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Tungpunkom, Patraporn,

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Staying in Balance: Skill and Role Development in Psychiatric Caregiving

by

Patraporn Tungpunkom

DISSERTATION

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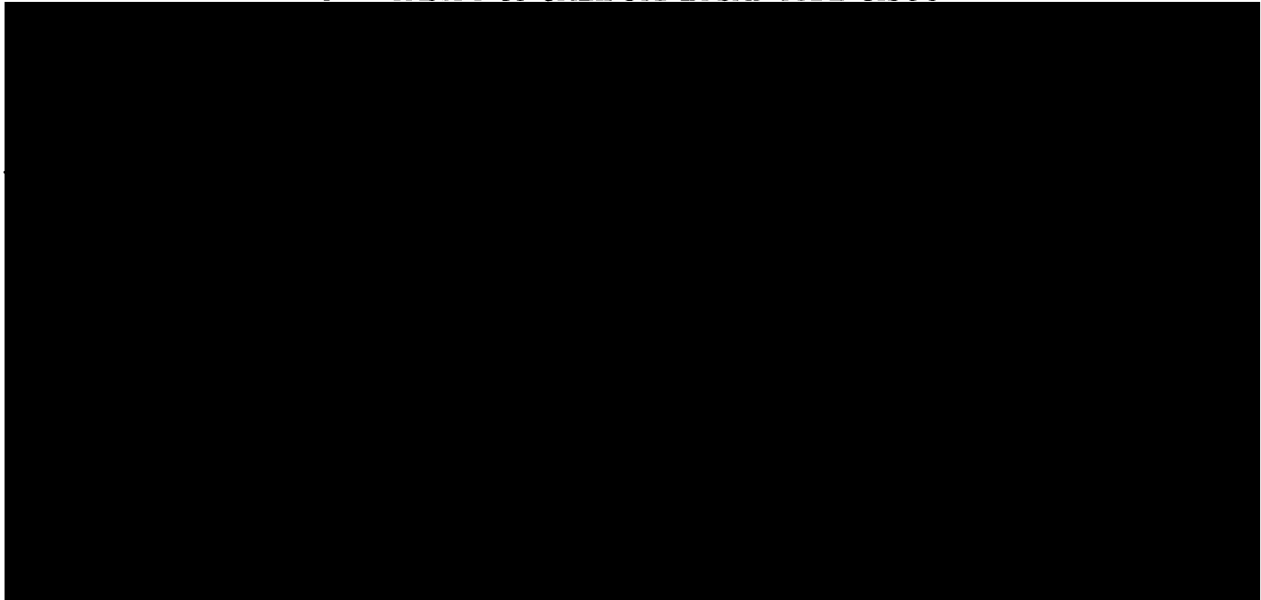
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STAYING IN BALANCE: SKILL AND ROLE DEVELOPMENT IN PSYCHIATRIC

CAREGIVING

Dedication

This dissertation is dedicated to my parents who have nourished and nurtured me all my life. They originally provided the opportunity for me to produce this work. I dedicated this also to my sister and her family who have always had faith in me.

Acknowledgement

First of all, thank you for all 31 mothers who lived with, and cared for, their mentally ill adult children at home, who were willing to share their experiences with me. Your willingness to share your lives with me will lead to a better understanding of psychiatric caregiving and may help others in a similar situation.

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Abstract

Staying in Balance: Skill and Role Development in Psychiatric Caregiving

Patraporn Tungpunkom

Prior research on family caregiving to the mentally ill has focused on the concepts of burden, coping, and social support. This literature also indicates that mothers are principle caregivers. However, little is known about the skills that maternal caregivers develop in order to function in their roles. This research has the overall goal of providing knowledge about maternal caregiving in rural Thailand, including the social and cultural context care, the tasks of caregiving and the skills that mothers employ, and their process of skill and role acquisition

Thirty mothers who lived with, and cared for, their adult children with schizophrenia or a related disorder were recruited for this qualitative study. Semi-structured in-depth interviews were conducted to elicit data on psychiatric caregiving, using open-ended questions and a series of related probes to elicit content related to specific skills and their development. The interviews were analyzed using grounded theory methods.

Two major types of activities emerged from the data: the caregivers' direct management of care and their self-adaptation to their roles. Major tasks of caregiving fell into three overall domains: maternal care tasks (those that were extensions of normal parenting), psychiatric symptom management, and medication management. Caregivers reported use of a body of skills that crossed these domains. Learning was experiential, often acquired through trial and error.

Caregivers experienced two types of self-adaptation: emotional and role adaptation. Emotional adaptation refers to how they adjusted their emotional responses to the illness, to recipients of care and to caregiving. Role adaptation refers to increasing sense of mastery of the role, developing expertise and accepting caregiving as an integral part of life. Adaptation was facilitated by both informational and instrumental supports. The metaphor "staying in balance" describes caregivers need to provide direct care while adapting to their role and mobilizing support for both care management and adaptation.

This study provided additional knowledge concerning psychiatric caregiving in terms of the home management activities and the caregiving skill needed to provide care at home. The concept of caregiving skill is also developed conceptually from the inductive and deductive approach.

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CHAPTER I: INTRODUCTION

There have been numerous research studies focused on caregiver burden, coping strategies, and social support in the psychiatric caregiving literature for many decades. There is sparse research on what caregivers actually do in order to take care of the ill relative at home. Information on how to manage care at home, expressed as a need by caregivers, is limited in scope. Therefore, the purpose of this research is to explore what maternal caregivers who live with, and care for, their adult children with schizophrenia or a related disorder actually do at home. The activities that they engaged in are called "caregiving skills." Although caregiving skill seems to be an important factor in doing caregiving and it has been receiving increasing attention from researchers (both in general and in nursing research), this concept is not yet solidly conceptually defined.

I was motivated to study caregiving skills for people with mental illness while I was a psychiatric nurse in the Psychiatric Unit at Chiang Mai University Hospital. I often received phone calls from caregivers asking how to handle typical problems at home, such as what to do when a mentally ill person could not sleep and wandered around the house. Although family caregivers frequently requested information about how to manage this behavior at home, such information is scarce. As in the US, there is a shortage of information about psychiatric home care management (Chesla, 1988). This problem is exacerbated by the trend in past research to focus on how family caregivers respond emotionally and socially to mental illness (e.g., the work of Karb & Tanarugsachock, 2000; Schene, Wijngaarden, & Koeter, 1998) rather than on behavioral responses or what they actually do in the caregiving situation.

This research expands knowledge concerning psychiatric caregiving. Additionally, it aims to develop the concept of caregiving skill, by exploring maternal caregiving activities, as well as how mothers develop these skills and strategies over time. To meet this aim, this study employs a retrospective qualitative design. Grounded theory (Strauss & Corbin, 1990; 1998; Strauss & Glaser, 1967) is applied to analyze data. Thirty Thai mothers who lived with, and cared for, their adult children with schizophrenia or a related disorder were interviewed with a semi-structured interview protocol comprised of a set of questions concerning the activity they engaged in to manage care. Demographic data were obtained to describe the situational contexts for caregiving. Mothers were also asked to rate the functional level of the care recipient at home. This information provided data on how mothers perceived the caregiving situation and the degree of demand or care that they had to provide.

The first chapter of this dissertation outlines the statement of the problem, the purpose, and the need for the study. In chapter two, a critical review and discussion of the relevant research is addressed. The conceptual framework that shaped and guided this study as well as research questions are provided. In chapter three, the methodology employed for this study is described. In chapter four, the findings are presented, including the context of care, the psychiatric tasks and skills applied by these mothers, and the process of skill and role development. In chapter five, I discuss the meaning of the results and how they are helpful for research and clinical practice. The concept of caregiving skill is also conceptually defined following the Hybrid Model explicated by Schwartz-Barcot and Suzie Kim (1993). The limitations of this study are addressed, as are future research directions.

Statement of the Problem

Caregiver burden has been investigated for many decades. It has been understood as a negative consequence of caregiving. Many research studies show that caregiver burden is highly associated with the disruptive behavior of the ill person (Biegel, Milligan, Putnam, & Song, 1994; Reinhard, 1995; Song, Biegel, & Milligan, 1997). Residing with the ill relative is also highly associated with caregiver burden (Solomon & Draine 1995). Another factor, social support, has been well researched and is negatively associated with (inversly related to) caregiver burden (Biegel et al., 1994; Reinhard, 1995; Solomon & Draine, 1995). Social support has been shown to reduce caregivers' psychological disturbance, negative affect, and emotional upset (Winfield & Harvey, 1993).

Research has provided information around the burden axis and about family understanding of mental illness. Much of this is based on study of expressed emotion research (EE, an indicator of family affective tone). However EE studies have largely looked at impact on relapse. Little is known about how to buffer stress and reduce burden in psychiatric caregiving.

Psychiatric symptoms, particularly disturbed behaviors, are known to be consistent predictors of burden. However little is known about the skills employed to manage them effectively in the home. It is unclear if enhanced skills reduce caregiver burden or if they improve quality of psychiatric home-care. The fact that psychiatric illness is unpredictable and changeable over time makes it difficult to transfer information about caregiving within the contexts of other chronic diseases. Caregiving skills deserve

investigation in general. The unique qualities of psychiatric home care and mental illness further compel us to study this phenomenon.

In Thailand, home care management is very important. Almost all psychiatric patients return to their families when they are discharged. Caregiving is the unpaid career born by woman that has been overlooked in research. This is true in the US as well, where in many studies the majority of caregivers are mothers (e.g., Chesla, 1988; Howard, 1994). While there are considerable data on the predominance of maternal caregivers, its impact has been neglected. Maternal care is often accompanied by a type of bonding that provides gratification to caregivers (Howard, 1994). This may influence caregiving practices and experiences. Therefore it is very important to look at maternal caregiving, specifically skill development and impact on care.

In Thailand, the fact that there are increasing numbers of people with psychiatric disorders living in the community makes caregiving skills a major issue. The number of visits to psychiatric hospital in Northern Thailand increased 9% between 1996-1999 (Suanproong Psychiatric Hospital, 1999). This statistic reflects an increasing demand for care for this specific population both in the hospital and community. It highlights the need to study caregiving skill.

Lastly, caregiving is cultivated. It is a learned activity within families and is culturally bound (Markson, 1979). Thus, the culture of each family influences the way caregiving is defined by the family members (Phillips, Luna, Russell, Baca, Mi Lim, Cromwell, & Torres de Ardon, 1996). If the meaning of caregiving differs from culture to culture, caregiving skills might vary as well. This study provides data on caregiving

skills of maternal caregivers in the northern region of Thailand in order to identify cultural determinants.

Purpose of the Study

This study aims to explore the activities that maternal caregivers actually do when living with, and caring for, their mentally ill adult children at home. My aim is to reveal information on the tasks of psychiatric caregiving and the skills required to manage these tasks. The specific aims are:

1. To describe the caregiving context including relevant demographic data, clinical and socio-cultural factors.

2. To explore psychiatric caregiving or the activities mothers performed in order to live with, and care for, their mentally ill children at home.

3. To describe the development of skill as well as role acquisition.

The Need for the Study

Despite extensive literature in psychiatric caregiving, there are major gaps in our knowledge about caregiving skills and how they are acquired. This is an important area of study due to its potential impact on outcomes for both providers and recipients of care. There is also limited information on specific properties of maternal caregiving in mental illness and in other contexts. Knowledge about maternal caregiving skills will contribute to develop of intervention studies. This research will broaden our scope of knowledge about what caregivers do rather than how they cope emotionally with the caregiving situation.

CHAPTER II: LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

This chapter provides a context and rationale for the study. To begin, the literature and research on caregiving in a psychiatric setting is critically reviewed. Gaps and limitations in current research are identified. Then, in the second section, the conceptual framework and the research questions that shape and guide this study are provided.

Psychiatric Caregiving

Research on families who live with, and care for, a mentally ill person has focused on the concept of "caregiver burden." This trend has been directed at how families emotionally respond to, or cope with, the illness rather than on what families "do" in caregiving. This is because caring for a mentally ill person causes physical and emotional strain for family caregivers. A sizable number of research findings since the 1950's documented the negative consequences of caregiving (e.g., the studies of Biegel, Milligan, & Putnam, 1994; Carpentier, Lesae, Goulet, Lalonde, & Renaud, 1992; Jones, Roth, & Jones, 1995; Reinhard, 1995). Most researchers looked at variables predicting burden, for example the ill relative's disruptive behavior, demographic variables, and socio-economic variables. More recent research has focused on situational factors such as co-residing with the caregiver, social support, and the personality traits of the caregivers (e.g., Norbeck et al., 1991; Reinhard, 1994; Rose, 1997; Solomon & Draine, 1995). The results of these studies have provided directions for clinical intervention for family caregivers in order to decrease burden, enhance communication skills, develop behavior management strategies, and prevent relapse.

Some qualitative researchers have looked at the overall experience of living with and caring for chronically mentally ill relatives (e.g., Chesla, 1989; 1994; Howard, 1994; Rose, 1992). Chesla (1989) shed some light on "caregiving practice," while Howard (1994) and Rose (1992) focused on how caregivers respond (to the illness. Recently researchers have focused more on caregiving tasks (e.g., Schene, Wijngaarden, & Koeter, 1998) and how caregivers respond and manage their emotions in order to take care of their mentally ill family member at home (e.g., Karp & Tanarugsachock, 2000). Thus, the trend in current research is likely to move toward what families "do" in terms of the kinds of activities that are unique to this context of caregiving.

There is a strong need to clarify the nature of psychiatric caregiving. The purpose of the following section is to address the questions, "What is psychiatric caregiving?," and "How does it affect both family members and ill relatives?" The specific aims are (a) to describe the experience of living with, and providing care for, a mentally ill relative ; (b) to review the concept of Expressed Emotion, research on how families and ill relatives affect each other; (c) to describe the formal health care programs available to help families; and (d) to identify the crucial issues and unmet needs of family caregivers to the mentally ill in the community. These four areas will provide the context for the research questions of the current study.

The Experience of Psychiatric Caregiving

A developing body of research examines experiences of family caregivers for the mentally ill. Most studies, to date, have been based on qualitative methods (Chafetz & Barnes, 1989; Chesla, 1988; 1989b; 1994; Eakes, 1995; Guarnaccia & Parra, 1996; Howard, 1994; Norbeck, Chafetz, Wilson, & Weiss, 1991; Rose, 1983; 1992; 1997).

Recent research has investigated caregivers' perspectives on the meaning of the illness and on their reactions to that meaning. These studies describe how families provide care, how they cope with their situations, and how they find the support to help them do so. These reports also focus on subjective aspects of caregiving, and on its emotional consequences.

Caregiving and Meaning of the Illness

Chesla (1988; 1989b; 1994), using interpretive phenomenology, investigated parents' caring practices and coping with their children with schizophrenia. Informants were 14 parents who lived with their ill adult child (diagnosed with schizophrenia and/or schizoaffective disorder). Chesla found that caregiving practices were derived from the meaning of the illness to the families, or what she called their "illness explanatory model." These included a "strong biological model," a "rational control model," a "normalizing model," and a "survival-through-symptoms model." To illustrate, the families showing preference for a strong biological model held the belief that the illness resulted from biological imbalance. Thus, they focused on food intake, medications, and other factors that would affect this imbalance. Families oriented toward a rational control model believed that they could use reasoning to manage care for their ill children. Thus, these families tried to persuade their child to think in rational ways and to behave on the basis of age-appropriate activities. They would try to keep their child away from other mentally ill people and would try to build a productive environment. As a result, according to Chesla, they would avoid bringing their child to a support group to meet other families and patients.

While caregiving patterns generally varied with the meanings parents attributed to the illness, some parents also used "secondary patterns" of caregiving, which were not always congruent with their "illness explanatory model." It was evident that other factors apart from the meaning of the illness derived from experience influenced caregiving practices. These factors included information obtained from health care professionals, from books, pamphlets, mass media, and from other family caregivers with similar experiences. This confirms findings by Rose (1997) and Norbeck and associates (1991) regarding information sources. Rose (1997) found that information from health care professionals was most helpful when congruent with the caregiver's personal knowledge about their ill relative. This congruence between outside information and lived experiences supports the caregiving role.

As explanatory models vary, so do the individual experiences and coping strategies of each caregiver. Coping strategies influence the way families provide care. For example, Chesla (1994) found four types of care among the parents of children with schizophrenia: Engaged Care, Conflicted Care, Managed Care, and Distanced Care. Persons who were very engaged in caregiving were very content with their caregiving role, whereas others experiencing conflicts between their own concerns and needs of their ill relatives found care burdensome (Chesla, 1994). Coping, therefore, is a reflection of how caregivers appraise their situation and react to it through types of care (Chesla, 1988). This work shed light on how families actually "do" caregiving but not specifically on "caregiving skill" and caregiving tasks. This study goes beyond "caregiver burden," however it is still limited to how caregivers "respond" to the illness based upon the illness

explanatory model. Nevertheless, it provides background understanding for further investigation on caregiving skill.

Another important qualitative study was conducted by Howard (1994). Using a grounded theory approach, she investigated 10 mothers who lived with, and cared for, an adult child with schizophrenia. She conducted in-depth interviews, obtaining retrospective data about their experience of caregiving from the onset of the illness until the time of the interview. The author described a model of maternal care that included "watching, working, and waiting." She also described stages of learning to live with the ill child, including "perceiving problems," "searching for solutions," "enduring the situations," and "surviving the experience." These four over-lapping stages represent learning about caregiving through the life span trajectory. For example, in the first stage, "perceiving the problem," the mothers would meet with difficulties and dilemmas. They proceeded to learn more about the disorder in stage two as they searched for solutions. By the third stage, mothers understood more about the illness and found some meaningful support to help them endure their situation. At the final stage, "surviving the experience," the mothers found ways to care for themselves and others by sharing their difficult situations while they continued caregiving. As noted above, these stages overlap and do not follow a strict linear progression. However, they are helpful in understanding adaptation to caregiving.

It is very interesting that this investigator distinguished between "maternal care" and psychiatric caregiving. She suggests that the caregiving role may be influenced by maternal factors, such as the absence of any expectations of "pay-back" for the caregiving provided. The support these mothers received came from spouses, co-workers, friends,

and health care providers who listened to their problems. In each stage the mothers manifested subjective experiences, such as grief, which were found to parallel the lifelong process of caregiving.

Bonding with the ill relative and caring without expectation of payback may not be limited to mothers. Rose (1992), using grounded theory, found that different family caregivers (i.e., spouse, parent, sibling, and adult child) continued to see the ill relative as worthy despite losses from the illness. Her study participants believed that they had a type of bond with the ill relative, which the investigator conceptualized as "power relating." Power relating gave relatives the ability to influence their ill relative and to manage the situation. The sense of being able to manage protects the family caregiver from being overwhelmed and from seeing their experience in exclusively negative terms. These findings expand Rose's earlier work on the experience of the caregiver at the time of the first hospitalization of their ill relative (1983). In an earlier study, she found that family caregivers tried to understand and accept the mental illness. They searched for past behaviors that they could identify as the cause of the illness. Their interaction with the ill relative prior to hospitalization depended on their pre-conceptions about the mental illness. Rose's later work provides insight into the other factors that influence caregiving, in addition to the meaning of the illness. These include the pre-existing relationship of the ill persons and caregivers, and situational factors such as social support, personal values and knowledge.

In summary, Rose's concept of the power of relating suggests the importance of the family in psychiatric caregiving. Health care providers merely establish a comparable bond and power of relating with the patient at the beginning of the illness. Thus, the

family caregiver is a key person who can facilitate initiation and continuation of care. In spite of the significant contribution of this research, it must be noted that the investigator focused on the perspectives of caregivers whose relatives were hospitalized. The fact that they could pause from caregiving during these periods may have influenced their interview responses.

Caregiving and Social Support

Several studies indicate that social support can be either a resource or a coping strategy for family caregivers (Chafetz & Barnes, 1989; Norbeck, et al., 1991; Rose, 1997). According to Rose (1997), who investigated the perception of social support of family caregivers of people with a chronic mental illness (schizophrenia and bipolar disorder), social support was a resource if it was perceived as available. It becomes a coping strategy when support is mobilized, or when the person seeks help to deal with stress. "Help" included professional support, friend support, family/extended family support, and spiritual support. Professional support tended to be a resource for the family when it confirmed their judgment about caregiving activities. In contrast, professional support could be a source of stress when the advice or information was vague and incongruent with the caregiver's perspectives and goals. Friends' support could be both a resource and coping strategy for the family, especially when caregivers perceived that the friends could be trusted enough to allow ventilation of feelings. Extended family provided both practical help and emotional support to caregivers. However, relatives could not always help caregivers in terms of day-to-day activities, since they were not perceived as knowledgeable about the current problems. Spiritual support could provide emotional strength. A strong belief and trust in God sometimes helped the family

caregiver to cope, and gave them hope for the patient's future. This evidence supports

other studies identifying hope as a coping strategy for family caregivers (Chafetz &

Barnes, 1989; Howard, 1994; Scott, 1994).

Norbeck and associates (1991) suggest that the social support needs of caregivers

of a chronic mentally ill relative may differ from the general social support needs of other

caregivers due to the uniqueness of the psychiatric illness. In their study, the authors

investigated the social support needs of 60 caregivers for people in three age groups: 20

children who were diagnosed with pervasive developmental disorder, 20 adults diagnosed

with either schizophrenia or bipolar disorder, and 20 elderly parents who suffered from

Alzheimer's disease. They described the differences in the support needs across the three

groups of caregivers depending on the length of the caregiving period and the stage of life

of the caregivers themselves. The general categories of social support needs of these

specific caregivers were similar to the general social support needs in other populations

(Norbeck et al., 1991). These included the needs for emotional support, feedback

support, information/cognitive support, and instrumental support. However, in-groups of

adults diagnosed with either schizophrenia or bipolar disorder, unique support needs were

derived from the disruptive behavior of the ill relative. Norbeck and associates focused

on the types of support that family caregivers needed, whereas Rose's (1997) study,

focused on the resources that the caregiver could rely on. Together, these two studies

offer an initial comprehensive picture of what caregivers of chronically mentally ill

relatives need, and clarify how and where caregivers seek help.

Guarnaccia and Parra (1996) conducted a study focusing on the personal values

and cultural factors that influenced the caregiving experience. The investigators

completed in-depth interviews with 90 families (45 Hispanic-Americans, 29 African-Americans, and 16 European-Americans). Interviews were used to obtain data on their experiences with the health care system, their social support needs, their perceptions of the illness, and problems that arose for them while caring for their ill relatives. The results showed that European-American caregivers, who believed that the mental illness was a medical problem, would seek help from the health care providers more frequently than those in the other two groups, who believed it came from a wide range of causes. This tendency influenced how they sought social support. African-American and Hispanic American families sought support from family members more than European-Americans families who sought support from health care providers. Furthermore, more European-American caregivers reported negative effects of caregiving on their physical and mental health. Unfortunately, some aspects of the methodology of this study limit the value of these finding. For example, the authors did not adequately address methods for analysis of interview data, which appeared limited to a simple content analysis, nor did they explain comparisons between groups with different ethnicities. In addition, the authors did not mention any procedures to prevent response bias, specifically bias introduced by ethnicity of interviewers and interviewees. Different ethnicity and cultural backgrounds may influence both subjects' responses and their interpretation by interviewers.

Caregiving and Grief

Chronic mental illness never ends. Although the level of function may improve, vulnerability to psychosis appears to be long term. Furthermore, schizophrenia and related disorders typically have an onset in early adulthood, disabling a person who has a

full life to live. These realities are the major factors that trigger feelings of loss, sadness, and grief in the caregivers. Eakes (1995), using a qualitative approach, interviewed ten parents of adult children with schizophrenia using the Burke/NCRCS Chronic Sorrow questionnaire (caregiver version). She found that eight out of the ten parents experienced "chronic sorrow." These parents reported anger, frustration, and confusion that occurred periodically over the course of the child's illness. The on-going nature of the illness and the prospect of endless caregiving were the major factors that triggered chronic sorrow. It is interesting to note that the two parents who did not show chronic sorrow were a stepmother and biological father . This suggested that family structure and blood-bonding (maternal love or bonding) influenced chronic sorrow. It is important to note that the author did not provide information about living situations and the employment of specific child/parents dyads. Two out of the six ill children were employed and three lived with their parents, whereas, two lived separately in the same town, and one lived in a nearby town for one year. Factors such as living nearby or working independently may have influenced the parent's feeling. Thus, these variables may also be factors that affect chronic sorrow. Further research should pay careful attention to these factors.

<u>Caregiving and Coping Strategies</u>

Out of the broad range of coping strategies, those most frequently employed in psychiatric caregiving include cognitive and action-oriented strategies (Eakes, 1995). In the Eakes study referred to in the previous section, only three of the parents who experienced chronic sorrow used emotional coping strategies. Their experience of chronic sorrow appears similar to the grief experiences of mothers in Howard's (1994) study. Eakes also asked about the factors that parents found helpful and not helpful when

they experienced chronic sorrow. While parents found some health care professionals were helpful, all had major conflicts related to lack of communication and their own involvement in the treatment regimen. This suggests the need to respect parents as important sources of care and to include them in the process of treatment planning.

Caregiving and Social Isolation

A number of studies cite the stigma experienced by families. Sometimes this reflects ideas families and others have about causation of illness, leading to self-blame for the illness (Rose, 1983); or, being blamed by others (Chafetz & Barnes, 1989; Kelly & Kropt, 1995; Lefley, 1996). The unpredictable nature of disruptive or deviant behavior is another issue that makes families voluntarily isolate themselves from social or leisure activities (Chafetz & Barnes, 1989; Kelly & Kropt, 1995). However, some family caregivers appear to build their own networks to support each other, for example, the groups offered through the Alliance for the Mentally Ill (AMI).

Uncertainty is a concept thought to be particularly pertinent to the experience of caregiving for persons with chronic illness, and it is probably not limited to psychiatric caregiving. Chafetz and Barnes (1989), using a qualitative approach, interviewed 20 caregivers about their problems. They found that because the course of the mental illness is unpredictable, it triggers feelings of uncertainty that increase the burden of care. Ironically, they found that uncertainty also permitted hope for a better life for their ill relative. In their sample, caregivers also felt loneliness despite the use of support groups. Family members perceived themselves as alone on this path of caregiving. Understanding was not enough for them, since it did not reduce isolation. They needed other people's help. Since the need for privacy was another factor that influenced them,

they sought support from family members first, followed by other friends who were in similar caregiving situations.

Caregiving and Managing Emotion

Karp and Tanarugsachock (2000) investigated how caregivers of people who suffer from depression, manic-depression, or schizophrenia managed their emotions over time. They found four stages of emotional experiences. These included "emotional anomie", "getting a diagnosis", "perceiving illness permanency", and "acceptance." These four stages moved the caregiver from the bewilderment about an illness to an understanding that they cannot control the illness of their relative and, eventually, greater acceptance. Moreover, accepting involved knowing they cannot control the illness, which required caregivers to let go without guilt, to still love their ill relatives, and to live life together.

Summary and Critique

In summary, family members develop their own sense of meaning and their own caregiving practices and emotion management in providing care over time. Two studies (Chesla, 1988; Howard, 1994) focused on what families "do" in the caregiving situation. The other researchers focused on how caregivers try to "survive" or "cope" with the caregiving situations. This ranged from managing their own life patterns and emotions, to seeking help from others. The sources of information about the mental illness and about caregiving roles could be from friends/families, health care professionals, or published materials. Integrating their own lived experiences with information from others helps people take on the caregiving role effectively. Their subjective experiences include chronic sorrow, loneliness, stigma, guilt (self-blame), uncertainty, and hope.

Some people express positive feelings about caregiving in that they feel satisfied with their caregiving role and expect no 'pay-back.'

Although the studies cited here provide good insights into the experience of psychiatric caregiving, it should be noted that almost all of the informants in these samples were drawn from support groups or from health care agencies. For example, Chesla (1988; 1989b; 1994) and Howard (1994) recruited their subjects from a group of the Alliance for Mental Illness (AMI). The majority of the caregivers were parents, in particular, mothers. These selection biases must be taken into consideration when interpreting the findings. According to a national survey of National Alliance Mental Illness (NAMI) members, family caregivers/parents who participate support groups are predominantly Caucasian and usually from upper middle class families (Biegel & Song, 1995; Steinwachs, Kasper, & Skinner, 1992). They are knowledgeable, articulate, and want to share their perspectives to let their voice be heard. They may not represent other caregiver groups who are not members, who come from more diverse and/or under-served populations, and who feel socially isolated, marginalized and powerless.

The criteria for chronic mental illness varied from one study to another. Some defined the concepts of chronic mental illness and caregiver clearly (e.g., Chafetz & Barnes, 1989), while others did not. Generally, the modal diagnosis contributing to disability or chronicity was schizophrenia. However, not all people with schizophrenia are dependent on caregivers. Other factors such as deviation of illness and variations in functional level might alter the experience of the caregiver and change the results of research. If, for example, Eakes' (1995) had provided information about the living situation and employment of specific parent/child dyads, we would know whether these

variables influenced chronic sorrow, a subjective experience of the caregiver in that study. At a time when the consensus regarding diagnostic categories has not been fully achieved, researchers should be sensitive to the need for careful reporting of results. This lack of consensus and diagnosis is still a problem in research on chronic mental illness. It is a potential threat to the generalizability of research results since the information we obtain may come from different contexts of caregiving related to types of mental illness.

The maternal aspect has not been adequately addressed, although, the majority of caregivers for people with a chronic mental illness are mothers. This invisible aspect of care may influence caregiving practices and experiences, in that maternal care is often accompanied by a type of bonding that provides gratification to caregivers. It is important to look at how mothers feel and distinguish between maternal care and other extended care.

In addition to other research on the caregiving experience, a number of studies have addressed caregiver burden, a negative caregiving consequence of living with, and taking care of, chronically mentally ill relatives. Researchers have investigated the premise that psychiatric caregivers experience burden as a result of their roles. What is still unclear is the definition of burden, how it is measured, and what factors affect the perception of caregiver burden. These are interesting questions which some of the research discussed below should clarify.

Caregiver Burden

Burden is a concept that represents the negative consequences of caregiving. It has been studied among caregivers of the chronically mentally ill since the mid-1950s and early 1960s (Loukissa, 1995; Maurin & Boyd, 1990). Psychiatric burden has been

conceptualized as the difficulties encountered in the caregiver's life as a result of taking care of mentally ill relatives (Platt, 1985; Maurin & Boyd, 1990). In the literature since the 1960's, burden has usually 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 in taking care of the mentally ill relative, such as the decrease of family leisure time and vacations, or financial loss from the 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, Roth, & Jones, 1995; Maurin & Boyd, 1990).

Earlier studies, published in the 1960s-1980s, investigated various factors associated with burden. These included the characteristics of the ill patient, the characteristics of the caregiver, the association of the two dimensions of objective and subjective burden, factors that mediate burden, the effect of burden on the family, and intervention programs influencing caregiver burden (Loukissa, 1995; Maurin & Boyd, 1990). Despite this body of work, there is still a great need to clarify the effects of burden on the family. Limitations in past research constrain our understanding of caregiver burden. These include a paucity of theoretical frameworks, inconsistencies between the theoretical and the operational definitions of burden (Maurin & Boyd, 1990), and the complexity of the phenomenon of burden itself. Recent research has begun to more rigorously investigate the personal and situational factors that affect caregiver burden (Rose, 1997).

<u>Personal and Situational Factors Associated with Caregiver Burden</u>

There are a number of factors identified in research between 1989-1998 associated with caregiver burden. These factors include: (a) personal factors - characteristics of the ill relatives, i.e., functioning level and the severity of the illness; characteristics of the caregivers, i.e., age, state/trait personality; and (b) situational factors, i.e., level of social support, living with the ill relative. The following section reviews these factors in terms of their implications for the caregiving experience.

<u>Characteristics of the Ill Relative</u>

Factors such as the ill relative's disruptive behavior, functional level, diagnosis, duration of the illness, and gender affect caregiver burden. The relative's disruptive behavior is a major predictor of burden (Biegel, Milligan, Putnam, & Song, 1994; Reinhard, 1995; Song, Biegel, & Milligan, 1997). In a study by Reinhard (1995), the relative's behavior explained 23% of the variance associated with caregiver burden. Disruptive behavior was highly correlated with burden in work by Biegel et al. (1994) and Song et al. (1997). Song and his associates found that it explained 57% of the variance of caregiver burden when taken together with the other contextual variables (such as caregiver health and social support). While this evidence strongly confirms the effect of disruptive behavior on burden, two studies (Biegel et al., 1994; Song et al., 1997) apparently used the same sample. This might bias the results and limit any generalizability. Additionally, the inconsistent characterization of disruptive behavior lessens external validity. It is apparent that the three main studies used different tools to assess disruptive behavior although all instruments showed good individual reliability.

Solomon and Draine (1995) found that after controlling for family characteristics, stresssors related to severity of illness explained 6% of the variance in subjective caregiver burden. These illness-related stressors included schizophrenic diagnosis, hospitalization, functional level, year of illness, current crisis, and living situation.

The gender of the ill relative, and the duration of the illness were also associated with disruptive behavior and with caregiver burden. Parents who cared for a female child and parents who cared for long periods reported more burden related to disruptive behavior (Cook, et al., 1994). Gallagher and Mechanic (1996) also found that living with a person with a long-term illness was significantly correlated with poorer health of the caregiver.

Winfield and Harvey (1993) found that caring for an ill female relative was associated with greater caregiver burden. Moreover, caring for a "non-turbulent" ill relative (turbulence refers to reckless, destructive, violent behavior and trouble with drug abuse and police), as measured by Life Skill Profile (Rosen, Hadzi-Pavlovic, & Parker, 1989), was associated with less caregiver burden. This study investigated positive variables that predicted caregiver burden and caregiver distress. However, the statistical findings are not reported clearly enough to determine the unique contribution of each variable in explaining the variance of the caregiver outcomes.

Consistent with research on disruptive behavior, symptomatic status seems to influence perceptions of caregiver burden. Health care professionals also use the diagnosis of the illness in order to predict caregiver burden. Mueser, Webb, Pfeiffer, Gladis, & Levinson (1996) investigated the perception of health care professionals and caregiver themselves in terms of burden related to manic symptom in persons with

bipolar disorder. They found identical results in both caregivers and health care professionals in terms of the correlation of burden with symptoms. Relatives of persons with bipolar disorder reported significantly more burden from manic symptoms than did the relatives of people with schizophrenia. This finding is congruent with reports from professionals who believe that caregiving for bipolar disorder was most burdensome because of manic symptoms.

In the same source, looking at ratings for negative and positive symptoms, there were no differences in burden reported by caregivers of bipolar disorder and the caregivers of people with schizophrenia. This is not congruent with the health care professionals' position. Mental health professionals believe that caregiving for schizophrenia would be more burdensome than caregiving for bipolar disorder, in relation to positive and negative symptoms. This suggests the presence of a false assumption by outsiders in terms of burden correlated with specific illnesses. This assumes that schizophrenia posed more difficulties than other psychiatric disorders in the "chronic mental illness" category. This may reflect a bias in terms of schizophrenia from researchers who have given particular attention to this illness.

Characteristics of the Caregiver

When individuals take on a caregiving role, they also bring their own personalities, cultural backgrounds, their knowledge and skills, and past experiences into the caregiving process. Some of these factors may serve as a buffer for caregiver burden while others may be precipitating factors. The effects of these personal factors on caregiving and perception of the caregiver burden will be reviewed in the following section.

Ethnicity is associated with the perception of caregiver burden (Cook, Lefley, Pickett, & Cohler, 1994; Horwitz & Reinhard, 1995). Cook et al. (1994) found that White parents had higher burden related to disruptive behavior than other ethnic groups. Horwitz and Reinhard (1995) found that after statistically controlling for income, gender, age, diagnosis, perceived stigma, and living situation, ethnicity explained 16% of the variance in caregiver burden. Black and White parents did not differ in engaging in caregiving duties, but White parents were more likely to perceive burden than Black parents ($p < .001$). This direction is the same for sibling groups although it was not statistically significant; Black siblings engaged more in caregiving duties ($p < .001$) but were less likely to perceive burden than White siblings. The differences in ethnicity reflect different cultures, beliefs, and also different perceptions of the illness. The authors also examined feelings of stigma of these caregivers and found that Black caregivers perceived mental illness as less stigmatized than White caregivers. Stigma influenced the perception of burden of these caregivers. White caregivers who perceived that mental illness was more stigmatized were more burdened by caregiving. Therefore, the perception of stigma is another factor which influences burden perception, in addition to the ethnicity of the caregiver.

Although the results provide good insights into the effects of ethnicity on caregiving and caregiver burden, it should be noted that "caregiving duty" was measured by a tool which contained only two questions: "How involved are you in (name's) life?" and "How much responsibility do you have for taking care of (name)?" (Horwitz & Reinhard, p.142, 1995). Each caregiver was asked to rate the answer 1 through 3 to represent "none" to "a great deal." Although the tool demonstrated good validity and

reliability, the closed-ended question style does not elicit substantial information. Further, these self-reports may be influenced by several factors including the ethnic match between interviewer and interviewee, the subjects' attitude toward the interview situation, and the tendency to provide a socially desirable response. Despite these problems, this study identified a significant variable affecting caregiver burden and made the researchers aware that the perception of burden is not value free.

The age of the caregiver is associated with caregiver burden (Cook et al., 1994; Winfield & Harvey, 1993). Winfield and Harvey (1993) found that older female caregivers, typically mothers, reported less burden. In contrast, Cook and associates (1994) found that older parents had significantly higher levels of burden in terms of ongoing responsibility for the child in the areas of finances, shelter, and "ultimate obligation." This discrepancy reflects different conceptualizations of burden. The first, by Winfield and Harvey (1993), measured burden in terms of the impact of specific caregiving tasks on caregivers' employment, housework, and social relationship. The latter measured subjective burden (worrying about their ill child's life). However, the results of these two studies suggest the importance of the caregiver age on perception of burden. It seems that older caregivers find that caregiving tasks affect their life less than those of younger caregiver, who may need to work outside the home competing demands from employment, family, and from their social life. However, when caregivers age they may worry about their ill child's future including concerns about who would assume a caregiving role when they are no longer able to do so.

Furthermore, Cook and associates (1994) found that younger parents reported more burden related to their children's behavior than did older parents. Parents who had

a higher formal education reported less burden related to the adult child and his/her needs, less worry on their behalf, and less responsibility for their well-being. This suggests that the caregivers time in role and educational level may influence their ability to problematic behavior. It also suggests that they seek information and support over a period of time. This study did not control for social support when attempting to identify the predictors of caregiver burden, a potential bias.

Finally, a sense of mastery (Reinhard, 1994; Solomon & Draine, 1995), and self-efficacy (Solomon & Draine, 1995) is negatively correlated with burden. Solomon and Draine further found that satisfaction with coping was significantly negatively correlated to caregiver subjective burden. These two studies suggest the importance of the personality traits of the caregiver. The personality traits might endow caregivers with either strength or vulnerability in facing difficult situations.

Situational Factors

Social support, professional support, and family support are significantly and negatively correlated with subjective burden (Biegel et al., 1994; Reinhard, 1995; Solomon & Draine, 1995). Support has also been shown to reduce caregivers' psychological disturbance, negative affect, and emotional upset (Winfield & Harvey; 1993).

Living with an ill relative is a major factor influencing sense of burden. Solomon and Draine (1995) found it was positively correlated with caregiver burden, explaining 6% of the variance of subjective burden. Gallagher and Mechanic (1996) found that it decreased women caregiver's physical health with a corresponding increase in the number of visits to their physician, and limited their activity. In contrast, Winfield and Harvey

(1993) found no difference between caregivers who lived with their ill relative and those who did not, in terms of caregiver psychological distress. However, in this study these caregivers lived with their mentally ill relatives who were more likely to be their sons or daughters and who had fewer "turbulent behaviors" and more "responsibility" behavior as measured by the "Life Skills Profile" (Rosen, Hadzi-Pavlovic, & Parker, 1989). This might confound the results because non-turbulence was negatively correlated with caregiver distress.

Solomon and Draine (1995) also found that ill relative's functional level was negatively associated with caregiver burden. Furthermore, when the authors evaluated the feedback comments of caregivers, 34 out of 134 of caregivers expressed relief and felt their life had eased once the ill relative no longer resided with them. This indicates that some caregivers prefer to live separately from the ill relatives to reduce feelings of distress. To be able to live separately also indicated a high functional level of the ill relative and the adequate of external social and community support. In summary, living with the ill relative seems to affect the physical and psychological well-being of the caregiver, depending on the functional level and disruptive behavior of the ill relative.

Summary and Critique

Generally, two broad types of factors affect caregiver burden: personal and situational. Personal factors refer to characteristics of the ill relative and the caregiver. Situational factors include social/professional/family support and the living situation. Some characteristics may be a buffer for caregiver burden, such as sense of mastery and self-efficacy of the caregiver. Some may be a major predictor of caregiver burden, such as the disruptive behavior of the ill relative. If the caregivers receive support and

information on how to manage disruptive behaviors, it decreases their sense of burden, supporting the need for further study of caregiving skill. Living with the ill relative appears to increase burden, particularly in the context of disruptive behavior, although this variable needs further study. The age of the caregiver also predicts burden. Age influences problems and concerns. However, further studies of age and caregiving need to control confounding variables such as social support and skills in behavior management.

This body of research would show enhanced validity if the studies used consistent measures for key variables or used standardized instruments (for example burden scales, and disruptive behavior scales). Many researchers developed their own tools to measure disruptive behavior. Additionally, burden is inconsistently conceptualized and operationalized. This also poses a threat to internal and external validity. For example, some researchers identified objective burden as the prevalence of the task existed (Jones et al., 1995). The caregiver was asked to select tasks from a pre-determined list in terms of their "prevalence." The "prevalent tasks" identified by the caregiver were then interpreted as the caregiver's objective burden. However, objective burden may not be determined by specific tasks provided, but rather by the tangible cost that resulted from the tasks, such as decreasing their leisure times or vacation, or disturbing work. In this sense a specific task may or may not have overload or burden them. Thus, the problems of conceptualization and measurement can reduce the validity of the results.

Caregiver burden is a negative consequence of taking care of the mentally ill relative. In other words, it is how the ill relative negatively affects caregiver's well-being. In another body of studies, researchers have investigated how the family caregiver affects

the ill relative or the course of illness. Many of these focus on the construct of

"expressed emotion."

Family Affective Tone: Expressed Emotion Research

During the past three decades a substantial literature has developed on family

affective tone and clinical outcomes. Much of research focuses on the construct of this

literature consists of Expressed Emotion (EE). This line of research originated from a

group of British investigators who noted higher rates of hospital readmission among

persons living in family homes compared to persons discharged to "Lodging Houses"

(Brown, Bone, Dalison, & Wing, 1966). They hypothesized that the emotional

environment of the family household might lead to re-admission. Three of five

dimensions of EE have been considered as the salient factors predicting relapse of the ill

relative. These include criticism, hostility, and emotional over-involvement. Two other

dimensions of expressed emotion that were not associated with relapse were warmth and

positive comments. Despite its limitations, the model of expressed emotion is still

considered important in predicting relapse in schizophrenia and other disorders.

The EE concept has limitations including confusion about whether it is a 'state' or

a 'trait.' Several studies show that EE levels among parents decline during the period of a

hospitalization (e.g., Kuipers & Bebbington, 1988; Parker et al., 1989). Based on similar

empirical evidence from other studies, EE may be more likely to represent a state than

trait (Birchwood & Smith, 1987). If it were a state, it would change over time implying

measurement difficulties. A second concern regarding this concept is its potential, by

linking symptoms to family factors, to promote blaming the family as the "cause" of the

illness (Hatfield & Lefley, 1987). A third limitation is that the model focuses on

relatively few select risk factors for relapse without testing the other situational factors which might effect EE level and/or relapse rates (Linszen, Dingemans, Nugter, Van der Does, Scholte, & Lenior, 1997).

Recent research studies expand knowledge about these factors, such as socio-demographic variables that might affect both EE level and relapse rates (Linszen et al., 1997), the association of EE with perceived burden (Scazufca & Kuipers, 1996), and systematic study of the dynamic pattern of EE (Wuerker, 1996). Linszen and associates (1997) studied risk factors for relapse in addition to EE. These included gender, education, prognostic score (clinical psychiatric assessments), pre-morbid functioning, income, one-parent households, age at onset of first psychotic episode, type of onset, prior psychotic episodes/admissions, schizophrenic diagnosis, psychopathology score at the end of treatment, substance abuse, and duration of untreated psychosis. They used a stepwise survival analysis and Cox regression model to select possible predictors. The result showed that high EE remains the major predictor of relapse. Within this group, cannabis abuse is another factor that significantly predicts relapse although there is no interaction between cannabis abuse and EE. This study strongly confirms that EE level is a significant predictor of relapse after taking the other possible risk factors into account.

The central question about EE and caregiver burden is, "Does EE result from the reciprocal interaction between ill relative and caregiver?" Wuerker (1997) studied the communication patterns of both high and low EE families in schizophrenia and bipolar disorder. She used a Markov model that allowed her to capture the process and the dynamics of the communication patterns over time. She divided the analysis into two groups: one for the dyadic family (ill relative with one parent) and another for the triadic

family (ill relative with two parents). For the overall sample (both high and low EE-families) a person's response depended on the initial message they sent and the response from other people. For the dyadic families, the results showed that in families of people with bipolar disorder, EE status had a slight effect on communication patterns. The high EE-families were more likely to respond to neutral messages with an attempt to control than were low EE-families. In contrast, high EE families of people with schizophrenia were more likely to respond to either a neutral or a dominating message by asserting control. The low EE families did not compete for control. In the triadic family, both high and low EE-families of people with bipolar disorder were competitive for control. While low-EE families with schizophrenia were less likely to compete, high EE-families strongly competed for control.

The different results between the dyadic and triadic families in bipolar disorder and the finding that dyadic families were not as competitive as triadic families, suggests that the number of people can alter the communication pattern in families. In reality, people with mental illness have a chance to communicate with all members in their families. The sibling's communication style and that of other household members should be taken into consideration when studying the communication patterns of the family. This study provided insights on EE as a result of a reciprocal communication process in which both parents and ill relative affect each other. Additionally, this might demonstrate limits of a research dominated by data collection from one principle family member.

Should high EE-families also perceive a high burden of care? One implication of the EE concept is that family members are less likely to have a positive attitude toward the ill relative, as evidenced by hostility and criticism, two dimensions of high EE. The

emotional over-involvement dimension reflects the responsiveness of the family members involved with the ill relative's life. Scazufca, and Kuipers (1996) showed that high EE-families perceived more burden, in both objective and subjective dimensions, than did the low EE-families. High EE-families also reported more deficits in the ill relative's social role performance. This result reflects the negative affective tone that the caregivers had toward the ill relatives in high EE-families.

Barrowclough and associates (1996) tested how the EE level was associated with caregiver distress and attributions in relatives of people with schizophrenia. They found that high EE-families reported more depressive reactions than did low EE-families on a subscale of the General Health Questionnaire (GHQ; Goldberg & Williams, 1988). These results confirm previous findings that high EE-families are more affected by the ill relatives (Scazufca & Kuipers, 1996). These findings also indicate that this group of families should receive psychoeducation interventions, not only to reduce relapse of the ill relative, but also for their own physical and psychological well-being. However, low EE-families should not be overlooked when helping them deal with caregiving situations. They also reported burden, although to a lesser degree, than high EE-families.

Summary and Critique

Research on expressed emotion expanded from a narrow focus on relapse to include variables such as burden and stress, both of which could be considered caregiver outcomes. It is evident that EE might be a result of reciprocal communication processes between the family members and the ill relative. The more negative tone family members had in terms of their ill relative, the more hostility and criticism of their behavior. High EE families are more likely to report burden/stress in taking care of their ill relatives and

are more likely to report deficits in the ill relative's social role performance. This confirms not only that EE is a robust predictor of an ill relative's relapse, but it could also explain high levels of burden. Disruptive behavior, which is a major predictor of caregiver burden should be added as a variable in the EE studies. However, the theoretical structure of EE is still not clear. The ill relative's disruptive behavior may, or may not, cause family members to be highly critical. It may or may not be a precipitating factor for high EE status. Despite the need for further research, this concept appears to be related to burden and has strongly shaped intervention research.

Intervention Research

The various kinds of programs aimed at helping families with a relative with chronic mental illness can be broadly categorized into family psychoeducational programs, support groups, and formal community support programs. Psychoeducational programs will be reviewed in depth because of all the interventions they have been most validated in clinical trials. They are currently recommended in practice guidelines for treatment of schizophrenia (Lehman, Steinwachs, & et al., 1998). The other programs will be briefly discussed.

Family Psychoeducational Programs

Family psychoeducational interventions developed in tandem with research on family stress/burden and EE research. These interventions address the psychological well-being of both families and ill relatives and focus on areas such as caregiver burden/distress and high relapse rates of ill relatives. Family psychoeducational programs originated in the 1970s and 1980s and include the work of Goldstein, Rodnick, and Jones, (1978); Falloon et al., (1985); and Anderson, Reiss, and Hogarty, (1986). As a group,

these interventions propose the following objectives: (a) to increase the knowledge of mental illness, its treatment, and behavioral management, (b) to teach and enhance coping strategies, and communication skills and/or provide support resources and information, (c) to establish a relationship between the health care provider and family, (d) to decrease cost of care.

Tenets of the Program

There are five main types of psychoeducational programs that share common features but are differentiated by their specific objectives.

1. Crisis-Oriented Family Treatment developed by Goldstein and his associates (1978) is aimed at decreasing family crisis. This program was designed to help the ill relative and family via six lectures during hospitalization. It included discussion and counseling in the areas of stress management, coping strategies, and information relevant to the current psychotic episode.

2. The Psychoeducation Program by Anderson and associates (1981; 1986). This program's specific aims include: (a) providing knowledge in the area of mental illness and its treatment; (b) strengthening families' capacity in the area of coping strategies and problem solving; and (c) establishing the connection between families and health care professionals. There are six sessions in a model training program. Session 1 focuses on the introduction to the principles of psychoeducation and the experience of schizophrenia for ill relatives and families. Session 2 focuses on teaching about mental illness and treatment and information about coping with schizophrenia. Session 3 focuses on the connection between practitioners and families. The aim of session three is to understand family backgrounds and problems. Thus, the tasks in this session include reviewing the

patient's history and treatment. Session 4 focuses on behavior management, medication compliance, and how to take care of the ill relative's needs and demands. Session 5 focuses on issues of vocational and social skills. The last session focuses on other family issues, for example, parental issues, and childbearing. The phases and duration of each session are flexible.

3. The Behavior Family Management Model (BFM; Falloon and associates, 1982; 1985a; 1985b) is aimed at teaching families effective problem-solving and communication skills. This program is conducted both in the family's homes and in the hospital. The individual family's needs and strengths are first assessed at intake. Education about the mental illness and its treatment, as well as problem solving skills is provided in the family home. Multifamily groups are conducted in the hospital setting after the first 9 months of in-home sessions.

4. The Family Social Intervention Program developed by Leff and colleagues (1982; 1985a; 1985b) is aimed at reducing relapse of the ill relative. The family intervention includes a home-based psychoeducation program, a multifamily support group, and home-based family therapy through four lectures and four home visits.

5. Psychoeducational Multifamily Group program (PEMFG). A major study of the Psychoeducational Multifamily Group program was developed by McFarlane and his colleagues (1994, 1995). This approach was derived from previous programs (excluding the crisis-oriented program of Goldstein). The investigators' aim was to compare the PEMFG with two conditions: (a) psychoeducation and single-family therapy (PESFT), and (b) multifamily groups who received no education. The intervention begins with a lecture, followed with problem solving techniques during 2 years of biweekly meetings

with the clinician. During the clinical trial, monthly sessions continue for 2 years or until the ill relative relapses. Ill relatives attend only the sessions on illness management. In the single family sessions, the clinician meets with the family alone.

Outcome Parameters

Because these five intervention programs share certain common features and aims, their outcome parameters are similar. These can be categorized into two broad areas: (a) family member outcomes, and (b) ill relative outcomes.

Family member outcomes. The decrease of family distress/ burden was the aim of several programs through stress management, coping strategies for daily living, and problem solving. As predicted, the intervention reduced family distress and burden as evident from the differences of pre-post test score from non-equivalent comparison group (F = 2.17) (Kane et al., 1990) and from the report of the family in the treatment group (Falloon, & Pederson, 1985; Falloon et al., 1982).

Ill relative outcomes: symptom control and relapse rate reduction. In these programs, the information provided on communication skills and behavior management directly affected family EE and increased behavior management skills. The results show that the intervention programs seem to be a robust buffer against the relapse of the ill relative. It is evident that family members who attended the intervention program reported significantly decreased relapse rates than those others at 6 month, $p < 0.05$, (Goldstein et al., 1978); at 9 months ($p < 0.01$) and 2 years ($p < 0.001$) (Falloon et al., 1982; Falloon & Pederson, 1985); at 9 months ($p < 0.05$) but non-significant reduction at 2 years (Leff et al., 1982; 1985a); at 1 and 2 years follow-up ($p < 0.01$) (Hogarty et al., 1986; 1991); and at 1 years ($p < 0.01$) (Randolph, 1994).

Comparison between the single family and multi-family groups showed that the psychoeducation multi-family groups had significantly lower relapse rate after four years, and two years respectively (McFarlane et al., 1994; 1995). Some studies also found a positive effect of the intervention programs on the care recipient's functioning (Falloon & Pederson, 1985; Falloon et al., 1982; Levene et al., 1989).

<u>Comparisons of Intervention Models</u>

To date, only a few studies have compared different model programs. Recent work of McFarlane and his associates (1996) compared multi-family programs and crisis intervention programs. The families and ill relatives in the multi-family groups, comprised of six ill relatives and their family members, met with two assertive community treatment teams (described by Mueser et al., 1998) twice a month for two years after completing the psychoeducational workshops. The assertive community treatment teams facilitated discussions on problem solving techniques based on concerns and questions of group members. The crisis family intervention group received only psychoeducation intervention during the crisis period and on a single family basis. The results showed that ill relatives who received the multi-family intervention reported a higher rate of employment than did their counterparts in the crisis family intervention group. However, this outcome parameter is difficult to explain since it does not correspond with the content of the program provided. In other words, occupational advocacy was not in the outline of either program. However, Smeby (personal communication, 1998), who conducted multi-family interventions in Sweden, found that some parents in multifamily groups provided employment opportunities to other parents' sons/daughters. In other words, they developed social networks that enhanced the

employment rate of the ill relatives. In addition, Penn and Mueser (1996) reviewed 12

studies and found that intervention programs conducted for at least nine months were

more likely to decrease relapse than programs offered for only three months.

Support Groups

Biegel and Song (1995) state that support groups originated in US as early as 1635

when the "Scots Benevolent Society" emerged to meet the needs of families with a

member suffering with mental illness. The numbers of support groups have substantially

increased in the past two decades, due to patients' rights and family organizations. One

example of well-established support groups in the US are those provided through local

chapters of the Alliance for the Mentally Ill (AMI). The National Alliance for the

Mentally Ill (NAMI) was founded in the US in 1978. There are now approximately 1,040

local chapters that have approximately 8,700 family members (Steinwachs, Kasper, &

Skinner, 1992). NAMI local affiliates offer drop-in groups and other forms of support.

Surveys of NAMI members indicate that the majority are White (Steinwachs, Kasper, &

Skinner, 1992) and upper middle class (Biegel, & Song, 1995). However, these data

describe members of the national organization, and may not apply to "drop-in" members

who use support groups in local chapters. Cook and Knox (1993) stated that support

groups affiliated with NAMI try to reach out to families from lower socio-economic

status, but they have achieved only moderate success.

The Tenets of Family Support Groups

Most family support groups are self-help groups in which the members of the

group are expected to take primary responsibility for the direction of the group. Health

care professionals may lead some. The guiding principle of the self-help group is the

belief that change will occur through reciprocal helping in which members share experiential knowledge, serve as role models, and deal with current issues of relevance to the group members (Hatfield & Lefley, 1987).

Factors Affecting Support Group Participation

The support group, unlike the other intervention programs, is based on voluntary participation. Although other types of programs may be voluntary, they are more likely to be a part of treatment such as psychoeducation programs, and more likely to be conducted in the hospital or health care agencies. According to Yeats and associates (1992) the factors affecting support group participation include knowledge, accessibility, and intent to utilize services. The desire to maintain privacy may also influence participation (Chafetz, & Barnes, 1989).

Biegel and Song (1995) interviewed 94 White and 104 African-American caregivers from lower social class families (as indicated by the Hollingshead and Redlich Scale). They found that of the 151 caregivers who were not members of support groups, 42% had never heard of support groups for families of persons with mental illness. Among 134 caregivers who had heard about support groups, 36% were current support group members and 64% had never participated in a support group. Among those caregivers who were support group members, 79% heard about the support group from a health care professional while 33% heard from nonprofessional sources such as newspapers, TV, Church, and relatives/friends.

Consistent with other study findings, factors presenting a barrier to support group participation include concern for privacy and lack of accessibility. Further factors included lack of time, lack of need, and difficulty with transportation. All factors were

reported by both White and Black informants, except lack of transportation, which was reported significantly more often by Black caregivers than did White caregivers. Biegel and Song (1995) also asked these caregivers about "hypothetical" barriers. The results show that lack of time, accessibility, transportation difficulties, difficulty in sharing feelings, confidentiality, fear of neighborhood crime, lack of need, and not knowing anyone in the group were all "hypothetical" barriers for both Black and White caregivers. Only fear of neighborhood crime differentiated Black subjects from White subjects, with Black caregivers reporting more fear of crime.

Recommendations from the health care professional were a significant factor, both as the source of notification about the group and as the "facilitating" factor to join the group. The strong point of this study is that it was conducted with the lower socio-economic class families that have been found to be less likely to join support groups. Also, this study shed some light on the factors that need to be considered for the success of support group interventions.

Outcomes

Studies of support group outcomes have examined satisfaction (Biegel & Yamatani, 1986; 1987; Kane, DiMartino, & Jimenez, 1990), personal benefits, increased knowledge about mental illness and its treatment, coping ability, problem solving strategies (Kane et al., 1990; Norton, Wandersman, & Goldman, 1993), and caregiver's well-being outcomes such as depression and distress (Kane et al., 1990). Family members who have joined support groups report positive effects in each of the different outcome domains.

Formal Community Support Program

In the US, the locus of care for people with mental illness has changed over time. It can be categorized into three different periods, a pre-institutional, institutional (asylum), and a deinstitutional period. From the 19th century to the deinstitutional period, people with mental illness were treated in long-term hospitals and were separated from their families. The deinstitutionalization process began in the 1950s with the introduction of antipsychotic medications. Criticism of State Mental Hospitals, belief in the superiority of community based care, and advances in drug treatment were major factors changing the locus of care from hospitals to community settings. Many former residents of long-term facilities were discharged to families (Chafetz, Goldman, & Taube, 1983). Currently, newer cohorts of people with severe and persistent mental illness have been diverted from long term hospital care, avoiding long separations from families.

Community Support Programs

To respond to the changes in the locus of care, various kinds of community support models have been developed in the US. These can be categorized in terms of common and unique features. They all share the basic principle of providing a range of supports to patients which are not limited to psychiatric treatment and which include help with housing, medical care, and income (Mueser et al., 1998). In this way, community support programs can decrease the burden on families and increase family collaboration within formal systems of medical care.

The most intensive community support programs include Assertive Community Treatment (ACT) and Intensive Case Management Models (ICM). Both models share the feature of intensive support (e.g., frequent contacts, outreach), while used the

multidisciplinary team (ACT) or a Clinical Case manager (ICM). These two models have been modified to suit specific populations in different settings and circumstances. They have had varying success in their implementation (Mueser et al., 1998). They have been recommended in the treatment guidelines for schizophrenia, especially for people with high acute care utilization (Lehman, Steinwachs and others, 1998)

Outcomes

In a 1998 report, Meuser et al. reviewed clinical trials of intensive community support programs for people with schizophrenia. Outcomes domains been generally patient-focused (time in hospitals, housing stability, time in jail, level of symptoms, medication compliance, substance abuse, social adjustment, vocational functioning, and quality of life) but include the domain of patient and relative satisfaction. Intensive case management appears to have positive effects on time in hospital, housing stability, and patient satisfaction. Several studies have found negative effects, for example a study by Curtis et al. (1992) that showed increased acute care utilization. However the literature to date indicates that the case manager model is effective for high-risk patients (Mueser et al, 1998). The review notes that these programs have the potential to help families to care for ill relatives, particularly family caregivers who are full-time employees or who are elderly. Family advocacy groups strongly support ACT programs (Meuser, et al., 1998).

Thus far, studies reviewed here have been conducted in the US. While these are useful, they may not be totally applicable to caregiving in other areas. A number of sources maintain that caregiver burden is bound to culture (e.g., Cook et al., 1994; Horwitz & Reinhard, 1995). The "Illness Explanatory Model" proposed by Chesla, (1988) also suggest that beliefs about the meaning of mental illness influence caregiving

practice. Caregiving research conducted in Thailand provides information on cultural

determinants of caregiving.

Psychiatric Caregiving in Thailand

Ten studies have been conducted in Thailand concerning family caregivers of

persons with chronic mental illness. The heterogeneity of the methods and variables in

the research studies make systematic review difficult. However, as a group, they all focus

on important variables including relapse rates, caregiver stress/burden, social support,

help-seeking behavior, personal factors involved in the well-being of the caregiver, and

intervention research.

As in research conducted in the US, disruptive behaviors were reported as the

most stressful symptoms for relatives (Charearnkul, 1996; Koolratr, 1983; Nithikool,

1992). As in the western literature, these included problem such as waking up during the

night and aggressive violent or behaviors. Family members who received affirmative

support, financial support, and instrumental support were more likely to manage stress

than those with less support. These supports came from other family members in the

household and other relatives (Tubsateinthai, 1990). Relatives were also an important

source of knowledge about the mental illness (Ratanatikanon, et al., 1997).

Family caregivers reported their needs to know how to manage care at home.

They worried about the cost of care and felt stigmatized (Koolratr, 1983). They also

expressed concerns about medication side-effects and the issue of medication non-

compliance (Charearnkul, 1996). Caregivers noted problems of conflicting information

from health care practitioners. This was most stressful for those with one to five years of

experience in the caregiving role, and least stressful for those with 10 or more years of experience (Nithikool, 1992).

Nithikool (1992) found that caregivers who resided in rural areas reported more stigma than did those who resided in urban areas. She divided the caregivers into two groups, one of parents, and another of significant others such as siblings or in-laws. She found that the parent caregiver group reported more self-blame about the cause of the illness and more worry about the ill relative's future. They experienced their decreased leisure time and reduced personal life opportunities as stressful.

Klinhom (1997) found that family caregivers' quality of life was significantly and positively associated with a sense of coherence. She found a moderate degree of sense of coherence in family caregivers as measured by the Sense of Coherence Tools developed by Antonovsky (1987), translated and modified to Thai by Hanuchearnkul (1989). This personal factor allowed caregivers to maintain their physical and psychological well-being.

Five Thai researchers looked at treatment interventions (Boalert, 1992; Chareamkul, 1996; Koolratr, 1983; Teameeyapradit, et al., 1994; Yamboonruang, 1997). The protocols of the programs varied widely. Two studies provided group counseling (Boalert, 1992; Koolratr, 1983), another two provided psychoeducational groups (Chareamkul, 1996; Teameeyapradit, et al., 1994), and one study provided a pre-discharge program (Yamboonruang, 1997). However, the common features of these programs included providing information about mental illness, its treatment, and about health care systems. Teameeyapradit, et al., (1994) found that caregivers in their intervention group reported lower rates of relapse than controls, at an 18 months follow-

up. Other intervention studies report decreased stress/burden (Boalert, 1992;

Yamboonruang, 1997), and a better understanding of mental illness and health care

systems (Koolratr, 1983).

Although the studies in Thailand include intervention research, they study diverse

types of interventions and are difficult to compare. Some were limited in terms of design,

using only descriptive methods. Furthermore, because Thailand is in the process of

developing documentary systems, there may be additional unpublished or published

studies in local journals. The difficulty of disseminating information may contribute to

the lack of homogeneity of the research. Most of these studies are modeled on western

studies; relying upon western research literature that may have cultural biases as well as

problems with translation. Qualitative research studies could not be located for this

review, presenting a gap in this body of literature for Thai people. More importantly,

although some investigators modified existing instruments, usually from western

research, most instruments cited reflected individual expert opinion or were based on a

literature review. Despite report of good content validity, these instruments were

evaluated in terms of notions of experts who were knowledgeable in that area and

familiar with the western world's body of knowledge. Instruments that include the

perspective of the caregivers in the Thai context were scarce.

Support Groups in Thailand

Family support groups are usually hospital based and led by clinical practitioners

in Thailand. Information on the illness and its treatment is provided in the group.

Additionally, there are open sessions for discussing questions raised by family caregivers.

Family self-help groups have not been developed. In Thailand, accessibility to support

groups is a major problem for family caregivers. Support groups are usually provided in the hospitals, which are usually located in urban areas. Transportation is a major problem for caregivers who reside in rural areas. In fact, support group members usually are caregivers who reside in urban areas or who have the ability to come to the hospital, which means ability to pay for transportation or owning a car. The community district nurse serves only to provide the patient with services related to continuing medication regimens. Moreover, in order to meet the district nurse, family caregivers and patients still need to commute to the district hospital, which is usually located in the central area of each district.

Formal Community Support Programs

In Thailand, the evolution of psychiatric care has been similar to developments in the US and other western countries. Physical treatments such as restraints, hydro-therapy, and seclusion were considered ineffective and have changed to new methods corresponding to newer conceptualizations of mental illness. Treatment is divided into two dimensions. The first is physical treatment, such as pharmacotherapy and electroconvulsive therapy (ECT). The second is psychosocial therapy, such as individual psychoanalysis, hypnosis, group psychotherapy, psychodrama, family therapy, therapeutic community, and behavioral therapy. These general treatment methods have changed and improved over time in response to evolving knowledge about mental illness (Areephak, 1981). However, in Thailand, in contrast to the US, all patients discharged from hospitals return to live with their families. This has been a consistent pattern over time.

Although community care services in Thailand do not include existing assertive treatment such as the ACT model as in the US, in some rural areas the district nurses

provide continuing care for the mentally ill. District hospitals in rural areas provide psychotropic medications. However, as discussed above, patients still need to come to the hospital for follow-up for their psychological assessments and medications and others treatments.

Conclusion and Discussion

There has been a great deal of research on the experience of psychiatric caregiving, caregiver burden, expressed emotion, and various types of intervention programs. Research in the Thai context is beginning to develop. However, there are number significant gaps in present knowledge. These gaps are related to dominant research methodology, maternal caregiving aspects, difficulty of associating intervention with outcomes, the difficulty of measuring caregiving skills, and the major impact of ethnicity and culture on caregiving.

The first gap originates from the most common research design. Study participants are generally recruited from hospitals or mental health care agencies. This is evident in both US and Thai contexts. Moreover, in the US, most research represents white and upper middle class families because most recruitment occurs from support groups consisting of mainly Caucasian members. This lack of diversity should be taken into account when interpreting and applying the results. This body of research may not represent many of the people who live in the community, particularly those who do not receive inpatient care. Further studies should implement strategies to expand research beyond these populations. An associated challenge is determining how to access caregivers who do not attend support groups or whose relatives do not receive in-patient care, or who may feel marginalized by "mainstream" recruiting strategies.

Secondly, although the evidence from intervention research shows that programs are effective, it is not clear which program elements contribute to specific outcomes. Is it the element of learning skills or general support? It would be useful to know how specific elements contribute to specific outcomes. It is still not known whether overall support, consisting of all elements, produces to positive outcomes, or whether specific elements are more important than others. It may be very hard to achieve, as phenomena such as burden or stress are experiential existential human conditions that are not necessarily definable by discrete elements.

Difficulty studying caregiving is, in part, due to the ambiguity of the concept. Previous research studies have mainly focused either on subjective aspects of caregiving (such as burden, stress, chronic sorrow, uncertainty), on social support needs or coping strategies. Some of the qualitative research studies touch briefly on the caregiving process. However, the operational nature of psychiatric caregiving and its major related concept, caregiving skill, are rarely defined. Although some family intervention programs provide information about mental illness, its treatment, social skill training, coping strategies, and behavior management, the curriculum is derived from the professional's knowledge, not caregivers' experience. We assume that we know what families want and what should benefit them. However, we do not know how they become skillful or effective in caregiving.

Thirdly, samples are not defined in terms of level of psychiatric knowledge or caregiving skill. To do so, it is also necessary to develop tools to assess these factors. For example such tools should allow practitioner to group caregiver according to skill level before providing interventions. It is also important to investigate how programs

might be tailored to different family profiles. This notion is confirmed by a study by Pollio, North, and Foster (1998). They investigated the content and curriculum of psychoeducation groups. They found a discrepancy between perceived needs of caregivers and the content offered by psychoeducation groups that emphasized negative symptoms and family relationships. It may be important to determine if matching interventions to skill levels promotes support group participation.

Fourth, it is evident from this review that ethnicity and culture influence caregiver burden. Caregivers from different ethnic groups may perceive different levels of burden under the same circumstances. This suggests that cultural sensitivity must be taken into consideration when one interprets or replicates studies cross-culturally.

Finally, it is important to have more consistent definitions and measures of concepts of burden, psychiatric symptomatology, and "chronic mental illness." It is difficult to compare findings from studies targeting different kinds of clinical populations and different types of families. The lack of homogeneity of the research protocols and theoretical and operational definitions is a major limitation. This review, however, has pointed to some important directions for future research, particular in the dimension of understanding, from the caregiver's point of view, the nature of caregiving and its impact on quality of life.

CONCEPTUAL FRAMEWORK

Although this study employed grounded theory to analyze the data, an organizing framework guided its development. The organizing framework derived from theoretical perspectives on caregiver burden, stress appraisal theory (Lazarus & Folkman, 1984), and family caregiving by Archbold, Stewart, Harvath, and Lucas (1986, 1987). The picture of the organizing framework of this study can be found in Figure 1.

Caregiving skill Organizing Framework

Two broad types of resources affect the caregiving process: exogenous and endogenous. Both can serve as protective factors or stressors for caregiver, altering both the process of caregiving and its outcomes.

Exogenous Resource

The exogenous resources include level of support, other stressful life events, and the ill relative's characteristics. Each concept will be briefly discussed in terms of how it relates to the caregiving process and outcome.

Level of Support

Social/family/relative and friend support is negatively associated with caregiver burden. The level of support alters the caregiver's cognitive appraisal about the caregiving situation. This occurs when one takes on a caregiving role, and appraisal as whether it is stressful. Support can serve as the resource for the person and it leads to how one copes when dealing with a caregiving situation at the secondary appraisal level (Lazarus & Folkman, 1984).

Other Stressful Life Events

Other stressful life events such as bankruptcy, and loss of significant others can serve as other potential stressors affecting the caregiver. These add to the caregivers' stress as they take on the role and alter their caregiving experiences. Therefore, this variable was used as an exclusion criterion for this study.

Ill Relative Characteristics

Ill relative characteristics including functional level, degree of disruptive behavior, and care demands are the factors that affect the cognitive appraisal of the caregiving situation. As indicated in the literature review, disruptive behavior is the major predictor of caregiver burden. The Appraisal of whether one can handle the anticipated situation will alter the perception of care need and lead to performance when one takes on the role.

Endogenous Resources

Endogenous resources include caregiver characteristics, and the caregiving skill level that affects the caregiving process. When one takes on the caregiving role, she or he will bring her or his own personality and a sense of ability and knowledge to the caregiving process.

Caregiver Characteristics

Caregiver characteristics affect caregiving skill when one enters the caregiving process and leads to a caregiving outcome including self-efficacy, sense of mastery, sense of preparedness, and coping strategies.

Self-efficacy. Self-efficacy serves as a buffer for caregiver burden. This term refers to the perceptions of individual confidence in effective performance related to

specific tasks (Haley, Roth, Cloeton, Ford, West, Collins, & Isobe, 1996; Mawat &

Laschinger, 1994). It is a personal resource that mediates stress and facilitates caregiving.

Sense of mastery. A sense of mastery refers to an overall sense of control over

one's life (Pearlin, Mullan, Semple, & Skaff, 1990). It, thus, refers to the overall sense of

one's ability in the caregiving role and alters the caregiving process. Like self-efficacy,

mastery has been interpreted as a personal coping resource to mediate caregiver burden

(Solomon & Draine, 1996).

Sense of preparedness. Sense of preparedness refers to the caregiver's perception

of his or her own preparedness for doing caregiving (Archbold, Stewart, Greenlick, &

Harvath, 1992). It indicates how caregivers learn about their role before entering the

role, and how they evaluate themselves as well prepared.

Coping strategy. Coping strategy refers to the effort to deal with the stressful

situation when one evaluates resources simultaneously at the secondary appraisal level

(Lazarus & Folkman, 1984). There are two coping strategies based on Lazarus and

Folkman: emotionally oriented and problem oriented coping strategies. Coping

strategies, in the caregiving context, refer to the caring practices that caregivers provide to

the care recipient after the primary and secondary appraisal process (Chesla, 1988). Thus,

coping strategies influence caregivers in terms of choosing caregiving skills to deal with

particular caregiving situations.

Caregiving Skills

Little is known about caregiving skills. This is a gap in our knowledge that makes

this worthwhile to study, due to its potential contribution to caregiving outcomes. Based

on the skill acquisition model (Dreyfus & Dreyfus, 1986), the skills of the individual will

be acquired over time from novice to expert. This model refers to differing levels of ability to provide caregiving effectively. All personal characteristics (self-efficacy, sense of mastery, sense of preparedness) affect the caregiving skill level. However, these associations need further study.

Caregiving Process

The caregiving process is the interaction process that occurs when caregivers bring their own personality, skills and knowledge to caregiving. In this process, caregivers need to appraise all factors related to the caregiving situation to evaluate whether it is stressful and try to deal with the situation. Therefore, the characteristics of the ill relatives are also included.

Stress/Burden Perception

The perception of stress and burden is influenced by the skill level, and by multiple variables characterizing the ill relative. The perception of stress and burden will affect the caregiving outcome. This appraisal will occur simultaneously with other appraisals that occur during the process. It is not meant for separate measurement but only presents the dynamics of caregiver appraisal.

Exogenous Resources

Endogenous Resources

Level of Support
-Social
-Family
-Relative
-Friend

Caregiver characteristics
-Self-efficacy
-Sense of mastery
-Sense of preparedness
-Coping strategy

Other Stressful Life Events

Ill relative characteristics
-Functional level
-Behavior problems
-Care demand or tasks

C
A
R
E
G
I
V
I
N
G
Process

Caregiving Skill

A gap
In Our
Knowledge

Perception of Stress and Burden

Caregiving Outcome: Caregiver experience/quality of caregiving

Figure 1. Caregiving Skill Organizing Framework

Caregiving Outcomes

There are two types of caregiving outcomes: caregiver experience and the actual

quality or effectiveness of care provided.

Caregiver experience: negative and positive. Caregiving experience refers to the

overall perception of the caregiver toward the caregiving role. The experience could be

negative and positive. This is influenced directly by the stress/burden appraisal. The

negative states include feelings of stress, strain, and burden. The positive state includes

creating hope for themselves and the care recipients, feeling good about the role

(gratitude), and finding information to increase caregiving skills to deal with the

caregiving situation (Tungpunkom, 1998).

Quality of caregiving. Quality of caregiving according to several major sources,

refers to the level of caregiver's performance that conforms to standards of care of each

caregiving role (Levine, Cartwright, Inoue, Stewart, & Archbold, 1997; Philips,

Morrison, & Chae, 1990a; 1990b). The quality of caregiving differs from the caregiving

experience because it focuses more on what the caregiving activities achieve. It refers to

the outcomes of caregiving tasks rather than subjective experience. Therefore, this type

of outcome is more likely to be influenced by the skill level of the person providing care.

Definition of Terms

For the purposes of this research caregiving is defined in terms used by

Schumacher, Stewart, & Archbold, (1998), and Pearlin, Mullan, Semple, & Skaff, (1990).

Caregiving refers to the activities derived from the illness condition that household

members perform for a mentally ill relative.

Research Assumptions

My research assumptions are:

1. Psychiatric caregiving is unique due to the changeable and unpredictable nature of the illness. This uniqueness makes caregiving tasks in psychiatric settings different from other chronic diseases.

2. Family caregivers who live with, and care for, their ill relative with schizophrenia or a related disorder will develop their caregiving skills to manage care under specific contexts which will differ from individual to individual over time. This caregiving skill is an important factor that leads to a high quality of care and positive caregiver experience.

Research Questions

The purpose of this study was to explore how families actually provide care for their mentally ill relatives at home. The context for the research was Thai mothers who lived with, and cared for, their adult children with schizophrenia or a related disorder continuously for at least six months but not more than ten years. The research design used was a retrospective qualitative design. The specific research questions were:

1. What are the contexts of caregiving for these mothers, including relevant demographic, clinical and cultural factors?

2. What are the tasks of psychiatric caregiving and what are the required skills applied by Thai maternal caregivers?

3. What is the process of skill and role development as described by these mothers?

CHAPTER III: METHODOLOGY

This chapter presents the methodology for this study. It is divided into six sections: (a) research design, (b) description of the research setting, (c) sample, (d) data collection methods, (e) procedures, and (f) data analysis, which includes special issues related to qualitative research within the Thai cultural context.

Research Design

This retrospective qualitative study used grounded theory methods. A semi-structured in-depth interview was used to obtain data on demographic factors, the development of caregiving skills, knowledge about roles, and learning sources. The Life Skill Profile (LSP) was also used to elicit information about the functional level of the care recipients, rated by the caregivers. Together, these data demonstrated how mothers perceived the care situation and how they developed and applied skills over time.

Grounded theory methodology was used in this study because, as Strauss and Corbin point out, it is rooted in the belief that people are actors who play an active role in anticipating problematic situations based on the meanings they perceive in that situation. These meanings are defined and redefined through interaction (Strauss & Corbin, 1998). Learning to live with, and care for, a mentally ill person is based upon the meanings perceived through the reciprocal relationships of mothers and care recipients. These meanings change throughout the caregiving process through mutual interaction as well as interactions in broader contexts (such as the household and the community).

Research Setting

Data collection occurred at Suanproong Psychiatric hospital. However, one informant was recruited from the outpatient unit at Maharaj Nakorn Chiang Mai Hospital, a hospital affiliated with Chiang Mai University. This test case provided the opportunity for a preliminary interview and final assessment of the protocol.

Suanproong Psychiatric Hospital was the third psychiatric hospital established in Thailand in 1938. It has 700 beds as well as outpatient services (e.g., medication visits). It serves, but is not limited to, residents in the Thai northern region, which covers 17 provinces. Types of services provided by this hospital include psychosocial treatment, Electric Convulsive Treatment (ECT), medication management, and occupational and recreational therapies. The outpatient medication program mails medications to patients living in remote areas who are unable to come to the hospital due to the transportation difficulty. Many family caregivers come to the hospital every 1-2 month to obtain medication refills. These mothers were the target population for this study.

Sample

The criteria for participant selection were as follows:

1. Mothers who functioned as the primary caregiver of an adult child (18 years or older) who had been diagnosed with schizophrenia or a related disorder for at least one year (diagnosed by the Diagnostic and Statistical Manual of Mental Disorders-Revised edition (DSM IV-R) and International Classification of Disease (ICD-10)).

2. Continuous co-residence with the care recipient for at least 6 months prior to the time of interview, but not more than 10 years.

3. Thai ethnicity and language.

The exclusion criteria were:

1. Caregiving for additional family members with a chronic disease in the household (e.g., dementia, HIV)

2. Residence in households experiencing extreme levels of stress due to major life events such as recent bereavement, serious legal problems, or natural disasters.

3. Communication problems (such as difficulties with speech or hearing that would interfere with ability to complete the interview).

Purposive sampling, as discussed by Polit and Hungler (1991), was employed to recruit participants. The participants were in a caregiving role for at least six months but not more than ten years. This range of time would allow them to recall the skills they applied when they lived with, and cared for, the care recipients.

Access Procedure

The researcher approached potential participants who visited the hospital to obtain continuing medication, or to accompany a care recipient experiencing acute symptoms. Information on the study and its objectives were provided and any questions were answered. The voluntary nature of participation was emphasized. Interview appointments were made for a time and location that was convenient for the participants.

Human Subjects

The Committee on Human Research (CHR) approved this project of UCSF and by the appropriate hospital ethics committees in Thailand. Informed consent was obtained before the interview was conducted in all 31 cases (including the preliminary case). Participants were reimbursed for time and effort at the end of interview. Informed consent forms can be found in Appendix A.

Data Collection

In-depth semi-structured interviews were used to collect data. All informants

agreed to allow their interview to be audio-taped. Field notes were written for every

interview to capture nonverbal communication and other relevant contextual information

beyond the interview questions. In view of the focus of attention on maternal caregiving

skills and on the individual experience of mothers, interviews were conducted without the

presence of the recipients of care. Interviews were conducted in hospital or ambulatory

service settings where the participants were recruited. This provided private space where

the informants could speak freely. Care recipients who accompanied their mothers were

told that their mothers would be interviewed about the experience of living together at

home, and were requested to wait in the waiting area while the interview was conducted

in an assessment room. The interviews ranged in length from 40 minutes to 2 hours and

20 minutes. The average length was 1 hour and 15 minutes.

Instruments

A structured interview protocol was developed for this study. It consisted of

closed and opened-ended items. It took about one to two hours to administer. The

interview protocol included three sections. The first section obtained demographic data.

It was completed before more open-ended questions in order to establish rapport with the

participant to help them feel more at ease. The second section contained a guide for the

semi-structured in depth interview. It included questions about major components of

caregiving skills: knowledge, strategies/activities, and skill development/learning process.

These questions were developed based upon a review of the literature of caregiving skills,

the skill acquisition model explicated by Dreyfus and Dreyfus (1986, 1996), and the role

acquisition model discussed by a number of nurse researchers (Schumacher, 1995;

Stewart et al., 1993). In addition, a set of probes concerning the development of the skills

over time was modified from a qualitative research study by Chesla (1988). The third

section contained questions about the functional level of the care recipient through the

Life Skills Profile (LSP). The interview protocol can be found in Appendix B.

Developing the interview protocol, especially the caregiving skill section (the core

interview schedule), involved mapping each item to the corresponding theoretical

concepts (e.g., components of caregiving skills: knowledge, strategies, and skill

development/learning process) to ensure data were obtained for each concept. The

schematic mapping is summarized in Table 1.

Table 1.

Theoretical Concepts and Related Interview Items

Component of Interview Protocol	Questions and Probes Appeared in the Interview Protocol
Part I: Demographic data	
Caregiver characteristics	Items 1-5
Situational contexts	Items 6-10
Care recipient characteristics	Items 11-18
Part II: Caregiving skills components	
Knowledge about role content (mental illness, perception of care needs, and the care provided at the beginning of illness episode)	Item number one which composted of seven sub-questions (1.1-1.7) and a set of probes to elicit the information on the learning process or the judgment and the learning source (a-d)
Strategies/activities -Perception of care needs in the present and the care provided in a general day	Items 2-3
-Perception of care needs for atypical situation and care provided	Item 4 and a set of probes to elicit the information on the learning process or the judgment and the learning source (a-d)
Caregiving skills development - A shift on caregiving skill from past to the present	Item 5 and a set of probes to elicit the process of learning and judgment
- The ability to provide information on caregiving to others (role mastery)	Item 6
Part III: Functional level of care recipient rated by the mothers	Life Skill Profile Questionnaire (39 items) developed by Parker and Rosen (1989); Thai version translated and modified by Rungreankulkij (2000)

Note. The actual items can be found in Appendix B.

The Life Skill Profile (Parker & Rosen, 1989) rates the level of function in people with schizophrenia. It was developed for use by professionals and non-professionals. It is a 39 item questionnaire scoring functional status in five factor areas: self-care, non-turbulence, social contact, communication, and responsibility. In previous research, the test-retest reliability of the total scores from 129 ratings by three non-professional groups (i.e., parents, case workers, and residential care providers) was 0.89. The test-retest reliability for each subscale ranged from 0.78-0.90. Inter-rater reliability across all three groups was 0.77-0.83. The concurrent validity was tested with the Katz Adjustment Scale (KAS), which measures social functioning of ill relatives. The total scores on both scales were moderately correlated (r = 0.65) (Parker et al., 1991). The caregivers were asked to rate the frequency of individual levels of functioning using a four point Likert scale.

The Thai Version

The interview protocol (sections one and two) were initially developed in English and subsequently translated to the Thai language by the researcher. The revisions occurred after preliminary use of the Thai version with the first informant. Four native Thai colleagues with graduate preparation in nursing reviewed the revisions. The objective was to discuss and resolve questions of equivalent meaning. Some items were rewritten until all reviewers concurred that the language was clear, understandable, and reflected the meaning of the original English version. Several items were re-ordered to improve the flow of the interview. The last version was composed of six major questions and relevant probes.

The LSP was translated into the Thai language by Rungreangkulkij (2000) and was used in her dissertation research. In its original form the LSP asks if specific behaviors occur (e.g., "Does this person wash himself without reminding?" "Does this person generally take offence readily?"). If the behavior occurs it is rated on a four point scale in terms of frequency (e.g., washes often) or in terms of intensity ("extremely ready to take offense."). In this translated version, questions were posed in terms of problems (e, g., Does this person have a problem with washing) and rated on a single four points scale (none, little, moderate, and severe). Data on the reliability of the Thai version was obtained with 126 Thai mothers of adult children with schizophrenia. Reliability (alpha) of the total scale score was 0.96, within subscales the reliability ranged from 0.82-0.90 (non-turbulence = 0.85; self-care = 0.85; social contact = 0.88; communication = 0.90; and responsibility = 0.82), which was considered high (Rungreangkulkij, 2000).

For this project, seven original items from LSP were selected for new translation due to ambiguity in the Thai language. These were translated and back translated by the investigator and three native Thai nurses with recent doctoral training and 5-6 years of US residence. One item concerning self-care was modified to make it closer to the original.

Data Analysis

Descriptive analyses were used to develop family profiles for each caregiver, based upon socio-demographic variables, the context of care, and the level of disability of the care recipient.

Interview Data

The interviews were transcribed for content and checked for accuracy by a separate reviewer. The researcher also checked accuracy by randomly choosing tapes to

compare with the transcriptions. During the data analysis, some of original tapes were replayed in order provide a vivid picture and memory of the atmosphere of interview.

The preliminary interview demonstrated a potential problem of use of selection criteria. The hospital records used for sampling reported time since the first formal diagnosis of a severe mental illness. However the mother in the preliminary interview functioned as caregiver before seeking psychiatric services and had more than 10 years experience in the role. On the basis of this experience, subsequent informants were asked to confirm their time in the caregiving role. In practice, it proved difficult to determine the exact onset of caregiving, or the time when a transition occurred from normal mothering to maternal caregiving. For example, two mothers (Cases 15 & 16) identified a caregiving role for less than one year but in the interview described managing the patients' illness and well being for longer periods.

Thirty transcribed interviews provided data for a comprehensive understanding of psychiatric caregiving skill, as well as other findings about Thai maternal caregivers. Data collection concluded at the point of data saturation, when no new data appeared. Morse (1995) notes that data saturation does not occur when the researcher hears the same story again and again, but rather when the researcher has "heard it all." Negative cases were considered as important data to understand the variation of the phenomenon and to provide a more complete picture. In this sample, overall stories became somewhat repetitive by the twentieth case. This probably reflects the highly cohesive quality of this sample. However, data saturation in terms of the variation of the skills was not completed until thirty interviews were analyzed.

Grounded theory techniques as developed by Strauss and Glaser (1967), Glaser

(1978), and Strauss and Corbin (1990, 1998) were used to analyze thirty transcribed

interviews. Memos developed during interviews and in the process of data analysis

provided additional data for constant comparison of cases. Constant comparison was

used during coding procedures and in developing categories, so that emerging findings

could guide ongoing data collection and analysis. Analysis included three levels of

coding. During initial, open coding procedures, interviews were examined line by line or

paragraph by paragraph, identifying types of specific events, activities, and behaviors.

Open coding generates initial categories of tasks activities and skills, to define their

properties and dimensions, and to discover the relationships among concepts (Strauss &

Corbin, 1998). A second level of analysis grouped codes according to common

properties in order to identify major categories and subcategories. These procedures

produced two major types of caregiver function: direct care management and caregiver-

self adaptation. Activities within these areas were further identified as skills, or

behaviors sharing a common caregiver objective. For example, a group of skills were

employed to maintain privacy or secrecy, such as use of medical, rather than psychiatric

diagnoses to describe the problem, or efforts to keep the care recipient at home as much

as possible. The third level of analysis involved 'axial coding' (Strauss, & Corbin, 1998),

or to determine prominent patterns by linkage of categories and sub-categories together.

This process demonstrated that the tasks of direct caregiving fell into three major

domains: maternal care, symptom management, and medication management. Within

each domain, caregivers meet specific types of needs such as personal care in the

maternal area, or monitoring behavior for symptom management. Two major types of

caregiver self-adaptation emerged: emotional adaptation and role adaptation. Finally, the processes of skill and role acquisition were examined, based upon the sequences of actions and personal changes that mothers described from the onset of mental illness in the family until the time of interview.

Theoretical sensitivity shaped data analysis. For example, mothers reported administering medications surreptitiously, usually putting medications in the patients' meals. Reasons for this behavior identified by these earlier participants were confirmed or explored with subsequent informants by using probes focusing on this strategy. Further investigation revealed that this caregiving activity was applied when caregivers perceived that patients refused medication because of poor acceptance, or denial, of their illness. This explained the rationale for covert use of medication, and the identification of "justified deception" as a caregiving skill.

Cross-Cultural Research Translation

The informants in this study were non-English speakers, thus the issue of translation played a great role in data analyses. Twinn (1997) notes that validity and reliability of qualitative research from non-English speaking cultures is enhanced by accurate translation, including development of interview schedules and data analysis. To maximize the reliability of the results, Twinn suggests that translation of the findings should be completed by one researcher. Therefore, this finding was analyzed and translated from Thai to English by the researcher.

Translation in Data Analysis

All transcribed interviews in this project were kept within the source language (Thai) during open coding, in order to keep the original meaning of the narrative.

Translation to English occurred at the level of categories. However, one fully transcribed interview and the story line, as well as all codes of the first ten interviews were translated into English. This provided an overall sense of data content and analyses for members of the dissertation committee. During data analyses, some categories and subcategories were re-named for better understanding within the English language, but keeping equivalent meaning, with member of committees who have English as a first language.

Ethical Concerns

This study was approved by the Committee on Human Research at UCSF and by the research committee at each study site establishing that study procedures were not harmful to the participant and protected confidentiality. However, additional ethical issues surfaced during the course of the investigation. Emerson (1983) noted that by using oneself as an instrument in qualitative research, the researcher needs to be aware of the potential ethical dilemmas. In this study, there was an ethical concern involving maintaining the boundaries between the roles of nurse researcher and clinician. This was particularly difficult when mothers reported misunderstandings about psychotropic medications. Some mothers encouraged the patients to stop taking the medications when symptoms were no longer apparent. Because of poor financial resources, some tried to take medications less frequently to help the supply last longer (from three times to twice a day). This reflected their lack of knowledge about medications and the importance of their continual use. This placed the researcher in a difficult position of not wanting to bias the data, but also wanting to address these misunderstandings.

While a variety of ethical issues can occur throughout an investigation, the most important overall ethical principle is "beneficence" or "above all, do no harm" (Polit &

Hungler, 1991). To avoid acting as a clinician, but to note potentially harmful behavior, all comments were reserved until after the interview. At that time, participants received general, standard explanations about use of psychotropic medications, referring them to their usual source of care for individual advice or counseling.

Reports of other types of potentially dangerous behavior also posed ethical issues regarding confidentiality. The consent form ensured all informants of protection of their privacy and confidentiality as much as possible. A difficult situation arose during an interview with one mother who expressed feelings of hopelessness regarding her caregiving role. She reported that sometimes she had experienced fleeting thoughts about homicide. At the end of the interview, she was encouraged to seek help about her feelings with the usual source of care (hospital nurse). The mother agreed with this proposal.

Trustworthiness of the Results

Memos on theoretical issues, the researcher's feelings and impressions, and any relevant issues were written during the interviews. Maintaining reflexivity while writing memos promoted awareness of how the interviewer's thoughts related to the informant's story. Sandelowski (1986) suggests that memos prevent the researcher from over-involvement or bias. This procedure enhances credibility, which is the degree to which the findings can represent the true experience of the participants.

Medical records served as another data source for this study. Additional relevant data were obtained from hospital charts including information about the history of the illness since the first hospital admission, the medication regimen, and demographic data.

These data were used to confirm reports from the informants and to contribute to the credibility and reliability of the information for each informant.

Although the interviews were conducted only once and the investigator did not review the overall results with the informants themselves, at several points and at the end of each interview, mothers were asked to respond to summaries of their comments and to note whether these summaries were correct. This validation check enhances the credibility of the information.

Use of the semi-structured in-depth interview presented all informants with the same questions, although not necessarily in the same order. To assess inter-rater reliability, one interview was randomly chosen to test the coding variation between the researcher and two other colleagues, one an expert in qualitative study and the other trained in quantitative research. Both were informed of the aim of the study and the research questions, then were asked to open code the transcribed interview. A high degree of agreement was met among all three raters. Several codes were named differently, but they conveyed the same meaning and were definitively re-named by consensus after discussion. Although all interviews were not examined by both colleagues, congruence of open coding in the interview sample demonstrates evidence of credibility (Truth value of the study).

The procedures described above reduced the potential for investigator bias. Although this research was theoretically driven, with determined definitions of the concepts of skill and role acquisition, the interview format was open ended, eliciting data from the perspective of the informants. As noted above, writing memos promoted distance between the researcher's perceptions and the mothers' descriptions of their lived

experiences. This helped the researcher to allow the data to be described neutrally, rather than imposing unacknowledged assumptions on the data.

CHAPTER IV: RESULTS

The presentation of findings corresponds with the research questions: (a) the context of caregiving including relevant demographic data, clinical, cultural factors; (b) the tasks of psychiatric caregiving and the required skills used by Thai maternal caregivers; and(c) the process of skill and role development described by these mothers.

The Context of Caregiving

The context of caregiving included caregiver characteristics, care recipient characteristics, and the situational context of care including social support.

Caregiver Characteristics

Thirty mothers who met the inclusion criteria agreed to participate in this project. The age range was from 41-65 years (average 50.97). The majority were agricultural workers and had completed elementary school. Sixteen out of thirty described their income as "barely enough to support the household." It should be noted that in the Thai context this does not indicate extreme poverty. Although they reported that they earned barely enough income, these mothers had what Thai people consider the four factors meeting basic needs: food, home, medicine, and clothing. The characteristics of the caregivers can be found in Table 2. Five did not know the diagnosis of their children. Thirteen thought their children's illnesses were due to "neurosis" or "stress." Table 3 provides a summary of the diagnoses perceived by the mothers. Twenty-nine participants did not know the name of the medication their sons or daughters used, but 28 could describe its appearance and 15 knew the purpose of the medication (e.g., "the yellow one

is for sleeping, the white one is for hallucinations"). It is not unusual for Thai people to

know the appearance and use of the medication rather than its name.

Table 2.

Characteristics of the Maternal Caregivers

Characteristic	Frequency	Percent
Caregiver's occupation		
Farmer	14	46.7
House wife	5	16.7
Freelance	5	16.7
Merchandise	5	16.7
Government service	1	3.3
Total	30	100.0
Caregiver's educational level		
None	3	10.0
Elementary school	22	73.3
Secondary school	3	10.0
High school	2	6.7
Total	30	100.0
Household income		
Comfortable	2	6.7
Enough for a few extras, but need to budget carefully	4	13.3
Some income, but not any for extras	8	26.7
Barely enough to support the household	16	53.3
Total	30	100.0

Table 3.

Diagnosis Perceived by Maternal Caregiver

Perceived diagnosis	Frequency	Percent
Schizophrenia	1	3.3
Psychosis	8	26.7
Neurosis	6	20.0
Stress	7	23.3
Seizure	1	3.3
Crazy	2	6.7
Do not know	5	16.7
Total	30	100.0

Care Recipient Characteristics

Information about the characteristics of the care recipients was obtained from the study participants and from hospital records. There were 23 males and 7 females. Twenty-one were diagnosed with schizophrenia, four with schizophreniform disorder, and five with non-affective psychosis (Diagnoses in medical records were based on DSM-IV or ICD-10 criteria). They ranged in age from 18-42 years (average 26). The time since diagnosis ranged from one to ten years. The number of inpatient hospitalizations ranged from zero to ten. All of the patients took psychotropic medications. None were reported as using illicit drugs. However, eight care recipients were described as using alcohol and 15 were reported as smoking cigarettes. Only two were reported to have medical problems. One had allergies and another had sinus problems.

Life Skill Profile (LSP) scores, indicating functional level as rated by the mothers, ranged from 89-156. Only one mother rated the score as 89. The others rated it from

110-156. The average score was 137.23, which is considered high in comparison to normative scores for people with schizophrenia reported by LSP developers (Parker & Hadzi-Pavlovic, 1995). Therefore, this care-recipient group was considered to have a high functional level or to be perceived as showing low disability by mothers (see Table 4.). The reliability for total scales score is .88. The reliability of subscale scores ranged from .29-.75 (non-turbulence = .74; self-care = .29; communication = .74; social contact = .75; responsibility = .49).

Table 4.

LSP Score

Scale Score	Mean	Std Dev	Minimum	Maximum	Number
Self-care	18.40	2.35	11	20	30
Responsibility	18.40	2.35	11	20	30
Social-skill	18.03	5.04	9	24	30
Non-turbulent	43.70	4.61	31	48	30
Communication	20.50	3.98	9	24	30
Total	137.23	16.12	89	156	30

Situational Context of Care

Twenty-one caregivers lived in nuclear families (parents and children) while 9 lived within extended families including grandparents, grandchildren, and sons or daughter-in laws. The number of family household members ranged from 2-8 (the average was 4). This nuclear family is characteristic in these areas, but 13 mothers reported getting help from others in taking care of their children. These included family household members, other relatives, and neighbors. Twenty-eight mothers were

Buddhist. Only two were Christian. The characteristics of caregiving are found in Appendix A.

The interview protocol included questions about "seeking help from other" to elicit information about the social context of care, particularly sources of support. In addition, mothers discussed mobilization of support spontaneously, describing caregiving activities. These sources fell into two general categories, informational support and instrumental support. Caregivers received help from informal and formal sources to learn about mental illness and its treatment. They used local healers as sources not only in terms of mental illness, but also concerning other related networks. When their sons or daughters demonstrated unusual behaviors, 21 mothers reported bringing care recipients for spiritual treatment at the beginning of the illness episode. When there was no improvement and with suggestions from others or from the local healers themselves, mothers subsequently took the care recipients to the psychiatric hospital for proper treatment.

Informational Support

Two mothers reported that it was the shaman who told them that their children were neurotic or mentally ill and suggested taking them to the psychiatric hospital. Two others reported that monks suggested taking the care recipients to the psychiatric hospital for proper treatment. However, some mothers continued to get spiritual treatment (i.e. getting holy water) along with psychiatric treatment for the care recipients. One mother reported that she herself believed in traditional/local treatment while her husband relied

on psychiatric treatment. Therefore, both of them compromised by getting both treatments for their daughter.

Mothers reported that friends or neighbors suggested taking the care recipients to the psychiatric hospital. When mothers had to deal with a crisis situation, friends or neighbors also suggested other related networks, such as emergency (rescue) workers who would come to take care recipients to the hospital when they are aggressive. However, the emergency workers are available only in large cities and suburban districts. In remote areas, mothers needed to seek help from the head of the village or police. Many times in these crisis situations neighbors would come to help, especially in rural Thailand. Neighbors also advised mothers on managing care. One mother reported that her neighbor suggested a particular communication style in order to talk to and encourage the care recipient. Another mother reported her neighbors' advice regarding caution concerning the harmful behavior of the care recipient.

Seeking help from formal sources such as police occurred when mothers faced aggressive behavior or suicide attempts. But to seek help from the police in this circumstance meant to ask their help to transfer the care recipients to the hospital, yet not to arrest them. Police could make decisions that would affect how care would be provided consequently. One mother described calling the police when her son was very aggressive. The police confined her son at the police station. They questioned whether his behavior was a reaction to amphetamines, requiring a substance abuse program. When they learned about his previous symptoms (obsession about his bad breath and brush his teeth very often a day), the police helped the mother to hospitalize her son.

Health care providers were sources of information about the psychiatric hospital

and other facilities and knowledgeable about how to manage care, especially in terms of

medications. Seven mothers reported getting suggestions about taking the care recipients

to the psychiatric hospital from people who worked in medical or health science fields.

These included district nurses, pharmacists, and medical doctors and nurses. Five

mothers reported getting information about medication side-effects from the psychiatrists

and psychiatric nurses (beyond the standard information that was provided by the

psychiatrist and psychiatric nurses).

The infrastructure, in terms of communication, in Thai rural areas is quite well

developed. People in rural areas have access to the media such as radio and television

programs, and some remote areas are beginning to have public telephone service within

the villages, or even individual household telephone service. Two mothers reported that

they learned about mental illness and substance abuse from television programs. One

mentioned getting information about aggressive behavior. Another mentioned

information on substance abuse.

<u>Instrumental Support</u>

Mothers required direct assistance, or instrumental support, when they could not

handle the caregiving situation by themselves. This occurred when they had to leave the

care recipient (e.g., to leave the household) or during disturbing situations or crises that

they could not handle on their own. Under these conditions, they might call upon

husbands, grandparents, and other siblings in the household. Mothers also sought

assistance from other relatives, such as siblings who lived outside the family household.

In Thai society, especially in rural villages, all people know each other, treating other villagers as if they were relatives. Therefore, in situations such as suicide attempts, neighbors would come to provide help or any support that the mothers needed. One mother reported the neighbors helping to stop aggressive behavior when her son tried to harm her husband. Another one reported help when her son attempted suicide. The last mother reported receiving help in order to make her son take his medication. Neighbors nearby helped prepare the medication and encouraged the care recipient to take it.

Eleven mothers reported getting help from the police, chiefly in terms of transporting people directly to the psychiatric hospital. Only one mother reported that the police confined her son at the police station before referring him to the hospital. Two mothers reported help from other emergency health workers (for aggressive behavior and when the care recipient did not return to the hospital after a visit home). However, most depended on the police since the emergency workers are available only in suburban districts near the city. Mothers turned directly to the hospital when situations were most disturbing or difficult to control. This included both the psychiatric hospital and the general hospital that provided medical care after suicide attempts by overdose or poison. Mothers without cars might mobilize transportation from neighbors.

Caregiving Tasks and Skills

The term "caregiving task" refers to areas or types of needs that mothers were obliged to address, in order to live with, and to care for, a mentally ill adult child at home. These fell into three overall domains: maternal care, referring to normal parenting and household management; symptom management, referring to activities to control or

influence behavior; and management of psychotropic medication. "Caregiving skills" are

behaviors that respond to these areas of need. Interview data indicated that mothers

developed repertoires of caregiving skills that crossed domains and tasks. The definition

of each skill is presented in Table 5.

Table 5.

Skill Definitions

Skills	Definitions
1. Monitoring	The activities involved in watching, observing for care needs or problems that may arise in order to be ready to provide care. Monitoring was characterized as either discrete or intrusive.
2. Reminding	A verbal reminder urging care recipient to do something properly.
3. Advising-reasoning	Verbally suggesting something and giving rational for the suggestion to the care recipient. This skill is derived from the "vivo" code of Thai term "sang-som." Mothers in this study saw this term as an inseparable word.
4. Providing Reality	The activities that mothers need to do to provide the outside reality to the care recipient. These included confronting and asking others to re-assure.
5. Doing-for	The partial care that mothers provided to the care recipients (e.g. helping in taking a shower, grooming).
6. Coaching	The instructions that mothers provided to the care recipient to help them to do something (e.g., personal hygiene).
7. Maintaining privacy	The activities involved in keeping the mental illness a secret (e.g., using the medical diagnoses instead of schizophrenia, moving away from the town, keeping the care recipient in the household).

Table 5. (Cont.)

Skill Definitions

Skills	Definitions
8. Distancing	The behavior responses that a mother used to give herself space from the situation encountered. These included emotional and physical behaviors (e.g., keeping quiet during argumentation, go away from the harmful situation).
9. Bargaining	The technique of making conditions by using a bargaining chip to trade to obtain the desired rule or appropriate behavior. The fears or desires of the care recipient were used frequently as a bargaining chip. The activities also included threatening.
10. Mediating with others	The activities involved in mediating interpersonal conflicts between the care recipient and others.
11. Caregiver self-defense	The reflex responses that mothers had when they were hit or physically assaulted by the care recipient.
12. Administering medication	The activity of handing out the medication to the care recipient directly.
13. Adjusting PRN medication	The decision-making relating to adjustment of the amount of a PRN dose, especially sleeping pills.
14. "Justified' deceiving	The activities of discreetly putting the mediation into the care recipients' meal or drink under the condition that the care recipient lacked insight about their mental illness and the importance of the medication.
15. Controlling the environment	The activities engaged in meeting the objective of controlling the environment or factors related to the problem without directly controlling the care recipient (e.g., asking for collaboration from friends, hiding the vehicle).

Table 5. (Cont.)

Skill Definitions

Skills	Definitions
16. Seeking help from others	The activities of seeking help from the contextual support in order to manage care (e.g., asking help from the head of village to transfer the care recipient to the hospital).
17. Negotiating with health care provider	Techniques of negotiating with health care providers in relation to medication adjustment, hospitalization or home visits.

Note. All these skills are described in more depth in the following section.

Maternal Care

Maternal care refers to the domain of normal parenting and household management. Information in this area was often provided in response to questions such as "How do you take care of your child in general?" or, "What do you do together in a typical day?"

Personal care needs. Most mothers reported providing care in the areas of hygiene, grooming, and preparing meals, especially during periods of symptom exacerbation. Mothers used reminding when they thought the care recipient could perform personal care activities. In general, the mothers needed to remind their sons or daughters nearly every day to take showers, especially when they found that the care recipients had poor general hygiene. One mother said:

I: What do you need to do to help him nowadays?

M: Now it's better. It is better in the way that he uses soap when he takes a shower. Back then he didn't use it.

I: What did you do?

M: I would observe him first. I didn't do anything. I noticed that he would wear old clothes. He didn't like to take a shower, to brush his teeth, to shampoo or anything like that. I had to remind him to do it. But now he starts to do it. He is better. He doesn't have a bad odor much after he quit smoking.

I: Back then when he had that problem, what did you do?

M: I talked to him---I told him to take a shower, using soap, and shampoo his hair. 'There is shampoo over there.' In the evening, I said 'brush your teeth. Otherwise you're going to have a bad breath and it will annoy people who come close to you.'" (Mother Case 10).

Most mothers reported preparing meals for everyone in the household, including their ill children. One mother commented that:

"I just let him be by himself. At meal time, I will cook and tell him to eat, eat together..." (Mother Case 7).

If necessary more active coaching was used, providing instructions for self-care activities. The reminding and coaching increased when the care recipient had acute symptoms. One mother described how she instructed her son to take a shower:

About taking a shower, I have to tell him to use soap. I really have to tell him to use it and at the particular place 'at your wrist, your ankle, and your feet.' Sometimes, he acts like a kid, some other times he acts like an adult (laughing). One person can be both kid and adult, you know?
(Mother Case 11).

When reminding and coaching were ineffective, skills in "doing-for" were used, generally for care recipients at a low level of functioning who required partial care and close supervision. The mother cited below attempted to "do for" her son after unsuccessful attempts to remind or coach.

M: When he woke up and he was supposed to brush his teeth but he didn't. Well, I have to wait for tomorrow (to do it for him). So I said. 'Come here,' he has been like a boy. 'So come here you have to brush your teeth. Sit down and do it like this' (brushing the teeth for her child). 'Well, I have to do like this?' he asked me. I said 'Yes, You have to do like this' (laughing). Even shaving his beard, I have to tell him to do so.

I: What did you do about shaving his beard?

M: I have to hand him a razor and hold it for him and give him soap. He would do it but if I just only told him, he wouldn't. Although in the past he wouldn't wear any clothes without ironing them, now he is like this.

I: Now?

M: Now everything can happen, everything, whatever.

IV: What is it like?

M: It's been like, excuse me, I have to tell him to do everything from head to toe...I have to tell him what to do, wash your feet, take a shower and shampoo...(Mother Case 11).

One mother stated how after the first episode of illness she had to take care of her adult son as if he was a young boy:

> Now he is OK. He can stay by himself. I don't need to take care of him as if he was a boy anymore. He is growing and he is all right..." (Recalling how she provided care at the beginning of his first episode) "Sometimes (at the beginning). I had to do some tasks for him, such as grooming. I had to dress him up when he could not do that. But he could do some other tasks by himself." (Mother Case 30).

Socialization needs. Another task of maternal care involved socialization. The Thai mothers in this study used several skills to both control the care recipients' behavior and to encourage them to socialize well with others. They wanted the care recipients to develop and maintain relationships with friends, relatives, and neighbors and to make contributions to community activities. They also wanted to protect them from negative social influences. Control was most important for sons if they were prone to violent behavior. For the female care recipients, the mothers were concerned about the possibility of rape, the risk of HIV infection, and unwanted pregnancy.

Skills of advising and reasoning were used when mothers noted that care recipients were isolated and preoccupied with their thoughts. Mothers would encourage the children to maintain relationships with others by advising them on how to respond to

people, how to greet neighbors, and how to make brief conversation. They also encouraged care recipients to participate in community activities such as weddings, house-warming parties, and funerals. For example, one mother reported that she considered her daughter to be obsessed with thoughts of a re-union with her husband. In fact, the daughter was very isolated. The mother tried to encourage her daughter to meet and talk with people. She advised her on how to respond to neighbors and how to greet people:

> Sometimes when the neighbors come to visit us when we (the parents) were not home, she always kept to herself in her room. She did not come out to talk to them. She was afraid. I told her, 'Why do you have to be afraid of people and hide from them? If there are relatives or someone coming and you know him or her, why don't you welcome them and show some hospitality? Tell them that I am not home and where they can reach me. But if somebody whom you did not know comes to our house, then you shouldn't talk to them. You don't need to come out to talk to them in that case. (Mother Case 1).

One mother reported how she urged her son to make a contribution to community activities. When the neighbor had a house-warming party, she advised him to help:

> I just let him be by himself. When the neighbor has a party or anything like that 'Son, why don't you go and help them out with preparing the party?' Sometimes he goes, sometimes he doesn't. But if he doesn't go, I wouldn't force him and the neighbors would understand that, you know, they know that he has been like this. (Mother Case 7).

In contrast, one mother, whose son was very independent and good at socializing, tried to limit his opportunities to go out with friends at night. She was concerned about the risky behavior that the men might engage in. Therefore she tried to advise and reason with her son in order to enhance his awareness of any dangers. Another mother also used advising and reasoning skills to control her daughter's social behavior. Essentially, the goal was to pressure the child using possible negative consequences of social activity.

Now she does not go out. When she went out I would say to her, '(name), aren't you afraid of being raped and having a chance to get HIV infection? Did you know that nowadays they rape even young girls?' So now she does not go out anywhere (Mother Case 12).

Mothers also used bargaining skills to control undesirable social behavior of the care recipients. The desires and fears of the care recipients could be used to negotiate rules for acceptable behavior. For example, when the care recipients wanted to go out and possibly engage in what mothers considered risky or dangerous behavior, the mothers exerted control by offering a substitute, perhaps a gift of a much wanted item or access to favorite foods. In contrast, some mothers used unwanted consequences to bargain with the patients. For example, the mothers might threaten that they would take the care recipient to the hospital if they went out, or engaged in other problematic behaviors. Both advising-reasoning and bargaining strategies contained desire, warnings, or threats about consequences. However, bargaining involved threats of unwanted consequences. It conveyed a stronger restriction.

One mother used bargaining with her daughter, a high functioning and a very out-going person. The mother related that her daughter had initiated a verbal and physical dispute with a neighbor. After this, she did not want her daughter to go out. Based on her experience, she could not simply advise or reason with her daughter. Therefore, she decided to buy a small radio for her daughter who liked to listen to music. This gift encouraged her daughter to stay home.

I didn't blame anyone for that (the fight). I just kept quiet but advised my daughter not to go out anymore. Then I bought a radio for her... 'Well, I bought a small radio for you.' She likes to listen to the music. So I bought a small radio and will not let her go anywhere. Nowadays, the neighbor asks 'where is (care recipient's

name) we don't see her much.' I don't let her go out much. When she went out, she caused problems, you know. I cannot not know where she is. (Mother Case 18).

Another mother described her bargaining strategy. She followed her son to observe whether he engaged in risky behaviors. After advising and reasoning with him many times, she tried to stop him by using bargaining. She threatened to take him to the hospital. After this, her son went only to places within the village where she could watch him and feel safe about any consequences.

I told him that, 'if you still go out frequently, I will bring you to the hospital in which you cannot go anywhere' (Mother Case 15).

A more controlling strategy of limiting social opportunities was reported by a mother who cared for a daughter with schizophrenia:

I don't want her to go anywhere. I don't let her to do any job [outside the home] because her father has a good salary and it is enough for her. It is enough and I don't want my daughter to go anywhere. I am concerned about the man issue, you know? If any man meets and deceives her only for sex and she gets pregnant, so I have to raise that baby? Well I don't want her to go out and she doesn't want to go out either (Mother Case 8).

When mothers wanted to avoid dealing directly with care recipients, they used the "controlling the environment" skill. Mother might use this strategy after efforts to control the care recipient's behavior had failed. It could also be used simultaneously with advising-reasoning and bargaining. To control the social environment, mothers approached the care recipient's friends to seek collaboration. The following excerpt describes how this occurs:

Last night his friends asked him to go out with them. I said to them, 'Don't ask him out. Now there is some news, bad news about a violent group who tries to steal cars and hurt people. Your car is new. If (her son's name) goes with you all and gets killed, what are you're going to do?' I don't want him to go. His younger

sister doesn't want him to go either. We are afraid of the chance of him being robbed or killed...(Mother Case 5).

Providing meaningful activities. Almost none of the care recipients in this study had outside employment. Only one person had a paid job, while others were in the process of finding jobs. Most of the time the care recipients stayed home, where caregivers were concerned about providing meaningful activities for them. The tasks their mothers assigned included household chores or tasks in the field (agricultural work) that they could perform together.

Reminding skills were used to assign household activities to care recipients who seemed to lack motivation, seen in behavior such as sleeping all day or being preoccupied and withdrawn. The mother would ask for help with a household task and periodically remind him/her to do it. One mother reported how helpful her son was, as long as she pointed out tasks and reminded him to do them:

> In the afternoon when I have to go to pick the vegetables from the field, I ask for his help. He will do whatever I ask. I even ask him to buy something for me, and he will do it, but I have to tell him. 'Wash the dishes, clean the house' - he does all this stuff. But if I didn't remind him, he wouldn't do it (Mother Case 23).

Most mothers reported that they lowered their expectations in terms of both performance of the task and willingness to participate. If the care recipients did not want to do a given activity, the mothers did not pressure or force them to do so. Instead, they would do it themselves, because they thought that it was the mothers' responsibility to do the work, and because some feared that the care recipients' symptoms might get worse if they were forced. As one stated:

> In the evening he filled the water bottles (to be kept in the refrigerator), washed the dishes. When he eats, he will pile up the dishes. 'Son, wash the dishes'.

'Yeah,' but he didn't do them. So I have to do them instead...sometimes he did them. Sometime he didn't do them, you know...(Mother Case 7).

She also added that sometimes her son yelled back at her if she pushed him a little bit.

Therefore, learning from this experience, either she or her husband would do the task, in order to keep the atmosphere peaceful:

Yeah sometimes he would yell back at me. Well, let it go. Whatever he did, I let it go. I don't take it personally. I let it go. If I am fine I will do it by myself. I won't ask him to do the task. Sometimes his father filled the water bottles. We don't keep him busy with tasks much. We don't know what to do. This is it. There is no way out (Mother Case 7).

Advising and reasoning skills were used most frequently to encourage meaningful occupational activity. Mothers would identify jobs or set goals for job seeking and then attempt to advise the care recipients to apply for, or do, the job. However, advising did not include coercion. From the mother's perspective, the patient's voluntary participation was a priority. Mothers also gave emotional support when the care recipients could not get a job as the mothers had planned. For example, one mother prepared a Thai dessert for her son to sell at a festival, but she did not force him to go after he refused:

(She told her son) 'Well, I prepared all the necessary materials for you to sell a Thai dessert in front of our house. So if you get better, you can do that, so you don't need to go anywhere. Last year at the Songkran Festival we planned to do it, so we can start it now.' He said, 'No, I can't. It cannot be started.' 'Why can't you?' 'I said that I cannot. I do mean it' (Mother Case 9).

One mother stated that her son wanted to resume employment where he had worked before the onset of his illness. She tried to help him get his job back, but she was told it was against the work re-employment policy. Her son needed to find a new job after his condition improved. She had to give him advice and emotional support when he was not successful in his search:

He didn't do anything – he just slept all day. When I came back from work he said, 'Mom, I am getting bored staying at home,' so I collected my savings for him to go find a job. But he didn't get one. When he came back, he really was disappointed and got stressed. I had to tell him, 'Son, you can try again next time. Nowadays the economy has collapsed so it is hard to get a job. Although you cannot go back to work at the same place, you will find another one.' I told him things like this (Mother Case 17).

Another example illustrates how a mother advised her son to get a job without

pressure or coercion:

When the neighbors or some villagers want to hire people for agriculture work, (she asked her son), 'Do you want to go? If you want to go, I will get that job and money for you' but he never ever get that offer. He said he doesn't want to go, so I didn't want to force him. My husband and I saved our money and sent him to school for a good education until he finished junior high school. We have to save as much as we can. If he doesn't want to get a paid job, that is ok, you know. We can live with this situation. At least we have rice to eat (Mother Case 7).

Sometimes the mothers simply planned for a future life or career for their children

and waited for the right time to start. They want to make sure that their children were

getting better and would be able to do the job. One mother reported the basis for her

plans to advise:

She can read and write, so I think to myself, if she is getting better and can be well I will find a career for her -- sewing or anything like that -- a career that allow her to live on her own, earn some money, you know. Presently she depends on us (parents). We cannot raise her until she is old (Mother Case 12).

Maintaining a protected milieu. Maternal care meant maintaining a protected

milieu, particularly when their children had already engaged high-risk behaviors,

including using drugs, alcohol, and smoking cigarettes. By identifying the consequences

of using drugs, alcohol, and smoking, the mothers intended to help the care recipients to

quit or keep them from starting these behaviors. One mother reported how she used

advising/reasoning. She talked to her son about the consequences of using drugs, alcohol, and nicotine and how to behave when a peer was trying to persuade him:

> I told him, 'Because you have been like this, don't use drugs (amphetamines) or anything like that. When your friends ask you to join or try to convince you to use them, don't listen to them. You are ill. You had a nervous break down. Don't use them. The doctor also advised you to not use that kind of stuff -- alcohol, cigarettes and other drugs.' He still smokes cigarettes but not chain smoking. He doesn't smoke frequently. He said he tried to quit, too. So I told him, 'Son, don't smoke anymore. There is a stop smoking campaign on the news. They are all quitting. 'I try to quit, Mom,' he said to me (Mother Case 27).

Advising and reasoning were used mostly in relation to the problem of cigarette smoking. Most mothers reported using these skills to convince the care recipients of the negative consequences of smoking. Although the care recipients did not stop immediately, they did decrease the amount of cigarette smoked per day, which gave the mothers some relief:

> In the early morning he will smoke cigarettes. But he will not smoke one by one. I don't want him to smoke. I said it is dangerous. It is not good. He said he eat sweet candy so he ask for the money to buy that. I told him not to smoke. So he smokes not too frequently. He smokes once in a while and then he will be able to quit it later. That's what he told me. So I said the better way is not to smoke it at all. It deteriorated your health. He says he will try--so now I observe him and see that he tried to stop it and he tried to eat sweet candy instead (Mother Case 16).

Another mother reported how she controlled the number of cigarettes available to her son. Normally, she tried to please her son, providing whatever he wanted, especially his favorite food, in order to keep him from going out and from getting worse. She told her son about their financial status to make him understand and feel a part of the household problem, and indirectly to control his cigarette smoking:

> Sometime I tell him the truth. I asked him, 'Don't you realize how much it costs to buy one package of cigarettes for you?' (It costs 29 Thai Baht per package). He used to smoke one package per week. 'I don't have many customers now and I

have to pay for the rent for the house too. Can you smoke the other kind of cigarette (one that cost less money) or smoke only 5 Thai Baht's worth?' Back then he would ask me to buy his cigarettes but now he won't ask anymore. He will wait until I offer them to him because he knows my financial status (Mother Case 9).

Beyond reasoning, more active bargaining was used to maintain a protected milieu. Mothers used the fear or desire of the care recipient as a bargaining chip. One mother used undesired consequences to bargain with her son to stop using alcohol. She used medication as a bargaining chip because she assessed that her son knew the importance of the medication and depended on it. Therefore, she told him that if he did not stop drinking, she would not get the medication for him. However, this only made her son claim that he decreased the frequency of his drinking:

> I told him stop drinking. He didn't listen to me. He drank everyday. 'If you're still drinking, I won't go get medication for you,' I said to him. 'I don't drink everyday, Mom.' 'If you keep drinking, you don't need to take medication. If it runs out this time, I won't get it for you. When you are ill, I go get medication for you wherever the hospital is. You never ever get by yourself.' (Mother Case 28).

Skills to control the environment were used when advising and reasoning and bargaining skills were not effective. If the care recipients were unable or unwilling to control their own behavior, mothers exerted external control of the milieu. One mother stated that she asked her older son to visit her ill child at his apartment and move him back to her home. This was because she wanted to closely supervise him and to prevent peer pressure influencing him toward risky behaviors:

> While he stayed at his apartment, I didn't look after him. He lived there for about two months. So I didn't take care of him at that time. But I was so worried about him. So I asked my older son to visit him to see how he was doing, and bring him home. Take him home. Because when he stayed at the apartment, he had so many friends, good or bad, you never know, you know. I don't know. I could think in many ways. I didn't see it, you know. I just thought about it, so I thought

if he refused to come back with his brother, I would have to force him. 'If he doesn't want to come home instead of staying with his friend, let him stay. Tell him don't ever come back home,' I said (Mother Case 15).

Another mother tried to control her son's drug use. She hid the motorcycle that he used to ride to the village where the drug dealer lived. Additionally, she tried to limit his chances of meeting a group of drug abusing friends. At first, she asked for collaboration from the care recipient's friends to stop using drugs or to stop asking her son out. When this was unsuccessful, she decided to confront them and refuse to let them visit her son at home:

> I asked them not to take him to that village. I said, 'Don't lead him to drink, do drugs or anything like that. It is not good. He has a neurosis. Don't take him to do that kind of stuff.' (Asking for cooperation did not work. So she decided to confront them and expel them from her home). "I got them out of my house. They said they just came visit him, not to take him to do drugs, but they actually did. They did drugs, smoked stuff. They stole the plate [license plate] and the headlight of a motorcycle (in order to buy drugs). So I scolded them and got them out of my house. Since then they haven't come to visit anymore. And he never goes to that village either. (Mother Case 4).

Managing stigma. Thai mothers do not necessarily see mental illness as shameful. However, they are aware of negative social consequences for the care recipients, including teasing, rejection, and avoidance by others. This problem may occur when the care recipients engaged in community activities demonstrate symptoms of mental illness. To manage the stigma that may happen or has already occurred, mothers used several skills such as maintaining privacy, advising-reasoning, and controlling the environment.

Skills in maintaining privacy were applied mostly at the beginning of the illness episode or when the mothers still had hope for recovery. Mothers often used physical symptoms as more socially acceptable explanations of the illness, such as insomnia, brain

trauma, and so on. If they admitted to a psychiatric diagnosis, some mothers preferred to

call their children's illness a neurosis or stress response, rather than a more stigmatized

disorder, such as schizophrenia. One mother explained that she decided to bring her son

to the medical clinic at first instead of a psychiatric clinic or hospital:

> I am afraid that in the future when he gets a job, it will affect his personal history.
> To be treated...in Chiang Mai, everyone knows that if you went to (Name)
> Psychiatric hospital, you are a crazy person. So I am afraid and concerned about
> that problem. But when I took him to clinic, he didn't get better -- he's still
> depressed. So I thought that to have a problem with stigma is better than to lose
> his life or his future (and she decided to bring him here) (Mother Case 21).

Mothers made decisions related to problems of stigma, not only at the beginning,

but also during later phases of the illness. One mother described her explanation of her

son's illness:

> The others asked me, 'Where is your eldest son? We don't see him much.' I said
> 'Well, he hurt his leg and he cannot walk so well (her son had been in a
> motorcycle accident). He will have an operation so he cannot walk for very long.'
> So I have to lie to them to keep it secret, you know. So now nobody knows about
> this. (When asked why she did this)...Well, I am worried that he will be treated as
> inferior. When he is cured, I am afraid that people will discriminate against him
> (Mother Case 9).

Not only the mothers, but also the care recipients themselves were concerned

about stigma. Therefore, skill dealing with stigma included protecting the secrecy of the

psychiatric illness as much as possible. For example, one mother decided to move her

son to another city:

> He asked me, 'Mom, did you tell others? Do they know that I am like this?' At
> first, I denied it, even to myself I could not accept it at all, you know. I denied it
> to others. I lied that he was hit by a car and got a brain injury. (When asked why
> she did that) This is because I don't want anybody to know, because once people
> know that someone is mentally ill, their reactions will change. Whatever he does,
> people will laugh at him. This is a major problem, especially within the village.
> People would know that he was ill when he went to help others, such as at

funerals. I tried to encourage him to do some community activities, to adjust himself to the outside world. So when he did something wrong or awkward, people would laugh at him which made him getting worse (Mother Case 19).

Advising and reasoning were used to help certain care recipients in dealing with being teased or hearing other derogatory comments. One mother reported how she advised her daughter to cope with the derogatory comments from neighbors. Sometimes the neighbors or the villagers would call her daughter a crazy person and spread the word that she had been admitted to the psychiatric hospital:

> I told her to steady her mind ("Tam jai"). 'Don't pay attention to anybody's words. Don't rely on their words...none of them raised you.' I told her things like that, so she said she wouldn't pay attention to them anymore. Her younger sister also told her the same as I did (Mother Case 12).

Sometimes Buddhist philosophy could help care recipients deal with the problem of stigma. In one case, a care recipient came home and complained that no one responded to his greetings or paid attention to him. He felt upset and offended since he believed that people reacted to him this way because of his illness. His mother knew her son believed in Buddhist philosophy, and so she reassured him:

> He is interested in Buddhist philosophy. He knows the history of the Buddha and everything. It is good that he didn't do anything wrong to anybody. If he gets angry and hurts people, it could be a bad karma for the next life. He said that too. And he feels better when I talk to him about that. I also told him not to pay attention to them (when someone says he is crazy). 'You are not a crazy man. You know what you are doing and know who you are, and that's enough' (Mother Case 26).

Another mother also used the care recipient's belief in Buddhist philosophy as a strategy to deal with stigma:

> I told him, 'don't take it personally (when was called a crazy man). Don't pay attention to them. It can be right or wrong. You are the religious person. You

have to let go. Don't take it personally and try to take revenge. If you do that it is no way for you to have enlightenment (Mother Case 5).

Skills to control the environment were used when mothers needed to directly influence people teasing or people making derogatory comments to the care recipient. They also tried to explain the symptoms to others in their own terms, offering explanations for behavior that appeared awkward, inappropriate, or strange to others. These skills were used simultaneously with advising and reasoning skills to encourage or support the care recipients and to ask collaboration from others. One mother reported that after she advised her son how to respond to the derogatory comments from others, she also went to talk to the neighbors asking for understanding and empathy:

> Don't call him "crazy." Don't call him things like that. He is not
> that bad. He is not disoriented. He knows everything like us. He feels
> embarrassed to be called something like that. Please don't call him that.

Sometimes she would point out the negative consequences of becoming angry and responding to provocation:

> Don't call him "crazy" or "idiot." He is not an idiot. He's a good person like us.
> Don't insult him. If he gets angry and does something to you, you cannot sue him
> because he has been treated in the psychiatric hospital (Mother Case 5).

Talking about negative consequences of teasing or provoking was mentioned by another mother. This mother also tried to advise her son to think in positive ways, in order to calm him down:

> I said, [to neighbors] 'You all know that he is mentally ill. But why do you still
> tease him about that? If he does something back, I won't take responsibility for
> that. If he hits back and you get hurt, I won't take responsibility for your bill.
> Because you have already known that he is ill.' So I said that to them and then
> they just went away. When they were gone I told my son that 'They just tease you.
> They just want to make fun of you. They just want to know whether you will get
> their joke or not.' 'I know, mom, they know that I am sick, but why do they still

want to tease me?' 'They just want to make fun of you because they are familiar with you. They want to know whether you will be a decent person, a lazy person, or a hot-tempered person. They just want to test you.' So I have to talk to him like that, you know, otherwise he will get angry more and more (Mother Case 25).

Interpersonal conflicts. Interpersonal conflicts may occur when individuals with

severe mental illness interact with others. Caregiving involved managing conflicts that

occurred between either the care recipient and mother or care recipient and other

household members. Mothers used advising and reasoning, distancing, bargaining, and

mediating skills to deal with these caregiving activities.

When conflict occurred between mothers and the care recipient, mothers would

advise and reason, invoking aspects of Buddhist philosophy or Thai tradition, such as

good karma, leading a good life. As in other behaviors, this produced a sense of

responsibility or guilt that persuaded the care recipient to stop the verbal conflict.

One mother told her story of arguing with her daughter about household chores.

When she asked her daughter to help with cooking, she refused and would only take care

of her pet (a mouse). After a period of arguing, the mother invoked Thai beliefs related to

Buddhist philosophy. She said that this made her daughter listen to her, although she

continued her refusal to help with cooking:

> I stop saying things even when she didn't help me. I don't want to bother or make the situation worse. It is worthless. Since we eventually will live together as usual, I said, 'I will keep quiet. I am the one who cook, I will get good karma ("Bhoon"). You don't help me to do that then you'll eat a bad karma ("bhab")'
> (Mother Case 2).

Mothers used distancing for conflict management, responding with silence to stop

an argument. This also allowed them both to calm down. The key concept here is

acceptance of the care recipient without agreeing or disagreeing.

One mother described a conflict with her son regarding drug use. When she tried to advise and reason with her son about the negative consequences, including exacerbation of symptoms, her son would argue about whatever she tried to point out. When she realized that her son would not listen to her, no matter what she said, and that the atmosphere was becoming tense, she interrupted the conflict by distancing, withdrawing from the argument:

> I know that his emotions are in upheaval, so I keep quiet---now he doesn't argue with me as much as in the past. He is just listening. Whatever I said, he will keep listening. Except when he really cannot keep quiet (the care recipient said) 'no, now we don't do drugs. We just hang out. That's all (Mother Case 15).

Mediating skills are used when other siblings tease or criticize the care recipient about his/her odd behavior or personal hygiene. The mothers would mediate the situation by trying to advise others not to be critical, while advising the care recipient to improve his/her behavior.

One single mother related that her younger son sometimes criticized his ill brother for poor hygiene and odd behavior, for example "robot walking," and "staring." The mother tried to mediate between both parties:

> His brother scolded him 'don't stare at me, it's very annoying' so I told my younger son 'didn't scold on your brother' and said to my ill son '(name) why don't you try not to stare at people too long' when I said that to him. He listened and smiled (Mother Case 9).

Only one mother reported using higher authorities to intervene with argumentative behavior. She tried to advise and reason with her daughter about helping with household chores, especially cooking. The argument started when the mother reproached her daughter, claiming that because she had raised her daughter, she should be able to expect

her to give something back (such as cleaning house, cooking). Advising and reasoning

skills were unsuccessful. To stop the argumentative behavior, the mother said:

> 'Stop arguing. It is useless. We should stay together and love each other. If you
> don't listen to me I will call the police and take you to the hospital. I don't want
> you to stay with me anymore. I am too tired of arguing. I say that I will go get
> them, so she is quiet then. She's scared (Mother Case 2).
> When asked why she used this strategy, the mother reported that the daughter

would not respond to anything but threats. This resembles other types of bargaining to

influence behavior. This strategy was more likely to serve the mother's well-being than

the daughter's. However, it was an extreme strategy that worked (keeping the living

situation in balance) in terms of the mother's point of view and learning experience.

Symptom Management

Symptom management activities differ from maternal tasks in that they move the

caregiver into a more specialized role involving skills and knowledge about the illness

that go beyond normal parenting, even normal parenting of a disabled person. Mothers

identified skills required to meet the tasks of managing psychotic symptoms, dealing with

aggressive behavior, and dealing with suicidal attempts and threats.

Psychotic symptoms. The task of managing psychotic symptoms applied most to

active ("positive") symptoms such as hallucinations, delusions, and paranoid ideas. To a

lesser extent it could also apply to more deficit type ("negative") symptoms including

inertia and lack of motivation. Mothers usually described the symptoms in terms of

concrete behaviors such as "hearing voices" or "laughing inappropriately." However,

they sometimes used clinical terms, especially "hallucinations." The use of both clinical

and behavior terms shows that the mothers could assess or detect symptoms on their own.

During exacerbation of the illness, mothers discretely monitored the care recipients' behavior. This included direct observation to make sure that the symptoms truly occurred and to confirm their own judgments. However, when the mothers had no chance to monitor symptoms themselves, they would ask for information from others who were with the care recipient when the symptom recurred. For example, one mother reported that her son came home and complained that people laughed at him, yet the mother thought it was his delusion. So the mother asked her younger sister who accompanied him:

> I don't know. I didn't go with him. He went with his aunt, three times. When he went to the fruit garden, people laughed at him (the care recipient said). So he didn't want to go again. I asked his aunt who was it who laughed at him? She said nobody did. He just thought so himself (Mother Case 28).

Once mothers were confident of the symptoms, they would try to use 'providing reality', 'controlling the environment', or 'seeking help from others' skills. In this case, the mother eventually sent her son to the psychiatric hospital for treatment when he showed more symptoms.

Confronting the symptoms (providing reality skills) were used after observing odd behaviors due to hallucinations or delusions such as talking to themselves, inappropriate laughing or in one case, eating rocks. Mothers asked what the care recipients were doing and asked why in order to pull the care recipient back into the real world. The mothers explained the irrational or inappropriate elements of the behavior, for example, saying there were no voices that she could hear. One mother told me how she confronted her daughter when she checked her illusions and hallucinations:

> Yesterday she said she had an illusion, and she felt like she heard voices. I said 'you might think this up yourself about illusions.' She asked me whether I heard it or not. I said to her, 'If I heard, wouldn't I be neurotic. I didn't hear, I didn't see anything...you just think to yourself'—[when asking what is the result] she didn't say anything but quiet. I said, 'you were the one who sees things. You have illusion eyes, you think by yourself. You see that person, this person', things like that (Mother Case 8).

One mother reported how she tried to pull her daughter back when she was laughing by herself. She found that confronting would stop her daughter and delay the symptom:

> I discreetly observed her and found that sometimes she was laughing and talking to herself. So I asked her, '(name) why are you laughing...talking to yourself...don't you feel ashamed when people see you to do that? 'I didn't do it,' she said she didn't do it (Mother Case 12).

Two mothers who took care of sons with schizophrenia also reported using these skills. One of the mothers reported:

> Sometimes he asked me to do it with him, trying to watch the sun at noon. 'Mom, why don't you come and see the light from the sun? There are orange, red, green,' he dragged me to see the sun. 'Well, I cannot do that, (name). It will cause blindness. It is too hot and too strong (the sun beams) to see it. No one can do that' (Mother Case 5).

Reassuring was a type of communication skill that aimed to provide external reality to the care recipients. Re-assurance skills were used for paranoid symptoms, since these usually make people extremely fearful. For example, one care recipient was afraid that the police would try to kill him, since he believed that he raped a woman (a delusion). The mother tried to re-assure him by telling that no one would kill him and that his thoughts were incorrect. She also asked help from a relative to provide additional confirmation of external reality to the son. When her son could not understand the explanations about his paranoid suspicious ideas, he was reassured about their

consequences as a last strategy. The mother then asked her older brother (who was in a high position in the military) to re-assure her son that he would be protected from whatever happened:

> I took him to call his uncle. He serves as a general in the military in (province's name). I told my brother first about his symptoms...about his fear of being killed by the police. So his uncle told him, 'If anyone dares to do that to my nephew, we'll see,' so he felt better (Mother Case 17).

Skills in controlling the environment were used for agitated or dangerous behavior. In the context of rural Thailand a particularly dangerous behavior was fire setting or misuse of kitchen gas. Almost of the houses are made from wood. Therefore, mothers were universally concerned about accidental fires. Thus, when mothers observed these behaviors, they would turn off the gas or lock the kitchen.

One mother told me she observed her son pacing about the house a lot. This behavior, along with past experience (she once woke up in the middle of the night and saw her son setting fire to boil some water) made her sensitive to the risk of his accidentally burning down the house:

> He walked back and forth, back and forth. I have to be careful about many things such as gas or anything like that. He might accidentally turn it on. I am concerned about that. I don't know. In the evening, I will lock the kitchen. I am afraid (Mother Case 7).

Seeking help from others to control strange or dangerous behavior due to the psychiatric illness of the care recipient was used when the mother could not handle the situation alone. Initially, mothers would ask for help from other household members or relatives. The second level of seeking help was to approach the head of village or

emergency workers. The final help-seeking strategy was to transfer the care recipient to the psychiatric hospital.

One mother described this help seeking behavior. On one occasion, her son cut down some fruit trees, her source of income. He did have good intentions to make fire wood for cooking. She needed to ask her older son's help to stop the care recipient's behavior and subsequently sent him to the hospital. More recently, he attempted to set a fire near to the house. All her relatives and the head of the village came to help to stop him. Finally, she had to get the help from police to get him to the hospital:

> (Last time) when he got better, we came to take him home. He stayed home about one month. Then there he goes again, he started to set fires near the house. He gathered wood together. All the relatives came. I didn't know what to do. Well, I came to ask help from the head of village. He came and suggested that I call the police (Mother Case 25).

Aggressive behavior. Aggressive behaviors included any physical abuse and/or deliberate property damage due to the psychiatric illness. Mothers in this study used a range of skills to respond to the task of managing these behaviors and their consequences.

Reasoning was first applied to calm the care recipients and by pointing out the negative consequences of their behavior. Both family obligation and/or the sense of individual responsibility and guilt were used to reason with care recipient. To illustrate these skills, one mother shared her experience about an incident when the care recipient attacked his father. He got knife from the kitchen and tried to hurt his father when he thought that his father laughed at him and said that he was lazy:

> He (care recipient) got a knife from the kitchen and went directly to his father. I could not stop him at the beginning. People who were with his father tried to stop him. So when I got to the place I said 'don't do that. If your father died, who would raise you up' I said that to him (Mother Case 28).

This made her son stop trying to hurt his father but his father was forced to sleep at a friend's house to avoid him. After that incident, she continued reasoning with her son about how important his father was to him and how hard it would going to be if she alone had to care for him.

Distancing skills were used when a mother feared physical harm from the care recipient. She might avoid face-to-face interaction, or leave the environment (for example, going to another house) until the care recipient calmed down. Distancing skills also included the mother's efforts to maintain emotional distance from the situation. It was more likely to be applied when verbal efforts to stop the care recipient's behavior were not effective. One mother described how she dealt with her son's delusion that she was not his mother and his possible assault behavior. She had to assess signs of aggressive behavior and use distancing skills to avoid physical harm:

> At night, I want to stay with him. But I have to prepare the way to escape from him when he gets aggressive. I tie a rope to the window. When he is about to hurt me, he will kick the door to close it. I have to jump through the window otherwise I am going to get hurt by him. So I have to sleep at my mom's house (Mother Case 13).

Distancing was not abandonment, because it allowed for remote observation. When this mother stayed at her mother's place (not too far from her own house), she discreetly observed her son to see how was he doing. She also put food and cigarettes in a bag and put them on a stair. Once she was sure that he had calmed down, she returned home.

In the case of aggressive behavior, controlling the environment included hiding knives, swords, or any other objects that could be used as weapons. These skills were used after a prior aggressive episode and until the symptoms receded:

> Sometimes, when she had a knife or something like that in her hand, nobody could deal with her. Nobody wants to get involved with her. There has to be somebody to reason and convince her (to calm her down and get rid of weapon). Knives or anything like that have to be hidden. But now I don't do that anymore. They are everywhere. It doesn't matter now" (Mother Case 22).

The skill of mediating was used when the care recipients had been deliberately aggressive outside the home. Apologies and the explanations of the mental illness could reduce negative consequences of behavior, in terms of social roles. The mothers asked for understanding and empathy toward the care recipients and tried to clarify that aggressive behavior resulted from the illness, not from the person themselves. This mother explained her daughter's hurtful behavior and asked for forgiveness:

> He (the person who was kicked by the care recipient) got very angry and went home. (I went to talk to him) 'Please do forgive her. She didn't have a good awareness. If she were aware, she wouldn't do that, you know. Please don't take it personally. She has been like this. When she is ok, she will be nice to others. If she got stressed out, she didn't know anyone even her dad and her mom, we also were hit by her.' So I have to explain this way. Then he (a man who was hit) didn't take her personally. I have to tell them that even her parents, she also hit us (Mother Case 22).

Self-defense skills were developed as a last resort when the mothers have been hit or otherwise physically assaulted by the care recipient. Self-defense was a reflex. After they reacted (some hit the care recipient; some protect themselves), mothers would call for help from others. The aim of self-defense was to stop any harmful action at that moment. As one mother, after being hit by her daughter, said:

> I protected myself, you know (laughing). I don't know. 'don't do that' and tried to grasp her hands. I didn't realize that she would kick at my belly. So I told her I had a cesarean section before. I don't have a normal labor. I had to go under operations two times, so I said that to her (Mother Case 18).

In this case, mother tried to protect herself as well as reasoning with her daughter. Her daughter stopped hitting her and isolated herself. This mother then had to find a favorite food to please her daughter in order to make her feel better. She used distancing skills by leaving her daughter alone for a while (with her own radio) until she got better and became pleasant again.

When it was evident there was a threat of danger to family members and neighbors, some mothers went directly to the police for help. The police could confine the care recipients overnight or transfer them to the hospital for assessment and perhaps admission. Some mothers asked for help from relatives or neighbors. Most care recipients who were very aggressive and could not calm down were eventually transferred to the controlled environment of the hospital:

> We (parents and relatives) have to restrain him. We cannot let him be like this. He will be aggressive. It is good that we have a car so we put him on the back, restrain him or something like that. He would complain along the way (Mother Case 26).

In one case, a son become romantically preoccupied with one woman and assaulted her boyfriend. When a neighbor informed the mother, she was stunned and decided to call the police:

> ...Someone came to tell me that he hit that man. I was very frightened. I didn't know what to do. So I called the police and they took him to the hospital. The police came to get him at home. They confined him one night at the police station. I felt sorry for him. They confined him and took him to the hospital in the morning (Mother Case 19).

Suicidal attempts or threats. When the care recipients actually tried to kill themselves, when they said they would do so, or when they expressed a desire to die, mother employed a range of skills. A first level of response to suicidal behavior involved monitoring skills, being with the care recipients all the time. Mothers appeared to ignore the threat but would watch the care recipient intensively. One mother described how she monitored plans to kill himself:

I: What did you do when he said that?
M: I don't know. I have to keep quiet because if I said something that disagreed with him, it is useless. He has a strong intention. He said if he goes to stay with his brother, he would steal his brother's gun to kill himself. So his older brother is very scared of that. When he comes to visit us, he hides his gun. He has a strong intention of killing himself.
I: What did you do then?
M: He (the care recipient) is hopeless. I have to take care of him closely. Sometimes, late at night, I have to check on him. When he gets up and goes to the bathroom, I feel frightened and I have to follow him and watch him all the time... (Mother Case 19).

In other situations mothers may try to reason with the care recipient to convince them not to carry through an attempt or remark about self-harm. The bonding between mother and child would sometimes pull the care recipient back to reality. One mother shared her story on how she dealt with suicidal threats:

M: He will kill himself. He said if he had a gun he would shoot himself. He mentioned everything. If he had a gun, he would shoot himself, or take strychnine (rat poison).
I: What did you do when he threatened you like that?
M: When he threatened me like that, sometimes I keep quiet. I tried to gather my thought first. I said, 'I am pregnant for nine months and raised since you were a baby.' So I have to remind him of that. He listened to that. 'So calm down, drink cold water to make you feel relaxed.' I have to soothe him. He listened to me as well (Mother Case 11).

Strategies to control the environment to prevent suicidal attempts occurred when the mothers tried to hide all weapons or potential material to perform suicide. These included sharp materials, ropes, sleeping pills and other medications. These activities were similar to the activities used to control the environment in situations of aggression. These skills were used after either the first suicidal attempt or suicidal threat. One mother shared her story when she found out that her daughter tried to hang herself:

I: What did you do after that (after seeing her daughter about to hang out herself)?

M: I hid a rope, the one she was about to use to hang herself, and other sharp materials, such as knives. I keep everything in a bag and hide them (Mother Case 12).

These mothers did not call for help until their children actually demonstrated suicidal behavior, that is to say, made an attempt. In most cases, mother would send the care recipient to the hospital for further medical treatment and for re-admission to the psychiatric hospital. The care recipients who needed the most medical care were those who had taken strychnine (rat poison) to kill themselves. Other suicidal behaviors included attempts to hang themselves or only to make suicidal threats. One mother shared her experience with her son. He was with his two friends who did not know that he put strychnine in his drink:

I: Could you tell me what happened at that time and why he wanted to kill himself?

M: I didn't say anything. It was harvest season. So his father told him to help. He didn't say anything. In the evening, he bought alcohol. I don't know where he got the strychnine from, two bags. He took one bag. So I asked him, 'what did you take?' He said he drank alcohol. He choked and vomited. At that time his two friends were with him. He said, 'if I die, I would forgive everything for both of you'. So one of his friends asked him, 'what did I do?' Then he just ran away so we tried to catch him. He

lost consciousness at that time, he took both alcohol and strychnine. So we took him to the hospital for a lavage (Mother Case 28).

Medication Management

The tasks of medication management include maintenance of supplies, promoting compliance, and making adjustments in regimens. In several respects, tasks in this area resemble those in formal caregiving and in professional nursing. To maintain supplies, mothers monitored quantities of medications, making judgments about sufficiency. Activities included making sure that there are sufficient medications for the care recipient. Medication compliance required knowledge of psychotropic medication regimens and the importance of taking medications as prescribed. Medication adjustment involved the most technical knowledge and skills, including knowledge of side effects of medications.

Maintenance of supply. Mothers developed skills in monitoring supplies by remembering the dates of renewal, by checking directly with the care recipient if he/she keeps the medication, or by direct monitoring when mothers themselves keep medication for the care recipient. Normally, the medication was placed at a central location in the house, for example, on the refrigerator. Monitoring also meant observing the care recipient's symptoms. Two mothers said that when they saw symptoms reappear, it was an indicator that the medication had run out. These symptoms were not necessarily psychiatric symptoms, but rather subtle changes or early signs in their appearances. For example, one mother reported that when she saw her daughter had a tic at her mouth and a change in her pacing, this provided her with the intuitive sense that her daughter's medication must have run out, and her hypotheses was true when she checked on it. The

mothers took responsibility for going to the hospital to get more medication. The care

recipients may or may not accompany them. One of two mothers shared her expertise in

assessing subtle changes and how her son responded:

> I asked him whether his medication has run out or not. If it runs out, I will get it
> for him. Sometimes when it runs out, he would complain about having a
> headache. So I know at that moment that his medication runs out. If his
> medication runs out, he cannot sleep. He will be restless, go back and forth
> between lying down and getting up (Mother Case 28).

Medication compliance. Compliance was a major issue. Almost all of the

mothers (29) reported working on medication compliance with care recipients.

Reminding skills were useful for care recipients who were in agreement with taking

medication and who had insight concerning its use and importance. Mothers would

remind the care recipients to take it, for example, by asking if the care recipients have

taken it as prescribed and on time.

> I: You just mentioned that you take care of him about the medication. How
> did you do?
> M: Taking care about medication. I just remind him to take it. I don't give it to
> him. But he takes every time and three times a day.
> I: How do you know that he takes it?
> M: I know. After meal, I told him. I said 'son, take your medication' he said
> 'yes' and then he took it. Sometimes if he has to go somewhere, he
> prepares his medication. He knows that he has to take medication (Mother
> Case 27).

Advising and reasoning were used either with reminding skills or alone, when the

care recipients seemed to accept the medication but lacked motivation to take it

independently. Mothers reasoned with the care recipient to emphasize the importance of

the medication. This is illustrated in following example:

Well, son, take your medication so you will be cured. When you are cured so you can go to do some merchandise or anything like that. When you earn some money, you can buy medication for yourself. That's what I told him (Mother Case 25).

Medication compliance skills included preparing and administering medications directly to the care recipient. Doing this gave mothers confidence that the care recipient took them on time and in the right amount.

> I: When he has medications to take, how did you take care of that?
> M: I will watch him. Sometimes he forgot to take them, so I had to remind him. Sometimes I have to put them in his hand, you know.
> I: Why did you have to put them in his hand? How did you think of that?
> M: I thought if I didn't give them to him now, later we would forget. He will forget to take them. He won't take them. Right after he eats his meal, I will put them in his hand. So he'll take them (Mother Case 7).

Bargaining was used when the care recipient did not respond to reason or lacked awareness. Mothers resorted to using higher authorities to control or force adherence. For example, one mother asked the health care provider to explain the importance of the medication to her son when he accompanied with her to the hospital. This allowed him to believe, and to conform to, the medication regime. Another mother used a threat, saying that she would call the emergency worker and would take the care recipient to the hospital for re-admission if he or she did not take the medication:

> I: How did you know that she take medications?
> M: I know since they have disappeared. I don't think that she will drop them or throw them away. If she throws them away, she will do it in front of me.
> I: Did she throw them away before?
> M: Only one time. She might get stressed out or something. So I have to threaten her that I have the number and will make a phone call to the emergency worker. Then she'll get them again and take them. She's afraid (to go to the hospital). I have to threaten her like that (Mother Case 29).

Five mothers reported using deception to administer medications when care recipients would not comply with the medication regimen. This was because the care

recipients lacked insight about their mental illnesses, refused all medications, and showed acute symptoms. This is called "justified" deceiving since it was done as a last resort when other strategies had failed. It was justified in terms of the danger of relapse. Four mothers reported surreptitiously putting the medication in the care recipients' food or drink. Two out of four reported that this deception failed. The care recipients refused to take the drink or food the mothers provided. Another type of justified deceiving occurred when mothers told the care recipients that the medication was a health supplement and not a psychotropic drug. This approach increased care recipient's willingness to comply. Justified deceiving also included misleading the care recipient in order to take him or her to the hospital to get medication or other continuing treatment. Once the care recipient' symptoms were stable, and if care recipients had some insight, mothers would quit these strategies.

As stated above, this strategy was a skill of last resort and was applied because of the importance of adherence to medication. The mothers knew that once the care recipients took the medications, they would get better. This strategy was the last choice before the mothers transferred the care recipients to the hospital for treatment of acute symptoms. One mother shared her decision:

> I: Do you think this strategy by yourself [to put medication in a drink]?
> M: The strategy for medication? Yes I did (laughing).
> I: When you put it in his drink, how did you think about that?
> I: I don't know what to do. I don't know the other way. Sometimes I hand it to him. He didn't take it. He didn't believe me. He hates me. He said I forced him to take medication. I asked help from the others. The neighbors. I visit them. Sometimes we went to funeral. He went also. I asked them to give him a drink, the drink that they will serve in at the funeral. Sometimes I prepared from home because I tried to find the way to make my son taking medication. I have to tell his brother to go back to

get the drink he likes at home. Sometimes he wanted to drink coffee that they served at the funeral. I told the neighbors if all guests go home, please hide the coffee from him. Otherwise he will drink it. Everybody knows that he is neurotic. So they hide the coffee from him. They offer him another kind of drink. So they offer to make a drink for him. Sometimes he refuses since he is afraid that they will put the medication in his drink. They said they would make it very special for him. Then, one person will grind the medication while another makes his drink (Mother Case 3).

Medication adjustment. Mothers who were in a caregiving role for a period of time learned about the important of medication from their experiences. Some observed the side-effects of medications and realized that the dose needed to be adjusted. The medication schedule could also be adjusted for the convenience of the caregivers. When the mothers needed to change the medications (in terms of side effects, amount, and type or time of administration) they often consulted the psychiatrist, asking him or her make changes, for example, a change from three times a day to two times a day. The following excerpt illustrates how mothers tried to negotiate with the psychiatrist:

M: His younger brother is a student. So I decided to go back to work and left him stay home alone. He is getting better. Then he goes back to work at the same place. First they let him leave for medical leave. And he can come back to work when he is getting better. I prepare medication for him. He didn't take it when he was at work. He took it only when he was home, only in the morning and in the evening when I am with him.

I: He didn't take the noontime dose?

M: He didn't take the noontime dose. So I reported this to the psychiatrist. Consult them. I said I don't know what to do but I want to have a two times medication (laughing). So they prescribed that for him (Mother Case 3).

Mothers also negotiated with the psychiatrist to get a particular medication that they believed was best for their child:

M: She got the right medication. So I told the doctor not to change the medication. She got the right one. Don't change to the new one. I don't want it.

I: How do you know that she got the right one?

M: She got the right one because she is getting better. She didn't argue with me much. Before she took another type, she argues with me all the time. But this one when she took it she is getting better (Mother Case 2).

Five mothers described using their own judgment to adjust the medications. Three of them adjusted the dose of sleeping pills. Two of them adjusted the medication when the child appeared to have side effects. One mother who tried to taper off her son's sleeping pill explained her desire to make her son as normal as others were, and to decrease his dependence on the medication:

M: ...I want him to be better and look normal. So I want him to try to stop the bedtime medication. When he stops he cannot sleep.

I: Why do you want him to stop medication?

M: Because I want him to be normal. I want to try to see whether he can sleep on his own. I want him to get out of this circumstance. I want him to be able to sleep by himself as others do. But now he doesn't take the sleeping pill. Back then he took both (Psychotropic drug with a sleeping pill). Now he does not take the sleeping pill. He can stop taking that. But when I came here I saw the sign saying that if you want to stop the medication, you have to consult the psychiatrist---I am lazy to ask the doctor. I don't want to talk in detail, so I told my son that we cannot stop at one time but we have to do systematically. I told him the doctor said that, I don't tell him that I read from the sign...(Mother Case 9).

In conclusion, the mothers in this study used 17 skills to take care of their mentally ill children at home. Some skills were used across tasks, for example, advising and reasoning. Some skills were applied only for specific tasks, for example, coaching skills. The application of various skills for particular tasks is shown in the matrix in Table 6.

Table 6.

Tasks and Skills Matrix

Caregiving types/skills	1. Monitoring	2. Reminding	3. Advising-	4. Providing	5. Doing-For	6. Coaching	7. Privacy	8. Distancing	9. Bargaining	10. Mediating	11. Self-	12. Adminis	13. Adjusting	14. Justified	15. Controllin	16. Seeking	17. Negotiatin	Total
I. Maternal care 1.1 Personal care		x			x	x												3
1.2 Socialization			x						x						x			3
1.3 Provision of meaningful activities		x	x															2
1.4 Maintenance of a protected milieux			x						x						x			3
1.5 Conflict Management			x					x	x	x								4
II. SX. Management 2.1 Managing Psy. Symptoms	x		x												x	x		4
2.2 Dealing with aggressive behavior			x					x	x	x					x	x		6
2.3 Dealing with suicidal attempts/threats	x		x												x	x		4
III. Med. Management 3.1. Maintaining supplies	x																	1
3.2 Med. Compliance		x	x						x				x		x			5
3.3 Med. Adjustment														x			x	2
Total	3	3	8	1	1	1	1	2	4	2	1	1	1	1	6	3	1	40

The Process of Skill and Role Development

Mothers were asked about their experiences at different points in time and their development of expertise, or their most effective use of skills. Specific questions were used to elicit information on skill acquisition such as "Looking back on it now, what might you have done differently to resolve the situation?" or "Can you remember one or two specific times when you felt like you suddenly found a new way to handle a problem with your child?" Mothers not only described what they did, but why and how they did it, providing an opportunity to understand their judgment and their evolving sense of

mastery or expertise in providing care. They described evolving expertise with discovery

of the more effective skills developing through trial and error. For example, if past

experience showed scolding or harshness to be ineffective, mothers used this knowledge

to deal with the care recipient in a more supportive way.

Mothers described developing abilities, sometimes based on increasing awareness

or understanding of the ill person. They were able to note subtle changes in behavior,

such as anxiety or sleep disturbance and to interpret these as possible indications of non-

compliance with medication. They were also able to intervene earlier in crisis. If acute

they perceived an exacerbation of acute symptom, they knew how to access the hospital

for timely treatment.

> I: How did you know that he was getting worse?
> M: I can tell. He talks differently, acts differently. It is some kind of thing that isn't ordinary. He will talk. He will start become paranoid about people. You can tell by his symptoms. The way he talks and behaves will be changed. He will be agitated.
> I: So you took him to the psychiatric hospital? (She has already mentioned this before)
> M: Yes (Mother Case 19).

Many mothers emphasized learning the importance of communication style. Most

expressed that they had learned by experience that "harsh words" or "scoldings" were

countered productive. Instead, they learned to "talk nicely" or tried to be "convincing."

Based on their caregiving experiences, the mothers knew that a better way to deal with

the care recipients was talking with them in a gentle manner.

> I: At that time (when symptom exacerbated) what did you do to take care of him?
> M: I took care of him at home. I have to advise him about socialization. When we eat together I have to advise him. I was with him all the time. Don't

scold at him, you know, you have to talk to those kind of person nicely. You have to talk very nicely.

I: Why did you think you have to talk to him very nicely?

M: I have to. Otherwise he will be something else. He will be more aggressive (Mother Case 27).

When a strategy failed, they continued to try others until they found a way that was effective for them. It was not clear from these data if skill acquisition was a direct function of duration of time in role, or if there were common types of stages in learning. Development of expertise may occur at different times for different individuals, as a function of personal individual characteristics and contextual factors, as well as time in role. However, learning was experiential. At some point in their caregiving experience, they developed a repertoire of skills that they could choose from for various circumstances.

One mother shared her experience dealing with her son's paranoid ideation. Instead of confronting, she learned to use distancing and accepting, achieving her goal (control her son) in a shorter time:

I: Do you have any experience of doing something and finding that it's more effective?-From your experience when you did something for a while and you found that you should do other way which is better?

M: Yes, sometimes. When he did something, I would be the one who kept quiet. And go along with him. Sometimes I act angry. For example, when he said somebody gossiped or said something about him, something like that. So I act like I am angry to that person who said something to him. And said something like I will go to talk to that person.

I: What happened when you did that?

M: He will be quiet. He may perceive that I accept him and go along with him.

I: You didn't do like that before?

M: No, back then I argue with him.

I: Will he argue back?

M: Yes, and we will go on and on and never end. Sometimes, in the past, he argued with his father all day long (about his paranoid ideation). It is very

annoying. (Now) I said to him 'how come they said that to you'. I said something like that so he will keep quiet in a shorter time. (Mother Case 19).

In sum, skills were acquired through experience, often by trial and error, as mothers in this study learned how to respond to their ill sons or daughters. However additional questions about skill and role development over time require further investigation.

<center>Role Development</center>

This study did not aim to investigate response to illness in the sense of burden, but interview data provided insights regarding emotional aspects of role adaptation. Mothers in this study provided information on emotional responses that were integral to their behavioral responses, such as using a skill of 'distancing' or 'self-defense.' These descriptions provided an understanding of how they adjust themselves emotionally to the mental illness, to the care recipient, and to the caregiving role.

Emotional Adaptation

All feelings that mothers expressed were coded and categorized together in terms the associated type of behavior trigger and in terms of how mothers adjusted emotions to situations. For example, when a mother expressed anger about assaultive behavior, they would then be asked how they dealt with that feeling.

Angry feelings usually triggered by verbal or physical assaults. Mothers also expressed anger when the care recipients did not listen to advice to modify behavior. One example of this occurred in relapse to drug use:

> I: At that time, how did you end up with following him and throwing him with a rock at him? [She tried to punish her son]

M: I got angry when I saw the amphetamine.

I: You saw the amphetamine and you got angry?

M: Yes, but later on I found out that it was not amphetamine. It was vitamin. He just tried to burn and inhale it (Laughing) (Mother Case 4).

Sometimes mothers feel frightened:

M: He was gathering wood to burn the house. Actually he didn't burn the house but he just set a fire near the house.

I: What did you do at that time?

M: I don't know, police came and they brought him here.

I: Who called the police?

M: I did. I told the head of the village and then he called the police.

I: How did you think about that?

M: How did I think? If I didn't do that, I could not help him. I was frightened that he would harm me. He had knife, ax in his hand you know. I was frightened that he would harm me you know (Mother Case 25).

Another example:

I: How come you bring him to the hospital?

M: Someone told me about that. He had symptoms. He might be crazy.

I: Who told you?

M: My relatives, you know. And I thought to myself, I am afraid that he will harm me.

I: Does he have a sign showing that he will harm you?

M: Yes, he will harm me.

I: What does he do?

M: He will harm me. When I said something he doesn't listen. He acts aggressive to me. He threatens me. When I give him the medication, he doesn't take it. So I bring him here (Mother Case 30).

Data suggested that at first mother adapted to anger and fear by telling themselves that those behaviors were not because of the person, but from the mental illness. Bonding between mother and child also helped adaptation. Their belief in Karma was one of important factors that helped these mothers endured the situation.

She hit me one time. She claimed that I complained too much. Back then she hit me when she was admitted at the psychiatric hospital at the beginning of her episode. She used a stick to hit me. It was my 'karma' that I have a neurotic daughter. So I went to the police. The police came and asked her why she did that.

'She complained too much' that's what she said. I complained about whether she took medication. She didn't understand my good intentions. I cried many times about my daughter. I have to have tolerance for that. The policeman said to her that if she hit me again, he would take her to the psychiatric hospital - if she did it one more time. She said 'no, I won't do it again'. That's what she told the police. If she wasn't neurotic, he could take her whenever he wants. But because she is neurotic, so I have to live with it. With my 'karma' you know. When she hits me, I forgive her. She is my daughter. I have to be tolerant and live with my 'karma'. (Mother Case 2).

When the mothers had gone through multiple episodes of their children's illness and when they began to realize that these disorders could not be cured, they expressed feelings of hopelessness. Understanding this aspect of illness reduced expectations, with decreased of distress.

Nowadays I just go along with him. That's all. Because I accept that, Back then I thought he would understand (when she tried to reinforce the reality) and he will be better something like that. Now I think he has no choice. If he likes to do anything, just let him do it. You know. If he likes to watch TV, let him do it. So I will compromise like this (lower her own expectation) (Mother Case 19).

In summary, to adapt to the illness, mothers need two key concepts: understanding the illness, and mobilizing personal philosophy of acceptance (i.e., karma and bonding between mother and child).

Beside the emotional adaptation to the mental illness per se, mothers also expressed the feeling toward their own children as individuals. Mothers expressed feelings of empathy with the care recipients that helped them to tolerate distressing behavior from aggressive behavior:

I: Can you tell me what your relatives did to make him [care recipient] calm down and bring him to the hospital?
M: Yes, we have to tie his hands something like that you know. We cannot let him be like that, to be aggressive. So we took him into the car. Tighten his hands anything like that. He will complain along the way to the hospital. But I didn't come with him.

I: You didn't accompany him?

M: No, I feel pity for him you know. When I saw him like that. I feel empathy with him...(Mother Case 26).

To adapt, mothers have to go through grieving related to loss of some of their child's characteristics due to the chronicity and incurability of the illness. Another example in terms of tolerating chronicity is following.

I have taken him to psychiatric hospital many times, about two or three times. They said here is the best. So I brought him here until now. I thought he will be cured but he hasn't. Now I thought he could not come back, you know. It made me feel hopeless when I realized that I could not pull my son back to the normal world. I feel sad because I feel loss of him. He was so healthy, good looking. He is quite good looking. His intellectual level was also good before. But now he forgets things here and there. He said he was treated with Electric Convulsive Treatment (ECT) (Mother Case 19).

Mothers mentioned "karma" as the explanation of how the care recipients got the illness. The belief in karma enabled them to let go of their feelings and accept the care recipients and the illness. This is because they believed that they could not do anything about karma, but just had to let everything happen. The only thing they could do was to take care of the care recipients as the best they can. Thus, the belief in karma in this context constitutes a coping strategy. One mother shared her conversation with two other mothers who cared for their mentally ill children:

We said it might be their karma to be like this. Before they were not like this (laughing). Well, whose karma, it's that person who has to pay back (laughing). So I said let go, we are at this age. We should divide it (karma) equally (laughing). We should get it. It is their karma to be like that and our karma, parents, to have to take care of them also. So we put it in this way. Another one said 'isn't that true?' I said 'it is true' (laughing). We knew it. It happened (Mother Case 11).

Mothers reported that they prayed to 'Buddha' to ask for a good life for the care recipients and for themselves. Mothers also expressed that in order to live with the care

recipients peacefully, they had to lower their expectations of the care recipients. The ability to let go (because it was karma) and the empathy they have for the care recipient also lowered their expectations toward the care recipients. Besides belief in karma, lower expectations were a key point that enabled the mother to accept the care recipients, their behaviors, and the illness. This lower expectation can be seen from some excerpts through the text when discussing about the care in the area of providing meaningful activities and also from the following excerpt:

I: Since you have been taking care of him almost 8 years, do you take care of him different from at the beginning?

M: Ah huh.

I: What is the difference?

M: It is something, well, when I take care of my son, I don't think that he will become normal. I don't think so. He will be like this. He will not be the same as other people. You know. It is something that already broken. His mind is broken. His mind is flowing. Sometimes he says thing here and there. He didn't remember it and hold on to it. His mind is not normal. It is broken (Mother Case 25).

Role Adaptation

In order to understand how they perceived their caregiving role, mothers in this study were asked about what they did to assure care when they went out, and about the advice they would give to others in a similar situation. Responses to these questions provided considerable data about role adaptation. "Role adaptation" refers to how mothers integrate themselves with caregiving role; how they made the transition from as extraordinary work to caregiving role as part of their life.

Almost all the mothers in this sample assumed a 24-hour caregiving role. One mother described how she perceived the caregiving role as part of her life and the family obligation associated with:

I: In terms of taking care of your son, is there any person who suggests you to do this?

M: No, I have to think and decide by myself on what I should do. We were born together like this. We share life together, so we have to take care of him until we, parents, pass away, you know. After that it depends on his sibling to take care of him. What we're going to do, you know. It has been like this. This is it (Mother Case 7).

Worries about role replacement in the future form a general issue for these mothers. They view their caregiving roles as part of their lives and plan to find prospective persons to replace them:

I am worried about one thing. I am worried that they will have a problem among siblings when we, parents, pass away, you know. She doesn't have a future. Hypothetically, if she just eats and sleeps, sleeps and eats like this. And if her younger sister gets married, her younger brother gets married, I don't think she can stay with one of them. They're going to have a problem. If she has her own future, that would help (Mother Case 12).

One mother also prepared the care recipient for the future possibility of living with other siblings. Belief that care now will protect him in future:

I: What is the issue that you are most concerned about and found that it is very important in terms of taking care of your son?

M: I am worried that his illness will be come back, you know. If I am getting old and pass away, who is going to take care of him? I am worried that he cannot stay with them. I don't know where is he going to stay in the future. That is the thing that I am most worried about.

I: So what do you do then?

M: I prepared him, improved him. I advise-reason him to behave. I have to take care of him closely (Mother Case 5).

Evidence of their ability to advise or supervise other household members or others in similar caregiving situations is an indicator of mastery of the caregiving role. Thirteen mothers reported getting help from others household members in taking care of the care recipients. Some described how they advised or made suggestions about how to deal with

the care recipients. One mother, who had to work outside the home, instructed her

husband about her son's needs:

> Since he came back from the hospital, I told my husband about the
> communication style. Don't say something that provoked his anger. Don't say
> something like that. And remind him to take medication also. So he did that
> (Mother Case 17).

The mothers' mastery of caregiving meant they were the ones to teach other people in the

family how to care for the ill child:

> I said to his father 'don't argue with him. If he said something, don't argue with
> him. Listen to him. His father loves to argue with him. It is something that doesn't
> have a reason. His father doesn't understand. So I am the one who knew that, my
> daughter also. We know that this person (the care recipient) is being like this. We
> got into the point, you know. The point that he has been like this, we should act
> correspondingly (to his condition) (Mother Case 10).

> When asked about advice they might give to others, all mothers discussed both

process and context of caregiving-not only task but the way to do it. Many of them

described the importance of talking in a tender way. 'Being with' as much as possible

with the care recipient is another strategy that mothers suggested. However, in addition

to these caregiving strategies, all of them emphasized the importance of medication.

Their comments reflected their experiential learning in the role of caregiving.

CHAPTER V: DISCUSSION

The purpose of this chapter is to discuss the major findings of the study in terms of current knowledge in psychiatric caregiving, the significance of the findings, limitations of the study, and implication for nursing practice and research.

The Context of Care

The majority of mothers in this study were agricultural workers, housewives, and merchants (e.g., owners of small grocery stores). These occupations provided the opportunity for mothers to be with the care-recipient almost 24 hours a day. It was evident from the interviews that the mothers sometimes brought the care-recipient with them to the field, where they worked together. Their almost constant contact expanded the range of the tasks and skills involved in caregiving. This fact probably differentiates them from caregivers with more limited contact. Mothers in this study represent a group of family caregivers who are most vulnerable to stress, as residing with an ill relative is one of the strongest predictor variables for caregiver burden (Solomon & Draine, 1995; Gallagher & Mechanic, 1996).

Almost of the mothers in this study resided in the rural area and 29 of them were Buddhist. These two aspects: rural social structure and traditional or cultural practices influenced their caregiving approaches. Traditional self-care that combines spiritual and medical practices is common for Thai people, especially in rural areas (Songprasert, Wareerak, Sillapakit, Ployleamsang, & Pongpan; 1993). It was evident from this study that 21 of 30 mothers first sought traditional treatment, using herbs, and holy waters. These traditional self-care methods have been utilized since ancient times for Thai

people, especially by mothers who served as health care managers in the household (Puttaprayoonrawong, 1991).

A belief in "karma," which is one aspect of Buddhist philosophy, was a major source of support for the mothers in their coping with their caregiving role and their emotions. The notion of karma is complicated and varies not only from culture to culture, but also from individual to individual. Although, it refers to "the intentional action whether physically, verbally, or mentally that occurred in the past, present, or the future, whether bad or good" (Prayut-Prayutto, n.d., p.5), some believed that karma was similar to fate and cannot be changed. This is also true for some mothers in this study, who believed that it was their karma to have a son or daughter with mental illness, and it was the karma of the care recipient to have such illness. This belief in karma can help the mothers to let go of their negative emotions and accept the condition of care recipient and their caregiving role. This belief might contribute to their tendency to use the skill of advising-reasoning, which reflect the respect, acceptance that they have toward their child. Karma belief also helps these mothers to not see the illness as shameful and not to blame themselves for the cause. Bhuddist culture also influenced the communication style that they used. Taking care of the disabled person also brought them "Bhoon" (a good karma) for their life. In other word, it is the way that they can make merit. This made them feeling good about themselves and to their role.

The feelings of letting go and accepting the illness and their role might also result from endurance that mothers learn over time, beyond the influence of any other cultural factors, as Karp and Tanaragsachock (2000) found in their caregiver study. This aspect of

acceptance requires continued study. However, the Bhuddist belief in Karma has parallel with other forms of spiritual help seeking. For example, it is somewhat similar to the beliefs of caregivers in Rose (1997)'s study. She found that a strong belief in God enabled primary caregivers to cope and to have hope for the care recipients' future.

The close knit social structure of rural Thai society also affects caregiving. Mothers in this study universally sought help within personal networks for situations that they could not handle on their own. Formal support, such as hospital care, was the last resort if assistance from relatives and neighbors failed. This was true even after the first episode of illness. Mothers in this study continued to rely first on family members and neighbors, although their needs might evolve as they acquired experience managing the illness. For example, early in their roles, caregivers might need very concrete information about how to get treatment. In later episodes, with more knowledge of resources, they might need help with complex care or problematic situations.

Culture and social structure also influenced how mother perceived functional level of the care recipient. This is suggested by the relatively high functional ratings that mothers gave their children (LSP scores). As noted in Chapter III, Methodology, the Thai version of the LSP used in this study (Rungreunkulkij, 2000) asks mothers about severity of problems with 39 functions. Caregiver expectations for a given behavior may have influenced whether a behavior was considered to be a problem, and whether it was considered to be severe. For example, the Life Skill Profile (LSP) considers lack of social activities as a concern. However when these mothers reported that the care recipients stayed home, this was not considered a problem. Rather, it allowed them to

keep the care recipients under their direct supervision (In the LSP, it is a social skill problem). In this case, the cultural differences in perceptions of the situation cause major difference in scoring. In Thailand, especially in the villages, people are well known to others and social contact is not a concern. Rather as interviews indicate, the concern lies in how the mothers control high-risk social behaviors. Another example, the LSP item on money management cannot apply to these rural Thai residents who do not have their own money to manage unless they are gainfully employed. There is no equivalent to disability income as provided in the US and elsewhere. This may at least partially explain the unacceptable level of the reliability (.29) in the sub-scale score on self-care in this study (in addition to the small sample size).

They also were more accepting of some dependence in the area of personal care. For example, mothers scoring self-care (e.g., taking a shower, grooming) might report "no problem" because they naturally provided care as part of their parenting (maternal role). In fact, the mother's skill level might affect perception of problems and ratings of their severity. To the extent that a mother feels competent to provide care in a given area, she may not perceive a problem. This personal skill factor may contribute to high levels of function reported by these mothers. These findings point out not only the need to develop culturally specific instruments, but the largest question of cultural expectations for the mentally ill and their impact on caregiving.

The social and ethnic context of caregiving has been studied by many researchers, for example, by Guarnaccia and Parra (1996). In their study, they found that Hispanic American and African-American caregivers seek help from other family members more

than European-American caregivers who seek help directly from the health care provider. They looked at how caregivers sought social support in terms of their perception of the illness, rather than in terms of family or social structure. This, however, alerts us to the varied patterns of using support in the caregiving context. These resources and help seeking patterns appear to be influenced by many factors including cultural background, the belief of illness cause and the family or social structure.

<div align="center">Psychiatric Caregiving Tasks and Skills</div>

The three major caregiving domains (maternal care, symptom management, and medication management) represent attributes of the activities. Maternal care activities are similar to normal parenting in that they address routine living (e.g., grooming, nutrition). The tasks of symptom and medication management are close to more formal caregiving. For example, activities of illness symptom management, such as monitoring, are comparable to activities of staff in a psychiatric treatment setting. Moreover, mothers have learned from their experience that medication is the most important factor influencing the care recipients' functional level. Therefore, the tasks of medication management were emphasized most by these mothers especially medication compliance. These mothers also observed the side effects and other symptoms related to medication. These are technical tasks requiring specialized knowledge and judgment, comparable to nursing care. The fact that caregivers attempt to assume these tasks speaks to their need for basic knowledge about mental illness and its treatment.

Skill acquisition among these mothers was experiential. They learned a range of skills that allow early detection of problem prevention of crises. A son who kicked the

door gave cues to impending aggression. A daughter's resumed tic signaled a lack of medication, perhaps a need to replenish the supply.

By a process of trial and error, mothers identified skills that "worked" for them. However, whatever work for them was sometimes expedient and not necessarily productive in the long term or indicative of quality of care. Further, their learning processes were unnecessarily stressful to caregivers. Their stories described experiences of assault, helplessness, and fear. Eventually they learn management of care. Health care professionals could help to decrease their stress in this process by providing the information required about home care management.

Schene and colleagues (1998) used the Involvement Evaluation Questionnaire (IEQ) to obtain the information on caregiving domains with 480 Dutch family caregivers. They used principal component analysis to find the domains of caregiving from 36 caregiving items. Interestingly, they found four domains of caregiving: (a) tension-where the items focused on the emotions that caregivers experienced, (b) supervision-regarding medication compliance, protected milieu and suicidal attempts, (c) worrying-which focused on the care recipients' safety, health, and future, and (d) urging-concerned with personal self-care. Although their findings differ somewhat from these identified in this study, it is evident that some tasks in these four domains are similar to those reported by the mothers in this study.

The experience of stigma reported by these caregivers has been described in other contexts of caregiving (Chafetz, & Barnes, 1989; Kelly, & Kropt, 1995; Rose, 1983). Prior research has dealt more with the family experience of stigma than skills or its

management. It is interesting to note differences between comments on stigma by these mothers in the rural northern region of Thailand, and Nitikool's (1992) comparative study of parental caregivers in the rural and urban areas in central region of Thailand. She found that parents in rural areas reported more self-blame and stigma than those who resided in urban areas. This might reflect greater independence and distance from neighbors in urban settings. There may also be differences in the quality of stigma reported by various groups. Mothers in this study did not report personal feelings of shame about the mental illness itself, but they still needed to protect children from negative consequences. Future studies may further clarify different aspects or dimension of stigma.

In response to tasks of caregiving, mothers could choose a range of responses on a continuum of restrictive orientation: nonrestrictive skill leaving more space for choice and autonomy for the recipient of care, and with restrictive solutions effectively controlling behavior or environment. This appeared to be both a function of experiential learning (less restrictive options developed with skills in monitoring, advising, etc.). Non-restrictive skills left more space for the care recipient to be independent and, consequently, led to a better level of function in care patterns. The mothers stated very clearly that it was preferable to convince, rather than to assert control.

It is unclear to what extent duration in the caregiving role promotes differentiation of skills and development of less restrictive options. These may also be a function of personal style. These data suggest that there were some mothers with predominantly restrictive care patterns compared to others. This may reflect differences in the child's

needs or in the context of care. The relationships between these variables present an important topic for future research on the process of skill development among maternal caregivers to the mentally ill.

As noted above, caregiving skills fell along a continuum from what might be termed normal parenting to more technical skills similar to professional nursing. However, as also noted previously, the specialized nature of the skill did not always indicate quality of care. For example, caregiver and nursing monitoring share a common meaning: being watchful but ready to provide care as needed. However, the maternal care provided might be different than nursing interventions. Some mothers in this study were knowledgeable about detecting hallucinations and delusions, but their strategy in providing reality was not always helpful. Responses such as: "If I were crazy I'd here voices too" could make the care recipients feel more isolated. Hospital nurses usually orient patients to reality with respectful comments and try to acknowledge the care recipient's experience.

Administering medication is a restrictive intervention that urges the care recipient to take the medication right away and that allows the mother to observe. This is in some ways comparable to what nurses do in an acute psychiatric unit. However, some mothers required education about the right amount and right time to administer medications as well as when to adjust them. Some mothers appeared to adjust psychotropic medications in response to the manifestation of symptoms. For example, when a symptom disappears, a mother might encourage the care recipient to stop taking the drug.

Other skills used by the mothers in this study raise ethical question, such as "justified deceiving." Justified deceiving refers to the activity of discreetly putting the medication into the care recipients' meals or drinks when the care recipients did not have insight about their mental illness and refused to take the medication. This skill needs to be addressed because it can cause greater paranoia for some care recipients when they realize what their mothers are doing. It also breaks the trust between the mother and the care recipient. Health care providers need to provide information about alternative choices for medication compliance, such as providing injections for long-term medications.

In addition, this practice raises questions on the meaning of skill, and what should be labeled as a skill. Skill has been defined here as "effective performance..." Mothers find that deception is effective in some ways. Mothers applied this skill based on experience that the medication is the most important factor enabling their sons or daughters returns to a normal functional level. The question is whether expedient effects or their good intentions justify the use of deception.

Finally, it is evident that some skills described by these mothers in this study are also found in other research studies of Chesla (1989), Schene et al. (1998), and Seloilwe, (1997) for example, advising-reasoning skills, reminding skills, bargaining skills, and justified deceiving skills. The congruence of findings with current research further supports how mothers, under similar circumstances, use similar skills/strategies to provide care across the caregiving context.

The advising-reasoning was the most frequently used skill mentioned by the mothers in this study. This skill is comparable to "parenting" skills of raising children, advising and reasoning with them about life lessons. Moreover, this skill is similar to the care practice of mothers who believed in a "rational model" of caregiving (Chesla, 1988). According to Chesla, parents in this model believed that their sons or daughters could be influenced by rational thinking in order to control or change their irrational behaviors. Although this study did not investigate the "illness explanatory model" of the mother, the congruence of this skill with the present study supports understanding of common strategies across cultural and social backgrounds in caregiving. Reminding skills are confirmed in a study by Schene et al. (1998), where the caregivers need to urge the care recipients in activities of daily living. Although, the skills are labeled differently, the activities are similar.

Bargaining and justified deceiving are also congruent with the finding by Seloilwe (1997). She found that family caregivers who lived with people with mental illness in Botswana sometimes had to set conditions in order to stop unwanted behavior. Also, caregivers put medications in tea or soup when care recipients refused to take them. This indicates that there are problems in psychiatric caregiving that may occur across cultures.

It is intriguing to note that mothers emphasized a communication style that is congruent with the finding about the effects of criticism on outcomes in schizophrenia. The body of research on "Expressed Emotion" identified three salient factors predicting relapse: criticism, emotional over-involvement, and hostility (Barrowclough, Tarrier, & Johnston, 1996). In addition to uncritical communication, mothers in this study

expressed acceptance of the care recipient and the illness. The sense of acceptance appeared to lower their expectations and to accept the care recipient as they were. In other words, acceptance and letting go may contribute to the type of family affective tone that has been shown to reduce relapse in some studies of schizophrenia. In this study, mothers, by experiential learning, learned that besides "talking nicely," they needed to provide positive reinforcement to the care recipient as well. Compliments or verbal rewards encouraged the care recipient to maintain proper behaviors and enhanced their self-esteem.

<div align="center">Skill and Role Development</div>

Mother in this study benefited from the cultural and traditional factors that allow them to adapt to the caregiving role. These factors included belief in Karma, and belief in making merit ("bhoon") for their next life. Understanding and empathy also facilitated adjustment to the role of maternal caregiving. This resembles Schumacher's definition of role acquisition (1995). The understanding of the care recipient's condition leads the mother to adjust her expectations regarding the care recipient's age-appropriate behaviors and to more unconditionally accept her role. Reciprocally, one mother reported that her son appeared to have empathy for her role and tried to take care of her after she returned from work in the evening. Her son would prepare her bed and do some errands for his mother. Another mother reported on the decreasing use of cigarettes per day by her son after she shared him a financial household problem. Based on Tungpunkom (1999b), this reciprocal relationship may not work in psychiatric caregiving if the care recipient has problems with cognitive processes. However, this finding supports Schumacher's

description of reciprocal action between caregivers and care receivers in the role-making process during caregiving.

According to Thornton and Nardi (1975), the sources of information about roles, role content, and personal reaction to the role are the most important determinants of role acquisition. The mothers in this study appeared to be naïve about their role at the beginning, unlike other caregivers (i.e., frail elderly) who often have a model or manual instruction of things to do. Eventually, mothers learned how to manage care at home (the role content) based on their experiential learning. The emotional adaptation toward the care recipient also enabled them to adapt to the role.

Although the process of the role acquisition in this study did not necessarily occur in a linear fashion from beginning to end, mothers in this study did appear to acquire mastery in their role over time. Therefore, the role-making process explicated by Schumacher (1995) somewhat fits this circumstance. This process reflects the interaction between caregiver and care recipient who each bring their own personality, background, knowledge and skills into the pot of role-making process. On the other hand, reciprocal empathy between mother and child helped the care recipient be a good care receiver, by not demanding too much or becoming frustrated. In conclusion, outside learning sources might be important only at the beginning of the caregiving process. Later in the process, caregivers learned how to provide care based on successful past experience.

In summary, many factors that influenced role adaptation emerged from the data: the belief in karma, bonding mother and child, and contextual support. The influence of

these factors on caregiving skill requires more study, as the concept of caregiving skill becomes more developed.

Conclusion

The metaphor, "staying in balance" illustrates the interplay in which skills and roles were acquired over time. Table 7 summarizes the three elements of psychiatric caregiving.

Table 7.

Three Elements of Psychiatric Caregiving

	Staying in Balance	
Caregiving Management	Cargiver Self-Adaptation	Contextual Support
Maternal caregiving Symptom management Medication management	Emotional adaptation: to care recipient; and to the illness Role adaptation	Instrumental support Information support

The two domains of caregiving activities: caregiving management and caregiver self-adaptation, and contextual support interplay with each other. The interplay of these three elements can be found in Figure 2. Mothers who reported having all three elements experienced more balance in their roles and their lives. Mothers who had adequate resources in only two elements, such as caregiving management and caregiver self-adaptation, but lacked contextual support reported more stress in their role. For example, single mothers who lacked household member's help reported stress in their roles. Some mentioned fleeting thoughts of suicide due to their stress:

> One day, my youngest son said something like he won't respect me anymore. We had an argument. He said something like I scolded him for something when he

was not wrong. I was so stressed out about his brother (the care recipient). So I thought to myself, my son talked to me like that, I thought about taking medication to kill myself. But who would raise and take care of them when I die? So it has to be dying together. It is just a fleeting thought, a momentary thought. Fortunately, a customer came so I had someone to talk to. Consequently I realized that I could not do that. It is a great gift to have life. I cannot kill myself. It is just a fleeting thought. So now I know that those people who kill themselves might have a fleeting thought like this, you know (Mother Case 9).

On the other hand, mothers who had contextual support but lacked skills in managing care or lacked adaptation to their role, expressed feelings of stress. This can be illustrated through one case when the mother, at the beginning of the illness episode, tried to argue with her son about his paranoid ideation. Conflict was the result of this argument. Later on, when she become more expert in her response to her son, she found that approaching that kind of situation with acceptance was more effective and led to a peaceful living situation.
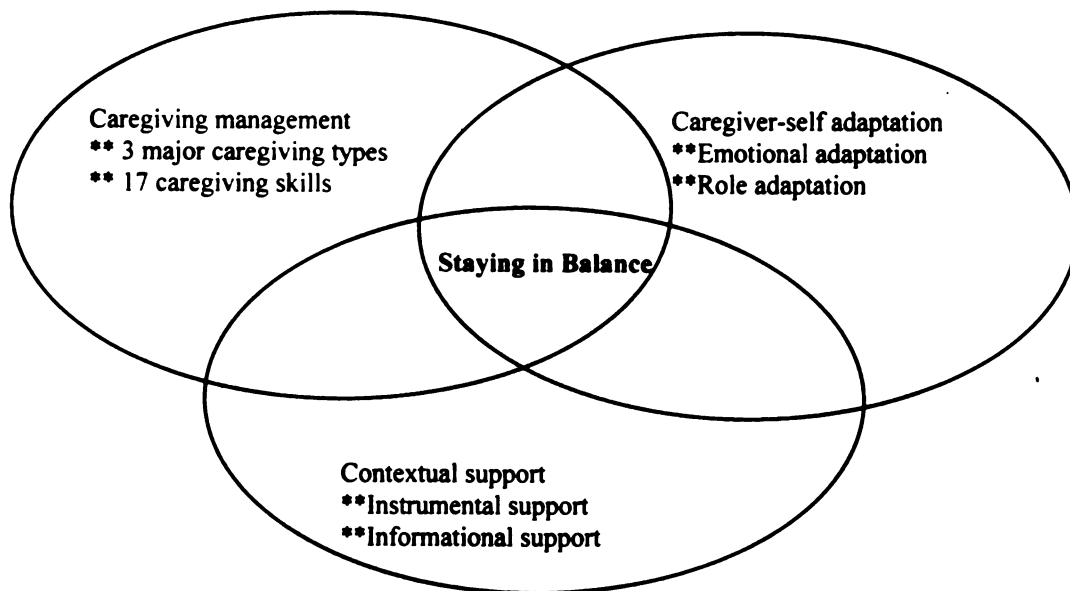

Figure 2. Interplay of the Three Elements for "Staying in Balance"

Significance of the Findings

To our knowledge, this study is the first to examine actual behaviors of primary caregivers. This study addresses a gap in the literature on psychiatric caregiving tasks and caregiving skills. The three types of caregiving identified here-maternal care, symptom management, and medication management-appear to provide a comprehensive picture of what, and how, mothers need to do when living with, and caring for, their mentally ill children at home. It may be useful for others mother under similar situations and to the health care providers who work with this or comparable populations.

How the maternal caregiver provided care at home is the highlight of this study. It has been called, in this study, "caregiving skill." However, it is important to note that some expedient 'skills' that may be counter-productive need to pay more attention and it raises the question of the definition of skill and the quality of care.

Mothers in this study also learned a range of skills that allow early intervention, prevention of crisis, e.g., identifying warning signs. However, it is evident in this study that some caregiving skills were oriented toward helping the care recipient while others were oriented toward the caregiver benefit. This is an important distinction. This is the first step in looking at the caregiving outcome in terms of effective performance or quality of care. While further investigation is needed to determine the outcomes of both orientations, and while health care providers need to be sensitive to the needs of caregivers, this study needs to pursue activities that may contribute to quality of care.

This study also shed some light on the influence of cultural aspects of caregiving skill. It is evident that how mothers in this study experienced stigma differed from

mothers in the other areas (such as in Bangkok). Mothers in the rural areas in the

Northern region of Thailand did not find it as shameful to have mental illness as those

residing in the rural area in Bangkok (Nitikool, 1992). This difference might have

influenced the way mothers responded to the illness, hence, producing differences in

caregiving skills used. The difference in contextual support also affected to how mothers

handled the situation and the quality of care. For example, some mothers in this study

frequently sought help from the head of the village, while others who resided in the

urban areas sought help from emergency workers.

Schizophrenic type disorders frequently have a cyclical character, with the

possibility of repeated acute episodes. This places special demands on caregivers who

alternate between relatively routine living and management of unpredictable crises.

Interviews suggest that maternal bonding helps mothers to endure the situation,

influencing perceptions about roles and caregiving. Mothers in this study expressed

unconditional acceptance of their role and of the care recipients. They promptly forgave

the care recipients' disturbing behaviors and sometimes acted as an advocate for them.

This study has illuminated the community context of care in rural Thai society. In

a country facing severe economic pressure, intervention at the community level is

essential. This study has identified the points at which caregivers perceive needs to seek

help from the community and which responses they consider most effective. The results

of this study clearly indicate the importance of educating key community leaders (e.g.,

head of village, local healer) in basic knowledge of psychiatric illness and its

management.

Finally, this study provides a model of three elements of psychiatric caregiving that permit caregivers to stay in balance when living with and taking care of the mentally ill person at home. These include caregiving management, referring to direct skills to manage care; caregiver adaptation, referring to how well caregivers adapt to their roles; and contextual support, referring to how much and what type of resources are available to them in providing care. If caregivers have these three elements, they will be more likely to stay in balance.

In conclusion, the findings of this research present important aspects of home care management for people with mental illness in Thailand, where nearly 100% of hospitalized psychiatric patients return to their families. Findings have implications for current care in terms of mothers that sometimes lack knowledge about mental illness, about medications, and about how to manage care. This research also raises many questions about the meaning of skill and suggests directions for future research.

Limitations

This study employed purposive sampling to recruit only mothers who provided care continuously for at least six months, and not more than ten years, in order to get a cohesive sample and rich data on psychiatric caregiving. However, its non-random character reduces generalizability and suggests that findings should be applied to other settings with caution. Nevertheless, purposeful sampling of mothers ensures that this sample represents the maternal caregiving and how it impacts to caregiving outcome. What mothers in this study described about managing care may apply to many mothers of people with SMI. Cultural differences might impede the generalizability of the finding

across caregiving contexts on some specific strategies. The findings also need to be interpreted carefully in terms of the differences of duration of caregiving role, personal characteristics, or clinical context such as diagnosis. However, the aim of this study was to describe caregiving for persons with psychiatric disorders in the northern region of Thailand. Hopefully, it will be useful to other mothers in similar circumstances.

Implications for Nursing

These findings can be useful in nursing in two broad areas: knowledge development and clinical practice.

Knowledge Development

The concept of caregiving skill needs further development. Although it has received increasing attention from researchers (i.e. Schumacher, 1998; Wrubel & Folkman, 1997), this concept has not been conceptually defined for family of the mental illness. A definition could be developed applying the hybrid model of concept development (Schwartz-Barcott & Suzie Kim, 1993). Three steps in this model have been employed to date. The first theoretical step occurred when the caregiving skill concept was identified, because of a gap in the psychiatric caregiving literature. There are numerous research studies focused only on caregiver burden, caregiving support, and personal coping strategies. Currently, there is an important shift to studying how families respond emotionally or socially to the illness and how families provide care in terms of the actual activities they perform in the home. However, the concept of caregiving skill is still unclear.

This research began the second step of conducting fieldwork to explore this concept. This was a major aim of this project. The last step is to define this concept based on the literature and the findings of this study. Ideally, all three steps build to a completed concept definition based on deductive and inductive approaches. Therefore,

Caregiving skill refers to effective performance derived from experiential learning in particular tasks provided to the ill person. This performance comprised of multiple behavioral domains, depending on the nature of the illness and the particular role one undertakes.

For example, the caregiving role for caregivers of people with a physical chronic disease will differ from the caregiving role for caregivers of people with a psychiatric illness. Based on the perspective of skill acquisition (Dreyfus & Dreyfus, 1986), caregivers who are engaged in caregiving longer are more likely to skillfully provide care than others who are new to the role. However, this association needs further investigation. Further work is needed to confirm this hypothesis and to identify the range of skills required in different cultural and social contexts.

Clinical Practice

Maternal caregivers in this study needed to adapt themselves to the caregiving role. The transition from the normal parenting to the role of psychiatric caregiver begins at the first episode of illness. Therefore, nurses can facilitate this by providing the required information especially regarding home care management, in order to enhance the quality of care. In addition, the data suggested that the important factors easing this transition come from other sources. These include suggestions and information from

relatives, friends, or local health care providers. For example, they may suggest the caregivers bring the care recipients for proper treatment at the psychiatric hospital. If the family caregivers lack this informational support, it may take longer for them to discover what to do. This is consistent with the transition framework of Meleis and her associates (in press), where nursing therapeutics are key factors that facilitates the transitions through critical points (i.e., from the normal parenting to caregiving role). Mothers in this study also show the evidence when they master the role, that is, to be skillfully in providing care. However, the transition from the beginner caregiver to the skillful caregiver cannot be located from the data. Future research should be investigated on this critical point.

Health care professionals in Thailand can develop curricula about psychiatric home care that are culturally appropriate. To make the program most beneficial for the caregiver that reside in rural areas, many strategies should be employed. Firstly, manuals or pamphlets on how to manage care can be developed and provided in out-patient areas or in the family visitation areas in the psychiatric ward for the target population who come for medication refills or caregivers who accompany the patient who has had an exacerbation of symptoms or with the patient at the first of the illness episode. Also this information can be disseminated through the district hospital to the outreach population. Videos serve an important function for caregivers who do not read. These can be used to show how to manage aggressive behavior or other symptoms. Information about mental illness and its treatment should be disseminated through mass media including TV, and radio programs targeting the outreach population to facilitate the first transition of care.

Support groups are just beginning and some aspects of Thai culture or tradition might impede their utilization (e.g., Thai people tend to not express their ideas, instead than only listening). Health care providers might find caregivers who are knowledgeable and articulate to serve as role models for others, or to support other caregivers in the group. Furthermore, these persons can be trained by health care providers in order to lead groups. It might be very interesting to compare lay and professional leaders in terms of support group participation and other relevant outcomes. It is important to develop measures appropriate to culture in terms of conceptualization of key factors such as problems or burden. It is also critical to develop tools that assess caregiving skill level, since caregivers at different skill levels may have different needs and concerns in support groups.

The psychiatric community should utilize information about the local healer or key person in the community and to consider strategies such as "training the trainer" programs. Such programs can provide information about mental illness (basic information on the cause, the clinical symptoms and the treatment) and services. The structure of Thai society in villages is particularly suitable for this approach. Most of the mothers in this study reported seeking help and advice from the head of the village or local healer. Investing in education at this level is an important part of establishing health care services in the community. This will prepare them to be an informational and instrumental resource and launch to "mental health for all" in the outreach areas.

The belief in karma helps these maternal caregivers adapt to a caregiving role and to the mental illness of the care recipients, thereby influencing caregiving and its

outcome. This belief should be utilized and address in the support group to lessen the problem of stigma and the affective tone of the community toward the mentally ill person. Future research might further explore the impact of family affective tone and communication style on outcomes in rural Thailand. The similarity between these data and those obtained in different cultures suggests need for further investigation. As stated in the introduction, caregiving is culture bound and a learned behavior. Therefore, it is important to look at variables such as family interaction in specific cultures.

<div align="center">Future Research</div>

This study focused only on the mother, who served as a primary caregiver. Although the skills that mothers applied were based on their evaluation of what works best in each context, it is necessary to hear from the care recipients. Therefore, future research should include care recipients in the study to hear their perspectives on care that they received. Their perspectives on caregiving skills may or may not differ from the data obtained here.

Additionally, other household members were sometimes involved in caregiving, thus, they should be included in future research to reveal the larger picture of household management. This will also provide a comparison for the psychiatric caregiving tasks that emerged from the data from mothers. The difference in status might influence the type of tasks and the different skills required. For example, the "doing-for" skill appears related to only the mother since it is part of general maternal care.

In summary, this study provides fundamental information on the tasks and skills in psychiatric caregiving in rural Thailand. Further research may determine how skills

influence caregiving outcomes for both caregivers themselves in terms of burden and for the care recipient. Additionally, research in psychiatric caregiving should explore how skill interact with other factors such as self-efficacy, sense of mastery, and sense of preparedness. Those concepts and their measurement have been well studied by many researchers but research to date has not clarified the concept of caregiving skill. Additional measures of caregiving skill, will enhance research on associations among those concepts.

The type of bonding between mother and son or daughter appears to strongly influence caregiving. The unconditional acceptance mothers express about sons or daughters may contribute to their preference for non-restrictive skills, their willingness to "do for" when children will not, and their commitment despite lowered expectation. Future research might explore the effect of maternal bonding in others culture.

Finally, the aim of this retrospective qualitative study was not to test the skill acquisition model, but rather to demonstrate skill acquisition during the process of caregiving. Thus, this study provides evidence of skills acquired but not information on progression of step by step skill acquisition as explicated by Dreyfus and Dreyfus (1986). Future prospective research designs should be conducted to examine this progression.

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APPENDIX A: CHARACTERISTICS OF CAREGIVING

Appendix A: Characteristics of Caregiving

ID	Caregiver Characteristics					Care-recipient Characteristic						Situational Context		
	Age	Education Level	Occupation	Perceived DX of ill child	Caregiving Role	Age	Sex	Hospital Diagnosis	Illness Period	Frequency of Admission	LSP Score (156)	Income	Religion	Number of Family Member
1	65	Elementary	Farmer	Not know	5	30	Female	Schizophreniform	5	1	133	OK	Buddhism	3
2	55	Elementary	Freelance	Psychosis	3	22	Female	Schizophrenia	3	6	124	Barely	Buddhism	2
3	43	Elementary	Freelance	Neurosis	6	26	Male	Schizophrenia	6	7	146	Barely	Buddhism	6
4	46	Elementary	Farmer	Psychosis	4	23	Male	Psychosis	4	2	144	Barely	Buddhism	5
5	60	Elementary	Farmer	Psychosis	7	42	Male	Schizophrenia	7	1	152	Barely	Buddhism	5
6	58	Elementary	Merchandise	Neurosis	4	33	Male	Psychosis	4	1	144	Barely	Buddhism	4
7	57	None	Housewife	Neurosis	8	27	Male	Schizophreniform	8	7	136	Barely	Buddhism	4
8	54	Elementary	Housewife	Psychosis	10	32	Female	Schizophrenia	10	6	144	Extra	Buddhism	6
9	48	Junior high	Freelance	Stress	2	26	Male	Schizophrenia	2	1	133	OK	Christian	3
10	52	Elementary	Merchandise	Neurosis	1	33	Male	Schizophrenia	1	None	135	Few extra	Buddhism	4
11	52	Elementary	Housewife	Psychosis	5	32	Male	Schizophrenia	5	3	110	Barely	Buddhism	2

ID	Caregiver Characteristics					Care-recipient Characteristic						Situational Context		
	Age	Education Level	Occupation	Perceived DX of Ill Child	Caregiving Role	Age	Sex	Hospital Diagnosis	Illness Period	Frequency of Admission	LSP Score (156)	Income	Religion	Number of Family Member
12	47	Elementary	Farmer	Stress	2	19	Female	Schizophrenia	2	1	154	Barely	Buddhism	5
13	45	Elementary	Housewife	Psychosis	10	30	Male	Schizophrenia	10	10	117	Barely	Buddhism	2
14	49	Elementary	Merchandise	Neurosis	6	24	Male	Schizophreniform	6	None	153	Extra	Buddhism	6
15*	43	Elementary	Freelance	Stress	7 mth	18	Male	Psychosis	1	1	154	Few extra	Buddhism	4
16*	54	Elementary	Farmer	Not know	8 mth	22	Male	Psychosis	1	None	151	Few extra	Buddhism	4
17	46	Junior high	Gov. service	Psychosis	4	27	Male	Schizophrenia: Delusional dis.	4	1	133	Barely	Buddhism	3
18	54	High school	Freelance	Seizure	5	22	Female	Psychosis	5	1	143	Barely	Buddhism	4
19	57	High school	Housewife	Psychosis	10	28	Male	Schizophrenia	10	10	133	Barely	Christian	2
20	53	Elementary	Merchandise	Psychosis	9	32	Male	Schizophrenia	9	2	150	Barely	Buddhist	8
21	41	Junior high	Housewife	Stress	1	21	Male	Schizophrenia	2	None	153	Few fr extra	Buddhism	3
22	53	Elementary	Merchandise	Stress	10	31	Female	Schizophrenia	10	9	114	Barely	Buddhism	4

ID	Caregiver Characteristics					Care-recipient Characteristic						Situational Context		
	Age	Education Level	Occupation	Perceived DX of Ill Child	Caregiving Role	Age	Sex	Hospital Diagnosis	Illness Period	Frequency of Admission	LSP Score (156)	Income	Religion	Number of Family Member
23	46	Elementary	Farmer	Stress	2	19	Male	Schizophrenia	2	7	133	OK	Buddhism	3
24	47	Elementary	Housewife	Stress	1	27	Male	Schizophrenia	1	4	156	Barely	Buddhism	4
25	54	None	Farmer	Psychosis	7	28	Male	Schizophreniform	7	6	138	OK	Buddhism	4
26	50	Elementary	Merchandise	Psychosis	8	25	Male	Schizophrenia	8	3	135	OK	Buddhism	5
27	52	Elementary	Farmer	Neurosis	2	27	Male	Schizophrenia	2	3	154	OK	Buddhism	4
28	48	None	Freelance	Neurosis	9	26	Male	Schizophrenia	9	None	133	OK	Buddhism	4
29	57	Elementary	Housewife	Crazy	4	21	Female	Schizophrenia	4	Many	89	Barely	Buddhism	2
30	43	Elementary	Farmer	Crazy	1	18	Male	Schizophreniform	1	1	147	OK	Buddhism	4

APPENDIX B: INTERVIEW SCHEDULE

<u>Interview for psychiatric caregivers</u>

This is a protocol for a semi structured, in depth interview for mothers providing care to mentally ill adults. It has three sections. The first obtains demographic data. It is important during this phase of the interview to establish rapport and to put the participant at ease. Therefore, it is not necessary to complete every item at the outset. Some may be completed at the end of the interview. It is may be preferable to focus on fewer items to avoid setting an example of very brief responses ("yes" or "no") to later open-ended questions.

The second section contains a guide for the semi-structured interview. It includes questions about major components of caregiving skills. Under each question comments are listed that can serve as probes to help the participant to understand and to response to the question. These questions and probes cover the information that you should attempt to obtain each interview. However, the order of questions may change according to the response style of individual participants. It may not be necessary to ask each question directly, or to use all suggested probes. The participant may provides information to some questions without being asked directly to do so. To be sure that each interview is complete, it is important to review this protocol at the end of the interview, and to make sure that you have attempted to obtain corresponding information. It may be helpful to end the interview (see below) by saying "I'd just like to check my notes to make sure that I haven't forgotten any questions."

It is possible that some participants will have difficulty responding to all questions during one interview. If they require more time, the interview may be administered in two parts.

The interview should be conducted in a private and comfortable place. It is also important to have a quiet room for audio-taping. The audio-taping should begin when you start conducting the in-depth interview on the second part. Begin by introducing yourself and explaining the study in order to obtain informed consent. If the person consents, begin as follows:

"Today we are going to talk about your experience in taking care of your child at home. I am going to ask about the things that you do at home for your child and about how you learned the best ways to take care of him/her. This information may help me to understand more about what families do for people with mental illnesses. It is your experience that is important. There are no right or wrong ways to answer any of the questions, because they are about your own life, and you are the expert for that. First I will ask you about some questions about yourself and your family"

The third section contains questions about the functional level of the care recipient through The Life Skills Profile. It consists of 39 items.

INTERVIEW PROTOCOL

Participant number_____
Date_____
Interview length_____

Part I. Demographic Data	Notes /Comments

1. Name:

Q: What is your name?_____

2. DOB:

Q: What is your date of
birth?_____(age_____)

3. Religion:

Q: What is your religious practice?_____

4. Education:

Q: What is the highest level of your education?

  1. Primary school
  2. Junior high school
  3. High school
  4. Diploma
  5. BS/BA/Community College
  6. MS/MA or more

5. Occupation:

Q: What is your occupation? _____

6. Income:

Q: Which item best describes your family income?
  1. Comfortable for extras
  2. Enough for a few extras but a need to budget carefully
  3. Some income but not any for extras
  4. Barely enough to support the household

7. Type of family: Notes/Comments

 Q: Who lives in your
household?_____

_____

  (make notes for every person and select the choice best fit below)

1. Nuclear family (Parents or single parent and sons/
daughters)

2. Extended family (Grandparents, parents, sons/daughters,
and other relatives)

8. Number of household members:_____
(record from question number 7)

9. Multiple roles:

Q: Who else (beside your child) in the household needs your
help/care?_____

10. Role support:
Q: Who else in the household helps in taking care of your ill
child_____

1.3 Care recipient Characteristics (number 11-18)

11. Diagnosis:
Q: Has anyone ever told you about your child's diagnosis?
What did they say? Do you understand?
Agree?_____
(make notes and select a best fit choice below)

 1. Schizophrenia

 2. Schizoaffective disorder

 3. Other non-affective Psychosis (specify:_____)

*DX from medical record_____

12. Date of birth:

Q: What is your child's date of birth?_____

Q: How old was he/she when he/she was first diagnosed with (diagnosis)?

    Age at first diagnosis:_____

13. Gender:

Q: Is your child male or female?

   1. Male
   2. Female

14. Treatment received:

Q: How many times has your child stayed overnight in the hospital for this mental illness?

The number of hospitalizations:_____

Q: When was the last time (name) was in the hospital? Do you remember how long he/she stayed there?
_____days

Q: Is your child taking any medication that was given by somebody else?
   1. Yes
   2. No

 IF yes follow with

Q: Who?
Q: Can you tell me the names of each and what they are for_____

15. Co-habitation:

Q: How long have you lived together since the first diagnosis:_____

16. Substance abuse: Notes/Comments

*Q: Do you know if (name) drinks alcohol? Has s/he used any for the last 6 months? Beer? Wine? Whisky?
    1. Yes
    2. No

Does s/he use any other drugs?
(If Yes of any of the above questions, use the following probes as needed to make a ratings of mild to severe, using criteria from the scale below)
a. How much? How often?_____
b. Does it cause any problems?_____
c. What kind of problem?_____
with general health? Emotional condition? Getting into trouble? Getting arrested or going to the hospital?

d. Rating:_____

Rating scale:
1. Mild: No indication that it causes psychological and physical problems which are persistent or recurrent and no evidence of recurrent, dangerous use which persists <u>more than one month</u>.

2. Moderate: Evidence of psychological and physical problem related to use. Problem has existed <u>at least one month</u>.

3. Severe: Evidence of psychological and physical problem <u>plus the disturbance of important activities or society withdraw related to use.</u>

4. Extremely severe: meet criteria for severe <u>plus related problem are so severe that they make non-institutionalized living difficult</u> (for example constant drinking lead to the disruptive behavior make the client is frequently reported to the police and seeking hospitalization)

9. Unknown

Modified from the Case Management Rating Scale for Alcohol Use Disorder, from Drake, R.E., Osher, F.C.,

Teague, G.B., Hurlbut, S.C., & Beaudett, M. S., (1990)
Schizophrenia Bulletin, 16, p. 67.
17. Medical problem: Notes/Comments

Q: Does your child have any medical problem?
    1. Yes
    2. No

If yes: Q: What is it?_____

* Confirm from medical record

Medical diagnosis_____

18. Functional level:
Functional status score_____(from the life
skill profile)

Part II. Caregiving skills:

1. Now let's go back to when your child's illness first began.
Tell me about how you found out that your child had a
mental illness?
    1.1. What did you think cause it?
    1.2. What did s/he do at that time?
    1.3. When (name) did (repeat response from 1.2)
        - What were the first things that you did about them?
        - Were there other things you did at that time to try
          to care of (name)
        - What else did you consider doing?
        - Did you consider asking others to help you?
        - Who?
    1.4. Why/how did you do that?
    Probes:
    a. Have you learned to do things like(cite specific
    examples from prior responses) from anybody? Who?
    b. How about health care Professional (such as nurse,
    psychiatrist), do they help you some ways to learn how
    to take care of (child's name)? How did they help?
    Can you tell me about a specific example?
    c. Have you gotten any new ideas or learned how to do
    things for (name) from a
        - TV program?

- From listening to the radio?
- From something you read?
d. There are probably some things that you had to
figure out on our own, by yourself. Is this true?   Notes/Comments
   - Can you give me an example?
   - How did you figure out what to do in this
    situation?

1.5. How did things work out? Did things end up the
way you wanted them to?
1.6. Looking back on it now, what might you have done
differently to resolve the situation?
1.7. Are your ideas about the cause different now than
earlier?
   - Have they changed?
   - How have they?
   - Why?

2. Let's shift from the past to the present and talk about how
(name) is now. What is s/he like?
Probes:

   a. Do you have to do anything to help because of the
    way s/he thinks? The kinds of beliefs that s/he has?
   b. Are there problems with the way s/he acts with
    people that you need to deal with?

3. Please tell me, what do you do to take care of him /her at
home in a typical day?
Probes:

   a. In the morning
   - What do you do?
   - Why/How do you do it?
   - What is the result or does it work?
   b. In the afternoon
   (Use probes as in a.)
   c. In the evening
   (Use probes as in a.)
   d. At night
   (Use probes as in a.)
   e. When you are going out?
   (Use probes as in a.)

4. Are there some days when you have to do something

unusual for (child's name)/ or Are there times when your
child does things you didn't expect? Tell me what happen?

    4.1.What did you think cause it?

    4.2. What did s/he do at that time?

    4.3. When (name) did (repeat response from 4.2)   Notes/Comments

        - What were the first things that you did about them?

        - Were there other things you did at that time to try
          to care of (name)

        - What else did you consider doing?

        - Did you consider asking others to help you?

        - Who?

    4.4. Why/how did you do that?

Probes:

*a. Have you learned to do things like(cite specific
examples from prior responses) from anybody? Who?*

*b. How about health care Professional (such as nurse,
psychiatrist), do they help you some ways to learn how
to take care of (child's name)? How did they help?
Can you tell me about a specific example?*

*c. Have you gotten any new ideas or learned how to do
things for (name) from a*

    - TV program?

    - From listening to the radio?

    - From something you read?

*d. There are probably some things that you had to
figure out on our own, by yourself. Is this true?*

    - Can you give me an example?

    *- How did you figure out what to do in this
      situation?*

5. Can you remember one or two specific times when you
felt like you suddenly found a new way to handle a problem
with your child?

    5.1. Tell me what happened?

    5.2. What did you do?

Probes:

a. How did you figure out what to do?

b. How did you come up with ideas that work?

    5.3. How did it change thing from how they were
    before?

6. If you had a friend who was in a similar situation (taking
care of mentally ill adult child), what would you suggest to
him or her in terms of taking care of the ill child at home?

Probes:
   a. *What do you think people need to know from the*
      beginning to help their child?
   b. *How about things people need to know if they are*
      going to help their children to maintain their ability
      to function-to be able to take care of themselves,
      what would you suggest them to do?
   c. *How about daily living, what would you suggest to*
      them?

Notes/Comments

* I have asked you a lot of questions. May be there are some
things that I should have asked. Is there anything else that
you think is very important to know when you are taking
care of a person with a serious mental illness, like (name)?
(Wait for a while).

PART III. Life Skill Profile questionnaire (39 items)

If you do not have anything more to tell me, I would like to
ask you some specific
questions regarding what your child is like at home.
   - Ask 39 questions regarding the functioning level of the
care recipients (see attached)

I'd like to take just a moment to look at my notes and to
make sure that I have asked all the questions that I was
supposed to ask"

End with "You have shared a lot of your experience with
me. Thank you for taking the time to share this very
important information. Before we finish the interview, can
you tell me what you think about this interview? Again, I
wish to assure you that all information will be kept
confidential.

APPENDIX C: CONSENT TO BE A RESARCH PARTICIPANT

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY
Staying in Balance: Skill and Role Development in Psychiatric Caregiving

A. PURPOSE AND BACKGROUND
Patraporn Tungpunkom, RN, MSN, PhDc of the School of Nursing is conducting a study
with Linda Chafetz, RN, DNS, to learn about the caregiving skills of the mothers of
adults with schizophrenia or related disorders. Because I provide care to a client at (site's
name), I am being asked to participate in this study.

B. PROCEDURES
If I agree to be in this study, the following will happen:

1. I will participate in an interview which takes one to two hours.
2. I will be asked about the way I take care of my mentally ill children.
3. The interview will be audiotaped if I agree.

C. RISKS/DISCOMFORTS
1. It may be difficult and painful to discuss the experience of living with and taking care
an adult child with schizophrenia or a related disorder. I can choose a quiet and private
place to be interviewed.
2. Some of the questions may make me feel uncomfortable but I am free to stop the
interview at any time or to decline to answer any questions.
3. Confidentiality: All information in my interview will be kept as confidential as
possible. No individual name or identification will be used in any reports or publications
resulting from this study. All information will be kept in a safe place at all times. Only
the researchers will have access to the files and audiotapes. The audiotapes will be erased
within one year.

D. BENEFITS
There are no direct benefits to me from being in the study. It will, however, give me an
opportunity to discuss my experiences of living with and taking care of an adult child
with schizophrenic or a related disorder. However, outcomes of the study will contribute
to an understanding of the needs of people who take care of mentally ill relative and the
skills that they use. This may lead to effective intervention programs to help this specific
population.

F. COST/FINANCIAL CONSIDERATIONS
There are no costs to me for participating in this study.

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G. REIMBURSEMENT/PAYMENT

For my time and my effort, when I complete the interview, I will be reimbursed $10.00 in cash for my participation in this study. If I stop the interview early or decline to answer any questions I will still get the same amount.

H. QUESTIONS

The study has been explained to me by Patraporn Tungpunkom. If I have any question about this study I may call Patraporn at (053) 946013 or Dr. Linda Chafetz at (415) 476-2726.

If I have any questions or comments about participation in this study I will first talk with Patraporn or Dr. Linda Chafetz. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research project. I can reach the committee office between 8:00 AM and 5:00 PM Monday through Friday by calling 476-1814, or by writing to the Committee on Human Research (CHR) , Box 0962, University of California, San Francisco, CA, 94143-0962.

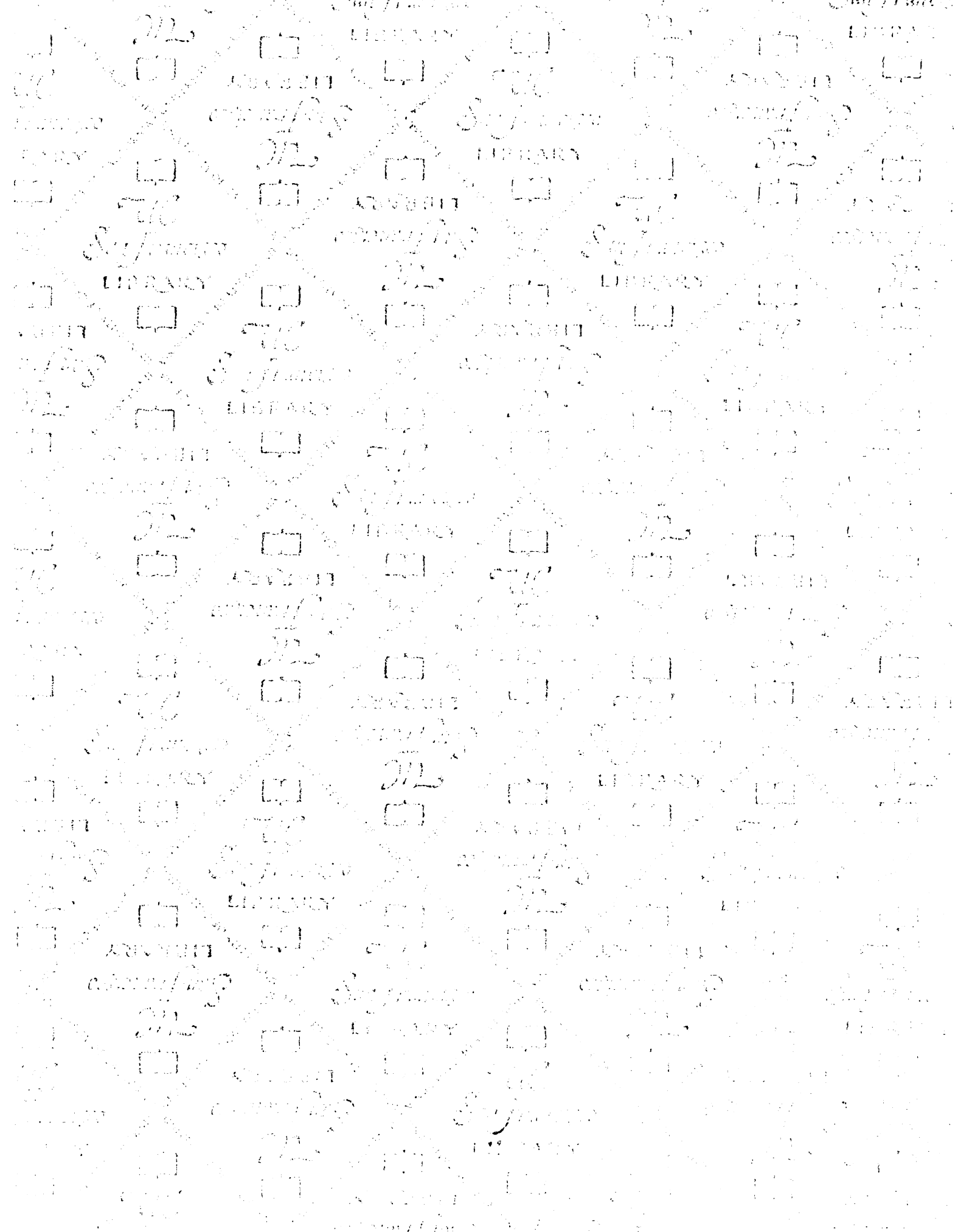I. I have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I have a right to refuse this interview, to decline to answer any questions, or to stop the interview at any time. Refusal or withdrawal from this study will be without jeopardy to my status of care at present and in the future. If I wish to participate, I should sign below.

_____
Date

_____
Subject's Signature

_____
Date

_____
Person Obtaining Consent

May 20, 1999