



Family caregivers' experience of providing informal care for stroke survivors in Sri Lanka



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Background

Stroke prevalence in Colombo, Sri Lanka,

- 10.4 per 1000 adults aged over 18 years
- 37 per 1000 adults aged over 65 years
- 2:1 male: female ratio

- Chang et al. (2015)

- Due to the increasing population of elderly, there is an impending epidemic of stroke!

- Wijeratne et al. (2011)





Background cont.

Easily accessible / available health care



Increasing survival rate of patients with stroke



Many stroke survivors with disabilities to be looked after by informal family caregivers at home

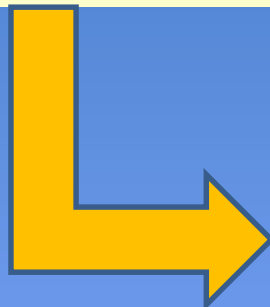


Background cont..

In Sri Lanka,
No family support system (e.g. Home Nursing)
available within community



After the discharge from acute care
hospitals....



family caregivers are left to
adjust to the new caregiving
role on their own



Objective

To explore family caregivers' experience on providing informal care for dependent stroke survivors.



Method

Qualitative exploratory research

Participants

Purposively selected 10 informal family caregivers of stroke survivors treated at the stroke unit of the National hospital Sri Lanka with hemiplegia & diagnosed with stroke

Spouse/ relatives who were 18 years or older, speaking either Sinhala or English

Data collection

through in-depth interviews in Sinhala. Lasted 35- 55 mins

Setting

At participant's homes



Method cont..

Tools

Interview guide

E.g. “Describe your caregiving on an ordinary day?”

probing questions

E.g. “Can you explain about it further?”

2 Pilot interviews

Ethical considerations

guided by the Codex rules and guidelines for human subjects research

Approval

Ethical Review
Committees of
University of Sri
Jayewardenepura &
National Hospital Sri
Lanka



Method cont..

Data analysis

Qualitative content analysis of translated / transcribed audio recorded interview scripts

Content analysis process

1. multiple reviews of the text to get an overall meaning
2. extracting of meaning units
3. revising the meaning units
4. meaning units were condensed and coded
5. similar codes were grouped into sub-categories and further on into categories



Findings

- **Socio demographic information**

Characteristics	Descriptions	
Age (range)	33 to 69 years	
Sex	Male	2
	Female	8
Ethnicity	Sinhala	8
	Tamil	1
	Moor	1
Religion	Buddhism	7
	Hindu	1
	Christian	2
Highest educational level	Up to advanced level**	4
	Up to ordinary level*	4
	Higher education	2



Findings cont..

• Socio demographic information

Characteristics	Descriptions	
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
Monthly income of the participant: Rs.	No income	7
	<20,000	1
	20,000-50,000	1
	50,000-80,000	1
Financial assistance/ sponsorships	Yes	0
	No	10



Findings cont..

Table 1 Content analysis process

Meaning unit	Condensed meaning unit	Code	Sub category	Main category
Now <u>I can't go out...</u> <u>for any reason</u> I can't just go out. No one else is there to look after him... I have to stay looking after him. No way to go and visit relatives... can't go to daughters' 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. (1)	Home bound (1)	Restricted social life	Life alterations

Findings cont..

Table 2 subcategories, categories and theme

Sub category	Category	Theme
Increased workload Restricted social life Physical problems Depending on others	Life alterations	Caring with love against all odds
Financial problems Knowledge deficiencies Insufficient facilities at home	Lack of resources	
Taking the full responsibility Dedicated for tender, loving care	Compassionate care	
Self-strength Supportive social network Feeling rewarded	Coping strategies	





Theme

Caring with love, against all odds

Family caregivers ignored all own discomforts, difficulties and pains, and dedicated to look after their beloved family member in their best possible ways



Category 1

Life alterations

Increased workload Restricted social life
Physical problems Depending on others

- *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)*
- *Physically I felt like exhausted.. no sleep.. no meal.. actually I got sick.. (10)*



Category 2

Lack of resources

Financial problems
Knowledge deficiencies
Insufficient facilities at home

- *economy.. we don't have money in our hand to do things as we want. Even I cannot go for any work ,as I can't leave him. (1)*
- *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)*



Category 3

Compassionate care

Taking the full responsibility
Dedicated for tender, loving care

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



Category 4

Coping strategies

Self-strength

Supportive social network

Feeling rewarded

- *Strength was the courage in my mind.. keeping the mind strong, without letting it drop down.. (9)*
- *we received the help of neighbors also.. we are Christians.. but there were bodhi puja (Buddhist's prayers at Bo tree) for him at the temple too...(10)*



Practical Implications

- proper system of referral to a social worker prior to the discharge of stroke survivor from the hospital
- provision of family caregiver education prior to the discharge
- respite care
- value of a community health nurse and community based rehabilitation
- further research with quantitative approach in order to generalize these findings



Acknowledgement

Heartfelt thanks to

- all the participants of the study
- supervisors for their guidance
 - Prof. Carina Elgan
 - Dr. Kerstin Samarasinghe
- CNMF conference organizers and reviewers for the opportunity



Questions ?
Thank you!