

CHAPTER I

INTRODUCTION

This first chapter introduces the family caregivers, background, significance of research problem, purpose of the study, research question and definitions.

Background and Significance of Research Problem

Schizophrenia is often seen as a prolonged disease, and sometimes lasts for a lifetime. There is a strong sense of helplessness, loss of control, disruption, and it may increase a degree of dangerous behavior (Marsh, 1992; Kongsakon et al, 2005). This illness causes patients to be unable to control perceptions, thoughts, emotions and behaviors. It is difficult for schizophrenics to adjust themselves in building relationships with others, making decisions, and living independently (Ram, Bromet and Eaton, 1992; Alloy, Acocella and Bootzin, 1996; Laidlaw et al, 2002). Schizophrenia is a well known illness that influences social relationships. It is a severely disabling condition that has multiple effects upon affects individuals, their families, and the wider social context (Thornicroft et al, 2004; Browne and Courtney, 2005).

The highest incidence of a person with schizophrenia (a PWS) is before the age of forty-five, but it can affect anyone at any age, usually attacking people between the ages of sixteen to thirty (NAMI, 1999; Saunders and Byrne, 2002). Its diagnosis is made through continuous presence of symptoms for six months or more, and deterioration in function involving care of self, work, or social relationships (Pipatananond et al, 2002; Phillips et al, 2002). According to the report from the Department of Mental Health

(2005), approximately 343,680 Thais suffer from mental illness. In 2001 to 2004 the Thai Mental Health survey showed that the persons with a diagnosis of schizophrenia have the highest incidence rate and present a major mental health problem. The incidence rates are 537.03 per 100,000 population and persons diagnosed with schizophrenia continue to increase every year (Department of Mental Health, 2005). Currently, the cause of schizophrenia is still poorly understood. Caring for a PWS in hospital is usually not fully recovered when he/she is discharged from inpatient care to home because this illness cannot be cured yet. When a PWS gets better, a psychiatrist will let him/her rehabilitation at home. At this time, family caregivers will play an important role to care for a PWS.

In general, the term of a family caregiver is referred to as a person who takes care of others, which includes both personal and health care (MacCormack, 1994; Brady and McCain, 2005). In addition, when one family member becomes ill, the other family member is expected to provide physical and emotional care (Phengiard, 2001; Yanwaree, 2002). The family is considered as the best institution for a PWS' recovery (Loukissa, 1994; Subgranon and Lund, 2000). Recent surveys reveal that the majority of PWS now live with his/her family, and also having a family member to be a family caregiver. The family members are the significant persons closest to the patient, spend the most time and are highly attached to the patient, which puts them in a position to provide significant care of the PWS (Doornbos, 2001; Browne and Courtney, 2005; Sethabouppha and Kane, 2005).

According to literature, most of PWS have problems performing their expected roles, at least some of the time. They are often dependent on the family for the activities

of daily living, personal care, symptoms management, and medication administration (Reinhard, 1994; NAMI, 1999; Kongsakon et al, 2005). Family caregivers may have difficulties coping with the patients' denial of their illness, fail to consistently manage medication intake, and accepting assistance from others. Family caregivers may be unable to care for their relative due to a lack of skills, knowledge, and resources (Ponganutree, 1993; Hattapanom et al, 1996). If family caregivers cannot provide appropriate care for a PWS, a PWS will be vulnerable to relapse and readmission (Chien and Norman, 2003; Kongsakon et al, 2005).

Several studies in the United States have shown that effective treatments of persons with schizophrenia required family involvement and therefore lead to the best outcome. It found that the family caregiver was the significant person for enhancing a wellness of a PWS (Mueser et al, 2003; Lane et al, 2003; Milliken and Northcott, 2003). However, current studies relating to family caregivers are focused on the need of family caregivers in caring for their ill members (Yamamoto and Wallhagen, 1998; Subgranon and Lund, 2000; Chien and Norman, 2003), but not pay attention of caregiving process of a PWS yet.

According to previous research of family caregiving, Tuck et al (1997) found that parents of children with schizophrenia struggled to frame illness related events as normal while trying to live with the uncertainty of the illness. Chesla (1994) found that parents' caring practices were influenced by their notions of basic parenting concerns and values. Ayres (2000) described the meaning of caregiving as a process of integrating expectations, explanations, and strategies into the caregiving role. Badger (1996) used grounded theory methods to identify stages in the process of family members' responses

to depression. Contextual factors identified in that study as influencing the process were family functioning, relationship changes caused by the illness, understanding of symptoms, stigma, and need for self-preservation. Although many qualitative researches identified existing knowledge in family caregivers and caregiving process, but those studies did not explain the continuum of caregiving for a PWS. To understand a whole process of caregiving for a PWS, the grounded theory is a selected approach to explore in this study.

Purpose of the study

The purpose of this study was to explore the caregiving process of a PWS as perceived by family caregivers.

Research Question

To understand the process of family caregiving in Thai culture, the research question created for this study was:

1. What are the processes of caregiving for a PWS from the perspective of Thai family caregivers?

Definitions

For the purpose of this study, the following definitions were utilized:

A Family Caregiver was defined as a family member who related to a PWS by kinship, blood linkage, adoption or marriage provided unpaid care for a PWS at home.

A Family Caregiving Process was defined as a continuum of providing care for a PWS by: a) obtaining medical care and treatment for the patient, bringing them for follow up appointments; b) providing personal care for everyday activities such as bathing the patient, helping them to bathroom, washing their clothes; c) providing mental support and; d) providing for the needs of another, including physical, emotional, social, spiritual and other needs by the member of family who are close relative (Davis, 1992; Taylor et al, 1997; Songwathana, 1998; Yanwaree, 2002).

A Person with Schizophrenia (a PWS) was a person who had been diagnosed with the disorder that involved characteristic psychotic symptoms from psychiatrist of DSM IV or ICD-10, were characterized by profound disruption in cognition and emotion, affecting the most fundamental human attributes: language, thought, perception, and sense of self, impairment in the individual's level of functioning in major life areas (NAMI, 1999; Schultz and Videbeck, 2002), and are receiving outpatient treatment for schizophrenia (Chien and Norman, 2003).

Summary

An overview of the significance and background of this study was described in Chapter 1, followed by purpose of the study and research questions deemed necessary for completing the study. Most of the literature described family caregivers who lived with family members suffering from schizophrenia and who took a major role in caregiving. With the continuing trend of downsizing and resettlement of PWS in their home, families will increasingly play a major role in the care of those individuals. Nurses and other health care professionals would need information concerning the caregiving that the families can provide for their PWS and how the families dealt with those situations. This study was aimed to explore the caregiving process of family caregivers for PWS.