

## ORIGINAL ARTICLE

## The effective post-stroke adaptation behavior model requires a family support system

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### KEYWORDS

Adaptation  
Physiological;  
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Family health

### Abstract

**Purpose:** This study aimed to explain the effective post-stroke adaptation behavior based on the Roy's adaptation model (RAM) through the patient experiences when undergoing the adaptation process after stroke.

**Methods:** This study was qualitative used a phenomenological approach. The participants were patients undergoing post-stroke recovery at home with the following inclusion criteria: post-discharge from the hospital 2–3 months, and in stable medical condition. The data were collected through in-depth interviews. The data analysis was performed through content analysis. We used Lincoln and Guba's criteria to establish the trustworthiness of the study.

**Results:** Three thematic categories structured the meaning of the stroke survivor's experience: (1) Problems after stroke; (2) Adaptive coping strategies and (3) Effective adaptation response.

**Conclusion:** A thematic analysis integrated with Roy's adaptation model generated an effective post-stroke adaptation model. We recommend the development of a family empowerment intervention framework to improve the adaptation behavior of stroke survivors.

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### PALABRAS CLAVE

Adaptación  
fisiológica;  
Adaptación  
psicológica;  
Accidente  
cerebrovascular;  
Salud familiar

### El efectivo modelo de comportamiento de adaptación postapoplejía requiere un sistema de apoyo familiar

#### Resumen

**Objetivo:** El objetivo de estudio es explicar el comportamiento efectivo de adaptación postaccidente cerebrovascular, basado en el *Roy's adaptation model* (RAM), a través de las experiencias del paciente que se somete al proceso de adaptación después del accidente cerebrovascular.

**Métodos:** Estudio cualitativo con enfoque fenomenológico. Los participantes fueron pacientes en recuperación postaccidente cerebrovascular, en casa, con los siguientes criterios de

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inclusión: dos a tres meses tras el alta del hospital y en condición médica estable. Los datos fueron recogidos a través de entrevistas en profundidad. El análisis de datos se realizó a través del análisis de contenido. Usamos los criterios de Lincoln y Guba para establecer la confiabilidad del estudio.

*Resultados:* Tres categorías temáticas estructuran el significado de la experiencia del sobreviviente del accidente cerebrovascular: 1) problemas después del accidente cerebrovascular; 2) estrategias de afrontamiento adaptables y 3) respuesta de adaptación efectiva.

*Conclusión:* Un análisis temático integrado con el modelo de adaptación de Roy generó un modelo de adaptación postaccidente cerebrovascular efectivo. Recomendamos el desarrollo de un marco de intervención familiar para mejorar la adaptación de los supervivientes a un accidente cerebrovascular.

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### What is known?

Adaptation responses are the key to achieve optimal quality of life after stroke. The effective post-stroke adaptation model is structured based on the three thematic categories of stroke survivor's experience include problems after stroke, adaptive coping strategies, and effective adaptation response.

### What it contributes?

The effective post-stroke adaptation model can be used as a framework to develop a home-based intervention model for the stroke survivor.

## Introduction

The national stroke prevalence in Indonesia is 0.8%. According to incident reports, stroke prevalence was estimated to be 0.91% in urban areas and 0.78% in rural areas. Stroke is the leading cause of death in urban areas (15.9%) and the second (11.5%) in rural areas. It is the leading cause of death in the 45–54 age group in Indonesia and first in both urban (28.8%) and rural (17.4%) areas.<sup>1</sup>

Strokes produce a broad range of persistent neurological deficits. Research shows more than 60% of patients still disabled after a stroke, 50% of them suffer from hemiparesis, and 30% still unable to walk without assistance.<sup>2</sup> In another study, the proportion of post-stroke disabilities increased from 21% at the beginning after stroke to 43% after 1 month, and 39% remained disabled after 5 years.<sup>3</sup> There were 35% of patients remain disabled after 3 months of a stroke attack. The risk of disability will be higher in patients who are unemployed, housewives, retired, low educated, or have inadequate income.<sup>4</sup>

Beyond physical disabilities, stroke patients also suffer from psychological problems like depression. Depression

occurs and gradually worsens once patients realize that they are unable to perform routine activities. It intensifies as they perceive body changes, lose their productivity, and their role evolves (e.g., family, career, relationships, etc.). Study revealed that 32% of stroke patients were depressed 3 months after stroke.<sup>5</sup> Depression decreases the quality of life, particularly in the context of previous role limitations based on physical and emotional problems, general health, social functioning, and diminished mental status.

Prolonged disabilities require significant coping strategies to commence adaptive behavior. Common issues faced by stroke survivors are physical disability, depression, inadequate knowledge regarding stroke, and diminished family support, all of which influence the patient's coping mechanisms. Subsequently, maladaptive coping causes ineffective adaptation responses.<sup>6</sup> The adaptation model of Calista Roy can be used to evaluate survivors' experiences when facing stroke-related problems and the subsequent adaptation process. This theory posited that every person possesses adaptation skills to mitigate internal or external stimuli. People utilize coping skills to respond to any stimulus. Acceptance and adaptation to current circumstances are expected goals that determine people's ability to confront the stimuli.<sup>6</sup>

This study aimed to explain the effective post-stroke adaptation behavior based on the Roy's adaptation model (RAM) through the patient experiences when undergoing the adaptation process including perceived stimuli, coping strategies to face these stimuli, and adaptation behavior following a stroke.

## Method

### Study design

This qualitative research used a phenomenological approach. We used RAM to develop research objectives and frameworks as well as suitable interview question items.

## Participants

The participants were patients undergoing post-stroke recovery at home with the following inclusion criteria: they were within the 2–3 months post-discharge window from the hospital and in stable medical condition. We selected participants who met these criteria based on data provided by the Abdul Aziz General Hospital in Singkawang City, West Kalimantan Province, Indonesia. Participants were selected through the purposive sampling method following the research objectives. Based on this data, we conducted home visits to interview participants living in and around Singkawang City. We interviewed eleven participants who met the inclusion criteria but found no new data for meaning unit, sub-category, category, and theme in the final three participants, which indicates data saturation has reached. The results and conclusions were therefore based on the eleven participants.

## Data collection

The research instrument utilized in this study was the researcher equipped with interview guidance and data that were arranged according to the study's purpose using RAM as a framework. The following are the interview topics guide with the participants:

- Problems that are often experienced and felt to bother participants after a stroke.
- Participants' views on their physical appearance, bodily functions, and the future after stroke.
- Participants' efforts to solve the problems after a stroke.
- Participants' efforts to meet their daily needs, maintain healthy conditions, and return to social life.
- Participants' efforts to communicate and relate with others after a stroke.
- Participants' efforts to overcome negative views about themselves after a stroke.
- Family support and its impact on participants.

The data were collected through in-depth interviews conducted by researchers to explore the experiences of participants throughout the process of adjusting their life post-stroke. Interviews with each participant were carried out within 60–90 min. Information was captured using a voice recorder. The overall process of in-depth interviews with participants was conducted over three months from January to March, 2019.

## Data analysis

We used content analysis to evaluate the data through the following stages: transcribing the interviews; searching the contents of interrelated sentences that comprise certain meanings (meaning units), coding each meaning unit, grouping meaningful data following the study objectives; determining categories and subcategories derived from the meaning units; arranging themes from several categories; and drawing conclusions by reviewing the entire contents of the data, identifying the "red thread" of subcategories, categories, themes, and relationships between themes.

## Trustworthiness

We tested the validity of the data by increasing the criteria of credibility, transferability, dependability, and conformability. Data credibility was improved through data analysis conducted by a team of researchers and experts over six months starting from the transcription of the data to explanations of the research results from which conclusions were drawn. The experts assisting in the data analysis are senior researchers in qualitative research who have a high level of experience conducting a content analysis. After compiling qualitative data from several subcategories and main categories, we clarified our findings and reengaged with the participants to discuss our conclusions. We also triangulated the data sources by explaining the data with the participants' families. In order to meet the transferability criteria in this study, we documented all research processes starting from the interview stage and ending with the final data analysis. In addition, we also presented representative direct quotes submitted by participants while we were delivering the results of the study. The criteria for dependability and conformability were verified by recording all research field activities and asking experts to review and provide suggestions for the entire research process.

## Ethical aspects

We strived to protect human rights and welfare at all times. We guarantee the confidentiality of participants by creating a participant code. We do not publish personal data or any data related to the identity of participants. The study protocol was carefully reviewed by the ethical clearance committee of Health Polytechnic Pontianak Indonesia under Institutional Review Board number 149.2/KEPK-PK.PKP/V/2019.

## Results

Participants in this study were stroke survivors undergoing the recovery process at home. Participants ranged from 45 to 68 age years (six women and five men). Eight had graduated from senior high school, one from junior high school, and two from elementary school. Before their strokes, eight participants were still working while the other three were either not employed or retired. Nine participants suffered ischemic strokes and the other suffered a hemorrhagic stroke. The sociodemographic characteristics of the participants are reported in [Table 1](#).

Qualitative data analysis revealed three themes, nine categories, and nineteen subcategories as described below.

### Problems after stroke

The "problem after stroke" theme was based on the categories of physical problems and aggravating conditions.

#### Physical problems

Reduced mobility and speech impairment were found to be the main stimuli acknowledged by participants in their post-stroke adaptation. All participants agreed that mobil-

**Table 1** Demographic characteristics of participants.

Characteristic	<i>n</i>	%
<i>Gender</i>		
Male	5	45.5
Female	6	54.5
<i>Age</i>		
40–49	3	27.3
50–59	6	54.5
60+	2	18.2
<i>Type of stroke</i>		
Ischemic	9	81.8
Hemorrhagic	2	18.2
<i>Education</i>		
High school	9	81.8
Elementary	2	18.2
<i>Profession before stroke</i>		
Business	4	36.3
Army	1	9.1
Taxi driver	1	9.1
Farmer	2	18.2
Unemployed	3	27.3

ity impairment was the most impactful concern following their strokes. Specific problems involved physical weakness, as mentioned by participants below:

“My arm was weak, my left leg as well. Moreover, I felt too weak to move and was not as fast as before.” (P2, P3)

In addition to mobility problems, five of the eight participants recognized speech impairment as another very significant impediment to daily life, as mentioned by participants below:

“At the beginning of my stroke, it was hard for me to speak. At times, I couldn’t speak at all.” (P1) “I couldn’t speak fluently to friends.” (P5, P10)

### Aggravating factors

We identified the existence of family, financial, and social concerns that further aggravated the participants’ existing physical problems. All of these influenced the participants’ coping ability toward problems and their adaptation behavior in response to disabilities. The participants acknowledged several familial problems that existed following their strokes, such as unacceptable behavior from family members, abandonment by close family members, and lack of attention from their spouses:

“My husband ignored me. I was disappointed every day. He developed a pattern of returning home after being away three consecutive days.” (P5)

Financial problems arose because of high medical costs and the loss of income streams. Two of the eight participants suffered hardship because of the costs of medical treatment following their strokes:

“It was difficult for me and became even more difficult. I have no money to pay the medical bills.” (P3, P11)

Three of the eight participants lost their jobs following their strokes:

“After losing my job, I had no financial resources to pay the medical bills; that is on my mind more than anything now.” (P1)

Another escalating problem experienced by the participants was their inability to partake in social activities. Five of the eight participants mentioned that they were not participating in religious, social, or family activities after their strokes:

“I used to participate in social and family gatherings; sometimes I joined religious activities in our mosque as well, but I no longer do so.” (P3)

### Adaptive coping strategies

The theme of adaptive coping strategies was based on the categories of psychological adaptive coping strategies, spiritual coping, and adjustments for a healthier lifestyle.

#### Psychological adaptive coping

We identified positive thinking, emotion control, and acceptance of circumstances as the coping strategies used by participants to confront disruptive stimuli following a stroke. Positive thinking was demonstrated through the participants’ efforts to acknowledge that other patients were facing similar difficulties; they conditioned themselves to believe that nothing changes after a stroke; they perceived stroke as a curable disease; the felt that many body parts still functioned normally:

“People were suffering more than me. They were unable to eat, they couldn’t do anything other than survive, so I stopped thinking about it.” (P1)

Another form of adaptive psychological coping demonstrated by participants was emotion control. Half of the participants used mechanisms to control their emotions when dealing with problems. They squelched angry thoughts by imagining happy times and fun activities, and they refused to dwell on their problems as burdensome to their quality of life. The following statements reflect the participants’ efforts to control their emotions:

“If we keep thinking about the negatives, it makes life harder; just let it be.” (P4)

Participants also exhibited adaptive psychological coping through the acceptance of their current conditions. This was illustrated through the participants’ efforts to endure, their sincerity, and being grateful for surviving after their ordeal. Half of the participants accepted their current conditions following their strokes, as mentioned in this statement:

“Although I am sick, I am also grateful. Praise God, I am still able to speak.” (P4)

#### Spiritual coping

We also identified efforts to be closer to God, otherwise known as spiritual adaptive coping. Participants increased

their efforts to worship more frequently; they prayed and surrendered to God to mitigate post-stroke concerns:

“After praying, my heartfelt relaxed.” (P5, P9)

Three of the eight participants exhibited contradictory factors as they did not actively worship more after their strokes. Participants mentioned that physical weakness adversely affected their ability to worship, as mentioned in this statement:

“I rarely pray after my stroke; I have been weak and find it hard to stand up; What should I do?” (P8)

### Adjustments for a healthier lifestyle

We identified healthier lifestyles as part of the participants’ efforts to return to optimum physical condition after their strokes. This category is described by three subcategories noted by the participants: regular therapy, physical exercise, and healthy diets. Regular therapy included physical examinations, hospital visits, and a consistent administration of medicine:

“I receive regular checkups from interns, neurologists, and regular hospital visits as well.” (P2)

Other efforts to achieve optimum recovery included physical exercise, walking, and stretching. Six of the eight participants walked and stretched regularly in the morning post-stroke:

“I walked in the morning, strolling near the house while moving my arm.” (P1, P9)

Attention to healthier diets is another way to achieve optimum recovery and prevent recurrent strokes, as mentioned below:

“I maintain a healthy diet and control my high blood pressure by avoiding poor food choices.” (P4)

### Effective adaptation response

The theme of effective adaptation response was based on the categories of physical adaptation response, positive self-concept, social role functioning, and family support.

#### Physical adaptation response

We identified the participants’ efforts to perform common daily activities of independent living as part of their physical adaptation response post-stroke. Examples were their efforts to shower, use the toilet, and feed themselves either by themselves or with minimal assistance. They adapted by utilizing the healthy, unaffected parts of their bodies to perform these activities, as stated below:

“I eat, shower, and perform bowel movements by myself. I try to do things independently, beginning with the little things.” (P1)

The participants’ challenge to fulfill their own needs as part of their goal to achieve independence despite their physical limitations:

“I am sick, but I prefer to do things myself rather than seek help from others.” (P1)

The functioning parts of the body were optimized to support weaker parts, as mentioned below:

“My left arm is weak so I learned to use my right hand.” (P2, P9)

#### Positive self-concept

We identified positive thinking toward oneself, body image, and concentration on future possibilities as examples of positive self-concept demonstrated by the participants. Positive body image and functionality were expressed in three responses, namely, not feeling embarrassed because of body changes, physical weakness, or speech impairment:

“I don’t feel shy about going to the office to receive my retirement payments. I do this myself.” (P4)

Adaptive self-concept responses were also expressed through the participant’s expectations of better futures:

“I still hope for a better future, and I often dream about my children’s eventual success.” (P1)

#### Social role functioning

We identified the participants’ efforts to perform tasks based on self-ability, and social participation post-stroke is otherwise known as social role functioning. Performing tasks within their abilities were described as adaptive responses, for example, changing jobs by selling items from home and performing household tasks, as mentioned in the following statements:

“I no longer have a job; instead I stay home and bake cakes to sell.” (P4)

Adaptive responses to social functioning after a stroke were also demonstrated by participants who engaged in religious activities and family gatherings, as mentioned below:

“I am a member of Charismatic (a church organization); yesterday I visited that community again.” (P1)

“I will go if my neighbor invites me to attend a wedding ceremony, a religious event, or other social activities.” (P2)

#### Family support

Direct familial assistance to participants includes financial support, help with household activities, and fulfillment of basic needs:

“My husband supports me in many ways; he picks up the children from school, cooks, and shops for our groceries.” (P2)

Participants also received emotional support from their families when they were visited during hospitalization. They provided motivation, attention, love, and respect, as mentioned below:

“I get more attention from my family. They don’t leave me alone. Everyone is good for me.” (P2)

Family is the main support system for stroke survivors. Diminished family support can be the major cause of delays in the adaptation process. In this case, patients tend to have

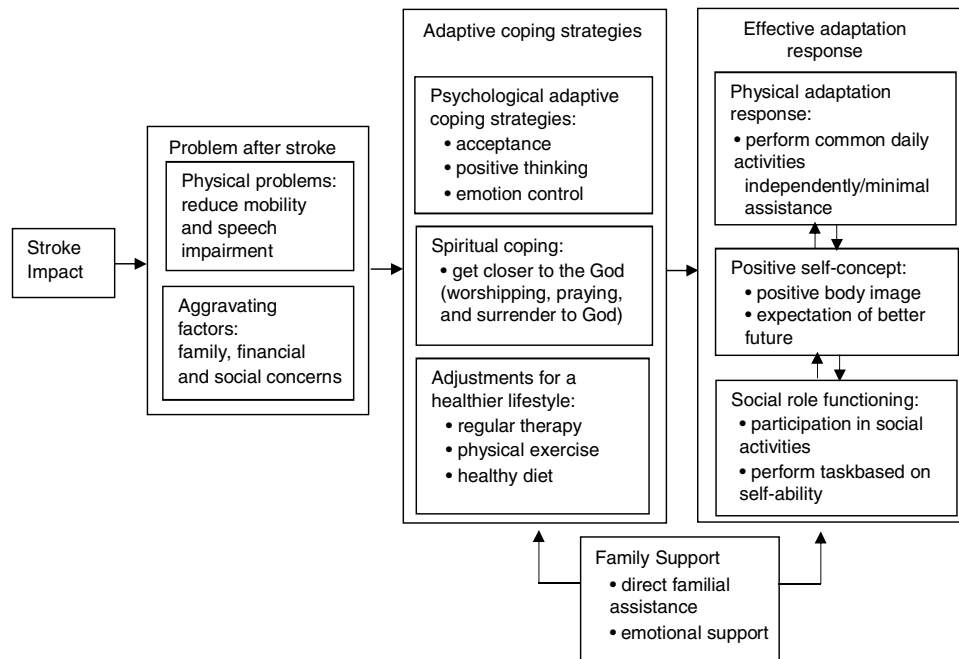


Figure 1 Effective post-stroke adaptation model based on thematic analysis and Roy's adaptation model.

negative thoughts about their future, as mentioned by one participant:

"I am disappointed with my husband; I feel desperate with no hope for the future." (P5)

Another effective adaptation response was exhibited through efforts to maintain good relationships among family members. It can be seen through the respect and help offered as well as the attention paid among participants and their families, as mentioned by this participant:

"My husband and I help each other. If I see he is busy, I go to him, and he does likewise; Although I am sick, we keep helping each other." (P2)

A thematic analysis integrated with RAM generated an effective post-stroke adaptation model, as shown in Fig. 1.

## Discussion

This study found that mobility and speech impairment were the main debilitating factors for participants. These caused them to lose their ability to perform certain activities. Some were even fired by their employers. There are significant proportions of post-stroke patients who cannot perform certain daily activities, including eating independently (42% of women and 26% of men), dressing oneself (59% women and 37% men), and moving from a bed to a chair (59% women and 35% men) as reported in Ref. 7 Research shows that 50% of all post-stroke patients experience impaired mobility caused by hemiparesis (muscle weakness or partial paralysis), and 26% are unable to perform daily activities. Speech disorders and depression are also common causes of disability in stroke survivors.<sup>8</sup> Post-stroke disabilities often persist over long periods, thereby causing significant changes in the lives of participants and their families. These circumstances

challenge participants to not only survive but also adapt to return their optimum body functionality despite the hardship. Post-stroke patients often fear that their physical and psychological problems, inadequate social and financial support, and their lack of access to adequate rehabilitative services will increase their risk of experiencing functional disorders and declining socioeconomic status.<sup>9</sup>

Other contextual stimuli are family, financial, and social problems. These are categorized as contextual stimuli because they contribute to the participants' responses to focal stimuli. Strokes often result in long-term hospitalization and recovery. Some patients lose their jobs following a stroke, thus resulting in additional financial burdens on their families. Hospital bills, medication costs, and major investments in mobilization equipment can cripple a family financially. Although the direct costs of care and medication are often paid by health insurance programs, patients and their families are still affected by indirect costs such as income loss or the patient's inability to meet familiar responsibilities. Reducing family members' effective time while providing in-home patient care was also a major indirect family burden, in other words, their productive working time was significantly reduced because of their care responsibilities.

Approximately 36% of all stroke patients report having hardships before their stroke. One year after the stroke, 61% report increased hardship of which the major causes were financial problems and dissaving previous funds. The number of patients in high-income brackets decreased from 59% to 44% within a year after a stroke. Among patients with middle income before the stroke, 35% experienced decreased income within twelve months of the stroke.<sup>10</sup> Most stroke patients credited their financial decline to the consequences of post-stroke disabilities. These disorders and financial barriers significantly impact their mental health.<sup>11</sup>

Certain post-stroke stimuli cause significant changes in participants' lives. These changes often force people to resort to coping mechanisms to overcome their problems and limitations. Accepting current circumstances, positive thinking, and emotion control are all adaptive coping mechanisms. Those utilizing adaptive coping strategies demonstrated an effective adaptation behavior response. Adaptive coping revealed their ability to perform control processes to overcome their problems. Adaptive coping mechanisms are key to adjusting one's life after a stroke.<sup>12,6</sup> We must support stroke survivors during their coping process to help them confront post-stroke problems by providing appropriate discharge plans, social and financial support, social insurance, and training programs specifically designed for stroke survivors and their families.<sup>9</sup> Nursing interventions targeted at increasing the ability of patients to use flexible coping strategies can improve the patients' post-stroke quality of life.<sup>13</sup>

Another identified adaptive coping method is religious-spiritual coping, as demonstrated through the participants' efforts to augment the frequency of their religious activities, such as worshipping, praying, and surrendering to God. Religious spiritual coping is a set of religious and spiritual practices based on a relationship with God and other highest elements that are used by individuals to control and cope with situations of stress, illness, and suffering.<sup>14</sup> Participants who augmented their spiritual participation after stroke exhibited effective adaptation behavior related to important physiological and psychological aspects. Lack of religious engagement, stroke relapses, and poor physical functioning are factors that can cause low self-acceptance of disabilities following a stroke.<sup>15</sup> Depression is another common problem, with 87% of stroke patients experiencing some post-stroke depression (PSD) after discharge.<sup>16</sup> The use of religious spiritual coping mechanisms often mitigates PSD.

Another adaptive coping strategy is to adopt healthier lifestyle decisions to achieve optimum physical recovery. Participants performed physical activities, such as walking and stretching, to improve functional capabilities, resume previously enjoyable activities, and thereby improve their overall health. However, several studies have revealed that most patients eventually revert to unhealthy lifestyles following strokes, thereby increasing their risk of recurrence. A study comparing the prevalence of 5 lifestyle-related stroke risk factors in adults with and without stroke includes inadequate physical activity, low consumption of fruits and vegetables, smoking, excessive alcohol consumption, and overweight or obese. This study proves the higher prevalence of 4 lifestyle-related stroke risk factors in stroke patients compared to adults without stroke including inadequate physical activity (56.5% vs 49.5%), smoking (30.1% vs 16.6%), low fruit and vegetable consumption (51.7% vs 46.0%), and overweight/obesity (70.2% vs 64.5%). Conversely, excessive alcohol consumption showed a lower prevalence in stroke patients compared to adults without stroke (5.4% vs 6.1%).<sup>17</sup> A cohort study confirmed that genetic and lifestyle factors are independently associated with the incidence of stroke.<sup>18</sup> We must develop better educational programs for patients undergoing rehabilitation to increase their knowledge about strokes, reinforce the basic principles of healthy lifestyles, and reduce the risks of recurrent strokes.

Direct family assistance and emotional support improved patient adaptability following a stroke. Families helped the patients by performing physical tasks, fulfilling basic needs once the patients were unable to do them alone, reminding the patients to administer their medicine, and ensuring that they attended regular checkups. Harmonious relationships between participants and their families demonstrated effective interdependent adaptation responses post-stroke. RAM explained that interdependent mode adaptation responses are demonstrated through mutual relationships, including mutual bilateral care, knowledge and skill sharing, commitment, and time allotment.<sup>12,6</sup> Familial social support is associated with a reduction of depression severity,<sup>19</sup> functional capacity, and the quality of life of post-stroke patients.<sup>20</sup> Support from family members is also associated with the progressive improvement of the patient's functional and psychosocial status. Patients who received considerable family support demonstrated significantly decreased depression levels following their strokes. Perceived social support exerted a protective influence on subsequent post-stroke depression.<sup>21</sup>

The limitation of this study is that we did not include patients who had severe strokes, cognitive impairments, and unstable medical conditions as participants. So that the results of this study do not describe the adaptive behavior of patients with these criteria. This may limit the generalizability of this study. This study also did not consider cultural factors that could influence the adaptive behavior of post-stroke patients, thus limiting the generalizability of this study.

In conclusion, a thematic analysis integrated with RAM generated an effective post-stroke adaptation model. According to this model, we recommend the development of an intervention framework to improve the adaptation behavior of stroke survivors. This intervention would comprise health education related to stroke and common problems encountered following a stroke, training for patients and their families regarding adaptive coping strategies, and assistance for patients when learning how to adapt their behavior. Families should be involved in every aspect of these interventions in order to prepare them to deliver optimum support and hopefully improve both the adaptive behavior and quality of life of post-stroke family members.

## Conflict of interest

The authors declare that there is no conflict of interest in this study.

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