CHAPTER 2

LITERATURE REVIEW

The literature review is an important part of the research process. It guides the researcher from the research question to the data analysis process. Related literature that is relevant and which will guide to the development of this proposed study was included and discussed in this chapter as follows:

1. Concepts of chronic mental illness and schizophrenia

2. Concepts of caring

3. Coping strategies of family caregivers

4. Needs of family caregivers

5. Muslim religious beliefs and illness

1. Concepts of Chronic Mental Illness including Schizophrenia

1.1 Definition of Chronic Mental Illness

Chronic disease, as identified by the Commission on Chronic Illness are those diseases characterized by all impairments or deviations from normal that include one or more of the followings: permanency, residual ability, non-pathological alteration, require rehabilitation, or a long period of supervision, observation, and care (Roberts, 1954 cited in Lubkin, 1990). In other words, it is an illness that last for more than three months in any given year or that requires one month or more of confirmed hospitalization (Janosik & Davies, 1991). It also involves the total human

environment for supportive care and self-care, maintenance of functions, and prevention of further disability (Lubkin, 1990).

Chronic mental illness (CMI) is defined by "the number of hospitalizations; length of stay, severe and prolonged functional disability, and a need for mental health services lasting 2 years or more" (Price-Hoskins, 1987, p. 1179). In general, as stated by Lubkin & Curtin (cited in Lubkin, 1990), CMI is "the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability" (p. 6). More specifically, CMI accordingly to Scholler-Jaquish (1996) is "a psychiatric disorder that persists over time with remission and recurrence of severe and disabling symptoms, while chronically mentally ill are persons who have manifested symptoms of chronic mental illness" (p. 686). These symptoms are severe with persistent emotional disorders that interfere with their abilities to live and function independently (Scholler-Jaquish, 1996). The extent of disability as defined by the National Plan for the Chronically Mentally Ill includes disorders that interferes with the individuals' ability to perform the activities of daily living, such as personal hygiene and self-care, self direction, interpersonal relationships, social interactions, learning, recreation, and economic self-sufficiency (Department of Health and Human Services, 1981 cited in Scholler-Jaquish, 1996).

1.2 Manifestations of Chronic Mental Illness

Family members with CMI is diagnosed when it is believed that the individual family member will have manifestation of the disease process throughout his or her lifetime and may have transient and recurrent symptoms (Scholler-Jaquish, 1996).

Very often, CMI is identified in retrospect, by looking back at the individual's history of behavioral problems and symptoms, which emerges as a pattern, that reveals the chronicity.

Family members with CMI will have numerous psychological as well as behavioral manifestations, which often are very disturbing not only to themselves but also to the other family members and to the society as a whole. According to Price-Hoskins (1987), these manifestations can be summarized as the seven symptoms of chronic mental illness as such: 1) dependence, 2) social incompetence, 3) stigma, 4) the sick role, 5) long-term relationships with institutions, 6) symptomatic behavior, and 7) low level functioning.

Dependence is defined as "reliance on others to meet basic needs for love, affection, nurturing, shelter, protection, security, food, and warmth" (p. 1183). CMI individuals tend to develop one of two extremes: they either need nobody and nothing, or they sense no inner resources and need everybody and everything (Price-Hoskins, 1987).

Social incompetence is "the inability to navigate the norms expected for functioning and interpersonal relationships" (p. 1183). CMI individuals are devoid of interpersonal relationship, cannot meet the need through relationships and cannot tolerate closeness (Price-Hoskins, 1987; Scholler-Jaquish, 1996).

Stigma is defined as "a sign of disgrace" (p. 1183). It means that family member with CMI carry social stigma as if the illness in itself is a disgrace, a reproach and a shame (Price-Hoskins, 1987). Sick role is defined as "a set of institution and societal expectations that people who are sick must meet" (p. 1184).

These societal expectations are forfeiting decision making to professionals who care for the sick person, tolerating treatment without complaint, and abandoning the sick role as soon as possible. They are unable to abandon this sick role and their attempts may lead to exacerbation of symptoms and rehospitalization (Price-Hoskins, 1987).

The family member will also have prolonged relationship with mental health services and institutions, requiring treatment at least for 2 years for follow-up care, monitoring, adjustment to medication and assistance from family in developing a healthy lifestyle while living with chronic condition (Price-Hoskins, 1987). Symptomatic behavior of family member with CMI includes signs of psychosis, for example, hallucinations and delusions; posturing, difficult interpersonal relationships, side effects of medications, inappropriate behavior, feelings of hopelessness, overwhelming sense of worthlessness, and also episodes of depression. These symptoms are often symptoms of chronicity and they create discomfort for themselves as well as for others. Some may exhibit bizarre behavior, which require long-term tolerance and compassion for them (Price-Hoskins, 1987). When depression accompanies disorders such as schizophrenia or Alzheimer's the risk of suicide increases significantly (Scholler-Jaquish, 1996).

The prolonged levels of functioning of those with CMI are impaired functioning in activities of daily living, including self-care, personal hygiene, grooming, and comfort; dependent living, and inability to support oneself financially. They have limited skills in solving problems and inability to acquire job skills. They may work or hold a job but not able to live independently (Price-Hoskins, 1987). In

fact most of them are dependent on family for financial, emotional, social and physical support.

1.3 Definition of Schizophrenia

The term schizophrenia was first coined by the Swiss psychiatrist Eugen Bleuler in 1908 (Townsend, 1999). The word was derived from the Greek "skizo" (split) and "phren" (mind) (Birchwood et al., 1989 cited in Townsend, 1999). According to Shives (1994) Bleuler defined schizophrenia as "a serious psychiatric disorder which tends to be chronic and generally leads to severe disability" (p. 441). Johnson (1997) described it as "not a single disease" but a heterogenous disorder, with some common features such as disturbance in thinking, and preoccuaption with self and inner fantasies (p. 566). Stuart and Laraia (1998) described it as a serious and persistent brain disease, that resulted in psychotic behavior, concrete thinking, and difficulties inprocessing information, interpersonal relationship, and problem solving.

1.4 Characteristic Symptoms of Schizophrenia

The Diagnostic and Statistical Manual of Mental Disorders, 4th edition text revision (DSM-IV-TR) criteria for the diagnosis of schizophrenia (American Psychiatric Association, 2000, p. 312) are:

(a) At least two or more of the following are present for a significant portion of time during a 1-month period:

    i.   Delusions

    ii.   Hallucinations

    iii.   Disorganized speech (e.g. incoherence)

    iv.   Grossly disorganized or catononic behavioar

v.   Negative symptoms, that is, affetcive flattening, alogia, or avolition

(b) Social /occupation dysfunctions: work, interpersonal relations, or self-care are markedly below the level achieved prior to onset.

(c) Duration: continuous signs of the disturbance persist for at least 6 months.

(d) Schizoaffective and mood disorder with psychotic features have been ruled out.

(e) Exclusion of substance abuse and general medical condition.

The main characteristics of schizophrenia include impaired communication, loss of contact with reality, deterioration of form previous level of functioning at work, social relations, and self care. There is also disturbance of language, thought process, perception, mood, lasting longer than 6 months (Shives, 1994; Townsend, 1999).

The characteristic symptoms of schizophrenia can also be listed as primary and secondary symptoms. The primary symptoms are described by Bleuler (1950 cited in Buchanan & Carpenter, 2000; Maj & Sartorius, 1999; Shives, 1994) as four As' which include associative disturbances or looseness, affective disturbances or inappropriate mood, autism, and ambivalence. They are the specific fundamental symptoms of schizophrenia and they are present at all times in all cases. The secondary symptoms or accessory symptoms identified by Bleuler may be absent at times and even throughout the whole course. These symptoms are delusions, and hallucinations. A delusion is defined as "a false or fixed belief that cannot be changed by logic" (Shives, 1994, p. 444). Hallucinations are "false perceptions without any external or environmental stimulus and can involve any senses (Shives, 1994, p. 444).

Visual hallucinations occur in 15%, auditory in 50%, and tactile in 5% of all patients, and delusions in more than 90% (Cutting, 1990, cited in Maj & Sartorius, 1999). In DSM-IV-TR, bizarre delusions have been attributed as major diagnostic importance, in that, the presence of any delusion of this kind qualifies for a diagnosis of schizophrenia (APA, 2000). Other secondary clinical symptoms may also include loss of ego boundaries, anhedonia or loss of feeling, mood swings, somatic complaints, change in appetite, cognitive deficits and lack of will or avolition (Shives, 1994). In terms of cognitive deficits the schizophrenic tend to perform at lower levels in most cognitive tests which include conceptual reasoning, psychomotor speed, new learning, memory, motor and sensory perceptual abilities, attention span and problem solving (Maj & Sartorius, 1999). Mood swings may be exhibited in various emotions such as anger, anxiety, and depression without any obvious reason for such behavior (Shives, 1994). The schizophrenia person may lose interest in his/her jobs, neglect personal hygiene, or incapable of carrying out tasks as part of daily routine, appear disheveled, dirty, or inappropriately dressed (Shives, 1994).

The characteristic symptoms of schizophrenia can also be categorized as "positive" and "negative" symptoms. The positive symptoms appear to reflect an excess or distortion of normal functions. These positive symptoms include distortions in thought content (delusions), perception (hallucinations), language, thought process (disorganized speech), and self-monitoring of behavior (grossly disorganized or catatonic behavior) (APA, 2000). The positive symptoms may comprise of two dimensions. The psychotic dimension includes delusions and hallucination, while the disorganization dimension includes disorganized speech and behavior (APA, 2000).

The negative symptoms include restrictions in emotional expressions (affective flattening), fluency and productivity of thought and speech (alogia), and in the initiation of goal-directed behavior (avolition) (APA, 2000). These negative symptoms may be caused by factors such as positive symptoms, medication side-effects, depression, environmental understimulation, or demoralization, thus a distinction should be made between true negative symptoms and negative symptoms due to secondary causes in the diagnosis of schizophrenia (APA, 2000). As a result of this differentiation, enduring negative symptoms that are not attributed to secondary causes are known as "deficit" symptoms (APA, 2000). Negative symptoms are common in prodromal and residual phases of the illness (APA, 200).

2. Concepts of Caring

Caring has many definitions as defined by many authors and nurses. Caring is a process and an art that requires commitment, knowledge, and continued practice, and encompasses a "feeling of dedication to another to the extent that it motivates and energizes action to influence life constructively and positively by increasing intimacy and mutual self-actualization" (Bevis, 1981 cited in Harrison, 1990, p. 401). Watson (1989) who listed the 10 carative factors views caring as a therapeutic interpersonal process, assuming that "caring" can be effectively demonstrated and practiced only interpersonally. Additionally, Watson et al. (1979 cited in Kyle, 1995) also proposed a model of caring behaviors based on instrumental and expressive activities. The instrumental activities included physical action-oriented behaviors, for example, procedures and performing procedures, and cognitive-oriented helping behaviors, for

example, teaching. This view of caring as activities were also shared by authors such as McFarlane (1976 cited in Kyle, 1995) and Griffin (1983).

Caring is also viewed as a set of caring behaviors. Weiss (1988 cited in Kyle, 1995), proposed a caring model, which consisted of three behavioral components: verbal caring, non-verbal caring, and technically competent behavior. According to Swanson (1993) caring is "a nurturing way of relating to a valued other whom one feels a personal sense of commitment and responsibility" (p. 354). Every human being has a desire for confirmation and love (Erickson, 1987 cited in Rundqvist & Severinsson, 1999). Caring according to Rundqvist and Severinsson (1999) means creating an atmosphere of trust, satisfaction, physical and spiritual pleasures as well as feelings of development in order to change (maintain, start or support) process of health. This is achieved through different forms of "purging", "playing" and "learning". The core of caring is also expanded in terms of "faith", "hope", and "love" (Rundqvist & Severinsson, 1999). Gaut (1983) stated that in all caring relationship, "respect for persons" should be the underlying principle while Gadow (1985 cited in Kyle, 1995) regarded caring as a commitment to the "protection and enhancement of human dignity". Although caring is a universal phenomena and a fundamental activity, expressed through both diverse and universal caring modalities through different cultures (Leininger, 1988), it is very much influenced by the caregivers' culture, values, experience, perceptions and also factors such as age, maturation levels, costs, levels of stress, responsibility and behaviors of the care recipient (Bevis, 1981 cited in Harrison, 1990). According to Leininger (1988) caring also includes

constructs like compassion, empathy, love, concern nurturance, presence, support, and trust.

2.1 Caring: Caregivers' Perspectives

The concept of "caring" by family caregivers caring for members with chronic mental illness varies with each family caregiver. Recent research has investigated caregiver's perspectives on the caring for chronic mental illness and their reactions to that meaning. These studies describe the meaning how family caregivers provide care, how they cope with their situation, and how they find support to help them.

Caring is seen as absence of any expectations of "pay-back" for the care provided, which is very much influenced by what is known as "maternal factors" (Howard, 1994). She used grounded theory, in-depth interviews, investigated 10 mothers who lived with, and cared for and adult child with schizophrenia. Here she described the meaning of caring as "watching, working, and waiting". She also described the stages to live with the ill child as "peceiving problems", "searching for solutions", "enduring the situations", and "surviving the experiences" which represent learning about their caring. These meanings are helpful in understanding of adaptation by family caregivers caring for their mentally ill person.

Caring is a kind of bonding with the ill relative' whereby family caregivers continued to provide care as worthy despite losses from the illness (Rose, 1992 cited in Tungpunkom, 2000). This type of bonding provides the caregivers the ability to

influence the family member with chronic mental illness and to manage the situation (Tungpunkom, 2000).

The meaning of caring on the other hand can also be perceived as caregiving activities such as maternal care, symptom management, and medication management (Tungpunkom, 2000). Maternal care activities are those related to normal parenting that address routine living, for example, grooming and nutrition; symptom management activities mean monitoring of symptoms related to the mental illness; while medication management includes observing side effects, giving medication and monitoring compliance to medication (Tungpunkom, 2000).

Rose (1998) in her interpretative study on 15 family caregivers explored the meaning of caring. Her study revealed the 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" in terms of goals setting, sustaining hope, and stepping back. Those meaning on caring have effects on responses as caregiver's roles.

Chelsa (1989) using interpretative phenomenology studied 14 parents who lived with their schizophrenia adult child and found that the meaning of illness as perceived by the caregiver has great profound influence what caring means to them and on their caring practices. To illustrate, the family caregiver who believes that illness resulted from biological imbalance will tend to focus on food intake, medications and other factors that affect this imbalance. On the other hand, the caregiver who believes in rational control will tried to use reasoning to manage care

for their ill children. To these caregivers caring mean persuading their child to think rationally and behave accordingly to their age-appropriateness activities.

However, culture and traditional factors do play a role in how caregivers see the meaning in their caring. Belief in Karma, and belief in making merit (bhloon) for their next life facilitate their role as caregivers by being more understanding and empathetic in the care- recipients conditions (Tungpunkom, 2000). 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). Islamic caring can be expressed via intention and thought by understanding what, when, who, and why via action level by relating caring to knowledge, skills and resources (Salleh, 1994 cited in Rassool, 2000). It can be further achieved by studying the attributes of Allah from the Holy Qurán and the Prophet's sayings (Rassool, 2000). The Holy Prophet stated, "Each of you is a guardian and is charged with a responsibility, and each of you shall be held accountable for those who heaven been placed under your care" (cited in Rassool, 2000, p. 1481). The spiritual aspect of caring can also be achieved as an act of "doing good" (Maaruf) or evading "wrong doing" (Munkar).

In summary, the concept of caring has many definitions just as meaning of 'caring' varies among family caregivers. The meaning of caregiving as expressed by family caregivers identified by Rose (1997), Tungpunkom (2000), and Chelsa (1989) showed some similarities as defined by Swanson (1993), Leininger (1988) and Bevis, 1991, cited in Harrison, 1990). Family caregivers, in providing care through time,

have developed their own meaning of caring. Thus, it is very important that nurses understand the meaning of caregiving as perceived by caregivers in order to assist them in their important role as caregivers.

2.2 Impacts of Caring

Knowing the severe, prolonged functional disability and the chronicity of chronic mental illness, caregiving for family members with chronic schizophrenia are not without problems. The family caregiver not only has to cope with the long-term and disabling physical and behavioral problems associated with the care recipient's illness, but also have to adapt their needs, lifestyles, daily routines, income, relationship to fit into the regime of the ill care-recipient. Many studies have examined the negative impacts of caring which affects the physical, psychological, emotional, social and financial well being of family caregivers. Most studies, to date, have been based on qualitative methods (Chafetz & Barnes, 1989; Howard, 1994; Norbeck et al., 1991; Rose, 1983).

The emotional and psychological impacts experienced by family caregivers that have been identified were tension, stress, anxiety, resentment, depression with accompanying feelings of hopelessness and powerlessness, and a sense of entrapment (Fadden et al., 1987; Gibbons, Horn, Powell & Gibbons, 1988; Glendy & Mackenzie 1998; Holden & Levine, 1982; Maurin & Boyd, 1990). Adverse feelings of sadness, anger, fatigue, guilt, grief and depression have been found in Alzheimer Dementia Related Disease (ADRD) caregivers (Butcher et al., 2001; Gallagher & Mechanic, 1996; Lindgren, Connelly & Gaspar, 1999). Butcher et al. (2001) in their study investigated experiences of 103 family caregivers caring for ADRD and found that

caregivers experienced negative feelings of "enduring the stress and frustration" and "suffering through the losses." Enduring the stress and frustrations to the caregivers meant, "caregiving" was stressful, frustrating, never ending, sometimes embarrassing and anger."

Some family caregivers have also experienced chronic sorrow. A study done by Eakes (1995) using qualitative approach, interviewed 10 parents of adult children with schizophrenia using the Burke/NCRCS Chronic Sorrow questionnaire. She found that eight out of 10 parents experienced chronic sorrow with feelings of frustration, anger, and confusion that occurred periodically over the course of the child's illness. The ongoing of the illness and the prospect of endless caring were the major factors that triggered chronic sorrow.

Physical ill health and risk for mortality were also reported among family caregivers (Glendy & Mackenzie 1998; Schuiz & Beach, 1999). The physical ill health that was reported included minor somatic and mental health problems. A study done by Salleh (1994) reported 23% of the primary of caregivers of Malay schizophrenia developed neurotic disorders resulting from stress, and nearly half of them had neurotic depressions.

The social and economic impacts reported were financial, marital, legal housing, employment, interpersonal conflict, and feeling of less-connected to one another within the family (Doombos, 1996; Glendy & Mackenzie, 1998; Maurin & Boyd, 1999). Study done by Jacob, Frank, Kuper, and Carpenter (1987) investigated 68 spouses and 12 significant others and found that caregivers living with care-recipients experienced greater financial worry and social isolation.

2.2.1 Family Caregivers' Burden

Burden is a concept that represents the negative consequences of caregiving. There were significant research conducted about family caregivers which stated that the majority of families acknowledged feeling burdened by the persistent and chronic mental illness of the family member since mid-1950s and early 1960s (Loukissa, 1995; Maurin & Boyd, 1990). Psychiatric burden has been conceptualized as difficulties, which were experienced by the caregiver's life as a result of caring for the family member with chronic mental illness (Maurin & Boyd, 1990).

Maurin and Boyd (1990) reviewed the literature on burden. They differentiated the difference between burden and distress. Distress was the impact of all the pressures of life on a family member, whereas burden was limited to the impact of the relative or family member who has a mental illness.

Literature review showed that since 1960's burden has been considered in terms of two dimensions: objective and subjective burden (Hoenig & Hamilton, 1966). *Objective burden* refers to the tangible damage incurred by the family taking care of the mentally ill relative, such as decrease of family leisure time and vacations, financial lost for cost of never-ending care. *Subjective burden* refers to the caregiver's cognitive appraisal of the caregiving situation and the perception that it is burdensome (Jones, 1996; Maurin & Boyd, 1990).

Earlier research studies in the 1960s to 1980s investigated factors associated with burden: characteristic of the ill patient, characteristic of the caregiver, the association between objective and subjective burden, the effect of burden on family, and intervention programs influencing caregiver's burden (Loukissa, 1995;

Maurin & Boyd, 1990). Despite these studies, there were still limitations in certain areas: on clarification of the effects of burden on family, inconsistencies in the theoretical and operational definition (Maurin & Boyd, 1990). This has led to constrain in understanding fully the caregiver's burden. Recent research studies have begun to investigate the personal and situational factors that affect caregiver burden (Rose, 1997). They were characteristics of the ill family member and characteristics of the caregiver.

2.2.1.1 Characteristics of the ill family member

Factors such as ill relative's disruptive behavior, functional level, diagnosis, duration of illness, and gender affected caregiver burden (Biegal et al., 1994; Reinhard, 1995; Song, Biegel & Milligan, 1997). The ill relative's disruptive behavior was a major predictor of burden (Biegal et al., 1994; Reinhard, 1995). Study done by Reinhard identified that ill relative's behavior explained 23% variance associated with caregiver's burden while those done by Song and his associates were 57% (Song et al., 1997). These two studies strongly confirmed the effect of ill disruptive relative behavior on burden. Winfred and Harvey (1993) found that caring for a female family member with mental illness was associated with greater caregiver burden. Salleh (1994) found that active symptoms such as hostility, violence, over activity, restlessness and acting out bizarre ideas were distressing to caregivers.

2.2.1.2 Characteristics of the caregiver

When family member took the role as a caregiver, they also brought in personalities, cultures, values, their knowledge and skills, past experiences

into the caregiving process. Some of these factors served as buffer for the caregiver while others might be precipitating factors. Study done by Howitz and Reinhard (1995) found that White parents were more likely to perceived burden than Black parents in their caregiving roles. Black siblings engaged in more caregiving roles than the White siblings. The differences in ethnicity reflected different cultures, beliefs and their perceptions on mental illness. The authors examined the feelings of stigma and found that the White caregivers perceived mental illness as more stigmatized than the Black caregivers, and therefore, to them experienced more burdens. The age was associated with caregiver burden (Winfred & Harvey, 1993). The authors in this study found that older female caregivers especially mothers reported less burden than the younger female caregivers.

2.2.2 Family Caregivers' Strengths

Though emphasis in literature focuses on caregivers burden and stressors, there were also studies conducted on positive impacts of caring such as the strength of caregivers. Doornbos (1996) identified that caregivers possessed strength such as functional abilities, family adaptability and conflict management. Functional abilities referred to "family capability to do what was necessary to function and to preserve the integrity as a family unit" (Doornbos, 1996, p. 218). The family adaptability was due to their flexibility and ability to change in response to various situation and developmental stressors. Acton and Wright (2000) in their study on concept of self-transcendence and adult family caregivers of dementia, found that negative experiences can promote growth and self development, enabled the caregivers to look beyond self, present difficulties and extend concern for others, to

find personal meaning and wholeness in the context of life changing events during caring.

In summary, caregiver's burden, which can be subjective or objective burden, had negative impacts on family caregivers caring for their members with chronic schizophrenia. These negative impacts they had may be physical, psychological, emotional or social. On the other hand, caring for members with schizophrenia can also have positive impacts on family caregivers such as functional abilities, family adaptability, conflict management, and promotion of growth and self-development. These positive impacts were looked upon as strengths of caring experienced by these family caregivers.

3. Coping Strategies of Family Caregivers

3.1 Definition of Coping and Coping strategies

Coping is "any behavior or cognitive activity that is used to deal with stress" (Ignatavicius & Bayne, 1991). It is "the constantly changing cognitive and behavioral efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). Coping strategies on the other hand, are "a set of behaviors people under stress used in struggling to improve their situation" (Kneisl, 1996, p. 66). Ignatavicius and Bayne (1991) defined coping strategies as "mechanisms by which the individuals tries to control the causative problem or the stress related feelings that arise" (p. 88).

3.2 Lazarus and Folkman Model of Stress

A person's interpretation of the event is viewed as important because the meaning given to the event by that person will determine the level of stress experienced as being stressful or dangerous (Lazarus & Folkman, 1984). This is a cognitive process and it consisted of *primary appraisal* which is evaluation of significance of what is happening for his or her well-being, and *secondary appraisal,* the evaluation of coping resources and options (Lazarus & Folkman, 1984). These appraisals are very much influenced by factors related to the person and to the environmental event in which the stress is appraised (Lazarus & Folkman, 1984). Factors related to person include depth of feelings that the event arouses in a person, depth of commitment, beliefs and control (Lazarus & Folkman, 1984). Events about which people feel strongly are more apt to be stress producing than event that arouses little or no feelings. The depth of commitment is also important appraisal factor because a committed individual will often tries harder to cope than a noncommitted person. Beliefs are also influential factor of stress appraisal. A person with strongly held religious beliefs that God can influence the course of the events might appraise the event differently from a nonreligious person. Lastly, control is also an important appraisal factor. Most people want to maintain a sense of control and not having control is appraised as a stressor (Ignatavicius & Bayne, 1991).

The factors related to environmental event include unpredictability, uncertainty, timing, ambiguity and duration of events (Lazarus & Folkman, 1984). Events that are unpredictable is seen as more stressful than predictable events. A person's uncertainty about an event can increase stress. The timing of events has an

impact on the level of stress and events that are in the distant future are usually perceived as less stressful than events that are closer in time. Duration of events such as chronic, long-term events can wear down a person's ability to cope (Ignatavicius & Bayne, 1991). It is generally accepted that the more the ambiguous the situation the more stressful it is.

3.3 Coping Strategies

Coping strategies may be physical, cognitive, social and emotional level (Kneisl, 1996). As a result of the multifaceted challenges and stressors faced, family caregivers developed a wide rage of coping strategies. Lazarus and Folkman (1984) identified problem-focused coping and the emotion-focused coping strategies (pp.149-179). The problem-focused coping strategy requires necessary information, time, accurate appraisal and ability to generate alternatives. Some family caregivers took positive actions by using problem-solving approach to cater for the problems faced by the mentally ill member (Doornbos, 1996; Glendy & Mackenzie, 1998; Saunders, 1999).

On the other hand, emotion-focused coping strategy is used if former method is not appropriate. Examples of emotion-focused coping strategies include confrontation, distancing or denial, self-control, accepting responsibility, event review, emphasizing positive aspects of an event, tension reduction strategies (meditation, yoga exercises and physical exercises), humor, social support, and faith (Ignatavicius & Bayne, 1991).

Social support by family and friends and community can be helpful (Ignatavicius & Bayne, 1991). Social support is a powerful aid to coping, and by

seeking support from others people gain information, physical help, and other forms of assistance (Glendy & Mackenzie, 1998; Ignatavicius & Bayne, 1991; Nobeck et al., 1991; Teschinsky, 2000). Social support in terms of illness information and behavior management, financial help, acceptance of the patient's mental illness, respite care and direct help with caregiving activities were noted helpful for family caregivers of psychiatric patients (Nobeck et al., 1991). Findings from studies of social supports also stated that persons who are supported instrumentally and emotionally are healthier than those not supported (Ryan & Austin, 1989; Stewart, 1989).

Faith in God, a deity or an ultimate meaning of life can be effective way to coping (Ignatavicius & Bayne, 1991). For spiritual individuals and those having strong faith in God or believing in transcendence can be beneficial. Prayer, increased religious activity, and acceptance of God's will, reduce the perception of stress.

Fadden et al. (1987) identified cognitive strategies used such as wishing the situation would go away, and hoping for a cure for the illness some day. Acceptance of chronicity of the deviant behavior of the mental illness over time was another coping strategy (Glendy & Mackenzie, 1998; Teschinsky, 2000).

In summary, family caregivers as they went through the caring process, have devised different coping strategies to help them coped with the burden and difficult realities of caring for their loved ones' with chronic schizophrenia. These coping strategies included cognitive, emotional and behavioral strategies. Understanding the various coping strategies used by family caregivers will enable nurses to assist them

to cope better their burden and difficulties. Successful coping leads to better adaptation of family caregivers in their care giving roles.

4. Needs of Family Caregivers

Several studies have also documented the needs of family caregivers in caring for chronic mentally ill. These needs were informational need, emotional need and social support need. Informational need such as illness, treatment, management of untoward behavior, community services available were important as they helped the caregivers to manage effectively the illness and to cope with the daily stress of caring. Emotional needs of caregivers to talk and release their tension were also identified (Glendy & Mackenzie, 1998).

Social support needs such as financial, family support groups, home health aides, counseling community-based services were documented (Chafetz & Barnes, 1989; Collin, Given et al., 1994; Glendy & Mackenzie, 1998). Norbeck and associates (1991) noted that the social support needs of caregivers of chronic mentally ill differ from the general social support needs of other caregivers because of the uniqueness of mental illness. In their study on social support needs of 60 caregivers caring for people in three age groups: 20 pervasive developmental disorder children, 20 schizophrenic and bipolar disorder adults, and 20 Alzheimer elderly parents; differences in support needs were noted. These differences depended on length of caregiving period and stage of life of caregivers. The unique social support needs for caregivers caring especially for adult schizophrenia or bipolar disorders were those needs related to disruptive behavior of the ill family member. However, those general

support needs, which were similar, included emotional support, feedback support, information/cognitive support, and instrumental support. Studies on interventions with caregivers that have been identified included educational, supportive or a combination. (Collin, Given et al., 1994; Hutchinson, 2000). Caregivers reported a significant reduction of anxiety, personal distress, more positive family outcome, increased adaptive coping behaviors, better home management and improved quality of live and also greater used of community resources that were available (Basolo-Kunzer, 1994; Collins, Given et al., 1994; Hutchinson, 2000) However, studies to examine the short-and long-term outcomes of intervention and the impact on health and well-being of caregivers have been strongly recommended (Collin, Given et al., 1994).

In summary seeing to the needs of caregivers were fundamental as these needs helped to support them in their role as caregivers, reducing their psychological disturbance, negative effect and emotional upsets and maintaining their well-being. These needs include social support needs, information needs, financial needs and emotional support needs and they vary with each family caregiver. Nurses understand the needs of family caregivers are important to help them in their caregiving.

5. Muslim Religious Beliefs and Illness

Religious beliefs are important in many people's lives and they influence lifestyle, attitudes, and feelings about illness (Kozier, Erb & Bufalino, 1989). Religion helps people to strengthen one's inner strength, and helps one to accept illness. In the Islamic context, the Islamic religion provides the spiritual pathway for salvation and a way of life and there is no spirituality without religious thought and practices

(Rassool, 2000). Muslim embraces the acceptance of the Divine, and they seek meaning, purpose and happiness in world life and thereafter (Rassool, 2000). This is achieved through the belief in the "Oneness of Allah" and the application of Qur'anic practices and guidance of the Holy Prophet.

Muslims' worldview towards health and illness incorporates the notion of receiving illness and death, with patience, meditation and prayers (Rassool, 2000). Muslims understand that illness, suffering and dying are part of life and a test from Allah (Rassool, 2000). According to Athar (1993 cited in Rassool, 2000) "Illness is an atonement for their sins, death as part of journey to meet their God" (p.1479). However, they are strongly encouraged to seek care and treatment. It is stated that, "illness is one of the forms of experiences by which the human arrive at knowledge of Allah" (Al-Ghazzali, 1968 cited in Rassool, 2000, p. 1479). Health and illness is seen as part of a continuum of being, and prayer remains the salvation in both health and in sickness. Seeking for treatment is not regarded as a sign of conflict as the Prophet Muhammed said, "Seek treatment, because Allah did not create a sickness, but has created a treatment for it accept for old age" (cited in Rassool, 2000, p. 1481). There were a number of verses of the holy Qur'an concerning healing as stated, "It is for those who believe, a guide and a healing" (Fussilat 41:44 cited in Al-Hilali & Khan, 2002, p. 3). Ritual practices include praying, which is communication to Allah, and is performed daily, five times a day (Salat) facing east, reading the Koran verses and meditation.