*The Journal of Mental Health Policy and Economics*
*J Mental Health Policy Econ* **4**, 123-132 (2001)

# Substitution between Formal and Informal Care for Persons with Severe Mental Illness and Substance Use Disorders

**Robin E. Clark,[1]* Haiyi Xie,[2] Anna M. Adachi-Mejia[3] and Anjana Sengupta[4]**

[1]*Ph.D., Associate Professor, Director of the Behavioral Health Policy Institute, New Hampshire-Dartmouth Psychiatric Research Center and Dartmouth Medical School, Hanover, NH, USA*
[2]*Ph.D., Assistant Professor, New Hampshire-Dartmouth Psychiatric Research Center and Dartmouth Medical School, Hanover, NH, USA*
[3]*M.S., Doctoral Candidate, New Hampshire-Dartmouth Psychiatric Research Center and Dartmouth Medical School, Hanover, NH, USA*
[4]*Ph.D., Assistant Professor, New Hampshire-Dartmouth Psychiatric Research Center and Dartmouth Medical School, Hanover, NH, USA*

## Abstract

**Background:** Persons with severe mental illness (SMI) often get extensive informal care from family members and friends as well as substantial amounts of formal treatment from paid professionals. Both sources of care are well documented, but very little is known about how one affects the other.
**Aims:** This analysis estimates the extent of substitution between direct care provided by family and friends and formal treatment for people with severe mental illness and substance use disorders. Separate estimates are generated for short-term and long-term effects.
**Methods:** Data are from a randomized clinical trial conducted at seven mental health centers in New Hampshire between 1989 and 1995. The study includes detailed data for 193 persons with dual disorders measured at study entry and every six months for three years. Hours of informal care were compared with total treatment costs within each six-month period to measure short-term effects. Average amount of informal care over three years represented long-term caregiving practices. Measures of informal care are from interviews with informal caregivers. Treatment costs are based on combined data from management information systems, Medicaid claims, hospital records, and self reports. We used mixed effects repeated measures regression to estimate longitudinal effects and a multiple imputation technique to test the sensitivity of results to missing data.
**Results:** In the short-term, persons with bipolar disorder used significantly more formal care as informal care increased (complementarity). The relationship between short-term informal and formal care was significantly weaker for persons with schizophrenia. For both diagnostic groups there was a long-term substitution effect; a 4-6% increase in informal care hours was associated with an approximate 1% decrease in formal care costs.
**Discussion:** Although they must be confirmed by further research, these findings suggest that there is a significant and strong relationship between care given by family and friends and that supplied by formal treatment providers. The analysis indicates that the short-term relationship between informal care and formal treatment tends to be complementary, but differs according to diagnosis. Long-term effects, which are possibly related to changing role perceptions, show substitution between the two forms of care. Missing data for family care hours in some time periods was a concern in this study. However, the consistency in results between the analyses that used imputed data and the model using only original data increase our confidence in the findings. Although there may be some endogeneity between formal and informal care in other treatment settings we believe the unique characteristics of the service-rich environment in which this study was conducted limit that concern here.
**Implications for Health Care Provision and Use:** The amount of care provided by informal caregivers has a significant impact on formal treatment costs. Models of care that explicitly acknowledge the interplay between the two types of care are needed to ensure efficient combinations of formal and informal care.
**Implications for Policy:** How to best to encourage informal support, without overburdening caregivers, is a key challenge facing policy makers and providers of mental health services. The merits of various approaches to reducing caregiver burden is a subject that needs more attention from researchers. In the interim, the demands on informal caregivers may mount as efforts to reduce health care spending continue.
**Implications for Research:** Informal care is not often included in economic evaluations of mental health treatment. Although additional research is needed to understand better the mechanisms by which informal care and formal treatment are related, we believe our results offer a strong argument for including measures of informal care in future economic evaluations.

Received 19 March 2001; accepted 2 February 2002

## Introduction

Persons with severe mental illness (SMI) often get extensive informal care from family members and friends as well as substantial amounts of formal treatment from paid professionals. Both sources of care are well documented, but very little is known about how one affects the other. The extent

---

***Correspondence to**: Robin E. Clark, Dartmouth Medical School, Department of Community and Family Medicine, Strasenburgh 7250, Hanover, NH, USA
Tel.: +1-603-650 1246
Fax: +1-603-650 1153
E-mail: robin.clark@dartmouth.edu.
**Source of Funding**: This project was supported by grants #MH-00839, #MH-46072, #MH-47567 from the National Institute of Mental Health and AA-08341 from the National Institute on Alcohol Abuse and Alcoholism and by the New Hampshire Division of Mental Health and Developmental Services.

to which informal care is associated with increases or decreases in formal treatment has important implications for public policy and for people with SMI. Changes in access to formal care may also affect the burden and well-being of caregivers. Too often, policy initiatives consider only reimbursable services and ignore the role that informal caregivers play in the lives of people with mental disorders.

In this paper we use longitudinal data from a randomized clinical trial to explore short- and long-term relationships between formal and informal care. We then consider the implications of our findings for mental health services, policy, and research.

## Background

Several studies of long-term care for frail elderly patients have examined the question of substitution between formal and informal care.[1-4] Generally, these studies have found a tendency for informal care to decline slightly as formal care increases. Despite ample evidence that families of people with severe mental illnesses, such as schizophrenia and bipolar disorder, provide substantial amounts of care[5-7] and that treatment for severe mental illness can be quite expensive,[8] we know surprisingly little about the relationship between formal and informal care.

Although studies of care for frail elders show that formal and informal care can substitute for one another, these findings may not apply to people with SMI. Characteristics of elderly patients and their caregivers are quite different from those of people with severe mental illness. Elders' informal caregivers tend to be spouses or adult children. Caregivers for adults with SMI are more likely to be parents. Compared to the chronic conditions that affect most elders, the earlier onset of schizophrenia and bipolar disorder-typically in the late teens or early twenties-means that relatives of persons with SMI spend a longer portion of their lifespan as caregivers. Caregiving may become a more deeply ingrained part of their identity than it is for those with shorter caregiving careers. These factors could lead SMI informal caregivers to be relatively unaffected by the availability or use of potential substitute care. On the other hand, the demands of caregiving for people with SMI- which can include coping with social stigma, frequent crisis intervention, and day-to-day struggles with negative symptoms- may be perceived as particularly onerous by family members. These demands imply a greater likelihood of service substitution among caregivers for persons with SMI than for those of frail elders.

The policy implications of formal/informal service substitution are subject to different interpretations. In the long-term care field, some policy makers have expressed concern that services such as home health aides may undermine the role of family caregivers and shift costs from private citizens to government payers. They see substitution as undesirable. Providers, researchers, and caregivers in the mental health arena - as well as some in other areas such as developmental disabilities - tend to take a different view, focusing primarily on the role of formal services in reducing the stress and responsibilities that caregivers face. From this perspective, some substitution of formal for informal care is desirable. Perhaps from both perspectives, knowing the degree of substitution may be more important than determining its existence. A small amount may be desirable, a great deal may not.

### *Evaluating the Relationship between Formal and Informal Care*

Several theories have addressed the relationship between formal and informal care. Theorists have considered the closeness of family ties,[9] the sufficiency of social networks,[10] the specific types of care that are needed,[11] the stress experienced by caregivers,[12] caregivers' role perceptions,[13] and the economic incentives for substitution of formal for informal care.[1] None of these theories addresses all of the unique features associated with early onset mental illness. A combination of economic, stress and coping, and role theories is needed to provide a comprehensive explanation of formal/informal care interaction in mental illness.

Greene's economic model of substitution in demand, which includes patient needs and family characteristics as predictors of formal/informal care substitution, offers strong hypotheses about the relationship between the two types of care. The substitution model is especially relevant to political debates over the division of responsibility for long-term care between government and private citizens. The stress-coping-adaptation model proposed by Hatfield and others focuses primarily on the psychological factors that might lead to substitution.[12] Long-term changes in caregiving patterns are explained by Tessler and others' application of role theory.[13]

#### Substitution

The economic premise of the substitution model is that, if formal and informal services are truly interchangeable, family members and other potential informal caregivers will base their decisions about whether to provide care or to purchase it on the relative price of the two types of care. If the total economic cost of formal care is greater than the lost earnings and other opportunity costs faced by a potential caregiver, that person may choose to provide the care informally rather than purchasing it. Cargivers also consider their own preferences or utilities in making such a choice.

In the case of severe mental illness, it is unlikely that formal and informal care would be perfect substitutes. Informal caregivers can perform some services that are also available from formal care providers, like helping patients manage their money, but not others, such as prescribing medications. Thus, our focus is on the degree of substitution rather than on the unlikely possibility that one source of care might completely replace the other.

Theories that focus on family stress and adaptation[12] suggest a similar response, but for different reasons. Put simply, they predict that informal caregivers who feel overburdened may seek to shift some responsibility to formal caregivers as a way of reducing their own stress. The ability to shift caregiving responsibility depends, of course, on the availability of a suitable substitute. It seems likely that both price and stress play a central role in caregivers' short-term decisions.

### Complementarity

Some formal treatment approaches could actually increase family involvement. Family interventions are among the most effective psychosocial approaches for reducing relapse in persons with schizophrenia.[14] When a person with SMI enrolls in a family-oriented treatment program, informal caregivers may participate in therapy sessions or support groups. They may also be urged to engage in specific activities with the patient outside of formal treatment sessions, such as recreational outings or assistance with instrumental activities of daily living. Thus, an opposing hypothesis to price- and stress-based substitution is that increases in the amount of formal care that patients receive are associated with more, rather than less, informal care.

### Informal Care over Time

Previous studies have focused only on short-term changes without attending to the long-term patterns of care. Because there is little incentive to incur additional cost or to prolong stress, substitution due to a change in relative prices or a desire to relieve acute stress should take place rapidly, assuming that access to formal care is unrestricted. In addition to responses based on stress or opportunity cost, there may be a more stable pattern of informal care that is related to caregivers' role perceptions.[13] Beliefs about one's responsibility to family members or friends may endure in the face of significant amounts of stress and high economic burden. For example, compared with siblings, parents often feel a stronger obligation to care for adult children with SMI.[15] The dearth of longitudinal data on informal care makes this component of caregiving even more poorly understood than the short-term responses. Nevertheless, some studies suggest that families vary in their long-term commitment to caregiving.[16,17] Variations in the long-term pattern of informal support are likely to have a significant impact on patients and on their use of formal services. We propose a model of informal caregiving with separate short- and long-term components, which may affect use of formal services in different ways.

## *A Model of Formal and Informal Care for Severe Mental Illness*

We used a modified version of the substitution model to examine formal/informal care relationships for people with SMI over a three year period. The model assumes a formal treatment system that relies more heavily on outpatient care rather than on long-term institutional care. Formal/informal care patterns may differ in systems that rely heavily on institutional care. In addition to its use of economic theory, our model borrows aspects of stress reduction and role perception theories. Specifically, we distinguished between short term effects-changes in informal care or treatment cost occurring within the same six-month period-and longer term effects based on the entire three-year pattern of care. The functional form of our model presupposes partial, rather than full, substitution. Another important difference between our model and Greene's[1] substitution conceptualization is that it does not assume a simultaneous relationship between the amount of informal care a person receives and the decision of formal care providers to supply care. A simultaneous equations model makes sense in the case of home health agencies, which may ration care to frail elders based on the availability of informal care, but it does not reflect current standard practice in treating severe mental illness. All people with SMI are thought to need formal services. With the exception of one study, which suggests that access to informal care may affect release from public long-term stay institutions, there is little evidence that the availability of informal care would deter a mental health provider from offering services.[18]

The theoretical model shown in **Figure 1** assigns explanatory variables to four groups: patient characteristics and clinical status, caregiver characteristics, treatment factors, and amount of informal care. These variables may affect patients' use of formal, and in some cases informal, care. They are included as covariates in this analysis primarily to reduce variation in formal care related to factors other than the amount of informal care provided. This is not intended to be a causal model describing the inter-relationships between each variable and the amount of informal care provided- those relationships are beyond the scope of this paper.

Patient characteristics include age, gender, education, previous amount of formal services used, psychiatric diagnosis, and stage of substance abuse. Differences in formal service use by age, gender, and diagnosis,[8] and level of substance abuse,[19] are well documented in the literature. Educational level is included as a proxy for premorbid functioning, which may also affect service use. Prior service use is a strong predictor of future use.[20] The association between psychiatric symptoms and formal costs has not been explored in great depth, psychiatric symptoms are a general measure of distress and have been shown to influence family interactions.[21] Although it is associated with significant amounts of family burden,[22] bipolar disorder may differ from schizophrenia in its long-term course, impact on functioning and in the associated demand for both formal and informal care.[23-25] Schizophrenia, which is often associated with persistent negative symptoms and cognitive impairment, may place greater demands on both formal and informal caregivers over longer periods of time.[23]

Caregiver characteristics were represented by caregiver age, which we view as a proxy for the caregiver's opportunity cost - caregivers 65 years of age and older are more likely to be retired and, therefore, to be more available for informal care. The ethnic homogeneity of the study sample did not allow a meaningful examination of caregiver's ethnicity and service use.

Treatment factors included the type of treatment to which the patient was assigned (Assertive Community Treatment or Standard Case Management) and a time factor which allowed for changes in treatment responses over time. Assertive Community Treatment has been associated with lower costs in some studies.[26] Both programs provided substantial amounts of service in patient's homes, which reduced the effects of travel

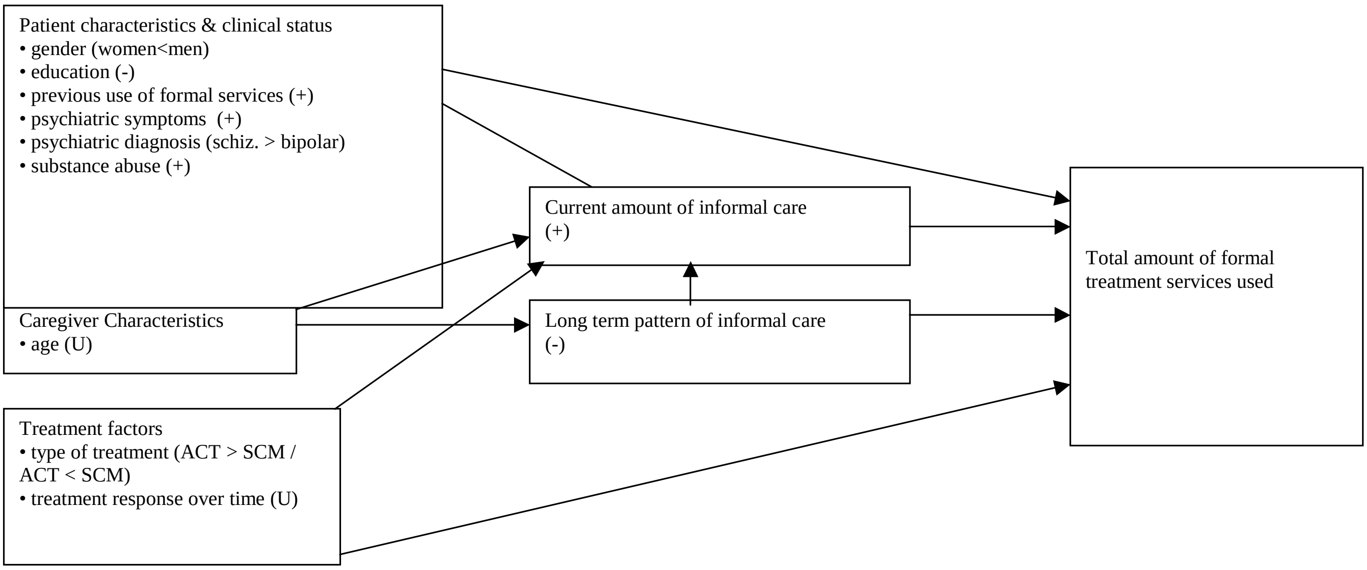

Figure 1: A Model of the Relationship Between Formal and Informal Care for Severe Mental Illness

*Notes*: Predicted relationships between each variable and formal care are in parentheses. + indicates a positive associations, - indicates a negative association, U indicates that the direction of the relationship is undetermined by the theoretical model.

time on patients' use of services. An earlier analysis of these data found similar responses (rates of recovery) to substance abuse treatment over time.[27]

## *Hypotheses*

Based on theoretical predictions and prior empirical evidence we developed the following hypotheses.

- Informal care will be a partial substitute for formal care in both short- and long-term contexts.
- Because functional impairments associated with schizophrenia may increase caregiver stress more than bipolar disorder, short-term informal care will be negatively related to formal care for patients with schizophrenia but unrelated to formal care for patients with bipolar disorder.
- Because of greater residual impairment associated with schizophrenia, formal service costs will decrease over time for patients with bipolar disorder but not for patients with schizophrenia.

Directional hypotheses for other independent variables are shown in **Figure 1**.

## Methods

We used data from a randomized clinical trial of treatments for co-occurring severe mental illness and substance use disorder (SUD). The study compared a standard case management (SCM) program with enhanced substance abuse treatment to an assertive community treatment (ACT) program with integrated mental health and substance abuse treatment. Both programs were implemented at seven community mental health centers (CMHCs) in New Hampshire and gave intensive services, many of which were delivered in the client's home or in other community settings. Participants entered the study between 1989 and 1991 and were followed for three years. They were interviewed at six-month intervals to assess progress. Results of clinical effectiveness and of cost-effectiveness analyses have been published elsewhere.[27,28]

## *Sample*

Mental health center clients were eligible for the study if they met the following criteria:(i) DSM-III-R diagnosis of schizophrenia, schizoaffective, or bipolar disorder; (ii) an active DSM-III-R substance use disorder (SUD) within the past six months; (iii) age between 18 and 60 years; (iv) absence of additional severe medical conditions or mental retardation; and (v) willingness to provide well-informed written consent to participate in the study. Clinicians referred 306 potential participants to the study, 240 of these were initially assessed to meet study criteria; 13 of these did not complete the assessment/enrollment process and four were subsequently found ineligible and excluded from the study. Of the original 223 persons who enrolled, 203 completed the study. Study dropouts were not significantly different from those who did not remain in the study, except that they were more likely to be SCM participants (14% versus 3.7%, X2 = 7.33 (df = 1), p = .007). For a more extensive discussion of attrition and group comparability see Drake, et al.[27] We were unable to collect complete cost data on ten of the 203 participants who completed the study (five participants from each treatment group). The primary reason for incomplete cost data was that these participants received significant amounts of treatment from an out-of-state provider for one or more six-month measurement periods, preventing us from accurately assessing mental health treatment costs. The resulting final sample analyzed in this paper is 193 participants: 100 in ACT and 93 in SCM.

Patients were predominantly male (74%), nonminority white (96%), unemployed (82%), had never been married (61%), and had at least a high school education (63%). Average age at study entry was 34 years. Slightly more than half (53.6%) had schizophrenia, 22.7% had schizoaffective disorder, and the remaining 23.6% were diagnosed with bipolar disorder. All had a substance use disorder as defined by DSM III-R criteria; 72.6% had an alcohol use disorder and 41.8% had a drug use disorder, primarily cannabis or cocaine. Participants lived in a mix of small urban and rural areas.

Patients were asked to nominate for study participation the family member or friend who gives them the most assistance. Over the course of the study, informal caregivers for 174 of the 193 clients were interviewed at least once. Most were interviewed several times at six-month intervals; 45 caregivers completed all seven interviews. The number of informal caregivers interviewed at each measurement period was as follows: study entry, 66; six months, 111; one year 141; 18 months, 151; two years, 142; 30 months, 140; three years, 134. Lower response rates at study entry and six months were due to delayed research funding and were not related to caregiver or patient availability or willingness to be interviewed. Comparison of informal caregivers who completed all interviews with those who completed fewer interviews showed no significant differences in average number of caregiving hours per month. Participants whose caregivers, for any reason, did not participate in the study were not significantly different from others on demographic or clinical variables at study entry. Patient reports of family contact frequency did not differ for those whose caregivers participated and for those who did not. Because of the low response rate at study entry, we used only the final six periods (six months through 36 months) in our analysis.

The majority of informal caregivers (67%) were parents, 17% were siblings. Another 11.5% were grandparents, spouses, children or other relatives; 4.5% were not related to the study participants. Caregivers ranged in age from 25 to 88 years (mean = 56, s.d. = 12); 82% were women. In 18% of the cases, caregivers and study participants lived together.

## Formal Service Use

*Treatment costs* were used as a summary measure of all formal services used. Costs are a better measure of resource consumption than natural service units (e.g. visits, days, etc.) because they weight intensive services, like inpatient care, more heavily than less intensive ones, such as counseling. Cost estimates were based on an analysis of service utilization data from CMHC management information systems for most outpatient services; a combination of self-reports, CMHC clinical reports, and hospital records for inpatient services;[29] and Medicaid payments for outpatient services supplied by private providers. Because all CMHCs contracted with the state, outpatient services were defined and tracked in the same way across all seven centers. Service units for all CMHC outpatient services were computed separately for each program operated by the center and were based on patient contact hours rather than on staff hours. ACT and SCM costs were combined with other outpatient services, including: day treatment, medication management, and emergency intervention. Unit costs were determined for the 1991, 1992, and 1993 fiscal years from independently audited cost reports. Inpatient costs were based on bed-day rates determined from Medicare cost reports for the year in which the hospitalization took place. Services of private providers, which were a small percentage of all outpatient costs, were valued at Medicaid payment rates. Housing costs were excluded from this analysis.

Average three-year treatment cost for ACT participants was $82,870 and $84,915 for SCM. Costs are expressed in 1995 dollars.

## Informal Care

One primary informal caregiver per patient reported amounts of time and money spent on behalf of the study participant by all family members. More detail on the types of care provided and on how that care compares to informal assistance for people without chronic illness is provided in Clark and Drake[6] and in Clark.[30] For purposes of this analysis, we focused only on caregiving time and defined both short-term and long-term measures of caregiving patterns. Short-term care was measured by total hours of informal care during each six-month period. Long-term informal care was measured by computing mean monthly caregiving hours across all periods with non-missing data.

## Other Measures

*Substance use outcomes* were measured by combining information obtained from self-reports, case manager ratings of substance use, clinical records, and laboratory tests. Each participant was assigned a Substance Abuse Treatment Scale (SATS) rating [31] for each measurement period. SATS ratings were based on Osher and Kofed's[32] model of treatment and recovery where: 1 = early engagement, 2 = late engagement, 3 = early persuasion, 4 = late persuasion, 5 = early active treatment, 6=late active treatment, 7= early relapse prevention, 8 = late relapse prevention. This rating combined alcohol and drug use outcomes in a single measure. Although this scale is ordinal in nature, we treated it as a continuous measure in our analysis because the scale represents underlying change in substance use, which is a continuous process with many potential measurement points. The number of categories (eight) makes this scale perform more like a continuous than a categorical variable.

*Other measures* included: treatment cost in the six months prior to randomization; psychiatric diagnosis, determined with the Structured Clinical Interview for the DSM III-R;[33] psychiatric symptoms measured with the Expanded Brief Psychiatric Rating Scale, BPRS;[34] patient age; and education.

Because formal services were free to patients and families, all study participants faced the same direct price for services; however, informal caregivers may have faced different

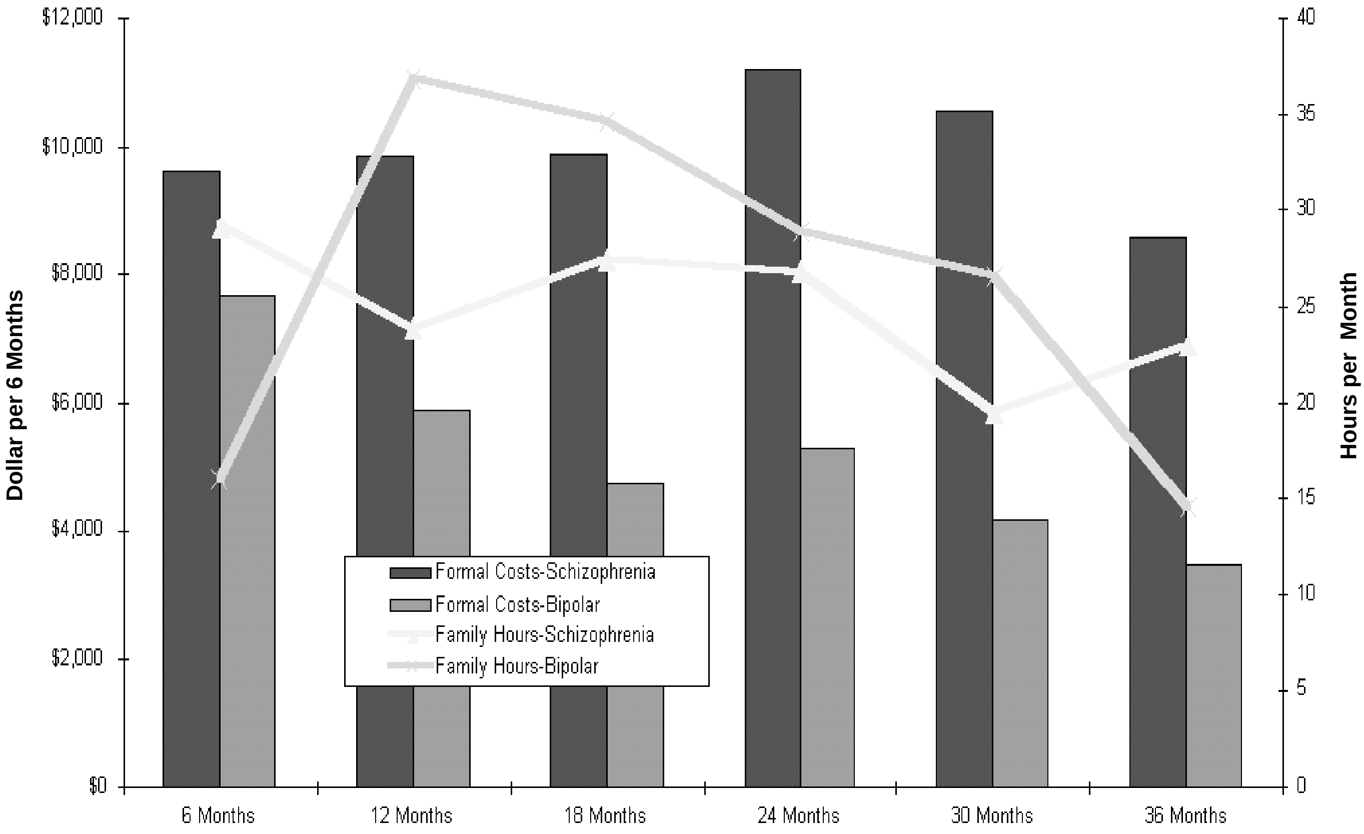

Figure 2. Median Formal Care Costs and Informal Care Hours

opportunity costs, including different utilities for caregiving. To model caregiver opportunity costs, we used a binary variable equal to 1 if the primary caregiver was age 65 or older (customary retirement age) and 0 if younger. Although this is an incomplete proxy for opportunity costs, it serves as an general indicator of potential income loss associated with caregiving. Another categorical variable equal to 1 if the patient was assigned to ACT and 0 if assigned to SCM was included to account for any differences in treatment costs related to the interventions.

### *Data Analytic Procedures*

We used mixed-effects linear regression with repeated measures to model the formal/informal care relationship over three years.[35,36] A major advantage of mixed-effects regression, compared to conventional repeated measures approaches, is its ability to model correlated longitudinal or cluster data and incomplete (missing at random) data.

We regressed total mental health costs in each of the six post-randomization measurement periods on each of the variables shown in **Figure 1**. Interactions between informal hours and diagnosis and between time and diagnosis were also included based on evidence that treatment course and family support might be different for people with schizophrenia than for those with bipolar disorder.

Due to the relatively large amount of missing data for informal caregiving, we used a multiple imputation procedure to estimate the values for missing data. The method we used is based on data augmentation methods and Monte Carlo Markov Chain methods.[37]

Results are presented for three models: the full model with original data and no imputation (No Imputation Model), the full model with imputed data, (Full Imputed Data Model), a partial model excluding psychiatric symptoms (BPRS) and caregiver age, which also had missing observations (Reduced Form Imputed Data Model).

## Results

Both formal and informal costs varied greatly across study participants. However, this variation was reduced when the variables were transformed by taking their natural log. Mean formal treatment costs for all patients appeared to be stable, beginning at $13,461 (s.d. = $12,927) in the first six-month period and ending at $13,802 (s.d. = $18,667) in the final period. However, when the values were logged to normalize distributions and reduce the effects of extreme values, formal costs showed a significant decline: logged means were 8.90 (s.d. = 1.54) and 8.49 (s.d. = 2.12) respectively; t = 2.50, df = 193, p = .01. The change in mean informal care, from 55.2 (s.d. = 77.14) hours per month during the first six months to 39.05 (s.d. = 53.05) hours in the final period, was also statistically significant: logged means were 3.11 (s.d. = 1.53) and 2.74 (s.d. = 1.57) respectively; t = 2.17, df = 91, p = .03. Differences in both formal and informal costs were confirmed

Table 1. Mixed Regression Models Predicting Total Mental Health and Substance Abuse Treatment Costs (ln) for Each Time Period After Study Entry.[1]

| Variable Name | Parameter estimate (t-ratio) | | |
|---|---|---|---|
| | No Imputation<br>N = 640 | Full Imputed Data[2]<br>N=763 | Reduced Form Imputed Data[3]<br>N=1134 |
| Baseline Mental Health Costs (ln) | 0.22***<br>(5.76) | 0.23***<br>(6.25) | 0.23***<br>(6.89) |
| Stage of Substance Abuse Treatment | 1.16***<br>(6.15) | 1.04***<br>(6.21) | 0.93***<br>(6.66) |
| Stage of Substance Abuse Treatment Squared | -0.11***<br>(5.98) | -0.10***<br>(6.04) | -0.09***<br>(6.30) |
| Psychiatric Symptoms BPRS Total Score | 0.01<br>(1.73) | 0.01<br>(1.52) | - |
| Informal Caregiver Age (0 = <65 years, 1 = >=65 years) | -0.09<br>(0.49) | -0.04<br>(0.25) | - |
| Patient Education ( 0 = more than high school, 1 = up to some high school) | -0.05<br>(0.33) | -0.12<br>(0.79) | 0.10<br>(0.70) |
| Patient Gender (0 = male, 1 = female) | -0.17<br>(0.92) | -0.12<br>(0.70) | -0.05<br>(0.33) |
| Average Hours Informal Care (ln) (all periods) | -0.23**<br>(2.69) | -0.22**<br>(2.81) | -0.15*<br>(2.21) |
| Psychiatric Diagnosis (0 = bipolar, 1 = schizophrenia spectrum) | 1.03**<br>(3.20) | 1.04***<br>(3.45) | 0.71**<br>(2.61) |
| Current Informal Hours (bipolar disorder) | 0.29***<br>(3.46) | 0.28***<br>(3.53) | 0.16*<br>(2.27) |
| Current Informal Hours (ln) * Schizophrenia (interaction term) | -0.25**<br>(2.71) | -0.26**<br>(2.90) | -0.15<br>(1.91) |
| Time (bipolar disorder) | -0.08<br>(1.24) | -0.09<br>(1.47) | -0.17**<br>(2.99) |
| Time * Schizophrenia (interaction term) | 0.07<br>(1.00) | 0.08<br>(1.15) | 0.13*<br>(2.09) |
| Treatment Assignment (0 = ACT, 1 = SCM) | 0.17<br>(1.05) | 0.12<br>(0.85) | 0.06<br>(0.45) |

* < 0.05
** < 0.01
*** < 0.001
1 = Six six-month periods. Random intercept and slope at the individual level. N's refer to the number of observations included in each model (n of participants x time periods with non-missing data). The "no imputation model" includes 149 participants, the "full imputed data model" includes 151 participants, and the "reduced form imputed data model" includes 189 participants.
2 = Using imputed values for informal care hours.
3 = Imputed values for informal care. Psychiatric symptoms and caregiver age eliminated.

with Wilcoxin signed-rank tests. **Figure 2** shows the median amounts of each type of care over three years.

Results of the mixed-effects regression analysis shown in **Table 1** reveal a fairly complex relationship between formal and informal care. Patients with higher average amounts of informal care throughout the three-year period had significantly lower treatment costs than those who consistently received less informal care. In the short-run (defined as the number of informal hours and total treatment costs during the same six-month time period), patients with bipolar disorder showed evidence of complementarity. The short-term relationship was significantly weaker for persons with schizophrenia, but still positive. The effect for bipolar disorder, the comparison category, is represented by the coefficient for current informal hours and is inconsistent with our hypothesis of no relationship. The coefficient for schizophrenia, illustrated by the interaction between schizophrenia and current informal hours, was inconsistent with our hypothesis of substitution between informal and formal care. Subtracting the (comparative) coefficient for persons with schizophrenia from that for bipolar disorder (+0.29 -0.25 = + 0.04) the overall short-term effect is slightly positive, or complementary. These results held for the first two models and were only slightly different in model 3, where the interaction between schizophrenia and informal hours, compared to bipolar disorder, was just above the .05 level of significance (p = .057).

As predicted, prior costs, schizophrenia, more severe psychiatric symptoms, and substance abuse were positively associated with use of formal services, although the variable for psychiatric symptoms was above the conventional .05 level of significance (p = .08 in the No Imputation Model and p = .13 in the Full Imputed Data Model). The relationship between substance use and treatment costs was curvilinear. In lower stages of recovery, costs increased as patients became engaged in treatment. This is represented by the raw stage-of-treatment score. When substance abuse stage-of-treatment scores were squared to weight more heavily patients in higher stages of recovery (i.e. with less substance use), the relationship reversed. This suggests that patients use significantly less treatment as they approach or achieve abstinence.

Caregiver opportunity cost, represented by the binary caregiver age variable, was not a significant predictor of formal care, nor was patient gender or education. Treatment assignment was also not significant, nor did it interact with either of the two informal care variables (not shown in **Table 1**). Time and time by schizophrenia variables were not significantly associated with formal treatment in the No Imputation and Full Imputed Data Models, indicating that formal treatment costs did not change significantly over time, when other factors are controlled. However, the reduced-form imputed data model showed lower formal treatment costs over time for people with bipolar disorder and a significantly smaller decrease for people with schizophrenia relative to those with bipolar disorder.

Correlations among explanatory variables were generally low. However, short-term informal care hours (ln) were positively correlated with long-term informal care at relatively high levels (r = .72 to r = .83). Differences between short-term and long-term care coefficients may have been influenced by collinearity. However, alternative models with only long-term care or only short-term care terms showed substantially similar results to those observed in the full model.

## Discussion

The findings indicate that formal and informal care are significantly related. Psychiatric diagnosis moderated formal and informal care relationships in the short term. In the No Imputation and Full Imputed Data Models patients with bipolar disorders had roughly 1% higher formal care costs for each 4% increase in informal treatment hours they received. The ratio was1% to 6% in the Reduced Form Imputed Data Model. This suggests that increased involvement in formal treatment may have encouraged greater family involvement for people with bipolar disorder.

The positive short-term relationship between formal treatment costs and informal care hours for persons with schizophrenia was much weaker than that for persons with bipolar disorder. One explanation for this result is that providing assistance to persons with schizophrenia is more demanding or stressful for caregivers and, thus, less likely to increase in response to formal care. An alternate explanation could be that people with schizophrenia were hospitalized more often and, therefore, received less informal care. However, further analysis did not show a significant relationship between inpatient costs and informal care. Other comparisons by diagnosis showed no differences in the total amount of informal care provided or in other caregiver characteristics, such as age or kinship.

Overall, the short-term relationship between informal and formal care was positive. However, the effect was stronger for people with bipolar disorder than for those with schizophrenia. The diagnosis-specific findings suggest that future analyses should take diagnosis into account when exploring the relationship between formal and informal care over short periods of time.

Regardless of diagnosis, patients who consistently received higher amounts of informal care (long-term) were less costly to treat in the formal system. This result held when a variety of other factors were taken into account, such as patient characteristics, historical costs, psychiatric symptoms, and substance use. The magnitude of response was a 1% decrease in formal costs for every 4%-6% increase in mean hours of informal care. These results suggest a long-term relationship in which consistently high levels of informal care may substitute for formal care, or vice versa. Although we believe we have controlled for the most plausible determinants of receiving informal care, we cannot completely rule out the possibility of unmeasured differences between patients who received high and low amounts of informal care.

The slightly declining amounts of informal care over time (shown in **Figure 2**) are consistent with the hypothesis that informal caregivers changed their role perceptions in ways that affected the amount of care they gave. However, this interpretation remains speculative in the absence of direct long-term measures of caregiver role perceptions. Even though average informal care decreased over time, the change was not large and caregivers continued to provide substantial amounts of assistance. Coupled with short-term results, these findings suggest that the relative price of formal care, caregiver stress, and role perceptions may all play a role in determining the relationship between formal and informal care.

### *Limitations*

The data used in this analysis have some limitations that must be considered when interpreting findings. There were few ethnic minorities in our study; some studies suggest that patterns of informal caregiving may differ across cultures.[38] Many mental health studies are conducted in large metropolitan areas, but our sample was taken from a mix of small urban and rural communities where the problems faced by patients and families may be different. Readers should also be aware that results for people with SMI alone may differ from those of patients in treatment for co-morbid SMI and substance use disorder. Measures of short-term and long-term patterns of informal care are both conceptually and technically (as measured by correlation coefficients) somewhat endogenous. Role perceptions probably lead informal caregivers to relative consistency in the amount of care they provide over time. However, large standard deviations in informal care measures suggest that there is also significant variation both within and between caregivers over time. We believe the different relationships observed in short- and long-term patterns of care are meaningful, but acknowledge that more work is needed to fully understand them. Limitations notwithstanding, we believe these data offer an important first glimpse at the relationship between formal and informal care for people with co-morbid SMI and substance use disorders and that they are relevant for this group in many areas of the United States and in other industrialized countries.

The amount of missing data for family care hours was an important concern in this study. However, the consistency in results between the two analyses that used imputed data (**Table 1**) and the No Imputation Model increase our confidence in these findings.

Finally, it is important to note that this analysis demonstrates associations between formal and informal care but does not prove causality. Our theoretical and empirical models viewed informal care hours as affecting formal care costs, but the relationship can just as easily be reversed, with formal care utilization dictating how much time family caregivers invest.

## Implications for Practice, Policy, and Research

Policies and practices that encourage informal support could reduce formal care costs over time. Although the clinical benefits of informal care have received little attention from researchers, an earlier analysis of these data showed that patients who received more assistance from their families reduced their substance use more than those whose families gave less assistance.[39]

Potential benefits to patients must be carefully weighed against the significant amounts of stress and health problems many caregivers experience.[40] Clearly, any policy that seeks to increase informal care without specifically addressing the needs of caregivers is not only inequitable, but probably doomed to failure. Passing additional responsibilities to informal caregivers without additional support would most likely result in less care as caregivers become more discouraged and experience deteriorating health.

How to best to encourage informal support, without overburdening caregivers, is a key challenge facing policy makers and providers of mental health services. A variety of family support mechanisms are available, ranging from psychoeducation and social support [41] to economic support such as income tax credits.[42] Family members may also be encouraged by the implications from this study that formal care can reduce the demands on their time. Although interest has increased somewhat since this study was initiated, the merits of various approaches to reducing caregiver burden is a subject that needs continued attention from researchers. In the interim, the demands on informal caregivers may mount as efforts to reduce health care spending continue.

## Conclusions

Determining the optimal mix of formal and informal support is a complex task that must be approached from several different perspectives, including those of patients, families, formal service providers, and taxpayers. Family caregivers may see decreases in the hours they devote to care as a much-needed respite from the inexorable tasks of caring for someone with SMI. Some taxpayers may worry about any shift from private to public responsibility. Whatever the perspective, these data suggest that care given by traditional treatment providers cannot be viewed in isolation from that provided by family members and friends.

A good deal more remains to be learned before firm conclusions can be drawn about the association between formal and informal care for people with SMI. Our findings should be viewed as preliminary. Observing treatment over longer periods of time and in a variety of populations and settings will broaden our understanding of that relationship.

### Acknowledgements

Special thanks to study participants with dual disorders and their families.

## References

1. Greene VL. Substitution between formally and informally provided care for the impaired elderly in the community. *Med Care* 1983; **21**(6):609-619.
2. Hanley RJ, Wiener JM, Harris KM. Will paid home care erode informal support? *J Health Polit Policy Law* 1991; **16**(3):507-521.
3. Moscovice I, Davidson G, McCaffrey D. Substitution of formal and informal care for the community-based elderly. *Med Care* 1988; **26**(10):971-1102.
4. Tennstedt SL, Crawford SL, McKinlay JB. Is family care on the decline? A longitudinal investigation of the substitution of formal long- term care services for informal care. *Milbank Q* 1993; **71**(4):601-624.
5. Carpentier N, Lesage A, Goulet I, Lalonde P, Renaud M. Burden of care of families not living with young schizophrenic relatives. *Hospital and Community Psychiatry* 1992; **43**:38-43.
6. Clark RE, Drake RE. Expenditures of time and money by families of people with severe mental illness and substance use disorders. *Community Ment Health J* 1994; **30**(2):145-163.
7. Franks DD. Economic contribution of families caring for persons with severe and persistent mental illness. *Adm Policy Ment Health* 1990; **18**: 9-18.
8. Rice DP, Miller LS. The economic burden of schizophrenia: conceptual and methodological issues, and cost estimates. In: Moscarelli M, Rupp A, Sartorius N, editors. *Schizophrenia: Volume I in the Handbook of Mental Health Economics and Health Policy*. West Sussex, England: John Wiley and Sons, 1996.

9. Cantor MH. Life space and the social support system of the inner city elderly of New York. *Gerontologist* 1975; **15**(1):23-27.
10. Scott JP, Roberto KA. Use of informal and formal support networks by rural elderly poor. *Gerontologist* 1985; **25**(6):624-630.
11. Litwak E. *Helping the Elderly: The Complementary Roles of Informal Networks and Formal Systems*. New York: Guilford Press, 1985.
12. Hatfield AB, Lefley HP. *Families of the Mentally Ill: Coping and Adaptation*. New York: Guilford Press, 1987.
13. Tessler R, Fisher G, Gamache G. A role strain approach to the measurement of family burden: the properties and utilities of a new scale. Paper presented at Rutgers University, Institute for Health , Health Policy and Aging Research., 1988.
14. Dixon LB, Lehman AF. Family interventions for schizophrenia. *Schizophr Bull* 1995; **21**(4):631-643.
15. Horwitz AV. Siblings as caregivers for the seriously mentally ill. *Milbank Q* 1993; **71**(2):323-339.
16. Marsh DT, Lefley HP, Evans-Rhodes D, Ansell VI, Doerzbacher BM, LaBarbera L, et al. The family experience of mental illness: Evidence for resilience. *Psychiatr Rehabil Jl* 1996; **30**:3-12.
17. Fisher GA, Tessler RC. Family bonding of the mentally ill: An analysis of family visits with residents of board and care homes. *J Health Soc Behav* 1986; **27**(9):236-249.
18. Holmes AM, Deb P. Factors influencing informal care-giving. *J Mental Health Policy Econ* 1998; **1**(2):77-87.
19. Dickey B, Azeni H. Persons with dual diagnosis of substance abuse and major mental illness: Their excess costs of psychiatric care. *Am J Public Health* 1996; **86**(7):973-977.
20. Hargreaves WA, Shumway M, Hu T, Cuffel B. *Cost-Outcome Methods for Mental Health*. San Diego, CA: Academic Press, 1998.
21. Rosenfarb IS, Goldstein MJ, Mintz J, Nuechterlein KH. Expressed emotion and subclinical psychopathology observable within the transactions between schizophrenic patients and their family members. *J Abnorm Psychol* 1995; **104**(2):259-267.
22. Perlick D, Clarkin JF, Sirey J, Raue P, Greenfield S, Struening E, et al. Burden experienced by caregivers of persons with bipolar affective disorder. *Br J Psychiatry* 1999; **174**:55-62.
23. Mohamed S, Paulsen JS, O'Leary D, Arndt S, Andreasen N. Generalized cognitive deficits in schizophrenia. *Arch Gen Psychiatry* 1999; **56**(8):749-754.
24. Miklowitz DJ, Goldstein MJ, Nuechterlein KH, Snyder KS, Mintz J. Family factors and the course of bipolar affective disorder. *Arch Gen Psychiatry* 1988; **45**(3):225-231.
25. Miklowitz DJ, Goldstein MJ, Nuechterlein KH. Verbal interactions in the families of schizophrenic and bipolar affective patients. *J Abnorm Psychol* 1995; **104**(2):268-276.
26. Latimer EA. Economic impacts of Assertive Community Treatment: A review of the literature. *Can J Psychiatry* 1999; **44**(5):443-454.
27. Drake RE, McHugo GJ, Clark RE, Teague GB, Xie H, Miles K, et al. A clinical trial of assertive community treatment for patients with co-oc curring severe mental illness and substance use disorder. *Am J Orthopsychiatry* 1998; **64**(2):201-215.
28. Clark RE, Teague GB, Ricketts SK, Bush PW, Xie H, McGuire TG, et al. Cost-effectiveness of assertive community treatment versus standard case management for persons with co-occurring severe mental illness and substance use disorders. *Health Serv Res* 1998; **33**(5):1283-1306.
29. Clark RE, Ricketts SK, McHugo GJ. Measuring hospital use without claims: a comparison of patient and provider reports. *Health Serv Res* 1996; **31**(2):153-169.
30. Clark RE. Family costs associated with severe mental illness and substance use. *Hosp Comm Psychiatry* 1994; **45**(8):808-813.
31. McHugo GJ, Drake RE, Burton HL, Ackerson TH. A scale for assessing the stage of substance abuse treatment in persons with severe mental illness. *J Nerv Ment Dis* 1996; **183**:762-767.
32. Osher FC, Kofoed LL. Treatment of patients with psychiatric and psychoactive substance abuse disorders. *Hosp Comm Psychiatry* 1989; **40**:1025-1030.
33. Spitzer RL, Williams JB, Gibbon M. *Structured clinical interview for DSM-III-R-patient Version (SCID-P)*. New York, NY: Biometric Research Department, New York State Psychiatric Institute, 1988.
34. Lukoff K, Liberman RP, Neuchterlein KH. Symptom monitoring in the rehabilitation of schizophrenic patients. *Schizophr Bull* 1986; **12**: 578-602.
35. Gibbons RD, Hedeker D, Waternaux C, Davis JM. Random regression models: A comprehensive approach to the analysis of longitudinal psychiatric data. *Psychopharmacol Bull* 1988; **24**:438-443.
36. Laird NM, Ware JH. Random-effects models for longitudinal data. *Biometrics* 1982; **38**:963-974.
37. Schafer JL. *Analysis of incomplete multivariate data*. London: Chapman and Hall, 1997.
38. Cook JA, Lefley HP, Pickett SA, Cohler BJ. Age and family burden among parents of offspring with severe mental illness. *Am J Orthopsychiatry* 1994; **64**:435-447.
39. Clark RE. Family support and substance use outcomes for persons with mental illness and substance use disorders. *Schizophr Bull* 2001; **27** (1):93-101.
40. Dyck DG, Short R, Vitalliano PP. Predictors of burden and infectious illness in schizophrenia caregivers. *Psychosom Med* 1999; **61**:411-419.
41. Dixon L. Providing services to families of persons with schizophrenia: present and future. *J Mental Health Policy Econ* 1999; **2**(1):3-8.
42. Pear R. Clinton seeks aid for care of those with chronic ills. *NY Times* 1999 January 4; **1**.