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Economic Expenditures Associated with Instrumental Caregiving Roles of Adult Siblings of Persons with Severe Mental Illness

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ABSTRACT: Siblings of persons with mental illness who assume primary caregiving roles experience substantial and tangible economic impacts associated with this responsibility. This study investigated mailed survey responses collected from 156 adult siblings of persons with mental illness from New York State to examine instrumental costs associated with providing support to siblings with illness. Genders of both siblings, severity of the relatives' mental illness, and number of surviving parents in the family distinguished those occupying primary caregiving responsibility from those not in primary roles. Current caregivers incurred greater instrumental costs in the form of financial expenses, time spent in care activities, and crisis involvement than did those who were not primary care providers. Additional demographic and behavioral factors related to siblings with and without illness were associated with specific dimensions of instrumental expenditure. As siblings become increasingly engaged in caregiving, social service professionals must assume leadership in promoting programs and policies that meaningfully support family involvement for relatives with mental illness.

KEY WORDS: caregiving; sibling relationships; mental illness; instrumental care.

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INTRODUCTION

Throughout the past decades the service delivery landscape for persons with mental illness has shifted from a hospital-based to that of a community-based system. The emphasis on community-based care combined with changing social and demographic trends has raised concern regarding the growing number of elderly parents providing support for their adult children with mental illness (Greenberg, Seltzer, & Greenley, 1993; Greenberg, Seltzer, Orsmond, & Krauss, 1999; Lefley, 1987; Lefley & Hatfield, 1999; Seltzer, Greenberg, Krauss, & Hong, 1997a). As parents age their capacities as caregivers will diminish; however, their adult offspring with illness will continue to need on-going community-based support (Greenberg, Seltzer, Krauss, & Kim, 1997; Horwitz, 1994, 1993; Lefley, 1987; Lefley & Hatfield, 1999; Pruchno, Patrick, & Burant, 1996).

Siblings of persons with mental illness may represent a vital source of long-term informal support for many adults with mental illness residing in the community (Horwitz, 1994, 1993; Lefley, 1987). Expectations that adult siblings will assume caregiving responsibility for their siblings with mental illness must be made with caution, as such individuals may hold obligations to their own children, spouses, work, or other responsibilities (Horwitz, 1994; Reinhard & Horwitz, 1995). In the absence of sustained family involvement, care for millions of people with mental illness will be in jeopardy and may increasingly fall to the obligation of a limited system of public resources (Clark & Drake, 1994; Greenberg et al., 1999; Hatfield, 1978; Horwitz, Tessler, Fisher, & Gamache, 1992; Pruchno et al., 1996). Systematic examination of siblings without disabilities as sources of informal care is particularly timely and represents an issue of importance for persons with mental illness, their families, and policy makers (Greenberg et al., 1997, 1999; Horwitz, 1994, 1993).

Though some siblings do report involvement in caregiving to be gratifying and fulfilling, virtually all also experience strain associated with providing support to their relative with illness (Greenberg et al., 1997). Numerous studies and personal accounts have documented the psychological impacts and burdens of growing up with a sibling with mental illness; however, *economic* or *instrumental* impacts represent another often overlooked dimension of caregiving involvement. It is important to consider the economic expenditures associated with caregiving for several reasons. Direct financial outlays provided to a sibling (e.g.: paying rent or bills, buying food or medication, providing spending money, etc.) have the obvious implication of reducing the available income of a caregiver and thereby decrease (the caregiver's) personal well-being. Costs are typically thought to include only monetary outlays; however, time spent assisting a relative involves lost opportunities to earn income or spend in leisure activities (Clark, 1994; Nas, 1996). Consequently, both financial outlays as well as the time devoted to caregiving are considered costs that affect the quality of life of caregivers (Clark, 1994; Nas, 1996). Regardless of the personal satisfaction that may be associated with providing care, expenditures of time and money potentially place the employment and financial resources of some caregivers at risk.

To guide the current investigation we adopt a predictive framework based on the *push-pull* model introduced by Greenberg and Seltzer and their colleagues (1999). The framework postulates that various life influences and obligations affect the degree to which siblings become involved (or not involved) in caring for brothers or sisters with mental illness. While, push factors serve to influence siblings toward involvement in caregiving, pull factors lead siblings away from caregiving activities. The model is not inconsistent with more widely employed coping and adaptation frameworks (e.g., Hill, 1949; McCubbin & Patterson, 1983) formulated to reflect adaptation to a catastrophic event, such as the mental illness of a family member. These frameworks, however, typically regard instrumental support activities as stressors that influence psychological well-being or subjective burden, while the *push–pull* model is particularly suited for examining the influence of various factors on patterns of instrumental support activity.

To date, instrumental caregiving among adult siblings of persons with mental illness has been addressed in a limited number of empirical efforts. This evolving area of inquiry suggests that many siblings provide instrumental support to their brothers and sisters with mental illness, while also demonstrating that this relationship may be influenced by particular familial circumstances or change over time (Gerace, Camilleri, & Ayres, 1993). Viewed from the perspective of a *push–pull* framework, issues related to the sibling without illness represent one grouping of *push* factors which influence caregiving activities (Greenberg et al., 1999). Abundant theoretical and research evidence suggests that females are more strongly socialized to assume caregiving roles than are males (Greenberg et al., 1999; Horwitz et al., 1992). Similarly, the quality of childhood sibling bonds has been postulated as a predictor of subsequent involvement in caregiving, suggesting that closer childhood relations lead to greater participation in caregiving as adults (Greenberg et al., 1999; Horwitz et al., 1992; Horwitz, Reinhard, & Howell-White, 1996; Jewell & Stein, 2002). Previous research has also suggested that closer geographic proximity between the sibling pair serves as a *push* factor, increasing the extent to which siblings provide care (Greenberg et al., 1999; Pruchno et al., 1996). Another *push* factor that may serve to increase participation in caregiving involves affiliation with support groups (e.g.: NAMI). Experts argue that such groups may enable family members to gain insight into their relative's illness and more effectively cope with demands of caregiving (Lefley & Hatfield, 1999; Lukens, Thorning, & Herman, 1999). Obligations to other adult responsibilities may be conceptualized as a *pull* factor, restricting caregiving activities. That is, multiple competing life roles experienced by the sibling without illness, such as, work, marriage, or child rearing may inhibit their involvement in caregiving (Greenberg et al., 1999; Horwitz et al., 1992).

We can also conceptualize factors related to the relative with mental illness in terms of the *push–pull* framework to understand involvement in caregiving. While some findings have suggested that the presence of behavioral challenges may inhibit the extent to which siblings provide care (Seltzer et al., 1997a), others find that greater perceived need of a sibling with illness is related to higher levels of current caregiving involvement (Jewell & Stein, 2002). We support the latter, that more severe psychiatric episodes and difficulty maintaining treatment compliance will serve as a *push* factor, relating to greater participation in caregiving. Broader familial factors are also posited to influence involvement. When individuals who occupy closer relational bonds are not available, persons who possess the next closest familial association are presumed to take-on more extensive caregiving responsibility (Horwitz, 1993). As such, when parents are no longer available to provide assistance, sibling involvement will increase—a *push* factor. The availability of other siblings without illness may limit the extent a sibling is involved in caregiving (Pruchno et al., 1996)—serving to *pull* siblings away from caregiving.

The available literature related to sibling caregiving hints at the complex and multidimensional nature of involvement in care. Unfortunately, most existing research on this topic has used limited sample sizes, been restricted to subjects recruited via support groups or a particular treatment site, or relied on information solicited indirectly from interviews with parents. Moreover, unlike related research focused on caregiving involvement among parents of adults with mental illness (e.g.: Clark, 1994; Clark & Drake, 1994; Franks, 1990), examination of instrumental caregiving among siblings has emphasized the use of *soft* measures (e.g.: Likert scales). Reliance on such scales has not permitted objective estimations of instrumental support and limited previous reports to subjective perceptions concerning extent of involvement. Though prior studies have suggested that many siblings participate in caregiving for their relatives with mental illness, this involvement has been characterized as relatively sparse or limited in intensity (Greenberg et al., 1997; Horwitz, 1993; Jewell & Stein, 2002; Pruchno et al., 1996). Given such findings, expenditures of time and money associated with caregiving may *not* impose significant additional burdens to siblings. However, these studies have typically sampled families in which parents were the primary caregivers; consequently we know little about families in which siblings occupy the primary care role. To date, there are no data to show how expenditures vary among siblings who occupy primary familial caregiving roles in contrast to non-primary caregivers.

Research Objectives

This investigation seeks to reaffirm and extend previous findings concerning sibling caregiving activity while examining the extent to which demographic and behavioral characteristics of the sibling respondent, the sibling with illness, and familial factors are associated with involvement in instrumental care. We utilize a cross-sectional method to examine instrumental caregiving costs incurred by adult siblings of persons with mental illness.

The first objective of this study involves specific examination of siblings who currently maintain primary caregiving roles for their relatives with mental illness and to identify demographic and behavioral characteristics that distinguish those who currently occupy primary caregiving roles and those who do not. Based on prior research and the influence of the proposed *push* and *pull* factors, we hypothesized that variables related to the sibling respondent, sibling with illness, and family composition would distinguish those siblings who reported being primary caregivers from non-primary caregivers. The second objective involves examining whether siblings who report occupying primary caregiving roles incur more substantial instrumental support expenditures than those who are not caregivers. We expect that siblings who identified themselves as primary caregivers would incur greater economic costs related to providing support to their relatives with illness as measured by hours of time spent in caregiving, financial expenditures, and involvement in crisis management activities.

METHODS

Participant Recruitment

All data utilized for this investigation were collected as part of a larger project designed to improve understanding of the impact of severe and persistent mental illness on adult siblings of persons with mental illness. The primary research method utilized involved a self-administered mailed questionnaire. All participants self-identified as a sibling without mental illness of a brother or sister with a severe mental illness and were at least 18 years of age. Data were collected from April 2000 to August 2001, within New York State.

The absence of any meaningful sampling frame of siblings of persons with mental illness precluded the use of simple probability sampling techniques. Consequently, in an effort to increase the representativeness of the sample, several non-probability sampling procedures were employed to identify participants. Published advertisements were posted in regional newspapers and mental health newsletters. Brochures describing the study were distributed at regional mental health conferences, mental health service agencies, and community organizations. To obtain a more geographically diverse sample, information pertaining to the study was sent to 1000 random member households of NAMI-NYS (National Alliance for the Mentally Ill: New York State Chapter), constituting approximately 15% of the total member mailing list. Although it was not possible to specifically target siblings in this mailing effort, interested siblings were invited to complete an enclosed return slip to request a survey. Snowball sampling methods were utilized to increase recruitment beyond the conventional methods discussed above. Specifically, participants voluntarily provided the names of other potential subjects. Identified individuals were then introduced to the study either by letter or phone; interested and eligible siblings were mailed surveys. All questionnaires were returned to the researchers via mail and participants were not required to provide their name or the name of their relative.

A total of 179 questionnaires were collected. Information from one survey was excluded because of missing data. Eligibility was further restricted to those whose relative with mental illness was reported as: (a) currently alive, (b) residing outside a long-term institutional facility for most of the past year, and (c) living in the United States. This current paper is based on data collected from the sample of 156 completed questionnaires that met the study criteria.

Sample Characteristics

Of the 156 adult sibling respondents included in the sample, 38.5% were affiliated with a sibling support group (e.g.: NAMI). The typical sibling respondent was 44.5 years old (*SD* = 12.1; *range* = 21–81) and female (76.3%). Overwhelmingly, respondents were

Anglo 90.4%, while 9.6% reported being of other ethnicity. Reported average annual household income was approximately $51,600 (*SD* = $19,000; *range* = $11,700 to a cut-off score of $85,000). Just over half of the respondents reported being currently married (51.3%). Most respondents were employed either full or part time (87.2%), while 65.4% were employed full time. To assess the extent to which respondents occupied concurrent adult life commitments an additive index was used involving the summed responses across three categories (*yes* coded 1 & *no* coded 0): (1) married, (2) employed (full time), and (3) minor children residing in household (adapted from Horwitz et al., 1992). The index ranged from 0 to 3 (0 = *no adult life commitments* to 3 = *adult life commitments in all categories*); respondents reported an average of 1.4 (*SD* = .87; *range* = 0–3) adult life commitments. The proximity the respondent lived in relation to the sibling with illness was measured on a five point scale (0 = *co-resides with the sibling* through 4 = *more than 2 hours normal travel time*). On average, respondents reported a score of 2.6 (*SD* = 1.3; *range* = 0–4) for this index (*note*: only six siblings reported co-residence).

A scale was created to measure the extent to which the sibling without illness felt emotionally close to the family member with illness. Items in the scale were adapted from the *Positive Affect Index*, (Bengtson & Black, 1973) and measures used previously by Greenberg, Seltzer and their colleagues to study siblings of persons with disabilities (e.g.: Greenberg et al., 1997; Seltzer et al., 1997b). This 12 point scale, with higher scores corresponding to greater emotional closeness, was comprised of four items measured on Likert scales: (1) I like my sibling, (2) I enjoy being with my sibling in spite of the problems s/he has, (3) I am proud of my sibling and (4) an item rating the experience of having a brother or sister with mental illness. The scale showed acceptable internal consistency (Cronbach's alpha of .84). In addition, we conducted a principle components factor analysis to determine whether the items measured a single underlying dimension. All variables were significantly inter-correlated in the .30–.60 range, suggesting a reasonable degree of congruity. As expected, the four variables converged to a single dimension (all factor loadings exceeded .58, with three exceeding .85). Given these findings in conjunction with the prior use of similar measures, we were reasonably confident the scale would assess the respondents' emotional closeness toward their sibling with illness. On average, respondents reported closeness levels of 6.6 (*SD* = 3.0; *range* = 0–11).

The average age of respondents' siblings with illness was 43.9 (*SD* = 11.3; *range* = 21–84) and more than half of individuals were male (65.4%). Most respondents indicated that their sibling had a diagnosis of schizophrenia or schizophrenia spectrum disorder (84%). Two variables assessed the severity of psychiatric impairment. Respondents were asked to indicate whether their relative had been psychiatrically hospitalized over the past year (1 = *1 or more times* & 0 = *none*); while a second item assessed their relative's self maintenance difficulties over the past year in two areas: (a) compliance with prescribed medications and (b) compliance with psychiatric or treatment programming (both areas coded 0 = *none* to 3 = *extreme*). Nearly one third (30.8%) of respondents indicated that their relative had been hospitalized at least once within the past year, while reporting an average self maintenance difficulty rate of 2.7 (*SD* = 2.1; *range* = 0–6) on this seven point index. Over one third (37.2%) were described as employed for most of the past year (including full or part time employment, sheltered employment, or student), while 62.8% were unemployed. Concerning broader family characteristics, respondents had an average of 1.3 (*SD* = 1.5; *range* = 0–8) siblings in their family without mental illness. Nearly half, (46.8%) reported that both parents were living, while 29.5% and 23.7% reported one and no parents living.

Instrumental Caregiving Variables

Three items encompassed both direct financial expenditures and time costs associated with caregiving: (1) *financial expenditures*, (2) *time spent in care related activities*, and (3) *involvement in crisis management*. To assess financial support and expenditures associated with caregiving, respondents were asked to estimate the amount of money they spent over the past month related to the care and assistance of their relative with mental illness, including money provided as well as direct expenses related to the care of their sibling. An upper cut-off at 500 dollars/month was imposed (approximately the 90th percentile) to reduce the undue influence of a small number of outlier scores (less than 6% of scores of the total sample). Respondents reported spending approximately 68.7 dollars (*SD* = 135.4; *range* = $0–500) related to caring for their relative during the past month. Time spent in support activities measured the extent to which respondents reported providing assistance to their sibling with illness in specific care related activities over the past month, including the sum of five open-ended items: (1) personal hygiene, housework, & meal preparation, (2) money management assistance, (3) shopping, (4) transportation, and (5) case management activities (categories adapted from previously used measures, see Clark, 1994; Clark & Drake, 1994; Greenberg et al., 1999; Horwitz et al., 1992). To avoid inflated estimates, each individual category was capped to a maximum of 15 hours (affecting less than 2% of items). On average, respondents reported engaging in 4.0 hours (*SD* = 6.8; *range* = 0–40) of instrumental support during the prior month. An item, involvement in crisis management, was included to examine the potentially unpredictable and episodic nature that often characterizes the course of mental illness. This item measured the frequency of crisis episodes in which the sibling respondent was involved in providing assistance to their relative during the past year (0 = *none* through 5 = *5 or more*). Nearly half (48.7%) of the respondents reported providing assistance to their relative during a crisis episode on at least one occasion over the past year (1.2 (*SD* = 1.6); *range* = 0–5).

Caregiver Status Variable

A single item was used to code whether the sibling respondent was the primary caregiver for their brother or sister with mental illness. Respondents who identified themselves as the current primary familial support for their sibling were considered as *primary caregivers* (coded 1); if others occupied this role, siblings were considered as *non-primary caregivers*. About one third (*n* = 53) of respondents identified themselves as the current primary caregiver; while the remainder (*n* = 103) did not currently occupy this role. Those reporting they shared caregiving responsibility equally with another adult familial caregiver (other than the parent of the sibling with illness) and specifically identified themselves as the primary support were considered primary caregivers. However, under circumstances in which a sibling shared responsibility equally with the parent of their brother or sister with illness, we did not consider the sibling to be the current primary caregiver.

In Table 1 the characteristics of the two groups of siblings are contrasted. As shown in the table, the two groups are similar in regard to several characteristics, but did exhibit a few notable differences. Siblings who reported being a primary caregiver were more likely to be female and were on average 10 years older than non-primary caregivers (51 vs. 41 years old). Though most siblings did not report having minor children, non-primary caregivers were more likely to have children under 18 and were less likely to be affiliated with a support group. Both groups were equally likely to be married, be employed full time, had similar household incomes and were predominantly of Anglo ethnic decent. The groups were also similar in terms of geographic proximity,

TABLE 1

Characteristics of the Primary Caregivers and Non-Primary Caregivers[a]

Characteristic	*Primary Caregiver (N = 53)*	*Non-primary Caregiver (N = 103)*	*Test Statistic*
Respondent Variables			
Gender (*female*)	90.6%	68.9%	$\chi^2 = 9.05^{**}$
Age (*years*)	51.2 (12.8)	41.1 (10.2)	$t = 5.03^{***}$
	[*range* = 21–81]	[*range* = 22–80]	
Ethnicity (*Anglo*)	90.3%	90.6%	*ns*
Marital Status (*married*)	47.2%	53.4%	*ns*
Employment Status (*employed FT*)	62.3%	65.0%	*ns*
Minor Children (*yes*)	18.9%	30.7%	$\chi^2 = 1.66^{+}$
Household Income (*thousands*)	50.8 (19.2)	51.5 (18.9)	*ns*
	[*range* = 11.7–85.0]	[*range* = 14.0–85.0]	
Geographic Proximity (*0–3*)	2.5 (1.2)[b]	2.6(1.3)[b]	*ns*
Adult Role Commitments (*0–3*)	1.3 (.9)[b]	1.5(.9)[b]	*ns*
Emotional Closeness (0–11)	7.0 (2.6)[b]	6.4(3.0)[b]	*ns*
Support Group Affiliation (*yes*)	60.4%	27.2%	$\chi^2 = 16.29^{***}$
Sibling w/Illness Variables			
Gender (*female*)	47.2%	28.2%	$\chi^2 = 5.59^{*}$
Diagnosis (*schizophrenia spectrum*)	79.2%	86.4%	*ns*
Age (*years*)	49.4 (12.5)	41.2 (9.6)	$t = 4.56^{***}$
	[*range* = 21–84]	[*range* = 21–77]	
Employment Status (*employed*)	35.8%	37.9%	*ns*
Hospitalized in Past Year (*yes*)	34.0%	29.1%	*ns*

TABLE 1 *(Continued)*

Characteristic	*Primary Caregiver (N=53)*	*Non-primary Caregiver (N=103)*	*Test Statistic*
Self-Maintenance Difficulties (*0–7*)	2.8 (2.1)^{b}	2.6 (2.1)^{b}	*ns*
Family Background Variables			
Other Siblings w/out Illness	1.4 (1.9) [*range*=0–8]	1.2 (1.3) [*range*=0–6]	*ns*
Surviving Parents (0–2)	.6 (.8)^{b}	1.6(.6)^{b}	t=8.33***

[a] Mean (*SD*) reported unless indicated.

[b] Range equals to maximum and minimum possible values.

$^{+}p < .10$, $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

emotional closeness to their relative with illness, and number of adult role commitments. Primary caregivers were more likely to have a sister with illness and had siblings who were on average about 8 years older (49 vs. 41 years old). Both groups described their siblings to be similar in regard to the proportions with a diagnosis of schizophrenia spectrum disorder, rates of employment, likelihood of recent psychiatric hospitalizations, and level or current self-maintenance difficulties. Primary caregivers had fewer surviving parents but no difference was observed in reference to the number of other well siblings in the family.

RESULTS

To identify factors distinguishing primary caregivers from those who did not occupy this role, a logistic regression analysis was conducted. Those characteristics of the sibling respondent, relative with mental illness, and family identified through bivariate analyses to be significantly associated with sibling caregiver status, and variables suggested by previous research to be related to caregiving involvement were considered in the analyses. The rationale for this approach was to include variables related to caregiver status, while also incorporating factors with latent or indirect relationships to caregiver status not evident in bivariate analyses. Preliminary analyses were conducted to reduce the list of potential covariates to be entered in the model. Variables that did not add to the variance explained or alter the pattern of findings were excluded. We retained variables related to the sibling respondent (gender, age, household income, geographic proximity, adult role commitments, emotional closeness, support group affiliation); the sibling with illness (gender, hospitalized in past year, self-maintenance difficulties); and family background (other siblings, number of surviving parents). Variables related to whether the sibling respondent had minor children (*note: adult role commitments was retained*), ethnicity, and the age of sibling with illness were excluded. Overall, the model correctly classified 82.1% of the cases (χ^2 (12, $N = 156$) = 79.5, $p < .001$). In reference to individual covariates in the model, we report trends up to $p < .10$. As seen in Table 2 current caregivers were more than three times as likely to be female. In addition, respondents were more likely to be caring for male relatives who have more self-maintenance difficulties and have fewer surviving parents. *Post hoc* examinations revealed no significant interactions among factors.

Though the prior analysis suggests that specific factors relate to caregiver status, we also examined whether siblings who assume primary caregiving roles experience economic impacts associated with providing instrumental support. Simply, it is possible that siblings who report occupying the primary caregiving role do not face appreciable costs beyond those routinely encountered by non-primary caregivers. Table 3 provides a comparison of current caregivers and non-primary caregivers in reference to time spent in support activities, financial support and expenditures, and involvement in crisis management situations. Primary caregivers incurred greater costs associated with assisting their relatives across the categories of instrumental support than did non-primary caregivers. Instrumental costs for primary caregivers were estimated at approximately 139 dollars and slightly over eight hours each month in contrast to less than 33 dollars and about two hours for non-primary caregivers. The last column of Table 3

TABLE 2

Summary of Logistic Regression Analysis Predicting Sibling Caregiver Status ($N = 156$)

Predictor Variable	*b(SE)*[a]	*Exp(B)*[b]
Respondent Variables		
Gender	1.28 (.68)*	3.58
Age	.01 (.03)	1.01
Household Income	.01 (.00)	1.00
Geographic Proximity	−.17 (.20)	.84
Adult Role Commitments	−.20 (.35)	.82
Emotional Closeness	.11 (.08)	1.12
Support Group Affiliation	.57 (.52)	1.77
Sibling w/Illness Variables		
Gender	−1.27 (.61)*	.28
Hospitalized in Past Year	.26 (.33)	1.30
Self-Maintenance Difficulties	.27 (.13)*	1.31
Family Background Variables		
Other Siblings	−.16 (.18)	.83
Surviving Parents	−2.37 (.48)***	.09
Constant	−1.22 (1.89)	.48

[a] Unstandardized regression coefficients (*standard errors*).
[b] Odds Ratios.
Model correctly classified 82.1% of the cases.
Model $\chi^2 = 79.5$, df = 12, $p < .001$.
*$p < .05$, ***$p < .001$.

TABLE 3

Involvement in Domains of Instrumental Support for Primary Caregivers and Non-Primary Caregivers

Domain of Support	*Primary Caregivers (N = 53)*	*Non-Primary Caregivers (N = 103)*	*t Value*	*95% CI of the Difference*
Financial Support & Expense	138.9 (185.6) [range = 0–500]	32.5 (80.1) [range = 0–400]	3.99***	53.1 – 159.8
Time Spent in Caregiving	8.1 (8.2) [range = 0–40]	2.0 (4.7) [range = 0–28]	5.00***	3.7–8.6
Crisis Management	1.9 (1.7) [range = 0–5]	.9 (1.4) [range = 0–5]	3.80***	.5–1.6

***$p < .001$.

provides estimated differences in instrumental support incurred by current caregivers vs. non-primary caregivers. On average, current caregivers are likely to expend between 53.1–159.8 dollars and 3.7–8.6 hours more each month in instrumental support than were non-primary caregivers (95% *CI*s). Primary caregivers were also more than twice as likely to be involved in crisis management activities, 1.9 compared to .9 episodes per year for current versus non-primary caregivers, respectively. Because the dependent measures in these analyses were positively skewed, each analysis was replicated using log transformed dependent measures to normalize these data (Kleinbaum, Kupper, & Muller, 1988). Results using transformed variables did not meaningfully differ from those reported above.

To consider whether current caregivers differed from non-primary caregivers in regard to extent of involvement in instrumental support, after controlling for other potential influences, multiple regression analyses were conducted. Such procedures allow for examination of the relationship between independent variables and a dependent measure while accounting for the effect of covariates (Kachigan, 1986; Kleinbaum et al., 1988). Separate analyses were conducted for: (1) financial expenditures, (2) time spent in care related activities, and (3) involvement in crisis management. Caregiver status was included as a predictor variable in the models in conjunction to the same set of predictor variables used in the forgoing logistic regression analysis. In these analyses log transformed dependent variables were utilized, consistent with approaches used in similar investigative efforts (Clark & Drake, 1994). Regarding individual covariates, we report trends up to $p < .10$.

As shown in Table 4, after controlling for other variables, current caregivers differed significantly from non-primary caregivers in the amount of support provided across each dimension of instrumental care. As the first two columns of the table show, the overall model explains approximately 39% of the variance (adjusted R^2) in time spent in care related activities. Caregiver status (primary vs. non-primary caregivers) was the strongest predictor of the amount of time expended in instrumental support, as current caregivers spent significantly more time in these activities. Additional factors including: closer sibling relationship, support group affiliation, closer geographic proximity, and higher self-maintenance difficulties significantly related to increased time spent in care for relatives with illness. Similarly, we observed a relationship between recent psychiatric hospitalization and time spent in care at a trend level ($p < .10$).

The third and fourth columns of Table 4 indicate that the model explained approximately 19% of the variance in financial expenses incurred in relation to caregiving activity. Overall, the variables in this model are less accurate predictors of financial assistance than the model examining time spent in caregiving. Indeed, the best predictor of

TABLE 4

Summary of Multiple Regression Analyses Predicting Involvement in Instrumental Support (N=156)[a]

	Time Assistance[b]		*Financial Assistance*[b]		*Crisis Assistance*[b]	
Characteristic	b[c]	β[d]	b[c]	β[d]	b[c]	β[d]
Respondent Variables						
Gender	.19	(.07)	.24	(.04)	.01	(.01)
Age	.01	(.01)	−.01	(−.09)	−.02	(−.04)
Household Income	−.01	(−.12)	.01	(.06)	.01	(.03)
Geographic Proximity	−.19***	(−.22)	.07	(.04)	−.01	(−.02)
Adult Role Commitments	−.07	(−.06)	−.03	(−.01)	−.03	(−.04)
Closeness of Relationship	.05*	(.14)	.12$^+$	(.15)	.03	(.12)
Support Group Affiliation	.44**	(.19)	.77*	(.17)	.12	(.09)
Sibling w/Illness Variables						
Gender	−.01	(.00)	−.03	(−.01)	.04	(.04)
Hospitalized in Past Year	.20$^+$	(.13)	.26	(.08)	.32***	(.36)
Self-Maintenance Difficulties	.11**	(.21)	.16$^+$	(.15)	.01	(.03)
Family Background Variables						
Other Siblings	−.03	(−.05)	.07	(.05)	.01	(.03)
Surviving Parents	−.04	(−.03)	−.41	(−.14)	.01	(.01)
Caregiver Status	.94***	(.39)	1.37**	(.27)	.37**	(.27)
Constant	.84		.48		.11	
R^2	.44		.26		.27	
Adjusted R^2	.39		.19		.21	

[a] Model $F(13, 142) = 8.54$, $p < .001$ for time assistance; Model $F(13, 142) = 3.75$, $p < .001$ for financial assistance; Model $F(13, 142) = 4.10$, $p < .001$ for crisis assistance.

[b] Log transformed value.

[c] Unstandardized regression coefficients.

[d] Standardized regression coefficients.

[+] $p < .10$, *$p < .05$, **$p < .01$, ***$p < .001$.

financial expenditures was caregiver status, as current caregivers incurred greater financial expenses than did siblings not in primary roles. Additionally, support group affiliation was significantly related to greater financial expenses associated with caregiving. Similarly, closer sibling relationship and higher reported self maintenance difficulties were related to greater financial expense at a trend level ($p < .10$).

The last two columns in Table 4 show that the overall model explains approximately 21% of the variance in the involvement of sibling respondents in crisis management activities related to their relatives' care. Controlling for other factors, findings suggest that current caregivers were significantly more likely to be engaged in crisis management activities than non-primary caregivers. Not surprisingly, the factor most strongly related to involvement in crisis management activities was psychiatric hospitalization over the past year.

In general, these findings indicate that siblings who are primary caregivers are likely to incur greater instrumental caregiving costs in terms of financial and time expenditures as well as frequency of crisis intervention. Additionally, emotional closeness of the sibling relationship, support group affiliation, and factors related to the severity of psychiatric illness also related to one or more dimensions of instrumental support. Importantly, these findings are evident after controlling for other factors in the models. No significant interaction effects were identified among covariates during *post hoc* analysis within any dimension of instrumental support.

DISCUSSION

A principal objective of this study involved identifying demographic and behavioral factors that distinguished adult siblings who are current caregivers and those who did not occupy this role. We find, consistent with prior research, that those siblings who report being primary caregivers are more likely to be female (Horwitz et al., 1992; Greenberg et al., 1999). Related research has suggested that within families where parents were primary caregivers, siblings tended to offer more instrumental support to sisters with disabilities (Pruchno et al., 1996). In contrast, we find that caregivers tended to provide more assistance to brothers. We also find that respondents were more likely to report being a primary caregiver for siblings who exhibited greater self-maintenance difficulty. This supports the position that care relates positively to the perceived level of need of the siblings with illness (Horwitz et al., 1992; Jewell & Stein, 2002), but appears to conflict with reports that greater behavioral challenges may inhibit caregiving involvement (Seltzer et al., 1997a). As anticipated, parental availability emerged as a significant predictor of caregiver status. This reaffirms the earlier findings of Horwitz (1993), indicating that when parents are not available, siblings are more likely to assume primary care roles. Such results are encouraging in that they suggest that individuals with greater psychiatric impairment are likely to receive on-going familial support, after parents are deceased.

A second objective involved estimating the extent to which siblings who assume primary caregiving roles experience economic impacts associated with providing instrumental support to their relatives with mental illness. It would be plausible to assume that the responsibilities as a primary caregiver would not be associated with appreciable costs beyond that routinely encountered by non-primary sibling caregivers. Such findings would not be inconsistent with prior research examining support provided to siblings with disabilities (e.g.: Greenberg et al., 1999; Horwitz, 1993; Jewell & Stein, 2002; Pruchno et al., 1996).

Interestingly, when viewed as a whole, our findings suggest that instrumental care provided by siblings for their relatives with mental illness was fairly modest. However, when comparing those who reported being primary caregivers to those who were not a somewhat different picture emerged. Our findings strongly suggest that siblings who take on primary roles for their relatives incur economic costs associated with providing this care, beyond that which is experienced by those not in such roles. In comparison to siblings who did not occupy caregiving roles, current caregivers incurred approximately three times the financial expense, three times as many hours in care and support, and were twice as likely to respond to a crisis situation related to their relative with mental illness. On average, primary caregivers expended 1277 dollars and 73 hours more each year than non-primary caregivers, though considerable variation exists in these estimates.

Findings reported herein illustrate the importance of considering factors such as caregiver status when examining instrumental support activities among siblings of persons with mental illness. It should be acknowledged, however, that these estimates of involvement still appear substantially lower than those collected by others concerning care provided by parents to adult children with mental illness (e.g.: Clark & Drake, 1994; Franks, 1990). Differences in research design across studies notwithstanding, the sizable discrepancy in the estimates of instrumental support provided by parents as contrasted to siblings involved in caregiving may be a basis of concern and warn of potential shortfalls in informal care provided to relatives with mental illness.

As anticipated, caregiver status was strongly associated with each of the three dimensions of instrumental support examined: financial expenditures, time spent in care related activities, and involvement in crisis management. Additional factors emerged as significant predictors for one or more dimensions of instrumental support (while adjusting for the impact of caregiver status) and are important to consider in light of previous findings. Though support group affiliation was not found to be associated with caregiver status, affiliation was related to the amount of time and financial expenditure associated with care, lending support to perceptions of experts in the field (Lefley & Hatfield, 1999; Lukens et al., 1999). It should be noted that we conceptualize support group affiliation as a factor predicting caregiver status and extent of involvement in care, though we are unable to establish temporal order in this study. It is plausible that affiliation could be either a predictor or an outcome variable, warranting closer examination in future investigations.

Consistent with our findings concerning caregiver status, respondents were more likely to expend time caring for siblings who exhibited more significant psychiatric impairment, as evidenced by more self-maintenance difficulty. Likewise, we observe (at a trend level) respondents incurred more financial expense if siblings had more self-maintenance difficulties. Similarly, siblings were more involved in crisis management activities if their relative had experienced a psychiatric hospitalization within the past year. Closer geographic proximity and perceived emotional closeness of the sibling relationship also related to more time in support activities, as previously suggested (Greenberg et al., 1999; Horwitz, 1993; Horwitz et al., 1996, 1992; Jewell & Stein, 2002). Though emotional closeness related to financial assistance at a trend level; geographic proximity did not relate to other dimensions of instrumental support or caregiver status. This suggests that time spent in caregiving with a relative with illness may be more sensitive to the emotional bonds and geographic distance than other aspects of caregiving.

Surprisingly, we find no evidence that the demands of multiple adult role commitments compete with an ability to be a primary caregiver or predict particular dimensions of instrumental support (Greenberg et al., 1999; Horwitz et al., 1992). Our findings may reflect that there was limited variation concerning role commitments in this particular sample of sibling respondents. Additionally, we observe relationships between caregiver status and factors including parental availability, gender of the respondent, and gender of sibling with mental illness; however, these factors did not predict any specific dimensions of instrumental support. In regard to parental availability, caregiver status appears to mediate the relationship between parental availability and extent of instrumental support extended. That is, after we consider whether a sibling occupies a primary care role, parental availability does not enhance our ability to predict involvement in particular dimensions of instrumental support. Genders of the respondent and sibling with mental illness do not appear to predict particular dimensions of instrumental support examined herein.

Overall, we were less effective in predicting financial expenses and involvement in crisis management activities, than time spent in support for relatives with mental illness, although all of the equations were statistically significant. We speculate that our measures of financial assistance and involvement in crisis management were not as refined as that used to model time involved in caregiving. Future investigations may benefit by delineating particular categories of financial expense or activities related to crisis management to comprehensively examine these issues.

There are several limitations associated with this investigation. Though longitudinal data would afford a preferable method to examine changes in economic costs incurred by individual caregivers over time, such data was not available. Despite efforts to include participants from a broad range of familial backgrounds, individuals from lower socioeconomic status, ethnic minority groups, and families not actively seeking assistance for the care of their relatives' mental illness are under-represented in this sample. Since the researchers were blind to the identities of those who participated in the study, it is possible that more than one respondent from the same family was included in the sample, potentially compromising the generalizability of findings. The study was limited to New York State, as such, comparable data are necessary to fully investigate caregiving expenditures in other regions. We observe considerable variation relative to our mean estimates in time and financial expenditures. Similar statistical results have been reported in prior research employing sampling techniques that require participants to report actual economic costs over a relatively short time interval (e.g.: Clark & Drake, 1994; Franks, 1990). Though this approach may result in increased likelihood that particular estimates over a given interval may be atypical of normal expenditures, these findings also likely reflect a wide variation in expenditures across families (Clark & Drake, 1994). Additional efforts were made to avoid inflating economic estimates; however, additional issues may contribute to error in our estimates. Response bias may influence financial estimates to be somewhat high. However, it is also likely that our non-primary caregiver estimates are higher than would be expected from a broader sample of siblings who are less involved with their siblings with illness, serving to underestimate actual economic cost differences between our caregiver and non-primary caregiver groups. Additionally, previous research has suggested that non-Anglo siblings may be more involved in direct caregiving activities than Anglo siblings (Horwitz & Reinhard, 1995); therefore our time estimates may be lower than would be observed among more culturally diverse samples. Consequently, the precise estimates of instrumental costs presented in this study should be interpreted with caution.

Despite the evident shortcomings, there are several strengths associated with this investigation. First, siblings represent an under examined component of families in which a member is chronically disabled. Second, our data indicate that siblings who assume roles as primary caregivers incur economic costs potentially affecting their own well-being and lifestyles and which are likely to be experienced over sustained periods of time. Finally, given the current climate of fiscal accountability (Mullen & Magnabosco, 1997), outcomes such as economic costs (even rough estimates) may be of value in the development of timely programs and policies.

Implications for Practice, Planning & Social Policy

The results of this study have broad implications for program planning and policy development, at both the individual and societal levels. At an individual level, mental health professionals occupy positions to facilitate a process of active and on-going preparation for the end of parental involvement and a transition of care to other family members. Siblings often report feeling overlooked by the formal mental health service system (e.g.: Landeen et al., 1992; Lukens, Thorning, & Lohrer, 2002; Marsh, Appleby, Dickens, Owens, & Young, 1993). Emphasis toward forging collaborative partnerships with siblings (without disabilities) within the treatment system, particularly around service planning and crisis management, will be essential to maintaining family caregiving involvement in the coming decade.

At a societal level, this study demonstrates that siblings are subject to economic impacts associated with caregiving responsibilities. However, siblings are not legally bound to assume such roles; as such, these costs are borne on an unpaid and voluntary basis. Options that safeguard employment or mitigate the costs associated with caregiving represent an important focus for policy development. The aims of such policies should be to support family involvement among those who desire to occupy such roles. Coercion, financial or otherwise, to prompt family involvement may facilitate unhealthy caregiving relationships that would have adverse consequences for both caregivers and persons with mental illness. However, in light of the notable costs that confront our society to provide long-term assistance to persons with mental illness; policies that strengthen the abilities of family members who desire to maintain on-going caregiving involvement can serve as both socially and fiscally responsible interventions.

Existing federal and state laws which protect those providing assistance to *select* family members (e.g.: spouse, parent, and children—but *not* siblings) offer a model upon which to build meaningful policies to support siblings. The Family and Medical Leave Act, enacted in 1993, grants leave to caregivers who need to assist relatives with health concerns (U.S. Department of Labor, 2001). Expansion of this policy to include siblings could support sibling caregivers who provide care or respond to crisis situations, potentially straining their employment. Similarly, caregiver tax credits represent potential entitlements to provide sibling caregivers financial relief from the direct costs associated with providing uncompensated support. Some states, such as California, have implemented such credits for select caregivers (California State Department of Finance, 2001). Modestly adapted, such initiatives may offer viable and relatively inexpensive methods to reach many sibling caregivers.

A salient question confronting our present mental health service system concerns to what extent adult siblings of persons with mental illness will assume primary care responsibilities in the coming years. These preliminary findings suggest that once caregiving responsibility is passed on to siblings, these roles may be taken on with earnest by some. To the extent that siblings assume caregiving responsibilities formerly carried-out by their parents, additional demands placed on the formal mental health system may be lessened (Hatfield, 1978; Horwitz et al., 1992). As siblings increasingly assume primary caregiving roles, mental health professionals, policy makers, and researchers must assume lead roles in promoting programs and policies to support sibling involvement in the care of their relatives with mental illness. Such focus is necessary to examine the long-term outcomes associated with caregiving and to assist all family members, including those with illness, to more effectively cope with severe mental illness.

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