

Predictors of Burden Among Lower Socioeconomic Status Caregivers of Persons with Chronic Mental Illness

David E. Biegel, Ph.D.
Sharon E. Milligan, Ph.D.
Patricia L. Putnam, M.S.S.A.
Li-Yu Song, Ph.D.

ABSTRACT: This study uses a stress-coping-support framework to examine the predictors of caregiver burden with a sample of 103 lower social class family caregivers of persons with chronic mental illness. Results of multiple regression analyses show that the greater the frequency of client behavioral symptoms and the lower the amount of perceived support from family members, the higher the level of overall caregiver burden. Examination of the predictors of specific types of burden—family disruption, stigma, strain, and dependency—reveal that different constellations of variables predict different types of burden. The need for mental health agencies to address caregiver and client concerns is addressed. Implications are presented for practice and future research.

Research for this paper was supported in part by grant #89-1022 from the Office of Program Evaluation and Research, Ohio Department of Mental Health and by the Center for Practice Innovations, Mandel School of Applied Social Sciences, Case Western Reserve University. Kyle Kercher, Ph.D., is thanked for providing statistical consultation for this paper, Elizabeth Robinson, Esther Sales and Mark Singer are thanked for reviewing an earlier draft of the paper.

For reprints or a copy of the survey instrument, contact: David E. Biegel, Ph.D., Henry L. Zucker Professor of Social Work Practice and Professor of Sociology, Mandel School of Applied Social Sciences, Case Western Reserve University, 10900 Euclid Avenue, Cleveland, Ohio 44106-7164 (216) 368-2308.

Sharon E. Milligan, Ph.D., is Associate Professor, Mandel School of Applied Social Sciences, Case Western Reserve University, Cleveland, Ohio.

Patricia L. Putnam, M.S.S.A., is a Doctoral candidate, Mandel School of Applied Social Sciences, Case Western Reserve University.

Li-Yu Song, Ph.D., is Research Program Manager, Center for Practice Innovations, Mandel School of Applied Social Sciences, Case Western Reserve University.

INTRODUCTION

Individuals with chronic mental illness suffer emotional disorders that are severe and long-standing, and that interfere with such functional capacities as self-care, interpersonal relationships, work and education. They often require prolonged or repeated institutional care and continued assistance in order to live successfully in the community. Chronic mental illness affects not only the client but also the entire family system. Normal patterns of family interaction are disrupted, and reassignments in tasks and roles assumed by particular family members may occur. As with other chronic illnesses, the effects of this illness upon family caregivers is often stressful (Biegel, Sales, & Schulz, 1991; Bruhn, 1977; Leventhal, Leventhal, & Nguyen, 1985).

Studies over the past several decades have provided consistent evidence that family caregivers of persons with chronic mental illness suffer from a number of significant stresses and moderately high levels of burden (Brown, Bone, Dalison, & Wing, 1966; Cook & Pickett, 1988; Davis, Dinitz & Pasaminick, 1974; Doll, 1976, 1975; Fisher, Benson, & Tessler, 1990; Freeman & Simmons, 1963; Grad & Sainsbury, 1963; Hatfield, 1978, 1979a, 1979b, 1981a, 1981b; Hoenig & Hamilton, 1966; Kint, 1978; Kreisman & Joy, 1974; Kreisman, Simmons, & Joy, 1979; Pasaminick, Scarpetti, & Dinitz, 1967; Sainsbury & Grad, 1962; Thompson & Doll, 1982; Waters & Northover, 1965). Relatives of persons with mental illness shoulder significant caregiving responsibilities, often with inadequate assistance from mental health and human service agencies (Bernheim & Switalski, 1988; Grella & Grusky, 1989; Hanson, 1991; Hatfield, 1978; Holden & Lewine, 1982; Spaniol & Jung, 1983).

A number of researchers believe that deinstitutionalization has led to a greater strain on families today because many clients who would have been hospitalized in the past are now treated in community based programs. Family strain can increase because clients may not follow through and utilize community services, or needed resources such as housing or job training may be unavailable in the community. In addition, because length of hospitalization has decreased, many clients are returning to communities and to their families with severe emotional problems (Pepper & Ryglewicz, 1984). Even though studies indicate that families exhibit high tolerance toward family members with mental illness, often it is at considerable cost to the family (Doll, 1975; Kreisman, et al., 1979; Lamb, 1982). Because of the chronic nature of mental illness, burdens of families can continue, with

varying levels of intensity, for long periods of time (Davis, Dinitz, & Pasaminick, 1974).

The burdens of caregiving are multiple and pervasive, often contributing to feelings of guilt, resentment, worry, and grief. Significant issues and problems facing caregivers of persons with mental illness cited in the research and practice literature include: managing their relatives' symptomatology and behaviors; isolation of caregivers due in part to the "stigma" of mental illness; interference with personal needs of family members; inability of the client to carry out the tasks of daily living; improper use of medication; and perceptions of mental health professionals as not being helpful and blaming families as a causal agent of the client's disease (Biegel, Sales, & Schulz, 1991).

Although there is general agreement in the literature that family caregivers of persons with mental illness, like caregivers of persons with other chronic illnesses, experience significant levels of burden (see Crotty & Kulys, 1986, for exception), there remain many significant gaps in our knowledge (Biegel, Sales, & Schulz, 1991; Ravies, Siegel, and Sudit, 1990). Overall, the extant research on families of persons with mental illness has a number of significant limitations. First, research studies tend to be atheoretical and do not build upon caregiving research with other populations of chronically ill or disabled persons. Thus, theoretical models of caregiver adjustment such as stress-coping paradigms, which have been used extensively with other caregiver populations (i.e., Alzheimer's Disease), have been applied to caregivers of persons with mental illness in only limited instances (see Hatfield & Lefley, 1987, for exception). Second, while there have been a number of studies that have examined issues pertaining to burden of caregivers who provide care for a family member with chronic mental illness, there has been little systematic study of the wide range of variables that can predict caregiver distress. Further research is needed to document the correlates of burden and to examine the relative importance of specific variables as predictors of caregiver burden, such as whether the person with mental illness lives with the caregiver or elsewhere (Carpentier, Lesage, Goulet, Lalonde, & Renaud, 1992; Fisher, et al., 1990). In addition, in large part, analyses of the predictors of caregiver burden have not examined the contribution of individual predictor variables while controlling for other predictor variables, thus limiting understanding of how variables interact with each other and which variables have the most impact upon caregiver burden. Third, studies have tended to draw their samples from support groups for persons with mental illness.

Respondents in many of these studies are predominantly white, middle-class persons who are not representative of the diversity of the caregiver population. Finally, many studies utilize self-report data and do not use standardized scales. In studies that do use standardized scales, there is little agreement on specific measures among the studies.

This study attempts to address these limitations through use of a stress-coping-support theoretical framework with a sample of lower social class black and white caregivers stratified by race. A review of research examining factors affecting the degree of distress experienced by family caregivers across a variety of chronic illnesses, including cancer, heart disease, Alzheimer's disease, and mental illness, found that predictors of caregiver burden fall into two broad classes of variables, which will be used as predictors in this study (Biegel, Sales, & Schulz, 1992; Biegel, Sales, & Schulz, 1991). The first set of variables relates to the ill family member. It includes such objective illness characteristics as length of illness, hospitalization history, and frequency of client behavioral problems. Illness characteristics are indications of illness severity as well as its resultant care demands. Previous research with a number of chronic illnesses had consistently found this variable to be an important determinant of caregiver burden. In addition, certain demographic characteristics of the client, such as age and gender, have been identified as predictors of caregiver burden with other chronic illnesses and are also included in our framework. The second set of predictor variables relates to the status of the caregiver. Demographic characteristics of caregivers (e.g., age, gender, race, family relationship to client, marital status and socioeconomic status), caregiver's health status, and caregiver's other caregiving responsibilities may impact caregivers ability to respond to the demands of the caregiving situation.

Two additional sets of variables that have been found to be important in affecting caregiver burden in chronic illnesses are also included in our framework. The first of these relates to the nature of the caregiver's involvement with the client (in this study, determined by where the client is living and the caregivers frequency of contact with the client). The second set of variables is the nature of social supports available to the caregiver, including both the overall support system surrounding the caregiver as well as the specific supports, both informal and formal, available to help fulfill their caregiving role. This study aims to examine the correlation of these individual predictor variables with the level of caregiver burden, as well as the relative contribution of individual predictor variables while controlling for other predictors.

METHODOLOGY

Study Sample

Data for this analysis derive from a sample of 162 adults with severe mental disability who are currently being served by mental health case management agencies and who agreed to have their family caregiver, defined as a family member who provides emotional and concrete support to the client, contacted for a study interview. A screening form was used to identify the primary family caregiver. Two thirds of the clients contacted refused permission for investigators to contact their family caregiver. Other investigators who have obtained caregiver samples through initial contact with clients with mental illness also report difficulties in caregiver access (Richard Tessler, personal communication, September, 1992). There were no statistically significant differences between clients who refused and clients who consented by race or gender. Clients who refused were slightly older than clients who consented, 44.9 years vs. 42.1 years.

We were able to contact family caregivers of 148 of these clients, and 120 of them, or 81%, agreed to be interviewed. Of the 120 completed interviews, 17 were eliminated from the final sample because respondent scores on the Hollingshead and Redlich Two Factor Index of Social Position, a measure of social class, indicated that their social class rating was too high for our study of lower social class caregivers (Hollingshead & Redlich, 1958). Of the resultant 103 cases in our study sample, 55 were white and 48 were black.

Interviews took approximately 75 minutes and were conducted in the caregiver's home, at a community mental health center, or at the investigators' university, depending upon the caregiver's preference. Caregivers were given a cash payment of \$10 upon the completion of the survey interview. The survey instrument contained primarily closed-ended questions and inquired about client and caregiver demographic characteristics, client illness characteristics and behavioral problems, and caregiver burden, social networks and social support, and health status.

Instruments

Client Behavioral Problems. Caregivers were asked to report the frequency of a wide range of possible client behaviors, for example, sleeping problems, taking medication, hallucinations, money management, suspiciousness, or forgetfulness. A thirty-seven item behavioral problems scale was developed for this study that was based on selected items used in research with caregivers of Alzheimer's disease patients (Schulz, Williamson, Morycz, & Biegel, 1992), from selected items in the Family Distress Scale developed by Pasaminick et al. (1967) in research with families of persons with mental illness, and from a review of the research literature of behavioral problems identified by caregivers of persons with mental illness. The reliability of this scale was high (Cronbach's $\alpha = .92$).

Caregiver Burden. A twenty-seven item scale of overall caregiver burden was developed for this study based on items included in the Caregiver Burden Scale (CBS) developed by Zarit, Reever, and Bach-Peterson (1980) for use with caregivers of Alzheimer's disease patients, selected items in the Family Distress Scale developed by Pasaminick (1967), and items generated from a review of the research literature on burdens of caregivers with mental illness. The scale measures feelings that caregivers have about their psychological well-being, social life, as well as their feelings about

their family member with mental illness (e.g., feeling inadequate, resentful, stressed, useful, depended upon, embarrassed, in regard to the care recipient). The reliability of this scale was very good (Cronbach's $\alpha = .89$).

Previous studies with caregivers of persons with mental illness have conceptualized burden into two components, objective burden and subjective burden (Doll, 1975, 1976; Hoenig & Hamilton, 1966; Thompson & Doll, 1982). Objective burden has been defined as disruptions to family life caused by the person with mental illness; subjective burden is the emotional costs of having a person with mental illness in one's family. From the 27 items in our overall burden scale, using exploratory factor analysis, the following four burden subscales were created—Family Disruption (11 items), Client Dependency (4 items), Stigma (6 items), and Caregiver Strain (5 items). The first subscale is very similar to previous measures of objective burden, while the remaining three subscales can be said to be components of subjective, or emotional, burden. Each of the four subscales was highly correlated with the overall burden scale, while the subscales were moderately correlated with each other, with correlation coefficients ranging from .37 to .56. Reliability of these four subscales was moderate to good, with Cronbach's standardized alphas as follows: Stigma (.83), Family Disruption (.79), Dependency (.67), and Strain (.64).

Physical Health. Respondents were asked to rate their overall health on a five point scale from excellent to poor. This question was developed and validated by the National Center for Health Services Research (Brook et al., 1979) for the Health Insurance Study.

Social Support and Social Networks. Previous research with family caregivers of persons with mental illness has demonstrated the importance of asking respondents about the specific social support they receive in caring for their family member with mental illness, in addition to examining their overall social support systems. Family caregivers of persons with mental illness have reported significant social support deficits in addressing the burdens of their caregiving, despite positive overall levels of support (Biegel & Yamatani, 1986). As a measure of overall social support, the study utilized the Interpersonal Support Evaluation List (ISEL), which has been well validated in previous research (Cohen, Mermelstein, Kamareck, & Hoberman, 1985). This 16-item scale asks respondents to indicate, on a four-point scale from Definitely True to Definitely False, their opinion concerning items that measure appraisal, belonging, self-esteem and emotional support. The reliability of this scale was high, with a Cronbach's α of .85.

Concerning social support received in connection with their caregiving role, respondents were asked whether they thought the amount of help and support they received from their family members was much less than needed, somewhat less than needed, about enough, somewhat more than needed, or much too much. They were also asked the same question concerning help received from agency professionals.

Client and Caregiver Characteristics. Data were collected on the following demographic and socioeconomic characteristics of caregivers: age, gender, race, marital status, years of education, major occupation, income, household size, and years of education and major occupation for the caregiver's spouse, if applicable. Education and occupation levels of the caregiver (and the caregiver's spouse, if any) were used to calculate the caregiver's family socioeconomic status, using the Hollingshead and Redlich Two Factor Index of Social Position. In addition, caregivers were asked whether

they provided assistance to other household members having significant physical health, mental health, or substance abuse problems.

The following data about the family member with mental illness were collected from the caregiver: age, gender, length of illness, recent hospitalizations, and place of residence. Caregivers were also asked about their family relationship to, and amount of contact with, their family member with mental illness.

Analysis Plan

Based upon previous caregiver research using the stress-coping-support model, twenty-one predictor variables, classified into *client characteristics* (illness severity and demographics), and *caregiver characteristics* (demographics, health status, life situation, other caregiving responsibilities, proximity and contact with client, and social support) were identified as potentially influencing the degree of caregiver burden. In order to examine the unique contribution and relative importance of these potential predictors of caregiver burden, a series of multiple regression analyses of the predictors of overall burden and our four burden sub-scales (family disruption, stigma, strain, and dependency) was conducted. Because the number of predictor variables was too large to enter in a regression analysis given our sample size, bivariate correlation analyses were conducted first. Variables which were statistically significant in the bivariate analyses were then used as predictor variables in the regression analyses. In order to compare the results of this study with previous research, bivariate findings as well as the results of our multiple regression analyses are presented. We begin with a discussion of the sample characteristics.

FINDINGS

Sample Characteristics

Clients ranged in age from 22 to 69, with a mean age of 40 years, and are almost equally divided by gender. Slightly more than half (53%) of the clients live with their family caregiver, while one quarter live in their own homes or apartments. The remainder of clients live with friends or relatives, or live in a more restrictive environment such as a group home.

Clients have experienced mental illness over an average period of almost fifteen years, with a range of from 1 to 41 years. More than four-fifths of all clients have been hospitalized for mental illness, with a mean of four hospitalizations for the sample. The most frequent pattern after hospitalization is for the client to return to the caregiver's home, with clients returning an average of about three times after hospitalization. The average length of the client's most recent hospitalization was about one month, with a range from 1 to 180 days.

Caregivers ranged in age from 24 to 87 years, with a mean age of about fifty-five years. More than one-third of caregivers (38%) were

elderly, age 60 years and older. Similar to other caregiver populations, more than three-quarters (77%) of caregivers were women, while slightly fewer than one-quarter (23%) were male. Caregivers were almost equally divided by race, with slightly more than half being white (53%) and slightly under half (47%) being black. Half of caregivers were married, while half were not. The mean social class score on the Hollingshead and Redlich Two Factor Index of Social Position was 50.11, which falls into Social Class IV, the second lowest social class. More than half (55%) of the caregivers were parents of the family member with mental illness, while the remaining caregivers were either a sibling (20%), spouse (11%), child (8%), or other relative (6%). More than one quarter (28%) of caregivers had caregiving responsibilities for other family members in addition to their family member with mental illness. Caregivers were asked how frequently they had contact with their family member with mental illness during the past month and the past year. Findings indicated high levels of contact, with more than three quarters (79%) of caregivers reporting daily contact with their family member in the last month, while almost the same percentage (75%) reported daily contact over the past year.

Almost two thirds (63%) of caregivers reported their health as good to excellent, while the remaining one third (37%) of caregivers reported their health as fair or poor. Caregivers reported their overall social support to be fairly high, with a mean of 32 on the social support scale which ranged from 0 to 48, low to high support. However, half (50%) of caregivers indicated that they did not receive sufficient support from their family members in caring for their relative with mental illness, while more than two fifths (41%) indicated that they did not receive enough support from agency professionals. Caregivers scores on the overall burden and four sub-burden scales ranged from low to moderate levels, with high scores indicating higher levels of burden. The mean score on these scales were as follows: overall burden scale—28.61 (range = 0 to 108), perceived disruption sub-scale—9.28 (range = 0 to 44), stigma sub-scale—4.32 (range = 0 to 24), perceived strain—6.30 (range = 0 to 20), and perceived dependency—7.81 (range = 0 to 16).

Predictors of Caregiver Burden

Bi-variate Analyses —Four predictor variables were significantly related to the degree of overall burden. The strongest single predictor of overall burden was the frequency of client behavioral problems ($r = .58$, $p \leq .001$). The greater the frequency of client behavioral problems, the

higher the level of overall burden. No other illness variables were significantly related to the level of overall burden.

In addition, each of the three caregiver social network variables was related to the degree of overall burden. Thus, caregivers who had lower overall perceived social support ($r = -.28, p \leq .01$), or who felt that they were not getting enough support from family members ($r = -.23, p \leq .05$) or agency professionals in caring for their relative with mental illness ($r = -.26, p \leq .01$), reported higher levels of overall burden.

There were no statistically significant relationships between demographic and socioeconomic characteristics of either clients or caregivers and the level of overall burden. In addition, neither client proximity and degree of contact with the caregiver, nor the respondents' other caregiving responsibilities or self-reported health, were related to levels of overall burden.

After examining the bivariate predictors of overall burden, we repeated the same sets of analyses for the predictors of each of the four burden sub-scales—family disruption, stigma, strain, and dependency. The value of examining specific types of burden was reinforced by the fact that, except for the frequency of client behavioral problems, no other statistically significant predictor of overall burden was significantly related to all four types of burden. In addition, five variables which were not predictors of overall burden did correlate with specific types of burden.

As was the case with overall burden, the strongest single predictor of each type of caregiver burden was the frequency of client behavioral problems. Additional findings showed that caregivers who were white ($r = -.27, p \leq .01$), in poorer health ($r = .20, p \leq .05$), had clients who returned more times to the caregivers' home after hospitalization ($r = .23, p \leq .05$), had lower overall levels of social support ($r = -.29, p \leq .01$), and reported not getting enough help from agency professionals ($r = -.28, p \leq .01$) had higher levels of family disruption. Not receiving enough support from family members ($r = .21, p \leq .05$) was associated with higher levels of stigma. Strain was predicted solely by the frequency of client behavioral problems ($r = .50, p \leq .001$). Younger caregivers ($r = -.34, p \leq .001$), caregivers who weren't parents ($r = -.21, p \leq .05$), caregivers whose ill family member did not live with them ($r = -.24, p \leq .05$), and caregivers not receiving enough support from family members ($r = -.22, p \leq .05$) had higher levels of client dependency.

Multiple Regression Analyses – A series of separate multiple regression analyses for overall burden and the four burden sub-scales were

conducted, utilizing predictor variables that were statistically significant in the respective bivariate analyses. Because different variables were used in each regression equation, we will not attempt to compare explained variance across regression models. As a first step, caregiver race was included in each of the five multiple regression equations to test for possible interaction effects. There was not a direct effect of race nor were there any statistically significant interaction effects of race with other predictors of overall caregiver burden or caregiver family disruption, stigma, strain, or dependency. Therefore, race was dropped from the analyses in the equations presented here.

The number of cases in each regression equation varied from 76 to 99 because of missing data on particular variables. For overall burden, predictor variables included the frequency of client behavioral problems, overall social support, family support and agency support. As shown in Table 1, the regression equation explained 41% of the total variance in overall burden. Of the four predictor variables, only the frequency of client behavioral problems and family support were significant after controlling for the effect of the other predictor variables. However, agency support was almost statistically significant. Thus, caregivers who reported more client behavioral problems and not enough help from their family members in caring for their relative with mental illness had higher levels of overall burden.

TABLE 1
Regression Coefficients of Predictors
of Caregiver Burden (N = 89)

<i>Variables</i>	<i>B</i>	<i>Beta</i>	<i>T Value</i>	<i>p Value</i>
1. Frequency of Client Behaviors	.37	.57	6.34	.0000
2. Sufficiency of Family Support	-3.38	-.19	-2.18	.0319
3. Sufficiency of Agency Support	-2.79	-.16	-1.89	.0626
4. Sufficiency of Overall Support (ISEL)	-.09	-.04	-.47	.6417

Simple R = .66; Adjusted R-Sq. = .41; F(4, 84) = 16.33; P = .0000

Note: B = Unstandardized Regression Coefficient

Beta = Standardized Regression Coefficient

TABLE 2

**Regression Coefficients of Predictors
of Caregiver Burden Subscales**

<i>Variables</i>	<i>B</i>	<i>Beta</i>	<i>T Value</i>	<i>p Value</i>
<i>Family Disruption (N = 76)</i>				
1. Frequency of Client Behaviors	.13	.44	4.65	.0000
2. Sufficiency of Agency Support	-1.73	-.23	-2.61	.0112
3. Number of Times Returned Home after Hospitalization	.51	.22	2.50	.0148
4. Caregiver Health	1.34	.20	2.16	.0344
5. Sufficiency of Overall Support (ISEL)	-.09	-.11	-1.10	.2762
Simple R = .68; Adjusted R-Sq. = .43; F(5, 70) = 12.21; P = .0000				
<i>Stigma (N = 96)</i>				
1. Frequency of Client Behaviors	.08	.41	4.48	.0000
2. Sufficiency of Family Support	-1.18	-.22	-2.35	.0210
Simple R = .46; Adjusted R-Sq. = .20; F(2, 93) = 12.51; P = .0000				
<i>Strain (N = 99)</i>				
1. Frequency of Client Behaviors	.08	.50	5.70	.0000
Simple R = .50; Adjusted R-Sq. = .24; F(1, 97) = 32.46; P = .0000				
<i>Dependency (N = 95)</i>				
1. Frequency of Client Behaviors	.07	.45	5.20	.0000
2. Client Living Status	-2.20	-.28	-3.30	.0014
3. Sufficiency of Family Support	-.92	-.21	-2.53	.0132
4. Caregiver Age	-.06	-.20	-1.93	.0565
5. Family Relationship to Client	-.25	-.03	-.31	.7611
Simple R = .62; Adjusted R-Sq. = .35; F (5, 89) = 10.96; P = .0000				

Note: B = Unstandardized Regression Coefficient
Beta = Standardized Regression Coefficient

Table 2 reports findings of the separate multiple regression analyses of family disruption, stigma, strain and dependency. The regression models ranged in variance explained from 20% to 43%. After controlling for the effects of other predictor variables that were entered into the four separate regression equations, the frequency of client behavioral problems was the strongest single predictor variable for each of the four burden subscales. As shown in Table 2, there were a number of specific variables that were significant for individual subscales, but with the exception of the lack of family support, which was a statistically significant predictor of stigma and dependency, all of the other significant variables predicted only one specific type of burden.

Turning to an examination of findings from each of the regression analyses, family disruption was predicted by greater frequency of client behavioral problems, lack of agency support, having the ill family member return to the caregiver's home with greater frequency, and poorer caregiver health. Stigma was explained by greater frequency of client behavioral problems and lack of family support. Caregiver strain was explained solely by the greater frequency of client behavioral problems, the only variable entered into the regression equation. Finally, dependency was explained by greater frequency of client behavioral problems, the client not living with the caregiver, and lack of family support.

DISCUSSION

As indicated earlier, previous research findings concerning the correlates of caregiver burden are based on bivariate analyses. Therefore, in order to compare the findings of this study with previous literature, we will first discuss the results of our correlational analyses for overall burden, and then discuss the findings of the multiple regression analyses. Our comparisons with previous research is complicated by the fact that caregiver characteristics in the cited studies are often incompletely reported. In general, however, the studies cited below are similar to the present study in utilizing samples mainly derived from patient populations, by the fact that the samples of most of the studies are predominately lower and lower middle social class caregivers, and the fact that in most studies the highest percentage of caregivers are parents. Studies by Doll and colleagues (Doll, 1975; Doll, 1976; Thompson & Doll, 1982), Herz, Endicott and Spitzer (1976) and Pasa-minck (1967) were most similar to the racial distributions of caregivers

in the present study. However, it should be noted that studies cited by Biegel & Yamatani (1986), Cook and colleagues (Cook, 1988; Cook & Pickett, 1988) and Crotty & Kulys (1986) utilized predominately middle class caregivers. As will be seen below, similarities and differences between results of the present study and previous research do not appear to be based upon differences in sample characteristics between previous studies and the present research.

The finding in this study that the level of client behavioral symptoms is related to caregiver burden is consistent with previous studies, which found that degree of client impairment and the nature and type of client symptoms were related to levels of caregiver burden (Lefley, 1987). For example, Doll (1976) found that caregivers whose family members had more serious symptoms reported higher levels of burden. Two thirds of caregivers of clients with serious symptoms in Doll's study reported feeling trapped, as compared with less than half of caregivers of less severely disturbed clients; and two thirds of relatives with serious symptoms felt shame, as compared with one third of relatives of less disturbed clients. Similarly, in another report using the above data set, Thompson and Doll (1982) report that caregiver embarrassment was related to the number of behavioral symptoms of the client.

Focusing on objective burden, the disruption the client has on everyday life, Thompson and Doll (1982) found that over half of families of impaired clients reported severe burden, as compared with less than one in ten families whose clients were asymptomatic. Thus, severity of client distress affects both subjective and objective components of caregiver burden, with caregivers finding client behavior to be both emotionally upsetting as well as interfering with family activities and family life. Although client symptoms were associated with levels of caregiver burden, Thompson and Doll (1982) report that caregiver burden did not disappear even when clients had few symptoms. Thus, in families whose clients did not have symptoms, two thirds of the caregivers felt overloaded, a third felt trapped, and one in five reported feelings of exhaustion (Thompson and Doll, 1982). This demonstrates that the level of client symptoms by itself is not a sufficient explanation of caregiver burden. This finding is reinforced by the results of our multiple regression analyses, which showed that, after controlling for client symptoms, a number of other variables are also significant predictors of caregiver burden.

The current study found little relationship between burden and other measures of the severity of illness, such as length of illness, number of hospitalizations, number of days of most recent hospitalization, and

number of times returned home after hospitalization. Previous research findings are inconsistent concerning the role of these illness characteristics and caregiver burden. For example, while Thompson and Doll (1982) and Brown and colleagues (1966) indicate that caregivers report higher burden with a greater number of hospitalizations, Crotty and Kulys (1986) report no relationship between the number of hospitalizations or recency of last hospitalization and caregiver burden. There are also inconsistent findings in the literature concerning the relationship between the length of hospitalization and caregiver burden (Hoenig & Hamilton, 1966; Herz, Endicott, and Spitzer, 1976). It should be noted, however, that inconsistencies in the measurement of length of hospitalization makes it difficult to compare these two studies. Several studies did find a relationship between length of illness and caregiver burden, such that the longer the illness, the higher the level of caregiver burden (Hoenig & Hamilton, 1966; Brown et al., 1966; Grad & Sainsbury, 1963).

The finding in this study of no relationship between client gender or age and caregiver burden was generally consistent with previous research (Doll, 1975; 1976; Thompson and Doll, 1982; Crotty & Kulys, 1986; Hoenig & Hamilton, 1966). However, Grad and Sainsbury (1963) did find that caregivers of elderly clients were more burdened than caregivers of younger clients, and Cook and Pickett (1988) found that caregivers of older clients and female clients had higher levels of burden.

Turning to findings concerning caregiver characteristics and caregiver burden, the present study did not find any relationships between caregiver demographic and socioeconomic characteristics and caregiver burden. In general, previous research findings with caregivers of persons with mental illness are inconsistent concerning these relationships. Caregiver gender and age have been found to be more consistent predictors of caregiver burden with other chronic illnesses (Biegel, Sales, & Schulz, 1991; Cook, 1988; Crotty & Kulys, 1986; Grad & Sainsbury, 1963; Hoenig & Hamilton, 1966; Thompson & Doll, 1982).

The lack of an association in this study between the caregiver's family relationship to the client (parent vs. non-parent), and caregiver burden is consistent with the work of Thompson and Doll (1982) and Gubman, Tessler and Willis (1987). However, other researchers have found significant differences in caregiver burden according to the caregiver's family relationship to the client. For example, Hoenig and Hamilton (1966) report finding a correlation between caregiver burden and the relationship of the caregiver to the client. More objective burden was

reported in the conjugal than in the parental home, with the parental home reporting less objective but more subjective burden. The authors interpreted this finding to mean that parents are less able to tolerate family members with mental illness than are other types of caregivers. Our objective burden finding was also inconsistent with the earlier work of Grad and Sainsbury (1963), who reported higher overall burden levels among spouse caregivers.

There was no relationship in this study between caregiver health and burden. No previous studies examined the relationship between caregiver health and burden, though several studies did report on associations between caregiver health and other variables. For example, Grad and Sainsbury (1963) find that one fifth of the caregivers attributed their neurotic symptoms, such as insomnia, headaches, excessive irritability, and depression, to concern about the client's behavior. Brown et al (1966) report an indirect relationship between caregiver health and burden. They indicate that almost half of caregivers of clients with multiple admissions report that their health (the caregiver's) was negatively affected, as compared with one quarter of caregivers of clients with one admission.

There has been little prior research concerning the frequency of caregiver-client interaction and the level of caregiver burden. While this study found no significant relationships with any of the variables measured in this area, Grad and Sainsbury (1963) found that client living status was related to caregiver burden. Clients who lived alone but who remained in contact with the family had a severe effect on the family. However, clients who lived in lodgings, boarding houses, or hotels were not a problem, either to those with whom they lived or to their own families. Anderson and Lynch (1984) found that greater levels of interaction between family members and clients were associated with higher stress experienced by family members.

This study found that caregivers who felt that they were not getting enough support from family members or agency professionals had higher levels of caregiver burden. No direct comparison of this finding with the research literature is possible because the role of caregiver social support and caregiver burden has been examined in very few studies, and such examinations have not tested the statistical relationship between these two variables. However, previous research does indicate that caregivers are isolated, lack intimate relationships, and suffer from the tendency of relatives and friends to avoid visiting their household. These findings reinforce the findings from our current study (Biegel & Yamatani, 1986; Leff, 1983).

Turning to an examination of the regression analysis findings, several points should be noted. First, the study shows the major role played by the severity of illness (client behavioral symptoms) in affecting the amount of overall caregiver burden and each of the specific types of burden—family disruption, stigma, strain and dependency. Not only was the frequency of client behaviors the only one of twenty independent variables to significantly predict overall caregiver burden and the specific types of burden, but it also had the strongest effect (as seen by the Beta weights) in each of the regression equations. It should be pointed out that the frequencies of client behavioral problems was the only one of five variables measuring illness severity that had a significant effect in either the bi-variate and multivariate analyses.

Although there were some correlations between illness severity variables, namely, as would be expected, the number of hospitalizations was associated with both the length of illness and the number of times that clients returned to the caregivers' home after hospitalization, neither length of illness nor any of the hospitalization variables was associated with the frequency of client behavioral problems. This lack of association may be due to several factors. Specific client behaviors that caregivers report occur most frequently, such as the family member being overreliant on them, may not be necessarily related to the need for hospitalization. Second, this lack of association may be consistent with the cyclical nature of mental illness in which patient symptoms often go up and down over the life course of the illness. Since caregivers were asked to assess the client's behavior in the last month, we would not necessarily expect an association between such behaviors and other illness characteristics unless the client's behavior has been very consistent over time.

Second, findings from this research indicate that the severity of client illness, though the strongest predictor of caregiver burden, is not sufficient by itself to explain caregiver distress. Although there are differences in predictors across types of burden, social support is a significant predictor of overall burden and three of the four burden sub-scales. Our findings indicate that it is not the caregiver's system of overall support that affects the level of caregiver burden, but whether caregivers feel that they are receiving a sufficient amount of help from family members and/or agency professionals in caring for their relative with mental illness. This finding can be understood by considering the strong stigma of mental illness that is still very prevalent in our society. Because of such stigma, families with mentally ill relatives often report that their family members avoid discussing and/or interacting with

their relative with mental illness and that the caregivers' friends often try to avoid this subject as well. This finding is reinforced by earlier work of Biegel and Yamatani (1987) who found that middle class caregivers who were support group members reported strong overall systems of social support, but often felt they had no one to talk to, concerning the specific problems and needs they experienced as caregivers of persons with mental illness.

IMPLICATIONS FOR PRACTICE AND RESEARCH

Findings from this study have important implications for both practice and future research. Implications for practice are based upon study findings pertaining to the role of client behaviors and caregiver social support in predicting caregiver burden. The major role played by severity of the illness (client behavioral symptoms) in affecting the amount of overall and specific types of caregiver burden suggests that the most effective interventions to address caregiver burden will be those which impact directly on the behavior of the client and the interactions between the client and the caregiver.

Family caregivers of persons with mental illness have repeatedly told researchers over the past several decades that the managing of problematic client behaviors was a major concern. Family intervention methods for treating schizophrenia, often called psychoeducational approaches, which help families learn how to alter their behavioral interactions with their family member with mental illness, have shown considerable success in reducing relapse rates (Hogarty, Goldberg, & Schooler, 1974; Hogarty, Schooler, & Ulrich, 1979; Schooler, Levine, Severe et al., 1980). In a recent community based test of the effectiveness of multiple family psychoeducational groups with a client population consisting of white and minority clients in the New York State mental health system, McFarlane found that the multiple family psychoeducational group format achieves an unprecedented relapse rate of under 10% a year (McFarlane, 1990). Family psychoeducational interventions place a heavy emphasis on addressing client behavioral problems. Given the strong association found in the current study between client behavioral problems and caregiver burden, it can be hypothesized that psychoeducational interventions can reduce the level of caregiver burden.

Support groups for families of persons with mental illness may also be helpful in assisting caregivers to address problematic client behaviors

through teaching families techniques of behavior management, through providing opportunities for behavioral rehearsals and role modeling, and through the provision of peer support. However, it should be noted that the membership of support groups for families of persons with mental illness, like that of support groups in general, is predominately middle class and white. For example, only 10% of the low income caregivers in the current study were support group members. Thus, barriers to participation in support groups by lower social class whites and blacks need to be acknowledged, and strategies developed to address these barriers (Bestman, 1986; Davis, 1982). Further work is also needed to examine the effects of both psychoeducational interventions and family support groups in affecting the relationship between client behavioral problems and caregiver burden.

Findings from this research demonstrating the importance of social support in predicting caregiver burden have implications for whom mental health agencies identify as the "client." Mental health agencies, which have widened their conceptualization of the client over the past decade from the person with mental illness to also include the family caregiver, may need to widen the focus yet further to include the caregiver's support system. Mental health agencies need to address family caregivers' concerns that their families are not giving them the support they need. Meetings with the caregiver and their family members could be held to address this issue and to discuss ways in which other family members could provide more support to the caregiver in caring for the relative with mental illness. Such an approach needs to address the lack of information and fears that family members often have about mental illness. In fact, the needs of families of persons with mental illness for adequate information from mental health professionals—about the nature of mental illness, the management of client behavioral problems, medication, and the availability of resources for clients and caregivers—has been a consistent theme in the caregiving literature over the past two decades.

Mental health agencies also need to address the finding that the lack of perceived support from agency professionals is associated with higher levels of family disruption. Caregivers need assistance in finding more time for leisure and non-caregiving activities. Respite care is a widely utilized intervention modality in caregiving with Alzheimer's disease and other chronic illnesses. It allows the caregiver some time off while the ill family member is cared for by others. Respite care might be a useful service to offer to those caregivers who live with a family member with mental illness (such caregivers constitute one half of our

sample), yet there are few respite programs offered by the mental health system.

Turning to implications for further research, this study builds and expands upon previous research through the use of a theoretical framework developed with other caregiving populations, the use of techniques which control for the effect of third variables, and through the use of a lower class sample of caregivers that was not generated through support group membership. Nonetheless, findings from the present study, as well as past research, indicate that there are many gaps in our understanding of the factors affecting the burden of families caring for relatives with mental illness. This study, though addressing some of the limitations of past research, is hampered by its sample size relative to the large number of predictor variables, and by its cross-sectional design. Future studies with caregivers of persons with mental illness should build upon the large number of caregiver studies with other chronic illnesses, such as Alzheimer's disease, cancer, heart disease and stroke, in addition to building on previous research studies with caregivers of persons with mental illness. In fact, a major limitation of current caregiving research is the tendency of researchers to focus only on caregiving studies of particular illnesses, diseases, or population groups.

Theoretically based, longitudinal studies of family caregivers of persons with mental illness that utilize larger, more representative samples of caregivers are needed in order to examine the effects of caregiving on the caregiver over time. The relationship between illness stressors and caregiver burden needs to be further examined in order to obtain a fuller understanding of the interplay of this relationship over time. Such studies need to take into account both the stage of illness and the type of illness, as both of these variables can affect caregiver outcomes (Biegel, Sales and Schulz, 1991; Gubman and Tessler, 1987). Family caregivers of persons with mental illness are affected by both the episodic as well as enduring nature of the client's illness. While levels of caregiving burden change over time, Pasaminick's research demonstrates that such burden can continue over many years (Davis, Dinitz, & Pasaminick, 1974; Pasaminick, 1967). Future studies also need to take into account the multi-dimensional nature of caregiver burden. In order to fully understand the concept of burden and the variables associated with higher levels of burden, it is necessary to separately examine the components as well as the overall dimensions of caregiver burden. Further research is needed to continue to refine this concept.

Additionally, future studies with caregivers of persons with mental illness should examine long term outcomes of caregiving, such as its effects on the caregivers' physical and mental health status. While the effects on the depression levels of caregivers have been examined with a number of chronic illnesses, there have been few studies of the effects of burden on the depression levels of family caregivers of persons with mental illness (Cook, 1988). Finally, given the findings of the present study that caregivers do not feel they are getting enough support from family members or mental health professionals, future studies should also attempt to collect data from members of the caregivers' family and from mental health professionals, in order to obtain a more complete understanding of the nature of interactions between family caregivers and their support systems.

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