

## **CHAPTER 5**

### **CONCLUSION**

The conclusion of this study is presented in three parts: summary of the study, implications and recommendations.

#### **Summary of the Study**

This hermeneutic phenomenological study was conducted to explore lived experiences of family caregivers caring for members with chronic schizophrenia at home at Kelantan, Malaysia. The participants consisted of purposive sampling of 10 primary caregivers who met selection criteria and who brought their members with chronic schizophrenia for follow-up care at the Outpatient Psychiatric-Mental Health Clinic, USM, Kelantan. Data collection was done between December 2001 to February 2002, using in-depth interviews at participants' homes. The instruments used included the Demographic Data Record Form, Interview Guide and Observation Guide. Descriptive analysis was used to describe the demographic data while Giorgi's method of data analysis was used as a guide to analyze the ten cases of transcribed interviews.

The findings revealed that the family caregivers were mostly females, being parents to the care-recipients, with elementary education, and continued working even after taking the role as primary caregivers. They had an average age of 60.6 years, with

income less than RM1, 000 per month. Most of them had experience caring for the 'sick' family member. Most of the care-recipients were females, single, aged between 20-40, did not complete secondary school. Most of them had been suffering from schizophrenia for at least 6 to 12 years.

Conclusions of the study on the lived experiences of family caregivers caring for members with chronic schizophrenia at home were drawn and described. Three main themes emerged to describe the meaning of caring to family caregivers. "Caring for the well-being of family members with chronic schizophrenia" that included physical, mental, emotional, social and spiritual well-being. Caring was perceived to be a "responsibility as a parent" whereby they were obligated to care for the 'sick child' and continue to provide unconditional love, seeing to the welfare and happiness of the 'sick' child. Caring was also seen as "being a burden" because of distressing symptoms and behaviors of the illness of the 'sick' family members, and the long-term heavy responsibility. Five main themes emerged from these caring experiences. Family caregivers' experiences in "managing the illness", included symptoms and behavior management, medication management, and taking care-recipients to clinic or hospital. The theme on "providing daily care" demonstrated family caregivers' awareness in all aspects of care in order to meet the needs of the 'sick' family member with chronic schizophrenia. This aspects of care included physical, emotional, social, financial and spiritual care.

Another important caring experience by family caregivers that was reflected in the theme "changes of feelings during caring". It provided an understanding of how

family caregivers perceived their caring experiences as being both satisfying and stressful, after years of caring. These changes of feelings were very much affected by the distressing, disruptive behaviors of the 'sick' family members, their ability to manage the 'sick' family member, phase of the illness as well as other factors such as their knowledge of the illness, experiences, family support, assistance in caring, and their coping abilities. The theme on "future concern" as presented by family caregivers reflected their commitment towards caring and their concern for their 'sick' family members being unemployed, what would happen to them and who would care for them in the future. The theme on "coping experiences" described how family caregivers used different coping strategies such coping behaviors, hope, beliefs in God and learning through experiences to cope with the problems encountered during their daily care. The praying to God as a way of coping strategy demonstrated the profound influence of religious beliefs (particularly Islam) on their values of family caregivers, and illustrates how Islamic philosophy is adapted to some aspects of their everyday caring practices for their 'sick' family members.

Family caregivers also described their needs during caring in seven themes such as "keep themselves healthy", "information needs", "expression of feelings", "temporary replacement", "financial support", "support resources" and "inner strength". They provided understanding of how family caregivers perceived their needs to sustain their caring role. This study also identified negative impacts experienced family caregivers such as "being burdened" by disruptive distressing symptoms, heavy responsibility, financial loss, and loss of independence. Other negative impacts include "being

ashamed”, “feared by other members in the family”., “ physical ill health” , and “loss of job” . Family caregivers also described their experiences of positive impacts such as “gaining knowledge and experiences”, and “self-fulfillment”.

## **Implications**

Based on the findings of this study, the following possibilities for nursing practice, nursing education, and nursing research are suggested.

### **Implication for Nursing Practice**

Findings of this study provide important implications for nursing practice. The findings on the lived experiences of family caregivers caring for members with chronic schizophrenia can be used to help psychiatric-mental health nurses and others understand how caregivers construct their views on their caring, for example, how caregivers think, act and reflect on their caring experiences, how they feel about their caring experiences, their needs when caring, and the impact of the experience on them.

As the number of chronic schizophrenia clients continue to be discharged and coming home to stay with their families, psychiatric-mental health nurses will increasingly find themselves involved in community and home health care. Understanding these will enable nurses to provide accurate assessment and formulate realistic goals to assist family caregivers. These findings suggested nurses should provide psychological and emotional support for family caregivers as well as for the other family members, to allow them to ‘talk it out’ or to express their negative feelings of sadness or

frustrations especially during the early phase of caring. These findings also highlighted the importance of nurses to assess caregiver's needs, their religious and cultural practices, and how nurses can encourage the use of their cultural practices and religious beliefs to assist them in their coping.

This study confirms the strong influence of religion, in particular Islam on caregivers' beliefs, values and caring experiences. Recognition of this leads to the suggestion that nurses encourage the use of these belief systems to support and promote caregivers' caring for their 'sick' family members.

This study suggests that caring experiences for family caregivers can be both satisfying and stressful. The structure of the experiences of family caregivers caring for members with chronic schizophrenia can be used as a basis for orientation programs for family caregivers who are inexperienced or new in their caring roles. It may include information on schizophrenia and its symptoms, its process, how to manage distressing disruptive behaviors, how to recognize symptoms medication compliance, social skills, feelings commonly experienced during early phase of caring, and ways of coping.

### **Implication for Nursing Education**

Findings of this study provided implications for educators in nursing to emphasize the roles of psychiatric-mental health nurse in seeing to the many needs of family caregivers caring for members with chronic schizophrenia, providing better and more effective care to them as well as their members with chronic schizophrenia. Nurse educators should emphasize also the importance of understanding the meaning of 'caring' as perceived by each family caregivers when assisting them in the planning and

implementation of care for their 'sick' family members at homes. Based on the findings psychiatric-mental health nurses can provide educational plan for family education for caregivers as well as the sick family members based on their educational level, their understanding of this mental illness and their caring experiences. Family education may include knowledge about chronic schizophrenia, how the negative symptoms attribute to 'sick' family member's social and occupational dysfunction, the illness process especially the residual phase, how to identify symptoms to reduce relapses or illness exacerbations, how to manage behaviours related to negative symptoms, social skills such as communication skills, encouraging interactions, medication compliance, psychotropic drugs and its side effects, and ways of effective coping during home-health care.

Schools of nursing need to emphasize the need for continuity of psychiatric care to the homes of family members with mental illness, with caring extended not only for the discharged patients but also for the family caregivers and the other members in the family.

### **Implication for Nursing Research**

This study had provided basic information on the experiences of family caregivers caring for chronic schizophrenia at home. For further nursing researchers the results of this study can be used as support evidence or guidelines for establishing some educational programs to enhance and promote caring of family caregivers, and to provide references for a study on experiences of family caregivers caring for chronic schizophrenia.

## **Recommendations**

The findings of this study provided a basis for further exploration of lived experiences of Malay family caregivers. Nevertheless, several recommendations are suggested for further researches as follows:

1. This study focused on family caregivers' caring experiences, which served as primary caregivers, it is necessary to hear from the care-recipients their experiences of the caring received. Therefore, future research should include perspectives on caring received by care-recipients.
2. There should be a study to explore religious practices as coping strategies to reduce burden by family caregivers.
3. The research on experiences of family caregivers should be extended to cover other chronic mental illness such as Alzheimer's disease and Depression.
4. A participatory action research should be used to develop a care model to assist family caregivers in their caring for members with chronic schizophrenia, in order to achieve practical knowledge, which is the ultimate goal of the nursing science.