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I am submitting herewith a dissertation written by Mary Cosby Weathers entitled "Stress and Coping Among Mother Caregiversof Mentally Ill Adult Children." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Ph.D., with a major in Social Work.

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STRESS AND COPING AMONG MOTHER CAREGIVERS OF MENTALLY ILL ADULT CHILDREN

A Dissertation

Presented for the

Doctor of Philosophy

Degree

THE UNIVERSITY OF TENNESSEE, KNOXVILLE

Mary Cosby Weathers

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DEDICATION

This study is dedicated to my mother, Annie, my son, Charles and his wife, Linda, my grandaughter, Eboné, my sister, Ollie, and her husband, Henry, my significant other, Amadou Niang, and to the loving memory of my father, Lifford Cosby.

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MCW

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ABSTRACT

The purpose of this research was to learn about the caregiving experiences of mothers who were caregivers to their mentally ill adult children. All subjects in the sample (N=56) completed a structured interview. In addition, a sub-sample of ten (10) mothers (five white and five black) volunteered to answer a series of open-ended questions about their experiences as caregivers.

These mother caregivers rated the perceived amount of stress associated with selected stress items on a 3 point Likert-type scale. Response choices were "no stress," rated 1, "moderate stress," rated 2 and "severe stress," rated 3.

Coping strategy items were also rated by these mother caregivers on a 3 point Likert-type scale. Response choices were "never," rated 1, "sometimes," rated 2, and "often" rated 3. Resource utilization was rated on a 4 point Likert-type scale. Response choices were "no help," rated 0, "of little help," rated 1, "somewhat helpful," rated 2 and "very helpful," rated 3. T-tests were used to determine if a statistically significant difference existed between black and white mother caregivers' mean stress scores, mean coping strategy scores, and mean resource utilization scores. The t-test findings indicated that little difference existed between sources of stress, coping strategy use, and resource utilization among black and white mother caregivers.

Results from the analyses of the mother caregivers' responses to the series of open-ended questions indicated that black and white mother caregivers' descriptions of

themselves, their mentally ill adult children, and families were similar. The presence of a mentally ill adult family member impacted the mother caregiver's life and her family.

Mother caregivers faced major challenges in the role of caregiver. Challenges ranged from getting through the day to getting the mentally ill adult child to keep doctor's appointments.

The needs of mentally ill adult children are many. However, these mother caregivers identified some additional resources that were lacking or in limited supply.

These mother caregivers felt more affordable living situations and educational training opportunities were needed for the mentally ill. The mothers themselves needed education on new medications and treatments for the mentally ill.

It is recommended that this study be replicated with a larger sample to determine the generalizability of the findings to a larger population.

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CHAPTER 1

INTRODUCTION

The caregiving literature has shown that black and white women are called upon to serve as caregivers to disabled spouses, children, and elderly parents (Abel & Nelson, 1990; Chenoweth et al., 1986; Robinson, 1989, 1990; Shanas, 1979). The bulk of research on women caregivers has focused on the experiences of white women (Biegel & Blum, 1990). The findings of such studies may have only limited application to the experiences of black women caregivers, who are underrepresented in the study samples. Thus, any generalization from such research to black women caregivers would be based on inadequate evidence.

Some research that has been done on the experiences of black women caregivers suggests that black women are likely to report problems with caregiving responsibilities due to their life circumstances (National Survey of Caregivers, 1987). The problems reported by black women include disadvantages in social and socioeconomic status, housing, and lack of access to resources (Chatters & Taylor, 1989). These problems, possibly exacerbated by the effects of racism and sexism, may lead to heightened levels of stress and hardship for black women caregivers.

Research has established that caregiving creates stress in caregivers (Hatfield, 1982). Women placed under stress may be at added risk for emotional, psychological and physical problems (Syme & Berkman, 1976). The unusual stress of caring for a mentally ill adult child may negatively affect women's mental and physical health, and

black mothers may be particularly at risk. However, it is not known whether black mothers who care for mentally ill adult children experience greater levels of stress than white mothers. Because such specific knowledge is lacking, current social programs and services may not be adequately addressing the needs of black mother caregivers. Research into the caregiving experience of black mothers of mentally ill adult children can provide information about a significant category of private caregivers.

Purpose of the Study

The purposes of this study are: (1) to identify sources of stress for black mothers who serve as caregivers for mentally ill adult children; (2) to determine whether the experiences of black mother caregivers differ significantly from that of their white counterparts; and (3) to determine whether coping strategies and resource utilization vary by race.

Conceptual Framework

Examples of questions addressed in this study include "What situations and circumstances create stress for black and white mother caregivers?" and "What are some coping strategies employed by such caregivers?" Symbolic interactionism, a social psychological theory, provides the general conceptual framework for addressing these questions. The underlying assumption of symbolic interactionism is that people are the creators and definers of their own realities, and are therefore best qualified to speak for themselves about those realities (Blume, 1969).

Symbolic interactionists typically begin research studies by asking, "How do subjects view themselves and other participants in their situation?" Because of a primary commitment to uncover the respondents' views, researchers using the symbolic interactionism approach usually do not formulate a hypothesis before collecting their data. Instead, they begin their investigation with rather broad research questions in mind (Blume, 1969).

It is important for social workers to understand the meaning individuals assign to various situations and aspects of their lives. For example, a social worker may be aware that black mother caregivers experience severe stress. But before meaningful assessment and intervention can be made by the social worker, he or she must be able to determine how black mother caregivers view their situations.

Problem of the Study

How does the experience of caring for mentally ill adult children affect both black and white mothers? What are the principal sources of stress for these caregivers, what resources are available to them, and how do they cope? Second, if there is a significant difference in the level of stress in black and white mother caregivers, what accounts for that difference?

Research Questions

The research questions to be answered in this study are:

1. What situations and circumstances creates stress for black and white mothers who are responsible for caring for mentally ill adult children?

2. What are the coping strategies employed by such caregivers?
3. What resources are available to such caregivers, and which do they actually utilize?

Definitions

In this study key concepts are defined as follows:

Caregiver refers to a mother who has taken on the role of caring for a mentally ill adult child.

Caregiving encompasses all the activities a caregiver may engage in for the purpose of caring for a mentally ill adult child and enhancing the dependent child's well-being.

Caregiver stress refers to emotional, mental and physical trauma that may result when a caregiver's personal resources are overtaxed.

Coping strategies are behaviors employed by caregivers to ameliorate and survive caregiver stress.

Resources are funds, friends, relatives, and professional services that may be used to ease the burden of caregiving.

Mentally ill adult child refers to any individual between 21 and 49 years of age who has been diagnosed mentally ill by a qualified psychiatrist.

Rationale for the Study

Mothers who provide care for mentally ill adult children have received relatively little attention in the research literature, although their numbers are increasing. There is a growing population at increased risk of mental and physical

illness (Goldstein & Caton, 1983; Hatfield, 1981, 1983; Jennings, 1987; Minoff, 1988).

This study may provide useful data for those charged with developing policies to address the long-term needs of the mentally ill and their families. Such data may help in the design and implementation of services and programs for caregivers and care recipients alike. Furthermore, data from this study will add to a body of professional knowledge that may prove useful in the delivery of services. Lastly, the findings of the study may generate hypotheses for additional research.

CHAPTER 2

LITERATURE REVIEW

The literature review is divided into four sections. The first section provides a brief overview of the historical roles of the family and of the state in providing care systems for mentally ill people in America from the Colonial era through deinstitutionalization (DI). The second section reviews relevant research on family caregivers. The third section describes research on how caregiver characteristics such as age, race and socioeconomic status affect caregivers' level of stress. The fourth section presents a discussion of research on caregiver stress and coping strategies.

Since the founding of this country, families and states have shared the responsibility of caring for mentally ill Americans; perhaps it would be more accurate to say that they have alternated in the role. During periods when governmental funds have been scarce, caring for the mentally ill has become principally a family responsibility, more specifically a woman's responsibility.

At a time when women are serving as major providers of informal care for mentally ill relatives, it is important to know how women caregivers' age and race affect the caregiving process. Such factors are also likely to influence stress, coping strategies, and resource utilization.

Family and State Care of the Mentally Ill: An Overview from Colonial Times through Deinstitutionalization

In the colonial era (late 18th Century) well-to-do families cared for mentally ill relatives in their homes, typically allowing them a great deal of freedom except when they were violent, then they were chained or locked in strong room, cellars and outhouses (Deutsch, 1937). Mentally ill members of poor families, on the other hand, were usually housed in jails or "poorhouses."

Deutsch's 1937 book, The Mentally Ill in America, provides a particularly vivid description of the plight of the mentally ill in Colonial times. States assumed no responsibility for mentally ill citizens; officials' primary concern was for the welfare of the unimpaired.

The construction of workhouses and almshouses in the early part of the 19th century was the first major involvement of states in the care and treatment of the dependent mentally ill (Bachrach et al., 1987). The construction of workhouses and almshouses permitted the segregation of the mentally ill from criminals (Deutsch, 1937; Grimes, 1934; Grob, 1931), but no form of treatment was available to the inmates of these institutions.

By the mid-1860's, many well-to-do families were placing their mentally ill relatives in private facilities, where they received "moral treatment" pursuant to a therapeutic regime popularized by a French physician, Phillippe Pinel. His contention was that, if mentally ill people were treated with kindness and respect and encouraged

to talk about their problems, they would get better (Mechanic, 1980). Dependent mentally ill people housed in jails, prisons and asylums did not receive "moral treatment."

In the latter half of the 19th century, state mental hospitals were financed and constructed with government funds. Newly enacted commitment laws enabled rich and poor families alike to shift the burden of caring for the mentally ill to state mental hospitals after long periods of home care, usually because of one of the following conditions: (1) physical and mental exhaustion on the part of the family; (2) inability to control violent and unpredictable behavior; (3) inability or unwillingness to provide for the physical care of the dependent relative; (4) incapacitation of the caretaker by illness or death (Bachrach et al., 1987). While some families were reluctant to institutionalize mentally ill family members, many others opted for institutionalization as a means of lessening their burdens.

The inpatient populations of state mental hospitals rose steadily, peaking in the mid-1950s. However, the number of hospitalized mental patients dropped from approximately 559,000 in 1955 to about 132,000 in 1980, a reduction of three-fourths (McCuen, 1988).

At the beginning of the 20th century state mental hospitals had become custodial facilities for the chronic mentally ill. Many of the chronic patients grew old and died in state mental hospitals.

In the latter part of the 20th century treatment and care of the mentally ill shifted back to communities resulting from a focus on community mental health.

Under the policy of deinstitutionalization (DI), large numbers of mental health patients were transferred from hospitals to family and community care.

According to Grob (1987), the U.S. government established the policy of deinstitutionalization following World War II, when it established new programs and priorities. The new focus was on social psychiatry that included new facilities and social workers, psychologists, nurses and psychiatrists. McCuen (1988) suggests a second motive for deinstitutionalization. His contention was that over the years the cost of maintaining the mentally ill in state mental hospitals had skyrocketed thereby creating a burden on the federal government's budget. A way to alleviate (this and reduce burdens would be to return the mentally ill to the communities for care and treatment. Around the same time new psychoactive drugs were demonstrating their effectiveness in keeping ex-hospital patients in the community. Another factor that helped the deinstitutionalization movement was a focus on moral rights and issues of the mentally ill. For example, advocates such as mental health activists, patients' rights lawyers, and families had little faith in the federal government's ability to correct the inhumane and grim conditions found behind the walls of the institutions.

As more attention was focused on these issues the policy of deinstitutionalization gained increasing public support (Aviram, 1990). Aviram (1990) contends that no longer would state mental hospitals escape scrutiny. He states "the public perception of the institutionalized mentally ill contradicted the social norm of what constituted humane care for the mentally ill" (Aviram, 1990, p. 54).

Most scholars agree that there was insufficient scientific justification for the subsequent large-scale departure of severely mentally ill patients from state hospitals to community facilities and families. Torrey (1982) posits that mental health workers were not properly trained to work with chronic patients in the community. Chu and Trotter (1974) argue that the belief that chronic patients could function in the community was based on a small number of high functioning patients that adjusted well in the community following their release to halfway houses.

In summary, since colonial times, the burden of caring for the mentally ill in the United States has shifted between families and the government. Furthermore, the wealthy had enjoyed a greater range of options for care. For example, during colonial times wealthy families cared for mentally ill relatives at home, while relatives of the poor were placed in jails or "poorhouses." Toward the end of the 19th century rich and poor families began achieving greater equity in the type of care that their mentally ill relative received. Newly enacted commitment laws enabled rich and poor families alike to shift the burden of caring for the mentally ill to state hospitals. However, state mental hospitals often did not provide humane living conditions and were costly for government to maintain.

Concern about humanitarian treatment of patients and the economic feasibility of government supported care increased over the years. During the 1950's, the policy of deinstitutionalization, which encouraged the release of mental patients to their families and the community, was developed. Deinstitutionalization did relieve the financial burden on the federal government as the federal government got out of the

business of maintaining state mental hospitals. However, this transfer of the mentally ill from state hospitals to community care placed undue stress, hardship, and burden on families.

Research on Family Caregivers

In 1982, Goldman observed that most mentally ill Americans lived with their families, and that their number included many adults living with their parents. More recent estimates show that 2.1 million mentally ill live with their families (Essence, 1994).

Although family care has become commonplace, the mental health community has not evinced much interest in the effects that this pattern of involvement may have on the families (Kreisman & Joy, 1974). Early studies of familial caregivers focused on the role families might play in the etiology of the illness, suggesting that therapeutic intervention at the family level might aid the recovery of the mentally ill member. Viewing families as culprits overlooked the suffering and guilt endured by family caregivers. Only during the past two decades have families of the mentally ill been systematically studied in their role as caregivers (Aviram, 1990).

Early studies focused on family perceptions, reactions and attitudes regarding the mentally ill. For example, Clausen and Yarrow (1955) investigated wives' perceptions of and reactions to their husbands' mental illness. They reported that the wives tried to understand the behaviors they observed, and experienced a wide range of reactions, including acceptance, denial and anxiety about the future. Not

surprisingly, the wives' responses were greatly affected by their spouses' inability to function as husbands and fathers.

Creer and Wing (1974) conducted intensive interviews in the home of eighty (80) families caring for mentally ill relatives to identify sources of stress and burden. They concluded that sources of stress were many and varied. Not only were families exposed to unpredictable behaviors, but they were also concerned about the welfare of the mentally ill relative, in the event that something should happen to them (the caregivers). According to Creer and Wing, these families routinely faced anxiety-provoking situations and experienced "frequent guilt, depression, disappointment, frustration, and anger" (Hoeing & Wing, 1966, p. 170).

Hoeing and Wing (1966), Doll (1976) and Thompson, Doll and Lefton (1977) studied the concept of "burden" more intensively, distinguishing between objective -- "adverse effects on the household" -- and subjective burden -- the "sense of loss, grief, guilt and anxiety due to the abnormal behavior in the family member."

Doll's (1976) study of subjective burden reported that factors such as economic status, education, age, and sex did not affect the caregiving burden significantly. He felt the burden was related to the severity of the psychiatric condition of the mentally ill relative. Doll's findings suggest that black mothers at the bottom of the socioeconomic ladder are likely to experience the greatest sense of burden, although caregiving mothers from all socioeconomic levels share in the sense of burden occasioned by the adult child's psychiatric condition.

Thompson, Doll, and Lefton (1977) studied objective burden, which encompasses all the disturbing and disruptive effects mentally ill relatives have on their families. They concluded that the onset of florid psychiatric symptoms in the mentally ill family member increased the intensity of the family burden. They found that single caregivers experienced the greatest sense of burden. Single mother caregivers were more likely than their married counterparts to experience an extreme sense of burden; married women may have perceived their burden with less intensity because of the presence in the home of supportive husbands.

Hatfield (1978), Spaniol and Zipple (1986), and Bernheim et al. (1985) found that families' perceptions of hardships and burden were related to such issues as the effects the mentally ill family member had on domestic routines, social and leisure life, income, financial stability, marital stability, emotional overload, feelings of being trapped, and effects on the mental health and physical well-being of other family members.

Chenoweth and Spencer (1986), Faloon et al. (194), George and Gwyther (1986), Montgomery et al. (1986), Thompson & Doll (1982), Zarit et al. (1980), and Zarit (1986) sought to clarify the nature of subjective and objective burdens in order to understand more about their effects on the family. In their studies, objective burden refers to the economic and social impact the mentally ill had on the family while subjective burden refers to the family's perception of and attitude toward the mentally ill family member. A social cost did not necessarily imply an emotional cost (Falloon et al., 1984; Thompson & Doll, 1982).

Some researchers have focused on the effects of isolation on family caregivers. Bernheim and Lehman (1985) found that when family caregivers are isolated for long periods of time from friends and other family members and kept from their normal social activities, they have more difficulty dealing with the stress of caregiving, and are more likely to experience "burnout."

Summary

Research on family caregivers has documented that living with mentally ill relatives can be stressful and burdensome, and that this burden can take many forms--emotional, psychological, physical, financial, etc.

Research has shown that families who care for mentally ill relatives encounter two types of burdens as a consequence of stress: objective and subjective. Caregiving families' level of stress and burden is influenced by demographic characteristics such as age and race. For example, younger single caregivers may experience both objective and subjective burdens while older caregivers may experience more objective burdens.

Research on Caregiver Characteristics

Age and Caregiving

The 1982 National Long-Term Care Survey and Informal Care Survey found the average age of a female caregiver was 46 years. Twenty-eight percent were under 35 years of age, while 15 percent were older than 65.

The literature does not make clear which caregiver age group experiences the greatest hardship. Brody (1985) contends elderly female caregivers (age 65 to 70)

who are physically disabled are more likely than younger caregivers without physical disabilities to experience severe burden and hardship.

Cantor (1983) examined similar data and reported younger female caregivers experience the greatest hardship. One thing younger and older female caregivers have in common is a lack of preparation for the role. They do the best they can, relying on experience and the advice of others (National Long-Term Care Survey and Informal Care Survey, 1982).

Race/Ethnicity and Caregiving

Few studies have focused on race/ethnicity of caregivers. Abel and Nelson (1980) observed that a major barrier to this type of research is the difficulty of "disentangling cultural values from socioeconomic necessity" (p. 36). For example, Cox (1990) examined the caregiving experiences of black and Hispanic daughters responsible for disabled elderly parents, and found that caregivers of both groups have a deep sense of filial obligation. Because of this and other cultural values, many caregivers from ethnic groups are reluctant to seek support outside their families.

Monk et al. (1989) investigated the utilization of formal and informal support services by families of blacks and Hispanic dementia patients. They found that Hispanic caregivers were more likely than blacks to take advantage of social support services when they were available. The researchers also found that Hispanic caregivers experienced more psychological burden than black caregivers because families may not be available to lend support.

Mintzer et al. (1992) assessed Cuban-American Hispanic and Caucasian non-Hispanic daughters who were primary caregivers to their mothers suffering from Alzheimer's disease. They found that Cuban-American mothers were significantly more likely to be living in their daughters' homes while Caucasian non-Hispanic mothers resided in institutional settings. In addition, they found that Cuban-American daughters were more aware of the financial aid resources and were more depressed than Caucasian non-Hispanic daughters.

Social Class/Socioeconomic Status and Caregiving

Social class and socioeconomic status are indicative of an individual's occupation, income, and education; for the purposes of this study they are used interchangeably. Little scholarly attention has been devoted to the effects of social class/socioeconomic status on caregivers' stress level.

Some researchers have maintained that poor people and members of minority groups are likely to have fewer caregiving responsibilities for disabled and dysfunctional relatives because life expectancy in these communities is lower than among middle- and upper-class whites (Syme & Berkman, 1976). Syme and Berkman (1976) have also observed that low-income and elderly minority caregivers often are in poor health and need assistance themselves.

According to Thoits (1984), women in middle and upper socioeconomic levels are in better health and have more economic resources than less advantaged women, and experience fewer hardships and burdens. According to Belle (1983), the lives of women at the bottom of the socioeconomic ladder are less privileged than those of

relatively well-to-do women so poor women experience greater hardships and burden. We can expect from Belle's observation that poor and minority women's life circumstances and their limited access to resources will cause them to experience greater difficulty than relatively well-to-do women with caregiving responsibilities.

Stress and Caregiving

Stress is produced by "any event in which environmental demands, internal demands or both tax or exceed the adaptive resources of an individual, social system or tissue system" (Monat & Lazarus, 1985, p. 3). Many kinds of stressors can affect the lives of caregivers (Chiriboga et al., 1989). Stress research has dealt with the effects of both acute and chronic stress on caregivers.

Lazarus and Folkman (1984) examined the effect of day-to-day "hassles" (chronic stress) on the physical and emotional well-being of middle age women and men. They concluded that their subjects' well-being was more strongly influenced by the pressures of day-to-day annoyances than by exposure to normal life events (acute stress). Day-to-day annoyances refer to situations and problems that occur daily. Life events (acute stress) refer to marriage, divorce, retirement, moving, and other events that individuals experience throughout their lives.

Research has documented that stress exposure can trigger a variety of physical and psychological problems, including heart disease, clinical depression and cancer (Brown & Andrew, 1986; Kaplan, 1985; Lynch, 1977; Stein & Schiefer, 1985). Baltes and Baltes (1990), Elder (1981), and Gergen (1977) argue that stress must be

considered within a "life span context" in order to understand an individual's response to it.

Jones (1990) investigated the relationship between stress and various psychological and physical problems of black women. Her study involved 47 women ranging in age from 25 to 50 years from various socioeconomic levels, married and single, employed and unemployed, and with and without dependent children. A major finding of this study was that chronic conditions--relationship conflicts, racism, ethnicity and inadequate resources--were major sources of stress for black women.

Coping Strategies and Caregiving

Coping strategies are the learned adaptive responses caregivers use to meet the demands of their role or stressful life situations. Some scholars view coping as a part of the personality, a fixed style of thinking and behavior. Jahoda (1955) and White (1976) argue that a person's coping style does not change; it is consistent across stressful events and situations and people can be classified as active or passive, flexible or rigid, effective or poor copers. Jahoda (1955) examined the coping styles of married women and reported coping styles do not change and they are a part of the woman's personality. Since coping styles are part of a woman's personality, we can expect a woman's coping styles to be consistent across most situations. White (1976) conducted a similar study on a group of women and his conclusions supported Jahoda's (1955) findings.

Coping styles are likely to affect coping strategies. Mother caregivers who are rigid, passive and not flexible in coping styles might experience more difficulty using

some coping strategies. Mother caregivers that are active, flexible and effective style copers are likely to use a wide range of coping strategies in the caregiver role.

In any event, coping strategies are an attempt to prevent a stressful event from having a destructive physical or physiological impact on the individual (Chesler & Barbarin, 1987). Chesler and Barbarin (1987) studied the impact stress had on the physical and psychological health of middle aged men and women, and they reported that both middle aged men and women were at risk of physical and psychological problems when stress was prolonged and severe.

Spaniol (1987) investigated coping strategies of caregivers in families with mentally ill members, and compared them with those of caregivers in families with no mentally ill members. In many ways, strategies used in families with mentally ill members were not very different from those used by other families. The major difference was that the problems of families with mentally ill members were more intense and more persistent.

Summary

Researchers have studied the effects of various demographic characteristics, such as age, race/ethnicity, and social class, on caregivers' level of stress. Day-to-day "hassles" (chronic stress) influenced the well-being of individuals more than (acute stress) marriage and divorce. Researchers differ in their assessment of the impact of age on stress among caregivers. Women at the bottom of the socioeconomic ladder may experience more hardships and burdens than women in middle and upper socioeconomic levels because of different life styles. Researchers

have studied stress in non-caregivers and found that stress can negatively impact the lives of those exposed to chronic stress. Caregivers and non-caregivers have coped with stress in a variety of ways. Non-caregivers may be active or passive, rigid or flexible, effective or poor copers. Non-caregivers and mother caregivers' coping strategies aren't much different, but the intensity of their problems is.

Chapter 3

METHODOLOGY

This chapter is divided into two sections. The first section presents a description of the methodology of the study. This section includes explanations of the study research design, obtaining the sample, data collection procedures, the instrument used, data analysis procedures, and limitations of the study. The second section provides an explanation of human subject assurances and includes a description of the procedure for obtaining consent from subjects, safeguards for confidentiality, the procedure for minimizing risk to the subjects, and the potential risks and benefits of the study.

Description of the Study

Research Design. The research design is a cross-sectional survey of mothers who are caregivers to their mentally ill adult children. Mothers supplied data on the impact their mentally ill adult children had on their lives in several areas and described perceived sources of stress, coping strategies they used to manage stress, and resources that they employed to assist them in the caregiver role. Results of the study are based on data collected from 56 mothers who volunteered for the research study.

Obtaining the Sample. Permission and cooperation to recruit subjects for the study were obtained from the following agencies: Seven County Services, Inc., (SCS), provider of community mental health services, Bridgehaven, a Louisville Kentucky day program for chronic mentally ill adults, and chapters of the Kentucky

Alliance for the Mentally Ill, a consumer organization for mentally ill individuals and their families. Criteria for subject selection required that subjects be mothers of a mentally ill adult child and perform caregiving tasks for their mentally ill child.

The investigator's original intent was to recruit middle-aged mothers between 40 and 59 years of age as subjects. Because of an insufficient number of mothers in this age group, mothers older than 59 years who met the study criteria were also recruited for the proposed research. Subjects were not required to live with their mentally ill adult children but were expected to have daily or frequent contact with them and perform caregiving tasks.

Four approaches were used to recruit subjects for the study through SCS, Bridgehaven, and chapters of the Kentucky Alliance for the Mentally Ill.

Approach 1.

The investigator attended a support group meeting for relatives of mentally ill clients of Seven County Services, Inc. (SCS). At the meeting the investigator discussed the objective of the study and requested volunteers to participate in the proposed research. Ten (10) mothers from the support group gave their names and telephone numbers to the investigator. These mothers were contacted via telephone and times were scheduled to conduct the interviews with the ten (10) subjects.

Approach 2

The investigator met with other workers at SCS to discuss the objective of the proposed research and to request their assistance in recruiting potential participants. These workers contacted mothers of clients, discussed the objective of the proposed

research, gave them the investigator's name, and encouraged interested mothers to contact the investigator. Four (4) mothers contacted the investigator. A time was arranged to conduct the interview with each one.

Approach 3

Presidents of various chapters of the Kentucky Alliance for the Mentally Ill in and outside of the Louisville area were contacted by the investigator. The investigator met with presidents of chapters of the Kentucky Alliance in Louisville, Lexington, Frankfort, Georgetown, Versailles, and Danville, explained the objective of the proposed research and requested their assistance in recruiting potential subjects who held membership in their chapters.

A total of twenty (20) mothers from the various chapters volunteered for the study. Their names and telephone numbers were mailed to the investigator. These mothers were contacted by the investigator via telephone and times were arranged to conduct the interviews.

To locate Black mothers, the President of the West Louisville Alliance for the Mentally Ill was contacted by the investigator. The West Louisville Alliance for the Mentally Ill is composed of Black mentally ill individuals and their families who reside in the western half of Jefferson County, populated mostly by Blacks. Members of the organization were contacted by the president. Eighteen (18) mothers volunteered for the research. Their names and telephone numbers were given to the investigator. These mothers were contacted via telephone and times were arranged to conduct the interviews.

Approach 4

The investigator met with Bridgehaven social workers to discuss the proposed research and request their assistance in locating potential subjects for the study. These social workers sent letters with the investigator's name and telephone number to mothers who met the study's criteria. Four mothers contacted the investigator via telephone at which time the investigator arranged times to conduct the interviews. The four approaches yielded a total of fifty six (56) participants for the study. The characteristics of the subjects will be described in the following chapter.

All subjects in the sample (N=56) completed a structured interview. In addition a subsample of ten (10) (five blacks and five whites) volunteered to answer a series of open-ended questions about their experience as caregivers.

Data Collection Procedure. Data collection began in July 1993 and ended December 29, 1993. Potential subjects were contacted via telephone by the investigator to schedule times for each interview. Each interview lasted from one to one-and-one half hours. Prior to conducting the interview, each mother caregiver was given the opportunity to ask questions before reading and signing a written consent form (see Appendix A). Identification code numbers were assigned to each mother. The identification code numbers were kept in a Master Code Book which was kept in a locked file cabinet in the investigator's home.

Instrument. The interview schedule used in the study is an adaptation of a survey questionnaire developed and used by Chesler et al. (1988) to assess the impact of chronic physically ill children on family environments. The interview schedule is

divided into five sections. Section one gathers demographic information about the mother and the mentally ill adult child. Section two consists of a battery of 27 stress items on which mother caregivers indicated the intensity of stress associated with each stress item. The perceived amount of stress was measured on a three (3) point Likert-type scale. Mother caregivers were given a card with the three telephone response choices written on it. Response choices were "no stress" rated 1, "moderate stress" rated 2, and "severe stress" rated 3. Section three consists of a battery of 20 coping strategy items on which mothers indicated the degree to which they used each coping strategy. Each coping strategy was measured on a three (3) point Likert-type scale. Mother caregivers were given a card with the three response choices written on it. Response choices were "never" rated 1, "sometimes" rated 2, and "often" rated 3.

Section four consists of a battery of a 15-item resource inventory list on which mother caregivers indicated the helpfulness of a given resource. Resources helpfulness was measured on a four (4) point Likert-type scale. Mother caregivers were given a card with the four response choices written on it. Response choices were "no help" rated 0, "of little help" rated 1, "somewhat helpful" rated 2, and "very helpful" rated 3.

Section five consists of a series of open-ended questions. Ten mother caregivers, five blacks and five whites, volunteered to answer the open-ended questions. Their responses were tape recorded, transcribed, and analyzed (Appendix B).

Data Analysis. Data was analyzed with the Statistical Package for the Social Sciences for the Personal Computer (SPSS-PC) (SPSS, Inc., 1988). All responses were coded and no identifying information is reported.

Descriptive statistics (frequencies and percentages) are reported for all demographic variables, and measures of central tendency were examined. T-tests were used to determine if a statistically significant difference existed between black and white mothers' mean stress scores, mean coping strategy scores, and mean resource scores. The transcripts were analyzed to discover differences in perceptions of black and white mother caregivers of themselves, their mentally ill adult children, families, sources of stress, challenges, resources used, and desired additional resources.

Findings from the analyses of the responses to the open-ended questions are used to supplement data obtained from the structured questions in the interview schedule.

Limitations. There are several limitations to the study, the primary one being the inability to generalize beyond the population surveyed--mother caregivers of mentally ill adult children served by Seven County Services, Bridgehaven, and members of the Kentucky Alliance for the Mentally Ill.

All participants in this study were members of support groups or organizations; therefore, they are not representative of all mothers who care for mentally ill adult children in the larger population. This creates a major limitation in

the generalizability of the findings because the findings cannot be generalized to mother caregivers in other social contexts.

The cross-sectional design precludes a more comprehensive perspective of mother caregivers' experiences over time, which a longitudinal study would have provided.

Human Subjects Assurance

Procedures for Obtaining Consent

All participation in the study was voluntary. Each participant signed an appropriate written consent form.

Safeguards for Confidentiality

The interview schedule and transcripts contained only identification codes for each subject. All information has been held in confidence. Only the investigator has access to the data, which is kept in a locked file cabinet. Only group data were reported, and all identifiable data will be destroyed six months after the completion of the study.

Potential Risk

It was conceivable that some items on the questionnaire and in the open-ended questions could elicit emotional responses (e.g. crying, blame, sadness). The investigator's years of experience as a mental health therapist equipped her with skills to deal with emotional responses.

Procedures for Minimizing Risk

The study did not involve the use of any drug or chemical substance. Therefore, there was no risk of physical harm to the participants. Participants were assured that they could end their participation at any time of their choosing, and that their names would not appear with the results of the study. Last, participants were also assured that their refusal to participate did not jeopardize their right and their children's right to future services from agencies. Arrangements were made between the investigator, Seven County Services, and Bridgehaven staff to provide follow-up to participants if they had concerns and issues following their participation in the study.

Potential Benefits

The benefit subjects may receive is the pride in knowing that the information they provide will contribute to increasing the knowledge and understanding of mother caregivers.

Potential Benefits to the Social Work Community

The benefit the social work community may receive from this study is greater understanding of the burdens and hardships caregivers endure as caregivers. Furthermore, knowledge gained from the study can be useful in assessment and intervention strategies.

CHAPTER 4

RESULTS

The results chapter is divided into four sections. Demographic data and other sample characteristics are reported in the first section. Analyses of the relationship between race and other selected variables, as they relate to research questions posed, are reported in the second section. Findings from the analysis of the responses to the open-ended questions are reported in the third section. The final section presents two case studies of mother caregivers (Annie, a black mother and Amy, a white mother) to provide more holistic portrayals of mother caregivers who participated in the study. These case studies are based on data gathered from two participants in the study.

CHARACTERISTICS OF THE SAMPLE

Subjects were all birth mothers of mentally ill adult children except one, an adoptive mother. The subjects were either active in the Louisville, Kentucky Alliance for the Mentally Ill or parent education groups at Seven County Services, or were mothers of active clients of Bridgehaven.

Respondents' ages ranged from 44 to 79--a span of 35 years. The mean age of respondents was 62 years. Table 1 shows ages and race of caregivers.

Table 1. Ages and Race of Caregivers

	Race					
Age	Blacks		Whites		Total	
	N	%	N	%	N	%
44-49	2	11.1	0	0	2	3.57
50-59	7	38.9	9	23.7	16	28.57
60-69	8	44.4	20	52.6	28	50.00
70-79	1	5.6	9	23.7	10	17.86
Totals	18	100	38	100	56	100

The table indicates that almost half of the black mother caregivers (8, 44.4%) were in their sixties and that over half of white mother caregivers (20, 52.6%) were in their sixties. Nine (23.7%) white mothers were in their seventies compared to 1 (5.6%) black mother in this age category. Table 2 shows marital status of caregivers by race.

Table 2. Marital Status of Caregivers by Race

	Race					
Marital Status	Blacks		Whites		Total	
	N	%	N	%	N	%
Married	10	55.6	22	57.9	32	57.1
Widowed	2	11.0	12	31.6	14	25.0
Divorced	4	22.2	3	7.9	7	12.5
Separated	1	5.6	0	0	1	1.8
Single	1	5.6	1	2.6	2	3.6
Totals	18	100	38	100	56	100

As the table indicates, over half of the mother caregivers of both races were married. White mother caregivers were more likely than black mother caregivers to be widowed. Table 3 shows employment status by race.

Table 3. Employment Status of Caregivers by Race

	Race					
	Blacks		Whites		Total	
Employment Status	N	%	N	%	N	%
Working full-time	12	66.7	7	18.4	19	33.9
part-time	2	11.1	8	21.1	10	17.1
Not employed	4	22.2	23	60.5	27	48.2
Total	18	100	38	100	56	100

The table indicates that over three-fourths of black mother caregivers were employed, compared to two-fifths of white mother caregivers. Three-fifths of the white mother caregivers were not employed. Table 4 shows occupation of employed mother caregivers by race.

Table 4. Occupation of Employed Caregivers by Race

	Race					
	Blacks		Whites		Total	
Occupation	N	%	N	%	N	%
Professionals	2	14.3	9	60	11	38
Skilled crafts	2	14.3	5	33.3	7	24.2
Service Providers	8	57.1	1	6.7	9	31
Factory Workers	2	14.3	0	0	2	6.9
Total	14	100	15	100	29	100

As the table indicates, only employed mother caregivers are depicted in this table. More white mother caregivers were in the "professional" category (9, 60%) and "skilled crafts" categories (5, 33.3%) than black mother caregivers. Black mother caregivers were more likely to be in service provider occupations or to be factory workers. Table 5 shows education of caregivers by race.

Table 5. Education of Caregivers by Race

	Race					
	Blacks		Whites		Total	
Level of Education	N	%	N	%	N	%
Less than H.S.	3	16.7	3	7.9	6	10.7
H.S./GED	6	33.3	9	23.6	15	26.8
Some College	7	38.8	16	42.1	23	41.1
College Graduate	1	5.6	5	13.2	6	10.7
Master's completed	1	5.6	5	13.2	6	10.7
Totals	8	100	38	100	56	100

As the table indicates, white mother caregivers were better educated than black mother caregivers. White mother caregivers were much more likely to have completed college or have graduate degrees than were black mother caregivers. Table 6 shows annual incomes of caregivers by race.

Table 6. Annual Income of Caregivers by Race

	Race					
	Blacks		Whites		Total	
Annual Income	N	%	N	%	N	%
Under $5,000	1	5.6	1	2.6	2	3.5
$5,000-$15,000	9	50.0	5	13.2	14	25.0
$15,000-25,000	4	22.2	6	15.8	10	17.9
$25,000-35,000	3	16.6	14	36.8	17	30.4
$35,000-45,000	1	5.6	5	13.2	6	10.7
$45,000 and over	0	0	7	18.4	7	12.5
Totals	18	100	38	100	56	100

White mother caregivers' annual incomes were higher than black mother caregivers' annual incomes. Over half of the black mother caregivers had incomes less than $15,000, while about two-thirds (68.4%) of Whites had incomes greater than $25,000. Table 7 shows length of time in caregiver role.

Table 7. Length of Time in the Caregiver Role by Race

	Race					
	Blacks		Whites		Total	
Years in Role	N	%	N	%	N	%
Under one year	0	0	1	2.6	1	1.8
1 to 5 years	2	11.1	4	10.5	6	10.7
6 to 10 years	7	39.9	6	15.8	13	23.2
11 to 15 years	4	22.2	9	23.7	13	23.2
more than 15 years	5	27.8	18	47.4	23	41.1
Totals	18	100	38	100	56	100

As the table indicates, white mother caregivers had been in the caregiver role more years than black mother caregivers. Eighteen (47.4%) white mother caregivers versus five (27.8%) Black caregivers had been in the role more than 15 years.

White mother caregivers were either Catholic (37%) or Protestant (63%). All black mother caregivers were Baptist Protestants. Table 8 shows health status of caregiver by race.

Table 8. Health Status of Caregiver by Race

	Race					
	Blacks		Whites		Total	
Health Problems	N	%	N	%	N	%
Heart problems	4	22.1	10	26.3	14	25
High blood pressure	11	61.1	8	21.0	19	34
Arthritis	1	5.6	9	23.7	10	17.8
Diabetes	1	5.6	9	23.7	10	17.8
Obesity	1	5.6	2	5.3	3	5.4
Totals	18	100	38	100	56	100

Four (22.1%) of the black caregivers reported having heart problems. Eleven (61%) black mother caregivers reported having high blood pressure. Ten (26.3%) white mother caregivers reported having heart problems. Eight (21%) white mother caregivers reported having high blood pressure. Just under one fourth (23.7%) of the white mother caregivers reported arthritis, compared to one (5.6%) black mother caregiver. One (5.6%) black mother caregiver reported obesity, compared to two (5.3%) white mother caregivers. There was a higher incidence of diabetes (9,

23.7%) among white mother caregivers than black mother caregivers (1, 5.6%). Table 9 shows ages of mentally ill adult children by race.

Table 9. Ages of the Mentally Ill Adult Child by Race

	Race					
	Blacks		Whites		Total	
Ages	N	%	N	%	N	%
20-29	5	28	8	21	13	23.2
30-39	11	61	20	53	31	55.4
40-49	2	11	10	26	12	21.4
Totals	18	100	38	100	56	100

As Table 9 indicates, about three-fifths of black mother caregivers' and slightly over one-half of white mother caregivers' adult children were in the 30-39 age category. A higher percentage of black adult children than white adult children were in the 20 to 29 age category and a higher percentage of whites were in the 40-49 age category.

Black mentally ill adult children were almost evenly divided between males (10, 56%) and females (8, 44%). Over three-fourths of white mentally ill adult children were males and less than one-fourth were female. Table 10 shows the marital status of the mentally ill adult children by race.

Table 10. Marital Status of the Mentally Ill Adult Child by Race

	Race					
	Blacks		Whites		Total	
Marital Status	N	%	N	%	N	%
Married	0	0	1	2.6	1	1.8
Widowed	1	5.6	0	0	1	1.8
Divorced	0	0	5	13.2	5	8.9
Separated	0	0	1	2.6	1	1.8
Single (never married)	17	94.4	31	81.6	48	85.7
Totals	18	100	38	100	56	100

Most of the mentally ill adult children had never married. One black adult child was widowed, six white adult children were separated or divorced, and one white adult child was currently married. Table 11 shows level of education of the mentally ill adult children by race.

Table 11. Level of Education of the Mentally Ill Adult Children by Race

	Race					
	Blacks		Whites		Total	
Level of Education	N	%	N	%	N	%
Less than H.S.	4	22.2	7	18.4	11	19.6
H.S./GED	9	50.0	13	34.2	22	39.3
Some College	5	27.8	12	31.6	17	30.4
College Degree	0	0	4	10.5	4	7.1
Masters completed	0	0	2	5.3	2	3.6
Totals	18	100	38	100	56	100

Over half of the black mentally ill adult children had completed high school or had their General Education Diplomas (GED). None, however, had completed college. Five (27%) had attended college compared to 12 (31.6%) white adult children with some college. About 16% of the white mentally ill children had completed college or had graduate degrees. Table 12 shows employment status of mentally ill adult children by race.

Table 12. Employment Status of Mentally Ill Adult Children by Race

	Race					
	Blacks		Whites		Total	
Employment Status	N	%	N	%	N	%
Working full-time	1	5.6	0	0	1	1.8
Working part-time	0	0	7	18.4	7	12.5
Not employed	17	94.4	31	81.6	48	85.7
Totals	18	100	38	100	56	100

As Table 12 indicates, most black and white mentally ill adult children are not employed. One black mentally ill adult child is employed full-time, and seven of the white mentally ill adult children are employed part-time. Table 13 shows religious denomination of mentally ill adult children by race.

Table 13. Religious Denomination of Mental Ill Adult Children by Race

	Race					
	Blacks		Whites		Total	
Religious denomination	N	%	N	%	N	%
Protestant	18	100	24	63.2	42	75.0
Catholic	0	0	13	34.2	13	23.2
Jewish	0	0	1	2.6	1	1.8
Totals	18	100	38	100	56	100

All of the black mentally ill adult children were Protestant. Over three-fifths of the white mentally ill adult children were Protestant, only one was Jewish, and about one-third was Catholic. Black mentally ill adult children practice the same religion as their mothers. Table 14 shows the number of hospitalizations of mentally ill adult children by race.

Table 14. Number of Hospitalizations of Mentally Ill Adult Children by Race

	Race					
	Blacks		Whites		Total	
Hospitalizations	N	%	N	%	N	%
None	0	0	1	2.6	1	1.8
1 to 5 times	11	61.1	18	47.4	29	51.8
6 to 10 times	7	38.9	16	42.1	23	41.0
11 to 18 times	0	0	2	5.3	2	3.6
more than 19 times	0	0	1	2.6	1	1.8
Totals	18	100	38	100	56	100

As Table 14 indicates, approximately three-fifths of black mentally ill adult children had been hospitalized from 1 to 5 times, and the other two-fifths had been hospitalized 6 to 10 times. A slightly greater percentage of white mentally ill adult children had been hospitalized 6 to 10 times than black mentally ill adult children. Table 15 shows the age of adult children when diagnosed mentally ill.

Table 15. Age of Adult Child When Diagnosed Mentally Ill

	Race					
	Blacks		Whites		Total	
Ages	N	%	N	%	N	%
2 to 10 years	1	5.6	2	0.5	3	5.4
11 to 15 years	0	0	5	13	5	8.9
16 to 20 years	12	66.6	22	58	34	60.7
21 to 30 years	5	27.8	9	24	14	25
Totals	18	100	38	100	56	100

As Table 15 indicates, the majority of mentally ill adult children in this sample were diagnosed between 16 and 20 years of age. Table 16 shows the living situations of mentally ill adult children by race.

Table 16. Living Situations of Mentally Ill Adult Children by Race

	Race					
	Blacks		Whites		Total	
Living Situations	N	%	N	%	N	%
With mother	11	61.1	11	29.9	22	39.2
Own apartment	7	38.9	26	68.4	33	59
Other (prison, jail)	0	0	1	2.6	1	1.8
Totals	18	100	38	100	56	100

As Table 16 indicates, three-fifths of the black mentally ill adult children lived with their mothers, compared to over one-fourth (29.9%) of the white mentally ill adult children. Two-thirds (68.4%) of the white mentally ill adult children lived in their own apartment, compared to two-fifths (38.9%) of the blacks. One (2.7%) white was in prison.

The mean number of individuals in black mother caregivers' households was 2.7, compared to 2.1 living in white caregivers' households. Table 17 shows mean scores of each stressor across the whole sample (higher scores indicate higher stress). As Table 17 shows, the three top stressors for the caregivers were: (1) the fact my child has a mental illness; (2) concern over the mentally ill child's future, and (3) child's symptoms of the mental illness. This finding is consistent with previous research. Creer and Wing (1974), Hoeing and Wing (1966), and Doll, Lifton, and Thompson (1977) identified these same items as major stressors for family caregivers. Table 18 shows the mean stress scores by race.

Table 17. Mean Stress Scores and Standard Deviations Across Whole Sample

Stressor	Mean Scores	S.D.
Fact that my child has a mental illness	1.821	.43
Concern about child's future	1.768	.49
Child's symptoms of mental illness	1.768	.50
Difficulty accepting situation	1.679	.47
Concern over what would happen to family if something happened to her	1.643	.43
Time away from family	1.636	.49
Guilt feelings about child's mental illness	1.589	.50
Feelings of sadness	1.571	.68
Loss of time for self	1.389	.74
Not knowing where to go for help	1.321	.81
Physical fatigue	1.179	.74
Relationship with my spouse	1.139	.83
Worry over the effect the mental ill adult child's illness has on the other children	1.130	.75
Lack of information/knowledge about mental illness in general	1.054	.80
Relationship with friends/neighbors	.875	.79
Relationship with professional staff	.821	.74
Loss of time and energy at work	.786	.89
Reactions of society to me and my family	.786	.76
Contact with public agencies	.732	.82
Relationship with parents/spouse's parent	.703	.83
Worry over my own physical health	.661	.67
Worry about my own mental health	.643	.77
Fear of nervous breakdown	.589	.79
Difficulty with Medicaid/Medicare	.411	.73

Table 18. Mean Stress Scores by Race

Stress Items	Blacks (N=18)	Whites (N=38)
Difficulty accepting situation	1.833	1.605
Concern over child's future	1.833	1.737
Fact that my child has a mental illness	1.778	1.842
Child's symptoms of mental illness	1.778	1.842
Guilt feelings	1.611	1.579
Lack of time for myself	1.556	1.306
Loss of time for family	1.529	1.684
Feelings of sadness	1.500	1.6056
Child not receiving proper treatment	1.333	1.632
Relationship with spouse	1.125	1.162
Not knowing where to go for help	1.222	1.363
Financial problems	1.176	1.026
Loss of time and energy at work	1.111	.632
Worry over the effect that the mentally ill adult child's illness has on other children	1.059	1.162
Lack of information/knowledge about mental illness in general	1.056	1.053
Relationship with parents/spouse's parents	.875	.613
Worry about my own mental health	.833	.553
Relationships with friends and neighbors	.776	.921
Language used by professionals	.778	.632
Fear of nervous breakdown	.772	.526
Contact with public agencies	.611	.789
Relationships with professional staff	.556	.947
Worry over my own physical health	.556	.711
Reactions of society to me and my family	.444	.947
Difficulties with Medicaid/Medicare	.222	.500

As Table 18 indicates, black and white mother caregivers' lives are affected by many of the same stresses and circumstances. For black mother caregivers, the stresses with the highest mean scores were: (1) accepting the situation; (2) concern over child's future; (3) fact that my child has a mental illness; (4) child's symptoms of mental illness; and (5) guilt feelings. For white mother caregivers the stressors with the highest mean scores were: (1) the fact that my child has a mental illness; (2) child's symptoms of mental illness; (3) concern over child's future; (4) loss of time for family; and (5) child not receiving proper treatment. Scores range between 1 and 3 with no stress = 1, moderate stress = 2, and severe stress = 3. Table 19 shows mean scores of coping strategies across the whole sample.

Table 19. Mean Scores of Coping Strategies Across Whole Sample

Coping Strategies	Mean Score	S.D.
Trust God	1.818	.47
Count on self	1.750	.47
Attitude that life must go on	1.607	.62
See things in positive way	1.536	.73
Read books or other written material	1.500	.66
Ask relatives to help	1.411	.69
Accept things as they are	1.3827	.73
Talk with other people	1.232	.66
Talk to my family about the problem	1.196	.67
Cry a lot	1.143	.67
Talk with spouse about personal feelings	1.094	.79
Ask for professional help	1.073	.65
Try not to think about the problem	1.056	.68
Keep it all inside	1.036	.76
Change chores around house	.830	.75
I do nothing	.804	.67
Ask friends and neighbors to help	.732	.70
Spend time at work	.560	.67

Table 19 indicates that the three coping strategies with the highest mean scores are trusting God, counting on self, and having the attitude that life must go on. Scores range between 1 and 3 and Never = 1, Sometimes = 2, Often = 3. Table 20 shows coping strategy mean scores by race.

Table 20. Mean Scores of Coping Strategies by Race

Coping Strategy	Blacks	Whites
	Mean Scores	Mean Scores
Attitude that life must go on	1.944	1.447
Trust God	1.824	1.816
See things in a positive way	1.667	1.474
Count on self	1.556	1.842
Read books or other written materials	1.500	1.500
Ask for Professional help	1.444	1.395
Ask relatives to help	1.412	.921
Accept things as they are	1.353	1.395
Cry a lot	1.333	1.053
Talk about the problem with others	1.167	1.263
Try not to think about the problem	1.125	1.026
Talk to my family about the problem	1.111	1.237
Keep it all inside	1.056	1.026
Change chores around the house	.944	.771
Talk to spouse about personal feelings	.944	1.171
Do nothing	.833	.789
Ask friends and neighbors to help	.722	.737
Ask religious body	.667	.816

As Table 20 indicates, there are many similarities in coping strategies used by black and white mother caregivers. The three top coping strategies used by black mother caregivers are: (1) adopt the attitude that life must go on; (2) trust God; and (3) see things in a positive way. The three top strategies for white mother caregivers are: (1) count on self; (2) trust in God; and (3) read books or other written material. Black and white mother caregivers had a similar mean score for "trust God." Black mother caregivers had a slightly higher mean score for "seek professional help" than white mother caregivers. Table 21 shows mean scores of resource utilization across the whole sample.

Table 21. Mean Scores of Resource Utilization Across the Whole Sample

Resource Utilization	Mean Score	S.D.
Financial assistance	1.679	.37
Other parents with special children	1.589	.86
Other relatives	1.376	.41
Close friend	1.250	.77
Social worker	1.232	.73
Spouse	1.125	.75
Other children	1.232	.73
Respite	1.125	.60
Psychiatrist	.911	.84
Minister/church member	.786	.86
Medical doctor	.661	.86
Parents	.625	.86
Psychologist	.571	.79
Neighbor	.571	.79

As Table 21 indicates, the three resources with the highest mean scores across the whole sample were financial assistance, other parents with special children, and other relatives. Scores range between 0 and 3. No help = 0, Of little help = 1, Somewhat helpful = 2, Very helpful = 3. Table 23 shows mean scores of resource utilization by race.

Table 22. Resource Utilization Mean Scores by Race

	RACE	
RESOURCES	**BLACKS' Mean Scores**	**WHITES' Mean Scores**
Financial assistance	1.833	1.605
Other relatives	1.778	1.237
Other parents with special children	1.444	1.658
Close friend	1.333	1.211
Social worker	1.222	1.237
Other children	1.167	1.263
Spouse	1.111	1.132
Parents	.889	.500
Other friends	1.056	.842
Minister/church member	.732	.816
Neighbors	.500	.605
Medical doctor	.500	.605
Psychiatrist	.500	1.105
Psychologist	.389	.658

As Table 22 shows, the three resources used most by black mother caregivers were: (1) financial assistance; (2) other relatives; and (3) other parents of special children.

The three top resources used by white mother caregivers were: (1) other parents with special children; (2) financial assistance; and (3) other children within the family. This section has presented demographic and descriptive data of mother caregivers, their circumstances, and their mentally ill adult children. The following section presents results of t-tests that examine the relationships between race and other selected variables.

Analysis of Relationships Between Selected Variables

This section presents the findings from examining relationships between selected variables, and is organized around the research questions to determine if there is a statistically significant difference between black and white mother caregivers in sources of stress, types of coping strategies employed, and resource utilization.

Is there a statistically significant difference between black and white mother caregivers' sources of stress? A t-test was conducted to compare the mean stress score for black mother caregivers with the mean stress score for white mother caregivers. A statistically significant difference was not found between black and white mother caregivers on the mean stress score. As shown in Table 23 the mean stress score for black mothers was 58.9383 compared with 55.7474 for white mother caregivers, or a difference of 3.1909 in the mean between the races, a statistically nonsignificant difference ($t = .188$, $p = .310$).

Table 23. T-test for Racial Differences on Mean Scores for Sources of Stress

SCORES Race	Number Cases	Mean Scores	Standard Deviation
Black	18	58.9383	5.698
White	38	55.7474	7.555

This finding is consistent with that of previous researchers, who found that sources of stress for family caregivers were varied and many. In their 1974 study, Creer and Wing found varied sources of stress among caregivers, including exposure to unpredictable behaviors, anxiety and guilt feelings, and worry over the welfare of the mentally ill relatives if the caregiver could not continue caregiving tasks. These and other sources of stress were identified by black and white mother caregivers in this study.

The second question was "Is there a statistically significant difference between the coping strategy mean scores of black and white mother caregivers?" A t-test was conducted to analyze the findings pertaining to this question. The mean scores of black and white mother caregivers varied only slightly. The mean score for the black mother caregivers was 43.6861, and the mean score for the white mother caregivers was 43.8473, as shown in Table 24 below. The difference was statistically nonsignificant ($t = .887$, $p = .219$).

Table 24. T-test for Racial Differences on Mean Coping Strategies Scores

Race	Number Cases	Mean Scores	Standard Deviation
Blacks	18	43.6861	3.104
Whites	38	43.8473	4.121

This finding supplements that of previous researchers. Jahoda (1955) and White (1978) classified individuals as active or passive, flexible or rigid, or effective or poor copers depending on their choice of coping strategy. These investigators did not attempt to evaluate the effectiveness of a coping strategy.

The third question was, "Is there a statistically significant difference in resource utilization between black and white mother caregivers?" A t-test was conducted to analyze the findings pertaining to this question. The mean scores between the two racial groups varied little as shown in Table 25 below. The mean score for black mothers was 28.2667 and the mean score for whites was 31.3056, a difference of 3.0389 between the two racial groups. This was a statistically nonsignificant difference ($t = .194$, $p = .706$).

Table 25. T-test for Racial Difference on Resource Utilization Mean Scores

Race	Number Cases	Mean Scores	Standard Deviation
Black	18	28.2667	3.033
White	38	31.3056	3.314

This finding indicates that blacks and white mother caregivers utilize available resources at about the same rate. This finding differs from John's (1990) finding which indicated that inadequate resources were a major stressor for African-American women.

This section has presented statistical analyses of selected variables in this study. Results indicated that black and white mother caregivers differ little in sources of stress, coping strategies, and resource utilization. The lack of statistical difference between black and white mother caregivers' sources of stress and coping strategies is consistent with the findings of previous researchers. However, at least one previous study has shown that black mother caregivers do not utilize resources as much as white mother caregivers. Results of the current study show no significant difference between black and white mother caregivers' resource utilization.

While the findings of this study are informative and revealing, caution should be exercised in their interpretation. First, the sample size of black subjects was small and is not representative of the larger population. Only black mother caregivers who were active in self-help groups participated in the study. All black mother caregivers of mentally ill adult children are not members of self-help groups. Therefore, their sources of stress, coping strategies, and resource utilization may differ significantly from black mother caregivers who participated in this study. Second, the majority of the white mother caregivers in this study were elderly, retired and active in self-help groups. These white mother caregivers are not representative of all white mother caregivers in the larger population. Some white mother caregivers are younger,

employed, less educated, single, and have lower annual incomes. Third, the stress scale, coping strategy scale, and resource utilization scale had low reliabilities. The low reliabilities of the three sets of items may have prevented the detection of potentially important differences between black and white mother caregivers.

Mothers' Responses to the Open-ended Questions

The goal of the open-ended questions is to derive from the mother caregiver's point of view an in-depth understanding of how caring for a mentally ill adult child impacts her life and her family's life, and how she manipulates available resources to help relieve her caregiving burden.

Ten mother caregivers, five blacks and five whites, volunteered to respond to a series of open-ended questions designed to generate the desired information. The investigator asked each mother caregiver the questions listed below. Their responses are grouped by race. An introduction precedes the responses to each question and a summary of the analysis of the responses concludes the discussion on each question. Responses are grouped by race for clarity purposes.

The open-ended questions were:

1. In general, how would you describe yourself, your mentally ill adult child, and your family?
2. What are some major challenges you face frequently?
3. What are things that create the most stress for you?
4. What resources do you use?
5. In addition to the resources that you have used, what additional resources would be helpful and beneficial?

In response to question one, black and white mother caregivers expressed both negative and positive comments that indicated how they perceived themselves. Although the ten mother caregivers appeared surprised by the question, their

responses appeared to be candid. Black mother caregivers gave the following responses:

> *"At times I get excited quickly. It all depends on what the circumstance is at the time. I am learning to be calm now and to take things as they come."*
>
> *"I'm intelligent but not very patient. I have no patience. I tolerate a whole lot. I am learning how to be more tolerant."*
>
> *"I feel good about myself. I let nothing bother me. I decided to let things go."*
>
> *"I'm intense and strong. Very few things upset me. My religious convictions help me to be this way."*

White mother caregivers gave the following responses:

> *"Gee, I've never thought about that, but I'm kind of laid back. I think, not very sociable, lazy in some respect. I'm more of a mediator and peacemaker than anything else."*
>
> *"I have been forced to be strong. I got that from my mother. Mother was very strong."*
>
> *"I'm easy going, have a positive outlook on life. My health is good."*
>
> *"I am strong. I am the one my family depends on for everything."*
>
> *"Some times I let things get to me. When this happens I bounce back quickly."*

Black and white mother caregivers' self descriptions suggest that the nature of caregiving affects the caregiver personality in such a way that old behaviors and attitudes are subject to modification. New behaviors and attitudes may replace long-standing ones when they negatively impact the mother caregivers' interactions with the mentally ill adult children.

When describing their mentally ill adult children, mother caregivers' descriptions of their mentally ill adult children tended to be influenced by their children's current emotional stability. When symptoms of their children's psychiatric condition were under control, mother caregivers' descriptions were positive.

Black mother caregivers described their mentally ill adult children as follows:

"My daughter has a mental problem and is not able to take care of her children. She was a good mother before she got sick."

"When he is stable I am stable. He is stable when he takes his medicine. When not on his medicine he is too active, talks to himself, and gets upset easily."

"He is a loner but he gets along well with people when he is taking his medication."

"He has his bad time every year around Christmas. He stops taking his medicine and gets paranoid. Prior to then he is responsible, washes his own clothes and cooks his own meals."

"He is a good boy but a sick boy. I wish he was normal."

"She is persistent and demanding. At times she drives me nuts."

"He is smart and educated. Sometimes he looks and acts normal."

White mother caregivers described their mentally ill adult children as follows:

"He gets real stressed at the least little thing. It keeps him from working. It's hard to cope with him when he gets real stressed."

"He's a boy in a man's body. He is unstable and totally dependent upon me. He could not survive a week on the streets. He doesn't know how to pay bills, judgment bad."

"When on medicine my son is stable. He is in prison now and not getting the best care. When he killed my husband he was paranoid and real sick. He thought my husband was out to get him."

"That's hard. At times he can be really nice but that's not often. Most of the time he is angry with me because of his paranoia."

"She drives me crazy at times. She telephones me all the time. Sometimes I don't like her but I will always love her. She is a mental case, nothing like her sister."

"How do you describe a mentally ill person? Well, she was once pretty and took care of herself. Now that she is getting older, she acts and dresses like most mentally ill people."

Black and white mother caregivers are possibly never totally free from apprehension and uneasiness because at any time their mentally ill adult children may discontinue medications and disrupt their lives and other family members. Mother caregivers' descriptions are transitory. When the mentally ill adult child is symptom free and stabilized after a psychotic episode, mother caregivers' descriptions of their mentally ill adult child are again positive.

Mother caregivers' descriptions of their families varied. Some families were described as close knit, caring, and supportive. Others were described as distant, disruptive, and disturbed. Black mother caregivers gave the following descriptions of their families:

"I am not very involved with my family. My grandchildren, my son, and I are close. My son helps me with things I have to do. I get together with other family members at Christmas. They know little about what goes on in my life."

"We are a caring family. We care about each other and will do what we can for each other. My family understands my situation."

"I don't get along with my sisters. My children are helpful and we are friends. They help me take care of Don. Without their help I would have more trouble caring for Don."

"My daughter is real helpful. When her brother needs help she helps out by taking him shopping, etc. We work together helping Ray maintain himself on his own.

"Families suffer a lot when one of its members is mentally ill. My family has been through considerable pain because of David's illness. As a family I think we are close and support each other. My family looks out for each other. When things get too rough for me to handle by myself, they come to my rescue."

White mother caregivers' descriptions of their families were similar to those given by Black mother caregivers.

"My family is dysfunctional because of Jim's mental illness. Because of Jim's mental illness my relationship with my husband and my other children is not good. Having a mentally ill person in the family disrupts everything."

"My family has been devastated by Tom's illness. There is friction between me and my younger son who resents having to do for his older mentally ill brother."

"Great bunch of kids. Always there when I need them. They do things with their brother. He doesn't get as mad with them as he does with me because he knows they won't put up with his foolishness."

"If my family didn't help me out sometimes, life would be too overwhelming for me. My family is there when I need them, ready to help in any way they can."

"My family is the best family in the world. It's caring, loving, and supportive."

These mother caregivers' responses reflect those often expressed by families with a mentally ill relative. Some families grow closer with a catastrophe such as mental illness. Other families grow distant and uncaring. In any event, families are affected when one of their members is a victim of mental illness. Some families experience relationship problems, isolation, and open conflict among their family members.

Mother caregivers defined "challenges" as problems that they had to solve. Black mother caregivers described challenges they frequently face:

"Taking care of my mentally ill daughter's children and seeing to it that my daughter keeps her doctor's appointments and that she takes her medicine. Some how I manage to get these things done."

"Getting Frank to his doctor's appointments, making sure he keeps himself clean. I have to talk him into taking a bath."

"Verbal abuse when he's not taking his medicine."

"My greatest challenge is living with the fact my child has a mental illness."

"Accepting John the way he is is a challenge. He is real sick right now because he is not taking his medicine. Sometimes I am able to talk him into staying on his medicine when he does he treats me with kindness and respect."

White mother caregivers gave these responses when asked about challenges they frequently face:

"Sometimes just getting through the day is a challenge. Accepting his mental illness is a challenge."

"Having to go to his apartment to clean and shopping are challenges. I am tired when I leave work but I have to do these things for my child."

"Dealing with his anger is a challenge."

"My biggest challenge is controlling my quick temper. I have no patience. I pray daily for patience."

"Challenges are nothing but problems. Caring for my daughter is a major problem because she will not admit to having a mental problem. This in itself creates many challenges I must address every day."

Mother caregivers face many challenges or problems daily. Occasionally they must find solutions to three or four problems simultaneously. One black mother caregiver said, "Not all solutions are found in books." We must rely on wisdom,

experience, and sometimes trial and error. It is interesting to note that only one of the ten mothers mentioned that managing her anger was a problem. Not expressing anger and other emotions can be a source of severe stress.

When asked about sources of stress, mother caregivers gave a wide variety of responses. Black mother caregivers gave the following:

"Getting my son to keep his clinic appointments when I am away from home."

"Verbal abuse from my child. Negative comments from neighbors. Worry about his future when I'm gone."

"My daughter's negative attitude about the need for medication. Her refusal to take her medicine sometimes."

"My son's demands. He demands money from me all the time. This and his other expectations cause me a lot of stress."

"He wanders about a lot at night. I worry about his being arrested or beaten up or killed."

White mother caregivers described similar sources of stress:

"The relationship between my husband and our daughter. At times they are at each other's throat. My husband don't understand our daughter's illness. I love both of them and their not getting along creates considerable stress for me."

"When he gets psychotic and has to be hospitalized."

"His being evicted from his apartment. Where would he live if this happened."

"His not taking his medicine and getting into fights."

"His approaching women for sex."

The primary sources of stress for both black and white mother caregivers relate to the mentally ill adult child's current functioning and adjustment. However, mother

caregivers may vary in how they experience what appears to be an identical source of stress. What causes stress for one mother caregiver may not necessarily cause stress for another.

Mother caregivers were next asked which resources they utilized most. Black mother caregivers gave the following responses:

"Bridgehaven and Seven County services."

"His care manager. With his help my son is learning how to pay bills and shop for groceries."

"My other children and friends."

White mother caregivers cited the following resources as the ones used most.

"Support groups, my mother, and trusting God."

"Schizophrenic Foundation and talking with other parents with mentally ill children."

"Doctors at VA hospital and myself."

"The Kentucky Alliance for the Mentally Ill."

"My family and the Alliance."

Both black and white mother caregivers utilize many resources to assist them in their role. Their memberships in various support groups and association with relatives of other mentally ill individuals have not lessened stress but have provided them with an arena where they can discuss disappointments, fears, joys, hopes, and dreams with an understanding and caring audience. The mother caregivers' contacts with representatives of the mental health and medical professions have been sources of help for most of them. The most significant resource cited by this group of

caregivers was the family. It is interesting to note that money was not identified in this section as a frequently used resource. However, when caregivers were given a written list of resources money was identified as the most used resource.

Finally, mother caregivers were asked about what type of additional resources would be helpful to them. Black mother caregivers gave the following responses:

"I would like to see arts and crafts groups and rehabilitation opportunities."

"Organizations that could teach my son how to become self sufficient."

"Education. We need education about new drugs coming out. Professionals need to talk with families more. It is the family that knows about the mentally ill family member. When they want information from you they want an immediate response. The way I see it the scale needs to be balanced."

"Need better housing for our mentally ill relatives."

"Better housing."

"More places where the mentally ill can go for recreation activities."

"Better housing."

White mother caregivers also identified a number of additional resources:

"We need decent and affordable housing for the mentally ill."

"Adequate housing that does not require half of their income."

"We need better housing for the mentally ill."

"Better housing."

"Better housing."

The most cited new additional resource needed was better and affordable housing for the mentally ill. Mother caregivers also saw a need for activities and organizations

that would offer their mentally ill adult children the chance to become more independent and self-sufficient.

Two Case Study Presentations

The following section attempts to bring the mother caregivers' analyses of their situation to life by presenting case studies of two mothers who participated in the study.

The first mother caregiver is a 62-year-old black woman. She has been married to John for 34 years. Although the marriage has lasted many years, there have been many ups and downs. One problem that bothers Annie is John's belief that he was too easy on the children when they were growing up. When their son Tim became mentally ill, John thought he may have contributed to Tim's mental illness by being too easy on him. John has never accepted Tim's mental illness.

Annie admits that her family life never lived up to her expectations. She wanted a warm, loving family but John was not the kind of husband that showed much affection. Although affection was lacking in the marriage, John has been there for Annie when she needed him.

Annie has worked most of her married life. Her last job, as a cafeteria worker for the Board of Education, lasted 18 years and ended 5 years ago when she fell and hurt her right leg. She has not worked since the accident. Her monthly Social Security check is around $700. John is retired but works weekends tending bar at a local country club. Their combined annual income is $15,000. They own their home and are able to get the things they need.

Tim, 27, the oldest of their six children, is schizophrenic (a severe mental illness) but manages to maintain himself in his own apartment. He was diagnosed mentally ill at the age of 20 and has been hospitalized in the state hospital more than 10 times. Annie worries about Tim because he sometimes stops taking his medicine. When this happens he walks the streets all hours, talks to himself, and thinks people are out to get him. When he comes to his parents' house he argues with his father and younger brother Don who lives with them. Don is paralyzed and bedridden as a result of an automobile accident.

Annie feels that the state hospital staff have been helpful and supportive. The social worker at the mental health clinic has been there for her when she needed her in times of crises. Annie admits that it has been difficult accepting the fact that Tim has a severe mental illness and that he will never be able to live a full productive life. When he first got sick she knew little about mental illness and didn't understand his bizarre behavior. She worried about the effect his behavior had on the other children. She believes that nobody really knew how much she suffered emotionally, because she kept a lot of things inside.

Then Annie made the decision to learn as much as she could about her son's mental illness. When she learned that he was diagnosed Schizophrenic, she contacted the Schizophrenia Association. They sent her information to read. Annie's contact with the Schizophrenia Association has been a vital resource for her and has done much in helping her understand Tim's mental illness. Annie's relatives and her close friend Betsy have been her vital resources.

The white mother presented as a case study is Amy, a 68-year-old widow. Her husband, Henry, died ten years ago following a heart attack. Amy and Henry parented two children, James and Fran. Both James and Fran are mentally ill. James was diagnosed at age 23, and Fran at age 21. James lives alone in his own apartment and works part-time. Fran lives at home and helps out around the house.

Amy graduated from college and never worked outside the home when James and Fran were growing up. When they were in their teens she worked several years as a dress-maker. She has an annual income of $35,000. She is a Protestant and attends church regularly.

Amy has been in the caregiver role for twelve years. When she first learned that both James and Fran were mentally ill she was devastated. She began to read to learn all she could about their illnesses. Each child has a different diagnoses, James, schizophrenic, and Fran, manic depressive. Henry never really accepted the fact that the children were mentally ill. It was hard on Amy at first and it caused her a lot of stress because she "knew" people would say all kinds of things about the family.

Amy's reading about mental illness helped her learn more about her children's situation. However, only after James and Fran saw many physicians was Amy able to accept that the children were mentally ill. Sometimes Amy tries not to think about her problem. She cries often, and prays for changes in her situation.

When Amy's husband was living she could talk with him about her feelings and draw strength. She now draws strength and support from members of the Alliance for the Mentally Ill and a few friends who have stood by her over the years. She has

good relationships with James' and Fran's mental health workers. There was a time she did not take vacations because of James and Fran. She now takes time for herself, takes vacations, attends conferences and other meetings that offer information about mental illness.

Amy believes medication has done wonders for James and Fran. She admits that she becomes stressed when symptoms of James' or Fran's mental illnesses are florid.

CHAPTER 5

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

SUMMARY

This study was designed to examine the caregiving experience of mothers of mentally ill adult children and to determine if sources of stress, coping strategies, and resource utilization varied by race.

The fifty six (56) mother caregivers in this study were all biological mothers of mentally ill adult children, except one, an adoptive mother. Of the 56 mother caregivers 18 were black, and 38 white. The mentally ill adult children were either active clients with Seven County Services (SCS) or Bridgehaven. The mother caregivers were members of various chapters of the Louisville, Kentucky Alliance for the Mentally Ill or Bridgehaven, or were participants in Seven County Services parent support groups for families of the chronically mentally ill.

Data for the study were collected by the investigator during a one to one-and-one-half hour face-to-face interview in the privacy of the participants' home or another designated place. The interview schedule that guided the collection of the data consisted of structured questions pertaining to demographic characteristics of the caregiver and the mentally ill adult child, three batteries of items assessing caregivers' perceptions of stresses, coping strategies, and resource utilization, and a series of open-ended questions that ten respondents (five black and five white mother caregivers) completed. Their responses were tape recorded. The tapes were

religious denominations. White mother caregivers were either Protestant or Catholic, while black mother caregivers were all Protestant.

Black mother caregivers had been in the caregiver role fewer years--an average of six years, compared to an average of fifteen or more years for white mother caregivers. The average number of persons living in black mother caregivers' households was 2.7, compared to 2.1 persons in white mother caregivers' households. More white mentally ill adult children lived on their own than did black mentally ill adult children who lived with their families.

The mentally ill adult children ranged in age from 20 to 49 years old. On average, white mentally ill adult children were older than blacks. Compared to white mentally ill adult children, black mentally ill adult children had less education, lower incomes, fewer hospitalizations, and were more likely to live at home. The majority of white mentally ill adult children were males. Among black mentally ill adult children, there was almost an equal number of males and females.

The majority of the mentally ill adult children had never married. White mentally ill adult children were either Catholic, Jewish, or Protestant, while black mentally ill adult children were Protestant. The majority of black and white mentally ill adult children were diagnosed mentally ill between 16 and 20 years of age.

Husbands and fathers had difficulty accepting the adult child's mental illness. Their reactions to the adult child's mental illness included denial, rejection, resentment, and blame.

Time away from the family was a major source of stress for both black and white mother caregivers. However, being away from the family was more stressful for black mother caregivers than white mother caregivers because more black mentally ill adult children lived with their families than white mentally ill adult children. White mother caregivers also had concerns about time away from the family if employed and the mentally ill adult child lived in the home.

The three top stresses for all the mother caregivers were: (1) fact that my child has a mental illness; (2) concern over the child's future; and (3) symptoms of the mental illness. Black mother caregivers' three top stresses were: (1) accepting the situation; (2) concern over the child's future; and (3) the fact that my child has a mental illness. The three top stresses for white mother caregivers were: (1) fact my child has a mental illness; (2) symptoms of child's mental illness; and (3) concern over child's future.

The four top coping strategies used by all mother caregivers were: (1) trusting in God; (2) counting on self; (3) feeling life must go on; and (4) seeing things in a positive way. Black mother caregivers' four top coping strategies were: (1) adopting the attitude that life must go on; (2) trusting God; (3) seeing things positively and (4) counting on self. White mother caregivers' four top coping strategies were: (1) counting on self, (2) trusting in God; (3) reading; and (4) seeing things in a positive way.

The three top resources used by mother caregivers were: (1) financial assistance; (2) other parents with special children; and (3) other relatives. There was little

difference in the use of these three resources by black and white mother caregivers. However, white mother caregivers were more likely to ask their other adult children to help, while black mother caregivers asked relatives such as sisters or brothers.

Summary of Findings from Analysis of Responses of Mother Caregivers to the Open-ended Questions

The majority of the respondents in both groups had minimal difficulty in describing themselves. From their perspective, their dominant characteristics were strength, capability, impatience, intolerance, explosiveness, and religious faith.

Neither group expressed more religious faith than the other. Mother caregivers worked to modify behaviors and attitudes that negatively affected their interactions with their mentally ill adult children and tried to adopt new behaviors and attitudes.

Mothers' descriptions of their mentally ill adult children were influenced by their children's current emotional stability and their compliance with treatment regimes (e.g., staying on medication, and keeping clinic appointments). Dominant characteristics of mentally ill adult children were aggressiveness, demanding behavior, lack of control, disruptiveness, loving behavior, and sensitivity. Mother caregivers described their families as supportive, close knitted, caring, disturbed, disruptive, and distant.

Major challenges for mother caregivers were getting through the day, getting child to take medicine, getting child to keep doctor's appointment, getting child to take care of personal hygiene, rehospitalization of child, symptoms of the illness, loss of control over time for self, doing for child when physically fatigued, and meeting

needs of other family members. A major challenge for one mother caregiver was handling her anger.

Major stresses for mother caregivers were relationship with spouse, reactions from neighbors, keeping peace between family members, finances, symptoms of child's mental illness, child's inability to lead a normal life, concern over child's welfare when she was no longer around, physical fatigue, and isolation.

Major resources used by mother caregivers were Seven County Services parent groups, Kentucky Alliance for the Mentally Ill, Bridgehaven social workers, case managers and Seven County Services mental health workers.

Mother caregivers' desired additional resources were: more affordable living situations, opportunities for education and training, and more education on new medications.

CONCLUSION

Women spend many years of their lives caring for disabled and dysfunctional, relatives. Current trends in locus of care for the dysfunctional disabled, and elderly indicate increasingly that women of all ages, racial and ethnic backgrounds, and socioeconomic status as will be called upon to assume caregiving responsibilities sometime during their lives.

Women, especially those who have limited incomes and are members of minority groups, will out of necessity combine caregiving tasks with jobs outside the home. Because many low income minority women are in service and factory occupations, they are more likely to experience more job-related physical fatigue than women in

professional positions. For low income minority women, the added burden of caregiving increases their risk of "burnout." Stress becomes a critical issue for women when caregiving responsibilities dominate their lives. It becomes even more critical if women have other dependent children who need care.

The number of mentally ill adult black children living with their families is likely to increase in the future because black families are less able to make financial contributions to their children's living arrangements outside the home. On the other hand, some black families may benefit from having their mentally ill adult children live at home because their income may help meet household expenses.

Sources of stress for mother caregivers are varied and numerous. For example, mother caregivers are on call all hours and must handle crises confronting their mentally ill adult children when they occur. This constant vigil is one source of severe stress for these caregivers.

Mother caregivers' coping strategies are also varied and numerous. The intensity and source of the mother caregiver's stress will dictate coping strategy selection. Stress manifests itself in various ways: high blood pressure, heart trouble, anxiety, depression, etc.

In some situations, mother caregivers shoulder most if not all caregiving responsibilities with limited help. Added to this burden is ongoing grieving of mother caregivers over the loss of the person they once knew.

Mother caregivers in this study were aware of mental health resources that provided services to them and their mentally ill adult children. In addition, they were

aware of gaps in services and had aligned themselves with organizations which are advocates for the mentally ill. Some mother caregivers were successful in recruiting family members, friends and other relatives to assist at times. However, the mother caregiver made the most sacrifices. They continue to hope for a new drug or treatment that will cure their mentally ill adult child of his or her psychiatric disorder.

RECOMMENDATIONS

This study confirms what others have suggested, that socio-demographic variables affect the caregiver role. Although the findings of this study provided an answer to the three primary research questions, meaningful generalizations can only be made if further studies utilize a larger and more diversified sample.

The study findings were derived from limited case studies and a questionnaire. These findings must be formulated into meaningful hypotheses and rigorously tested in subsequent studies.

While the study findings yielded answers to the research questions, the t-tests were not statistically significant. Future testing must employ a series of meaningful statistical techniques such as multiple regression to examine the strength of relationships between demographic variables and; stresses, coping strategies, and other caregiving variables identified in the study.

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APPENDICES

APPENDIX A

CONSENT FORM

You are invited to participate in a study of middle-aged mothers who care for mentally ill adult children. We hope to learn how middle-aged mothers function in their role as caregivers. You were chosen because you care for a mentally ill adult child in your home or the mentally ill adult child's residence.

This study does not involve the use of any drugs or chemical substances. Therefore there is no risk of physical harm to subjects. There is, however, a chance that some items on the survey questionnaire and open-ended question section may elicit some emotional responses (e.g. crying, blaming, sadness). The investigator's experience as a mental health therapist has equipped her with skills to deal with emotional responses if it becomes necessary during the interview. An agreement has been reached with Seven Counties (SCS) and Bridgehaven to provide follow-up to subjects with issues and concerns after the interview. Risk to subjects is minimal because qualified individuals are available during the study and at the completion of the study to address concerns and issues.

Should you agree to participate in the study, the investigator will conduct a onetime, face to face interview at your convenience at a place of your choosing. Part of the interview will be taped. The time required is estimated not to exceed one to one-and-one-half hours. The benefit you may reasonably expect is the pride of knowing that the information you provide will contribute to increasing the knowledge and understanding of middle-aged mother caregivers. Ultimately the knowledge and information gained from the study can play a significant role in policy initiatives that could increase services and programs for this group of caregivers.

To maximize confidentiality, subjects will be assigned identification code numbers which will be used instead of names. The identification code number will appear on the survey instrument, open-ended section, audio tapes, and transcripts. The identification code number will be listed in a Master Code Book. The Master Code Book will be maintained in the investigator's home under lock and key in a fireproof file. The investigator will be the only person with a key and access to the study file. Any information that is obtained in connection with this study will never be associated with the subjects. The survey instrument, open-ended question section, audio tapes and transcripts will be destroyed by fire at the completion of the study.

Your decision whether or not to participate will not influence your future relations with Seven County Services, Bridgehaven, or the Louisville and Kentucky Alliance for the Mentally Ill.

Subjects may withdraw at any time from the study without penalty or prejudice. Subjects can refuse to answer any questions without penalty or prejudice.

If you have additional questions later, I, Mary C. Weathers, phone 1-227-6719 will be happy to answer them.

You will be offered a copy of this form to keep.

You are making a decision whether or not to participate. Your signature indicates that you have read the information provided and have decided to participate. You may withdraw at any time after signing this form should you choose to discontinue participation in the study.

_____ _____

Signature of Caregiver Date

_____ _____

Signature of Investigator Date

APPENDIX B

Interview Questionnaire
Caregiver Information

1. Race
   1. Black 2. White 3. Other

2. How are you related to the person for whom you provide care?
   1. Biological Mother
   2. Step-Mother
   3. Adoptive Mother
   4. Other (specify) _____

3. List all household members and relation to you.

   _____ _____
   _____ _____
   _____ _____
   _____ _____
   _____ _____

4. What is your birth date? Month ___ Year ____ Age _____

5. What is your current marital status?
   1. single
   2. married
   3. divorced
   4. widowed
   5. separated

6. Number of years _____

7. What is the highest level of schooling you have completed?
   1. 8th grade or less
   2. Exact grade level through 12 _____
   3. GED
   4. Some college
   5. Highest degree

8. What is your occupation? _____

9. How many hours do you work a week? _____hours.
   1. less than 20 hours
   2. 21 to 40 hours
   3. more than 40 hours

10. What is your approximate family income (last year)?
    1. less than $5,000 a year
    2. between $5,000 and $15,000
    3. between $15,000 and $25,000
    4. more than $40,000 a year

11. What is your religious preference?
    1. Protestant
    2. Catholic
    3. Jewish
    4. Other
    5. No religion

12. How long have you been in the role of caregiver?
    1. less than a year
    2. 1 year to 5 years
    3. 6 years to 10 years
    4. 11 years to 15 years
    5. more than 15 years

13. How is your health?
    1. Excellent
    2. Good
    3. Fair
    4. Poor

14. What health problems do you have? (If checked 3 or 4).

15. Who does the housekeeping and cooking? Write 1 for the major worker and 2 for the assistant. (If there is no assistant do not write 2).

    Housekeeping (1) (2) Cooking (1) (2)
    1. myself
    2. my spouse
    3. parent
    4. children
    5. other

Adult Child Information

16. Race
    1. Black
    2. White
    3. Other

17. Sex
    1. male
    2. female

18. How is the adult child related to you?
    1. biological child
    2. step-child
    3. adoptive child
    4. other (specify)

19. What is your child's birth date? Month ____ Year ____ Age _____

20. What is your adult child's marital status?
    1. single
    2. married
    3. divorced
    4. separated
    5. widowed

21. Number of years _____

22. What is the highest level of schooling the adult child has completed?
    1. 8th grade or less
    2. exact grade level through 12th grade
    3. GED
    4. some college
    5. highest degree
    6. post college study

23. Is the adult child employed?
    1. Yes
    2. No

24. What is his/her job or occupation? _____

25. How many hours does he/she work a week?
    1. less than 20
    2. 21 to 40
    3. more than 40 hours

26. What is his/her approximate income (last year)?
    1. less than $5,000 a year
    2. between $5,000 and $15,000
    3. between $15,000 and $25,000
    4. between $25,000 and $40,000
    5. more than $40,000

29. What is his/her religious preference?
    1. Protestant
    2. Catholic
    3. Jewish
    4. Other
    5. No religion

At this time I would like to ask you about your adult child's mental disorder.

28. How long has your adult child been mentally ill?

29. At what age was he/she diagnosed as having a mental disorder?

30. What was the impact on you of the diagnosis?

31. What did you tell your adult child about his/her mental illness.

32. How many times has he/she been hospitalized?
    1. none
    2. 1 to 5 times
    3. 6 to 10 times
    4. more than 10 times

Now lets talk about your experience as a caregiver. When we deal with mental illness, there are many kinds of stresses we experience. Some of these stresses are worse than others. Using the answers on the cards as a guide rate the following potential stresses. I will read in terms of whether they were very stressful for you, moderately stressful or not stressful for you at all.

	very stressful	moder. stressful	not stressful
33. The fact that my child has a mental illness.			
34. Financial problems			
35. Concern that if something happened to me it would be hard on the rest of the family.			

36. Relations with friends and neighbors

37. Fear of nervous breakdown

38. Not knowing where to go for help

39. Difficulty accepting the situation

40. Concern about my child's future

41. Concern that child would not receive proper treatment

42. Guilty feelings about my child

43. Worry about my mental health

44. Lack of info/knowledge about the illness in general

45. Language used by professionals

46. Loss of time and energy at work

47. Worry about my physical health

48. Worry about the effect on other children

49. Relations with my spouse

50. Time away from family

51. Relations with parents/spouse's parents

52. Loss of time for myself

53. Relations with professional staff

54. Contact with public agencies

55. Reaction of society towards myself and family

56. Symptoms of my child's illness

57. Feelings of sadness

59. Physical fatigue

60. Other

Now I would like talk about ways you have or attempted to cope with these stresses. In "times of difficulty," people cope with stresses in many different ways. Using the answers on the card I gave you please let us know how often you use these potential coping strategies.

	never	sometimes	often
1. I do nothing	_____	_____	_____
2. Read books or other written material	_____	_____	_____
3. Ask others for info	_____	_____	_____
4. Ask relatives to help	_____	_____	_____
5. Ask for prof. help	_____	_____	_____
6. Ask friends or neighbors for help	_____	_____	_____
7. Ask religious body for help	_____	_____	_____
8. Feel that life must go on	_____	_____	_____
9. Try not to think about the problem	_____	_____	_____
10. Accept things as they are	_____	_____	_____
11. Trust in God	_____	_____	_____
12. Keep it all inside	_____	_____	_____
13. Cry a lot	_____	_____	_____
14. Count on myself	_____	_____	_____
15. Spend more time at work	_____	_____	_____
16. Changed chores around the house	_____	_____	_____

17. Talk to my spouse about personal feeling _____ _____ _____

18. Talk to my family about the problem _____ _____ _____

19. Talk about the problem with other people _____ _____ _____

20. Try to see things as positively as possible _____ _____ _____

21. Other _____ _____ _____

Now I would like to talk with you about to whom you turn for support and assistance. We have a list of several potential sources of help. Using the answers on the card, tell me how helpful each of these sources have been for you, in general. If you have had no contact with these, let us know.

	very helpful	somewhat helpful	of little help	no contact
22. spouse	_____	_____	_____	_____
23. social worker	_____	_____	_____	_____
24. close friend	_____	_____	_____	_____
25. my parents	_____	_____	_____	_____
26. my other children	_____	_____	_____	_____
27. psychiatrist	_____	_____	_____	_____
28. psychologist	_____	_____	_____	_____
29. other relatives	_____	_____	_____	_____
30. other friends	_____	_____	_____	_____
31. physician	_____	_____	_____	_____

32. other parents with special children	_____	_____	_____	_____
33. neighbors	_____	_____	_____	_____
34. ministers or church members	_____	_____	_____	_____
35. financial assistance	_____	_____	_____	_____
36. respite care	_____	_____	_____	_____
37. other	_____	_____	_____	_____

I have just a few more questions to ask you about your experience as caregiver to an adult child.

1. In general, how would you describe yourself, the child, and your family?

2. What are some major challenges you face frequently?

3. What are things that create the most stress for you?

4. What resources do you use?

5. Of all the resources you have or have not received which do you think you need most?

6. What are the most helpful?

7. What do you think would be helpful that you don't have available to you?

VITA

Mary Cosby Weathers was born in Limestone County, Alabama on October 8, 1934. She attended both elementary school and high school in Louisville, Kentucky. In 1952, she entered Howard University, Washington, D.C., graduating with a B.A. in History and Government in 1956. After graduating, she taught 7th and 8th grade students at Bond Washington Elementary School, Elizabeth, Kentucky. After three years of teaching, she became a social worker trainee at Central State Hospital, Lakeland, Kentucky. After successfully completing the one year training program, she entered Kent School of Social Work, University of Louisville in 1960 and completed requirements for her M.S.S.W. in 1962. Since then, she had held numerous social work and administration positions with Central State Hospital, Seven County Services, and the University of Louisville. In January, 1971 she joined the Sociology faculty at Kentucky State University in 1989 and is an Assistant Professor in the Division of Social Work/Criminal Justice. In 1984 she began her doctoral work at the University of Tennessee, Knoxville. Dr. Weathers was co-author of a Model Demonstration Project title: Training Senior Citizens to Serve as Effective Board Members on Human Services Boards while an administrator in University College, University of Louisville, in 1979. She is a member of Delta Sigma Theta Sorority, Inc.