REVIEWS

The everyday life of adult family members of working aged survivors of stroke during the first year after the stroke – an integrative review

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Received: January 27, 2013 **Accepted**: May 5, 2013 **Online Published:** May 10, 2013
DOI:10.5430/cns.v1n3p7 URL: http://dx.doi.org/10.5430/cns.v1n3p7

Abstract

The purpose of this integrative review was to describe the everyday life of adult family members of working aged survivors of stroke during the first year after the occurrence of the stroke. The studies were researched from Medline, Cinahl, PsycINFO, Medic and Linda databases. The data consisted of 40 articles which were published in scientific journals during 2007-2012. The quality of the articles were assessed with the critical appraisal tools JBI QARI and JBI MAStARI[1]. The articles were analyzed with thematic analysis. The everyday life of adult family members included initially becoming the family member of a survivor of stroke, living as their family member, and eventually coming to terms with life with the survivor of a stroke. Becoming the family member meant living in a focused state of chaos, trying to be strong for the loved one, and going forward in life. It also emphasized the need to rebuild and find a balance in the shadow of the illness and the needs of this complex situation. Coming to terms with the changed life situation of the family member consisted of trying to stabilize emotional wellbeing amid bouts of anxiety and depression. The results of this research should help nurses to better meet the needs of family members at the right time in order to help them deal with expected problems. There is much evidence about older caregivers' needs, but only scant evidence about younger caregivers and their working aged relatives, especially just after the stroke. This integrative literature review gives important information about the everyday life of family members of working aged survivors of stroke and helps nurses to better understand them and their needs.

Key words

Family nursing, Everyday life, Family, Stroke survivor, Working age

1 Introduction

Stroke is a leading cause of death and disability around the world. According to WHO [2] there were 15.3 million strokes in the world and more than a third of which resulted in death. In Finland, every year there are about 14 000 people who will have a stroke and every fourth one is of working age [3]. According to predictions, there will be over 20 000 new stroke events each year in Finland during the 2030's. Stroke refers to cerebral infarction, cerebral hemorrhage, or SAH-induced brain dysfunction [4]. It is usually a family caregiver who is responsible for the survivor of stroke at home. Having a stroke is an unexpected and traumatic event which often places the family member in the caregiver role. It is difficult for family members to accept when a loved one goes into the hospital because of stroke [3]. While the patient is in the hospital, all the thoughts of the family members are concentrated on the sick person, often forgetting their own feelings and needs [5]. The family can easily be perceived as a background factor in patient care [6].

The needs of the family members in the nursing care of critically ill patient have been researched extensively [5, 7, 8]. According to several studies [5, 6, 9, 10] family members need support from nurses in order to cope with their loved one and the illness. The starting point of family nursing is the interaction between the nurse and the family members [6]. According to Yura &Walsh [11] *"… the client may be an individual or a family and it fulfills the criteria defining a system, because it consists of interrelated parts that are capable of reacting to changes in the environment in its efforts to maintain a steady state"*. In order to help family members at the right time, nurses must listen and be able to recognize the need for help [6, 7, 9]. When the family member knows that a person who cares and gives them attention exists, this can be very comforting [12, 13].

There is much evidence about older caregivers' needs, but only scant evidence about younger caregivers and the working aged survivor of stroke. In many studies the focus is on the patient, leaving the family member in the background. This integrative literature review gives important information about the everyday life and feelings of family members of working aged survivors of stroke, and helps nurses to better understand them and their needs.

2 Purpose of the review

The purpose of this integrative literature review is to describe everyday life of the family members of working aged survivors of stroke during the first year after the stroke. The research question of the review is:

What knowledge exists from existing research about the everyday life of family members of working aged survivors of stroke during the first year after the stroke?

Table 1. Inclusion and exclusion criteria

Inclusion criteria:

The research

- explored adult (≥18 years to ≤65years) family members' experiences during the first year or acute phase after the occurrence of the stroke.
- was published in a scientific journal**.**
- was published during 2007–2012.
- was written in English or Finnish.

Exclusion criteria:

The research

- explored adult family members' experiences after the first year post stroke.
- dealt with child or coronary patients and their family members.
- focused on psychiatric or neuropsychological problems.
- focused on pathophysiology and/or medical care.
- was a duplicate.
- was done in Far-East, where the culture is different.
- focused on stroke patients´ end of life care.
- was a literature review.
- was a dissertation.
- focused on survivors over 65 years of age.

Table 2. Systematic literature search process

Medline	Cinahl	PsycINFO	Medic (Eng/Fin)	Linda (Fin/Eng)
Keywords: stroke/or brain infarction/ or brain stem infarctions/ or cerebral infarction; family/ or family characteristics/ or marital status/ or marriage/ or single person/ or spouses; social support; "Quality of Life"/ or "Activities of Daily Living"/ or "Life Change Events" →findings: n= 134 -Searches MeSH-keywords, titles and abstracts. - Limits: Years 2000-2012, English and Finnish language.	Keywords: Stroke OR Stroke Patients OR Stroke Units, Family OR Extended Family Spouses OR Caregivers OR Significant Other →findings: n=410 -Searches MeSH-keywords, titles and abstracts. - Limits: Years 2000-2012, English and Finnish language.	Keywords: (cerebrovascular accidents/stroke.mp.) family/ or family members, social support/ or social networks/or support groups/ "quality of life"/or life changes/ or life satisfaction/ or lifestyle changes/ or wellbeing/"activities of daily living"/ →findings: n= 124	Keywords: (aivohalvau* stroke AND perhe* lähei* puolis* family* relativ*) →findings: n= 11	Keywords: (aivohalvau? OR stroke) and (perhe? or family) →findings: n = 36
Excluded duplicates n=1	Excluded duplicates n= 23	Excluded duplicates n= 5	No duplicates	No duplicates
Included based on the titles: n= 86	Included based on the titles: n=194	Included based on the titles: n= 39	Included based on the titles: n= 11	Included based on the titles: n= 3
Included based on the abstracts: n= 59	Included based on the abstracts: n= 151	Included based on the abstracts: n= 29	Included based on the abstracts: n= 2	Included based on the abstracts: n= 1
Included based on full text: n= 27	Included based on full text: n= 65	Included based on full text: n=17	Included based on full text: n= 2	Included based on full text: n= 0
Limits: Years 2007-2012 included in this integrative literature review after evaluating full text: n=12	Limits: Years 2007- 2012 included in this integrative literature review after evaluating full text: n=21	Limits: Years 2007- 2012 included in this integrative literature review after evaluating full text: n= 6	Limits: Years 2007- 2012 included in this integrative literature review after evaluating full text: n= 1	Limits: Years 2007- 2012 included in this integrative literature review after evaluating full text: n= 0

Note: Databases total: n= 715, duplicates n= 29. Included based on titles n= 333, based on abstract n= 242 and based on full text n=111. Limits: Years 2007- 2012 included in this integrative literature review after evaluating full text n= 40.

3 Method and data

The integrative literature review brings together information about a given research topic. In this review, the topic is data concerning the everyday life of family members of working aged survivors of stroke. The integrative review method is the only approach that allows for a combination of diverse methodologies. It also has the potential to play a greater role in evidence-based practice for nursing. An integrative review can combine data from the empirical and the theoretical literature [14]. Conclusions are drawn on the basis of existing research data [14-17]. This integrative review has been conducted using Whittemore and Knaffl`s [14] five stages as the framework for data collection, analysis and synthesis: identification of the topic, literature search, data evaluation, data analysis and presentation. Synthesis from a variety of different studies is made to determine the exact knowledge about everyday life of family members of survivors of stroke.

Table 3. Evaluation of selected studies (MAStARI evaluation points ranged from 6 to 9 and QARI evaluation points ranged from 8 to 10)

Databases Medline n=12	Bäckström & Sundin 2007 Sweden QARI 10/10	Ko et al. 2007 USA MAStARI 9/9	Ski & O´Connell 2007 Australia MAStARI 9/9	Pierce et al. 2008 USA QARI 10/10	Visser-Meily et al. 2008 The Netherlands MAStARI 9/9	Wallengren et al. 2008 Sweden QARI 10/10	Bäckström & Sundin 2009 Sweden QARI 10/10	Green & King 2010 Canada MAStARI 9/9
	King et al. 2010 USA MAStARI 9/9	Adriaansen et al. 2011 The Netherlands MAStARI 9/9	McPherson et al. 2011 Canada MAStARI 9/9	Tellier et al. 2011 Canada QARI 10/10				
Cinahl n=21	Drummond et al. 2007 USA QARI 8/10	Mackenzie et al. 2007 UK MAStARI 9/9	Pierce et al. 2007 Canada QARI 10/10	Silva-Smith 2007 USA QARI 10/10	Larson et al. 2008 Sweden MAStARI 9/9	Lefebvre et al. 2008 Canada QARI 10/10	Puymbroeck et al. 2008 USA MAStARI 9/9	Smith et al. 2008 Canada QARI 8/10
	Haley et al. 2009 USA MAStARI 9/9	Klinedinst et al. 2009 USA MAStARI 7/9	Pierce et al. 2009 USA MAStARI 7/10	Shanmugham et al. 2009 USA MAStARI 7/9	Bulley et al. 2010 UK QARI 10/10	Eames et al. 2010 Australia QARI 10/10	Greenwood & Mackenzie 2010 UK MAStARI 9/9	Le Dorce & Signori 2010 Canada QARI 9/10
	Pierce et al. 2010 USA QARI 10/10	Wallengren et al. 2010 Sweden QARI 10/10	Lutz et al. 2011 USA QARI 10/10	Klinedinst et al. 2012 USA MAStARI 6/9	Saban & Hogan 2012 USA QARI 10/10			
PsycINFO n=6	Rochette et al. 2008 Canada MAStARI 7/9	Steiner et al. 2008 USA MAStARI 9/9	Wallengren et al. 2008 Sweden QARI 10/10	Almborg et al. 2009 Sweden MAStARI 9/9	MacIsaac et al. 2011 Canada MAStARI 8/9	Kitzmuller et al. 2012 Norway QARI 10/10		
Medic n=1	Virtanen et al. 2011 Finland MAStARI 9/9							
Linda n=0								

3.1 Literature search

The literature search (see Table 1) was conducted systematically [14, 18] using Medline, Cinahl, PsycINFO, Medic and Linda databases. The search was limited works from 2007–2012, and the studies were selected by two authors of the integrative review according to the inclusion and exclusion criteria (see Table 1). The time limit was set in order to keep the number of the studies reasonable and having the focus on the most recent research.

3.2 Search outcome

The research data (N=40) consisted of quantitative (n= 21) and qualitative (n= 19) studies. Most of the studies were from the USA (n=15) and Canada (n=9). The others were from Sweden (n=7), Great Britain (n=3), Australia (n=2), the Netherlands (n=2), Finland (n=1), and Norway (n=1). The studies accepted for the review were usually carried out by collecting the material with interviews and questionnaires using instruments such as the Health Related Quality of Life. Sample sizes varied from 6 to 183. The studies were analyzed by grounded theory, phenomenology, content analysis, thematic analysis and different kinds of statistical methods. The systematic literature search process is presented in Table 2.

3.3 Data evaluation

The studies included in this review were evaluated by JBI QARI and JBI MAStARI evaluation tools [1]. The quality of the selected studies was good, since all the studies received at least 50% of the maximum points. In the qualitative measurement tool (QARI) maximum points are 10 and in quantitative measurement tool (MAStARI) maximum points are 9. The selected studies according to QARI had points from 8 to 10, and according to MAStARI from 6 to 9. The evaluation of research articles is presented in the Appendix.

3.4 Data analysis

The data were analyzed with thematic analysis, which will identify and report themes that occur in the data. The theme describes the phenomenon from the point of view of the research question [19-22]. The studies were read and expressions answering the research question were selected from the results, on the basis of which the themes and the subthemes were formed (see Table 4). Mind maps were developed from the themes relating to life after stroke during the first year.

Table 4. Themes and subthemes

Themes	Subthemes
Becoming the family member of a survivor of stroke	- *Living in a focused state of chaos* - *Staying strong* - *Trying to go forward in life*
Living as the family member of a survivor of stroke	- *Rebuilding of life* - *Balancing of life in the shadow of the illness* - *Taking care of very complex needs*
Coping and coming to terms with the reality of life with a survivor of stroke	- *Balancing emotional wellbeing* - *Dealing with anxiety and depression caused by the life situation*

4 Results

The everyday life of a family member of a working aged survivor of stroke both at the time of the stroke and during the next year included becoming a family member of a survivor of stroke, living as a family member of a survivor of stroke, and coming to terms with coping as a family member of a survivor of stroke (see Table 4).

4.1 Becoming the family member of a survivor of stroke

Becoming a family member of a stroke survivor describes the initial changes brought about when the loved one suffers a stroke. After the event, life changes in a chaotic manner, and everything that was familiar and safe seems to break down. In spite of the situation, family members try to stay strong and keep moving forward in life. In the long run they try to find the same kind of direction they had before the event, but with the changes integrated into their new life.

Living in a focused state of chaos. During the first weeks after the stroke, the life of the family member was entirely focused on the stroke survivor amid the chaos brought about by the abrupt change in life situation. The world outside the stroke experience lost meaning for the family member, and they felt uncomfortable and lonely in it [23]. One wife described herself as being like “a walking shadow” [24]. During the first weeks it was important to the family members that the sick person got the best care possible [24]. Some of them felt the presence of God, and received comfort from it [26].

Staying strong. Some of the family members treated the situation caused by the stroke like being on a mission, although they sometimes felt they had lost their way and were fighting to continue forward. They got strength from moments they felt they were succeeding in the mission, and felt as if they were living a normal life. Taking part in the care helped family members to feel important and connected to the patient during the acute phase [25, 27]. Already at the beginning of the situation family members were aware of the changing life situation and that they must be strong in this changed situation, but it took a long time before they understood the lifelong influences of stroke [23, 29, 30].

Trying to go forward in life. Stroke patients and all family members were faced with enormous challenges when they moved forward through three phases: the crisis caused by stroke, expectations of rehabilitation of the patient and the crisis caused by discharge to home [31]. Family members were sure that their actions helped the sick person to rehabilitate, but they expressed that they also needed emotional and concrete support from others [25]. A turning point was reached when the patient was discharged, and the responsibility for care fell on the shoulders of the family member [23] .

4.2 Living as the family member of a survivor of stroke

Being a family member of a stroke patient describes the situation when the family member’s life begins to find a new direction in the changed situation, after which life must be rebuilt in a new way including the management of care of the survivor of stroke.

Rebuilding of life. Many of the family members felt they had lost the life that they had together. They coped with situations which were changing all the time, including their personal relationship which was different for example on emotional and physical levels. Many of the family members, especially spouses were grieving the loss of the person they once had known. The other family members were a support network. The changes in the stroke patient`s personality sometimes made the family member feel like an outsider in the situation [23-25, 30-34]. Family members related that during the course of stroke it was very difficult to care for their loved one. One wife tried to explain how difficult it was for her to understand the loss of her partner in view of the everyday speech and memory problems [34]. Spouses who decided to carry on their life together had to find a new shared path to the future. New hobbies helped them to find acquaintances and friends, which broadened their living space. A history of a strong and long lasting marriage had an important impact on the success of the relationship after the stroke [25].

Balancing of life in the shadow of the illness. Insecurity about the future and fear of the possibility of a new stroke were constantly present in their new lives. They were secure only about meeting the physical needs such as moving, toileting, and hygiene. Many of the family members described changes in their thoughts and expectations about their lives [34]. Role changes with couples caused fear and insecurity to some of the spouses. Some of them gave up their work which influenced the economic situation of the family [25]. Young female family members who were caregivers of their spouses shared their experiences and gave support to each other through the Internet during the first year after the stroke of the loved one. They did everything they could to keep their family and together by searching for a balance in their lives. Families were connected with other people, gave and received support, and shared their feelings of caring for the stroke patient [35].

Taking care of complex needs. Recognizing the needs of the family members from the first moments are important [36-38]. The family members whose sick relative was in the hospital longer had a better opportunity to plan for the patient's discharge with the healthcare staff. The young female family members and the family members of female patients were more active than older ones to take part in conversation about the goals and needs of patient care [39]. The family members had many needs that they expected to be filled by the healthcare professionals rather than other family members or friends. They wanted information about the illness, rehabilitation and possible alternative therapies. It is very important that nurses recognize what the family member of the stroke patient wants to know by listening carefully to what she or he is saying [36 , 39-41]. Family members need information aimed at the changes and the influences of the stroke and how they would affect daily life. They also found the manner in which information was given to be important [42, 43].The informational needs of the family members were dependent on their personal commitment to the survivor of stroke, especially during periods of change. The impact of the information during those times was vital to their wellbeing [41].

The experiences and the support needs of family members fluctuated according to their ages. Younger caregivers found getting the information and guidance about care to be significant. They were more critical towards the healthcare system and the staff than the older family members. The older family members wanted to keep external framework of the family in good condition and they were extremely happy to the care of the stoke patient. This helped them to cope during the difficult times [36, 44, 45]. The very exact information distributed in a website (StrokEngine, Caretalk, Caring –Web) developed in Canada and the USA which dealt with stroke and rehabilitation, and the possibility to be in contact with the healthcare professionals and peers, received positive feedback from family members. Using websites reduced the use of healthcare services. Giving advice and being available through the Internet was the way to have social contacts with peers for one male family member [26, 35, 42, 46-50]. In addition to the informational needs, the family members experienced different physical and emotional needs. Lack of energy, tiredness and sleeping difficulties were very familiar to them. Some family members felt like they were invisible to the healthcare professionals when at the bedside of the stroke patient [51].

4.3 Coping and coming to terms with the reality of life with a survivor of stroke

Coping of the family member of the survivor of stroke describes the situation when the family caregiver recognizes the need for personal wellbeing in spite of anxiety and depression occasionally caused by the life situation. Many of the family members experience depression after the stroke, but find it hard to speak about.

Balancing emotional wellbeing. When seeking their own wellbeing, their natural tendency to never think about themselves, only about their loved one, had to change. Family members realized at some point that the continuation of life for the whole family was important. They also gained strength when caring for the loved one as they felt the value of life enjoyed the feeling of being needed, strived for a positive attitude on life, and learned new skills [23, 33, 52]. It was demanding to adapt to life as a caregiver, including giving physical help to the loved one and adapting to a new role regarding making decisions inside of the family. Worries about economic situations and decreasing finances, and later the possibility that the loved one might go back to work caused stress for the family members. For most of them, staying hopeful was difficult when it seemed the situation would never change [33]. The quality of life of the stroke patient influenced the emotional wellbeing of the caregiver and vice versa [53, 54]. Female family members, more often males felt a negative influence on quality of life and wellbeing as a result of the stroke [55]. The quality of life of the female caregivers did not become better during the first year [56]. The bigger the impact of caring for the stroke patient is on the life of the family member, the more sensitive the nurse must be to recognizing the emotional state of the family member.

Dealing with anxiety and depression caused by the life situation. Depression caused by the uncertain future was connected to fear of another stroke. Especially the female family members experienced physical symptoms and their health deteriorated. The male family members were more concerned about the state of health of the stroke patient. Some of them behaved and acted like parents [57] .

Depression caused by the stroke is common with the patients and their family members, but it is often overlooked. Some of the family members hide their symptoms; so healthcare professionals do not recognize them[58]. Some of the family members told about their depression during the first year after the event of the stroke. Others related that the symptoms of depression were relieved when the patient had been home from the hospital for about one month. Those family members who had a strong feeling of control over the life situation felt less pressure and depression during the year after the stroke. Connected to this feeling of control were the time used in caring the loved one during the day, their own health condition, and their relationship to the survivor of stroke [59-61].

5. Discussion

5.1 Credibility of the review

On the basis of the systematic literature search and the comprehensive keywords, the authors tried to insure finding relevant studies important to the goal of this integrative review. Two authors of the review evaluated all of the literature searches. The choice of the data was based on the evaluation of the studies and to the consensus of the findings, which increase the reliability of the integrative review [62]. The inclusion and the exclusion factors were agreed upon by the research group. The studies accepted for the review represent a variety of everyday life of the family members of the stroke patients. All of the studies were published in peer-reviewed scientific journals.

5.2 Findings

Becoming a family caregiver of the working aged survivor of stroke means living in a state of focused chaos while the life of the family changes at a rapid rate. Everything that was earlier clear, including the health of the loved one, is not clear anymore. The family members have to stay strong, and to most of them this was clear at the beginning. Being able to help their loved one to recover was an important factor in enabling caregivers to move forward in life with purpose. According to Cameron and Gignac[63] many family members hoped that they might take part in the rehabilitation of the patient together with the healthcare professionals. Cameron and Gignac [63] found out that caregivers needed emotional support like having someone to talk to and they felt anxiety of adapting to provide care in the home to the survivor. In our study, the results were fairly similar. Caregivers also needed emotional support and they were very willing to care their nearest one after discharge; they felt it as their duty.

After becoming a family member of a stroke survivor, life must be rebuilt because the previous life is no longer possible. The family members attempt to control their lives in the shadow of the illness, although they face many challenges, not the least of which is insecurity about the future. The complex array of needs surrounding the stroke survivor's life were also found in the research of Cameron and Gignac [63], Greenwood, Mackenzie, Cloud & Wilson[64], and MacIsaac, Harrison & Godfrey[37]. Caregivers' need for information was mostly reported by new caregivers of stroke patients in the research of MacIsaac et al.[37]. Caregivers were dissatisfied with the amount, quality and delivery of information. In this study, caregivers wanted information about the illness, rehabilitation and possible alternative therapies. Another major challenge was simply getting all the information needed in order to be an effective caregiver during the recovery phase of the patient.

In this study, coping was the most important thing to the family member. They tried to balance their emotional wellbeing which was influenced directly by the distress and depression caused by the life situation. According to the results of this review, being able to care for their loved one gave strength to the family members. Greenwood et al.[64] got the same kind of results in their study, where the family members experienced satisfaction through caring for their loved one. The health condition of the family member affects depression [59-61]. According to Berg et al.[65] , depression of the family member is connected to the severity of the disorder of the patient, and the depression of the family member will be predicted best by their reaction during the acute phase of the disorder. In the study of Shanmugham et. al.[61] caregivers experienced a significant decrease in depression during one month after the discharge. In this review, Klinedinst et al.[58] realized that family members were able to hide their symptoms of depression from the health professionals making it difficult for them to know when to give help.

6 Conclusion

It is important that nurses recognize the changing reality of everyday life in family nursing of the stroke patient. In the acute phase it is essential to support family members so they will manage to live through the focused chaos in the best way possible. When the family member begins to find the new direction in their changed life situation, the healthcare professionals have to help them to manage by responding to their different needs. It is essential to the coping of the family member of the survivor of stroke that during nursing care, the presence of the family member next to the patient is encouraged. Nurses can help the spouse to move forward in life for example by giving concrete guidance in the matters connected to patient care, and by listening. It has to be possible for the family member to take part in peer support groups and have a chance to talk about feelings and thoughts. Identification of the changing needs of the family members during every phase of the nursing process will help the nurses give the right kind of support at the right time. In the future it is important to do further research of working aged, critically ill stroke patients, and especially their family members. When the family caregiver is well observed and cared for, it is obvious that he or she will have much more capacity to take care of the patient, and it will affect the quality of life for all. It has been found that sometimes even slight attention paid to family members by the nursing staff, a touch or a smile at the right time, may have a remarkable and long lasting impact on their lives. It is obvious that on the basis of these research findings it would be interesting to study further experiences of different kind of caregivers. In addition to this, it would be important to make some comparisons between younger and older caregivers' experiences.

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