause of stroke. They also take responsibility for themselves that their sinful act caused the stroke on them or their loved ones.

*“The bad spirit got to her when she went to use the toilet, she should not have gone alone since she just gave birth, the bad spirit possessed her. It is*

*‘ልክፍት’.*”  
[caregiver\_1]

Some have tried different treatment options in addition to the medical treatment including holy water, reading Quran, and taking different herbs. These treatments they have been taking or considering taking were based on the recommendation of family members and friends who were not health professionals.

*“There was a lot of advice thrown at us, my mother’s face was distorted right after the stroke and they suggested using “feto” (ፊቶ) to put it in water and drink it as tea, or to put into their face... another one was to use ‘gebto’ (ገብቶ) ... I know we can make liquor out of it but not to lower blood pressure...but we used some of the recommendations ...”*

[caregiver\_11]

Family members were concerned about the recovery process. They did not know how long it was going to take after the survivors left the hospital and went home. It was very hard for the caregivers and their families to see the survivors suddenly stop what they were doing. Participants' notion about the recovery process was not what they expected, or they did not know what to expect after discharge from the hospital.

### New body

Stroke survivors mentioned disability, not feeling like themselves, discomfort with their body and having no control of their body after the stroke which they mentioned as a new body.

Stroke survivors reported facing difficulties to perform daily activities such as feeding themselves, taking baths, walking independently and taking care of their new-born because of the disability after stroke. They reported their inability to move around freely was also dependent on the weather; cold weather forced them to miss even their therapy sessions.

*"This thing, the stroke, it does not like cold, it took me more than 20 minutes to get up this morning because it was very cold, it just ties up my hand and leg."*  
[stroke survivor\_10]

A new mom who survived a stroke just 20 days after giving birth described her inability to take care of her newborn as any mother would do. Even years after the stroke, they consider the mobility limitation as a scar and continuous reminder of the powerlessness that is brought upon them by the stroke.

*"I am not lucky enough to hold my child, breastfeed her or even help to bathe her; my heart aches when I think of my incapacities...it's sad...I just could not command my hand to ...as I want to..."*  
[Stroke survivor\_1]

Caregivers reported that it took some time to get used to seeing the survivor with new body posture or facial features. They mention how hard it was to see their loved one's physical appearance, activity level change, and difficulty with their speech which they say led them to take over tasks the survivors used to do.

### Living on the breadline

Both the survivors and their family members reported financial strain and the struggle for living on the breadline in an aftermath of a stroke. This is related to the disability (inability to work) and added treatment costs (medication, transportation, and related costs). The transportation cost was reported as a big

headache since they may need to take a taxi because public transportation is not conducive for them to take because of their disability.

The disability results in the inability to return to work, prevents them to be employed and forced the survivors to leave on their pensions only. In addition to the stroke survivors' inability to return to work, caregivers also had to give up their jobs for full-time care provision of the survivors. Participants described the difficulties they have to provide sufficient living for their families in many ways.

*"... he would at least bring something to eat, as he always did, we both were daily labourers our life was from hand to mouth, he used to wash cars and I worked in people's houses washing clothes or ...; but now he is not working could not even sit up on his own and I have to be here all the time because he does not want anyone else to take care of him, there are days where my children went to sleep in the empty stomach "*  
[ caregiver\_5]

Participants also reported another strain they were facing which is the difficulty to send their children to school. They reported that they make their children miss school because they might not have another person to help them to come to the physiotherapy sessions or there might not be enough food at home to provide so they sometimes miss school to do some daily labour to bring home some bread for the other siblings.

*".... sometimes I make my older boy miss school so that he would help with putting him into the taxi or the wheelchair; I cannot bring him alone and I do not always get other people around."*  
[ caregiver 2]

### Psychological toll

Stroke survivors and caregivers reported emotional up and downs, anxiety, frustration, and psychological problems they face after the stroke. Fear, trauma, sleep problem, anger, and suicidal ideation were also reported.

Both stroke survivors and their family members reported sleep problems. Some reported that they have no sleep at all some nights and usually poor-quality sleep. They reported it as something devastating which leads to fatigue during the day. Some caregivers reported the lack of sleep was because they need to take care of the survivors. They must provide late-night or mid-night medications for the survivors or help them to use the bathroom which causes sleep disturbance and exhaustion during daytime.

*“In good nights...when I am lucky, I sleep up to 6 hours but it’s just terrible it’s full of nightmares and the next morning my body feels like I have been running throughout the night; it’s exhausting”*  
[Caregiver\_3]

Caregivers also reported a lack of sleep because they were also taking care of the survivors. On another note, caregivers must provide late-night and midnight medications for the survivors or help them to use the bathroom which causes sleep disturbance and exhaustion during daytime.

*“If he is up at night, I would not be able to go to sleep also he will tell me to sit by his side, in the middle of the night ... there were many nights I did not even close my eyes for a bit...he just did not sleep so I have to stay up too”*  
[caregiver\_10]

Participants have also reported serious emotional tolls. The most frequently reported emotional problems were stress, hopelessness, irritability, rapid mood changes, and feeling sad.

*“I have never felt any happiness in the last 12 years .... I cannot even remember a day that I was happy .... It’s just sadness .... ”*  
[stroke survivor\_9]

Stroke survivors reported that they suffer from the thought that the stroke is going to happen again at any moment now. A little bit of headache feels a lot after a stroke; they also reported there were times when they went to the emergency room thinking that it is happening again. Caregivers also reported that they would panic with the thought that their loved one is going to die anytime; especially when they passed even a minute from their medication time, they would feel distressed about it.

Trauma among stroke survivors’ children was another negative experience reported. Children face a huge amount of fear of losing their parents and get overwhelmed by the feeling. In some cases, this resulted in miss school and insisting to come to their check-up and physiotherapy sessions fearing that their parents might not come back home.

*“My daughter wants to come to the hospital every time I come for a check-up or physiotherapy .... She is 9 years old, and she doesn’t trust when I come to the hospital because last time, she was very scared, so she will miss school and come with her mom”*  
[Stroke survivor 8]

Participants also reported changes in their emotions and emotional expressions after the stroke. They report being suddenly upset and tearful which on many occasions lead them to be frustrated when they face

different social situations because they feel embarrassed about their disability. Caregivers have also reported that they were less motivated to do what they used to, and they felt that their personality has changed a lot, reporting feelings of anger often for simple things and frequent mood changes.

*“I fear to death that my children will also have stroke....it is a very scary thought...always in my head, I don’t want them to be like me...”* [stroke survivor 12]

The emotional tolls and the trauma associated have led some to have suicidal ideation and attempts. They reported that they consider overdosing themselves or shooting themselves with a handgun or running into a moving bus to end their life. Sometimes emotional turmoil hits the participants and leads them to wish to end their life not to suffer any more.

*“I thought about ending my life.... a lot .... it’s just I didn’t think I could .... I just did not want to live like this....it was all darkness.... very hard to explain... .... I thought of going to the streets and standing in front of a bus...”*  
[stroke survivor 9]

### **Elephant in the room**

This theme describes the awkward and embarrassing moments survivors and caregivers face which resulted in affecting their social life. Survivors and caregivers face different aftermath of stroke which brings them emotional discomfort and presses them to intentionally ignore certain circumstances. They also reported feuds within the family, a mix of too much sympathy and too much criticism.

Survivors distance themselves from different social activities; caregivers reported that they did not have enough time to take part in one. They also reported the society as understanding the problem not expecting them to participate in different social events. Some survivors reported that they were reluctant to participate especially in happy events thinking that they would cloud others’ happiness with their inability to move around freely and they feel ashamed to take pictures.

*“Sometimes I wanted to go to a friend’s or relatives’ weddings, but I do not want to ruin their memories, or pictures with my disability; I do not want to get in people’s ways. I just do not go; maybe if it is death I might just go like after the third day to pay my respect and condolences”*  
[stroke survivor\_3]

Stroke survivors also reported that it is hard to continue the same relationship with friends they had before the stroke. It is hard for their friends to accept their changes after the stroke, and it is hard to talk

about it. They said they were also unable to do things they used to do together with their friends before the stroke mainly due to their disability; and because it brings sadness, they deliberately ignore their friends. They said talking to a new friend is easier because they do not know them before they had a stroke, so it was easier to accept them as they are now.

Some survivors reported that they have been exposed to too much emotional involvement like being overly protective or criticism about their conditions. Too much emotional involvement from extended families and friends makes them and caregivers uncomfortable which led them to not attend family events like birthday parties, weddings, and other social events. Survivors also reported that some family members think they were faking their condition for the sake of drawing attention which they say breaks their hearts.

*"I cannot take their pity any more it is too much (kenfer meteta) .... All I want was to spend a nice time .... Just like old times.... But every conversation will be about my situation, and I hate that they pity me so much ... even if I told them to stop pitying me ...I still see it in their eyes; it would be nice if I could make new friends who did not know about the old me ....it might be easier for them to accept you like this...."*  
[stroke survivor\_7]

Caregivers reported that people around them like to throw their personal beliefs about the stroke and how they should see what is happening in their life. They expressed that they have been told how they should be feeling or doing instead of asking them how they are feeling which has led them to restrict themselves from different social events. Even when people are not talking about it, though it is an obvious issue, it brings discomfort and awkwardness; they said it is like an 'elephant in the room'.

*"Friends and family say it is for the best that this happens to our family, that God tests those he loves...and am angry with their opinion and comments because I am the one in it and I don't see any good in what is happening to mom"*  
[caregiver 11]

Some caregivers reported their relationship with their boy/girlfriends which they have been building before the stroke is suffering due to not giving enough attention and time to the relationship. Taking care of the survivor was also reported as time-consuming resulting in their personal life to pause.

*"We were supposed to be married and start living together this year but my father ... it happened to us, this happen...so I have to give time for my family; we even broke up with my fiancé because she could not understand what I am dealing with; I*

*could not have a wedding while my father is like this"*

[caregiver 3]

A caregiver reported a long bitter quarrel within the family about different types of treatment options, physiotherapy sessions and caregiving schedules for the stroke survivor. They reported that they put off these discussions because it would generate arguments within the family. This family feud resulted in never speaking to each other again in some members.

*"I argue with my brother a lot about the medication our father is taking .... He only wants to take him to the holy water ...while I insist that he should also take his medication with it"*

[caregiver\_3]

### Finding the Silver Lining

Participants reported the common coping mechanisms they have employed. Stroke survivors reported surviving the stroke as a blessing. They considered the time given to them to do things right and to count their blessings. They reported that the situation after the stroke has been taken as a reminder to count their blessings, to tell their loved ones how much they meant to them, to thank God and to take time for themselves. Caregivers also have set their minds to be thankful to God that they have their loved ones around despite all the limitations.

*"I used to be a soldier ... I am the man of the house, I wanted everything to be done my way, only my way ... I have never listened to my wife nor the children ...but after the stroke, it gave me time to be calm, I do not shout like I used to ... I realize I was the one disturbing my family ...now I listen to them, pray to God, have time for myself... I have never felt calmer ...it's just sad it took a stroke to realize this "*

[stroke survivor\_10]

A participant also reported that stroke made the family gather around, rely on each other, and felt happy that they can rely on each other during such a tough time as this.

*"We used to live very separate life with my siblings, due to many reasons work, marriage, ... after our father became like this the house gets full again, they all visit frequently and spent a lot of time, our mother is very happy; they also cover for me when I need to go out or stay out late"*

[caregiver\_3]

Though some participants reported seeing the light at the end of the tunnel and can enjoy the opportunity and the second chance after the stroke; some reported

the experience after stroke as a situation where they cannot think of getting out of it. They reported that trying to find something good out of this was impossible.

*“All I see is a mess; I do not know how we are going to come back from this...as I told you my sister’s marriage is destroyed because her husband cannot tolerate the time she spends taking care of our mom; as well as my life and marriage ... it’s like I have to be in two places at once ....everything is a mess...cannot see a better future because things are getting worse by the day...”*  
[caregiver\_11]

It has been reported that celebrating little milestones that the survivor achieves has been helping families and extended relatives to bond over it and help them get closer. Reading books, praying, taking a long walk, spending time with family and sleeping to avoid certain situations were the reported ways of dealing with different emotions and situations.

### Feedback

At the end of the interview, we asked the participants how they felt about talking or taking part in this interview; most of the participants took their time to answer the questions and were open about their experiences.

Participants reported that they were nervous in the beginning, but they were glad they were asked and talked about the issues out loud because mostly they would just say *“I am fine”* and move along. But they reported that they were glad they were able to speak and felt heard.

Participants also reported being anxious while talking about their experiences. It made them face different feelings they were putting aside even though they felt good at the end, and it was emotional to think about the emotions they are going through.

*“I am sorry about earlier .... It is just hard to talk about things nowadays because ... it gets hard with time to talk about it when no one is there to talk to you about it”* “  
[stroke survivor\_9]

*“Thank God someone is considering what I am going through .... and interested in what I am feeling ...you know after her stroke, and she became like this no one wants to know how I am feeling or what I am going through .... They might say thank God your mother has you by her side, but they do not consider or ask who is by your side ...”*  
[caregiver\_11]

*“As a man, it’s hard to see your father like this but it’s even harder to put your feelings out there and let the rest of the family know that you are tough, or I do not cry because I am a man.... but feelings pile up .... that might be the reason that I cried .... I do not understand you telling me that crying is a good thing .... But I feel good now .... It made me think about my brothers that they may want to talk ... not just about medical bills, medication time or physiotherapy time.... but I will ask them to talk.... we created this front to be strong, especially for our mother and try not to feel ... now am thinking about what our little brother must be going through ....”*  
[caregiver\_7]

### Discussion

In this qualitative study, we interviewed a good number of stroke survivors and caregivers to explore the social and psychological experiences of stroke survivors and caregivers and their coping mechanisms. Our study is unique in many ways. First, it was conducted in a resource-limited setting where social services are entirely left to families and where there is limited access to rehabilitation care for stroke survivors. The limited available service is also limited to physical rehabilitation where the needs of the survivors are multifaceted, including psychological services. Second, we have included the overlooked patients’ caregivers while their role and burden are very high in such settings. Third, we have included the perspectives of recent and chronic survivors and their caregivers which can be essential for interventions targeting stroke survivors and the informal caregivers.

We identified six themes in this study: explanatory model, new body, living on the breadline, psychological toll, elephant in the room and finding the silver lining. The explanatory model describes participants’ understanding of and causes of stroke. This theme narrates the survivor’s and caregivers’ expression of the journey after a stroke. The second theme new body explained survivors’ experience with their bodies being uncomfortable after a stroke. It elaborates on how they feel like they have no control over their body mainly because of the disability that came after the stroke.

The third theme, living on the breadline emphasizes the financial struggles of survivors and caregivers; and hand to mouth existence they face after stroke. In this theme transportation and medication cost contribute to the struggle they deal to make ends meet. The fourth theme, psychological toll describes different psychological problems like anxiety, sleep problems, stress, sadness, and trauma they experience after the stroke. Suicidal ideation was also another psychological problem that was raised in this theme.

**Table 2:** Summary of theme with their description

<b>Theme 1</b>	<b>Theme 2</b>	<b>Theme 3</b>	<b>Theme 4</b>	<b>Theme 5</b>	<b>Theme 6</b>
<b>Exploratory model</b>	<b>New body</b>	<b>Living on a breadline</b>	<b>Psychological toll</b>	<b>Elephant in the room</b>	<b>Finding a Silver lining</b>
Insight about stroke Cause Early days Physiotherapy journeys Treatment options	Disability Not feeling like themselves no control over their body Unable to take care of a newborn	Financial crises Forced Retirement Unable to go back to work Children missing school	Fear Panic Anxiety Sleep problems Trauma Loss of interest Suicidal ideation	Social isolation Family feud Too much sympathy Too much criticism	Taking it as a second chance in life Time to count their blessings Time to serve their loved ones Family sticking together Adjusting to a new lifestyle Adjusting to medication Adjusting to the role shift Coping through praying Talking with friends, reading and Taking a walk

The fifth theme elephant in the room refers to different situations and controversial issues like disability, the changes within their family, and social situations which brings them sadness or arguments. It explains how participants tend to deliberately avoid discussions and hold themselves from participating in social events and ignore family arguments.

The final theme finding a silver lining, how the participants were able to see the light at the end of the tunnel and gained hope. This theme describes the positive things like caregivers getting a chance to serve their families, taking it as a second chance and taking time to count their blessings through this chaotic event. In this theme, participants describe how they try to adjust to the new normal and how they have been using prayers and talking to friends as a way of coping.

Post-stroke recovery usually involves a continuum of care (15, 16). In this continuum, communication about the recovery process among physicians, survivors, and families plays a significant role in improving outcomes (17). The survivors and their family members may not fully understand this process as was seen in our study. Service providers need to work in collaboration with the survivors and caregivers to prepare them regarding what to expect, the estimated duration of possible changes, and the resources required.

The financial crisis was one of the most frequently raised consequences of stroke in this study. This is an

understandable outcome of the problem in a country where there is no social security and where needs are expected to be met by the family who even under normal circumstances could have been struggling for survival. In some cases, victims of stroke were the breadwinners of their families. Caregivers who also used to contribute to the family economy would be forced to work shorter hours or stop working because of the time-demanding nature of caregiving to stroke survivors. The cost of medical care, rehabilitation and transport also increases the financial burden on the family in addition to the cost of living. As was suggested in previous studies, this might call for compensating strategies for informal caregivers to alleviate their financial challenges (18).

The emotional roller coasters were reported by both the survivors and their caregivers. The emotional problems may be serious enough to end their life. The psychological consequence may be more pronounced in low-income settings where the treatment gap for both physical and psychosocial care is high (7, 19). This warrants the need for psychological support for both the survivors and their caregivers. The psychological support may also have a positive contribution to their physical rehabilitation (20) and better quality of life (21)

Stigma related to stroke was reported to lead to depression and lower quality of life among stroke survivors in previous studies (22, 23, 24). In our study participants described how they distance themselves



from different social gatherings due to low self-perception, altered self-image, and negative self-talk; which needs a comprehensive intervention focusing on self-perception and self-image (25).

Though it is not commonly reported in stroke studies, stroke survivors in our study reported the negative consequences of expressed emotion towards them. Some reported overprotection while others reported over criticism. Since the concept of expressed emotion is usually reported in mental health conditions such as schizophrenia (26), it is important to assess the role of expressed emotion in the stroke care journey in the future studies.

It was evident in our study that caregivers play an important role in poststroke care. However, it was seen that they suffer from lack of information, loss of job, economic constraint, and psychological problems as also seen in other different studies (27, 28). Their needs can be addressed through the Timing it Right framework. This framework describes the changing needs of caregivers in the recovery trajectory. It has been shown that caregivers also benefit from receiving support from healthcare professionals (29), family, friends, and caregiving peers (30).

The coping mechanisms applied by the survivors and the caregivers are important aspects of the care process (31). In the current study, participants used different adaptive coping mechanisms such as considering their survival as a second chance in life. Some caregivers also took it as an opportunity to serve their loved ones. The other coping mechanisms including praying, being grateful, and talking and spending time with family and friends can be communicated as effective health promotion strategies (32, 33, 34, 35).

Though this study can be considered the most comprehensive report in such a setting, it is not free from limitations. First, though understanding stroke survivors with communication difficulties to ensure long-term care is very important (36); the findings in this study may not reflect the experience of stroke survivors with communication difficulties. Second, since we only recruited participants who came to the rehabilitation clinic and possibly had better social support and economic status, we may have missed some worse experiences and consequences of the illness.

In conclusion, we explored the consequences of stroke among stroke survivors and their caregivers and found that survivors face an inability to return to work because of disability. Financial strain, and different emotional ups and downs including sadness, hopelessness, trauma, and suicidal thoughts are also important findings of this study. Caregivers are found to be hidden patients with experiences of their own physical health, sleep problems, financial stress, and emotional burden. These all show the need for urgent

and compressive interventions. Taking a walk, praying, sleeping, and reading books have been reported as useful coping mechanisms.

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#### **Availability of data and materials**

The datasets generated and analysed during the current study are not publicly available to protect participants' privacy but are available from the corresponding author upon rational request.

#### **Competing interests**

The authors declare there is no conflict of interest.

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#### **Authors' contributions**

SS and AA conceived the study, and they were part of the whole process of the study. CS participated in the design of the study, reviewed all versions, and made corrections. WF participated in the design of the study and analysis of the data, reviewed all versions, and made corrections. All the authors read and approved the last version.

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