

CHAPTER II

REVIEW OF LITERATURE

This chapter describes literature involving family caregiving for a person with schizophrenia. It includes a context of schizophrenia, family caregivers, and concepts of family caregiving.

Schizophrenia

Schizophrenia is one of the most devastating of the psychiatric illnesses and it has significant economic and social effects (Thieda et al, 2003). It affects approximately 1% of the population worldwide (Barbato, 1998). It causes lifelong suffering, prohibiting the patient from leading a normal and productive life, shortening life expectancy by ten years (World Health Report, 2001). Schizophrenia progressively impairs the personal, domestic, social and occupational ability of patients. This results in poor self-care, rejection by the family and society, unemployment and dependence on others (Kongsakon et al, 2005).

The symptoms of schizophrenia are usually divided into two groups, termed positive and negative symptoms (Brady and McCain, 2005). Positive symptoms are those found in person with schizophrenia, but not in other people. These include hallucinations (usually hearing voices that are not there, voices that criticize or condemn); delusions (false beliefs, often about a threat or persecution); paranoia; inappropriate behavior; disorganized or incoherent speech. Negative symptoms refer to

feelings or actions that are lost by person with schizophrenia. For instance, most persons with schizophrenia lose ambition, have less energy or enthusiasm, withdraw from social contact, and show less emotion (referred to as flattening of affect). Negative symptoms often become more of a problem in people who have had schizophrenia for years (McGurk and Meltzer, 2000). Symptoms of schizophrenia are often reported as having the greatest impact on other family members (Perlick et al, 1999), regardless of diagnosis. Positive symptoms of schizophrenia can be perceived by family caregivers as odd or bizarre and sometimes frightening (Rose et al, 2002). Negative symptoms of schizophrenia may be even more disturbing and frustrating to family members (Rose, 1996).

The person who is having a first episode of schizophrenia may have been ill for a long time before getting help. Usually they come to treatment because delusions or hallucinations have triggered disturbing behavior (NAMI, 1999). At this point, the person often denies having a mental illness and does not want treatment. With treatment, however, delusions and hallucinations are likely to diminish. Most people make a good recovery from a first episode of schizophrenia, although this can take several months. As a result of their illness, PWS have difficulty maintaining many of the essential life roles and resources including: stability, independent housing, and close interpersonal relationships with friends and relatives (Browne and Courtney, 2005).

Mental illnesses especially schizophrenia represent unique experiences for family caregivers, in the large part because of enduring social and cultural climates of secrecy, stigma, and a tendency to perceive mentally ill persons as weak, dangerous, and unpredictable (Crisp et al, 2000). The person afflicted with the illness often resists the

diagnosis, may not cooperate with treatment, and will often resist the efforts of family caregivers to intervene (Karp and Tanarugsachock, 2000). This is the reasons because caring for a mentally ill person causes physical and emotional strain for family caregivers.

Families try to make sense of mental illness as a personal experience. They need to deal with problems that occur as a result of the illness (Karp and Tanarugsachock, 2000). The basis of family reaction to their person with schizophrenia associated symptoms often was rooted in how the family interpreted these symptoms. Families reported the most distressing symptoms exhibited by the relative with schizophrenia to be related to negative symptoms, such as lack of energy, lack of purposeful activity, and a generalizes unresponsiveness (Hinrichsen and Lieberman, 1999). Families often attributed these negative symptoms to their persons with schizophrenia's personality and perceived character flaws, unaware that these negative symptoms are characteristic symptoms of schizophrenia. Often families thought that the persons with schizophrenia's symptomatic behaviors were purposely designed to aggravate, annoy, or provoke other family members (Hooley and Campbell, 2002).

Additionally, parents, spouses, and siblings are often unable to deal with their own individual or family developmental needs because the focus is so often on the persons with schizophrenia and sequelae of illness. Siblings and parents are embarrassed by the symptoms and behaviors of the persons with schizophrenia and avoiding bringing others to the home (Friedrich et al, 1999; Brady, 2004). Most studies have found a relationship between negative family environments and relapse (King and Dixon, 1995; Hooley and Campbell, 2002), while only one study did not (King, 2000). In Brady's (2004) recent

study, mothers expressed painful memories of having been accused of causing schizophrenia in their children. The mothers worried about their son's fates after their own deaths (Vanaleesin et al, 2003). Marital discord, divorce, and feeling trapped in an unhappy marriage were related to having adult offspring with schizophrenia. Thus, normal social interactions that are instrumental in building and keeping a social network for all members are often precluded in families with persons with schizophrenia.

Schizophrenia is a chronic disorder that needs constant management. At the moment, it cannot be cured, but the rate of recurrence of psychotic episodes can be decreased significantly by maintaining medication (Reinhard, 1996). Although responses vary from person to person, most persons with schizophrenia need to take some type of medication for the rest of their lives as well as use other approaches, such as supportive therapy or rehabilitation.

Relapses occur most often when persons with schizophrenia stop taking their antipsychotic medication because they feel better, or only take it occasionally because they forget or don't think taking it regularly which is important. It is very important for persons with schizophrenia to take their medication on a regular basis and for as long as their doctors recommend (Chien and Norman, 2003; Kongsakon et al, 2005). If they do so, they will experience fewer psychotic symptoms.

There are many strategies to help persons with schizophrenia take their drugs regularly. Some medications are available in long-acting, injectable forms, which eliminate the need to take a pill every day (NAMI, 1999). Medication calendars or pillboxes labeled with the days of the week can both help them remember to take their medications and let caregivers know whether medication has been taken. Electronic

timers on clocks or watches can be programmed to beep when they need to take their pills, and pairing medication with routine daily events, like meals, can help them adhere to dosing schedules (Kongsakon et al, 2005).

Some qualitative researches showed about the overall experience of living with and caring for chronically mentally ill relatives (Saunders and Byrne, 2002; Ackerson, 2003; Vanaleesin, 2003; Sethabouppha and Kane, 2005), while Rose et al (1996) focused on how caregivers respond to the illness. Recently researchers have focused more on caregiving tasks (Schene et al, 1998) and how caregivers respond and manage their emotions in order to take care of their mentally ill family member at home (Karp and Tanarugsachock, 2000). Thus, the trend in current research is likely to move toward what family caregivers do in terms of the kinds of activities that are unique to this context of family caregiving.

The sources of information about the persons with schizophrenia and process of family caregiving could be from the other family members/friends, health care providers or public health care. Integrating their own lived experiences with information from others helps people take on the caregiving role effectively.

Family caregivers

In a typical Thai household, either nuclear or extended family, family members are usually assigned responsibilities. The father is often the household authority and responsible for the welfare of the whole family. The mother is responsible for domestic duties such as housework, raising children, and caring for family members. Children are expected to be responsible for the welfare of their aging parents (Yoddumnern-Attig and

Attig, 1993). The family is also expected to provide care for ill and elderly members. It is a social obligation that the family is responsible for the care of their sick members (Caffrey, 1992)

Traditionally, families are the primary health care resource for ill people in Thai society. Women, particularly mothers and grandmothers, play a major role as primary caregivers in families (Yoddumnern-Attig and Attig, 1993). If there are no women who can perform this role within the family, they will ask their relatives, particularly women, to take this temporary role. Women also make the decisions about seeking treatment. They provide both treatment and care for the sick family members and elderly. For example, if it is a minor illness, both modern and traditional medicine such as herbs or food will be considered. The decision to select health care is usually made by the head wife of the household (Yoddumnern-Attig and Attig, 1993).

Familial roles have also been altered by modernization. Parental roles and duties as well as the value of children have changed in relation to the increased importance of education (Yoddumnern-Attig and Attig, 1992). Parents are more invested in the education of their children in order to ensure the children's future economic status. They also expect their investment in their children's education to ensure security in their old age. The traditional norm of filial obligation is still strong in Thai culture. Children are required to repay their parents by taking care of them when they are getting old. Since the family size is smaller and there has been an increase in the number of women in higher education and the workforce, sons are more actively involved in the welfare of parents, rather than leaving the sole responsibility to daughters (Yoddumnern-Attig, 1992). At present, the repayment can be seen in terms of financial support instead of

providing care to their parents. The change in family roles can be seen by the increase in the number of elderly living alone without caregivers (Caffrey, 1992). The roles of women in the family are also affected by modernization. Women now have equal access to education which opens up career opportunities. All of these factors combined are expected to have a major effect on the availability of women providing care to their family.

At the present time, familial authority in Thai society is shared between wives and husbands through mutual cooperation and support. This change is mainly a result of changes in women's status in Thai society. Women's status has changed due to advanced education and the increased number of women in the political arena (Pongsapich, 1996). Women's roles have extended into income generation and social advocacy. Men's roles are now more involved with household duties such as child care and food preparation (Yoddumnern-Attig, 1992). However, women are still expected to perform as the primary caregivers and make decisions about the health of family members (Kanungsukkasem, 1993).

The Thai family has a strong relationship in accordance with the social norms. The family is tied by the bond and a sense of caring between family members such as father, mother, and children; husband and wife; and other relatives in the same family. Furthermore, in Thai society, children are taught to always honor their parents and expected to take care of their parents as a way to show their gratefulness or *Katanyoo*. Thai society is comprised of a majority of Buddhists. Buddhist teachings state that children have the responsibility to take care of their parents for their up-bringing. Thai

people believe that if someone treats their parents in a good manner, they will get the same treatment from their offspring in the future (Podhisita, 1991).

The family member who cares for the patient is called the caregiver (Craven and Hirnle, 1996). In general, the term of caregiver may be used to refer to any person who takes care of others and is involved in the delivery of care from a doctor to volunteer (MacCormack, 1994). As described above, care may be divided into formal and informal care. Caregivers may include formal and informal care. The term of informal caregiver refers to the relative, friend or significant other of the patient, who provides unpaid care to an ill or dependent care recipient in the home or community (Walker et al., 1995; Reinhard, 1996).

Some researchers attempt to categorize family caregivers into primary caregivers and secondary caregivers on the basis of whether the caregivers live with the care recipient (Davis, 1992). However, many studies restrict the caregiving definition to the care done by family members and usually define primary family caregiver as the family member such as a spouse, parent, or child who most consistently provides care for a relative or in case of dependent, provides care needs (Pearlin et al., 1990; Meares, 1997).

Family structure is described by who the members are and what their relationships are to one another (Craven and Hirnle, 1996). The traditional nuclear family, composed of husband, wife, and their children who live together, is also called the conjugal family and is the family of marriage and procreation. Some families may form a part of a large extended-family structure that consists of a nuclear family and individuals related by blood and/or marriage e.g., grandparent, uncles, aunts, cousins. Additionally, influences of societal changes, such as the women's movement, employment of mothers, marriage,

divorce, and remarriage result in other family structures such as communal family that consists of groups of individuals joining together in one large household, farm, or community as a family unit (Berk, 1998).

Punyodyana (1969 cited in Yoddumnern-Attig, 1992) proposed that Thai society is tightly integrated by numerous principles, social roles and rules, and sumptuary laws. The hierarchy was significant in Thai society. Social behaviors were directed by prescriptions that distinguish a lower status person from a high-ranking person. The relationships between people of different status shape interactions and structure hierarchical positions in society Thai people acknowledge the differences between social statuses and tend to behave according to their status. However, a person of lower status was likely to display less formal behaviors (Yoddumnern-Attig, 1992). Klasner (1998) and Phengjard (2001) described the hierarchy and its expression through a patron-client system. The hierarchical structure defined sets of duties and responsibilities and indicated appropriate behavior. The patron performs the role of protection, support, benevolence, and compassion, while the client offered deference, diffidence, consideration, and respect.

In this study, the researcher used the term of family caregivers to refer to the family members who are closely related by kinship, blood lineage, adoption and marriage and take care of the persons with schizophrenia. A family caregiver is an unpaid person who helps a person with physical care, psychological care or coping with disease and living in the same house with persons with schizophrenia.

The concept of family caregiving

The term of caregiving is always used when someone becomes frail due to physical or mental problems or other disabilities and someone close to the patient provides care for them (Brady and McCain, 2005). In the publications related to caregiving that are viewed by scholars, it is defined as two distinct areas of knowledge development. Caregiving has been used mainly to describe the care given by family members and a process developed through theoretical research. However, when a family member, friends or significant other, who are not professionals, referred to as persons who care, the relevant items of terminology used is lay-caring, lay nursing, informal caring, caretaking, caregiving, and family caregiving (Pepin, 1992).

Caregiving is distinguished from intergenerational, interspousal, or other intra familial aid by the criterion of “dependence on another person for any activity essential for daily living.” (Walker et al, 1995). Pearlin et al (1990) indicated that caregiving referred to activities and experiences involved in providing help and assistance to family members who lacked the capability to take care of themselves. Moreover, they viewed caregiving as an effective component of ones’ commitment to the well-being of another, as well as the behavioral expression of this commitment.

Davis (1992) has proposed four types of caregiving as below;

1. Direct care services. These are the services traditionally considered to be provided by informal caregivers. They may range from supplying transportation, running errands, preparing meals, and housekeeping for the care recipient. The family caregiver might also provide personal care services such as bathing, feeding, and toileting, to home

health care activities such as administering medications and changing dressings for the PWS.

2. Emotional support. Initiating and maintaining social contact with a care recipient is frequently identified by informal caregivers as the most important service they provide.

3. Mediating with formal organization. This type of caregiving service could include activities such as managing financial resources, contracting with service people for home repairs, and filling out legal forms or other documents.

4. Financial assistance through monetary gifts or household purchases.

Van Hooft (1995) had a similar opinion. He indicated that caregiving was a motivational orientation that was strongly tied to realistic actions. Commitment was an expression of deep care that provided the internal motivational strength to act. Therefore, in this study, commitment to the caregiving role was defined as a caregivers' intention to care for a family member with schizophrenia who was important to the caregiver, whether or not the caregiver had affection for the care-recipient and whether or not the caregiver had accepted obligations with regard to the care-recipient.

Seltzer and Li (1996) explained that when caregiving began, there was a transformation in the direction, amount, and necessity of help previously exchanged by family members from more reciprocal to more unilateral, and with increasing amounts of assistance required for the survival of the care recipient.

Swanson et al (1997) analyzed the concept of caregiving and proposed the conceptual definitions of caregiving as a task, a transition, a role, and a process as below:

1. Caregiving as a task emphasized the provision of care for individuals in the areas of activities of daily living and instrumental activities of daily living. These activities included personal care and health care, shopping, transportation, financial management, meal preparation, and household help.

2. Caregiving as a transition extended the perspective of caregiving beyond task by incorporating the following important components: provision of care, performance of care activities, care management, delegation and management of activities, and the care transfer from a caregiving individual to an institution.

3. Caregiving as a role was viewed as a simple extension of the roles customarily enacted by family members or others. It was the role of the caregiver to acknowledge the patient's prognosis and to promote maximum physical and psychological comfort (Peri, 1995).

4. Caregiving as a process that occurred over time or a series of changes, and assumed the tasks and roles of caregiving within this process.

Taylor et al (1997) reported that caregiving as a process of taking responsibility for and providing for the needs of another, including physical, emotional, social, spiritual and other needs by the family member who was the closest relative that was most directly involved in the care of the ill relative.

Songwathana (1998) defined caregiving as; (1) Giving people attention, comfort and support by giving time, energy, love, compassion, and being with the patient, not separate from or leaving the person alone; (2) Sharing, sufferings, and giving both material and non-material things, in order to meet their needs; (3) Feeling concern and sympathy every time and everywhere, even when far away; (4) Willingly giving love and

compassion, without any expectation of repayment; the unconditional giving of loving kindness and compassion; and (5) Reaching out with love with emotional reciprocity and with a commitment to do things because of moral responsibility and duty.

Sterritt and Pokorny (1998) explored the meaning of caregiving. Four major themes emerge: (1) caregiving is a traditional family value; (2) caregiving was an act of love; (3) social support was a mediator of the caregiver burden; (4) caregiving was a female role. Additionally, caring for one's family member at home emerged as a personal and family value, something participants believed was right to do and they could feel good about.

Schumacher et al (2000) defined caregiving as the "ability to engage effectively and smoothly in nine core caregiving processes." These nine core caregiving processes included monitoring, interpreting, making decisions, taking action, making adjustments, providing hands-on care, accessing resources, working together with the ill person, and negotiating the health care system.

Related Literatures

The literature reviews are critical look at the existing research that significant to this study. It shows the relationships between different work, and show how it relates to this study. In other words, the literature review select what parts of the research to discuss such as the methodology, and show how it relates to the other work such as what other methodologies have been used, how are they similar, how are they different. The literature reviews provide the context of research by looking at what work has already been done in the research area.

Rose (1998) conducted an important qualitative study of family caregivers of persons with serious mental illnesses, recruited from two large urban hospitals, in an attempt to increase understanding of the meaning that they assigned to the caregiving experience. The findings indicated that “caregiving meant accepting a responsibility to influence the impact of the illness on the relatives’ lives.” Furthermore, the meaning of caregiving revolved around three concerns. First, caregivers were concerned with finding the essence of the person obscured by the illness and thus worked toward not losing sight of the person beneath the illness. Second, the theme of finding a place for self in influencing the illness emerged and was related to caregivers’ attempts to develop routine responses to illness-related behaviors that would make the illness better. A final theme, helping the relative to move forward, involved focusing on the future by setting goals, sustaining hope, and stepping back.

Schene, Van Wijngaarden, and Koeter (1998) explored family caregiving processes for persons with schizophrenia. Their random sample of 40 caregivers was obtained from the Dutch family organization for persons with schizophrenia. Four caregiving domains were identified including tension, supervision, worrying, and urging. Tension referred to the strained interpersonal relational relationships between caregivers and their relatives, whereas worrying dealt with painful interpersonal cognition about the clients’ safety, care, and health. Supervision, on the other hand, included the caregivers’ tasks of ensuring and guarding relative to issues of medication, dangerous behaviors, and rest. Finally, urging referred to activation and motivation of clients to engage in activities of daily living and other activities.

Schumacher, Stewart, and Archbold (1998) indicated the fact that the concept of doing caregiving well was just beginning to be explored in the nursing literature, and thus there is a lack of clarity as to the meaning of this concept. In an effort to develop this concept, family caregiving for cancer patients was examined by interviewing the patients as well as their primary caregivers. Using qualitative analysis, the concept was defined as the “ability to engage effectively and smoothly in nine core caregiving processes”. These nine core caregiving processes included monitoring, interpreting, making decisions, taking action, making adjustments, providing hands-on care, accessing resources, working together with the ill person, and negotiating the health care system.

Similarly, Mays and Lund (1999) explored the lived experiences of 10 male caregivers of severely mentally ill relatives, recruited from community mental health centers and a National Alliance for the Mentally Ill (NAMI) chapter, by using an informal interview guide that addressed psychosocial, physical, financial, and crisis management categories. These researchers found themes of burden, commitment, and role affirmation. Relative to these themes, the caregivers experienced decreased levels of stress over time, a long-term commitment to the role based on duty and emotional attachment, and a sense of pride in accomplishment of their roles.

Tungpunkom (2000) explored the lived experiences of 30 maternal caregivers that providing care for their mentally ill adult children at home. The interview protocol included questions about “seeking help from other” to elicit information about the social context of care, particularly sources of support. This research found that mothers discussed mobilization of support spontaneously, describing caregiving activities. These

sources fell into two general categories, informational support and instrumental support. They used local healers as sources not only in terms of mental illness, but also concerning other related networks.

Tennakoon et al (2000) described that caregivers used emotional and practical strategies to cope with negative symptoms and difficult behaviors, and experienced more worry about this illness. These findings suggest that increasing the range of coping strategies among caregivers as well as focusing on improving participants' negative symptoms and associated behavioral problems might help to reduce caregivers' distress.

McDonnell et al (2003) indicated that family caregivers having high levels of burden related to caring for their family patients (schizophrenia). Demands of caregiving include paying for psychiatric treatment, supervision of a mentally ill family member, dealing with societal stigma associated with mental illness, and emotional distress that may result from symptoms of a family member's illness.

Ackerson (2003) explored the experience of parenthood with the dual demands of severe mental illness and parenting. Themes that emerged were problems with diagnosis and treatment, stigma, chaotic interpersonal relationships, the strain of single parenthood, custody issues, relationship with their children, social support, and pride in being a parent.

Sethabouppha and Kane (2005) explored the lived experiences from Thai Buddhist family caregivers of serious mental ill relatives to understand their perspectives about Buddhist caregiving. A phenomenological study of 15 Thai Buddhist family caregivers were conducted following Cohen et al (2000)'s process for analysis. Analysis of the interviews revealed five major themes: caregiving is Buddhist belief, caregiving is

compassion, caregiving is management, caregiving is acceptance, and caregiving is suffering. Thai Buddhist caregivers were able to continue to maintain compassion, management, and acceptance in caregiving to their seriously mentally ill relatives.

Several caregiving literature exceptions were noted where the emphasis was clearly placed on understanding family caregiving processes. For example, Bowers (1987 cited in Doornbos, 2001) explored the caregiving of adult children for their aging parents and distinguished family caregiving activities by purpose rather than task. Five conceptually distinct categories of family caregiving, including anticipatory, preventative, supervisory, instrumental, and protective care, were identified.

Preparation for families assuming the caregiving role is an under explored area in the caregiving literature as well. It appears as though many families are thrust into the role without the prerequisite information and training. Although some psychoeducational programs for schizophrenia families have been developed, tested, and found to produce positive outcomes (Dixon and Lehman, 1995). Lefley (1996) identified a notable lack of information and help from the treatment system for families dealing with behaviors associated with mental illness. Specifically, caregivers for persons with a variety of chronic, physical illnesses spoke of feeling unprepared, both technically and emotionally, for their caregiving responsibilities (Levine, 1998).

When reviewing the empirical research related to family caregiving, it is important to make a distinction between family-related research and family research. Family-related research derives data from individuals and explores relationships among family members, whereas family research focuses on family unit as the entity of investigation. Conceptualizations and definitions of family must correspond with the type of research

being conducted. Although some of the family caregiving research is explicit about the perspective taken and the definitions used, other studies are less clear (Feetham, 1991).

Thus, the caregiving research is limited in terms of studies that clearly delineate the type of family research that is being conducted, those that explore family caregiving in families with schizophrenic patients, and those that approach this phenomenon from process orientation. Therefore, using a family-related approach where the parental care providers' perspectives are captured, this study investigate family caregivers' process of caregiving in schizophrenic patients, including issues of preparation, quality of care, and professional understanding.

Summary

A review of the literature reveals that the majority of relevant studies have explored family caregiving of people with schizophrenia and determined it is very difficult and affects both the caregiver and patient throughout their lifetime. There is no cure, only the control psychiatric symptoms. As described earlier, Schizophrenia remains poorly understood and inconsistently managed and are often unpredictable in terms of outcome. People with schizophrenia are often dependent on family for daily living, providing personal care, monitor symptoms, help with medication management, providing for the needs of another, and intervening on the patient's behalf to get treatment (Reinhard, 1994). The family caregivers started their activities each day from the morning until the time to sleep, depending on symptoms of their relatives. At this

point, the family caregivers must understand, or know how to provide care for their relatives by using unobtrusive observation of their mood and develop calming strategies when dealing with the unpredictable situation before them.

According to the perspective of the family caregivers, when a person becomes ill, the family is expected to provide physical and emotional care (Phengiard, 2001; Yanwaree, 2002). So the family caregivers are very important for treatment, care and managing the care of relatives. Yet, little is known about the interaction between the family caregiver and a person with schizophrenia, despite the fact that family caregivers can generate to manage care for their relatives and must use their inner strengths to confront the situation of care, but they still need help and often require health care support. How Thai family caregivers care for the PWS, and what the process of caregiving looks like is still largely unknown. To understand the interaction of the family to the PWS so that psychiatric nurses can utilize this knowledge to provide care is the focus of this research.