

Everyday Life Condition in Stroke Survivors and Their Family Caregivers in Iranian Context

Asghar Dalvandi^{1,2}, PhD; Hamid Reza Khankeh², PhD; Sirkka-Liisa Ekman¹, PhD; Sadat Seyed Bagher Maddah², PhD; Kristiina Heikkilä¹, PhD

¹Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden;

²University of Social Welfare and Rehabilitation Sciences, Tehran, Iran

Corresponding author:

Asghar Dalvandi, RN, MsN, PhD; Department of Nursing, University of Social Welfare and Rehabilitation Sciences, Koodakyar St. Daneshjoo Bolv, Evin, Post Code:19834, Tehran, Iran

Tel/Fax: +98 21 22180036; Emails: asghar.dalvandi@gmail.com, asghar.dalvandi@ki.se

Received: 2 October 2012 Revised: 18 November 2012 Accepted: 8 December 2012

ABSTRACT

Background

Stroke is an unexpected major life incident that effect on physical functioning and can lead to changes in lifestyle and inability to manage self care, work or leisure. To explore the everyday life situation as experienced by stroke survivors, and their family caregivers, this study was conducted 3-6 month after stroke.

Methods

Twelve stroke survivors and thirteen family caregivers were interviewed and a qualitative content analysis was conducted to analyze data.

Results

The results were categorized into two central themes that were identified as; (1) Being challenged by changes in everyday life situation including; the struggle with physical dysfunctions, inappropriate daily plan for leisure activities, changes in mood, being faced with economical problems and being worried about changing roles (2) striving to cope with new conditions including; trying to preserve self-worth, seeking to support from spirituality, learning and re-learning and regaining independency.

Conclusion

Physical dysfunction was the major concern for both the survivors and their family caregivers in their everyday life situation. This problem led to, and forced them, to be dependent on others. Training is needed to teach stroke survivors and their families strategies of how to cope with and overcome ongoing challenges of everyday life after stroke and to re-organize their lives and improve skills of the survivors to deal with the new situation at home.

A daily plan for spending their time and leisure activities would ease this work. More investigation will be needed to clarify the process of life after stroke to cover this gap.

KEYWORDS: Stroke survivors; Family caregivers; Everyday life; Content analysis

Please cite this article as: Dalvandi A, Khankeh HR, Ekman SL, Maddah SSB, Heikkilä K. Everyday Life Condition in Stroke Survivors and Their Family Caregivers in Iranian Context. *IJCBNM*. 2013;1(1): 3-15.

INTRODUCTION

Stroke is an unpredictable incident which suddenly disrupts one's life and commonly leads to changes in everyday activities for both stroke survivors and their family members.¹ The majority of stroke survivors have to deal with different kinds of changes in their lives.² The effect of stroke is significant on physical functioning and can lead to changes in lifestyle and inability to manage self care, work or leisure.^{3,4} Stroke survivors are often left with such impairments that influences activities of daily living (ADLs) and instrumental activities of daily living (IADLs) negatively, such as mobility.⁵ People who have sustained such a life-disrupting injury need to find a new "I am" as well as a new "I can".⁶ According to Corbin and Strauss (1987), illness or injury that causes an inability to perform valued activities of everyday life may lead to a loss of certain aspects of the self, such as perceptions of competence and identity.⁷

Everyday life after stroke is affected by the medical consequences of the stroke; how survivors and their family members handle the changes of everyday life together is important.⁸

Impairment or disability caused by stroke can lead to restricted or less diverse participation in everyday life, as activities may be located more in the home and involve fewer social relationships than before.⁹ Limitations and restrictions in activities and participation of stroke survivors in such activities may be the most relevant aspect of everyday life after the stroke.¹⁰ Moreover, the experience of caregivers regarding those functions and conditions associated with stroke, from other contexts, can be another relevant aspect of everyday life that should be taken into account.¹¹

Stroke survivor's experience of disability and how the disability affects their functioning in everyday life often depends on their relationship with family members.¹² In Iran, the impact of religion

on family- structure, bounds and the family's role - is as important as the social foundation.¹³ The families' method of coping with stroke may require special provision to ensure that care-giving responsibilities are fulfilled, while the demands of everyday life are met.¹⁴

According to Lagerström et al. in Iranian culture and society, the family is the most important factor that dominates an individual's whole life. The family in Iranian society is an important source of belonging to each other, for exerting influence, power, support and security. It is usual to communicate with extended family members who have responsibilities and obligations toward each other.¹⁵ Iran is a Muslim society,¹⁶ and the Muslim patients understand that illness, suffering and dying are part of life and a test from Allah. Moreover, the Muslim patients' attitude towards health and illness incorporate the notion of approaching illness and death with patience, meditation and prayers.¹⁷

Therefore, families try to preserve family structure, functioning and emotional feelings by seeking help given by members of the extended family and friends.¹⁸ Iranian family caregivers are an essential part of health care services,¹⁹ seeking to gain information about how to deal with events of stroke.²⁰ Despite these efforts, families with stroke survivors are faced with inadequate social insurance. It creates a burden for family caregiver's which influences financial resources and the patient's care, and restricts activities and the time spent on different types of assistance and tasks.¹⁸⁻²¹

Previous studies about everyday life after stroke have commonly focused on instrumental activities of daily living (IADL) or personal activities of daily living by assessment of health and disability in general.²² To support and help those who are afflicted with stroke to cope with daily life, knowledge of the individual experience is needed.²³ Moreover, to our knowledge, no study has yet explored the everyday life

condition after stroke for stroke survivors and their families in Iran, by a qualitative approach in order to understand what the main problems are and how the survivors and their family caregivers solve the problems in everyday conditions.

Therefore, this study used a qualitative approach to focus on everyday life conditions after stroke in order to enlighten the domains of everyday life that are important for stroke survivors in an Iranian context. The aim of this study is to describe the everyday life conditions as experienced by stroke survivors and their family caregivers 3-6 months after stroke.

SUBJECTS AND METHODS

A qualitative content analysis was conducted using a semi-structured interview to investigate what the text (data) reveals about everyday conditions of life after stroke. Also, an interpretation of the underlying concept of the categories will be provided through the systematic classification process of coding.²⁴

Participants

Twelve stroke survivors and thirteen family caregivers, living in the capital city of Tehran, Iran, took part in this study. The demographic characteristics of the participants are presented in table 1. The inclusion criteria for selection of stroke survivors was that they had been discharged from the hospital between February to July 2009 to July 2012, had suffered a stroke within the past 3-6 months, had no severe co-morbidities and lived in their own homes. Based on inclusion criteria, patients and their family caregivers were contacted by telephone. Twelve stroke survivors participated in the study. Thirteen family caregivers who were responsible for taking care of the participating survivors, such as children and spouses, also participated in the study. Data collection was continued until saturation. The interviews were conducted

first with the stroke survivors, and then with their family caregivers at their own place. Because researchers aimed to know how stroke survivors' life is, the primary data analysis showed the need for interview with family caregivers. The exclusion criteria for participating in this study for both stroke survivors and their family caregiver were their ability and willingness.

Data Collection

The first author (AD) contacted each of the participants and explained the research objectives. If the participant agreed to take part in the research and signed the informed consent form, an interview was arranged. Based on the participant's request, interviews were carried out at the stroke survivor's home. Individual semi-structured interviews were conducted in a private place. In the interview guide, the researcher followed the content domains that were initially developed with collaboration of experts. The domains and some questions are shown in Box 1&2. Probing was used when needed in order to clarify the answers.

Box 1: Interview domains

Main interview domains

Major challenges
Family reaction
Feeling and dealing
Changes in life
Managing life
Seeking resources
Help from others
Coping with new life
Role of spirituality

Box 2: Example of main questions during the interviews

How do you live with this event? Or How is your life after this event?

What change has happened in your life? Please explain more? Or how has your life Been changed by this event?

How do you spend your day and what challenges do you have? Or would you let me Know your daily life and the kind of challenges you have?

How do you manage yourself and your life?

Table 1: Demographic characteristics of the participants (n=25)

Characteristic	Stroke survivors	Family caregivers
Age (range)	55-70	20-68
Sex		
Female	5 persons	7 persons
Male	7 persons	6 persons
Employment		
Official staff	3 persons	2 persons
Retirement	3 persons	1 persons
Worker	3 persons	3 persons
Household	3 persons	7 persons

The interviews were carried out by the first author (AD) and recorded by audio-tape-recording device. Then, these records were transcribed verbatim. The interviews took 45 to 60 minutes depending on the tolerance and interest of the participants in explaining their own experiences. Three interviews were repeated in order to clarify some ambiguities during the first interviews and to find some more information regarding the phenomenon under the study.

Data Analysis

The interviews were analyzed using qualitative content analysis.²⁴ The researcher was engaged in data analysis by over reading the interviews several times; the data was divided into meaning units, condensed MU, coded, categorized and finally thematized.²⁴ The condensation of MU was done by a process of reducing the text while still preserving the core. The MUs were subsequently coded according to the content of the material, and researchers labelled codes through assigning codes on the MUs. After the coding process, all the codes were categorized, and then the underlying meanings were interpreted as themes (table 2).

Ethical Considerations

The research project was approved by the ethics committee of University of Social Welfare and Rehabilitation Sciences (USWR) (801.4.84.1292, Oct12, 2005). The ethical procedures for the study guaranteed the confidentiality and independence of

the participants. All the participants were informed about the purpose and design of the study and the nature of their participation. Written informed consent was taken from them before participating in the study and for the audio-taping of interviews.

Trustworthiness

The researchers tried to improve trustworthiness of this study by using strategies recommended by Lincoln and Guba.²⁵ For these, the participants were contacted to give them a summary of the primary results to determine whether the concepts were true to their point of view (member check). As a further validity check, the transcripts and the analysis process was checked and verified by the research team and some experts as expert check. Two of the interviews were translated into English for two English experts who were members of the research team, as well as the whole analysis process, so that all co-authors could participate in the verification process of the emerging themes. Besides, the research team had a weekly routine meeting to evaluate the process of the study.

RESULTS

Both stroke survivors and their family caregivers expressed experiences from their own perspective. In this paper, the themes show the common aspects of experiences of everyday life conditions. The analysis resulted in two central themes;¹ being challenged by

Table 2: Example of meaning units, condensed meaning units, sub-themes and themes

Meaning unit	Condensed meaning unit	Sub-themes	Themes
<i>One side of my body died, I couldn't move somewhere by myself without help because my left hand and leg didn't work.</i>	The left side of my limbs died And I couldn't move somewhere by myself	The struggle with physical dysfunction	Being challenged by changes in everyday life situation
<i>My husband becomes overweight and one side of his body was paralyzed. During moving and transferring him, I had lots of problems, after sometimes I got Carpal tunnel syndrome in both hands besides; I became weakness bodily and lost my energy. I really need helping by aid assistance.</i>	I had problems to move and transfer my husband because of his overweight; I got body weakness and loss of energy.		
<i>But I didn't let my husband to be limited physically, and I help him to walk with his can after he get better I just take care him to go somewhere.</i>	I need aid assistance but I help him to walk and go somewhere.		
<i>Physiotherapists took me forward and backward like toddler baby who is going and experiencing to walk, until I was able to walk by myself.</i>	I learned to walk by myself under coaching of physiotherapist	Learning and re-learning	Striving to cope with new condition
<i>I lost my right hand's function, I learnt how to button my clothing by using one handed techniques.</i>	I tried to button my clothes by learning technique		
<i>I should show them that their efforts could be effective that is why I always laugh and show happiness.</i>	Family caregivers' efforts could be effective towards happiness		
<i>I never lost my hope to come back to life, right now, with some limitation I should manage my life and my feeling morally, and don't let my family to feel suffered.</i>	Hope to come back to life I should manage my life to prevent my family suffering I used to care for my mother and my children learnt to care for me.	Regaining independency	
<i>I myself used to care my mother and I didn't want that my family and children were tired by my overworking and being hated and frustrated, I didn't want to be over changed on my family.</i>	I felt that I had been frustrating to my family		
<i>When I was noticed that, I couldn't back to my last normal life as used to be. I get depressed and I felt inability and weakness. But I accepted to be adapted with new situation, I found that how much my family effort and paid attention to me, and my wife was only person that understood me.</i>	I perceived reality, which I couldn't go back to life as I was. I accepted I needed to adapt to the new situation My family and wife paid attention to patient	Seeking to support from spirituality	
<i>I was worried about my life, I immersed inside, when I saw that my wife focused on side I felt sadness and tired, I tried to cope by going to some religious place and made pilgrimage.</i>	I am worried regarding my life; I tried to deal with it by going to religious places and making pilgrimage.		

changes in everyday life condition including the struggle with physical dysfunctions, inappropriate daily plan for leisure activities, changes in mood, economical problems and worry about changing roles,² attempt to cope with new conditions including trying to preserve self-worth, search for support from spirituality, learning; re-learning and regaining independence.

In the following quotations, the survivors are marked by (P) and family caregivers by (F).

Being Challenged by Changes in Everyday Life Conditions

Struggling with Physical Dysfunction

Stroke survivors described that inability to move and the weakness of the body were the most common dysfunctions caused by stroke. The physical dysfunction affected mainly their hand, arm, leg movement and even the entire half of their bodies. Stroke survivors suffered from physical limitation which causes them to be dependent on others. Based on Iranian culture that encourage people to be independent, stroke survivors' liked to be self sufficient. Some survivors couldn't go to their workplace and also they experienced limitations of social isolation and transportation.

"One side of my body died. I couldn't move anywhere by myself without help because my left hand and leg didn't work" (P8).

Family caregivers experienced that the survivors' body limitations, inactivity, and immobility were problematic as they faced problems with moving and transferring their survivors.

"My patient, her husband, became overweight and one side of his body was paralyzed. When transferring him, I had lots of problems. After some time, I got Carpal tunnel syndrome myself in both hands. Besides, I became weak bodily and lost my energy. I really need somebody to help. But I didn't let my husband be limited physically, and I helped him to walk with his cane. After he got better I just helped him to go out" (F1).

Inappropriate Daily Plans for Leisure Activities

Due to lack of discharge planning, follow up by the health care system and social insurances, the survivors were faced with inappropriate plans for spending their time and leisure activities, which caused both the survivors and their family caregivers get frustrated. The survivors perceived that they were a burden on their family members in their homes and the family members might want to push them out from their home and reject them.

"I was involved in this difficult situation. I did not know what I and my family should do. I was isolated at home and from morning till night I thought about my previous normal life and sometimes I interfered in my children's affairs. They were tired about this monotone situation and I even sometimes felt they hated me" (P3).

Family care givers believe that having an appropriate daily plan including proper leisure time which could allow stroke survivors to break out of their routines from time to time can be therapeutic in a similar way to rehabilitation.

"My husband sat on a chair in front of our home in our alley and every day he was watching the children playing and the people who were crossing to the street. He has some friends. They came for a few hours and sat next to him, and they chat to each other. If he needed something, I used to call him by wireless phone. But after leaving that home, everything changed and in a new apartment on the fourth floor without an elevator, he is isolated again" (F6).

Being Faced with Economical Problems

Stroke survivors perceived that they were under distress due to economical issues. Their pensions were not enough to cover their life due to rehabilitation and treatment expenses.

"Due to the financial shortage, I couldn't go to a public rehabilitation clinic and use the rehabilitation facilities. Financial status is crucial. My life has become

very hard” (P7).

Family caregivers experienced that the economic problems -affect the whole family’s financial situation, and they felt disparate by this pressure. They expected the social insurance system to support the survivors’ rehabilitative care.

“We need some social support network system to help and support us, because our income and even the extended family’s resources are not enough to support us” (F3).

Being Worried about Changing Roles

Changes in roles and responsibilities made the stroke survivors feel uncomfortable, uncertain and worried about their future. They described that the stroke event had happened suddenly, and they were faced with a new situation. They had to take on unexpected roles in their new daily life because of the survivors’ physical condition. Several stroke survivors lost their occupation, and got dependant on other family members’ salaries, which caused them to feel useless. Many stroke survivors tried to play their previous roles despite the limitations. They perceived that the possibility of playing their roles would increase their sense of self-confidence, and reduce stress and fear of taking actions. In this way, they were supported by their family members.

“My life was normal; suddenly, it was disintegrated. It is like a quake and unpredictable. I used to be an active and hard working man, but I was changed by getting paralyzed and converting to a suffering and crippled man. I couldn’t make a new change in my life because of financial problems. After this event, I became unemployed. I lost my power and responsibility” (P1).

Family caregivers found that they had to change their own roles and occupations due to the new situation, even some of them had to leave their own jobs to help and provide care for stroke survivors at home as they were worried about the survivors’ health

situation. It means that they had to learn new skills. Moreover, in families whose father has been affected by stroke, the major challenge was economical problem after stroke.

“Our life after the accident looked like a ship without a captain who is stuck in a stormy sea and everyone tried to save it, because our father used to lead the family, and without him, we were fed up and worried. Thereafter, we tried to manage this new situation by improving our functional responsibilities to handle and control our lives” (F8).

Changes in Mood

Stroke survivors experienced the stroke event as traumatic and they had many emotional reactions to it, such as fear, anger, sadness, anxiety and frustration. Most of them experienced a range of negative emotions. They experienced times of hopelessness and low self-efficacy. For instance, they wouldn’t like to participate in any social activity, family ceremony and public affair.

“When I noticed that I couldn’t go back to my former normal life as it used to be, I had a bad feeling and I felt unable and weakbut I accepted my new situation. I found how much my family pay attention to my situation” (P10).

In some cases, family members tried not to show their despair to others, but kept up their appearance in order not to upset the others. Some family caregiver felt tired, but they showed that they were happy because they did not want the stroke survivor to suffer. They also showed their negative mood, they usually went outdoors, to the park for a walk, made visits to their friends and sometimes they went to visit religious places.

“After this incident, my husband became fragile and sensitive, often he just looked like a statue without any actions, and sometimes he cried and told me’ I lost everything and my life is destroyed, But I

supported him and usually I told him we would build our life together again” (F7).

Striving to Cope with a New Condition Trying to Preserve Self-Worthiness

The stroke survivors usually felt that their sense of self-esteem was dragged down because they could not perform their duties such as guiding and managing their families as before. Those who received assistance could feel a sense of worthlessness, especially those stroke survivors who had been independent in their life. Sometimes they kept up the appearance by not showing their needs to their spouses and children as they did not want to be considered as a disabled person. They would drink less because they don't want to put others in troubles.

“I didn't like to ask my family members for anything. I even drank less water and ate a little food so I didn't need to go to the toilet. I also tried to be more involved in household course to preserve my personality and value” (P3).

Family caregivers always tried to give the stroke survivors a sense of self-esteem. They usually encourage and give them some advice to help them to manage their own life. The family caregivers have done the best to participate stroke survivors in family decision making.

“I always ask him to do one easy task and step by step I help him to do some more difficult. He is one important member of our family and he should participate in our main decision making regarding how to manage our lives so that he feels self-sufficient” (F4).

Adherence to Spirituality

Stroke survivors believed that hope in future and faith in God can help them in terms of emotions and self-efficacy. They stated that they never lost their faith, and always believed in God. They followed God's commands. Even so, they stated that they really did not rely on human beings and

physician's skills. They believe that if they have some problems, it is God's willing and it was because of fate. For this reason, they can accept this horrible situation and can cope with that.

“God gives me this opportunity to go back to life again and I feel that I have the best family in the world. I should show them that their efforts are effective, so I always laugh and show happiness. I never lose my hope to come back to normal life” (P4).

The family caregivers felt they were absolutely obedient to the will of God. This belief and spiritual behaviour helped them to accept the realities and think positively about the stroke event. They perceived that participation in rituals and religious ceremonies could help them to adjust their life with the new situation.

“Because I believe that everything is from God; bad and good doesn't have any different. I requested help from God. While I returned home happily and gratefully, my husband saw that I became satisfied emotionally” (F1).

Learning and Re-Learning

The stroke survivors experienced that despite having some physical disability, they had to do some daily routines. Washing face and buttoning their clothes with one hand, going to the bathroom and sitting in a wheelchair were perceived so difficult. They indicated these efforts to be like re-learning their old skills again.

“Physiotherapists pushed me forward and backward like a toddler who is learning to walk, until I could walk by myself” (P10).

Family caregivers tried to reconstruct previous situations like getting together, and tried to interact positively with survivors emotionally. They also sought information and training in some new skills to help survivors at home and in social activities. Stroke survivors should try to learn everyday activities and self care again, because they have lost these capabilities after stroke. It is important for

their family to learn how to manage stroke survivors to help them to be independent.

"I lost my right hand's function, I learnt how to button my clothing using one hand" (P9).

"When this event happened, I went to my friend's home. His father had a stroke last year. I asked about his experiences and about what he did and how they managed the situation" (F11).

Regaining Independence

Stroke survivors stated that they had difficulties in managing ADL, related to the functional disabilities, such as urinary incontinence and problems with movement of their limbs. Survivors tried to get help from family members to be able to carry out their own personal care such as helping wash the dishes, dressing on their own and also cooperating in cleaning vegetables and cooking food in order to maintain or regain their independence. Some stroke survivors wanted to move to other places and see their friends or to go to movies.

"My wife bought a plastic stool and put it in the bath, and also she put a special rubber on the ground to protect me from slipping. She helped me in and I sat there. Then she turned my shower on. It was wonderful and that made me feel safe so that I am getting back to normal and having a bath as usual" (P6).

Family caregivers perceived that emotional and spiritual support motivated the survivors to be active in their lives, and participate in rehabilitation services at their home. They followed recommendations about how stroke survivors get independent sooner. In this regard, the family caregivers tried to support the stroke survivors by encouraging them to do as much as they could without help.

"I have to take care of my patient, because no one can always take care of him. I tried to get new information and look for any resources that were possible to access, and preserve our spirituality

to continue my efforts; we are placed in a new boat. I feel that without autonomy, ultimately our life would deteriorate like a plant without water" (F7).

DISCUSSION

This study describes the everyday life condition of stroke survivors 3-6 months after the stroke. The study has generated some new understanding as to what consequences stroke has to the stroke survivors and their family caregiver's everyday life conditions.

The results show that the main problems in everyday life are related to changes in physical activities, roles, spending time, mood, and economics. They attempted to cope with new conditions by trying to preserve self-worth and regaining independence by searching for support from spirituality and learning and re-learning.

This study shows that 3-6 months after the stroke, survivors felt that they were economically and practically dependent on the family's assistance. Survivors needed practical help from their family caregivers, to promote the level of their own health. Their salaries or income were not enough to cover the costs, and the social insurance did not cover the rehabilitation costs. It means that stroke survivors could not follow their recovery plan and they were isolated in their home. That is why stroke survivors' sense of self-worth decreased and the process of regaining independence happened slowly.

The same problems were noted by Habibazdeh et al.²⁶ who shows that despite progress in medical treatment in Iran, most of the stroke patients are faced with challenges in their life-style in terms of hemiplegia, disability, and dependence caused by complications of stroke. Also, Hassankhani et al.²⁷ showed that the physical disability caused disruption in activities of daily life, resulting in task performance limitations and dependence.

In their study, the changing mood

resulted in caregivers' psychological distress and depression among the stroke survivors, due to the increased hours of care provided per week, concerns for future care, caregiver appraisal, and self-losses. Even the role of spirituality as a health factor is found in several studies. The changing mood is also found by Bakas et al.²⁸ He noted that during the recovery period the stroke survivors' mood changed into anger, frustration and gratefulness. Spirituality gave them trust, confidence and hope. For instance, Giaquinto et al.²⁹ found that people with strong spiritual belief appeared to suffer from less emotional distress after surviving a stroke compared to those with weak spiritual beliefs.

To avoid economical, practical and emotional problems, and in order to manage the everyday life situation, stroke survivors strived to regain their independence. They tried to participate in family life by performing different tasks like sharing household chores. They also tried hard to learn new skills or re-learn old skills in order to gain independence. They attempted to be self-directing by self-encouragement and self-enforcing, taking the support of others and by believing in God's help, which helped them to accept the situation and gave them trust in the future. In these ways, they tried to regain independence. In this regard, the family caregivers and other family members and friends helped by encouraging them.

Mirzaei et al.³⁰ claim that Iranian patients highly demand respect for their right to autonomy in any decision making in order to feel self-worth as it has been found in this study.

One of the problems that caused challenges for the participants in this study was the lack of daily planning for spending time, which resulted in the situation whereby the family caregivers did not know how to help the stroke survivor and how to make a plan for the survivors' leisure time; also stroke survivors did not know how to use their abilities in a proper way for such time.

For the families with stroke survivors, this lack of time plan resulted in a period of confusion and for stroke survivors it resulted in confusion and ambiguity. Desrosiers et al.³¹ claim that having a daily activity plan and leisure time can provide a sense of purpose and enhance the survivors' health, independence, and quality of life.

In this line, even Mohammadi and Kaldi,³² found that although most family caregivers in their study were educated people, they did not receive any education related to providing care, and family caregivers have reported that they need education to assist in the caretaking of their relatives.

Based on the results of this study, survivors are faced with lack of daily plans for spending their time and have economic problems that hinder them in their process of becoming independent. Therefore, the stroke survivors', their family caregivers and the society need to seek a well-functioning rehabilitation plan so that the recovery period can be minimised and the cost for both society and families can be decreased. Therefore, regular contact with formal rehabilitation carers could be a way to facilitate the rehabilitation process and the attempt for better coping with stroke by the stroke survivors and their family caregivers. As Dowsell et al.³³ found, nurses can provide a service based on coaching, mentoring and motivating. The subjectivity and definitions of concepts between descriptive and abstraction level was presented and considered as the limitation of this study.

CONCLUSION

As this is the first study in the Iranian context of stroke survivors' and their families' experiences of their everyday life, further studies are required. Other studies should also cover the training of patients and families in regard to coping. Moreover, the provision of support and counselling for health professionals to assist them to deal with the stroke survivors'

independence is recommended as well. The development of multidisciplinary guidelines based on the results, and research into the effects of these guidelines are recommended to find out if interventions can improve the survivors' coping ability.

Physical dysfunction was the major concern for both the survivors and their family caregivers in their everyday life situation. This problem led to and forced them to be dependent on others. They tried to manage the situation with coping strategies.

The stroke survivors and their families need to be trained on how to cope with and overcome ongoing challenges of everyday life after stroke. They also need to learn how to re-organize their lives and to improve their skills so that they can deal with the new situation at home.

A daily plan for spending their time and leisure activities would facilitate this objective. This study has highlighted the situation of life after stroke and has found some fragmental data on life after stroke; therefore, more investigation will be needed to clarify the process of life after stroke by suitable qualitative research to cover this gap.

ACKNOWLEDGEMENT

We gratefully acknowledge the helpful participation of the participants, as well as the staff from the contacted neurology wards and clinics. Without their contribution, this study would not have been completed. The official support of the University of Social Welfare and Rehabilitation sciences is also acknowledged. We appreciate Karolinska Institutet for financial support for this study. We also thank Lesley Pocock for her linguistic revision.

Conflict of interest: None declared

REFERENCES

1 Ostwald SK. Predictors of life satisfaction

- among stroke survivors and spousal caregivers: a narrative review. *Aging Health*. 2008;4:241-52.
- 2 Rochette A, Desrosiers J, Bravo G, et al. Changes in participation after a mild stroke: qualitative and quantitative perspectives. *Top Stroke Rehabilitation*. 2007;14:59-68.
- 3 Duncan P, Reker D, Kwon S, et al. Measuring stroke impact with the Stroke Impact Scale: telephone versus mail administration in veterans with Stroke. *Med Care*. 2005;43:507-15.
- 4 Rochette A, Korner-Bitensky N, Bishop D, et al. Study protocol of The you call—we call trial Impact of a multimodal support intervention after a “mild” stroke . *BMC Neurology*. 2010;10:3.
- 5 Schmid AA, Rittman M. Fear of Falling: An emerging issue after stroke. *Top stroke Rehabilitation*. 2007;14:46-55.
- 6 Thompson N, Coker JL, Krause JS, et al. Purpose in life as a mediator of adjustment after spinal cord injury. *Rehabilitation Psychology*. 2003;48:100-8.
- 7 Corbin J, Strauss AL. Accompaniments of chronic illness: Changes in body, self, biography and biographical time. *Research in the Sociology of Health Care*. 1987;6:249-81.
- 8 Ekstam L. Changes in everyday life after stroke: Older individuals and couples daily occupations at home during the first year after stroke. Department of Neurobiology, Care Sciences and Society, Sweden, 2009.
- 9 Law M. Participation in the occupations of everyday life. *American Journal of Occupational Therapy*. 2002;56:640-9.
- 10 Geyh S, Cieza A, Schouten J, et al. ICF core sets for stroke. *Journal of Rehabilitation Medicine*. 2004;44:135-41.
- 11 Clark PC, King KB. Comparison of family caregivers: Stroke survivors vs. persons with Alzheimer's disease. *Journal of Gerontological Nursing*. 2003;29:45-53.
- 12 Mattingly CF, Lawlor MC. Disability experience from a family perspective. In: Crepeau EB, Cohn ES, Shell BAB,

- editors. Willard and Spackman's occupational therapy. Philadelphia: Lippincott, Williams & Wilkins; 2003. p. 69-79.
- 13 Taymoori P, Rhodes RE, Berry TR. Application of a social cognitive model in explaining physical activity in Iranian female adolescents. *Health Education Research*. 2010;25:257-67.
 - 14 O'Sullivan TL. Support for families coping with stroke or dementia: special considerations for emergency management. *Radiat Prot Dosimetry*. 2009;134:197-201.
 - 15 Lagerström M, Josephson M, Arsalani, N, et al. Striving for balance between family and work demands among Iranian Nurses. *Nursing Science Quarterly*. 2010;23:166-72.
 - 16 Mahmoodishan G, Alhani, F, Ahmadi F, et al. Iranian nurses' perception of spirituality and spiritual care: a qualitative content analysis study. *Journal of Medical Ethics and History of Medicine*. 2010;3:6.
 - 17 Rassool GH. The crescent and Islam: healing, nursing and the spiritual dimension. Some considerations towards an understanding of the Islamic perspectives on caring. *Journal of Advance Nursing*. 2000;32:1476-84.
 - 18 Dalvandi A, Ekman SL, Maddah SSB, et al. Lack of continuity of rehabilitation care for stroke survivors: Iranian family caregivers' experience. *Middle East Journal of Age and Aging*. 2011; 8: 28-34.
 - 19 Pahlavanzadeh S, Ghaedi Heidari F, Maghsudi J, et al. The effects of family education program on the family caregiver burden of elderly with dementia disorders. *Iranian Journal of Nursing and Midwifery Research*. 2010;15:1-2.
 - 20 Dalvandi A, Ekman SL, Maddah SSB, et al. Post Stroke life in Iranian people: used and recommended strategies. *Iranian Rehabilitation Journal*. 2009;7:17-25.
 - 21 Dalvandi A, Heikkilä K, Maddah SSB, et al. Life experience after stroke among Iranian stroke survivors. *International Nursing Review*. 2010;5:247-53.
 - 22 Hägglöf G. Participation in everyday life: very old persons' experiences of daily occupation, occupation of interest and use of assistive devices. The Sahlgrenska Academy at Gothenburg University, 2007.
 - 23 Faircloth AC, Boylstein C, Rittman M, et al. Constructing the stroke: sudden-onset narratives of stroke survivors. *Qual Health Res*. 2005;15:928-41.
 - 24 Graneheim U.H, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*. 2004;24:105-12.
 - 25 Lincoln YS, Guba EG. *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications, 1985.
 - 26 Habibzadeh H, Gofarnipoor F, Ahmadi F. A study on the effect of self care on activity daily living status in patients with cerebro vascular accident. *Journal of Medical Sciences*. 2007;7:126-30.
 - 27 Hassankhani H, Taleghani F, Mills J, et al. The challenges experienced by Iranian war veterans living with chemical warfare poisoning: a descriptive, exploratory study. *Scandinavian Journal of Caring Sciences*. 2010;24:290-8.
 - 28 Bakas T, Austin JK, Okonkwo KF, et al. Needs, concerns, strategies, and advice of stroke caregivers the first 6 months after discharge. *J Neurosci Nurs*. 2002;34:242-51.
 - 29 Giaquinto S, Spiridigliozzi C, Caracciolo B. Can Faith Protect From Emotional Distress After Stroke? *Stroke*. 2007;38:993-7.
 - 30 Mirzaei K, Milanifar A, Asghari F. Patients' perspectives of the substitute decision maker: who makes better decisions? *J Med Ethics*. 2011;37:523-5.
 - 31 Desrosiers J, Noreau L, Rochette A, et al. Effect of a home leisure education program after stroke: a randomized controlled trial. *Arch Phys Med Rehabil*. 2007;88:1095-100.

- 32 Mohammadi F, Kaldi AR. Self-efficacy and caregiver strain in Alzheimer's caregivers in the city of Tehran. Middle East Journal of Age and Ageing. 2006;3:8-12.
- 33 Dowswell G, Lawler J, Dowswell T, et al. A qualitative study of specialist nurse support for stroke patients and care-givers at home. Clin Rehabil. 1997;11:293-301.