



## Family experience in providing support and the achieving of post-stroke late adulthood development<sup>☆</sup>



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Family;  
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### Abstract

**Objectives:** Supporting the achievement of post-stroke late adulthood development is a unique experience that impacts heavily on families. The purpose of this study was to provide an overview of family experience in providing support post-stroke to a family member and enabling them to achieve late adulthood development and then to interpret this.

**Method:** The research used a qualitative design with a descriptive phenomenology approach. The participants were 14 caregivers of the elderly.

**Results:** The results (1) the impact of the bio-psycho-socio-spiritual on the elderly post-stroke survivor, (2) how the family fulfills the needs of the post-stroke elderly person, (3) the impact of the post-stroke period on the elderly by family members, (4) the achievement of post-stroke late adulthood development by family members, and (5) the meaning of providing care for the post-stroke elderly survivor.

**Conclusions:** This research identified 5 themes and recommendations are that psychoeducation for the carers of stroke survivors should be improved.

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### Introduction

Stroke is a serious and major problem all over the world, including Indonesia. The Basic Health Research done in Indonesia in 2013<sup>1</sup> shows that the prevalence of stroke in

Indonesia increases incrementally with age. The highest number of stroke cases diagnosed by health personnel are from age 75 and up (43.1%), and the lowest number is among the 15–24 year age group, with 0.2% of the total. The highest prevalence of stroke was found in North Sulawesi (10.8%) and the lowest in Papua (2.3%), while West Java had 6.6% of the total.

Post-stroke, the elderly will face both physical problems and psychological disorders, such as anxiety, anger, low self-esteem, social isolation, helplessness, and despair. A relationship between physical disability and despair, and in stroke patients there is also a relationship between

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cognitive disability and despair.<sup>2</sup> Post-stroke conditions can disrupt the ego development of late adulthood. A person who has self-integrity, which includes the elderly, will possess certain characteristics that include having a fit and healthy physique, the ability to relate well socially, a depth of spiritual maturity, and a strong and healthy intellect.<sup>3</sup> The psychosocial theory shows that the mental task of late adulthood is the development of ego integrity as opposed to despair. This means that the elderly need to evaluate and accept their lives and be accepting of their death.<sup>4</sup> Together, these two terms provide an understanding that integrity of the ego is one aspect of the self-integrity that must be achieved. In Indonesia, the practice is frequently observed whereby the post-stroke elderly still perform their daily activities, such as eating, bathing, dressing, and going to the mosque to pray with the community.

In contrast, other researchers have identified a different situation, in which older adults feel embarrassed by their physical changes and their inability to move as before, and they feel as though they are a burden on their families. Although the family keeps caring for the elderly post-stroke patient, this is accompanied by increased emotion due to the fatigue resulting from the care given to the elderly person. Both of these situations provide illustrations showing that elderly people and their families have different attitudes and different ways of achieving the developmental tasks of later life.

Previous related studies have included the quantitative research into the relationship between the family's coping strategies and the quality of life of the elderly post-stroke patient while undergoing post-hospital rehabilitation,<sup>5</sup> in Pontianak explain the major factors associated with stroke survivors' behavior as identified by family caregivers,<sup>6</sup> and quantitatively the relationship between independence in performing daily activities and life satisfaction in elderly people who have had a stroke.<sup>7</sup> Research show reveals the prevalence of depression following a stroke and considers the prevalence of depression in elderly people, both with and without a stroke.<sup>8</sup>

Based on a consideration of these factors in relation to stroke, the following research question was formulated: How does the family experience their support for the post-stroke elderly person in relation to their achieving of late adulthood development. Currently, there is no research investigating the experience of supporting the post-stroke elderly person to achieve late adulthood development, so it is necessary to use the qualitative phenomenological approach to investigate this question.

## Method

This research applied a qualitative research method using the descriptive phenomenology approach. Participant data was collected from a sample containing family members who were post-stroke. The selection of participants was based on criteria tailored to the research objectives; that is the family included a post-stroke elderly person and the main caregiver who was aged 18 years or above.

The research data were collected at the participants' homes. The interviews were recorded and the results transcribed. Data analysis was then performed. The preparation

of the report was completed between the third week of May and the second week of June 2017. The analytical method used the Colaizzi approach.<sup>4</sup>

## Results

The demographic characteristics of the elderly stroke patients who were the subject of this study are presented in [Table 1](#). [Table 2](#) shows characteristics of participants (caregivers) in this study.

This research identified 5 themes:

### 1. Impact of the bio-psycho-socio-spiritual on the post-stroke elderly person

This aspect of the psychological impact is divided into stress and anxiety. Five out of the 14 participants said that the elderly person was petulant, even to the extent of being grumpy, talking loudly, and being rude.

"My father is an impatient person ... he is very irritable, and when doing so he will curse... But that's hardly surprising because he was that way ever since ..." (P5)

In contrast to most of the other participants, participant 7 suffered from anxiety. This anxiety was expressed as a feeling of sadness.

"She is usually quite sensitive ... she tends to cry when left alone" (P7)

Some participants said the elderly needed help with their basic nutritional requirements, such as eating and drinking, while two participants said their family member required total assistance for any such activity.

"Urinating, passing motions all was done by me... my father was fully assisted. Also for shower... I bathe him, help him for passing motions and urinating... I carry him to toilet... there was a wheelchair ... he used a wheelchair and assisted chair ... he just sat ... and I will clean it up... all by myself." (P3)

Two participants stated that the elderly person previously went to the mosque to pray, but that after the stroke they only prayed at home. Differing from the other participants, participant 12 revealed that the elderly person preferred to go to the mosque to pray since the stroke.

Three of the 14 participants said that the stroke had affected the social life of the elderly person and that they now tended to withdraw from social situations. Their withdrawal was illustrated by their rare participation in social gatherings, by the emotional shutdown, and by their having only one close friend.

### 2. Families meet the needs of the post-stroke elderly

Families fulfill all the needs of the post-stroke elderly person, which include their daily routines, biological, psychological, spiritual, sexuality and social needs.

"Urinating and passing motions were assisted by me... I bathe him... I help him for passing motions and

**Table 1** Characteristics of stroke victims, including age, gender, marital status, stroke period and help needed with daily activities.

| Elderly code | Age (years) | Gender | Marital status | Stroke period (year) | Daily activity     |
|--------------|-------------|--------|----------------|----------------------|--------------------|
| 01           | 85          | Male   | Married        | 5th                  | Partial Assistance |
| 02           | 67          | Male   | Married        | 7th                  | Independent        |
| 03           | 67          | Male   | Married        | 13th                 | Total Assistance   |
| 04           | 62          | Male   | Married        | 2nd                  | Partial Assistance |
| 05           | 66          | Male   | Married        | 2nd                  | Total Assistance   |
| 06           | 60          | Male   | Married        | 2nd                  | Independent        |
| 07           | 77          | Female | Married        | 5th                  | Partial Assistance |
| 08           | 60          | Female | Married        | 5,5th                | Partial Assistance |
| 09           | 69          | Male   | Married        | 3rd                  | Partial Assistance |
| 10           | 78          | Female | Married        | 9th                  | Partial Assistance |
| 11           | 70          | Male   | Married        | 5th                  | Partial Assistance |
| 12           | 60          | Male   | Married        | 1st                  | Independent        |
| 13           | 60          | Male   | Married        | 1st                  | Partial Assistance |
| 14           | 76          | Male   | Married        | 8th                  | Partial Assistance |

**Table 2** Age, gender, education, occupation.

| Participant code | Age (years) | Gender | Education         | Occupation |
|------------------|-------------|--------|-------------------|------------|
| P1               | 39          | Female | High School       | Homemaker  |
| P2               | 63          | Female |                   | Homemaker  |
| P3               | 60          | Female | Elementary School | Homemaker  |
| P4               | 55          | Female | Elementary School | Homemaker  |
| P5               | 61          | Female | Junior High       | Homemaker  |
| P6               | 55          | Female | Junior High       | Tailor     |
| P7               | 52          | Female | Elementary School | Homemaker  |
| P8               | 62          | Male   | Elementary School | Security   |
| P9               | 54          | Female | Junior High       | Homemaker  |
| P10              | 75          | Male   | Bachelor          | Retired    |
| P11              | 64          | Female | Diploma           | Retired    |
| P12              | 55          | Female | High School       | Homemaker  |
| P13              | 57          | Female | Elementary School | Homemaker  |
| P14              | 69          | Female | High School       | Homemaker  |

urinating... I carry him to toilet... I clean the whole thing... all by myself" (P3)

The experience of two participants who had experienced adverse conditions after taking alternative medicines had become a lesson to the family regarding the use of alternative therapies.

"Nearly father surgery due to injury to the tongue due to alternative medicine. Alhamdulillah same medicine from doctor recovered. since then I just routine control to the hospital only." (P14)

### 3. Impact of post-stroke on the elderly person as perceived by the family

Caring for the post-stroke elderly person had a considerable impact on psychological, fisiological, social, and economic condition of the family member who cared for them.

"I am tired emotionally and physically... I am worried for him ...I am afraid my dad will die at any time ...it feels devastating." (P4)

### 4. Achievement of post-stroke late adulthood development as perceived by family care givers

Almost all participants expressed that achievement of late adulthood development included a strong understanding of religion, self-sufficiency in the performance of daily activities according to changes experienced by the elderly person, and positive self-acceptance.

"I do not want to help with daily activities... like walking to his room, going to the bathroom because he has to be independent. It is now or never for him to be independent." (P14)

## 5. Meaning of providing care for the post-stroke elderly family member

This included a test of perseverance, the means of doing good, and the meaning of punishment.

“If heaven were easy, God would not create hell.” (P9)

## Discussion

### 1. Impact of the bio-psycho-socio-spiritual on the post-stroke elderly

Due to a decline in the physical function of the post-stroke elderly person, most of them experience stress and anxiety. A stroke, clients typically experience two mental health disorders: anxiety and depression.<sup>9</sup> The highest rate of depression occurs in those elderly people with strokes who experience high levels of dependence in the fulfilling of their activities of daily living (ADL).<sup>8</sup> The results of this research showed that none of the elderly people suffered from depression, but they did experience stress and anxiety. The family’s level of confidence in health personnel was high, and almost all participants collected medication for the patient’s high blood pressure from the health services.

### 2. Families fulfill the needs of the post-stroke elderly individual

The family satisfies the needs of the elderly according to a three-level category of dependency: as needing total assistance, partial assistance, or being independent. Research describes how a family member with a stroke experiences loss of independence and struggles with the new phase of life as they recover from the stroke. The family’s role in relation to the patient is to maintain a balance in meeting their daily needs during this phase, providing just enough support to allow them to adjust to being independent once more.<sup>10</sup>

This study identified only two male caregivers, both of whom needed assistance in caring for the elderly person, unlike the female caregivers (wives or daughters) who were able to deliver the care by themselves. The study showed that of 30 caregiver respondents, most were women (18 people, or 60%) and only 12 were males (40%).<sup>11</sup>

The majority of elderly caregivers are women, which was confirmed by a study in Brazil, where care of the elderly is considered to be a woman’s responsibility. It has become the norm in society that women are closely related to those aspects of life that require care.<sup>12</sup>

### 3. Impact of post-stroke in the elderly as perceived by the family

The researchers looked at the impact of the stroke on the family: That caring for the elderly caused emotional, physical, and interpersonal problems for the caregiver, hence one purpose of this study was to understand the role of the family as caregivers.<sup>13</sup> According to study, the effect of a stroke is not only significant for the client but also for the

family members who provide care, and it often impacts negatively on their emotional well-being and physical health. Relationship changes also occur between the stroke patient and the family, for instance, there is a decline in family harmony and marital satisfaction.<sup>14</sup> Families also experience increased fatigue while caring for stroke patients.

One of the most common adjustments for a caregiver is the disruption to their normal social and holiday activities. Caregivers feel unable to leave the stroke patient alone at home because of safety concerns, and some do not even want to leave the stroke patient alone in a room, especially if the person is impulsive or less than aware of his or her limitations.<sup>15</sup>

### 4. Achievement of late adulthood development post-stroke, as perceived by the family

The achievement of late adulthood independent development must be tailored to the changes experienced. According to the study, many elderly people who experience a stroke can still perform their daily activities independently. If they do not become dependent on others, and if they can still feel useful, they will feel satisfied with their lives.<sup>7</sup>

To achieve self-integrity, a person needs to pay attention to physical enhancement, develop IQ skills, develop emotional maturity, improve his or her spiritual abilities, and constantly hone his or her sensitivity and social skills.<sup>3</sup> A study says that the ego’s integrity reveals an attitude of accepting lifestyle changes and believing in the choices made as being the best decision for him- or herself, and also being able to control him- or herself.<sup>4</sup>

Based on the understanding of self-integrity and ego integrity as given above, it can be concluded that achievement of late adulthood development (self-integrity) can be viewed as being based on the ability of the elderly person to adjust to their condition by showing a physical, psychological, social and spiritual balance, in which mental health will be maximally satisfied.

### 5. Meaning of providing care for post-stroke elderly

In this research, the meaning of the family’s caring for the elderly stroke survivor was largely defined as spiritual support. Human beings naturally seek a purpose or reason for living, and they feel that the value of their life is increased as the spiritual dimension grows.<sup>16</sup>

The results of the study showed that, although the psychological impact was felt by the family when caring for the post-stroke elderly person, the family caregivers were firm that it did not affect their welfare, and this was especially true of married couples. A study state that the psychological tension of caring for the post-stroke elderly person has no significant influence on the psychological welfare of the couple ( $p=0.772$ ).<sup>17</sup>

In this study, the participants were family members who care for elderly post-stroke survivors and support them in the achieving of late adulthood development. In order to improve the results related to developmental achievement, further research could explore the experience from two different points of view: that of the family members and that

of the elderly themselves. This study interviewed only two male participants. The length of time since the elderly person had had a stroke was too broad, extending from one to 13 years. This study did not consider the cultures of the participants involved in the care of the elderly.

The family should help the elderly to attend to their own daily needs as far as possible, encouraging them to engage with activities out of doors, to talk with the people around them, and to utilize the health facilities. Mental nursing specialists should be able to facilitate psychoeducation among the elderly and form support groups for the families and elderly post-stroke survivors.

Nursing education could help to develop the monitoring of families with elderly post-stroke members, especially in assessing stressors, coping resources, and coping mechanisms. Further research can be conducted in relation to the achievement of post-stroke late adulthood development through a qualitative methodology with an ethnographic approach, which could consider the different family cultures and involve more males of the family as caregivers.

## Conclusions

The results of this study provided an array of information to help the family achieve post-stroke development in the elderly. Some of the important information that can be conveyed to the nursing services are: (1) the impact of the bio-psycho-spiritual in the post-stroke elderly, (2) the family fulfilling the needs of the post-stroke elderly person, (3) the post-stroke effects on the family, (4) the elderly person's achievement of post-stroke development as perceived by the family, and (5) the significance of caring for the post-stroke elderly individual.

The bio-psycho-socio-spiritual impact on the post-stroke elderly and the post-stroke impact as perceived by the family can be inhibiting factors in the achievement of post-stroke late adulthood development. There are also differences between male and female caregivers with female caregivers being more independent, and male caregivers tend to seek help from others in providing care for the elderly person. The families also stated that they felt that the post-stroke elderly care received from the health services was better than the alternative treatments.

## Conflict of interests

The authors declare no conflict of interest.

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