

The Context of Caretaking in Rural Areas: Family Factors Influencing the Level of Functioning of Seriously Mentally Ill Patients Living at Home

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After the deinstitutionalization of psychiatric hospitals, many families became primary caregivers for seriously mentally ill individuals. Mental health services became further reduced with the advent of managed care and reductions in health and mental health care. The dearth of community-care options often results in psychiatric patients being quickly stabilized in hospital units and discharged to live with their families. The lack of community resources is particularly acute in rural areas. Given these realities the current study sought to determine if family caretaking variables are related to patient outcomes. Family factors including the perception of burden, expressed emotion (EE), and primary caregivers' social support were tested in a model of caretaking that examines the relationship between these factors and patients' symptom expression and social and occupational functioning. The sample includes 49 predominantly African American families living in a rural area and with a chronically ill family member who had been previously diagnosed with a psychotic disorder. Primary caregivers and patients were interviewed using adapted measures of burden, EE, and social support. Patients were administered a revised version of the Brief Psychiatric Rating Scale. Results suggest less perceived burden, increased caregiver support and, to a lesser extent, EE explain approximately one-fifth of the variance in patient functioning. These results support previous research demonstrating the importance of family factors for seriously mentally ill patient outcomes. Results are discussed in terms of implications for assisting families in the current era of diminished resources.

KEY WORDS: caretaking; families; mental illness; familial factors.

Over the past few decades, families have become increasingly involved in the care of the seriously mentally ill. Before the locus of treatment shifted from long-term hospitalizations in large institutions to community outpatient care, families generally had limited contact with patients in terms of daily caretaking. The deinstitutionalization of state and county psychiatric hospitals created a decreased reliance on institutions. Families, whether

by choice or necessity, have become more involved in caring for the mentally ill (Bachrach, 1977, 1983; Fisher, Benson, & Tessler, 1990; Hatfield, 1982, 1984; Hatfield & Lefley, 1987; Wodarski, 1983).

There is some evidence that family caretaking of the seriously and chronically mentally ill has increased with the advent of managed care reforms. Currently, institutionalized patients are stabilized during a relatively short hospital stay, averaging approximately 11 days (Saylor, 1997). After a brief hospitalization, a majority of patients are discharged to live with their families (Goldman, 1982; Hatfield & Lefley, 1987; Saylor, 1997). These changes have presented a unique set of challenges in rural settings (Bachrach, 1983; Murray & Keller,

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1991) where fewer mental health services are available for chronic patients discharged from psychiatric institutions. Even prior to the era of managed care, rural public mental health agencies have often been the only option for mental health services and these agencies have limited personnel (Murray & Keller, 1991). Faced with fewer resources than urbanites, those in rural areas use limited outpatient community mental health services for seriously mentally ill family members and rely upon the family to manage all other aspects of care.

Despite the high frequency of family involvement in the care of the seriously mentally ill, outcomes associated with the process of caretaking remain unstudied, particularly in subpopulations such as rural samples and ethnic minority families. It is unclear, for example, why some patients function better at home than others. What family factors are associated with positive patient functioning? Familial networks are functioning as de facto community placements for many seriously mentally ill individuals without access to other options given the failed promise of deinstitutionalization as a precursor to community networks of care. However, the structure of familial support varies across families and families vary in their approach to caregiving.

The context of family caretaking is particularly important to understand for chronic and debilitating mental illnesses like schizophrenia that are characterized by high rates of relapse and hospital recidivism (Anthony & Farkas, 1982; Appleby, Desai, Luchins, Gibbons, 1993; Gottesman, 1991; Walker, 1991). Although families cope with many initial challenges when faced with the onset of illness (Kates & Hastie, 1987; Torrey, 1988), it is just as crucial to investigate factors associated with long-term caregiving that is related to patient outcomes. Because the evidence for the role of family relationships in the onset of major mental disorders is scant at best, more attention should be focused on the importance of psychosocial factors in psychiatric relapse (Hooley & Hiller, 1997). Understanding the impact of care provided by family members should not be viewed as an attempt to assign blame to families coping with serious mental illness. Rather, an analysis of family variables could provide objective information that is helpful in determining how families can provide care that is related to decreased symptomatology and increased functioning, particularly among groups with limited access to comprehensive outpatient care.

Family networks may consist of biologically related nuclear or extended family members, fictive kin, formally or informally adopted kin, or relationships through conjugality or cohabitation (McAdoo, 1985). Through interacting and living with seriously mentally ill family members, monitoring illness and supervising treatment, families function as primary caregivers. It is within this caregiving role that several constructs may be associated with patients' level of functioning. Family caregivers must negotiate experiences related to providing care, including emotional interactions with patients, reliance on social support, and managing the emotional and resource-related burden associated with caring for the seriously mentally ill.

The current study examines the subjective experience of caring for mentally ill family members in a predominantly African American, rural sample. The sample represents a population of families with extremely limited access to resources for mentally ill individuals. The families included in the study represent an underrepresented population in the literature and they provide the opportunity to understand the process of caregiving in a distinct subgroup. We approach the study with the perspective that families who are providing care for psychiatrically disordered family members are negotiating and solving problems associated with this task. We construct a model of caretaking that incorporates caregiving as related to expressed emotion, family burden, and social support and examines the relationship of these factors to patient functioning.

Expressed Emotion

The importance of affect or "expressed expression" (EE) in families of mentally ill patients was initially identified by an investigation of emotional characteristics in patients' relatives (Brown, Birley, & Wing, 1972). Using interviews with relatives, households were determined to be either high or low in EE, which is defined as criticism, hostility, or emotional overinvolvement. Significant differences in outcome were found between patients released from the hospital to live with their families. Behavioral deterioration was seen in 76% of patients released to high EE homes, whereas only 28% of those returning to low EE homes similarly deteriorated. The difference persisted when psychiatric rehospitalization was used as the outcome measure (Brown, Monck, Carstairs, & Wing, 1962). A number of early studies supported this finding that patients relapsed more often when

they have relatives who exhibit high levels of EE (Karno et al., 1987; Leff & Vaughn, 1980; Vaughn & Leff, 1976, 1981; Vaughn, Snyder, Jones, Freeman, & Falloon, 1984).

Other studies have reported mixed results in terms of the predictive validity of EE for relapse and the generalizability of EE across cultures and settings. Kanter, Lamb, and Loeper's (1987) review of research on expressed emotion does not support a simplistic causal relationship between EE and relapse. Despite the widespread use of a model of EE and symptom expression as unidirectional and predictive, there is increasing evidence for the importance of other influences including reactions of family members. In addition, several studies have failed to replicate the relationship between EE and relapse (Fisher et al., 1990; Hogerty, 1985; Hogerty et al., 1986). Also, initial investigations of EE have almost exclusively used middle income, urban White subjects (Arieti, 1977). Others have discovered differences in predictive power and in rates of EE among families in nonindustrialized countries (Hatfield & Lefley, 1987), among Mexican American families in the United States (Karno et al., 1987), and in urban, predominantly African American settings (Moline, Singh, Morris, & Meltzer, 1985).

In this study, we support the initial emphasis of early EE studies that sought to determine how patient and family variables interact with each other however; we include familial perceptions and patient symptoms along with expressed expression in a multifactorial model of caregiving that can differentiate relative contributions to the course of illness (Kavanagh, 1992). Expressed emotion is conceptualized as a continuous measure of familial affective expression that is related to, but not causally predictive of patient functioning. We investigate expressed emotion in a sample of rural, predominantly African American families about whom little is known with regard to this construct.

Family Burden

Familial perceptions of burden have been investigated as important factors related to outcomes in families of the seriously mentally ill. Several studies found burden associated with the patient's level of functioning (Creer, Stuart, & Wykes, 1982; Jacob, Frank, Kupfer, & Carpenter, 1987; Lefley, 1987; Noh & Avison, 1988; Noh & Turner, 1987; Potaznik & Nelson, 1984). The majority of research on fam-

ily burden has found caretaking to be associated with a significant amount of perceived and objective burden for family members (Bernheim, 1989; Giel et al., 1983; Lefley, 1989; Pai & Kapur, 1982), however, Crotty and Kulys (1986) study of family burden and stigma reported that the overall level of burden experienced by families with schizophrenic patients was perceived as mild to moderate. Approximately one-fifth of the families did not perceive the patient as burdensome at all. Recently, family functioning and assessment of burden have been described as important measures of families' ability to adapt to caregiving for chronic mental illness over time (Heru, 2000).

However, many studies of family burden are limited by sampling issues and ethnic generalizability. In terms of sampling, previous research has tended to focus on middle- to upper-class families who may be more familiar with traditional etiologic theories that viewed the family as the primary source of pathology. Caretakers who have been told that they caused the disorder have experienced shame and an increased sense of guilt (Hatfield & Lefley, 1987). Several studies utilized samples of families with patients who had been recently hospitalized or relatives who belonged to a self-help group for families of schizophrenic patients. These families may have experienced a significant degree of burden due to the recency of the crisis that necessitated hospitalization or may have experienced selectively greater difficulty than others and therefore sought increased support from groups. Support group members tend to be White, married, well educated, and financially better off in comparison to the majority of relatives of the mentally ill (Maurin & Boyd, 1990). Finally, there is some evidence that caretaking burden differs across ethnic groups (see Calderón & Tennstedt, 1998). Several studies investigating African American and White family caregivers of elderly patients find African Americans reporting less role strain (Mui, 1992), higher resourcefulness (Gonzalez, 1997), less stress and more self-efficacy in managing caregiving problems (Connell & Gibson, 1997; Haley et al., 1996) in comparison to White caregivers. Further, African Americans report less burden in caring for demented elderly family members (Hines-Martin, 1992), veterans (Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999), and relatives with Alzheimer's disease (Cox & Monk, 1996) in comparison to other ethnic groups. Among caregivers for seriously mentally ill family

members, African Americans report less perceived burden than Whites (Guarnaccia, 1998; Horowitz & Reinhard, 1995; Stueve, Vine, & Struening, 1997) and more satisfaction with professional contacts (Biegel, Song, & Milligan, 1995). Explanations for less perceived burden among African American caregivers include strongly held beliefs about filial support and the use of prayer, faith, or religion as coping mechanisms (Connell & Gibson, 1997; Nkongho & Archbold, 1995). Social support may be another important source of coping.

In this study, family burden is included in the model of caretaking as an independent variable related to patient functioning. Investigating both measures of burden and expressed emotion as variables related to patient functioning represents a departure from the two separate lines of inquiry that conceptualized patient functioning as either caused by EE or predictive of levels of burden. The sample is made up of chronic, relatively stabilized patients living at home; therefore, families are not faced with the initial stressors associated with the onset of illness. The sample is not recruited from self-help groups and therefore not self-selected for people seeking support due to distress related to the experience of having a psychotically ill family member.

Social Support

Existing literature points to social support networks as having an important influence on perceptions of family burden and emotional expression. Support networks appear related to decreased levels of negative affect in families of schizophrenic patients from cultural and international subpopulations (El-Islam, 1979, 1982; Karno et al., 1987; Leff, Berkowitz, Shavit, & Strachan, 1989; Leff, Wig, Bedi, & Menon, 1990; Wig et al., 1987). The presence of a support network appears to be a significant mediator of burden in families coping with mental illness (Crotty & Kulys, 1986; Noh & Turner, 1987; Potaznik & Nelson, 1984; Spaniol, Jung, Zippel, & Fitzgerald, 1987; Stein & Test, 1980). Also, social support has been hypothesized as a significant factor in African American family functioning (Curry-El, Kohn, & Wilson, 1992; Kohn & Wilson, 1995; Wilson et al., 1996).

In this study we attempt to investigate the relationship between rural families' support networks and schizophrenic patient functioning. We include social support as a variable directly related to patient functioning and as a potential moderator of

both expressed emotion and family burden. Social support is conceptualized as the amount of objective and subjective support perceived by caretakers in the sample.

Summary of Study

This study investigates the relationship between family factors including expressed emotion, perceived burden, and social support and patients' level of functioning. The hypotheses are as follows: (1) higher levels of expressed emotion, higher levels of burden will be associated with lower levels of patient functioning and smaller caretaker support networks will be associated with lower levels of patient functioning, and (2) social support will moderate levels of expressed emotion and burden. The proposed model of caretaking includes three caretaker variables, family burden, expressed emotion, and social support, associated with the outcome, patient functioning.

METHOD

Participants

Participants were recruited from the Rural Mental Health Research Project, a study of rural families with a family member diagnosed with a psychotic disorder. Subjects resided in rural areas (defined as population of 2,500 or less). Subjects were recruited with the participation of county community mental health agencies ("Service Boards") in a southeastern state. Service boards provide public funded outpatient mental health services (including medication, therapy, case management, and emergency evaluations for inpatient hospitalization) for residents residing within a given catchment area. The participating community agencies for this study involved a total of eight counties in the rural southwestern and central areas of the state, including those with larger than average populations of African American residents.

In addition to rural residence, criteria for inclusion were based on patients with residence within a family household (including at least one biologically or conjugally related family member). The definition of family household was purposely broad to include the multiple forms of family composition that characterize African American family life (McAdoo, 1985); therefore, the identified primary family caretakers could include many different familial relationships

other than nuclear family members. Also, patients were required to have, at minimum, a 3-year history of chronic psychotic illness (including schizophrenia, schizoaffective disorder, bipolar depression with psychotic features, and/or delusional disorder with positive symptoms). Patients' history of chronic psychotic illness was verified through abstraction of agency records obtained by research staff and a separate evaluation using the Operational Criteria Checklist for Psychotic Illness (OPCRIT). OPCRIT is a computerized operational criteria diagnostic system based on DSM-III-R criteria (McGuffin, Farmer, & Harvey, 1991) that has been used in general schizophrenia studies (see Wickham et al., 2001). Subjects included both patients and the family member with whom they lived and was identified as the primary caretaker by both the patient and the community mental health agency.

The sample included 49 families. Demographic characteristics of the sample are presented in Table I. The sample was predominantly African American ($n = 34$) and the majority of families reported low socioeconomic status. The average number of years of education among both caretakers and patients was approximately 8 years. Median self-reported family income ranged from \$9,000 to \$12,000 annually and over half the sample (58.3%) reported receiving more than one form of public assistance. In this sample, primary caretakers tended to be female and patients tended to be male. The majority of the primary caretakers were unemployed (87%) and receiving federal disability payments. Over half (59%) of the caretakers were married or living as married (e.g. long-term cohabitation or "common-law" relationships). In contrast, the majority of patients were single. The caretakers were mostly parents or siblings, although over 10% were not immediate family members of the patient but included grandparents, aunts, and cousins. The mean age of caretakers was 58 years and patients' mean age was approximately 45 years.

Other than a relatively late age of illness onset, the illness characteristics of patients in the sample were similar to chronic psychotically ill patients seen in community mental health agencies. The mean age of illness onset among patients was 27 years ($SD = 10.1$), the average length of illness was approximately 15 years ($SD = 9.6$), and the average number of lifetime hospitalizations was 3.5 ($SD = 3.3$). The average total number of months spent in the hospital varied widely across patients with a mean of 8.1 months ($SD = 17.4$). All of the patients were being maintained on at least one antipsychotic medication

Table I. Demographic Characteristics of Caretakers and Patients^a

Variable	Caretaker ($n = 49$)	Patient ($n = 49$)
Gender		
Male	$n = 15$	$n = 30$
Female	$n = 34$	$n = 19$
Ethnicity		
African American	$n = 34$	$n = 34$
White	$n = 15$	$n = 15$
Marital status		
Never married	$n = 5$	$n = 26$
Married/common-law	$n = 29$	$n = 13$
Separated	$n = 1$	$n = 6$
Divorced	$n = 2$	$n = 1$
Widowed	$n = 12$	$n = 1$
Employed		
Yes	$n = 20$	$n = 6$
No	$n = 29$	$n = 40$
Status of unemployment		
Student	$n = 0$	$n = 1$
Homemaker	$n = 2$	$n = 1$
Disabled	$n = 9$	$n = 34$
Retired	$n = 18$	$n = 4$
Age (years)		
Mean	58.0	44.8
Standard deviation	16.9	14.0
Range	19–89	17–76
Education (years)		
Mean	8.4	8.8
Standard deviation	2.6	2.8
Range	1–13	1–14
Reported annual family income		
Median	\$9,000–\$12,000	
Range	<\$3,000–\$36,000–\$39,000	
Duration of caretaking (years)		
Mean	10.4	
Standard deviation	7.2	
Range	1–28	

^aThe subtotals do not always add up to the total n per group due to missing data.

($n = 12$), with the majority taking a combination ($n = 37$; most commonly an antipsychotic such as Prolixin, Haldol, and Navane, and an anticholinergic such as Cogentin). The medications among patients in this sample were not atypical. There were no significant differences between African American and White patients on any of the illness-related characteristics.

Procedure

Participating agencies sent letters describing the project to all families with patients who fit the inclusion criteria. Families expressed an interest in participating in the study via returned written consent

for contact from the study investigators or agency case managers. Study personnel contacted interested participants to schedule interviews. Written consent obtained in person, prior to interviewing included permission to interview the primary caretaker, the patient, and collection of background information from patients' agency records.

Teams of two trained interviewers (clinical psychology graduate students) traveled to patient homes to interview the patient and their primary caretaker who was identified by the case manager and confirmed by the patient. Each interview consisted of a battery of measures, which were read by the interviewer to the patient and the caretaker to avoid problems associated with low levels of education or lack of understanding and to decrease the potentiality of missing data. Interviews of family members were conducted simultaneously and separately, as space would allow.

Measures

Expressed Emotion

LEE Scale. Caretakers' perceptions of affective expression were measured using the overall score on the Level of Expressed Emotion Scale (LEE-Caretaker Version; Cole & Kazarian, 1988). This scale is theoretically based upon correlates of expressed emotion and provides an assessment of affective expression. The LEE was chosen for this study due to the relative ease of administration based on language and length, reported psychometric properties, and because the constructs are conceptually congruent with the variables of interest for the present study, e.g. family caretaker emotional expressiveness. The 60-item true/false self-report instrument was developed to provide an index of the perceived emotional climate in a person's most influential relationship. The LEE measures expressed emotion across four response styles of significant others including intrusiveness, emotional responsiveness, attitude toward illness, and tolerance/expectations. Examples of questions include "I don't butt into his/her conversations" (intrusiveness), "I calm him/her down when he/she is upset" (emotional responsiveness), "I say he/she wants attention when he/she is not well" (attitude toward illness), "I understand his/her limitations" (tolerance/expectations). Reported tests of reliability revealed high levels of internal consistency for the overall scale

(KR-20 = .95) and adequate 6-week test-retest reliability ($r = .82, p < .01$; Cole & Kazarian, 1988). When compared to a reliable and predictive measure of expressed emotion (the Influential Relationships Questionnaire), the LEE overall scale score correlated well ($r = .86, p < .0001$; see Cole & Kazarian, 1988).

Family Burden. Family burden was assessed using an adapted version of the Feetham Family Functioning Scale (FFFS; Roberts & Feetham, 1982) a scale used to measure perceived satisfaction with aspects of familial functioning. Similar measures have been used in both cross-sectional and longitudinal studies of families caring for family members suffering from chronic physical and mental illness (Brown & Lambert, 1999; Friedmann et al., 1997; Kazak, Barakat, Meeske, & Christakis, 1997; Kronenberger & Thompson, 1990; Weitzner & Knutzen, 1998). Cronbach's alpha reliability estimates for the FFFS range from .66 to .84 across scales, and .81 for the overall scale, and 2-week follow-up yielded a test-retest estimate of .85 (Roberts & Feetham, 1982). Evidence for concurrent validity has been based on correlation with the Family Functioning Index (FFI; Satterwhite, Zweig, Iker, & Pless, 1976), however, the moderate correlation obtained between the two measures ($r = .54, p < .001$) was explained as expected due to differences in focus across the two measures (Roberts & Feetham, 1982). The FFI limits the assessment of burden to the nuclear family while the FFFS assesses broader social units including extended family systems. This measure is appropriate for the present study given the heterogeneous family composition encountered among rural, predominantly African American families in our sample. For the present study many of the questions on the FFFS were adapted to refer specifically to the care of a seriously mentally ill family member. Also, based on pilot testing the wording of several questions was changed slightly to render them more understandable for individuals with low education levels, for example, the question "time spent for leisure and recreation" was changed to "time spent to have relax and have fun."

Social Support. Social support was measured using an index developed and used in a previous study of African American family functioning whereby support is defined by the density of the network identified by caretakers (see Wilson, 1989; Wilson & Tolson, 1990; Tolson & Wilson, 1990; Tolson, Wilson, & Hinton, 1995). This index was selected for use in this study in order to determine the amount and

kind of resources available to the families without adding an additional and lengthy assessment of social support. The measure includes questions to determine size of networks and characteristics of network members. Caretakers are asked to identify the people upon whom they rely for assistance including material (transportation, housework), financial, and emotional aid. Although density per se does not indicate a supportive network (see Heller, Swindle, & Dusenbury, 1986; Lakey & Heller, 1988), the interview emphasized that caretakers only list members that they "know they can rely on" and asked respondents to list the specific activities each network member performs. Asking respondents to include only helpful and reliable network members should alleviate the problem of differences in network helpfulness and/or satisfaction.

Patient Functioning. Patients' level of functioning was determined by their symptom severity as measured by a modified version of the Brief Psychiatric Rating Scale (BPRS), a brief semistructured clinical interview designed to measure symptomatic, social, and occupational functioning of seriously mentally ill patients. The original scale was developed as an easily administered interview instrument to evaluate psychiatric symptomatology and assess change over time. The original BPRS has acceptable interrater reliability coefficients (scales ranging from .56 to .87; Overall & Gorham, 1962) and acceptable correlations with a variety of patient outcome measures (Zimmerman, Vestre, & Hunter, 1975). The BPRS has been widely used as a symptom rating scale with schizophrenic subjects (Linszen, Dingemans, Nugter, & Van der Does, 1997; Morrison, 1988). Since the original scale was published the BPRS has undergone several revisions. Although the original version contains 18 items, the version used for this study includes a 24-item rating scale of patient symptoms over the past week, supplemented with additional information on patient's level of normal activity and functioning. Item ratings are based on patients' verbal report of functioning and behavioral observations of trained interviewers during administration. Scores are based on clinical analysis of interview responses and clinically judged behavioral ratings. For the present study a total BPRS score was computed on the basis of the sum of scores across scales and represented patients' level of functioning. Because the version used for this study was a substantially modified instrument, Cronbach's alpha coefficients of internal consistency were calculated using the sample data; the BPRS

obtained reliabilities of .92 for patient-reported items, and .81 for interviewer-observed items.

Hospitalizations. Patient's hospital records located at the community mental health agency were reviewed by researchers with patients' consent and through cooperation with the agencies. Charts were reviewed during the course of data collection as subjects entered the study. Patient charts were abstracted for information concerning diagnosis, rate of hospitalization, and use of medication. To confirm patients' diagnoses, researchers reviewed records of symptomatology during acute episodes of illness including the most recent hospitalization. This review included an independent diagnostic confirmation using the OPCRIT system (described above). In addition, the rate of previous hospitalizations was based on the number of hospitalizations and the total number of months spent in the hospital was tabulated. Patients' medication records were reviewed for the type and dose of psychopharmacologic agent prescribed and the frequency and length of time of use. Other information such as age of onset and family history of psychiatric illness was collected.

Preliminary Data Description

Preliminary data analyses were conducted to determine the zero-order correlations among all study variables. Results are presented in Table II. As can be seen, none of the independent variables are highly correlated. The highest degree of correlation between any variables was for burden and outcome ($r = .24, p = .09$) and support and outcome ($r = .24, p = .09$).

RESULTS

The mean, standard deviation, and range of the study variables are shown in Table III. Univariate analyses were employed to determine the effect of demographic variables on caretaking. No significant effects were found therefore, demographic variables do not appear to be significantly related to

Table II. Pearson's *R* Correlations Between Independent and Dependent Variables

Variable	2	3	4
1. EE	.09	-.13	-.17
2. Burden	—	-.03	.24
3. Support	—	—	.24
4. Function	—	—	—

Table III. Mean, Standard Deviation, and Range of Independent and Dependent Variables

Variable	Mean	Standard deviation	Range
EE	9.8	4.5	2–19.06
Burden	22.4	4.9	11–36
Support	2.0	2.4	0–12
Function	147	14.1	31–162

the study variables. In addition, we investigated significant demographic differences by ethnicity. Chi-square statistics indicate that White patients (47%) were significantly more likely ($\chi^2 = 9.81, \alpha = .044$) to be married than African American patients (19%). However, marital status was not significantly related to patient functioning. Other than marital status, there were no significant demographic differences between African American and White subjects.

Similarly, univariate analyses were employed to investigate significant ethnic differences on the independent and dependent variables. Results of these analyses are presented in Table IV, however caution is warranted given the overall sample size and unequal representation by race. As can be seen, African American and White caregivers reported differences on two of the three independent variables, perceived burden and perceived social support. The mean difference between African American and White caretakers' level of expressed emotion was not significant. African Americans perceived significantly less overall burden than Whites ($p < .05$) and significantly more social support ($p = .01$). African Americans reported having more people they are able to rely upon ($M = 2.6$) than Whites ($M = 0.73$). The mean difference between African American and White patients' level of functioning was not significant.

Table IV. Mean Difference Between African American and White Caretakers on Independent and Dependent Variables

Variable	Mean	Standard deviation	<i>F</i>	α
EE				
African American	10.2	4.5		
White	8.9	3.7	0.88	0.35
Burden				
African American	23.4	4.8		
White	20.1	4.3	5.1	0.03 ^a
Support				
African American	2.62	2.6		
White	.73	1.3	7.2	0.01 ^a
Function				
African American	148.2	13.8		
White	143.8	13.4	0.10	0.32

^aSignificance determined at the $\alpha < .05$ level.

Caretaking Model

To determine the relative strength of association between the caretaking variables and patient level of functioning, a multiple regression model was assessed in four steps. The initial model included the three caretaking variables, EE, burden, and social support, regressed on level of functioning. The second, third, and fourth steps included the three caretaking variables and introduced each of the three 2-way interaction variables separately, EE \times Burden, EE \times Social support, and burden \times Social support. After each step the models were analyzed for the incremental change in the *F* ratio and the amount explained variance. The model demonstrating the most explanatory power was retained for interpretation.

The results of the hierarchical regression procedure are shown in Table V. The table presents the four stepped models and the incremental change in the *F* ratio and *R*² estimation. As can be seen, each interaction term increased the amount of explained variance in comparison to the initial model with EE, burden, and social support. The initial model was marginally significant ($p = .061$) and accounted for approximately 15% of the variance in patient functioning. Adding the interaction between EE and support slightly increased the model's overall significance ($p = .058$) and amount of explained variance ($R^2 = .162$). Alternatively, adding the interaction term representing EE and burden decreased the significance of the model ($p = .088$) and minimally increased the amount of explained variance ($R^2 = .175$). However, adding the interaction between support and burden yielded a significant model ($p = .048$) and a greater level of explained variance in comparison to the other models ($R^2 = .191$). Including race as a dummy-coded variable (Cohen & Cohen, 1983) decreased significance and did not add significantly to the amount of explained variance ($F = 2.28, p = .06, R^2 = .21$).

Table V. Regression Models by Incremental Change

Variables	<i>F</i>	α	<i>R</i> ²
EE			
Burden			
Support	2.63	.061	.149
+EE \times Support	2.35	.058	.162
+EE \times Burden	2.17	.088	.175
+Support \times Burden	2.60	.048 ^a	.191

^aSignificance at the a priori level of $\alpha < .05$.

Table VI. Regression Coefficients of Model of Best Fit

Variable	<i>B</i>	β	α
EE	-0.843	-0.179	.201
Burden	1.88	0.433	.017
Support	9.68	1.104	.068
Support \times Burden	0.381	-0.911	.135

Using a procedure of model revision (Pedhazér & Schmelkin, 1991), a model was analyzed that assessed the effect of the strongest coefficients, burden and support, and their interaction, on level of functioning. Table VI shows the coefficients of the model considered best fitting these data based on significance and amount of explained variance. The model includes all of the main effects and one interaction effect between burden and support. Of the main effects tested the coefficients with the greatest magnitude and significance were burden ($b = 1.9, p = .02$) and support ($b = 9.7, p = .06$). These variables appear to be most important in explaining the variance in patients' level of functioning.

Summary

In this sample, the patients' level of functioning did not vary by demographic or illness-related variables other than total months spent in the hospital, which was a significant coefficient in a non-significant model. The series of multivariate models that assessed the effects of caretaking variables on the outcome variable found main effects for EE, burden, support, and an interaction effect for burden and support. The coefficients for burden and support represent the largest magnitude, and contribute most to the variance in patients' outcomes. Including the variable "total months of patient hospitalizations" increased the amount of explained variance slightly but rendered the model nonsignificant at the *a priori* level. Likewise, controlling for race did not improve the strength of association between caretaking variables and outcomes despite significant differences by race in univariate analyses of EE and support. The significance of the interaction term between burden and support provided evidence that support acts as a moderator of burden in this sample.

DISCUSSION

These results support previous research showing that family variables are important in the course of psychotic illness. More specifically, caretakers' per-

ception of burden appeared to be most strongly related to patients' functioning in this sample. In addition, social support was a moderator of burden. Although expressed emotion was less important in determining outcomes than was family burden and social support, it was associated with a better fitting model.

The relationship between caretakers' perceptions of burden and patient outcomes appeared to be strongest among the family variables measured. This finding supports the evidence from other studies that perceived burden impacts the course of a psychotic illness (Bernheim, 1989; Greenley, 1979; Kanter, 1985; Ryan, 1993). Although it is unclear precisely how caretakers' perceptions of burden affect the family members under their care, it is possible that increased burden is related to increased stress that influences the dynamics of family interactions and relationships.

Previous studies have found that families of the seriously mentally ill are under "extreme," "severe," or "profound" burden (Crotty & Kulys, 1986; Francell, Conn, & Gray, 1988; Lefley, 1989; Maurin & Boyd, 1990). In contrast, families in this study did not endorse high levels of burden. The scores varied but did not appear to be skewed toward higher levels of burden. In fact, most families were in the middle range of possible scores. This finding may be due to sampling effects in that the families in the present study have become accustomed to caregiving over longer periods of time in comparison to families in previous investigations of impact at the onset of illness. This study was particularly interested in understanding family factors that impact caretaking for serious mental illness that is chronic, long-term, and characterized by relapse and variation in functioning over time, because this is the reality for many families.

In addition to the limitations to generalizability based on the nature of the sample (post-onset, rural, predominantly African American), other limitations of this study should be noted. First, the sample size and unequal representations by race did not permit ethnic group comparisons. It could be argued that combining Blacks and Whites in the analyses could be obscuring important race/ethnicity differences in the relationship between caretaking variables and patient outcomes. Another concern is related to the relatively restricted range obtained on independent variable scores, particularly social support. It is unclear if the limited amount of reported support is a reality of rural life in this sample or an

artifact of measurement. In contrast, it is possible that social desirability affected caretakers' reports of burden and expressed emotion. Utilizing statistically transformed variables did not alter this study's results however it is possible that restricted variance of family variables decreased the stability of our regression models. Finally, this study cannot account for possible differences in rural caretaking options due to changes in the health care system and managed care. The impact of health care reform on caretaking in our sample is beyond the scope of the study. However, given the extremely limited mental health resources in the counties we studied, it is unlikely that options increased or changed significantly over the period of time these data were collected and analyzed.

Overall, it appears the constructs of burden, support, and, to a lesser extent, expressed emotion are important factors for families who are negotiating the experience of caring for a seriously mentally ill family member. These caretaking factors account for almost one-fifth of the variance in patient's level of functioning in this sample. Therefore, the caretaking model conceptualized by this study suggests familial networks have to manage subjective and objective burden, cope with emotional interactions with patients, and rely on support networks in order to successfully care for ill family members. Given these findings, the families in our sample can be conceptualized as problem solving networks capable of providing care. Despite this, the factors measured in this study include areas that could be strengthened by professional mental health services. Specifically, alleviating family burden through programs that support families or offer respite care may be effective in improving patient functioning.

Implications of Findings

At a general level this study supports the recommendations of previous researchers who were involved in rural family interventions (Hatfield, 1982, 1984; Kane, 1987; Kanter, 1985; Lefley, 1987c). These findings, combined with the administrative realities of rural population disbursement, create a demand for psychologists who are prepared to support innovative service roles in rural areas (Murray & Keller, 1991). Helping families in the period of shrinking resources should include viewing families as allies (Kanter, 1985; Lefley, 1987c) and as participants in treatment (Lehman & Steinwachs,

1998). Professionals can utilize a consultative approach that seeks to collaborate with the caretakers as primary care providers rather than dysfunctional family systems (Hatfield, 1982).

Interventions for alleviating subjective burden may be based on therapeutic models designed to alleviate the distress associated with caregiving. An example of such an approach is Torrey's (1988) work in teaching families to manage symptoms and moderate their reactions to the decreased expectations and disappointments that many family members experience. Information provided in psycho-educational interventions could help to reduce burden by increasing knowledge and perceptions of competence when faced with the responsibility of managing medications, understanding symptom behavior, and explaining patients' illness to others. Many caretakers interviewed in the present study reported that they did not know their family members' diagnoses, the type of medication they were receiving, or even the symptoms that typically characterize schizophrenia. Many reported having little to no contact with community mental health agency personnel or staff at the hospital where their family member was last admitted. Family psycho-education interventions could be provided as a routine part of discharge procedures from hospitals. Community agency personnel could reinforce this kind of educative information when patients are brought to outpatient clinics for medication management appointments. Also, family education approaches, such as the peer-intervention program instituted by regional chapters of the National Alliance for the Mentally Ill (NAMI), may provide support and information to families.

Alleviating objective burden through direct provision of resources is a more challenging problem given the lack of general resources in rural areas. One of the problems caretakers in the present study cited was lack of transportation for traveling to community agencies for appointments and other opportunities such as day treatment programs where available. However, availability of material resources can be improved by increasing social networks. Attributes of caregivers' social networks have a significant effect on the caregivers' perceived access to social resources (Tausig, O'Brien, & Subedi, 1992). Larger networks represent greater opportunity for financial and other forms of support, like transportation (Greenley & Simmons, 1983; Grusky, Tierney, & Manderscheid, 1985; Segal, 1978).

Future Research

The present research helps determine those family variables that are related to schizophrenic patients' functioning. Future research should attempt to find other variables involved such as familial understanding of illness and involvement in medication treatment. These factors may help explain more of the variance in patient functioning and would expand the caretaking model proposed here. Studies that follow patients prospectively and can therefore include other outcome variables such as rehospitalization rates would strengthen the evidence that family factors impact the course of illness. Longitudinal designs that include rates of relapse would enable replication of the outcome measure used in many other studies demonstrating the predictive validity of family variables. Also, differences between rural samples, like the one utilized for this study and a demographically matched comparison sample of urban families could determine if there are unique aspects of rural life that impact caregiving and course of illness.

Another potential direction involves attempting to understand how the family variables in this study are related to patient functioning. For example, it would be important to understand the mechanisms by which perceptions of burden are implicitly or explicitly communicated to patients and how that communication impacts their behavior. How does the subjective and affective experience of caretakers translate to patient outcomes? Are patient-caretaker interactions suggestive of perceived burden in ways that are similar to EE interactions? Also, it is unclear how support moderates burden. There may be aspects of caretaker support that can be replicated by mental health professionals. Beginning to answer questions related to underlying mechanisms will improve family interventions designed to alleviate burden.

The overarching goal of this study was to understand ways in which rural families have adapted to the current realities of caretaking in an era of fewer resources. It is important to understand the relevance of family factors to patient outcomes so dwindling mental health resources can be used to help families in ways that draw upon what we know is helpful. Ideally, interventions could proceed from an empirically informed basis. As studies that focus on family involvement become more numerous, an increased understanding of the factors related to caretaking can

help to engender positive outcomes for the chronically ill.

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