

# Factors Influencing Informal Care-giving

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## Abstract

**Background:** As downsizing of institutional care continues, patients discharged are likely to have more severe mental illnesses, and to have experienced longer tenures within institutions than patients who have been discharged in the past. As greater numbers of patients are removed from mental hospitals, the objective burden experienced by informal care-givers may increase, particularly if formal care levels are inadequate.

**Aims of the Study:** This paper documents who assumes informal care-giver roles, and the form such care-giving takes for patients discharged from a state hospital. Specifically, this paper identifies (i) what factors affect a person's decision to assume a care-giver role, including the participation of other network members in care-giving, (ii) what factors influence whether care-giving is provided in time or in direct purchase of care and (iii) how the patient's treatment location affects the decision of the network member to assume any care-giving role.

**Data and Analytical Methods:** Data for this paper are taken from a longitudinal study of the closure of a state mental hospital in central Indiana. Seventy-seven patients were asked to identify their community networks. Ninety-eight network members were surveyed about the informal care, both in time or through direct expenditures, they provided to these patients one year after discharge. Care-giving relationships were estimated using a multivariate probit model. Such a model estimates the extent to which the decision to provide care in either form depends on the care-giving activities assumed by other network members associated with a given patient, as well as the characteristics of individual patients and network members.

**Results:** Forty-one per cent of network members provided some level of informal care, with 13.3% providing some care in time, and 35.7% providing some care through direct expenditures. A positive relationship was found between participation in informal care-giving and the perception by the network member that patient needs were not being met by professionals. The decision to provide informal care was also found to be sensitive to the level of informal and formal care received by the patient. Care-giving in expense was found to be positively related to the care-giving decisions of other informal care-givers, but care-giving in time was not. Network members were more likely to provide care in time for patients who had been recently discharged to the community than for patients who remained in institutional settings.

**Conclusion:** These results suggest the transfer of persons with severe mental illnesses from state hospitals to the community may shift the care burden between formal and informal providers. If this is the case, discharge criteria should include such factors as the community resources available to the patient.

**Implications for Health Care Provision and Use:** The responsiveness of network members to perceived unmet need bespeaks the importance of informal care when the continuity of formal care cannot be assured. Findings also suggest there may be some substitution of formal and informal care when patients are discharged from institutions. Further analysis is required to determine whether network members' perceptions of unmet need are accurate, and means by which network members can be made better attuned to unmet needs actually experienced by patients. © 1998 John Wiley & Sons, Ltd.

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Persons with severe and persistent mental illness are increasingly treated not in state institutions but in the community. Numerous studies have documented that formal costs of care are lower when treatment is provided in the community.<sup>1–3</sup> Far less consensus exists about the quality of care delivered in such settings.<sup>4,5</sup> Our own research has shown that recently discharged patients are at higher risk of experiencing unmet need during the transition to the community than either their counterparts who remain in institutions, or those who have been established in the community for some time.<sup>6</sup> In addition, it has long been recognized that, as greater numbers of patients are removed from mental hospitals, the objective burden experienced by families of such patients increases.<sup>7</sup> 'Even when mentally ill individuals are not residing in the same house as their family, their very presence in the community may place a great burden on the family' (5; p. 81), and it may be necessary to provide additional support in some form to families to relieve these burdens.<sup>8</sup>

In this paper, we examine the extent to which friends and family of former mental hospital patients assume informal care-giver roles during the patient's transition to the community after discharge. We focus on recently discharged patients because the process of institutionalization and discharge can disrupt established care supports, placing these patients at particularly high risk for unmet need. We do not attempt to value these contributions (either in terms of opportunity cost to the care-giver, or of value to the

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patient), but seek to document who in the patient's social network assumes such roles and the form such care-giving takes. Specifically, our objectives are (i) to identify what factors affect a person's decision to assume a care-giver role, including the participation of other network members in care-giving; (ii) to identify what factors influence whether care-giving is provided in time or direct purchase of care and (iii) to determine how the patient's treatment location affects the decision of the network member to assume any care-giving role.

The remainder of the paper is organized as follows. First, we review the literature on the extent of informal care-giving and factors influencing the supply of informal care. Second, we describe our study setting, the data collected and the model used to measure the impact of various factors on informal care-giving. Finally, we present our results, and conclude with a discussion of possible policy implications of our findings.

## Literature Review

There is an extensive literature on informal care-giving for the frail elderly. It is not obvious, however, that such investigations can be extrapolated to people with other chronic illnesses, such as severe mental disorders. Mental illness has an irregular and unpredictable etiology, and is often associated with behavioural problems, neither of which encourages a commitment to informal care-giving. In addition, care-givers are more likely to be parents than offspring of patients, and the alternate care options available to persons with severe mental illness differ from standard eldercare. With these caveats in mind, we review the literature to obtain an idea of (i) the extent of informal care-giving for people with mental illness, (ii) the impact of treatment location on informal care-giving and (iii) factors which have been found to affect the supply of informal care for various types of patient.

Franks<sup>9</sup> conducted a survey of 408 members of the National Alliance for the Mentally III (NAMI), all of whom had family members with severe mental illnesses. She found family contributions to care were extremely high, and limited only by family resources. Rice *et al.*,<sup>10</sup> using Franks' most conservative estimates to extrapolate to the US population in 1985, valued the families' total contribution to care of persons with mental illness at \$2.5 billion. Franks also found family contribution depended on patient treatment location: families contributed, on average, \$4422 in money and \$10 738 in time to caring for patients residing at home, but only \$2059 in money and \$5588 in time when the patient resided in a public facility. Such a finding suggests there may be substitution between formal and informal care for the severely mentally ill.

The generalizability of Franks' results is suspect, however. First, since her sample was limited to NAMI membership, her estimates of contributions may be higher than would be found in the general population which may be less active on behalf of patients. Clark and Drake<sup>11</sup> found, by contrast, that families spent little on medical care for their mentally

ill family members (although this may have been because their analysis was based on a group of patients enrolled in a generously funded public treatment program). Second, Franks limited her analysis to care provided by family members, and thus may have excluded significant contributions made by non-familial members of the patients' social networks.

Two recent studies have examined the impact of treatment location on informal care-giving. Knapp *et al.*<sup>3</sup> found family costs were consistently higher when patients were placed in the community rather than in-patient care facilities (although the differences were not statistically significant 20 months after discharge). Tessler and Gamache<sup>12</sup> examined the contributions made in time to care-giving by persons in the social networks of recently discharged patients with severe mental illnesses. They found contributions to care depended on patient residence. In contrast to Franks'<sup>9</sup> study, they found a far greater proportion of their care-givers were minorities and economically disadvantaged. Such a finding suggests that (formerly) hospitalized patients and their care-giving networks may be substantially different from persons with mental illness who are established in the community.

Investigations of the supply of informal care-giving have focused on one of two sets of factors: the gap between patient need and formal care, and the opportunity cost of care-giving. Greene<sup>13</sup> found formal and informal care were substitutes in eldercare, and that informal care was the more sensitive to unmet patient need. In contrast, Moscovice *et al.*<sup>14</sup> found little evidence of substitution, and that formal care was more sensitive to patient need than informal care. There is also some evidence of a relationship between patient need and the form of care-giving in other patient populations. Leonard *et al.*,<sup>15</sup> in a study of families of disabled children, found care-giving in money, but not time, increased with need.

Several studies have examined the relationship between labor force participation and care-giving. Most have found a negative relationship between care-giving and employment.<sup>16</sup> Simultaneous equation models have been used to determine the direction of causality, with most studies suggesting care-giving reduces employment,<sup>17-19</sup> although there are exceptions.<sup>20</sup> These studies are flawed, however, because they restrict their analyses to samples of actual rather than all potential care-givers. Two studies which account for such selection effects, however, have generally supported the finding that care-giving reduces labor force participation.<sup>21,22</sup>

Almost all the above studies on the supply of informal care-giving are based on analyses of primary care-givers' efforts on behalf of frail elderly. Two studies<sup>19,23</sup> have shown that primary care-givers behave differently if there are other care-givers in the patient's social network. These analyses treat the participation of other care-givers as exogenous, and thereby exclude the probable interdependence of care-giving decisions by members of the patient's family and social network.

This review suggests that informal care for persons with severe mental illnesses can be significant, both as a proportion of the total care these people receive, and in terms of the

burden such care imposes on care-givers. There is, however, substantial variance in the contributions made. Thus, an examination of the factors that might explain the variation in informal care-giving is deserving of further study. Second, the social networks of persons with mental illness who have been recently discharged from hospital care may differ from those of persons with similar illnesses who are established in the community. Since such differences may affect the ability of a patient's network to provide care, analysis on this special population is warranted. Finally, it is likely that the decision to act as a care-giver depends in part on the care-giving effort of others in the patient's network. Thus, it is necessary to jointly analyze the participation decisions of all potential care-givers within a patient's social network.

## Data and Analytical Methods

### Sample

Data for this paper are taken from a longitudinal study of the closure of a state mental hospital in central Indiana. Patients and their network members were surveyed prospectively as part of the data collection effort by the Indiana Consortium for Mental Health Services Research (ICMHSR) to document the unfolding impact of the hospital's closure.

The ICMHSR received its mandate after the closure process had started, and 173 of 304 hospital residents with a severe mental illness had been discharged before this study began. Statistical comparisons of demographic (e.g., age, sex, race) and clinical characteristics (e.g., diagnoses) revealed no significant differences between patients surveyed and the total discharged population. Of the remaining 131 patients, 124 were contacted and 88 were surveyed prior to discharge (representing 67% of patients discharged after ICMHSR began collecting data, and 71% of patients contacted). Eleven patients were lost to follow-up one year post-discharge (seven respondents refused a follow-up interview, two could not be contacted, one had died and one was too ill).

Of the 77 patients interviewed at follow-up, 53 had been discharged to the community and 24 had been moved to other state hospitals. While discharge location was not randomized, only the availability of *formal* care support in either the community mental health center or mental hospital was explicitly considered in the discharge decision. The availability of informal care support apparently was not used by hospital staff in these decisions (the information on community supports reported in this paper was not available to hospital administrators at time of discharge and could not have been used in the decision process). Furthermore, no statistically significant differences in mean Global Assessment of Functioning (GAF) scores at baseline were found between the patients discharged to the community and those discharged to other state hospitals.

Patients were surveyed by trained interviewers who followed a prepared script. During the interview, patients were asked to identify the most important people in their lives. These responses defined the patient's social network.

Patients identified a total of 204 network members, averaging 2.6 network members per patient.

Ninety-eight network members were interviewed in their homes by trained interviewers following prepared scripts. The final sample represents 48% of the network members initially identified by patients (47 network referrals were considered ineligible because they were either professional care-givers or other patients in this study, 29 network members refused to participate, 20 could not be contacted, seven had died, one faced a language barrier and two others were outside the scope of the study). This sampling frame did not generate a random sample of potential care-givers. Of particular concern is the fact that the same factors which have led a network member to provide care might also have encouraged a network member to participate in this study. We adopted analytical methods which can control for such possible selection biases (see the appendix for details). The sampling frame did, however, yield a heterogeneous sample that is likely fairly representative of the social networks of similar institutionalized populations. In particular, the patients' networks may include, but, importantly, are not limited to, family members of the patient. Furthermore, networks are not limited to only actual care-givers, nor is the sample drawn from an otherwise self-selected group (such as NAMI membership).

Data from the network member interviews were then matched to data from the patient interviews. Since the number of network ties varies across patients, this creates an unbalanced panel of data for analytic purposes. Socio-demographic characteristics of patients and network members are given in **Table 1**. Network members have an average age of 51½ years, and are disproportionately female and African American. While about half of all network members are employed, median *family* income is only \$20 000–\$24 999 per year. Compared to that of Franks,<sup>9</sup> our sample of potential care-givers is noticeably younger and at greater socio-economic risk. Patients tend to be younger than network members (average age of 43 years). While less than 10% of patients report having a partner, one-third reported having children. Patients are disproportionately male and African American.

### Dependent Variables

Participation in care-giving activities is represented by two binary variables,  $t_{ij}$  and  $e_{ij}$ .  $t_{ij}$  takes on a value of 1 if network member  $j$  reports he/she regularly spends any time taking care of patient  $i$  because of his/her illness; 0 otherwise.  $e_{ij}$  takes on a value of 1 if network member  $j$  reports regularly buying or paying out-of-pocket any positive amount for room and board (housing and/or groceries), medical care (including personal care) or sundries (including clothing and other purchases) for patient  $i$ ; 0 otherwise. Because our definitions are based on *regular* contributions to patient care, we expect the frequency of informal care-giving observed in our study to be less than in studies where occasional contributions are also considered.

**Table 2** reports the proportion of network members

Table 1. Characteristics of patients and network members

	Network members (n = 98)	Patients (n = 77)
Married/cohabiting	46/97 (47.4%)	6/77 (7.8%)
Has children	79/97 (81.4%)	25/74 (33.8%)
Age (mean, in years)	51.46	42.83
Gender (female)	68/98 (69.4%)	17/77 (22.1%)
Race (African American)	41/97 (42.3%)	31/77 (40.3%)
Family income (median)	\$20 000–\$24 999/year	N/A
Works full-time	38/98 (38.8%)	1/77 (1.3%)
Works part-time	15/98 (15.3%)	12/77 (15.6%)

Table 2. Care-giving by network members

	All network (n = 98)	Family* (n = 81)	Non-family* (n = 16)	Community† (n = 55)	Hospital‡ (n = 34)
Time	13/98 (13.3%)	12/81 (14.8%)	1/16 (6.3%)	12/55 (21.8%)	1/34 (2.9%)
Expenditure	35/98 (35.7%)	32/81 (39.5%)	3/16 (18.8%)	19/55 (34.5%)	12/34 (35.3%)
room and board	6/98 (6.1%)	6/81 (7.4%)	0/16 (0%)	2/55 (3.6%)	2/34 (5.9%)
medical	1/98 (1.0%)	1/81 (1.2%)	0/16 (0%)	0/55 (0%)	0/34 (0%)
sundries‡	34/98 (34.7%)	31/81 (38.3%)	3/16 (18.8%)	19/55 (34.5%)	11/34 (32.4%)

\*One network member did not report family status vis-a-vis the patient.

†Nine network members were linked to one of eleven patients lost to follow-up.

‡Excludes three network members associated with two different patients who reported buying only birthday/Christmas gifts for the patient.

engaged in care-giving activities by type of activity. Forty-one per cent of network members provided some level of informal care, with 13.3% providing some care in time, and 35.7% providing some care through direct expenditures. Most expenditures were for basic living expenses (only one network member reported paying for medical treatment for a patient). This may have been due to the fact that these patients were treated within a fully funded public program. Network members in our sample were more likely to provide some care in either form if they were related to the patient. Finally, network members in our sample were more likely to provide some care in time if the patient was discharged to the community than another state hospital.

### Independent Variables

The decision to provide informal care depends on the costs to the network member of providing such care, the benefits to the patient of receiving such care and the value the network member places on the patient's well-being. The costs of informal care-giving depend on the opportunity costs forgone in time (from work and other household activities) and income. Factors which influence these costs are specific to the potential care-giver. Benefits depend on patient needs, and the ability of informal care to meet these needs. Thus, in addition to variables which capture care-

giver abilities, benefits will also depend on variables which reflect patient-specific need. The network member may benefit from an externality effect when the patient receives care. These externalities may be either purely altruistic in nature (the network member is better off because the care provided makes the patient better off) or paternalistic (e.g., the network member provides care to control the patient's symptoms, which makes the network member better off regardless of the impact on the patient's level of well-being). In either care, this externality effect will depend on the degree of connectiveness between the network member and the patient.

Thus, we divide our independent variables into three groups: network-member-specific variables, patient-specific variables, and an externality variable. These variables are described in **Table 3**. Because income and employment are potentially endogenous to our model, being determined jointly with any care-giving decision by the network member, they are not included in the reduced form specification. Instead, we include variables which proxy the productivity of the network member in domestic and labor market activities. These include network member age, gender and mental health. (We also considered whether the network member had at least 12 years of schooling and whether the network member reported his/her physical health as very good or better, but dropped these from the model since

Table 3. Data dictionary

Variable	Definition	Expected sign	
		Care in time	Care in expense
Patient characteristics			
average GAF	patient's average GAF score during follow-up surgery	–	–
drug/alcohol diagnosis	patient has a primary diagnosis of alcohol/drug abuse (ICD-9 303, 304, 305)	+	–
discharged to hospital	patient discharged to hospital = 1; 0 otherwise	–	–
patient gender	patient is female = 1; male = 0	?	?
patient race	patient is African American = 1; other = 0	?	?
patient employment	patient is employed = 1; not employed = 0	?	?
Network member characteristics			
network gender	network member is female = 1; male = 0	?	?
network age	network member age in years	?	?
network GAF	network member GAF assessed at end of survey	+	+
travel time	time it takes for network member to reach patient	–	+
perceived unmet need	care-giver believes patient has needs not met by professionals	+	+
Externality variable			
family	care-giver reports being related to patient	+	+
Specification variables			
$\rho$	correlation parameter across network members' care-giving decisions	complements > 0	substitutes < 0
Mills	Inverse Mills' ratio to correct for possible selection effects	?	?

neither variable was found to be statistically significant.) We also include the time the network member reports it takes to reach the patient to capture the relative cost of providing care in time rather than money. Lastly, we include a measure of unmet need experienced by the patient as perceived by the network member. Unmet need is represented by a binary variable which takes on a value of 1 if the network member believed the patient had needs in any of seven areas, including housing, employment, medications, therapy, daycare, welfare, training programs, support groups or family care, that were not being met by professional care-givers; 0 otherwise.\* While unmet need is experienced by the patient and would normally be considered a patient-specific variable, it is the perception of unmet need by the network member which influences the network member's decision on whether or not to provide care.

Patient variables are meant to capture the underlying health condition and need for care that informal care-giving activities might mitigate. These include whether or not the patient was diagnosed with a current alcohol or drug related problem (ICD-9 codes 303, 304 or 305), and the patient's

\* This definition of unmet need as needs not met by professional care-givers is used rather than unmet need overall because the latter is obviously endogenous to our model (i.e., unmet need overall accounts for any needs met by informal care-givers).

Global Assessment of Functioning (GAF) score, averaged over the three points in the interview process when GAF scores were recorded. (We also considered the effects of a diagnosis of schizophrenia and the presence of other chronic comorbidities, but dropped these from the specification when neither was found to be statistically significant.) We include socio-demographic variables that capture possible differences in need for care, including patient gender, race and employment. Lastly, we include a variable which identifies whether the patient was discharged to the community or another state hospital to determine how discharge location affects the care-giving decisions of network members. Because the patient and network member were co-resident in only one instance, we could not include joint residence as an independent variable. Our findings, however, are invariant to the inclusion/exclusion of this case.

The strength of the externality effect of patient's health on the network member is proxied by whether or not the two belong to the same family. We assume that family ties increase the externality effect (i.e., that family members will place a higher value on the patient's well-being than non-family members).

Patient and network member characteristics, including those used in the multivariate analysis, are reported in **Tables 4 and 5**. These have been stratified by care-giving

Table 4. Network member characteristics by care-giving status

	No Care (n = 58)	Any care (n = 40)	Care in expense (n = 35)	Care in time (n = 13)
Age (mean, in years)	52.8	49.6	49.9	53.1
Gender (female)	60.3%	82.5%	80.0%	92.3%
Race (African American)	40.4%	45.0%	40.0%	38.5%
Married/cohabiting	50.0%	43.6%	42.9%	58.3%
≥ 12 years in school	78.9%	67.5%	71.4%	69.2%
GAF (mean)	78.2	81.6	81.5	82.9
Physical health (very good or better)	68.4%	64.1%	67.6%	66.7%
Family income (median)	\$20 000–\$24 999	\$25 000–\$29 999	\$25 000–\$29 999	\$60 000+
Work full-time	36.2%	42.5%	45.7%	30.8%
Work part-time	15.5%	15.0%	17.1%	7.7%
Unmet patient need	8.6%	35.0%	37.1%	62.5%

Table 5. Patient characteristics by care-receiving status

	No care (n = 51)	Any care (n = 26)	Care in expense (n = 22)	Care in time (n = 11)
Age (mean, in years)	45.4	40.8	41.2	40.0
Gender (female)	8.3%	29.2%	25.0%	36.4%
Race (African American)	33.3%	50.0%	45.0%	36.4%
Married/cohabiting	1.7%	12.5%	10.0%	9.1%
GAF (mean)	58.8	52.8	53.3	53.5
Schizophrenia diagnosis	58.3%	87.5%	90.0%	81.8%
Drug or alcohol diagnosis	25.0%	20.8%	20.0%	27.3%
Community discharge	54.2%	70.8%	65.0%	90.9%
No. of network responses (mean)	1.6	2.1	2.2	1.9
No. of care-givers (mean)	0	1.5	1.6	1.2

and care-receiving status. Based on these percentages, care-giving is more likely to be provided by network members in our sample who are female, who have higher incomes and who perceive an unmet patient need. Care is more likely to be received by patients in our sample who are younger, female, African American, married or are residing in the community. Not surprisingly, the number of care-givers is correlated with the number of network members surveyed for each patient in our sample.

### A Panel Model Specification

In economics, models of families' market and household production are now well developed.<sup>24</sup> These models assume, however, that family members coordinate their efforts to achieve a common set of goals (25; ch. 2). The members of a patient's network, while connected to the patient, need not be connected to each other. There is little reason to believe that all network members' activities would be coordinated beyond caring for the patient. Thus, it is unreasonable to assume that members of patient networks would operate on such a mutual basis, particularly when not all network members share familial ties.

In contrast, studies of care-giving behavior in the health services literature have either ignored the possible interdependence of informal care-giving decisions within patient

networks, or assumed that informal care-givers treat the care-giving activities of others as exogenous.<sup>19,23,26,27</sup> We believe that, while care-giver activities may not be perfectly coordinated, there may still be possible interactions between (potential) care-givers since the benefits of any one member of the social network contributing care may depend on the amount and type of informal care provided by other network members.

We adopt an innovative empirical specification which is capable of accounting for such possible interdependences. We treat our data as an unbalanced panel with patients and potential care-givers as the two dimensions of the panel. The panel is unbalanced because the number of network members associated with each patient varies across patients. We then estimate the care-giving relationships using a multivariate probit model (multivariate in the sense that the choices whether or not to provide care in either form by all network members associated with a particular patient are grouped in the analysis to form a multivariate binary dependent variable). This model is described more fully in the appendix. Such a model allows us to estimate not only how the decision to provide any care in either form by a given network member depends on the characteristics of the patient and that particular network member, but also the extent to which such decisions depend on the care-giving activities assumed by other network members associated

with the same patient. This possible interdependence of care-giving activities within a patient's network is captured by the correlation coefficient in the multivariate probit model. If the decision of one network member to provide care decreases (increases) the likelihood that other members provide care, the correlation coefficient will be negative (positive).

For instance, suppose a network consists of a parent and a sibling of the patient. If the sibling adopted a position that he/she would only provide care when the parent was unable to do so (i.e., the sibling adopted a role of respite care-giver for his/her parent), the correlation coefficient would be negative because the one network member would be less likely to provide any care when the other network member provided care. If, instead, the patient's network consisted of two siblings, we might observe care-giving allocations motivated by a fairness principle. In this case, one sibling might be more likely to assume a care-giving role when the other sibling does so in order to more equitably share the informal care-giving burden. In this case, the correlation coefficient would be positive.

## Results

The results of the multivariate analysis are reported in **Table 6**. These results are based on the sample of 98 network members for whom data were available. These potential care-givers were matched with 54 patients. As in all binary choice models, the coefficient estimates cannot *directly* be interpreted as the marginal effects of the variables on the probabilities of providing care (as is the case with a standard linear regression model). In probit models, however, the sign of each coefficient is consistent with the sign of the marginal probability (e.g., if the coefficient is positive, increases in the corresponding variable result in a higher probability that some care will be provided). The effects of the independent variables on care-giving are most easily seen if the estimated coefficients are used to calculate the predicted probabilities of any care-giving being provided in either form for different network member and/or patient characteristics. The sign of  $\rho$ , the correlation coefficient, has a very particular interpretation in this case since it reflects how the care-giving decisions of the different members of a patient's network interact. When  $\rho$  is positive, care-giving between network members is complementary; when it is negative, care provided by different network members are substitutes; a zero value indicates care-giving decisions of network members are not conditioned by the participation of other network members in informal care.

The most statistically significant variable in the expense equation is care-giver perceived unmet patient need (which occurs when the care-giver assesses a patient need which is not met by professional care-givers). Based on these coefficient estimates, we predict a network member will be 2.8 times more likely to provide informal care in the form of monetary outlays when he/she perceives a need that is unfilled by professional care than when he/she does not perceive such a gap. Other patient characteristics, including

Table 6. Multivariate probit analyses of care-giving in expense and time (*t*-statistics in parentheses) (*N*=98)

Variable	Care in expense [Pr( $e_{ij}=1$ )]	Care in time [Pr( $t_{ij}=1$ )]
Constant	-4.581** (-1.997)	-7.246* (-1.857)
Average GAF of patient	-0.010 (-0.707)	-0.002 (-0.120)
Drug/alcohol diagnosis	-0.396 (-0.802)	0.134 (0.205)
Discharged to hospital	-0.137 (-0.264)	-2.920* (-1.809)
Patient gender	0.336 (0.638)	1.771** (2.460)
Patient race	-0.315 (-0.763)	-0.727 (-1.348)
Patient employment	0.269 (0.497)	1.883* (1.796)
Network member gender	0.528* (1.698)	2.363** (2.270)
Network member age	-1.712 (-1.556)	0.853 (0.476)
Network member GAF	0.047** (2.219)	0.044 (1.232)
Travel time	0.507 (1.239)	-0.983 (-1.508)
Perceived unmet need	1.104** (2.983)	2.044** (2.562)
Family	1.010** (2.216)	0.512 (0.552)
$\rho$	0.871** (2.138)	0.070 (0.121)
Mills	0.684 (0.666)	-1.301 (-0.860)
Log likelihood	-44.34	-21.15

\*\* $p < 0.05$ ; \* $p < 0.10$ .

health status variables and discharge location, are not statistically significant after controlling for perceived unmet need. The most statistically significant network member characteristics are mental health and gender. Network members with higher functioning scores are significantly ( $p < 0.05$ ) more likely to provide some care in expense than network members with lower function scores (this may be an income effect, since GAF scores are highly correlated with employment). Female network members are marginally significantly ( $p < 0.10$ ) more likely to provide any care in expense than male network members. If the network member is related to the patient, he/she is significantly ( $p < 0.05$ ) more likely to provide some care in the form of expense. Given the statistical significance of this variable, we can infer that informal care-giving in out-of-pocket expense is strongly motivated by an externality effect. Finally,  $\rho$  is positive and statistically significant ( $p < 0.05$ ) in this equation. This finding suggests that the probability that one network member engages in care-giving in out-of-pocket expense increases if other network members make any such expenditures, i.e., care-giving in expense is complementary across network members.

As with care-giving in expense, network member perceived

unmet need is the most statistically significant variable explaining the decision whether or not to provide any care in time: based on the coefficient estimates given in Table 6, we predict care-giving in time will be 20.8 times more likely when unmet need is perceived by the network member than otherwise. While other patient health status variables are not statistically significant once we control for perceived unmet need, discharge location remains marginally significant ( $p < 0.10$ ). A network member is more likely to provide some care in time if the patient resides in the community rather than in a state hospital ( $p < 0.10$ ). This suggests that patients who are discharged from hospital care can place a burden on network members even when their medical treatment is covered by a fairly generous public program. The only other statistically significant variables are gender, of both patient and network member. Some care-giving in time is more likely to occur when both the network member and the patient are female ( $p < 0.05$  in either case). Finally,  $\rho$  in this equation is not statistically significant. This suggests that the decision whether or not to provide care in time is independent of other network members' care-giving decisions.

In contrast to the equation describing care-giving in expense, care-giving in time does not appear to depend on whether or not the network member and patient are related. We have no explanation for this apparent difference in the sensitivity to altruistic motive by type of care-giving. Although not statistically significant, other differences across the two equations with respect to patient diagnosis, time it takes the network member to reach the patient and network member age are notable. Network members are slightly more likely to provide care in the form of time rather than expense if the patient has a current diagnosis of an alcohol or drug problem. Not surprisingly, network members who are further away from patients are more likely to give care in money rather than time. Finally, older network members are more likely to provide care in time, while younger network members are more likely to provide care through direct expenditure.

There are three limitations of this research deserving of comment. First, the study is not based on an experimental design. This raises three issues. Our findings are based on a sub-sample of all patients discharged from the hospital studied, and we must exercise caution when interpreting our results for other populations. However, since no significant differences were found between the patients surveyed for this study and the rest of the discharged population, we believe our findings apply to similar groups of institutionalized and severely mentally ill persons. Patients also were not randomized to discharge locations. However, since it appears community ties were not used to determine discharge location, endogeneity problems are unlikely to have arisen. Network members were not randomly sampled either, which could create problems if a network member's willingness to engage in care-giving activities also affects his/her willingness to participate in this study. Statistical controls for such effects suggest they had a negligible impact on our overall findings: the inverse Mills ratio was not

found to be statistically significant in the multivariate probit analysis.

Secondly, we were limited in our analysis by constraints imposed by sample size. We were unable to instrument for income and employment, the standard measures of the opportunity cost of money and time, respectively. Instead, our analysis is based on a reduced form where patient characteristics which affect household and market productivity are included in the empirical specification without reference to an explicit structural model to explain the nature of the relationships involved. The sample size also creates potential problems with respect to statistical power.

Finally, our measures of care-giving do not quantify the amount of care given by network members to patients. This limits the policy implications we are able to infer from our results since we cannot measure the burden assumed by care-givers, or measure the degree of substitution between formal and informal care. Nevertheless, our findings are informative for identifying network members who are likely to participate in care-giving activities at any level, and suggest that further research which measures the size and effects of such contributions is warranted.

## Discussion

We had three goals in this analysis. First, we wanted to identify any factors that might explain the decision to participate in informal care-giving. Second, we wanted to identify those factors that would influence the decision whether to provide care in time or money. Finally, we wanted to identify how the informal care-giving behavior of patient networks differs between patients discharged to the community and those transferred to other state hospitals.

Our most significant finding is the positive relationship between participation in informal care-giving and the perception by the potential care-giver of patient needs not being met by professionals. The responsiveness of network members to perceived unmet need bespeaks the importance of informal care when the continuity of formal care cannot be assured. Further analysis is required to determine whether network members' perceptions of unmet need are accurate, and means by which network members can be made better attuned to actual unmet needs experienced by the patient.

We also find that the decision to provide informal care is sensitive to the level of informal and formal care received by the patient. We find that care-giving in expense is positively related to the care-giving decisions of other informal care-givers, but that care-giving in time is not. However, we find that network members are more likely to provide care in time if the patient has been recently discharged to the community, although we find no such pattern exists with respect to care provided as direct expense. This finding suggests there may be some substitution of formal and informal care when patients are discharged from institutions.

Further research is needed to determine the generalizability of these findings to other severely mentally ill populations. In particular, as downsizing of institutional care continues,

patients discharged are likely to be more severely mentally ill and to have experienced longer tenures within institutions than patients who have been discharged in the past. Such research is warranted because our results suggest the transfer of persons with severe mental illnesses from state hospitals to the community may shift the care burden between formal and informal providers. If this is the case, discharge criteria should include such factors as the community resources available to the patient.

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## APPENDIX

### Empirical Model of Informal Care

Assume that, for each patient,  $i$ , there is a social network with  $J(i)$  members (where  $J(i) \geq 0$  to allow the possibility that some patients have no network ties). Each member,  $j$  ( $j=1, \dots, J(i)$ ), of the social network is considered to be a *potential* care-giver, where care may be provided either in time devoted to care-giving ( $t_{ij}^*$ ), or as direct expenditure on patient support ( $e_{ij}^*$ ). In our analysis, both time and expense are binary variables (i.e., we do not attempt to measure the amount of care provided, just whether or not any care was provided in either form). Thus, our analysis will indicate the factors which affect the propensity to provide any informal care, but not the effect of these factors on the amount of care provided. Independent variables include network member characteristics,  $x_{ij}$ , patient characteristics,  $z_i$ , and an externality variable,  $\lambda_{ij}$ , which measures how strongly improvements in the health status of patient  $i$  affect the well-being of potential care-giver  $j$ .

Our empirical specification is chosen to address three statistical issues. First, because some of the factors which may explain a network member's willingness to engage in informal care-giving may also affect his/her willingness to participate in this study, our results may be subject to selection bias. To correct for such possible effects, we use a Heckman two-step selection model.<sup>28</sup> The estimates from the first stage of this analysis are used to calculate a selection correction factor, the inverse Mills ratio, which is included in the multivariate probit model which predicts the care-giving activities of network members. The inverse Mills ratio is calculated from an equation which predicts whether or not each of the 77 patients was matched to any positive number of network members in the community. Explanatory variables include patient age, patient perceived unmet need, average Global Assessment of Functioning (GAF) score, a current drug or alcohol abuse diagnosis, discharge location, frequency of contact with family prior to closure of the state hospital and patient gender, race and employment. The results of this equation are reported in **Table A1**.

Second, because both our dependent variables have a binary structure (taking on a value of one if there is any care-giving activity, zero otherwise), we use a probit model to estimate the two relationships. Thus, the propensity to participate in care-giving by network member  $j$  ( $j=1, \dots, J(i)$ ) for patient  $i$  ( $i=1, \dots, N$ ) by providing care in either time,  $t_{ij}^*$ , or direct expenditure,  $e_{ij}^*$ , is expressed:

$$t_{ij}^* = \alpha_1 + x_{ij}\beta_1 + z_i\gamma_1 + \lambda_{ij}\delta_1 + u_{1ij} \quad (\text{A.1})$$

where

$$t_{ij}^* = 1 \text{ if } t_{ij}^* > 0 \\ = 0 \text{ otherwise}$$

$$e_{ij}^* = \alpha_2 + x_{ij}\beta_2 + z_i\gamma_2 + \lambda_{ij}\delta_2 + u_{2ij} \quad (\text{A.2})$$

where

$$e_{ij}^* = 1 \text{ if } e_{ij}^* > 0 \\ = 0 \text{ otherwise;}$$

where  $u_{kij}$  ( $k = 1,2$ ) are  $N(0,1)$  error terms. We assume independence between the decision to provide care in time and by direct expenditure ( $E(u_{1ij}, u_{2ij}) = 0$  for each  $\{i, j\}$  pair). Thus, the equations for care-giving in time and expense are estimated separately. We tested the robustness of this independence assumption using a bivariate probit model to estimate the interdependence of the decision to provide care in either form by individual network members. We found the correlation in error terms between equations (A.1) and (A.2) to be very small and not statistically significant. Such a finding supports the independent treatment adopted in this analysis.

Third, we account for possible interaction between (potential) care-givers by treating our data as an unbalanced panel with patients ( $i$ ) and network members ( $j$ ) as the two dimensions of the panel. We assume there is no interaction between members of different patients' network groups, i.e.,  $E(u_{kij}, u_{ki'j}) = 0$ , but allow for interaction within a

Table 7. Stage 1 estimation for selection model. Pr(patient has a network member surveyed = 1) (*t*-statistics in parentheses) (*N* = 77)

Variable	Definition	Coefficient ( <i>t</i> -statistic)
Constant	intercept	-0.447 (-0.606)
Patient age	age of patient in years	2.062* (1.762)
Any unmet need	patient assesses need for either treatment or living assistance not met by professionals	-0.341 (-1.152)
Average GAF of patient	patient's Global Assessment of Functioning score, averaged over three points in survey process when taken	-0.004 (-0.512)
Hospital	patient is discharged to a state hospital = 1; patient discharged to community = 0	0.531* (1.806)
Drug/alcohol diagnosis	patient has a primary diagnosis of current alcohol or substance abuse (ICD-9 303, 304, 305)	0.173 (0.534)
Contact	patient has contact with family at least once a week prior to hospital closure	0.952** (3.227)
Patient gender	patient is female = 1; male = 0	-0.337 (-1.012)
Patient race	patient is African American = 1; other race = 0	0.054 (0.208)
Patient employment	patient is employed = 1; unemployed = 0	-0.399 (-1.099)
Log likelihood		-66.325

\*\**p* < 0.05; \**p* < 0.10.

patient's network group, i.e.,  $E(u_{kij}, u_{kij'}) = \rho_k$ . These assumptions satisfy the sufficient condition for identification of such panel models.<sup>29</sup> Then, for a patient's network group of size  $J(i)$ , the joint density of  $[u_{ki1}, u_{ki2}, \dots, u_{kiJ}]$  is a multivariate normal, MVN ( $\mathbf{0}, \Sigma_k$ ), where

$$\Sigma_k = \begin{bmatrix} 1 & \rho_k & \cdot & \cdot & \cdot & \rho_k \\ \rho_k & 1 & & & & \cdot \\ \cdot & & \cdot & & & \cdot \\ \cdot & & & \cdot & & \cdot \\ \rho_k & \cdot & \cdot & \cdot & \cdot & 1 \end{bmatrix}_{J(i) \times J(i)}$$

resulting in an unbalanced panel probit model. Note that while the normal distribution which underlies the probit model generalizes to the multivariate case, no such generalization is possible for the logistic regression.

This multivariate probit model is programmed in SAS IML to generate estimates of both the coefficients on the independent variables as well as the correlation coefficient.

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