

Original Articles

Post Stroke life in Iranian people: used and recommended strategies

Asghar Dalvandi, PhD Student ^{1,2}, Sirkka- Liisa Ekman¹, PhD.; Sadat Seyed Bagher Maddah², PhD.; Hamid Reza Khankeh², PhD.; Kristiina Heikkilä, ^{1,3}, PhD.

1. *Department of Neurobiology, KarolinskaInstitutet, Stockholm , Sweden;*

2. *University of Social Welfare and Rehabilitation Sciences, Rehran, Iran;*

3. *School of Health Science and Social Work, Växjö University, Växjö, Sweden*

Objectives: Stroke survivors develop their own strategies to combat disabilities, developing strategies to maintain or reestablish a sense of continuity after the disruptive life event that stroke represents, using strategies to foster hope during the process of adjusting to life after stroke and drawing on spiritual practices. The aim of this study is to identify the used and recommended strategies of life after stroke among Iranian people.

Method: A grounded theory approach was recruited using semi-structured interviews with 10 stroke survivors, 12 family caregivers and 6 formal care givers.

Results: Five main concepts emerged describing as the used and recommended strategies of the participants including, improving functional performance, re-learning life skills and educational support, accessing to rehabilitative services, socio-economical support and well-suited coping strategies.

Conclusion: Participants valued better knowledge and skills regarding the adaptive strategies for stroke survivors and their family care givers are essential in accomplishing with activities of daily living and doing social roles for improving life after stroke. Also developing the socio- economic supports is crucial for assuring a more supportive approach to achieve rehabilitation services and design better educational program for them.

Keywords: Stroke survivors lived, used and recommended strategies, life modification

Submitted: 8 Dec 2008

Accepted: 5 Feb. 2009

Introduction:

Stroke is a major cause of disability and death worldwide, it affects 15 million people globally and 60% either die or are permanently disabled as a result of stroke. (1). The incidence of stroke per 100,000 per year in Western countries is between 100 to 300 per and in Iran are 372 (2,3,4). Stroke is a multifaceted disease with physical, psychological, and behavioral problems differing among survivors. Even those with similar types

of impairment may experience differences in degree of severity, trajectory of recovery, and social and financial resources (5).

Making an appropriate strategy is an important step in improving life for so many stroke survivors and their caregivers and may affect the success of rehabilitation and minimize the negative effects of recurrent stroke to the stroke sufferers and their families (6). developing strategies to maintain or re-establish a sense of

1. Correspondence: Dr. Asghar Dalvandi, Email: asghar.dalvandi@uswr.ac.ir

continuity after the disruptive life event that stroke represents (7,8); using strategies to foster hope during the process of adjusting to life after stroke and drawing on spiritual practices (9). There is limited information about used and recommended strategies on life situation after stroke among Iranian stroke survivors, their family care givers and formal care. This study was an attempt to identify the used and recommended strategies in this regards, as part of a more comprehensive project. It is hoped that the findings of this research will be useful for stroke survivors, their family care givers and also health administrators, health providers and educators to consider when designing strategies and educational practices in stroke rehabilitation.

The aim of this study is to identify the challenges and related strategies in life experiences and perceptions after stroke among stroke survivors, their family care givers and formal caregivers. The research questions are: What are the used strategies that participants experienced them on life after stroke? What strategies do they recommended for better life after stroke?

Method:

A qualitative study was conducted using individual interviews with participants in a grounded theory approach. The term grounded theory reflects the concept that theory emerging from this type of work is grounded in the data (10). Since recognition of facilitating factors and barriers is the first step in persuading participants to make better decisions about preventive and protective care, this study focused on the experiences, views and perceptions of Iranian stroke survivors, their family care givers and formal care givers views about challenges and related strategies about life situation of survivors. The data were collected and analysed during a 6-month period in 2006–07.

Participants and data collection: The participants for the study were selected initially using purposive sampling and then with theoretical sampling according to the codes and categories

that emerged from the interviews. Sampling started from a neurology ward in hospital in north of Tehran and the Clinical neurology for stroke survivors and then was extended to the participants' home or workplace. The criteria for selection were stroke survivors aged 55 to 70 years, maximum 12 month after stroke and for family care givers were to live with stroke survivors in their home. The aim of qualitative research is not to randomly select individuals in order to manipulate, control and generalize findings, but to gain a greater understanding of the phenomena (10). Data collection began with stroke survivors, their family care givers and formal caregivers.

The inclusion criteria for the stroke survivors was that they had been discharged from the hospital since the first Feb 2007 up to July 2007, were 55–70 years old, had suffered a stroke within the past 3–6 months, and resided in an urban area in Tehran.

Stroke survivors were selected purposefully. The researcher was referred to hospital and rehabilitation clinics formally and asked for permission to undertake the study. The documents were reviewed more than 400 cases. Based on inclusion criteria, 59 patients were included and contacted by telephone. Many persons refused to take part in this research due to various reasons: ten of them were not ready to taking part in any research, nine of them refused to let a stranger to their homes and six of them were tired as they had been interviewed with other researcher before. Finally, the procedure went on until 10 persons agreed to participate and were observed and interviewed together with 12 of their family caregivers. The observations and interviews were conducted on the survivor's homes.

After the permission and reviewing more than 400 documents and then selected 35 persons based on inclusion criteria and contacted by telephone at their homes. All Family care givers were selected among family members who have been responsible to take care for survivors such as offspring, wife or husbands.

Six formal caregivers working in a nursing home

and in stroke survivors' home were interviewed. The formal caregivers were selected with inclusion criteria such as: minimize two years experienced with stroke care, to have minimized bachelor or upper grades. The demographic characteristics of the participants are presented in Table 1.

Table 1: Characteristics of participants

participant	Age range	Employment	Gender
Stroke survivors persons 10	55-70	Official staff (2 persons) retirement (2 persons) worker (3 persons) household (3 persons)	Female 4 persons Male 6 persons
Family caregivers persons 12	20-68	Official staff (2 persons) retirement (1 persons) worker (3 persons) household (6 persons)	Female 6 persons Male 6 persons
Formal caregivers persons 6	28-54	RN 3 persons MSN Nurse 3 persons	Female 2 persons Male 3 persons

Interviews and observation

The researcher contacted each of the potential participants to explain the research objectives. If the participant agreed to take part in the research, an interview was scheduled. Based on the participant's request, interviews were carried out at the stroke survivor's home or clinic. Individual semi-structured interviews were conducted in a private place. The interview guide was initially developed with the help of expert peers and consisted of some open-ended questions to allow respondents to explain their own views and experiences as fully as possible.

At the beginning of each interview, the participants were asked about their concept of stroke, and what they understood by prevention, cure and rehabilitation, and then to explain their own experiences and perceptions about factors affecting on their life situation after stroke. For example, they were asked: "In your view, what is the meaning of life after stroke?" or "What factors facilitate were important in your life?" and "Explain some of your experiences in which you have made decisions which you think were better in your life". During the interviews, notes were made about the topics raised by the participants and these were raised later if participants had not

already spontaneously responded.

Some of these topics helped the researchers to develop an interview guide over time. The interviews were carried out by the researcher and were tape-recorded. Then, these records were transcribed verbatim and analyzed consecutively. Every interview took 1–2 sessions depending on the tolerance and interest of the participants in explaining their own experiences. The duration of each session was between 30 and 60 minutes, with an average of 45 hours.

During interview researcher have been observed and considered all situations around the participants and focus on what participants said about doing one thing but in reality they are doing something else, participants may not be consciously aware of, or be able to articulate, the subtitles of what goes on in interactions between themselves and others.

Qualitative analysis. Data from the interviews were analyzed concurrently using the constant comparative method. Open, axial and selective coding was applied to the data. During open coding, the transcript of each interview was reviewed multiple times and the data reduced to codes. The codes that were found to be conceptually similar in nature or related in meaning were grouped into categories. Codes and categories from each interview were compared with codes and categories from other interviews for common links. Interviewing stopped when data saturation occurred.

Saturation refers to the repetition of discovered information and confirmation of previously collected data. Data were considered "saturated" when no more codes could be identified and the category was "coherent" or made sense (11).

Validity. The conformability and credibility of the data were established in 3 main ways: (i) Participant's revision, (ii) in-depth prolonged engagement with data and (iii) faculty member's revisions. The participants were contacted after the analysis and were given a full transcript of their coded interviews with a summary of the emergent themes to determine whether the codes and themes were true to their point of view (member check). As a further validity check, faculty members checked about half of all transcripts (peer check). The results were also checked with some women

who did not participate in the research and they confirmed the aptness of the results as well. The researcher documented the steps followed in the research and the decisions made to save the audit ability for other researchers to perform the steps of the research in future studies (12).

Ethical considerations. The scientific research committee of social welfare and rehabilitation Sciences University approved the research. The ethical procedures for the study assured the confidentiality and autonomy of the participants. All participants were informed of the purpose and design of the study and the voluntary nature of their participation. Consent was sought from the participants for the audio-taping of interviews.

Results:

Based on findings of this study, 5 main categories and 29 subcategories were emerged. Physical activity, Role performances, Family function, relearning life skills, accessing to rehabilitative services, socio-economical support and coping mechanism were extracted as the majors' strategies (facilitators) of life after stroke.

Related sub categories were including :in life after stroke were mobility, self-care and self-responsibility, Self-care and self-responsibility , using of home services ,education by expert, encourage by kinds ,empower family, Life satisfaction , Family integrity , high level of education, Medical and rehabilitation recommendation ,Home Reinstalling, independency, physical activity, positive view to event, self confidentiality& self-efficacy, informational support, Consciences to fear (present, future), Use of mass media, accessibility to care and rehabilitation services, Instrumental support (IADL), help from social network, emotional support , Sense of belonged to and value by others ,having social insurance &financial support, Faith and believe in GOD and Making travel to other places.

The Emerged categories and their subcategories of the participants are presented in Table 2.

Table 2: Emerged categories and their subcategories

Categories	strategies (subcategories) Or (Facilities)
Functional performance	Physical activity Mobility Self confidentiality& self-efficacy Self-care and self-responsibility Independency Using of home services
Educational issues	high level of education Informational support Using of mass media Medical and rehabilitation recommendations
Care and rehabilitation services	Accessibility to care and rehabilitation services Effective services Home Reinstalling
Socio-Economical situation	having social insurance Having financial resource Helps from social network Sense of belonged to and value by others
Coping mechanism	accepting of reality Worshipping (praying) Faith and believe in GOD Making travel to other places

Based on participant's experiences and their viewpoints in this study, functional performances are divided into three subcategories including: physical activity, role performance and family functions.

Physical activity as a strategy: the result of this study has shown that, some stroke survivors by helping family and formal caregivers move to other place and after stability they are being taken out to see friends, even movies, travel to other cities, their family supported them emotionally and spiritually and its cause to be active in their life's, they used to rehabilitate services in their home and also took so many recommendations related physical activities.

One participant described an experience: "while I was coming to this centre, I saw lots of facilities there, rehabilitation team made practice physically and also I took more recommendation from them to practise at home, I am satisfied by these services because I can free body limitation". (p8)

Role performances as a strategy: Many stroke survivors perceived that doing role by themselves despite of some limitation due to stroke is very important, because it encouraged them to be

independent as soon as possible. In life and help them to return to primary role, this process increases sense of self-confidence until they can become independent, of course, when they are supported by family members and formal caregivers, this period will be shorter than they don't get support. In this regard, one participant described an experience: "I appreciate family members to give me more encouragement to be active in daily life and I hope I can go back to past as I need to take care by myself, because no one always can take care of me".p9 Another participant responded: "My family members depend on me and I am responsible to them".(p 3)

Family function as a strategy:

Findings shown that despite of this occurred event, family is seeking to use new information related to how to deal with this event and how to take services for stroke survivors and also family could manage in assisting of health care provider's recommendation and their resources. They could preserve integrity and power in their family and respect to survivors to give sense of intimacy.

One participant described that: "I love my family, during this time I understand how much they belonged to me and faith in me, they are doing everything that they can, they gave me sense of being together again and hope I can compensate "(p4)

Relearning as a strategy: Based on this study we need to cover and support stroke survivors and their family care givers with an appropriate discharge planning program, also it is necessary to provide special training courses for formal and informal care givers, how to care and rehabilitate for stroke survivors and their family care givers toward healthy life. Information support, using of special program in mass media and also taking medical and rehabilitation recommendation were the most items related to participants. In this regard one participant quoted: " the provision of supportive education is necessary for stroke survivors and their family caregivers from

hospital to home".(Fo-C 1) another expressed: "I need to learn, some times on radio and television they have programs about stroke recovery. I listen how to, use the information. Tools are very important and can help us to improve our situation".(p6)

Available rehabilitative care services as a

strategy: Good accessibility of services was seen as a facilitating factor for nursing rehabilitation as a new domain in Iran. The period of hospitalization for stroke patients is made about three weeks. Thereafter, the patients and their families are educated and cared for at their homes. Participants in this study experienced that rehabilitation unit might be extended by government and non-Government organization within the cities and country in order to access for them , these services which must be covered by social insurances by

governmental centers and private insurance agencies , they urged that caring services also be available and be covered by insurances companies to give them home care services, "Nurses are so valuable, because they can give patients and their family a sense of advocacy and morale besides the care being delivered, this is a fact, and I do emphasize that the role of nurses for patients is vital and important". (p1)

"If somebody came to our home for caring and helping us it would be fantastic. All family members have lost their energy and in times, we are so tired and agitated." (fa-C3)

Socio-economic support as a strategy; social support from family, from community and from a close personal relationship each has a beneficial effect in stroke patient, Participants regarded their friends or family as a source of encouragement to seeking social supportive resources. The concepts grounded under this category called social networking included social support from a family member (husband, children or sisters), support from friends, knowing someone with stroke or knowledge about related health promotion programs in the popular media, especially television health programs. These kinds of activities take stroke survivors to enforce them

sense of belonging to others and also friendship, having social insurance and financial aids from their family and relatives networking can cause sense of self confidence and self sufficiency in stroke survivors.

Regarding this subjects one participant quoted: "If somebody, some organization could help us, it would make my life like heaven". (P1), another one said: "Definitely, one of the most important necessities for every human being in the world is social insurance that supports people with stroke so they have stable community. We also need some social supportive network system to help and support us". (p3)

"During these times my family network visited and encouraged me to be happy and satisfied, I am so grateful to them because they come at my home to give a lift again." (p2)

Appropriate coping as a strategy

Despite of existence problems for stroke survivors and their family care givers, they tried to accept reality and they actually believe in GOD and to attract GOD consent for achieving to higher level of ability and mastery of situation by assisting of formal care givers and rehabilitation teams.

In this regard one participant said: "coping for them is so difficult because of the lack of experience but nurses could assist them to accept problems and limitations and also introduce facilities and resources to stroke survivors".

Other quoted: "In Iran according to family that is pivot, it should be reinforced and empowered (FO -c2), another participant told: Faith and believe in GOD and worshipping are so important to accept this tragedy event and also God gives me patience to be relaxed". (P4)

pointed out: "I experienced, if stroke survivors motivated to move early and taken related knowledge at home, it [stroke] could be better recovered.... and ...would prevent further limitation in physical, psychological and social functions and also stroke relapse". (Fo-c1).

Discussion:

Based on this study result, researcher inferred that five groups of concepts can make used and recommended strategies on life after stroke for

stroke survivors, their family care givers and formal care givers.

Participants perceived that functional performances are the pivotal keys in life after stroke. At the first time after discharge from hospital, stroke survivors and their family care givers try to find existence potentials and redefine all recourses again and looking for new ways to help them for achieving the best situation after stroke.

The findings also identified that sense of self confident can stroke survivors go back to life. in this regards one participants pointed out: for doing roles, despite of physical limitation, it encourage me to reach self care, then self- responsible until I could be independent again, in this way, role of family care givers and formal care givers are very important to advocate and support me to reduce my fear and learn me to use some instruments such as (can, walker, wheelchair, wall-handle in toilet and kitchen).

Others finding shown that stroke survivors and their family care givers have experienced some challenges and have been trying to find, how to organize this situation. Insufficient financial and social supports don't let them to use existence home care and rehabilitation services as well. Far from rehabilitation centers and transporting were other challenges in front of them.

Uncovering these services by social insurances agencies is the most important challenges for them, and they have to expense more family's incomes for home care and rehabilitation services.

Depend on family's atmospheres and level of education which are differences between them, having or not having information, medical and rehabilitation recommendations are so important as challenges and related strategy for stroke survivors and their family care givers.

Changing in life styles and loads of bio-psycho social exceeds tasks in post stroke life could caused family burden and lost of energy.

Insufficient education and train to know how to cope with new situation and how to use of rehabilitation instruments in home and

incompatible home environments and community are other barriers which they have faced. Despite of having a relative networking, after sometimes, cause of bilateral communications, slowly slowly, these relationships are going to less and at the results limitations and isolations come to them.

More finding of this study is confirmed by some domain of new International Classification of Functioning, Disability and Health as well as activity and participation which is defined by World Health Organization such as learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interaction and relationships; major life areas; and community, social, and civic life (13).

After event, good financial let them to supports and use some facilities such as formal care givers and rehabilitations services at their homes, this situation encourage survivors for better motions and functions and also protect families to not be more effort and prevent them from losing of energy and burden.

Such related strategy which are consistent with a care and recovery paradigm, have been reported to be positively correlated with rehabilitation outcomes in stroke survivors as in some qualities research studies have been told, survivors of stroke see their recovery as a return to the existence they had lived before, having their stroke, encompassing all the dimensions of that existence (14, 15,16).

Using of care givers also get opportunity for families to make better emotional communication with stroke survivors and their relatives and protect them to limitations and isolations. This finding confirmed many previously reported findings (17). They preserve family powers and abilities for living and despite of remaining of some problems cause of stroke, they are accepted this real event and trying to cope with new situation and being satisfied with life.

A strong faith in God and in God's actions was observed as a good coping with situation for the

participants in this research. Salvatore Giaquinto (2007) we found that faith is associated with emotional distress, which is a multifactor process negatively affecting quality of life. Religious and spiritual beliefs should be considered, because they have a weight in such complication (18).

Our results indicate that stroke survivors and their family care givers with the low level of performances, were worker, housekeepers and less educated. As The participants' fear emerged variously as a facilitator or as a barrier in the context of life after stroke, currently; however, it is unclear whether fear acts as a barrier or a facilitator in life's behavior.

The present research found that social networks are important because they serve as a source of advocacy and health information. Participants emphasized that spouse advocacy is one of the major facilitators to individual readiness to attend social activities. And the role of their family (wife/husband/children/sister) and friends in preparing survivors to make effective decisions seems to have the greatest facilitator effect in this regard.

Conclusion:

Participants valued better knowledge and skills regarding the adaptive strategies for stroke survivors and their family care givers are essential in accomplishing with activities of daily living and doing social roles for improving life after stroke. Also developing the socio- economic supports is crucial for assuring a more supportive approach to achieve rehabilitation services and design better educational program for them.

Acknowledgements

We gratefully acknowledge the very helpful participation of the participants, as well as the staff from neurology ward in Shohada hospital and Rofeideh neurogy clinic without whose contribution this study would not have been completed. The official support of the University of social welfare and Rehabilitation sciences in Iran is also acknowledged.

References:

- 1-Sharon ,O.K . Predictors of life satisfaction among stroke survivors and spousal caregivers: a narrative review. *Journal of Aging Health*, 2008; 4(3):241-252.
- 2-Dalvandi, A. Heikkilä, K, Maddah, S.S.B., Khankeh, HR., Ekman, S.L. Life experience after stroke among Iranian stroke survivors, *International Nursing Review*, accepted, Sep 2009.
- 3-Glamcevski II, M. T. & Pierson, J. Prevalence of and Factors Associated with Poststroke Depression: A Malaysian Study. *Journal of Stroke and Cerebrovascular Diseases*.2005; 14: 157-161.
- 4-Singh RB, Suh, I. L., Singh, V. P., Chaithiraphan, S., Laothavorn, P., Sy, R. G .,and et al. Hypertension and stroke in Asia: prevalence, control and strategies in developing countries for prevention. *J Human Hypertension*. 2000; 14:10-11.
- 5-Salman.R, R., Tabatabaei, S. S., Hoseini, S. G., & Maleki, S. Acute stroke epidemiology in Iran. In *Stroke Rehab symposium Official journal of the -UEMS European*. May,2006.
- 6-Oswald, S.K. Predictors of life satisfaction among stroke survivors and spousal caregivers: a narrative review. *Journal of Aging Health*. 2008;4(3): 241-252.
- 7-Hoffman J. 'Nothing can be done': social dimensions of the treatment of stroke patients in a general hospital. *Urban Life & Culture journal*. 1974; 3: 50–70.
- 8-Becker, G. Continuity after a Stroke: Implications of Life-course Disruption in Old Age. *The Gerontologist journal*.1993; 33(2):148-158.
- 9-Stanhope, M. & Lancaster, J. *Community & public health nursing*. 5th Edition, New York.,St. Louis: Mosby Co. 2000. pp;419-524.
- 10-Steubert HJ, Carpenter DR . *Qualitative research in nursing: advancing the humanistic imperative*, 3rd ed. New York, Lippincott, Williams and Wilkins. 2002;161-178.
- 11-Corbin,J. & Strauss, A. *Basics of qualitative research* (3rd ed.)Sage Publication ,Inc.Thousand oaks,California. 2008: pp; 159-170.
- 12-Gbenga O et al. Perceptions of barriers and facilitators of cancer early detection among low-income minority women in community health centers. *Journal of the National Medical Association*. 2005); 97(2):167–70.
- 13-W.H.O. *Toward a common language for functioning, disability and health (ICF)*.Geneva:2002.avaliabile :URL:http://www.who.int.
- 14-Thompson ,H.S., Ryan, A . *British Journal of Neuroscience Nursing*.2008: 4T(4);177 – 184.
- 15-Doolittle N. The experience of recovery following lacunar stroke. *Rehabilitation Nursing journal*. 1992: 17; 122–125.
- 16-Dowswell, G., Lawler, J., Dowswell, T., Young, J., Forster, A., & Hearn, J. Investigating recovery from stroke: a qualitative study. *Journal of Clinical Nursing*. 2000: 9; 507-515.
- 17-Friedland JF, McColl M. Social support interventions after stroke: results of a randomised trial. *Arch Phys Med Rehabilitation*. 1992: 73; 573-81.
- 18-Giaquinto, Salvatore; Spiridigliozzi, Cristiana Caracciolo, ; Barbara (2007) *Can Faith Protect From Emotional Distress After Stroke?*. *Stroke Journal*. 2007:38;993.