

# CHAPTER 1

## INTRODUCTION

### Background of the Study

Mental health problems are dramatically increasing. According to the World Health Organization (WHO), “No country and no person is immune to mental health disorders and their impact in psychological, social and economic terms is very high” (WHO, 2000, p. 1). The Bulletin WHO (2000) reported that mental disorders accounted for approximately 12% of the disability-adjusted life years lost in 1998 and that 5 out of the 10 leading causes of disability that were mental disorders, schizophrenia ranked fourth worldwide in terms of burden of illness (Brundtland, 2000). The top three were unipolar depression, alcohol dependence, and bipolar depression. This data suggest that mental health problems are among the most important contributors to the global burden of disease and disability (WHO, 2000).

Schizophrenia in comparison to all of the mental illnesses responsible for suffering, causes more lengthy hospitalizations, more exorbitant costs to individuals and governments, more fears, and more chaos in family life (Townsend, 1999). The annual cost of family caregiving and crime-and welfare-related expenditures due to schizophrenia was \$33 billion in the United States (Stuart & Laraia, 1998). According to the authors, more than 75% of taxpayer dollars spent on treatment of mental illness were used for people with schizophrenia. Data from the National Institute of Mental Health shows that 1% of the general population will have the symptoms of

schizophrenia and they occupy 25% of all inpatient hospital beds (Stuart & Laraia, 1998). A few factors have contributed to the dramatic increase of cases of schizophrenia worldwide. It is a chronic illness with 95% of people having it for their lifetime (Stuart & Laraia, 1998). This mental disorder manifested during the early years in a person's life, and with three out of four cases beginning between the ages of 17 and 25 years (Stuart & Laraia, 1998). Thus, there were many people who have grown old with this condition, adding to the increased population of schizophrenia. Also stated by Stuart and Laraia (1998) that patients with schizophrenia, 25% did not respond adequately to traditional antipsychotic medication, thus adding to the number of relapsed cases and increased further the number of people having chronic schizophrenias.

The radical shifts in society towards advanced technology, the lack of family and societal supports, and the changing life styles to fit into the modern advanced technology of today, all caused stressful life situations, which may account for the increase of schizophrenias. Many investigations have supported that stressful life events could precipitate schizophrenic symptoms in a genetically predisposed individuals (Goldstein, 1987). The increase in life expectancy due to advanced technology had led to a further rise of chronic schizophrenic population as a whole. In the 1960s the world wide trend of deinstitutionalization which shifted the focus of care from the large, long-term institution to the community-based care; the introduction of psychotropic drugs; and the strong belief of cost-effectiveness of caring for the chronic mentally ill patients in the community setting have resulted in many chronic mentally ill patients being discharged from hospital care to community-

based care. This shift has resulted in a greater need for after-care in the community. Unfortunately due to the rapid process of this change, the undue planning needs, the inadequate funding and lack of mental health centers, many of these chronically mentally ill often returned to their families for care and support. The family now has to assume the primary caretaking role. Some returned to live with families who were not prepared to receive them (Pickens, 1998). All these have led to increased burden for family caregivers, increased stress on financial, emotional and physical systems of the family.

Also in recent years, there has been a significant shift of responsibility of mentally ill persons from the formal care system to family caregivers in the community (Rose, 1998). This has also resulted in families becoming a source of support and care for these chronic mentally ill. Talbott (1984 cited in Rose, 1998) reported that 25% of discharged mentally ill persons returned home, received emotional and tangible aids from family members who were viewed as a major source of support for patients. Many family caregivers have to increase caring responsibilities as a result of this health legislation, social policy and technological advances.

Recent literature has documented the tremendous caregiver burden that family caregivers experienced with the advent of deinstitutionalization and community-based care (Norbeck, Chafetz, Skodol-Wilson, & Weiss, 1991; Reinhard, 1995). Furthermore, social stigma still exists towards mental illness (Townsend, 1999). Many families were embarrassed and uncomfortable with the schizophrenic difficulties and relapse, and tried to prevent this by withdrawing from social situations

(Baker, 1993). These have serious consequences on the family caregivers in terms of their psychological and emotional well-being.

Many studies have also reported on the caring impacts on caregivers' psychological, social and the well-being (Gilleard, Belford, Gilleard & Whittick, 1984; Biegel, Milligan, Putnam & Song, 1994; Fadden, Bebbington, & Kuipers, 1987; Given, Stommel, Collins, King & Given, 1991; Glendy & Mackenzie, 1998; Jones, 1996; Salleh, 1994; Schuiz & Beach, 1999). The psychological impacts reported were tension, stress, anxiety, resentment, depression with accompanying feelings of hopelessness, powerlessness and guilt feelings. Some family caregivers also developed neurotic disorders and neurotic depressions (Salleh, 1994). The social impacts included financial loss, marital conflicts, and loss of employment, illness-related stressors, social stigma as well as interpersonal conflict within the family unit.

In the Kelantan community, family caregivers assume primary responsibility for their members with chronic schizophrenias. There is still a strong negative social stigma attached to psychiatric hospitals, mental illness and those seeking care from the health care providers in the community. After discharged from hospitals, many of these patients very often return to live with their families. Due to the Malay culture and value system of traditional extended family, caregivers would provide personal care, emotional support and love, manage activities of daily living, and financial assistance to their chronic mentally ill family members. Acceptance of the mentally ill was believed to be good on the whole and was considered to be a great source of support for the psychiatric services in Kelantan community. Thus, the family homes were like the institution in which patients with chronic schizophrenia stayed with their

families. This has no doubt placed family caregiving in increasing importance in Kelantan.

In Kelantan, the lack of adequate community based-care system for psychiatric care, and the lack of psychiatric community health trained nurses have led to many chronic schizophrenics that were discharged for hospitals, coming home to stay with their families. The family caregivers would now have greater responsibilities in their family roles, thereby experiencing greater stress and burden. This burden was often increased due to lack of knowledge and experience in the caring of the chronic schizophrenia.

In last few years, the change of family system within Malaysia, the migration of younger generation to the urban towns and big cities in the other states (Noor Aini, 1998) have resulted in the shortage of family caregivers to care for the loved ones with chronic schizophrenia at home, and has placed a greater responsibilities to the older family caregivers. In Kelantan state, the fact that there are increasing numbers of people with psychiatric disorders living in the community created a major issue regarding caring for this chronic mentally ill at home. The number of cases of mentally ill seen at psychiatric clinic at psychiatric hospital in Kelantan has shown an increase between 1999–2001 (Record Census, 2002). It highlights the need to study the experiences of family caregivers who are responsible for caring of this specific population group at home.

The use of phenomenological approach in this study is very important because caring for members with chronic schizophrenia is a subjective experience and the meaning of caring varies with each caregiver being greatly influenced by their

perceptions, experiences and cultural and belief expectations. This study provides meaning of caring as defined by each family caregiver, which influences caregiver's practices and experiences. Caring is a central concept in nursing. Thus, understanding of the meaning of caring will help nurses to provide better quality care and continuous support for the family caregivers, according to their experiences, cultural dimensions of human care and beliefs systems. In this way nurses can assist family caregivers in sustaining this very important caregiving role. In view of this, more research of this kind is required.

A preliminary review of family caregivers literature reveals a focus on caregivers of elderly people with Alzheimer's and other types of dementia (Collins, Given & Given, 1994; Hutchinson, 2000). A review of literature related to experiences of family caregivers caring for chronic schizophrenic members showed that most of the available materials were from western perspectives (Saunders, 1999; Teschinsky, 2000; Wuerker, 2000). However, there have been a few research done from eastern perspectives from Asian countries such as Hong Kong, Korea, China and Thailand. Study done by Glendy and Mackenzie (1998) was on caring for chronic mentally ill relatives among Chinese families in Hong Kong. Literature review showed few studies done on burden of care of schizophrenia on Malay families. More of this of research is greatly needed. Therefore, this study using qualitative phenomenological approach, attempts to explore caring of family caregivers in the context of chronic schizophrenias from the perspectives of Malay families in Kelantan, Malaysia.

## **Significance of the Study**

This research will expand the scope of knowledge concerning psychiatric caregiving of family caregivers caring for family members with chronic schizophrenia. The researcher hoped to use the findings of the study to serve as basic knowledge that may help community and psychiatric-mental health nurses to provide better understanding and care of family caregivers caring for members with chronic schizophrenia in the local setting and culture in Kelantan. The findings will also enhance knowledge and skills among nurses and other health care professionals in providing better and more effective care to family caregivers and their members with chronic mental illness in the other states of Malaysia.

The findings will also contribute to the greater awareness among nurses of the needs of family caregivers when caring for the chronic mentally ill. This is one of the goals of nursing in community-family-care. Knowledge of the meaning of 'caring' to them may inform us about factors related to sustained caregiving, and may help us identify effective interventions for family caregivers who struggle in that role. This is highly relevant to nursing today, which not only provides care for the schizophrenic patients but also for the family members who play the important role as caregivers. It helps nurses to promote and maintain health among family caregivers, and to provide them an opportunity to move towards developing their full potential as healthy individuals in a healthy society.

## **Objectives of the Study**

The objectives of the study were to:

1. describe the meaning of caring;
2. describe the caring experiences of family caregivers;
3. identify the impacts of caring experienced by family caregivers; and
4. identify the needs of family caregivers when caring for family members

with chronic schizophrenia.

## **Research Questions**

The research questions were as follows:

1. What does caring mean to the family caregivers?
2. What are the caring experiences of family caregivers?
3. What are the impacts of caring experienced by family caregivers?
4. What are the needs of family caregivers when caring for family

members with chronic schizophrenia?

## **Philosophical Underpinning of the Study**

The hermeneutic phenomenology was used in this study to explore lived experiences of family caregivers caring for members with chronic schizophrenia.



Phenomenology has been and continuous to be an integral field of inquiry in the philosophical, sociological, and psychological disciplines. Phenomenology is a science whose purpose is to describe the particular phenomena, or the appearance of things, as lived experience (Streubert & Carpenter, 1995). It is a critical, systematic investigative method that has recently gained recognition as a qualitative research approach applicable to the study of phenomena in nursing (Streubert & Carpenter, 1995).

Burns and Grove (1997) defined phenomenology as a philosophy and a research method. As a philosophy, phenomenology is a way for philosophical inquiry into human experience (Taylor, 1993). As a research method phenomenology is a rigorous scientific process directed towards understanding human experiences based on the individual's language (Streubert & Carpenter, 1995). Phenomenology seeks to explicate personal meanings in experience and ultimately seeks to understand experience (Boyd & Munhall, 1993). Since professional nursing practice is enmeshed in the life experience of people, this phenomenological inquiry is well suited for the investigation of phenomena of this study. Using this phenomenology inquiry, the researcher aims to understand and describe the lived experiences of family caregivers caring for members with chronic schizophrenia.

Hermeneutic phenomenology is a research method based on the phenomenological philosophy. This notion of hermeneutic phenomenology was first presented by Husserl and Dilthey, and was changed significantly by Heidegger and Gadamer (Cohen, Kahn & Steeves, 2000). Husserl and Dilthey were interested in understanding the structure of the *live-world* or lived experiences. Heidegger

expanded this definition of hermeneutics to include an attempt to understand the phenomena of the world as they are presented to us; how we go about understanding this world, and understanding being itself (Cohen, Kahn & Steeves, 2000). On the other hand, Gadamer (1989 cited in Cohen, Kahn & Steeves, 2000) was not interested in the structure of phenomena but on how the phenomena was interpreted. Thus he furthered the work of Heidegger and contended that hermeneutic phenomenology was the study of how people interpret their lives and make meaning of what they experience. It was a “special kind of phenomenological interpretation analysis designed to unveil otherwise concealed meanings in the phenomenon” (Spiegelberg, 1974 cited in Streubert & Carpenter, 1999, p. 54). They are used to search out the relationships and the method enables the researcher to explore the richness of the experiences of family caregivers’ caring, to interpret the being, to discover the “essences” of the meaning in caring in an effort to create deeper understanding of human experiences (Streubert & Carpenter, 1999), and finally to offer analysis for the structures for the experiences. Thus, hermeneutic phenomenology is an appropriate conceptual method for this study.

### **Definition of Terms**

For the purpose of this study, the following terms were defined:

1. Caregiving refers to the actions, amount and extent of help provided by caregivers to the care-recipient and which can only be explained those experienced in the caring.

2. Family caregiver refers to primary family member who is the provider of major component of care, caring continuously for the mentally ill family member for at least 6 months, and staying at the home or living in the same compound with care-recipient.

3. Chronic schizophrenia: criteria – diagnosis, duration and disability are used. Diagnoses include schizophrenia disorder, which last continuously or intermittently over a period of two years and requires either outpatient or hospital treatment. Absence of prominent delusions, hallucinations, disorganized speech, and grossly disorganized or catatonic behavior. Presence of negative symptoms, that is, affective flattening, alogia, or avolition. The disability criteria is the low level of functioning: requiring assistance in performing activities of daily self-care, such as personal hygiene, grooming, and comforts; dependent living, and inability to support oneself.

### **Limitations of the Study**

This study employed purposive sampling to recruit caregivers caring for members with chronic schizophrenia, continuously for at least six months, and not more than 10 years, in order to get a cohesive sample and rich data on lived experiences. However, its non-random character reduced the generalizability and suggested that findings should be applied to other settings with caution. Nevertheless, purposeful sampling of caregivers ensures that this sample represents family caregivers lived experiences, needs and impacts of the caring experienced. Cultural differences might impede the generalizability of the finding across caring contexts in

some specific strategies. The findings also need to be interpreted carefully in terms of the differences of duration of caring for the 'sick' members, and personal characteristics of caregivers.

The interviews in this study were conducted in Malay while the writing of the results and the thesis was in English. This created difficulties and limited the study. Errors such as distortion of meanings might occur during the process of translation of data from Malay to English. Therefore, efforts were made to minimize this limitation by keeping as close to the meaning of original Malay transcribed interviews as was possible. English words used in the translations were checked against the meaning in Malay. Some Malay words that could not be substituted for English words were described by additional sentences to give full meaning. Although it would be best if translations could be checked by a psychiatric nurse expert in both languages, it was not possible due to limited financial support and lack of such personnel available. Thus, an English language expert with proficiency in Malay and English from the Language Unit in University Sains Malaysia was consulted and translations of transcribed interviews presented in the findings were checked.

There were few participants who had some difficulty to express themselves and interpret their caring experiences as this were their first time they ever shared such experiences in great detail. Thus, more probes would be required for such participants to explore the in-depth experiences encountered. Hermeneutic phenomenology involved interpretation of their experiences to uncover the meaning of the phenomena, and using too much probes might direct the participants from the originality of their lived experiences.