International Journal of Nursing Studies 94 (2019) 1–8

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns

Living on the edge: Family caregivers' experiences of caring for post-stroke family members in China: A qualitative study

Qi Lu[a,b,*], Jan Mårtensson[c], Yue Zhao[d], Linda Johansson[e]

[a] School of Health and Welfare, Jönköping University, Jönköping, Sweden
[b] School of Nursing, Tianjin Medical University, China
[c] School of Health and Welfare, Jönköping University, Department of Nursing, Box 1026, SE-551 11, Jönköping, Sweden
[d] School of Nursing, Tianjin Medical University, No. 22 Qixiangtai Road, Heping District, Tianjin, 300070, China
[e] School of Health and Welfare, Jönköping University, Institute of Gerontology, Box 1026, SE-551 11, Jönköping, Sweden

ARTICLE INFO

Article history:
Received 16 July 2018
Received in revised form 18 February 2019
Accepted 23 February 2019

Keywords:
China
Experience
Family caregiver
Interview
Qualitative research
Stroke

ABSTRACT

Background: Globally, one-third of the 15 million people with stroke suffer permanent physical, cognitive, and emotional impairment. Because of traditional Chinese culture and the limited development of the primary healthcare system, most stroke survivors are cared for and live with their family after hospital discharge. However, previous literature shows a lack of qualitative studies on family caregivers' experience of caring for their relatives in China.

Objectives: The aim of this study was to explore the experience of family caregivers taking care of stroke survivors in China.

Methods: An explorative design was used wherein qualitative semi-structured interviews were conducted with family caregivers in China. Family caregivers were selected from one city and three communities using a purposive sampling method until no new data were generated (n = 26). A thematic analysis was used for the data analysis in this study.

Findings: Family caregivers' experience was described as *living on the edge*, which pulled their lives in multiple directions, created an unstable situation, and reduced their well-being and health. The participants believed they *had total responsibility* and felt that this was expected from both themselves and society. Little external understanding and insufficient support was emphasised, resulting in the caregivers feeling *all alone*,*drained by caring*, and *like prisoners in their own lives*. The family caregivers had to face all of the family events and make all of the decisions by themselves. They expressed love for their family members with stroke, but this was often overshadowed by feelings of sadness, depression, sensitivity, and anger. This resulted in an inability to see how things could improve and in the family caregivers *being uncertain about the future*.

Conclusion: All of these findings increased understanding and added knowledge of this topic that has been seldom studied in China. Healthcare authorities and professionals should recognise and understand the lives and situations of family caregivers since their relatives had a stroke to further identify their difficulties and needs. Appropriate and effective support, both from government and society, should be planned and implemented for family caregivers to relieve them from caring for their relatives with stroke and maintaining the quality of their own lives.

What is already known about the topic?

- Stroke has a great impact on peoples' lives and can increase dependency on others. Most stroke survivors live with their families and are dependent on their care after hospital discharge.
- A higher prevalence of physical and mental health difficulties is experienced by family caregivers of stroke survivors than the general population.

* Corresponding author at: School of Nursing, Tianjin Medical University, No. 22 Qixiangtai Road, Heping District, Tianjin, 300070, China.
E-mail addresses: luqi8674866@hotmail.com (Q. Lu), Jan.Martensson@ju.se (J. Mårtensson), yuezhao35@hotmail.com (Y. Zhao), Linda.Johansson@ju.se (L. Johansson).

https://doi.org/10.1016/j.ijnurstu.2019.02.016
0020-7489/

- Traditional Chinese culture and the limited development of the primary healthcare system bring burdens and challenges to family caregivers who care for their relatives experienced a stroke.
- In China, most research on family caregivers of stroke survivors has been conducted using quantitative methods, where the experience of family caregivers is predefined. Little is known about Chinese family caregivers' experiences of caring for stroke survivors.

What this paper adds

- Increased understanding and added knowledge of the experiences of family caregivers caring for stroke survivors in China have been rarely studied.
- Family caregivers' experiences were described as living on the edge. Their lives were pulled in multiple directions, creating an unstable situation as well as decreased well-being and health.
- The need to develop better care and support for family caregivers was addressed. Healthcare authorities and primary healthcare providers should pay more attention to this group of people and contribute to improving their health and lives.

1. Introduction

Stroke is the second most common cause of death (CDC, 2017) and is responsible for a considerable proportion of health problems in both developed and developing countries (Deng et al., 2017). Approximately 15 million people have a stroke annually, and one-third suffer permanent physical, cognitive, and emotional impairment (WHO, 2017).

Over the past few decades in China, due to peoples' lifestyles and the changing environment, the population with chronic diseases has increased. As a result of the high prevalence of hypertension, diabetes, and cardiovascular disease, stroke has become a major cause of death (Sun et al., 2016). There are more than 2.4 million new stroke victims each year (Sun et al., 2016). Approximately 70–80% lose their ability to work to some extent, 40% have moderate dysfunction, and 15–30% have severe disabilities (Sun et al., 2016).

Stroke not only affects the person's entire life, but also influences the lives of family caregivers (Zheng et al., 2014). The World Health Organisation (WHO) (2011) stated that family support is essential for dependent persons. Globally and across high-income countries, families are responsible for approximately 80% of the support needs. In most families, children and spouses provide the main caregiving (WHO, 2011). Caregiving is not solely a task-oriented activity, but a process that interacts with multidimensional aspects and coping adjustments made by family caregivers (Lee, 2004). For instance, family caregivers assist with hygiene, give comfort, help with feeding, encourage rehabilitation activities, and interact with the therapeutic team (Santos Souza and Lima Argimon, 2014). There is a higher prevalence of mental health problems such as depression and anxiety reported by caregivers of stroke survivors than among the general population (Balhara et al., 2012; Visser-Meily et al., 2008). Also, caregivers often experience poor physical health and reduced energy, including sleeping difficulties, weight loss, fatigue, and increased risk of chronic diseases (Parag et al., 2008; Legg et al., 2013).

Because of traditional Chinese culture and the limited development of the primary healthcare system, approximately 80% of stroke survivors are cared for and live with their family after hospital discharge (Bai et al., 2008). Healthcare support for stroke survivors in China is deficient due to inadequate workforce qualifications, fragmented health information, insufficient quality improvement systems, and poor performance in the control of risk factors within the primary healthcare system (Li et al., 2017). Meanwhile, filial piety and familism play vital roles in the Chinese context, which encourages children and spouses to assume all of the responsibilities and obligations of caring for the relative who has experienced a stroke (Qiu et al., 2018). It is reasonable to assume that these factors have an effect on the health and well-being of family caregivers. It has been reported that 45% of family caregivers of hospitalised stroke survivors in China experience depressive symptoms (Qiu and Li, 2009) and 64% experience work and financial burdens (Jiang and Wang, 2007). Significantly higher physical, psychological, and social burdens on family caregivers of stroke survivors than the general population have also been reported (Pang et al., 2005; Yang et al., 2005).

However, there are few studies on stroke survivors' family caregivers in China (Lv et al., 2016; Liu and Wang, 2016). Most research on family caregivers of stroke survivors has been conducted using quantitative methods, whereby the experience of family caregivers is predefined (Liu and Wang, 2016). Therefore, little is known about family caregivers' life situation when caring for stroke survivors (Han et al., 2017) from an inside perspective. Hence, this study explored the experience of family caregivers taking care of stroke survivors in China.

2. Methods

2.1. Design

An explorative design (Braun and Clarke, 2006) was used wherein qualitative semi-structured interviews with family caregivers were conducted.

2.2. Participants

Family caregivers of those with stroke after hospital discharge from three communities in Tianjin, China, with 11 million inhabitants between October 2014 and April 2015 were asked to participate. According to the residents' community health management records, potential participants were identified and contacted by community nurses. A purposive sampling method was used to select the participants. The inclusion criteria in this study were that the caregiver must be 18 years old or older, be able to speak and understand Mandarin, have the main responsibility of caring for the person with stroke, and be related by blood or marriage to the person and provide care free of charge. All of the 26 family caregivers asked to participate in this study chose to do so and no one withdrew their participation during the study process. The characteristics of the caregivers and the person they cared for are presented in Table 1.

2.3. Data collection

The participants were briefed about this study and informed of their right to withdraw from participation at any time by nurses in the community hospitals. If the participants agreed to take part in the study, the first author (QL) obtained their phone numbers from the community nurses and made appointments. In order to generate rich data about the family caregivers' experiences taking care of their relatives who had experienced a stroke, individual semi-structured interviews were conducted by the first author (QL). QL is a nurse with clinical experience working with stroke survivors and their families. The interview setting was chosen by the participants and all of the interviews were conducted face to face and audio recorded either at the participants' homes or in a treatment room in the community hospitals. Written informed consent was provided at the beginning of the interviews and

Table 1
Characteristics of the family caregivers and stroke survivors.

No.	Gender	Age	Educational level[a]	Occupation[b]	Length of care	Relationship to stroke survivors	ADL of stroke survivors[c]	Stroke survivors involved in the interview
1	M	47	Low	Blue collar	20Y	Son	4	Yes
2	F	73	Medium	White collar	8M	Wife	2	No
3	F	65	High	White collar	7Y	Wife	4	No
4	F	74	Medium	Blue collar	5Y	Wife	1	Yes
5	F	49	Low	Blue collar	1Y-7M	Daughter	4	No
6	M	73	Low	Blue collar	1Y-11M	Husband	2	Yes
7	F	68	Medium	White collar	4Y	Wife	2	Yes
8	F	61	High	White collar	10Y	Wife	1	Yes
9	M	82	High	White collar	10Y	Husband	1	Yes
10	F	68	Low	Blue collar	2M	Wife	3	No
11	F	63	Low	Blue collar	1Y-3M	Wife	3	No
12	F	68	Low	Blue collar	4M	Wife	3	No
13	M	80	Low	Blue collar	3M	Husband	4	Yes
14	F	75	Low	Blue collar	12Y	Wife	4	No
15	F	58	Low	Blue collar	13Y	Wife	3	No
16	F	52	Medium	White collar	8Y	Wife	4	No
17	F	60	Medium	White collar	2Y-8M	Wife	4	No
18	F	54	Low	Blue collar	8Y	Wife	2	Yes
19	F	75	High	White collar	7Y	Wife	2	No
20	F	66	Low	Blue collar	4Y	Wife	2	No
21	F	44	Low	Blue collar	2Y	Daughter-in-law	1	Yes
22	F	45	Medium	Blue collar	3Y	Daughter	1	Yes
23	F	59	Low	Blue collar	6Y	Wife	3	No
24	F	27	Medium	Unemployed	3Y	Daughter	2	Yes
25	M	67	Low	Blue collar	3Y	Husband	4	No
26	M	76	Medium	White collar	35Y	Husband	4	No

[a] Low: elementary school or low vocational education. Medium: secondary school or intermediate vocational education. High: higher vocational education or university education.
[b] Blue collar: manual worker; white collar: clerical worker.
[c] 1: Barthel$\geq$60, basically independent. 2: 41 $\leq$ Barthel$\leq$59, moderate dysfunction, needs help. 3: 21 $\leq$ Barthel$\leq$40, severe dysfunction, obviously dependent. 4: Barthel$\leq$20, completely dependent.

signed by the participants. Of 26 interviews, 11 of the participants were interviewed with the stroke survivors present in the room. The median length of the interviews was 50 min (range 28–136). An interview guide was developed and confirmed in the author group, as well as pilot tested in the first three interviews, which resulted in some minor revisions. As these interviews were considered high quality, provided relevant information, and the revision, were minor, they were later included in the data analysis. Each interview started with the broad question "What is your experience of caring for your relative who experienced a stroke?" The interview guide then included several areas to deepen the knowledge of caregiver experience, including the caregiving experience during the acute period of stroke, caring after discharge from the hospital, and the effects on the life situation and relationship. In order to encourage the participants to describe their experiences as much as possible, follow-up questions were also asked such as "What happened next?," "What were you thinking then?," "How did that effect you?," and "What do you mean by that?"

2.4. Data analysis

In the end, 26 interviews were conducted and included in the analysis. In the last three interviews, no new data were generated, suggesting that sufficient data had been obtained to describe the topic. This study used a thematic analysis, which is a data-driven method for identifying, analysing, and reporting patterns within data. Braun and Clarke (2006) stated that a thematic analysis can be used to find patterns in qualitative data and highlighted six phases: becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Audio recordings of the interviews were transcribed verbatim by the first author (QL), and the third author (YZ) double-checked the transcripts. The first author (QL), who is fluent in both Mandarin and English, translated the first three interviews into English to make the data available to all of the authors. These three interviews were read multiple times by all of the authors in order to become familiar with the data and gain deeper understanding of the content. In these interviews, all of the authors independently highlighted data extracts in line with the aim of the study and then discussed them to reach a consensus. Then the first author (QL) identified the data extracts in line with the aim for the other 23 interviews and translated all of the data extracts into English. This translation was double-checked by the third author (YZ). The first (QL), second (JM), and last authors (LJ) then continued the data analysis by independently coding the data extracts from all of the interviews. This was accomplished by writing notes and codes in the margins of the extracts. Several meetings were held among the authors to discuss and reach agreement on the coding. An initial thematic map was created based on the coding in order to form themes. Across the data set, all of the authors found a sense of significance and relationships between the different themes. These themes were discussed, reviewed, and defined until agreement was reached. Finally, one main theme and five sub-themes reflecting the content of the interviews were developed.

2.5. Ethical considerations

This study was conducted in accordance with the Declaration of Helsinki (WMA, 1964). Ethical approval was granted by the Tianjin Medical University Ethical Committee (TMUEC201400202), China. Informed consent was obtained from both the family caregivers and their relatives with stroke. In line with beneficence and maleficence principles, it was decided beforehand that if the participant thought that the interview was affecting them negatively, it would be stopped immediately. Only the interviewer knew the participants' identities, while the other researchers worked with anonymous data transcripts. All of the data were

stored on a password-protected hard drive and used only for this project. In addition, no one outside the research group had access to the collected data. The participants who were interested in taking part of the result were informed that they could obtain the results later, but only as aggregated data.

3. Results

3.1. Living on the edge

From an overall perspective, the family caregivers of those with stroke mostly described a sombre picture of their daily lives. Caregiving affected them physically, psychologically, and socially to such a degree that they were *living on the edge* of what they were able to manage. Their lives were pulled in multiple directions, creating an unstable situation as well as decreased well-being and health. This was related to the participants *having total responsibility* for caring for their relatives who had experienced a stroke. They believed they had this responsibility but also felt that this was expected of people in their surroundings as well as from society. Little external understanding and insufficient support was emphasised, resulting in the caregivers feeling as *being all alone* as well as feeling *drained by caregiving* and as *being a prisoner in their own life.* That is, caregiving negatively affected their own health and social lives. The family caregivers had to face all of the events in their families and make all of the decisions by themselves. They expressed love and affection for the person with stroke, but this was often overshadowed by feelings of sadness, depression, sensitivity, and anger. This resulted in an inability to see how things could be improved and in the family caregivers *being uncertain about the future*. This state of *living on the edge* was described by a wife as follows:

> " . . . sometimes, I cannot control myself well. 'Just die' I shout at him. 'Go and die, die, to die . . . Why don't you die? Do you want to live? If you want to, just do well.' After I shouted, I looked at him, and thought how pitiful he was. I still have to take care of him. It is my duty . . . " (P23, wife)

3.1.1. Having total responsibility

The stroke and its consequences resulted in a different situation for the whole family. Family caregivers described that they had the responsibility to both make things work in daily life as well as take care of the person who had experienced a stroke when (s)he become dependent. For instance, there were changes related to decreased family income and those with stroke having difficulties performing household tasks. Family caregivers said that they felt that they had the responsibility to manage this new situation and that this was also expected from close family members as no one else could take on these tasks:

> "I have to take full responsibility . . . I have to deal with everything. I can't, I can't interfere with my wife's work. The whole family, elder and little, we all depend on her income. She must not lose her job." (P1, son)

Adapting to these life transitions and having this increased responsibility became a great challenge. After starting to take care of the person who had experienced a stroke, family caregivers felt that the daily household duties had increased. Male spouse caregivers especially stated that they had taken over activities such as cooking and washing and found them difficult to manage.

> " . . . I have never done housework before. All the housework was my wife's business. I didn't care about buying food at all for years. So many years, I have never been to the grocery store. But now, I have to do grocery shopping myself . . . and learn to cook, do laundry, and all the housework . . . Although my cooking is still bad." (P13, husband)

These opinions were not expressed by the female spouse caregivers. Instead, they highlighted that they were overwhelmed by other types of household chores such as fixing electrical and financial problems. Facing these new tasks and making decisions alone meant that even after many years, some still could not manage these tasks very well.

> " . . . I still cannot get used to the change. In the past, my husband arranged and dealt with everything in my family. He was the one making decisions. I did not worry about any household chores. Suddenly, he fell ill . . . then everything is my duty, I cannot accept and handle it . . . " (P15, wife)

Overload responsibility was not only composed of increased daily activities and caring for the person with stroke, but also guilt toward other close relatives, especially children and parents. This was because the family caregivers felt that they did not have enough time to care for others as well and this affected their parents' and children's lives to a great extent. This feeling and consideration sometimes led caregivers to assume even more responsibilities:

> " . . . my son's work is quite busy, but he has no choice, he has to help me take his father to the hospital, he brought his laptop to work while at the hospital. However, the company still cut his pay even though he completed the work. I feel very guilty. I did not give him any help, instead we affect his career development so much . . . But . . . what else can I do? . . . (eyes turn red)" (P3, wife)

3.1.2. Being all alone

The family caregivers described different degrees of loneliness and isolation when taking care of the stroke survivors. The source of loneliness and isolation included a lack of support and understanding from close family and friends as well as society.

> "At the beginning, my relatives and friends gave me some money to live, to pay my child's tuition fee . . . but gradually, no one can always be there to help me. I have to take care of him, so I can't continue to work, and have no income. The government really should consider how to help families like us to survive . . . " (P16, wife)

Lack of support also meant that no one guided them or helped them care for those with stroke. Additionally, the caregivers reported difficulties in obtaining understanding from others, both for themselves and the stroke survivors.

> " . . . Many people comforted me, but I knew they did not experience the event I was suffering. Even if I told them what happened on me, they would listen like they were hearing a story . . . Only if this really happened to them, they would know it is not a story but a calamity . . . " (P17, wife)

At the same time, the family caregivers expressed that they did not trust others to care for the person who had experienced a stroke. They felt that they actually were the best suited person for this responsibility, which resulted in increased burdens.

> " . . . Others . . . I cannot trust others to take care of my wife . . . I needn't. I can deal with it myself." (P25, husband)

However, some of the family caregivers said that they received adequate support and help from their wider family, friends, healthcare professionals, society, and other caregivers in the same situation, especially during the acute post-stroke period. This support enabled the family caregivers to more positively face and accept their life transition.

> "In the hospital, the doctor gave me a lot of information about his condition and wrote a letter to me. Very nice. In the ward, we had good relationships with the other patients' families, we helped each other, shared food, and so on . . . " (P8, wife)

3.1.3. Drained by caregiving

After hospital discharge, the family caregivers realised that their health condition had worsened. All of the family caregivers described in detail what they did for the stroke survivors every day. Moreover, they believed this led to their own decreased well-being and declining health, both physically and psychologically. Physical pain in their wrists, shoulders, waists, and backs resulted from the family caregivers assisting and moving those with stroke.

> " . . . My wrists hurt, once he fell on the floor, I tried to pull him up several times without success. He kept sitting back on the floor again and again, and my wrists started to hurt. One month later, the pain in my wrists was getting a little better . . . " (P14, wife)

Caring for and worrying that the person might suddenly die led to rapid weight loss as well as trouble sleeping. " *. . . when he was in the hospital for two weeks, I lost five kilos in weight, I do not know how I lost weight . . .* " (P12, wife). Moreover, due to a lack of adequate and effective support from family and society, their emotional status became unstable and sensitive. Some caregivers reported that they became angry or sad much easier than before they started caring for their relatives who had experienced a stroke.

Emotional pressure was also mentioned. For instance, some described that the acute period of stroke in the hospital caused them extreme hardship. They referred not only to increased physical burdens, but also to greater mental distress. This was related to the sudden threat of death and that they had to make all of the decisions for the stroke survivors regarding treatment, which was a new situation that they had not faced before and therefore lacked knowledge about. Some of the participants did not want to recall the time in the hospital and described that period while crying.

> "Now, I really understand what a stroke patient's family member once said: 'If the family has a relative with stroke, the family caregiver would become exhausted and die.' And, it is so right. (Eyes turn red.) In the hospital, we hired a nursing assistant to take care of him. But the mental stress for me was still too much to bear. I am so tired . . . Every day, I had to stay at the hospital. Doctors and nurses called me constantly, and there was no moment to relax. Paying the hospital bills, signing the consent forms, blood transfusion, protein transfusion . . . I cannot recall. It is too painful. Until now, whenever I recall this period, I must stop myself immediately, if not, I would not sleep, and am stuck with the pain again, especially at night . . . (tears fall but the participant is silent)" (P17, wife).

3.1.4. Being a prisoner in their own life

The family caregivers experienced the situation as being a prisoner where they watched their own life slipping away from them. They lost their freedom and the chance to choose their own lives because of all of the time spent taking care of their relatives. They were unable to go shopping, meet their friends, work, or even spend time alone. The joy in their life was absent, and they did not know if they would ever escape anxiety, sadness, and depression.

> "I studied at the Elderly University twice a week before, and I liked to draw every day when I was free. Now, I have given up the Elderly University. Where can I go? I cannot go anywhere, I cannot do anything I'm interested in. I spend all the time in with him. I do not have any time and energy to do anything else." (P12, wife)

Generally, the older caregivers said that they could not enjoy their lives after retirement as a result of being caregivers. The younger caregivers reported that they lost passion and personal development because of their caregiving responsibilities.

> "It is really working-age for me, and I really want to work to reduce the financial burden on my family, but I can't go to work . . . I would take any job no matter how hard the work would be, even delivering newspapers, it doesn't matter. My friends encouraged me to work, but I cannot . . . I cannot leave home . . . " (P1, son)

3.1.5. Being uncertain about the future

Uncertainty about the future was raised by the family caregivers during the interviews. The future was often described in negative words, such as fear, helplessness, and hopelessness. " *. . . hope is useless . . . the more you dream, the less you get in reality . . . no expectations, no disappointment . . .* " (P24, daughter).

The family caregivers suffered from anxiety about the future. This was related to them not knowing when and if the stroke survivors would recover or for how long they would have to keep caring for and supporting their spouses or parents. The family caregivers also reported that they did not know who would care for those with stroke if their caregivers became too old or frail, which filled them with fear and anxiety. Sometimes they said that death might be the best way to solve all of their problems and ease their pain. Hence, suicide was sometimes mentioned as a solution:

> "What is the meaning in my life? My whole life has been wasted, no significance of living. What is my life all about? Why am I alive? You tell me. Is life interesting? Is life full of meaning? I really want to jump off a building, just die, so tired (shaking head) . . . " (P25, husband)

3.2. Discussion of methodological rigour

Credibility, dependability, confirmability, and transferability are used to evaluate the trustworthiness of a qualitative study (Polit and Beck, 2012). Credibility was established as the authors have previous knowledge of performing qualitative interviews and thematic analysis as well as clinical experience regarding the care of patients with long-term diseases. However, there is a risk of bias because the authors understand the data based on their own opinions and experiences. To avoid such bias, the results were discussed with colleagues outside the research group, that is, a peer debriefing. To ensure dependability and confirmability, the same interviewer (QL) with no previous contact with the participants conducted all of the interviews. In addition, frequent discussions among the authors throughout the research process aimed to achieve agreement on the design phase, sampling, data collection, and especially data analysis, were applied to enhance the dependability and strength of the results. Furthermore, quotations from the interviews are presented in the results to provide readers with an opportunity to review and make their own judgements about the fairness and accuracy of the performed analysis. We have done our best to provide a detailed description of the context, participants, and data collection process to establish transferability.

One limitation of this study is that the stroke survivors were sometimes present during the interviews (n = 11), which might have prevented the family caregivers from speaking freely and increased the risk of obtaining embellished information. However, in the interviews when the persons with the stroke were present, a sombre picture of their experience of caring was described. Those few positive descriptions given came from both interviews when the person who had experienced a stroke was present and not present. Hence, these interviews were similar to the others, indicating that the family caregivers spoke freely even though the stroke survivor was present. Also, from an ethical standpoint, it seemed appropriate to let the participants decide if they wanted the stroke survivors to

attend the interviews as they felt that they were unable to leave their relatives unsupervised. During these interviews, some of the stroke survivors also briefly described their experience of family caregiving. These data were excluded from the analysis as they did not represent the perspective of the family caregivers.

4. Discussion

This study explored the experiences of family caregivers in China who were taking care of persons who had experienced a stroke. *Living on the edge* was identified as the main theme, which illustrated a sombre picture of the family caregivers' daily lives that affected them physically, psychologically, and socially to a large extent. Concurrently, *having total responsibility, being all alone, being drained by caregiving, being a prisoner in their own life,* and *being uncertain about the future* emerged as sub-themes to describe the lives of the family caregivers.

The participants in this study had full daily responsibility for caring for their close relatives who were stroke survivors. They believed they had this responsibility but also felt that this was expected from those around them and society. Consistent results presented by Qiu et al. (2018) and Mei et al. (2014) indicated that the study participants accepted the role of caregiver for the family member with stroke as an expected part of life. Chinese filial piety is an important value in the Chinese cultural context and encourages family members assume the role of caregivers (Cheng and Chan, 2006; Yang, 2009). Spousal caregivers emphasised that marital responsibility and a sense of obligation promoted them to become the main caregivers (Qiu et al., 2018; Xiao et al., 2014). However, high filial and marital obligations can have a negative influence on family caregivers because they wish to provide the best care possible for their parents or spouses, which can lead to guilt and self-blame (Lyonette and Yardley, 2003). For spouses, the ethical responsibility of conjugal fidelity is infinite and forbids them from leaving their sick partner. Consequently, it becomes their mission in life to provide care. This creates a conflict that involves an inability to live in the marriage yet also an inability to leave (Levinas, 1990). Studies by Kitzmüller et al. (2012) and Bäckström et al. (2010) indicated that within different cultures and religious contexts, the spouse caregivers are expected by both others and society to assume the responsibility of caring for persons who had experienced a stroke. Family caregivers of persons living with other disabling neurological diseases have also described this as a balancing act between their own expectations and those of others wherein one tries not to be overwhelmed by care work (Lerum et al., 2016; Ray et al., 2012).

In this study, total responsibility and a lack of support resulted in the participants being drained by caregiving, feeling all alone, and becoming prisoners in their own lives. Ohama and Soderberg (2004) indicated that the caregiver role is frequently characterised by reduced individual freedom and an increased sense of responsibility, because caregiving consumes a great amount of time and energy. Caregivers can be overwhelmed by a series of negative experiences, including unstable emotions, health decline, guilty feelings, anxiety, social isolation, depression, hopelessness, and lack of support (Ohama and Soderberg, 2004). However, family caregivers in Sweden have expressed that they were also able to maintain feelings of how everything used to be before their relatives experienced stroke. This was especially true for those still working, which was of vital importance for enduring, replenishing energy, and feeling relaxed (Kitzmüller et al., 2012; Bäckström et al., 2010). In the present study, due to their responsibilities, the family caregivers described that having a job became difficult or even impossible, which led to further economic stress. They did not want to ask for help from others as this might also affect their employment situation. According to statistics, Chinese family caregivers spend an average of 13 h per day caring for stroke survivors (Zhang, 2010). In addition to care time, Chinese family caregivers face financial pressures; for example, medical expenses have been highlighted as a main stressor for families of stroke survivors in China. Liu et al. (2012) reported that the monthly rehabilitation expenses for stroke survivors were more than 4000 RMB in Xiamen, Fujian Province, compared to the average personal monthly income of 3357 RMB.

Concurrently, the one-child policy in China has resulted in a "4-2-1" family structure, which means that one adult couple care for four old parents and one child. Consequently, family size has decreased sharply, resulting in every family member having more caregiving responsibilities (Liu, 2006). Additionally, the limited development of the primary healthcare system and medical insurance system are further barriers to support and reduce the responsibility of family caregivers in China (Bai et al., 2008). This might explain why the family caregivers in this study experienced difficulties in obtaining adequate help and support from their broader family members and society. The problem of balancing responsibilities and freedom has also been described by other Chinese family caregivers (Yang, 2010). However, this seems to be a general issue as other international research also portrayed the caregivers' situation as difficult due to increased workloads and great responsibilities (McLennon et al., 2014; Bulley et al., 2010; Woodford et al., 2017). However, this study highlighted this conflict within a Chinese context.

In this study, the family caregivers experienced a loss of hope and feelings of fear and anxiety when supporting their family members with stroke, which led to an uncertain future. Zhang and Lee (2017) stressed that hope plays an important role for caregivers in long-term care and support caregivers to find continuity and meaning in their lives and overcome uncertainty. Unfortunately, the caregivers in this study described their lives and futures with helplessness and hopelessness. Over the past two decades in China, 12 studies on the family caregivers of stroke survivors have been conducted using qualitative methods (Lv et al., 2016). However, only three have focused on the experiences of being a family caregiver (Liu and Wang, 2016). Too much responsibility, declining health, negative emotional status, and a lack of support were experiences reported in these qualitative studies (Wang, 2013; Zhang and Wang, 2014; Mei et al., 2014). However, none indicated that the caregivers experienced uncertainty over their situations and futures (Wang, 2013; Zhang and Wang, 2014; Mei et al., 2014). However, fear of an uncertain future has been described in research from Western countries (Woodford et al., 2017; Greenwood et al., 2009). For instance, uncertainty seems to be associated with poor communication from healthcare providers, lack of specific information on stroke, and discharge needs being unmet (Camak, 2015; Creasy et al., 2013).

Caregiving was not referred to only from a negative perspective. There were family caregivers who stated that they received good support and help from their wider family members, friends, healthcare professionals, society, and other caregivers in the same situation, especially during the acute post-stroke period. However, the main description of the caring experience was sombre. One explanation for this might be related to what Lippi (2016) found when studying the situation of families with persons who had schizophrenia. Namely, when family caregivers become overwhelmed and overburdened, it prevents them from feeling a sense of meaningfulness and experiencing positive aspects in caring. Also, a longer time spent on caregiving and inadequate social support have been found to be highly correlated to higher levels of burden (Rigby et al., 2009; Han et al., 2017). However, Zhang and Lee (2017) claimed that the family caregivers of stroke survivors can find positive meaning if they reached a "turning point," where the unbearable suffering becomes bearable. To reach such a turning point, caregivers

should have opportunities to express their suffering in order to gradually gain an understanding of their own situation (Rehnsfeldt and Eriksson, 2004). In most of the interviews in the present study, it was described that the interviewer was the first person who asked for and listened to the stories of the family caregivers. Due to a lack of opportunities to talk about their situation, the participants may not have reached the turning point, and this seems to be the case in other studies from China (Zhang and Wang, 2014; Mei et al., 2014). Also, according to the stress and coping model by Moos and Schaefer (1993), coping resources and processes influence how people resolve and adapt to stressful life circumstances. Coping resources refer to the relatively stable personal and social resources that influence how individuals manage life crises and transitions, which was limited in this study. Thus, this study identified the needs of increased support for family caregivers in China, from healthcare professionals as well as society, to relieve the burden and stress of family caregivers.

5. Conclusions

Having total responsibility, being all alone and drained by caregiving, being a prisoner in their own life, and being uncertain about the future resulted in caregivers living on the edge, describing a rather sombre picture of family members in China caring for their relatives who had experienced a stroke. Healthcare authorities and professionals should recognise and understand the life situation of family caregivers after their relative has experienced a stroke in order to identify their difficulties and needs. Offering and implementing appropriate and effective support, such as peer support, economic support, and household or volunteer services, for family caregivers should be prioritised.

Funding

This research was funded by the National Natural Science Foundation of China (Grant No.: 71673199) and the Tianjin Municipal Education Commission Scientific Research Project (Grant No.: 2018SK007).

Conflicts of interest

No conflicts of interest exist.

Acknowledgements

The researchers are most grateful to the family caregivers who shared their experiences and to the community health-care professionals who assisted with the selection of the participants.

References

Bäckström, B., Asplund, K., Sundin, K., 2010. The meaning of middle-aged female spouses' lived experience of the relationship with a partner who has suffered a stroke, during the first year postdischarge. Nurs. Inq. 17 (3), 257–268.
Bai, J.J., Cao, Q., Zhang, J.Y., Shen, X.F., Gu, X.R., Yan, S.J., 2008. Investigation on attending demand of main home caregivers of cerebral apoplexy patients. Fam. Nurs. 6 (10), 855–858.
Balhara, Y.P., Verma, R., Sharma, S., Mathur, S., 2012. A study of predictors of anxiety and depression among stroke patient-caregivers. J. Midlife Health 3 (1), 31–35.
Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol. 3 (2), 77–101.
Bulley, C., Shiels, J., Wilkie, K., Salisbury, L., 2010. Carer experiences of life after stroke – a qualitative analysis. Disabil. Rehabil. 32 (17), 1406–1413.
Camak, D.J., 2015. Addressing the burden of stroke caregivers: a literature review. J. Clin. Nurs. 24 (17-18), 2376–2382.
Centers for Disease Control and Prevention, 2017. Stroke Statistic Retrieved from. . http://www.strokecenter.org/patients/about-stroke/stroke-statistics/.
Cheng, S.T., Chan, A.C., 2006. Filial piety and psychological well-being in well older Chinese. J. Gerontol. B Psychol. Sci. Soc. Sci. 61 (5), 262–269.
Creasy, K.R., Lutz, B.J., Young, M.E., Ford, A., Martz, C., 2013. The impact of interactions with providers on stroke caregivers' needs. Rehabil. Nurs. 38 (2), 88–98.
Deng, C.Y., Lu, Q., Gong, B.Y., Li, L.Y., Chang, L.X., Fu, L., Zhao, Y., 2017. Stroke and food groups: an overview of systematic reviews and meta-analyses. Public Health Nutr. 21 (4), 766–776.
Greenwood, N., Mackenzie, A., Wilson, N., Cloud, G., 2009. Managing uncertainty in life after stroke: a qualitative study of the experiences of established and new informal carers in the first 3 months after discharge. Int. J. Nurs. Stud. 46 (8), 1122–1133.
Han, Y., Liu, Y., Zhang, X., Tam, W., Mao, J., Lopez, V., 2017. Chinese family caregivers of stroke survivors: determinants of caregiving burden within the first six months. J. Clin. Nurs. 26 (23-24), 4558–4566.
Jiang, X.Y., Wang, L.X., 2007. A study on the caring pressure of the main caregivers of stroke patients and the corresponding nursing strategies. Chin. Nurs. Manage. 7 (4), 23–26.
Kitzmüller, G., Häggström, T., Asplund, K., Gilje, F.L., 2012. The existential meaning of couples' long-term experience of living with stroke. Illn. Cris. Loss 20 (4), 339–362.
Levinas, E., 1990. Ethics and Infinity. Symposium Bokförlag, Stockholm.
Lee, R.L.T., 2004. Caring for family members with stroke: chinese family caregivers' experiences. AJNS 7 (1), 18–27.
Legg, L., Weir, C.J., Langhorne, P., Smith, L.N., Stott, D.J., 2013. Is informal caregiving independently associated with poor health? A population-based study. J. Epidemiol. Community Health 67 (1), 95–97.
Lerum, S.V., Solbrække, K.N., Frich, J.C., 2016. Family caregivers' accounts of caring for a family member with motor neurone disease in Norway: a qualitative study. BMC Palliat. Care 15 (1), 22.
Li, X., Lu, J., Hu, S., Cheng, K.K., Maeseneer, J.D., Meng, Q., Mossialos, E., Xu, D.R., Yip, W., Zhang, H., 2017. The primary health-care system in China. Lancet 390 (10112), 2584–2594.
Lippi, G., 2016. Schizophrenia in a member of the family: burden, expressed emotion and addressing the needs of the whole family. S. Afr. J. Psychiatr. 22 (1), 922.
Liu, W., 2006. Analysis of the four-two-one family structure resulting from the only-one-child policy. J. Shenyang Agric. Univ. 8, 462–464.
Liu, C.Y., Wang, J.J., 2016. Research Progress on experience of family caregivers of patients with stroke. Nurs. Pract. Stud. 13 (17), 22–24.
Liu, G.P., Zhou, Y.Z., Wu, Q.P., 2012. Disease burden of caregivers of stroke patients during rehabilitation in hospital and its influencing factors. J. Nurs. 19 (5), 29–32.
Lv, L.L., Hu, L.Y., Guo, H., 2016. Literature metrology analysis of the research status of stroke caregivers in China. Chin. Nurs. Res. 30 (3), 823–827.
Lyonette, C., Yardley, L., 2003. Predicting mental health outcomes in female working carers: a longitudinal analysis. Aging Ment. Health 10 (4), 368–377.
McLennon, S.M., Bakas, T., Jessup, N.M., Habermann, B., Weaver, M.T., 2014. Task difficulty and life changes among stroke family caregivers: relationship to depressive symptoms. Arch. Phys. Med. Rehabil. 95 (12), 2484–2490.
Mei, Y.X., Zhang, Z.X., Zhang, Y., Zhang, X., Yi, J.N., Lin, P.L., Zhang, Y.Q., 2014. Qualitative research on the experience and feelings of mother caregivers for stroke patients in communities. Chin. Health Serv. Manage. 31 (5), 389–391.
Moos, R., Schaefer, J., 1993. Coping resources and processes: current concepts and measures. Handbook of Stress: Theoretical and Clinical Aspects, 2. , pp. 234–257.
Ohama, M., Soderberg, S., 2004. The experience of close relatives living with a person with serious chronic illness. Qual. Health Res. 14 (3), 396–410.
Pang, D., Na, L., Lu, Q., Yang, P., 2005. A survey of primary family caregiver burden for community stroke patients. Chin. J. Nurs. 40, 285–287.
Parag, V., Hackett, M.L., Yapa, C.M., Kerse, N., McNaughton, H., Feigin, V.L., Anderson, C.S., 2008. The impact of stroke on unpaid caregivers: results from the Auckland regional community stroke study, 2002–2003. Cerebrovasc. Dis. 25 (6), 548–554.
Polit, D.F., Beck, C.T., 2012. Nursing Research: Generating and Assessment Evidence for Nursing Practice. Wolter Kluwer Health/Lippincott Williams & Wilkins, Philadelphia.
Qiu, Y.R., Li, S.J., 2009. Stroke: coping strategies and depression among Chinese caregivers of stroke survivors during hospitalisation. J. Clin. Nurs. 17 (12), 1563–1573.
Qiu, X., Sit, J.W.H., Koo, F.K., 2018. The influence of Chinese culture on family caregivers of stroke survivors: a qualitative study. J. Clin. Nurs. 27 (1-2), 309–319.
Ray, R.A., Brown, J., Street, A.F., 2012. Dying with motor neurone disease, what can we learn from family caregivers? Health Expect 17 (4), 466–476.
Rehnsfeldt, A., Eriksson, K., 2004. The progression of suffering implies alleviated suffering. Scand. J. Caring Sci. 18 (3), 264–272.
Rigby, H., Gubitz, S., Phillips, S., 2009. A systematic review of caregiver burden following stroke. Int. J. Stroke 4 (4), 285–292.
Santos Souza, M.B., Lima Argimon, I.I., 2014. Caregivers' conception of the care provided to the elderly. J. Nurs. Ufpe Online 8 (9), 3069–3075.
Sun, J., Guo, Y.T., Wang, X.N., Zeng, Q., 2016. mHealth for aging China: opportunities and challenges. Aging Dis. 7 (1), 53–67.
Visser-Meily, A., Post, M., Van de Port, I., Van Heugten, C., Van den Bos, T., 2008. Psychosocial functioning of spouses in the chronic phase after stroke: Improvement or deterioration between 1 and 3 years after stroke? Patient Educ. Couns. 73 (1), 153–158.
Wang, L., 2013. A qualitative study on caring experience of family caregivers of stroke patients with depression. Inner Mongolian Med. 7, 14–15.
WMA, 1964. WMA declaration of Helsinki-ethical principle for medical research involving human subject. 18th WMA General Assembly, .

Woodford, J., Farrand, P., Watkins, E.R., Llewellyn, D.J., 2017. I don't believe in leading a life of my own, I lead his life": a qualitative investigation of difficulties experienced by informal caregivers of stroke survivors experiencing depressive and anxious symptoms. Clin. Gerontol. 41 (4), 293–307.
World Health Organization, 2011. Chapter 5: Assistance and support. World Report on Disability Retrieved from. . http://www.who.int/disabilities/world_report/2011/en/.
World Health Organization, 2017. Stroke, Cerebrovascular Accident Retrieved from. . http://www.emro.who.int/health-topics/stroke-cerebrovascular-accident/index.html.
Xiao, L.D., Wang, J., He, G., De Bellis, A., Verbeeck, J., Kyriazopoulos, H., 2014. Family caregiver challenges in dementia care in Australia and China: a critical perspective. BMC Geriatr. 14 (6), 1–13.
Yang, H.B., 2009. A preliminary study on differences in filial piety between the only-child and the non-only-child. J. Zhangzhou Normal Univ. 22 (04), 168–172.
Yang, L.L., 2010. Influencing factors of the burden of main caregivers of cerebral apoplexy patients and nursing strategies. Chin. Gen. Pract. Nurs. 8 (20), 1856–1858.
Yang, H.H., Li, T.Y., Xu, Y.J., 2005. Research of the correlation between the burden level of the main home infirmarian of the stroke patients and their social support. Chin. J. Pract. Nurs. 21 (5), 6–8.
Zhang, J.Y., 2010. Effects of nursing intervention with improved resources on reducing primary family caregivers' burden in caring stroke survivors. Chin. J. Mod. Nurs. 16, 2233–2238.
Zhang, J., Lee, D.T.F., 2017. Meaning in stroke family caregiving: a literature review. Geriatr. Nurs. 38 (1), 48–56.
Zhang, W.W., Wang, Y.J., 2014. Qualitative Research on experience of children caregivers of patients with stroke during rehabilitation period. J. Nurs. 21 (20), 67–69.
Zheng, L.W., Zhang, D.M., Xu, L., Zhong, G.Q., Deng, L.J., Zheng, Z.H., 2014. The study on relationship between quality of life in stroke patients and cognition of main caregivers. Chin. J. Gerontol. 34, 168–169.