

INDIVIDUAL AND FAMILY ADAPTATION TO SEVERE AND PERSISTENT
MENTAL ILLNESS (SPMI) IN TAIWANESE FAMILIES

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ABSTRACT

CHIU-YUEH HSIAO: Individual and Family Adaptation to Individuals with Severe and Persistent Mental Illness (SPMI) in Taiwanese Families

(Under the direction of Marcia Van Riper)

Mental illness affects not only the individual family members but also the entire family system. Caring for a family member with mental illness can be a demanding, stress-filled experience. The purpose of this cross-sectional, descriptive study was to examine individual and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning), with potential predictors being pile-up of demands (i.e., family caregiver's awareness of patient suicidality, family history of mental illness, chronicity of mental illness, and stressful life events), social support, and meaning of family caregiving, in Taiwanese families of persons with severe and persistent mental illness (SPMI). In addition, this study assessed the mediating effects of social support and meaning of family caregiving on the relationship between pile-up of demands and family adaptation. The Resiliency Model of Family Stress, Adjustment, and Adaptation served as the guiding conceptual framework for this study.

A convenience sample of 157 individuals from 84 Taiwanese families was recruited from two psychiatric outpatient clinics in Taiwan. Data collection was done by mail. Family members completed a packet of self-report questionnaires. Data analysis consisted of descriptive statistics, principal component analysis, and mixed linear modeling. Findings from this study suggest that family members with a greater pile-up of demands, lower social support, and a less positive interpretation of family caregiving experienced more caregiver burden and lower levels of family functioning. Family members with a

greater pile-up of demands and lower social support also experienced higher levels of depressive symptoms. When family members interpreted the caregiving experience more positively, they seemed to adapt better. Social support and meaning of family caregiving partially mediated the relationship between pile-up of demands and family adaptation.

This study sheds light on what strengths and resources Taiwanese families need to adapt to caring for individuals with SPMI. Health care professionals need to collaborate with family members to develop culturally sensitive interventions designed to decrease ongoing demands and amplify individual, family, and community strengths and resources. They also need to help caregivers interpret the caregiving experience in a more positive manner, which in turn, can optimize individual and family adaptation.

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TABLE OF CONTENTS

| | |
|---|------|
| LIST OF TABLES..... | xiii |
| LIST OF FIGURES..... | xiv |
| CHAPTER I..... | 1 |
| INTRODUCTION..... | 1 |
| Family Caregiving in Taiwanese Families of Individuals with SPMI..... | 3 |
| Statement of the Problem..... | 5 |
| Family Caregiving in Family Mental Health Nursing..... | 7 |
| <i>Definition of Family</i> | 7 |
| <i>Milestones in Family Mental Health Nursing</i> | 7 |
| <i>Bridging Family Caregiving and Family Mental Health Nursing</i> | 8 |
| Purpose and Aims..... | 10 |
| Research Hypotheses..... | 11 |
| CHAPTER II..... | 12 |
| LITERATURE REVIEW..... | 12 |
| <i>Definition of Severe and Persistent Mental Illness</i> | 12 |
| <i>Epidemiology of Severe and Persistent Mental Illness</i> | 13 |
| <i>Mental Health Policy and System in Taiwan</i> | 14 |
| Theoretical Framework..... | 15 |
| <i>Resiliency Model of Family Stress, Adjustment, and Adaptation</i> | 15 |
| <i>Cross-Cultural Application of Resiliency Model</i> | 19 |
| <i>Family Caregiving Model of Taiwanese Caregivers of Individuals with SPMI</i> | 21 |

| | |
|--|----|
| <i>Pile-Up of Demands</i> | 22 |
| <i>Family Resources</i> | 23 |
| <i>Family Appraisal</i> | 23 |
| <i>Family Adaptation</i> | 24 |
| Pile-Up of Demands..... | 27 |
| <i>Mental Illness-Related Stressors</i> | 27 |
| <i>Family Caregiver’s Awareness of Patient Suicidality</i> | 27 |
| <i>Family History of Mental Illness</i> | 28 |
| <i>Value of family history</i> | 29 |
| <i>Effects of family history on family adaptation</i> | 29 |
| <i>Effects of genetic testing on identified individuals and families</i> | 30 |
| <i>Chronicity of Mental Illness</i> | 31 |
| <i>Stressful Life Events</i> | 33 |
| Social Support..... | 35 |
| <i>Definition of Social Support</i> | 35 |
| <i>Effects of Social Support on Family Adaptation</i> | 37 |
| <i>Racial and Ethnic Difference in Perceptions of Mental Illness and Mental Health Service Utilization</i> | 39 |
| Meaning of Family Caregiving..... | 42 |
| <i>Definition of Meaning</i> | 42 |
| <i>Effects of Meaning of Family Caregiving on Family Adaptation</i> | 43 |
| <i>Themes of Meaning of Family Caregiving</i> | 44 |
| <i>Cultural-Bound Meaning of Family Caregiving</i> | 45 |
| Family Caregiver Burden..... | 46 |
| <i>Definition of Burden</i> | 47 |

| | |
|--|----|
| <i>Contributing Factors Associated with Family Caregiver Burden</i> | 48 |
| <i>Symptomatic Behaviors of Mental Illness in the Context of Family Caregiver Burden</i> | 49 |
| <i>Diagnosis of Mental Illness</i> | 50 |
| <i>Family Structure and Relationships of Family Caregivers to Care Relationships</i> | 52 |
| <i>Race and Ethnicity</i> | 54 |
| Depressive Symptoms of Family Caregivers..... | 55 |
| Family Functioning..... | 57 |
| Summary of Literature..... | 59 |
| CHAPTER III..... | 61 |
| METHODOLOGY..... | 61 |
| Research Design..... | 61 |
| Subjects and Setting..... | 61 |
| <i>Inclusion Criteria</i> | 63 |
| <i>Exclusion Criteria</i> | 63 |
| <i>Procedures</i> | 63 |
| Variables and Measures..... | 65 |
| <i>Demographic Characteristics</i> | 67 |
| <i>Independent Variables</i> | 67 |
| <i>Mediator Variables</i> | 69 |
| <i>Dependent Variables</i> | 73 |
| Data Analysis Strategies..... | 78 |
| <i>Preliminary Data Analysis</i> | 78 |
| <i>Data Analysis</i> | 78 |
| Summary of Methodology..... | 84 |

| | |
|--|-----|
| CHAPTER IV..... | 85 |
| RESULTS..... | 85 |
| Sample Characteristics..... | 85 |
| Description of Characteristics of Measure and Study Variables..... | 91 |
| <i>Psychometric Properties of Measures.....</i> | 91 |
| <i>Description of Study Variables.....</i> | 92 |
| <i>Results of Principal Component Analysis.....</i> | 92 |
| <i>Descriptive Analysis of Study Variables.....</i> | 93 |
| <i>Pile-up of demands.....</i> | 94 |
| <i>Social support.....</i> | 96 |
| <i>Meaning of family caregiving.....</i> | 96 |
| <i>Family caregiver burden.....</i> | 96 |
| <i>Depressive symptoms of family caregivers.....</i> | 96 |
| <i>Family functioning.....</i> | 96 |
| Hypothesis Testing..... | 97 |
| CHAPTER V..... | 111 |
| DISCUSSION AND CONCLUSION..... | 111 |
| Synopsis of Major Findings..... | 112 |
| <i>Pile-Up of Demands.....</i> | 112 |
| <i>Components of Pile-Up of Demands, Social Support, Meaning of Family Caregiving, and Family Functioning.....</i> | 113 |
| <i>Family Caregiver Burden.....</i> | 117 |
| <i>Pile-Up of Demands, Social Support, and Meaning of Family Caregiving.....</i> | 118 |
| <i>Depressive Symptoms of Family Caregivers.....</i> | 119 |
| <i>Pile-Up of Demands, Social Support, and Meaning of Family Caregiving.....</i> | 120 |

| | |
|--|-----|
| <i>Family Functioning</i> | 122 |
| <i>Pile-Up of Demands, Social Support, and Meaning of Family Caregiving</i> | 122 |
| <i>Mediating Effects of Social Support and Meaning of Family Caregiving on Family Adaptation</i> | 123 |
| Limitation of Study..... | 124 |
| Implications for Nursing..... | 125 |
| <i>Nursing Education</i> | 126 |
| <i>Nursing Practice</i> | 128 |
| <i>Nursing Policy</i> | 133 |
| Implications for Future Research..... | 134 |
| Conclusion..... | 138 |
| Appendices..... | 141 |
| Appendix A: Demographic Information Sheet of the Family Caregiver..... | 141 |
| Appendix B: Perceived Stress Scale (PSS)..... | 144 |
| Appendix C: Perceived Social Support Scale (PSSS)..... | 145 |
| Appendix D: Meaning in Caregiving Scale..... | 146 |
| Appendix E: Caregiver Burden Scale-Brief 18 Items..... | 147 |
| Appendix F: Center for Epidemiologic Studies Depressive Scale (CES-D)..... | 148 |
| Appendix G: Family Function Scale..... | 149 |
| References..... | 150 |

LIST OF TABLES

| | |
|--|-----|
| Table 3-1 Variables and Measures..... | 66 |
| Table 4-1 Demographic Characteristics of Individual Family Caregivers..... | 88 |
| Table 4-2 Psychometric Properties of Measures..... | 91 |
| Table 4-3 Descriptive Statistics of Study Variables for Individual Family Caregivers..... | 93 |
| Table 4-4 Descriptive Statistics of Pile-Up of Demands for Individual Family Caregivers..... | 95 |
| Table 4-5 Mixed Model for Family Caregiver Burden..... | 98 |
| Table 4-6 Mixed Model for Depressive Symptoms of Family Caregivers..... | 98 |
| Table 4-7 Mixed Model for Family Functioning..... | 98 |
| Table 4-8 Testing the Mediating Effects of Meaning of Family Caregiving on Family Caregiver Burden..... | 100 |
| Table 4-9 Testing the Mediating Effects of Meaning of Family Caregiving on Depressive Symptoms of Family Caregivers..... | 102 |
| Table 4-10 Testing the Mediating Effects of Meaning of Family Caregiving on Family Functioning..... | 104 |
| Table 4-11 Testing the Mediating Effects of Social Support on Family Caregiver Burden..... | 106 |
| Table 4-12 Testing the Mediating Effects of Social Support on Depressive Symptoms of Family Caregivers..... | 108 |
| Table 4-13 Testing the Mediating Effects of Social Support on Family Functioning..... | 110 |

LIST OF FIGURES

| | |
|--|----|
| Figure 1. The Resiliency Model of Family Stress, Adjustment, and Adaptation..... | 18 |
| Figure 2. Family caregiving model of Taiwanese family caregivers of individuals with serve and persistent mental illness..... | 26 |

CHAPTER I

INTRODUCTION

The demands of mental illness on family caregivers highlight significant issues of family caregiving in Taiwan. Mental illness is not only an individual disease but also a family illness. Families usually act as the primary source of support for persons with severe and persistent mental illness (SPMI). Therefore, for mental health care to be holistic, it must expand its focus beyond the individual who has the mental illness. More attention needs to be directed at potential consequences for other family members, especially those who have assumed the role of caregiver for persons with SPMI, and for the family as a unit.

The trends of deinstitutionalization and accompanying changes in the legal rights of patients in mental health policy since the 1950s have resulted in the emergence of an emphasis on caring for people with mental illness in the community (Scheid & Horwitz, 1999). Taiwan, along with the rest of the world, is making a transition in mental health care from institutional health care to community-based mental health services. Unfortunately, many of the costs of community-based mental health services were either unanticipated or underestimated. Because of this, and the trend towards shorter average hospital stays, persons with SPMI are often discharged to communities lacking in sufficient mental health services to meet the needs of persons with SPMI (Biegel, Milligan, Putnam, & Song, 1994). The lack of sufficient services often results in what has been called the “revolving door syndrome”; persons with SPMI end up suffering frequent relapses and rehospitalizations (Sullivan, Wells, Morgenstein, & Leake, 1995). In addition, the lack of sufficient community-based mental health services often results in families

being expected to contribute a great deal towards the care of their family members with SPMI after they are discharged from the hospital (Solomon & Draine, 1995a; U.S. Department of Health and Human Services, 2001).

The majority of individuals with SPMI are likely to end up in living with their families (Maurin & Boyd, 1990; Saunders, 2003; Song, 1998, 1999). Even those who do not live with their families are likely to maintain contact with at least two family members (Beeler, Rosenthal, & Cohler, 1999). Families not only provide the core long-term assistance of housing and financial aid but also play the roles of family caregiver, informal case manager, crisis intervention specialist, and “invisible” rehabilitation agency (Marsh & Johnson, 1997; Solomon, Draine, Mannion, & Meisel, 1996; Sun & Cheng, 1997). Most families, however, are not prepared to assume these crucial roles and many struggle to manage unexpected situations in a society that provides limited assistance to families of persons with SPMI (Solomon, 1996).

Caring for family members with mental illness has been viewed as a type of stressful event that significantly disrupts equilibrium in the family system (Pearlin, Mullan, Semple, & Skaff, 1990). Several studies have indicated that caregiving for family members who are mentally ill is a burdensome and strenuous experience (Maurin & Boyd, 1990; Solomon & Draine, 1995a; Thompson & Doll, 1982). Family caregivers frequently struggle with the chronic, unpredictable, and uncontrollable psychotic symptoms exhibited by persons with SPMI. In addition, family caregivers face the social stigma against individuals with mental illness and the family members who care for them (Chafetz & Barnes, 1989; Guarnaccia & Parra, 1996; Horwitz & Reinhard, 1995).

In light of societal stereotypes about mental illness, family caregivers with an expectation of rejection by society may experience feelings of denial, embarrassment, isolation, fear, and guilt. Moreover, these feelings may discourage family members from

participating in social activities and disclosing information to other people about the condition of the family member with mental illness (Lefley, 1996). Researchers have identified family caregivers as “hidden patients” (Fengler & Goodrich, 1979) or co-victims. Maurin and Boyd (1990) concluded that “mental illness produced a significant burden for family members” (p.100). Given the multifaceted nature of the burden, family caregivers often become members of a vulnerable population that needs social support to achieve balanced levels of family functioning at both the individual-to-family and family- to-community levels.

Family Caregiving in Taiwanese Families of Individuals with SPMI

The dynamics of the caregiving process are inextricably linked to the ethnic and racial origins of families. Studies of family structure and kinship reflect the degree to which culture influences individualistic versus collectivist beliefs and values in relation to acceptance of caring for persons with mental illness (Lefley, 1996). Traditional Taiwanese families value the family unit more highly than the individual (Chuang, 1994). Parents often display a high degree of caregiving obligation to a sick child, and this commitment may threaten their physical and psychological well-being. Siblings tend to have a lower degree of involvement, but many do provide some caregiving if a brother or sister becomes ill.

In Taiwanese culture, wives, unmarried adult daughters, and daughters-in-law, particularly the first daughter-in-law, are responsible for performing more personal caregiving tasks such as feeding, bathing, dressing, and medication preparation (Chou, LaMontagne, & Hepworth, 1999). Although women are expected to assume the role of primary caregiver, the spouse of either gender will care for a sick partner when progenies are not available (K. T. Lee, 1996).

One study by Song (1998) explored factors associated with the family caregiver burden of persons with mental illness in central Taiwan and found that 95.5 % of mentally ill individuals live with their families and that the average length of caregiving involvement is ten years. Song's study highlighted critical concerns about the impact of family-based care on family members and how mental health care providers work with families to develop the adaptive capability of resourcefulness to cope with the demands and needs of family caregivers. The burden usually leads the family as a unit to cope with a demanding variety of developmental, medical, social, emotional, economical, and environmental issues. In Taiwanese culture, family caregivers and the individual with mental illness may face many other complicated challenges including learning about mental illness, interpersonal adaptation, management of stress, and boundary ambiguity of the caregiving obligation in the entire family system.

Along with the development of industrialization and modernization in Taiwan, the general family structure has changed from the extended family to the nuclear family (Directorate-General of Budget, Accounting and Statistics, Executive Yuan, Taiwan, R.O.C., 1998). This change in family structure may reduce the amount of available family resources, which in turn, may interfere with a family's ability to adapt to illness stressors (Chen & Rankin, 2002). In addition, family values and social expectation regarding the caregiving obligation continue to change to resemble those in Western culture. Because of this, family caregivers may start to question the need to put aside their own needs in order to meet family obligations and care for the family member with SPMI. Unwillingness to take on responsibility for family caregiving and to play traditional roles may compromise the quality of family caregiving. Furthermore, the need to weigh these competing demands may result in feelings of sorrow, worry, anxiety, tension, resentment, guilt, shame and depression among family caregivers of the mentally ill.

Statement of the Problem

To date, a growing body of mental health literature has concerned the consequences of caring for a family member with mental illness when there has been a significant transition of responsibility for the care of persons with mental illness from care in the traditional health care system to informal care by family caregivers. For example, investigators have explored the family caregiving consequences of caring for adolescents with mental illness (F. M. Lee, 2006; S. Y. Lee, 2006), adults with major depressive disorder (K. T. Lee, 1996; Liu, 1995), adults with schizophrenia (Chang, 2004; Chen, Yang, Liao, Le, Yeh, & Chen, 2004; Hou, 2004; Huang, Lee, & Mao, 1991; Lee, Tsai, & Young, 2000; Shen & Chang, 1993a; Yang, Hsieh, Wu, Yeh, & Chen, 1999; Yen, 2003), adults with neurotic disorders (O'Lee, 2000), adults with schizophrenia and bipolar disorders (Tsui, Yang, Shieh, Wu, & Chen, 1998), adults with unspecified diagnosis of mental illness (Lee, Ko, & Shu, 2006; Li, 2003; Shen & Chang, 1993b; Song, 1998, 1999, 2002; Shu, Lung, Lu, Chase, & Pan, 2001; Sung, Hixson, & Yorker, 2004; Tung & Beck, 2007; Tung & Gillett, 2005; Wu, 1995), or the elderly with dementia/ Alzheimer's diseases (Chou et al., 1999; Chu, 2005; Fuh, Wang, Liu, Liu, & Wang, 1999; Huang, Shyu, Chen, Chen, & Lin, 2003; Huang, 2004; Liu, Lin, Tsou, Lee, Yan, Wang, & Chaing, 1991; Shyu, Yip, & Chen, 1996; Yu, 1997).

Overall, empirical results have shown that family caregiver burden and depressive symptoms are likely to be found in Taiwanese families where the family member with SPMI is having more behavioral disturbances, social support is perceived as insufficient, and there is less regard for the value of family caregiving. These patterns in Taiwanese families were similar to those found in studies done in the United States (Biegel et al., 1994; Coyne, Kessler, Tal, Turnbull, Wortman, & Greden, 1987; Pearlin et al., 1990; Pinguart & Sörensen, 2003). However, other key components in the context of Taiwanese

family caregiving experience for persons who are mentally ill are still unexplored such as family caregiver's awareness of patient suicidality, family history of mental illness, chronicity of mental illness, and family functioning.

Existing studies have confirmed that caregiving consequences are related to poor health in the primary family caregivers, regardless of kin relationship. The information provided by family members other than primary family caregivers would be a valuable adjunct to understanding how the individuals with mental illness affect their family as a unit. Future studies should take into account other significant family members in the caregiver role to concisely evaluate the caregiving dynamic.

A prominent theme in the literature on family caregiving for individuals with SPMI is that family caregivers are often more interested in how caretaking responsibilities will affect their family as a whole rather than how these responsibilities will affect their own well-being. An extensive literature review of Taiwanese studies indicates that scholars have generally applied various stress-process models to explore the effect of caring for relatives with mental illness on family caregivers, particular primary family caregivers (Huang, 2004; F. M., Lee, 2006; Song, 1998, 1999; Yen, 2003). These stress-process models, however, were generally individual-level theoretical frameworks apt for studying the individual's stress and coping process rather than the family stress and coping process. Therefore, it is crucial for researchers to consider using a family-level theoretical framework (i.e., the Resiliency Model of Family Stress, Adjustment, and Adaptation) to their studies about the family caregiving experiences (McCubbin & McCubbin, 1993).

The cultural context, as defined by the family's racial or ethnic group, influences a host of factors that affect the caregiving process (Lefley, 1996). The evidence in the literature on the impact of individuals with SPMI on the primary family caregivers has significantly interconnected behavioral problems of care recipients, social support,

meaning of family caregiving, family caregiver burden, depressive symptoms of family caregivers, and family functioning with the cultural diversity of study populations. However, there are few studies on the relationship between specific caregiving experiences and caregiver outcomes in ethnically diverse families, such as the influence of individuals with mental illness on Taiwanese family caregivers. Additionally, little is known about how the family as a unit adapts to having a member with SPMI. Therefore, it is crucial to work toward a better understanding of the effects of caring for the mentally ill on non-Western families such as Taiwanese families.

Family Caregiving in Family Mental Health Nursing

Definition of Family

In Taiwan, family has traditionally been defined as a group of two or more persons bounded by birth, marriage, or adoption who live together in a household. However, this definition may not reflect the current situation in Taiwan and the rest of the world. Therefore, for this study, family is defined as “two or more individuals who depend on one another for emotional, physical, and economical support” (Hanson, 2005, p.7).

Milestones in Family Mental Health Nursing

Whall and Fawcett (1991) conducted a historical review of the literature on family nursing and clearly pointed out that the importance of the family in nursing care is a “focal phenomenon in nursing” (p.7). Florence Nightingale was the first nurse theorist concerned with the vital aspects of the family and home environment in the care of sick family members (Whall & Fawcett, 1991). Traditionally, nursing practice had consistently addressed individual-based or patient-centered nursing care, not family-focused nursing care, because of the historical ties of the nursing paradigm with the individual medical model (Hanson, 2005). Hanson (2005) regarded health and illness as family events that markedly influenced all individual members and further denoted that “all nursing practice

involves families” (p.4).

Psychiatric and mental health nursing is a specialized field of nursing research and practice that applies theories of human behavior as a science of nursing and therapeutic use of self as an art of nursing (American Nurse Association, 1982). It delivers continuous and comprehensive mental health nursing care with different aspects of nursing practice (i.e., health promotion, prevention of mental illness, intervention of mental and physical health problems, health maintenance, and rehabilitation) in a variety of populations (i.e., individuals, families, or communities) (American Psychiatric Nurse Association, 2007). Family nursing provides the health care needs for families within the scope of nursing practice across the individual, family, and community and addresses four dimensions of families: (a) the family as the context for the development of individual family members, (b) the family as a client, (c) the family as a system, and (d) the family as a component of society (Friedman, 1998). Over time, family-focused care has taken on a major degree of the responsibility for the provision of mental health care delivery service, and the entire mental health care profession has developed an interest in integrating family nursing into psychiatric and mental health nursing has emerged (Tennant, 1993). Professionals who practice family mental health nursing are aware of the importance of interaction between the mental health of individual family members and families and of the focus on “psychiatric and mental health care needs of the individual client in the context of the family, while also addressing the needs of the family as a whole” (Moriarty & Brennan, 2005, p.348).

Bridging Family Caregiving and Family Mental Health Nursing

In response to the era of deinstitutionalization, the place of family in the study of caring for individual family members with SPMI has grown significantly (Lefley, 1996). The promising advances in the study of family-centered care in nursing indicate that the

health of individual family members and collective health within the family are significantly intertwined (Hanson, 2005). Furthermore, it is critical in future research to move beyond the primary family caregiver to the inclusion of other key family members also committed to the mission of caregiving for people with SPMI.

Regarding the family unit as a whole, the way SPMI affects one family member may influence its effect on other family members as well, and, in turn, the level of family adaptation to SPMI impinges on the degree of individual and family adaptation. Family mental health nursing predominantly integrates the central value of the family into clinical practice to work with families on the issues of a pile-up of demands stemming from mental-illness related stressors and additional stressful life events. In relation to the emphasis on the family as a unit of nursing care practice, it is imperative to understand what potential stressors constitute the pile-up of demands placed on the family, and how families mobilize resources, appraise the meaning of family caregiving, and measure the effects of SPMI on family response.

The family is a primary social institution that strongly influences the development of cultural values, beliefs, and attitudes of individuals within the family context. The degree of stress stimulated by a particular stressor event varies across cultures. Cultural values and beliefs may predict the vulnerability of individuals to stress in terms of how individuals perceive stressor events and how they cope with problems (Lefley, 1996). Although stressors, resources, and adaptation to mental illness have been examined from the individual perspective, little work on family caregiving has addressed the core values of culture-bound family resiliency in response to SPMI, in particular from the family perspective. By exploring linkages among pile-up of demands, social support, meaning of family caregiving, and family adaptation, this study contributes crucial information on individual and family adaptation in Taiwanese families of individuals living with SPMI.

Consequently, the findings of the study will help researchers and clinical practitioners develop theory-guided and culture-driven interventions that meet the needs and interests of individuals and families to effectively reduce stress and to improve and maintain successful functioning of individual family members and the entire family unit.

Purpose and Aims

The purpose of this study was to examine individual and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning), with potential predictors being pile-up of demands (i.e., family caregiver's awareness of patient suicidality, family history of mental illness, chronicity of mental illness, and stressful life events), social support, and meaning of family caregiving, in Taiwanese families of persons with severe and persistent mental illness (SPMI). In addition, this study assessed the mediating effects of social support and meaning of family caregiving on the relationship between pile-up of demands and family adaptation. The aims of this study were as follows:

1. To describe pile-up of demands, social support, meaning of family caregiving, and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning) in families of individuals with SPMI.
2. To examine the relationships among pile-up of demands, social support, meaning of family caregiving, and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning) in families of individuals with SPMI.
3. To assess the potential mediating effects of social support and meaning of family caregiving on the relationship between pile-up of demands and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning) in families of individuals with SPMI.

Research Hypotheses

Based on the three aims of this study, the following research hypotheses were tested:

1. Pile-up of demands, social support, and meaning of family caregiving will significantly be associated with family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning) in families of individuals with SPMI.
2. Meaning of family caregiving will partially mediate the relationship between pile-up of demands and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregiver, and family functioning) in families of individuals with SPMI.
3. Social support will partially mediate the relationship between pile-up of demands and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregiver, and family function in families of individuals with SPMI).

CHAPTER II

LITERATURE REVIEW

Definition of Severe and Persistent Mental Illness

The expression “severe and persistent” refers to individuals with “long-term limitation of functional capacities for primary activities of daily living such as interpersonal relationships, homemaking and self care, employment, or recreation” (Bachrach, 1988, p.384). To avoid the association with misleading or pessimistic stereotypes of continuous and untreatable mental illness, the term “severe and persistent mental illness” has replaced the term “chronic” and has been widely accepted in the literature on mental illness (Parabiaghi, Bonetto, Ruggeri, Lasalvia, & Leese, 2006).

The report of the National Institute of Mental Health (1987), defined SPMI contingent on the following three criteria: (a) a psychiatric diagnosis criteria, described as non-organic psychosis or personality disorder; (b) the duration criteria, which defined “prolonged duration of treatment or illness” as having a two-year or longer history of previous hospitalizations or outpatient treatment; and (c) the functional disability criteria, which includes at least three of the following five categories of disabilities: dangerous or disturbing behavior, mild impairment in activities of daily living and basic needs, moderate impairment in social functioning, moderate impairment in performance at work and moderate impairment in non-work activities. The two levels of criterion of dysfunction assessed by the cut-off points of the Global Assessment of Functioning (GAF): mild, moderate or severe impairment (a GAF score of 70 or less, showing some difficulty in social, occupational, or school functioning) and only severe impairment (a GAF score of 50 or less, indicating severe symptoms or severe impairment in social,

occupational, or school functioning) (Ruggeri, Leese, Thornicroft, Bisoffi, & Tansella, 2000; Schinnar, Rothbard, Kanter, & Jung, 1990). SPMI conditions consist of “schizophrenia, bipolar disorder, and other severe forms of depression, panic disorder, and obsessive compulsive disorder” (U.S. Surgeon General, 2005, p.46).

Epidemiology of Severe and Persistent Mental Illness

Psychiatric disorders are not only widely prevalent but also highly disabling (Kohn, Saxena, Levav, & Saraceno, 2004). The Global Burden of Disease (GBD) has highlighted the magnitude of issues of mental illnesses in the world (Desai & Isaac, 2001). According to the report of the World Health Organization (WHO) in 2001, three of the top ten diseases leading to disability worldwide are (a) major depressive disorder, (b) schizophrenia, and (c) bipolar disorder.

Based on the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM), the prevalence rate of severe and persistent mental illness (SPMI) in Taiwan has increased from 1,178,726 in 2000 to 1,507,835 in 2005 (Department of Health, Taiwan, Republic of China, [R.O.C.], 2006). Based on a statistical estimation by the Taiwanese Department of Health (2006), schizophrenia and affective disorders are the two most prevalent forms of SPMI, increasing in prevalence from 0.96% of the population in 2000 to 1.3% of the population in 2005.

However, it is important to note that epidemiological data derived from studies of caregiving dynamics of Taiwanese families might underestimate the “real” pervasiveness of psychiatric illness. Two possible explanations might be that (a) people are reluctant to seek health care because of the traditional stigma about mental illness and (b) families tend to hide a family member with mental illness until the patient becomes uncontrollable and a threat to others.

Mental Health Policy and System in Taiwan

Increased public awareness of evident limitations of the mental health care system has created a climate for change in the need for advocacy for patients with mental illness and their families, especially family caregivers. In the promulgation of mental health regulations by the Taiwanese government since December 12, 1990, the aim of mental health policy changes has been to improve the welfare of patients by means of the establishment of a mental health administrative system with a social network of psychiatric and mental health providers (White-paper of Health Policy, R.O.C., 2007). The government implemented National Health Insurance (NHI) in March 1995, which provided all citizens access to a comprehensive health insurance program. The optimal goal of the NHI program is to provide equal-opportunity medical care for all Taiwanese citizens (Bureau of N. H. I., 2006). About 98% of all residents of Taiwan 22,315,000 were enrolled in this program in 2005 (Bureau of N. H. I., 2006).

The number of psychiatric beds has increased from 14,760 in 2000 to 18,556 in 2005 (Department of Health, Taiwan, Republic of China, [R.O.C.], 2006). Psychiatric community rehabilitation centers and half-way houses grew from 45 in 2000 to 126 in 2005 (Department of Health, Taiwan, Republic of China, [R.O.C.], 2006). However, expenditures for psychiatric disorders only accounted for 3% of NHI's budget in 2000 (Chien, Chou, Lin, Bih, Chang, & Chou, 2004). The provision of adequate mental health care services still cannot meet actual needs among the growing population with mental illness because of the inadequate reimbursement of the National Health Insurance. Hence, the government still faces some limitations including insufficient mental health hospital beds, a shortage of mental health rehabilitation centers, and a lack of community follow-up and support programs. Moreover, this problem with the mental health service system placed extraneous demands of caregiving on families who are taking care of sick

family members.

Theoretical Framework

Resiliency Model of Family Stress, Adjustment, and Adaptation

The guiding theoretical framework for this study on the relationship among pile-up of demands, social support, meaning of family caregiving, and family adaptation was grounded in the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993; Figure 1). The Resiliency Model of Family Stress, Adjustment, and Adaptation is an application of a family-level theoretical framework, and it describes a caregiving process that involves family members' efforts to achieve a balance between family demands and family resources at both the individual-to-family and the family-to-community levels of functioning (McCubbin & McCubbin, 1993). From a family-strengths perspective, the Resiliency Model explains how some family members and the family system as a unit are more resilient and are better able to adjust and adapt to undesirable circumstances than others.

The Resiliency Model builds on Hill's earlier ABC-X framework (Hill, 1949) as well as the Double ABC-X model (McCubbin & Patterson, 1983), the Family Adjustment and Adaptation Response (FAAR) Model (McCubbin & Patterson, 1983), the Typology Model of Family Adjustment and Adaptation Response (McCubbin & McCubbin, 1987), and the T-Double ABC-X Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 1989). In recent years, though, empirical literature has shown a growing inclination toward applying the Resiliency Model as a conceptual framework to gain further understanding of the resiliency or capability of families to recover from adverse events (McCubbin & McCubbin, 1996).

In the Resiliency Model, McCubbin and McCubbin (1996) defined resiliency as the positive behavioral patterns and functional competencies individuals and the

family unit demonstrate under stressful or adverse circumstances, which determine the family's ability to recover by maintaining its integrity as a unit while insuring, and where necessary restoring, the well-being of family members and the family unit as a whole (p.5).

The Resiliency Model consists of the following five fundamental assumptions: (a) families regard hardships and changes as natural and predictable aspects of family life over the life cycle; (b) families possess basic and unique strength and develop basic competencies, patterns of family functioning, and capacities to foster the growth and development of individual family members and the family unit and to protect the family from major disruptions in the face of family transitions and changes; (c) families have existing basic and unique strength and develop basic competencies, patterns of family functioning, and capacities designed to foster the growth and development of individual family members and the family unit and to protect the family from unexpected or nonnormative stressors and strains following a family crisis; (d) families derive benefit from and contribute to the network of relationships and resources in the community, particularly during times of family stress and crisis; (e) families face stressful circumstances and crises that require changes in family functioning to restore order, balance, and harmony (McCubbin & McCubbin, 1996).

The Resiliency Model encompasses two phases: family adjustment and family adaptation (McCubbin & McCubbin, 1993; Figure 1). The adjustment phase consists of six interactional components: stressor (A), such as a family member with mental illness; family vulnerability (V), which refers to stressors, strains, transitions already existing or occurring along with a stressor (i.e., mental illness); family typology (T) of established patterns of functioning; family resistance resources (B); family appraisal (C) of the stressors; and family problem solving and coping strategies (PSC). The adjustment phase

proposes that minimal transitory changes occur in the family unit as a result of encountering stressors. However, if minor changes in family functioning are not adequate to manage these stressors or demands such as a significant increase in caregiving, then the family moves into family crisis and begins the adaptation phase of the resiliency model.

Compared to the adjustment phase, in the adaptation phase family members and the family unit must change patterns of family functioning to deal with the stressor and to restore balance to the family. Five major factors contributing to the adaptation phase are as follows: pile-up of demands (AA) on the family system, which is caused by illness, family life-cycle changes, and unresolved strains; established patterns or new patterns of family functioning (R); family resources (BB), which include individual family members, family system resources, and social support (BBB) from the community; the family's situational appraisal (CC), schema and meaning (CCC), and problem-solving and coping strategies (PSC). These factors interact with each other and determine the degree of family adaptation including bonadaptation and maladaptation. The process of adaptation focuses on "the family's natural and self-healing resources and capabilities" (McCubbin & McCubbin, 1996, p.55). It involves changes within relationships among family members as well as relationships with the community to reestablish individual and family balance, harmony, and well-being (McCubbin & McCubbin, 1996).

Cross-Cultural Application of Resiliency Model

The Resiliency Model of Family Stress, Adjustment, and Adaptation has been used with families from different ethnic groups. Svavarsdottir and Rayens (2003) examined related factors that affect American and Icelandic parents' health perceptions about children with chronic asthma. This study found that a child's illness severity and caregiving demands significantly affected parents' perceptions of their child's health and that social coherence and family hardiness mediated the effect of family demands on health perceptions. A study by Van Riper (2000) indicated that family demands, family resources, and family problem solving and coping were significantly related to sibling well-being in 41 American families having a child with Down syndrome. Similarly, Van Riper (2007) also found that family demands, family resources, and family problem-solving communication were significantly associated with family adaptation in 76 mothers of children with Down syndrome. Tak and McCubbin (2002) assessed the relationships among family stress, perceived social support, and coping strategy and discovered that perceived social support was positively related to the degree of family coping in 92 American families having a child with congenital heart disease (CHD) who was less than 12 years old.

Kramer (1993) investigated the relationships among personal and family stressors, interpersonal vulnerability variables (i.e., marital history and quality of prior relationship), caregiver resources, appraisals of stressors, and caregiver adaptation (depression, quality of life, and caregiving satisfaction) in 72 American wife caregivers of individuals with Alzheimer's disease (AD). Results of this study revealed that personal and family stressors, interpersonal vulnerability variables, caregiver resources, and appraisals of stressors were significantly associated with depression and quality of life, respectively. Musil, Warner, & Zauszniewski (2006) examined associations among demographic

factors, pile-up of demands, learned resourcefulness, social support, and role rewards with the degree of family functioning among American grandmothers who were caregivers. Their findings indicated that more intrafamily strain and stressful life events and less perceived social support, learned resourcefulness, and role rewards were significantly related to a lower degree of family functioning.

Mu (2005) explored the relationships among uncertainty, coping strategies, and depression in Taiwanese fathers of children with epilepsy. Uncertainty was positively associated with paternal depression. Conversely, uncertainty was negatively related to the family coping patterns.

A study of the determinants of psychological morbidity among 108 Thai families of people with schizophrenia provided evidence that pile-up of demands, seeking spiritual support, and family functioning have a statistically significant influence on the psychological morbidity of family members (Rungreangkulkij, Chafetz, Chesla, & Gillis, 2002). Kuo (1999), in an assessment of family stress, adjustment, and adaptation in Taiwanese families with mothers in preterm labor, found that family hardiness, presence of another child in the family, and uncertainty of high-risk pregnancy significantly accounted for pregnancy adjustment for fathers, mothers, and families as a whole whereas tolerance for ambiguity, uncertainty of high-risk pregnancy, family hardiness, and social support failed to explain family functioning as an index of family adaptation for fathers, mothers, and families. However, family functioning was positively related to family hardiness and negatively associated with uncertainty of high-risk pregnancy in a sample of mothers. In addition, the results also revealed that there were no significant differences between fathers and mothers in pregnancy adjustment, family functioning, uncertainty of high-risk pregnancy, family hardiness, and social support.

Although all of the above studies used the Resiliency Model as the guiding conceptual framework, only a minority of these included data from multiple family members. Moreover, there were very few that analyzed the data at the family level. In addition, no Taiwanese scholar has used the Resiliency Model to explore family caregiving in Taiwanese families of individuals with SPMI. Therefore, there continues to be limited understanding of stress, coping, and adaptation at the family level in Taiwanese families of individuals with mental illness. Hence, studies such as this in which data were collected from multiple family members and analyzed at both the individual and family level will make an important contribution to the family caregiver literature.

Family Caregiving Model of Taiwanese Family Caregivers of Individuals with SPMI

The conceptual framework for this study was derived from the Resiliency Model of Family Stress, Adjustment, and Adaptation and empirical evidence from caregiver research. A key feature of the Resiliency Model is its capacity to address how a family unit utilizes its strengths and capabilities to adapt when a pile-up of demands (e.g., mental-illness related stressors and stressful life events) makes it necessary for individual family members and/or the family unit to change typical ways of functioning (McCubbin & McCubbin, 1993). For example, adult children may be forced to assume the caregiver role for their parent with mental illness. Or, the family may no longer be able to continue their routine of going on a family holiday every year because of a decrease in family income due to the primary breadwinner quitting work to care for a family member with mental illness.

Based on the Resiliency Model of Family Stress, Adjustment, and Adaptation, the conceptual framework for this study was primarily designed to address four main sets of

conceptual domains: (a) pile-up of demands, (b) family resources, (c) family appraisal, and (d) family adaptation (Figure 2).

Pile-Up of Demands

Family crises evolve and revolve over a period of time, and the family takes on the challenge to change and thereby achieve a fit at two levels of adaptation: the individual to the family and the family to the community (McCubbin & McCubbin, 1996). Families of individuals with SPMI rarely deal with one stressor at a time but rather experience a pile-up of demands (e.g., stressors, strains, and transitions) following the diagnosis of a family member with mental illness. Six categories of stresses and strains contributing to a pile-up of demands on the family system have been identified: (a) the stressor event (e.g., family member diagnosed with a mental illness, mentally ill family member suffers a relapse) and its associated hardships (e.g., financial difficulties related to a decrease in family income, curtailment of social relationships due to fear of discrimination related to family member's diagnosis of mental illness); (b) normative transitions (e.g., birth of a baby, child entering school, adult child marries, primary breadwinner retires); (c) prior strains accumulated over time (e.g., long history of difficult relationship between family member with mental illness and the primary family caregiver); (d) situational demands and contextual difficulties (e.g., increase in caregiving responsibilities due to an increase in the care recipient's mental illness-related symptoms or a relapse); (e) consequences of family's efforts to cope (e.g., family member who is the primary caregiver develops a stress-related illness that requires hospitalization); and (f) intrafamily and social ambiguity (e.g., lack of clear boundaries both within and outside the family regarding how to deal with the chronic and unpredictable caregiving responsibilities and social stigmatization) (McCubbin & McCubbin, 1993).

Family Resources

A family's ability to adapt to a pile-up of demands will depend, in part, on their resources. McCubbin and McCubbin (1993) emphasized three types of resources available to the family: (a) personal resources, which include intelligence, knowledge, skills, personality traits, physical, spiritual, and emotional health, a sense of mastery, self-esteem, a sense of coherence, and ethnic identity and cultural background; (b) family system resources, which include cohesion and adaptability, organization, shared parental leadership and clear general family boundaries, communication skills, problem solving, hardiness, and time together and routines; and (c) community resources, which include personal support (e.g., kin, friends, neighbors) and institutional support (e.g., health care services).

Family Appraisal

In the early work of the Double ABC-X Model of family stress and crisis (McCubbin & Patterson, 1983), the cC factor was defined as family definition or interpretation of the overall circumstances, including the initial stressor, additional stressor event, and resources the family has to cope with the pile-up of demands. Family appraisal in the adaptation phase of the Resiliency model involves two fundamental levels: situational appraisal (CC) and schema and meaning (CCC) (McCubbin & McCubbin, 1993).

A family's situational appraisal of its capability is regarded as an assessment of the relationship between the demands of the situation and family resources to cope with these demands (McCubbin & McCubbin, 1993). The more constructive or positive a family's appraisal of situation and the more resources a family has available to them the more effective family's capabilities become and the family ultimately achieves adaptation (McCubbin & McCubbin, 1996). Family schema refers to families, over time, developing

and shaping a collective set of shared or accepted values, beliefs, rules, priorities, and expectations that play a vital role in developing family meanings (McCubbin & McCubbin, 1993). Family schema is shaped, modeled, and reframed by the ethnic and cultural background over time in response to stressful life events and is more relatively stable than situational appraisals because it reflects family values and identity (McCubbin, & McCubbin, 1993). In the face of mental illness, the family unit is called upon to appraise its past and future in an attempt to assign meaning to the mental illness. In turn, a shared sense of family meaning results in subsequent changes in the family system that promote stability, balance, and harmony.

Family Adaptation

Family adaptation is the central concept in the Resiliency Model (McCubbin & McCubbin, 1993). McCubbin and McCubbin (1993) identify family adaptation as “the outcome of family efforts over time to bring a new level of balance, harmony, coherence, and functioning to a family crisis situation” (p.35). It presents a fit at two levels of functioning: individual-to-family and family-to-community (McCubbin & McCubbin, 1993). The adaptation phase involves the family’s long-term response to stressful events that require the family to change its established functioning. It encompasses a continuum of process with a range from bonadaptation (successful family adaptation) to maladaptation (unsuccessful family adaptation) (McCubbin & McCubbin, 1996).

In this study, the dependent variables reflect family adaptation and encompass family caregiver burden, depressive symptoms of family caregivers, and family functioning. Family demands include family caregivers’ awareness of patient suicidality, family history of mental illness, and chronicity of mental illness. In the face of mental illness-induced family demands, family resources (i.e., social support) and family appraisal (i.e., meaning of family caregiving) are mediators that theoretically reduce the

effect of family demands on family adaptation. The following section provides the conceptual background and variables of this proposed study along with empirical research support for the conceptual framework.

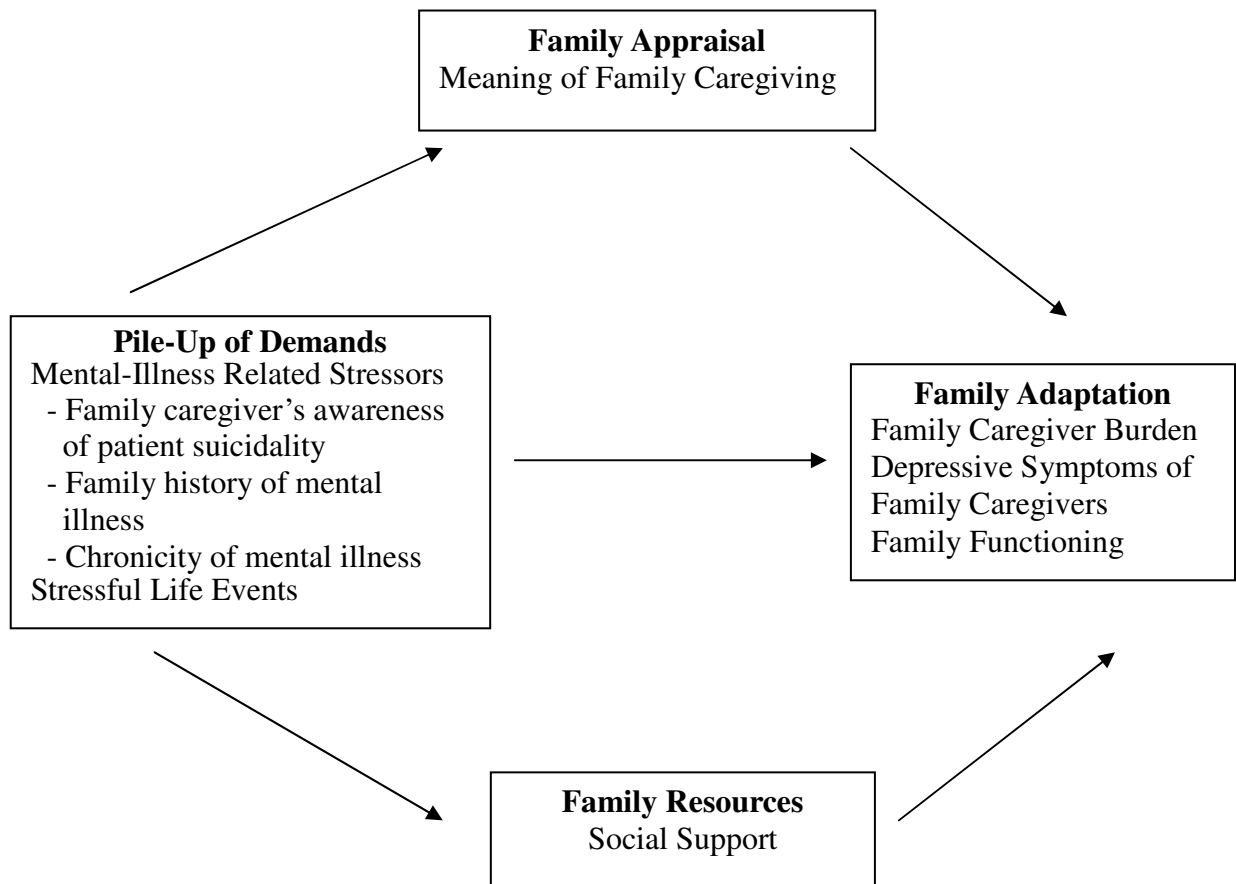


Figure 2. Family caregiving model of Taiwanese family caregivers of individuals with severe and persistent mental illness (Conceptual framework was based on the Resiliency Model of Family Stress, Adjustment, and Adaptation developed by McCubbin & McCubbin, 1993)

Pile-Up of Demands

Mental Illness-Related Stressors

Family Caregiver's Awareness of Patient Suicidality

According to statistical records from the Department of Health, suicide has been among the top 10 causes of death in Taiwan since 1997 (Department of Health, Taiwan, Republic of China, [R.O.C.], 2006). Approximately one person dies by suicide every three hours (Tzeng & Lipson, 2004). Furthermore, Cheng (1995) pointed out that 97 % to 100% of people committing suicide had suffered from mental illness. Hence, suicide is clearly related to psychiatric illness and is becoming an increasingly important issue for the mental health care system in Taiwan.

Because of the relatively high risk for suicidal ideation, attempts, and behaviors by the mentally ill people (Hu, Sun, Lee, Peng, Lin, & Shen, 1991), these co-morbid conditions create accumulative stressors on the family unit and indirectly contribute unpredictable burdens to family caregivers. The estimated risk of suicide for major depressive disorder is 20.4%, for bipolar disorder 15%, and for schizophrenia 8.45 % (Harris & Barraclough, 1997). Grad and Sainsbury (1963) documented that family's fear of patients' suicidal ideation of committing suicide was the second source of burden borne by family caregivers. Östman (2004) documented that in taking care of people with mental illness, the family members of re-admitted patients experienced more intense psychological aspects of burden than those of first-admitted patients. One-third of family caregivers expressed their concerns and worries about the patient's suicide attempts or self-damage. Jones, Roth, and Jones (1995) pointed out that while family caregivers were more likely to get use to the excessive stressors caused by relatives with mental illness, suicidal threats or gestures were the major source of subjective burden. As found in other research on the determinants of burden among caregivers of people with schizophrenia

(McDonell, Short, Berry, & Dyck, 2003), family awareness of the patient's suicidal ideation significantly resulted in family caregiver burden.

Family History of Mental Illness

It has long been known that mental illnesses tend to run in families (Wender, Kety, & Rosenthal, 1986). In fact, much of our understanding of the etiology of mental illness comes from family, adoption, and twin studies (Cowan, Kopinsky, & Hyman, 2002; Dawson, 1998; Wender, Kety, & Rosenthal, 1986). Evidence of aggregation or accumulation of a mental illness beyond that attributable to chance (i.e., whether or not the mental illness runs in the family) is sought by studying family histories (Dawson, 1998). An increased incidence of mental illness within the family is considered to be indicative of a genetic component (McGuinness, Noonan, & Dyer, 2005). The specific distribution of the condition among family members is suggestive of the condition's mode of inheritance. For example, if the condition affects both males and females and it seldom skips a generation, it is most likely inherited in an autosomal dominant fashion.

In the December 19th issue of *Science* in 2003, research on the genetics of mental illness was named the number two scientific "breakthrough of the year". Initially, researchers tried to identify genes passed down from one generation to the next that "caused" individuals to develop mental illness. More recently, there has been growing recognition that mental illness is inherited in a multifactorial pattern. That is, rather than there being a single causative gene, mental illness is most likely caused by the interaction of various genetic and environmental factors. Environmental factors that have been linked to the development of mental illness include stressful life events (Caspi, Sugden, Moffitt, Taylor, Craig, Harrington, McClay, Mill, Martin, Braithwaite, & Poulton, 2003; Kendler, Neale, Kessler, Heath, & Eaves, 1993) and availability of social support (Kessler, Kendler, Heath, Neale, & Eaves, 1992, 1994).

Value of family history.

Family history is widely used in many aspects of biomedical research and clinical practice because of its convenience, low-cost, and noninvasiveness (Kendler, 2001). Guttmacher, Collins, and Carmona (2004) emphasized that the value of the family history is “more important than ever” (p.2333) and postulated that “it will be crucial to conduct careful studies that establish the best approaches for ensuring that increased knowledge leads to behavioral changes resulting in improved health outcomes” (p.2334). According to Yoon and colleagues (2002) “family history of specific disease reflects the consequences of genetic susceptibilities, shared environment, and common behaviors” (p.304). Further, Kendler (2001) identified three vital values of family history in biomedical research: (a) as a risk factor that affects etiology, reproductive planning, or preventive treatments of patients; (b) as an alternative source of diagnostic information about patients and their family members; and (c) as a powerful screening tool for genetic testing with the ultimate goal of reducing the morbidity and mortality related to a certain disease.

Effects of family history on family adaptation.

To understand gene-environmental interactions in the subsequent physical and mental health of family members, scholars conducted a prospective-longitudinal study of mental illness in New Zealand (Caspi et al., 2003). The findings revealed that subjects with at least one short allele of the serotonin transporter gene (5 HT-T) had a significantly greater likelihood of manifestations of depressive symptoms in the face of stressful life events. Furthermore, researchers conducted studies of twins to identify genetic and environmental risk factors for common mental illness and documented that genetic influences significantly accounted for the perceptions of the adequacy of social support as

well as the effects of stressful life events on the degree of depressive symptoms (Kessler et al., 1992)

Robinson (1996) studied 39 families of persons with chronic mental illness (i. e., schizophrenic disorders, bipolar disorders, and depressive disorders) who were involved in a psychoeducational program to explore the association of casual attributions to mental illness that place family members responsible for with the level of family functioning. For fathers, mothers, and siblings as well as the family as a whole, the results revealed that the attribution of neither biology/heredity nor God/chance was significant for the degree of family functioning although respondents strongly considered heredity or biological issues as the most causal attribution to devastating mental illness. It must be emphasized, however, that no single gene can entirely determine the development of mental illness even for disorders presumed to have strong genetic predispositions, such as schizophrenia (Tienari, Wynne, Sorri, Lahti, Läksy, Moring, Naarala, Nieminen, & Wahlberg, 2004).

Effects of genetic testing on identified individuals and families.

In consideration of the risk-to-benefit ratio for collecting the information about family history, it is crucial to explore the nature of the potential risks for both individuals and their family members. As evidence of the growing importance of family history information and knowledge of psychiatric genetics increases, health care providers should take into account concerns regard the impact of genetic testing on dyadic relationships within the family, psychological responses of family members to genetic information, and societal perspectives (Appelbaum, 2004; Peterson, 2005). In general, the stigma against genetic psychiatric disorders still exists in society. In the late 1990s, Wong and Lieh-Mak (2001) issued a case report in which general misperceptions and prejudices of mental illness act synergistically with genetic knowledge to generate genetic discrimination such as discrimination in the workplace, stigmatization, and health insurance discrimination.

In a broader view of genetic information and the genetic testing, the burden of shame and guilt is inevitably attached to the identified individual and the family unit and people are likely to label it as a “mentally ill family”. Family members regard the individual with mental illness as a catastrophic event and assume that “this terrible illness colors everything-a family cannot escape” (Marsh, Lefley, Evans-Rhodes, Ansell, Doerzbacher, LaBarbera, & Paluzza, 1996, p.3).

In a study of patients and their families’ attitudes and perceptions about schizophrenia in the context of genetic counseling, Schulz, Schulz, Dibble, Targum, van Kammen, and Gershon (1982) found that two thirds of patients with schizophrenia planned to have children whereas their parents opposed their bearing children. In addition, the majority of both patients and their family members acknowledged the need for genetic counseling. Wasow (1985) found that family members of an individual with mental illness emphatically expressed their genetic fear of ruining the family and believed that mental illness terminated chances of future contentment because of social stigma. Stalberg, Ekerwald, and Hultman (2004) interviewed sixteen siblings of patients with schizophrenia and identified three salient themes: (a) sibling bond, which included love and sorrow, anger and envy, and guilt and shame; (b) coping patterns, which included avoidance, isolation, normalization, caregiving, and grieving; and (c) fear of heredity, which included impact of family history, fear of becoming mentally ill, and reflections about “bad genes.”

Chronicity of Mental Illness

Providing care for the family member with SPMI is a demanding task for family caregivers. The duration of family caregiving combined with the progression of the mental illness plus an anticipation of unpredictable reoccurrences and acute psychiatric episodes disrupts family routines and generates emotional distress. Broadly speaking, a

significant proportion of patients with mental illness are likely to develop chronic illnesses (Hatfield, 1997; Walton-Moss, Gerson, & Rose, 2005). The chronic conditions reflect “impairments or deviations from normal” (Donnelly, 1994, p.398). “The nature of the illness and the accompanying trajectory, as well as the need to manage symptoms and adhere to complex regimens, pose significant demands on both patients and families” (White, Richter, Koeckeritz, Lee, & Munch, 2002, p.219).

Craig and Hyatt (1978) identified the chronicity of mental illness as “regression or lack of change in mentally ill persons who have demonstrated potential and capability in the past, leads to helplessness and hopelessness on the part of the patients his/her family and mental health caretakers” (p.154). Bhugra (2006) refers to chronicity, as the likelihood of relapses in terms of the frequency of hospitalizations or the numbers of episodes of mental illness that may continue with various degrees of psychopathology over a long time.

A number of contributing factors pertaining to the chronicity of mental illness may affect the adaptation of family caregivers to their situation. Regarding reactions or attitudes of family members, Kriesman and Joy (1974) claimed that “number or length or hospitalizations that are in the process of accommodation to recurrent or prolonged disturbance in family life is virtually uncharted” (p.42). The prolongation of mental illness and the roller coaster emotions caused by the vicious cycle of repeated exacerbations and relapse have intensified pile-up of demands within families, creating a considerable additional burden on family caregivers (Biegel, Sales, & Schulz, 1991). Solomon and Draine (1995b) pointed out that families generally confront a loss of a lovely family member during periods of patients’ symptom exacerbation, whereas families typically encounter frustration during times of patients’ symptom remission.

Some studies have found longer durations of schizophrenia (Hwu, Wu, Cheng, Huang, Hu, Hwang, Chen, Yeh, & Chang, 2000) and affective disorders including bipolar disorders and major depressive disorder (Chakrabati, Kulhara, & Verma, 1992) were significantly associated with a higher degree of family caregiver burden. The frequency of relapses has consistently been associated with the degree of family caregiver burden (Huang et al., 1991; Song, 1999; van Wijngaarden, Schene, & Koeter, 2004). Rose (1996) extensively reviewed the literature on family caregiving studies and pointed out that family members usually experienced greater degree of subjective burden when patients had at least two previous hospitalizations because of mental illness. Östman (2004) interviewed 126 relatives of re-admitted individuals with mental illness. Relatives of re-admitted individuals with mental illness experienced greater burden of caring than those of first-admitted individual with mental illness. For relatives of re-admitted individuals with mental illness, 25% of them indicated that they wished the individual with mental illness had never been born or they had never met the patient and 21% of them believed that the patient would be better off dead.

Walton-Moss and colleagues (2005) reported that psychiatric disorders considered to result from chronic illness negatively influence levels of family functioning. In a sample of 86 families of persons with major depressive disorder, Miller, McDermut, Gordon, Keitner, Ryan, and Norman (2000) explored the relationship between characteristics of the patients and their spouses with family functioning. Their findings suggest that family functioning was lower if the patient remained mentally ill longer and had more episodes of mental illness.

Stressful Life Events

In addition to struggling with mental illness as a major stressor, families frequently experience multiple sources of stressful life events (e.g., death of a family member, loss

of job, economic strain, marital infidelity, etc.) (Doornbos, 2002a; Greenberg, Greenley, & Brown, 1997; Lefley, 1996; Noh & Turner, 1987; Noh & Avison, 1988; Song & Singer, 2006). Prior unsolved stressors or strains existing in the family may further magnify or precipitate additional demands for change on families (McCubbin & McCubbin, 1993). The empirical findings in relation to the association of family adaptation with life stressors other than those resulting from family members with mental illness have been mixed.

Several studies have indicated that socioeconomic status of family caregivers (e.g., income and education) was a significant predictor of family caregiver burden (Biegel et al., 1994; Cook, Lefley, Pickett, & Cohler, 1994), depressive symptoms of family caregiver (Fadden, Bebbington, & Kuipers, 1987), and family functioning (Doornbos, 2002a). Some researchers have examined the influence of family caregiver health and have found that the poor health status of family caregivers significantly contributed to their depressive symptoms (Hobbs, 1997; Pruchno & Patrick, 1999) and the degree of their burden (Song, 1999). Studies of family caregiver burden have demonstrated that the presence of other dependent family members besides the person with mental illness (e.g., children at home; Noh & Avison, 1988) and unresolved strains in the relationship between the family caregiver and the care recipient place the family caregiver at significant risk for experiencing burden (Laidlaw, Ceverdale, Falloon, & Kydd, 2002; Lyons, Zarit, Sayer, & Witlatcth, 2002; Pickett, Cook, Cohler, & Solomon, 1997) and developing depressive symptoms (Kramer, 1993). In contrast, some findings showed that neither the issue of socioeconomic status nor the self-report health status of family caregiver was related to the level of family caregiver burden (Biegel et al., 1994). Therefore, it is crucial to take into account the potential role of normative life events to contribute to the accumulative effects of demands on family members while proving care for an individual with SPMI.

Social Support

Social support has been extensively studied in the past decades by multidisciplinary scholars. The most influential and vital community resources in facilitating family adaptation to stress are those associated with social support (McCubbin & McCubbin, 1996). Numerous reviews of prospective studies have identified social support as a mediator between environmental stressors and family adaptation on the part of family caregivers living with mental illness (Haley, Levine, Brown, & Bartolucci, 1987; Haley, Roth, Coleton, Ford, West, Collins, & Isobe, 1996; Pearlin et al., 1990).

Definition of Social Support

Historically, researchers have investigated numerous types of social support because of their varying perspectives of social support (Barrera, 1986). Lin (1986) conceptualized social support as (a) “social” reflecting the person’s linkage to three distinct levels of social environment including intimate and confiding partnerships, the social network, and the community and (b) “support” representing perceived or actual support of instrument and expression. Sarason, Pierce, and Sarason (1994) reviewed an extensive selection of social support literature and conceptualized the construct of social support from three approaches: (a) structure of social network, (b) functional support, and (c) the distinction between received and perceived features of social support.

The structure of social network involves the “frequency of contact with network members and the structural characteristics of social ties” (Turner, 1999, p.201). Relevant properties of the structure of social support network include (a) dyadic characteristics (e.g., reciprocity, intensity, and complexity), and (b) characteristics of the network as a whole (e.g., homogeneity, geographic dispersion, and density) (Heaney & Israel, 2002). Patterson (1988) examined the content of social support functions and identified three broad categories of social support: (a) emotional support consists of love, trust and caring;

(b) informational support includes provision of suggestions, advice, and appraisals or information that helps the individual clarify problems and realize how one is doing; and
(c) instrumental support involves the assistance of concrete aid and services (i.e. money, labor, and time).

Received social support is the amount of social support that is actually available and refers to “the provision of direct help or material aid” (Gibson, 1992, p.148). Perception of social support can take the form of appraisal, interpretations or beliefs about the value of available social support and conceptualized as “information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligation” (Cobb, 1976, p. 300). Similarly, Shumaker and Brownell (1984) defined social support as “an exchange of resources between at least two individuals perceived by the provider or recipient to be intended to enhance the wellbeing of the recipient” (p13). The perception of the adequacy of social support includes “satisfaction with the support system and the extent to which interactions are available and helpful” (Bergeman, Plomin, Pedersen, McClearn, & Nesselroade, 1990, p.101).

In mapping the key role of social support in the demands-related illness, empirical evidence has consistently suggested that perceived social support is a more important and sensitive indicator of its effect on stressors than actual provision of assistance regardless of available social support (Callaghan & Morrissey, 1993; Hupcey, 1998; Vaux, 1988). Specifically, empirical evidence has revealed that perceived social support significantly contributes to mental health outcomes (Thoits, 1995). Turner, Frankel, and Levin (1983) regarded social support as perceived or experienced and postulated that “events or circumstances in the real world affect the individual only to the extent and in the form in which they are perceived” (p.74). The core aspect of social support is “the support

emanates not so much from what is done but from what that indicates to the recipient about the relationship” (Sarason et al., 1994, p.155).

Effects of Social Support on Family Adaptation

Studies have consistently regarded sufficient perception of or satisfaction with social support as one of the most important family resources that significantly enhance the coping capability of family members of persons who are mentally ill and assuage the degree of family caregiver burden (Baronet, 1999; Maurin & Boyd, 1990; Pinqart, & Sörensen, 2005; Rose, 1996; Saunders, 2003; Schulze & Rössler, 2005). Solomon and Draine (1995b) asserted that social support was the most powerful resource in helping families effectively deal with the stressful caregiving circumstances of individuals with mental illness. Potasznik and Nelson (1984) indicated that satisfaction with social support mediated the effect of stress on burden experienced by families with mental illness.

Magliano and colleagues (1998) gathered data from 236 families of individuals with schizophrenia in five European cities (i.e., Naples, Athens, Lisbon, Aylesbury, and Bonn) and discovered that family caregivers with reduction of social support generally experienced higher levels of family caregiver burden. Similarly, Song (1999), who interviewed 244 Taiwanese family caregivers, reported that the amount of perceived social support significantly affected the level of family caregiver burden in relation to potentially alleviating the influence of the patients’ behavioral problems on family caregiver stigma. Magliano, Fiorillo, Rosa, Malangone, Maj, and the National Mental Health Project Working Group (2005) compared the degree of burden and the amount of social support in family caregivers of individuals with schizophrenia and a long-term physical disorder in Italy. The results revealed that family caregivers in the schizophrenic group acquired less social support than those in the group of physical illness. In the

schizophrenia group, family caregivers with insufficient social support reported higher levels of family caregiver burden.

Lin (1986) postulated that “social support both directly affects depressive symptoms and significantly mediates the effect of undesirable life events” (p.334). Several published findings have supported the notion that less perceived social support significantly accounted for depressive symptoms of family caregivers of people with mental illness. For example, Haley and colleagues (1996) adopted a stress process model of caregiving developed by Haley et al. (1987) to further expand the understanding of relevant contributing factors of caregiver well-being in families having a mentally impaired member and postulated that social support mediated the relationship between stressors of family caregiving and family caregiver well-being (i.e., the degree of depressive symptoms of family caregivers and life satisfaction). Pickett, Vraniak, Cook, and Cohler (1993) explored differential effects of caring for a family members with mental illness among 24 Black and 185 White children with mental illness and discovered that White parents with insufficient social support were more likely to report the higher degree of depression. It is important to note that there have been studies in which the relationship between perceived social support and caregiver outcomes was not significant in terms of the psychological well-being of the caregiver (Provencher, Perreault, St-Onge, & Rousseau, 2003; Rivera, Rose, Futterman, Lovett, & Gallagher-Thompson, 1991; Lawton, Moss, Kleban, Glicksman, & Rovines, 1991; Yang et al., 1999).

Song, Biegel, and Milligan (1997) examined predictors of depressive symptomatology among 103 lower social class caregivers in the US who were living with chronically mentally ill adults. The results revealed that perceived social support from family members and mental health professionals significantly influenced the levels of depressive symptoms of family caregivers. Greenberg, Greenley, et al. (1997)

investigated the effect of the provision of mental health services on the degree of psychological distress of 778 family caregivers of member with mental illness. Their findings showed that family caregivers who experienced lower levels of depression had a greater collaborative relationship with health care providers in the client's treatment process and that the care recipient received more mental health services.

Therefore, it is crucial for health care providers to validate their partnership with families of the mentally ill and to provide them with information and advice about coping strategies to help these families experience increased support and decreased social isolation. Future studies should take into account the perception of caregivers about the quality and types of social support as well as the degree of collaborative relationship with mental health professionals.

Social support plays a key role in helping family members who care for individuals with mental illness to utilize their strengths as they deal with stressful life circumstances. Social support also helps improve family functioning in these families. Saunders (1999) used a convenient sample of 58 families with schizophrenia to explore the predictors of family functioning. Results of the study suggest that families who acquired more social support generally had more effective family functioning to deal with ongoing demands. Furthermore, Sun and Cheng (1997) postulated that perceived social support, especially satisfaction with support from relatives, strongly accounts for the degree of family functioning of families of the mentally ill regardless of the degree of symptoms of schizophrenia.

Racial and Ethnic Difference in Perceptions of Mental Illness and Mental Health Service Utilization

Different racial and ethnic groups may exhibit unique culturally bound beliefs and attitudes toward the utilization of and treatment outcomes from mental health services

(Lefley, 1996). In Taiwanese culture, the public views mental illness as punishment for misdeeds done by patients or other family members and therefore inevitably places a burden on families (Hwu et al., 2000). Within this orientation, persons with mental illness bring intense anticipated shame, fear of stigma, guilt, frustration, and humiliation upon families. These feelings may cause families to withdraw from their social networks or hesitate to access health service for support. Additionally, the behavior of patients may lead other relatives and friends to avoid any discussion about the emotional difficulties the family caregiver may be facing (Lefley, 1996).

Zhang, Snowden, and Sue (1998) found that Asian Americans, compared with Whites in terms of help-seeking behaviors for psychological problems, were less likely to use mental health care services such as visits to mental health care facilities or participating in a community mental health program or with a self-help group. Most studies have supported the evidence that Asian Americans who use mental health services are more severely ill and chronic than patients of other ethnic groups who use the same services (Lin & Cheung, 1999). Similarly, Matsuoka, Breaux, and Ryujin (1997) examined national utilization levels of mental health services, and they found that Asian Americans/Pacific Islanders are much less likely than European Americans to use all types of mental health services. Taken together, two possible explanations for this finding are that Asian Americans are reluctant to seek health care because of the traditional stigma Asians share about mental illness and that families tend to hide a family member with mental illness until the patient becomes uncontrollable and a threat to others.

Some health care professionals and members of the general public may view the family of the mentally ill person as a cause of the mental illness and its exacerbation, rather than a source of care and support (Karp, 2001; Wender et al., 1986). Because of this, the family may be excluded from the decision-making surrounding the affected

family member's care. Unfortunately, lack of family involvement in the decision-making process poses a larger problem for the family member with the mental illness. Families play an important role in the long term care of mentally ill individuals and are a major source of support and advice for them (Danielson, Hamel-Bissell, & Winstead-Fry, 1993). Family involvement in the treatment of mental illness has beneficial effects for both mentally ill individuals and their families.

In studies, family caregivers have frequently expressed dissatisfaction with health care providers in terms of being excluded from involvement in treatment planning, of lacking adequate information about community resources, of difficult communication, and of feeling blamed by mental health professionals for the patients' problems (Karp, 2001; Pickett et al., 1993). Studies indicate that between 31% and 77% of all types of families have some contact and receive some information from providers (Greenberg, Greenley, et al., 1997; Marshall & Solomon, 2000; Marshall & Solomon, 2004; Song et al., 1997). Rose (1997) adopted the qualitative approach to explore the perception of social support for 15 family caregivers of individuals with mental illness and identified four sources of crucial social support: (a) professional and system support, (b) friend support, (c) family, extended family support, and (d) spiritual support. However, family caregivers acknowledged that their needs for support were unmet because of the limitations of existing sources of social support. Consistent contact and exchange of reciprocal information between health care providers and families about the patients' illness and treatment allow families to recognize prodromol symptoms and to more effectively support their ill relatives.

The extent of family members' needs in relation to what they actually receive from health care providers may in fact be incongruent. As proposed by Sung and colleagues (2004), patients and their family caregivers might have perceptions of demands and needs

of family caregiving that differ from the expectations of health care professionals in terms of stress management and well-being. A study about the experiences of family caregivers of clients with schizophrenia in Hong Kong also reported similar results. Family caregivers expected information, support, and guidance from health care providers and these expectations often were not met (Ip & Mackenzie, 1998). Further studies should take into account the perception of family caregivers about the quality and types of social support as well as their degree of collaborating with mental health professionals.

Meaning of Family Caregiving.

Definition of Meaning

The conceptualization of meaning is a critical aspect of adaptation to stressful life events and circumstances (Park & Folkman, 1997). With respect to variation in family caregiving consequences, researchers have attempted to understand its potential explanations and to identify its meaning and strengths in helping caregivers to preserve their caregiver roles and caregiving tasks while adapting to the demands of caregiving. The meaning of an event (i.e., illness) develops through the appraisal process (Lazarus & Folkman, 1984). Meaning in the realm of coping with aversive life situations refers to “perceptions of significance” (Park & Folkman, 1997, p.116). Fife (1994) conceptualized meaning as “the individual’s perception of the ability he or she had to accomplish future goals, to maintain the viability of interpersonal relationships, and to sustain a sense of personal vitality, competence and power” (p.310). The sense of meaning in life is “one’s attempts to find meaning and positive value in certain life conditions or experience (such as caregiving)” (Noonan & Tennstedt, 1997, p.785). Meaning of family caregiving does not reside in tasks of family caregiving but emerges from caregivers’ active interpretation of social interaction within a continuing process (Phillips & Rempusheski, 1986). In

addition, meaning of family caregiving also acts as an anchor in caregivers' reactions to environmental stressors.

Effects of Meaning of Family Caregiving on Family Adaptation

A number of impressive family caregiving studies have indicated that the family caregiving experience has a negative impact on family caregivers of individuals with mental illness; however, little work has been conducted to further elucidate family strengths and competencies associated with positive aspects of family caregiving outcomes (Doornbos, 1996; Greenberg, Greenley, & Benedict, 1994, Rose, 1998a, 1998b). The construction of meaning of a particular event influences the efforts of individuals to cope with the stressful experiences they encounter (Fife, 1994). The development of a sense of shared family meaning about the pile-up of family demands that come with illness is a healing process with which families are able to generally find new ways to "put the disease in its place" and thus to adapt to caring for a loved member and address the needs of other family members as well (Cohen, 1999; Seller, 2000).

Rose (1998a) explored the development of meaning of family caregiving among families of people with mental illness. The result postulated the notion that meaning of family caregiving is a crucial element that provides an increased sense of control for caregivers to potentially alleviate negative family caregiver appraisals of stressful caregiving experiences. Pickett and colleagues (1997), who compared 222 parents of an adult offspring with mental illness with 434 parents of a healthy adult offspring, reported that experiencing positive parent/adult child relationships and deriving satisfaction from assisting their adult children significantly reduced the degree of caregiver burden regardless of their experiences in caregiving.

Zika and Chamberlain (1992) stated that "meaning in life is consistently related to positive mental health outcomes, while meaninglessness is associated with pathological

outcomes” (p.135). Noonan and Tennstet (1996) have further investigated the relationship of meaning of family caregiving to psychological well-being and identified two dimensions of personal experiences regarding caregiving meaning: (a) the cognitive dimension includes positive beliefs and values of caregiving experience and (b) the emotional dimension includes emotional satisfaction with the caregiver role, its benefits and rewards. In a study by Noon and Tennstedt (1997), the meaning of family caregiving was negatively related to depressive symptoms of family caregivers. Moreover, the results also indicated that family caregivers frequently used more management of meaning techniques (e.g., positive thinking, and low expectations) and utilized less management of distress techniques (e.g., spend time alone or exercising). Similarly, Yen (2003) interviewed 55 primary Taiwanese family caregivers of individuals with schizophrenia, and the findings indicated that meaning of family caregiving significantly related to the degree of depressive symptoms of family caregivers.

Themes of Meaning of Family Caregiving

In recent years, though, empirical literature has shown a growing inclination toward qualitative approaches to explicitly outline the role of meaning of family caregiving in the caregiving process (Butcher, Holkup, & Buckwalter, 2001; Rose, 1998a; 1998b, Rose, Mallinson, & Walton-Moss, 2002; Sethabouppha & Kane, 2005; Tuck, Mont, Evans, & Shupe, 1997). A few scholars have used ethnographic approaches to explore the meaning of family caregiving in ethnically unique families (Karp & Tanarugsachock, 2000).

Several salient themes of meaning characterizing the family caregiving experience for individuals with mental illness have been explored. The contents of meaning commonly addressed are as follows: gratification and satisfaction, family responsibility and reciprocity, friendship and company, doing what needs to be done, helping the relative to move forward (Noonan & Tennstedt, 1996, 1997; Rose, 1998a; Rose et al.,

2002), belief, compassion, acceptance, management, suffering (Butcher et al., 2001; Karp & Tanarugsachock, 2000; Rose, 1998b; Sethabouppha & Kane, 2005; Tuck et al., 1997), feeling helpful, appreciation for additional opportunity of a close relationship with the care recipient, and rewarding (Tarlow, Wisniewski, Belle, Rubert, Ory, & Gallagher-Thompson, 2004).

Cultural-Bound Meaning of Family Caregiving

Leininger (1988) defined culture as the “learned, shared, and transmitted values, beliefs, norms, and life practices of a particular group that guides thinking, decisions, and actions in patterned ways” (p.156). Dumas, Rollock, Prinz, Hops, and Blechman (1999) stated that “a person’s culture is an essential ingredient of his or her identity and behavior, and ignoring it threatens the effectiveness, appropriateness and ultimately the ethical acceptability of any intervention, as well as the validity of any research findings” (p.176).

Empirical evidence shows that cultural and ethnic differences result in a variation of family caregiving experiences and determine similarities and differences in family health beliefs, attitudes, emotional expression, religion (Guarnaccia & Parra, 1996; Lefley, 1996). The role of culture and ethnic traditions and beliefs contributes to the development of meaning regarding adaptation of the efforts of families to manage the demands that they face (McCubbin & McCubbin, 1996).

Compared to Western cultures, non-Western cultures place greater emphasis on collectivist cognitions and values such as the welfare of their families or the acceptance of persons with mental illness (Lefley, 1996). With respect to cultural values and norms, the intergenerational ties and filial obligation reflect the meaning of family caregiving (Choi, 1995). When a family member is ill, all family members—not only the primary family caregiver—share responsibilities regardless of the duration of time and energy actually spent in the caregiving process. Chou and colleagues (1999) have revealed that

Taiwanese families tend to take the primary responsibility of caregiving as a family obligation for caring for their dependent family members during a long-term of family caregiving involvement.

Family Caregiver Burden

Biegel and colleagues (1991) referred to caregiving as an “increment of extraordinary care” and explicitly described the nature of family caregiving as the provision of care to a family member who has a chronic illness involves a significant expenditure of time and energy over potentially long periods of time, involves tasks that may be unpleasant and uncomfortable, is likely to be nonsymmetrical, and is often a role that had not been anticipated. (p.17)

Family caregivers of people with SPMI are “an at-risk and underserved population” (Doornbos, 2002b, p.41). Lefley (1996) asserted that “the psychiatric and psychological literature on mental illness has concentrated on the well-being of patients, marginalizing or ignoring the well-being of the persons dedicated to their sustenance” (p.6). In the light of global trends toward a growing provision of mental health service for people with mental illness within the community context, the issue of the influence of community-based care on family members of people with mental illness requires further attention.

Historically, a substantial body of caregiving research in the field of nursing, social work, and gerontology has shown that family caregivers generally provide the individuals who are mentally ill with considerable support and significantly improve the patient’s outcome in terms of medication compliance, exacerbations of psychopathology, hospital readmissions, and community tenure (Biegel et al., 1991; Falloon, Boyd, McGill, Williamson, Razani, Moss, Gilderman, & Simpson, 1985; Lefley, 1996; McGill, Falloon, Boyd, & Wood-Siverio, 1983). However, researchers have acknowledged that the

families of the mentally ill generally bear an extensive burden as a consequence of caregiving (Karp, 2001; Rose, 1996; Thompson & Doll, 1982).

Definition of Burden

Earlier researchers of family caregiving primarily attempted to investigate the impact of transitional treatment process of the mental health system on the psychological, financial, and social costs of mental-illness caregiving (Hoenig & Hamilton, 1966; Swanson & Spitzer, 1970; Thompson & Doll, 1982). Caregivers widely report burden defined as “any individual whose presence and performance aroused either fear or shame must be burdensome and could not be living within a supportive environment” (Thompson & Doll, 1982, p.380). Potential difficulties include “the direct care needs generated by the illness, disruption of normal household routines and roles, financial concerns relating to medical costs and income loss, and emotional stresses triggered by the illness” (Sales, 2003, p.34).

Hoenig and Hamilton (1966) were the first scholars to classify burden into objective and subjective burden. Researchers have defined objective burden as the observable and concrete costs to the family caregiver as a result of the patient’s mental illness, such as financial difficulties, the requirements of patient supervision, the curtailment of social relationships, and the disruption in family routines (Hoenig & Hamilton, 1966; Maurin & Boyd, 1990; Thompson & Doll, 1982). Subjective burden refers to the extent family caregivers felt about to which the patients presence and behaviors (Hoenig & Hamilton, 1966) or emotional costs in terms of feelings of overload, embarrassment, entrapment, and resentment (Thompson & Doll, 1982). The correlation between objective and subjective burden is complicated. Several studies have proposed that the degree of objective burden contributes to the level of subjective burden (Jones, 1996; Maurin & Boyd, 1990).

Contributing Factors Associated with Family Caregiver Burden

The extensive literature on family caregiving experience provides evidence that caregiver burden is a global outcome with an emphasis on its link to an array of predictors (the perception of the stress and burden of the mentally ill family member on the family can be viewed as the end product of a variety of factors): (a) characteristics of patients (i.e., behavioral symptoms of mental illness, duration of mental illness, and diagnosis of mental illness), (b) characteristics of family caregivers (i.e., age, gender, living arrangement, types of kin relationships, the duration of family caregiving involvement, and socioeconomic status), (c) mediators of burden (i.e., social support and coping strategies), and (d) ethnic differences (Baronet, 1999; Chappell & Reid, 2002; Horwitz & Reubhard, 1995; Maurin & Boyd, 1990; Pinquart, & Sörensen, 2005; Rose, 1996; Schulze & Rössler, 2005). Nevertheless, it is crucial to discern that not all the empirical evidence from the caregiving literature consistently supports the link between these contributing factors and family caregiver burden.

A critical point to bear in mind is that the degree and content of the burden differs considerably depending on not only on the diagnosis of mental illness of the individual but also on the family structure and the closeness of kinship. To paint a clear picture of the burden over an extended period, its nature will be analyzed and discussed in the following four relevant domains: (a) symptomatic behaviors of mental illness (i.e., positive symptoms and negative symptoms), (b) diagnosis of mental illness (i.e., schizophrenic disorder, major depressive disorder, and bipolar disorders), (c) family structure (i.e., living arrangement) and relationships of family caregivers to care recipients (i.e., spouses/partners, siblings, children, parents, and a family unit), and (d) race and ethnicity.

Symptomatic Behaviors of Mental Illness in the Context of Family Caregiver Burden

The early literature on the consequences of family mental-illness indicated that severity of symptomatic behaviors and mental illness-related deficits statistically resulted in physiological, psychological, financial, and social costs to family members in response to the demands (Biegel et al., 1994; Coyne et al., 1987; Greenberg, Kim, & Greenley, 1997; Mueser, Webb, Pfeiffer, Gladis, & Levinson, 1996; Pinguart & Sörensen, 2003; Ricard, Bonin, & Ezer, 1999; Provencher & Mueser, 1997; Song et al., 1997; Song, 1999; Stueve, Vine, & Struening, 1997; Thompson & Doll, 1982). In general, researchers classified symptomatic behaviors of patients into (a) positive symptoms (the presence of abnormal thoughts, behaviors, and affects), such as hallucinations, delusions, agitation, disorganized speech and thought, and socially disruptive behaviors, and (b) negative symptoms (the absence or decline of thoughts, behaviors, affects, and normal daily functioning), such as apathy, depressed mood, social withdrawal, reduced social interests, and inability to follow through or complete tasks (Maurin & Boyd, 1990). In particular, negative symptoms of mental illness were most consistently related to adverse outcomes such as family caregiver burden (Dyck, Short, & Vitaliano, 1999) and even more burdensome than positive symptoms of mental illness (Fadden et al., 1987; Oldridge & Hughes, 1992; Schene, 1990).

Despite the increasing recognition of the significant relationship between the patient's symptomatic behaviors and the outcomes of family caregiving, little work in the field of family caregiving has further elucidated other potential features of psychiatric symptoms (i.e., family caregiver's awareness of patient suicidality, family history of mental illness, and chronicity of mental illness) associated with the level of family adaptation in family members caring for a person with mental illness. Hence, additional studies in understanding potential determinants of family caregiving consequences is

critical to helping families identify and establish strength to meet the needs of each family member.

Diagnosis of Mental Illness

In the past, much of the family caregiving research focused on schizophrenia or other psychotic spectrum disorders (Fadden et al., 1987; Maurin & Boyd, 1990). However, there is a growing concern with the caregiving experiences in families of people with affective disorders (Fadden et al., 1987; Perlick, Clarkin, Sirey, Raue, Greenfield, Struening, & Rosenheck, 1999). Rose and colleagues (2002) claimed that “schizophrenia, bipolar disorder, and major depression are often devastating illnesses that extract a significant toll on both patients and their families” (p.516).

To understand the development and processes of changes in of subjective burden in parents of adult children with schizophrenia, Jungbauer, Wittmund, Dietrich, and Angermeyer (2003) conducted narrative interviews and they found six developmental types of subjective burden: (a) constantly high level of burden; (b) increased burden; (c) reduced burden; (d) shifting burden; (e) preeminence of other burden; and (f) constantly low level of burden. The results indicated that 40% of parents experienced a consistently high degree of subjective burden, especially parents of adult offspring with severe and persistent psychosocial functioning impairments.

Similar findings were also detected in studies on the caregiving consequences of families of people with bipolar disorders or major depressive disorder. For instance, Perlick and colleagues (1999) conducted a longitudinal study to assess the effect of bipolar disorders and reported that 93% of primary family caregivers reported a moderate or greater level at least one domain of burden in terms of problem behavior, role dysfunction, and adverse effects. Fawcett (1993) regarded depression as a human condition that would not only affect the sick person but also family members. Fadden and

colleagues (1987) conducted a pilot study of the spouse caregivers of 24 individuals suffering from persistent depression in the UK and found out that the spouses significantly experienced a considerable degree of family caregiver burden in relation to giving up work, financial strain, difficulties in the marital relationship, and the restriction of social and leisure activities. In addition, the result indicated that the major proportion of the burden related to negative symptoms of patients such as misery, underactivity, and social withdrawal.

Jekins and Schumacher (1999) conducted a two-by-two comparative study to examine the differences of family burden across Euro-American and Latino families of individuals with schizophrenia or depression. They found no significant difference in burden across ethnic groups whereas caregivers of people with schizophrenia in all ethnic groups experienced more subjective aspect of caregiver burden than those of people with major depressive disorder.

In comparison with schizophrenia, Chakrabarti and Gill (2002) postulated that family caregivers of people with bipolar disorders experienced less degree of burden. In the study of primary family caregivers of 17 patients with major depressive disorder and 73 patients with bipolar disorders by Chakrabarti, Kulhara, and Verma (1992), the degree of family caregiver burden involving bipolar disorders was significantly higher than the burden involving major depressive disorders. Similarly, Ogilvie, Morant, and Goodwin (2005) found that family caregivers of people with bipolar disorders experienced a higher level of objective burden than those caring for people with major depressive disorder. Furthermore, Chakrabarti and Kulhara (1999) examined the effect of different diagnoses of psychiatric disorders including schizophrenia, affective disorders, generalized anxiety disorder, dysthymia, and obsessive-compulsive disorder on the degree of family caregiver

burden and concluded that more than 90% of families across different diagnostic groups experienced moderate to severe burden.

Family Structure and Relationships of Family Caregivers to Care Recipients

Females are generally regarded as the natural caregivers in terms nurturing roles. However, some studies have reported no gender differences in the experience of family caregiver burden (Biegel et al., 1994; Horowitz & Reinhard, 1995). To date, a number of studies of families about individuals with mental illness have clearly documented that living with the patient significantly influenced the extent of the burdens (Jones et al., 1995; Noh & Turner, 1987; Solomon & Draine, 1995a; Song, 1999). In some studies, however, living in the same residence with the patient did not show an independent impact on the degree of family caregiver burden (Baronet, 2003; Horowitz & Reinhard, 1995).

In a critical review of family caregiving studies involving SPMI, Hatfield (1997) claimed that “other members of the family- spouses, children and siblings- are also significantly affected, albeit in ways that are often different from parents” (p.254). A diverse constellation of relationships of family caregivers to the care recipient has been reported to be an influential factor in relation to the consequences of assuming an unpaid and unanticipated responsibility for individuals with SPMI.

Family caregiving research has generally addressed the individual as a unit of analysis in investigations of the effect of mental illness on the experience of burden of key family caregivers such as mothers (Ryan, 1993), fathers (Wintersteen & Rasmussen, 1997; Howard, 1998), siblings (Greenberg, Kim, et al., 1997; Greenberg, Seltzer, Orsmond, & Krauss, 1999; Stalberg et al., 2004), spouses (Fadden et al., 1987; Minnion, 1996; Noh & Avison, 1988; Jungbauer, Wittmund, Dietrich, & Angermeyer, 2004), and children (Valiakalayil, Paulson, & Tibbo, 2004). Only a few scholars have regarded the

dyad as a unit analysis such as parents (Cook et al., 1994), or the family as a unit analysis (i.e., the whole family; Doornbos, 1997; Jones, 1997; Marsh et al., 1996).

The influence of burden on family caregivers may vary depending on the type of family caregiver-care recipient relationship. Noh and Avison (1988) compared gender differences in the degree of burden experienced of husbands and wives of spouses who were mentally ill. They found that significant predictors of burden for husbands were patients' symptoms and stressful life events whereas predictors for wives were significantly related to the presence of children at home and ineffective coping strategies. Reinhard and Hortwitz (1995) conducted structured telephone interviews with 163 family members (86 parents and 77 siblings) of patients with mental illness. The findings indicated that siblings provided less assistance but perceived higher degree of burden than parents, particularly burden related to family frictions, stigma, and worry about the future. To the extent to which caring for siblings with mental illness generally involves nonnormative caregiving activities, it may be expected that the degree of burden on siblings is relatively higher than parents.

To explore the broad spectrum of family caregiver burden, Jungbauer and Angermeyer (2002) analyzed 42 in-depth interviews to explore the subjective aspects of burden experienced by spouses and parents of patients with schizophrenia. The results revealed that spouses expressed the burden involved in fragile partnership and taking over additional or untraditional role function. However, the burden for parents were feelings of guilt and self-blame regarding the causes of the mental disorder and understanding a lifetime responsibility and obligation.

Jones (1997) compared the nature of family caregiver burden experienced across four types of families caring for a member with mental illness and found that (a) parents were worried about the future of the patient especially when parents were gone; (b)

children had the sense of being robbed of a parent; (c) siblings had ambivalent feelings of an earlier relationship, a “sandwich” position, and an involuntary component; and (d) spouses had a positive feelings about the earlier relationship, a dream about what had been lost, and were ambivalence about the current relationship.

Race and Ethnicity

With the increased interest in differences in SPMI caregiving experiences of culturally diverse families, empirical findings indicate significant differences in the degree of family caregiver burden across ethnic /racial groups. Caqueo-Urizar and Gutiérrez-Maldonado (2006) interviewed forty-one primary family caregivers of persons with schizophrenia in South America and found that caregivers had high level of burden, particularly mothers. Donnelly (2001) designed a cross-cultural qualitative study to understand the nature of Korean American families’ experiences in caring for members with mental illness. Donnelly identified five main themes (a) realization of children’s illness, (b) battling the disease of incompetence, (c) poignant processes of caregiving, (d) suffering a way of life, and (e) journey toward spirituality.

A comparison study of the level of family burden between Black and White caregivers revealed that Black caregivers had lower levels of burden than White caregivers (Hortwitz & Reinhard, 1995; Knight, Silverstein, McCallum, & Fox, 2000; Pickett et al., 1993). Stueve and colleagues (1997) compared the differences in the perceived burden of caring for mentally ill American adults among 180 primary family caregivers in three ethnic groups—Black, Hispanic, and White. The finding showed that Blacks experienced less burden.

Caregiving has long been considered a form of obligation, fate, debt repayment, and virtue for Taiwanese families. Pragmatically, however, the sense of filial obligation and the social stigma of mental illness for Taiwanese families may be overwhelming. Studies

on the consequences of SPMI in Taiwanese families have examined the extent to which primary family caregivers frequently struggle with the patients' unpredictable, chronic, and uncontrollable psychotic symptoms as well as social stigma, stereotyping, and discrimination (Chang, 2004; Hou, 2004; Song, 1999; Tsui et al., 1995; Yang et al., 1999). Wu (1995) conducted a cross-cultural study among three groups including Taiwanese families in Taiwan and Los Angeles and Caucasian families in Los Angeles. The results showed that the degree of family caregiver burden was mild to moderate although there was no significant difference of family caregiver burden among these three groups.

Depressive Symptoms of Family Caregivers

The literature has increasingly addressed the psychological aspects of family caregivers during the significant transition of responsibility for care from the traditionally formal health care system to the informal care of family. The extensive literature indicates that the presence of mental illness significantly results in the psychological distress of caregivers (Chang, 2004; Chen et al., 2004; Coyne et al., 1987; Martens & Addington, 2001; Noh & Turner, 1987; Provencher et al., 2003; van Wijngaarden et al., 2004). Specifically, Fortinsky, Kercher, and Burant (2002) regarded depressive symptoms of family caregivers as a mood disturbance caused by the demand of caregiving circumstances. A number of studies have consistently documented the depressive symptoms of family caregivers as being the most powerful parameter of negative aspect of psychological well-being for family caregivers (Haley et al., 1996; Hobbs, 1997; Pickett et al., 1993; Song et al., 1997; Song, 1998; Yen, 2003).

A consistent finding has shown a high incidence and prevalence of depressive symptoms among caregivers of family members with chronic or serious mental illness. Around 20% have reported depression, a proportion twice as high as in the general population (Family Caregiver Alliance, 2005). In a cross-sectional study of families of

individuals with major depressive disorder, approximately 30% of spouses met the criteria for psychiatric disorders (Miller et al., 2000). Studies have consistently reported that family caregivers exhibited a higher degree of depressive symptoms or other mental health problems than noncaregivers, particularly primary family caregivers (Schulz, O'Brien, Bookwala, & Fleissner, 1995; Zarit & Zarit, 1998). These studies also reported that family caregivers were more likely to use psychotropic medications to alleviate their psychiatric symptoms than members of the general population (Schulz, et al., 1995; Zarit & Zarit, 1998).

Coyne et al. (1987) explored family members' experiences of living with individuals with major affective disorders, including both major depressive disorder and bipolar disorders, and assessed their levels of psychological distress (i.e., anxiety and depression). The results indicated that family caregivers significantly experienced psychological distress and over 40% of family caregivers met the criteria to be referred for psychological interventions to reduce the distress and difficulties of the caregiving experiences. Similarly, Song (1998) interviewed 244 Taiwanese family caregivers of individuals with mental illness and discovered that 45% had depression meeting the criteria of the Center for Epidemiological Studies Depression (CES-D) Scale ≥ 16 . Clients' behavioral problems, caregiver characteristics including being parents, female, being married, being unemployed, having poor health status, and having other caregiving responsibility, and insufficient social support significantly explained the extent of depressive symptoms of family caregivers. Hobbs (1997) examined the predictors of the level of depression in Black, elderly, low-income, and unmarried mother caregivers of adult children with schizophrenia and recognized that physical health, coping, and perceived social support were statistically significant and contributed 65.2% of the variance in the depressive symptoms of family caregivers.

Family Functioning

In the Resiliency Model of Family Stress, Adjustment, and Adaptation, family functioning in reaction to stressful life events is depicted as an outcome or a consequence in which families make efforts to achieve a new state of balanced functioning between the family and the community in regard to the experience of a mental illness. Over time, the family caregiving consequences in relation to family functioning, especially in the circumstance involving mental illness, have been described by researchers (Bachmann, Bottmer, Jacob, Kronmüller, Backenstrass, Mundt, Renneberg, Fiedler, & Schröder, 2002; Friedman, McDermt, Solomon, Ryan, Keitner, & Miller, 1997; Koyama, Akiyama, Miyake, & Kurita, 2004; Miller, Kabacoff, Keitner, Epstein, & Bishop, 1986; Miller et al, 2000; Saunders, 1999; Sun & Cheng, 1997).

It is notion that the family functions as “the primary environment for the individual with a mental illness”, and “what produces a positive outcome for the caregiver may also enhance the functioning of the ill member” (Doornbos, 2002b, p.41). Studies of families of people with mental illness have reported that positive family functioning significantly improved the development and course of patients’ mental illness and decreased the risk of suicidality (Keitner, Miller, Epstein, Bishop, & Fruzzetti, 1987; McDermt, Miller, Solomon, Ryan, & Keitner, 2002; Miller, Keitner, Whisman, Ryan, Epstein, & Bishop, 1992). It is crucial for researchers to understand the effect of mental illness on the family functioning and to improve care and function of both patients and their families.

The effect of mental illness on the family caregivers is likely a process of reciprocal exchange between the individual with mental illness and the family (Bulger, Wandersman, & Goldman, 1993; Horwitz, Reinhard, & Howell-White, 1996). Horwitz and colleagues (1996) found that the amount of support patients gave parents and siblings was significantly related to the quantity of support they received from family members.

The extent of positive family functioning by each family member and the family as a whole in reaction to different diagnoses of mental illness may be inconsistent. Bachmann and colleagues (2002) assessed whether the key family members of individuals with major depressive disorders and schizophrenia differ with respect to expressed emotion (EE) status as the index of family functioning. The result indicated that the types of mental illness did not significantly predict differences in family functioning of key family members.

In a study of 70 pairs of psychiatric outpatients with diagnoses of schizophrenia, major depressive disorder, and bipolar disorders and their primary family caregivers, Koyama et al. (2004) applied the Family Assessment Device (FAD) to measure the difference in the perceptions of family functioning by patients and their primary family caregivers among the three diagnostic groups. The findings showed no significant differences. In comparison with perceptions by the other two diagnostic groups, the extent of perceptions of family functioning of individuals with bipolar disorders and those of their primary family caregivers were significantly correlated. With regard to the problem-solving dimension of the FAD, the individuals with schizophrenia perceived more negatively than did their primary family caregivers whereas the patients with major depressive disorder perceived more positively than their primary family caregivers.

Miller et al. (1986) compared functioning of families having individuals with mental illness (i.e., major depressive disorder, alcohol abuse, adjustment disorder, schizophrenia, and bipolar disorder) to families without patients with psychiatric disorders. The findings indicated significantly impaired family functioning in the families of people with mental illness compared to family functioning in non-clinical families. In addition, families with individuals with major depressive disorder exhibited the lowest degree of family functioning across the psychiatric groups. Friedman et al. (1997) further examined the

impact of mental illness on the family and found that regardless of different diagnoses of mental illness (schizophrenia, bipolar disorders, major depressive disorder, anxiety disorder, eating disorder, substance abuse disorder, and adjustment disorder), families of the mentally ill experienced less satisfaction with the level of family functioning than did non-clinical control subjects.

Summary of Literature

Caring for a family member with SPMI generates excessive demands on families that require extensive role and task allocations in the family unit. A growing volume of caregiver studies have identified significant relationships among the degree of family adaptation with patient and family caregiver characteristics, family life events, perceptions of stressors, and family support resources (Hatfield, 1997; Loukissa, 1995; Maurin & Boyd, 1990; Ohaeri, 2003; Rose, 1996; Schulze & Rössler, 2005). However, there is lack of consensus on the relationships of these factors with family adaptation and the outcome of family efforts to cope with SPMI over time. In addition, several studies have reported the noteworthy effects of ethnic differences on family adaptation in families that include a family member with SPMI (Chappell & Reid, 2002; Horwitz & Reinhard, 1995; Pinguart & Sörensen, 2005).

From a cultural perspective, it is plausible to apply a culturally appropriate theoretical framework to help health professionals achieve a better understanding of adaptation in families experiencing SPMI and to deliver culturally sensitive intervention programs that improve family capabilities to confront demands of SPMI. Researchers have applied the Resiliency Model of Family Stress, Adjustment, and Adaptation to examine contributing factors related to family adaptation to chronic illnesses other than SPMI in Taiwanese family caregivers. However, the Resiliency Model of Family Stress, Adjustment, and Adaptation is a promising theoretical framework to explicitly capture an

understanding of Taiwanese families' resiliency in response to SPMI and deliver a culturally competent interventions (Chen & Rankin, 2002).

Based on a comprehensive review of the literature on family caregiving involving mental illness, this study based on the Resiliency Model of Family Stress, Adjustment, and Adaptation will extend previous caregiver studies by examining the relationship between pile-up of demands and family adaptation that Taiwanese individuals with SPMI and their families experience during caregiving experiences through the mediating effects of family resources (i.e., social support from family members, friends, and the community) and family appraisal (i.e., meaning of family caregiving). The results of this study will contribute to a broader knowledge of how Taiwanese families utilize culture-bound resilience as a family capability or strength to adapt to accumulative demands as well as stressors of daily routines over time. Consequently, it will lead to the development of an applicable model of family caregiving for Taiwanese individuals with SPMI that can guide nursing practice.

CHAPTER III
METHODOLOGY
Research Design

In this study, a cross-sectional, descriptive correlational design was used to explore the relationships among pile-up of demands, social support, the meaning of family caregiving, and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning) in Taiwanese families of individuals with SPMI. The mediating effects of social support and meaning of family caregiving on the relationship between pile-up of demands and family adaptation were also examined.

Subjects and Setting

A sample of 84 families of individuals with SPMI was recruited from two psychiatric outpatient clinics. To be included in the study, each family had to include at least one family member who provided some caregiving to the individual with SPMI. To improve the generalizability of the study, families were recruited from two hospitals; one of the hospitals was a teaching hospital (i.e., Tsy-Huey Mental Hospital), the other was a regional hospital (i.e., Jing-Ho Mental Hospital). Approximately 450-525 individuals with mental illness are seen in these two hospitals per day (Chou, personal communication, January, 5, 2007; Chien, personal communication, January, 19, 2007; Lin, personal communication, February, 17, 2007), averaging approximately 35 and 60 individuals with SPMI per day at Jing-Ho Mental Hospital and Tsy-Huey Mental Hospital, respectively (Chou, personal communication, January, 5, 2007; Chien, personal communication, January, 19, 2007; Lin, personal communication, February, 17, 2007)

The target sample size for this study was 130 family caregivers (65 families). A medium effect size of $R^2 = .13$ was chosen for use in the calculation of the power analysis based on a previous study on Taiwanese primary family caregivers of elderly individuals with dementia (Huang, 2004). Based on a 2-tailed test with a power of .9, effect size of $R^2 = .13$, and a .05 level of significance, the adequate sample size for this study was determined to be 99 family caregivers or approximately 50 families. However, since the behaviors or characteristics of individual family members are intertwined (Acock, van Dulmen, Allen, & Piercy, 2005), data obtained from individuals within the same family are likely to be more similar than data from unrelated individuals. Therefore the sample size needed to be adjusted appropriately. The degree of similarity of individual family members within the family sample is typically measured by a parameter known as the intraclass correlation (ICC). Kenny and Kashy (1991) found that the ICC of larger than .25 provided evidence of interdependence of family data (cited in Acock et al, 2005). To achieve adequate power for the sample size, it is crucial for researchers to take into account the design effect (DEFF) or inflation factor (IF) (Donner & Klar, 2000). The design effect is calculated as follows: $DEFF = 1 + (m-1) \times ICC$, where m is the average number of family caregivers. For the estimation of the sample size in this study, the usual estimate of required sample size should be multiplied by the design effect (i.e., $DEFF = 1 + [2-1] \times 0.25$). Consequently, the required sample size for this study was 62 Taiwanese families of individuals with SPMI or 124 family caregivers (average of two from each family). To adjust for potential missing collection data, five percent was added to the required sample size. Therefore, as noted above, the target sample size was 65 families (130 caregivers) of individuals with SPMI.

Inclusion Criteria

For inclusion in the study, at least one family member in each family who provides care for the individual with SPMI had to be willing to participate and had to meet the following inclusion criteria: (a) be at least 18 years of age, (b) live in the same household or have weekly contact with the affected family member, and (c) be able to speak either Taiwanese dialect or Mandarin. For this study, a family was defined as “two or more individuals who depend on one another for emotional, physical, and economical support” (Hanson, 2005, p. 7). Caregiver was defined as “one who contributes the benefits of medical, social, economic, or environmental resources to a dependent or partially dependent individual, such as critically ill person” (Anderson, 2002, p. 298).

Exclusion Criteria

Family caregivers of individuals with SPMI who have experienced an acute episode of mental illness requiring hospitalization within the past three months were excluded from this study.

Procedures

The protocol of this study was approved by the Institutional Review Boards (IRBs) at the University of North Carolina at Chapel Hill and two hospitals in Taiwan. The principal investigator gave presentations at each of the hospitals. The purpose of these presentations was to inform health care providers about the study and explain the recruitment procedures. Another purpose of the presentations was to establish collaborative partnerships with mental health care professionals as well. The principal investigator also provided the mental health professionals who were working at the outpatient psychiatric clinics with the invitation to participate form which described the research study in detail.

Mental health professionals in the outpatient psychiatric clinics approached family members who accompanied the individuals with SPMI to their appointment and made them aware of the study by giving them the invitation to participate form and the pre-stamped, pre-addressed return envelope. In addition, family members were encouraged to invite at least one other family member who had provided some caregiving to the individual with SPMI to consider participating in the research study. Family members were encouraged to contact the principal investigator by e-mail, phone, or mail (families were supplied with a pre-addressed, pre-stamped return envelope) if they were interested in participating in the research study.

The principal investigator contacted all family caregivers who expressed interest in participating in the research study. After describing the purpose of the study and what participation in the study entailed, the investigator gave the family caregivers the opportunity to ask questions. The principal investigator assured them that participation in the study was voluntary and that they and their family members could withdraw from the study at any time. They were also assured of confidentiality and an anonymous presentation of the findings.

Family caregivers who remained interested in participating in the study were mailed a packet that included a cover letter, a consent form, the questionnaires, and a pre-addressed, pre-stamped return envelope. The cover letter included the purpose of the study, the procedure for completion of the questionnaire, and the instructions for returning the written consent form and the questionnaires. Participants were instructed to sign the consent form and complete the questionnaires. Then, they were to return the signed consent form and the completed questionnaires to the principal investigator in the pre-stamped, pre-addressed return envelope. In addition, individual family caregivers were asked to independently complete the questionnaires. The principal investigator made a

follow-up phone call to those participants who had not returned the consent form and the packet of questionnaires after three weeks. In addition, the investigator sent each participant a thank-you card to express gratitude for the time they spent participating in the study.

Variables and Measures

Measures for the study included the following: (a) a demographic information sheet, (b) Perceived Stress Scale (PSS), (c) Perceived Social Support Scale (PSSS), (d) Meaning in Caregiving Scale, (e) Caregiver Burden Scale-Brief 18 items, (f) Center for Epidemiological Studies-Depression Scale (CES-D), and (g) Family Function Scale. For the actual study, all of the measures were in Chinese. However, an English version of each of the measures is included in Appendices A – G. See Table 3.1 for a summary of the variables and measures being used to assess each variable.

Table 3.1 Variables and Measures

| Variables | Measure |
|---|---|
| Independent variables | |
| Pile-up of demands | |
| Family caregiver’s awareness of patient suicidality | Demographic information sheet |
| Family history of mental illness | Demographic information sheet |
| Chronicity of mental illness | Demographic information sheet |
| Stressful life event | Perceived Stress Scale (PSS) |
| Mediator variables | |
| Social support | Perceived Social Support Scale (PSSS) |
| Meaning in family caregiving | Meaning in Caregiving Scale |
| Dependent variables | |
| Family caregiver burden | Caregiver Burden Scale-Brief 18 Items |
| Depressive symptoms of family caregivers | Center for Epidemiological Studies-Depression Scale (CES-D) |
| Family functioning | Family Function Scale |

Demographic Characteristics

Demographic data were collected for descriptive purposes. Demographic data about the family caregivers included: age, gender, relationship with the individual with SPMI, co-residence, marital status, educational level, religion, race/ethnicity, currently occupational status, monthly household income, average weekly hours of family caregiving involvement, and other family caregivers in the household.

Independent Variables

Family caregiver's awareness of patient suicidality. Family caregivers were asked the following question: "Has your family member with severe and persistent mental illness ever attempted or made threats about attempting suicide? (1= yes, 0 = no)".

Family history of mental illness. Family caregivers were asked the following question: "Among three generations of your family, do any other family members have a mental illness? (1= yes, 0 = no)", and the total number of individuals with mental illness in a family was calculated.

Chronicity of mental illness. The chronicity of the patient's mental illness was measured in terms of previous psychiatric hospitalizations (e.g., "How many times has the individual been admitted to the psychiatric hospital?"), and the length of mental illness (e.g., "How long has the individual been suffering from mental illness since initial diagnosis of psychiatric disorder?").

Stressful life events. The Chinese version of the Perceived Stress Scale (PSS) translated by Chu and Kao (2005) was used to assess the perceptions of stressful life events of family caregivers. Cohen, Kamarck, and Mermelstein (1983) argued that the influence of stressful life events was not objectively determined by the cumulative number of life events or scaling the magnitude of life events (e.g., death of a child or a spouse, business failure, marital infidelity, financial issues, legal problems, and medical

illness were judged to be most stressful life events) on one's life situations but the extent of cognitive response to life circumstances which the individual appraises as potentially threatening or demanding. The Perceived Stress Scale (PSS; Cohen et al., 1983) is a 14-item self-administered instrument designed to tap the degree to which people perceive the global stress in their lives during the previous month as unpredictable (e.g., "In the last month, how often have you felt that things were going your way?"), uncontrollable (e.g., "In the last month, how often have you felt confident about your ability to handle your personal problems?"), and overloading (e.g., "In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?"). It is a five-point scale ranging from 0 to 4 (0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, 4 = very often). The seven items (items 4, 5, 6, 7, 9, 10, and 13) were positively formulated (e.g., "In the last month, how often have you dealt successfully with irritating life hassles?") and are reverse-scored (e.g., 0 = 4, 1 = 3, 2 = 2, 3 = 1, and 4 = 0). The total score of the PSS is obtained by summing across all scores of 14 items (Cohen et al., 1983). Possible scores range from 0 to 56. The higher score reflects a greater level of perception of global stress (Cohen et al., 1983).

Cronbach's Alpha coefficient, calculated as a measure of internal consistency, was .84, .85, and .86 for three samples including two groups of college students and a group of participants in a smoking-cessation program, respectively. Test-retest reliability was obtained by comparing the scores from the same subjects who completed the same instrument under similar conditions (DeVellis, 2003). Test-retest correlations over two days in a sample of college students and over six weeks in a sample of participants in a smoking-cessation program were .85 and .55, respectively. The concurrent validity and predictive validity of the PSS were adequately established by significant correlations with the Life-Event Scores (i.e., number of life events and impact of life events) and

significantly accounting for health outcomes such as depressive symptomatology, physical symptomatology, and utilization of health services (Cohen et al., 1983; Cohen, 1986). In light of comparisons with Life-Event Scores, the PSS demonstrated a more effective measure to tap the predictors of health outcomes (i.e., physical and depressive symptomatology) (Cohen et al., 1983)

The 14-item PSS has been widely applied to diverse ethnic groups such as Taiwanese and Germans (Department of Psychology Carnegie Mellon University, 2006). The Chinese version of the PSS has been translated to assess the level of the global perception of stress to nonparticular events as well as ongoing life situations in one's life in a previous month (Chu & Kao, 2005). Cronbach's Alpha coefficient of the PSS reported in a sample of 351 working adults in Taiwan was .85 (Chu & Kao, 2005). For this study, Cronbach's Alpha coefficient was .96. A high score on the PSS indicates a high level of perceived deleterious stress.

Mediator Variables

Social support. The degree of social support that family caregivers perceive was assessed with the Chinese version of the Perceived Social Support Scale (PSSS) (Yen, 2003). The English version of PSSS is a 12-item self-rated instrument designed to assess the perceptions of social support from three sources: family (e.g., "I can talk about my problems with my family"), friends (e.g., "I have friends with whom I can share my joys and sorrows"), and significant others (e.g., "There is a special person in my life who cares about my feelings") (Blumenthal, Burg, Barefoot, Williams, Haney, & Zimet, 1987; Zimet, Dahlem, Zimet, & Farley, 1988). The PSSS uses a seven-point scale ranging from 1 to 7 (1 = very strongly disagree, 2 = strongly disagree, 3 = middle disagree, 4 = neutral, 5 = mildly agree, 6 = strongly agree, and 7 = very strongly agree). Higher scores indicate greater adequacy of perceived social support from family, friends, and significant others.

The scale of the PSSS in a sample of 136 female and 139 male undergraduate students at Duke University has shown a high degree of internal consistency as indicated by an overall Cronbach's Alpha coefficient of .88 (Blumenthal et al, 1987; Zimet et al, 1988). Reliability measured by Cronbach's Alpha coefficient for each subscale of the PSSS was (a) family= .87, (b) friends = .85, and (c) significant others = .91. The test-retest reliability over a 2-3 month period for the overall score and the family, friends, and significant others subscales was .85, .85, .75, and .72, respectively. In a cross-cultural study that applied the Double ABC-X Model to compare the well-being of American and Korean mothers of children with mental retardation, the internal consistency of the PSSS was .92 for the American group and .91 for the Korean group (Shin & Crittenden, 2003). Zimet et al (1988) provided evidence for the construct validity of the PSSS subscales showing a significant relationship between social support and depressive symptoms (i.e., perceived support from family, $r = -.24, p < .01$; perceived support from friends $r = -.24, p < .01$; perceived support from significant others, $r = -.13, p < .01$).

Yen (2003) translated the English version of PSSS into Chinese to assess the adequacy of perceived social support in a sample of 55 primary family caregivers of individuals with schizophrenia. Because of the fixed amount of time in administering questionnaires via the telephone interviews, the Chinese version was revised from a seven-point to a five-point scale. To condense the telephone interview, the 12 items were modified from a seven-point format to a five-point Likert-type format ranging from 1 to 5 (1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, and 5 = strongly agree). Possible scores range from 12 to 60. The higher scores point to a higher degree of perceived social support from family, friends, and significant others. In regard to internal consistency, Cronbach's Alpha coefficient for the overall score and the family, friends, and significant others subscales was .91, .95, .91, .91, and .72, respectively. In the current

study, Cronbach's Alpha coefficient for the overall score and the family, friends, and significant others subscales was .94, .89, .93, and .88, respectively. A high score on the PSSS reflects a high level of perceived social support.

Lynn (1986) recommended the use of the Content Validity Index (CVI) as a method to quantify the content validity of an instrument. Content experts are generally expected to assess the representiveness, clarity, and comprehensiveness of items from an instrument (Grant & Davis, 1997). Three to ten experts are considered sufficient to review the content validity determination (Lynn, 1986). Five experts including a psychiatrist, a psychiatric nurse, two lecturers at a school of nursing, and a family caregiver of an individual with schizophrenia were invited to evaluate the content validity of the Chinese version of the PSSS using a four-point Likert-type score (1 = the item is meaningless; it should be deleted, 2 = consider eliminating the item, 3 = this item could be used, but it should be modified, and 4 = this item can be used). The result indicated that most of items ranged from 3 to 4 points and its Content Validity Index (CVI) was 1.0 (Yen, 2003).

Meaning of family caregiving. The Chinese version of the Meaning in Caregiving Scale translated by Yen (2003) was used as an indicator of the meaning of family caregiving for family members caring for individuals with SPMI. The English version of the Meaning in Caregiving Scale was developed by Giuliano, Mitchell, and Clark (1990) to assess the positive aspects of meaning that family caregivers interpret or assign based on their experience. The 16-item self-administered measurement consists of three subscales: (a) reordering priorities, which identifies the extent to which family caregivers adjust or reestablish their life priorities and philosophy (6 items; e.g., "The experience of caregiving has made me change what I consider to be really important in life"); (b) relationship fidelity, which characterizes the meaning in caregiving as a sense of being needed and altruistic (6 items; e.g., "I am better able to accept my role as a caregiver

because I feel that this person needs me”); and (c) transcendent beliefs, which represents beliefs and values that transcend the immediate caregiving experience (4 items; e.g., “I believe that taking care of one another is what life is all about”). The Meaning in Caregiving Scale is a five-point scale ranging from 1 to 5 (1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, and 5 = strongly agree). Higher scores indicate greater degree of meaning in caregiving (Giuliano et al., 1990).

The Cronbach’s Alpha coefficient for the overall Meaning in Caregiving Scale in a sample of 166 primary family caregivers of adults with chronic medial illness was .89 (Giuliano et al., 1990). Reliability measured by Cronbach’s Alpha coefficient for each subscale of the Meaning in Caregiving Scale was (a) reordering priorities = .86, (b) relationship fidelity = .86, and (c) transcendent beliefs = .77. The test-retest reliability over a 4-6 week period for the scale as a whole and the three subscales (a, b, and c) was .85, .73, .85, and .87, respectively.

Yen (2003) translated the English version of the Meaning in Caregiving Scale into a Chinese version to assess the beliefs and values family caregivers have through family caregiving experiences in a sample of 55 primary family caregivers of individuals with schizophrenia. The Chinese version was modified from a five-point to a four-point Likert scale. The four-point Likert scale ranges from 1 to 4 (1 = disagree, 2 = somewhat disagree, 3 = somewhat agree, and 4 = agree). Possible scores range from 16 to 64. The higher scores demonstrate higher degrees of meaning derived through the family caregiving experiences (Yen, 2003). For internal consistency, the Cronbach’s Alpha coefficient for the whole Meaning in Caregiving Scale was .75. Content validity for the appropriateness of 16 items of the instrument was .75 (Yen, 2003). Cronbach’s Alpha coefficient for this study was .82. A higher score on the Meaning in Caregiving measure reflects a more positive interpretation of family caregiving experiences.

Dependent Variables

Family caregiver burden. The Chinese version of Caregiver Burden Scale-Brief is a self-administered instrument that explores the objective and subjective burden on family caregivers as well as both positive and negative aspects of family caregiving experiences (Song, 2002). The Caregiver Burden Scale-Brief consists of 18 items related to five subscales: family disruptions (7 items; e.g., “My daily routine is disrupted due to caring for him/her”), stigma (2 items; e.g., “Having a member with mental illness may cause me to feel ashamed”), guilt (2 items; e.g., “I feel what I am doing is not enough for him/her”), caregiver strain (3 items; e.g., “I am worried about his/her safety when he/she is alone”), and client dependency (2 items; e.g., “I feel that he/she depends on me”). Each item is assessed on a scale with five possible responses from 0 = never to 4 = almost always. Total scores of the Caregiver Burden Scale-Brief consist of four degrees: (a) mild to moderate: 8-20; (b) moderate: 21-32; (c) moderately severe: 33-44; and (d) severe: above 45. To assess the positive aspects of family caregiving experiences as well as balance them with negative influence, the designer included two positive items (items 13 and 16) in relation to positive family caregiving experiences (Song, 2002). Examples of two positive items are as follows: “Caring for him/her makes me feel that I am a helpful person” (item 13) and “I feel more optimistic due to caring for him/her” (item 16). The total score was obtained by summing across 16 items excluding two positive items. Possible scores range from 0 to 64. Higher scores indicated higher degrees of caregiver burden (Song, 2002).

The 18 items of the Caregiver Burden Scale-Brief were generated from the instrument of overall caregiver burden developed by Biegel and colleagues (1994) for use with family caregivers of individuals with Alzheimer’s disease and from a review of the literature on burdens of caregivers of family members with mental illness. The 18 items

were adopted for factor analysis and yielded a five-factor solution (i.e., family disruption, stigma, guilt, caregiver strain, and client dependency) that accounted for 55.84 % of the variance in the response data. The reliability for the overall scale and the family disruption, stigma, guilt, caregiver strain, and client dependency subscales was .88, .85, .90, .83, .65, and .69, respectively. The test-retest reliability over a 3-4 week period for the whole and each subscale was .90, .92, .74, .67, .81, and .75, respectively. In the current study, Cronbach's Alpha coefficient for the overall score and each subscale was .94, .89, .85, .71, .79, and .84, respectively. A high score on the Caregiver Burden Scale-Brief presents a high level of caregiver burden.

Depressive symptoms of family caregivers. The degree of depressive symptoms of family caregivers was assessed using the Chinese version of Center for Epidemiological Studies-Depression Scale (CES-D Scale; Chien & Chang, 1985). The English version of CES-D was designed for preliminary screening of the frequency of depressive symptoms in the general population during the week preceding interviews. It is a self-report instrument composed of 20 items. Possible scores range from 0 to 60, with a cutoff score of 16 indicative of risk of a clinically significant level of depressive symptoms (CES-D Scale ≥ 16) (Radloff, 1977; Weissman, Sholomskas, Pottenger, Prusoff, & Locke, 1977). The scale has a four-point format ranging from 0 to 3 (0 = rarely or none of the time, 1 = some or a little of the time, 2 = occasionally or a moderate amount of time, 3 = most or all of the time). Sixteen items are negatively worded, and four items (item 4, 8, 12, and 16) are positively worded and reversed score: "I felt that I was just as good as other people" (item 4); "I felt hopeful about the future" (item 8); "I was happy" (item 12); and "I enjoyed life" (item 16). The total score is computed by adding together all responses. Possible scores range from 0 to 60. The higher scores indicate greater degrees of depressive symptoms.

Cronbach's Alpha coefficient measuring internal consistency was .85 and .90 for a community sample and sample of patients with mental illness, respectively. Test-retest correlations over 2 to 8 weeks and 3 months to 1 year ranged from 0.51 to 0.67 and 0.32 to 0.54, respectively. Sufficient evidence for convergent validity of the CES-D indicated that the CES-D had strong correlations ranging from .51 to .72 with other scales designed to measure depressive symptoms (i.e., Lubin, Bradburn Negative Affect, and Bradburn Balance) (Radloff, 1977). Evidence also supported the discriminate validity of the CES-D because the correlations of the CES-D with Bradburn Positive and Negative Affect scales was significantly higher in a group of patients with mental illness than in the sample group of the general population (Radloff, 1977). In addition, four distinct factors of the 20 items extracted through a principal components factor analysis explained 48% of variance identified as depressed affect, positive affect, somatic and retarded activity, and interpersonal (Radloff, 1977).

The CES-D has been widely applied to diverse ethnic groups such as Taiwanese (Chien & Chang, 1985), Koreans (Cho, Nam, & Suh, 1998), and Japanese (Matsuu, Washio, Arai, & Ide, 2000). The Chinese version was translated by two bilingual psychiatrists to assess the prevalence of depressive symptoms in a general population in Taiwan (Chien & Chang, 1985). The Chinese version included 20 items with a cut-off score of 15 indicative of risk for a clinically significant level of depressive symptoms (CES-D Scale ≥ 15) (Chien & Chang, 1985). In measuring depressive symptoms in Taiwanese family caregivers of elderly with dementia (Cronbach's Alpha coefficient = .89, Huang, 2002), and adults with schizophrenia (Cronbach's Alpha coefficient = .92, Song, 1998), the Chinese version has demonstrated acceptable reliability. In the current study, Cronbach's Alpha coefficient was .88. A high score on the CESD indicates a high level of depressive symptoms.

Family functioning. The level of family functioning was assessed with the Chinese version of the Family Function Scale (Shiau, 1996), a measure based on Shiau's Family Health Nursing Model (Shiau, 1996). Shiau's model is based on system theory (Fawcett & Whall, 1990; Roy, 1983), the model of family well-being (Thomas, Lavohn, & Christensen, 1983), and the Double ABC-X Model (McCubbin & Patterson, 1983). The Family Function Scale is a self-report instrument with 34 items designed to assess ten dimensions: (a) problem solving (3 items), (b) decision making (3 items), (c) communication (2 items), (d) affection (5 items), (e) role (3 items), (f) couple relationship (2 items), (g) health care (6 items), (h) rules (2 items), (i) independence (3 items), and (j) education (5 items). The subjects can skip the education dimension (items 30 to 34) when the subject has a child over 15 years. It has a four-point scale ranging from 1 to 4 (1 = seldom, 2 = sometimes, 3 = often, and 4 = always). Seven of the items (items 9, 10, 13, 25, 26, 28, and 29) is negatively formulated (e.g., "Family members blame and argue with each other") and reverse-scored (e.g., 1 = 4, 2 = 3, 3 = 2, and 4 = 1). The four-point ratings of each item are summed to form a total score. Possible scores range from 29 to 116. Higher scores demonstrated higher degrees of family functioning (Shiau, 1996).

The psychometric properties of the Family Function Scale were evaluated in a sample of 60 people diagnosed with schizophrenia or bipolar disorders and their primary family caregivers who were living with them in the same household. The Cronbach's Alpha coefficient for the overall Family Function Scale was .91 and for each subscale was as follows: (a) problem solving, .89, (b) decision making, .86, (c) communication, .84, (d) affection, .82, (e) role, .67, (f) couple relationship, .85, (g) health care, .76, (h) rules, .75, (i) independence, .54, and (j) education, .70. Cohen's Kappa was computed as a measure of interrater reliability, which reflects a coefficient of agreement between two raters, was .89 (Shiau, 1996). McDowell and Newell (1996) suggested that Cohen's

Kappa > .08 or greater generally indicated the instrument has good interrater reliability. Hence, the interrater reliability of the Family Function Scale was sufficient.

Lee (1996) provided evidence for the reliable use of the Family Function Scale as a measure in the examination of degree of family functioning in families of individuals with major depressive disorder. The Cronbach's Alpha coefficient for the overall Family Function Scale was .95 and for each subscale was: (a) problem solving, .73, (b) decision making, .78, (c) communication, .68, (d) affection, .88, (e) role, .64, (f) couple relationship, .84, (g) health care, .64, (h) rules, .62, and (i) independence, .52 (Lee, 1996).

Because the ages of the children of subjects in Lee's study were fifteen years or older, the investigator deleted the education dimension of the scale. The intraclass correlation (ICC), a measure of a test-retest correlation, was .93 with a range of .66 to .96 for each dimension. The time lapse between the first and second administration was two weeks (Lee, 1996). Based on the criteria of Cronbach's Alpha coefficient, reliability of .70 is generally considered acceptable for a new instrument and a sufficient Cronbach's Alpha coefficient for a well-developed instrument is .80 (Nunnally, 1978). Therefore, the internal consistency reliability of the Family Function Scale has been consistently above .70 (Lee, 1996; Shiau, 1996). In the current study, the Cronbach's Alpha coefficient for the overall Family Function Scale was .93 and for each subscale was: (a) problem solving, .82, (b) decision making, .79, (c) communication, .76, (d) affection, .82, (e) role, .73, (f) couple relationship, .75, (g) health care, .78, (h) rules, .64, and (i) independence, .75. A high score on the Family Function Scale demonstrates a high level of family functioning.

Data Analysis Strategies

Preliminary Data Analysis

Coding is a crucial process of transforming data collection forms into numerical symbols in computer files and consequently creating a data set for the data analysis (Polit & Beck, 2004). To ensure the accuracy of the data set, the researcher independently entered data twice and compared the two versions for errors.

Reliability is the degree of consistency or accuracy with which an instrument measures the phenomenon of interest (DeVellis, 2003). Psychometric properties of all instruments in terms of the internal consistency reliability were obtained by calculating Cronbach's Alpha coefficients for the overall instruments and for their subscales. For missing items, the principal investigator imputed the mean of all nonmissing items as long as at least 75% were not missing (Fox-Wasylyshyn & El-Masri, 2005)

Data Analysis

SAS version 9.1 was applied to analyze data. Descriptive statistics were conducted for demographic characteristics of individual family caregivers and the family unit as well as both independent and dependent variables in this study. With respect to continuous variables, the researcher calculated the mean, the median, the standard deviation, and minimum and maximum and tabulated frequencies and percentages for the discrete variables. Statistical analyses were conducted with the level of significance, or alpha (α) as .05.

Principle component analysis (PCA) is the most widely used method for factor extraction, as it condenses variables into a small number of factors and aims to capture the underlying structure of highly interrelated variables from a correlation matrix (Polit & Beck, 2004). That is, PCA is a linear transformation of original variables and the weights (loadings) reflect the extent to which the variable is correlated to the identified factor

(Burns & Grove, 2005; DeVellis, 2003). In this study, the principal component analysis (PCA) was selected to analyze the linear combination of a set of discrete variables (family caregiver's awareness of patient suicidality) and continuous variables (family history of mental illness, chronicity of mental illness and stressful life events) that explain a maximum amount of the variance among the variables and only the first extracted components was used. The outcome of the linear combination of the original variables was defined as pile-up of demands.

The Hierarchical linear modeling (HLM; Raudenbush & Bryk, 2002), also called mixed linear modeling, was undertaken to examine the relationships of variables (i.e., pile-up of demands, social support, meaning of family caregiving, family caregiver burden, depressive symptoms of family caregivers, and family functioning) in model of Taiwanese family caregivers of individuals with mental illness. The mixed model has been widely applied in educational (Singer, 1998) and family research (Maguire, 1999) to provide a key feature that is essential for assessing nested data within a naturally hierarchical structure (e.g., students within schools or individuals within families). The mixed model involves regression models to formulate variations at two levels. The Level 1 model (within-family variation) estimates the variation of the dependent variables (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning) among individuals within each cluster (e.g., a family). The regression coefficient of each cluster's equation varies randomly over clusters, and the Level 2 model (between-family variation) accounts for the variation in these regression coefficients as a function of family characteristics. The Level 1 and Level 2 models analyze data simultaneously to explain both effects of individual and family characteristics on family adaptation (i.e., family caregiver burden, depressive symptoms of family caregiver, and family functioning).

The application of a mixed model in family research addresses important questions about within- and between-family variations. A promising strength of a mixed model is that it allows the researcher to simultaneously incorporate predictors with distinct values for each member of the family as well as for members who share values (Maguire, 1999). Therefore, it increases the statistical power and precision of the study (Barnett, Marshall, Raudenbush, & Brennan, 1993). Mixed models have the following attractive features over traditional analytic approaches such as repeated measures analysis of variance (RMANOVA). First, the approach assumes the incomplete data are missing at random (MAR) and includes all data available to increase the statistical precision of the estimation (Schafer, 1997). Second, it incorporates the nesting of participants within a higher-order level setting. Third, it permits the explanation of variation by predictors measured at the appropriate unit of analysis: (a) within-family predictors indicate separate scores of family caregiver burden, depressive symptoms of family caregiver, and family functioning for multiple family caregivers and (b) between-family predictors present the discrepancy scores of family caregiver burden, depressive symptoms of family caregiver, and family functioning for one family that are different from scores for another family. Fourth, it is flexible to accommodate any combination of predictors measured on a binary, ordinal, multinomial, or continuous scale. Finally, it can be applied not only to cross-sectional studies but also to longitudinal research (Krueger & Tian, 2004; Maguire, 1999)

The two-level hierarchical linear model was used to test hypothesis 1 in this study.

The Level 1 model (within-family variation) postulates that each outcome score (Y_{ij} ; i.e., family caregiver burden, depressive symptoms of family caregiver, and family functioning, respectively) is measured for the j^{th} individual family caregiver in the i^{th} family. The intercept (β_{i0}) represents the mean value of each outcome score (Y_i) for

family i when the predictors equal to zero. The regression coefficients are β_{iq} ($q = 1, 2, 3$) that captured the relationship between Y_{ij} (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning, respectively) and pile-up of demands, social support, meaning of family caregiving, respectively. The random error (e_{ij}) is assumed independently, normally distributed with mean 0 and variances σ^2 . The following formula describes the model.

$$Y_{ij} = \beta_{i0} + \beta_{i1} (\text{pile-up of demands})_{ij} + \beta_{i2} (\text{social support})_{ij} + \beta_{i3} (\text{meaning of family caregiving})_{ij} + e_{ij} \quad \text{where } e_{ij} \sim N(0, \sigma^2) \quad (1)$$

The Level 2 model (between-family variation) describes the relationships of family level intercepts (β_{i0}) as the sum of an overall mean (r_{00}) and a random deviation from that mean (u_{i0}), the slope of pile-up of demands (β_{i1}) as the sum of an overall mean for the slope of pile-up of demands (r_{01}) and a random deviation from that mean (u_{i1}), the slope of social support (β_{i2}) as the sum of an overall mean for the slope of social support (r_{02}) and a random deviation from that mean (u_{i2}), the slope of meaning of family caregiving (β_{i3}) as the sum of an overall mean for the slope of meaning of family caregiving (r_{03}) and a random deviation from that mean (u_{i3}), respectively. The random effects (i.e., u_{i0} , u_{i1} , u_{i2} , u_{i3}) are normally distributed with means 0 and variances τ_{00} , τ_{01} , τ_{02} , τ_{03} , respectively. The following formulas describes the model.

$$\begin{aligned} \beta_{i0} &= r_{00} + u_{i0} \\ \beta_{i1} &= r_{01} + u_{i1} \\ \beta_{i2} &= r_{02} + u_{i2} \\ \beta_{i3} &= r_{03} + u_{i3} \end{aligned} \quad (2)$$

When the Level 2 model (equation 2) is integrated into a Level 1 model (equation 1), the result is the mixed linear model (equation 3). The parameters of this model are estimated simultaneously. In this model, r_{01} , r_{02} , r_{03} are fixed constants that contribute to

the expected value (mean) model and random variables are e_{ij} and u_{i1}, u_{i2}, u_{i3} that contribute to the variance and covariance model. This model encompasses (a) fixed effects: the intercept (r_{00}) and three slopes for pile-up of demands (r_{01}), social support (r_{02}), and meaning of family caregiving (r_{03}), respectively; and (b) random effects: for the intercepts (u_{i0}), for the slope of pile-up of demands (u_{i1}), social support (u_{i2}), and meaning of family caregiving (u_{i3}), and for the individual family members within families (e_{ij}).

The following formula describes the model.

$$Y_{ij} = r_{00} + u_{i0} + r_{01} (\text{pile-up of demands})_{ij} + r_{02} (\text{social support})_{ij} + r_{03} (\text{meaning of family caregiving})_{ij} + u_{i1}(\text{pile-up of demands})_{ij} + u_{i2}(\text{social support})_{ij} + u_{i3}(\text{meaning of family caregiving})_{ij} + e_{ij} \quad (3)$$

For hypothesis 1 of this study, the mixed model was applied to test how pile-up of demands, social support, and meaning of family caregiving are significantly related to family caregiver burden, depressive symptoms of family caregivers, and family functioning, separately. The null hypotheses are separately for each outcome variable as follows:

$$H_0: r_{01} = 0 \text{ and } r_{02} = 0 \text{ and } r_{03} = 0 \quad (4)$$

To test hypotheses 2 and 3 in this study, the mediating effects of social support and meaning of family caregiving were hypothesized in the relationship between pile-up of demands and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning). A mediator variable at least potentially accounts for the relationship between the predictor and the criterion (i.e., *how* or *why* the relationship occurs) (Baron & Kenny, 1986). In general, researchers typically are interested in mediators when previous studies and theories have indicated a strong relationship between a predictor and a criterion and when they attempt to explore the mechanisms behind that relationship (Frazier, Tix, & Barron, 2004).

A series of four statistical analyses, as specified by Baron and Kenny (1986), were performed as well. The first step examined whether pile-up of demands was significantly associated with family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning). The second step examined whether pile-up of demands was significantly associated with mediator variables (i.e., social support and meaning of family caregiving). The third step examined whether mediator variables (i.e., social support and meaning of family caregiving) were significantly related to family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning), and the relationship was estimated when controlling for the effects of the pile-up of demands on the outcome of family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning). The final step examined whether the strength of the relationship between pile-up of demands and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning) is significantly reduced when mediator variables (i.e., social support and meaning of family caregiving) are added to the model. If mediator variables (i.e., social support and meaning of family caregiving) are complete mediators, the relationship between the pile-up of demands and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning) will not differ from zero after mediator variables (i.e., social support and meaning of family caregiving) are included in the model. If social support and meaning of family caregiving are partial mediators, which is likely, the relationship between pile-up of demands and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning) will be significantly smaller when mediator variables (i.e., social support and meaning of family caregiving) are included but will still be different from zero.

Summary of Methodology

The purpose of this study was to examine individual and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning), with potential predictors being pile-up of demands (i.e., family caregiver's awareness of patient suicidality, family history of mental illness, chronicity of mental illness, and stressful life events), social support, and meaning of family caregiving, in Taiwanese families of persons with severe and persistent mental illness (SPMI). This was a cross-sectional study with a descriptive correlational design. A convenience sample of 84 families of individuals with SPMI was recruited to participate from two psychiatric outpatient clinics in Taiwan. This study used eight Chinese versions of measurements: (a) demographic information sheet, (b) Perceived Stress Scale (PSS), (c) Perceived Social Support Scale (PSSS), (d) Meaning in Caregiving Scale, (e) Caregiver Burden Scale-Brief 18 items, (f) Center for Epidemiological Studies-Depression Scale (CES-D), and (g) Family Function Scale. Data was collected using mailed questionnaires. The internal consistency was tested for the reliability of the instruments used. Descriptive statistics, principal component analysis, and mixed linear modeling were applied to the statistical analysis.

CHAPTER IV

RESULTS

This chapter is organized into three sections. In the first section, descriptive statistics pertaining to characteristics of 157 individual family members from 84 Taiwanese families of individuals with SPMI are presented. In the second section, results of psychometric properties of six measures are presented first, followed by the description of study variables for individual family members and families. The final section includes the results of each hypothesis for this study.

Sample Characteristics

There were 147 eligible families who met inclusion criteria for this study and 129 families expressed interest in participating in this study (87.76 % participation rate). Of these 129 families, 84 families returned completed questionnaires, for the response rate of 65.1 %. In the majority of the families (78 %) more than one family member participated in the study; in 59 (70 %) of the families two family members participated and in 7 (8 %) three family members participated. Table 4-1 provides the descriptive and analytic data pertaining to the demographics of characteristics of individual family caregivers and the family.

Of the 157 family caregivers who participated in the study, 88 (56.1 %) were female and 69 (43.9 %) were male. The age of the family caregivers ranged from 22 to 87 years ($M = 48.62$, $SD = 14.66$). Role relationships for family caregivers were as follows: 47 (29.9 %) were caring for their child, 38 (24.2 %) caring for their parent, 32 (20.4 %) caring for their sibling, 21 (13.4 %) were caring for their spouse, 11 (7 %) were caring for a significant others, 5 (3.2 %) were caring for a friend, 2 (1.3 %) were caring for someone

they cohabitated with and 1 (0.6 %) was caring for their parent-in-law.

The sample of family caregivers was predominantly of Taiwanese descent (N = 133, 84.7 %) and other ethnicities were Provincial (N = 15, 9.6 %), Haka (N = 5, 3.2 %), and Aborigines (N = 4, 2.5 %). Two-thirds of the family caregivers (N = 105, 66.9 %) had at least a high school degree, and 79 % (N = 124) were currently employed. More than two-thirds (N = 108, 68.8 %) of the family caregivers lived with the individual with SPMI that they were caring for and the majority of family caregivers (N = 132, 84.1 %) were married. Regarding family income, nearly two-thirds (N = 102, 65 %) of the family caregivers reported a household income of more than 25,000 TD per month (which is equivalent to \$714.28 per month). In most of the families, the primary breadwinner was either the child of the individual with SPMI (N = 61, 38.9 %), the parent of the individual with SPMI (N = 56, 35.7 %), the spouse of the individual with SPMI (N = 36, 22.9 %), the sibling of the individual with SPMI (N = 2, 1.3%), the cohabitant of the individual with SPMI (N = 1, 0.6%), or the significant others of the individual with SPMI (N = 1, 0.6%). The number of children in a family ranged from 0 to 5 (M = 2.16, SD = 1.17).

Almost half of the family caregivers (N = 72, 45.9 %) indicated that there were multiple individuals with mental illness in their family. The total number of family members with mental illness in each family was 1 (N = 85, 54.1 %), 2 (N = 51, 32.5 %), 3 (N = 19, 12.1 %), and 4 (N = 2, 1.3 %). The duration of family caregiving ranged from 0.5 to 36 years (M = 10.69, SD = 7.28). Hours of caring for the individual with SPMI ranged from 2 to 144 hours weekly (M = 38.47, SD = 28.86) and about one half (N = 77, 49 %) of family caregivers reported that they spent more than 40 hours weekly taking care of the mentally ill. Most of the family caregivers (N = 146, 93 %) reported that they had a co-family caregiver who was also involved in taking care of the family member with SPMI. However, over 45 % (N = 72) reported that in addition to caring for the

family member with SPMI, they were also caring for additional family members with other chronic health conditions.

Table 4-1

Demographic characteristics of Individual Family Caregivers (N = 157)

| Characteristics | N | % |
|---|-----|------|
| Gender | | |
| Male | 69 | 43.9 |
| Female | 88 | 56.1 |
| Relationship with the individual with SPMI | | |
| Parent-in-law | 1 | 0.6 |
| Parents | 47 | 29.9 |
| Spouse | 21 | 13.4 |
| Cohabitant | 2 | 1.3 |
| Sibling | 32 | 20.4 |
| Child | 38 | 24.2 |
| Friend | 5 | 3.2 |
| Significant others | 11 | 7 |
| Co-residence | | |
| Yes | 108 | 68.8 |
| No | 49 | 31.2 |

Table 4-1 (Continued)

Demographic characteristics of Individual Family Caregivers (N = 157)

| Characteristics | N | % |
|--|-----|------|
| Marital Status | | |
| Single, not married | 23 | 14.6 |
| Married | 132 | 84.1 |
| Partnered | 1 | 0.6 |
| Widowed | 1 | 0.6 |
| Education Level | | |
| Elementary school | 23 | 14.6 |
| Junior high school | 29 | 18.5 |
| High school | 54 | 34.4 |
| University junior college | 49 | 31.2 |
| Graduate school or above | 2 | 1.3 |
| Monthly household income (TD) | | |
| < 25,000 | 55 | 35 |
| 25,000-35,000 | 41 | 26.1 |
| 35,001-45,000 | 40 | 25.5 |
| 45,001-55,000 | 17 | 10.9 |
| 55,001-65,000 | 4 | 2.5 |
| Family caregiver's awareness of patient suicidality | | |
| Yes | 87 | 45.9 |
| No | 70 | 54.1 |

Table 4-1 (Continued)

Demographic characteristics of Individual Family Caregivers (N = 157)

| Characteristics | N | % |
|--|---------------------------|------|
| Total number of family members with mental illness | | |
| 1 | 85 | 54.1 |
| 2 | 51 | 32.5 |
| 3 | 19 | 12.1 |
| 4 | 2 | 1.3 |
| Age (mean \pm SD; range) years | 48.62 \pm 14.66 (22-87) | |
| Duration of family caregiving (mean \pm SD; range) years | 10.69 \pm 7.28 (0.5-36) | |
| Hours of family caregiving weekly (mean \pm SD; range) | 38.47 \pm 28.86 (2-144) | |
| TD/US= 33.5 | | |

Description of Characteristics of Measures and Study Variables

Psychometric Properties of Measures

Table 4-2 reports the characteristics of each measurement including mean, standard deviation, score range, and Cronbach's alpha coefficient for the total scales and subscales of each measure. The results of psychometric properties of the measures were conducted from the data of individual family caregivers. Cronbach's alpha for the overall scale and subscale of each measure ranged from 0.64 to 0.96 which indicated an acceptable value of the internal consistency.

Table 4-2

Psychometric Properties of Measures (N = 157)

| Measures | Mean | SD | Min-Max | α |
|---|-------|-------|---------|----------|
| Perceived Stress Scale (PSS) | 24.04 | 10.21 | 4.3-52 | 0.96 |
| Perceived Social Support Scale (PSSS) | 37.28 | 6.56 | 21-52 | 0.94 |
| Family | 14.48 | 2.25 | 9-20 | 0.89 |
| Friends | 10.33 | 2.88 | 4-18 | 0.93 |
| Significant others | 12.46 | 2.29 | 5-18 | 0.88 |
| Meaning in Caregiving Scale | 40.98 | 5.94 | 26-55 | 0.82 |
| Caregiver Burden Scale-Brief 18 Items | 19.59 | 8.51 | 4-46 | 0.94 |
| Family disruption | 6.71 | 4.23 | 0-19 | 0.89 |
| Stigma | 1.77 | 1.40 | 0-8 | 0.85 |
| Guilt | 2.85 | 1.18 | 0-6 | 0.71 |
| Caregiver strain | 5.68 | 1.77 | 1-11 | 0.79 |
| Client dependency | 2.55 | 1.37 | 0-6 | 0.84 |
| Center for Epidemiological Studies-Depression Scale (CES-D) | 16.30 | 8.48 | 3-48 | 0.88 |
| Family Function Scale | 80.85 | 10.31 | 59-114 | 0.93 |
| Problem solving | 7.90 | 1.56 | 3-12 | 0.82 |
| Decision making | 8.21 | 1.64 | 3-12 | 0.79 |
| Communication | 4.61 | 1.03 | 2-8 | 0.76 |
| Affection | 14.76 | 2.38 | 10-20 | 0.82 |
| Role | 8.56 | 1.38 | 3-12 | 0.73 |
| Couple relationship | 4.3 | 1.18 | 2-8 | 0.75 |
| Health care | 14.46 | 2.17 | 7-20 | 0.78 |
| Rules | 9.37 | 1.11 | 7-12 | 0.64 |
| Independence | 8.48 | 1.36 | 5-12 | 0.75 |

Description of Study Variables

The strategy of the statistical data analysis for the present study was carried out in two steps. The principal component analysis was conducted first, followed by the descriptive statistics of major variables including mean, standard deviation, and score range for individual family caregivers and families, respectively.

Results of Principal Component Analysis

Principal component analysis was applied to detect a given component (i.e., pile-up of demands) that accounts for maximum amount of variance in a linear combination of a set of original variables (i.e., family caregiver's awareness of patient suicidality, family history of mental illness, number of patients' hospitalizations, duration of patients' mental illness, and stressful life events). All original variables were standardized to a mean of 0 and standard deviation of 1 first, followed by the principal component analysis performed. The component (i.e., pile-up of demands) was selected with an eigenvalue of 1.82 explaining variance of 36%. The formula of the principal component analysis for an identified variable (i.e., pile-up of demands) is given as follows:

$$Y = 0.507107 X_1 + 0.275061 X_2 + 0.356337 X_3 + 0.498130 X_4 + 0.540439 X_5$$

where

Y = pile-up of demands

X₁ = family caregiver's awareness of patient suicidality

X₂ = number of patients' hospitalizations

X₃ = duration of patients' mental illness

X₄ = family history of mental illness

X₅ = stressful life events

Descriptive Analysis of Study Variables

Table 4-3 describes the results of descriptive statistics including mean, standard deviation, and range for all study variables (i.e., pile-up of demands, social support, meaning of family caregiving, family caregiver burden, depressive symptoms of family caregivers, and family functioning) for individual family members and families, respectively.

Table 4-3

Descriptive Statistics of Study Variables for Individual Family Caregivers (N=157) and Families (N=84)

| Variables | Individual Family Caregivers (N=157) | | | Families (N=84) | | |
|--|---|-------|-----------|-----------------|------|--------------|
| | Mean | SD | Range | Mean | SD | Range |
| Pile-up of Demands | 0.81 | 0.41 | 0.03-1.59 | 0.82 | 0.40 | 0.09-1.54 |
| Social Support | 37.28 | 6.56 | 21-52 | 37.23 | 5.16 | 25.5-49.67 |
| Meaning of Family Caregiving | 40.98 | 5.94 | 26-55 | 40.86 | 4.52 | 30.5-51.33 |
| Family Caregiver Burden | 19.59 | 8.51 | 4-46 | 19.86 | 6.61 | 9-35 |
| Depressive Symptoms of Family Caregivers | 16.30 | 8.48 | 3-48 | 16.62 | 6.84 | 6-34 |
| Family Functioning | 80.85 | 10.31 | 59-114 | 80.40 | 8.12 | 67.32-109.33 |

Pile-up of demands.

Table 4-4 presents the descriptive statistics of pile-up of demands at different level of the component variables (i.e., family caregivers' awareness of patient suicidality, family history of mental illness, chronicity of mental illness including duration of patients' mental illness, number of patients' hospitalizations, and stressful life events).

For analytic purposes, component variables were dichotomized as follows: (a) the family caregivers' awareness of patient suicidality was dichotomized into yes (with a mean of pile-up of demands 1.12 and standard deviation 0.24) and no (with a mean of pile-up of demand 0.42 and standard deviation 0.2), (b) family history of mental illness was dichotomized into one individual with mental illness (with a mean of pile-up of demands 0.59 and standard deviation 0.32) and above two individuals with mental illness (with a mean of pile-up of demands 1.06 and standard deviation 0.36), (c) duration of patients' mental illness was characterized into 1-9 years (with a mean of pile-up of demands 0.63 and standard deviation 0.41), 10-19 years (with a mean of pile-up of demands 0.78 and standard deviation 0.36), and at least 20 years (with a mean of pile-up of demands 1.12 and standard deviation 0.32), (d) number of patients' hospitalizations was dichotomized into 1-3 years (with a mean of pile-up of demands 0.66 and standard deviation 0.38) and at least 3 years (with a mean of pile-up of demands 0.87 and standard deviation 0.41), and (e) the total score of stressful life events was dichotomized into less than 23 (with a mean of pile-up of demands 0.58 and standard deviation 0.33) and at least 23 (with a mean of pile-up of demands 1.03 and standard deviation 0.37), respectively.

Table 4-4

Descriptive Statistics of Pile- Up of Demands for Individual Family Caregivers (N=157)

| Components | N | Mean | SD | Range |
|--|-----|------|------|-----------|
| Family caregivers' awareness of patient suicidality | | | | |
| Yes | 87 | 1.12 | 0.24 | 0.62-1.59 |
| No | 70 | 0.42 | 0.2 | 0.03-0.98 |
| Family History of Mental Illness | | | | |
| ≤ 1 | 85 | 0.59 | 0.32 | 0.03-1.24 |
| > 1 | 72 | 1.06 | 0.36 | 0.28-1.59 |
| Chronicity of Mental Illness | | | | |
| Duration of Patients' Mental Illness (years) | | | | |
| 1- 9 | 54 | 0.63 | 0.41 | 0.03-1.43 |
| 10-19 | 64 | 0.78 | 0.36 | 0.21-1.59 |
| ≥ 20 | 39 | 1.12 | 0.32 | 0.42-1.57 |
| Number of Patients' Hospitalizations | | | | |
| 1-3 | 45 | 0.66 | 0.38 | 0.03-1.59 |
| ≥ 3 | 112 | 0.87 | 0.41 | 0.11-1.57 |
| Stressful Life Events | | | | |
| < 23 | 77 | 0.58 | 0.33 | 0.03-1.21 |
| ≥ 23 | 80 | 1.03 | 0.37 | 0.25-1.59 |

Social support.

Social support was measured by the Chinese version of the Perceived Social Support Scale (PSSS) (Yen, 2003). The range for the score from the individual family members was 21 to 52 with a mean of 37.28 (SD = 6.56). The range for the score from the family unit was 25.5 to 49.67 with a mean of 37.23 (SD = 5.16).

Meaning of family caregiving.

Meaning of family caregiving was measured by the Chinese version of the Meaning in Caregiving Scale translated by Yen (2003). The range for the score from the individual family members was 26 to 55 with a mean of 40.98 (SD = 5.94). The range for the score from the family unit was 30.5 to 51.33 with a mean of 40.86 (SD = 4.52).

Family caregiver burden.

Family caregiver burden was measured by the Chinese version of Caregiver Burden Scale-Brief (Song, 2002). The range for the score from the individual family members was 4 to 46 with a mean of 19.59 (SD = 8.51). The range for the score from the family unit was 9 to 35 with a mean of 19.86 (SD = 6.61).

Depressive symptoms of family caregivers.

Depressive symptoms of family caregivers was measured by the Center for Epidemiological Studies-Depression Scale (CES-D Scale; Radloff, 1977). The range for the score from the individual family members was 3 to 48 with a mean of 16.30 (SD = 8.48). The range for the score from the family unit was 6 to 34 with a mean of 16.62 (SD = 6.84).

Family functioning.

The range for the score from the individual family members was 59 to 114 with a mean of 80.85 (SD = 10.31). The range for the score from the family unit was 67.32 to 109.33 with a mean of 80.40 (SD = 8.12).

Hypothesis Testing

Hypothesis 1: Pile-up of demands, social support, and meaning of family caregiving will significantly be associated with family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning) in families of individuals with SPMI.

Mixed linear models were conducted to test this hypothesis. Results of statistical analysis are shown in Table 4-5 through Table 4-7. Greater pile-up of demands ($\beta = 4.2$, $p < .01$), lower social support ($\beta = -0.73$, $p < .001$), and less positive interpretation of family caregiving ($\beta = -0.37$, $p < .001$) significantly increased the degree of family caregiver burden (Table 4-5). Greater pile-up of demands ($\beta = 5$, $p < .001$), lower social support ($\beta = -0.9$, $p < .001$) significantly increased the level of depressive symptoms of family caregivers while meaning of family caregiving did not have a significant effect on the level of depressive symptoms of family caregivers (Table 4-6). Lower pile-up of demands ($\beta = -3.62$, $p < .01$), greater social support ($\beta = 0.99$, $p < .001$), and more positive interpretation of family caregiving ($\beta = 0.34$, $p < .001$) significantly increased the degree of family functioning (Table 4-7).

Table 4-5

Mixed Model for Family Caregiver Burden

| Effect | Estimate | SE | t |
|------------------------------|----------|------|----------|
| Pile-up of demands | 4.20 | 1.24 | 3.4** |
| Social support | -0.73 | 0.12 | -6.24*** |
| Meaning of family caregiving | -0.37 | 0.13 | -2.97*** |

* $p < .05$; ** $p < .01$; *** $p < .001$

Table 4-6

Mixed Model for Depressive Symptoms of Family Caregivers

| Effect | Estimate | SE | t |
|------------------------------|----------|------|----------|
| Pile-up of demands | 5.00 | 1.06 | 4.71*** |
| Social support | -0.90 | 0.09 | -9.93*** |
| Meaning of family caregiving | -0.07 | 0.10 | -0.70 |

* $p < .05$; ** $p < .01$; *** $p < .001$

Table 4-7

Mixed Model for Family Functioning

| Effect | Estimate | SE | t |
|------------------------------|----------|------|----------|
| Pile-up of demands | -3.62 | 1.18 | -3.08** |
| Social support | 0.99 | 0.10 | 10.38*** |
| Meaning of family caregiving | 0.34 | 0.10 | 3.38*** |

* $p < .05$; ** $p < .01$; *** $p < .001$

Hypothesis 2: Meaning of family caregiving will partially mediate the relationship between pile-up of demands and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregiver, and family functioning) in families of individuals with SPMI.

Results of a set of regression analysis conducted for a mediating effect of meaning of family caregiving between pile-up of demands and family caregiver burden (Table 4-8), depressive symptoms of family caregiver (Table 4-9), and family functioning (Table 4-10) were reported respectively.

Four conditions for a mediating effect of meaning of family caregiving between pile-up of demands and family caregiver burden were as follows (Table 4-8): (a) pile-up of demands had a significant positive relationship with family caregiver burden ($\beta = 13.62, p < .001$), (b) pile-up of demands had a significant negative relationship with meaning of family caregiving ($\beta = -8.00, p < .001$), (c) meaning of family caregiving had a significant negative relationship with family caregiver burden ($\beta = -1.05, p < .001$), and (d) when both pile-up of demands and meaning of family caregiving entered together, the strength of the relationship between pile-up of demands and family caregiver burden decreased from 13.62 to 7.41, and the latter result was still significant ($p < .001$). Hence, the results indicated that meaning of family caregiving partially mediated the relationship between pile-up of demands and family caregiver burden. That is, family caregivers who encountered more pile-up of demands interpreted the family caregiving experience more negatively, which would, in turn, be associated with greater family caregiver burden.

Table 4-8

Testing the Mediating Effects of Meaning of Family Caregiving on Family Caregiver Burden

| Step and Variable | Estimate | SE | t |
|---------------------------------|----------|------|-----------|
| Step 1 | | | |
| Y: Family Caregiver Burden | | | |
| X: Pile-Up of Demands | 13.62 | 1.28 | 10.64*** |
| Step 2 | | | |
| Y: Meaning of Family Caregiving | | | |
| X: Pile-Up of Demands | -8.00 | 0.98 | -8.12*** |
| Step 3 | | | |
| Y: Family Caregiver Burden | | | |
| X: Meaning of Family Caregiving | -1.05 | 0.08 | -13.42*** |
| Step 4 | | | |
| Y: Family Caregiver Burden | | | |
| X: Pile-Up of Demands | 7.41 | 1.26 | 5.87*** |
| Meaning of Family Caregiving | -0.79 | 0.08 | -9.46*** |

* $p < .05$; ** $p < .01$; *** $p < .001$

Four conditions for a mediating effect of meaning of family caregiving between pile-up of demands and depressive symptoms of family caregivers were shown as follows (Table 4-9): (a) pile-up of demands had a significant positive relationship with depressive symptoms of family caregiver ($\beta = 13.70$, $p < .001$), (b) pile-up of demands had a significant negative relationship with meaning of family caregiving ($\beta = -8.00$, $p < .001$), (c) meaning of family caregiving had a significant negative relationship with depressive symptoms of family caregiver ($\beta = -1.01$, $p < .001$), and (d) when both pile-up of demands and meaning of family caregiving entered together, the strength of the relationship between pile-up of demands and depressive symptoms of family caregivers decreased from 13.70 to 7.86 and the latter result was still significant ($p < .001$). Hence, the results indicated that meaning of family caregiving partially mediated the relationship between pile-up of demands and depressive symptoms of family caregivers. That is, family caregivers who encountered more pile-up of demands interpreted the family caregiving experience more negatively, which would, in turn, be associated with higher depressive symptoms.

Table 4-9

Testing the Mediating Effects of Meaning of Family Caregiving on Depressive Symptoms of Family Caregivers

| Step and Variable | Estimate | SE | t |
|---|----------|------|-----------|
| Step 1 | | | |
| Y: Depressive Symptoms of Family Caregivers | | | |
| X: Pile-Up of Demands | 13.70 | 1.33 | 10.31*** |
| Step 2 | | | |
| Y: Meaning of Family Caregiving | | | |
| X: Pile-Up of Demands | -8.00 | 0.98 | -8.12*** |
| Step 3 | | | |
| Y: Depressive Symptoms of Family Caregivers | | | |
| X: Meaning of Family Caregiving | -1.01 | 0.08 | -12.47*** |
| Step 4 | | | |
| Y: Depressive Symptoms of Family Caregivers | | | |
| X: Pile-Up of Demands | 7.86 | 1.34 | 5.87*** |
| Meaning of Family Caregiving | -0.74 | 0.08 | -8.80*** |

* $p < .05$; ** $p < .01$; *** $p < .001$

Four conditions for a mediating effect of meaning of family caregiving between pile-up of demands and family functioning were shown as follows (Table 4-10): (a) pile-up of demands had a significant negative relationship with family functioning ($\beta = -16.49, p < .001$), (b) pile-up of demands had a significant negative relationship with meaning of family caregiving ($\beta = -8.00, p < .001$), (c) meaning of family caregiving had a significant positive relationship with family functioning ($\beta = 1.34, p < .001$), and (d) when both pile-up of demands and meaning of family caregiving entered together, the strength of the relationship between pile-up of demands and family functioning decreased from 16.49 to 7.32 and the latter result was still significant ($p < .001$). Hence, the results indicated that meaning of family caregiving partially mediated the relationship between pile-up of demands and family functioning. That is, family caregivers who encountered more pile-up of demands interpreted the family caregiving experience more negatively, which would, in turn, be associated with lower family functioning.

Table 4-10

Testing the Mediating Effects of Meaning of Family Caregiving on Family Functioning

| Step and Variable | Estimate | SE | t |
|---------------------------------|----------|------|-----------|
| Step 1 | | | |
| Y: Family Functioning | | | |
| X: Pile-Up of Demands | -16.49 | 1.64 | -10.05*** |
| Step 2 | | | |
| Y: Meaning of Family Caregiving | | | |
| X: Pile-Up of Demands | -8.00 | 0.98 | -8.12*** |
| Step 3 | | | |
| Y: Family Functioning | | | |
| X: Meaning of Family Caregiving | 1.34 | 0.08 | 16.03*** |
| Step 4 | | | |
| Y: Family Functioning | | | |
| X: Pile-Up of Demands | -7.32 | 1.46 | -5.00*** |
| Meaning of Family Caregiving | 1.11 | 0.09 | 11.89*** |

* $p < .05$; ** $p < .01$; *** $p < .001$

Hypothesis 3: Social support will partially mediate the relationship between pile-up of demands and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregiver, and family functioning) in families of individuals with SPMI.

Results of a sets of regression analysis conducted for a mediating effect of social support between pile-up of demands and family caregiver burden (Table 4-11), depressive symptoms of family caregiver (Table 4-12), and family functioning (Table 4-13) were reported respectively.

Four conditions for a mediating effect of social support between pile-up of demands and family caregiver burden were as follows (Table 4-11): (a) pile-up of demands had a significant positive relationship with family caregiver burden ($\beta = 13.62, p < .001$), (b) pile-up of demands had a significant negative relationship with social support ($\beta = -9.63, p < .001$), (c) social support had a significant negative relationship with family caregiver burden ($\beta = -1.08, p < .001$), and (d) when both pile-up of demands and social support entered together, the strength of the relationship between pile-up of demands and family caregiver burden decreased from 13.62 to 5.83 and the latter result was still significant ($p < .001$). Hence, the results indicated that social support partially mediated the relationship between pile-up of demands and family caregiver burden. That is, family caregivers who encountered more pile-up of demands perceived less social support, which would, in turn, be associated with greater family caregiver burden.

Table 4-11

Testing the Mediating Effects of Social Support on Family Caregiver Burden

| Step and Variable | Estimate | SE | t |
|----------------------------|----------|------|-----------|
| Step 1 | | | |
| Y: Family Caregiver Burden | | | |
| X: Pile-Up of Demands | 13.62 | 1.28 | 10.64*** |
| Step 2 | | | |
| Y: Social Support | | | |
| X: Pile-Up of Demands | -9.63 | 1.12 | -8.57*** |
| Step 3 | | | |
| Y: Family Caregiver Burden | | | |
| X: Social Support | -1.08 | 0.06 | -18.27*** |
| Step 4 | | | |
| Y: Family Caregiver Burden | | | |
| X: Pile-Up of Demands | 5.83 | 1.10 | 5.29*** |
| Social Support | -0.87 | 0.07 | -13.11*** |

* $p < .05$; ** $p < .01$; *** $p < .001$

Four conditions for a mediating effect of social support between pile-up of demands and depressive symptoms of family caregivers were shown as follows (Table 4-12): (a) pile-up of demands had a significant positive relationship with depressive symptoms of family caregiver ($\beta = 13.70$, $p < .001$), (b) pile-up of demands had a significant negative relationship with social support ($\beta = -9.63$, $p < .001$), (c) social support had a significant negative relationship with depressive symptoms of family caregiver ($\beta = -1.09$, $p < .001$), and (d) when both pile-up of demands and social support entered together, the strength of the relationship between pile-up of demands and depressive symptoms of family caregivers decreased from 13.70 to 5.68 and the latter result was still significant ($p < .001$). Hence, the results indicated that social support partially mediated the relationship between pile-up of demands and depressive symptoms of family caregivers. That is, family caregivers who encountered more pile-up of demands perceived less social support, which would, in turn, be associated with higher depressive symptoms.

Table 4-12

Testing the Mediating Effects of Social Support on Depressive Symptoms of Family

Caregivers

| Step and Variable | Estimate | SE | t |
|---|----------|------|-----------|
| Step 1 | | | |
| Y: Depressive Symptoms of Family Caregivers | | | |
| X: Pile-Up of Demands | 13.70 | 1.33 | 10.31*** |
| Step 2 | | | |
| Y: Social Support | | | |
| X: Pile-Up of Demands | -9.63 | 1.12 | -8.57*** |
| Step 3 | | | |
| Y: Depressive Symptoms of Family Caregivers | | | |
| X: Social Support | -1.09 | 0.06 | -19.06*** |
| Step 4 | | | |
| Y: Depressive Symptoms of Family Caregivers | | | |
| X: Pile-Up of Demands | 5.68 | 1.07 | 5.31*** |
| Social Support | -0.91 | 0.06 | -13.99*** |

* $p < .05$; ** $p < .01$; *** $p < .001$

Four conditions for a mediating effect of social support between pile-up of demands and family functioning were shown as follows (Table 4-13): (a) pile-up of demands had a significant negative relationship with family functioning ($\beta = -16.49$, $p < .001$), (b) pile-up of demands had a significant negative relationship with social support ($\beta = -9.63$, $p < .001$), (c) social support had a significant positive relationship with family functioning ($\beta = 1.37$, $p < .001$), and (d) when both pile-up of demands and social support entered together, the strength of the relationship between pile-up of demands and family functioning decreased from 16.49 to 4.88 and the latter result was still significant ($p < .001$). Hence, the results indicated that social support partially mediated the relationship between pile-up of demands and family functioning. That is, family caregivers who encountered more pile-up of demands perceived less social support, which would, in turn, be associated with lower family functioning.

Table 4-13

Testing the Mediating Effects of Social Support on Family Functioning

| Step and Variable | Estimate | SE | t |
|-----------------------|----------|------|-----------|
| Step 1 | | | |
| Y: Family Functioning | | | |
| X: Pile-Up of Demands | -16.49 | 1.64 | -10.05*** |
| Step 2 | | | |
| Y: Social Support | | | |
| X: Pile-Up of Demands | -9.63 | 1.12 | -8.57*** |
| Step 3 | | | |
| Y: Family Functioning | | | |
| X: Social Support | 1.37 | 0.06 | -23.79*** |
| Step 4 | | | |
| Y: Family Functioning | | | |
| X: Pile-Up of Demands | -4.88 | 1.20 | -4.06*** |
| Social Support | 1.21 | 0.07 | 17.91*** |

* $p < .05$; ** $p < .01$; *** $p < .001$

CHAPTER V

DISCUSSION AND CONCLUSION

This study makes a significant contribution to existing knowledge about how Taiwanese individuals and families adapt to the ongoing challenges associated with caring for a family member with SPMI. It is one of the first Taiwanese studies of family caregiving to be guided by a family framework. Findings from this study suggest that family variables, such as those described in the Resiliency Model of Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993), play a critical role in determining family adaptation to caregiving experiences. In addition, findings from this study provide useful insights into how cultural beliefs, values, and norms influence family adaptation to caring for a family member with SPMI. Moreover, findings from this study will facilitate the development and testing of tailored, culturally sensitive interventions for Taiwanese families living with SPMI.

Another promising strength of this study is that unlike many of the existing studies about family caregiving, this study considered not only the impact of the caregiving experience on the primary caregiver, but the impact of this experience on other family members who provided care. Considerable effort was made to obtain data from multiple family members from each of the 84 families. In addition, the statistical approach that was used (i.e., mixed model) made it possible to present the results at both the individual and family level. Also, by examining the mediating mechanism of social support and meaning of family caregiving, findings from this study help to explain the interrelationships and mediating patterns among pile-up of demands, social support, meaning of family caregiving, and family adaptation.

This chapter includes a brief synopsis of major findings followed by further discussion of the findings and a comparison of these findings with related findings in the literature. It also includes a discussion of the strengths and limitations of this study, implications for nursing and future research, and conclusions.

Synopsis of Major Findings

Overall, the findings of this study suggest critical variables that need to be assessed when examining family adaptation in families living with SPMI. In this study, pile-up of demands, social support, and meaning of family caregiving were significantly associated with family adaptation. Meaning of family caregiving and social support partially mediated the relationship between pile-up of demands and adaptation in families of individuals with SPMI.

Pile-Up of Demands

The pile-up of demands variable used in this study was derived by conducting a principal components analysis. This variable reflects a composite of mental illness-related stressors (i.e., family caregiver's awareness of patient suicidality, family history of mental illness, number of patients' hospitalizations, duration of patients' mental illness), and stressful life events. To date, there has been no research on family caregiving utilizing this type of approach to explore the impact of pile-up of demands on family adaptation. However, in a study about parental stress in families of children with an intellectual disability, Saloviita and colleagues (2003) used principal component analysis to decrease the number of unrelated pile-up demand variables into a solution of eight components.

For this study, the component factor with the highest factor loading was stressful life events, followed by family caregiver's awareness of patient suicidality, family history of mental illness, duration of patients' mental illness, and number of patients' hospitalizations. This finding indicates that duration of patients' mental illness and

number of patients' hospitalizations explained a relatively small amount of variance in the pile-up of demands in contrast to other original variables (i.e., family caregiver's awareness of patient suicidality, family history of mental illness, and stressful life events). *Components of Pile-up of Demands, Social Support, Meaning of Family Caregiving, and Family Adaptation*

There is no existing research in which principal component analysis was used to examine the relationships among a number of pile-up of demands variables, social support, meaning of family caregiving, and family adaptation in families of persons with mental illness. Therefore, in an effort to help make comparisons between findings from this study and findings from earlier work on family caregiving, a series of additional statistical analyses were conducted to examine the relationships among the individual components of the pile-up of demands variable, social support, meaning of family caregiving, and family adaptation. The results of these analyses offered substantial support for the proposed model.

In the current study there was a significant relationships among three of the components of the pile-up of demands variable (i.e., family caregivers' awareness of patient suicidality, family history of mental illness, and stressful life events), meaning of family caregiving, and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers , and family functioning). That is, family caregivers who reported greater awareness of patient suicidality, more family members with psychiatric genetic conditions, and perceived greater stressful life events were more likely to interpret the family caregiving experience in a negative way and family adaptation was likely to be impaired. However, no previous studies documented the relationships among three of the components of the pile-up of demands variable (i.e., family caregivers' awareness of patient suicidality, family history of mental illness, and stressful life events), meaning of

family caregiving, and family adaptation (i.e., family caregiver burden, depressive symptoms of family caregivers, and family functioning).

Family caregiver's awareness of patient suicidality had a significantly positive relationship with family caregiver burden. This finding is consistent with the finding in previous studies that patients' suicidal threats or gestures place a significant burden on family caregivers (Grad & Sainsbury, 1963; Jones et al., 1995; McDonnell et al., 2003; Östman, 2004).

Regarding the impact of family history of mental illness on the other study variables, there was a significant association between family history of mental illness and social support. That is, as the number of family members with mental illness increased, adequacy of perceived social support decreased. One explanation for this finding is that when more than one family member is affected by a mental illness, this not only decreases the number of individuals who are able to provide caregiving, it most likely decreases the amount of time family members have to provide caregiving.

In addition to the significant relationship between family history of mental illness and social support, there was also a significant relationship between family history of mental illness and depressive symptoms of family caregivers. Family caregivers who had a greater number of family members with SPMI were more likely to have more depressive symptoms. While this may be due to the fact that they were caring for multiple family members with SPMI, it could also be due to the fact that they themselves had inherited genetic mutations associated mental illness (Wong, 2000).

The finding that duration of the patient's mental illness was not significantly related to any of the measures of family adaptation was not consistent with findings from a number of studies that reported a significant relationship between duration of the patient's mental illness and adaptation in families living with mental illness (Biegel et al., 1991;

Chakrabati et al., 1992 Hwu et al., 2000; Miller et al., 2000; Rose, 1996; Walton-Moss et al., 2005). However, findings from this study are consistent with the findings by Gallagher and Mechanic (1996) that duration of mental illness and severity of mental illness were not significantly associated with the health and functioning of non-mentally ill household members.

Failure to find a significant relationship between duration of the family member's mental illness, number of hospitalizations, and adaptation in families affected by SPMI may reflect differences in sample characteristics and/or measurement, rather than an actual lack of association. In the current study, the individuals with mental illness had severe and persistent mental illness; they had either been diagnosed with schizophrenia, bipolar disorder, or major depressive symptoms. The mean duration of the family member's mental illness was over 13 years and the mean number of hospitalizations was 3.35 times. In contrast to the sample for the current study, samples for the earlier caregiving studies were more homogenous in terms of the affected family member's conditions. For example, researchers focused on caregivers of individuals with Alzheimer's disease (Biegel et al., 1991), schizophrenia (Hwu et al., 2000), affective disorders (Chakrabati et al., 1992), and depression (Miller et al., 2000).

Regarding possible differences due to measurement issues, it appears that a wide variety of measures were used to assess indicators of family adaptation (i.e., family caregiver burden and family functioning). For instance, measures used to assess family caregiver burden, included the following: Family Burden Interviews Schedule (Pai & Kapur, 1981), the Family Caregiver Burden and Need Schedule (Hwu, Chen, Lin, & Wu, 1993), and Caregiver Burden Scale- Brief (Song, 2002).

The finding that there was a significant relationship between stressful life events and family caregiver burden was consistent with findings from a study by Noh & Avison

(1988). According to Noh and Avison, spouses of individuals with mental illness who experienced additional stressors in the form of stressful life events reported higher levels of family caregiver burden.

The relationship found between stressful life events and symptoms of depression in family caregivers in the current study is similar to findings from other studies of family caregiving. Greenberg, Greenley et al. (1997) reported that mental –illness related stressors and a substantial array of other life events had a significant impact on depressive symptoms in family caregivers of individuals with mental illness: the caregivers who experienced a greater number of stressors and stressful life events reported more depressive symptoms. In the study by Song and Singer (2006), there was a significant association between stressful life events and depression. Again, the caregivers who experienced a greater number of stressors and stressful life events reported more depressive symptoms.

Overall, these findings regarding relationships among components of pile-up of demands, social support, meaning of family caregiving and family adaptation provide empirical support for the argument by McCubbin and colleagues (1996) that families living with a chronic condition, such as SPMI, seldom deal with only illness related stressors. Most families of individuals with SPMI are also dealing with other stressful life events which may actually have a greater impact on family adaptation than stressors associated with the SPMI (Doornbos, 2002a; Greenberg, Greenley et al., 1997; Noh & Avison, 1988). Both nonnormative stressors associated with SPMI and co-occurring stressors related to normative aspects of the family life contribute to a “pile-up” of demands on these families.

Family Caregiver Burden

As discussed in Chapter II, research on the consequences of mental illness have suggested that the existence of mental illness is a source of stresses or strains in the family and family members tend to “pay a price” with respect to the burden of caring for the mentally ill on an ongoing basis. In the current study, family caregiver burden is a complex and multidimensional concept including family disruptions, stigma, guilt, caregiver strain, and client dependency. The mean family caregiver burden score for caregivers in the present study was 19.59 (SD = 8.51). This finding indicates that family caregivers experienced a mild to moderate degree of burden in providing care for the individuals with SPMI.

The degree of burden experienced by family caregivers in this study was slightly lower than what was reported by Song (2002), the researcher who developed the instrument used to assess family caregiver burden in this study. In Song’s study (2002), the mean family caregiver burden score was 20.21 (SD = 12.28) for 301 primary Taiwanese family caregivers of individuals with severe and persistent mental illness. Other researchers who have used the measure developed by Song, also reported higher caregiver burden scores. Chang (2004) compared the difference between family caregiver burden in 36 primary family caregivers of rehabilitation group and 45 primary family caregivers of outpatient service in Taiwan. The mean score for the rehabilitation group was 22.1 (SD = 9.5) and for the outpatient service was 26.9 (SD = 10.7). Hou (2004) examined contributing factors of the quality of life and family caregiver burden in 126 primary family caregivers in Taiwan and the mean score of the family caregiver burden was 25.9 (SD = 10.7).

Possible reasons why the mean family caregiver burden score was lower for caregivers in this study than caregivers in the studies by Chang and Hou may be due to

differences in sample characteristics. The sample for this study and the study by Song included families affected by three different types of mental illness; schizophrenia, bipolar disorders, and major depressive disorders. In contrast, the studies by Chang and Hou only included family caregivers of individuals with schizophrenia. Given the fact there is a relatively high rate of co-morbidity and relapse with schizophrenia, individuals with schizophrenia are likely to require intensive, long-term care from their family members. According to findings reported by Song (1999), the degree of family caregiver burden is higher for primary caregivers of individuals with schizophrenia than it is for primary caregivers of individuals with other types of mental illness.

Pile-Up of Demands, Social Support, and Meaning of Family Caregiving

The finding that pile-up of demands, social support, and meaning of family caregiving were significantly associated with family caregiver burden in families of individuals with SPMI provided support for Hypothesis 1. Family caregivers dealing with a greater pile-up of demands experienced a higher degree of family caregiver burden. This is consistent with the Resiliency Model of Family Stress, Adjustment, and Adaptation, the guiding framework for the study. It is also consistent with findings from other studies examining the relationships between stressors (mental-illness related and co-occurring stressors related to normative aspects of the family life) and family caregiver burden (Baronet, 1999; Laidlaw et al., 2002; Noh & Avison, 1988; Pickett et al., 1997).

In terms of the adequacy of perceived social support, family caregivers with higher perceived social support reported lower levels of family caregiver burden. This finding is consistent with findings from previous studies (Baronet, 1999; Magliano et al., 1995; Magliano et al., 1998; Maurin & Boyd, 1990; Potasznik & Nelson, 1984; Pinguart, & Sörensen, 2005; Rose, 1996; Sauder, 2003; Schulze & Rössler, 2005; Song, 1999).

Family caregivers with a more positive interpretation of family caregiving reported lower levels of family caregiver burden. Cohen, Colantonio, and Vernich (2002) reported similar findings in their study examining the relationship between positive aspects of caregiving and caregiving consequences in 289 primary family caregivers of seniors living in the community. Cohen and colleagues found that family caregivers with more positive feelings about caregiving were less likely to experience burden. Pickett and colleagues (1997) revealed that parents' positive appraisals of their relationship with their mentally ill adult child were significantly related to decreased levels of caregiver burden.

Depressive Symptoms of Family Caregivers

Research on family caregivers of individuals with mental illness has provided evidence that family caregivers frequently experience psychological distress (i.e., depressive symptoms). The mean CES-D score for family caregivers in the present study was 16.30 (SD = 8.48). Applying the suggested cutoff score of 15 or above for the Chinese version of the CES-D, which is indicative of an increased risk of clinical depression (Chien & Chang, 1985), 45.9% (n = 85) of family caregivers in the present study were at risk for clinical depression. The mean CES-D score for family caregivers in the current study was lower than the mean CES-D score for family caregivers in other Taiwanese studies. In the 1998 study by Song, the result indicated that the mean CES-D score for the primary family caregiver of individuals with mental illness was 17.1 (SD = 12.2). In a study about the primary family caregivers of elderly with dementia, the mean on the Chinese version of the CES-D score was 26.98 (SD = 10.14) (Huang, 2004).

However, the mean CES-D scores for family caregivers in the current study is actually similar to or higher than the mean CES-D score for family caregivers in most of the studies about family caregivers of individuals with mental illness done in United States (US) (Chen 2003; Haley et al., 1996; Hobbs, 1997; Song et al., 1997). Using the

English version of the CES-D, Haley et al. (1995) reported a mean score of 16.44 (SD = 8.19) for White family caregivers of individuals with dementia. Hobbs (1997) studied 100 Black family caregivers of individuals with schizophrenia and found the mean score on the CES-D to be 8.36 (SD = 9.15). Song et al. (1997) studied 103 family caregivers of individuals with chronic mental illness in the US. The mean CES-D score for family caregivers in Song's study was 12.71 (SD = 10.57). For White family caregivers in Song's study, the mean score on the CES-D was 14.58 (SD = 11.64). In contrast, the mean CES-D score for Black family caregivers was 10.51 (SD = 8.79).

The differences between the mean CES-D scores for Taiwanese families and those living in the US may be due to cultural differences. In a study by Chen (2003) which explored factors associated with caregiving outcomes in 78 Chinese-American primary family caregivers of individuals with mental illness, the mean score on the Chinese version of the CES-D was 23.82 (SD = 14.02). This would suggest the stigma and negative consequences associated with belonging to a family affected by mental illness may be greater for Asian and Asian-American families than it is for White and Black families living in the US. However, there is clearly a need for more research on this topic.

Pile-Up of Demands, Social Support, and Meaning of Family Caregiving

The finding that pile-up of demands, social support, and meaning of family caregiving were significantly associated with depressive symptoms of family caregivers in families of individuals with SPMI provided support for Hypothesis 1. Family caregivers with a greater pile-up of demands experienced higher levels of depressive symptoms, which was consistent with the findings of previous studies (Greenberg, Greenley, et al., 1997; Kramer, 1993). A study by Greenberg, Greenley et al. (1997) investigated the level of psychological distress among 778 family caregivers whose individuals with serious mental illness received mental health services. The results of this

study indicated that illness-related stressors and other life stressors unrelated to mental illness were significantly associated with higher levels of depressive symptoms. Kramer (1993) applied the Resiliency Model to examine factors contributing to caregiving consequences among wife caregivers of individuals with Alzheimer's' disease (AD). Findings from this study indicated that wife caregivers with increased personal and family stressors (i.e., duration of illness, duration of caregiving, the degree of level of impairment and disruptive behaviors, and caregiver age) and vulnerability (i.e., quality of prior relationship and marital history) reported the greater degrees of depression.

Family caregivers who perceived greater adequacy of social support reported lower CES-D scores, indicating decreased risk of clinical depression. This finding was consistent with the previous family caregiving studies in both Taiwan (Huang, 2004; Song, 1998; Yen, 2003) and the US (Greenberg, Greenley et al., 1997; Haley et al., 1996; Kramer, 1993; Pickett et al., 1993; Song et al., 1997).

The relationship between meaning of family caregiving and depressive symptoms of family caregivers was not significant when controlling for social support and pile-up of demands. This finding was contrary to the previous caregiving studies conducted in Taiwan (Yen, 2003) and the US (Cohen et al., 2002; Noon & Tennstedt, 1997). In the previous studies, meaning of family caregiving was significantly associated with depressive symptoms in family caregivers.

One explanation for the failure to find a significant relationship between meaning of family caregiving and depressive symptoms in family caregivers in the current study is that social support may have mediated the effect of meaning of family caregiving on the degree of depressive symptoms of family caregivers. In other words, at least some of the effect of meaning of family caregiving on depressive symptoms of family caregivers might be channeled through social support. This finding is consistent with earlier research

in Taiwan concerning primary Taiwanese caregivers of individuals with schizophrenia (Yen, 2003). Yen (2003) applied the Lazarus and Folkman's Transactional theory to examine relationships among meaning of caregiving, social support, and the level of depressive symptoms in caregivers of individuals with schizophrenia. According to Yen, social support was a mediator between the meaning of family caregiving and the level of depressive symptoms in Taiwanese family caregivers. This finding is consistent with arguments by McCubbin, Thompson, Thompson, Elver, and McCubbin (1994). According to McCubbin and colleagues, family appraisal contributes to individual and family adaptation (e.g., an increase in depressive symptoms), through fostering family resources.

Family Functioning

The mean family functioning score for family caregivers in this current study was 80.85 (SD = 10.31). This mean score is similar to the mean score for family caregivers (78.09) reported in a correlational study examining the relationship between family functioning and caregiving demands in Taiwanese families of individuals with major depressive disorder (K. T. Lee , 1996).

Pile-Up of Demands, Social Support, and Meaning of Family Caregiving

The finding that pile-up of demands, social support, and meaning of family caregiving were significantly associated with family functioning in families of individuals with SPMI provided support for Hypothesis 1. Family caregivers who encountered a lower pile-up of demands had a higher degree of family functioning. This finding was consistent with findings from previous studies of family caregiving (Clark, 1999; Musil et al., 2006; Saunders, 1999). Clark (1999) reported that family stresses and demands were significantly associated with the level of family functioning in families of individuals who had experienced a stroke. In a grandmother caregiver study by Musil et al. (2006), greater

pile-up of family stresses and strains was significantly correlated with the lower degree of family functioning. Furthermore, Saunders (1999) found that family functioning in families of individuals with schizophrenia was significantly affected by the amount of strain and stress (i.e., client behavior problems and family psychological stress).

In the current study, family caregivers who perceived a greater adequacy of social support reported higher levels of family functioning, which is consistent with findings from previous caregiving studies (Saunders, 1999; Sun & Cheng, 1997). There was a significant association between meaning of family caregiving and level of family functioning. Caregivers who interpreted family caregiving more negatively reported lower levels of family functioning. This finding is consistent with the finding reported by Barrowclough and Parle (1997). In their study of caregivers of individuals with schizophrenia maladaptive cognitive appraisal was significantly associated with high expressed emotion (EE).

*Mediating Effects of Social Support and Meaning of Family Caregiving on Family
Adaptation*

The finding that meaning of family caregiving partially mediated the relationship between pile-up of demands and family adaptation provided support for Hypothesis 2. This finding is similar to findings from a systematic review of families having a member with an ongoing health condition by Cohen (1999) and other studies about family caregiving (Noon & Tennstedt, 1997; Patterson & Garwick, 1994; Seller, 2000). Findings from Cohen's literature review provided empirical evidence that meanings regarding illness drawn from personal life experience as well as informed by culture mediate the demands of chronic illness upon family adaptation. Further, Patterson and Garwick (1994) proposed that families, as a whole, construct or share meaning at three levels mediating family responses to chronic illness: (a) situational meanings: the family

constructs and share meaning of situational stressors; (b) family identity: it reflects family structure and functioning; and (c) family world view: it reflects cultural worldviews, core assumptions, and existential beliefs.

The finding that social support partially mediated the relationship between pile-up of demands and family adaptation provided support for Hypothesis 3. This finding was consistent both theoretically and empirically. That is, it was consistent with theoretical models of stress and coping. In addition, it was consistent with findings from existing studies examining the interrelationships among variables related to stress and factors (e.g., social support) that mediate the relationship between the sources of stress (e.g., illness-related stressors, and co-occurring stressors related to family life) and caregiving outcomes (e.g., depressive symptoms of family caregivers and family caregiver burden) (Haley et al., 1996; Hobb, 1997; Pearlin et al., 1990). Farhood (1999) used the Double ABC-X Model (McCubbin & Patterson, 1983) to examine the relationship between objective stressors, perceived stress, coping, and resources among Lebanese families. According to their results, family resources, particularly social support, significantly mediated the effect of negative consequences of stress on family adaptation (i.e., physical and psychological health, depression, and marital and interpersonal relationships).

Limitations of the Study

Several limitations of this study should be borne in mind. First, the cross-sectional design of this study prevents an exploration of the assumed causal relationships implied when investigating mediating effects. Second, the sample for this study was a convenience sample recruited from two psychiatric hospitals in the south of Taiwan. Lack of random selection limits the ability to generalize the findings to the population of family caregivers of individuals with SPMI from other mental health services or those with individuals who have acute mental illness in Taiwan. Individuals who participated in this

study represent a voluntary sample. Voluntary samples of family caregivers who feel strongly about the issue being studied may anticipate certain outcomes (i.e., social welfare) or inflate view of their caregiving difficulties. On the other hand, individuals who have strong perception of social stigma toward mental illness or experience extremely distressed caregiving process may decline to participate in this study. Selection bias may be relevant threat of internal and external validity in this study. In addition, all of instruments were self-report instrument. There were no objective measures of study variables.

Due to the stigma attached to mental illness, participants may underreport the incidence or prevalence of mental-ill related stressors (i.e., family caregivers' awareness of patient suicidality, number of patients' hospitalizations, duration of patient's mental illness, family history of mental illness) and stressful life events, which in turn, will influence the significance of the relationship between the pile-up of demands and adaptation in families of individuals with SPMI.

Because the participants of this study did not speak English, it was not possible to use the instruments that McCubbin and colleagues developed and tested to assess the variables in the Resiliency Model. However, every attempt was made to find Chinese versions of these measures or Chinese versions of valid and reliable measures designed to assess concepts in the Resiliency model.

Implications for Nursing

The results of this study provide tenable explanations for why some family caregivers of individuals with SPMI experience negative consequences, while others families are resilient and thrive. In addition, the significant findings of this study have implications for nursing education, practice, health policy, and research.

Nursing Education

Contemporary nursing education in psychiatric and mental health nursing in Taiwan is primarily driven by the traditional medical model that targets illness-oriented and patient-centered medical care (Yen, 2003). However, the family plays a critical role in mediating the relationship between societal expectations and the interests of individual family members. The traditional medical model fails to recognize that not only can the individual with mental illness affect other family members and the family as a unit, the family can have a therapeutic effect on the individual with mental illness. Brody, Hoffman, Kleban, and Schoonove (1989) stated that “the homeostasis of the family as a whole is affected by a disturbance in any of its parts” (p.529).

The influence of a mental illness on the patient with SPMI may be as severe and persistent as its influence on their families. When the primary caregiver becomes overburdened with the demands associated with caring for the family member with SPMI, they may alter how they interact with other family members. For example, they may project their anger and frustration on other family members. Or, they may refuse to interact with other family members because they feel the other family members are not willing to help with the care of the family member with SPMI; the other family members think they are too busy to help. Findings from this study can serve as a reference for mental health professionals to incorporate caregiving issues within the context of family-centered health care into the content and curriculum of psychiatric and mental health nursing education in Taiwan.

Due in large part to advances made possible through the Human Genome Project (HGP), genomics has become the central science of medicine and health care (Feetham et al., 2005). As a result, all health care professionals need to acquire a basic understanding of genetics and genomics. This will play an important role in their ability to identify, refer,

support, and care for individuals and families living with genetic conditions (Van Riper, 2006).

There is growing recognition that most psychiatric disorders have a significant genetic component. Unlike many single-gene disorders such as sickle cell disease and cystic fibrosis, most prevalent psychiatric disorders are likely to be considered as complex genomic illnesses involving interactions between a number of genes and environmental factors across the life span.

As knowledge of the genomic nature of psychiatric disorders continuously develops, there is an increased expectation for health care professionals, especially nurses in psychiatric and mental health nursing, to keep pace with the rapid exploration of genomics knowledge and provide general information about genomics of mental illness to clients receiving mental health care and their families.

Kirk, McDonald, Anstey, and Longley (2003) proposed a competence-based education framework, *Fit for Practice in the Genetic Era*, indicating that all nursing professionals should be able to:

1. Identify clients who might benefit from genetic services and information.
2. Appreciate the importance of sensitivity in tailoring genetics information and services to clients' culture, knowledge and language level.
3. Uphold the rights of all clients to informed decision making and voluntary action.
4. Demonstrate a knowledge and understanding of the role of genetics and other factors in maintaining health and in the manifestation, modification and prevention of disease expression, to underpin effective practice.
5. Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information.

6. Recognize the limitations of one's own genetics expertise.
7. Obtain and communicate credible, current information about genetics, for self, clients and colleagues.

At present, psychiatric and mental health nursing programs that include education about genetics and genomics are scarce in Taiwan. Therefore, there is a crucial need for all health care educators to increase their awareness of the ongoing role of genetics and genomics in the health care and make efforts to incorporate genomic information involving genome-based knowledge (e.g., biological inheritance patterns, behavioral and environmental factors related to genomics), skill competencies (e.g., family genetic history assessment), and attitudes (e.g., ethical, legal, and social implications associated with genomics) into the nursing curriculum.

Nursing Practice

The results of this study suggest that social support and meaning of family caregiving act as intervening variables having a partially indirect effect on the relationship between the effects of pile-up of demands and family adaptation. From the theoretical perspective, the Resiliency Model primarily addresses family strengths and capabilities which may protect the family from the disruptions related to normative transition and non-normative stressors. Given the nature and extent of the demands of family caregiving, supportive interventions need to include interventions designed to help mediate the effect of demands of family caregiving on adaptation in families of individuals with mental illness. These interventions need to help enhance the family's ability to provide ongoing care to the family member with SPMI.

Findings from this study also indicate that the relationship between pile-up of demands and family adaptation was partially mediated by family resources and family appraisal. Therefore, other potential contributors may need to be considered. To help

families adapt to a family member's mental illness, nurses need to consistently collaborate with the family caregiver to assess for potential sources of demands related to caring for their mentally ill family member. In addition, nurses need to help family caregivers to feel empowered by helping them to identify their unique needs, as well as helping them to acknowledge and amplify individual, family, and community resources.

The efficacy of family interventions as evidence-based practice that improves physical and mental health of family caregivers has been established. Several effective family interventions include family support and advocacy groups, family consultation, family education, family psychoeducation, and psychotherapy (Marsh & Johnson, 1997). Among the families of individuals with mental illness, the preliminary study of evidence-based practice has indicated that family psychoeducation is an efficacious family intervention because patients and family members are included and the entire family is provided with coping skills and stress management skills training over a longer period of time (Dixon, McFarlane, Lefley, Lucksted, Cohen, Falloon, Mueser, Miklowitz, Solomon, & Sondheimer, 2001). Based on the identified needs of families and those of the individual with mental illness, the essential components of the underlying theoretically-based family intervention programs are as follows: (a) knowledge and treatment of mental illness; (b) management of symptoms, disruptive behaviors, and medication; (c) dealing with crisis; (d) information about complex mental health network; and (e) communication, interpersonal relationships, problem-solving skills, and stress-coping skills (Gasque-Carter & Curlee, 1999; Huang et al., 2003; McFarlane, Lukens, Link, Dushay, Deakins, Newmark, Dunne, Horen, & Toran, 1995; Solomon, 1996; Yang et al., 1999).

In addition to the psychoeducational programs for family caregivers, a few family interventions (e.g., psychiatric home care services) have targeted the family caregiver's

home environment that affects both the mentally ill and their family caregivers. Morris (1996) asserted that psychiatric home care services were designed to deliver the optimal health care to fit the unique needs of each individual with chronic mental illness and help them and their families create supportive home environments. Psychiatric home care services for mental illness provides services which are adjunctive to outpatient treatments or serves as alternatives to institutional care significantly promote the well-being of the individuals with mental illness and their family caregivers (Morris, 1996; Shu et al., 2001; Tung & Beck, 2007).

Shu and her colleagues (2001) conducted a longitudinal study to assess the effect of psychiatric home care and half-way house care in sixty individuals with chronic mental illness in Taiwan. The results indicated that families of mental illness receiving psychiatric home care service had significantly higher improvements in the quality of life and family caregiver burden than those receiving half-way house service. Similarly, Tung and Beck (2007) examined family caregivers' satisfaction and specific needs in relation to home care services for mental illness after the implementation of the NHI in Taiwan. The findings revealed that the majority of family caregivers expressed a high degree of general satisfaction and the prevalent unmet needs included timeliness of home care services provided in an emergency and the convenience of help received from home care providers over the phone.

According to McCubbin and colleagues (1996), social support regarded as one of valuable resources for families includes two types of support systems: (a) a formal resources (e.g., professionals and medical services) and (b) informal resources (e.g., neighbors, friends, and the extended family and its members). Because family resources may not be always available for the affected family, the interpretation of meaning attached to family caregiving experiences in mental illness is relatively crucial for family

caregivers who may appraise caregiving experience as a challenge or an overwhelming event. The findings from this study indicated that the cognitive appraisal in relation to meaning of family caregiving (i.e., improving a sense of self-growth, feeling pride in the ability to care for the care recipient, and experiencing pleasure or reward in caregiving) the family makes was significantly related to positive caregiving outcomes. The more positive values and beliefs of meaning in family caregiving the family caregiver has the more adaptive consequences the family caregiver develops. Individual and family counseling approaches may directly facilitate the likelihood that family caregivers reinterpret caregiving responsibilities for individuals with SPMI as meaningful, comprehensible, and manageable rather than burdensome. Therefore, it is crucial for family health care providers to address positive aspects of caregiving experiences as well as to target and develop strategies for assisting family caregivers.

Cultural values, norms, traditions, and practices significantly influence the culturally specific forms of intervention and treatment response. The effects of Taiwanese cultural beliefs on a sense of family ethics and values usually act as catalysts to motivate family members to accept being a caregiver role, which in turn delegating the caring responsibilities and even being reluctant to complain. However, a rapid transition to a nuclear family along with the high competition of achievement resulted in inherent caring dilemma and competing demands in the individuals and families in contemporary Taiwanese society.

In contrast to Western cultures, Asian culture—Taiwanese in this specific case—traditionally regards the family as the whole or emotional unit, and families tend to take the primary responsibility for caring for their dependent relatives during a long period of caregiving involvement, even at the expense of their own well-being. As a result, it is critical for nurses and other health care providers to appreciate and praise the efforts

family caregivers make in taking care of their family member with mental illness. Further, health care providers need to be aware of their own attitudes towards family caregivers and they need to avoid labeling family caregivers as origins of mental illness. To ease the plight of family caregivers in taking care of members with the mentally ill, health care providers should learn how to recognize the boundary ambiguity placed on family caregivers and help them express their concerns in family adaptation to mental illness.

Stigma of mental illness negatively influences not only the individual with mental illness but also the family unit as well (Sommer, 1990). The stigma attached to being part of a family that includes mentally ill individuals may result in family members questioning their own worth as an individual because of their genetic makeup. They may start to worry that they have “bad genes,” ones that will make them develop a mental illness. Or, they may start to worry about passing the “bad gene” to their children. They may also feel guilty that they were not the family member to get the “bad gene.” Additionally, feelings of stigmatization may result in family members viewing the experience of caring for a mentally ill family member as a negative experience filled with shame, embarrassment, and humiliation.

Up-to-date genomics information is a unique area of knowledge and its clinical application regarding the identification of a specific genetic trait or inheritable condition contributing to the individual and family’s health is important. It has been widely acknowledged that heritability for mental illness is substantially higher than other medical illness such as breast cancer (Plomin, Owen, & McGuffin, 1994). Feetham and colleagues (2005) noted that family history is a critical tool that provides genetic information within the context of the family about health and illness among family members as well as validates the interplay of multiple genes and environmental factors, which affects health and illness.

Although there has been an increase in the public's awareness of importance of a family history in terms of the provision a source of genetic information, health care professionals still underestimate the utility of family history (Van Riper, 2006). Family history assessment is now more critical than ever as it enables the health care professionals to understand genetic and genomic information in a family context and guide individuals and families to anticipate potential responses to genetic information. Nurses and other health care providers working with families of individuals with mental illness are expected to acquire a basic genomics knowledge and skill competencies for the clinical practice and provide the individuals and families with an understanding of the genomics of mental illness. In doing so, a potential impact of education regarding increased awareness of the role of genomics issues and concerns in mental illness may help family caregivers alleviate the guilt, shame, and stigma, in turn, improved family adaptation to living with the heredity nature of mental illness

The issues of ethical, legal, and social implications (ELSI) result from the HGP are immense. It is critical for health care professionals to recognize some key ELSI in the clinical practices and in turn, to help individuals and families maximize the potential benefits and minimize the potential risks of genomic discoveries. These key issues include: (a) privacy and confidentiality issues; (b) psychological impact and stigmatization; (c) genetic testing availability and interpretation of results; (d) reproductive issues; (e) quality control; and (f) commercialization efforts in relation to genetic information (Pestka, 2003).

Health Policy

Due to the rapid growth of the nuclear family, the process of providing care to a family member with SPMI generates tremendous demands on other family members. To alleviate the imbalance between the family demands and family resources, the Taiwanese

government has implemented National Health Insurance (NHI) as a predominant health policy since 1995. This program provides supportive services and programs to assist family members with their responsibility for a member with mental illness. However, there is evidence indicating that Taiwanese families which include individuals with mental illness are still being constrained by limited resources. There is still a need to improve the allocation of support and services for affected families in Taiwan through the NHI.

With a family lens, it is widely acknowledged that the collection and dissemination of genomic information and technology will affect not only the individuals with mental illness but also their families (Feetham, 1999). Generally, in Taiwan, there is poor acceptance of individuals with mental illness by the affected families and the whole society as well. Because of this, it may account for the incredible amount of stigma attached to mental illness contributing to the maladaptation experienced by individuals with mental illness and their families. To reduce the public stigmatization and labeling toward mental illness, policy makers need to develop a national genomics education campaign and research institutes designed to explore the ethical, legal, and social implications of advances in the detection and treatment of psychiatric disorders.

Implications for Future Research

Directions that require further attention from researchers include the use of family variables in the Resiliency Model, cross-cultural research, the development of culturally valid instruments, the use of longitudinal research designs, the heterogeneity of both individuals with mental illness and their family caregivers, the replication of the study findings, the use of mixed research methods, and family-centered mental health care in the genomic era.

With an emphasis upon the role of culture and ethnicity in the family caregiver literature, this study, based on the Resiliency Model, contributed a unique understanding of the plight of individuals caring for family members with SPMI in Taiwan. Clearly, findings from this study support the validity of the Resiliency Model. It is apparent that family adaptation following the presence of a family member with mental illness is a product of multiple factors interacting with each other simultaneously. There is a need of an exploration of a full Resiliency model in the future research to capture how other critical family variables such as family problem solving and coping (PSC) and family resources explain the variability in family adaptation. As what has been shown, the nature of family caregiving experience in SPMI may be at variance in different populations. Similarly, instruments designed and measured within diverse culture may vary. Future family researchers are required to develop more culturally valid instruments that match the conceptualization of their studies. In addition, the cross-culture family caregiving research (i.e., a comparative study between Taiwan and U.S.) may provide an understanding of how ethnic difference shapes the outcome of the family's process in response to pile-up of demands. It would be beneficial to explore the similarities and unique features of family caregiving experiences in mental illness across the spectrum of circumstance.

The family caregiving experience in relation to family adaptation is not static; rather, there are dynamic interactions and transitions over time as family caregivers are affected by individuals with a progression of SPMI. In addition, the relationship between pile-up of demands, social support, meaning of family caregiving, and family adaptation changes over time, in which family adaptation in turn may be a source of an additional demand that affects family's capabilities and strength to adapt to SPMI. Therefore, additional longitudinal studies will help explore the interrelationship among these variable as well as

possible feedback effects of family adaptation on pile-up of demands in families of people with SPMI over time.

Studies over the past decades have addressed the impact of the long-term care of members with mental illness on primary family caregivers, however, these primary family caregivers may not be representative of other family caregivers who are also involved in certain level of caring for the mentally ill. The significant differences in the degree of family adaptation among relationships to the mentally ill, especially children and adolescents, is an ongoing concern in family caregiver research. A larger sample size with different types of kin is suggested to understand the similarities and differences of the caregiving experiences among kin relationships. Consequently, it may provide a more comprehensive understanding of the nature of the caregiving experiences and its effects on the entire family unit.

Previous Taiwanese caregiver studies have focused on either the examination of families from the same diagnostic group or the exploration of families of various diagnoses as an undifferentiated group. A clear gap remains in the research on the influence of caring for individuals with different diagnoses of mental illness on family caregivers. As a result, a comprehensive profile of the similarities and differences in the perceived demands and consequences of family caregiving experiences of members with different types of mental illness is needed. Better understanding of contributors of the family caregiving consequences may have crucial clinical implications in relation to the focused development and appropriate evaluation of family interventions targeted for family caregivers of individuals with different diagnoses of mental illness. Apart from the scope of examining the process of family adaptation to caring for members with mental illness, the value of comparing families of the mentally ill and those without the mentally ill will further facilitate the efficacy and validity of the Resiliency Model. In addition, this

study primarily focuses on the impact of SPMI on the individual family members who provide certain amount of care and the family as a whole. Future research should take further steps to explore the consequence of having a family member with SPMI for the family members who are not involved in caregiving process as well as elucidate data from both the care recipient and the family caregiver.

This is one of first studies that examined individual and family adaptation to SPMI obtained data from at least one family caregiver in each family. Replication of the findings of this study in the future studies may enhance its external validity or the extent to which the study results can be generalized to other samples of families. It is evident that family caregiver research places a greater emphasis on quantitative approaches than qualitative methods. Quantitative research is deeply ingrained in traditional scientific approaches that emphasize the explanation of what may be directly or significantly observed with notions of human values, purposes, and intentions (Polit & Beck, 2004). The effect of mental illness on the family caregiving experiences is more likely a process of reciprocal exchange between the individual with mental illness and the family (Bulger et al., 1993). In recent years, though, empirical literature has shown a growing inclination toward qualitative approaches to gain further advanced understanding of the complex dynamic of family caregiving experiences involving mental illness. Lange (2002) suggested that researchers can adopt qualitative approach such as phenomenology or ethnography to gain a rich and detail data that accurately reflects the phenomenon of interest or particular values from the target culture. Moreover, the use of qualitative data will help researchers accurately assess the content validity of the instrument that reflects the desired content domain (Imle & Atwood, 1988). Therefore, future research may apply a mixed method including both quantitative and qualitative research methods to explore family adaptation to providing care for the member with SPMI.

Advances in genomic information and technologies of psychiatric genetics have implications for genomic research and clinical practice. The genomic nature of psychiatric disorders has significantly contributed to changes in genomic mental health care delivery for individuals and families living with mental illness. Three main dimensions of research in the era of genomic mental health care are clearly identified: genomics in biology, psychology, and society. These dimensions conceptualize a landscape for understanding how genomics play a critical role in the complex interactions between etiology of mental illness and other relevant importance of environmental factors across the life span. However, it is anticipated that the promise in the genomic era of mental illness has inevitably resulted in a host of ethical, social, and legal challenges for individuals and their family members. These challenges are in need for further explorations. Research and empirical evidence has indicated that few researchers on psychiatric mental health nursing conceptualized the family as a whole to integrate the core value of the family into clinical practice. The ethnic, legal, and social implications inherent in the genomic nature of psychiatric disorders for individuals and families are not clearly identified by health professionals, particularly psychiatric mental health nurses. It is imperative for future researchers to develop core competencies of basic genomics knowledge, skills-based training, and attitudes to meet the demands of nursing education, research, clinical practice, and policy-making decisions.

Conclusion

Findings from this study provide empirical evidence of the link between pile-up of demands, social support, meaning of family caregiving and family adaptation in Taiwanese families of individuals with SPMI. These findings are compelling and consistent with prior Western studies.

Despite of the predominant focus on family adaptation associated with family caregiving, this study is one of the first to incorporate the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) as a conceptual framework. The Resiliency Model, a stress and coping framework based on a family system approach, represents the caregiving experiences in terms of pile-up of demands, mediators (i.e., social support and meaning of family caregiving), and family adaptation. Use of this model helps to shed light on how individuals and families adapt successfully to and manage chronic mental illness than other families.

The findings generated from the current study provide substantial support for the Resiliency Model as well as previous research on caregiving experiences of families with mental illness. Particularly, it confirmed the noted importance of intervening factors (i.e., social support and meaning of family caregiving) in the explanation of individual and family adaptation among families of caring for a member with SPMI. Family caregivers with the higher levels of social support and a more positive interpretation of the family caregiving are able to adapt more effectively when they confronted with pile-up of demands. Caring for individuals with mental illness may result in enormous hidden costs for families over time; however, efforts to decrease or eliminate these costs may serve as a potential source of strength and gratification to the family caregivers. Findings from this study provide empirical evidence of the family resources and strengths individual family members and the family unit possess or develop when confronted with the ongoing challenges associated with caring for individuals with SPMI.

With a broader conceptualization of underlying mechanisms by which caregiving outcomes occur, health care professionals will be in a better position to develop possible avenues of intervention to enhance family strengths and resiliency. These interventions need to validate and affirm the family caregivers' efforts and encourage family caregivers

to seek support from others family members, friends, and significant others because family caregivers often neglect their own needs. In addition, it is critical for psychiatric mental health nurses and other health professionals to consider interventions that are likely to result in a “double barrel” effect. That is, the interventions will benefit both the individual with SPMI and his/her family. Interventions that improve the degree of adaptation among the family members in relation to providing more stable family environments that, in turn, may also assist the individuals with SPMI in adjusting to the community.

To conclude, this study provided support for the impact of the pile-up of demands on individual and family adaptation with the partial mediating effects of social support and meaning of family caregiving. While some of the effects were likely due to the increase in pile-up of demands, the role of contextual variables (i.e., length of time in caregiving role, diagnoses of mental illness, relationship to the individual with SPMI, and prior quality of relationship) needs further investigation to more fully understand the nature of family adaptation within the context of SPMI.

10. Marital Status:

- | | |
|--|--|
| <input type="checkbox"/> Single (never been married) | <input type="checkbox"/> Married |
| <input type="checkbox"/> Partnered (not living together) | <input type="checkbox"/> Partnered (living together) |
| <input type="checkbox"/> Divorced | <input type="checkbox"/> Separated |
| <input type="checkbox"/> Widowed | |

11. Number of children in your family:

11a. Age of your children:

12. Education: (The highest level of education you have completed)

- Elementary school
- Junior high school
- High school
- University/Junior College
- Graduate school or above

13. Your religion:

- | | |
|------------------------------------|-----------------------------------|
| <input type="checkbox"/> Buddhist | <input type="checkbox"/> Catholic |
| <input type="checkbox"/> Christian | <input type="checkbox"/> Taoist |
| <input type="checkbox"/> None | <input type="checkbox"/> Other |

14. Your racial heritage

- | | |
|---|-------------------------------------|
| <input type="checkbox"/> Taiwanese descents | <input type="checkbox"/> Hakka |
| <input type="checkbox"/> Provincial | <input type="checkbox"/> Aborigines |
| <input type="checkbox"/> Other | |

15. Your occupation (past, if not currently employed):

15a. Numbers of hours per day employed: _____ hours

16. Approximate monthly household income (Taiwanese dollar; Currency exchange rate (TD/USD = 33.5))

- | | |
|---|---|
| <input type="checkbox"/> Less than 25,000 | <input type="checkbox"/> 25,000 – 35,000 |
| <input type="checkbox"/> 35,001 - 45,000 | <input type="checkbox"/> 45,001 - 55,000 |
| <input type="checkbox"/> 55,001 - 65,000 | <input type="checkbox"/> More than 65,000 |

17. The primary bread-winner in the family:

- | | |
|--|---|
| <input type="checkbox"/> Grandparents | <input type="checkbox"/> Parent-in-law |
| <input type="checkbox"/> Parents (Mother/Father) | <input type="checkbox"/> Wife/Husband |
| <input type="checkbox"/> Cohabitants (Not married) | <input type="checkbox"/> Sibling |
| <input type="checkbox"/> Child | <input type="checkbox"/> Grandchild |
| <input type="checkbox"/> Friend | <input type="checkbox"/> Significant others |

18. Does any family member other than the family member with severe and persistent mental illness require your assistance?

_____ Yes _____ No

If yes, please indicate how many for each category?

| | |
|---------------------------------|--------------------------|
| _____ Grandparents | _____ Parent-in-law |
| _____ Parents (Mother/Father) | _____ Wife/Husband |
| _____ Cohabitants (Not married) | _____ Sibling |
| _____ Child | _____ Grandchild |
| _____ Friend | _____ Significant others |

19. Do you have other family members who share the responsibilities with you in caring for the individuals with severe and persistent mental illness?

_____ Yes _____ No

If yes, please indicate how many for each category?

| | |
|---------------------------------|--------------------------|
| _____ Grandparents | _____ Parent-in-law |
| _____ Parents (Mother/Father) | _____ Wife/Husband |
| _____ Cohabitants (Not married) | _____ Sibling |
| _____ Child | _____ Grandchild |
| _____ Friend | _____ Significant others |

Appendix B: Perceived Stress Scale (PSS)

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate *how often* you felt or thought a certain way. Although some of the questionings are similar, there are differences between them and you should treat each one as a separate. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

For each question choose from the following alternatives:

- 0 = Never
- 1 = Almost never
- 2 = Sometimes
- 3 = Fairly often
- 4 = Very often

| | | 0 | 1 | 2 | 3 | 4 |
|-----|--|---|---|---|---|---|
| 1. | In the last month, how often have you been upset because of something that happened unexpectedly? | | | | | |
| 2. | In the last month, how often have you felt that you were unable to control the important things in your life? | | | | | |
| 3. | In the last month, how often have you felt nervous and "stressed"? | | | | | |
| 4. | In the last month, how often have you dealt successfully with day to day problems and annoyances? | | | | | |
| 5. | In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life? | | | | | |
| 6. | In the last month, how often have you felt confident about your ability to handle your personal problems? | | | | | |
| 7. | In the last month, how often have you felt that things were going your way? | | | | | |
| 8. | In the last month, how often have you found that you could not cope with all the things that you had to do? | | | | | |
| 9. | In the last month, how often have you been able to control irritations in your life? | | | | | |
| 10. | In the last month, how often have you felt that you were on top of things? | | | | | |
| 11. | In the last month, how often have you been angered because of things that happened that were outside of your control? | | | | | |
| 12. | In the last month, how often have you found yourself thinking about things that you have to accomplish? | | | | | |
| 13. | In the last month, how often have you been able to control the way you spend your time? | | | | | |
| 14. | In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? | | | | | |

Appendix C: Perceived Social Support Scale (PSSS)

The following is to assess your social support when you are taking care of your ill family member, please select a most close scale value in accord with what you feel represent your received social support.

Scale

- 1 = Strongly disagree
- 2 = Disagree
- 3 = Neutral
- 4 = Agree
- 5 = Strongly agree

| | | 1 | 2 | 3 | 4 | 5 |
|-----|---|---|---|---|---|---|
| 1. | There is a special person who is around when I am in need. | | | | | |
| 2. | There is a special person with whom I can share joys and sorrows. | | | | | |
| 3. | My family really tries to help me. | | | | | |
| 4. | I get the emotional help and support I need from my family. | | | | | |
| 5. | I have a special person who is real source of comfort to me. | | | | | |
| 6. | My friends really try to help me. | | | | | |
| 7. | I can count on my friends when things go wrong. | | | | | |
| 8. | I can talk about my problems with my family. | | | | | |
| 9. | I have friends with whom I can share my joys and sorrows. | | | | | |
| 10. | There is a special person in my life who cares about my feelings. | | | | | |
| 11. | My family is willing to help me make decisions. | | | | | |
| 12. | I can talk about my problems with my friends. | | | | | |

Appendix D: Meaning in Caregiving Scale

The following is to assess your meaning of being a caregiver, please select a most close value in accord with what you feel represent your meaning of caregiving.

Scale

1 = Disagree

2 = Somewhat disagree

3 = Somewhat agree

4 = Agree

| | | 1 | 2 | 3 | 4 |
|-----|--|---|---|---|---|
| 1. | I accept the role of caregiver because he/she is my family. | | | | |
| 2. | My role as caregiver has allowed me and this person to have closeness in spite of his/her illness. | | | | |
| 3. | Since becoming a caregiver, I feel differently about what things in life are worth extra effort. | | | | |
| 4. | I owed him/her in the past life so that I have to pay him/her in this life. | | | | |
| 5. | I am happy that I can do something for him/her. | | | | |
| 6. | Since becoming a caregiver, I don't worry as much about the little thing in my life. | | | | |
| 7. | I believe that everything will be better in the future. | | | | |
| 8. | The experience of caregiving has made me change what I consider to be really important in life. | | | | |
| 9. | I feel I am a capable person after the experience of caregiving. | | | | |
| 10. | I believe that taking care of one another is what life is all about. | | | | |
| 11. | I am better able to accept my role as a caregiver because I feel that this person needs me. | | | | |
| 12. | My caregiving experience has changed my idea of what is important in a relationship. | | | | |
| 13. | My caregiving experience has given me a view of the positive things that family members can offer one another. | | | | |
| 14. | I could provide care which cannot be replaced by others. | | | | |
| 15. | Since becoming a caregiver, some things that used to worry me don't seem as important. | | | | |
| 16. | I feel it has been important to this person that I have been involved in caregiving. | | | | |

Appendix E: Caregiver Burden Scale-Brief 18 Items

The following is a list of the ways you may feel about caring the person with mental illness. Please read it and select the most scale value in accord with how you feel reflect your burden.

Scale

0 = Never

1 = Seldom

2 = Sometimes

3 = Usually

4 = Almost always

| | | 0 | 1 | 2 | 3 | 4 |
|-----|---|---|---|---|---|---|
| 1. | I feel what I am doing is not enough for her. | | | | | |
| 2. | My daily routine is disrupted due to caring for him/her. | | | | | |
| 3. | I lack the needed time for both my family and work while caring for him/her. | | | | | |
| 4. | I feel I do not care for him/her well. | | | | | |
| 5. | I feel afraid of his/her behavior and illness. | | | | | |
| 6. | I lack time for leisure activities (e.g., shopping, exercise, etc.) due to caring for him/her. | | | | | |
| 7. | I am afraid that his/her illness will occur again. | | | | | |
| 8. | My income has decreased due to the care that provides for him/her. | | | | | |
| 9. | Family members argue with each other due to caring for him/her. | | | | | |
| 10. | I feel that he/ she depends on me. | | | | | |
| 11. | My time for social activities (e.g., attending the wedding etc.) are reduced due to caring for him/her. | | | | | |
| 12. | Sometimes he/she can do by himself/herself, but he/she asks me to help him/her. | | | | | |
| 13. | Caring for him/her makes me feel that I am a helpful person. | | | | | |
| 14. | Having a family member with mental illness may cause other members of the family to be ashamed. | | | | | |
| 15. | Having a family member with mental illness may cause me to feel ashamed. | | | | | |
| 16. | I feel more optimistic due to caring for him/her. | | | | | |
| 17. | My marital relations is affected by caring for him/her. | | | | | |
| 18. | I am worried about his/her safety when he/she is alone. | | | | | |

Appendix F: Center for Epidemiologic Studies Depression Scale (CES-D)

The following is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

Scale

0 = Rarely or none of the time (less than once a week)

1 = Some or a little of the time (1-2 days a week)

2 = Occasionally or a moderate amount of time (3-4 days a week)

3 = Most or all of the time (5-7days a week)

| | | 0 | 1 | 2 | 3 |
|-----|---|---|---|---|---|
| 1. | I was bothered by things that usually don't bother me. | | | | |
| 2. | I did not feel like eating; my appetite was poor. | | | | |
| 3. | I felt that I could not shake off the blues even with help from my family or friends. | | | | |
| 4. | I felt that I was just as good as other people. | | | | |
| 5. | I had trouble keeping my mind on what I was doing. | | | | |
| 6. | I felt depressed. | | | | |
| 7. | I felt that everything I did was an effort. | | | | |
| 8. | I felt hopeful about the future. | | | | |
| 9. | I thought my life had been a failure. | | | | |
| 10. | I felt fearful. | | | | |
| 11. | My sleep was restless. | | | | |
| 12. | I was happy. | | | | |
| 13. | I talked less than usual. | | | | |
| 14. | I felt lonely. | | | | |
| 15. | People were unfriendly. | | | | |
| 16. | I enjoyed life. | | | | |
| 17. | I had crying spells. | | | | |
| 18. | I felt sad. | | | | |
| 19. | I felt that people dislike me. | | | | |
| 20. | I could not get "going" | | | | |

Appendix G: Family Function Scale

The following is a list of the ways you might have felt or behaved. Please tell me which most closely applied to you during the past month.

Scale

- 1 = Seldom
- 2 = Sometimes
- 3 = Often
- 4 = Always

| | | 1 | 2 | 3 | 4 |
|-----|--|---|---|---|---|
| 1. | Family members will solve problems when there is a problem in the family. | | | | |
| 2. | Family members will discuss the solution of problems. | | | | |
| 3. | Family members will try to solve problems through different solutions | | | | |
| 4. | The final decision will be made by the opinion of majority of family members. | | | | |
| 5. | Family members are allowed to have different opinions. | | | | |
| 6. | The important issues will be decided by relatively important family members. | | | | |
| 7. | Family members can directly discuss issues with each other. | | | | |
| 8. | Family members can share their thoughts and feelings with each other. | | | | |
| 9. | Family members are not satisfied with their responsibilities. | | | | |
| 10. | Family members blame and argue with each other. | | | | |
| 11. | Family members support each other while facing problems. | | | | |
| 12. | There is good interaction among family members. | | | | |
| 13. | There are conflicts, disharmony phenomena in the family. | | | | |
| 14. | Family members take responsibilities on their own. | | | | |
| 15. | Family members help complete chores with each other. | | | | |
| 16. | Family members follow daily routine. | | | | |
| 17. | Family members support each other. | | | | |
| 18. | Family members are satisfied with their sexual activities. | | | | |
| 19. | Family members regularly eat three meals. | | | | |
| 20. | Family members behave and dress appropriately. | | | | |
| 21. | Family members watch movies, exercises, or shop together. | | | | |
| 22. | Family members care about another family member's health. | | | | |
| 23. | Family members go to the hospital to receive the treatment when they are sick. | | | | |
| 24. | Family members accept suggestions and treatment from health care providers. | | | | |
| 25. | Family members easily change the rules of family. | | | | |
| 26. | Family members argue with each other when the rules are not obeyed. | | | | |
| 27. | Family members can arrange their own activities. | | | | |
| 28. | Family members are easily affected by other family members' situations. | | | | |
| 29. | Family members depend on each other. | | | | |

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