

## CHAPTER 4

### FINDINGS AND DISCUSSIONS

Hermeneutic phenomenology was conducted to explore the lived experiences of family caregivers caring for members with chronic schizophrenia at home in Kelantan, Malaysia. Ten primary caregivers caring for their member with chronic schizophrenia participated in this study. The findings obtained from this study were presented as follows: (1) description of demographic data, (2) lived experiences of family caregivers, and (3) discussions.

#### Description of Demographic Data

Ten caregivers who met the inclusion criteria agreed to participate voluntarily in the study. These 10 caregivers who were identified in their pseudonyms were described briefly as follows:

##### 1. Alia

Alia was a 54 years old divorcee. She had 6 years of primary education and has been working as a tailor. She has been caring for the 'sick' family member for about 4 years. She was a pleasant lady, talked and laughed loudly when sharing something that was amusing during the interview sessions. She also expressed negative feelings such as anger and frustrations in her caring experience.

The care-recipient was her eldest son aged 37 years. He has been having

schizophrenia for about 12 years. Physically looked untidy and sleepy. Emotionally he showed blunted affect, responded to questions very slowly, in monotonous tone, with no eye contact. He said he still heard voices. There were no symptoms of aggressiveness noted at time of interaction. Mother reported he needed supervision in self-care, showed lack of interest in housework or any activities, lazy and seldom socialized with friends.

## **2. Boris**

Boris was a male caregiver aged 59 years. He was a religious teacher but now a pensioner and working part-time, teaching religious studies. He was a pleasant, gentle and very cooperative man. He smiled and laughed appropriately during interview sessions. He had been the caring for the 'sick' family member for about 6 years. He also had to care for his two other children who were still schooling. His wife assisted him in the caring and helped to support the family financially by working part time in a factory. Boris had good relationship with his 'sick' daughter, wife and children.

The care-recipient was his eldest daughter aged 31 years old. She was a teacher's college student when first diagnosed with schizophrenia, 6 years ago. Physically she was slightly obese, dressed neatly and appropriately and was able to provide self-care by herself. She reported still hearing voices, and seeing shadows. She was very talkative when approached. Her father reported she always stayed in her room, and seldom mixed with the other members in the family.

## **3. Cathy**

Cathy was a 63 years old widow and had been a primary caregiver for

about 5 years. She had university education and was a teacher. Now she was a pensioner. She was a soft spoken, gentle, pleasant, and full of enthusiasm to share her caring experiences. She was well dressed, looked neat, cheerful and healthy. She maintained very good relationship with 'sick' family member and the other members in the family.

The care-recipient was his son aged 37 years, and having schizophrenia for nearly 12 years. He was first diagnosed with this illness while studying at university. Physically was looked healthy, neatly and appropriately dressed. When approached he answered logically but had short concentration span, with minimal blunted affect. Mother reported no signs of aggressiveness but always going out from the house and seldom converse with others in family.

#### **4. Dariah**

Dariah was a 61 years old widow. She was a fulltime housewife, and also had her own business as a hostel caterer to support the family, since her husband died. She was small sized, neatly dressed, pleasant, soft spoken, and very enthusiastic and happy to share her caring experiences. She had been caring for her adult schizophrenic daughter for nearly 9 years. She was assisted by her teenage daughter in the caring of the 'sick' family member. She reported experiencing lots of fear, very stressed and sad during caring at the beginning of the 'sick' family's illness. Now she felt happier and less stressed.

The care-recipient was her daughter, aged 35 years and had schizophrenia for nearly 12 years. Physically she was neat and appropriately dressed. When approached, she answered logically but very in a slow, monotonous tone, with

minimal eye contact and little facial expressions. Her mother reported she was able to do self-care by herself, but need reminding and supervision. She socialized with friends and sometimes went out with them. No aggressive symptoms reported recently.

### **5. Eliza**

Eliza was a 58 years old widow and a full time housewife. She had 3 years schooling. She had been the primary caregiver for about 9 years. Physically she was small-sized, pleasant lady, talked very gently and softly. At times looked quite anxious and expressed a lot of negative emotions of her experiences during caring. Now she felt more relieved and less stressed. Besides providing care to the 'sick' family member, she had to care of her granddaughter (daughter of the care-recipient) and perform housework. She was assisted in the caring role by her youngest, teenage daughter.

The care-recipient was her eldest daughter, aged 36 years. She was first diagnosed having schizophrenia while studying in university. She was neatly dressed, and able to provide self-care hygiene. When approached she smiled inappropriately, talkative, and sometimes answered illogically. Her mother stated that she showed lack of interest in housework, refused to do housework, and did not socialize with friends or with the other members of the family. She has been jobless all this while.

### **6. Fuziah**

Fuziah was a 51 years old divorcee, and had caring for the 'sick' family member for about 4 years. She had no former education, had been working in her own business as a seller to support self and family. She dressed neatly, soft spoken, polite

and cheerful during interview sessions. At times she was a bit nervous and shy, not able to express her feelings well when sharing her caring experiences.

The care-recipient was his eldest son, aged 27 years old. He was having schizophrenia for about 4 years and came to stay with the mother. Physically looked cheerful but a little untidy. He was able to perform self-care by himself but need supervision and reminding. At the moment he needed assistance due to his fractured leg. When approached he was able to answer logically, with good response. Mother reported he used to talk by himself, but not anymore now. He stayed indoors and watched television most of the time, and due to his fractured leg.

#### **7. Minah**

Minah was a 58 years old female caregiver, stopped working as nurse to take care of her 'sick' son. She had been primary caregiver for about 9 years. She was very a pleasant lady, neatly dressed, and looked healthy and cheerful. Besides this caring role, she had to care for her husband and did most of the housekeeping.

The care-recipient was his youngest son aged, 28 years old. He had been having chronic schizophrenia for about 9 year. He was dressed neatly and appropriately. He responded to questions slowly, with blunted affect, and not much eye contact. He exhibited purposeless movement of his hands while watching television and at times talked to himself. Her mother stated he needed assistance in self-care hygiene. Sometimes he went out to visit his friends or go shopping.

#### **8. Zak**

Zak was a 73 years old widower, still working as a carpenter at a furniture factory behind his house. His wife died 6 years ago. He took over as the primary

caregiver for his 'sick' daughter. He had elementary education. During interview sessions, he was a bit untidy, anxious but a pleasant man. He did express negative emotions such feeling stressed, and difficulties in his caring role. His adult son, who was staying with him, assisted him in the caring of the 'sick' family member and with the housework in the house.

The care-recipient was his daughter, aged 38 years old, studied until secondary school, never had a job before. She had schizophrenia for nearly 15 years. She was dressed neatly and appropriately, talk in slow, monotonous tone, she sometimes answered illogically, with not much eye contact facial expressions. Father reported she needed supervision in self-care. She cried most evenings, showed no interest in housework, and at times exhibited aggressive disruptive behaviors like fighting back and kicking, and refusing to take medication. In terms of social activities, she watched television and went shopping at nearby shops.

### **9. Minon**

Minon was a 58 years old lady. She had no formal education. She was not neatly dressed, and looked tired during the interview sessions. She has been the primary caregiver for her 'sick' daughter for about 7 years. She was assisted in the caring role by her husband and her adult son, who was living together with her. She was a housewife but also helped her husband in the padi fields. She was a friendly and pleasant lady, but quite shy and anxious. She was able to share her caring experiences but had some difficulty in expressing her feelings and perceptions of her caring experienced.

The care-recipient was her adult daughter, aged 21 years. She was having

schizophrenia for about 6 years. She was dressed neatly and appropriately. When approached she was able to answer logically, but in a slow soft tone, with eye contact. Mother reported she was able to do self-care and need supervision in medication only. She was jobless all this while, and helped her mother in household chores at home. No symptoms of aggressive behaviors reported by the mother the past few months.

#### **10. Nook**

Nook was a 60 years old man, had elementary education, working in small business. He has been caring for the 'sick' family member for about 8 years. He looked healthy physically, friendly and very cooperative to share caring experiences. His caring role was assisted by his wife who was a fulltime housewife. He expressed concern in the future for the 'sick' and need aid financially.

The care-recipient was his son, aged 31 years. He did not complete his secondary education, had been having schizophrenia for 8 years. He was not neatly dressed, able to respond logically but lacked eye contact and minimal facial expressions. Father reported he was jobless, did not talk much, and always by himself. He was able to perform self-care but need reminding. He often wandered out of the house many times a day and returned home after a short while. At home used to watch television.

Demographic data of characteristics of caregivers, care-recipients and situational characteristics were presented in Table 1.

**Table 1** Characteristics of caregivers, care-recipients and situational Characteristics (N=10)

Characteristics	Frequency
<b>Caregiver:</b>	
Gender	7
Male	3
Age in years	
51- 60	6
61- 70	3
71- 80	1
Marital status	
Widow/widower	5
Married	3
Divorced	2
Education level	
None	3
Elementary school	5
College	2
University	1
Household income in ringgit per month	
<500	4
500-1,000	4
>1,000	2
Number of years caring for 'sick' family members	
4- 7	5
8-12	5
Relationship with care-recipients	
Mother	7
Father	3
Occupation	
Teacher	3
Own business	2
Housewife	1
Nurse	1
Carpenter	1
Tailor	1
Pensioner	1
Working status after becoming primary caregivers	
Continued working	9
Stopped working	1



**Table 1 (continued)**

<b>Characteristics</b>	<b>Frequency</b>
<b>Knowledge of care-recipients suffering from mental illness</b>	
Only know mental illness	8
Able to state correct diagnosis	2
<b>Physically</b>	
Neat, clean and well dressed	8
Untidy and tired looking	2
<b>Personality</b>	
Friendly, pleasant, cooperative	8
Friendly, pleasant but shy	2
<b>Emotionally and psychologically</b>	
Felt mild stress	8
Felt cheerful and satisfied	2
<b>Socially</b>	
Interaction with others in family	6
Interaction with relatives	4
<b>Age in years</b>	
51- 60	6
61- 70	3
71- 80	1
<b>Care-recipient:</b>	
<b>Gender</b>	
Female	6
Male	4
<b>Age in years</b>	
20-30	4
30-40	6
<b>Marital status</b>	
Single	9
Divorced	1
<b>Educational level</b>	
Elementary school	1
Secondary school (lower)	6
College	1
University	2
<b>Duration (years) having schizophrenia</b>	
6 - 8	3
9 - 11	5
12 - 15	2

**Table 1 (continued)**

<b>Characteristics</b>	<b>Frequency</b>
Relationship with care-caregiver	
Daughter	6
Son	4
Occupation before illness	
Student in school	7
Student in college	1
Student university	2
Occupation after illness	
No job (has not been working)	7
Laborer (on and off)	2
Teacher (on probation)	1
Other medical/surgical problems	
Nil	0
Obesity	1
Fracture left leg	1
Appendicetomy done	1
Left parietal brain infarction	1
Number of admissions since diagnosis	
2-4	6
5-7	2
>7	3
Knowledge of self suffering mental illness	
Only knew mental illness	8
Able to state correct diagnosis	2
Physical condition (Self-care hygiene)	
Neatly and appropriately dressed	8
Moderately tidy and appropriately dressed	2
Emotional condition	
Flat affect	2
Minimal emotional response	4
Moderate emotional response	2
Appropriate response	2
Cognitive condition	
Hallucinations (not prominent)	3
Illogical think	4
Mild impaired speech	2
Logical thinking	4

**Table 1 (continued)**

<b>Characteristics</b>	<b>Frequency</b>
<b>Social condition</b>	
Social isolation (not making friends quiet, and keeping to self)	5
Anhedonia	5
<b>Situational characteristics:</b>	
<b>Types of family</b>	
Nuclear family	8
Extended family	2
<b>Number of family members living in the same household</b>	
1- 3	5
4- 7	4
8-10	1
<b>Family members assisting in the caring</b>	
Nil	5
Spouse	3
Son	1
Daughter	1
<b>Family members in the same household that need caring by participant (beside 'sick' family member)</b>	
Adult siblings	5
Younger siblings (still at school)	2
Spouses	1
Grandchildren	1
Nil	1

As depicted in Table 1, the 10 caregivers in this study have the age ranged from 51–80 years. The majority were female caregivers consisting of seven participants who were mothers to the care-recipient. The remaining three participants were male, who were fathers of the care-recipient. All participants were in caregiving role for at least 4 to 10 years. Five out of the 10 were either widows or widowers, and two were divorced. Majority of caregivers have no formal education or only elementary level. Only three from 10 have high education in college or

university level. Four participants earned an income of less than RM500 per month, another four earned between RM500 - RM1, 000 and only one participant earned high income of more than RM1, 000 per month. Two participants reported their income met their needs while eight participants said their income did not adequately meet their needs. Two participants reported their income was supported by spouses while the other eight participants by their working children. The occupation of participants varied from teachers, nurse, tailor, carpenter to own business and housewife, and mostly all continued working after taking the role as primary caregiver. Only one participant stopped working after caring for the sick family member. Eight of 10 participants knew that their care-recipients suffered from some kind of a mental illness but not able to provide the correct diagnosis, and only two participants knew their family members suffered from chronic schizophrenia.

Table 1 also provided a summary of the care-recipients characteristics. There were six female and four male care-recipients, with age ranged between 20-40 years. Majority was still single and were students at lower secondary school when first diagnosed with the mental illness. Six out of 10 care-recipients were daughters and four were sons. All care-recipients were diagnosed with chronic schizophrenia (Diagnoses in medical records were based on DSM-IV or ICD-10 criteria). Six care-recipients have at least been admitted to psychiatric-mental ward two to four times, the rest were admitted more than four times. All care-recipients were on psychotropic medications, and one reported smoking cigarettes. Eight from the 10 care-recipients knew they were mentally sick but only two of them were able to provide correct diagnosis of chronic schizophrenia. Of the 10 care-recipients, 4 had some kind of

medical-surgical problems: one was diagnosed with obesity, one had left parietal brain infarct about 9 years ago, one had appendicetomy done 1 month ago and the one had left leg fracture in a road accident and was on plaster of Paris (POP) cast. During the interview sessions, physically in terms of personal hygiene care, 8 out of 10 care-recipients looked neat and appropriately dressed, only 2 looked slightly untidy but appropriately dressed. Emotionally none indicated any hostility or any aggressing disruptive behaviors throughout all the interview sessions. When interacting, 2 care-recipients showed flat affect with not much eye contact; 6 showed minimal to moderate facial expression, while 2 other showed appropriate response. Cognitively, 4 out of 10 care-recipients still reported having auditory hallucinations and very talkative but not prominent, 3 out of 10 care-recipients sometimes provided illogical answers. The rest was able to answer logically but in slow, monotonous tone. Socially, nearly half of care-recipients were quiet, did not talk much and kept to self, unless approached. Only 2 care-recipients always stayed in house and not mixing with friends.

Eight caregivers was staying in nuclear family, and only two caregivers were staying with their extended family, which included their daughters and son-in-laws, grandchildren and their aged parents. Nearly half of the caregivers had at least one to three family members staying together with them. These family members were either children who were still schooling or young adults who were still single. Five out of 10 caregivers were not assisted in the caring of the 'sick' member. The other five caregivers were assisted in their caring by either their spouses or adult children. The adult children who assisted in caring were those staying together with the

caregiver in the same house and they were mainly daughters.

## **Lived Experiences of Family Caregivers**

The lived experiences of family caregivers caring for members with schizophrenia were described in 22 main themes which corresponded to the research questions in this study: (1) meaning of 'caring', (2) caring experiences (3) impacts of caring experienced by family caregivers, and (4) needs of family caregivers when caring.

### **Meaning of 'Caring'**

Throughout the years of caring, family caregivers have developed their own meaning of caring and how they see it is going to influence their caring practices on the family members. Three main themes that were constructed as to what caring means were: (1) caring for the well-being of the 'sick' family members, (2) responsibility as a parent, and (3) being a burden. These main themes were presented with its related sub-themes and supportive data from caregiver's perspectives.

#### **1. Caring for the Well-being of the 'Sick' Family Members**

Caring for the well-being of the 'sick' family member as described by the participants included all dimensions of care such as physical, mental, emotional, social, and spiritual well-being. Seeing to the physical and mental well-being was a very important aspect of caring by family caregivers and it included seeing to the physical health, having proper meals, seeing to the cleanliness of clothing, place of eating, sleeping, and toileting. It also meant seeing to the comforts and safety of the care-recipient by providing a comfortable room with necessities such as

attached toilet and bathroom. The well-being also included maintaining peace such as no fighting between 'sick' family members the others in the family, building trust within family, keeping confidentiality of care-recipients, and not causing anger to the care-recipients. It also included seeing to the social aspects of well-being such as expenditure of care-recipients and spending more time with them. As one participant expressed:

*...must care for well-being from physical, mental and financial aspects...caring for his meals, this is physical...caring for his health, his cleanliness, clothes, place he eats, place he sleeps, toilet and others. Like caring for his emotions: anger, do not anger until he becomes 'mengamok' (becomes angry and showing retaliation) ...expenditure must see everyday... Well-being means all must run well. And that also means...not fighting, peace, comforts, trust, must keep his feelings confidential...I must have more time for him...understand him more...*

(Minah)

## **2. Responsibility as a Parent**

The caregivers who participated in the study interpreted caring as their responsibility being parents to the 'sick' family member. They realized it was their responsibility to be available to them, to care for them and to continue showing love despite they being mentally sick. Two sub-themes were described by the caregivers as such:

### **2.1 Caring for the 'Sick' Child**

In the caring of the 'sick' child the caregivers expressed their meaning of caring as seeing to the medication, ensuring enough sleep, and making sure the sickness got better. The following excerpts illustrated this:

*It is part of my responsibility as a mother for a sick child... who can give better care to your own child at home than his own mother? That is seeing to his medication, his sleep, making sure his sickness gets better.*

(Minah)

*I am caring for a son that is not normal... I think I am not free in my life, not able to go ... have to be with him, but I think that is one of my responsibilities... What can we do? As a mother is to care for the welfare, care for his happiness.*

(Cathy)

*I being the mother, with this son's illness have to take care of him. Otherwise there is no one to care for him.*

(Alia)

## 2.2 Providing Unconditional Love

Providing unconditional love was also one of the expressions of the meaning of caring seen as a responsibility being a parent. Participants believed that being parents they were responsible to continue loving their 'sick' child and this was shown by caring for them till they die, caring until they were fully well, and caring for them even when not sick. Participants reported they even had to sort to all ways to show love to their 'sick' child by being patient and by telling them that they were loved.

*Responsibility caring for this daughter is not a problem... I continue to care until she is fully well... not sick also has to care for her.*

(Cathy)

*I will have to sort to all ways and have to be very patient. I love him very much.*

(Minah)

## 3. Being a Burden

Caring experience was viewed as being a burden by caregivers because of distressing behaviors of the 'sick' family member such as being uncooperative,



refusing to listen and obey, demanding for things from caregivers, inactivity and not participating in household chores, unpurposeful behaviors. The following excerpts demonstrated the meaning of caring seen as being a burden to one caregiver:

*During this time, these 2-3 years, he becomes a burden to me. He does not listen to me. I ask him to do things and so forth, many, many times, he does not listen. He asks for things that we cannot give to him. That is what burdens me. He behaves all sorts, and burdens me with his illness of people like this.*

(Alia)

Burden was also seen as a long-term heavy responsibility to bear by one carer, with no other persons in the family to help and took over, and feeling of uncertainty of recovering. As described by one caregiver in the following:

*When he will recover I do not know, will go on his lifetime with this illness or all his years with this illness, that I would not know... That is the reason I say burden me because I am the only person who take care of him. The other persons, his aunt, uncle his cousins did not. This is what that burdens me...because I am the only person caring for him.*

(Alia)

### **Caring Experiences**

In response to the question, “What are the experiences of family caregivers caring for members with schizophrenia?” the caregivers described their caring experiences in five main themes: (1) managing the illness, (2) providing daily care, (3) changes of feelings during caring, (4) future concern, and (5) coping experiences.

#### **1. Managing the Illness**

Managing the illness presented many challenges to the family caregivers who provided care for their family members with chronic schizophrenia. This was because the illness of chronic schizophrenia was a long-term, with many facets of chronic disability, and could be very distressing and disruptive to the

caregivers. The theme on ‘managing the illness’ described the participants’ knowledge and understanding of chronic schizophrenia and management. This theme consisted of three sub-themes:

### 1.1 Symptoms and Behavior Management

In this sub-theme two main issues were described by the caregivers. The first issue was on types of symptoms and behavior exhibited by family members suffering schizophrenia. Many types of distressing behaviors were described during their caring experience. The term “distressing” was used because of the negative effects they had on the caregivers. The word distress was defined as “mental anguish or severe strain or exhaust, make anxious or unhappy” (Mackenzie, 1988, p. 90). There were the distressing verbal behaviors such as raising voices, shouting loudly, and being angry with people entering the room occupied. This was confirmed by participant’s account of:

*...reply in an angry manner when ask if she wants to eat and during that time condition was serious.*

(Boris)

Sometimes participants reported experiencing distressing aggressive behaviors such as punching, hitting, fighting, kicking, biting and strangling as illustrated in the following excerpts:

*He did not want to take his medication. We advised him like this... like this... he fought and he kicked*

(Minah)

*I felt very, very worried, excuse her illness, her body was also big sized, she even pushed her mother, I myself had also been bitten on my hand because of trying to stop the quarrel with her sisters. She bit my hand till it bled. I did not bother... I cannot be angry... after that I went to emergency.*

(Boris)

*...while cooking in the kitchen, she came and strangled and fought nobody there to help me. Quite a long time before she let go of she shook and me she fought me...used a lot of energy... "Oh my god!" Long time before she let go. After that she came again and shook my head... "pok! pok! pok!"...felt like bursting...wanted to faint...no strength to run...*

(Eliza)

Besides those direct distressing, aggressive behaviors, participants also encountered the wandering behaviors such as going out, getting lost and returning home only in the early hours of the morning. One participant reflected on this:

*He said he wanted to go out shopping...I waited for him to come home but he did not, from morning till night. Searched and searched, but could not find him. Afraid that the might get lost in the village roads. Sad waiting for him. Thought of reporting to police but waited for him to come back. He returned 3.00 in the morning; his legs were swollen...and were admitted to the ward.*

(Minah)

There were also those negative behaviors of the 'sick' member that were reported to be very distressing and making them very angry. These behaviors included incapable of carrying out daily routine, being lazy, lack of interest and inactivity, refusing to do anything that was asked.

*He would not do it...I asked him many, many times, still he would not do it...he acted as if he did not understand...he answered, 'lazy'... he still made those particular behaviors...felt like scolding him always... he, if asked him anything, he would not do it, said lazy.*

(Alia)

*Asked her to do work, she did not want to do...everyday was like that...lived with this situation, I did not bother. Left her like that. What could I do?*

(Eliza)

## 1.2 Medication Management

Medication management is a very important aspect of care in the management of family members with chronic schizophrenia. This is because

medication helps to control and reduce the distressing behaviors of the affected and enable them to lead a better life but it has many adverse effects. For its effectiveness and safety, it requires adherence to the correct dose time taken, and continuous monitoring and supervision for a long term by the caregivers. Under the sub-theme ‘medication management’ participants discussed four main issues: (1) importance of taking medication, (2) reasons for not taking medication, (3) ways to ensure medication was taken, and (4) feelings expressed when medication was not taken. Each of these issues were explored and then related to the overall sub-theme.

### **1.2.1 Importance of taking medication**

The participants caring for their mentally sick family members were aware of the importance of taking medication. Through their experience and advice by doctors, they described that if medication was not taken or taken not following the rules, the mental illness would continue and become worst. They also reported that if medication were not taken for along time, their ‘sick’ family members would display disruptive behaviors such as feeling fierce, punching, pushing or hitting. This was one of the excerpt examples:

*Before pushing her mother, her tone is normal. Felt fierce and she said, “Only punch, hit the head like that”. And usually is because she did not take her medication for a long time and the time she should be taking the medication.*

(Boris)

### **1.2.2 Reasons for not taking medication**

No doubt the importance of taking medication had been emphasized by the caregivers, there was a few reasons reported why these sick family members did not take their medication. The reasons described by the participants

were: feeling bored of taking the medication; had been taking them for a long time, made them sleepy and slept; the sickness they were having, and being the 'sick patient'. As two participants described:

*Only fight when he was not taking the medication and said he got bored with the medication. I told him I wanted him to get well.*

(Fuziah)

*He did not want to take his medication because he said he has been on medication for a long time.*

(Minah)

### **1.2.3 Ways to ensure medication was taken**

Trying to do what was best in the caring for their sick family members, the participants described ways to ensure medication is taken. These ways were: giving in time, reminding their sick family members to take, and asking the 'sick' family members if they took the medication. At times the participants asked the family members to take the medication in front of them. Another way was to check the pills if they became less each day. For some reasons care-recipients at times did not want to take the medication. Thus, the participants had to sort ways such as talking nicely and sweetly, persuading, telling them they were loved so that finally they took the medication, for example:

*Talk to him nicely... 'You must take the medication, if you do not take this medication, we want you to get well. If you do not take the medication when will you get well?' ...*

(Minah)

### **1.2.4 Feelings expressed when medication was not taken**

The participants also expressed how they felt when their sick family members did not take their medication. They felt bored, angry, not happy, very, very worried that illness got worst but did not give up hope. One

participant shared:

*Sometimes I felt angry caring for her due to her behaviours... neglect taking her medication, but I did not give up hope... the feelings of me not happy, the problem was that she was not taking her medication, the illness was very high. When this condition was left like that, her illness continued and became worst.*

(Boris)

### 1.3 Taking Care-recipients to Clinic or Hospital

The participants described that their caring also included taking the 'sick' family member to clinic for follow-up care, for taking medication, and for enquiring more information on the illness, problems on managing the 'sick' member at home.

*I accompanied him to hospital for follow-up ...I want to know the progress of his illness, and to listen from the doctor himself, his illness, regarding his progress, or I have specific questions on the problems ...I want to know how to go about, need explanation of the doctor and also I want to meet the doctor myself...*

(Cathy)

Some participant also mentioned that they preferred to bring their 'sick' family members themselves to clinic as they could provide better account of the condition of the 'sick' family member at home. When they could not do so, other members of the family would bring the 'sick' family member to clinic.

*I took her to hospital to see doctor and took medication. Sometimes her brother took her, but the doctor who is treating her preferred me to bring her as they could ask about her condition at home.*

(Boris)

Most participants also brought their 'sick' family members to hospital for admission when they exhibited aggressive behaviors that were beyond their control. For example:

*After I was not able to care for her anymore, I informed the hospital ...took her to the hospital...took her to the ward where she was admitted.*

(Boris)

## **2. Providing Daily Care**

In the caring experiences, participants provided daily care to their 'sick' family member. In this main theme, five main issues were described such as (1) providing physical care, (2) emotional care, (3) social care, (4) financial care, and (5) spiritual care.

### **2.1 Physical Care**

Providing physical care is a very important aspect of caring experienced by family caregivers. In providing physical care, most participants prepared meals: food, and drinks for the 'sick' family member as well as for the other family members in the household. They also ensured self-care hygiene of the care-recipients such as cleanliness of clothes, bedrooms and toilets, eating places, and ensured the 'sick' family members took their bath daily. Participants also cared for the sleeping time and safety of the 'sick' family members. Participants also reported that they had to provide more physical care during periods of symptom exacerbation, otherwise, care-recipients only needed supervision and reminding. The following excerpts reflected the point:

*Caring for his health...caring for his health, his cleanliness, clothes, place he eats, place he sleeps, toilet and others...*

(Cathy)

*When time for meals I cared for him properly to make sure what he wanted to eat. Did not want to eat in the house, we eat outside. If he wanted to eat alone or eat anything ...at party, I was willing to see to it for him...*

(Minah)

*My caring...if he needed food, other things...he won't go, I was the one who looked for it and brought back...I managed his meals, no need to bathe him, he bathed himself, I washed his clothing, he did not wash his clothes.*

(Alia)

Participants reported providing more physical care during acute symptoms 'sick' family members. The care included seeing to their bath, meals, giving medications, being with them all the time and observing if asleep or awake.

The following accounted for this:

*I had to care for him more than other times when he was sick...seeing to his bath, his meals, if not he would not do it by himself...his meals, his medication. At night I always had to be with him 'every minute' to see if he was sleeping or awake. If he did not go to sleep I would not be able to sleep too.*

(Minah)

## 2.2 Emotional Care

Besides physical care, participants also provided emotional support to their 'sick' family member by giving more love and more attention to the 'sick' family members. They were cautious when talking, scolding, not raising voices so as not to make the 'sick' family members angrier. This was because they believed that anger could cause conflicts and arguments, which made the caring difficult.

*...sometimes he has bad mood, he did not want to talk, took his meal, bath, or took his medication... I talked to him nicely, for example,... "We wanted you to get well, if you did not take this medication when would you get well?" ...sometimes I had to tell him that I loved him...I had to sort to all ways and had to be very patient...*

(Minah)



*I continued to be more understanding about him... in the past, not so concerned... now I am more cautious when talking to him, take care not to raise my voice as he was less than normal. Sometimes if I felt like scolding him, I hold his hands and said to him, "Darling don't do this." If I want to ask help from him I said, "Come help mum this"... In the past I really did not care... but now, I am giving more attention and more love...*

(Cathy)

### 2.3 Social Care

Some participants narrated their caring experiences in providing social care by bringing their 'sick' family members for outing, shopping, picnic at the beach, or visiting the married family member who was staying away. This kind of social outing and visitation provided opportunity for 'sick' members who were not socializing much, to interact and socialize with siblings and other members of the family, to maintain relationships. The following excerpts accounted for this:

*Caring means providing him his daily needs ... took him outing with family, and making sure his sickness get better... if he was better I feel happier... no problems for my family... my husband and I went out, anywhere, we would take him along... whenever we went... shopping, outing, to the beach...*

(Minah)

*... we took him out for example, he wanted to eat" (barbequed meat served with gravy), we took him out.*

(Fuziah)

*...sometimes I did also want him (care-recipient) to be used to her (married daughter) ... I went to Kuala Lumpur and on the way I left him to her sister, so as to give him time to get used to her.*

(Minah)

Some participants in this study encouraged their 'sick' family members to go visiting their friends or allowing friends to visit them at home. They wanted care-recipients to develop social skills such as interdependent relationship with others outside the family. On the other hand, especially when 'sick' family members

went out and did not come home at the time agreed, it caused worry and anxiety to caregivers. One exemplar indicated this:

*New Year, his friends always came back, some engineers and doctors... came and visited him and he was happy to see them... but sometimes he said we wanted to go out and visit them ...said he wanted to go out. I waited for him to come home, but he did not...search and search, but could not find him...afraid he might get lost in the village roads...sad waiting for him...thought of reporting to police...*

(Minah)

At times bringing the care-recipient out to public places such as shopping could be a problem due to sudden abnormal behaviors of the 'sick' member.

*Yes, once in a while he still wanted to follow but I did not bring him along. Once during the New Year I brought him to supermarket. When he saw so many people he wanted to go home!...if he saw a lot of people he felt 'one kind' and wanted to run home!*

(Alia)

For female care-recipients, participants were concerned about the possibility of assault by outsiders and did not allow them to go out by themselves to town or public places without supervision. As one participant narrated:

*Took care of her afraid she might wander out anywhere. Afraid she gone out to the market area...*

(Zak)

Some participants reported that if they could not bring their 'sick' family member out, some kind of social activities were encouraged indoor such as watching television or listening to music from radio, as two participants narrated:

*I felt happy to see him watching television or listening to radio or bought rock music tape, which he liked.*

(Minah)

*Yes...the same for me...gave him food, drinks...after that I allowed him to watch television, then he went to sleep.*

(Fuziah)

There were a few participants in this study who encouraged their 'sick' family members to be self-independent to develop social skills such as go shopping by themselves and to manage their money. One participant allowed her 'sick' member to go out shopping by himself and bought whatever he wanted, but kept close observation by following from a distance. They believed that by allowing them to do things on their own such as buying things they liked, they were helping 'sick' family members to promote self-confidence, and to show to them that they were loved. The following excerpt reflected this point:

*New Year...happily he asked to go out to the supermarket...we allowed him to buy what he wanted...those expensive shoes, clothes, anything...I encouraged him to be independent...he went, but we followed from behind. Did not let him know.*

(Minah)

Some participants in this study provided social care by enhancing communication. They spoke nicely and step by step to their 'sick' family members so that they could understand and able to follow what was instructed. The same participant reflected her experience:

*I took care of him...I talked to him, like this, like a normal person...if other people, afraid they would scold him...he could not be scolded...we always spoke nicely to him, step by step... "Have to eat, want to go school again? To become well? Now I am here. If I am not here?" Finally he followed us slowly.*

Minah)

Most participants provided social skills in daily care activities by of allowing their 'sick' family members to be responsible for their own personal self-care such as bathing on their own, grooming, dressing, cleanness of their bedrooms, and reminded them as needed.

## 2.4 Financial Care

Participants described their caring also included seeing to the total expenditures of the 'sick' family member. Providing this care was important, as most of the 'sick' members were unable to work due to their dysfunctioning intellectual ability and thus, were financially dependent upon their caregivers to provide all the expenditures. Excerpt of one participant:

*His father sent money every month... sometimes RM200-RM300 per month. Able to spend for him.*

(Fuziah)

Participants also described that they faced difficulties when 'sick' family members demanded more money than they could afford, and caring for them became an additional financial burden. One participant commented:

*...sometimes he asked from me for... more money. What he wanted with the money I did not know. While food I got for him, cigarettes I got for him, so what did he want with those money? That was what that made me difficult... while money required to care for him and myself, was not enough, he wanted more! RM10, RM50... sometimes I went to him... "So much money what do you with it? If finish today, what will we be we eating tomorrow?"...*

(Alia)

## 2.5 Spiritual Care

Besides financial care, participants also expressed their experience in providing spiritual care to their 'sick' family members. This dimension of spiritual care was not related to religion, religious practices, God or Higher Being but was the awareness and ability to draw inner resources and strength, dealing with uncertainties in life, and finding meaning and purpose in life (Burkhardt, 1993). In this aspect of caring participants described how they promoted spiritual care by strengthening the inner-self of the their 'sick' family members, helping them to deal with

uncertainties and making their lives more meaningful. One participant promoted the spiritual well-being of his son by encouraging him to be patient, firm and be confident to overcome his illness. This was evident by:

*I give him advice for him to be patient, to continue to...fight the illness...because he was an educated person, had gone to university, and should be able to overcome his illness and not just to follow blindly ...his illness...he must be firm and have confidence to overcome the illness.*

(Cathy)

Another participant provided spiritual care by promoting courage and hope for the 'sick' family member as such:

*Sometimes I would talk to him and said, "Look at your friends, sure Nana (son) is not going to be sitting here in the house in this condition, want to work, get married, and hope to have a family like other people. So Nana had to get better soon. You have to be independent, you have to do now, and you have to care for yourself." He kept quiet when I said this.*

(Minah)

The same participant narrated her experience by providing "presence" such as listening, showing love, care, respect and being available.

*I spent most of my time caring for him...I did not think of him as a 'sick' person, I treated him like a normal person...I am always giving him attention, see to his condition, see to him if he is alright...he is my son and I love my son.*

(Minah)

### 3. Changes of Feelings During Caring

Caring for the family members with chronic schizophrenia is not easy because of the many disabilities and the distressing behaviors exhibited by the 'sick' family members. During the caring experience, participants reflected both positive and negative feelings. Thus the sub-themes reflected were 'negative feelings to positive feelings after years of caring', and 'negative feelings to more negative

feelings after years of caring’.

### 3.1 Negative Feelings to Positive Feelings after Years of Caring

At the beginning participants reflected negative feelings during caring such as feelings of sadness, disappointments, feelings of doubts, not so concerned, crying, worried and stressed. Reasons for such feelings as described by the participants were heavy responsibility after death of spouse, did not understand how to manage. Heavy responsibility after death of spouse was experienced because had no one to share and express feelings regarding caring. It was a new experience as none in the family had mental illness except the ‘sick’ family member. Examples:

*Of course I feel sad because I raise him up, give him education till university, then suddenly he became like this...so sad and any parents would feel sad too as they have given good education. At the beginning I feel that I cannot manage him especially after his father's death. I feel a heavy responsibility managing him.*

(Cathy)

*It's also sad. When it (mental illness) came, feel sad...sad that...do not want to think about it. In the past when her mother was alive can bear a little, now by myself, have to take full responsibility and is heavy...*

(Zak)

After years of caring, bit-by-bit they gathered knowledge of the illness, how to manage and they reflected their feelings as being positive. The positive feelings reported were feeling more relaxing, more happy, no more crying, no more sad, not worried, less stressed. Feelings of proudness and satisfaction were also reported as they gained confidence in their care and able to overcome their difficulties. These are revealed in the following excerpts:

*I feel more relax, and more proud of myself when I am able to overcome all these and I have learn a lot about life, which is more tough and stronger to overcome all these. And also I am more loving towards others who are sick. In the past really do not care,*

*but now I am giving more attention and more love.*

(Cathy)

*In the beginning it was 'teruk' (bad). Later I was used to it. Now it is not that bad...we take it easy. Surely for others it would look difficult to care for him. But for us it is common, but during the first time it happened to my son, I felt sad and cried and cried! Now no more...*

(Minah)

### **3.2 Negative Feelings to More Negative Feelings after Years of Caring**

On the other hand, a few participants reflected more negative feelings after years of caring. They described their feelings as very sad, very angry, and "serabut", a Malay meaning "mind was so crowded that one could not think anymore", feelings like wanting to scold the 'sick' family member and frustrations.

For examples:

*Since that time he got ill till today, no difference...same...it hurt me...no difference, the same...he still made those particular behaviors always. Felt like wanting to scold...I felt frustrated in my life with his condition he was in, very, very frustrated. Don't know...lah...fate!*

(Alia)

There were some who described their mixed emotional feelings in relation to the condition of the 'sick' member as such:

*Emotional feelings...feelings of wanting to scold her then came these feelings of sympathy because of her illness and future. If she is aggressive, feelings of fear because as old people said, 'she has been obsessed by 'outside people' meaning entered by 'jin' (outside people or jin refers to spirit), but still I did not give up hope...sometimes came this feelings I feel bored because she did not take her medication and I scolded her for not taking her medication.*

(Boris)

*...felt like wanting to scold her, felt hatred for her. She stopped doing (referring to the aggressive behaviors) and I felt relieved...*

*According to the village people they said ... male 'jin' who disturbed and lived in her made her crazy.*

(Eliza)

#### **4. Future Concern**

The participants expressed their concern for the future of their 'sick' family member. The two sub-themes identified were: (1) job concern and, (2) no other persons to take care.

##### **4.1 Job Concern**

Having a job would provide independence in terms of financial support. Persons with chronic schizophrenia due to their inability to solve problems, and cognitive disability, were usually unemployed and dependent on their family for financial support. Participants in this study expressed their concern with regard to the 'sick' family's future without job. One participant narrated:

*Only one problem...her future...If she did not pass her study (teaching course), I worried...because she would not be independent...so hard...worried if her post (teacher) stopped... wanted to help her so that life would not be difficult... if she worked, for her expenses she could use her money...considered she could support herself...also I would be old and die, who would care for her then?*

(Boris)

##### **4.2 No Other Person to Take Care**

Participants also expressed their concern as who would care for the 'sick' family members in the future when they died. This was revealed in the following excerpts:

*When I am old and die, who will care for him? Her future will not be guaranteed. If she wanted to depend on her sisters and brothers, how long? Only for a short while...for her to depend on her brothers and sisters,...if they wanted to support her, they also have their own children,...so how long could they supported her?*

(Boris)



*My future is not known yet... either I go first (die) or he (son) is the one to go first. If he goes first, thanks goodness... if I go first, difficult for him. Who will take care of him? His brothers and sisters will not accept him. I am the one now caring for him.*

(Alia)

## **5. Coping Experiences**

As a result of the multifaceted challenges and stressors experienced, family caregivers developed a wide range of coping strategies. Participants in this study described their different way of coping during caring experience. Four sub-themes as reported by the participants were: (1) coping behaviors, (2) religion and beliefs in god, (3) hope, and (4) learning through experience.

### **5.1 Coping Behaviors**

Participants described various coping behaviors such as being more understanding about the 'sick' family member's behavior, being more patient, and trying not to think too much of the situation and acceptance of the mental illness over the years. The followings were examples from participants:

*Do not think too much, we also became sick psychologically.  
Have to be very patient.*

(Minah)

*Have to work hard, understand how to care for him... continue to be more understanding about him... Accept this as fate, as from heaven, thus strengthen my spirit to manage...*

(Cathy)

### **5.2 Religion and Beliefs in God**

Most participants also described their coping experiences by using religion and praying to their God. They believed that the sadness regarding their family members' mental illness was bestowed on them from God and was a test of

their patience. Thus, they had to accept mental illness of the 'sick' family members.

As one participant described:

*Belief in God... this sadness is from God, he made our son like this to know how patient we could be... its part of life and not within our power.*

(Minah)

*Have to accept the situation he was in. Given by God like this to test our patience as mother ... have patience or not.*

(Alia)

Some participants reported that religious studies had taught them the meaning of life's obstacles and had helped them to accept the illness of the 'sick' family member as fate. Participants described ways of religious practices such as reading verses from Islamic religious book, from *Koran*, and praying to Allah. Things they prayed for included strength and tolerance to deal with their everyday problems, for longevity to care for the 'sick' family member. They reported feelings of less stressful, more at ease, "free" and no worries. Below were some examples:

*Hoping and praying to God to be stronger, and more hardworking to face problems.*

(Cathy)

*Did not want to think... read... read a little, prayed along the room corridor... prayed for tolerance... prayed for longevity to care for her (daughter)...*

(Zak)

*I did not know... Wanted to say also it's not right. How? God had given. Going to be 12-14 years I had been caring for him... sometimes I went and cried alone in the room ... prayed to God... "Why my fate is like this... that he (son) became like this? For other people God had given a short time, for us forever".*

(Alia)

*Felt stressed... early in the morning I woke up, seek God, prayed, bath... I cried almost every night ... so many years! I did not tell to*

*anybody. In the evening I went to mosque, I learnt and read Koran ...attended religious classes...*

(Dariah)

*Always pray, perform praying rituals, pray in the mosque. After praying I ask from God ...ask and depend on God. What can we do? It was fate. I pray to God, my heart feel free...at ease, no more worries.*

(Eliza)

One participant believed that if she did “good” by caring for her ‘sick’ son to get well, she and her family would be blessed as confirmed by her words:

*All these happenings are from God's work and are not within her power. All religion is good. From Muslim's views if we do good, one day God will bless our children, our grandchildren or our next generation...*

(Minah)

### 5.3 Hope

Hope has been used as coping strategies by caregivers to cope with their caring. Participants in this study expressed their hopes for their ‘sick’ family members with chronic schizophrenia to get well, get better, able to work like other people’s children and be independent. One participant hoped that his ‘sick’ son would recover from the mental illness, have a family of his own and able to support her financially. The following excerpts were expressions of the participants:

*Hope he will get well, hope he will get better when we see other people's children working.*

(Minah)

*Hope that she will recover, though not fully recovered...hope she can be independent, able to work, and her job confirmed...I did not give up hope, as long as I live, has life I will continue to care for her.*

(Boris)

*Hope he is well...not having illness, not sitting and talking by himself, can work, can have a wife, and can bring some money to*

*me for expenses in the house after that I do not know. That's what I hope for.*

(Fuziah)

#### **5.4 Learning through Experiences**

The participants in the study indicated that experiences that were learned through the years of caring were essential and facilitated them in coping. This was because they knew about the 'sick' family member's illness, how to handle and manage the 'sick' family member through observation for changes in behavior and daily routine habits, able to reduce their fear, sadness and giving them confidence in their caring. As reported by some participants:

*We learnt from his illness that he was like that, we already knew by seeing his condition changes...I already knew if it's like that ...wanted to sleep what to do, in the morning what he wanted to drink...I already knew what to do. It's an experience.*

(Minah)

*...her illness was not balance (severity of illness varies through the day)...from morning, afternoon to night...we were able to identify...if she was not able to wake up at 6.00am meaning her illness got worse or not getting better...In the afternoon she gave no problem as that was the time for schooling.*

(Boris)

*He did not talk by himself if he took his medication, did not talk by himself and he slept.*

(Fuziah)

Besides coping through self-learning, participants also reported getting information from the health personnel especially the doctors when bringing their 'sick' family members for follow-up care at the clinic. Participant asked the doctor personally regarding the illness of their sick family member, its progress as well as management of certain problems. As these participants narrated:

*Wanted to know the progress of his illness, and to listen from the doctor himself, their illness, regarding his progress, or I had specific*

*questions on the problems ...I wanted to know how to go about, needed explanation of the doctor and also I wanted to meet the doctor myself...*

(Cathy)

*Last time did not know how to overcome...now able to overcome...I now easy... we feel experienced...if we saw other sick people I had gone through it. If there was anyone who wanted to talk about it I knew because I have gone though it...*

(Dariah)

## **Impacts of Caring Experienced by Family Caregivers**

Caring of family members with chronic schizophrenia had strong impacts on the physical, emotional, and social life of the caregivers. Some impacts brought negative consequences while some were seen as positive by the caregivers. In response to the research question, “What are the impacts of caring experienced by family caregivers caring for members with schizophrenia?”, six main themes were described: (1) being burdened, (2) being ashamed, (3) feared by other family members, (4) physical ill health, (5) loss of job, (6) gaining knowledge and experience, and (7) self-fulfillment.

### **1. Being Burdened**

In this main theme “being burdened”, 4 sub-themes were identified by participants in this study. There were: (1) distressing disruptive behaviors, (2) heavy responsibility, (3) financial loss, and (4) loss of independence.

#### **1.1 Distressing Disruptive Behaviors**

Most participants in the study reported that their caring experiences were a burden because of the distressing disruptive behaviors of the ‘sick’ member. These behaviors included refusing to listen, refusing to do things asked, behaving

abnormally and asking things that cannot be given. The following excerpt demonstrated the caring experience as being a burden to one caregiver:

*During this time, these 2-3 years, he became a burden to me. He did not listen to me. I asked him to do things and so forth, he did not listen. He asked for things that we could give to him. That was what burdened me. He behaved all sorts, and burdened me with his illness of people like this...*

(Alia)

## 1.2 Heavy Responsibility

Besides being burdened by the distressing disruptive behaviors of the 'sick' family members, participants also reported being burdened by heavy responsibility. The responsibility of caring for the 'sick' family member was perceived as heavier than caring for other siblings because they are caring for an abnormal child. They had to spend more time, more attention, and more caring, besides seeing to the demands made by the 'sick' family member. The responsibility increased when the 'sick' family members became sick during exacerbations of the illness. As shown in the participants' words:

*I am caring for a son that is not normal; this responsibility thus became heavier than caring for the other siblings...*

(Cathy)

*I felt burdened...I felt caring for other children (other siblings) was easier, caring for her was difficult ...her talks was not rational, did not know when was day or night...made me busy, lost of time ...nobody wanted to help to replace me...*

(Dariah)

*Even though she had not been well once, she had to call for her father...and this responsibility was heavier, more when she was sick. Not sick also had to care for her.*

(Boris)

The heavy responsibility was also a result of being the sole carer, with

no one to share the caring role especially after the spouse died, and nobody to discuss problems. Thus, the caregiver had to assume full responsibility. The following excerpts accounted for this:

*In the past when her mother was alive, could bear a little...she cared for her...Now by myself, had to take full responsibility and was heavy...I became the main caregiver.*

(Zak)

*In the past, at the beginning of the illness, I felt I could not manage him especially after his father's (her husband) death...I felt heavy responsibility managing him...before when I had problems I shared them with my husband...*

(Cathy)

Another cause of heavy responsibility was no one to relieve the caregiver temporary, when caregiver gone to attend some personal function, or during admission of 'sick' family member to hospital. And some participants reported that even when there was other family members or relatives to take over temporary, they believed that the caring given was either not good enough or unmanageable, and the 'sick' family members returned home. They were worried and afraid that the 'sick' family members would not be treated well. As two participants shared their views:

*When I say burdened me because I was the only person who took care of him. The only person, while his aunt, his uncle, his cousins did not care. There was nobody who wanted to care for him. While I had some work and went to Kuala Lumpur, asked his stepmother to care for him for a while...he stayed for 2 days, and then he came back and broke into the house through the window...real sad for me...*

(Alia)

*I took care of her. Nobody else. I gave her brother and sister to care for her for a week, as I went to Pahang (another state). They could not manage her. Other people did not know how to care for her like I did...other children, I was worried and afraid they did not speak nicely to her. I did not allow them to talk bad to her, I felt hurt, I could not. She was my child too.*

(Dariah)

### 1.3 Financial Loss

Another burden reported by most participants was financial loss. They had to spend more money to pay for the daily expenses, the medication and treatment of the 'sick' family members who were totally dependent on them. One participant shared that his 'sick' family member was a spendthrift when she became sick. The following account reflected this point:

*Impacts from this caring...had money problem because this daughter of mine, her spending was more, she was a spendthrift...she was not careful with her spending, specially when she got the illness.*

(Boris)

Another participant reflected that the financial loss was also contributed by 'sick' family members' aggressive behavior such as damaging things and selling expensive things in the house. This exemplar illustrated this:

*...when she woke up, we saw she had thrown all the things out from the fridge. After that damaged...she threw off clothes... her jewellery she threw inside the paper basket...we did not know...she took jewellery to sell...she scolded us ...she took and sold off...*

(Eliza)

### 1.4 Loss of Independence

Loss of independence was also another burden that caused impact to the participants both physically and psychologically. They reported not able to go anywhere, had to be with the 'sick' family members at home to ensure 'sick' family member was fine, not causing harm to self, and took their. If they wanted to go anywhere, they needed to have the 'sick' family with them. They reported that if they had to leave the 'sick' family member alone at home because of work, they were worried and feared that 'sick' family member forget to take medication, or not



able to prepare own meals.

*When I wanted to go anywhere, less free because we must have him...*

(Cathy)

*When I wanted to go anywhere it was difficult...worried he was left alone in the house...thought of him of alone in the house...his disturbance, had to take care of him well enough...had to see he took his medication morning and evening...scared that if he wanted to eat by himself, did not know how to cook rice, difficult for him.*

(Fuziah)

*Regarding freedom, I felt free as I do not listen to him, I could go anywhere...but at times also I felt not able to because had to leave him alone...yes, it is a burden.*

(Alia)

This loss of independence to some participants became so burdened that they hoped somebody would take over the caring permanently, such as hoping the 'sick' family member would get married, and took over the over the caring role. As one participant expressed in her own words:

*Must gave him a wife to take care...so difficulty, tired of caring...want to go anywhere was difficult...he was a grown up and 27 years old, but still I had to care for him...from young till old I have to care for him...sad this thing...*

(Fuziah)

Loss of independence to some participants also meant hindrance in speech such as when talking or scolding. They needed to be cautious of the 'sick' family members' feeling. As one participant illustrated:

*We were not free in our speaking...when we talked, wanted to scold, definitely freedom was hindered, as we must be cautious...because had to take care of his feelings.*

(Cathy)

## 2. Being Ashamed

Five participants in the study reported being shameful of the mental

illness of the 'sick' family member. They felt ashamed because neighbours came to know of their child who was not normal as having mental illness and can be laughed at. Some participants described their feelings of being ashamed related to the shameful behavior of their care-recipient such as running off to the public area without any clothes on. As a result of being ashamed, the participants reported having less interaction with other people in the neighborhood and tended to keep to themselves. The followings were participants' reflection of their experiences of being ashamed:

*Feel ashamed also. In the past I felt ashamed because people around me came to know that my son was not normal, could be laughed at by other people. So other people laughed at him...I accept this as my fate.*

(Cathy)

*I feel ashamed because the community knew about my daughter's condition...*

(Boris)

*Yes there was once...she ran out without clothes! Once!...Ashamed! ...felt ashamed ...because she... her behavior*

Zak)

*I talked to nobody except my son, my husband, or to my relatives... it was a shame if I were to share my feelings with others (friends) regarding my son...*

(Nook)

When the care-recipients became better, no more exhibiting those distressing behaviors and behaved normally in public, participants no longer felt ashamed. One participant narrated:

*Felt ashamed. Other people did not have like this...our child got it...many did not accept our child...Did not feel it now ...relieved...at ease because she was able to care for herself, wore her own clothes...now she was normal...had recovered...she went out, nobody knew.*

(Dariah)

### 3. Feared by Other Family Members

Due to the distressing aggressive behaviors of 'sick' family members with chronic schizophrenia especially during the acute exacerbations, participants reported fear by the other siblings in the family of being hurt by the 'sick' family member such as pushing, hitting, being bitten or strangling. As one participant shared the feelings experienced:

*During this time...most frightening...she slept and nobody was allowed to enter her room. At one time her mother entered her room, and unexpectedly she tried to push her mother out...all her sisters and brothers felt scared to enter her room.*

(Boris)

### 4. Physical Ill Health

During the caring, some participants in this study reported experiencing mild physical ill health such as body tiredness, heaviness of head, having high blood pressure, and sore throat. One participant reported going to see a doctor in for her health problems while another participant relieved her tiredness by resting when the 'sick' family was asleep.

*My body was tired, my thought was tired, tired the whole body... Yes, at one time I had this...my head felt heavy, my blood pressure shot up suddenly, had sore throat,...I went to have myself checked at private clinic at Kota Bharu...yes, my blood pressure was raised and I let the doctor knew of my problems.*

(Alia)

*It was normal if I felt tired...I rested when he slept...I could rest...*

(Fuziah)

### 5. Loss of Job

Caring for the 'sick' family member to some extent required the caregiver

to leave their well-paid job to care totally for the 'sick' family member during the early phase of the illness. One participant from this study revealed that she had to take half-pay leave, and then finally stopped working to care for her adult schizophrenic son. The following excerpt reflected this:

*I had to take half-pay leave, and then finally had to stop work as a dental nurse to care for him. If asked other people to take care of him, the caring would not be like we took care for him...we ourselves knew how to care for him.*

(Minah)

## **6. Gaining Knowledge and Experience**

After years of caring for the 'sick' family members with chronic mental illness, participants reported gaining knowledge and experiences, learned bit by bit through the years of caring. They observed the changes of behaviors of the 'sick' family member especially if not taking medication continuously. Care-recipients became more aggressive and the mental illness relapsed. The knowledge and experiences gained made them more confident, not afraid or worried, and more happier in their caring. They believed they knew enough of the illness and was able to share and teach others whose children were having the same health problem.

*If she did not take her medication, her illness came back, meaning became aggressive again. I was not afraid, nor worried. I felt happy, felt satisfied with my caring because like this, like this I knew the medication...I had know this illness, for some others I could share, I could teach, I could comment, and I could show...*

(Boris)

## **5. Self-Fulfillment**

Besides feeling burden, some participants in the study experienced feelings of fulfillment in their caring. This was because they felt they were able to overcome the problems, able get through the feelings of sadness they once had, and now

able to manage the illness of the 'sick' family members. Their endurance and hardships promoted growth, self-development and self-fulfillment in their lives. They described being able to cope with their negative emotions, have stronger spirit, more patience when faced with people of the same illness, able to interact with them, understand their feelings, and not afraid to talk with them. As described by one participant:

*These positive impacts...more patient, more understanding, regarding illness more understanding how to cope with emotions: anger, sadness, more stronger in spirit, more patience and when faced with people like this, we knew how to interact with them, and we knew their feelings, we knew a bit of their illness...we were not afraid to talk with them because we knew their illness "*

(Cathy)

Another participant reflected on the impact of caring experience:

So while caring for her, felt proud, able to overcome all these...it was a trial, her illness was also decreasing from time to time...some of the community praised me besides my children. Even though whatever, I felt happy, felt satisfied, with my caring...

(Boris)

### **Needs of Family Caregivers when Caring**

In response to the fourth research question, "What are the needs of family caregivers when caring for members with schizophrenia?" seven main themes were identified: (1) keep themselves healthy, (2) support resources, (3) financial support, (4) temporary replacement, (5) inner strength, (6) expression of feelings, and (7) informational needs.

#### **1. Keep themselves Healthy**

Keep themselves healthy was also mentioned by participants as an important need to care for the 'sick' family member. They were aware that they

needed to keep themselves healthy because if they fell sick, there would be nobody to care for the 'sick' family member. For examples:

*Must be healthy. If not healthy how can I take care of him?*

(Minah)

*Sometimes we needed rest during the free time. Health is also a must. If I fell sick who would take care of him?*

(Alia)

## 2. Support Resources

One of the support resources that were frequently reported as needs required during caring included medication. They were aware of the importance of this need. Other support resources need as reported by participants were food, drinks, and clothes. The following excerpts from participants confirmed this:

*Medication-first, medication time, we must give him...night and morning...*

(Minah)

*Yes, food drinks, clothes, all these I need to have. Like clothes, did not always buy but ... only this year bought one pair...*

(Alia)

## 3. Financial Support

Financial support was one of the important needs of participants described during caring for 'sick' family members. This was partly attributed to care-recipients' unemployment, making them totally dependent on financial support. Money was required to pay for medication, hospital treatment, hospitalizations and other expenditures of 'sick' family members.

*My needs to care for him...money also needed more, because he smoked cigarettes... while the money required to care for him and herself was not enough, he wanted more...RM10, RM50, sometimes he asked more!*

(Alia)

*I hope there was help...financial help provided for him (son) for paying his medication. Needed more money for expenditures...the*

*relatives in Kuala Lumpur provided money to help me buy medication.*

(Nook)

Some participants reported that though they do not need money now, but in the future they might do so.

*Needed more money in the future to pay for medications, treatment and hospitalizations, as both of us were pensioners.*

(Minah)

#### 4. Temporary Replacement

Some participants in this study expressed their heavy responsibility as being sole carers and needed help to relieve them temporary especially when they went out somewhere. As revealed in the following account:

*Needed people to care for him... this caring, considered as for temporary relieve like when we went out somewhere...*

(Fuziah)

#### 5. Inner Strength

Inner strength was one of the needs mentioned by participants when caring for 'sick' family member. They needed this inner strength to manage and cope with the distressing and disruptive behaviors of the 'sick' family member. They seek this by praying to God. This inner strength included having patience, more understanding, and more love.

*I must strengthen my inner spirit to manage him ...this I prayed to God...*

(Cathy)

#### 6. Expression of Feelings

Participants in the study reported the need to talk about their difficulties so that these were released and not kept inside. 'Talking it out' made them felt

more relaxed and less stressed. Usually they turned to their own family members such as their spouses, or adult children who were staying with them, to release their feelings. If they could not go to any of them, they would look towards their closed relatives such as own sisters to express their feelings and also for advice. The followings were examples:

*We expressed our feelings so that we didn't feel all kept inside...*  
(Alia)

*I talked it out to my sister...yes good, ...she gave advice like that, like that...*  
(Zak)

*Yes, I discussed with her mother (wife). If with the outsiders I could not. With outsiders I had never talked about it. The son who helped me to care for her, yes... with the family, wife and children.*  
(Boris)

## **7. Information Needs**

Information need was one of the needs also mentioned. Two participants reported the need for information regarding illness of the care-recipient, and how to manage. This information was obtained from psychiatric doctors who were attending to their 'sick' members during clinic follow-up. None reported obtaining information from nurses at clinics. None reported a need to know more about medication, its actions and side-effects. Most participants described as having enough information about illness, which was learnt. They reported that they also learnt through their own experiences through years of caring by observing the changes of behavior of 'sick' family members. Some participants reported gaining some information from religious studies and their cultures, which assisted them in their caring. As one participant described from his own believes and knowledge:

*Every illness all has medication, except death...this problem on*



*mental illness, meaning thoughts must have vessels and nerves...very bad must have the veins which are not healthy, ...food which is not balanced cause mental illness...*

(Boris)

Another participant described her need for information regarding illness as follows:

*Must have knowledge regarding his mental illness, how it occur, how to overcome, the different health problems and the effects on him, and how to manage hi*

(Cathy)

## Discussions

This session presented an overview of the findings generated from this study. The research outcomes in conjunction with current literature were also discussed.

### Meaning of 'Caring'

Caring is a wide concept, with many definitions. It can be viewed as a process and an art that requires knowledge and continued practice (Bevis, 1981 cited in Harrison, 1990). It can also be viewed as a set of caring behaviors or a set of caring activities. Besides, it also has a moral and ethical aspect. In this study participants presented and interpreted meaning of caring as "caring for the well-being of the family member". According to the Oxford Advanced Learner's Dictionary (1995) well-being means "a state of being healthy and happy" (Hornby, 1995, p. 1353). Well-being according to Kozier, Erb, Berman, and Burke (2000) is "a subjective perception of vitality and feeling well. It is a state that can be described objectively, occurs in levels, and can be plotted on a continuum" (p. 167). This caring of the well-

being as perceived by the participants included not only physical-mental aspect but also the emotional, social and the spiritual well-being. This reflected caregivers' awareness that to care for their 'sick' family members with this chronic mental illness of schizophrenia, caring is more than just the physical well-being.

In view of this chronic schizophrenia, which has severe functional disability in self-care, social incompetence, and inability to live and function independently, participants want to enhance the quality of life and maximize their 'sick' family members' personal potential. Thus, participants ensured that besides seeing to the physical needs like meals, clean clothes, comfortable and safety home, they took their 'sick' family members outing, spending more time with them, understanding them more, maintaining peace, giving lots of trust and love, not angering nor fighting with them, and seeing that all these run smoothly from day to day.

By doing this they believed they were helping their 'sick' family member to move forward to better, quality of live despite their disability. This is similar to study done by Rose (1998) in her interpretative study on 15 family caregivers which revealed meaning of caring as "finding the essence of the person obscured by the mental illness", "finding a place for self in influencing the illness" and "helping a relative to move forward".

The participants also interpreted caring as "responsibility as a parent." As a parent, they are responsible to care for the mentally 'sick' child, making sure the 'sickness' or mental illness gets better, to be with them, continue to provide love for the 'sick' family member despite their sickness, and enduring the situations. This meaning of caring is partly a result and influence of their religion, cultural beliefs and

values of being parents and how they perceived their role function as parents. In Islamic beliefs caring is seen as a responsibility for parents who brought to this world their children by virtue of birth as stated by the Holy Prophet, "Each of you is a guardian and is charged with a responsibility, and each of you shall be accountable for those who heaven been placed under your care" (cited in Rassool, 2000, p. 1481). For the Muslims, caring is "a natural outcome of having a love for Allah and the Prophet and the will to be responsible, sensitive, concerned with the motivation and commitment to act in the right order to achieve perfection" (Salleh, 1994 cited in Rassool, 2000, p. 1481). Thus, by being responsible and committed as parents towards caring for their 'sick' family member, is an outcome of showing love for their God and Prophet. Besides caring of a 'sick' family member caring can be seen as an act of "doing good" (Maaruf) (Rassool, 2000) and will be blessed in this world or in the next life (Al-Qasas 28: 84, cited in Al-Hilali & Khan, 2000). This finding of parent responsibility is supported by studies such Howard (1994) and Tungpunkom (2000) where both authors used the term "maternal care". This obligation of apparent responsibility enabled the participants to endure the sufferings and frustrations, being with the 'sick' family members throughout the years of caring and to continue to provide unconditioned love despite hardships and burden. The sub-theme on providing of unconditional love seen as a responsibility being a parent, is expressed by continuing to show love to the 'sick' child, caring until they were fully well or even when not sick, continuing to show presence and provide support. These constructs of caring are similar to those constructs found in Leininger's (1988) constructs of caring, such as love, concern nurturance, presence, and support.

In addition, the caregivers in this study also reflected meaning of caring as “being burden” by the distressing behaviors of their care-recipients. This perception of caring, as being burden is consistent with many studies done which predicted that disruptive behavior of the ‘sick’ family members was a major predictor of burden (Biegel et al., 1994; Reinhard, 1995). The distressing behaviors were, uncooperativeness, unreasonable demands, and refusing to listen and obey, inactivity, not participating in household chores. These distressing behaviors made them emotionally upset and angry. This finding is consistent with study done by Gopinah and Chaturvedi (1992) who found that behaviors that were most distressful were those related to activity and self-care, not aggressiveness or psychotic behavior. This negative perspective of caring perceived reflected their lack of knowledge regarding the illness process, its cognitive and behavioral manifestations and also the management of illness during times of acute and residual phases. This may be partly attributed to most of participants’ having low educational level, and their lack of wanting to know more about the illness and medication.

This study also found that burden is expressed as a long-term heavy responsibility to bear with no other persons in the family to help and take over. This kind of burden is seen as objective burden (Hoenig & Hamilton, 1966) and has great impact on the life of the caregivers. The finding of this theme indicates that there is a need to understand the perceptions of “being burden” as interpreted by the family caregivers in their caring experiences. The finding also suggested the importance of educating family caregivers about the mental illness on chronic schizophrenia, how to manage the symptoms more effectively, and means of coping in the long-term.

## **Caring Experiences**

Persons with chronic schizophrenia have numerous psychological as well as behavioral manifestations which include severe symptoms of chronicity such as dependence, social incompetence, impaired functioning in activities of daily living, inability to support oneself financially, limited skills in solving problems. They also exhibit bizarre behavior, which require long-term tolerance and compassion for them (Price-Hoskins, 1987). In fact most of them are dependent on family for physical, emotional, social financial support. Thus, caring for this group of people was a challenge, and the experiences caring for them varies as compared to caring for a group of people with only physical illness. And that was the reason why the researcher chose to the caring experiences of family caregivers caring for chronic schizophrenia rather than caring for other chronic physical illness.

The theme on “managing the illness” provides a fuller understanding of how family caregivers experience caring for their ‘sick’ family in the real situation at homes. Caregivers were faced with the distressing, disruptive behaviors of their ‘sick’ family members ranging from uncooperativeness, distressing verbal behaviors, to aggressive behaviors, hostility and wandering behaviors during early phase of illness and during exacerbations. The caregivers were vigilant of the onset of disruptive behaviors, and they sort to all ways to control such as using medication control, verbal control by persuasion and patience, and caring actions. This is consistent with the study done by Tungpunkom (2000) who identified symptom and medication management as two of her major psychiatric caregiving domains. The author described her symptom management activities as monitoring of symptoms relating to

mental illness, while medication included observing side effects, giving medication and monitoring medication compliance.

Participants reported also bringing their 'sick' family members to hospital and clinic for follow up care for treatment and collecting medication. They were very much aware of the importance of their sick family members taking their medication. Therefore, medication management was emphasized most by these family caregivers especially medication compliance. The family caregivers have learned through their experience and from psychiatric doctors at clinics the importance of medication in controlling their disruptive behaviors and functional level. These caregivers observed the side effects and other symptoms related to medication. The medication management was close to formal caregiving and comparable to activities of staff in a psychiatric treatment setting. Thus, caring required specialized knowledge and skills and were comparable to nursing care. The fact that family caregivers attempt to assume this aspect caring speaks to their need for basic knowledge about mental illness, its treatment, medication and their side effects and management.

Besides seeking modern health care, there were some caregivers who reported seeking traditional healers if they perceived that modern medicine could not help much in the treatment. Traditional healers known as "*bomoh*" used "*air tawar*" which was "chanted water" to treat the 'sick' family members. This traditional remedy was still practice among some Malay families. This kind of traditional self-care was quite similar some previous studies. Study described by Tungpunkom (2000) found that 21 mothers out of 30 sought traditional treatment using herbs and holy water for their adult schizophrenic siblings.

Family caregivers also reported they learnt through trial and error how to handle their care-recipient behaviors to prevent further aggression. However, whatever work for them was sometimes expedient and not necessarily a productive, quality care in the long term. Furthermore, this kind learning to care from own experience is very stressful to the family caregivers by their expression of feelings such as fear, assault, and helplessness. Finally through the years they learnt the management of caring for their 'sick' family members. Nurses could help to decrease their stress in this caring by providing information to participants as well as 'sick' family members about course of mental illness, its manifestations and especially identifying symptoms indicative of relapse and the management of disruptive behaviors during an emergency. Identifying the symptoms indicative of relapse will help to decrease the number and severity of relapses (Moller & Murphy, 1998).

Providing daily care in this study included physical, mental, social, emotional and spiritual care. Physical care as described by the participants in this study was preparing meals, drinks and food for the 'sick' family members. It also included seeing to the personal hygiene of the 'sick' family members such as cleanliness of clothes, bathing, and toileting. Participants in this study reported that most of the 'sick' family members were able to perform personal hygiene care and they only needed to be reminded or supervised. However, they were required to provide more care such as assistance in feeding, bathing and toileting when 'sick' family members were acutely ill or during exacerbations of the illness. The findings indicated that participants knew how to adjust the physical care needs accordingly to the severity of the illness of the 'sick' family members. At the same time when 'sick' family

members were in remission, they encouraged responsibilities for self-care.

Persons with chronic schizophrenia exhibited poor memory and attention span, anhedonia, avolition, anergia and impaired thought process (Maj & Sartorius, 1999; Moller & Murphy, 1998; Shives, 1994). These symptoms caused the sufferers inability to perform activities of daily living, self-care and neglect personal hygiene. Thus, they looked untidy, disheveled and inappropriately dressed (Maj & Sartorius, 1999; Shives, 1994; Townsend, 1999). Therefore, providing daily care was very important for the 'sick' family members to help them cope with their activities of daily lives.

Participants also reported providing physical care in terms of providing comfort and safety for 'sick' family members such as clean bedrooms, eating places, close watch when 'sick' family members went out by self, ensuring female care-recipients stayed indoors at night. Providing safety and protection from harm for 'sick' family members was viewed as important part of caring because the impulsive aggressive and hostile behaviors during acute symptoms or exacerbations of illness might caused injury to self and to others (Shives, 1994; Stuart & Laraia, 1998). Providing financial care was also perceived as vital in the caring. This was because most of the 'sick' family members in this present study were jobless. Those who had jobs had difficulty sustaining them or still in probation because of inability to complete tasks, poor concentration, or poor social relationships. This characteristic of occupational dysfunction was one of the major diagnostic criteria for schizophrenia (APA, 2000). Thus, all were financially dependent on the caregivers. Participants reported that financial income was assisted by working parents who had to continue to



work, adult siblings who had stable jobs and from relatives.

Another aspect of daily care provided by participants in this study was social care. Social care in this context includes providing recreational activities, and developing and maintaining inter-relationships. Participants described that social care as bringing 'sick' family members shopping, picnic at the beach and visiting friends and other siblings, allowing 'sick' family members to go shopping by themselves, and making friends. Nearly half of participants reported that the indoor social activities provided were listening to music and watching television. These findings indicated that participants were aware of the importance of developing and maintaining interrelationships and recreational activities. They wanted their 'sick' family members to develop socialization skills such as inter-relationships, interactions with other siblings, other family members and friends and to maintain these relationships so that they became more self-confident and reduce social isolation. They believed such outdoor activities would provide a change from the usual home environment and instilled interest in the 'sick' family members. However, from researcher's own observation and interaction during interview visits, nearly 50% of care-recipients tend to keep themselves, quiet and did not interact much with caregivers, unless approached. Some care-recipients sometimes talked incoherently and in a very slow monotonous tone.

According to Moller and Morphy (1998) behaviour related to social dysfunctions were social withdrawal and social isolation from life's activities and were caused by included inability to communicate coherently, anhedonia and personal hygiene deficit and deterioration social skills. These findings may possibly indicate

that these care-recipients had social dysfunctions such as withdrawal and social isolations despite participants providing those social care. The explanation could be that social care provided by participants were not the structured, systematic learning-oriented approach towards the acquisition of social skills which were taught as part of the psychosocial programmes (Owens & Johnstone, 2000) According to Anthony and Liberman (1986) social skills were those skills that promote problem solving, promote relationships, promote supportive networks and engage in work. The areas for intervention included holding conversations, friendship, conflict management, leisure and recreations activities and medication management (Birchwood & Spencer, 1999). There were many studies that investigated on social skills training programmes among chronic psychiatric patients and had shown its effectiveness in increasing ability, comfort, assertiveness in social situations (Wallace et al., 1980), as well as improved symptoms and reduced rates of relapse in patients with serious mentally ill patients (Brady, 1984). In view of these findings, it is suggested that nurses should provide education regarding social skills that participants could integrate in their social care or provide references to health institutions that have such services.

The findings in this study revealed that participants went through various changes of feelings during their years of caring. At the beginning of their caring, that is, early phases of the illness, most caregivers in one way or another experienced negative emotions. The negative emotions included sadness, frustrations, crying, disappointments, feelings of loss and hopelessness, and feeling stressed. These were caused by factors such as lack of knowledge of the mental illness, it's process, symptoms, medications, inexperience in managing the distressing symptoms and

behaviors, fear of being harmed by the 'sick' family member during the acute, aggressiveness phase of illness, and also inability to cope with the stressful situation of the new role as caregivers. This is consistent with many studies done on caregivers' experiences and burden (Jones, 1997; Marin & Boyd, 1990; Winfred & Harvey, 1994).

Over the years of caring, the caregivers have learned ways to cope, and to accept the mental illness of their family members in one-way or another. The acceptance of the 'sick' family illness was partly a belief that all this was fate and was a test of patience from God. As Al-Ghazzali (1968) stated, "Illness is one of the forms of experiences by which human arrive at the knowledge of Allah" (cited in Rassool, 2000, p. 1479). The 'sick' family member was cared for just like any normal family member in the family and caring thus, became like a routine. They reflected positive feelings such as feeling more relax, more happy, no more crying, no more sad, not worried, less stress, more proud and satisfied with their caring. They gained confidence in their care and able to overcome their difficulties. However, they still have to endure and cope with various prolonged problems of the mental illness.

The findings also indicated that feelings of caregivers were not stagnant but changed and fluctuated according to the severity of the illness process of their 'sick' family members, the presence of family support during those critical times and their coping styles. When the 'sick' family members were not exhibiting those distressing, disruptive behaviors and easy to manage, participants felt more relax, less stressful and more happier. On the other hand, when 'sick' family members refused to take their medications, exhibited those distressing symptoms and behaviors, and family

members showed lack of emotional support, caregivers felt very stressed, tensed, and sad. They were also fearful 'sick' family members becoming too aggressive to be handled and caused harm to them.

Most participants in this study have been caring for their 'sick' family members for more than 4 - 10 years. However, findings in this study reported some caregivers still having negative emotions and facing difficulties despite years of caring. These could be attributed by problems such as spouses passed away resulting heavier responsibility, lack emotional support from other family members, being the sole carer, and lack of financial support. Another important factor that could have contributed to this negative emotions of family caregivers could be the persistent negative symptoms of this chronic mental illness much as affective flattening, avolition, and avolition (APA, 2000). These symptoms caused the 'sick' family members to have social dysfunction, and occupational dysfunctions, and making the 'sick' family members totally dependent on the caregivers. This indicated that duration of years of caring no doubt made most caregivers more experienced, but did not necessarily lead to making some family caregivers happier and less stressful in their caring role.

The findings of the present study indicated some levels of negative emotions expressed by some participants, though not prominent. There were many studies done which showed that high levels of criticism, and hostility in the relatives of schizophrenic patients, referred to as high "expressed emotion" (EE), was a predicted psychotic relapses. Study done by Hogarty, Anderson, and Reis (1986) on 103 patients with schizophrenia and schizoaffective psychosis for high EE households. The authors reported relapse rates were reduced by 20% with family education and

social skills training. Thus, it is suggested that nurses should provide family education such as coping strategies to reduce and manage stress, and social skill training for participants as a means to reduce relapse of the 'sick' family members.

This finding also provided insights regarding emotional responses that were integral towards adjusting themselves emotionally to the mental illness, to the care-recipient, and to the caring role as primary caregivers.

Nevertheless, most caregivers in this study were worried and expressed concern for the 'sick' family member's future without job and having no one to take care of them. This theme is similar to the findings identified by Herz, Endicott, and Sptizer (1976) on 24 caregivers on their caregiving feelings. Worry about the future, fear and tension were some of the negative feelings reported. Some participants even perceived that caring for the 'sick' family member was part of their lives and plan to find perspective person to replace them when they die, or prepared the care-recipient for the future possibility of living with the other siblings. They believed that by doing that will protect the care-recipient in the future.

This theme on coping experiences reported by caregivers providing a better understanding of how caregivers cope with their day to day lives in caring for their 'sick' family members. Caregivers in this study reported a wide range of coping experiences to cope with the long-term caring. Coping behaviors such as accepting the mental illness as fate, being more understanding, more patience towards the care-recipients were reported by most caregivers. They have learned to accept and reconcile the disabilities or deviant behaviors of chronic schizophrenia over time, and to avoid disappointments that would have occurred from unrealistic expectations.

The coping strategy of participants in this study indicated strong influence by religion and praying to God. They believed that their child's illness was brought to them from heaven as a test for patience being a mother and cannot be changed. Muslims understand that illness, suffering and dying are part of test from Allah. "Illness is an atonement for their sins, death as part of journey to meet God" (Athar, 1993 cited in Rassool, 2000, p. 1479). This belief helped mothers to let go of their negative emotions, help them to accept their family members' mental illness, and not to blame themselves. This belief also helped them to use caring ways of management such as advising, persuasion, not angering or scolding the care-recipient and more tolerating and loving towards their sick family members. In other words, it was a way that made them feel good about themselves and to their caring experience.

Thus, most caregivers turned towards their religion and prayed to their God for strength, to solve their problems, and relieve their tension, a way of expressing their negative feelings. Health and illness was seen as part of being, and prayer remains the salvation in both health and in sickness (Rassool, 2000). Praying was seen as a communication to Allah and was performed daily, five times a day (Salat) facing east, reading the Koran verses and medication.

The findings in this study also indicated that participants used the emotion-focused coping strategy of Lazarus model of coping stress (Lazarus & Folkman, 1984) where religion played a very important role in the stress appraisal. Because religion was used as a strong appraisal factor which influenced their interpretation to see event as less stressful, those participants who were more committed to their religion could be seen to have ability to cope well in their caring experiences and thus,

had a sense of fulfillment.

Problem-focused coping strategy was not much used by participants. This could be due to fact that this kind of coping strategy requires necessary information, accurate appraisal and ability to generate alternatives (Lazarus & Folkman, 1984). Most of the participants in this study did not have necessary health information regarding the mental illness of the 'sick' family member, its process, the medication and thus unable to provide accurate appraisal and generate alternatives. Thus, it is suggested that nurses should provide the necessary accurate information regarding chronic mental illness, its process, medication and management as well as teach participants to use problem-focus strategy as an alternative means of coping strategy.

### **Impacts of Caring Experienced by Family Caregivers**

Burden is a concept that represents negative consequences of caregiving. There were many significant research conducted about family caregivers which stated majority families acknowledged being burden (Hoenig & Hamilton, 1966; Jones, 1996; Loukissa, 1995; Maurin & Boyd, 1990) Most participants in this study reported that caring experience was a burden to them because mainly of the distressing disruptive behaviors of the 'sick' member, loss of independence in their life, great financial loss and difficulties, as well as emotional and physical ill effects such as being stressful, tiredness, increase blood pressure and minor body aches. It was a burden because they were caring for a family member who was 'sick' and not normal, and who required all aspects of care, including more time spent. Besides, most participants in this study have family members staying together in the same household, including siblings, son and daughter in-laws. Participants have to care for

the younger siblings and do shared household chores.

On the contrary of losing jobs as mentioned by some studies, most participants continued to work besides caring for the 'sick' family member. This study reflects the great burden on family caregivers playing this dual role functions. There is a great need for nurses to help family caregivers to reduce their burden.

The experience of stigma and feelings of shame reported by these caregivers indicated a strong negative social stigma attached to mental illness in the Kelantan community and have also been described in other context (Chafetz, & Barnes, 1989; Rose, 1983, Tungpunkom, 2000). Nithikoon (1992, cited in Tungpunkom, 2000) in her comparative study of parental caregivers in the rural and urban areas in central Thailand found that parents in rural areas reported self-blame and stigma than those who resided in urban areas, and reflected greater independence and distance from neighbors. However, findings in this study indicated that caregivers did not report self-blame, but reported feelings of shame about mental illness itself, feared gossip about them from the neighbors, and need to protect their children from negative consequences. Future studies may further clarify different aspects of stigma.

### **Needs of Family Caregivers when Caring**

Participants from this study reported many needs such as being healthy, need financial support, need somebody to express their feelings out, need temporary relief and inner strength. These findings are similar to many studies done on needs of family caregivers (Chafetz & Barnes, 1989; Glendy & Mackenzie, 1998; Hutchinson, 2000).

Financial need was a commonly mentioned issue by most caregivers. This



need was caused by impairment of the 'sick' family member earning capacity, cost of expenses and treatment for them, and their own inadequate income. Most described their income as inadequate to support the 'sick' family member and that source of extra income was assisted by their spouses, adult working children or even relatives. This was because the illness of their 'sick' family member was long-term and life long.

Most caregivers do reported expressing their feelings to their spouses, adult children or to the immediate family members to release their tension and to gain support in handling the 'sick' family member's problems. This aspect of finding is surprisingly similar to the study done by Chafetz and Barnes (1989) on 20 caregivers caring for adult child schizophrenia. These authors reported that caregivers also seek family network first because they knew the 'sick' family member, thus could provide better comfort and understanding. However, social support needs from friends, neighbors or even health personnel were not mentioned as a means to express their feelings or sharing their problems in this study. This finding in a way reflected some stigmatization on mental illness of their 'sick' family members. They felt ashamed and embarrassed. Thus, by not expressing their problems especially to friends and neighbors, they were able to keep privacy the mental illness of their 'sick' family members to within the close family. This finding is similar to study done by Baker (1993) who reported that many families were embarrassed and uncomfortable with the schizophrenic difficulties and relapse of their family members, and tried to prevent this by withdrawing from social situations.

Two caregivers expressed a need for information about their 'sick' family

members illness, the medication, their progress, and management of the problems associated with the mental illness. They believed that doctors were the persons to provide such information. This finding supported the study done by Glendy and Mackenzie (1998) who identified these needs, as social support needs. On the other hand, most caregivers did not express this information need but they learnt by themselves through years of caring. Some participants did seek information for general guidance to assist them in their caring from religious teaching as they believed God provided them guidance and healing as stated, "it is a guidance and a healing for those who believe" (Fussilat 4: 44 cited in Rassool, 2000, p. 1481).

In summary, as depicted in Figure 1, there were 4 main concepts: caring experiences of family caregivers, meaning of caring, needs of family caregivers when caring, and impacts of caring. Each has a profound on each other. Through the years of caring experiences, family caregivers developed their own meaning of caring. These meaning of caring are "caring for the well-being", "responsibility as a parent" and "being a burden".

The caring experiences of the family caregivers were also very much influenced by their needs when caring. As indicated in this study the needs were keep themselves healthy, support resources, financial support, temporary replacement, inner strength, expression of feelings and information need. If these needs were not met, family caregivers would experience greater burden in their caring. For example, if the needs for financial support and keeping healthy were not met, family caregivers would experience financial loss in their caring experience. They would not be able to provide the daily care for the 'sick' family members and manage the illness of the

'sick' family members. The family caregivers might not experienced self-fulfillment, and that was negative impact on the family caregivers.

The impact could also influence how caregivers perceive their caring. For example, if the family caregivers experienced too much negative impacts such as financial loss, disrupting behaviors, being ashamed, and heavy responsibility, family caregivers might perceived their caring as "being burdened".

On the other hand, how they perceived the meaning of caring could have an effect on the way they experienced their caring. For instance, the family caregivers in this study perceived caring as responsibility of parent. The caregivers thus would care for the 'sick' family members like a parent caring for their children, providing continuous unconditional to the 'sick' family members and continued to care and support the 'sick' family members despite being sole carers, being ashamed, or being burdened.

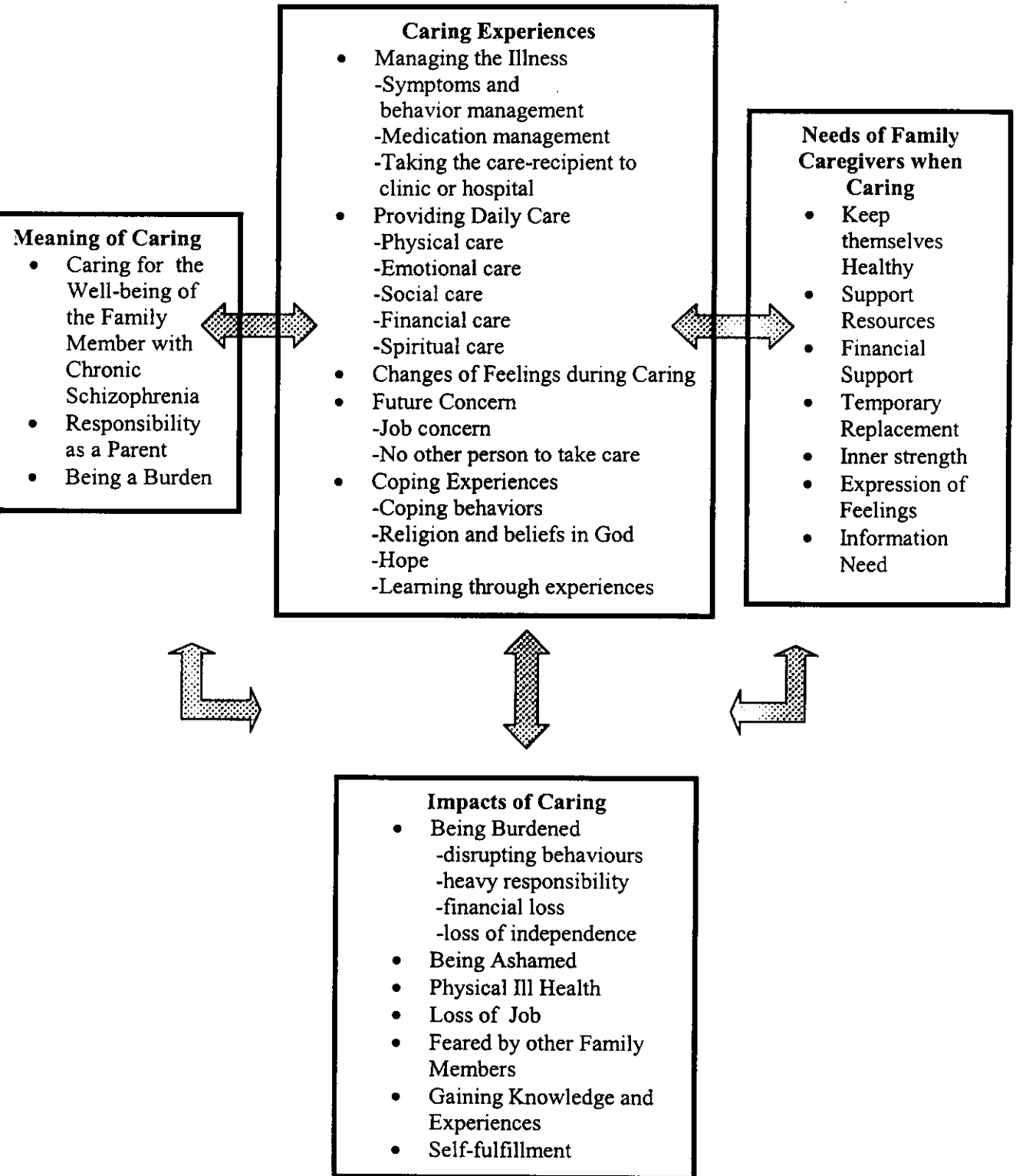


Figure 1: Caregivers' Lived Experiences in Caring for Family Members with Chronic Schizophrenia at Home