

## CHAPTER 4

### FINDINGS AND DISCUSSION

A hermeneutic phenomenological study was conducted to explore the lived experiences of stroke survivors at their homes in Bandung, Indonesia. Ten stroke survivors were involved as participants in this study. The findings are presented in this section as follows; (1) characteristic of the participants, (2) lived experiences of stroke survivors, and (3) discussion of the findings.

#### Characteristics of the Participants

Demographic data obtained from the participants recorded gender, age, marital status, educational level, household income, occupation, length of time since their stroke, other current medical problems, type of family, relationship with caregiver, and religion. These data are presented in Table 1.

**Table 1. Characteristic of stroke survivors (N=10)**

Characteristic	Frequency
Gender	
Female	6
Male	4
Age in years	
31 – 40	1
41 – 50	3
51 – 60	1
61 – 70	5
Marital status	
Widow	1
Married	9

**Table 1 (continued)**

Characteristics	Frequency
Education level	
Elementary school	3
Junior high school	2
Senior high school	4
Undergraduate	1
Household income in Rupiah per month	
1,000,000 - 2,000,000	5
2,000,001 - 3,000,000	4
3,000,001 - 4,000,000	1
Adequacy of family income	
Adequate	8
Inadequate	2
Occupation before illness	
Housewife	5
Teacher	2
Laborer	1
Retired	2
Occupation after illness	
Teacher	1
No job	5
Retired	4
Duration of having stroke	
3 months – 1 year	4
1.5 – 2 years	1
2.5 – 3 years	1
3.5 – 4 years	2
4.5 – 6 years	2
Other current medical problem	
Hypertension	4
Diabetes Mellitus	1
None	5
Type of family	
Nuclear	9
Extended	1
Primary caregiver	
Spouse	5
Daughter	2
Daughter and wife	2
Daughter and husband	1
Religion	
Islam	10

**Table 1 (continued)**

Characteristics	Frequency
Barthel Index score	
40 – 50	1
51 – 60	1
61 – 70	3
71 – 80	2
81 – 90	-
91 – 100	3

As depicted in Table 1, participants consisted of six females and four males. Most were 61-70 years old. One was a widow and nine were married. Four participants had senior high school education, two had elementary and junior high school, and only one had a university undergraduate degree. Most of the participants who had elementary and junior high school education lived in a rural area. Half had a family income between Rp. 1,000,000 - 2,000,000 per month. Most their family income to be adequate while two participants felt it to be inadequate. Prior to the stroke, five participants had been housewife, two teachers, one a laborer, and two retired government employees. Following the stroke, five participants no longer work, four had been retired, and one being a teacher. The illness history ranged from 3 months to 6 years. Half of the subjects had another disease, of which the most common was hypertension, suffered by four of them. Nine participants lived in a nuclear family and one participant with an extended family. The majority of the stroke survivors' caregivers were spouses only, the rest were daughter, husband, and wife. All of the participants were Muslim. The Barthel Index (BI) score (the Barthel Index of the activities of daily living (ADL) is a method of assessing and communicating to other health professionals the degree of disability in a particular individual – the

higher the score the better able the patient is varied, three were in the 61-70, and another three in the 91-100 range.

The ten stroke survivors were originally contacted which met the inclusion criteria and voluntary participate in the study. Their backgrounds and illness history described briefly as the following.

### **Participant 01**

Participant 01 was married. He was 62 years old, and lived with his wife and daughter. Before having his stroke he had retired from a government employee as a staff in the engineering department, where he had worked as a field supervisor and used to go to work by motorcycle. His job was to supervise laborers who were building structures such as bridges or office buildings. He had been diagnosed as suffering a stroke about five years previously. This event saddened him, because after the stroke he only could work in his little shop attached with his house and could only wait for buyers to come to his shop because he was too unstable to walk without assistance, and also had a decreased listening ability.

Since his stroke, he had concentrated more on his Islamic religious practice, participating in not only compulsory things but also voluntary worship options such as praying at midnight, fasting 2 days a week, and charitable works. He believed that performing these kinds of religious practices would help him recover from his illness. His Barthel Index score was 100, indicating that he could perform all necessary activities of daily living by himself, although his wife and his daughter, his main caregivers who took care of him when he needed assistance, helped him with such things as his monthly hospital visit or accompanying him if he wanted to go to outside the home.

### **Participant 02**

Participant 02 was married, 57 years old, and lived with his wife and two children. Before his stroke he had been a government employee in the Department of Economic Cooperation, training new employees from other cities or provinces, sometimes traveling to other provinces to perform his duties. He had had his stroke four years previously, which had been a terrible blow because of its influence on his job, causing him to retire early because of the aftermath of stroke, which resulted in a difficulty to speak clearly, weakness in the left side of his body forcing him to use a cane for walking, and blurred and double vision. His problems worsened after a fracture of his left femur two years after the stroke. Even with these disabilities, however, he decided to return to work, as he did not want to stay at home all the time doing nothing. He eventually found a new job in his hometown working at a private business (economic cooperation office), where he normally went by bus.

His Barthel Index score was 100, so he could perform the activities of daily living independently. His wife was the main caregiver who performed caring for him if the participant asked for help because the participants wanted to perform activity of daily living by him.

### **Participant 03**

Participant 03 was married, 47 years old, and lived with his wife and three children. Two of his children were teenagers and only one still young enough to need more attention. He used to take his youngest children by himself to school by motorcycle, because he lived at rural area (suburb) that was difficult to get vehicle and after stroke he could not do so longer. Prior to his stroke he had been a government employee in the education department as a teacher in an elementary

school, but following the stroke he was given permission from the school to take a rest for recovery until he could return to work. He also had a small shop attached to his house. Before his stroke, he had normally gone to the market in the early morning before going to his school. He had had his stroke three months prior to his entry into this research. The stroke had been a calamity for him and for his family, as following it he could not work properly or go to the market because of the weakness of the right side of his body which would cause him to fall down if he stood on his feet for more than a half hour of so. At the time of our interviews, he mostly stayed at home.

He believed that as a father he was responsible for earning the money and supporting his family. His Barthel Index score was 80, indicating that he needed minor help for feeding, transferring, walking, and climbing stairs. During his recovery phase, his wife was the main caregiver who took care of helping him meet his needs and performing the activities of daily living.

#### **Participant 04**

Participant 04 was married, 61 years old, and lived with his wife and three children, all of whom were grown. At the time of his stroke he was already retired from his job as a government employee, an officer in the religion department, where he had given Islamic speeches for people not only in his hometown but also in other places. He also worked as a secretary in an Islamic foundation. Before stroke, when he had been healthy he had never worried about his diet, often eating high-cholesterol food. Therefore, his body weight was 80 kg and height was 160 cm. He had stroke since six years ago. After stroke, his body was lost about 20 kg than before. This event made his family worry, because the participant was often to get faint. He also resigned from the secretary and mostly he stayed at home. Meanwhile, he only gave

speech about the religion at his hometown because of the aftermath of stroke, which caused some memory loss, which he tried to regain through reading, although he now had more difficulty than before the stroke in remembering new information. Reading was also more difficult now, and he could not work as much as before.

He believed that religion was the way to solve his problems, although sometimes he felt pessimistic about his recovery. To help with his psychological problems, he used religion ceremonies as a coping mechanism, including voluntary worship options such as fasting two days a week and voluntary prayer. His Barthel Index score was 100, indicating he could perform some activities of daily living independently. However, he still had weakness and numbness in his arm and legs that caused him to tire easily. His wife and his children were the main caregivers who took care of him if he needed help, such as accompanying him to the hospital.

#### **Participant 05**

Participant 05 was a widow, 50 years old, who lived with her children. Most of the children were adult, only the youngest was still a teenager, so, the children could help the mother at home. Her husband had died in 2001 one year before her stroke. Before her stroke, she had been able to fulfill her responsibilities as a mother who worked at home to take care of her children. The stroke was unexpected, even though she had had hypertension about eight years previously. She was also worried about the cost of the education for her children because her only income was money from the government through her husband's pension; she did not have any job after the husband died.

She believed that her problems were a test from God, so she tried to perform religious practices such as prayer in order to gain spirit and encourage God to help

her. She also believed that she could recover from her stroke and perform her responsibilities again. Her Barthel Index score was 70, and she needed someone to help her with dressing, going to the toilet, transferring, walking, and climbing stairs. Her children were the main caregivers who took care of her, although sometimes her mother also came to her house to care for her. They served her meals (special diet) and helped her with anything she needed help with. However, the participant was still able to perform some activities with her right hand.

### **Participant 06**

Participant 06 was married, 68 years old, who lived with her family. Before her stroke, she had been a housewife and mother. She had been active socially, visiting her relatives and her neighbors, and attending the Islamic speech at the mosque every week. She lived in a rural area in a suburb of east Bandung, an area which still practices cultural traditions such as community self-help (*gotong royong*) and close contact among neighbors, and is known for such things as good manners and humility. She was diagnosed stroke four months prior to the interviews.

She believed that everything that came to her was from God and that God gave this stroke to her as a test, and her response was to perform not only her compulsory prayers but also additional prayers. Sometimes she felt shame due to her disability, but she believed that she could recover from the stroke. Her Barthel Index score was 70, and she needed help for feeding, dressing, transferring, walking, and climbing stairs. Her husband and her children were the main caregivers, and she could only perform simple activities of daily living such as grooming.



**Participant 07**

Participant 07 was married, 60 years old, and lived with her husband and family, which consisted of her daughter and son-in law and two grandchildren. She had five children, but four of them lived in other cities/houses. Before her stroke she had been a housewife, taking care not only of her house but also looking after her grandchildren. She had had her stroke four years previously, which had made her very sad because she had felt healthy before.

She believed that her worship to God made her mind more peaceful and calm. Her Barthel Index score was 60, and she needed help going to the toilet, transferring, using wheelchair, and climbing stairs. Her husband and her children were her main caregivers, and they helped her with such things as meals and looking around.

**Participant 08**

Participant 08 was married, and 35 years old. She lived with her husband and small children who still needed care and attention from a mother. Before her stroke, she had been a responsible mother who took care of her family. She had had the stroke five months prior to the interviews. It had been a terrible blow for her and the family because she now had difficulty caring for her children, and the stroke was a financial blow because she did not have health insurance, which made her inclined to seek only a minimum of medical treatment.

She believed that performing religious practices would enhance her spirit to recover. Her Barthel Index score was 80, and she needed minor help with going to the toilet, transferring, walking, and climbing up stairs. She could perform some activities such as feeding, bathing, and grooming. Her husband was the main caregiver who took care of her.

**Participant 09**

Participant 09 was married, 63 years old, and lived with her husband and youngest child. She had five children, and four of them lived in other houses. She believed that the wife of a family should work at home and the husband would earn the money for the family. Before her stroke one year previously, she had been a housewife, and her main outside activity was going to the mosque for Islamic speeches. The stroke made life difficult, as the hospital where she had to go for her regular check-up was a long distance from her home. In addition, she also suffered from hypertension since the stroke.

Her Barthel Index score was 70, and she needed help eating, dressing, going to the toilet, transferring, walking, and climbing stairs. Her husband was the main caregiver who assisted her with the activities of daily living that she could not do independently.

**Participant 10**

Participant 10 was married, 44 years old, and lived with her husband and children. Before her stroke she had been an employee with a private company, a field worker in a factory – she not only took care of her family but also earned money for the family. However, after the stroke one year before the interviews she had had to retire early. She had had hypertension since she was 39 years old.

At the time of the interviews she did religious practices such as prayer more than before having the stroke, as she believed that through prayer she would recover sooner from the stroke. Her Barthel Index score was a low 40, however, and she had many problems with eating, grooming, dressing, bowel movements, toileting, transferring, mobility, and climbing stairs; actually, overall, she could not perform

any activities of daily living independently, and her husband, her main caregiver, had to help her with almost all activities daily living.

### **Participant Summary**

The participant demonstrated varies ability to face the problems. The time influenced the present abilities and coping approaches of the stroke survivors since they had stroke. Those who had had their stroke more than four years previously, all had a BI of 100 and could cope more easily with their problems and daily activities. While those who had had their strokes less than four years previously all had a BI of less than 100 had varying degrees of BI and more difficulty coping.

### **Lived Experiences of Stroke Survivors**

The descriptions of lived experiences of stroke survivors focusing on the main themes which correspond to the research objectives of this study: to describe the meaning and feelings of being a stroke survivor, to describe the impact of a stroke on the stroke survivor's life, and to describe the needs of stroke survivors.

### **Meaning of Being a Stroke Survivor**

The stroke survivors have developed their own meaning of being in this condition, and they center around four main themes: (1) being obedient to the doctor, (2) regressing to childlike status, (3) being under supervision and assistance, and (4) being tested from God (Allah).

#### **1. Being Obedient to the Doctor**

Being obedient to the doctor was a major theme of most of the participants, as they had to comply with the doctor's regarding their treatment during the recovery

period from their stroke. Seven participants reported that being obedient to the doctor was an important part of their life as a stroke survivor. The doctor had most superior position influencing the patients in medical treatment compared to their other health providers. The participants believed what the doctor said, for example in what medicine they used, the diet and exercise programs, and regular check-ups at the hospital. They believed that by obeying the doctor or following the doctor's instructions they would recover from the stroke. As three participants expressed:

*We have to obey the doctor, and consume medicine 3 times a day. We always check with the nutrition department, and don't consume too much fat, including "nangka" and "durian" fruits and chicken meat, so there were too many kinds of food that must not be eaten. I just follow the doctor's instructions. That is the reason why I check up regularly to the hospital monthly and get 5 kinds of medicines.*

Participant 01

*Before the stroke, my diet was not healthy therefore my cholesterol was high. After the stroke I followed the doctor's suggestions such as low fat, low salt, more vegetables and fruit, and exercise regularly. So, now my blood pressure is quite normal.*

Participant 04

*I followed the diet that was suggested by the doctor and the department of nutrition. I also had a list of food that I had to eat and the food that I had to avoid. It was low in salt, low in fat, and low in calories because I had diabetes so I had to be careful with the calories...I always went to the hospital to check out my body every month. I followed everything that the doctor suggested to me*

Participant 07

## **2. Regression to childlike status**

All participants reported that before their stroke, they had gone to work or fulfilled their responsibilities, but after their stroke they had many disabilities and

could not perform their tasks independently. They felt that during their time as a stroke survivor they could not do many activities such as moving, speaking, and/or performing their jobs freely, and what abilities they did have were reduced. All of these problems were due to their new disability, and the aftermath of the stroke such as weakness or paralysis of the body. These disabilities caused the participants to have negative perceptions, and six of them felt that after the stroke they had become more like a child, because of the many limitations in performing their own activities of daily living. As some participants stated:

*Before the stroke I usually worked at home and I did everything as a mother. But after the stroke everything was lost. I was like a child so I was forced to depend on someone else to do what I wished.*

Participant 06

*I feel like a child that I cannot do anything. I depend on someone else to assist me.*

Participant 07

*Roughly, being a stroke survivor I must be patient because I became like a child after the stroke, with limitations in walking, difficulty in performing many activities...*

Participant 08

*I felt like a child. So many limitations I had....*

Participant 09

### **3. Being under supervision and assistance.**

The participants reported that just to walk around, they were to be under supervising and/or have assistance from someone. Normally, they did not want to bother someone else but were unable to perform their tasks by him/herself, and a

family member had to take care of them. Almost all of the participants had at least one of disability, for example limitation in walking. Also, for most of them, when they went to the rest room, they had to be assisted because the caregivers worried about them getting in an accident. As four participants stated:

*As a stroke survivor I must be patient with things like limitations in walking, difficulty to carry something, even going to the rest room they must supervise me because I can not do it by my self.*

Participant 02

*I really depend on someone else to conduct all of the activities for me everyday, and I just sit and sleep on the bed. Fortunately my husband loves me and takes care of me.*

Participant 07

*If I want to walk or go to the rest room I have to be supervised by my husband. Thus, anything that I do I need someone to help me.*

Participant 09

*I think, being a stroke survivor is so bad an experience. I can not perform what I want to do freely. I depend on someone else, and I have to ask the other if I need something.*

Participant 10

#### **4. Being Tested from God (Allah).**

Although the stroke had many negative effects for the participants, most also tried to be reflective about what happened. They often could lead to get closer to the God. They realized that during their life they might have sinned or made mistakes, and everything that happened in their lives was a test from god, to see if they could pass the test or not. To please the God they could do good things for others, such as

charity. They also believed that the stroke was a test from the God to the human. As some participants stated:

*A human being has limitations, and then the god gives a test through disease to see if the human being can pass or not.... To be aware that I have many sins means that maybe the God will avoid me. Maybe I have not performed my religious duties properly. We have to be patient, although we have to suffer for a long time. Generally, as long as I live in this world, I have to do good deeds. Maybe if I didn't get this disease I would forget to be a good person.*

Participant 02

*I accept my condition like this as a test from the God for me....*

Participant 03

*I believed that the illness was a test from the God. And I believed that the God gave the illness and also the drugs to cure it, and the doctor is a means to cure the illness...*

Participant 04

*I believed that everything that came to me was from the God. The God gave a test to me.*

Participant 06

## **The Feelings of Being a Stroke Survivor**

Feelings were connected with the meaning of being a stroke survivor. The stroke survivors identified five common feelings of being a stroke survivor: (1) uncertainty about hope, (2) being bound at home, (3) dependence on someone, (4) powerlessness, and (5) low self-confidence.

### **1. Uncertainty about Hope.**

The stroke survivors identified a feeling of “uncertainty about hope” regarding their healing process. The degree of hope among the stroke survivors varied. Five participants perceived that they still had at least some hope that they would be able to

deal with the disability. They reported that by performing their religious practice, exercising and using alternative and/or complementary therapies, they could cope with the problem more easily. However, the other five participants felt that they had little or no hope of getting better again, as they did not know when they would recover from the stroke and the effects of the aftermath of stroke were still heavy on them. The hopelessness was also expressed by some participants who felt they did not know if in the future they would be disabled forever or not. Five participants felt that at the time of the interview, which had been at least 1 year since the stroke, that they did not feel they had made good progress, as they were still having problems in walking, speaking, and so on. As some participants stated:

*According to my religion we have to maintain intense effort, intention and discipline in order to keep healthy. We have to keep being patient and giving thankfulness to Allah in accepting all Allah's treatment. And to be sure of Allah's help and not lose your hope*

Participant 01

*I only was being patient to deal with the problem. I hope I can manage my responsibilities again.*

Participant 02

*After the stroke everything was lost... while suffering from the stroke my experience was not good. I had many difficulties, therefore I could not go to anywhere, I could not do anything, it was very bad. Sometimes I felt no hope to face the problem in the future.*

Participant 06

*The first time when I realized there were many obstacles limiting me in the performance of my activities I felt that I would not have hope again. Gradually, my condition improved and I felt better than before. But I did not know when I would recover from the stroke, I did not know my future. Maybe I would be disabled forever. You see, until now I still have disabilities such as I cannot walk properly, speak properly and so on... The stroke influenced my life. After the stroke I did not have the spirit to conduct the activities...*

Participant 09



*The stroke was so difficult for me, I could not go anywhere and I just stayed at home. I did not know when the stroke would be healed.*

Participant 10

## **2. Being Bound at Home.**

The feeling of being bound at home was a dominant feeling for five of the participants, especially those whose Barthel Index score was below or equal to 70. These patients were unable to move freely, which was especially difficult for people who had formerly been quite active but were forced into inactivity. Five participants had formerly preferred to go outside to conduct their jobs than to stay at home. This feeling of being bound at home was strongest among the stroke survivors who could not perform any activities fully on their own, or were forced to stay in their bed or a wheelchair. They felt that restricted like a prisoner because they had no independence to do things on their own. Their families were also worried about this inability. As some participants stated:

*After I had the stroke, I could not do this or that and I could not go to anywhere. I felt restricted, and like prisoner who had no freedom to act even in my own home.*

Participant 02

*Since I had the stroke, I have only stayed at home and I could not go to anywhere, I just stayed at home.*

Participant 03

*I wish to be normal again like the others who can go anywhere, perform an activity. Nowadays, if I want to see or talk to my brother I can only make a phone call. My family always tells me not to use the car, as they are worried about me suddenly fainting. My family sent my car to the first son to prevent my using it. Formerly I was an active and hard worker, with many activities.*

Participant 04

*I can not do anything. Previously, before I had the stroke, I usually worked at home as a mother, I did not have a job outside. At home I performed washing, cleaning, and so on. I could enjoy my life with my family. But now everything is lost and I cannot do anything.*

Participant 07

*Even though I stay at home I still have disabilities due to the stroke, such as I cannot walk, I can only stay at home in the chair. I cannot work at the fields, and I still have difficulty speaking.*

Participant 09

*After discharge, I still had disabilities such as difficult to move, difficult to speak, sometimes I had a headache. Also my activities were changed, as most days I spend sitting on a chair. The stroke was so difficult for me, I could not go anywhere I just stayed at home.*

Participant 10

### **3. Dependence on Someone.**

Most of the participants reported that one of their strongest feelings, as part of the aftermath of the stroke was that they felt dependent on someone to do or help them with their daily activities due to their disability and/or partial paralysis of the body. They had to accept such things as they could not walk, or only a little with help, and it was difficult to move and work. Therefore, they depended on the caregiver to meet their wants. As four participants expressed:

*I ask my son or my relative to help me if I want to go to somewhere such as to the hospital. Actually I often feel sad because I always make someone busy...*

Participant 04

*Before the stroke I was just a housewife who took care of my family, and my husband was the main earner of money. But now, after I had the stroke and my husband has died already, all the responsibility is in my*

*hands such as managing the money, taking care of the children, controlling my children, and so on. Nowadays, I cannot perform anything. I cannot walk properly, it is difficult to move my hand and my leg, difficult to work, and I am dependent on another. It is terrible for me.*

Participant 05

*As I mentioned the last day, before the stroke I usually worked at home and I did everything as a mother. But after the stroke everything was lost. I was like a child and I depended on someone to do what I wished. Now I only can sit down and assist a little bit in things I need done. I cannot do more. I am sad to see my husband do everything for me...*

Participant 06

*I feel like a child. So many limitations I have, even if I want to walk or go to the rest room I have to be supervised. Thus, anything that I do, I need someone to help me.*

Participant 09

#### **4. Powerlessness.**

Powerlessness among the participants was a central theme that emerged during the interviews, particularly for seven of the participants during the early post-stroke phase when the impact of the stroke was most severe. Mostly they suffered weakness or paralysis in various parts of their body. The disabilities remained for a long time, and were a significant influence on their feelings. All of the participants had been active before their stroke, but following the stroke they had many disabilities preventing them from perform their activities independently. Two of them were confined to their wheelchairs, and the other eight could perform only limited activities or tasks. Most of them stayed at home. As some participants stated:

*For me being a stroke survivor was terrible because it made me powerless, I could not do the activities of daily living, it was difficult to walk and difficult to participate in social activities.*

Participant 05

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Participant 05

*As I mentioned the last day, before the stroke I usually worked at home and I did everything as a mother. But after the stroke everything was lost. I was like a child and I depended on someone to do what I wished. Now I only can sit down and assist a little bit in things I need done. I cannot do more. I am sad to see my husband do everything for me...*

Participant 06

*I feel like a child. So many limitations I have, even if I want to walk or go to the rest room I have to be supervised. Thus, anything that I do, I need someone to help me.*

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*For me being a stroke survivor was terrible because it made me powerless, I could not do the activities of daily living, it was difficult to walk and difficult to participate in social activities.*

Participant 05

*I was sad because the stroke made me powerless, I could do only limited activities of daily living, it was difficult to walk, and difficult to have social relationships.*

Participant 06

*I could only sit in my chair every day. If I wanted to walk around my husband had to help me. I always thought, if this is just my leg and my hand why are they not healing? I felt very weak, for example just to sit down I could not do this by my self. I felt useless.*

Participant 07

*I feel that everything that I do is difficult, it is difficult to move and difficult to communicate with others. I felt sad after I realized that the stroke had made me disabled. I had difficulty being a stroke survivor because of the many difficulties I had such as difficulty speaking clearly, difficulty walking properly, and difficulty just to perform the daily activities.*

Participant 08

*My life changed after the stroke. After the stroke I could not perform anything, I could not even move my right hand. I was too weak to perform most activities. I felt powerless to carry out my responsibilities.*

Participant 10

## **5. Low Self Confidence.**

Prior to the stroke five participants had had a job. Before the stroke, all could perform their activities freely and with confidence. After the stroke, they had many obstacles in performing the tasks because of their disability and this caused a reduction in their self-confidence. This loss of self-confidence was also exacerbated by the weakness of their body and new verbal communication problems. Five of them could no longer undertake social activities such as meeting with their neighbors, going to the mosque, or helping with various social maintenance or cleaning activities in their communities as they had before. As two participants stated:

*The most prominent effect was the loss of confidence to express an opinion verbally. Before I was sick I could express my opinions without any problem, but now I have a problem in speaking. It causes miscommunication with others.... Sometimes I doubt when I say something to someone whether he/she understands what I said...*

Participant 02

*I cannot participate in social relationships due to my disability, especially my verbal communication. My speech is not clear and sometimes I even feel ashamed to meet people. This is my big problem... Since I had the stroke I have lost confidence to have contact with people. I worry that she/he did not understand and would insult me. I have a disability in speaking, but I still understand what others say...*

Participant 08

## **The Impact of Stroke on the Stroke Survivor's Life**

After having a stroke the participants must then live through the experiences of the impact of the stroke. The participants identified five major themes around the impact of a stroke: (1) being unable to be active, (2) having to adjust to the emotional changes, (3) being unable to undertake social activities, (4) failure to fulfill former responsibilities (5) being growth in spiritual life.

### **1. Being Unable to be Active**

Five participants had been laborers before they had stroke, and three also had had a second part-time job to earn extra income. In Indonesian culture, men have a greater responsibility to earn money for the family than women (Statistics Indonesia, 2002). This cultural tradition was also evident in the study, as all of the male participants had, prior to their strokes, worked at an outside job while all of the females had taken care of their families and home. Three of the five male participants had been employees, with one other retired. One female had also been a laborer, but

the rest had been housewives who had responsibility for their homes. All of the participants changed from an active lifestyle to forced inactivity due to the impact of their stroke. They tried to cope with this new inactivity in different ways – some tried to find a new job closer to their hometown or work in their home. Others simply stayed at home. There were three sub-themes were identified among the participants corresponding to their imposed inability to be active: (1) unable to be active in daily living, (2) unable to remember many things, and (3) sexual dissatisfaction.

### **1.1 Unable To Be Active In Daily Living**

Unable to be active in daily living was experienced by most of the participants, in two main ways: (1) difficulty in performing daily activities, and (2) being unable to communicate properly.

#### **1.1.1 Difficulty in Performing Daily Activities**

Mobility, or the ability to move freely within the environment, is fundamental to normal daily functioning (Craven & Hirnle, 2000). Their strokes prevented the participants in this study from moving or performing many or most of their normal daily activities. Seven participants reported that they had many difficulties in such things as walking, limitations in moving their body or in coordination of different parts of the body, and paralysis. They also reported that they could not go to anywhere, and these problems led the participants to tend to stay at home rather than work or go outside. The other three participants could still perform some activities, but not as much as before the stroke. They tried to work and help themselves at home. As some participants expressed:

*So, we have no freedom in every activity like walking, eating, riding a motorcycle.*

Participant 01

*Now, the result of the stroke is a limitation of mobility such as walking, and also coordinating the different parts of the body is more difficult than before...*

Participant 02

*Before I had the stroke I had many activities such as working at my job, teaching people every morning, and so on. But now I just teach people, and not every day.*

Participant 04

*I had many difficulties therefore I could not go to anywhere, I could not do anything, it was very bad*

Participant 06

*While I have been a stroke survivor my condition has not changed, I still have disabilities and am paralyzed...*

Participant 07

*I have difficulty being a stroke survivor. The stroke makes me like a kid. So many difficulties I have, such as difficulty to speak clearly, difficulty to walk properly, and difficulty to perform most activities.*

Participant 08

### **1.1.2 Being Unable to Communicate**

Communication is basic and essential to human life. Through communication, people relate to their environment and each other (Craven & Hirnle, 2000). Disruption of this ability influences most human activities in their surroundings. Strokes can affect the communication function (Nazarko, 2002). In this study, some participants reported that they had experienced limitations concerning their career because after



their stroke they could not communicate effectively, especially those participants who had been teachers. They all now had difficulty in simply expressing an opinion verbally, and it was difficult to speak clearly. This problem also caused problems in social relationships, such as with neighbors.

*The most prominent problem is the confidence to express an opinion verbally. Before I was sick I could express my opinion without any obstacles, but now I have a problem in speaking. It causes miscommunication with the others.*

Participant 01

*Normally, I went to school to teach the students first and then worked at my shop. But after I had the stroke I could not go to school or work at the shop any longer...*

Participant 03

*The impact of the stroke was that it was difficult to walk, I had memory loss, and it was difficult to speak. Although I still kept social relationships with my neighbors I had difficulty in communicating verbally.*

Participant 06

*Speaking was difficult after the stroke, so I communicated much more rarely with my neighbors. Before the stroke I did not have any special social relationships, but after stroke I had even less.*

Participant 07

## **1.2 Unable to Remember Many Things.**

Memory loss was also a common problem in the stroke survivors, as after the stroke they had problems in remembering many things from their former lives, both personal and related to their jobs. This presented an obstacle for the participants as far as resuming their old jobs, especially those who had been teachers. The problem was seen in both long-term and recent memories, and they also found it difficult to remember new information. Some participants tried to cope with this problem by

using notes or a notebook to record necessary or new information. As some participants expressed:

*One physical change was memory change, such as I now often forget something.*

Participant 02

*My job is a teacher and sometimes I have difficulty remembering and even have difficulty in reading... I felt my memory had decreased, I often forget something, and my eye is unclear to read.*

Participant 03

*Nowadays, many of my memories are lost. So if I teach people I have to bring a book, not like before the stroke. After the stroke I lost my memory and it is now difficult to remember new information....*

Participant 04

*Also my memory was damaged I often to forget things.*

Participant 07

### **1.3 Sexual Dissatisfaction**

Sexual activity is a sensitive issue, but some participants did talk a bit about their dissatisfaction with their sexual lives, and the impact of the stroke on their sexual activity. Most of the male participants felt uncomfortable talking with their spouse about their sexual life, and they also perceived that after the stroke their sexual function had lessened. The female participants reported that after the stroke they could not make their spouse satisfied. As three participants stated:

*The sexual problem influenced my psychological state. It was uncomfortable for me and for my wife.*

Participant 02

*I also had difficulty regarding the relationship with my wife in terms of our sexual life. So much changed after the stroke. Actually it was not a big problem even though I felt sad because I could not make my wife satisfied.*

Participant 03

*For my sexual life, since I had the stroke 3 years ago, my desire has decreased. Maybe because of the effects of my stroke such as paralysis and weakness, I don't have enough power.*

Participant 07

## **2. Having to Adjust to the Emotional Changes**

Another thing that made life difficult for the stroke survivors in this study was the emotional changes that had to be faced following their stroke. Before the stroke, five participants had had jobs, including teacher, laborer, and government employee, making them feel productive in their lives and able to fulfill their responsibility to be the money earners for their family. After the stroke, this changed, and they mostly had to stay at home, as they could no longer perform their task properly. This sudden major change in their daily life naturally impacted on their emotional stability and forced the participants to adjust their emotional outlook. Some participants felt pessimistic about being able to face their new problems, and to solve these problems they asked the God for help. As one participant expressed:

*Sometimes I felt pessimistic about my ability to face the illness. Then, I had to do much reflection to my self. I tried to gain my spirit to life.... I believed that the illness was a test from the God. And I believed that the God gave the illness and also the drugs to cure it.*

Participant 04

Two participants reported that they could accept their condition. They felt that being a stroke survivor was a process. They accepted the effects of the stroke gradually, such as the acceptance of their disabilities and the treatment. The degree of

acceptance corresponded with the severity of the stroke – that is, participants who had a less severe stroke and less disability showed better acceptance. Two participants reported that the impact of stroke was not an obstacle to the performance of their job, and they could accept the condition as part of their normal life. Even though they had a new disability, they could accept the disability by using several approaches, including ways to maintain their physical health. As one participant stated:

*...I had no problems before accident, no worries, no fears, no doubts, but in fact my blood pressure was 190 mmHg over. I just followed the doctor's instructions. The stroke has not had much influence on my life except that now I must control my desires, watch the food I eat, not lose my temper. I do not have any difficulties that make me stay at home. I still can work. I did not feel that the stroke has been an obstacle for me, even though my condition is not as before the stroke. There has been no change in the social activities I can participate in the neighborhood.*

Participant 01

Acceptance of the stroke was not easy for some participants who had to adapt to unfamiliar conditions, such as their diet, which many of them were uncomfortable with. However they wanted to recover so they gradually accepted their treatment. They also learned to accept the stroke and the healing as a process. As one participant expressed:

*At the beginning I felt that I was forced to follow the orders. Gradually I accepted the diet, I visited the hospital every month, and I did exercise everyday...*

Participant 04

### **3. Being Unable to Undertake Social Tasks**

Social relationships for the participants to keep in contact with people in the local environment were perceived as necessary by all the stroke survivors, particularly

for those who had worked in the public domain. Before the stroke, five participants had had regular outside activities, and they used to meet people regularly and interact with many others. After the stroke most of them experienced social problems. The participants reported that their social relationships became more limited following their stroke, as they could not meet or visit their neighbors as they had. Their new disability was the main contributory factor to the reduced social relationships, especially if they suffered a communication problem. A related impact to the social relations limitations following the stroke was a reduction in social activities. Following the stroke, the participants could not go to work and could not conduct activities in social organizations, or other social activities around their village such as social services, involvement in neighborhood committees, or involvement in religious practices. As some participants expressed:

*There was influence on my social relationship with my neighbor. For example, before if a neighbor died I usually visited him/her family but now could not.*

Participant 04

*Relationships with my neighbors were still no problem, but many social activities I could no longer manage.*

Participant 05

*Actually the stroke influenced my life. Before the stroke I could perform activities freely without any obstacles. After the stroke I had many impairments, and I felt burdened because the stroke influenced everything of my life.*

Participant 06

*All my activities had to be assisted by someone because I could not manage them by myself. My husband and my children were so close with me. They were ready to help me any time.*

Participant 07

*I could not make carry on my social relationships due to my disabilities, especially my poor verbal communication... My speech was not clear ...*

Participant 08

*My difficulties changed my life as I became inactive. I could not visit my neighbors, or conduct social relationships as before. Now I only stay at home.*

Participant 09

#### **4. Failure to Fulfill Former Responsibilities**

Failure to fulfill their normal responsibilities was a serious concern of seven participants. Some perceived this failure as a weakness. Before their strokes, the male participants had had several responsibilities such as teacher, Islamic leader, and income earner; one female participant also was a laborer. Five female participants were housewives with the responsibility of taking care of their families. After their strokes their responsibilities changed, and they could not perform their tasks, or had difficulty with them. They could not go to work or accomplish their jobs, go to give an Islamic speech, carry out their responsibilities as a wife, or fulfill their duties as a parent - two participants, who had young children who needed security and support from them, reported that they failed to do their duties as a parent because of the aftermath of the stroke. As some participants expressed:

*Before I was sick I could go to the market to buy goods for sale and work at my shop. Also I could go to school to teach the students.... usually I went to school first and then worked at my shop. But after I had the stroke I could not go to school and work at my shop.... Since I was sick I could not take care of my children such as drop and pick up my children from school on the motorcycle.... So related to my disability, I felt sad I could not do what I had to do. I worried about my children, especially their care in daily life.*

Participant 03

*Before I had the stroke I had many activities such as working at my job, teaching the people every morning, and so on. But now I only teach people but not everyday. I always used my car to go to work but after I had the stroke I did not dare to use the car. Also my family did not allow me to use it.*

Participant 04

*During the recovery phase after the stroke I could not perform my duty as a mother, and my child cared for me, such as giving me a meal. I felt sad because I could not be a mother for my children. Since I had the stroke, I cannot go to anywhere. I just stay at home. In my mind I just think about my left hand and my leg and how to recover as soon as possible.*

Participant 05

*After the stroke I could not work again like before as a housewife, such as cooking, washing, and cleaning inside the house. Fortunately, my husband helps me to with these jobs. I mean that that I cannot do anything. You can see my body; my hand and my leg are weak. How to perform the activity of daily living if my body is like this?*

Participant 06

*Before the stroke I could perform the activities of an ordinary wife such as cooking, washing, ironing, and cleaning around the house, having a relationship with my neighbors and sending my child to school. But since I had the stroke I cannot perform these activities.*

Participant 08

*As I said before, the stroke changed my life wholly. Before the stroke I was an active woman - I could go to my job, take care the family, and earn some money. Now everything is gone. I am so sad to see my body and my life.*

Participant 10

## **5. Being Growth in Spiritual life.**

Spirituality was an important aspect for the participants, and most of them had changed their spiritual behavior following the stroke. At least partly to compensate for their physical limitations, they embraced religious practices. There were three sub-themes corresponding with the increased spiritual aspect: (1) Praying to Allah (God)

for Healing, (2) religious control of behavior, and (3) worshipping of God as the main goal of life.

### 5.1 Praying to Allah (God) for Healing

Many participants believed that prayer was one way to solve their problem. They believed that through praying to the God the problem would improve – which also indicated that they still had hope of being healed. Usually, they practiced prayer or “Sholat” at least 5 times a day, while still taking their medicines. Some participants performed not only the compulsory prayers but also voluntary or additional prayers such as a prayer at midnight. Many also engaged in charitable work and fasting 2 days a week. The participants reported that after performing the religious practices they felt more comfortable in their mind, with feelings of calmness and peace. As some participants stated:

*We always have to pray and make requests to Allah (the God) as much as possible.... for our recovery, particularly in doing “sholat” (the 5 obligatory prayers for Muslims), while still taking the medicines. We have to be patient and give thankfulness to Allah in accepting all of Allah’s treatment and to be sure of Allah’s help and not lose hope.*

Participant 01

*...and also we have to ask to the God for help to solve the problems. Both medicine and religion are mixed together... My effort to solve the problem was speaking exercises at least 5 times a day through prayer.*

Participant 02

*To enhance the recovery I performed prayer (sholat) in the nighttime. Also I performed fasting 2 days every week. I felt happy after I prayed to the God.*

Participant 04



*I only prayed to the God to solve my problem. When I did pray I felt more calm and peaceful. I hope that my illness will be improved soon. I usually pray at least five times a day. I believe that the problem came from the God.*

Participant 06

## 5.2 Religious Control of Human Behavior

Islam for Muslims is not only a religion but also a complete way of life that advocates peace, mercy, and forgiveness (Akhtar, 2002). Some participants were able to reduce their negative emotions caused by the stroke such as anger and disappointment, and they performed good deeds in order to get closer to the God. During the aftermath of the stroke they perceived that to be patient was important. As three participants stated:

*...But in my opinion it must be controlled by religion so I was not so disappointed. It also made me more aware that I was getting advanced in years. When I was young I was satisfied with my life. Now, I hope to live longer to have time to do more good deeds, and learn to control my desires...We have to be patient and give thankfulness to Allah in accepting all of Allah's treatments and to be sure of Allah's help and not lose hope.... I now realize there is one key word: patience.*

Participant 01

*Another problem was irritation, for example I was often angry if something did not satisfy me. And then gradually the anger decreased because I realized that I have to be patient.*

Participant 02

*Sometimes I felt pessimistic about dealing with the illness. At such times I had to rethink my situation and be reflective. I tried to regain my spirit to live. Fortunately, I believed that the illness was a test from the God. And I believed that the God would cure it.*

Participant 04

### 5.3 Worshipping of God as the Main Goal of Life

Most of the participants reported that worship of God was the most important goal of life. They perceived that during the time they lived in the world, they had to pray, perform charitable acts, undertake regular fasting, and if possible make a pilgrimage to Mecca. They also believed in life after death, which they had to prepare for by worshipping God. As two participants expressed:

*As human beings we must worship God in many ways, such as "Sholat", charity, pilgrimage to Mecca - all of them are relationships with the God. Also we have to have good relationships with other humans.*

Participant 01

*I am aware that I have many sins related to the duties of my religious practice, or avoidance from the god. Maybe I have not performed the good orders properly. We have to be patient, although we have to suffer for a long time. Generally, as long as I live in this world, I have to do good deeds. Maybe if I didn't get this disease I would not remember to do the good things.*

Participant 02

### The Needs of Being a Stroke Survivor

None of the participants had had a previous stroke, so they all had minimal knowledge about strokes. After discharge, they were sent to their homes or communities, where they had to adapt to the new conditions of their disability. Normally, the health providers give new stroke victims as much information as they can about dealing with the changes in life style that follow a stroke, but often this instruction is inadequate to fully prepare the patients for their new lives. Post-hospital care of stroke survivors is available in community hospitals (*Puskesmas*), but stroke survivors often prefer to go to a big hospital if they have insurance because in the big hospital they can get more advanced treatment. The stroke survivors identified a

number of important needs, most commonly and importantly (1) information, (2) understanding, (3) joy/leisure time, and (4) choices of therapy.

### **1. Information.**

Information was an important need of all participants. They felt that their health providers did not give enough detailed information about their stroke. They wanted more detailed information related to the stroke such as how to prevent a recurrence, medications, diet, and exercise, especially for use after they returned home. As one participant expressed:

*I only want to be healthy, and for this I entrust everything to the doctor. Anything that the doctor ordered to me I would follow, such as CT scans, blood tests, and so on. I needed information about the stroke such as how to prevent a second stroke, the meals that I have to eat and the meals that I have to avoid, and how to exercise.*

Participant 03

The participants also needed health teaching from health providers, not only about their medication but also any new knowledge available about prevention of a second stroke. The participants asked their health providers to give them more information about healthy behavior when they visited the hospital every month. As one participant expressed:

*As a stroke survivor I need services from the health provider. For instance, when I go to the hospital to have my body checked, also I want the health provider to teach me what I have to do at home.*

Participant 08

### **2. Understanding and Attention.**

The participants realized that being a stroke survivor, with their many disabilities, meant that they needed other people to be responsible for them, and that

therefore they needed understanding and attention from the people around them – usually their spouses and/or their children. They also needed more attention from the health providers than is required from most other illnesses, and especially they need a medical doctor with high status. They want the health providers to be more responsive in taking care of them. As two participants expressed:

*As a stroke survivor I need understanding from my husband and my children that I cannot perform all of the duties of a housewife due to my disability.*

Participant 06

*For me as a stroke survivor I need attention from the doctor and health providers... I want the health providers give me something that helps me to recover soon.*

Participant 09

### **3. Joyful/Leisure Time.**

The participants reported that as a stroke survivor they faced many limitations, and needed time to do certain things. They felt that happy or leisure time was necessary to relieve the boredom or stress that built up during the day due to their problems. Also they needed more private time to reflect on their situation, which was so different from normal people. As two participants expressed:

*One need I have is just happy time for myself, such as reading a book by myself to enhance my knowledge about my religion.*

Participant 04

*We have to understand our religion - if not we will get angry easily, therefore I always read something about religion.*

Participant 01

#### 4. Choices of Therapy.

Health is a dynamic state in which the person constantly adapts to changes in their internal and external environments (Craven & Hirnle, 2000). Most of the participants in the study tried to improve their condition not only from the medications the doctors gave them, but also from available alternative therapies to try to get better. Most felt that these therapies were helpful and enhanced the healing process, and gave them more influence and control over their physical, psychological, and spiritual problems. As three participants stated:

*As well as medicine for decreasing the blood cholesterol I ate Cangkudu fruit... I also used other methods such as massages, avoiding saying angry words, and taking the water for ritual prayer to control my blood tension.*

Participant 01

*Until now I have only sought for help from the doctor (medicine) to cure my illness. I have not looked for traditional medicine yet. However, my neighbor gave me the holy water to enhance my recovery.*

Participant 03

*The effort to cure the illness included medicines and alternative medicines. I always went to the hospital every month to check my body. Also I found alternative medicines and I have some drugs and get massages.*

Participant 04

## Discussion

In this section the findings of the study was examined and discussed as they relate to previous studies and other current literature, based on the demographic data,

the meanings and feelings of being a stroke survivor, the impact of the stroke on the stroke survivor's life, and the needs of stroke survivors.

### **Demographic Data**

In this study the most common age range was 61-70, and six of the ten participants were female. The participants were selected from the outpatient department of a neurological clinic. Stroke is gender related - men are more likely to suffer a stroke, but because women live longer there are more female stroke victims extant (Sacco & Lipset, 1995). Indonesian statistics confirm this, as most stroke patients are over 60 years in age (Department of Health, West Java Province, 2000). The number of stroke victims is also increasing as the life expectancy of Indonesian people has been increasing - in 1999, the average life expectancy was 64.2 years, and in 2000, it had increased to 65.6 years.

The time since the participants had suffered the stroke ranged from 3 months to 6 years, and the longer the time since the stroke, the better the participant had adapted to their disability (Jonkman, deWeerd, & Vrijens, 1998). Previous studies also found that there was a settling in period of from three months to two years following the stroke before the victims become used to their new condition ([Http://www.Irishhearth.ie/patientqueries/stroke3.htm](http://www.Irishhearth.ie/patientqueries/stroke3.htm)). The affected body organs begin to regain their functions after this time, especially the neural-related problems, and functional recovery continues beyond 3-6 months ([Http://www.strokecenter.com/poststroke.html](http://www.strokecenter.com/poststroke.html)).

Four out of the ten stroke survivors had a senior high school level education. Only one had graduated from university. In Indonesian demographics, about 63% of Indonesians have an elementary education, 33% high school, and 4% a university

degree (Statistics Indonesia, 1998). Those with university degrees are more likely to be urban residents than rural, as people who live in rural or village areas have difficulty finding transportation to get to school, and there are only limited education facilities locally.

Eight participants reported that their income was sufficient for their expenses while two said their income was not adequate. This study found that financial burdens imposed by a stroke affect not only the stroke survivors but also the family members, as half of the stroke survivors were the main earner of money for the family, and their inability to work influenced the income of the family. A recent study confirmed that strokes cause cost burden in caring for a stroke victim (Youman, Wilson, Harraf, & Lalit, 2003).

Besides the stroke, most of the participants also had other medical diseases, of which the most common was hypertension. Hypertension is the most important risk factor for stroke. One study has noted that men with a systolic blood pressure above 180mmHg had six times the risk of stroke, and men with a systolic blood pressure of 160-180mmHg had four times the risk, of normotensive men (Shaper, Philips, Pockock, Walker, & Macfarlane, 1991). Another study found that reducing systolic blood pressure to less than 140 mmHg reduced the incidence of stroke in elderly people by 36% (Besdine, 1993). A recent study in Indonesia found that the most common risk factors for stroke in Indonesia were hypertension, heart disease, cigarette smoking, and diabetes mellitus (Misbach, 2001).

Most participants lived in a nuclear family. Only one lived in a larger extended family. They all preferred to stay at home with their family rather than staying in the hospital during their recovery phase because this would be less expensive, and they

felt more secure with family members. This finding is similar to a recent study found that a home rehabilitation program had the opportunity to make or share in the decisions, more active and motivated, led to improvements in patients' daily life functions (Ljungberg, Hanson, and Lovgren, 2001). Findings is consistent with normal hospital policy that patients should be discharged as soon as their health status is stable and only visits the hospital for regular checkups.

All of the participants in this study were Muslim, and performed their religious practices regularly, which they perceived helped them be peaceful and calm. According to Koenig (2001), religious beliefs and practices are rooted within established religious traditions consistently associated with better health and predict better health over time. Another study found that spiritual practices could assist with coping after a stroke by altering the victim's appraisals concerning meaning and control (Ellison & Levin, 1998).

The Barthel Index (BI) scores ranged from 40 to 100. Participants who had a BI score below or equal to 80 had difficulties in performing the activities of daily living by themselves and needed someone to help partly or totally, depending on the caregiver to meet their basic needs. The three participants with 100 BI scores could perform their activities of daily living independently and could thus cope better with the problems. The highest possible BI score is 100, and patients who achieve this score are continent, can feed, dress and bathe themselves, get up out of bed and chairs without assistance, walks at least a block unaided, and ascend and descend stairs. This does not mean that they are able to live alone, however, although they can get along without full time attendant care, as they may not be able to cook, keep house, or meet the public (Mahoney & Barthel, 1965).



### **Meaning of Being a Stroke Survivor**

In this study, the participants felt that the most common meaning of being a stroke survivor was that they had to “obey the doctor”. Through obeying the doctor’s orders, their health would improve and/or they would recover from their stroke. Obeying the doctor’s instructions was a central aspect of their lives following their discharge from the hospital. They preferred to obey the doctor, especially in regard to taking their medicines, because the participants trusted their doctors more than other health providers. This obedience was also influenced by their religious beliefs, as the Islamic religion suggests that humans should look for help and make a strong effort to heal. According to Guwandi (2001), the relationship between the doctors and the patients is based on paternalism and trust, and it is believed that doctors are able to cure illnesses. Islamic beliefs say that strong effort is seen as obligatory for human beings to achieve their goals, as stated by the Holy Koran, “Verily never will Allah change the condition of a people until they change it themselves” (Ar Ra’d: 13,11, cited in al-islam.com). This obligation to look for help encouraged the participants to adhere to their medical treatment. In addition, human beings are encouraged to look for medication, as the Holy Prophet Mohammed (may peace be upon him) states that there is a remedy for every malady and it is excellent to get treatment (Hadisth number in Sahih Muslim [Arabic]: 4085, cited in al-Islam.com). Compared with other chronic illnesses, adherence to long term-therapies for chronic illness in developed countries averages 50%. In developing countries the rates are even lower, and many patients experience difficulty following the treatment recommendations (WHO, 2001). However, this study found that, in this Indonesian setting, adherence to long

term-therapies was high, and at least part of the reason was the relationship between the doctors and the patients and the beliefs of the participants.

The second most common meaning of being a stroke survivor found in this study was the feeling of “regressing to childlike status” – in other words, the sufferers felt that they had gone down in their status as an adult human, that they were no longer independent adults but had many limitations in their daily lives and could not do many things independently – were, indeed, more like dependent children. They all reported that their physical ability had declined, for example many now needed a wheelchair and/or a cane for walking. They also found that their cognitive functions and sensory perceptions had decreased. It is well understood that strokes can lead to neurological problems or deficits (i.e. LeMone & Burke, 2000), and the most frequent stroke symptoms involve some form of motor disability (Misbach, 2001). Strokes also disturb the thought centers, recollection, reasoning, feeling, communication, language, movement, cognition & memory, both short term and long term (Reeves, Roux, & Lochart, 1999; Gibbon, 1994). The findings of this study are similar to a study done by Hilton (2002), which explored what a stroke meant to elderly women and found that they also perceived deterioration and decline, and the feelings of robustness they had had during their youth and most of their adult years was irretrievably lost. Another study by Doolittle (1991) noted that the participants described their feelings as one of going downhill, and it was difficult to return to their previous strength and motor activity.

The participants identified another meaning of being a stroke survivor as “being under supervision and assistance”. In this study, seven stroke survivors could not perform the activities of daily living independently, and needed a caregiver to help

them with these tasks. The caregivers also worried about further problems happening to the participants, and felt responsible for supervising and/or assisting the participants. This decreased ability to perform the normal activities of daily living also reduced their ability to join in social activities. Other studies have also noted this – for instance, a study done by Gresham, Fitzpatrick, Wolf, McNamara, Kannel, and Dawber (1975) studied residual disability in survivors of stroke and found that of the 119 stroke patients evaluated, 62% had suffered a decrease in social activity.

All of the participants also felt that their illness was a test from the God, which was also found in a study by Fryback (1993) conducted to learn how people with terminal illness described health; he found that spirituality involved a belief in a higher power, spirit guide, God, or Allah, and that God gave an illness as a test of patience.

### **Feeling of Being a Stroke Survivor**

The meaning and feelings of being a stroke survivor are interconnected. Feeling refers to expressing emotion or sensitivity (Merriam-Webster Dictionary Online). The findings in this study revealed the feelings the participants noted most often as uncertain hope, being bound at home, dependence on someone, powerlessness, and low self-confidence.

Nilson (1997) found that hope was an important feature of early post-stroke recovery due to the potential for rapid and spontaneous recovery during the few weeks after a stroke. Hopelessness is a sustained subjective state in which an individual sees no alternatives or personal choices available to solve problems or to achieve desired goals (Gorman, Raines & Sultan, 2002). Lack of hope can develop

from an overwhelming loss of control and is related to a sense of despair, helplessness, apathy, and depression (ibid). In this study, many participants noted a feeling of “uncertainty about hope”. The feeling of uncertainty emerged because some of the stroke survivors still hoped for a better quality of life in the future although they still suffered from the new stroke-related disability, while others reported that they were still uncertain about recovering from their stroke and felt hopeless about facing the aftermath of the stroke. This latter was most noticeable in participants who had had the stroke a longer time previously, but the disability was still with them and there did not seem to be any progress in the healing process, nor did they know when they would be healed from the stroke. This feeling corresponded with the fact that the aftermath of their stroke resulted in them having many limitations concerning their normal daily activities, especially in the period immediately following the stroke, and having to accept and deal with these limitations influenced the mood of the survivors, and to a greater or lesser extent they experienced a loss of spirit to struggle with the illness, and a feeling of hopelessness. The feeling of having hope appeared more strongly among the stroke survivors who performed religious practices to help them cope with their problems; it seemed that the spiritual practices helped the participants to regain a sense of hope, and adjust their life goals expecting goodness from a higher power. This finding is similar with a study done by Burton (2000) who found that stroke patients had feelings of uncertainty about the future, particularly in most individuals who had been unprepared for their stroke. Another study done by Folden (1994) identified the process stroke survivors used to manage the multiple functional deficits produced by a stroke event and found that the process described by the participants included maintaining hope.

A feeling of “being bound at home” was also common among the stroke survivors and their families, and was linked with the physical disability caused by the stroke. Most participants had such a disability, particularly obstacles to moving or conducting daily activities. The disability changed the participant’s roles in their lives and households. They no longer had the freedom to do their jobs independently and only stayed at home. They also felt like a prisoner who had many limitations on their life, even when going to the rest room they were supervised by someone. Most participants tried to cope this problem by keep active in daily life. This again is similar to a previous study done by Haggstrom (1994), which identified the experience of living of 29 stroke survivors and found that this feeling of isolation was common among them. It is also consistent with the study done by Burton (2000), who talked with stroke victims and found this common feeling of being isolated or stuck in a cage.

In a related way, a feeling of “dependence on someone” was common among the participants. They were dependent on someone to carry out their activities of daily living. This feeling of dependency also influenced the social relationships between the participants and their neighbors. This finding is consistent with a study done by Doolittle (1991), which examined the implications of lacunar stroke for acute care and found that patients described how bodily and social immobility led to dependency, which further led to a lack of social control.

Another commonly perceived feeling among the stroke survivors were identified as “powerlessness”, a perceived lack of personal control over certain events around one and even over one’s self. In order to maintain a good mental attitude about one’s life, an individual needs to maintain a sense of power and control over their

destiny and environment (Gorman, Raines, and Sultan, 2002). Loss of this sense of control can negatively affect an individual's view of his or her effectiveness. Incapacitating illnesses force the individual to confront his or her powerlessness over a situation (Gorman, Raines, and Sultan, 2002). With the stroke patients of this study, as soon as they were discharged from the hospital they began a new life that was different from the previous life, as they could no longer perform their previous roles, and began to confront this feeling of powerlessness. The powerlessness was a direct result of the many disabilities that interfered with their activities of daily living, when many of them could no longer even move their affected hand(s) or leg(s). They felt they were not longer in control of either themselves or their environment. This was often especially frustrating, as they could not even perform simple activities to help themselves as they tried to recover from the stroke. Hand in hand with the feeling of powerlessness was a feeling of uselessness, as they could not take care of their responsibilities, and also frustration. Most participants cope this feeling by referring to the Islamic teaching. These findings were similar to the study done by Burton (2000), who found that slower recovery times than might have been expected were often associated with feelings of despondency and frustration, and spending too much time reflecting on the victim's pre-stroke life. Another study also noted the feelings of dependency on others, leading to a feeling of powerlessness (Potter & Perry, 2001).

Another widespread feeling was "low self-confidence" after the stroke. The stroke survivors felt ashamed to try to have relationships with people around them. This feeling was strongest during the beginning phase of the recovery, as the patients encountered for the first time the meaning and extent of their many disabilities. They reported that difficulty speaking and many of changes of body image interfered with

making social relationships with both their family and their neighbors, going to the mosque and performing simple social cleaning services in their neighborhood. A study done by Dowswell, Lawler, Young, Forster, & Hearn (2000) which investigated recovery from strokes also found that many stroke patients were uncomfortable with their newly disabled state and were either ashamed or did not wish to burden their friends, relatives or former acquaintances with their post-stroke selves. The participants were often to cope this problem by doing exercise and prayer to God. They believed that God would help them, and their stroke would be recovered.

In this study the participants did not show many feelings of depression or mood disorders, which can be common in newly disabled people. The factors mitigating this tendency in the participants were likely the good support they all received from a spouse and/or family members, and also the spiritual practices that all of them engaged in to one degree or another, especially prayer. It has been found before that a spouse and/or family members play a central role in caring for the stroke survivors and can also have a significant influence on their outlook and outcomes (Langhorne, 2001). That spiritual practice, especially prayer, can help new victims of catastrophic accidents prevent serious psychological problems (Robinson-Smith, Johnson & Allen, 2000).

### **The Impact of the Stroke on the Stroke Survivor's Life**

A major overall impact of a stroke is how it changes the ability of the stroke survivors to interact with their environment. In this study, the participants underwent many changes, such as being unable to be as active as formerly, facing many

emotional changes, being unable to do formerly routine social tasks, failure to fulfill former responsibility, and stronger religious behavior.

“Being unable to be active as before” was a common complaint of most participants, as the stroke had led to disabling physical changes in their bodies. They perceived that being unable to be active included being unable to participate in the many normal activities of daily living, memory impairment, and sexual dissatisfaction. Most participants had problems of mobility and movement. According to LeMone & Burke (2000), motor deficits depend on the area of the brain involved. A stroke may cause weakness, paralysis, and/or spasticity, leading to the physical limitations faced by stroke survivors in conducting the normal activities of daily living.

In this study participants perceived that being unable to be active in daily living included difficulty in performing activities, and also reduced ability to communicate. The aftermath of the stroke made them unable to perform their jobs. Most needed help from a caregiver. The communication problem also decreased the ability of the participants to have relationships with other people. These findings were in agreement with a previous study done by Mumma (1986), which identified perception of losses following a stroke and found that stroke patients described their inability to communicate as extremely depressing and frustrating. Other contributory factors to limitation of activities of daily living were fatigue and weakness, which has also previously been noted, i.e. in a study done by Gader, Stegmayr, and Asplund (2002), who studied post-stroke fatigue in a 2-year follow-up study of stroke patients in Sweden and found that fatigue was frequent and often severe, even long after the actual stroke.



The cognitive function was also noticeably disrupted in many participants. Loss of memory was seen as a major problem resulting from the stroke, including an inability to remember new information. Other cognitive functions were also less than previously, which had a negative impact on their lives, particularly for those who had been teachers. Geddes (1996) studied strokes in the north of England, and also found that the stroke patients reported cognitive impairment, problems with lower limbs, and speech difficulties as the most common residual impairments.

Sexual problems were also of concern among the participants, as following the stroke they found a decrease in their sexual desire and ability to satisfy their spouse. The loss of ability, feeling of uselessness, and low self-confidence all contributed to their sexual problems. Due to cultural constraints, these sexual issues were not openly talked about among the participants and family, as most people believe sexual matters to be private, and will only talk, if necessary, to a health provider, spiritual leader or someone who is trusted and well known. This is also consistent with a study done by Kimura, Murata, Shimoda, & Robinson (2001), who examined sexual dysfunction among 100 patients following a stroke and found that there was widespread dissatisfaction with their sexual functioning after a stroke. Another study found that a majority of stroke survivors had a marked deterioration in sexual function and satisfaction, with a corresponding decline in sexual desire, activity, and satisfaction among their spouses (Korpelainen, Nieminen, and Myllilla, 1999). Depressive symptoms have also been linked to decreased libido following a stroke (Carod, Egido, Gonzales, and Varela De Seijas, 1999).

The psychological impact of their stroke was also influenced by the physical problems that occurred during the aftermath of their stroke. The participants had to

adjust their emotional outlooks as part of the recovery process. Three participants believed they would never be healed, thinking the paralysis would never leave them. However, other participants had a more positive outlook after their illness, feeling that the illness came from the God and the human being had to be patient and give a strong effort if they wanted to be healed. They accepted that their stroke was a part of life and accepted the contribution of their religion in helping them face the problem. Better acceptance came from participants who realized that as a stroke survivor they would never again be entirely free from the effects of their stroke, and would have to always live with their disability. Part of the acceptance was the realization that recovering as much as they could from their new disability would take time, and adapting to their new lives as stroke survivors was a process, and adaptation would be gradual. This pattern was also noticed in a study conducted by Kirkervold (2002), who examined the unfolding illness trajectory of stroke victims and found that the adjustment process was gradual and prolonged. Generally adaptation is a function of time, and those victims who survived over one year had better acceptance than those who had had their stroke less than a year previously, and were still in the early adaptation phase. Religion also had a considerable influence on acceptance of a stroke, as religious beliefs and spiritual practice act as a coping mechanism to assist with the psychological problems new stroke victims face. A study done by Ellison & Levin (1998) also found that prayer or religious commitment can be helpful to general health, together with social and emotional support, enhancing personal efficacy, and acquiring coping strategies that emphasize positive cognitive beliefs and emotions.

In this study the participants identified an important social impact as “being unable to undertake social tasks” such as maintaining or beginning social

relationships and activities with their neighbors. Normally, before the stroke, most of the participants had maintained social relationships among the neighbors and carried out social activities, for example performing community self-help to clean the environment and/or to build public service places, or performing religion practices together at the community mosque once a week. Such activities are important to individuals and the community, and involve all citizens, men, women, and children; however, after their stroke some participants were unable to perform such activities because of their many new physical limitations, including difficulty in verbal communications. One participant could no longer work as an activist in his religious organization due to his disability. Again, these findings echo many other studies which document that stroke survivors often manifest social disabilities along with their physical disabilities (i.e. Ahlsio, Britton, Murray 1984; Evans, Nortwood 1983; Labi, Phillips, Gresham 1980). One study conducted by Evans and Northwood (1982) identified social relations in stroke rehabilitation and found that the perception of social needs being met by the stroke patient correlated with positive adjustment to the physical limitations resulting from the stroke, and another by Burton (2000) found in a phenomenological study that stroke patients changed their roles, particularly in the early stages of their post-stroke lives.

Also, the “failure to fulfill former responsibility” was a concern to the participants, most notably a failure as income earners and as parents. Eight of the participants stated that they could not fulfill their responsibilities as they had before, and now they mostly just stayed at home. This, of course, was in contrast to the period before the stroke when they were healthy, and they did their jobs and carried out their responsibilities without any obstacles, for example their work as a teacher, a laborer, a

government employee, or a housewife. After the stroke the participant's life changed from a condition of freedom to one of many restrictions. They could not do their jobs because they had disabilities that prevented them, for example, two participants had been teachers and had limitations in the performance of their jobs, another two participants had worked as laborers but had had to retire earlier due to the disability, and the participants who had been housewives could no longer fulfill their responsibilities as before. These problems also had a negative influence on the family income, which, in the cases where the victim had had a job, was less following the stroke. Some participants coped with the problem by continuing to work at home or looking for another job in their hometown. Some, however, could not cope with the financial problems, and had to ask for help from others such as their children. This was also found in a study done by Mumma (1986), which identified losses in stroke patients and found that the three major categories of loss were: activities, abilities, and independence. The loss most often described by patients was loss of their mobility.

The impact of the stroke also had an influence on the spiritual practices behavior of the victims, and "being growth in spiritual life" emerged from the interviews as a central theme of most participants. Some used their religion as a coping mechanism to help them deal with their problem, and most performed more spiritual practices following their stroke than they had previously. They found calmness, peace and psychological satisfaction by remembering the God. Mostly the participants performed prayer to Allah (the God) for healing, based on Islamic beliefs as stated in the Holy Koran, "Those who believe, and whose hearts find satisfaction in the remembrance of Allah: for without doubt in the remembrance of Allah do hearts find satisfaction" (Ar-ra'd: 13, 28). This finding agrees with a previous study by

Kyllo (1996), which identified a spiritual component in stroke rehabilitation, through the spiritual practices used by stroke patients, which he suggested that the patients used as sources of strength and hope to cope with the grief, lack of control, and hopelessness experienced after a stroke. Another study found that spiritual practices assisted with coping after a stroke by altering the appraisals made about meaning and control (Ellison & Levin, 1998), and one by Robinson-Smith, Johnson & Allen (2000) identified stroke victims who prayed after a stroke and found that prayer was a specific self-care strategy that some patients might use after a stroke to enhance their confidence and quality of life. Religious practices were also beneficial for relieving negative emotions, making the prayers usually feel more comfortable in their minds after performing religious practice. According to Lev (1992), prayer, as one specific efficacious self-care strategy, can improve coping and reduce stress. The participants reported that the religion controlled human behavior. They also reported that after their stroke they had a more positive attitude towards performing good deeds, showing patience, and they had more spirit for life. This is appropriate when considered with the Islamic beliefs that the Muslims are recommended to be patient and perform "sholat" (prayer) to get Allah's help as required by the Holy Koran: "Nay, seek (Allah's) help with patient perseverance and prayer: it is indeed hard, except to those who bring a lowly spirit" (Al Baqarah: 2, 45). In addition, Muslims believe that health is a blessing from the God (Allah) as stated by the Holy Koran: "And when I am ill, it is He who cures me" (Asy-Syu'araa': 80).

### **The Needs of a Stroke Survivor**

This was the first experience of being a stroke survivor for all of the participants, and they mostly did not know or understand how to manage the

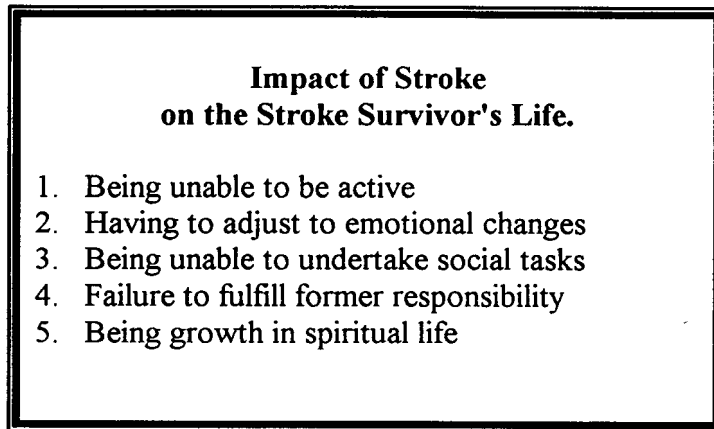
aftermath of a stroke. Thus 'information' was a central of need for them – information about how to manage their medication, exercise properly, manage their diet, and prevent a recurrence of the stroke. Most felt that during their early treatment they had received inadequate information from the health providers, who are limited in number, especially in the outpatient department of Hasan Sadikin hospital if compared with the number of patients, and often do not have enough time to give more detailed information to the stroke survivors. However, the participants expected that the health providers should give them health teaching regarding dealing with the aftermath of their stroke, that such teaching was necessary to prepare them for their discharge from hospital, and afterwards all stages of recovery. This finding is consistent with a study done by Lui & Mackenzie (1999), which identified elderly Chinese patients' perceptions of their rehabilitation needs following a stroke, and found that information needs covered all data concerning the illness, its treatment and recovery.

The participants also recognized another important need of stroke survivors is "understanding and attention", especially during the period immediately following the stroke, from the people surrounding them. Some participants were unable to perform all or some of the activities of daily living independently, and because of their new disabilities they needed to help from another. Thus they needed understanding from their family members. And also they needed attention from the health providers, particularly related to the medical services. They wanted the health providers to be more responsive to them, that they needed this attention to help them regain their spirit and find motivation to deal with the problems they faced. In the same study, Lui & Mackenzie (1999) also found that during stroke recovery, the major psychological

support valued by the informants included giving them reassurance and a sense of security, offering verbal encouragement, listening to their worries, showing a caring attitude and respecting them as individuals.

A need for 'joy/leisure time' was identified by some participants as necessary to help them regain their competency after losing some ability, for example memory loss. They had to spend more time re-learning by themselves, for example reading a book, because their ability to concentrate on one thing was less than previously. This need was also noted in a study by LeMone & Burke (2000), who found that stroke victims may show intellectual changes such as memory loss, decreased attention span, poor judgment, or an inability to think abstractly.

The impact of the stroke forced the participants to adjust their behavior to deal with the problems caused by the stroke. One behavior was to "look for alternative therapies". They tried to maintain or improve their health by having strong determination and also by using medicine, both modern medicine and alternative and complementary therapies such as (in this study) herbal therapy and massage therapy, which they perceived that they received benefit from. Other studies have also found similar behavior, that is, stroke survivors seeking alternative or complementary therapies such as herbal therapy, massage therapy, acupuncture, and moxibustion (Moon, Whang, Park, Ko, Kim, Bae, & Cho, 2003). Other behavioral changes included regulation of the diet, which again has been noted by others as a behavior to reduce the chance of a secondary stroke (Sauvaget, Nagano, Allen, Grant, & Beral, 2003). These activities were important for them to help them feel they were taking positive steps to maintain their health and recover from the stroke.

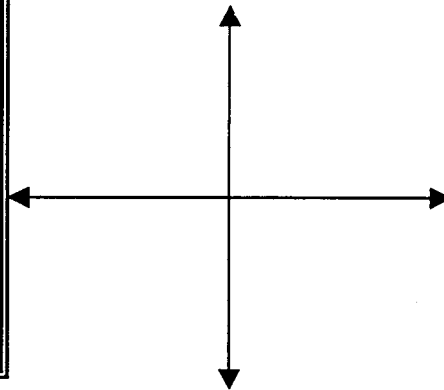


**Meaning of Being a Stroke  
Survivor**

1. Being obedient to the doctor
2. Regressing to childlike status
3. Being under supervision and assistance
4. Being tested from God (Allah)

**Feeling of Being a Stroke  
Survivor.**

1. Uncertainty about hope
2. Being bound at home
3. Dependence on someone
4. Powerlessness
5. Low self-confidence



**Need of a stroke survivor**

1. Information
2. Understanding and attention
3. Joyful/leisure time
4. Choices of therapy

Figure 1: The Lived Experience of Stroke Survivors at Home