

The impact on everyday life for relatives to persons with stroke in Uganda

Gunilla Eriksson, Julius Kamwesiga, Susanne Guidetti

Division of Occupational therapy, Department of Neurobiology Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden.

Stroke – a great challenge



- Stroke
 - burden in Africa is increasing
 - causes impairments, activity limitations and participation restrictions
 - decreased functioning in daily life
 - a stressful situation for family members
- The everyday life situation for **the family members** to people living with consequences of stroke are unexplored

Content

- Introduction and rationale
- Aim
- Methods
- Findings
- Conclusion



Aim

- to explore and describe the life situation for **family members to persons with stroke** in Uganda and their experiences of being part of a family-centred and mobile-phone supported rehabilitation intervention



Methods

- Data collection 6-24 months after stroke onset
 - After the mobile-phone supported rehabilitation was completed
 - Assessment instruments; Caregiver Burden Scale, LiSat-11
 - Open-ended interviews
- Data analysis
 - Descriptive statistics
 - Grounded theory approach



Results from assessments

- Participants:
 - 16 family members responded to assessment instruments,
 - 10 daughters, 3 sons, 1 wife, 1 father ,1 niece
 - Mean age: 36,5 years; range 20-50
- Caregiver burden (22 items; 1-4 scale; score range 22-88)
 - Low burden: 4
 - Moderate burden:10
 - High burden: 2
- LiSat-11 (6-graded scale) (5-6=satisfied; 1-4=dissatisfied)
 - Global life satisfaction; Satisfied: 6; Dissatisfied: 10



Findings from interviews

- Participants
 - 10 family members shared their experiences in an interview
 - 4 daughters, 2 sons, 1 wife, 1 mother, 1 father, 1 granddaughter
- Categories
 - **Feels obligated but is just a natural commitment**
 - **A tightly scheduled everyday life**
 - **Being the supporting family member**
 - **The caregivers approach as rehabilitators**
 - **The mobile-phone supported rehabilitation intervention**

Feels obligated but is just a natural commitment

- Obligation – demand from the rest of the family
- Everyday life had to change a lot
 - quit jobs
 - move to the family member with stroke



- *"It is not a sacrifice, he is my father, I can help him"*

A tightly scheduled everyday life

- Busy days; being caregiver, own family, work
- Heavy household chores
- Big families, small-spaced homes
- *"I had to program myself so everything fitted in the daily schedule"*
- Schedule: 6 am to 10 pm
 - Exercises, assistance with self-care, meals, PT, work, taking care of children



Being the supporting family member

- Sense of loss of the person
- Fear for not recovering
- Having a way to communicate
- Continuous surveillance - obligation to check on them
- Worries
 - did not improve enough to go back home
 - getting access to rehabilitation
 - economy



The caregivers approach as rehabilitators

- *“We do the exercise everyday all the time, we participate”.*
- *”Yes, for us we want our mother to, want her, we want our mother to be back again”*
- *“We really had a lot of struggling with her”*
- Analysing activities - pieces of activities that was manageable – a part of the rehabilitation



The mobile-phone supported rehabilitation intervention

- *“We reply, we do it because it is a must”*
- *“Sometimes we were bored, but now she is not bored. she makes her life to be busy, good!”*
- *...”because in that way you show that you are concerned about the recovery of the client and follow up. If you don´t follow up you do not care. When you don´t care they are not interested”*



Conclusion



- High impact on everyday life situation
- Committed
- Heavy work load
- Responsible
- Felt supported by the rehabilitation programme



- Information to caregivers within the program