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by

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**How Important is Race and Ethnicity?  
Examining Caregiving Practices of Siblings Caring for a Brother or Sister  
Diagnosed with a Severe Mental Illness**

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**How Important is Race and Ethnicity?  
Examining Caregiving Practices of Siblings Caring for a Brother or Sister  
Diagnosed with a Severe Mental Illness**

**by**

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## **Dedication**

I would like to dedicate this dissertation to my grandfather, William Douglas Holmes, and my mother, Lena Roberta Earl, for always standing by my side and making sure I had the means to make it this far.

I love you both.

Tara

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*"No duty is more urgent than that of returning THANKS."  
- ST Ambrose*

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***"My friends are my estate."  
- Emily Dickinson***

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**How Important is Race and Ethnicity?  
Examining Caregiving Practices of Siblings Caring for a Brother or Sister  
Diagnosed with a Severe Mental Illness**

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Tara Roshell Earl, Ph.D.

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Supervisor: King E. Davis

Adult siblings of persons with severe mental illness are likely to assume increasing roles in the care and support of their relatives with severe mental illness. The current mental health policy system is not only severely fragmented, it has failed to recognize and address the unique needs of ethnic minority siblings as caregivers. The present study investigated the amount of instrumental support and expectations of future caregiving responsibilities of adult siblings of persons with severe mental illness. Caregiving practices of White siblings and siblings of color were compared. Data was obtained by survey responses from 93 siblings of persons with severe mental illness. Participants were solicited from national advocacy groups, county mental health centers, and adult outpatient community mental health clinics from across the country.

Bivariate and multivariate analyses indicated that siblings of color provided care differently than White siblings, there was a marked difference in the caregiving practices

of siblings of color and White siblings, female siblings were more likely to spend time caring for their relatives than males, midlife roles (career, family, children) often competed with a sibling's ability to provide care, and feelings of closeness to one's family did influence the sibling's level of involvement and expectations of providing care in the future.

As the health care arena continues to advance, mental health providers and policy makers need to actively consider cultural diversity and ensure that their programs and policies incorporate this into their plans. As siblings increasingly begin to assume caregiving responsibilities, mental health professionals, policy makers, and researchers must broaden or update their definitions of "support system" for adults with mental illness. Instead of turning to the aid of mothers and fathers out of habit, they are encouraged to look beyond parents, especially when working with families of color. Encouraging involvement from siblings as early in the treatment phase as possible may help to achieve optimal patient outcomes in the long run.

## Table of Contents

<b>List of Tables</b> .....	xii
<b>List of Figures</b> .....	xiv
<b>Chapter 1: Introduction</b> .....	1
Statement of the Problem.....	3
Significance of the Problem.....	5
Conceptual Framework.....	7
Conceptualizing Factors that Effect Caregiving .....	7
Caregiving in Minority Communities.....	9
Childhood Socialization Experiences—A Set of <i>Push</i> Factors .....	11
Feelings of Closeness with the Family—A Set of <i>Push</i> Factors .....	11
Multiple Competing Midlife Roles—A Set of <i>Pull</i> Factors .....	13
Severity of Behavior Problem—A Set of <i>Pull</i> Factors.....	13
Broadening the Scope of the Conceptual Framework of <i>Push</i> and <i>Pull</i> Factors.....	14
Other Factors To Consider when Studying Persons of Color and Caregiving.....	14
Purpose of the Study and Research Questions.....	15
<b>Chapter 2: Literature Review</b> .....	16
Severe Mental Illness in Society.....	16
Defining Severe Mental Illness.....	17
Justifying the Need to Focus on Siblings as Caregivers .....	18
Recognizing the Role of the Sibling as a Caregiver .....	19
Systematic Examinations of Sibling Caregiving Practices.....	20
Ethnic Minority Siblings as Caregivers .....	24
Empirical Literature Review on Siblings as Caregivers .....	25
Early Research Studies .....	25
Sibling Roles and Burden .....	26
Siblings and Social Support.....	26

Qualitative Research on Sibling Caregiving.....	29
Sibling Caregiving for Persons with Mental Retardation and Mental Illness .....	31
Families and Mental Illness .....	32
Family Burden .....	34
Parents to Siblings: Mindset Shifts .....	35
Sibling Relationships and Bonds .....	35
<b>Chapter 3: Research Design and Methods .....</b>	<b>39</b>
Investigative Procedures .....	39
Unit of Analysis-Sample Description .....	39
Participant Recruitment .....	40
Communicating with Study Participants .....	44
Instrumentation .....	45
Purposive Sampling .....	46
Quota Sampling .....	47
Snowball Sampling .....	48
Survey Development.....	48
Development of <i>Sibling Project</i> Survey .....	49
Modifying the SPS Questionnaire for This Study .....	52
Variables and Operationalization.....	53
Study Variables.....	54
Research Hypotheses .....	59
Statistical Analysis.....	60
ANOVA Analysis.....	60
Crosstabulations.....	61
Independent Samples T-Test.....	61
Multiple Regression .....	61
Logistic Regression.....	62
Statistical Power Analysis.....	63
Testing Major Assumptions for the Statistical Models.....	64

<b>Chapter 4: Results</b> .....	67
Results of Hypotheses Related to Instrumental Support.....	72
Results of Hypotheses related to Expectations of Future Caregiving.....	81
<b>Chapter 5: Discussion</b> .....	89
Summary of the Study .....	89
Discussion of Research Question 1: .....	90
Discussion of Research Question 2: .....	92
Discussion of Research Question 3: .....	93
Discussion of Research Question 4: .....	94
Limitations and Strengths .....	97
Implications and Recommendations .....	101
Recommendations for Future Policy and Practice.....	102
Recommendations for Future Research.....	104
Conclusions.....	106
<b>Appendix A: A Collection of Quotes and Experiences Shared by the Study</b> Respondents .....	108
<b>Appendix B: Empirical Research Studies on Sibling Caregiving between 1992 and 1999</b> .....	110
<b>Appendix C: Sibling Study Cover Letter and Questionnaire</b> .....	114
<b>Appendix D: Variable Modifications</b> .....	136
<b>Appendix E: Normality, Linearity, &amp; Homogeneity Tables</b> .....	138
<b>Appendix F: Demographic Characteristics of Respondents by Race/Ethnicity</b>	142
<b>Appendix G: Correlation Matrix</b> .....	148
<b>Appendix H: Statistical Differences of Respondents by Race/Ethnicity</b> .....	149
<b>Definitions</b> .....	150
<b>Bibliography</b> .....	153
<b>Vita</b> .....	173

## List of Tables

<b>Table 4.1:</b>	Demographic Characteristics of Sibling Respondent .....	68
<b>Table 4.2:</b>	Demographic Characteristics of Sibling w/Mental Illness .....	71
<b>Table 4.3:</b>	Mean Levels of Instrumental Support among Whites and Siblings of Color .....	72
<b>Table 4.4:</b>	Mean Levels of Instrumental Support among Siblings from All Race Categories .....	74
<b>Table 4.5:</b>	Mean Levels of Instrumental Support among Male and Female Siblings .....	75
<b>Table 4.6:</b>	Relationship Between Instrumental Support for Feelings of Closeness to Family for Sibling Respondents .....	77
<b>Table 4.7:</b>	Mean Levels of Instrumental Support for Reported Behavioral Problems of Siblings with Mental Illness .....	79
<b>Table 4.8:</b>	Percentages of Reports of Expectations of Future Caregiving among White Siblings and Siblings of Color .....	81
<b>Table 4.9:</b>	Percentages of Reports of Expectations of Future Caregiving among Female and Male Siblings.....	82
<b>Table 4.10:</b>	Percentages of Reports of Expectations of Future Caregiving among White Siblings and Siblings of Color .....	83
<b>Table 4.11:</b>	Relationship Between Expectations of Future Caregiving and Feelings of Closeness to Family of Origin for Sibling Respondents .....	84
<b>Table 4.12:</b>	Percentages of Expectations of Future Caregiving for Reported Behavioral Problems of Siblings with Mental Illness.....	85
<b>Table 4.13:</b>	Mean Levels of Instrumental Support among Competing Factors for Siblings .....	87

<b>Table 4.14:</b> Relationship Between Expectations of Future Caregiving and Competing Factors for Sibling Respondents .....	88
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## List of Figures

<b>Figure 2.1:</b> Percentage of People Experiencing Psychiatric Disorders during their Lifetime** .....	17
<b>Figure 4.1:</b> Primary Diagnoses for White and Persons of Color .....	70
<b>Figure 4.2:</b> Time Spent Providing Care by Gender and Race .....	76

# Chapter 1

## Introduction

*...Yeah, my parents would always say, "oh she's shy." I think that even to tell family members that there was something wrong was not right and my parents just never had that comfort level. I don't think really they had that comfort level until about 10 years ago when I "came out of the closet" and publicly acknowledged that I had a sister with a mental illness and a sister with developmental disabilities. It was so freeing for me and I think it helped them know that it was "okay."*

*...I went to the library and the bookstores and looked for all of these books that I was sure was out there didn't really find anything.*

*...I'm the oldest of nine children and in our culture, the oldest always takes over after mom and dad decides that they can't handle it...I'm very much involved in taking my brother to the doctors, being a part of his treatment...By helping my brother, I feel very strongly that I help my mom and I help myself and I help others.*

*... In terms of caregiving, since he was disabled at such a young age. I always felt like that was my role to be his mentor and his friend and his protector. I asked [my brother] one time what he would do when mom and dad had passed away or were unable to care for him and he said "well of course I'm going to move in with you."*

The introductory narrative is a composite taken from siblings who referred back to the time when their brothers and sisters were first diagnosed with schizophrenia (see Appendix A for more narratives). The narrative illustrates the important role that siblings of persons with severe mental illness play in their families. Investigating the burdens and rewards of siblings as caregivers is particularly relevant because any person with a brother or sister diagnosed with a severe mental illness may become a primary caregiver. The concept of caregiving does not become "real" for people until they are faced with the responsibility. In other words, people do not think about it or conceptualize caregiving until they are in the midst of doing it, which could explain why caregiving has been linked to such concepts as "burden" (see Biegel, Milligan, Putnam, & Song, 1994; Cook,

Lefley, Pickett, & Cohler, 1994; Francell, Conn, & Gray, 1988; Greenberg, Kim, & Greenley, 1997; Horwitz & Reinhard, 1995; Lefley, 1989).

Unlike a diagnosis of mental retardation, schizophrenia and other severe mental illnesses [for instance, schizoaffective disorder and bi-polar disorder] are commonly diagnosed during early or later adulthood when most individuals are linked to ongoing family systems (Greenberg, Seltzer, Orsmond, & Krauss, 1999). As a result, siblings of persons with severe mental illness often undergo major familial and personal adjustments that include having to deal with changes in their sibling's personality, their discomfort and unfamiliarity with the illness, and the unforeseen episodic relapses that are commonly related to schizophrenia and other forms of severe mental illness (Cook, et al., 1997b; Denberg, 1991; Earl, 2003; Greenberg, Kim, & Greenley, 1997; Greenberg, Seltzer, Orsmond, & Krauss, 1999; Landeen, Whelton, Dermer, Cardamone, Munroe-Blum, & Thornton, 1992; Marsh, Appleby, Dickens, Owens, & Young, 1993a; Nechmad et al., 2000; Reibschleger, 1991).

In response to the "burden" of illness in families, it has been noted that parents, particularly mothers, assume the major responsibility for caregiving of a child or an adult with a severe mental or physical illness. Several studies have concluded that since the era of deinstitutionalization, families account for the majority of care provided to persons with a severe mental illness (see Benson, 1994; Cook, et al., 1997; Doll, 1976; Grob, 1991; Horwitz & Reinhard, 1992; Lefley, 1996; Lefley & Hatfield, 1999). As parents age, become disabled, exhausted, or die, critical questions are raised about the assumption of the caregiving role within families. However, only minimal research

information is available to answer questions about the caregiving practices of siblings of persons with a severe mental illness who traditionally assume the roles.

## **STATEMENT OF THE PROBLEM**

Siblings as caregivers of a family member diagnosed with a severe mental illness are an important group to study because they are often involved in the lives of their brothers and sisters for the longest period of time (Bank & Kahn, 1982; Cicirelli, 1991; Shortt & Gottman, 1997). Recently, researchers have begun to look at the caregiving practices of siblings (Greenberg, Seltzer, Orsmond, & Krauss, 1999; Landeen, et al., 1992; Horwitz, et al, 1992; Horwitz, 1993a, 1993b; Horwitz, 1994; Marsh, Appleby, Dickens, Owens, & Young, 1993b; Marsh, Dickens, Koeske, Yackovich, Wilson, & McQuillis, 1993a; Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997). When race and ethnicity are included in the equation, pertinent research literature is almost non-existent. To date the only literature that is directly related to sibling caregiving and ethnicity is from a study conducted by Horwitz and Reinhard (1995), in which the researchers examined ethnic differences in caregiving duties among parents and siblings of persons with severe mental illness. Repeated literature searches revealed that there is no other literature available on this topic—illustrating a need for more research.

The risk of severe mental illness does not differ significantly by race and ethnicity (Kessler, et al., 1996; Kessler, et al., 1994; Robins & Regier, 1991). Although minority families will experience mental health issues with a similar epidemiological pattern as White families, the level of research knowledge about how minority siblings (or minority families) experience caregiving is inadequate. We cannot assume that these patterns will

be the same as White siblings or White families. We do not know enough about the caregiving beliefs or practices of siblings of color. There is a dearth of research, knowledge, information and relevant theory. Therefore, this exploratory dissertation study will address the problem by examining the relationship between race, ethnicity and sibling caregiving practices.

The four questions that will be raised in this dissertation study, along with the corresponding research hypotheses, are as follows:

Q1: *To what extent does race and ethnicity differentiate caregiving practices by siblings?*

H1: White siblings of adults diagnosed with a severe mental illness will provide less instrumental support than siblings of color.

H2: White siblings of adults diagnosed with a severe mental illness will be less likely to have expectations of participating in future caregiving responsibilities than siblings of color.

Q2: *Are females providing more care than male siblings?*

H3: Sisters of adults diagnosed with a severe mental illness will provide more instrumental support than brothers, regardless of race and ethnicity.

H4: Sisters of adults diagnosed with a severe mental illness will be more likely to expect that they will have caregiving responsibilities in the future than brothers, regardless of race and ethnicity.

Q3: *What potentiates or pushes siblings to become involved in the caregiving process?*

H5: Siblings who report having feelings of closeness to his or her family of origin will provide more instrumental support than siblings who do not report feelings of closeness to his or her family of origin.

H6: Siblings who report having feelings of closeness to his or her family of origin will have expectations of playing a role in providing future caregiving than siblings who do not report feelings of closeness to his or her family of origin.

Q4: *What mitigates or pulls siblings away from becoming involved in the caregiving process?*

- H7: Siblings who report that their brother or sister has more behavior problems will provide less instrumental support than siblings of adults with fewer behavior problems.
- H8: Siblings who report that their brother or sister has more behavior problems will be less likely to expect having future caregiving responsibilities than siblings who report fewer behavior problems from their brother or sister.
- H9: Siblings who report being married, employed at least part time and have children under the age of 18 living in their households will provide less instrumental support to their brother or sister diagnosed with a severe mental illness; nonetheless, these factors will not predict the sibling's likelihood of expecting to have a role in providing future caregiving.

#### **SIGNIFICANCE OF THE PROBLEM**

It is important to study sibling caregiving practices because it is projected that there will be more siblings caring for their brothers and sisters than ever before, particularly as the overall population grows (Greenberg, 1999). Along those lines, it is important to focus on ethnic minorities because it is also reasonable to project that there is going to be an increase in the number of persons of color who will be called upon to fulfill this role according to the U.S. Surgeon General's report on race, culture, and mental illness (U.S. DHHS, 2001). Thus, we cannot assume that there will not be differences in sibling caregiving practices by race or ethnicity. Additionally, community mental health centers, practitioners, policy makers, and other advocates may not be able to help these caregivers without ethnic-specific research information. At this point, we simply do not know how to address the needs of this population. We do not know how to

get them involved in voluntary participation, advocacy or support programs. We do not know how to identify who they are. We do not know about their characteristics, or their interests, or their coping strategies. Given the extent of the unknowns, it is difficult to connect sibling caregivers of color into the existing mental health system.

This is also significant because not knowing the answers to these unknowns could exacerbate the condition of the individuals for whom they are caring (Greenberg, 1997). If this were to happen, siblings diagnosed with a severe mental illness could go untreated and end up in emergency/higher cost care. Thus their dependence on state and local mental health care could increase. These individuals could lack the quality of care that is clinically recommended or they could become abandoned and ultimately end up in much higher cost care (long term residential programs, inpatient hospitals, or state hospitals, where available). These options could possibly be avoided by continuing to research and investigate sibling caregiving practices.

It is expected that the findings and policy recommendations from this study will be of significant help to those interested in family systems and frameworks in regards to caregiving practices. Social workers, psychologists, psychiatrists, nurses, marriage and family therapists, cross cultural professionals, consumers, siblings, family members, advocates, researchers, and policy developers may find this study both informative and important. The findings from this study could also inform and help shape future training programs and curricula specific to sibling caregiving.

## CONCEPTUAL FRAMEWORK

There are few theoretical models that increase knowledge about siblings caring for a relative diagnosed with a severe mental illness (Greenberg, et al., 1999; Horwitz, 1993a). However, even the models that do exist were not developed to explain the caregiving practices of siblings of color. As in the research literature, there is a paucity of theorizing on siblings of color as caregivers. In order to understand the involvement of minority and non-minority siblings in the caregiving process, a sibling caregiving framework developed by Greenberg, et al. (1999) will be examined and applied. This framework was created to examine how particular factors influenced the degree to which siblings become involved, or not, in the care for their brothers and sisters diagnosed with a severe mental illness.

### Conceptualizing Factors that Effect Caregiving

Greenberg and colleagues (1999) developed a conceptual framework that postulates the caregiving relationship between siblings without disabilities and their brothers or sisters with mental illness can be understood as the product of *push* and *pull* factors. *Push* factors are variables [childhood socialization experiences, feelings of closeness with the family, family obligation] that increase sibling caregiving activities, while *pull* factors are variables [midlife roles: marriage, parenthood, career responsibilities, severity of consumer sibling's behavior problems and illness] that decrease an individual's involvement with their siblings.

Another way to conceptualize *push* and *pull* factors is to use the terminology of potentiating and mitigating factors (Stice, 2004). Stice used the terms potentiating and mitigating similar to the way Greenberg and colleagues conceptualized *push* and *pull* factors. The two sets of factors are essentially the same and offer an alternative way of thinking about this phenomenon of caregiving. Potentiating and mitigating factors mirror push and pull factors, respectively.

In theory, if an individual has more potentiating factors than mitigating factors, he or she should be more likely to take a primary role in caring for his or her brother or sister diagnosed with a mental illness. In this dissertation study, the conceptualization is that siblings of color will provide more care than White siblings, despite the magnitude or degree of the potentiating (push) and mitigating (pull) factors. The researcher theorizes that there are “culturally relevant” factors: poverty, oppression, degrees of expressed emotion, rewards (in contrast with burden), stigma, poor information resources, and mistrust (Davis, 1997, 1998; Kung, 2001; Whaley, 2001) that influence the way members from ethnic minority communities come to conceptualize and respond to issues of caring for family members.

In their work, Greenberg and colleagues were interested in trying to determine why some siblings seemed to be more actively involved in caregiving, while others were not. Although the researchers had such an interest, they did not question the participation of siblings of color as caregivers. The absence of an examination of siblings of color in the Greenberg, et al. study reflects the gap in the knowledge base and research as a collective whole. Research that is driven by a clear conceptualization of sibling caregiving involvement or practices is needed.

## Caregiving in Minority Communities

Minorities are more likely to rely on seeking informal support sources (faith community, friends, and other family members) rather than formal support sources, like advocacy and consumer groups (Neighbors, Musick, & Williams, 1998). There are factors and similarities that cut across specific ethnic groups, despite whether the group is African American, Latino, Asian, or Native American. When looking at these groups for commonalities, there are strong similarities; for instance, the “familism” of Latinos and “extended families” of Blacks mean practically the same thing, but rarely are the two concepts compared (McAdoo, 1998). Other factors, such as poverty, oppression, stigma, poor information resources, and mistrust have influenced the way members from ethnic minority communities have come to conceptualize and respond to issues of mental illness (Davis, 1997, 1998; Kung, 2001; Whaley, 2001). Thus, in order to be able to recognize and address the needs of adult sibling caregiving practices, it is essential to understand the many factors and dynamics that impact this population.

Dilworth-Anderson and McAdoo (1988) raised concerns about the way conceptual approaches and theoretical perspectives are used to inform the study of ethnic minority families. More specifically, they questioned how the “values and attitudes of researchers serve as antecedents for developing and perpetuating particular conceptual and theoretical frameworks” (p.265). In other words, a lot of the theory that fuels the work of practitioners and policymakers stems from the conceptual and theoretical knowledge bases of researchers. Therefore, the researcher must be sure to convey the most accurate picture as possible for the population of study.

It is possible that siblings of color may be likely to exhibit caregiving patterns that are different from Whites. These differences may be both quantitative and qualitative in nature. Lawson (1986) reported that “minorities, including Blacks, tend to be more tolerant than Whites of mentally ill family members” (p. 59). Lawson (1986), a psychiatrist also reported that Black families possess strengths like extended families and mechanisms of informal care that are especially useful in dealing with a relative diagnosed with a mental illness. Choi (1993) discusses the need to view caregiving in a cultural context because “caregiving has focused almost exclusively on White caregivers, for whom the impact of caretaking has been evaluated in terms of constraints placed on individual freedoms and opportunities and on effects on nuclear family relationships” (p. 26). Several sources of literature have explored and proposed differences between the ways in which support and care is provided between White and non-White families (Dilworth-Anderson & McAdoo, 1988; Hays & Mindel, 1973; Hennessy & John, 1996; Horwitz & Reinhard, 1995; Lin & Cheung, 1999; Lopez, 2002; Navaie-Waliser, et al., 1988; Taylor, 1986; Zayas & Palreja, 1988).

In regard to the *push* and *pull* framework and siblings of color, there are gaps in what Greenberg and colleagues conceptualized. In the framework developed by Greenberg and colleagues, the following sets of factors were discussed: *Push* factors (childhood socialization experiences & feelings of closeness with family) and *Pull* factors (competing midlife roles & severity of sibling’s behavior problems). This framework will be used to guide the discussion below, which first provides an overview of push and pull factors, and then better amplifies the lacunae in the knowledge base.

### **Childhood Socialization Experiences—A Set of *Push* Factors**

Childhood socialization experiences represented one set or grouping of push factors which Greenberg and colleagues (1999) proposed would influence siblings toward greater involvement in caregiving activities. In their research, childhood experiences are explained in the context of females being socialized from a very early age to assume more caregiving roles than males. This observation is consistent with other research and theoretical evidence on gender roles and caregiving (Greenberg, et al., 1999; Horwitz, et al., 1992; Ungerson, 1987). Seltzer, et al. (1991) conducted one of the first comprehensive studies on gender differences in adult siblings of persons with mental retardation. Their findings suggested that females provided more care and companionship and reported more positive aspects of the experiences than males.

Seltzer and colleagues also found that brothers and sisters reported more positive feelings and fewer worries about future caregiving when the sibling with mental retardation was of the same sex. Nevertheless, overall they found that females were more likely to provide care and fulfill the role of primary caregiving than males. These patterns are consistent with the push and pull framework, which suggest that females will be more actively involved in caregiving than males regardless of race or ethnicity.

### **Feelings of Closeness with the Family—A Set of *Push* Factors**

The second set of push factors related to the quality of childhood relationships to the family of origin, suggesting that closer childhood relations between siblings led to greater involvement in caregiving as adults. This concept is also consistent with other

research in this area (Bank & Kahn, 1982; Cicirelli, 1991; Greenberg, et. al., 1997; Horwitz et. al., 1992).

When parents are no longer available to provide assistance, sibling involvement will increase, which is another push factor. Research suggests that most care is provided by one individual, rather than being shared by several relatives (Horowitz & Dobrof, 1982; Johnson, 1990; Pruncho, Patrick, & Burant, 1996). The concept of feeling close to the family is further supported when Horwitz (1993a) uses the serial model of caregiving to examine sibling involvement in caregiving. Horwitz posits that primary assistance will be provided by persons with the strongest or closest relational bond to the individual in need. Successively, more distal relations are progressively less likely to engage in caregiving activities. For instance, parents are more likely to be involved in caregiving than are siblings, while siblings are more likely to be involved than cousins. When individuals in closest relation are no longer available to carry the responsibility, the individual who possesses the next closest bond is presumed to assume caregiving responsibilities.

Age is also likely to be grouped in “closeness with the family” domain. There is an increasing likelihood that as siblings become older, they will move into primary caregiving roles as their parents age and become unable to provide care (Greenberg, Seltzer, & Greenley, 1993). Furthermore, siblings who are closer in age will share a bond that is different from the others, which could be considered a push factor towards involvement in caregiving. The push and pull framework inherently suggests the relation of persons within a family unit will influence the siblings involvement in caregiving.

### **Multiple Competing Midlife Roles—A Set of *Pull* Factors**

The factors that could discourage caregiving involvement, or *pull* a person away from providing care, are conceptualized by Greenberg and colleagues as “multiple competing midlife roles.” Personal responsibilities such as work, marriage, child rearing, social activities, as well as caregiving activities are all potentially competing demands for a sibling. Research concerning sibling caregiving involvement suggests that competing demands on time between work and child rearing serve to inhibit or restrict an individual’s involvement as a caregiver (Horowitz, et. al., 1992). The *Push* and *Pull* framework suggests that siblings will be less involved in caregiving because they will prioritize their personal responsibilities over the needs of their brother or sister diagnosed with a severe mental illness.

### **Severity of Behavior Problem—A Set of *Pull* Factors**

Another set of factors that could *pull* a sibling away from becoming involved in caring for their brother or sister diagnosed with a severe mental illness is the extent to which there are elevated levels of behavior problems. In other words, if the sibling with the severe mental illness presents a lot of disruption in the family due to his or her behavior, that will limit the amount of care and support he or she receives. Caring for an adult with elevated levels of behavioral problems adds major challenges to the caregiving process (Greenberg, Seltzer, & Greenley, 1993; Orsmond, et al., 2003).

## **Broadening the Scope of the Conceptual Framework of *Push* and *Pull* Factors**

### ***Other Factors To Consider when Studying Persons of Color and Caregiving***

Factors like guilt, shame, personal blame, family obligation, cultural obligation, religiosity, stigma, and perceived failure to carry out the caregiving role have been discussed in the literature on caregiving and persons of color (Dilworth-Anderson & McAdoo, 1988; Hennessy & John, 1996; Horwitz & Reinhard, 1995; John, et al., 2001; Lin & Cheung, 1999; Lopez, 2002; Navaie-Waliser, et al., 2001; Smerglia, Deimling, & Barresi, 1988; Taylor, 1986; Weisman & Lopez, 1996; Zayas &alleja, 1988). These factors can be conceptualized as either push or pull factors depending on the way in which they are internalized for the individual. Additionally, for persons of color the extended family plays a critical role in defining one's family (Martin & Martin, 1978). The authors describe the extended family as a combination of three major elements:

1. the extended family base—controlled by a dominant family figure;
2. the sub-extended family—these individuals (who are or are not related by blood) may or may not live in the same household, city or town, and;
3. the mutual support system—often discussed as informal support networks like churches and community supports.

Cultural values and norms for persons of color are thought to be another group of push factors, leading to greater involvement in caregiving (Lawson, 1986; McAdoo, 1991). Both theoretical and empirical evidence suggests that African American and Hispanic/Latino families maintain a stronger sense of familial obligations than do White families, thus influencing greater sibling involvement in caregiving (Horowitz & Reinhard, 1995). This, along with the additional factors just mentioned, is an area that

Greenberg and colleagues (1999) do not mention in their conceptualization of *push* and *pull* factors for sibling caregiving.

By building on the push and pull framework as it applies to siblings of color, we will be able to understand *who* will need services and explore questions raised in this dissertation study that have not been raised in prior research.

### **PURPOSE OF THE STUDY AND RESEARCH QUESTIONS**

Due to the dearth of research in the area of caregiving practices for family members beyond the mother, this study will help fill the gaps and explain the caregiving practices of siblings. The specific aim of this dissertation is to study the extent to which caregiving by adult siblings of persons with severe mental illness is influenced by race and ethnicity. As previously mentioned, this study will specifically address the following research questions:

1. To what extent does race and ethnicity differentiate caregiving by siblings?
2. Are females providing more care than male siblings?
3. What motivates (potentiates) siblings to become involved in the caregiving process?
4. What prevents (mitigates) siblings from becoming involved in the caregiving process?

## **Chapter 2**

### **Literature Review**

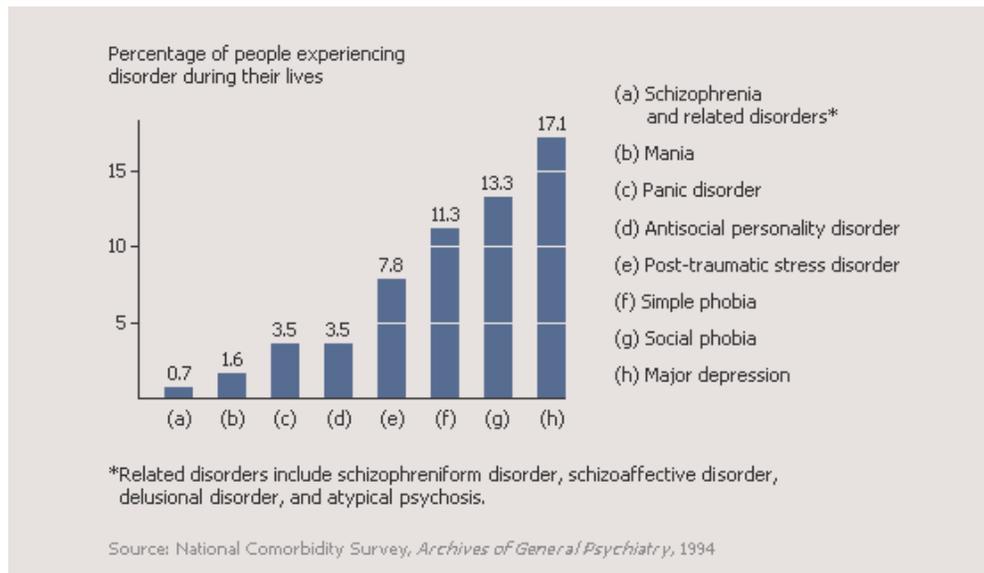
The purpose of this chapter is to provide a discussion of the literature as it relates to mental illness and sibling caregiving practices. The knowledge base pertaining to exploration of sibling caregiving for persons of ethnic and cultural backgrounds is limited and in need of further development. The chapter will begin with a general discussion of mental illness in society and define severe mental illness, for the purposes of this study. Following sections will chronicle the systematic, empirical and qualitative research literature on the topic, while highlighting significant limitations, such as the paucity of studies that focus specifically on siblings of color.

#### **SEVERE MENTAL ILLNESS IN SOCIETY**

Severe mental illness (SMI) or severe and persistent mental illness (SPMI) affects a significant proportion of those diagnosed with mental disorders, and it is considered a more debilitating class of disorders than other forms of mental illness (U.S. Department of Health and Human Services, 1999). The 1999 U.S. Surgeon General's Report on Mental Illness estimated that, in any given year, about 10-11 million people are diagnosed with a mental illness and 5-6 million people meet the criteria for SMI (U.S. Surgeon General, 1999). This means approximately 5-6 percent of the adult population in the U.S. is diagnosed with a mental illness and 3 percent of the adult population in the United States meets the criteria for SMI (Biegel & Shulz, 1999; Kessler, Abelson, & Zhao, 1998; Kessler, et al., 1996; U.S. DHHS, 1999). Figure 2.1 illustrates the

percentage of people in the United States who experience a particular mental illness at some point during their lives. The percentages are derived from the National Comorbidity Survey, in which researchers interviewed more than 8000 people aged 15 to 54 years (Kessler, et al., 1994).

Figure 2.1: Percentage of People Experiencing Psychiatric Disorders during their Lifetime\*\*



\*\*The percentages are lower than in other reported documents because homeless people and those living in prisons, nursing homes, or other institutions were not included in the survey.

## Defining Severe Mental Illness

There does not seem to be a consensus on the clinical delineation of the classification of mental illness and severe mental illness (Biegel & Shulz, 1999; Kuntz, 1995). The United States Senate has attempted to characterize this population by reporting that “severe mental illness is defined through diagnosis, disability, and duration, and includes disorders with psychotic symptoms such as schizophrenia, schizoaffective disorder, manic depressive disorder, as well as severe forms of other disorders such as major

depression, panic disorder, and obsessive compulsive disorder” (National Advisory Mental Health Council, 1993). This definition is consistent with other descriptions and definitions of severe mental illness. For instance, other sources have reported that an individual experiencing a severe mental illness is someone who has mental conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning ([www.NAMI.org](http://www.NAMI.org), retrieved 9/15/2004).

### **JUSTIFYING THE NEED TO FOCUS ON SIBLINGS AS CAREGIVERS**

Empirical research on siblings as caregivers for a mentally ill relative is extremely limited. Existing research looks at caregiving siblings as an aggregate group with relatively small sample sizes. Furthermore, the research has failed to identify and distinguish the cultural and ethnic differences within the aggregate groups, nor does it examine how the differences influence sibling caregiving practices. As a result, there are several things we do not, but should, know about this population. For instance, there is little in the literature that addresses how siblings conceptualize caregiving responsibilities for a brother or sister with a severe mental illness, nor is there much that addresses the point at which a sibling actually begins, or ends, caregiving responsibilities. We know even less about other important factors, like ethnicity and culture, that might influence sibling caregiving practices for different individuals. We simply cannot assume that caregiving practices are the same for every individual.

## **RECOGNIZING THE ROLE OF THE SIBLING AS A CAREGIVER**

Over the past ten to fifteen years there has been an increased recognition of the role of adult siblings as caregivers for relatives with severe mental illness. In the United States, siblings represent more than 80% of the population (Gallo, 1988, as cited in Marsh 1998). Despite these numbers, in regards to their role as potential primary caregivers of their mentally ill relatives, siblings are often ignored by practitioners who fail to consider and understand their experiences, needs, or concerns (Marsh, 1998). A major reason is that, historically, the caregiver role has primarily focused on the parent. Specifically, it has been the mother who receives the label of “primary caregiver” (Lefley, 1987; Maltitudes & Pruncho, 2002). Despite what history has led us to believe, as parents grow older they either become too tired to continue to care for their mentally ill child or they die. This is commonly known as “aging out.”

The aging out phenomenon is particularly germane to this discussion because it highlights the fact that siblings are often overlooked when practitioners and clinicians develop treatment plans or utilize the person in the environment treatment model (Cook, et al., 1997; Marsh, et al., 1993a; Marsh, et al., 1993b; Thompson & Doll, 1982). Nonetheless, the literature consistently tells us that the sibling is the family member who is most likely to take on the caregiving responsibility (Greenberg, et al., 1999; Hatfield & Lefley, 1993; Horwitz, 1993a; Horwitz, 1993b; Seltzer, Greenberg, et al., 1997). For example, the following is a narrative of a sibling recalling her mother’s burden; she talks about how her mother became too tired to continue providing care for her child:

*Well, my mom predominantly, has dealt with, I hate to call it a burden, but it has been for her. From the time of my sister being diagnosed with a developmental disability, let alone a mental illness, which my parents sorta understood but not really, she was the one who looked at the programs and was there when Evelyn had issues or was “not behaving well, was not feeling well, or something’s going wrong”, but literally she was decompensating, that’s what it was. My mom had to deal with it and just dealt with it. She didn’t communicate to any body until she realized, about 15 years ago, she could clearly communicate to me about it. She didn’t communicate much with my oldest sister, she would tell my dad, but wouldn’t tell anyone at church...wouldn’t tell her good friends. It was “her burden” that she kept and wore and ironically when my dad retired, even more so since they’ve been in Austin, which has been about 7 years now, she told my dad, “it’s your turn now to do the rippin’ and running to do the meds and do the doctors exams and so forth.*

Earl, T.R., unpublished data, 2003

## **Systematic Examinations of Sibling Caregiving Practices**

Greenberg, Kim, and Greenley (1997) focused specifically on siblings of adults with severe mental illness. They systematically examined the relationship between various factors associated with subjective burdens experienced by this group. This study was the first to systematically examine burden in relation to the sibling as a caregiver. Greenberg and colleagues used a sample of 164 siblings to analyze their experiences of subjective burden. They also examined objective burden, family attributions, caregiving context, health, gender differences, and the nature of the disabled sibling’s illness. Subjective burden, the variable of interest, was measured according to four scales: a global measure of subjective burden and three measures of specific types of subjective burden, namely, stigma, fears, and worries about the future. They tested two main hypotheses (p. 233):

- H1: objective burdens of care (i.e., the amount of care provided and the disabled sibling’s psychiatric behavior) will be positively related to higher levels of subjective burden; and

H2: caregivers who appraise their disabled siblings as having control over their behavior will report higher levels of subjective burden than will those who attribute the symptoms and behavior to an illness and, therefore, beyond the sibling's control.

There were several noteworthy findings that will be incorporated into this dissertation study:

- Older siblings tended to worry less about their ill sibling's future care than did younger siblings.
- The well-sibling's gender and education were positively related to global feelings of burden. Sisters and those siblings with higher levels of education reported significantly greater subjective burden.
- Younger siblings taking care of an older sibling reported higher levels of subjective burden and stigma than those taking care of a younger sibling.
- There was a trend where siblings worried more about the future care of a sister than of a brother with mental illness.
- Siblings who provided more care tended to report more feelings of subjective burden than did less involved siblings.
- No relationship was found between the amount of care and feelings of stigma and fears.
- Well-siblings who thought their ill sibling had control over their symptoms experienced higher levels of subjective burden, stigma, fears, and worries about the future.
- Psychiatric symptoms were significantly related to higher levels of stigma.

Greenberg and colleagues (1999) completed another important study where they investigated the current involvement and expectations of future caregiving roles for siblings of adults with mental illness or mental retardation. The study highlighted a set of *push* and *pull* factors that influenced the extent to which a person was or became a

caregiver. Conceptually, the researchers concluded that *push* factors pushed siblings towards greater involvement with caring for their brother or sister and *pull* factors pulled them away. Some of the factors that would push a sibling into an increased caregiving role included childhood socialization experiences and feelings of closeness within the family. Some examples of factors that would pull a sibling away from providing care to their brother or sister diagnosed with a severe mental illness involved midlife roles such as, marriage, parenthood, and a career. The severity of the brother's or sister's behavior problems was also identified as a pull factor.

The researchers mailed questionnaires (78.2% response rate) in order to collect data from 61 siblings of adults with serious mental illness and 119 siblings of adults with mental retardation. The following five hypotheses were tested in the study (p. 1215):

- H1: Siblings of adults with mental illness will provide less instrumental and emotional support at the present time and will have more limited expectations of future caregiving responsibility than siblings of adults with mental retardation.
- H2: Sisters of adults with disabilities will provide more support than brothers and will be more likely to expect that they will have caregiving responsibilities in the future.
- H3: The extent of current sibling instrumental and emotional support for the brother or sister with disabilities and the expectation of future caregiving responsibility will be a function of the sibling's feelings of closeness to his or her family of origin.
- H4: Siblings who are more strongly established in midlife roles will provide less support currently to their brother or sister with disabilities, but these factors will not predict expectations of future caregiving responsibility.
- H5: Siblings of adults with more behavior problems will provide less current support and will be less likely to expect future caregiving responsibilities than siblings of adults with fewer behavior problems.

The two groups of siblings showed differences in their expectations about their responsibility for caregiving. Siblings of adults with mental illness were more likely to provide instrumental support if the siblings were close during adolescence and if the disabled sibling continued to live with their parents. Almost 60 percent of siblings of adults with mental retardation expected to assume primary caregiving responsibility, while only one-third of the siblings of adults with serious mental illness shared the same expectation. For both groups, sisters provided more emotional support than brothers and siblings with young children provided less support.

This study raised an interesting dilemma regarding the shift of caregiving responsibilities for persons with disabilities. Addressing this dilemma will be critical in future research that examines sibling caregiving practices:

*...substantial numbers of adults with disabilities are now being cared for by their aging parents and will need to turn to the public service system to meet their needs. Without a dramatic shift in public resources for community care, the needs of many adults with disabilities will go unmet. (p. 9).*

While this study was very influential in advancing the research on sibling caregiving practices, the researchers reported several limitations. Some of the limitations included a potentially biased study sample (based on the way in which the sample was identified and recruited), a small number of siblings of a person diagnosed with a severe mental illness, and siblings of adults with mental retardation were asked a very specific question about future caregiving and siblings of a person with severe mental illness were not asked the same type of question. Another very important limitation of this study is the fact that race and ethnic differences were not discussed in the findings. Thus, the

findings of this study should be interpreted with caution as they did not completely represent the population of sibling caregivers.

### **Ethnic Minority Siblings as Caregivers**

Very little attention has been given to minority siblings as caregivers for a relative with mental illness. The lack of literature and research in this area is directly linked to explaining why the mental health system has failed to reach this population. Some researchers used “race” as a category in their design, but very few reported findings. To date, there has been only one systematic research study to focus on minority sibling caregiving practices.

Horwitz and Reinhard (1995) reported that ethnicity had an important impact on the caregiving duties family members perform and the burden that results from such duties. Since this is the only study that has sought to systematically examine the role or influence of ethnicity on sibling caregiving practices, it is necessary to detail the hypotheses and key findings as they will serve to inform this dissertation study. Horwitz and Reinhard tested four hypotheses in total, but only two were related to the sibling caregiving process (see Horwitz and Reinhard, 1995 for the other hypotheses). Those two hypotheses were:

H3: Black siblings will report more extensive caregiving duties than White siblings.

They based this hypothesis on their theory that Blacks are accustomed to working within an extended kinship network, therefore their approach or perception of

caregiving duties will be different from White siblings who are accustomed to more individualistic networks.

H4: Black siblings will feel less burdened by their caregiving duties than White siblings. (p. 140)

This hypothesis stemmed from the expectation that Blacks had a sense of family obligation that extended beyond parent-child ties, which suggested that sibling caregiving would seem more normative in these communities. If this expectation was accurate, then the researchers posited that comparable levels of caregiving would seem less burdensome for Blacks than for Whites.

The findings from the study, reported in an article titled *Ethnic differences in caregiving duties and burden among parents and siblings of persons with severe mental illness*, described the findings from a study with a sample of 70 siblings and 78 parents, mostly Black, of persons with severe mental illness. The study compared the differences in caregiving duties and burden between both Black and White parents and siblings. In terms of the findings related to the sibling portion of the sample, Black siblings reported having more caregiving duties, but experiencing less caregiver burden, than the White siblings. Due to the small sample sizes for Hispanics and Asians siblings, the researchers did not report findings for these groups.

## **EMPIRICAL LITERATURE REVIEW ON SIBLINGS AS CAREGIVERS**

### **Early Research Studies**

Earlier research defined family as one unit and mostly compared the amount of support provided by parents or spouses, instead of siblings (Horwitz, et al., 1992;

Horwitz, 1993a). Investigations during the 1950s and 1970s were based on the theory of familial transmission of schizophrenia and focused on siblings from the aspect of their susceptibility to the disease (Lidz, 1963, 1973, 1976; Lidz, et al., 1963; Lidz, Fleck, & Cornilson, 1966). Case studies were often used to explain how some well siblings “escaped” the pathological family network (Adams, 1968).

### **Sibling Roles and Burden**

With the introduction of the concept of family burden in the 1960s, research shifted to the emotional impact of growing up with a brother or sister with schizophrenia. This was accompanied by the emergence of self-help groups and published case histories of siblings themselves. In the 1980s, the research was mostly descriptive. Researchers studied sibling shame, poor self-esteem, and feelings of stigmatization. Different patterns of subjective burden were distinguished. Recently, greater efforts have been made to systematically define the variables associated with the burden experienced by siblings. The bulk of this research occurred between 1992 and 1999 (Greenberg, Kim, & Greenley, 1997; Greenberg, et al., 1999; Horwitz, 1993; Horwitz, et al., 1992; Horwitz & Reinhard, 1995; Landeen, et al. 1992; Marsh, et al., 1993b; Marsh, et al., 1993a.; Seltzer, et al., 1997).

### **Siblings and Social Support**

Horwitz and colleagues (1992) examined the role of adult siblings in providing social support to their severely mentally ill relatives. The researchers interviewed a sample of 283 patients from state hospitals or 24-hour crisis care facilities in Ohio shortly

after they were discharged. The researchers asked for permission to interview close family members, such as parents, siblings, or extended family. The study was based on personal interviews from a sub-sample of 109 sibling respondents, out of a list of 146 respondents.

The study categorized the responses to the interviews with siblings into two dimensions of support: subjective feelings and provision of concrete forms of material, financial, or other kinds of assistance. They compared predictors of sibling caregiving versus parental caregiving according to six main areas: need, personal relationships, caregiver involvement, social networks, gender of caregiver, and race. Findings indicated that greater patient need, positive attitudes towards the mentally ill sibling (personal relationships), and other role involvement (caregiver involvement) were the major factors that influenced sibling caregiving. Comparative analyses showed that personal relationships and alternative role involvements (caregiver involvement) were better predictors of sibling caregiving rather than parental caregiving.

Horwitz (1993) tested the hypothesis, derived from the serial model of social support, that adult siblings will provide more support to their seriously mentally ill relative when parents are not available. He interviewed 108 siblings. Results supported the serial model and indicated that, over the life course, siblings could in part replace parental caretakers as providers of social support to their seriously mentally ill relative. Specifically, siblings with one or no living parents provided more help than siblings with two living parents. Siblings with only one brother or sister provided more help than siblings with multiple brothers or sisters. Finally, siblings who provided more assistance

were more likely to be African American or Puerto Rican, to live at a closer distance, and to regard their siblings as having a very serious illness.

Horwitz (1994) conducted an exploratory study to examine how obligation, reciprocity, and the quality of personal relationships affected whether siblings provided social support to their relative diagnosed with a mental illness. The primary question for this study was, “Do kinship responsibilities extend beyond spousal and parental/child bonds so that relationships between adult siblings can become sources of long-term social support?” (p. 274). In order to answer this question Horwitz interviewed 108 siblings who had a brother or sister diagnosed with schizophrenia (80%) and manic-depression (15%). The diagnoses for the remaining 5% were unknown. Reciprocity stood out as the best predictor of sibling social support. In other words, reciprocity was important in creating bonds when one sibling was mentally ill. Siblings reported more help and more willingness to provide help to mentally ill relatives who reciprocated through affection, gifts, chores, and so forth. When siblings did not perceive reciprocity, they tended to withhold support without guilt or worry about how they would be perceived by others.

Horwitz’s studies were the first to systematically examine the possibility of viewing the sibling as one who could provide support to a sibling diagnosed with a mental illness. This research study, however, explored the siblings as being potential supports for their brothers or sisters diagnosed with a severe mental illness, and not as being the primary caregiver. The information offered little insight on the experiences of the individuals who were actively serving as the primary caregiver. However, in several instances, Horwitz acknowledged this and made recommendations for future research to explore the siblings who were the primary caregivers.

## **Qualitative Research on Sibling Caregiving**

There was a body of research studies that used qualitative methods as a way of informing the literature. These studies raised questions, provided narrative, and sought out the personal experiences and voices of siblings who had a brother or sister diagnosed with a severe mental illness (Landeem, et al., 1992; Marsh, et al., 1993b; Marsh, et al., 1993a).

Landeem et al. (1992) examined the practical concerns of well siblings of persons with schizophrenia by conducting a descriptive study that included a needs assessment survey and a workshop designed to increase well siblings' knowledge about schizophrenia. The results of their study indicated that well siblings wanted more information about schizophrenia. The 88 sibling respondents expressed a desire to learn more about the prognosis of mental illness and ways in which they could improve how they communicated and problem solved with their mentally ill siblings. Overall, the study's findings highlighted that well siblings of persons with schizophrenia had specific needs that varied from other family members, such as parents.

Marsh et al. (1993a & 1993b) examined the experiences of both siblings and children of people with serious mental illnesses over three phases of their life spans: during childhood, adolescence, and adulthood. The researchers point out that the response patterns varied over the life span because siblings, in particular, reported that they did not deal with the mental illness of a family member until adolescence or adulthood. Surveys and interviews were the two data collection methods in both studies. Respondents were members of the Sibling and Children (SAC) Network of the National Alliance of the Mentally Ill (NAMI).

The results from the 1993a study (N=60), *Troubled journey: siblings and children of people with mental illness*, pointed to the impact that severe mental illness had on the lives of the respondents. Some respondents reported major transformations in their lives, like having to deal with an illness that was not familiar and having to figure a way to respond to the needs of their sibling, while taking care of their personal responsibilities. Others shared stories about how they were afraid to have a family of their own because they feared that the mental illness would affect their children. Overall, the respondents expressed a need for more support and information about their relative's illness. On average, sibling respondents ranked needs for personal support, skills to cope with the illness, and for working through their reactions to the illness as being "very important."

The findings from the subsequent study titled, *Anguished voices: Impact of mental illness on siblings and children*, 1993b, were consistent with the 1993a study. In this study (N, not mentioned) respondents participated in interviews and two national surveys. The respondents presented at a workshop before a group of psychologists who were attending an annual meeting of their state psychological association. First the respondents shared their experiences; then they made recommendations to the audience. This study took excerpts from the detailed discussions and utilized the narrative to explain how mental illness impacts both siblings and children of relatives diagnosed with a mental illness.

While the most obvious limitation of these types of studies was the fact that the individuals were already motivated to seek support, they still offered valuable information that has helped to move the field in the direction of paying closer attention to the phenomena of subjective and objective burdens. These studies also identified some

of the key factors that influence the pattern and extent of involvement by siblings caring for their brothers and sisters. More importantly, these studies brought “human voices and experiences” to the previous literature. Through a partnership with the National Alliance of the Mentally Ill (NAMI), these siblings had a platform that enabled them to share their findings while identifying the need for more information on how families care for relatives diagnosed with a severe mental illness like schizophrenia.

### **Sibling Caregiving for Persons with Mental Retardation and Mental Illness**

The next phase of research focused on information from families with persons who were mentally retarded (Seltzer, et al., 1997; Greenberg, et al., 1999). Since mental retardation has been widely studied and society has tended to view persons with mental retardation as being more in need of custodial care, several aspects of this body of research had been well developed, thus providing a basis for comparing sibling caregiving practices between siblings caring for a relative with mental retardation versus a relative diagnosed with a severe mental illness.

Seltzer et al. (1997) contrasted 329 siblings of adults with mental retardation with 61 siblings of adults with serious mental illness. The researchers examined (1) the pervasiveness of the impact of the brother or sister on the sibling’s life, (2) the closeness of their current relationship and frequency of contact with the mentally ill sibling, and (3) the factors related to the sibling’s level of psychological well-being. Findings suggested that siblings of adults with mental retardation were significantly more likely than siblings of adults with serious mental illness to perceive that the sibling with a mental condition had a pervasive influence on their life and their decisions. These siblings were also more

likely to evaluate their “sibling experience” as mostly positive than were siblings of individuals diagnosed with a severe mental illness. In addition, siblings of adults with mental retardation had closer relationships with their disabled sibling than siblings of adults with serious mental illness. Finally, siblings of adults with mental retardation reported better psychological well-being when they had a close relationship with the disabled sibling. In contrast, siblings of adults with serious mental illness reported more favorable psychological well-being when they perceived a less pervasive impact of the disabled sibling on their life. In other words, the less involved they were with their disabled sibling, the better they felt.

Three contextual differences were discussed in regards to the family experiences between adult siblings of persons with serious mental illness and those with mental retardation. The differences were: (1) timing of the diagnosis in the family life course; (2) the predictability of the course of the disability; and (3) the level of societal stigma and support for the disability (p. 1). One of the major limitations with this study is the differences in the sample sizes. There were 329 siblings of adults with mental retardation and 61 siblings of adults with severe mental illness.

## **FAMILIES AND MENTAL ILLNESS**

The literature on the ways in which families provide care to a relative has offered many contributions to the study and treatment of severe mental illness (Goldman, 1982; Lefley, 1987; National Institute for Mental Health (NIMH), 1999; Steinwachs, Kasper, & Skinner, 1992a). However, there have been a number of limitations.

In spite of the many studies that explore the influence of the family on the relative and consider ways in which families could become effective caregivers, there is very little research that includes siblings in their scope. For example, Muhlbauer (2002) used qualitative methods to examine different phases in the journey or experiences of family members as caregivers. The findings indicated that family members (parents, siblings, and significant others) of a relative diagnosed with a mental illness experienced substantial difficulty with memory and concentration, and problems with hallucinations, delusions, violent behavior, substance abuse, social skills, money, and coping with stress and change. While the findings were interesting and informed some of the experiences of family members, like siblings, the sample involved only 26 respondents, thus was not representative of the entire population of siblings and other family members.

Marsh (2001) authored a book titled: *A Family-Focused Approach to Serious Mental Illness: Empirically Supported Interventions*. The book included siblings and focused on the availability of empirical evidence for five family interventions (family consultation, family support and advocacy groups, family education, family psychoeducation, and psychotherapy). The book presented materials for clinicians and practitioners that would enable them to gain insight into the experiences of individuals within a family unit. Some of the recommendations for working with siblings included a three-step model (pp. 286-287):

Step 1: *Family consultation*--which would offer a useful means of addressing the concerns of siblings, while also informing them about other resources.

Step 2: *Practitioners working with siblings*—for instance, by developing an individual family service plan, or joining support groups like the National Alliance for the Mentally Ill’s Family to Family national network.

Step 3: *Referrals*--for individual counseling and/or psychotherapy.

## **FAMILY BURDEN**

Research has also explored and investigated family burden as it relates to caregivers of mentally ill relatives (Cook, 1997a; Cook et al., 1997b; Greenberg et al., 1997; Harvey & Burns, 2003; Karp, 2003; Kung, 2001; Lefley, 1998; Lefley, 2003; Marsh et al., 1993a; Ohaeri, 2003; Saunders, 2003; Tessler & Gamache, 2000). Much of the literature has described families as being highly burdened by their relative’s mental illness (Cook, et al., 1997b)—a concept also referred to as *caregiver burden*. The term “caregiver burden” refers to a person’s emotional response to changes and demands that occurs as they give help and support to others (Zarit, et al., 1980). The vast majority of caregivers are referred to as “informal caregivers” meaning they are not paid for their time and work. Most caregivers are parents or spouses, but other family members and friends can also be caregivers.

An examination of the literature on the topic of burden reveals two primary domains: objective burden and subjective burden. Objective burden involves loss of financial income and subjective burden pertains to emotional distress (Grad & Sainsbury, 1963, 1968, as reported by Cook, et al., 1997b). At best, the literature on family burden included a brief section on the “sibling experience,” but those sections do not discuss cultural or ethnic differences. Furthermore, the conceptualization often fell short of

recognizing the experiences of siblings of color. Additionally, most of the sections that discuss the “sibling experience” tended to focus on younger siblings as opposed to adult siblings.

### **PARENTS TO SIBLINGS: MINDSET SHIFTS**

Despite the fact that parents initially assume responsibility for their severely mentally ill children, there is a growing recognition that the ability of parents to provide care for their mentally ill child eventually diminishes and ultimately ends (Lefley, 1987). Research to date has focused either globally on the family or specifically on the mother. As a result, there is a major gap about the specific role of the sibling as caregiver. As parents begin to “age out,” the responsibility for providing care increasingly shifts to the adult sibling (Greenberg, Kim, & Greenley, 1997; Greenberg et al., 1999; Horwitz, 1993a, 1993b, 1994; Horwitz, et al., 1992; Landeen, et al., 1992; Pruncho, Patrick, & Burant, 1996; Seltzer, et al., 1997; Samuels & Chase, 1979).

### **SIBLING RELATIONSHIPS AND BONDS**

Sibling relationships are the least studied relationships in the family system, yet they are one of the longest-lasting relationships in people’s lives (Shortt & Gottman, 1997). Moreover, siblings share a common social, cultural, and genetic heritage, making the sibling bond a unique factor within the family network (Nechmad, et al., 2000). Sibling support is intense during childhood and adolescence (Shortt & Gottman, 1997; Jenkins, 1992), weakens in adulthood (Bank & Kahn, 1982; Ross & Milgram, 1982), and strengthens again in old age (Cicirelli, 1989; Connidis, 1989).

The relationship between siblings may vary through the years, but many people find that it helps to keep them rooted to their past, able to cope with the present, and willing to hope for the future (Bank & Kahn, 1982; Cicirelli, 1995). For instance, when parents were neglectful or abusive, Jenkins (1992) found that siblings leaned on one another for support, which further supported the notion about the strong bond between siblings.

The importance and uniqueness of the bond between siblings is primarily discussed in the family therapy, foster care, and adoption literature. The social science literature tends to largely emphasize the concept of “burden.” Beyond the scope of the concept of burden as a topic, there is very little empirical research on siblings as caregivers, particularly in regard to caring for a brother or sister with mental illness (see Appendix B).

Bank and Kahn (1982) reported that “when other relationships cannot be relied upon, intense sibling relationships are activated” (p. 19). Research shows that after the death of a parent, the relationship between siblings becomes more powerful (Greenberg, et al., 1999; Horwitz, 1994; Horwitz, et al., 1992). Greenberg and colleagues (1999) further echo the need for research on siblings as caregivers, asserting that “the systematic examination of siblings without disabilities as sources of support is particularly timely and represents an issue of increasing importance for persons with mental illness, their families, and policy makers” (p.1214).

Wishnick (2001) interviewed caregivers, such as parents, siblings, and other extended family members in order to evaluate the effectiveness of a public mental health system’s ability to meet the needs of consumers with severe mental illnesses. In their

findings, siblings reported a need for more support and information about their relative's mental illness at a higher rate than parents or extended family members. The findings also suggested that addressing the needs of the caregiver was highly related to positive outcomes and lower recidivism rates for the consumer sibling. Thus, implying that meeting the needs of the caregiving sibling directly influences the functional capacity of the sibling with the mental illness.

While most studies systematically examine the relationship between siblings, Bank and Kahn (1982) attempted to develop a unified and comprehensive theory that would integrate various perspectives and provide a better understanding of the nature of the bond. The authors suggested that there were three recurring, predictable conditions that allowed a strong bond to develop: 1) high access or frequent contact between siblings; 2) the need for meaningful personal identity; and 3) insufficient influence. They observed that:

*... sibling bonds will become intense and exert a formative influence upon personality when, as children or adolescents, the siblings have had plentiful access and contact and have been deprived of reliable parental care. In this situation, siblings will use one another as major influences, or touchstones, in a search for personal identity. When other relationships—with parents, children, or spouses—are emotionally fulfilling, the sibling bond will be weaker and less important. (p.19)*

Ignoring the diversity within the United States could lead to incorrect assumptions about the variety of ways families interpret and provide care. Researchers can no longer "melt" diverse and culturally distinct "White" populations, like Italians, Jews, and Irish; nor can they lump together those labeled as "Blacks," such as, Haitians, Jamaicans, African and African Americans. Likewise, researchers cannot group family together as one unit, ignoring the unique roles of each individual, especially that of the sibling. Acknowledging different cultural beliefs, in addition to different familial roles,

may help us know what to expect from family members, in this case siblings, coming from culturally distinct groups.

Above all, we cannot assume that there is a universal definition and expression of caregiving vis-à-vis mental illness because there is not much research literature on race and culture. Researchers need to accept, record, and interpret the behaviors and responses of sibling caregivers within their cultural and ethnic context. This will help us understand the needs of this population and determine whether they are 1) assuming the role of caregiver in the absence of their parents, 2) responding to caregiving differently than their White counterparts, and 3) experiencing burden in the way that it has been previously documented in the literature.

## **Chapter 3**

### **Research Design and Methods**

This chapter provides a discussion of the research design and methods utilized in this study. As a way of acknowledging diversity, the design and methodology was developed to enable the researcher to address the ways in which ethnicity influences how caregiving roles are practiced (instrumental support/direct caregiving) and planned for (expectations of future caregiving roles). Siblings of color may conceptualize caregiving differently from White siblings, which in turn could result in a method of caregiving that looks drastically different from what is commonly thought or assumed. The next section addresses the investigative procedures, followed by a discussion about how the questionnaire was prepared for this study. The chapter continues with details about the variables examined in the study and a discussion about the sample subjects. The chapter ends with a discussion about the statistical analyses utilized to examine the data.

#### **INVESTIGATIVE PROCEDURES**

##### **UNIT OF ANALYSIS-SAMPLE DESCRIPTION**

Adult siblings of persons diagnosed with severe mental illness comprised the sample for this study. Participants identified themselves as being siblings, without a severe mental illness, and at least 18 years of age. Since the goal was to examine the impact of race and ethnicity on sibling caregiving practices, there was an emphasis on recruiting adult siblings who self-identified as being a person of color, such as African American, Hispanic/Latino, Asian American, and Native American. White siblings were

recruited to serve as a reference or comparison group. The term “sibling” was defined as a birth sister or brother, step-sister or brother, sister or brother in-law, or a person that the respondent considered a sister or brother.

Additional criteria for inclusion into the sample related to the sibling diagnosed with the severe mental illness, specifically: a) the sibling diagnosed with the severe mental illness had to be alive, b) the sibling had to have a formal diagnosis from a mental health professional, such as a psychiatrist, psychologist, primary care physician, or a social worker, and c) the sibling had to be diagnosed with a severe mental illness, including schizophrenia, schizoaffective disorder, major depressive disorder, and bipolar disorder. Data collection began February 2005 and ended June 2005.

## **PARTICIPANT RECRUITMENT**

Recruiting participants was one of the primary challenges. There were no existing representative sampling frames of adult siblings of persons diagnosed with severe mental illness. Therefore, it was not possible to use probability sampling techniques. Instead, in an effort to increase the inclusion of people of color in the sample, non-probability sampling procedures were used. The researcher attended conferences, workshops, community meetings, and talked to community leaders and members in order to gather contact information. A combination of quota, snowball, and purposive sampling procedures were employed in order to yield the most representative and sufficient sample as possible.

One method of recruitment involved sending written requests to the consumer advocacy sector, asking them to advertise or publish details about the study. Specifically,

advertisements were published on the main website of the National Alliance for the Mentally Ill (NAMI), in the *NAMI Advocate*, monthly newsletters for various local NAMI *Family to Family* chapters across the country, and on [Soulciti.com](http://Soulciti.com), a website geared towards informing African Americans living in Austin, Texas.

Another recruitment strategy involved attending the African Symposium 2004 section of the NAMI annual conference in Washington, D.C. During the keynote presentation, this research project was presented and attendees were invited to talk with the researcher in the exhibit hall, where brochures and materials were made available, along with a voluntary contact sign up sheet. Those who expressed interest in the study provided their contact information, identified if they were a sibling, or provided information for someone whom they thought would be willing to participate.

In an effort to recruit participants from the public mental health sector, collaborations were garnered with the Texas State Hospital system, Dr. Warren E. Smith Health Centers in Philadelphia, Austin/Travis County Mental Health Mental Retardation system, Dallas Metrocare Services, and Truman Medical Center in Missouri. Due to the current HIPAA laws concerning privacy, the researcher remained “blind” to all client information. The agency identified clients who met the criteria for the study and the researcher included a letter asking for permission to contact their brothers or sisters. Additionally, out of respect for the privacy of the client and recognizing the possible stigma of mental illness, the researcher was careful to not include any outwardly visible information that linked the materials to a mental health related research study.

### **Soliciting Client Households**

Materials sent directly to client households included a letter from the collaborating agency briefly describing and supporting the study, a question and answer sheet that informed the reader of the process of the study, a permission form from the researcher asking for their permission to contact their sibling to participate in the study, and a re-sealable postage paid card where the client: 1) indicated that he or she was willing to grant permission to the research, and 2) provided the contact information for up to two siblings. Materials were sent to 2000 clients, accounting for more than 70 (n=2,750) percent of the total number of mail outs to individuals diagnosed with a mental illness. Clients who were willing to grant the researcher permission to contact their siblings were informed in writing that they themselves would not be financially compensated. They were asked to indicate their decision, complete the card, and return it back to the researcher. For clients who chose to talk directly to the researcher, a “Sibling Study” line and toll free number was provided on all forms.

### **Soliciting Clients During Outpatient Therapy**

The same materials mentioned above were also distributed to clients during outpatient therapy sessions. However, in this approach the therapist explained the study to the client and asked if he or she was interested in providing their sibling’s contact information. If the client was not interested, they were assured that their benefits would not be affected in any way. If a client was willing to grant permission to the researcher, they were given the option of completing the postage paid card and having the therapist

put it in the mail, or they could take it home to complete it themselves. In most cases, the client opted to have the therapist put the card in the mail for them.

### **Possible Limitations**

There were a few complications during the recruitment process. For instance, it was not possible to directly identify siblings. They were commonly not recognized through the mental health services system (short of doing a chart review) and they tended to not frequently attend NAMI events. Therefore, in the consumer advocacy sector, parents of potential participants contacted the researcher or encouraged their children to participate in the study, thus introducing potential sampling bias (Rubin & Babbie, 2005). With this type of bias, the sample of respondents who were encouraged to participate by their parents could possibly limit the generalizability of the findings because this particular group may not represent the larger sample of sibling respondents. In other words, it may not be likely that the majority of respondents would have been encouraged to participate by their parents, who incidentally, were also members of an advocacy group.

In the public mental health sector, the same barrier was present. Moreover, there was some concern about sending materials in the mail, targeting ethnic minorities asking them to participate in mental health related research. Given the history of stigma in research attached to mental illness, a large number of mailings pertaining to the study (n=2,750) were sent out in order to make contact with enough persons with mental illness, and in turn obtain contact information for their siblings. The researcher

anticipated that at least 10 percent of persons with mental illness would respond to the mailings. A little over 5 percent responded to the mailings.

While persons with mental illness were solicited through their households and outpatient therapy sessions, it was not possible to test for differences between the two groups because the researcher was blind to their identities. It is possible that the two sampling frames differed in some way. For instance, the involvement of the therapist may have had an influence on the client to agree to provide their sibling's contact information. Again, due to the anonymity of the person with mental illness, it was not possible to detect.

#### **COMMUNICATING WITH STUDY PARTICIPANTS**

Once a potential participant was identified, the researcher contacted the person over e-mail or telephone to provide details about the participation process and answered any questions. If they were interested in the study, the researcher confirmed their mailing address and sent out a study package. Siblings were informed that all information would be kept confidential, that their participation would be voluntary, and that refusing to participate would not negatively impact them or their sibling with mental illness. Every participant was compensated fifteen dollars -- in the form of a bank-issued money order -- within 7 days of when the researcher received their questionnaire. Participants were asked to return the questionnaire, in the postage paid envelope included with the study package, within 2 weeks of receiving it.

## **Instrumentation**

A sixteen page self-administered questionnaire, *Sibling Caregiving*, was used as the primary data collection instrument in this study. The questionnaire was a modified version of the *Sibling Project Survey* questionnaire designed by Dr. Ellen Lukens, professor in the School of Social Work at Columbia University. The questionnaire consisted of demographic items, open- and closed-ended questions concerning the type of care the respondent provided, items that captured the nature of the relationship between the respondent and member of his or her family, and future plans that have been made to care for the person with the mental illness. A more detailed overview of the questionnaire is provided later in the chapter.

There were several reasons that the researcher decided to use a self-administered survey method for this study. First, self-administered surveys, in contrast to personal interviews for instance, represent an effective research method to facilitate collection of data from geographically dispersed samples (Dillman, 1978; 2000). Second, some of the questions or issues in the survey could have seemed sensitive or personal. When sensitivity is a concern, Rubin and Babbie (2005) assert that the self-administered method is more effective and appropriate than other methods. Third, it has been found that when asking questions that deal with socially desirable behaviors, more accurate information was reported when less intrusive methods of survey administration were utilized (Fowler, 1993; Sudman & Bradburn, 1982). In other words, the researcher believed that respondents may have felt less compelled to respond in a biased or “socially desirable” manner when completing a pencil-and-paper, self-administered survey than they might have in the presence of an interviewer during a face-to-face interview or over

the telephone. Since the primary target sample population consisted of adult siblings of color, every effort was made to ensure that the questionnaire was culturally appropriate.

It was expected that the study sample would be between 20 to 55 years of age, which also meant that many participants could have been married, had families, worked full-time or part-time, and experienced a variety of external mitigating or pull factors. The researcher speculated that the self-administered survey method would be more effective and preferred for this type of participant because of its potential to complement their busy lifestyle and schedule. In order to obtain a representative sample of siblings, quota, snowball, and purposive sampling methods were collectively employed.

### **Purposive Sampling**

In general, purposive sampling involves selecting a sample of observations that the researcher believes will yield the most comprehensive understanding of the subject of study (Rubin & Babbie, 2005). This sampling effort involved contacting county mental health centers in the state of Texas with a request to solicit information about next of kin contacts of persons diagnosed with mental illnesses. In order to respect the privacy of the siblings with mental illness, the mailing process was arranged by the respective county agency departments. Thus, the researcher remained blind to the identities of all individuals to whom information was sent. Each study package included the general purpose of the study, the researcher's contact information, a copy of the consent form for the person's records, and a postage paid postcard that served as the researcher's proof of consent from the respondent.

The researcher also contacted leaders of local NAMI chapters across the country to ask for their help in locating minority siblings. The leaders, in turn, contacted people who they believed would be suitable for the study and asked them to attend a meeting to learn about the study and decide whether they wanted to participate. One group, in particular, was a Hispanic family support group where members spoke limited English. Since the study materials were only available in English, the Spanish speaking leader facilitated communication between the researcher and the group and assisted members with the questionnaire.

### **Quota Sampling**

Quota sampling is described as a type of non probability sample in which units are selected into the sample based on pre-specified characteristics, so that the total sample has the same distribution of characteristics that are thought to exist in the overall population (Rubin & Babbie, 2005). In order to obtain a diverse sample, the researcher collaborated with a local community mental health mental retardation center to solicit potential participants by contacting clients of color with mental illness. Specifically, the agency, on the behalf of the researcher, sent study materials to 1000 clients who had identified an emergency contact as a “sister,” “brother,” “step sister/brother,” or “sister/brother in law.” Materials were sent to 600 Black clients and 400 Hispanic/Latino clients.

## **Snowball Sampling**

Snowball sampling occurs when a participant is asked to recommend additional people to participate in the study based on the assumption that the he or she knows where to “find” such respondents. This type of sampling is commonly used with populations that are considered “hard to access” (Rubin & Babbie, 2005). At the end of the questionnaire, there was an optional section that asked the respondent to provide names, phone numbers, and e-mail addresses of other siblings who might want to participate. Of the 130 questionnaires sent, 32 (24.6%) participants provided additional contacts.

## **Survey Development**

The original survey was a 16-page self-administered questionnaire titled *Sibling Caregiving*. Drs. Ellen Lukens and Steven Lohrer (a Doctoral candidate at the time) created the questionnaire as a part of the *Sibling Project*, a research collaboration between the School of Social Work at Columbia University and the New York State Psychiatric Institute. In large part, the development of the questionnaire was informed by prior studies conducted with siblings of adults with mental illness. The researchers borrowed measures from several sibling studies conducted by other researchers. The questionnaire covers three temporal domains: a) instrumental caregiving, b) future caregiver status, and c) background and demographic items. The following discussion first provides a description of the development of the *Sibling Project* survey, which is also published in Dr. Steven Lohrer’s dissertation (2001, pp. 53-58); and then discusses how the questionnaire was modified for this study.

## **Development of *Sibling Project Survey***

The original data collection instrument, the Sibling Project Survey (SPS), was designed for the research purposes of the Sibling Project, a collaboration between Columbia University and the New York Psychiatric Institute. To address potential concerns related to the validity, reliability, and ease of administering the questionnaire, the development of the questionnaire was guided by specific considerations. The foundation of the SPS was based on data collected during the focus group phase and the in-depth interview phases of the larger project, known as the Sibling Project. The earlier phases of the Sibling Project revealed major conceptual domains and key issues that served as topic areas for the questionnaire. In addition, the SPS was influenced by systematic reviews of existing instruments and indexes, particularly those previously administered to caregivers of adults with mental illness (cf. *Sibling Survey* created by Greenberg, 1997; instruments by Horwitz and colleagues, 1992; *Caregiver Help Scale* used by Stueve, Vine, & Struening (1997); measures used by Tessler & Gamache, 1994; and the *Burden Assessment Scale for Families of the Seriously Mentally Ill* created by Reinhard, et al., 1994).

To the extent possible, the arrangement of the SPS was guided according to the broad design principles outlined by Dillman (1978; 2000). These principles stress the application of social exchange theory and efforts to establish respondent trust, as well as enhance perceptions of rewards, and reduce respondent cost as a means of increasing survey accuracy and response (Dillman, 1978; 2000). Additional design elements used in the SPS incorporated important stylistic considerations. For instance, questions were distinguished from answer options by use of lower case letters for questions while upper

case letters were used for answer categories. Moreover, SPS utilized an attractive questionnaire layout, established a vertical flow for items, and prominently displayed a logo for the project.

Design considerations were also integrated into the development of the structure of the SPS to enhance the validity of data collected and to address potential sources of error in recall, including: social desirability, question order effects, forward telescoping, and recall decay. In general, concern exists regarding the accuracy of data obtained from retrospective survey designs, since such investigative efforts are contingent on the abilities or willingness of respondents to provide information (Dillman, 1978; Sudman & Bradburn, 1982).

The SPS attempted to reduce social desirability bias by assuring confidentiality in the form of a signed letter from the principal investigator. Respondents were also allowed to remain anonymous. The order of items in the questionnaire were carefully considered during the design phase of the SPS. In an effort to limit the potential threat that emotions or information triggered by one question would influence or contaminate a later one, known as question order effect (see Rubin & Babbie, 2005 for a more detailed exposition on this topic), items related to financial contribution and time involvement in caregiving were placed prior to items presumed to be more emotionally laden (e.g., in-depth psychological items and items relating to the recall of specific historical events). It should be noted, however, for reasons of conceptual clarity related to the overall survey, items related to the anticipated future caregiving involvement were placed toward the end of the questionnaire. An effort was made to sequence some items in chronological order.

Particular attention was focused on the design of items used to estimate time expenditures associated with caregiving activity to avoid potential sources bias, particularly in reference to forward telescoping and recall bias. Forward telescoping (or telescoping), a problem attributed to respondents' inclusion of events which occurred outside the specified time period under consideration into estimates of behavior, serves to make more distant events appear more recent to the research scientist (Sudman & Bradburn, 1982). In other words, telescoping bias would involve inclusion of an event (either intentionally or unintentionally) that occurred more than a year ago into reports of events which occurred over the past year, resulting in over-reporting of information.

Recall delay relates to a respondent's difficulty or inability to accurately remember events in question (Subman & Bradburn, 1982). An individual may simply forget over time or not be able to recall events with accuracy after some period of time has passed, resulting in inaccuracies in information collected. In order to limit inaccuracy related to telescoping and recall delay, the SPS utilized brief and specific time frames (e.g., the past month) or estimations based exclusively on the most recent event to establish time and financial estimates of caregiving involvement. However, it was necessary to utilize longer time frames relating to estimations of events which were not expected to occur with regularity (e.g., psychiatric crisis).

Prior to administration, the SPS was pre-tested by the research team at Columbia University and the New York Psychiatric Institute. This process served as an additional method to enhance the validity, reliability, and ease of administration of the questionnaire. Volunteers who were eligible for inclusion in the study completed the questionnaire and participated in subsequent interviews to comprehensively review the

questionnaire with research staff. Interviews focused on clarity and presentation of items, opinions regarding items, as well as comprehensiveness of the instrument. In response to feedback gained during the pre-testing phase, minor revisions to items on the survey were made, most often in response to problems or difficulties encountered in answering multiple response items.

### **MODIFYING THE SPS QUESTIONNAIRE FOR THIS STUDY**

The layout and design from the original SPS questionnaire was preserved for this study. For instance, the logo, *Sibling Caregiving*, was prominently displayed on the cover, instruction page and on all corresponding forms. The same factors that were considered in the development of the SPS – such as social desirability, question order effects, forward telescoping, and recall delay – were preserved in the questionnaire.

However, there were sections that were modified in order to more accurately address the targeted sample population—siblings of various ethnic backgrounds, socioeconomic status, and geographic areas of the country (the complete questionnaire is provided as Appendix C). The modified items and additional scales came from Greenberg and Seltzer’s (2003) questionnaire. For example, in section D6, the following two items were included: *b) I have talked with my spiritual/religious advisor;* and *e) I have searched for information on the Internet or World Wide Web.* The word “undoubtedly” was changed to “possibly,” based on an assumption that respondents for this study may not have thought a lot about or have heard many things about what caused their sibling’s mental illness.

A scale adapted for use in Greenberg and Seltzer’s (2003) questionnaire was included as item D8. This scale asked about the respondents’ views and opinions of what might have caused their sibling’s problem. The 14-point scale, with items ranging from *a*

*biochemical imbalance in the brain to he/she inherited it to problems in school during childhood to of God's will*, was measured on a 4-point Likert-type scale: 1) definitely not, 2) probably not, 3) probably and 4) definitely.

For item D10, an additional item was added to determine if the respondent felt that persons from his or her spiritual or religious community treated them differently because their sibling had a serious mental illness. Items from Bengston and Schrader's (1982) Positive Affect Index (PAI) concerning the respondent's relationship with his or her mother and father were included as D12 and D13, respectively. Generally, the PAI has been used to evaluate positive feelings towards the sibling respondent and their consumer sibling(s), mother, and father. The Index assesses the amount of positive affect that the respondent has for another person and the positive affect that he or she perceives another person has towards him or her. The questionnaire utilized items where the respondent was able to report his or her affect towards his or her mother or father.

The sibling questionnaire was pre-tested on 3 individuals: two adult siblings and one expert in mental health and schizophrenia research. One sibling was a Black woman currently participating in the care of her sister who had been diagnosed with schizophrenia. The other sibling was a White woman who primarily cared for her brother. The third person was an expert and scholar in the areas of mental health, severe mental illness, issues relating to African Americans, and psychometric instrument design. The comments and feedback from the consultants was consistent. They reported that 30 to 35 minutes to complete the questionnaire was too long. Most of their comments and suggestions were incorporated into the final version.

## **VARIABLES AND OPERATIONALIZATION**

Approximately 70 items and five subsections encompassed the structure of the questionnaire. *Section A* focused on demographic items related to the sibling respondent

without mental illness and family background information. *Section B* focused on items pertaining to instrumental or direct caregiving involvement. *Section C* focused on the brother or sister diagnosed with the mental illness and *Section D* included items that pertained to the conceptualizations, beliefs and feelings of the sibling without mental illness as they related to having a relative diagnosed with a mental illness. Respondents were asked about the sources they utilize for support and how they obtained information about mental illness. Finally, *Section E* focused on future caregiving involvement. The following section discusses the variables and the methods by which each variable was operationalized.

## **Study Variables**

The goal of the study was to examine the ways in which siblings reported providing care for their brother or sister with a mental illness and to determine whether they expected to provide care in the future. Direct caregiving was referred to as *instrumental support*. Using the term instrumental support was guided by measures utilized in the previous research of Lohrer (2001) and Greenberg et al. (1999). In their work, the researchers conceptualized the term in regards to the objective or direct caregiving involvement patterns. The expectation of future caregiving roles or involvement was derived from the conceptual framework of Lohrer (2001). In this study, the concept was captured by respondents indicating whether (or not) they expected to provide care in the future for their sibling with mental illness.

***Dependent Variables.*** There were two main dependent variables in the study. The first dependent variable, instrumental support, was measured by two items: 1) the

amount of money the respondent reported spending on direct caregiving for their sibling over the past month; and 2) the number of hours that the respondent engaged in direct caregiving activities over the past month. Direct caregiving (also referred to as instrumental support) was described as: grooming, paying bills, managing money, providing transportation, phone expenses, helping with rent, and participating in social or recreational activities.

The second dependent variable, expectation of future caregiving involvement, was operationalized on the basis of whether the respondent indicated that they expected to provide care for their sibling in the future. Respondents were asked whether any member of the family was expected to take primary responsibility for providing help to the adult diagnosed with a severe mental illness after the parents were no longer the primary caregivers. The sibling was able to indicate that they expected to have a role in the future care of their relative, whether it was he or she alone as the primary caregiver or they and another relative. The first two response categories were collapsed into one category (code 1). The remaining response categories indicated that the sibling identified someone, such as another family member or a service provided to become the primary support for their relative.

DV1: *Instrumental Support (Ordinal Variable)*. The following two items in the sibling questionnaire were used to measure this variable: Questionnaire p. 4: Q: B3 & B6

DV1a: B3: Over the past MONTH, provide your best estimate of the amount of money you have spent related to your sibling (include: money given for rent, medication, bills etc. and/or costs to travel to your sibling, phone expenses, etc.).

DV1b: B6: Estimate the TOTAL time you spent in the past MONTH engaged in care related activities for your sibling.

DV2: *Expectation of Caregiving Responsibility in the Future (Dichotomous Variable)*. The following item was used to measure this variable:  
Questionnaire p. 15: Q: E2

Who will be the primary support person for your sibling in the future? If parent(s) are primary caregivers, consider when your parent(s) are no longer able to help.

1. I will
2. I and another relative(s) will be equally involved with my sibling with mental illness, specify relationship to you
3. 

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Other family member, specify relationship to you
4. Someone else, specify (friend)
5. Agency / service provider
6. Uncertain
7. Not applicable, sibling does not need ANY special care or support

***Key Predictor Variables.*** Twelve key predictor variables were analyzed in the study. *Gender* compared the extent of instrumental support and expectations of future caregiving, between males (coded 0) and females (coded 1), as reported by respondents.

*Race* was also utilized to compare the average differences in caregiving between respondents. *Race* was coded a few different ways. The recoded variable had four categories: 1=Black/African American, 2=White, 3=Hispanic/Latino, and 4="Other." The "Other" category (n=6) consisted of persons who reported as being Asian or Asian/Pacific Islanders (n=4), Native American (n=1), and other (n=1). The three main racial groups were also made into dummy coded variables. The categories were White (coded 1)/Non White (coded 0), Black (coded 1)/Non Black (coded 0), and Hispanic/Latino (coded 1)/Non Hispanic/Latino (coded 0).

*Marital status* was assessed by the respondent reporting whether they were married, legally separated, divorced (not remarried), single (never married), or other.

*Employment status of the respondent:* respondents were asked to report their employment status over the past 12 months. Respondents were given four response choices: homemaker, unemployed, work part-time (30 hours or less per week), and work full-time (more than 30 hours per week). For this analysis the variable was recoded into two categories: 1) not working at all (coded 0) and 2) working at least part time (coded 1).

*The number of children under age 18 currently living in respondent's household:* respondents were asked to report whether they had children living in their household under 18 years of age. This variable was dichotomized to indicate whether the respondent reported having no children under 18 living in their household (coded 0) or whether they reported at least one child, under 18, living in their household (coded 1).

*Geographic distance between respondent and sibling with mental illness:* respondents were asked to report how long (in minutes and hours) it usually took them to get to their sibling's home by vehicle. They were able to report that they lived with their sibling or that , it took 0 to 30 minutes, between 30 and 60 minutes, between 1 and 2 hours, or more than 2 hours. The variable was recoded into the following categories: 1= lives with sibling, 2= 0 to 60 minutes, 3= 1 to 2 hours, and 4=more than 2 hours.

*Behavioral problems demonstrated by the sibling with the mental illness:* respondents were asked, “*Over the past year, has your sibling experienced any of the following?*” The Likert-type response set included nine items where the respondent could respond: *no, 1 time, 2 or more times, or don't know*. Five items, in particular, were selected as indicators for behavioral problems, 1) been admitted to a psychiatric hospital, 2) been admitted to a drug/alcohol rehabilitation program, 3) been held in police custody

or jail/prison, 4) had episodes of violent behavior toward others, and 5) attempted suicide. Each response category was given a score. The scores were summed and averaged. The average or mean scores were used to produce the data for the new variable that measured geographic distance (see Appendix D).

*Emotional closeness to family of origin* was assessed in three different ways: emotional closeness between sibling and mother, father and sibling with mental illness during their teenage years. Items from Bengston and Schrader's (1982) relationship scale for mothers and fathers were included in the questionnaire (see page 14 of the Sibling Questionnaire for more details). The items for both mother and father scales were summed and a mean score was created using SPSS V.11.5. The new variables created were based on the mean scores of the two scales. Greenberg and colleagues (2001) created a 25-item scale that asked the respondent's family environment when he or she was a teenager (between ages 13 and 17). A principal component analysis was run to determine the number of constructs within the scale. Three domains or constructs were identified: a) reciprocal relationships, b) stigma/shame/worry, and 3) family environment.

***Demographic and Background Variables.*** The demographic and background variables included in the analysis pertained to the respondent and the sibling diagnosed with a mental illness. The following section briefly lists the variables for either the respondent or the sibling with the mental illness. A more detailed analysis and discussion is provided in Chapter 4. The demographic and background variables for the respondent included the respondent's age, gender, highest level of education, race/ethnicity, marital status, and employment status. The demographic and background variables for the sibling diagnosed with the mental illness included the sibling's age,

gender, race/ethnicity, primary mental health diagnosis, highest level of education, and employment status. In addition, two separate variables were created; one looked at the birth order between the respondent and the sibling with the mental illness, and the other examined the dyad between the siblings. For example, the variable examined whether it was a female respondent reporting to care for a female sibling, male respondent caring for a male sibling, a male respondent caring for a female sibling, or a female respondent caring for a male sibling.

## **RESEARCH HYPOTHESES**

Methodologically, this dissertation study was similar the Greenberg et al. (1999) study. However, the focus of the research questions and hypotheses for this study were different. The ways in which this study differed from the Greenberg, et al. (1999) study are enumerated below:

The current study

1. did not include a sample of siblings who currently or will care for a brother or sister with mental retardation; and
2. did not include an interview with the mother of the siblings prior to administering the questionnaire.
3. did not draw its sample from an ongoing longitudinal study, but did use a non-probability cross sectional design
4. did not focus specifically on the caregiving practices of siblings of color.

This study sought to determine if the findings from the Greenberg, et al. (1999) study were consistent for siblings of color. This was tested by the following hypotheses:

- H1: White siblings of adults diagnosed with a severe mental illness will provide less instrumental support than siblings of color.

- H2: White siblings of adults diagnosed with a severe mental illness will be less likely to have expectations of participating in future caregiving responsibilities than siblings of color.
- H3: Sisters of adults diagnosed with a severe mental illness will provide more instrumental support than brothers, regardless of race and ethnicity.
- H4: Sisters of adults diagnosed with a severe mental illness will be more likely to expect that they will have caregiving responsibilities in the future than brothers, regardless of race and ethnicity.
- H5: Siblings who report having feelings of closeness to his or her family of origin will provide more instrumental support than siblings who do not report feelings of closeness to his or her family of origin.
- H6: Siblings who report having feelings of closeness to his or her family of origin will have expectations of playing a role in providing future caregiving than siblings who do not report feelings of closeness to his or her family of origin.
- H7: Siblings who report that their brother or sister has more behavior problems will provide less instrumental support than siblings of adults with fewer behavior problems.
- H8: Siblings who report that their brother or sister has more behavior problems will be less likely to expect having future caregiving responsibilities than siblings who report fewer behavior problems from their brother or sister.
- H9: Siblings who report being married, employed at least part time and have children under the age of 18 living in their households will provide less instrumental support to their brother or sister diagnosed with a severe mental illness; nonetheless, these factors will not predict the sibling's likelihood of expecting to have a role in providing future caregiving.

## **STATISTICAL ANALYSIS**

### **ANOVA Analysis**

One-way between groups analysis of variance (ANOVA) was used to simultaneously compare the differences between two or more groups. The use of “one-way” in the title indicates that only *one* independent variable (IV) is being considered

(also sometimes called one *factor*). When two IVs (or factors) are examined at the one time it is called a *two-way* ANOVA. A factor in a one-way ANOVA has two or more levels (Hair et al., 1985). An ANOVA was used to examine hypothesis H7.

### **Crosstabulations**

Crosstabulations, a combination of two (or more) frequency tables arranged such that each cell in the resulting table represents a unique combination of specific values, was used to examine frequencies of observations that belonged to specific categories on more than one variable (Hair et al., 1985). Categorical (nominal) variables or variables with a relatively small number of different values were crosstabulated. Column and row percentages were utilized to compare relationships between the variables.

Crosstabulations were used to examine hypotheses H2, H4, and H8.

### **Independent Samples T-Test**

An independent samples t-test was utilized to test the mean difference between two groups on a particular dependent variable. For example, in order to test the difference between gender on instrumental support (the dependent variable), males and females would be analyzed. This t-test assumes that: 1) all observations are independent of one another, 2) the dependent variable is metric, 3) the dependent variable is normally distributed, and 4) there is homogeneity of variance between the groups (Hair et al., 1985). Independent samples t-test were utilized to examine hypotheses H1 and H3.

### **Multiple Regression**

A multiple regression model was used to account for (predict) the variance in two dependent variables: instrumental support and emotional support. This model required

that the dependent variable be metric, which was based on linear combinations of interval, dichotomous, or dummy independent variables. Multiple regression can establish that a set of independent variables explains a proportion of the variance in a dependent variable at a significant level (significance test of  $R^2$ ), and can establish the relative predictive importance of the independent variables (comparing beta weights) (Hair, Anderson, Tatham, & Black, 1985). This study employed a simple or simultaneous entry multiple regression model, in order to see how much variance in the dependent variables can be explained by the set of 12 independent variables. The sample size/predictor variable ration of at least 10 to 1 was met in the analysis. The multiple regression analysis was used to examine hypotheses H5 and H9.

### **Logistic Regression**

A binary logistic regression analysis was used to determine the relationship between 12 independent (predictor) variables on the dichotomous dependent variable: *Expectation of future caregiving responsibility*. Logistic regression combines the independent variables to estimate the probability that a particular event will occur, i.e. a subject will be a member of one of the groups defined by the dichotomous dependent variable (Schwab, 2005). When the variables do not satisfy the assumptions of normality, linearity, and homogeneity of variance, logistic regression is the statistic of choice since it does not require that these assumptions are met.

This form of regression required that the dependent variable be dichotomous. The independent variables could be either metric or dichotomous (Hair, Anderson, Tatham, & Black, 1985). The model requires that there be a minimum sample

size/predictor variable ratio of 10 to 1. The requirement was met in the analysis. The logistic regression model was used to examine hypotheses H6 and H9.

### **Statistical Power Analysis**

A power analysis was run with the program NCSS-PASS specifying 12 predictors (entered simultaneously in one step) in a linear multiple regression. The researcher used R-squares of .36 and .42 (as reported in the Greenberg et al., 1999 article) and significance levels were set at .05 and .10, providing the following results:

\*To achieve power of at least 80% with an R-square of .36, 43 people would be required at  $\alpha=.05$ , and 37 people would be required at  $\alpha=.10$

\* To achieve power of at least 80% with an R-square of .42, 36 people would be required at  $\alpha=.05$ , and 31 people would be required at  $\alpha=.10$

It should be noted, however, that this is the significance for the entire model when all predictors are entered simultaneously. With so many predictors and so few people, it is possible that the model would be significant, but that each individual predictor would not be significant. For some, the N's proposed in the power analysis could be considered too low and would violate sample size/predictor variable ratio assumption of a multiple linear regression model. According to a general rule, a regression model requires (assumes) a ratio of 15 cases per predictor variable (Hair et al., 1988). This would require an N of 180 (15 cases multiplied by 12 predictor variables). Nevertheless, the power analysis would help support the idea that the researcher can expect similarly high R-squareds for this study. In other words, it would be feasible to use fewer people in the sample, rather than what the general guidelines recommend. For example, it would be possible to use 100 people, rather than the recommended 180.

## Testing Major Assumptions for the Statistical Models

As mentioned previously, both multiple linear regression models and logistic regression models have a number of assumptions or requirements designed to yield the best relationship between the dependent variable and set of predictor variables. In addition to the requirements mentioned in the previous sections, tests for normality, linearity and homogeneity were run on the dependent and independent variables, prior to doing any analyses.

**Normality.** Multivariate statistics assumes that the variables are normally distributed (Hair et al., 1985). In order to test for normality, the dependent variable and predictor variables had to be metric, so ordinal variables were treated as metric with caution by the researcher. Variables could not be nominal or dichotomous as these level variables were not expected to be normally distributed. The hypothesis for normality states that the null hypothesis for the variable is normal (i.e., the actual distribution of the variable fits the pattern we would expect if it is normal). If the researcher failed to reject the null hypothesis, she concluded that the distribution was normal. If the distribution of the variable was not normal, she employed a transformation in order to induce normality. If the transformed variable induced normality, that variable was substituted into the analysis. The logarithmic transformation, the square root transformation, and the inverse transformation were examined in this analysis. When a transformation did not induce normality, the variable remained in the analysis due to the exploratory nature of the research study. See Appendix E for details on the normality tests in this analysis.

Since there is not a direct test for multivariate normality, researchers generally test each variable individually and assume that they are multivariate normal if they are individually normal, though this is not necessarily the case. There are both graphical and statistical ways to examine normality. Graphical methods include examining histograms

and normality plots. Statistical methods include diagnostic hypothesis tests for normality, with a general rule that states a variable is reasonably close to normal if its skewness and kurtosis have values between  $-1.0$  and  $+1.0$  (Schwab, 2005). For the purposes of this dissertation study, skewness and kurtosis was utilized as an indicator of normality. Nevertheless, it should be noted that neither the graphical or statistical method was absolutely definitive.

***Linearity.*** The assumption of linearity presumes that the relationship between variables is linear, or that they would perform better if the relationships were linear. In order to evaluate for linearity the dependent and predictor variable had to be metric; ordinal variables were treated as metric with caution by the researcher. If a relationship was nonlinear, the statistics which assume it as linear would underestimate the strength of the relationship, or fail to detect the existence of a relationship (Schwab, 2005). Schwab explains that *linearity means that the amount of change, or rate of change, between scores on two variables is constant for the entire range of scores for the variables.* As with the assumption for normality, there are both graphical and statistical ways to evaluate linearity. Graphical methods include the examination of scatter plots, often overlaid with a trend line. Statistical methods include diagnostic hypothesis tests for linearity; a general rule states a relationship is linear if the difference between the linear correlation coefficient ( $r$ ) and the nonlinear correlation coefficient ( $\eta$ ) is small (Hair et al., 1985). Furthermore, if the correlation ( $r$ ) or partial correlation ( $\eta$ ) was statistically significant at the .05 level, the researcher concluded that there was a linear relationship between the variables.

If the relationship was not statistically significant, a logarithmic transformation, square root transformation, and inverse transformation were used to try to induce linearity. If a transformed variable induced linearity, that variable was substituted in the

analysis. If nothing induced linearity, the researcher concluded that there was not a relationship between the variables. See Appendix E for linearity results.

***Homogeneity of Variance.*** Homogeneity refers to the assumption that the dependent variable exhibits similar amounts of variance across the range of values for an independent variable. The test for homogeneity requires that the independent variables be non-metric and the dependent variable be metric (ordinal or interval). When the independent variables are ordinal, we use the categories the same way we would for a non-metric variable.

As with the other assumptions above, there are graphical and statistical methods for evaluating this assumption (Schwab, 2005). The graphical method is called a box-plot. The statistical method is the Levene statistic. Neither of the methods is absolutely definitive. The null hypothesis for the test of homogeneity of variance states that the variance of the dependent variable is equal across groups defined by the independent variable, i.e., the variance is homogeneous. To satisfy the assumption, the Levene statistic should not be statistically significant. If the assumption was not supported, a transformation was run in order to try to satisfy the assumption. If the transformation did not work, the researcher acknowledged that the model may have had less power and the analysis could have been biased or systematically incorrect, as reported by Schwab (2005).

## Chapter 4

### Results

The following chapter presents the results of the study. The chapter begins with an overview of the demographic data related to the respondents who participated, followed by a description of the sibling with mental illness. The findings pertaining to the investigation are organized according to the dependent variables: instrumental support and expectations of future caregiving, and their corresponding hypotheses.

*Demographic information for sibling respondent.* Questionnaires were mailed to 120 potential participants. A total of ninety-three questionnaires were completed and returned, yielding an overall response rate of 77.5%. The descriptive statistics in Table 4.1 indicates that the average age reported by the respondents was 43, with a range from 19 to 73 years old. More than fifty percent (53.8%) of the sample reported being younger than their sibling diagnosed with mental illness. Almost 60% (n=52) of the respondents reported that they lived within a 30 minute drive to their sibling with the mental illness. Twenty-four percent reported living more than a two-hour drive to their sibling with mental illness. Over the past 12 months, 65% (n=60) reported working at least part-time (30 hours a week or more). Just under half (49.5%) of the sibling respondents reported graduating from college and 52.7% reported being married. The sample consisted of 77% females and 23% males. About one-third (32%) of the respondents were sisters caring for another sister, 45% were sisters caring for brothers, close to 7% were brothers caring for sisters, and 16% were brothers caring for another brother. As far as the

racial/ethnic composition of the sample, 28% reported being Black; 37% reported being White, non Hispanic; 29% reported being Hispanic/Latino; and about 6% reported being from other groups.

**Table 4.1: Demographic Characteristics of Sibling Respondent (N=93)**

<b>CHARACTERISTICS</b>	<b>RESULTS (%)</b>
<b><i>Gender</i></b>	
Male	22.6
Female	77.4
<b><i>Race/Ethnicity</i></b>	
Black	28.0
White	36.6
Hispanic/Latino	29.0
Other	6.5
<b><i>Employment Status</i></b>	
Homemaker	18.3
Unemployed	17.2
Work Part-time	18.3
Work Full-time	46.2
<b><i>Age (in years)</i></b>	M=42.64(S.D.=12.35) [range = 19 – 73]
<b><i>Age Order</i></b>	
Older than sibling with M/I	44.4
Younger than sibling with M/I	53.8
<b><i>Caregiving Gender Dyad</i></b>	
Sister w/o M/I and Sister w/M/I	32.3
Sister w/o M/I and Brother w/M/I	45.2
Brother w/o M/I and Sister w/M/I	6.5
Brother w/o M/I and Brother w/M/I	16.1
<b><i>Marital Status</i></b>	
Married	52.7
Other	47.3
	<i>(Table Continued)</i>

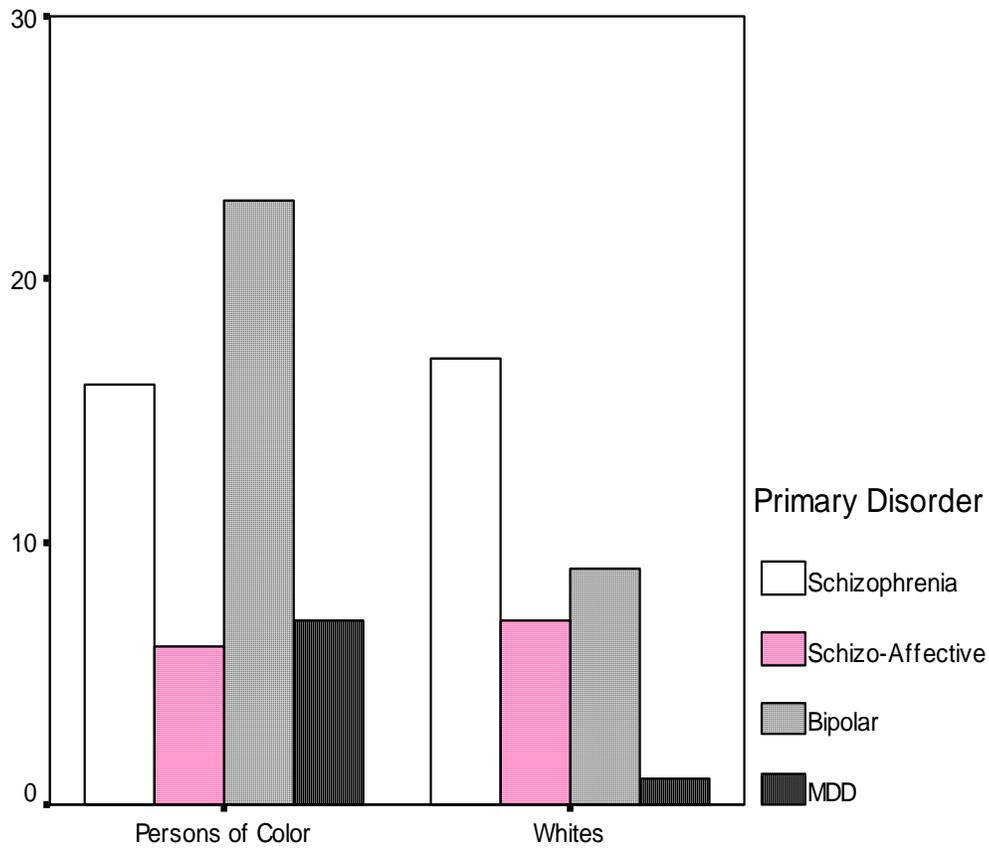
**Table 4.1: Demographic Characteristics of Sibling Respondent (continued)**

CHARACTERISTICS	RESULTS (%)
<b><i>Level of Education</i></b>	
Less than High School	7.5
High School Graduate	16.1
Some College	25.8
College Graduate	19.4
Some Graduate School	10.8
Graduate Degree	20.4
<b><i>Distance from Sibling w/ Mental Illness</i></b>	
0 (Lives w/Sibling)	15.0
More than 0 < 30 minutes	40.9
Between 30 minutes and 1 hour	9.7
Between 1 hour and 2 hours	9.7
More than 2 hours	23.7
<b><i>Mother Alive</i></b>	
Yes	72
No	28
<b><i>Father Alive</i></b>	
Yes	51.6
No	47.3
<b><i>Person Considered Primary Support</i></b>	
Mother	34.4
Father	2.2
Both Mother and Father	9.7
Sibling Respondent	20.4
Sibling Respondent and Relatives	20.4
Others	13.0

***Demographic information for sibling with mental illness.*** Descriptive statistics pertaining to race/ethnicity were assumed to be the same for the sibling diagnosed with mental illness as they were for the respondent sibling. If a respondent had more than one sibling with a mental illness, he or she had the opportunity to describe the situation for only one of the siblings for the questionnaire. The average age reported for the sibling

with mental illness was forty-two. The minimum reported age was 2 years and the maximum age was 71 years. The primary mental illness was schizophrenia in 36% of the cases and bi-polar disorder in 34% of the cases. Schizoaffective disorder was the third highest reported for 14% of the sample. Figure 4.1 illustrates the diagnoses for Whites and persons of color:

**Figure 4.1: Primary Diagnoses for White and Persons of Color**



**Table 4.2: Demographic Characteristics of Sibling w/Mental Illness (N=93)**

<b>CHARACTERISTICS</b>	<b>RESULTS (%)</b>
<b><i>Gender</i></b>	
Male	61.3
Female	38.7
<b><i>Race/Ethnicity</i></b>	
Black	28.0
White	36.6
Hispanic/Latino	29.0
Other	6.5
<b><i>Employment Status</i></b>	
Unemployed	59.1
Volunteer	4.3
Work Part-time	17.2
Work Full-time	12.9
Other	5.4
<b><i>Age (in years)</i></b>	M=42.56(S.D.=14.56) [range = 2 – 71]
<b><i>Primary Mental Illness</i></b>	
Schizophrenia	35.5
Schizo-Affective Disorder	14.0
Bi-Polar Disorder	34.4
Major Depressive Disorder	8.6
Other	7.6
<b><i>Level of Education</i></b>	
Less than High School	21.5
High School Graduate	28.0
Some College	24.7
College Graduate	15.1
Some Graduate School	1.1
Graduate Degree	6.5

For the purposes of this investigation, and depending on the type of analysis, the variable race/ethnicity was either dichotomized into White siblings and siblings of color, or categorized into 1=Black, 2=White, 3=Hispanic/Latino, and 4=Other. Instrumental support was measured by two separate variables, *B3* (DV1\_a) and *B6* (DV1\_b). As explained in Chapter 3, *B3* measured the amount of money a respondent reported spending in caregiving related duties over the past month, and *B6* measured the number of hours respondents reported spending on caregiving related activities over the past month. The following explains the findings from the examination of the hypotheses concerning instrumental support. The key predictors analyzed for these hypotheses were: race/ethnicity, gender, feelings of closeness with family of origin, and the number of behavior problems by the sibling with the mental illness.

### RESULTS OF HYPOTHESES RELATED TO INSTRUMENTAL SUPPORT

H1: White siblings of adults diagnosed with a severe mental illness will provide less instrumental support than siblings of color.

**Table 4.3: Mean Levels of Instrumental Support among Whites and Siblings of Color (N=93)**

	White Siblings (n=35)	Siblings of Color (n=58)	Test Values
Reports of money spent (money/past month--DV1_a)	44.09(63.35) <sup>a</sup>	148.79(357.94) <sup>a</sup>	F= 8.064* <sup>b</sup> t= 2.172(63)*
Reports of time spent in caregiving activities (hours/past month--DV1_b)	8.94(10.23) <sup>a</sup>	27.58(50.41) <sup>a</sup>	F= 8.883* <sup>b</sup> t= 2.702(63)*

a. mean(standard deviation)

b. Levene's test for equality of variance not assumed for either analysis.

\*  $p < 0.05$ .

It was hypothesized that White siblings would report spending less money on caregiving related duties than siblings of color over the past month. An independent samples t-test was utilized for this hypothesis. The homogeneity of variance assumption was not met for the analysis and the null hypothesis was not rejected ( $F=8.064$ ,  $p < .05$ ), thus equal variances were not assumed when interpreting the statistical significance of the test. However, there were statistically significant differences in the means in the amount of money reported over the past month for Whites ( $M=44.09$ ,  $S.D.=63.35$ ) as compared to sibling of color ( $M=148.79$ ,  $S.D.=357.94$ ,  $t=2.172(63)$ ,  $p < .05$ ). Therefore, siblings of color reported spending about three times the amount of money of White siblings (\$148.79 compared to \$44.09, respectively) in caregiving related duties over the past month.

The homogeneity of variance assumption was not met for DV1\_b ( $F=8.883$ ,  $p < .05$ ), and equal variances were not assumed in interpreting the statistical significance of the independent samples t-test. There seemed to be a statistically significant mean difference in the amount of time spent in caregiving related activities for White siblings ( $M=8.94$ ,  $S.D.=10.23$ ) as compared to siblings of color ( $M=27.58$ ,  $S.D.=59.41$ ,  $t=2.702(63)$ ,  $p < .05$ ). In this situation the findings suggest that siblings of color reported spending more time caring for their relatives than White siblings.

**Table 4.4: Mean Levels of Instrumental Support among Siblings from All Race Categories (N=93)**

	White Siblings (n=35)	Black Siblings (n=25)	Hispanic/Latino Siblings (n=27)	Asian Siblings (n=4)	Other (n=2)
Reports of money spent (money/past month--DV1_a) F= 1.292 <sup>b</sup>	44.09(63.35) <sup>a</sup>	220.60 (447.69) <sup>a</sup>	97.59(290.87) <sup>a</sup>	20 (24.50) <sup>a</sup>	400 (NA) <sup>a</sup>
Reports of time spent in caregiving activities (hours/past month--DV1_b) F= 13.203* <sup>b</sup>	8.94(10.23) <sup>a</sup>	27.58 (50.41) <sup>a</sup>	17.65(22.67) <sup>a</sup>	113.75 (140.85) <sup>a</sup>	247 (NA) <sup>a</sup>

a. mean(standard deviation)  
b. Levene's test for equality of variance not assumed for either analysis.  
\* p < 0.05.

In order to better understand how Whites and siblings of color differed in the amount of instrumental care they provided, a secondary ANOVA was run to test the differences in the means for each sibling race category. The findings confirmed the previous analyses and suggested that siblings from the “other” race category reported spending the most money over the past month (M=\$400, S.D.= NA), but this category was so small (n=2) that the results were interpreted with extreme caution. Black siblings (n=25) were next to have reported spending more money (M=\$220.60, S.D.= 447.69), followed by Hispanic/Latino siblings (n=27, M=\$97.59, S.D.= 290.87). The ANOVA analysis was not statistically significant (F=1.292, p >.05) and the results were not conclusive.

On the other hand, the ANOVA analysis for the amount of time siblings reported spending in caregiving activities was statistically significant (F=13.203, p >.05). The

“Other” sibling category reported spending more time (M=247 hours, S.D.= NA) than the other groups of siblings, but due to the small sample (n=2) the results were not reliable. Asian siblings reported spending the most time (M=113.75 hours, S.D.= 140.85), followed by Hispanic/Latino siblings (M=17.65 hours, S.D.= 22.67), and then Black siblings (M=16.44 hours, S.D.= 21.25). Overall, a decision was made fail to reject the null hypothesis and conclude that White siblings of adults with severe mental illness provided less instrumental support than siblings of color.

H3: Sisters of adults diagnosed with a severe mental illness will provide more instrumental support than brothers, regardless of race and ethnicity.

**Table 4.5: Mean Levels of Instrumental Support among Male and Female Siblings (N=92)**

	Male Siblings (n=21)	Female Siblings (n=71)	Test Values
Reports of money spent (money/past month--DV1_a)	160.71(375.02) <sup>a</sup>	94.42(259.86) <sup>a</sup>	F= 2.19 <sup>b</sup> t= .925(91)
Reports of time spent in caregiving activities (hours/past month--DV1_b)	11.10(11.90) <sup>a</sup>	23.27(46.0) <sup>a</sup>	F= 3.625 t=2.013(89.27)*

a. mean(standard deviation).

b. Levene’s test for equality of variance > .05.

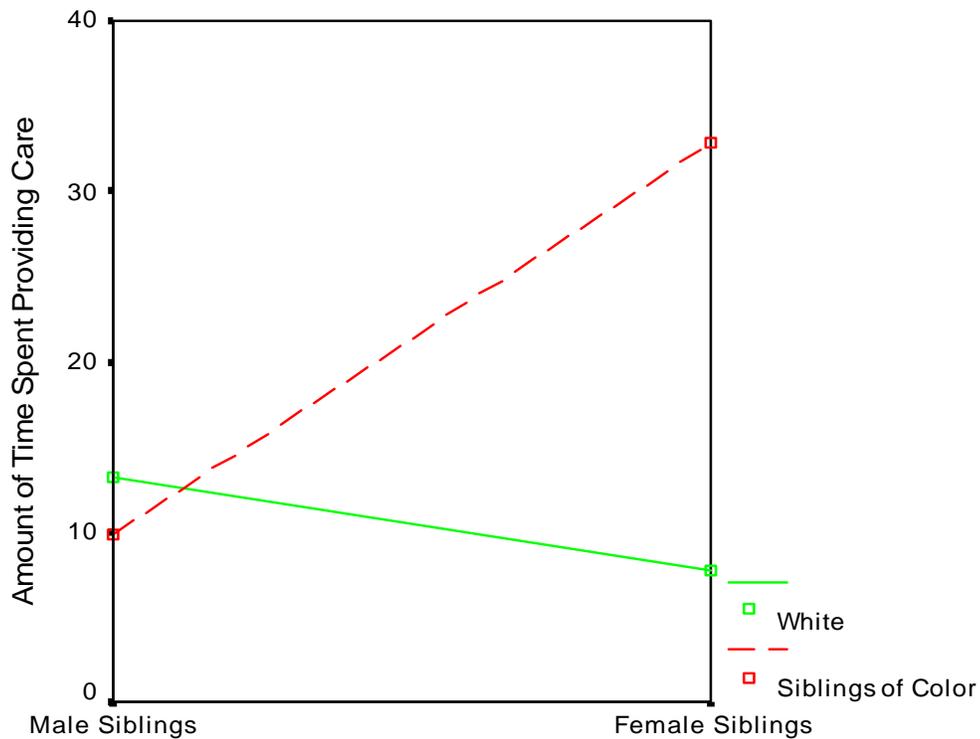
\* p < .05

To test whether there was a difference between the gender of the sibling and the amount of money (DV1\_a) and time (DV1\_b) they reported spending over the past month an independent samples t-test was utilized. The relationship between the gender and the amount of time spent in caregiving duties was statistically supported, suggesting that females spent twice the amount of time caring for their relatives than males (23.27 hours versus 11.10 hours; F=3.625, t= 2.013(89.27), p<.05). It was hypothesized that female respondents would provide more instrumental support than male siblings, the null

hypothesis was not rejected because female siblings reported spending more time with their brothers and sister and not more money.

Since the hypothesis also mentioned that the differences would be present regardless of race/ethnicity, Figure 4.2 illustrates the interaction of gender and race of the sibling respondents. The female siblings of color (M= 32.82 hours) reported spending more time on caregiving related activities than White female siblings (M= 7.70 hours). Even though the interaction between the two variables was not supported ( $F=1.931$ ,  $p >.05$ ), one can still infer that race and ethnicity did not change the finding that females spent more time with their siblings than males.

**Figure 4.2: Time Spent Providing Care by Gender and Race**



H5: Siblings who report having feelings of closeness to his or her family of origin will provide more instrumental support than siblings who do not report feelings of closeness to his or her family of origin.

**Table 4.6: Relationship between Instrumental Support for Feelings of Closeness to Family for Sibling Respondents (N=89)**

	Closeness with Mother	Closeness with Father	Reciprocal Closeness	Emotional Closeness	Family Environment
	B Coefficient	B Coefficient	B Coefficient	B Coefficient	B Coefficient
Reports of moneyspent (money/past month) DV1_a <sup>a</sup>	39.249	-87.363	68.302	-89.115	213.260
F=2.876(5)*					
T Values	1.883	-1.990*	1.521	-1.746	3.184*
Reports of time spent in caregiving activities (hours/past month) DV1_b <sup>b</sup>	-9.315	.826	5.628	-3.918	-4.073
F=1.442(5)					
T Values	-2.120*	.189	1.259	-.774	-.614

a. Model  $R^2 = .148$  (Adjusted  $R^2 = .096$ )

b. Model  $R^2 = .81$  (Adjusted  $R^2 = .025$ )

\*  $p = 0.05$ .

Feelings of closeness to family of origin was measured by five separate variables: closeness between sibling and mother, closeness between sibling and father, the reciprocal relationship between sibling respondent and sibling with mental illness during adolescence, the family environment for respondent sibling during his or her adolescence, and the emotional state (having feelings of stigma, shame, guilt or worry) of the sibling respondent during adolescence. The five predictors were simultaneously entered into the multiple regression analysis in order to determine if the combination of,

or any individual, variables contributed to whether a respondent was more likely to have reported spending more money on their sibling's care. An overall statistical significance was found ( $F=2.876(5)$ ,  $p. <0.05$ ) for amount of money spent in caregiving duties.

Multicollinearity was not a problem in the analysis. See Appendix G for details about the intercorrelations between study variables.

Sibling respondents who reported being close to their father spent about \$87 less in caregiving related activities than other siblings. Respondents who reported feelings of worry, guilt, or shame (family environment predictor variable) in their household during adolescence reported spending approximately \$200 over the past month on caregiving duties for their sibling with mental illness. The findings also indicated that a one unit change in the mean score for siblings being close to their mother produced about a nine percent ( $b= -9.312$ ) decrease in the amount of time they reported spending caring for their sibling ( $t= -2.120$ ,  $p. < 0.05$ ). Since the entire hypothesis was not statistically significant a decision was made to fail to reject the null hypothesis. More research is needed to better understand the relationship between how a sibling feels about their family of origin and the amount of care they provide their sibling with mental illness.

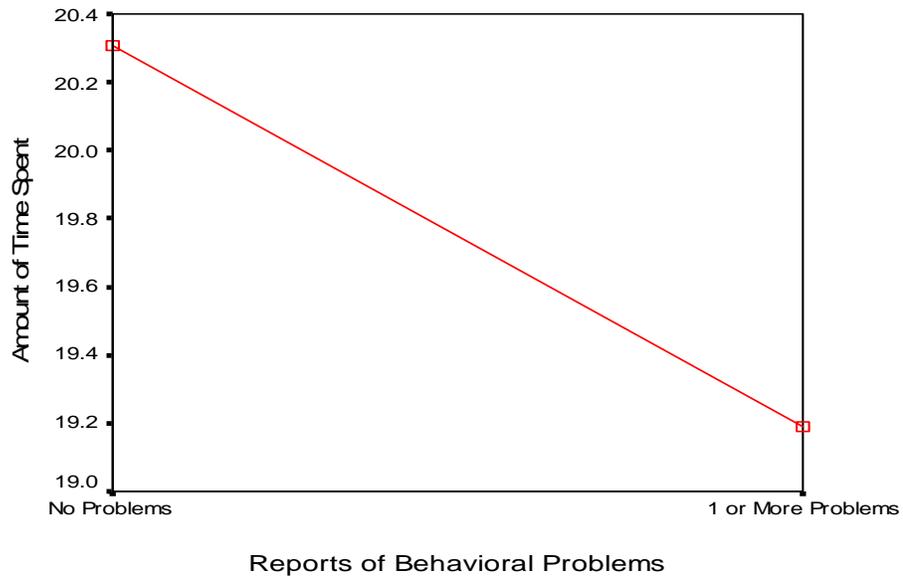
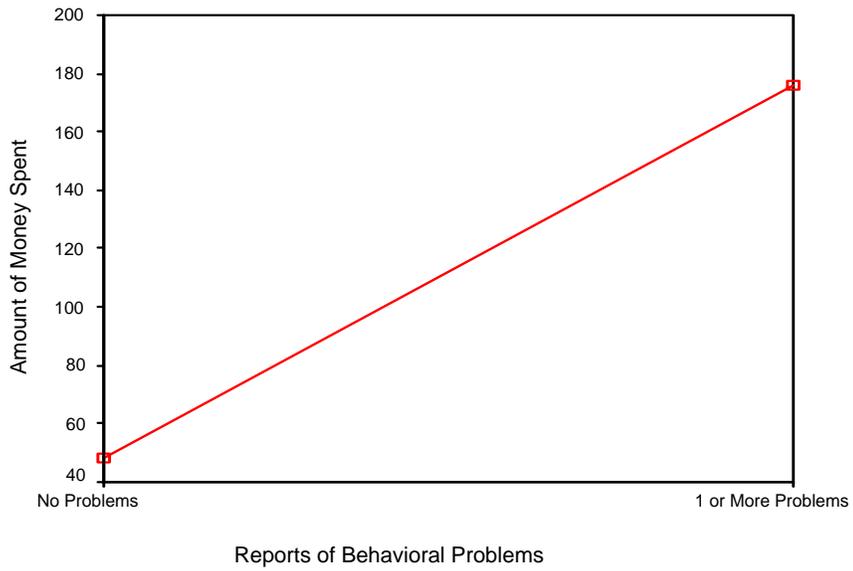
H7: Siblings who report that their brother or sister has more behavior problems will provide less instrumental support than siblings of adults with fewer behavior problems.

**Table 4.7: Mean Levels of Instrumental Support for Reported Behavioral Problems of Siblings with Mental Illness (N=77)**

	No Reports of Behavioral Problems (n=39)	One or More Reports of Behavioral Problems (n=38)
	Mean Difference	Mean Difference
Reports of money spent (money/past month) DV1_a  F=3.43(1)^	48.59 (93.70) <sup>a</sup>	175.79 (418.08) <sup>a</sup>
Reports of time spent in caregiving activities (hours/past month) DV1_b  F=.014(1)	20.31 (51.08) <sup>a</sup>	19.19 (26.17) <sup>a</sup>

a. mean(standard deviation).  
^ p. < 0.10

This hypothesis predicted that siblings who reported that their brothers and sisters had one or more behavioral problems in the past year would provide less instrumental support than those that reported that their relatives had no behavioral problems in the past year. Based on the examination of the ANOVA analysis, respondents who had siblings with at least one or more behavioral problems in the past year appeared to spend more money on caregiving duties than those who had siblings with no behavioral problems (M=\$175.79, S.D.=418.08). While the relationship between the independent variable and DV1\_a was marginally significant (DV1\_a: F=3.43(1), p< 0.10), the null hypothesis was not rejected. The following plots the relationship between the variables:



**RESULTS OF HYPOTHESES RELATED TO EXPECTATIONS OF FUTURE CAREGIVING**

H2: White siblings of adults diagnosed with a severe mental illness will be less likely to have expectations of participating in future caregiving responsibilities than siblings of color.

**Table 4.8: Percentages of Reports of Expectations of Future Caregiving among White Siblings and Siblings of Color (N=93)**

	White Siblings (n=32)	Siblings of Color (n=61)
Sibling Does not Have Expectations (DV2)	20.0%	43.1%
Sibling Does have Expectations (DV2)	80.0%	56.9%
Test Values	$\chi^2 = .5.162(1)^*$	
* p < 0.05.		

Expectation of future caregiving responsibility was dichotomized into whether the respondent expected to have future caregiving responsibilities or not. Two by two crosstabulations and logistic regression analyses were used to examine the relationships for the hypotheses above. About 80% of the White siblings and about 57% of the siblings of color reported having expectations of providing care in the future, which did not support the hypothesis. The findings were contrary to the direction stated in the hypothesis, thus the null hypothesis was not reject. The value of Chi-Square was 5.162, p<.05, which confirmed the conclusions drawn in the analysis and supported the presence of a moderate measure of association between the variables.

H4: Sisters of adults diagnosed with a severe mental illness will be more likely to expect that they will have caregiving responsibilities in the future than brothers, regardless of race and ethnicity.

**Table 4.9: Percentages of Reports of Expectations of Future Caregiving among Female and Male Siblings (N=92)**

	Male Siblings (n=21)	Female Siblings (n=71)
Sibling Does not Have Expectations (DV2)	23.8%	18.3%
Sibling Does have Expectations (DV2)	76.2%	81.7%
Test Values	$\chi^2 = .311$	

A crosstabulation was run to examine whether female siblings differed from male siblings in their expectations of providing care in the future. It was hypothesized that female siblings would report having expectations of future caregiving more so than males, despite the sibling's race or ethnicity. The null hypothesis was not rejected and the findings should be interpreted based on their clinical meaningfulness and not their statistical significance. While the chi-square statistic was not statistically significant ( $\chi^2 = .311, p > .10$ ), the percentages suggest that females did report having expectations to provide care in the future at a slightly higher percentage than males (81.7% versus 76.2%).

**Table 4.10: Percentages of Reports of Expectations of Future Caregiving among White Siblings and Siblings of Color (N=93)**

	Black Siblings		White Siblings		Hispanic/Latino Siblings		Other	
	Males (n=5)	Females (n=20)	Males (n=8)	Females (n=27)	Males (n=8)	Females (n=19)	Males (n=0)	Females (n=6)
	<b>M</b>	<b>F</b>	<b>M</b>	<b>F</b>	<b>M</b>	<b>F</b>	<b>M</b>	<b>F</b>
Sibling Does not Have Expectations (DV2)	60.0	55.0	12.5	22.2	62.5	26.3	N/A <sup>a</sup>	16.7
Sibling Does Have Expectations (DV2)	40.0	45.0	87.5	77.8	37.5	73.7	N/A <sup>a</sup>	83.3
Test Values	$r^2 = .04(1)$		$r^2 = .37(1)$		$r^2 = 3.16(1)^{\wedge}$		N/A <sup>a</sup>	

a. No statistics reported because gender of participant is constant.

<sup>^</sup>  $p < 0.10$ .

Race did not seem to make a difference. If the sibling was female, she would be more likely to have expectations of being a primary caregiver to her relative in the future than her male counterpart. A marginal relationship ( $r=3.16(1)$ ,  $p < .10$ ) was found between siblings who reported being Hispanic/Latino. For Hispanic/Latino males, 62.5% did not expect to have caregiving responsibilities in the future, as compared to the 37.5% who expected to have caregiving responsibilities in the future. About 74% of the Hispanic/Latino females expected to have caregiving responsibilities and nearly 26% did not expect to have responsibilities.

H6: Siblings who report having feelings of closeness to his or her family of origin will have expectations of playing a role in providing future caregiving than siblings who do not report feelings of closeness to his or her family of origin.

**Table 4.11: Relationship between Expectations of Future Caregiving and Feelings of Closeness to Family of Origin for Sibling Respondents (N=93)**

	Closeness with Mother	Closeness with Father	Reciprocal Closeness	Emotional Closeness	Family Environment
Step 1 Coefficients	.233	-.410	.400	-.130	-.044
Test Values					
Wald Statistic	.498	1.487	1.368	.110	.007
Exp( $\beta$ )	1.262	.664	1.492	.878	.957

a. Unstandardized Regression Coefficients are reported. Model  $\chi^2 = 4.135$ ,  $df = 5$ ,  $p > 0.10$ . Failed to reject null hypothesis. The model is not statistically supported.

b. If found statistically significant, the model would have classified 68.5% of cases.

A logistic regression was run to test whether sibling respondents who reported having feelings of closeness to their family of origin was related to expectations of future caregiving responsibilities. Feelings of closeness to the family of origin was measured by five separate variables: closeness with mother, closeness with father, feelings of reciprocal closeness between the siblings during adolescence, feelings of emotional closeness between the siblings during adolescence, and the sibling's family environment during adolescence. After simultaneously entering the predictor variables, the findings from Step 1 were not statistically significant, thus the results did not suggest a relationship between the variables. Furthermore, the overall model was not supported ( $\chi^2 = 4.135(5)$ ,  $p = .530$ ), resulting in a decision to fail to reject the null hypothesis. Additionally, the  $\beta$  coefficient for the five predictor variables did not suggest individual contributions to the model. Multicollinearity was not a problem in the analysis. See Appendix G for details about the intercorrelations between study variables.

H8: Siblings who report that their brother or sister has more behavior problems will be less likely to expect having future caregiving responsibilities than siblings who report fewer behavior problems from their brother or sister.

**Table 4.12: Percentages of Expectations of Future Caregiving for Reported Behavioral Problems of Siblings with Mental Illness (N=77)**

	No Reports of Behavioral Problems (n=39)	One or More Reports of Behavioral Problems (n=38)	Test Values
	%	%	
Sibling Does not Have Expectations (DV2)	25.6	36.8	$r^2 = 1.126(1)$
Sibling Does Have Expectations (DV2)	74.4	63.2	
$\chi^2 = 1.126$			

The findings of the crosstabulation, to examine whether siblings were more likely to have expectations of future caregiving responsibilities when their brothers or sisters had fewer behavioral problems, were not statistically supported, resulting in a decision to fail to reject the null hypothesis ( $\chi^2 = 1.126, p > .05$ ). Despite the absence of statistical support of the crosstab model, the percentages in the “no reports of behavioral problems” row was noteworthy. The percentages were 25.6% versus 74.4%, suggesting that siblings who had a brother or sister with no behavioral problems were more likely to have expectations of future caregiving. A difference could also be observed for the “one or more reports of behavioral problems” row.

H9: Siblings who report being married, employed at least part time and have children under the age of 18 living in their households will provide less instrumental support to their brother or sister diagnosed with a severe mental illness; nonetheless, these factors will not predict the sibling’s likelihood of expecting to have a role in providing future caregiving.

The concept of “competing” factors was tested in this hypothesis. Competing factors were discussed in Chapter 1, under the conceptual framework section. They are described as situations that could possibly occupy the sibling’s time or distract them from being able to devote a large amount of time to the role of primary caregiver for their brothers or sisters. Being married, having a child under the age of 18 in the household, and working at least part-time were considered competing factors for the purposes of this study. It was assumed that if an individual had other, immediate family obligations or responsibilities, he or she would not be as involved in providing direct caregiving or instrumental support to their sibling with mental illness. Thus, the siblings who reported one or all of the three competing factors were predicted to provide less instrumental support than the siblings who reported not having as many competing demands on their time. Nevertheless, it was also hypothesized that the demands would not predict the sibling’s reports of whether they had expectations of having future caregiving responsibilities. Regression analyses (a multiple regression analysis for instrumental support and a logistic regression for expectation of future caregiving) were utilized to test the hypothesis. Table 4.13 displays the results of the dependent variable *instrumental support* and Table 4.14 displays results from the second dependent variable, *expectations of future caregiving*.

**Table 4.13: Mean Levels of Instrumental Support among Competing Factors for Siblings (N=92)**

	Marital Status	Children Under 18 Years in Household	Sibling Employment Status
Reports of money spent (money/past month) DV1_a <sup>b</sup>	2.33(1.47) <sup>a</sup>	.33(.47) <sup>a</sup>	.65(.48) <sup>a</sup>
F= .084 <sup>c</sup>	b= 10.556 t= .465	b= 9.136 t= .129	b= -14.197 t= -.220
Reports of time spent in caregiving activities (hours/past month) DV1_b <sup>b</sup>	2.35(1.47) <sup>a</sup>	.33(.47) <sup>a</sup>	.65(.48) <sup>a</sup>
F= .648 <sup>d</sup>	b= -.195 t= -.061	b= -8.902 t= -.890	b= -10.340 t= -1.132

a. mean(standard deviation).  
b. Regression analyses were done to examine the relationships between the variables  
c. Model  $R^2 = .003$  (Adjusted  $R^2 = -.031$ ).  
d. Model  $R^2 = .022$  (Adjusted  $R^2 = -.012$ )

The findings did not support the section of the hypothesis concerning instrumental support. In other words, after each predictor variable was entered simultaneously, an overall relationship ( $F = .084$ ,  $p > .10$  for DV1\_a and  $F = .648$ ,  $p > .10$  for DV1\_b) was not found. Additionally, none of the predictor variables offered any individual contributions to the dependent variable (see Table 4.13 for beta and t values). It is also important to note that multicollinearity was not a problem in the analysis (see Appendix G).

**Table 4.14: Relationship between Expectations of Future Caregiving and Competing Factors for Sibling Respondents (N=93)**

	Marital Status	Children Under 18 Years in Household	Sibling Employment Status
Step 1 Coefficients	-.331	-.176	.668
Test Values			
Wald Statistic	3.734 <sup>^</sup>	.107	1.992
Exp( $\beta$ )	.718	.839	1.951

a. Unstandardized Regression Coefficients are reported. Model  $\chi^2 = 5.619$ ,  $df = 3$ ,  $p > 0.10$ . Failed to reject null hypothesis. The model is not statistically supported.

b. If found statistically significant, the model would have classified 68.8% of cases.

<sup>^</sup> =  $p < 0.10$ .

For the second dependent variable, expectation of future caregiving, an overall relationship between the set of predictor variables and the dichotomous dependent variable was not found (Model  $\chi^2 = 5.619$  (3),  $p > .10$ ). Marital status seemed to be individually related to the expectations of future caregiving ( $b = -.331(1)$ ,  $Wald = 3.734$ ,  $p = .053$ ). This finding suggests that if a sibling reported being married, the odds that he or she would also have expectations of future caregiving responsibilities were decreased, as opposed to if he or she reported being legally separated, divorced or never married. Collectively, these analyses resulted in a decision to fail to reject the null hypothesis.

## **Chapter 5**

### **Discussion**

#### **SUMMARY OF THE STUDY**

This chapter provides an interpretation, discussion, and recommendations based on the research questions, hypotheses, and overall purpose of this study. The presentation of results are organized according to the four main research questions: Q1) To what extent does race and ethnicity differentiate caregiving practices by siblings, Q2) Are females providing more care than male siblings, Q3) What potentiates or pushes siblings to become involved in the caregiving process, and Q4) What mitigates or pulls siblings away from becoming involved in the caregiving process. The sections that follow provide an overview of the limitations and strengths of the study and ends with a discussion of the implications and recommendations for future research. While some of the hypotheses and findings were statistically significant, their clinical significance and meanings are discussed. A few supplemental analyses that were not apart of the results chapter are discussed in this chapter as a way of addressing the main research question (and title) of this study: How important is race and ethnicity? The researcher believed that this was a necessary way of illustrating how this study contributed to our understanding of the influences of race and ethnicity on sibling caregiving practices.

## **DISCUSSION OF RESEARCH QUESTION 1:**

### ***To What Extent does Race and Ethnicity Differentiate Caregiving Practices by Siblings?***

It was hypothesized that White siblings would report that they spent less money and less time caring for their brother or sister with mental illness than siblings of color. It was also proposed that White siblings would be less likely to have expectations of caring for their brother or sister in the future. The hypothesis was statistically supported, resulting in the rejection of the null hypothesis. Siblings of color reported spending more than three times the amount of money and time on their sibling with mental illness than White siblings (\$148.79 versus \$44.09) and (27.58 hours versus 8.94 hours). When a supplementary analysis was run to examine the average amount of money reported by individual racial groups, the “Other” sibling group reported spending the most money, totaling \$400 over the past month. Black siblings reported spending about \$220, Hispanic/Latino siblings reported spending about \$98, and Asian siblings reported spending only about \$20 over the past month.

The same supplementary analysis was run to look at the breakdown of time spent on caregiving activities for each racial group and the “Other” category reported spending about 247 hours over the past month in caregiving activities. The next remarkable amount of time reported came from the Asian siblings at about 114 hours. Hispanic/Latinos reported about 18 hours and Black siblings reported about 16 hours. These reports were significantly different from the average 9 hours reported by their White counterparts.

The pattern of caregiving changed, however, when the researcher examined whether respondents expected to have future caregiving responsibilities. Eighty percent of the White siblings expected to provide care in the future, while only 57% of siblings of color had such expectations. When the racial categories were examined individually, 100% of siblings from the Asian and “Other” groups had expectations, 63% of the Hispanic/Latino siblings had expectations, and 44% of the Black siblings expected to provide care in the future. Again, making a direct comparison between the White siblings and siblings from the “Other” and Asian groups should be done with caution due to the marked difference in sample size of the categories.

The research question asked whether race and ethnicity differentiates sibling caregiving practices, this dissertation study suggests that race and ethnicity does indeed influence caregiving practices. Appendix H details the statistical differences of the variables examined in this study by race and ethnicity. Crosstabulation analyses indicated that there was a statistically significant difference between the racial categories for the following variables: level of education ( $\chi^2 = 32.97(15)$ ,  $p < .05$ ), reports of behavioral problems over the past year ( $\chi^2 = 12.66(3)$ ,  $p < .05$ ), and the reciprocal relationship between siblings during adolescence ( $\chi^2 = 71.68(57)$ ,  $p < .10$ ). Even though most of the differences for the racial groups were not statistically significant, the findings are clinically meaningful or significant. It is possible that findings are explicating a phenomenon for caregiving practices by siblings of color that has not been previously studied. Nevertheless, while the numbers many not suggest significance or importance, we cannot ignore the possibility that siblings of color are doing more in the present, while White siblings are planning to do more in the future. Such a finding could have

numerous implications for future policy, practice and research planning. To better understand this statement, the researcher compared the percentage of siblings who reported that their family had made legal or financial arrangement for the long term care of their sibling with mental illness. White siblings reported that their family made financial and legal arrangements at twice the rate of siblings of color (68% versus 32%,  $\chi^2 = 11.46, p < .05$ ). Perhaps this is a finding that encourages the field to look at the relationship between long term caregiving practices, especially because of the disparity found between Whites and siblings of color.

#### **DISCUSSION OF RESEARCH QUESTION 2:**

##### ***Are Females Providing More Care than Male Siblings?***

Based on the findings of this study, female siblings reported spending twice the amount of time in caregiving activities than male siblings (23 hours versus 11 hours, respectively). Even though male siblings reported spending more money than female siblings (\$161 versus \$94) the analysis was not statistically significant. Nonetheless, the information is reported in this discussion because it prompts the need to further investigate how we view males as caregivers. Perhaps because of higher incomes, male siblings may be more able to send money as a way of supporting their brothers and sisters than female siblings. After all, this would not be far removed from the traditional gender roles often emulated in the larger society. We just do not know at this time and more research looking at male caregiving practices is definitely needed.

The next part of the first hypothesis stated that females would provide more instrumental support than males, regardless of race and ethnicity. Female siblings of

color reported spending about four times more of their time caring for their relatives than White female siblings (33 hours versus 8 hours). Although the hypothesis was not statistically significant, this analysis was statistically significant and is included in this discussion based on its clinical meaningfulness or the potential contribution to our knowledge about sibling caregiving practices and race and ethnicity. In the conceptual framework of this dissertation, the researcher proposed a major difference between siblings of color and White siblings, asserting that one of the major problems in the dearth of research studies. More research is needed to further examine gender roles in caregiving according to race and ethnicity.

### **DISCUSSION OF RESEARCH QUESTION 3:**

#### ***What Potentiates or Pushes Siblings to Become Involved in the Caregiving Process?***

In order to address this question, five separate variables were analyzed with the dependent variables, instrumental support and expectations of future caregiving. The five variables pertained to the respondent sibling's closeness with their mother and father, their reciprocal and emotional closeness with their sibling with mental illness, and their family environment during adolescence. Overall, there was a relationship between the amount of money a sibling reported spending and feelings of closeness to their family of origin. Siblings who reported being close to their father, spent less money than other siblings. Additionally, reports of feelings of worry, guilt, or shame in a sibling's household during adolescence (family environment) was related to the amount of money a sibling reported spending to care for their brother or sister.

While the overall model was not statistically significant and the null hypothesis was not rejected, the clinical significance is noteworthy. The findings suggested that siblings who were closer to their mother spent less time with their sibling than those who were not as close to their mother. While this finding does not directly tell us that being close to their mother pushed or potentiated siblings to become involved in the caregiving process, it does offer insight into how the process develops.

Initially it might seem counter-intuitive, but it does support an assumption that if mothers are actively involved in being the primary caregiver, this would affect how much their children participate in the process. In other words, if mom is seen as the “do it all” figure in the family, other family members may not recognize any burdens or hardships that mothers may experience. Thus, further supporting the thrust of this study, there is the need to investigate the role of siblings in the caregiving process after their parents are gone or no longer willing or able to carry the responsibility of caring for their relative with mental illness.

#### **DISCUSSION OF RESEARCH QUESTION 4:**

##### ***What Mitigates or Pulls Siblings Away from Becoming Involved in the Caregiving Process?***

It was hypothesized that if a respondent’s brother or sister presented with one or more behavioral problems over the past year, then the sibling would be less likely to provide instrumental support than siblings of adults with no or fewer behavioral problems. The findings were the exact opposite of the hypothesis, resulting in a failure to reject the null hypothesis. Nonetheless, the results have clinical significance, which warrants further discussion. Respondents reported spending three times more money per

month for brothers and sisters who presented with one or more behavioral problems, than respondents of siblings with no reports of behavioral problems (\$175 versus \$49). It is possible that the sibling with mental illness presents in crisis more often, which causes the sibling respondent to feel the need to help with the cost of care.

There were about five items from the questionnaire that comprised the behavioral problems variable, ranging from has your sibling: *been admitted to a psychiatric hospital, been held in police custody or jail, been admitted to a drug/alcohol rehab program, to attempted suicide*. For a more detailed discussion about the variable see Chapter 3. For example, if the sibling with mental illness had attempted suicide and/or been admitted to a psychiatric hospital, and he or she was not employed and did not have ample health insurance, then the sibling without mental illness may have had to help with the medical bills.

A closer look at the findings broken down by race indicated that 29% of the White siblings, 44% of Black siblings, 75% of the Hispanic/Latino siblings, and 75% of the Asian siblings reported having a brother or sister with one or more behavioral problems over the past year. This finding was statistically significant ( $\chi^2 = 12.66(3)$ ,  $p < .05$ ). Going back to the discussion in Question 1, we saw that Blacks and Hispanic/Latinos reported spending more money than the other sibling groups; additionally, in this particular discussion we see that siblings of color also have brothers and sisters who have had a higher rate of behavioral problems over the past year than White siblings.

In order to better understand what mitigates or pulls a sibling away from providing care, three additional variables were examined: marital status of the sibling

respondent, whether there were children in the household under 18 years of age, and the sibling's employment status. In combination, the variables were referred to as "competing factors" in this study. The first part of the hypothesis suggested that siblings who reported having competing factors would provide less instrumental support to their sibling with mental illness than siblings who do not report the combination of the variables. The second part of the hypothesis presumed that those factors would not predict the sibling's likelihood of having future caregiving expectations.

The first part of the hypothesis was not statistically significant, but one variable from the second analysis marginally offered some information. There was a relationship between a sibling's marital status and their likelihood to have future caregiving expectations. The variable marital status was treated as an ordinal level variable with categories ranging from married to never married. Expectation of future caregiving had two categories: 0) no expectations of future caregiving and 1) expectations of future caregiving. Since the b coefficient was negative the relationship categories were interpreted inversely. For example, if a sibling reported being married, he or she was less likely to have expectations of future caregiving.

The researcher went back and examined the average age of the siblings to see if the findings had anything to do with the age of the respondent. In other words, the researcher wanted to know if being young and married was any different than being older and possibly more settled. Being an older and more settled person could mean that the sibling would have expectations of future caregiving more so than the younger, single sibling. The test to examine the mean differences was not statistically significant ( $F=.911(19)$ ,  $p > .10$ ), but the reported means implied that married siblings were about 20

years of age, siblings who were legally separated were about 22 years old, those who were divorced were about 26 years old, single siblings were about 28 years old, and siblings who were in the “Other” category were about 50 years old.

## **LIMITATIONS AND STRENGTHS**

While the findings previously discussed offer information that could inform and influence future research on the many phenomena of sibling caregiving practices, there are clear limitations to this study. First, the use of the cross-sectional design did not allow the researcher to sufficiently infer cause-effect relationships between the variables in the study. Second, it was problematic to assess changes in instrumental care and expectations of future caregiving over time from data collected at a single point in time. Also, it was not possible to determine if the sibling respondents will actually continue to provide caregiving and support to the extent reported in this study; nor was it possible to determine if their expectations of future caregiving will alter over time. The use of longitudinal data would have been preferable to assess the questions raised in this study. With this aim in mind, the researcher included an optional page at the end of the questionnaire where respondents could voluntarily provide their contact information and indicate if they wanted to be contacted further regarding the study.

Respondents were asked to reference the sibling with mental illness in their family with whom they maintained the most contact. Several respondents reported having more than one sibling with mental illness, thus limiting this study’s access to information concerning caregiving practices of a person with multiple siblings with mental illness. Also, because the sample targeted siblings of color, the researcher

decided not to ask if the actual respondent had a mental illness. Being sensitive to and aware of the history of the relationship between stigma, people of color, and mental health, the researcher wanted to create an environment that allowed the respondent to feel comfortable sharing personal information about their family.

The sampling techniques used within the study were intended to represent siblings of adults with mental illness from varying backgrounds. Despite efforts to recruit participants from states all across the country, the majority of the sample was primarily from Texas. Thus, the sample did not accurately represent siblings from the United States. Since the study relied on volunteers, generalizing to siblings who chose not to participate or respond to materials mailed to them must be made with caution. An advantage to the sampling technique was the fact that an effort was made to recruit important groups like Spanish speaking Hispanic/Latinos, persons from various economic backgrounds, persons of Asian descent, and Native Americans. In the beginning phase of the study a Spanish version of the questionnaire was proposed, but due to several limitations plans changed. In place of the Spanish version of the questionnaire, the researcher collaborated with a Spanish speaking member of a local Hispanic NAMI group and offered to have the questionnaire translated in Spanish for those who wished to participate. The sample included individuals associated with national family advocacy groups, mental health treatment (public mental health clinics), and psychiatric state hospitals. There was also a case where the sibling with mental illness was reported as being 2 years old. The case remained in the study sample due to the exploratory nature of the study. It was decided that this case could also inform the

findings. The actual respondent was over 18 years of age, as required for inclusion into the study.

The analysis could have been enhanced by incorporating more in-depth methodological approaches, such as personal interviews. This would have added a more comprehensive understanding of the way in which the respondents provided care and more details about their future expectations. Personal interviews would have also allowed the researcher to obtain more data on the way siblings of color conceptualize caregiving as compared to White siblings. Including quotes throughout the document provided some insight, but clearly not enough to make any generalizations.

Although the researcher employed various recruiting methods to enhance the validity of the data collected in the study, reporting bias or social desirability bias could have still presented a threat to the validity of the data set. The variable for income was not interpreted in the analysis because the researcher suspected reporting bias. The reports seemed to over represent the income of the respondents. For example, some respondents reported that they were unemployed, but yet reported an annual income of \$75,000 or above.

As found with most mail surveys, the researcher was not able to maintain control over who actually completed and returned the questionnaires. The researcher offered compensation in the amount of \$15 for completed and returned questionnaires. For individuals associated with the public mental health centers and psychiatric hospitals, the researcher remained blind to their identities as stated by current HIPAA laws, raising the possibility that some respondents were actually the person with mental illness. Written materials attached to the questionnaire stated that the focus of the study was

intended for persons who did not have mental illness. It was also possible that respondents associated with advocacy groups participated at the request of their family members or friends, and not because of their personal interests.

Finally, though this sample may be the first to examine caregiving practices with a sample of siblings of color, the sample size presents a potential short-coming, particularly in reference to higher levels of data analysis. Although preliminary examinations did not suggest any problems with statistical power, the findings should not be generalized beyond this study. Sample sizes across groups of siblings of color are small and conclusions should be handled with caution.

Despite the limitations, there were several strengths associated with this research effort. Recognizing the challenges associated with locating and recruiting people of color, this study successfully gathered information from a sizeable sample of siblings (N=93). There was a great deal of interest in the study from persons all over the country and had there been more time to collect data, the sample size would have been greater. Towards the final stages of recruitment, the researcher located members of a Chinese and South Asian focused NAMI family group. Due to time constraints, members were not able to participate. Nevertheless, the members asked to be contacted for future research. This type of exposure was priceless because it illustrated the needs and interest of siblings in caregiving situations better than any single article or publication. Siblings, as a group, have been commonly overlooked in the research literature and this study may contribute to and complement existing research by providing a preliminary look at siblings of color.

## **IMPLICATIONS AND RECOMMENDATIONS**

This dissertation began with a few questions and presuppositions. The researcher began this project as a way of examining a caregiving phenomenon that has been otherwise overlooked: caregiving practices of siblings of color. Although still limited, the research literature on sibling caregiving practices had focused primarily on the experiences of mostly White siblings (for example, Greenberg, et al., 1999; Landeen, et al., 1992, Marsh, et al., 1993a and b) or siblings people with mental retardation (Seltzer, et al., 1997; Greenberg, et al., 1999). One of the major elements that previous research did not address was caregiving practices of people of color. There was an absence of research, knowledge, and information that addressed the needs of this particular population. The argument to pay more attention to people of color was taken to a national audience with documents like the Surgeon General's 2001 (U.S.DHHS, 2001) report on race, ethnicity, culture and mental health, and the 2003 President's New Freedom Commission report (New Freedom Commission, 2003). These reports identified and highlighted several deficits for people of color vis-a-vis mental health service utilization and provision and encouraged more research in the area. The aim of this exploratory dissertation study was to address the problem by contributing to the knowledge about caregiving practices by siblings of color.

Early in this document the researcher mentioned a number of things we did not know about siblings of color. We did not know how to address their needs; we did not know how to get them involved in voluntary participation, advocacy or support groups; we did not know what they looked like; nor did we know about their interests or characteristics. The researcher also pointed out that due to the extent of what we did not

know, it would be difficult to propose ways to effectively integrate them into the mental health system.

A few preliminary, but noteworthy, findings resulted from this dissertation study. There is now some evidence to support and propel more research on siblings of color.

Key findings from this study include:

- Siblings of color provide care differently than White siblings,
- There are marked differences between different racial or ethnic groups in how they respond to caregiving (for instance, some siblings may prefer to spend time with their relatives, whereas other groups might prefer to spend money),
- Female siblings are more likely to spend time caring for their relatives than males, and
- Relationships and feelings of closeness to one's family do influence one's caregiving practices. Different relationships may yield different caregiving outcomes.

Combining the theoretical work of Greenberg and colleagues *Push* and *Pull* factors and the findings of this study, the researcher is able to make a few suggestions for future research and policy planning.

## **RECOMMENDATIONS FOR FUTURE POLICY AND PRACTICE**

Undoubtedly, caregivers are the backbone of home and community care. The shift in policy and responsibility of care to the caregiver while “saving the health system money” seems to have taken advantage of caregivers and failed to actually include them in the treatment process. A vigilant emphasis should be made toward creating

collaborative partnerships or relationships between siblings of persons with mental illness and mental health service providers and policy makers. However, it should be noted that the collaboration should recognize and respect the sibling with mental illness' privacy and rights, thus not creating an environment that would have adverse consequences between the siblings.

As the health care arena continues to advance, mental health providers and policy makers need to acknowledge cultural diversity and ensure that their programs and policies incorporate this into their plans. For instance, it is one thing to recognize the heterogeneity within specific ethnic or cultural groups, and something quite different to assume that if someone belongs to a specific ethnic or cultural group, that he or she adheres to all of the cultural values and practices of the group. It is essential to acknowledge how a person's social world also shapes their caregiving practices. The practice community has been saturated with several models concerning cultural competency and health disparities; while nothing is conclusive, there should not be any excuses why programs are not moving towards more efficacious ways to work with diverse client populations. The term diversity should not solely be linked to a person's cultural background. Instead, the field should view the term as a way of improving and expanding the crucial people and components of the caregiving process. So, instead of turning to the aid of mothers and fathers out of habit, look deeper into the patient's social support system and encourage participation from members who have the potential to be there in the long run. In a sense, this is the aim of discharge planning or wraparound services. A sibling's participation can be as important to a patient as their parent's presence.

Health care professionals should keep current with policy trends from the Federal Government. It is no secret that the Federal Government sets the platform for policy development for both the public and private mental health sectors. Therefore, if the Federal Government fails to encourage the social service arena to advance their understanding of culture and service provision or utilization that will become an extremely problematic situation given the link to funding and program vitality. For sibling caregiving, there are two major disadvantages for this population: 1) being ignored and 2) having their cultural uniqueness overlooked. If this population is already being left out of the loop in regards to caring for their mentally ill brother or sister, then the problem is further compounded when their needs are viewed to be the same regardless of race, ethnicity, or culture. Or, equally problematic is when their actions are characterized as being “abnormal” because they are different from what has come to be seen as the norm. If policy, as far up as the Federal level, does not take culture into account, then all of the efforts to end disparities or understand and respond to cultural differences, will have been in vain, thus illustrating a huge waste of funding. The bottom line is that we have to start somewhere.

#### **RECOMMENDATIONS FOR FUTURE RESEARCH**

The research community can really be the vehicle to truly push this issue to the forefront. After all, that is the purpose. It is no longer good enough to simply say that different groups were left out of a study because they were “hard to reach” or because the researcher did not really have the means to understand or communicate with the group. While timing can often limit a researcher’s ability to be as comprehensive as he or she

would like, it should not be used as an excuse for why they did not try to include as many diverse populations as possible to be able to produce findings that truly represent their entire population of study. Take the pharmaceutical community, for example; scientists have broadly played down the role of cultural factors in the diagnosis, treatment and outcome of mental disorders. In part, this could be because modern psychiatry is based on the idea that mental illnesses are primarily organic disorders of the brain. This approach suggests that the symptoms, course, and treatment of disorders should be the same regardless of the patient's cultural background. While this has offered priceless insights and details about how the brain functions and malfunctions, society continues to grow more diverse and we do not want to use this information as an excuse to ignore evidence concerning culture.

Culture is the backdrop for the interpersonal dimension of the diagnostic interview and informs the overall conceptualization of diagnostic symptoms. Because the clinical encounter is often intercultural and interracial, the dynamics of cross-cultural clinical work are crucial for understanding and refining diagnostic categories and practices. Cultural values include expectations about age, gender, and family dynamics as well as beliefs about health and health care (Geertz, 1973). There were about seven factors mentioned in the conceptual framework that were described as being relevant to studying people of color. These factors (poverty, oppression, degrees of expressed emotion, rewards (in contrast with burden), stigma, poor information resources, and mistrust) should be studied in future research on sibling caregiving practices. Due to limitations in this study, the factors were not able to be tested, but future research should make every attempt to test their influence.

Given the new wave of literature and budding research on racial disparities, the climate is ripe for an opportunity to create and test several models of sibling caregiving. Researchers should employ several groupings and topics for studying sibling caregiving practices. They should look at the influence of culture between male and female siblings, they should break down culture into a variety of groups and look at between and within group differences, and they should study culture groups in more detail. The point is that there are now many possibilities to contribute to the field that simply require one to move beyond some of the existing excuses and just take a shot at developing a model that could further unpack the sibling caregiving phenomenon.

## **CONCLUSIONS**

This research study started off with the intention of replicating the methodology of Greenberg and colleagues (1999) and that was accomplished. Greenberg's study compared siblings of persons with both mental illness and mental retardation, while this study compared siblings of color and White siblings of persons with mental illness, not mental retardation. Greenberg and colleagues concluded that siblings were likely to provide instrumental support if they were close to their brother or sister during adolescence and siblings with young children provided less support than siblings with older children.

While this study did not examine siblings of persons with mental retardation or tested for emotional support between the sibling with mental illness and the sibling respondent, this study was able to take a sample consisting of siblings from various racial or cultural backgrounds and conclude that females provided more care than males, feelings of closeness to family of origin was an important factor, and midlife roles often competed with a sibling's ability to provide instrumental support to their sibling with

mental illness. Without a doubt, both this dissertation study and Greenberg's study make a strong argument for the need to the factors that impact sibling caregiving practices with as diverse and representative a sample as possible.

## **Appendix A:**

### **A Collection of Quotes and Experiences Shared by the Study Respondents**

*Although it has been very painful to deal with my sister's mental illness, there have also been many good things that have come out of it regarding my learning...I now know the 'ropes'.*

*Growing up with two siblings with mental illness has taught me that there are different 'realities' people experience. I hope it has made me a more thoughtful person. It has influenced my career choice to a great extent.*

*My family has lied and pretended about mental illness—we are all very well educated (mother and father included) but, I am shunned because I try to talk about mental illness when I am around them.*

*My mother and father were blamed for my brother's illness by the mental health professionals and they were never comfortable about getting help from them afterwards.*

*My father never fully accepted my brother's illness and blamed it as bad behavior.*

*I absolutely hate the HIPAA laws because they make managing a relative's mental illness almost impossible, if they don't sign that it is okay...I always keep his case manager informed of this situation even though she cannot always tell me things.*

*I believe growing up with my sister had a huge impact on me. I was extremely shy when I was young and think that it was particularly due to all the constant stress in our home. I was always extremely tense. Once I left for college, met my husband and married, I grew emotionally. However, I think I am more able to understand those with disabilities as a result.*

*Prior to my brother's illness, my relationship with him was very good in almost all ways. He was loving and protective and guided me in the right direction. At the onset of his illness we were unaware of what mental illness was...we thought his behavior was due to drugs and/or alcohol.*

*My experience as a caregiver, during my career, to my sister with mental illness and brother has been rewarding.*

*I was completely frightened when my sister woke up in the middle of the night screaming. It began a learning process—lots of anger with finding assistance, proper medication and a doctor...I am so disoriented and seeking help for myself.*

*My brother's mental illness has provided an opportunity for our family and close friends to get invaluable insights into human nature through hands on experience and numerous open discussions.*

*My brother was never really a nice person. He has always been a 'disruption'. Over time, I came to know God and I have learned to forgive.*

*I feel very proud to have a brother like him and know he will succeed like any other normal person.*

*As the illness began to manifest, I began to be impacted emotionally and psychologically.*

*Today has been hard, my brother was released from the hospital. He has no I.D., money, or transportation and I am suppose to let him 'go'. The systems wants me to give up and let him go but it is really hard. How can you give up on someone you love? I know I have to, otherwise he will take over my life.*

*I take care of my sister and husband, both diagnosed with bi-polar. I feel like she and my husband are at a place where I cannot reach them.*

*It is a nightmare for the rest of your life.*

*I am afraid that this runs in the family.*

*I suppose he has been ill since he was a boy, but my parents overprotected him, saying his problems were because 'other' envied him. If he has disruptive behavior it was because he 'was a man'. They only wanted to hide his behavior.*

*Trying to keep my family together was a task. My family is my first choice...I became mother and that was a problem not being that much older or younger than my siblings. Nonetheless, it came together and I kept us together as a family.*

*I have learned a lot from my sister's illness, however, it has been the most painful experience of my life and I would give anything for her to be well.*

*I do not think it is a matter of positive or negative experiences, you just have it and learn to live with it and be happy as much as you can.*

*I love my brother extremely, if it was not for him in my childhood, as well as in my adult life, I would not be half the man I am today!*

## Appendix B:

### Empirical Research Studies on Sibling Caregiving between 1992 and 1999

Authors	Horwitz , Tessler, Fisher, Gamache, (1992)	Landeem, J., Whelton, C., Dermer, S., Cardamone, J., Munroe-Blum, H., & Thornton, J, (1992)	Horwitz, Allan, (1993)
Study Title	The role of adult siblings in providing social support to the severely mentally ill	Needs of well siblings of persons with schizophrenia	Adult siblings as sources of social support for the seriously mentally ill: A test of the serial model
<b>Sample</b>			
Final Sample Size	109 siblings	88 well siblings, 19 spouses	108 siblings
Sample Characteristics	Siblings nominated by relative with mental illness	Siblings and spouses	Siblings of mentally ill brothers or sisters
<b>Design</b>			
Type	Pretest-posttest with random assignment	Pretest-posttest with non-equivalent groups	Pretest-Posttest with random assignment
<b>Outcome</b>			
Results	Hierarchy of obligations (based on the Serial Model) determines which person will provide care. Siblings were not as involved as parents.	87% of respondents indicated a desire for more information about the prognosis of schizophrenia. Most siblings indicated that at times they had difficulty communicating with their relative. Female siblings indicated more problem-solving difficulties with relatives (42%), compared to male siblings (30%). Most siblings were concerned some fulfillment in their lives (46%). Siblings indicated a need for assistance in learning how to better communicate with relative in day-to-day situations. Siblings wanted to learn more about mental health legislation and how to support a relative through a structured program.	Serial model was supported, therefore siblings provided more contact, intimacy, and help when parents were not living. Over the life course, siblings can in part replace parental caretakers as providers of social support.

## Appendix B (cont'd):

### Empirical Research Studies on Sibling Caregiving between 1992 and 1999

Authors	Marsh, D., Dickens, R., Koeske, R., Yackovich, N., Wilson, J., McQuillis, V., (1993a)	Marsh, D., Appleby, N., Dickens, R., Owens, M., Young, N., (1993b)	Horwitz, (1994)
Study Title	Troubled journey: Siblings and children of people with mental illness	Anguished voices: Impact of mental illness on siblings and children	Predictors of adult sibling social support for the mentally ill: An exploratory study
<b>Sample</b>			
Final Sample Size	60 NAMI siblings and/or children and 75 non-NAMI affiliated siblings and/or children	Not specified in study	108
Sample Characteristics	Siblings and/or children NAMI and non-NAMI affiliated		Siblings of mentally ill brothers or sisters
<b>Design</b>			
Type	Two surveys to compare the experiences of those who were siblings and/or children of a mentally ill relative and belonged to a NAMI support group and those who did not belong to a NAMI support group..	Siblings and adult children of people with mental illness who belonged to a NAMI support group interviewed and asked to share their personal experiences. This was based on their responses to two national surveys that they participated in a previous study (see Marsh et al., (1993a).	Hypothesis Testing
<b>Outcome</b>			
Results	Specific suggestions included increased support for siblings and children within educational programs designed to sensitize families and professionals to the needs of their relatives and clients.	Eleven themes were discussed: (1) subjective burden; (2) objective burden; (3) developmental risks; (4) familial consequences; (5) education and career; (6) personal legacy; (7) interpersonal legacy; (8) intimacy, commitment, and sexuality; (9) marriage and childbearing; (10) caregiving responsibilities; and (11) coping, adaptation, and resilience.	Reciprocity between ill and non-ill siblings is an important predictor of reported and projected support. Neither norms of family obligation nor relational quality are highly correlated with support from non-ill sibling. There is great potential of siblings as providers of social support to mentally ill siblings.

## Appendix B (cont'd):

### Empirical Research Studies on Sibling Caregiving between 1992 and 1999

Authors	Horwitz, A., Reinhard, S., (1995)	Seltzer, M., Greenberg, J., Krauss, M., Gordon, R., Judge, K., (1997)	Greenberg, J., Kim, H., Greenley, J., (1997)
Study Title	Ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illnesses	Siblings of adults with mental retardation or mental illness: Effects of lifestyle and psychological well-being	Factors associated with subjective burden in siblings of adults with severe mental illness
<b>Sample</b>			
Final Sample Size	78 parents and 70 siblings of mentally ill relatives	329 respondents of persons with MR, 61 respondents of persons with MI	164 siblings of persons with serious mental illness
Sample Characteristics	Parents and siblings of mentally ill relatives	Respondents with mentally retarded or mentally ill siblings	Siblings of persons with serious mental illness
<b>Design</b>			
Type	Hypothesis testing, Interviews	Comparative analysis between siblings of adults with mental retardation and serious mental illness, hypothesis testing, self-administered questionnaire, scales	Hypothesis testing, Interviews
<b>Outcome</b>			
Results	Ethnicity can be a critical factor affecting levels of informal caregiving. Black and White parents report substantially more have equivalent caregiver duties, but White parents report substantially more burden. Black siblings report more caregiving duties than White siblings but report less caregiver burden. Ethnic differences remained after controlling for income, gender, age, diagnosis, perceived stigma, and coresidence.	Siblings of adults with MR were more likely to report a positive sibling experiences than siblings of adults with SMI. Siblings of adults with MR had closer relationships with ill-sibling than siblings of adults with SMI. Siblings of adults with MR had better psychological well-being than siblings of adults with SMI. Siblings of adults with SMI had more favorable psychological well-being when they perceived less pervasive impact of ill-sibling on their lives.	Well-sibling's experience of burden was consistently related to the symptomatology of the ill-sibling. Those who viewed ill-sibling's behavior as outside their realm of control, exhibited lower levels of subjective burden.

## Appendix B (cont'd):

### Empirical Research Studies on Sibling Caregiving between 1992 and 1999

Authors	Greenberg, J., Seltzer, M., Orsmond, G., Krauss, M., (1999)
Study title	Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving
<b>Sample</b>	
Final Sample Size	61 respondents with mentally ill siblings and 119 respondents with mentally retarded siblings
Sample Characteristics	Respondents with mentally retarded or mentally ill siblings
<b>Design</b>	
Type	Hypothesis testing, mailed questionnaire
<b>Outcome</b>	
Results	Siblings of adults with MR provided more emotional support and were more likely to expect to have primary caregiving responsibilities in the future than siblings of adults with SMI. Both groups provided less instrumental support if they had minor children living at home. Those who lived in close proximity were more likely to be supportive. For siblings of adults with SMI, if siblings were close during adolescence, they were more likely to provide instrumental support. Sisters provided more support than brothers. Siblings of women with SMI expected to have future caregiving responsibilities, more so than siblings with a brother with SMI.

**Appendix C:**

**Sibling Study Cover Letter and Questionnaire**

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# SIBLING CAREGIVING

UNIVERSITY OF TEXAS AT AUSTIN SCHOOL OF SOCIAL WORK  
CREATED BY ELLEN LUKENS, PH.D., COLUMBIA UNIVERSITY. MODIFIED BY TARA R. EARL, 1/8/05

Dear Sibling,

Welcome to my project! The purpose of this project is to improve our understanding of the impact on siblings of having a brother or sister with mental illness. We especially want to learn more from siblings and family members about their feelings, needs, and problems as well as knowledge and experiences with existing services. Information collected during this study will be used to assist me in designing meaningful programs and services for persons with mental illness and their families. The study is being conducted by the University of Texas, School of Social Work and the Hogg Foundation for Mental Health. For the results to accurately represent sibling caregivers, your participation in the study is particularly important.

Participation in this study will take approximately 1 hour. It is important to me that you be fully aware that taking part in this study is voluntary. All information that you provide to me will be kept completely confidential. Should you become uncomfortable while completing the questionnaire you may skip items or discontinue your participation at any time without penalty or loss of benefits or services to which you or your family member are otherwise entitled.

To protect your privacy, your name and all information collected during the study will be kept confidential and will be maintained by Tara Earl, M.S.W., the Principal Investigator for the study. Forms containing your name will be kept separately from other information collected during the study and then destroyed when the study is over, unless you volunteer to be contacted, by me, for future research in this area. To protect your sibling's privacy, you will not be required to reveal the name of your relative with mental illness at any time. I, the Principal Investigator, will not release individual data that you provide during the study to any other agency or individual beyond the faculty sponsor (Dr. King Davis) without your written permission to the extent legally possible.

If you have any questions about your participation in this study, please call Tara Earl at (512) 232-7117. Further, The Institutional Review Board (IRB) at the University of Texas at Austin has reviewed this study. If you wish you may contact Dr. Clarke Burnham, Chair of the Board, with questions about your rights as a research participant at (512) 232-4383.

Sincerely,

---

Tara Earl, M.S.W.  
Principal Investigator

---

King Davis, Ph.D.  
Faculty Sponsor

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SIBLING CAREGIVING  
TARA EARL ♦ P.O. BOX 2243 ♦ AUSTIN, TX 78768  
(512) 232-7117 TOLL FREE: 1-888-404-4336

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# SIBLING CAREGIVING

UNIVERSITY OF TEXAS AT AUSTIN  
CREATED BY ELLEN LUKENS, PH.D., COLUMBIA UNIVERSITY. MODIFIED BY TARA R. EARL, 1/8/05

*Conducted by*

**Tara R. Earl, M.S.W., Principal Investigator, Doctoral Candidate**

**School of Social Work**

**University of Texas at Austin**

**The Hogg Foundation for Mental Health**

*Contact Address:*

TARA EARL, M.S.W.  
SIBLING CAREGIVING  
P.O. BOX 2243  
AUSTIN, TX 78768

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# SIBLING CAREGIVING

UNIVERSITY OF TEXAS AT AUSTIN SCHOOL OF SOCIAL WORK  
CREATED BY ELLEN LUKENS, PH.D., COLUMBIA UNIVERSITY. MODIFIED BY TARA R. EARL, 1/8/05

## INSTRUCTIONS

Thank you for agreeing to participate in this survey. The questions on the following pages ask about you, your family, your family life, and your brother or sister with mental illness.

Please:

- ❖ **read the instructions for each set of questions carefully.**
- ❖ **answer all questions to the best of your ability.**
- ❖ **look over the questionnaire before you return it to make sure you did not skip any questions.**

I want to stress that your answers will be kept completely confidential. No one in your family (or anyone else) will ever be told your answers to any of the questions. It is also important to stress that nothing you or anyone in your family tells us will affect the services your brother or sister with mental illness receives.

YOU ARE ELIGIBLE TO PARTICIPATE IN THIS STUDY ONLY IF YOU ARE:

- 18 YEARS OLD OR OLDER**
- HAVE A BROTHER OR SISTER WHO HAS BEEN DIAGNOSED WITH A MENTALLY ILLNESS**



**WHEN YOU HAVE FINISHED THE SURVEY, PLEASE RETURN IT USING THE PRE-ADDRESSED, STAMPED ENVELOPE VIA U.S. MAIL.**

# Sibling Caregiving

PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT YOURSELF AND YOUR FAMILY

A1) What is your gender? (CHECK  ONE ANSWER)

- FEMALE
- MALE

A2) What is your date of birth?   19  (WRITE ANSWER IN BOXES)  
MONTH YEAR

A3) What is your current marital status? (CHECK  ONE ANSWER)

- MARRIED
- LEGALLY SEPARATED
- DIVORCED (NOT REMARRIED)
- SINGLE (NEVER MARRIED)
- OTHER, specify \_\_\_\_\_

A4) Do you have any children? (CHECK  ONE ANSWER)

- YES
- NO

→ If YES, how many children under the age of 18 live with you?  CHILDREN

A5) Currently, how many people live in your household?  PEOPLE

A6) Currently, (not including yourself) how many people in your household are your family or relatives?  PEOPLE

A7) Which of the following best describes your race / ethnicity? (CHECK  ONE ANSWER)

- BLACK, NON-HISPANIC (AFRICAN-AMERICAN, AFRICAN, CARIBBEAN)
- WHITE, NON-HISPANIC
- HISPANIC / LATINO(A)
- ASIAN / PACIFIC ISLANDER
- OTHER, specify \_\_\_\_\_

A8) What is your highest level of education? (CHECK  ONE ANSWER)

- LESS THAN HIGH SCHOOL
- HIGH SCHOOL GRADUATE
- SOME COLLEGE
- COLLEGE GRADUATE
- SOME GRADUATE SCHOOL
- GRADUATE DEGREE

A9) Presently, where do you live? CITY/TOWN \_\_\_\_\_

STATE / PROVINCE \_\_\_\_\_ ZIP CODE \_\_\_\_\_

## Sibling Caregiving

A10) For most of the past 12 months, what has been YOUR employment status? (CHECK  ONE ANSWER)

- HOMEMAKER (NOT LOOKING FOR WORK)
  - UNEMPLOYED (LOOKING FOR WORK)
  - WORK PART-TIME (30HRS/WEEK OR LESS)
  - WORK FULL-TIME (MORE THAN 30HRS/WEEK)
- IF EMPLOYED (FULL OR PART TIME), what is your occupation? \_\_\_\_\_

A11) Are you currently a student? (CHECK  ONE ANSWER)

- YES
- NO

A12) IF NOT MARRIED, CHECK HERE  and SKIP ►► TO NEXT QUESTION # A13

What was your SPOUSE'S employment status for most of the past 12 months? (CHECK  ONE ANSWER)

- HOMEMAKER (NOT LOOKING FOR WORK)
  - UNEMPLOYED (LOOKING FOR WORK)
  - WORK PART-TIME (30HRS/WEEK OR LESS)
  - WORK FULL-TIME (MORE THAN 30HRS/WEEK)
- IF EMPLOYED (FULL OR PART TIME), what is spouse's occupation? \_\_\_\_\_

A13) What was your approximate HOUSEHOLD income for 1999? (CHECK  ONE ANSWER)

- |  |  |
|--|--|
| <input type="checkbox"/> \$ 0 - \$ 14,999      | <input type="checkbox"/> \$ 45,000 - \$ 54,999 |
| <input type="checkbox"/> \$ 15,000 - \$ 24,999 | <input type="checkbox"/> \$ 55,000 - \$ 64,999 |
| <input type="checkbox"/> \$ 25,000 - \$ 34,999 | <input type="checkbox"/> \$ 65,000 - \$ 74,999 |
| <input type="checkbox"/> \$ 35,000 - \$ 44,999 | <input type="checkbox"/> \$ 75,000 AND ABOVE   |

A14) How many siblings do you have?  SIBLINGS

A15) How many OLDER siblings do you have?  SIBLINGS

A16) How many siblings do you have who have a mental illness?  SIBLINGS

A17) LIST YOUR SIBLINGS & THEIR AGES (LIST FROM OLDEST TO YOUNGEST & Do NOT INCLUDE YOURSELF)

IF NECESSARY	Sibling 1	<input type="checkbox"/> BROTHER	Age <input type="text"/>	IS 1 <sup>ST</sup> SIBLING MENTALLY ILL? <input type="checkbox"/> YES <input type="checkbox"/> NO
		<input type="checkbox"/> SISTER		
	Sibling 2	<input type="checkbox"/> BROTHER	Age <input type="text"/>	IS 2 <sup>ND</sup> SIBLING MENTALLY ILL? <input type="checkbox"/> YES <input type="checkbox"/> NO
		<input type="checkbox"/> SISTER		
	Sibling 3	<input type="checkbox"/> BROTHER	Age <input type="text"/>	IS 3 <sup>RD</sup> SIBLING MENTALLY ILL? <input type="checkbox"/> YES <input type="checkbox"/> NO
		<input type="checkbox"/> SISTER		
	Sibling 4	<input type="checkbox"/> BROTHER	Age <input type="text"/>	IS 4 <sup>TH</sup> SIBLING MENTALLY ILL? <input type="checkbox"/> YES <input type="checkbox"/> NO
		<input type="checkbox"/> SISTER		

CONTINUE ON BACK OF PAGE IF NEEDED

## Sibling Caregiving

A18) Is your mother alive? (CHECK  ONE ANSWER)

YES  
 NO  
→ If YES, what is your mother's age?  YEARS OLD

A19) Is your father alive? (CHECK  ONE ANSWER)

YES  
 NO  
→ If YES, what is your father's age?  YEARS OLD

A20) Are or have your parents been divorced or legally separated from one another? (CHECK  ONE ANSWER)

NOT APPLICABLE (NEVER MARRIED TO ONE ANOTHER)  
 YES  
 NO  
→ If YES, how many years ago did this occur?  YEARS AGO

A21) Currently, do any other family members, relatives, or someone else (other than your sibling(s) with mental illness) have a disability or major medical problem requiring on going care and assistance from you? (CHECK  ONE ANSWER)

YES  
 NO  
→ If YES, how many?  PEOPLE

A22) (Other than your sibling(s) with mental illness) Do you anticipate providing long-term care for a family member, relative or someone else in the future? (CHECK  ONE ANSWER)

YES  
 NO  
→ If YES, what is person(s) relation to you (e.g.: child, mother, mother-in-law, etc.)? \_\_\_\_\_

A23) Other than your siblings, have any other members of your family or relatives been diagnosed with a mental illness? (CHECK  ONE ANSWER)

YES  
 NO  
→ If YES, what is person(s) relation to you (e.g.: niece, aunt, father)?  
 MOTHER  FATHER  AUNT  UNCLE  GRANDMOTHER  
 GRANDFATHER  
 CHILD  NEPHEW  NIECE  COUSIN  OTHER,  
specify \_\_\_\_\_

## Sibling Caregiving

THIS SECTION FOCUSES ON YOU & YOUR INVOLVEMENT WITH YOUR SIBLING WITH MENTAL ILLNESS  
 ☞ *Note: If you have more than one sibling with mental illness, please respond to the following items in reference to ONE sibling, preferably with whom you have the most contact.*

B1) Are you a current member of a sibling or family support group (such as: National Alliance for the Mentally Ill (NAMI))?  
 YES (CHECK  ONE ANSWER)  
 NO

B2) How long does it usually take you to get to your sibling's home (either driving or how you usually get there)? (CHECK  ONE ANSWER)  
 0 (I LIVE WITH MY SIBLING)  
 MORE THAN 0, BUT LESS THAN 30 MINUTES  
 BETWEEN 30 AND 60 MINUTES  
 BETWEEN 1 AND 2 HOURS  
 MORE THAN 2 HOURS

B3) Over the past MONTH, provide your best estimate of the amount of money you have spent related to your sibling (include: money given for rent, medication, bills etc. AND/OR costs to travel to your sibling, phone expenses, etc.).  
 \$  DOLLARS

B4) In the past MONTH, have you taken time off from work for reasons related to your sibling? (CHECK  ONE ANSWER)  
 N/A, I DO NOT WORK  
 YES  
 NO  
 → IF YES, during the past month, how many hours did you take off work for your sibling?  HOURS

B5) During the past MONTH, estimate the time you have spent engaged in the following activities related to the care of your sibling (include all activities performed in person and over the phone and at work).

A Bathing, Grooming	<input style="width: 30px; height: 20px;" type="text"/>	HOURS
B Housework, Meal Preparation,	<input style="width: 30px; height: 20px;" type="text"/>	HOURS
C Money Management Assistance	<input style="width: 30px; height: 20px;" type="text"/>	HOURS
D Shopping	<input style="width: 30px; height: 20px;" type="text"/>	HOURS
E Transportation	<input style="width: 30px; height: 20px;" type="text"/>	HOURS
F Medical Management (medication management/scheduling appointments)	<input style="width: 30px; height: 20px;" type="text"/>	HOURS
G Engaging in Social / Recreational Activities / Leisure Time	<input style="width: 30px; height: 20px;" type="text"/>	HOURS

B6) Estimate the TOTAL time you spent in the past MONTH engaged in care related activities for your sibling.  TOTAL HOURS

B7) During the past YEAR, how often has your sibling had crisis situations which required your assistance?  TIMES  
 IF ANY, estimate the amount of time you spent dealing with the LAST crisis.  HOURS

## Sibling Caregiving

- B8) **Currently, who in your family would you consider to be the PRIMARY SUPPORT for your sibling?** (CHECK  ONE ANSWER)
- MOTHER IS THE PRIMARY SUPPORT
  - FATHER IS THE PRIMARY SUPPORT
  - BOTH MOTHER AND FATHER ARE EQUALLY INVOLVED WITH MY SIBLING
  - I AM
  - I AND ANOTHER RELATIVE(S) ARE EQUALLY INVOLVED WITH MY SIBLING WITH MENTAL ILLNESS, *specify relationship to sibling* \_\_\_\_\_
  - OTHER, *specify relationship to sibling* \_\_\_\_\_
  - NOT APPLICABLE, NO ONE IS SUPPORT IN FAMILY

THE FOLLOWING QUESTIONS ARE ABOUT YOUR SIBLING WITH MENTAL ILLNESS.

 *Note: If you have more than one sibling with mental illness, please respond to the following items in reference to ONE sibling, preferably with whom you have the most contact.*

- C1) Sibling's date of birth   19  
MONTH YEAR
- C2) What is your sibling's gender? (CHECK  ONE ANSWER)
- FEMALE
  - MALE
- C3) When you first realized your sibling was ill, about how old was he or she? (CHECK  ONE ANSWER)
- 10 or younger  11-15  16-20  21-25  26-30  31-35  36 or older
- C4) When your sibling was first FORMALLY diagnosed with a mental illness, how old was he or she? (CHECK  ONE ANSWER)
- 10 or younger  11-15  16-20  21-25  26-30  31-35  36 or older
- C5) What is your sibling's primary type of disorder? (CHECK  ONE ANSWER)
- SCHIZOPHRENIA
  - SCHIZO-AFFECTIVE DISORDER
  - BIPOLAR DISORDER (MANIC-DEPRESSIVE DISORDER)
  - MAJOR DEPRESSIVE DISORDER
  - OBSESSIVE COMPULSIVE DISORDER
  - OTHER, *specify* \_\_\_\_\_
  - UNCERTAIN
- C6) Does your sibling also have a substance abuse disorder? (CHECK  ONE ANSWER)
- YES
  - NO
  - UNCERTAIN
- C7) Does your sibling have any additional medical / health concerns or conditions? (CHECK  ONE ANSWER)
- YES, *specify* \_\_\_\_\_
  - NO
  - UNCERTAIN

## Sibling Caregiving

C8) Where does your sibling presently live? City/Town \_\_\_\_\_  
 State / Province \_\_\_\_\_ Zip Code \_\_\_\_\_

- C9) What is your sibling's highest level of education? (CHECK  ONE ANSWER)
- LESS THAN HIGH SCHOOL       COLLEGE GRADUATE  
 HIGH SCHOOL GRADUATE       SOME GRADUATE SCHOOL  
 SOME COLLEGE       GRADUATE DEGREE

- C10) Over the past YEAR, which best describes your sibling's employment status? (CHECK  ONE ANSWER)
- UNEMPLOYED  
 VOLUNTEER WORK / SHELTERED EMPLOYMENT WORK  
 WORK PART-TIME (30HRS/WEEK OR LESS)  
 WORK FULL-TIME (MORE THAN 30HRS/WEEK)  
 STUDENT

- C11) In what type of HOUSING has your sibling resided for most of the past year? (CHECK  ONE ANSWER)
- LIVES IN SUPPORTIVE HOUSING PROGRAM  
 LIVES WITH PARENTS  
 LIVES WITH ME (AND NOT WITH PARENTS)  
 LIVES WITH OTHER FAMILY MEMBER, specify relation \_\_\_\_\_  
 LIVES INDEPENDENTLY  
 OTHER, specify \_\_\_\_\_

- C12) Currently, what types of FORMAL SERVICES is your sibling receiving? (CHECK   ALL THAT APPLY)
- RESIDENTIAL PROGRAM / SUPPORTIVE HOUSING PROGRAM  
 DAY / VOCATIONAL / EDUCATIONAL PROGRAM  
 COMMUNITY CASE MANAGEMENT SERVICES  
 PSYCHIATRIC SERVICES  
 COUNSELING / PSYCHOLOGICAL SERVICES  
 NONE (sibling does not receive any formal services)  
 OTHER, specify \_\_\_\_\_

C13) What sources of INCOME and ASSISTANCE does your sibling receive? (CHECK YES OR NO FOR ITEMS a - f)

	YES	NO	DON'T KNOW
a <u>Employment</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b <u>SSI / Disability (SSDI) / Social Security (SSA)</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c <u>Housing Subsidy / Section 8</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d <u>Other Benefits such as welfare, TANF / AFDC, Food Stamps</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e <u>Workers Comp. or Unemployment</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f <u>Help from family / friends to buy food, rent, medicine, etc.</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Sibling Caregiving

C14) Over the past YEAR, has your sibling experienced any of the following: (ANSWER FOR EACH ITEM a - h)

	NO	1 TIME	2 OR MORE TIMES	DON'T KNOW
a	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C15) Currently, does your sibling have problems in any of the following: (ANSWER FOR EACH ITEM A - C)

	NOT AT ALL	RARELY	SOMETIMES	OFTEN
a	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C16) Over the past YEAR, which best describes your sibling's level of impairment? (CHECK  ONE ANSWER)

NONE                       SLIGHT                       MODERATE                       SEVERE                       EXTREME

C17) Is your sibling aware that he/she has a mental illness? (CHECK  ONE ANSWER)

YES  
 NO  
 MAYBE/UNCERTAIN

C18) How well did your sibling function BEFORE he/she started having mental health problems? (CHECK  ONE ANSWER)

HE/SHE FUNCTIONED **BETTER** THAN MOST PEOPLE HIS/HER AGE  
 HE/SHE FUNCTIONED **AS WELL AS** OTHER PEOPLE HIS/HER AGE  
 HE/SHE FUNCTIONED **MORE POORLY** THAN OTHER PEOPLE HIS/HER AGE

## Sibling Caregiving

There are often feelings, worries and concerns that go along with having a relative with mental illness. The following set of questions asks how often you have certain feeling or concerns related to your brother or sister's mental illness. Please  check the response that best reflects your answer.

 Note: If you have more than one sibling with mental illness, please respond to the following items in reference to ONE sibling, preferably with whom you have the most contact.

D1) How often do you feel the following:	NOT AT ALL	RARELY	SOMETIMES	OFTEN
a) I feel embarrassed by my sibling's behavior....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) My ill sibling and I take care of each other....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I am afraid of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) My parents are afraid of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I like my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) We as a family talk about the fact that my sibling has a mental illness....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) I worry that in some ways I am like my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) I feel angry at my parents regarding their involvement with my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Starting social relationships is awkward because of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) My sibling with illness has taught me a lot....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) I am really affected by my sibling's illness....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) I enjoy being with my sibling in spite of the problems he /she has....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) I feel like it is difficult to enjoy life because of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) I have little to do with the rest of my family because of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) My parents lean on me a lot....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) I feel sad about what my sibling has to face....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) My sibling is physically aggressive or violent towards me....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) I am proud of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) My sibling leans on me....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) I resent my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u) I feel emotionally abused by my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Sibling Caregiving

D1) (con't) How often do you feel the following:	NOT AT ALL	RARELY	SOMETIMES	OFTEN
v) I feel sad and lonely....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w) Everyone in my family seems angry....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) My family is able to enjoy themselves in spite of what my sibling faces....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y) I am preoccupied by the needs of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
z) I enjoy life....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
aa) I enjoy my work....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
bb) I worry about the future....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
cc) I feel hopeful about my sibling's future....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
dd) I feel relatives (outside my immediate family) treat me differently because of my sibling's illness....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ee) I am afraid that my sibling may be physically harmed by someone..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ff) I am worried because I cannot predict what my sibling will do....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
gg) I feel mixed-up about how much I should be doing for my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hh) I feel I had to give up some of my own life plans because of my sibling's problems....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Some people experience feelings of loss surrounding the mental illness of a brother or sister. Thinking about the PAST YEAR, please  *check* the response that best reflects your answer.

D2) How often do you feel the following:	NOT AT ALL	RARELY	SOMETIMES	OFTEN
a) I get sad when I think about how my sibling used to be before the illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I feel my family is incomplete because my sibling is no longer the person he/she was.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I experience feelings of guilt about normal things (e.g.: job, social life, mate, children) because my sibling has not been able to do these things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I feel it is unfair that my sibling became mentally ill.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I feel my own achievements are harder to enjoy when I think of my sibling with mental illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I feel like I lost the person I used to know.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) I recall the memories of how my sibling used to be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) I feel that because of my sibling, our family will never be the kind of family I'd hoped it would be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Sibling Caregiving

D3) **Who do you turn to for EMOTIONAL SUPPORT regarding issues with your sibling with mental illness?**

	NOT AT ALL	RARELY	SOMETIMES	OFTEN
a) Parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Intimate partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Other well-siblings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Colleagues / Co-workers (if employed)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Self-help organizations (such as NAMI)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Mental health professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Religious organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D4) **Who do you turn to for support regarding OTHER aspects of your life?**

	NOT AT ALL	RARELY	SOMETIMES	OFTEN
a) <u>Sibling with Illness</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Intimate partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Other "well"-siblings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Colleagues / Co-workers (if employed)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Self-help organizations (such as NAMI)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Mental health professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Religious organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D5) **In my contact with professionals regarding the needs of my sibling....**

	NOT AT ALL	RARELY	SOMETIMES	OFTEN
a) I have felt angry or frustrated....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I have felt supported....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I have been given the information that I needed...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I have felt confused....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I have felt excluded or ignored....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I have felt listened to....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Sibling Caregiving

D6) In order to understand my sibling...

	NOT AT ALL	RARELY	SOMETIMES	OFTEN
a) I read on the topic of severe mental illness....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I have talked with my spiritual/religious advisor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I have attended workshops & conferences....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I have attended self-help groups....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I have searched for information on the Internet or World Wide Web	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D7) Possibly, you have thought a lot and heard many things about what caused your sibling's mental illness. How likely do you believe that the following factors contributed to his or her illness?

	NOT AT ALL LIKELY	NOT VERY LIKELY	SOMEWHAT LIKELY	VERY LIKELY	DON'T KNOW
a) The way he or she was raised	<input type="checkbox"/>				
b) Stressful circumstances in his/her life	<input type="checkbox"/>				
c) A chemical imbalance in the brain	<input type="checkbox"/>				
d) A genetic or inherited problem	<input type="checkbox"/>				
e) His/her own character	<input type="checkbox"/>				
f) An infection or physical trauma before birth	<input type="checkbox"/>				
g) An act of God	<input type="checkbox"/>				

D8) You may have a wide variety of views about the cause of your sibling's mental illness. To what extent do you believe that each of the following is a cause of your sibling's mental health problems?

My sibling has mental health problems because...	DEFINITELY NOT	PROBABLY NOT	PROBABLY	DEFINITELY
a) Of a biochemical imbalance in the brain.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) It runs in our family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Of birth injury/trauma.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Of a head injury during childhood or adolescence.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) he/she inherited it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) of alcohol or drug use.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) of difficult relationships in our family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) he/she is a lazy sort of person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) of stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) he/she has no self-discipline.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) of problems in school during childhood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Sibling Caregiving

D8 (con't) My sibling has mental health problems because	DEFINITELY NOT	PROBABLY NOT	PROBABLY	DEFINITELY
l) of military service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) of the way he/she was raised.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) of God's will.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D9) **More and more information is available about GENETIC CAUSES of severe mental illnesses.**

**What kind of impact do you think this information has had or will have on the following:**

	VERY NEGATIVE IMPACT	SOMEWHAT NEGATIVE IMPACT	SOMEWHAT POSITIVE IMPACT	VERY POSITIVE IMPACT	DON'T KNOW
a) The quality of treatment your sibling receives	<input type="checkbox"/>				
b) The promise for better treatment and/or prevention in the future	<input type="checkbox"/>				
c) The stigma faced by your parents	<input type="checkbox"/>				
d) The stigma you face as a sibling of someone with a mental illness	<input type="checkbox"/>				
e) The stigma faced by your sibling	<input type="checkbox"/>				

D10) **Do you feel that the following groups of people have treated you differently because your sibling has a serious mental illness?**

	DEFINITELY NOT	PROBABLY NOT	PROBABLY So	DEFINITELY So	DON'T KNOW
a) Relatives	<input type="checkbox"/>				
b) Friends or classmates	<input type="checkbox"/>				
c) Teachers	<input type="checkbox"/>				
d) Romantic partners/potential partners	<input type="checkbox"/>				
e) Mental health professionals	<input type="checkbox"/>				
f) Employers (if employed)	<input type="checkbox"/>				
g) Spiritual/Religious community	<input type="checkbox"/>				

## Sibling Caregiving

The quality of the sibling relationship during childhood or teen years can help us understand adult sibling relationships. This set of items asks about what your family was like when you were growing up. Please complete this whether or not your brother/sister had mental health problems while you were a teenager. Please  *check* the response that best reflects your answer.

D11) <u>When I was a teenager (13-17) ...</u>	NOT AT ALL	RARELY	SOMETIMES	OFTEN
a) My sibling and I took care of each other....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I was proud of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) My parents leaned on me a lot....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I enjoyed being with my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Everyone in the family seemed angry....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I knew my sibling had problems....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) We as a family talked about the fact that my sibling was having problems...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) I felt embarrassed by my sibling's behavior....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) I was afraid of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) My parents were afraid of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) I liked my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) I worried that I might be like my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) My parents tried to protect me from what was going on with my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) I felt angry at my parents regarding their involvement with my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) I was teased by my peers because of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) I did not want to bring friends home because of my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) I was really affected by my sibling's illness....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) I felt left out of things at home....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) I had little to do with my family....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) I was very involved in trying to help my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u) I resented my sibling....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) I was physically hurt or abused by my sibling with illness....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w) Life at home seemed sad and lonely....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) My family was able to enjoy themselves....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y) My sibling leaned on me....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Sibling Caregiving

The quality of the parent/child relationship during can help us understand personal relationships within the family. This set of questions asks about your relationship with your mother and father. Please  *check* the response that best reflects your answer.

	NOT AT ALL	RARELY	SOMETIMES	OFTEN
<b>D12) The following asks about your relationship with your mother:</b>				
b) How well do you feel that your mother <u>understands</u> you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) How well do you feel your mother <u>trusts</u> you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) How <u>fair</u> do you feel your mother is toward you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) How much <u>respect</u> do you feel from your mother?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) How much <u>affection</u> do you feel that your mother has for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) How much do you <u>understand</u> your mother?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) How well do you <u>trust</u> your mother?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) How <u>fair</u> do you feel you are toward your mother?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) How much do you <u>respect</u> your mother?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) How much <u>affection</u> do you have toward your mother?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) How much does <u>your mother lean on you</u> regarding your brother/sister with the mental health illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) How much do <u>you lean on your mother</u> regarding your brother/sister with the mental health illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>D13) The following asks about your relationship with your father:</b>				
	NOT AT ALL	RARELY	SOMETIMES	OFTEN
n) How well do you feel that your father <u>understands</u> you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) How well do you feel your father <u>trusts</u> you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) How <u>fair</u> do you feel your father is toward you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) How much <u>respect</u> do you feel from your father?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) How much <u>affection</u> do you feel that your father has for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) How much do you <u>understand</u> your father?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) How well do you <u>trust</u> your father?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u) How <u>fair</u> do you feel you are toward your father?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) How much do you <u>respect</u> your father?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w) How much <u>affection</u> do you have toward your father?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) How much does <u>your father lean on you</u> regarding your brother/sister with the mental health illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y) How much do <u>you lean on your father</u> regarding your brother/sister with the mental health illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Sibling Caregiving

### WHAT DO YOU THINK THE FUTURE WILL BE LIKE FOR YOUR SIBLING?

**IF YOUR SIBLING CURRENTLY LIVES WITH OR IS CARED FOR BY YOUR PARENT(S), CONSIDER THE FUTURE WHEN YOUR PARENT(S) ARE (IS) NO LONGER ABLE TO PROVIDE HELP.**

E1) In the future, do you anticipate your sibling having problems in any of the following: (ANSWER EACH ITEM A - C)

	NO	MINIMAL	MODERATE	EXTREME
a) Compliance with medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Compliance with other services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Housing stability (e.g.: where he/she lives)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

E2) Who will be the **PRIMARY SUPPORT PERSON** for your sibling in the future?

**IF PARENT(S) ARE PRIMARY CAREGIVERS, CONSIDER WHEN YOUR PARENT(S) ARE NO LONGER ABLE TO HELP**

- (CHECK  ONE ANSWER)*
- I WILL
- I AND ANOTHER RELATIVE(S) WILL BE EQUALLY INVOLVED WITH MY SIBLING WITH MENTAL ILLNESS, *specify relationship to you* \_\_\_\_\_
- OTHER FAMILY MEMBER, *specify relationship to you* \_\_\_\_\_
- SOMEONE ELSE, *specify (E.G.: FRIEND,)* \_\_\_\_\_
- AGENCY / SERVICE PROVIDER
- UNCERTAIN
- NOT APPLICABLE, SIBLING DOES NOT NEED ANY SPECIAL CARE OR SUPPORT

E3) Who will be responsible for the **LONG-TERM RESIDENTIAL** care of your sibling in the future?

**IF PARENT(S) ARE PRIMARY CAREGIVERS, CONSIDER WHEN YOUR PARENT(S) ARE NO LONGER ABLE TO HELP**

- (CHECK  ONE ANSWER)*
- I WILL
- I AND ANOTHER RELATIVE(S) WILL BE EQUALLY INVOLVED WITH MY SIBLING WITH MENTAL ILLNESS, *specify relationship to you* \_\_\_\_\_
- OTHER FAMILY MEMBER, *specify relationship to you* \_\_\_\_\_
- SOMEONE ELSE, *specify (E.G.: FRIEND, AGENCY)* \_\_\_\_\_
- AGENCY / SERVICE PROVIDER
- UNCERTAIN
- NOT APPLICABLE, SIBLING DOES NOT NEED ANY RESIDENTIAL CARE

E4) Where do you think would be the **BEST** place for your sibling to live in the future?

**IF PARENT(S) ARE PRIMARY CAREGIVERS, CONSIDER WHEN YOUR PARENT(S) ARE NO LONGER ABLE TO HELP**

- (CHECK  ONE ANSWER)*
- IN A COMMUNITY RESIDENCE (E.G.: A GROUP HOME)
- IN AN INSTITUTION (E.G.: HOSPITAL OR NURSING HOME)
- WITH ME
- WITH ANOTHER FAMILY MEMBER, *specify relation to you* \_\_\_\_\_
- INDEPENDENTLY, WITH SUPERVISION (e.g.: service provider checks on him/her)
- INDEPENDENTLY, WITHOUT SUPERVISION
- OTHER, *specify* \_\_\_\_\_

## Sibling Caregiving

E5) Has your family made any legal or financial arrangements for the long term care of your sibling? (CHECK  ONE ANSWER)

YES  
 NO  
 DON'T KNOW  
 NOT APPLICABLE, SIBLING DOES NOT NEED ANY SPECIAL CARE OF SUPPORT

→ If YES, specify which type(s) of specific arrangements have been made: (CHECK   ALL THAT APPLY)

Guardianship  
 Health Care Proxy  
 Benefit Payee Transfer  
 Estate Planning / Trust  
 Application for Residential Services  
 Other, specify \_\_\_\_\_

→ If yes, were most of these arrangements made while your parents were providing primary care for your sibling? (CHECK  ONE ANSWER)

YES  
 NO

E6) If a genetic test became available that would tell you something about your risk for developing an illness like your sibling's would you want to have the test?

DEFINITELY NOT     PROBABLY NOT     PROBABLY     DEFINITELY

E7) If a genetic test became available that would tell you something about your risk for passing an illness like your sibling's on to your children would you want to have the test?

DEFINITELY NOT     PROBABLY NOT     PROBABLY     DEFINITELY

E8) Overall, for YOU, the experience of having a brother or sister with mental illness has been ...

MOSTLY NEGATIVE     NEUTRAL     MOSTLY POSITIVE

Please feel free to share any additional experiences, comments, or feedback.

Optional Items



*The next section will be detached from the earlier sections of the survey.*



✓ **Please note: Your name and any additional information you provide will be maintained separately from your survey responses.**

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP: \_\_\_\_\_

PHONE: (with area code): \_\_\_\_\_

EMAIL: \_\_\_\_\_

- I DO NOT WISH TO BE CONTACTED FURTHER REGARDING THIS STUDY
- I WOULD BE WILLING TO BE CONTACTED FURTHER REGARDING THIS STUDY
- I WOULD LIKE A COPY OF THE RESULTS ONCE THEY BECOME AVAILABLE

*Do you have or know of another sibling who may want to participate in this study?*

NAME: \_\_\_\_\_

PHONE (with area code): (\_\_\_\_\_) \_\_\_\_\_

EMAIL: \_\_\_\_\_

NAME: \_\_\_\_\_

PHONE (with area code): (\_\_\_\_\_) \_\_\_\_\_

EMAIL: \_\_\_\_\_

**THANK YOU FOR TAKING THE TIME TO FILL OUT THIS SURVEY.  
YOUR PARTICIPATION IS GREATLY APPRECIATED.**

**OVER FOR RETURN INSTRUCTIONS**



**SURVEY RETURN INSTRUCTIONS**



**WHEN YOU HAVE FINISHED THE SURVEY, PLEASE  
RETURN IT USING THE PRE-ADDRESSED, STAMPED  
ENVELOPE VIA U.S. MAIL.**

## Appendix D:

### Variable Modifications

#### Dependent Variable Modifications

**DI E2:** Variable E2, recoded variable where response categories 1 and 2 were collapsed because they both involved the respondent reporting that they expected to be primarily involved in supporting their relative in the future. The variable was dichotomized into 2 categories, 1) the respondent reported being involved in future caregiving and 2) the respondent did not report being involved in future caregiving.

#### Predictor Variables

**SIB AGE:** Variable *dob*, the respondent's birth date reported by month and year, was used to create variable *sib\_age*, which was computed by subtracting the year 2005 and the year from the reported date of birth.

**PT AGE:** The sibling with the mental illness's birth date reported by month and year, was used to create variable *pt\_age*, which was computed by subtracting the year 2005 and the year from the reported date of birth.

**GDYAD:** Dyad between gender of sibling and gender of patient with sis/sis as reference group.

**SISBRO:** Recoded respondent gender and gender of sibling with mental illness into a dummy coded variable: *sis/bro*—(2) dummy coded variable. Reference grouping was sister/sister.

**BROSIS:** Recoded respondent gender and gender of sibling with mental illness into a dummy coded variable: *bro/sisr*—(3) dummy coded variable. Reference grouping was sister/sister.

**BROBRO:** Recoded respondent gender and gender of sibling with mental illness into a dummy coded variable: *bror/bro*—(4) dummy coded variable. Reference grouping was sister/sister.

**R SIBRACE:** Recoded *sibrace* into 4 categories, *black*, *white*, *hispanic*, and *other*. Native Americans, Asian, and Other categories were combined to create the *other* category.

<b><u>BLACK:</u></b>	Dummy coded variable. 1= Black and 0=non Black.
<b><u>HISP:</u></b>	Dummy coded variable. 1= Hispanic and 0=non Hispanic.
<b><u>OTHER:</u></b>	Dummy coded variable. 1= other and 0=non-other.
<b><u>R C4:</u></b>	Recoded variable C4, the age of the sibling when he or she was formally diagnosed with a mental illness, and collapsed categories 1 and 2. A dichotomous variable was not created due to the variance within the variable.
<b><u>DI E2:</u></b>	Dichotomized DV2, <i>r_futsup</i> , in order to determine whether the respondent reported being involved as the primary support for their sibling in the future.
<b><u>MOMMEAN:</u></b>	Computed mean of scores of mom scale, page 14 of questionnaire.
<b><u>DADMEAN:</u></b>	Computed mean of scores of dad scale, page 14 of questionnaire.
<b><u>SIBOLDER:</u></b>	Computed whether respondent was older than sibling.
<b><u>BEH PRO:</u></b>	Dichotomized variable that examines reports of behavior problems of sibling. 0= no reports of behavioral problems, 1= at least 1 or more report of behavioral problems.
<b><u>TN RECIP:</u></b>	One of the variables that describes the sibling relationship and family environment during ages of 13-17. This variable examines the reciprocal relationship between siblings. A factor analysis was run to identify the factor loadings for the scale used on page 13 (question D11) of the Sibling questionnaire. Items, D11a, b, c, d, k, t, & y, loaded on this factor.
<b><u>TN FAM:</u></b>	One of the variables that describes the sibling relationship and family environment during ages of 13-17. This variable examines the family environment of the respondent. A factor analysis was run to identify the factor loadings for the scale used on page 13 (question D11) of the Sibling questionnaire. Items, D11e, i, j, n, o, r, s, u, v, w, & x, loaded on this factor.
<b><u>TN EMTN:</u></b>	One of the variables that describes the sibling relationship and family environment during ages of 13-17. This variable examines the feelings of stigma/shame/worry experienced by the respondent. A factor analysis was run to identify the factor loadings for the scale used on page 13 (question D11) of the Sibling questionnaire. Items, D11f, g, h, l, m, p, & q, loaded on this factor.

## Appendix E:

### Normality, Linearity, & Homogeneity Tables

**Normality Tests  
(Key Predictors & Demographic Variables)**

Variables	Assumption Met* (Yes/No)	Transformation(s)
B3 (DV1_a)	No	None
B6 (DV1_b)	No	Logorithm
Sibchil2	No	None
B2 (Geographical Distance)	No	Logorithm
R_C4 (age of formal diagnosis for sib with mental illness)	Yes	N/A
C16 (level of impairment of sib with mental illness)	Yes	N/A
Mommean (closeness between sibling respondent and mother)	No	None
Dadmean (closeness between sibling respondent and father)	Yes	N/A
Sibeduc	No	None

\*Skewness and Kurtosis have values between -1.0 and 1.0.

**Linearity Tests  
(B3 (DV1\_a) and Key Predictors & Demographic Variables)**

Variables	Assumption Met* (Yes/No)	Transformation(s)
Sibchil2	No	None
Sibeduc	No	None
B2 (Geographical Distance)	No	None
R_C4 (age of formal diagnosis for sib with mental illness)	No	None
C16 (level of impairment of sib with mental illness)	Yes	NA
Mommean (closeness between sibling respondent and mother)	No	None
Dadmean (closeness between sibling respondent and father)	No	None

\*Pearsons correlations or eta are significant at the 0.05 level.

**Linearity Tests  
(B6 (DV1\_b) and Key Predictors & Demographic Variables)**

Variable	Assumption Met* (Yes/No)	Transformation(s)
Sibchil2	No	None
Sibeduc	No	None
B2 (Geographical Distance)	No	None
R_C4 (age of formal diagnosis for sib with mental illness)	Yes	NA
C16 (level of impairment of sib with mental illness)	No	None
Mommean (closeness between sibling respondent and mother)	No	None
Dadmean (closeness between sibling respondent and father)	No	None

\*Pearsons correlations or eta are significant at the 0.05 level.

**Homogeneity Tests  
(Key Predictors & Demographic Variables)**

Variable	Assumption Met* (Yes/No)	Transformation(s)
DI_E2 (DV2)	Yes	N/A
B1 (whether respondent is member of family support group)	No	None
Marital	No	None
Momliv (mother alive or not)	Yes	N/A
Dadliv (father alive or not)	Yes	N/A
R_Sibrace	Yes	NA
C6 (substance abuse d/o for sib with mental illness or not)	No	None
Sibolder (whether respondent is older than sib with mental illness or not)	No	None
Beh_pro (no, or one or more behavioral problems for sib with mental illness)	No	None
Sibemploy	Yes	N/A

\*Pearsons correlations or eta are significant at the 0.05 level.

## Appendix F:

### Demographic Characteristics of Respondents by Race/Ethnicity

CHARACTERISTICS	RESULTS (%)
<b><i>Race/Ethnicity (n=93)</i></b>	
Black (n=25)	28.0
White (n=35)	36.6
Hispanic/Latino (n=27)	29.0
Other (n=6)	6.5
<b><i>Gender</i></b>	
<b><i>Male (n=21)</i></b>	
Black	23.8
White	38.1
Hispanic/Latino	38.1
Other	0.0
<b><i>Female (n=72)</i></b>	
Black	27.8
White	37.5
Hispanic/Latino	26.4
Other	7
<b><i>Employment Status</i></b>	
<b><i>Homemaker (n=17)</i></b>	
Black	17.6
White	58.8
Hispanic/Latino	17.6
Other	5.9
<b><i>Unemployed (n=16)</i></b>	
Black	18.8
White	6.3
Hispanic/Latino	68.8
Other	6.3
<b><i>Work Part-time (n=17)</i></b>	
Black	29.4
White	23.5
Hispanic/Latino	23.5
Other	23.4
<i>(Table Continued Next Page)</i>	

CHARACTERISTICS	RESULTS (%)
<b><i>Work Full-time (n=43)</i></b>	
Black	32.6
White	46.5
Hispanic/Latino	20.9
Other	0
<b><i>Age (in years)</i></b>	M=42.64(S.D.=12.35)* [range = 19–73]
<b><i>Age Order</i></b>	
<b><i>Older than sibling with M/I (n=40)</i></b>	
Black	26.0
White	42.0
Hispanic/Latino	24.0
Other	8.0
<b><i>Younger than sibling with M/I (n=50)</i></b>	
Black	27.5
White	35.0
Hispanic/Latino	32.5
Other	5.0
<b><i>Caregiving Gender Dyad</i></b>	
<b><i>Sister w/o M/I and Sister w/M/I (n=30)</i></b>	
Black	20.0
White	36.7
Hispanic/Latino	30.0
Other	13.3
<b><i>Sister w/o M/I and Brother w/M/I (n=42)</i></b>	
Black	33.3
White	38.1
Hispanic/Latino	23.8
Other	4.8
<b><i>Brother w/o MI and Sister w/M/I (n=6)</i></b>	
Black	0
White	16.7
Hispanic/Latino	83.3
Other	0
	<i>(Table Continued Next Page)</i>

CHARACTERISTICS	RESULTS (%)
<b><i>Brother w/o M/I and Brother w/M/I (n=15)</i></b>	
Black	33.3
White	46.7
Hispanic/Latino	20.0
Other	0
<b><i>Level of Education</i></b>	
<b><i>Less than High School (n=7)</i></b>	
Black	14.3
White	0
Hispanic/Latino	85.7
Other	0
<b><i>High School Graduate (n=15)</i></b>	
Black	33.3
White	13.3
Hispanic/Latino	46.7
Other	6.7
<b><i>Some College (n=24)</i></b>	
Black	20.8
White	45.8
Hispanic/Latino	16.7
Other	16.7
<b><i>College Graduate (n=18)</i></b>	
Black	11.1
White	61.1
Hispanic/Latino	22.2
Other	5.6
<b><i>Some Graduate School (n=10)</i></b>	
Black	50.0
White	20.0
Hispanic/Latino	30.0
Other	0
<b><i>Graduate Degree (19)</i></b>	
Black	36.8
White	47.4
Hispanic/Latino	15.8
Other	0
	<i>(Table Continued Next Page)</i>

CHARACTERISTICS	RESULTS (%)
<b><i>Distance from Sibling w/ Mental Illness</i></b>	
<b><i>0 (Lives w/Sibling) (n=13)</i></b>	
Black	30.8
White	15.4
Hispanic/Latino	46.2
Other	7.7
<b><i>More than 0 &lt; 30 minutes (n=38)</i></b>	
Black	26.3
White	47.4
Hispanic/Latino	26.3
Other	0
<b><i>Between 30 minutes and 1 hour (n=9)</i></b>	
Black	11.1
White	55.6
Hispanic/Latino	22.2
Other	11.1
<b><i>Between 1 hour and 2 hours (n=9)</i></b>	
Black	22.2
White	33.3
Hispanic/Latino	22.2
Other	22.2
<b><i>More than 2 hours (n=22)</i></b>	
Black	31.8
White	31.8
Hispanic/Latino	27.3
Other	9.1
<b><i>Mother Alive</i></b>	
<b><i>Yes (n=67)</i></b>	
Black	23.9
White	34.3
Hispanic/Latino	32.8
Other	9.0
<b><i>No (n=26)</i></b>	
Black	34.6
White	46.2
Hispanic/Latino	19.2
Other	0
<i>(Table Continued Next Page)</i>	

CHARACTERISTICS	RESULTS (%)
<b><i>Father Alive</i></b>	
<b><i>Yes (n=48)</i></b>	
Black	29.2
White	41.7
Hispanic/Latino	22.9
Other	6.3
<b><i>No (n=44)</i></b>	
Black	25.0
White	34.1
Hispanic/Latino	36.4
Other	4.5
<b><i>Person Considered Primary Support</i></b>	
<b><i>Mother (n=32)</i></b>	
Black	34.4
White	31.3
Hispanic/Latino	31.3
Other	3.1
<b><i>Father (n=2)</i></b>	
Black	0
White	50
Hispanic/Latino	0
Other	50
<b><i>Both Mother and Father (n=9)</i></b>	
Black	11.1
White	66.7
Hispanic/Latino	11.1
Other	11.1
<b><i>Sibling Respondent (n=19)</i></b>	
Black	15.8
White	42.1
Hispanic/Latino	42.1
Other	0
<b><i>Sibling Respondent and Relatives (n=19)</i></b>	
Black	36.8
White	26.3
Hispanic/Latino	21.1
Other	15.8
<i>(Table Continued Next Page)</i>	

CHARACTERISTICS	RESULTS (%)
<i>Others (n=12)</i>	
Black	25.0
White	41.7
Hispanic/Latino	33.3
Other	0

## Appendix G:

### Correlation Matrix

*Intercorrelations among Study Variables (n=93)*

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	
1. Marital Status	--																	
2. Race/Ethnicity	.12	--																
3. Level of Education	-.10	-.28*	--															
4. Closeness with Mother	-.00	-.10	.31*	--														
5. Closeness with Father	.17	.12	-.03	-.06	--													
6. Behavioral Problems	.08	-.28*	-.19	-.14	.06	--												
7. Employment Status	.12	-.18	.32*	.18	-.02	-.09	--											
8. Children Under Age 18	-.39*	-.02	-.17	-.02	-.09	.09	-.14	--										
9. Reciprocal	-.03	.17	-.14	.13	.00	.24	-.05	.09	--									
10. Emotional Closeness	-.01	.01	-.11	-.14	-.13	.11	-.13	-.02	-.09	--								
11. Family Environment	-.02	-.03	-.15	-.39*	.05	.16	-.03	.01	-.13	.56*	--							
12. Geographic Distance	-.05	.02	.03	-.12	.06	.09	-.09	.11	-.05	-.02	.07	--						
13. Long term	-.06	.05	.27*	.13	.01	-.20	.04	-.07	-.14	-.07	.02	-.15	--					
14. Gender of Respondent	-.09	.00	.01	-.13	-.19	.05	-.08	.05	-.08	-.08	-.07	.07	.06	--				
15. Primary Disorder	.04	.05	-.19	-.08	.14	.14	-.03	.13	.13	.10	.12	.14	-.27*	-.08	--			
16. Age (Respondent)	a	a	a	a	a	a	a	a	a	a	a	a	a	a	a	--		
17. Age (Sibling with MI)	a	a	a	a	a	a	a	a	a	a	a	a	a	a	a	a	a	--

\* Correlation is significant to at least  $p < .05$  level (2-tailed).

a Cannot be computed because at least one of the variables is constant.

## Appendix H:

### Statistical Differences of Respondents by Race/Ethnicity

VARIABLES	RESULTS (Chi-Square)
<i>Gender</i>	$\chi^2 = 2.614(3)$
<i>Employment Status</i>	$\chi^2 = 4.863(3)$
<i>Level of Education</i>	$\chi^2 = 32.97(15)^*$
<i>Distance from Sibling w/ Mental Illness</i>	$\chi^2 = 11.24(9)$
<i>Child in the Household Under Age 18</i>	$\chi^2 = 1.85(3)$
<i>Reports of Behavioral Problems from Sibling with Mental Illness</i>	$\chi^2 = 12.66(3)^*$
<i>Closeness with Mother</i>	$\chi^2 = 93.25(99)$
<i>Closeness with Father</i>	$\chi^2 = 87.07(78)$
<i>Mother Alive</i>	$\chi^2 = 5.02(3)$
<i>Father Alive</i>	$\chi^2 = 2.03(3)$
<i>Marital Status</i>	$\chi^2 = 16.22(12)$
<i>Reciprocal Relationship During Adolescence</i>	$\chi^2 = 71.68(57)^\wedge$
<i>Emotional Closeness between Siblings During Adolescence</i>	$\chi^2 = 54.64(54)$
<i>Family Environment During Adolescence</i>	$\chi^2 = 68.56(81)$
<i>Person Considered Primary Support</i>	$\chi^2 = 23.30(18)$

\*p < .05, ^ p < .10

## **Definitions**

### **Schizophrenia**

Schizophrenia, the most common diagnostic category associated with SMI, is a chronic, severe, and disabling brain disease (National Institute on Mental Health, 2001). Schizophrenia ranks among the top 10 causes of disability in developed countries, like the United States (Murray, & Lopez, as reported on by the National Institute of Mental Health, 2004). Schizophrenia and other severe mental illnesses [schizoaffective disorder, major depression, manic depressive disorder, and bi-polar disorder] are commonly diagnosed during early or later adulthood when most individuals are linked to varying family systems (Greenberg, Seltzer, Orsmond, & Krauss, 1999). The onset of schizophrenia is commonly referred to as an “acute” phase, characterized by a state of mental impairment, hallucinations, delusions, and disorganized speech and behavior, all of which may cause the person to become fearful and withdrawn from family and friends (National Institute of Mental Health, 2001). The National Alliance of Research on Schizophrenia and Depression (NARSAD) reported that in any given year there are more than two million people affected by schizophrenia in the United States ([www.narsad.org](http://www.narsad.org), retrieved 8/14/2004). They further estimate that approximately one percent of the world population, that is, about one in every hundred individuals, will develop schizophrenia.

### **Bipolar Disorder**

Bipolar disorder, also known as manic-depressive disorder, is a brain disorder that causes unusual shifts in a person's mood, energy, and ability to function (Baldessarini et al., 2003). The disorder is generally considered to be a biochemical disorder of the brain and its associated hormonal systems. Different from the normal ups and downs that everyone goes through, the symptoms of bipolar disorder are severe ([www.nimh.gov](http://www.nimh.gov)).

More than 2 million American adults, or about 1 percent of the population age 18 and older in any given year, have bipolar disorder (Narrow, as reported by NIMH.com). Bipolar disorder typically develops in late adolescence or early adulthood. However, some people have their first symptoms during childhood, and some develop them late in life (Regier et al., 1993). Bipolar is often not recognized as an illness, which could result in people suffering for years before it is properly diagnosed and treated.

### **Schizoaffective Disorder**

Schizoaffective disorder involves symptoms of both schizophrenia and manic depressive disorder (also referred to as bipolar disorder). The National Alliance for the mentally ill (NAMI) defines it as "the presence of psychotic symptoms in the absence of mood changes for at least two weeks in a patient who has a mood disorder" ([www.nami.org](http://www.nami.org)). The diagnosis is used when an individual does not fit diagnostic standards for either schizophrenia or "affective" (mood) disorders such as depression and bipolar disorder (manic depression). The onset of the illness usually begins in early adulthood and is more commonly diagnosed in women ([www.nmha.org](http://www.nmha.org)).

### **Major Depressive Disorder**

Major depression disorder is also referred to as major depression or clinical depression. It is characterized by a severely depressed mood that persists for at least two weeks (APA, 2000). Episodes of major depressive disorder may start suddenly or slowly and can occur several times through a person's life. This disorder may occur or coexist as a result of another serious illness such as diabetes or HIV/AIDS ([www.nimh.gov](http://www.nimh.gov)).

### **Instrumental Support**

In this dissertation direct caregiving was referred to as *instrumental support*. Using the term instrumental support was guided by measures utilized in the previous research of Lohrer (2001) and Greenberg et al. (1999). In their work, the researchers

conceptualized the term in regards to the objective or direct caregiving involvement patterns. In the Sibling questionnaire, instrumental support was captured through questions asking respondents whether they did tasks such as bathing, grooming, providing transportation, managing medication, and engaging in social or recreational activities with or for their brother or sister with mental illness.

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