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# THE INFLUENCE OF SUPPORT SYSTEMS AND INTERNAL SYSTEM RESOURCES ON FAMILY WELL-BEING OF CAREGIVERS OF A DEPRESSED FAMILY MEMBER

By

Diane K. Richardson

#### A THESIS

Submitted to
Grand Valley State University
in partial fulfillment of the requirements for the
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2000

Thesis Committee Members:

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#### ABSTRACT

# THE INFLUENCE OF SUPPORT SYSTEMS AND INTERNAL SYSTEM RESOURCES ON FAMILY WELL-BEING OF CAREGIVERS OF A DEPRESSED FAMILY MEMBER

By

#### Diane K.Richardson

Health professionals are interested in families who have a high level of well-being in spite of coping with the difficulties related to caring for a depressed elderly family member at home. The Resiliency Model of Family Stress, Adjustment, and Adaptation provided the conceptual framework to explore the hypothesis of a positive relationship between family social support and family well-being, and family internal system resources and family well-being. Thirty caregivers volunteered and were interviewed in their homes using the Family Crisis Oriented Personal Scale (F-COPES), the Family Hardiness Index (FHI), and the Family APGAR. Although weak, positive correlations were noted for the hypothesized relationships, these were not statistically significant and the hypothesis was not supported in this study. Significant, moderate positive relationships found among selected subscales of the FHI and F-COPES indicate that some internal family resources support coping measures of families with a depressed family member.

#### **DEDICATION**

This research is dedicated to the families who graciously allowed me into their homes and so willingly shared their caregiving experiences. The many examples of loving care and dedicated support for each other demonstrated the strength that comes from the relationships within a family. Thank you for your willingness to share this aspect of the life of your family.

#### **ACKNOWLEDGMENTS**

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In this study of families, I realize how blessed I am to have a loving family and I wish to thank them for their support. Finally, I am most grateful to my husband who has so generously provided support, computer assistance and loving encouragement through this lengthy project.

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#### CHAPTER 1

#### INTRODUCTION

Scientific and technological advances in psychiatric health care and changes in social values have resulted in deinstitutionalization and shorter hospital stays for patients with mental health disorders (McCausland, 1987). As a result, increased responsibility for providing care falls to family members. These families often feel inadequately prepared or equipped for the task.

Families of the mentally ill face numerous stressors. They are expected to deal with complex psychiatric illnesses with minimal information, skills or support (Bartol, Moon, & Linton, 1994). Symptoms can be difficult to manage because the illness frequently takes an unpredictable course of sudden exacerbations (Chafetz & Barnes, 1989). In addition, the caregiver often experiences difficulties associated with financial problems, fatigue, social isolation and the stigma connected with mental illness (Chafetz & Barnes). But families frequently identify the most stressful issue as the implication, by mental health professionals, that they are somehow responsible for causing the patient's illness. In addition, rules of confidentiality limit the family's access to information from the mental health system about the family member and this limits their ability to gain understanding and cope more effectively.

Although much research has been done regarding caregiver burden, few studies have addressed the issue of promoting family well-being. Families of mentally ill persons

possess strengths that enable them to cope with the various stressors related to caregiving (Doornbos, 1996). These strengths must be explored and family well-being promoted if home care is going to be successful (Norbeck, Chafetz, Skodol-Wilson, & Weiss, 1991). Home care nurses are in a position to promote interventions that would enhance social support and family internal system resources and promote family well-being. More research is necessary to determine which aspects of support most effectively result in increased family well-being.

The purpose of this study is to examine the relationships among family social support, family internal system resources, and family well-being when providing home care to a depressed family member. This study replicated Fink's research (1995) in which well-being was studied in 65 families who provided care to a parent over age 60 and needed assistance with at least one physical activity. However, this study addressed family well-being in families caring for a family member over the age of 65 with a diagnosis of depression.

#### **CHAPTER 2**

#### LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

#### Literature Review

Although an extensive search of nursing and social work literature was done, no studies were found related to the promotion of family well-being in caregivers of depressed family members. However, numerous studies described caregiver burden, social support, hardiness, and caregiver well-being. The literature review will be organized under the following subheadings: (a) Caregiver burden related to a chronic and/or medical illness, (b) Caregiver burden related to mental illness, (c) Social support related to mental illness caregiving, (d) Hardiness related to medical and mental illness caregiving, (e) Well-being related to medical and mental illness caregiving. A summary of these studies follows each topic.

Caregiver burden related to a chronic and/or medical illness. Clipp and George (1993) examined issues of caregiver burden related to dementia and cancer patients. The study compared 272 spouse caregivers of dementia patients with 30 spouse caregivers of cancer patients on variables related to well-being when caring for a loved one with a chronic illness. There was no overlap between the two groups in terms of diagnosis. The majority of the caregivers were Caucasian and over the age of 60, with 59% percent female and 41% male. Instruments included a 34-item cancer symptom checklist, a 32-item Alzheimer's Disease Symptom Checklist, the Affect Balance Scale (Bradburn, 1969)

and multi-item checklists related to caregiver social life and social support. The dementia caregivers tended to be older in age and had been caring for their family members for a longer period of time. In addition, the dementia caregivers were more negatively affected by their roles as caregivers both physically and emotionally (p = <.0005). Caregivers of dementia patients were more likely to be at risk for increased stress as evidenced by these factors: poorer self-health, increased use of anti-anxiety medications, lower life satisfaction, and decreased social activities. The differences between the two groups of caregivers' well-being might be explained by the added difficulty of coping with symptoms of dementia such as confusion, aggression, and wandering. However, the study showed that caregivers of dementia patients were more likely to be involved in support groups. Validity and reliability statistics were not available for this study.

In another study on caregiver burden related to a chronic and/or medical illness, Snowdon, Cameron, and Dunham (1994) conducted research that examined factors related to caregiver burden in families caring for a child with developmental disabilities. Fifty families were studied using a convenience sampling procedure. Questionnaires were mailed to the families, so it is not known if the responses reflect family consensus or the opinion of the primary caregiver. Ninety-seven percent of the respondents were mothers. Four instruments were used in this study. The Family Inventory of Resources for Management (McCubbin, Comeau, & Harkins, 1981) measured extended family social support, family strengths, and financial well-being. Norbeck's Social Support Questionnaire (Norbeck, Lindsey, & Carrieri, 1983) assessed functional support, social networks, and network loss. Feetham Family Functioning Survey (Feetham & Humenick, 1981) measured family satisfaction with the community, divisions of labor, and

relationships between family members. (In this study, Snowden et al. stated validity of the instrument and reported test/re-test reliability was .85.) Also, the Family Hardiness Index (McCubbin, McCubbin, & Thompson, 1986) was used to measure hardiness as a characteristic that buffers a family from effects of stress and thereby promotes family adjustment and adaptation. Construct validity and reliability (alpha = .82) were reported. The results of this study showed that internal coping mechanisms such as hardiness were effectively used even when social support was limited. A higher degree of satisfaction with family functioning was related to higher levels of support. Hardiness was defined as adaptation resources such as internal strengths of a family which enable the family to view stressful events as potentially beneficial and growth producing. Caregivers described personal and family growth even in the midst of difficult situations. The authors speculated that internal coping mechanisms such as family hardiness are actually strengthened by the stressful experiences.

Munkres, Oberst, and Hughes (1991) conducted a study examining caregiver burden when dealing with a medical illness. Their research explored the differences in patient and family reaction to a new diagnosis of cancer compared with patient and family reaction to news of a recurrence. The sample included 28 patients with an initial diagnosis of cancer, and 32 patients who were experiencing a recurrence. Cognitive appraisal models of stress and coping provided the theoretical framework for this study. The following tools were used: the Modified Symptom Distress Scale, the Self-Care Burden Scale (Oberst, Hughes, & Chang, 1992) and the Family Hardiness Index, McCubbin et al. (1986). Ninety-five percent of the subjects were middle class and well educated. Seventy-five percent were married. The initial treatment group had been ill for

an average of 10 months. The recurrence group had been ill for an average of 46 months. This difference in length of illness was significant between the groups (p = < 0.001). The recurrence group reported more distress for all symptoms, but only general bodily discomfort was significantly higher than the initial illness group (p = < 0.001). One factor that related to coping effectively with caregiver burden was family hardiness. Family hardiness was also correlated with less mood dysfunction. However, the Family Hardiness Index scores were the same for both groups (x = 2.42, SD= 0.32). The study focused primarily on the patient's response to the illness and did not explore family issues or caregiver burden in depth other than the information that was obtained by the Family Hardiness Index.

Nolan et al. (1992) explored caregiver burden as it related to perceived stress and ability to cope effectively among families of patients awaiting heart transplants. A descriptive, multi-institutional study was completed using a nonrandom sample of 35 women and 3 men, with a mean age of 44 years. The primary caregiver answered the questions related to family issues. The Family Model of Resiliency, Adjustment, and Adaptation (McCubbin & McCubbin, 1987) provided the theoretical framework for the study. The Family Crisis Oriented Personal Scale (F-COPES) (McCubbin, Olson, & Larsen, 1981) was used to evaluate family coping strategies. The Family Inventory of Life Events (FILE) (McCubbin, Patterson, & Wilson, 1983) measured family coping behaviors. The Family Perception of the Transplant Experience Scale (FPTES) (McCubbin & Thompson, 1987), a 14-item self-report scale, assessed the family's appraisal of the transplant experience during the organ-waiting period. Fifty-three percent of the subjects reported moderate levels of stress and 47% reported low levels of stress. None of the

subjects reported high levels of stress. Independent t tests showed no significant difference in the FILE scores based on race or gender. Pearson's correlation demonstrated a moderate relationship between the FPTES score and the FILE score (r = 0.38, p = 0.03). Family stress increased as the experience of the transplant became more negative. Also, families were helped to view the stress in a more positive manner. These reframing coping strategies (as measured by the F-COPES reframing subscale) resulted in decreased stress (r = -0.39, p = 0.03). The results of the study indicated the family members coped more effectively with the stress of waiting for news of a transplant by utilizing higher numbers of coping strategies (Nolan et al.).

In summary, four studies were reviewed concerning caregiver burden as it relates to a chronic and/or medical illness. Clipp and George (1993) studied spouse caregivers of 272 dementia patients and 30 spouse caregivers of cancer patients. Their study found that caregivers of dementia patients were more likely to experience negative consequences related to caregiver stress. Snowden et al. (1994) studied caregiver burden related to caring for a child with developmental disabilities. One of the tools used in this study was the Family Hardiness Index. The results showed that internal coping mechanisms such as hardiness were effectively used even when social support was limited. Families described personal and family growth even when circumstances were stressful. Finally, Munkres et al. (1992) and Nolan et al. (1992) explored caregiver burden related to medical illness. The results showed that family hardiness and utilization of coping strategies enabled families to deal more effectively with the stress related to caregiver burden associated with a medical illness.

The ability to generalize findings from each of these studies is limited due to the

small sample sizes. Also, it is difficult to generalize these findings to family issues because the definition of a family is not clear in these studies. More research is needed in the area of specific family variables and family members with a diagnosis of depression. However, the research still adds some valuable information to the database related to caregiver burden. Longitudinal studies with larger samples of more homogenous groups using a consistent instrument would provide useful data.

Caregiver burden related to mental illness. Providing care for a mentally ill family member can be extremely challenging. Caregiver burden related to mental illness is the second factor examined for the current study. Coyne et al. (1987) studied the effects on caregivers of living with a depressed person. Their sample included 42 caregivers living with a depressed person and a control group of 23 caregivers living with a person who had a history of depression, but was not currently experiencing symptoms. A 33-item scale of items related to subjective and objective burden and the Hopkin's Symptom Checklist-25 (HSCL-25) (Derogatis, Lipman, Rickels, Uhlenuth, & Covi, 1974) measured caregiver burden. The HSCL-25 results showed that caregiver burden was significantly higher in caregivers caring for a patient who was currently experiencing a depressive episode (t (63) = 2.72, p < .01). According to the scale used in this study, 40% of the persons living with a person currently experiencing a depressive episode met the criterion for needing psychological intervention as a result of stress associated with caregiving responsibilities.

Montgomery, Gonyea, and Hooyman (1985) and Thompson and Doll (1982) conducted studies that compared objective and subjective caregiver burden. Both studies concluded that subjective burden such as feeling resentful, embarrassed or trapped caused

more stress than objective burdens such as financial burden or disruption to everyday routines. Fadden, Bebbington, and Kuipers (1987) also conducted a study related to burden that results from caring for a depressed person. Twenty-four patients with spouse caregivers were studied. The Social Behavior Assessment Schedule (Platt, Hirsch, & Weyman, 1983) and Camberwell Family Interview (Rutter & Brown, 1966) were used as measurement tools. The results of this descriptive study were similar to the previously stated research, but they specifically identified three caregiver burdens: financial stress, decreased leisure activities, and problems in the marital relationship. In addition to these stressors, numerous families complained that the mental health system added to their burden by not providing information regarding the illness and not making resources available.

In summary, Coyne et al. (1987) studied caregiver burden related to caring for a person currently experiencing a depressive episode and found that 40% of the caregivers met criteria for requiring psychological intervention as a result of the stress associated with caregiver responsibilities. Additional studies supported the findings of the caregiver stress related to caring for a depressed person (Montgomery, Gonyea, & Hooyman, 1985, Thompson & Doll, 1982; and Fadden, Bebbington, & Kuipers, 1987.)

The weakness of these studies is the inability to generalize findings due to small sample sizes. Longitudinal studies using a cross-section of the population would greatly enhance the body of research. Also, additional studies focusing on family burden rather than individual caregiver burden would be beneficial.

Social support related to mental illness caregiving. Rose (1997) researched perceptions of social support among 15 caregivers of psychiatric inpatients. Symbolic

interactionism was used as the theoretical framework. This qualitative study examined social support in providing care for mentally ill persons. Semi-structured, open-ended 45-90 minute interviews were conducted. A process of theme identification was used in the data analysis. The results identified four types of social support: family, friends, spiritual resources, and professionals. Caregivers stated that support from immediate family was most effective because family members seemed to most accurately understand their circumstances. The families also found strength in their religious faith. However, support from mental health professionals was frequently inadequate. Caregivers complained that the system moved too slowly and the caregivers' need for support was often unmet. The study concluded with recommendations for further research in the area of social support for caregivers. The main limitation of this study was the small sample size. Also, the data from the qualitative approach are difficult to accurately replicate and therefore generalize results. According to Rose, a longitudinal study would be helpful for identifying trends and changes in caregivers' perception of social support.

Unfortunately, other studies echoed similar negative comments about the mental health system. Francell, Conn, and Gray (1988) interviewed 86 family caregivers by using a survey of six, open-ended questions related to caregiving. Interviewers met with family focus groups consisting of 10-15 people. It is not known if some families had more than one representative in the group. The caregivers' primary complaint was the lack of information and involvement in treatment. They also described feeling abandoned by professionals when their family member was in a crisis. Francell et al. concluded that attempting to access community resources was stressful, fighting for entitlements was frustrating, and maneuvering through a maze of fragmented services was discouraging.

Because of these difficulties, family members turned elsewhere for support.

Chafetz and Barnes (1989) conducted research with 20 family members of psychiatric patients. In an interview, the caregivers were asked to state three problems that related to the caregiving experience and then review a list of 21 pre-identified caregiving problems. The results concluded that emotional strains were more stressful than specific caregiving tasks. As was previously stated, the best support was found from immediate family members because they seemed to understand the difficulties and be most empathetic. Stigma was not an issue with family members and a sense of self-reliance was encouraged. In addition, caregivers received support from extended family and friends, especially those who were able to be non-judgmental.

In summary, three studies were reviewed regarding social support related to mental illness caregiving. Rose (1997), Francell et al. (1988), and Chafetz and Barnes (1989) studied types of support and each study found that support from immediate family was most helpful. In addition, all three studies concluded that support from mental health professionals was inadequate.

None of these three studies reported validity or reliability statistics. Qualitative studies are difficult to replicate and generalize results because of methods and small samples. The specific definition of family was not clearly identified in these studies. Further research in the area of social support for families caring for depressed family members would be valuable.

Hardiness related to medical and mental illness caregiving. Hardiness was the fourth area reviewed for this study. Research has found family hardiness to be a positive

factor in a family's ability to cope with stressors related to caregiving (Munkres et al., 1992). The study found that stress related to caregiving could be overcome by a sense of commitment and control over the environment. Schott-Baer, Fisher, and Gregory (1995) also explored issues related to caregiver hardiness. They studied 54 caregivers of cancer patients and used Orem's self-care theory as a theoretical framework. One of the tools used was the Health-Related Hardiness Scale (Pollack & Duffy, 1990). Moderate significant positive correlation occurred between self-care scores and hardiness scores. Reliability for the control subscale was 0.70 and the reliability for the commitment/challenge subscale was 0.86. The results showed that a caregiver with a high level of personal hardiness tended to cope more effectively with caregiver burden.

In summary, Munkres et al. (1992) and Schott-Baer et al. (1995) studied hardiness related to medical and mental illness caregiving. Both studies concluded that caregivers with high levels of hardiness tended to cope more effectively with caregiver stress.

Additional studies exploring the effect of hardiness on families using a consistent instrument such as the Family Hardiness Index would be beneficial.

Well-being related to medical and mental illness caregiving. Fink (1995) researched the topic of family resources and demands as related to strains and well-being of caregiving families. Fink's study is the object of replication for this research. In Fink's study, the following hypotheses were tested: (a) family social supports and internal family system resources will increase family well-being both directly and indirectly by decreasing strains and (b) family demands will increase strains and have a negative effect on well-being. A nonrandom sample of 65 caregivers providing care for elderly parents was obtained and a descriptive cross-sectional design was used. Fink defined a family as at

least two adults in addition to the care recipient. A phone interview was conducted with the person designated by the family as the person who was most involved in providing care. It should be noted that only 20 of the 65 families actually lived in the same home with the recipient of the care.

Fink's (1995) study focused on general family concerns related to caring for an elderly parent and did not specifically focus on mental health issues. Eleven measurement tools were used to assess the variables. The Family Social Support Index (Kahn & Antonucci, 1980), which lists 35 items related to sources of support, measured family social support. Internal family system resources were measured by the Family Hardiness Index (McCubbin, McCubbin, & Thompson, 1986). This 20-item tool measures the family's strengths and ability to effectively problem-solve. Family life changes were measured by the Family Stressors Index (McCubbin & Patterson, 1987a), which is a 10item tool used to determine changes in the past year. The Zarit Burden Scale (Zarit, Orr, & Zarit, 1985) was used to measure caregiver strain. This instrument is a 22-item tool to assess caregiver burden. Family strains were measured by the 10-item Family Strains Index (McCubbin & Patterson, 1987b). Four measures were used to assess the variable of family well-being: Family APGAR (Smilkstein, 1978), Bradburn Affect Balance Scale (Bradburn, 1969; Bradburn & Caplovitz, 1965), perceived individual health, and perceived family health. The Family APGAR (Smilkstein, 1978) is a 5-item questionnaire that gives a general impression of family functioning. Individual well-being was measured with the 8-item Bradburn Affect Balance Scale. Perceived individual and perceived family health were rated with a single global response for each (Loveland-Cherry, 1990). Each of the tools demonstrated reliability and validity in the past and in the reviewed study.

As expected, Fink's (1995) study showed that the variables of family social support and internal family resources were positively related to family well-being (p = <.01) and accounted for 65% of the variance in family well-being. Longitudinal studies with larger sample sizes would be useful in providing more information. The small sample and cross-sectional design makes it difficult to generalize the findings from this study. Reliance on self-report questionnaires limits the study. However, this research is a valuable starting point for research related to family caregiver support and well-being.

Only one other study in addition to Fink's (1995) research addressed the issue of family internal system resources. Doornbos's 1996 study focused on the variables of family stressors, family coping, and family health by studying families of mentally ill. The specific diagnostic categories of the patients were not identified in the study. Eighty-five families were included in the sample for this descriptive study. The sample was obtained by nonprobability sampling methods. Questionnaires were mailed to families. Seventythree percent were one-respondent families and 27% were two-respondent families. Three variables were addressed. Family stressors were examined by using the Family Inventory of Life Events and Changes Scale (FILE) (McCubbin, Patterson, & Wilson, 1983) which is a self-administered questionnaire with 9 sub-scales to measure family stress. The Family Crisis Oriented Personal Scale (F-COPES) (McCubbin, Olson, & Larsen, 1981), which is a 30-item self-administered questionnaire, measured family coping. Four instruments were used to assess family health: the Cohesion Scale and the Adaptability Scale of the Family Adaptability and Cohesion Evaluation Scales (Olson, Portner, & Lavee, 1985), the Family APGAR (Smilkstein, 1978), and the Family Environment Scale (Moos & Moos, 1981). The Family Adaptability and Cohesion Evaluation Scales are self-administered

questionnaires of 10 items each. The Family APGAR is a 5-item questionnaire that assesses overall family functioning. Finally, the Family Environment Scale, which is a 9-item questionnaire designed to evaluate openly expressed emotions within a family, measured family health.

Doornbos (1996) found that families of mentally ill persons (compared to normative families) reported more stressors, relied more on coping strategies, experienced less cohesion, and had greater adaptability. These families also reported a decreased level of satisfaction with family functioning, but experienced significantly less family conflict. This study provides valuable information related to family strengths and well-being.

In summary, two studies provided useful information regarding well-being related to mental illness caregiving. Fink (1995) determined that family social support and internal family resources had a positive effect on family well-being. Doornbos's (1996) research showed that families of mentally ill persons reported more stressors, and a decreased level of family function satisfaction, but experienced less family conflict.

Further research could build on these concepts and expand the knowledge base with longitudinal exploration of how the variables change over a period of time. In addition, developing ways to assist families with problem-solving skills would be valuable, as well as to address issues related to family support.

In summary, numerous articles are available regarding caregiver burden. In recent years, research has moved beyond the topic of burden and has begun to focus on effective coping. However, more research is needed regarding the specific areas of family support and internal system resources such as hardiness. It is important for professional nurses to know what kind of support is beneficial and then understand how to not only develop

interventions to increase support, but also how to build on family strengths that already exist. Research in these areas is crucial to building nursing's knowledge base, specifically in the area of mental health nursing.

#### Conceptual Framework

In order to understand the promotion of family well-being, McCubbin and McCubbin's (1996) Resiliency Model of Family Stress, Adjustment, and Adaptation was used. The model describes family behavior in response to stress. It begins with Hill's (1958) ABCX Model which describes a family stressor as A, the event, interacting with B, the family's available resources to meet a crisis, interacting with C, the family's perception of the crisis which results in X, the crisis.

McCubbin and McCubbin (1996) expanded on this model by exploring the concepts of vulnerability and regenerative power and by investigating the reasons some families seem better able to defend themselves against a crisis and better able to recover after a crisis. Factors that increase stress were also addressed. They found that overload of responsibility, and intra-family role and boundary ambiguity result in higher stress. Social ambiguity, such as absence of norms and absence of procedures for managing the situation, predisposes a family to crisis. The authors continue describing how coping effectively involves an interaction of resources and perceptions of the event. Family resources include cohesiveness and adaptability. Finally, they conclude that the post-crisis adaptation can either be functional or dysfunctional.

McCubbin and McCubbin (1996) organized these post-crisis concepts in the Resiliency Model of Family Stress, Adjustment, and Adaptation. The model states that at point AA there is a pile-up of stressors which leads to BB, the implementation of family

resources, and also includes CC, the family's perception of the crisis, which results in XX, the family's adaptation to the crisis, which can be either functional or dysfunctional (See Figure 1).

This study primarily explored two of McCubbin, Thompson, and McCubbin's (1996) concepts: the Double B factor and the Double X factor. The Double B factor describes the importance of family resources. Family resources are divided into two categories. When a family encounters stress it first utilizes resources that are currently available. The second category of resources includes coping resources that are strengthened or developed in response to a crisis such as self-reliance, self-esteem, family integration, social support, and collective group support. Cherry (1989) expands the Double B factor of family adaptation to include shared values, social network, and community resources that help to positively affect the family's ability to cope with a crisis.

McCubbin, Thompson, and McCubbin's (1996) Double X factor describes the concept of family crisis and adaptation. Adaptation involves the process of balancing that moves the family to a level of functioning that promotes unity and growth. According to the model, balancing involves assimilation, accommodation, and compromise. The end result, namely adaptation, can be either functional or dysfunctional.

Successful home care of a depressed family member depends on the family's ability to use existing resources and develop new resources. The result is a change in family homeostasis. As in Fink's (1995) study, the Double B factor of family adaptive resources is conceptualized as family social support and family internal system resources. Family adaptation (the Double X factor) is conceptualized as family well-being. The Double X

factor of family adaptation will be used as a framework in examining this study's variable of family well-being.

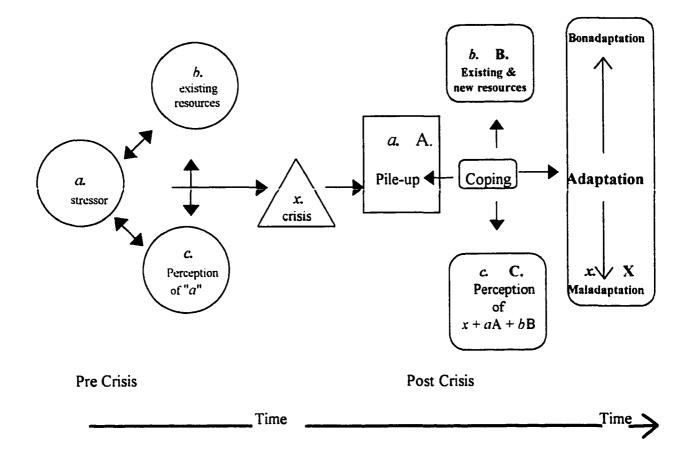


Figure 1. Resiliency Model of Family Stress, Adjustment, and Adaptation.

Note: Bolded areas reflect the variables addressed in this study.

Note: from "Resiliency in Families: A Conceptual Model of Family Adjustment and Adaptation in Response to Stress and Crises, by M. A. McCubbin and H. I. McCubbin, 1996, in H.I. McCubbin, A.I. Thompson, & M.A. McCubbin (Eds.), Family assessment: Resiliency, coping and adaptation. Inventories for research and practice (pp. 1-64).

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In summary, McCubbin, Thompson, and McCubbin's Resiliency Model of Family Stress, Adjustment and Adaptation was used as a theoretical framework. The concept of family resources supported the exploration of variables of family social support and family internal system resources. McCubbin's concept of adaptation provided the framework for this study's variable of family well-being.

#### Research Question

What is the relationship among family support systems, family internal system resources, and family well-being experienced by the caregiver providing home care to a depressed family member?

#### Hypothesis

Family social support and family internal system resources are positively related to family well-being in families providing care at home for a depressed family member.

#### **Definition of Terms**

The following terms are defined for this study: family social support, family internal system resources, hardiness, family well-being, caregiver of a depressed family member, and depressed family member. Family social support is defined as perceived support from friends, relatives, and community resources (Fink, 1995). Family internal system resources are defined as strengths and assets of the family system that can be drawn upon to meet the needs of the family unit and its individual members (Fink). In this study, hardiness was examined. Hardiness is defined as adaptation resources such as internal strengths of a family which enable the family to view stressful events as potentially beneficial and growth producing (McCubbin, McCubbin, & Thompson, 1986). Family well-being is defined as the family members' satisfaction with the functioning of the family

unit, their perception of their own health and emotional well-being, and their perception of the family's health (Fink). For the purposes of this study, family will be defined as at least two adults who are directly involved in the care of a depressed person. At least one of the adults will be living in the same home with the depressed person. A depressed family member is defined as a person over the age of 65 who is living with a family member and receiving assistance from the family member with whom he or she is living and has a diagnosis of depression from either a physician or the Mental Health Team of the agency providing home care.

#### CHAPTER 3

#### METHOD

#### Research Design

A correlational design was used to examine the relationships among types of family social support, family internal system resources, and family well-being. The advantages of a correlational design are that it is possible to examine interrelationships between variables in a short period of time and also be able to examine a variable such as family well-being which does not lend itself to experimentation. However, limitations exist with a correlational design. It is weak in its ability to define causal relationships (Polit & Hungler, 1995). Since random selection was not used, there is a chance of faulty interpretation. Also, pre-existing factors could explain the dependent variable.

It is important to recognize the following potential threats to internal and external validity associated with the design. The following alternative hypothesis is a potential threat: Other support that is readily available to the caregiver such as spiritual support or respite care might influence family well-being. Unfortunately, due to the limitations of this research, this potential threat was not controlled. Study subjects completed the instruments in their homes. Therefore, there was the potential for emotional and family role factors to influence the subjects' responses. This potential threat was not addressed in this study. Another threat to external and internal validity is the style of the researcher

who administered the questionnaires. The study addressed this threat by having one person administer the questionnaires for consistency.

#### Setting and Sample

The setting for this study was the homes of families who were providing home care for a depressed family member. A home care agency's Mental Health Team followed the depressed family member.

Thirty-seven family caregivers were contacted. Seven refused to participate in the study (a 19% refusal rate). Those who refused stated they were too stressed to participate or, in two cases, the family member did not believe the patient was depressed. A convenience sample of 30 was used for this study. A disadvantage of this sampling method relates to the difficulty generalizing the results to a larger group. However, by using a convenience sample, the study was completed in a timely manner. Although a longitudinal study is desirable, this study focused on the earlier stages of caregiving when the family requests help. The criteria used to select subjects included being able to speak English, giving informed consent, and caring for a family member age 65 or older with a diagnosis of depression. The diagnosis of depression was determined either by the patient's physician or the home care agency's Mental Health Team. In addition, the participant family member was asked to complete a characteristic information questionnaire developed for this study (see Appendix B).

#### **Instruments**

Three instruments were used to measure the variables in this study. The Family

Crisis Oriented Personal Scales (F-COPES) (Appendix C) measured family social support.

The Family Hardiness Index (Appendix D) was used to measure family internal system

resources, namely hardiness. The Family APGAR was used to measure the dependent variable of family well-being.

Family social support. The Family Crisis Oriented Personal Scales (F-COPES) (see Appendix C) (McCubbin, Olson, & Larsen, 1981) was used in this study to assess family social support. The instrument was used with permission (Appendix E). F-COPES is a 29-item questionnaire. Item 18 was not included in the analysis due to a low factor loading (McCubbin, Olson, & Larsen, 1981). The instrument is divided into five subscales designed to evaluate a family's coping strategies. Each item is rated on a scale from 1 to 5 (strongly disagree to strongly agree). Scores are obtained by summing items after reversing responses on the negatively stated items. Scores can range from 9 to 45 on the subscale of Acquiring Social Support (a family's ability to acquire support from family and friends), 8 to 40 on the subscale of Reframing (a family's ability to redefine stressors and make them manageable), 4 to 20 on the subscale of Seeking Spiritual Support (a family's ability to acquire spiritual support), 4 to 20 on the subscale of Mobilizing Family Support (a family's ability to obtain community resources and accept assistance), and 4 to 20 on the subscale of Passive Appraisal (a family's ability to respond to stressors with minimal reactivity). The score for the complete instrument ranges from 29 to 145. Higher scores indicate more effective coping abilities.

Construct validity for the F-COPES was derived from factor analysis (McCubbin & Thompson, 1987). The Cronbach's alpha for F-COPES (all 29 items) from previous studies, was .86. Cronbach's alpha for each of the subscales was identified as follows:

.83 on Acquiring Social Support, .82 on Reframing, .80 on Seeking Spiritual Support, .71 on Mobilizing Family to Acquire and Accept Help, and .63 on Passive Appraisal subscales

(McCubbin et al., 1981). Construct validity was derived from factor analysis (McCubbin & Thompson, 1987). The coefficient alpha for the F-COPES in this study was .87 overall. In this study the internal reliability for each of the subscales was identified as follows: .78 on Acquiring Social Support, .77 on Reframing, .89 on Seeking Spiritual Support, .64 on Mobilizing Family to Acquire and Accept Help, and .55 on Passive Appraisal subscales.

Family internal system resources. The Family Hardiness Index (FHI) (see Appendix D) (McCubbin, McCubbin, & Thompson, 1986) measured the variable of family internal systems resources, specifically, hardiness. The instrument was used with permission (Appendix E). The Index is a 20-item instrument. The subject responds with an assessment of the degree to which each statement describes the respondent's current family situation. The FHI contains three sub-scales: (a) Commitment (b) Challenge, and (d) Control. The eight-item Commitment scale measures a family's ability to work together in difficult situations. The six-item Challenge subscale assesses the family's ability to see life experiences as growth opportunities. And finally, the six-item Control subscale measures a family's internal sense of control over its circumstances. Responses range from zero (completely false) to three (completely true). A total score is obtained by adding the values of the responses for all 20 items (i.e., False = 0, Mostly False = 1, Mostly True = 2, True = 3, and Not Applicable = 0). However, for items 1, 2, 3, 8, 10, 14, 16, 19, and 20, the values are reversed (i.e., False = 3, Mostly False = 2, Mostly True = 1, true = 0. and Not Applicable = 0). Scores can range from 0 to 24 on the Commitment subscale, and 0 to 18 on both the Challenge and Control subscales. The score for the total instrument ranges from 0 to 60, with higher scores reflecting higher degrees of internal system resources.

Validity and reliability have been established. The overall internal reliability for the FHI using Cronbach's alpha is 82 (McCubbin, McCubbin, & Thompson, 1986). Internal reliabilities for the three subscales are .81 for Commitment, .80 for Challenge, and .65 for Control. Reliability statistics for the total FHI in Fink's study (1995) have been established as follows: .87 for caregivers, .86 for partners and .87 for the total group. The coefficient alpha for the total FHI in this study was .69. Internal reliability for each of the subscales was identified as follows: .65 for Commitment, .60 for Challenge and .65 for Control. Construct validity has been established through significant positive correlations between the total FHI and other scales measuring family flexibility, family stability, and family life satisfaction (McCubbin, McCubbin, & Thompson, 1986). The correlations were .22 for family flexibility as measured on the Family Adaptability and Cohesion Evaluation Scales, and 23 for family time and routines as measured on the Family Time and Routines scale (p = <.05). The correlations ranged from .11 to .20 on family satisfaction, marital satisfaction, and community satisfaction as measured on the Quality of Family Life scale (p = < .05).

Family well-being. The Family APGAR was used to measure family well-being. The Family APGAR is a five-item questionnaire that measures satisfaction with overall family functioning. Each item contains three responses ranging from "almost always" to "hardly ever." Scores can range from 0 to 10. According to the instrument, a score of 0 to 3 suggests a severely dysfunctional family, a score of 4 to 6 suggests a moderately dysfunctional family, and a score of 7 to 10 suggests a highly functional family. From previous studies, the Family APGAR had a reliability coefficient of .86 (Good, Smilkstein,

& Good, 1979; Smilkstein, Ashworth, & Montano, 1982). The coefficient alpha for this study was .78.

#### **Procedure**

Data collection began by obtaining permission for research from Grand Valley State University and a West Michigan home care service. The research study was presented to a West Michigan home care service Mental Health Team. Team members were asked for referrals. Referrals were then screened for appropriateness using the following criteria: English-speaking and a caregiver of a depressed family member who is at least 65 years old and receiving services from the West Michigan home care service Mental Health Team. At least one other family member should be involved in the care, though not necessarily living with the caregiver or depressed family member. A phone call was placed to the caregiver to schedule a time to meet in the home. When the meeting took place in the caregiver's home, the researcher explained the purpose of the study, the questionnaires that would be used, and the approximate length of time (30 minutes). Confidentiality was emphasized and the fact that the caregiver's decision to participate or not participate would not affect the patient's care. If the caregiver agreed to participate, he/she was asked to sign the consent form (see appendix F). The questionnaires were administered in the following order: the participant characteristics information questionnaire (Appendix B), the F-COPES, the Family Hardiness Index, and the Family APGAR. The researcher asked the caregiver to complete each questionnaire by circling the most appropriate response. Caregivers completed the questionnaires independently when possible. In some cases, especially with elderly caregivers, the researcher read the questions to them. When the questionnaires were completed, this researcher thanked the

caregiver and gave him or her a copy of the letter of appreciation (Appendix G).

Three risks to the caregiver were possible. First, the questions might raise stressful issues. This risk did not occur but would have been addressed by discontinuing the meeting if signs of distress were noted or allowing time for the caregiver to process feelings or offering follow-up with a Mental Health Team social worker. The second risk to the caregiver was fatigue from completing the questionnaires. This did not occur but if it had the caregiver would have been given the option of stopping the meeting. Finally, breech of confidentiality was a risk. To decrease this risk, questionnaires were coded by number and the family member's name was not written on any of the forms. A potential positive effect of the study was giving the family member validation for the role of a caregiver.

#### **CHAPTER 4**

#### DATA ANALYSIS

The data from this study were analyzed by using the Statistical Package for the Social Sciences (SPSS). Correlational statistical tests, primarily Pearson's correlations, were used to explore the variables of resources (hardiness), support, and well-being to test the hypothesis. Descriptive data were summarized. The research question asked, "What is the relationship among family support systems, family internal system resources, and family well-being experienced by the caregiver providing home care to a depressed family member?" The hypothesis stated that family support systems and family internal system resources are positively related to family well-being.

## Sample Characteristics

Data were collected on 30 family members by meeting with the caregivers in their homes and asking them to complete the three previously identified questionnaires. A summary of the data describing the relationship of the caregiver to the patient is presented in Table 1. As noted, almost half were spouses of the patient. The age of the caregiver varied from 18 years old to 101 years old with a mean age of 60 years. The sample of family caregivers included 19 married individuals (63.3%), 6 single (20.0%), and 5 divorced (16.7%). Nineteen caregivers were female (63.3%) and 11 were male (36.7%). All of the caregivers were white with the exception of one black caregiver.

Table 1

Relationship of Caregiver to Patient

Variable	n (%)
Husband	8 (26.7)
Wife	5 (16.7)
Daughter	6 (20.0)
Son	3 (10.0)
Granddaughter	4 (13.3)
Daughter-in-law	3 (10.0)
Sister	1 (3.3)

The group of family caregivers included 16 people (53.3%) who were either retired or not working. The remainder fell into a variety of occupational categories. Among the working family caregivers, work outside the home averaged 15.8 hours a week. The average level of education was twelfth grade.

Sixteen of the 30 homes (53.3%) included only the patient and the caregiver. In addition, 11 homes (36.7%) were made up of the patient, caregiver, and only one other family member. There was a wide range in the period of time a family member had been providing care for the depressed, elderly patient ranging from one month to 62 years with a mean of 7.7 years. The mean amount of time per day the caregiver spent with the

patient was 15.2 hours, with a range from 2-24 hours a day of care. Eleven caregivers (36.7%) only had one other family member involved in the care. This other person was usually a son (36.7%) or daughter (26.7%). An additional nine families (30%) had either two or three family members providing assistance. The main source of support outside the family was identified as Visiting Nurse Services.

The patients in this study ranged from an age of 66 years old to 92 years old with a mean age of 78.6 years. Caregivers identified the most common activity-of-daily-living needs as assistance with scheduling appointments (identified by 90% of the caregivers), assistance with transportation (identified by 86.7% of the caregivers), medication administration (identified by 80% of the caregivers), help with a bath (identified by 60% of the caregivers) and meal preparation (identified by 60% of the caregivers). The patients in this study had an average of 2.7 medical problems. The range was 1-6 medical problems. Hypothesis

It was hypothesized that family support systems and internal system resources are positively related to family well-being. The relationship between family support systems and well-being was examined and the relationship between internal system resources and well-being was examined to determine if significant relationships existed.

## Frequency Statistics

Frequency statistics were collected on the F-COPES, FHI, and Family APGAR instruments. Higher scores indicated higher levels of coping, support, and well-being. A summary of these statistics is presented in Table 2.

Table 2
Frequency Statistics for Instruments

Variables	Possible Score Range	Actual Score Range	M≠(SD)
F-COPES Subscales:			
Acquiring Social Support	9-45	14-40	28.20 (7.72)
Reframing	8-40	12-40	31.90 (5.67)
Seeking Spiritual Support	4-20	4-20	13.33 (4.89)
Mobilizing Family Support	4-20	5-20	15.50 (3.82)
Passive Appraisal	4-20	6-20	14.93 (3.53)
F-COPES Total Scale	29-145	44-129	102.73 (17.81)
FHI Subscales:			
Commitment	0-24	13-24	19.83 (3.01)
Challenge	0-18	3-17	12.07 (3.30)
Control	0-18	6-18	13.50 (3.13)
FHI Total Scale	0-60	29-58	45.50 (6.91)
Family APGAR	0-10	3-10	8.30 (2.02)

## **Hypothesis Testing**

Correlational statistical tests were used to determine the relationship between family social support and family well-being using the F-COPES and Family APGAR instruments respectively. Correlational tests were done on each of the five subscales of the F-COPES: acquiring social support, reframing, seeking spiritual resources, mobilizing family to acquire and accept help, and passive appraisal (see Table 3 for correlations between family support as measured by F-COPES subscales and family well-being as measured by the Family APGAR). Using a *p* value of 0.05 or lower, no statistical significance was noted in the relationship between these variables and the hypothesis was not supported.

Table 3

<u>Correlations between Family Social Support and Family Well-Being</u>

F-COPES subscales	Well-Being
	r (p)
Acquiring social support	.25 (.18)
Reframing	.08 (.69)
Seeking spiritual resources	.09 (.63)
Mobilizing family to acquire and accept help	.09 (.64)
Passive appraisal	.01 (.97)
Total score	.19 (.16)

In addition, correlational statistical tests were used to determine the relationship between family internal system resources and family well-being using the FHI and Family APGAR instruments respectively. Correlational tests were done on each of the three subscales of the FHI: commitment, challenge and control (see Table 4 for correlations between family internal system resources as measured by FHI subscales and family well-being as measured by the family APGAR). There was no statistical significance in the relationship between these variables and therefore the hypothesis was not supported.

Table 4

Correlations between Family Internal System Resources and Family Well-Being

FHI subscales	Well-Being r (p)
Commitment	.22 (.24)
Challenge	.13 (.51)
Control	.01 (.97)
Total score	.16 (.20)

## **Incidental Findings**

Correlational statistical tests examined the relationships between the subscales of the FHI and F-COPES (see Table 5). Although weak to moderate, a statistically significant positive relationship occurred between mobilizing resources and challenge (r = .38, p = .04). This relationship indicates that the more innovative and open to learning new things a family is, the more likely its ability to seek resources and accept help.

Table 5

Correlations between F-COPES Subscales and FHI Subscales

		FHI subscales	
F-COPES subscales	Commitment	Challenge	Control
	r (p)	r (p)	r (p)
Acquire	.42 (.20)	.22 (.23)	16 (.40)
Reframe	.16 (.41)	.19 (.32)	23 (.23)
Spiritual	.13 (.50)	.29 (.12)	01 (.98)
Mobilize	.21 (.26)	.38 (.04)	.11 (.55)
Passive	.34 (.07)	.34 (.06)	.33 (.07)

Correlational statistical tests were also used to determine the relationships between F-COPES subscales and several items of demographic data. The same tests were used to determine the relationship between FHI subscales and the same items of demographic

data. Although not statistically significant, weak relationships were noted among the F-COPES subscales of commitment and control and number of years of caregiving (commitment r = -.26, p = .17 and control r = -.30, p = .11). This was a negative relationship, that may indicate that the levels of commitment (the ability to work together as a family in difficult circumstances) and control (the family's internal sense of control over its circumstances) were higher when the years of caregiving were lower. Also, a weak, statistically significant relationship was noted between the commitment subscale and the caregiver's age (r = -.40, p = .03). The relationship was a negative one, indicating that the younger the caregiver, the higher the level of commitment. It should be noted that these interpretations must be made with great caution. There were no other relationships noted in the data.

## Impressions from Caregiver Interviews

Several interesting items emerged from the process of studying family caregivers. Most of the caregivers who were phoned and asked to participate in the study willingly agreed. However, seven family caregivers refused. Five of the seven stated they were too stressed and overwhelmed with the responsibilities of caring for an elderly, depressed family member and would not participate in the study. Interestingly, two of the caregivers said they would be willing to participate, but they did not believe their family member was depressed (even though this diagnosis had been confirmed by the patient's primary nurse). These seven families were not included in the study.

Out of the 30 family members who participated, most of them focused on the positive aspects of the caregiving experience. Families were able to utilize healthy coping strategies in the midst of severe stress. On the F-COPES, they identified the most

important coping strategies as: seeking advice from the family physician, having faith in God, and accepting that difficulties occur unexpectedly. They were grateful for the opportunity to spend time with their family member and described how family relationships were strengthened. They stated they had found the ability to be flexible and cope with change. Interestingly, none of the families brought up the issue of financial stress. In general, they viewed the opportunity to provide care at home as a positive and rewarding experience.

Some of the caregivers identified the negative aspects of caregiving. They talked about the physical demands of providing care. This was especially prevalent with older caregivers. The second most common problem was not receiving enough support from family members outside of the home. Caregivers frequently mentioned the lack of appreciation and assistance from other family members. However, in general, the positive comments about the experience outweighed the problem issues. Many caregivers said the interview was a positive, affirming experience.

## **Summary**

The data analysis did not indicate a statistically significant relationship between the variables of family support and well-being or family internal system resources and well-being and therefore the hypothesis for this study was not supported. Weak, statistically significant relationships were noted between acquiring support and commitment, mobilizing resources and challenge, caregiver age and commitment, and the relationship among the subscales of commitment and control and number of years of caregiving.

#### CHAPTER 5

#### **DISCUSSION AND IMPLICATIONS**

## Discussion Related to Hypothesis

The findings of this study do not support the hypothesis that family social support and family internal system resources are positively related to family well-being. The hypothesis was tested using correlational statistical tests among the variables of social support (F-COPES), internal system resources (FHI), and well-being (Family APGAR). No statistically significant correlations were found specific to the hypothesis.

## Discussion Related to Conceptual Framework

This study was guided by the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1996). The model proved to be a useful framework for this study. First of all, the model focuses on families. Since so much of the literature focuses on caregiver stress, it was helpful to be guided by a model that centered on family responses to stress. The variables of this study closely corresponded with the components of the model. After a "pile-up" of stressors (such as stressors related to providing home care for a depressed, elderly family member), the implementation of family resources and the family's perception of the crisis results in the family's ability to adapt, which in this study, is defined as well-being.

One of the problems with the model in terms of the findings in this study is that there is not a direct relationship between social support, internal system resources and well-being. In the model, social support and internal system resources are included in "existing and new resources". The model does not link resources directly with adaptations (well-being in this study), but instead describes how resources are related to "coping" and influenced by perception which then leads to adaptation. This leaves room for some ambiguity when conceptualizing variables and interpreting the results of this study. Also, there is a lack of clarity in the model regarding the terms: coping and resources.

The model is complex and has many factors. Only two components of the model were used in this study, which could explain why the hypothesis was not supported.

Another explanation could be that the model is not useful in a study of depressed patients.

Perhaps caring for a depressed, elderly person does not reflect a severe stressor or family crisis to the extent the model describes. Further work on operationalizing the model would be useful.

#### Discussion of Findings Related to Previous Research

Family Support Systems (F-COPES). The current study did not support the proposed positive relationship between support systems and well-being. This relationship is supported in other research. Nolan et al. (1992) and Doornbos (1996) studied coping strategies among families of cardiac transplant candidates and families of the seriously mentally ill, respectively. Both studies used the F-COPES instrument and found that these families utilized a higher number of coping skills than normative families. However, these studies focused primarily on the component of the model labeled "pile-up." Nolan found a moderate inverse relationship between the F-COPES subscale of reframing and the pile-up

of family stress as measured by the FILE instrument. In other words, use of reframing techniques was associated with a decrease in stress. The F-COPES is a reliable, valid instrument and appropriate for use in the current study even though the relationship between family support systems and well-being was not supported.

The reason there was no statistically significant correlation between these variables in the current study might be attributed to a small sample size. The sample size might have been too small to get the needed variability. Nolan's study was slightly larger with 38 subjects and Doornbos's study included 85 families.

Family Internal System Resources (FHI). The current study did not find a significant correlation between family internal system resources and family well-being. This finding differs from the research on hardiness. Snowden, Cameron, and Dunham (1994) used the FHI to assess hardiness in families of children with disabilities. Their research included 50 families and the results showed that even though hardiness was not a significant predictor of family functioning (a comparable variable to this study's family well-being), hardiness is a component of effective coping. The current study replicates Fink's (1995) research on the influence of family resources and family demands on the strains and well-being of caregiving families. Using regression analysis, Fink found a significant relationship between family social support and well-being. Also, a significant relationship was noted between family internal system resources and well-being. Fink's study included 65 families.

Although the findings in the current study do not support the hypothesis, there is a positive, although weak and nonsignificant correlation. Since the current study replicates Fink's study, this result is somewhat surprising. However, the current study is made up of

a much smaller sample size (N = 30) and the current study may not have obtained sufficient variability.

Family Well-Being (Family APGAR). The Family APGAR is a valid, reliable instrument for measuring family well-being. Unfortunately, the current study's data cannot be compared to Fink's (1995) research because no data for the mean APGAR scores are listed and regression analysis was used for the statistical analysis. In Doornbos's (1996) study, the Family APGAR was used to measure the variable of satisfaction with family functioning. The results showed a lower level of satisfaction in the sample families (families coping with serious mental illness) compared to higher levels of satisfaction in the normative families. The current study's findings concur with Doornbos' research even though the current study's data do not support the hypothesis.

In summary, there was a weak, positive relationship that was not statistically significant between the variables in the current study. The findings in the current study are similar to data from previous research. Further investigation of these relationships is warranted.

## Limitations and Recommendations for Future Research

The most significant limitation of this study was the small, non-random sample. A research design using a larger, random sample would enhance generalizability.

Longitudinal studies would provide useful data regarding the changing needs of families over time (Rose, 1997). Also, the subjects were chosen from one site and tended to reflect the typical population of the agency. Most of the caregivers were middle or upper middle class, although income was not specifically addressed. It would be helpful to use multiple sites and identify the income level in future studies. Because of their financial security, the

families in this study did not experience stress related to meeting their basic needs, therefore, they could more easily focus on issues related to hardiness and social support. Since the families experiencing severe stress refused to participate, the study included higher functioning families, which might have influenced the results. All of the families were white except for one black family. In the future, valuable data could be obtained by focusing on a diversity of ethnic backgrounds since family coping is often a unique part of various cultures. The current study sample was composed of a wide range of caregiver ages, ranging from 18 years old to 101 years old. Since providing care for an elderly person requires physical strength and stamina, future research might be more useful if the caregiver age range was narrower or if the physical requirements were measured. Another limitation of the study was that the level of the patient's depression was not measured.

The data for this study were obtained by meeting in the home of the caregiver and asking the caregiver to complete three questionnaires. Meeting in the caregiver's home was both a limitation and strength of the study. In most cases, the patient was in the same room or an adjoining room when the caregiver was completing the questionnaires.

The caregiver might have been hesitant to answer questions honestly. However, because the data were collected in a face-to-face meeting, each questionnaire was completed and there were no missing data. Also, an advantage of meeting in the home was that the respondent was more comfortable in his or her own setting.

The potential threats previously identified did not occur. No signs of distress occurred in caregivers when answering the questionnaires. There was no need to stop the meeting or offer follow-up with a Mental Health Team social worker. None of the caregivers experienced extreme fatigue while completing the questionnaires. All thirty

caregivers willingly participated in the study with no apparent difficulty.

Another strength of this study was the focus on family well-being. Even though the hypothesis was not supported, this study provides a solid foundation for future research. Because families are faced with the challenge of providing health care at home, more work needs to be done in the area of promoting family well-being.

## Implications for Nursing

In recent years, the length of hospital admissions has dramatically decreased.

Patients are being discharged to the care of family members and these family members are often poorly equipped physically and emotionally to deal with these challenges. Internal system support and social support for families is more important today than ever before. Although the hypothesis in this study was not supported, nonsignificant weak relationships in the hypothesized direction were noted between internal system support and well-being as well as between social support and well-being. Nurses need to be aware of these relationships and focus on developing nursing interventions that promote family well-being in all clinical settings, and especially in home care. In addition, awareness that commitment to caregiving and the sense of having control of the caregiving situation may be higher in the earlier years of caregiving may help nurses develop more interventions to assist caregivers who have been providing care for longer periods of time.

Nurses must make an effort to accurately assess these variables. The nurse must take time to understand the family's perception of effective support (Rose, 1997). These assessment skills begin in the nursing education setting. Students should be taught to utilize the available instruments for assessment and then receive training regarding developing a plan of care to address the issues of family hardiness, social support and

well-being. The instruments could be used at the conclusion of care to measure outcomes and add to the research base.

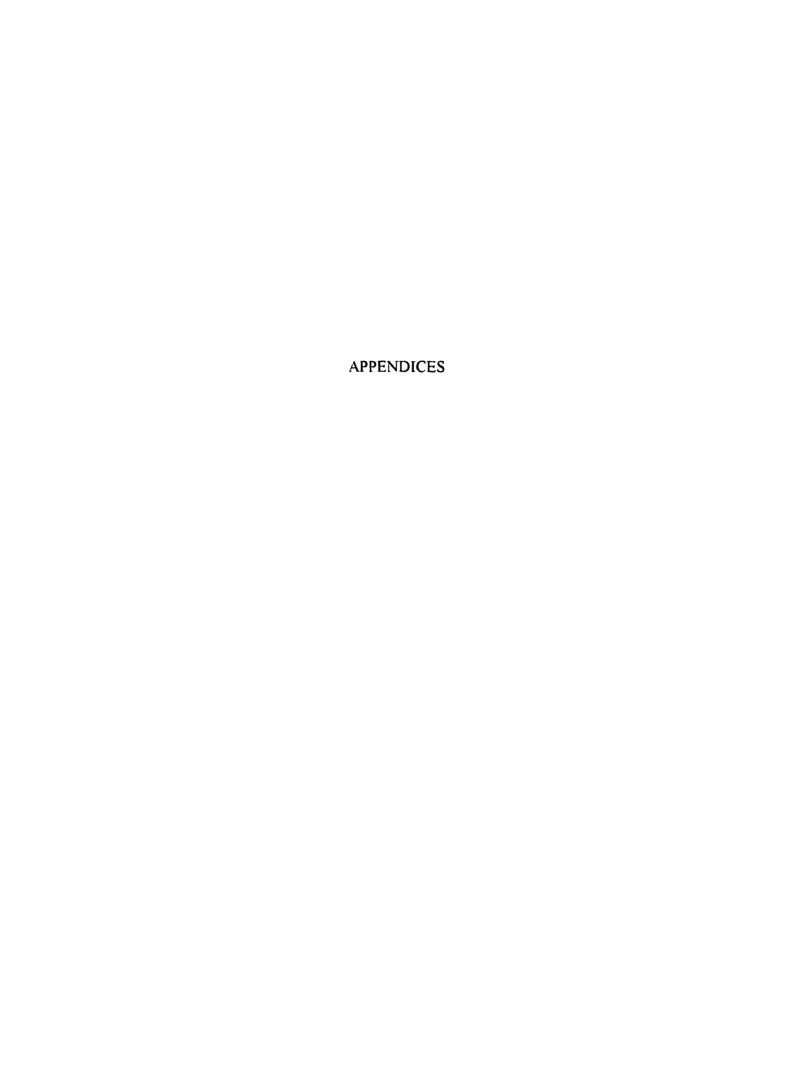
The results of this study are important to nursing administrators. Administrators are in a key role to develop policies and outcome monitors that will improve the care given to patients and their families. The nurses' knowledge of family coping is crucial in order to effectively evaluate the care given by an organization. When participating in community projects, a nursing administrator can be an advocate for the needs of family caregivers. Nurses in leadership roles are in a position to coordinate interdisciplinary and interagency resources needed by patients and their families.

Education is a key role of the nurse. This study includes many areas where the nurse could effectively provide education. The patient and the family members need to accurately understand depressive illness. Nurses can decrease the stigma attached to mental illness by providing information about the disease and the various treatment modalities. In addition, the nurse can educate the patient and family about issues related to the aging process, the patient's medical problems, and strategies to promote health and well-being. Also, families and patients need information about specific ways to improve their ability to function effectively as a family unit and cope with the many stressors they encounter. As previously stated, family caregivers in this study identified three important coping strategies: seeking advice from the family physician, having faith in God and accepting that difficulties occur unexpectedly. This information can be used to assist families in building their coping skills. The nurse is in a key position to provide education regarding available resources such as support groups and respite care (Norbeck, Chaftez, Skodol-Wilson & Weiss, 1991; Montgomery, Gonyea & Hooyman, 1985). Due to

decreasing health care dollars for care in the home, the nurse must be able to teach families how to access support through extended family, friends, neighbors, churches and volunteer organizations. Assessing the caregiver's knowledge would be an important component of future research. The nurse's educative role goes beyond the patient and family. The nurse needs to be an advocate for patients and their families at the agency level and in the community. Advocating for legislation that provides assistance for families is also a crucial component of this role.

## Summary

As more and more health care occurs in the home and within the structure of the family, nurses must be skilled in assessing family internal system resources, social support and well-being. Interventions that promote family health must be developed, utilized, and evaluated. Outcome studies are necessary to evaluate the effectiveness of these strategies. Further research regarding these family issues is needed to expand the base of nursing knowledge in order to effectively intervene in this rapidly growing area of nursing practice. Good patient care includes good family care.



## APPENDIX A

Permission to Use Resiliency Model of Family Stress

#### APPENDIX A

## Permission to Use Resiliency Model of Family Stress

January 3, 2000

Diane Richardson 5401 Edgelawn SE Grand Rapids, MI 49508

Dear Ms. Richardson:

You have permission to use and duplicate for subjects the Resiliency Model of Family Stress, Adjustment and Adaptation, the Family Hardiness Index and the F-COPES (Family Crisis Oriented Personal Evaluation Scales) in your study regarding the influence of support systems and internal system resources on families of caregivers of a depressed family member. You also have permission to re-print the Reisliency Model of Family Stress, Adjustment and Adaptation, the Family Hardiness Index and the F-COPES within the appendix of the thesis.

Since/el/,

H. I. Mc Cubbin University of Wisconsin-Madison

## APPENDIX B

Participant Characteristic Information

## APPENDIX B

# Participant Characteristics

1. What is your relationship to the patient?
2. What is your age?
3. What is your marital status?MarriedSingleSeparatedDivorced
4. What is your gender?MaleFemale
5. What is your race? (Check all that apply)American Indian
Black(non-Hispanic) AsianWhite (non-Hispanic)
Eskimo Aleut Pacific Islander Hispanic
6. What is your occupation? How many hours/week do you work
outside the home?
7. What is your level of education?
8. How many people live in your home (including yourself and the patient)?
9. How long have you been providing home care for your family member?
10. How many hours a day are you involved in providing care to your family member?
11. Who is the family member who is most involved in the patient's care (in addition to
yourself).
a. What is his/her relationship to the patient?
b. How much time do they spend per week with the patient?
0-5 hours 6-10 hours over 10 hours

## APPENDIX B

12. How many other family members are involved in the patient's care at least one time
week?
13. What is their relationship to the patient?
14. What other support do you receive from outside the family?
15. What is the patient's age?
16. What are the patient's current medical problems?
17. What kind of assistance does the patient require? (Check all that apply)
bathingtoiletingfeedingassistance with walking
assistance with transferring from bed to chairtransportation
giving medications scheduling appointments

## APPENDIX C

Family Crisis Oriented Personal Scales

## APPENDIX C

## Family Crisis Oriented Personal Scales

PAMELY STREET COPPES AND HEALTH PROJECT ISSELLINGUE Drive University of Wissenste-Hudson



## F-COPES

#### FAMILY CRISIS ORIENTED PERSONAL SCALES

Hamilton L McCubbin

David H. Oteon

Andres & Larson

#### -

The Family Crisis Oriented Personal Evaluation Scales is designed to record effective problemsolving attitudes and behavior which families develop to respond to problems or difficulties.

#### DESIGNATION

First, read the list of "Response Choices" one at a time.

Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response <u>very well</u>, then circle the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then circle the humber 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

w	HEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:	Strongly Disagree	Mederately Disagree	Nellher Agree Ner Disegree	Moderately Agree	Strangly Agree	
1	Sharing our difficulties with relatives	1	2	3	4	5	
2	Seeking encouragement and support from friends	1	2	1	4	5	
3	Knowing we have the power to solve major problems	1	2	3	4	5	
4	Seeking information and advice from persons in other families who have faced the same or similar problems	1	2	3	4	5	
5	Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5	
6	Seeking assistance from community agencies and programs designed to help families in our situation	1	,	,	4	5	
7	Knowing that we have the strength within our own family to solve our problems	1	2	,			
8	Receiving gifts and favors from neighbors (e.g. food, taking in sail, etc.)	1	2	3	4	5	
9	Seeking information and advice from the family doctor	1	2	3	4	5	I
10	Asking neighbors for favors and assistance	1	2	3	4	5	]

## APPENDIX C

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:	Brrang iy Disagree	Mederately Disegree	Molther Agree Ner Disagnes	Mederately Agree	Birangly Agree	
11 Facing the problems "head-on" and trying to get solution right away	1	2	3	4	5	
12 Watching television	ı	2	3	4	5	
13 Showing that we are strong	1	2	3	4	5	
14 Attending church services	11	2	3	٠	5	į
15 Accepting stressful events as a fact of life	ı	2	3	4	5	
16 Shering concerns with clase friends	1	2	3	4	5	ļ
17 Enowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5	
18 Exercising with friends to stay fit and reduce tension	1	2	3	4	5	
19 Accepting that difficulties occur unexpectedly	1	2	3	4	5	
20 Doing things with relatives (get-togethers, dinners, etc.)	1	2	3	4	5	
21 Seeking professional counseling and help for family difficulties	1	2	3	4	5	
22 Believing we can handle our own problems	1	2	3	4	5	
23 Participating in church activities	1	2	3	4	5	1
24 Defining the family problem in a more positive way so that we do not become too discouraged	Ţ,	2	,		5	1
25 Asking relatives how they feel about problems we face	1	,	1,	4	5	
26 Feeling that no matter what we do to prepare, we will have difficulty handling problems		,	با	4	5	]
27 Seeking advice from a minister	1	2	3	4	5	
28 Selleving if we wait long enough, the problem will go away	1	2	3	4	5	_
29 Sharing problems with neighbors	1	2	3	1	5	
30 Having faith in God	1	2	3	4	5	1

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## APPENDIX D

Family Hardiness Index

## APPENDIX D

## Family Hardiness Index

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FAMILY HARDINES
and Health Project
and Health Project
Table Linder Drive
Table Wisconsin-Madison
Manlyn A. McCubbin
Hamilton I. McCubbin
Madison, Wisconsin 53706

## FAMILY HARDINESS INDEX ©

Directions:

Please read each statement below and decide to what degree each describes your family. Is the statement False (0), Mostly False (1), Mostly True (2), or Totally True (3) about your lamily? Circle a number 0 to 3 to match your leelings about each statement. Please respond to each and every statement.

			14	Mostly		Nor	
IN	OUR FAMILY	Faise		True	True	Applicable	
١.	Trouble results from mistakes we make	0	1	2	3	NA	
2.	It is not wise to plan ahead and hope because things do not turn out anyway	0	1	2	3	NA .	
3.	Our work and efforts are not appreciated no matter how hard we try and work.	0	1	2	3	NA.	
4.	in the long run, the bad things that happen to us are are balanced by the good things that happen	0	1	2	3	NA.	
5.	We have a sense of being strong even when we face big problems	6	1	2	3	NA .	
6.	Many times I feel I can trust that even in difficult times that things will work out	a	1	2	3	NA .	
7.	While we don't always agree, we can count on each other to stand by us in times of need	٥	1	2	3	NA	
8.	We do not feel we can survive if another problem hits us	G	1	2	3	NA.	
9.	We believe that things will work out for the better if we work together as a family	0	1	2	3	NA.	
10.	Life seems duff and meaningless	٥	.1	2	3	NA	
11.	We strive together and help each other no matter what	q	1	2	3	NA	
12.	When our family plans activides we try new and existing things	a	1	2	3	NA.	
13.	We listen to each others' problems, hurts and lears	a	1	2	3	NA.	
14.	We tend to do the same things over and over its boring	0	1	2	3	NA.	
15.	We seem to encourage each other to try new things and expenences	G	1	2	3	NA.	
16.	It is better to stay at home than go out and do things with others	0	1	2	3	NA	
17.	Being active and learning new trings are encouraged	0	1	2	3	NA.	
18.	We work together to solve problems	0	1	2	3	NA.	
19.	Most of the unnappy things that happen are due to bed luck	0	1	2	3	NA	
20.	. We realize our lives are controlled by accidents and luck		1	2	3	NA.	

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## APPENDIX E

Permission to Use Instruments

#### APPENDIX E

## Permission to Use Instruments

January 3, 2000

Diane Richardson 5401 Edgelawn SE Grand Rapids, MI 49508

Dear Ms. Richardson:

You have permission to use and duplicate for subjects the Resiliency Model of Family Stress, Adjustment and Adaptation, the Family Hardiness Index and the F-COPES (Family Crisis Oriented Personal Evaluation Scales) in your study regarding the influence of support systems and internal system resources on families of caregivers of a depressed family member. You also have permission to re-print the Reisliency Model of Family Stress, Adjustment and Adaptation, the Family Hardiness Index and the F-COPES within the appendix of the thesis.

Since/el/,

H. I. Mc Cubbin

University of Wisconsin-Madison

APPENDIX F

Consent Form

#### APPENDIX F

#### Consent Form

I understand that this is a study of how families manage when caring for a depressed family member at home. The knowledge gained from this study is expected to improve home care and support for family members of depressed persons. I also understand that:

- 1. participation in this study will involve completing four questionnaires, the total of which will take approximately thirty minutes to complete.
- 2. I have been selected for participation because I provide home care for a depressed family member.
- 3. it is not expected that this study will lead to any physical or emotional risks to me.
- 4. the information I provide will be kept strictly confidential and the data will be coded so that identification of individual participants will not be possible except by the researcher.
- 5. participation in this study will not affect the care provided to my family member by Visiting Nurse Services.
- 6. I may contact Diane Richardson at Visiting Nurse Services (616-774-2702) if I have any questions.
- 7. a summary of the results will be made available to me upon my request.

## I acknowledge that:

- "I have been given an opportunity to ask questions regarding this research study, and these questions have been answered to my satisfaction."
- "In giving my consent, I understand that my participation in this study is voluntary and that I may withdraw at any time without affecting the care my family member receives from Visiting Nurse Services."
- "I hereby authorize the investigator to release information obtained in this study to scientific literature. I understand that I will not be identified by name and all data will be reported as group data."
- "I have been given the phone numbers of Diane Richardson and the chairperson of the Grand Valley State University Human Research Review Committee. I may contact them at any time if I have questions."

I acknowledge that I have read and understand the above information, and that I agree to participate in this study.

Witness	Participant	Patient
Date	 Date	Date

## APPENDIX G

Letter to Participant

APPENDIX G

Letter to Participant

Dear family member:

Thank you for your willingness to participate in this research study examining the well

being of family members who care for an elderly depressed person at home. Your help in

this study is very much appreciated.

If you have any questions please feel free to contact me at Visiting Nurse Services (616-

774-2702) or you may call Paul Huizenga, the chair of the Grand Valley State University

Human Research Review Committee at (616-895-2472).

Sincerely,

Diane Richardson, RN,C.

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