



# Developing A Comprehensive Manual For Family-Centered Stroke Caregiving: A Guide To Effective Family Intervention Strategies.

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## Abstract

**Introduction:** Stroke is considered as one of the leading causes of disability in the world. It has been a long-term care is required for the stroke survivors and the role of caregivers in in omittable.

**Objective:** to develop a comprehensive family centred intervention for the caregivers of stroke survivors

## Methodology

Qualitative methods can be adopted to understand the needs of the caregivers. Expert interview with people working in the field and the caregivers and thorough literature search will be conducted to develop the program.

## Result

The intervention mainly includes to improve the knowledge about stroke, problem solving, coping and role modification for the caregivers after the stroke

## Future plan

The intervention can be provided with the caregivers to set the feasibility of the intervention

## Conclusion

Stroke is considered as an illness of the family and an intervention which considering the family members of the stroke survivors is the need of the time.

## Introduction

Stroke is one of the leading causes of morbidity and disability and it is considered one of the major public health concerns of the world (Go et al 2014). It is a major cause of disability that affects 32.2 million people around the world (Feigin et al.,2017). And recovery of stroke is a long-term process and most of the rehabilitation occurs at home. So that most of the stroke survivors were in need of an assistance from the family caregivers (Devi et al 2002). Family caregivers mainly include partner, relatives, son or daughter or parents who involved in the care of chronic disabling condition such as stroke (Alliance et al 2006).

Stroke survivor is part of the family and this can lead to dramatic changes in the family resulting in significant burden and paucity of the resources in the family. The changes which happened due to the illness were found to be irreversible in a healthy family member (Evans et al 1986). Stroke will have an increasing effect on the physical and emotional well-being of the caregivers (AHA 1993, NSA 1994). The long-term rehabilitation and care will be the family's responsibility and so stroke was called as a family's illness (Brocklehurst et al 1981). In acute illness, the patient is usually hospitalized and the medical staff bear the responsibility to treat the patient. While in chronic and disabling condition like stroke, patient lives at home, and depends on the family for the ongoing care and treatment.

This family caregiving of the stroke survivor will have an increased stress, related to the biographic disruption of life experienced and it will limit their ability to utilize internal and external resources in dealing and coping with their daily problems (Greenwood and Mackenzie, 2010). Caregivers stress commonly associated with long-term institutionalization of the stroke survivors (Gaugler et al 2007). Caregiver stress can result in several negative outcome such as interfere with rehabilitation of the survivor, social isolation and increased risk of mortality for the caregivers (Schulz, R 1999). Caregiving stress can also result from meeting the daily demands of the survivor with physical, emotional and cognitive as well as impaired communication and social skills (Williams, 1994). There are chances of having hardships in the family relationship such as blaming, denial of the illness, grieving associated with the illness, rejection of the person with illness, over protectiveness, worry about the responsibilities of caring, problems of interacting with the medical system, reduced options for family interaction, increased financial burden and over all increase in family tension (Mishal and Murdaugh 1987).

## Methodology

### Design

This study adopted qualitative interviews with different stakeholders of stroke survivors and conducted a literature search to develop an intervention program for caregivers of stroke survivors. The researcher developed an interview guide to understand the needs of the caregivers. In-depth interviews were conducted with experts in the field of working with stroke and with caregivers of stroke survivors. The interview guide is attached in Table 1.1. A literature search was also conducted and the findings were triangulated with the results from the expert interviews to identify the needs of the caregivers.

## Setting

The study was conducted at the Department of Neurological Rehabilitation Centre in a tertiary care centre in South India. Experts from different departments, such as Psychology, Nursing, Physiotherapy, Occupational Therapy, Physiatry, and Social Work, who work with stroke survivors, were involved in this study. Additionally, caregivers from the Neurological Rehabilitation Center were also included to identify the needs of the caregivers.

## Data collection

The data was collected using in-depth interviews with caregivers and experts. The interview guide was prepared through a literature search and consultations with experts in the field. The interview guide was able to capture the needs of the caregivers of stroke survivors

## Ethical consent

The study was part of an ongoing Ph.D. program focused on the development of a family-centered intervention for family caregivers of stroke survivors- a feasibility study. Ethical clearance was obtained from the institute's ethical committee. The participants were informed about the study, and informed consent was obtained from them before their participation

## Data analysis

The interviews were recorded and later transcribed. Codes were generated from the transcriptions, and they were validated by peer research scholars who were not part of the study. After identifying the codes, they were further validated by experts, and the final themes, representing the needs of caregivers of stroke survivors, were identified. Based on the identified needs, a literature search was conducted to develop an intervention program. After the program was developed, its content was evaluated

## Results

The interview mainly resulted in the themes such as information needs, financial needs, welfare needs, personal needs, treatment needs and emotional needs

### Information needs

All the experts and caregivers of stroke survivors were expressed the needs to understand about the illness. They want to know about the prognosis, nature and treatment options, how long the treatment has to be continued etc. so in the intervention program there should be a component to teach the caregivers about the illness and it will enhance the caring for the stroke survivors.

### Financial needs

Stroke is considered as a long term illness and have an impact on the finances of the family will be affected. The experts and caregivers reported that there have issues with buying medicines, coming for follow up, other costs such as household expenses, child's education, travelling expenses etc.

## **Welfare needs**

The welfare needs mainly include the welfare benefits from the government. It mainly restricting towards the disability certification and getting the disability pension. The other welfare schemes can be used for the patient to help in the treatment cost in the hospitalisation. The person with stroke and having a disability for more than 6 months will be eligible to avail the disability certificate and utilise the benefits of the same.

## **Personal needs**

The caregivers and experts are identified it is important for the caregivers to spend time for their own needs. They have difficulties to attend family function and other personal activities, and some caregivers reported disturbance in sleep and appetite related to the caregivers role. These are mainly due to the improper ways to address their personal care needs.

## **Treatment needs**

The caregivers and the experts were identified the needs of the patient to continue the treatment. How to avail the follow up appointments and how long these treatment has to be carried out and the problem related to transportation for the follow up appointments etc. occupational therapist and physiotherapist were not available in the locality, so there won't be any proper follow up treatment possible. These are one of the major concerns of the caregivers of the stroke survivors.

## **Emotional needs**

The experts are identified that the caregivers should be mentally and physically fit to care the stroke survivors. If they were not fit to take care of the survivors then proper caring may not be possible. Also the caregivers reported that sometimes they will be feeling low, will be tired of taking care of the survivor, there will be burden of role multiplicity. So these needs has to be addressed in the sessions of the psychosocial intervention for the caregivers.

After identifying these needs such as the informational needs, financial needs, welfare needs, personal needs, treatment needs and emotional needs a comprehensive intervention program were developed with the consultation of the experts in this field.

## **The intervention will be having the following sessions**

1. Educating about the illness
2. Session on coping skills of caregivers
3. Session on problem solving skills of the caregivers
4. Session on communication skills of the caregivers
5. Session on role modification of the caregivers

## Educating about the illness

### Psycho-education on stroke

Psychoeducation sessions for caregivers of stroke survivors can provide important information and support to help caregivers manage the demands of caregiving and improve their well-being

**Introduction:** Begin the session by introducing yourself and any other facilitators, and providing a brief overview of the purpose and goals of the session.

**Overview of stroke:** Provide an overview of stroke, including its causes, symptoms, and types. Discuss the impact of stroke on the survivor's physical and cognitive functioning, as well as the emotional and psychological impact on both the survivor and caregiver.

**Educate about the risk factors for stroke:** This includes learning about the various factors that can increase the likelihood of having a stroke, such as high blood pressure, diabetes, smoking, and physical inactivity.

**Discuss the signs and symptoms of stroke:** It is important to know the signs and symptoms of stroke, such as sudden numbness or weakness in the face, arm, or leg, especially on one side of the body; sudden confusion or trouble speaking or understanding; sudden trouble seeing in one or both eyes; sudden trouble walking, dizziness, loss of balance or coordination; and sudden severe headache with no known cause.

**Immediate measures to take in case of a stroke:** This includes understanding the importance of calling for ambulance immediately if stroke is suspected, as well as being familiar with the steps to take to manage the situation until help arrives.

**Understanding stroke treatment options:** This includes learning about the various treatments that are available for stroke, such as medication, surgery, and rehabilitation.

**Lifestyle changes:** This involves making changes to one's lifestyle to reduce the risk of having a stroke, such as quitting smoking, exercising regularly, maintaining a healthy diet, and managing chronic conditions like high blood pressure and diabetes.

**Stroke prevention:** This includes understanding the importance of preventive measures such as regular health check-ups, controlling blood pressure, cholesterol and blood sugar levels, and taking medications as prescribed.

**Recovery and rehabilitation:** This involves learning about the recovery process after a stroke and the various rehabilitation options that can help a stroke survivor regain their strength, independence, and quality of life.

## Session to improve the coping the skills of the caregivers of stroke

Caring for a stroke survivor can be a challenging and stressful experience for caregivers. Coping skills can help caregivers manage the demands of caregiving and maintain their well-being.

**Understanding stress:** Discuss the impact of stress on caregivers, including the physical, emotional, and cognitive symptoms of stress. Provide an overview of the stress response and the importance of managing stress for caregiver well-being.

**Identifying coping strategies:** Discuss a variety of coping strategies that caregivers can use to manage stress, including relaxation techniques, mindfulness, exercise, and social support. Encourage caregivers to share their own coping strategies and experiences.

**Building resilience:** Discuss the concept of resilience and how it can help caregivers manage the challenges of caregiving. Provide strategies for building resilience, such as cultivating optimism, practicing self-care, and seeking social support.

## Session to improve Problem solving skills for the caregivers

Problem-solving skills are important for caregivers of stroke survivors, as they often face complex and challenging situations. Here is an outline of a potential problem-solving session for caregivers of stroke survivors:

**Overview of problem-solving:** Provide an overview of the problem-solving process, including defining the problem, generating solutions, evaluating options, and implementing and monitoring the solution. Discuss the importance of problem-solving skills for caregivers and the benefits of effective problem-solving.

**Identifying problems:** Provide examples of common problems that caregivers of stroke survivors may face, such as medication management, mobility issues, and communication difficulties. Discuss the importance of identifying problems early and seeking appropriate support.

**Generating solutions:** Provide strategies for generating solutions to problems, such as brainstorming, consulting with healthcare professionals, and researching available resources. Encourage caregivers to share their own strategies and experiences.

**Evaluating options:** Discuss the importance of evaluating the pros and cons of each potential solution, and provide strategies for doing so, such as creating a decision matrix or weighing the risks and benefits of each option.

**Implementing and monitoring the solution:** Discuss strategies for implementing the chosen solution, including creating a plan of action, identifying potential barriers, and seeking support as needed. Discuss the importance of monitoring the solution and making adjustments as needed.



**Communication and teamwork:** Discuss the importance of effective communication and teamwork in problem-solving, and provide strategies for working collaboratively with healthcare professionals and other members of the care team.

**Conclusion:** Allow time for questions and discussion, and provide caregivers with additional resources and information to support their problem-solving skills.

Overall, problem-solving sessions can provide important support to caregivers of stroke survivors, helping them effectively manage the challenges of caregiving and provide high-quality care to the survivor. It is important to tailor the content and delivery of the session to the specific needs and preferences of caregivers, and to provide a supportive and compassionate environment for learning and discussion.

### **Session on communication skills**

Effective communication is essential for caregivers of stroke survivors, as it can help improve the quality of care provided to the survivor and reduce stress for the caregiver. Here is an outline of a potential communication session for caregivers of stroke survivors:

**Introduction:** Begin the session by introducing yourself and any other facilitators, and providing a brief overview of the purpose and goals of the session. Allow time for caregivers to introduce themselves and share their experiences and concerns.

**Understanding communication:** Discuss the importance of effective communication for caregiver well-being and the quality of care provided to the stroke survivor. Provide an overview of the communication process, including verbal and nonverbal communication, active listening, and assertiveness.

**Active listening:** Provide strategies for active listening, such as paying attention to nonverbal cues, paraphrasing, and asking open-ended questions. Discuss the importance of empathy and validating the survivor's feelings and experiences.

**Assertiveness:** Discuss the importance of assertiveness in communication, and provide strategies for assertive communication, such as using "I" statements, expressing feelings and needs, and setting boundaries.

**Nonverbal communication:** Discuss the importance of nonverbal communication in caregiving, and provide strategies for improving nonverbal communication, such as using appropriate body language, maintaining eye contact, and using touch.

**Dealing with difficult communication situations:** Provide strategies for dealing with difficult communication situations, such as disagreements with healthcare professionals or conflicts with the survivor. Discuss the importance of staying calm and maintaining a respectful tone.

**Cultural and linguistic considerations:** Discuss the importance of cultural and linguistic considerations in communication, and provide strategies for effective communication with diverse populations.

**Conclusion:** Allow time for questions and discussion, and provide caregivers with additional resources and information to support their communication skills.

Overall, communication sessions can provide important support to caregivers of stroke survivors, helping them effectively communicate with healthcare professionals and the survivor, reduce stress and improve the quality of care provided. It is important to tailor the content and delivery of the session to the specific needs and preferences of caregivers, and to provide a supportive and compassionate environment for learning and discussion.

### **Session on role modification for the caregivers**

After a stroke, many survivors may need to modify their roles and activities to adapt to changes in their physical and cognitive abilities. Here is an outline of a potential role modification session for stroke survivors:

**Introduction:** Begin the session by introducing yourself and any other facilitators, and providing a brief overview of the purpose and goals of the session. Allow time for survivors to introduce themselves and share their experiences and concerns.

**Understanding role modification:** Discuss the importance of role modification in stroke recovery, and provide an overview of the role modification process, including identifying current roles and activities, assessing physical and cognitive abilities, and developing a plan for modification.

**Identifying roles and activities:** Provide strategies for identifying current roles and activities, such as making a list of daily tasks, reflecting on pre-stroke activities, and consulting with caregivers and healthcare professionals.

**Assessing physical and cognitive abilities:** Provide strategies for assessing physical and cognitive abilities, such as working with a physical or occupational therapist, and using cognitive assessment tools.

**Developing a plan for modification:** Discuss strategies for developing a plan for role modification, such as setting realistic goals, breaking down tasks into smaller steps, and using adaptive equipment or technology.

**Coping with emotional reactions:** Discuss the emotional reactions that may occur during role modification, such as frustration, grief, and loss, and provide strategies for coping with these reactions, such as seeking social support, engaging in enjoyable activities, and practicing mindfulness.

**Implementing the plan:** Discuss strategies for implementing the plan for role modification, such as gradually increasing activity levels, monitoring progress, and adjusting the plan as needed.

**Conclusion:** Allow time for questions and discussion and provide survivors with additional resources and information to support their role modification efforts.



Overall, role modification sessions can provide important support to stroke survivors, helping them adapt to changes in physical and cognitive abilities, set realistic goals, and engage in meaningful activities. It is important to tailor the content and delivery of the session to the specific needs and preferences of survivors, and to provide a supportive and compassionate environment for learning and discussion.

## Discussion

This study aimed to identify the needs of caregivers of stroke survivors and develop an intervention program to address those needs. Several studies have explored the needs of caregivers of stroke survivors, which align with our current study. Li et al. (2017) conducted a study titled 'Needs and rights awareness of stroke survivors and caregivers: a cross-sectional, single-center questionnaire survey' and found that caregivers primarily required psychological support, social support, treatment and care, and information. In our manual, we have included sessions on these domains to address these needs.

Another study by Silva et al. (2020), titled 'Needs for family caregivers of Cerebrovascular Accident survivors,' identified needs such as early health education on the disease, restructuring of care for family caregivers, and the need for personal time and self-care. Our manual includes education about the illness, discussions on coping skills, and problem-solving strategies to address these needs of caregivers.

Lu et al. (2022) conducted a study titled 'Needs of family members caring for stroke survivors in China: A deductive qualitative content analysis study using the caregiver task inventory-25' and identified needs such as learning to cope with the new role, providing care according to the care recipient's needs, managing one's emotional needs, appraising supportive resources, and balancing caregiving needs with personal needs. These needs align with the ones identified in our study, and our manual will address them accordingly.

A systematic review by Alexandra et al. (2020) titled 'The long-term unmet needs of informal carers of stroke survivors at home: a systematic review of qualitative and quantitative studies' identified needs such as obtaining adequate information, self-care, service accessibility, emotional and psychological support, and relationships. Additionally, a systematic narrative review by Zawawi et al. (2020) identified caregiver needs ranging from information needs to support in caring for stroke survivors and taking care of themselves.

Considering the findings from all these studies, the manual for caregivers of stroke survivors has been developed, aiming to address their information needs, coping strategies during the illness, and self-care practices. The feasibility of this manual can be further tested with caregivers of stroke survivors.

## Conclusion

Stroke is recognized as a family illness, emphasizing the significance of caring for the family caregivers of stroke survivors. In the present study, we have developed a manual based on the identified needs of stroke caregivers to facilitate their care. The manual aims to address these needs in the most effective manner, ensuring that the caregivers can provide the best possible care for the stroke survivors. This, in turn, will contribute to the speedy recovery and well-being of the stroke survivors

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