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Caring for stroke survivors: experiences of family caregivers in Sri Lanka – a qualitative study

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ABSTRACT

Background: Stroke is a life-changing event for both stroke survivors and their family caregivers. After receiving acute care at the hospital, family members are expected to take care of stroke survivors at home and to continue treatment and rehabilitation. The new role of “informal caregiver” is a challenge that creates many difficulties for family caregivers that are not explicit in the Sri Lankan context.

Objectives: This study aimed at exploring family caregivers’ experiences of providing informal care for dependent stroke survivors.

Methods: The sample was chosen by purposive sampling with a maximum variation by age, ethnicity, religion, educational level, relationship, and monthly income. Ten informal family caregivers to stroke survivors with hemiplegia who had been treated at the National Hospital of Sri Lanka participated in in-depth interviews analyzed using conventional content analysis.

Results: Qualitative content analysis of data resulted in an overriding theme, “Caring with love, against all odds,” along with four categories, “Life alterations,” “Lack of resources,” “Compassionate care,” and “Coping strategies.” Although the increased workload, restricted social life, physical problems, and knowledge and financial deficits were challenging for the family caregivers, self-strength and supportive social networks helped them to compassionately care for their stroke survivor.

Conclusions: The phenomenon of family caregivers providing informal care for stroke survivors was explicated as compassionate care, notwithstanding numerous difficulties. The findings motivate further research and strategies to minimize family caregivers’ burden and facilitate the positive aspects of caregiving to promote the health and well-being of both stroke survivors and their families.

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Family caregivers; informal care; nursing; Sri Lanka; stroke survivors; qualitative

Introduction

Stroke is a life-changing event that affects not only stroke survivors but their family members as well.¹ After the acute-phase management at a hospital, in settings where a formal post-discharge management is not established, as in Sri Lanka, family members and relatives take over the informal role of caring for stroke survivors at home.² The family members, close relatives, friends, or neighbors who are not trained health professionals, but care for the stroke survivor at home irrespective of time limitations and without any payment, are termed “informal caregivers.”³

Informal caregivers experience life after stroke as “lives turned upside down.”⁴ Due to the abrupt onset of disability and the chronic, often unpredictable, nature of stroke recovery, caring for stroke survivors often puts a considerable burden on informal family caregivers.^{1,5} With constant and long-term informal care giving, family caregivers’ own needs were neglected, and family relationships were negatively affected.^{6,7} Because of heavy responsibility, uncertainty, worries, and restraints in social life,

informal caring was highlighted as a burden for family caregivers, leading to stress, anxiety, exhaustion, isolation, increased psychological morbidity, and reduced quality of life.^{6–9}

However among those negative experiences, there are positive aspects of caregiving as well, that is, care recipients’ progress, strengthened relationships, feeling appreciated, and increased self-esteem, as reported in a systematic review conducted to uncover “positive experiences of caregiving in stroke.”⁹ In addition, appreciating and giving more meaning to life, feeling needed, useful, appreciated, and good about themselves were also reported in a study by more than 80% of stroke family caregivers.¹⁰

In Sri Lanka, the prevalence of stroke in the Colombo district was 37 per 1000 adults aged over 65 years.¹¹ Moreover, due to the increasing population of elderly people, there is an impending epidemic of stroke in Sri Lanka.¹² Because of the accessible and advanced health care in Sri Lanka, the survival rate of stroke patients is on the increase, leaving many stroke survivors with disabilities to be rehabilitated.¹³ Of the stroke survivors, 35–40% will experience moderate to severe impairment, and 10–15%

will be bedbound at the end of one year.¹³ Therefore, stroke has become a leading cause of adult disability in Sri Lanka.¹²

Although a family member is expected to take care of the stroke survivor, the Sri Lankan family caregivers do not receive formal preparation for the caregiving from health care professionals at the discharge of the patient from hospital. Moreover, there is no well-established family support system at the community level in the Sri Lankan health care system.¹³ Therefore, family caregivers are left on their own to adjust to the full impact of care of their stroke survivor. In such a context, their experience of caregiving would be considerably different from caregivers of other countries.

No study of informal caregivers experience has previously been done in Sri Lanka. It is envisaged that a study in this area would help gather information as well as gain more insight into informal caregivers' experiences, especially since professional home care is yet to be developed in Sri Lanka. A deeper understanding of the informal caregivers' experiences and situation could be used to develop routines to facilitate the care and rehabilitation at home. Thus, this study aimed to explore Sri Lankan family caregivers' experiences of caring for stroke survivors.

Method

A qualitative exploratory research approach, which aims to describe and clarify human experience as it appears in people's lives,¹⁴ was used in the study. Adherence of the study to the COREQ guidelines¹⁵ was ensured. Ethical approval for the study was obtained from the Ethical Review Committees of University of Sri Jayewardenepura, (Ref. 41/15) and National Hospital Sri Lanka (Ref. AAJ/ETH/COM/2015).

Sampling and participants

Permission to access the stroke clinic at the National Hospital of Sri Lanka (NHSL) was obtained from the hospital authorities. With assistance from the nurse in charge, the first author identified stroke survivors who were discharged from the Stroke Unit of NHSL not less than one month earlier, with the diagnosis of stroke and having physical disabilities with hemiplegia. Informal caregivers, such as spouses, blood relatives, and relatives-in-law, who were 18 years or older and provided care at home for their stroke survivor with hemiplegia during most days of the week were identified as "family caregivers" and were given verbal and written information about the study and invited to participate in the study. Purposive sampling ensured the maximum variation by age, gender, educational level, duration of caring experience, and so forth, among the selected family caregivers (Table 1).

Data collection

Data collection took place from February to August 2016 at a convenient time for the family caregivers in a quiet place in their own homes. In-depth interviews were conducted by the first author in the Sinhala language. The interviews lasted between 35 and 55 min and were audiotaped with participants' consent. The interview guide, revised through two pilot interviews, comprised open-ended questions. The participants were asked to describe their experience of being a family caregiver using

Table 1. Sociodemographic characteristics of participants.

Characteristics of participants	Descriptions	
Age (range)	33–69 years	
Sex	Male	2
	Female	8
Ethnicity	Sinhala	8
	Tamil	1
	Moor	1
	Other	0
Religion	Buddhist	7
	Hindu	1
	Christian	2
Highest educational level	Primary	0
	Up to ordinary level*	4
	Up to advanced level**	4
	Higher education	2
Employment	Government sector	0
	Private sector	2
	Self-employed	1
	Not employed	7
Marital status	Unmarried	0
	Married	10
	Divorced/Separated	0
	Widowed	0
Relationship to the stroke survivor	Wife	6
	Son	2
	Daughter	1
	Daughter-in-law	1
Disabilities of the stroke survivor addressed during care	Walking	10
	Feeding	10
	Speaking	8
	Cognition	8
Duration of experience as the family caregiver	1 year	4
	1.5 years	3
	2 years	2
	2.5 years	1
No. of other family members	Fewer than five	5
	More than five	5
Monthly income of the participant in Rs	No income	7
	<20,000	1
	20,000–50,000	1
	50,000–80,000	1
Total family income per month in Rs	<20,000	2
	20,000–50,000	3
	50,000–80,000	4
	>80,000	1
Financial assistance/sponsorships	Yes	0
	No	10

*Ordinary level = Grade 11

**Advanced level = Grade 13 (university entrance examination).

their own words and in as much detail as possible. The opening questions was:

Can you please describe in as much detail as possible how you experience being a caregiver?, Can you please tell me what it is like to be a caregiver?, Has it affect your life?, Can you describe your caregiving on an ordinary day?

In order to encourage the participants to provide more detailed information and reflect on being a family caregiver, probing questions were posed such as: "How did you feel then?, What were your thoughts?, What do you mean? and How would you describe that?"

Saturation in the study area was achieved by the ninth interview, when additional sampling provided no new information,¹⁴ thus, altogether, 10 interviews were conducted.

Preunderstanding

All authors are female registered nurses and have a nursing perspective on the research question in focus. The first author has

context-specific knowledge about the care of stroke survivors, while the second and the third authors are European researchers who had limited knowledge about context-specific perceptions and understandings of being a family caregiver to stroke survivors in Sri Lanka.

Data analysis

The interviews were transcribed verbatim and translated into English by the first author who is fluent in both languages. Qualitative conventional content analysis was used because of the need to interpret meaning from the textual data.¹⁶ The qualitative conventional content analysis was conducted in several steps¹⁶ (Table 2). The first step involved multiple reviews of the transcribed narrative text to get an overall understanding of what it is like to be a family caregiver. The second step involved identifying meaning units (e.g. words, phrases, sentences, sections) in the text relating to the family caregivers' experience of being informal caregivers and extracting them from the interview text. The third step involved reviewing the meaning units to ensure they contained sufficient information related to the aim of the study. In the fourth step, the meaning units were condensed by reformulating them into shorter sentences describing the experience. The condensed meaning unit was reviewed and labeled with a code (Table 2). In the fifth step, codes with similar meanings, were grouped into varied subcategories, and subcategories with similar meanings were grouped into categories. All steps were undertaken with discussions between all authors, and finally, an overarching theme emerged that illuminated the latent content of the data. The categories are described under the findings, along with quotes to illustrate the range of experiences and ideas articulated by different participants as indicated by the number within brackets.

Findings

The analysis comprised an overriding theme "Caring with love, against all odds" and four categories "Life alterations," "Lack of resources," "Compassionate care," and "Coping strategies" (Table 3).

The theme describes the nature of ordinary family caregivers, looking after a family member who was victimized by stroke. They are unselfish, self sacrificing, loving caregivers, who ignored all of their own discomforts, difficulties, and pains, and dedicated themselves to looking after their beloved family member in their best possible ways, though the only incentive they received was a slight improvement of the stroke survivor.

Life alterations

Physical and psychosocial aspects of the lives of family caregivers were affected by the caregiving role. Their lifestyles, routines, and life status were significantly altered in an unfavorable way.

Mainly, their workload was increased, as they had to undertake caring work and responsibilities previously borne by the stroke survivor, in addition to their own usual work. Some of the family caregivers were looking after their small children together with the stroke survivor, which was causing them to feel overburdened.

I feel it as a big workload... I wake up in the morning thinking about things to be done for him. (3)

The family caregivers felt more homebound, and missed attending even the most common social gatherings, such as weddings, funerals, and alms giving, which people generally do not miss. It was due to lack of free time or because the stroke survivor could not manage his/her self-care when left alone.

Now I can't go out... for any reason, I can't just go out. No one else is there to look after him. (1)

Some of the family caregivers were getting physical problems such as back, neck, and leg pain; high blood pressure; and commonly, tiredness. Moreover, they were missing the freedom to get rest or sleep and the support they had previously from the stroke survivor. Seeking treatment also was difficult, as they couldn't leave the stroke survivor.

Physically, I felt like exhausted... no sleep... no meal... Actually, I got sick.... (10)

Many family caregivers became dependent on other family members, relatives, neighbors, or friends for support in providing care and for finances or meals when the family income was affected.

We were living freely without troubling anyone. Now today, we have to beg from others... It's so sad... so harsh. (9)

Lack of resources

Providing care was challenging for family caregivers due to various deficiencies. Predominantly, the lack of finances, facilities at home to provide essential care, and knowledge about stroke care made the caregiving more difficult.

Loss of income either of the stroke survivor or of the caregiver was a major reason for financial problems. In addition, the family caregivers were bearing numerous expenses regularly for a long time for the stroke survivor, mainly for transportation and treatments such as physiotherapy and Ayurveda. In some situations they had given up treatment, as they could no longer sustain such a big cost.

We hired a person who performs exercises. Rs. 1000 per day. Later, we had to face some financial difficulties. so we couldn't continue that. (7)

The family caregivers lacked knowledge of how to care for their stroke survivor. As a consequence, they tended to make decisions based on what they had heard from other people or to just guess what to do. They were also unaware of support services provided by the government and how to obtain those. Some of the caregivers didn't have a bathroom or a toilet inside the house. Therefore, they had to prepare a chair with a hole to support the elimination of the stroke survivor at the bedside. In some houses, the toilets were a squatting type, and again, a chair with a hole was used over that.

We don't have a toilet inside... Two or three of us somehow lift him and bring there... There is no commode... We have kept a chair. (7)

Further, family caregivers found it difficult to provide comfort for the stroke survivor within their homes, due to inadequate space and other facilities.

Compassionate care

All family caregivers were providing compassionate care for their beloved family member. They were dedicating their lives

Table 2. Example of the analysis process.

Meaning unit (statements corresponding to the aim of the study)	Condensed meaning unit	Code	Sub-category	Category
Now / can't go out... for any reason, I can't just go out. No one else is there to look after him... I have to stay I can't go out easily, as there is no one to look after him. I can't go and visit relatives' places. (1)	I can't go out easily, as there is no one to look after him. I can't go and visit relatives and daughter.	Home bound	Restricted social life	Life alterations

to providing tender loving care for the stroke survivor without assuming it as a burden.

They took responsibility for all the aspects of patient care, including day-to-day activities, rehabilitation, and emotional well-being.

We bring him to visit his friends and relatives... We bring him out to see things, and it helps for his mental well-being. (10)

Moreover, the caregivers were responsible for the safety of the stroke survivor, especially in preventing falls and for the continuation of treatments. Almost all stroke survivors of these family caregivers followed Ayurvedic treatment as well; thus, they had to find herbs, prepare them in different forms such as ground herbal bundles and administer them to the stroke survivor as hot fomentation followed by oil massage which were indeed time consuming. The stroke survivors' needs were the priority for the family caregivers, who often neglected their own needs.

I never avoided anything, thinking that I'm tired... I did everything, no matter how exhausted I was. (6)

Coping strategies

Self-encouragement, self-strengthening of mind, and strong determination to somehow achieve recovery in the stroke survivor were common strategies the family caregivers used to cope with the caregiving role. Previous experience of caring also helped them to tolerate it more easily.

Strength was the courage in my mind... keeping the mind strong, without letting it drop down. (9)

Supportive social networks encompassed all the people (mainly the family members, relatives, friends, and neighbors) who extended a helping hand to them willingly. The family caregivers could rely on them, and their support was a relief for the caregivers. As one family caregiver disclosed, the family unity was an immense source of strength for him. In some cases family members, relatives, and neighbors helped with Ayurveda treatments and by staying with the stroke survivor for a few hours. One family caregiver explained how their neighbors helped them even with religious prayer, irrespective of their religion.

We received the help of neighbors also... We are Christians... but there were bodhi puja* for him at the temple too. (10)

*Buddhist prayers at the Bo tree

The stroke survivor's improvement was the only reward the family caregivers received in appreciation of their invaluable dedication and efforts. Unlike in any other disease, in stroke it takes a certain time through the rehabilitation to show even a slight improvement in survivors. They felt they were getting back their beloved family members through their efforts, and it brought them great pleasure.

I'm so happy that now he can stand up and move several steps while holding on. (3)

Discussion

The family caregivers' experiences of providing informal care for dependent stroke survivors could be described as compassion that outweighed the hardship, as expressed by the theme "caring with love against all odds." Despite all the difficulties faced, these family caregivers were compassionate and affectionate in taking care of their stroke survivors.

Table 3. Data analysis with derived codes, subcategories, categories, and theme.

Code	Subcategory	Category	Theme
Feeling overloaded	Increased workload	Life alterations	Caring with love against all odds
Homebound	Restricted social life		
Direct physical problems	Physical problems		
Depending on others for support in care	Depending on others	Lack of resources	
Poor income	Financial problems		
Lack of knowledge on caring	Knowledge deficiencies		
Lack of sanitary facilities	Insufficient facilities at home	Compassionate care	
Care in activities of daily living	Taking the full responsibility		
Committed to caring	Dedicated to tender, loving care		
Strong minds	Self-strength	Coping strategies	
Family and relatives' care	Supportive social network		
Feeling accomplished	Feeling rewarded		

Family caregivers' caring experiences could not be described without mentioning the significant changes that occurred within their lives, which were mainly due to the increased workload. Tiredness, exhaustion, reported in other studies^{5,7,8} was common to these family caregivers as well. Constrained lives with caring responsibilities led to limited opportunities for participation in cultural, social, and religious gatherings, in which Sri Lankans undeniably participate as a norm.

This study affirms the findings of a quantitative study from Australia, where more than 30% were unable to leave their family member alone and did not have enough time for themselves; thus, their social lives suffered as a result of caregiving.⁸

Lack of resources, including knowledge and skills of caring, was a critical challenge experienced by family caregivers. Inadequate knowledge of stroke, stroke-related caring, and rehabilitation resulted in numerous critical problems: being misled by wrong advice from laypeople, giving up treatments, readmissions due to complications, and irreversible deformities and contractions. This corroborates the findings of a systematic review⁶ that revealed the educational needs of caregivers regarding clinical aspects of stroke, prevention, treatment and functional recovery involved with patients' moving and lifting, exercises, psychological changes, and nutritional issues. Ninety-five percent of the occupational therapists who participated in a study also reported that the top needs of caregivers of stroke were related to lack of experience in caring skills for activities of daily living.¹⁷ In a study to evaluate the effects of an educational program on the knowledge, health, and psychosocial outcomes of stroke patients and caregivers, the latter reported feeling better informed with better self-efficacy for accessing stroke information and satisfaction with services.¹⁸ It emphasized that providing a standard program of awareness could alleviate the burden felt by the caregiver and improve health outcomes for both the patient and caregiver.¹⁹

Lack of finances due to either reduced family income or excessive expenses led to discontinuation of treatments and rehabilitation that obviously increased the risk of delay in recovery, and to complications and subsequent stroke attacks. None of the participants were receiving any government support, despite being eligible for it, due to poor awareness and inadequate information on how to obtain such support. Though there are social workers responsible for helping needy stroke survivors and families, referral to them has not happened as expected. Financial difficulty and lack of information about support services have been identified in many studies^{4-6,8,20} as priority problems and a major burden among family caregivers.

Amidst all the above dilemmas, the family caregivers were performing a commendable job in their role, to the best of their capacities. The culture-based attitudes, values, and practices of Sri Lankans, expressed as a sense of their prime duty to take care of elders and disabled members within the family, might have inspired them to care for the stroke survivor unconditionally. Hamsanthy et al. (2015) also has expressed that the stroke survivors who participated in their study perceived their general health as good, and only 25% reported signs of depression, mainly due to the supportive family environment commonly seen in Asian countries.²¹ The generosity of Sri Lankans²² has created informal social security systems in different forms for the stroke survivor and family, to ensure that they are not abandoned, isolated, or helpless within the community.

Methodological consideration

Several measures were used before and during data collection to ensure trustworthiness of the study. An interview guide was developed and tested in pilot interviews. During analysis, continual discussions between all authors ensured the credibility of the findings. According to Lincoln and Guba (1985),²³ peer debriefing is described as a process of exposing oneself to interested peers for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind. The authors' different preunderstandings of the phenomenon in focus can thus be seen as a strength in this process. The large diversity among the participants contributed to ensuring trustworthiness in this study. Thus, the participants had various perspectives and contributed to the richer variation of the phenomenon under study.²³ Overall, the study was well suited to exploring family caregivers' experiences from their own perspectives.

Conclusion

This study gave an insight into the phenomenon of informal care of stroke survivors by family caregivers, explicated as compassionate care provided despite numerous difficulties. In efforts to minimize such difficulties, a proper system of referral to a social worker and provision of a family caregiver education program prior to the discharge of the stroke survivor from the hospital are suggested. Moreover, it is worthwhile to work on strategies of reducing the caregiver burden; thus, "respite care," which is not a concept in Sri Lanka yet, needs to be introduced in reforms of

the health care system as a high prospective need of the public. Primarily, the findings pinpoint the value of a community health nurse and community-based/home-based rehabilitation, which would be the most effective strategy in promoting the health of both the stroke survivor and the family caregiver. This study motivates further research with a quantitative approach to generalize these findings to other settings within the country or to other similar contexts.

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