Continuity of Care, Residence, and Family Burden in Ohio

RICHARD TESSLER and GAIL GAMACHE

University of Massachusetts, Amherst

FROM THE BEGINNING OF THE PROGRAM ON CHRONIC Mental Illness (PCMI), it was clear that, among its objectives, the Robert Wood Johnson Foundation (RWJF) intended families in each of the nine cities to be beneficiaries of an improved service delivery system. Changes in the organization, financing, and delivery of services should affect family members indirectly by increasing the clients' residential independence and continuity of care. Accordingly, the family research component was designed to address two issues related to family burden. One issue was the extent to which burden is increased when the mentally ill family member lives with the family, or conversely, the extent to which independent living arrangements for the client reduce family burden. The second issue concerned the extent to which the provision of care in a coordinated, continuous, and timely manner benefits the family as well as the mentally ill member.

As background, we wanted to establish the levels and distribution of burden. How were family members affected by having a relative with a severe and persistent mental illness? How much burden was there? How was burden related to shared as compared with separate residences? How were family members affected by interactions with the public system of care, and what difference did it make to them whether their relative was receiving continuous services? These were the basic questions

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that motivated the family study, which involved interviews with clients and kin in Columbus, Cincinnati, and Toledo, Ohio. The three Ohio sites represent a subgroup of the nine American cities chosen as RWJF grantees. We chose to focus on the Ohio sites because the presence of a single state mental health authority increased homogeneity among sites and centralized the data collection effort.

Major Constructs and Predicted Relationships

Of all the social supports available to persons in any society, kinship ties are the most enduring. The mutual-support obligations existing between spouses are among the strongest, upheld both in law and custom, and are surpassed only by the ties between parents and children, at least as long as the child is a minor. However, when an adult child is unable to achieve independent status, the obligation of parents may continue. For other primary kin, such as siblings, and secondary kin, such as grandparents, the felt obligation is typically less (Tessler et al. 1992). Thus, a major focus of interest is the connection between family role and the professional system of care.

When there exists one or more of these involved family members, a plausible hypothesis is that if the client is receiving services that are consecutive and related to one another, the carrying load of particular family members will be reduced. Although continuity of care has a long history in general medicine, in mental health it is a relatively new concept (Steinwachs 1979; Rogers and Curtis 1980). The recent emergence of the concept coincides with the growing decentralization of mental health services and the multifaceted problems of severely mentally ill persons, whose need for care is ongoing as well as episodic (Test 1979).

Although the concept of continuity of care is in broad use, it suffers nonetheless from a lack of clear definition and boundaries. Sometimes it is used expansively and is confounded with other system goals such as accessibility and quality of care. At other times it is used restrictively, as, for example, when it is limited to establishing contact with an aftercare program. Most researchers who work in the area now agree that the concept is an umbrella for a collection of criteria to evaluate the use of services (Bachrach 1981; Tessler, Willis, and Gubman 1986). Our approach is to operationalize continuity of care in terms of the provision of continuous case management services designed to assist the client to plan and receive needed services like therapy, medication, work or employment, and housing.

It is important to study families under varying conditions to include some who share a common residence with the client and some who do not. Probably as many as a third live with their families, some reside with spouses, but many others stay in their parents' home at a time when most in their age cohort have left the family home to live independently (Tessler, Goldman and associates 1982; Fisher et al. 1992). Family burden studies have paid little attention to the burden carried by family members when the client lives elsewhere. Even when the client lives independently, so long as he or she lives nearby, family members may be involved with the client, and some may expend a great deal of time and effort in providing assistance and support (Carpentier et al. 1992). Thus, it is important to assess the burden of these families and compare it with the burden experienced by families when the client lives with them, and to examine whether the provision of services to the client has different effects under the two residential circumstances (Gubman and Tessler 1987).

The concept of family burden has been criticized as being too broad (Poulshock and Deimling 1984), confounding qualitatively distinct dimensions, and focusing solely on the negative aspects of caring for a mentally ill relative (George and Gwyther 1986). Burden is a very general concept, referring to a broad range of difficulties experienced by family members in caring for and dealing with their mentally ill relatives.

Much of the burden experienced by relatives of the mentally ill arises from caregiving. Even when florid symptoms of psychopathology are controlled by medication, mentally ill persons often experience residual impairments that prevent them from functioning without assistance in everyday life. Many need help or reminding with such tasks as getting dressed, taking medication, doing laundry, preparing meals, shopping, going places, managing money, and making use of their leisure time. Mentally ill clients living in unsupervised settings or at home frequently rely on a family member to provide such assistance (Creer, Sturt, and Wykes 1982).

Another burden born by relatives of the mentally ill is dealing with behavior that is embarrassing or frightening. Because of their impairments, severely mentally ill persons may act inappropriately, make excessive demands for attention, threaten or attempt suicide, or act violently. Very often one or more family members are asked to do something about the client's bothersome behavior, leading them to take on the role of de facto guardians or controllers of the client. Even rare incidents of threatened or actual violence to self or other(s) are matters of great concern to relatives of the mentally ill (Fisher, Benson, and Tessler 1990).

Possible costs of mental illness are more than economic. Time spent worrying is a significant additional cost. Relatives of the mentally ill worry about a range of issues that affect the safety and well-being of the client. Even when people have not seen each other for a period of time, sometimes they worry anyway about the other person. Worry taps into the subjective dimension of family burden.

The presence of some correlation among measures of burden does not mean that there is a single underlying trait called burden that accounts for the correlations. For this reason, burden does not lend itself to a single measure. Our approach to measuring burden is multidimensional and organized to distinguish clearly between objective and subjective components.

Methods

Sample Selection

The sample was generated from the first cohort of the client study designed by the evaluation team. Patients were identified in state psychiatric hospitals and 24-hour crisis care facilities in Cincinnati, Columbus, and Toledo, Ohio, using selection criteria that emphasized the disabling nature of the patient's condition. A fair number refused to participate, thus biasing the patient sample so as to overrepresent the more cooperative individuals (see the article by Lehman et al. in this issue).

Near the end of the first postdischarge interview, 283 clients were asked to identify up to four family members or close friends who could be asked to participate in a family study. Approximately 7 percent gave no names or addresses, stating that they had no family or friends. Another 10 percent declined to provide names and addresses, thereby refusing permission to interview any family or close friends. (Clients who refused to give family names, or said they had none to give, were more likely to report episodes of homelessness and incarceration in the past year.) The remaining 234 clients named a total of 517 family members or family-like close friends. Of these, 409 "family" members associated with 204 clients were subsequently interviewed (mainly in person) at time 1 (T1); 354 were reinterviewed (mainly by telephone) at time 2 (T2); and 305 were interviewed (mainly by telephone) a final time at time 3 (T3). This article summarizes the findings for those 305 family members who completed all three interviews, describes the levels and types of burdens, and examines the hypothesized effects of continuity of care and coresidence.

The 305 family members are associated with 175 clients: 85 entered the study through the service system in Cincinnati; 60 entered by receiving services in Columbus; and 30 entered through the mental health system in Toledo. Compared with those who did not complete all three interviews, the 305 family respondents were more likely to be female and to be giving assistance in daily living. The proportion of clients having more than one family member interviewed declined over the three waves from 61 percent to 51 percent, reflecting a tendency for less involved relatives to drop out of the study. The attrition of family respondents also was affected by client symptomatology. The higher the level of symptomatology, indicated by a short form of the Symptom Checklist-90 to which the clients responded, the more likely the family respondent was to complete the study.

Research Design Issues

We strove to incorporate mental health services into the research design in two ways. The first was in the family interviews, where we included a module on family member contacts with mental health professionals, reasons for the contact, satisfaction, and attitudes toward mental health professionals in general. The results from the T1 interviews incorporating this module have been reported elsewhere (Tessler, Gamache, and Fisher 1991).

The other approach to the measurement of services, reported here, was to derive information about client service utilization from the *client interview* and to link it with the family burden data. This has some methodological advantages because the two sources of data are independent of one another, and the family impact of the client's use of services can be evaluated even if the family is unaware of the client's patterns of use. The fact that the clients were interviewed three times also makes it possible to measure continuity of care, which, as noted above, was an important part of the program logic. We hoped to test the hypothesis that less family burden would be associated with the clients' receiving continuity of care, and to examine this hypothesis under different conditions of client residence. Both the clients and the family members were interviewed at three points in time (see figure 1).

At T1, the vast majority of the interviews were done in person at the home of the family member. The exceptions that led us to conduct the interview by phone occurred when the respondent lived more than 50 miles away, or when the respondent did not want the interviewer to come to the house. At T2 and T3, separated by one year, we mainly did telephone interviews to reduce costs, except in a small number of cases where personal interviews were necessary.

We encountered a number of problems in implementing the research design. One involved the *timing* of the family panel in relation to the client panel. Ideally, the two panels should be parallel in time, but, as figure 1 shows, the family and client panels were out of temporal synchrony. This is problematic in analyses that link client reports of services received with measures of family burden. By the third wave of the family interviews, two years may have elapsed since continuity of care was measured. The best we could do was to limit the test to the T1 family data, which was most contemporaneous with the measurement of continuity of care.

A second problem was the small number of coresidence cases. Coresidence was to be a key independent variable, and we originally proposed stratified sampling to ensure equal proportions of respondents living with and apart from clients. However, the proportion coresident with one or

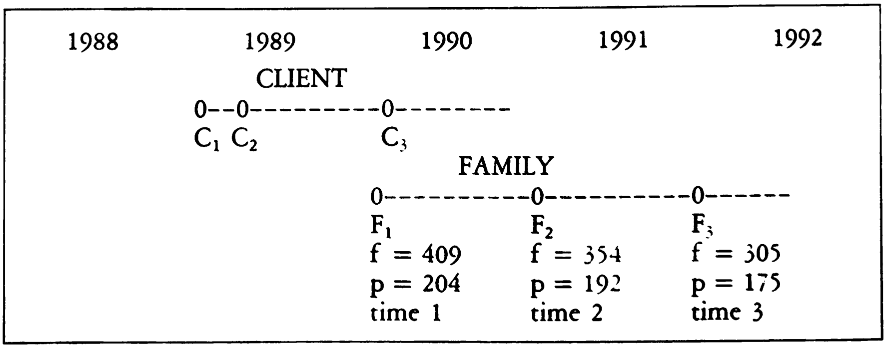

FIG. 1. Timeline: sequencing of the client and family data collections. C, client data collection; F, family data collection; p, number of clients associated with family members interviewed; and f, number of family members interviewed.

more respondents was never more than 18 percent at any given interview. Hence the analysis of coresidence was constrained by sample size limitations. It is possible that some of the clients were living with relatives who were not nominated or who refused to be interviewed.

Nonetheless, the results provide, from the family perspective, some insight into the relationships that exist between persons with severe mental illness and their family members under different conditions of client residence. We report on the support that they provide their relatives with respect to assistance given in activities of daily living (ADLs) and efforts they make to prevent or control behavioral problems. On the subjective side, we describe the kinds of things they worry most about. Finally, we report on whether continuous case management for the client helps to lessen the family's burden.

Measurement

Measures are presented below as independent and dependent variables. Alpha coefficients are reported when appropriate.

Independent Variables. Information about *continuity of care* (continuity) was derived from client reports at three points in time. Clients were asked in each (of three) interviews whether there was a person or team of people such as a case manager, a helping team, or a social worker who helped them plan and obtain the services they needed when they were not a patient in a hospital. If the client said at all three points in time that there was such a person or team, they were assigned a score of one. If such care was not continuously present, that client was assigned a score of zero. In addition, clients who dropped out during the course of the study were assumed to lack continuity of care and were also coded as zero.

The client reports of involvement with a case manager, helping team, or social worker were, in the majority of cases, accompanied by specific reports of services sites visited, programs attended, and types of professionals seen. If at each of the three interviews it appeared that the client was formally involved in the system of care, then continuity of care was assumed to have been obtained regardless of whether the same provider was involved. The resulting measure may be interpreted as continuity of care rather than as continuity of provider.

Coresidence (coresidence) was derived from family member reports of whether they were currently living with the client or had lived with the client in the past 30 days. The analyses to be reported focus on coresidence at time 1, a dummy variable in which 1 = client is currently living with the respondent. The omitted category includes clients living with noninterviewed kin (their own adult or minor children and spouses), alone, in group homes, or with roommates and girlfriends. It also includes a small number who were in psychiatric and penal institutions, or homeless.

The measure of *parent* (parent) is a dummy variable whereby 1 = the respondent's relationship to the client is a parent. *Other primary kin* (other primary kin) is a dummy variable whereby 1 = the respondent is a sibling, an adult child, or a spouse.

Dependent Variables. Our approach to measuring the objective burden of caregiving was to present the family member with a list of areas involving assistance in daily living in order to determine whether the respondent gave help in each. We refer to this dimension of caregiving as *care* (care). To enhance recall, the questions focused on the 30 days prior to the interview. At each point in time, we averaged the assistance given by respondents in each of the following areas: (a) grooming, bathing, or dressing; (b) medication; (c) housework or laundry; (d) shopping for groceries, clothes, or other things; (e) cooking or helping to prepare meals; (f) giving a ride or helping to use public transportation; (g) managing money; and (h) making use of time such as going to work, or school, or aftercare, or visiting with friends. This average is a percentage based on affirmative responses to any of the eight caregiving items; for example, a score of .25 means the respondent gave care in two out of eight areas of potential need. Cronbach's alphas over the three waves were .755 at T1, .695 at T2, and .777 at T3.

We approached the burden of supervision, which we refer to as *control* (control), in the same way that we approached the burden of assistance in daily living. For each of seven areas, respondents were asked whether they had tried to prevent or stop the client from (a) doing something embarrassing, (b) making excessive demands for attention, (c) keeping anyone up at night, (d) striking, injuring, or threatening anyone including the respondent, (e) making suicidal threats or attempts, (f) having too much to drink, and (g) using illicit drugs. This average, computed at each point in time, is based on *seven* items; for example, a score of 43 indicates that the respondent exercised or tried to exercise control in three out of seven areas. Computation of Cronbach's alphas over the three waves failed to meet a minimal standard of .70. The low alphas were not unexpected because issues of control occurred far more sporadically than problems in daily living within the 30-day measurement period; the summary measure may therefore be appropriately regarded as an index rather than as a scale measuring a unitary construct.

The concern that the 30-day response period may not have been representative is lessened somewhat by combining results from all three interviews. Therefore, "total" measures of care and control were constructed by averaging the total scores over the three points in time.

Worry (worry) represented the third dimension of burden under study. The worry items were not limited to the past 30 days. Respondents were asked how often they worried about their relative's safety, the kind of help and treatment that relative was receiving, the client's social life, physical health, and current living arrangements. Response categories were 0 = not at all, 1 = a little, 2 = a lot. Cronbach's alphas over the three waves were .770 at T1, .813 at T2, and .853 at T3. As measured, worry is assumed to be both a form of subjective burden and an expression of attachment. To be consistent with other summaries noted above, a "total" measure was constructed by averaging the total scores over the three points in time.

Results

The results are reported below for those 305 family members who completed all three interviews. Recall that the current study employs a broad definition of family, and includes secondary-kin relations as well as persons who were nominated by clients, despite being unrelated either by blood or by marriage, because they were considered to be "like family."

Sample Characteristics

The sample differs from many prior studies of family burden in that multiple family members were interviewed for slightly more than one-half (51 percent) of the clients, and the sampling frame was not limited to primary or active caregivers. The distribution of parents was 37 percent. Other primary kin totaled approximately 35 percent (siblings, 25 percent; adult children, 7 percent; and spouses, 3 percent). A variety of secondary-kin relations was also represented (19 percent), including small numbers of aunts and uncles, grandparents, nieces and nephews, cousins, in-laws, and the step- and half-relations of blended families. Approximately 10 percent of the respondents were actually "family-like" non-kin. At the first interview with family members, 17.1 percent of respondents reported that the client was a member of their household.

Table 1 reports the descriptive statistics for the family members. Slightly more than two out of three of the family respondents were female. Approximately one-half of the respondents were black, and nearly a third reported household income as "less than $10,000" in households that averaged almost three persons. This is an indication of extreme poverty. Respondents averaged less than 12 years of education, just over 50 years of age, and about one-half were currently employed. Approximately one-half of the respondents were currently married.

Contact with professionals is shown separately in table 1 for those who had contact at some point during their relative's illness, and those

TABLE 1
Respondent Characteristics by City

Variable	Total (N = 305)	Cincinnati (n = 152)	Columbus (n = 113)	Toledo (n = 40)	Level of significance
Race (% black)	48.5	61.2	32.7	45.0	.001
Sex (% female)	70.8	73.0	66.4	75.0	NS
Age (years)	50.6	51.6	48.5	52.9	NS
Education (years)	11.6	11.2	12.1	11.7	.018
Low income (% < $10,000)	30.6	32.4	24.1	42.1	.093
Currently married (%)	51.5	54.6	48.7	47.5	NS
Employed (%)	51.8	50.0	55.8	47.5	NS
Contact with[a] pros (% ever)	68.9	63.8	72.6	77.5	NS
Contact with[b] pros (%T2,T3)	42.3	42.8	38.9	50.0	NS
AMI member (% past and/or present)	9.2	6.6	10.6	15.0	NS
Parents (%)	37.1	34.2	36.3	50.0	NS
Other primary kin	34.4	36.8	31.9	32.5	NS
Coresidence at T1	17.1	14.5	17.7	25.0	NS

[a] Respondent ***contact with professionals*** is measured in the following ways: ***Ever*** is a dummy variable measured at time 1, whereby 1 = an affirmative response to the following item: "During the course of NAME's illness, did you ever meet or converse with (his/her) doctor, social worker, case manager, or any other mental health professional on any matter pertaining to NAME's care?"

[b] *T2 and T3* contact uses the same item as "ever," but the time frames are since time 1 and time 2, respectively.

who had contact with professionals during the course of the study. As many as 69 percent reported contact at some point, whereas 42 percent reported contact at T2 and/or T3. In some families, more than one member was in contact with professionals. There were families that relied on one member to serve as a liaison with the professional system of care, whereas in other families no member had recently been in contact with professionals.

Relatively few (9 percent) of the family respondents were formerly or presently members of a support group for families, such as the Alliance for the Mentally Ill (AMI). Further analysis indicated that the percentage of AMI members (past and present) goes up slightly if limited to mothers (17.4 percent), and still further if limited to white mothers (26.5 percent). There was also a significant race difference in AMI membership; 13 percent of the white respondents were AMI members compared with only 5 percent of the black respondents.

Table 1 also compares respondent characteristics across the three cities. Cincinnati is distinctive in having a significantly larger percentage both of black respondents and of respondents with the lowest education. There tends to be more extreme poverty in the Toledo sample, as indicated by the higher proportion reporting household income under \$10,000 ($P < .10$).

Table 2 reports the descriptive statistics for the clients. There were slightly more males (53 percent) than females, and whites (52.6 percent) than blacks in the client sample. The average client was 35.5 years old

TABLE 2
Client Characteristics by City

Variable	Total (N = 175)	Cincinnati (n = 85)	Columbus (n = 60)	Toledo (n = 30)	Level of significance
Race (% black)	47.4	57.7	31.7	50.0	.008
Sex (% female)	46.9	43.5	53.3	43.3	NS
Age (years)	35.5	36.6	33.6	36.1	NS
Education (years)	11.5	11.4	11.7	11.5	NS
Never married (%)	52.0	54.1	51.7	46.7	NS
Has children (% yes)	57.7	55.3	56.7	66.7	NS
Schizophrenia (% yes)	62.1	69.4	45.5	72.4	.008
Continuity of care	42.9	56.5	31.7	26.7	.002

and had 11.5 years of education. Fifty-two percent had never been married, although 58 percent had children. A majority (62 percent) of the clients were diagnosed as schizophrenic. Approximately 43 percent of the clients reported that they had had a case manager or helping team over the 12 months preceding the first family interview.

Three significant site differences also involve clients. The lowest proportion of black clients, and of persons diagnosed with schizophrenia, is found in Columbus. Examination of table 2 also reveals that clients entering the treatment system in Toledo reported significantly less continuity of care, compared with the other two cities.

Prevalence of Burden

Table 3 summarizes the prevalence of burden *over the course* of the study indicated by ADL assistance, supervision of behavioral problems, and worries about the mentally ill relative. Note that the items have been rank ordered, from most to least prevalent. For the care dimension, family members reported helping most by giving rides or assisting in the use of public transportation. About 40 percent said they helped in this

TABLE 3
Distribution of Total Care, Control, and Worry[a,b]

Respondent helped with	%	Tried to control	%	Respondent worried a lot about	%
Transportation	40.3	Attention seeking	24.3	Health	65.3
Use of time	30.2	Night disturbances	18.0	Safety	63.3
Meals	30.2	Embarrassing behavior	17.7	Services	56.1
Money	29.5	Alcohol	12.1	Social life	51.8
Medication	28.9	Suicide	10.5	Living arrangements	45.6
Chores	23.9	Drugs	10.2		
Shopping	23.3	Violence	8.5		
Dressing	19.7				
Total	65.3	Total	47.2	Total	84.6

[a] N = 305.

[b] Scores for each individual item represent the proportion helping, supervising, or worrying at T1, T2, and/or T3. Total scores shown in the bottom row refer to the proportions of family members reporting helping with ADLs, trying to control troublesome behaviors, or worrying about the client in at least one area over the course of the study.

way (this also suggests that 60 percent never helped with rides or transportation). Next in prevalence (about 30 percent) were reports of helping, reminding, or urging the client to make use of his or her time, such as going to work, school, or aftercare, or visiting with friends. About 30 percent of the respondents also reported cooking for the client or helping him or her prepare meals. Only slightly fewer reported helping the client to manage money, to take prescribed medication, to do housework or laundry, and to shop for groceries, clothes, and other things. Respondents were least likely to help with grooming, bathing, or dressing, which may reflect the low level of coresidence and thus the lack of opportunity for help in these areas.

For the control dimension, the most frequently reported area was trying to prevent or stop the client from making excessive demands for attention; followed by stopping or preventing the client from causing a nighttime disturbance; doing something embarrassing in public or before company; having too much to drink; talking about, threatening, or actually attempting suicide; and using drugs or pills such as marijuana, cocaine, amphetamines, or heroin. The least frequent report was of trying to prevent or stop the client from injuring someone or threatening to do so.

Respondents reported the most worry about the client's physical health and safety, followed by worries about the kind of help and treatment the client was receiving, and worries about the client's social life. Respondents under both conditions of residence reported the least amount of worry about the client's living arrangements. The bottom row shows the proportions reporting helping with the ADLs, trying to control troublesome behaviors, or worrying a lot about the client in at least one area over the course of the study. These proportions could be read as prevalence rates over a two-year period, although as operationalized they indicate the barest minimum level of burden.

Factors Affecting Family Burden

Next, we turn to some multivariate results designed to test the hypothesis that continuity of care and residence are each related to burden. Table 4 shows the results when the three T1 burden measures, chosen because they are the most contemporaneous with the client data measuring continuity of care, are regressed on continuity of care (past two years), residence (past 30 days), the interaction between continuity of care and

TABLE 4
Huber Regressions on Time 1 Care, Control, and Worry[a]

Independent variables	Burden variables[b]		
	T1 Care	T1 Control	T1 Worry
Continuity of care	.024	.021	.004
Coresidence	.203***	.107**	−.034
Continuity of care × coresidence	−.179**	−.125**	−.078
Parent	.106***	.074***	.336***
Other primary kin	.028	.044**	.157*
Intercept	.065**	.015	1.95***
Adjusted R^2	.118	.076	.036

[a] N = 305.
[b] Coefficients are metric coefficients.
$*P < .10$, $**P < .05$, $***P < .01$.

residence, and two control variables indicative of kinship. Variables that are typically included as statistical controls, such as age, race, gender, and education, are not listed in table 4 because they did not contribute significantly to the variance explained in burden for either clients or respondents.

Huber variance estimates are used to adjust for the duplication of continuity of care scores, measured as a client characteristic and thus repeated across multiple respondents. The method of estimation is least squares, but the standard errors have been adjusted to account for cluster sampling, that is, the presence of more than one respondent per client. The estimated metric coefficients are unchanged from ordinary least squares regression.

The results from the Huber regressions show that, contrary to prediction, continuity of care does not lead directly to less of a family burden. However, the significant interaction between continuity and coresidence indicates that continuity of care does reduce both care and control burden under the condition of a shared residence. As table 4 shows, continuity of care has no effect when clients do not reside with the family member. The coefficients of continuity of care are minuscule and insignificant (b = .024 for care, b = .021 for control, and b = .004 for worry). Under the condition of coresidence, however, the effect of continuity of care becomes −.155 (.024 − .179) for care, −.104 (.021 − .125) for control, and a somewhat smaller, but not significant, effect of −.074 on worry (.004 − .078).

Although coresidence was only present in a minority of cases at T1, when family respondents reported that the client lived with them, coresidence was associated with significantly more care and control. Respondents who shared their apartment or home with the client, or who, in some cases (e.g., an adult child), shared the client's home or apartment, tended to be more involved in helping with ADLs ($b = .203$) and in the management of behavioral problems ($b = .107$). This increase in burden is just about completely offset by the effect of continuity of care, which in the case of care is −.155 and in the case of control is −.104. That is, coresidence imposes a burden on the family member only when the client is not receiving continuity of care. Without continuity of care, coresidence tends to increase the burden of caregiving and supervision.

The subjective dimension of burden is indicated in table 4 by the regression of T1 worry on the identical set of independent variables (see column 3). These results indicate that, in contrast to care and control, the worry of family members has little to do with whether the client is receiving continuous services and where he or she is living. Family members with relatives who received continuous services worried just as much (or as little) as others whose relatives were not receiving professional help. Also, compared with the condition of coresidence, family members worried just as much (or as little) when the client lived elsewhere. Of all the worry items, the only one tending to vary by residence was worry about living arrangement, which was marginally lower when the client lived with the family member ($P < .08$).

As expected, both objective and subjective burden is significantly related to kinship. The single consistent finding shown in table 4 is that parents report more objective and subjective burden than other family members. Other primary kin also report more control burden, more worry, but not more care burden in comparison with secondary kin and friends.

Discussion

What do the results tell us about the impact of the Robert Wood Johnson Program in Ohio? We examined changes in burden over the three interviews on the assumption that, as time went on, the RWJ initiative developed more fully. However, comparison of the burden at T1, T2, and T3 fails to reveal a consistent pattern. In this way our results are similar to the findings from the client outcome study. In spite of improvements in continuity of care, there were no discernible changes in quality of client life and functioning (see the article by Lehman et al. in this issue).

We did detect a statistically significant decline in coresidence after the initial interview *if there was continuity of care*. When, in contrast, there was no continuity of care we did not detect a significant decline in coresidence. It may be that the differences were due to the disbursement of housing vouchers under the condition of continuity of care. This would reflect the linking of services and housing. Even without a rent subsidy the case manager may have assisted with securing housing.

If it is the case that mental health professionals in Ohio can be credited with linking clients to independent residences, they also seem to be helping in situations where clients and family members are living together. At least this is a plausible inference based upon the association of continuity of care with lower family burden. But recall that coresident family members are a small group, representing less than a fifth of the total number of family members under study.

It seems clear that the burden of caring for the client who has serious and persistent mental illness is not evenly distributed in families. Whereas some kin experience major changes in their daily routines, others appear almost unaffected by the mental illness of their relative, at least for the 90 days asked about in the three interviews. Whether particular kin are burdened is not only a function of whether they live with the client. Although coresidence does appear to engender more burden, a substantial proportion of relatives who did not live with the client were involved in both care and control. Fifty-eight percent of non-coresidents (compared with 88 percent of coresident family members) helped with care and 42 percent (compared with 64 percent of coresident family members) helped to control bothersome behaviors over the course of the study.

The distributions of care and control mirror the typical patterns of kinship obligation, with spouses (when present) and parents most involved, and siblings, adult children, and secondary kin less involved. The distribution of worry is similar except that parents worry the most, followed by adult children, and spouses.

It should also be noted that the burden of care and control is not evenly distributed by site either. Family respondents from Toledo reported more involvement in both care and control issues. However, the site differences did not remain significant in multivariate analyses.

Limitations

The sample, which was identified in public 24-hour settings, may underrepresent family members of clients who are isolated from the system of public care, those in private care, and younger individuals in the very early stages of illness who have not yet sought treatment. The urban settings may also overrepresent continuity of care and the availability of public services. In addition, limiting the measurement of burden to a 30-day recall period misses certain traumatic events, like violence or suicide attempts, for example, that can affect the family member after even one occurrence. The 305 family members who agreed to be interviewed three times probably overrepresent highly committed kin. Finally, it should be noted again that the lack of synchrony between the family and client interviews reduced the potential for comparing client and family outcomes.

Policy Implications

This section seeks to extrapolate from the research findings to a public policy space, and to place the findings in the context of what has been previously reported in the literature. The policy implications that follow should be interpreted within the context of the limitations of the study that we have described.

First, we think that the results indicate the relevance of family burden as a criterion for evaluating changes in the organization, financing, and delivery of mental health services. Lowering family burden was clearly a part of the program logic, and thus appropriate to include in the evaluation. The fact that the hypothesized link between continuity of care and family burden was not supported, except under the condition of coresidence, may indicate the need for a more direct approach to reducing the burden of mental illness on families.

To our knowledge, the RWJF initiative did not include new services for families. As a consequence, the program logic specifying a link between client services and family outcome is at best indirect, except perhaps when family members live with the client and thus experience more directly the impact of client services. Future initiatives should consider the accumulating evidence of the beneficial effects for services that are intended specifically for families (Pfeiffer and Mostek 1991). Among the possible approaches that have been highlighted are respite care (Geiser, Hoche, and King 1988), family education (Strachan 1992), including family members in treatment planning (Hatfield 1979), and developing mobile teams that are responsive to families when the client is in crisis (Francell, Conn, and Gray 1988).

An alternative interpretation of the lack of empirical support for a direct link between continuity of care and family burden is that professionals are doing their job by focusing their case management efforts on the most needy clients. These also tend to be the more burdensome clients. Without a randomized research design, it is very difficult to sort out the effects of services from baseline differences in client need and family burden.

Second, the higher objective burden found among coresident family members is consistent with other recent research findings indicating the negative effects of living with a person who has a serious mental illness (Gallagher and Mechanic 1993). Case managers may need to encourage adult persons with severe disorders to establish independent residences from their families of origin. When client and parent(s) are unwilling or unable to live apart, it becomes all the more important to link them with both client and family support services. Coresidential family care should not become an excuse for no mental health services. In addition, the preeminent involvement of parents, as distinct from other primary kin, also raises concerns about the future as both clients and their parents age (Lefley 1987; Horwitz et al. 1992).

In some respects, the main finding of our study was not the "colossal burden" of mental illness on family members, but rather the impact of mild to moderate levels, as well as the modest amounts of variance explained. This is similar to other empirical studies of the effect of mental illness on relatives (see Fisher, Benson, and Tessler 1990, table 1; and Crotty and Kulys 1986). Failure to document the high levels of burden alleged by family advocates may suggest not the diminution of client need, but rather the lessening of family support in situations where the limits of generosity and tolerance have been reached (Tessler et al. 1992).

Concluding Note

One indication of the positive response of family members comes from analysis of their attitudes toward mental health professionals. Depending on the reason for the contact, 53 to 73 percent of the relatives at T1 reported being very satisfied or satisfied with the outcome (see Tessler, Gamache, and Fisher 1991). The attitudinal results continued to be very positive at subsequent interviews, but only 34 percent reported contact with professionals at T2 and only 29 percent reported contact at T3.

Some examples from T3 indicate the positive nature of the attitudes of those respondents who did report recent contact with a variety of professionals, including family therapists, social workers, and psychiatrists. The vast majority (81 percent) agreed or agreed strongly with the statement, "The professionals I have dealt with were extremely interested in what I could tell them about the client's condition or problem"; 67 percent agreed or agreed strongly with the statement, "The professionals I have dealt with took very seriously the problems I faced in caring for the client." Very few (only about 6 percent) agreed or agreed strongly with the statement, "The professionals I have dealt with gave me the feeling that I am responsible for causing my relative's illness."

When the Ohio clients from Cohort 1 were asked during the first community interview, "Whom did you turn to *most often* for help with problems in the year before you were admitted to the hospital?" 40 percent said family members, compared with only 19 percent who mentioned a case manager, a psychiatrist, another therapist, or some other person in the mental health system. When the clients were asked 10 months later, "Whom did you turn to most often for help during the previous ten months?" 37 percent cited a family member, compared with 27.5 percent who mentioned a mental health professional. Clearly, from the clients' standpoint, the family has not been *entirely* replaced by the public system of care when they need someone to turn to for help and support.

In conclusion, we have much to learn about the nature of the kinship bond in the presence of illness and disability, the tendency to turn to kin during difficult times, and how mental health professionals can support family members. We hope that the results of the family burden study, coupled with findings from the site and client level evaluations also reported in this volume, will help inform both policy makers and service providers about how far we have traveled in public mental health and how much further there is to go in supporting both clients and their families.

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Address correspondence to: Richard Tessler, PhD, Social and Demographic Research Institute, W-34 Machmer Hall, University of Massachusetts, Amherst, MA 01003.