

Determinants of Need and Unmet Need among Cancer Patients Residing at Home

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Dehospitalization of cancer treatment, particularly for those with advanced disease, can complicate adjustment and strain the capacity of caregiver networks to meet patients' daily needs. Outpatient staff should be able to recognize patients who need help to meet their daily needs as well as those who are not getting enough help. This study describes the physiological and social determinants of need and unmet need for assistance among 629 cancer patients with advanced disease initiating a course of outpatient chemotherapy and/or radiation therapy. Areas of needs examined through telephone interviews with participating patients were: personal care, instrumental tasks (housework, shopping, and cooking), and transportation. Physiological factors (metastases, disease stage, and functional status) were associated with need for assistance in all three areas. Also, older age (over 65) and low income predicted need for help with personal care, and women were more likely than men to report illness-related need for assistance with instrumental tasks and transportation. Unmet need was primarily associated with patients' social support system (e.g., children living nearby and perceived resiliency of network helpers). These findings highlight the need for outpatient staff to evaluate patients' informal care resources as well as patients' symptoms and impairments in deciding who should be referred for home care services.

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The trend toward dehospitalizing medical care that characterized the 1980s is likely to continue into the 1990s and beyond, as reimbursement pressures continue and diagnostic and treatment technologies are further improved (Mor, Guadagnoli, and Wool 1987; Russell 1989). Transfer of treatment from inpatient to outpatient care is evident in the context of cancer therapy, where complex chemotherapy and radiation treatment protocols are administered increasingly in outpatient hospital clinics and physicians' offices. Similarly, use of oral chemotherapeutic agents and vascular access devices, as well as pumps for continuous infusion, have made the administration of some chemotherapeutic regimens at home more common (Cawley 1990; Kaluzny, Ricketts, Warnecke, et al. 1989; Yasko and Rust 1989; Mor, Stalker, Gralla, et al. 1988). With the shift away from the acute hospital as the locus of care, the boundaries of the health care system are expanding to include the home setting.

The burden of care during recovery from outpatient cancer treatment may be considerable. Although people react individually to treatment, nausea, vomiting, and exhaustion are experienced by the majority of patients receiving chemotherapy; diarrhea, mouth sores, and eye problems are also common (National Cancer Institute 1985; Love et al. 1989; Goodman 1989; Knobf 1990). Duration of symptoms also differs among patients, but some of the symptoms may be virtually continuous (National Cancer Institute 1985). Similarly, depending on the area irradiated, side effects from radiation treatment may include nausea, diarrhea, breathlessness, coughing, skin problems, and an array of other symptoms (Lipsztein, Dalton, and Bloomer 1985; Lancaster 1989; Grant 1990). Unlike chemotherapy, which is often administered as one treatment in cycles spaced two to four weeks apart (Love et al. 1989), radiation is generally administered on consecutive days of the week for periods ranging from two to seven weeks. Symptoms may last until several weeks after treatment has ended (National Cancer Institute 1990).

Despite patient differences in physiological reaction to cancer treatment, fatigue is universal and patients are cautioned to relinquish daily responsibilities to families and friends as necessary (National Cancer Institute 1985, 1990). Tasks of everyday living, such as cooking meals and shopping for groceries, may suddenly present a challenge to the cancer patient undergoing treatment (Grobe, Ahmann, and Ilstrup 1982; Wool et al. 1989). Even routine personal care, such as bathing and dressing, may become difficult or impossible to accomplish without the assistance of a helper (Guadagnoli and Mor 1991).

Results of surveys of cancer patients in treatment indicate that

families assume most of the burden of patient care at home (Mor, Stalker, Gralla, et al. 1988). However, there is some evidence that sufficient help in meeting disease- and treatment-related needs and problems is not always available. Nearly one-fifth (19 percent) of a sample of cancer patients in active outpatient chemotherapy treatment ($N = 395$) reported at least one unmet need in the domain of instrumental activities, defined to include chores, errands, transportation, and home health tasks. A lower proportion (4 percent) had insufficient assistance in difficulties with bathing and mobility, as well (Mor, Guadagnoli, and Wool 1987). A study in which 629 persons selected from the Pennsylvania Cancer Registry were interviewed revealed that 59 percent of the patients had experienced at least one unmet need since diagnosis (Houts, Yasko, Kahn, et al. 1986).

We investigated the impact of physiological and social factors on cancer patients' need for assistance with daily activities and whether those needs were being met. Separate domains of need were assessed, since the factors associated with meeting patients' personal care needs might differ from those associated with meeting their household management or transportation needs.

METHODS

Cancer patients' home care needs data were collected as part of a study of the home care needs and services used by cancer patients initiating chemotherapy or radiation therapy in Central Pennsylvania (the practices of 37 physicians serving 34 mostly rural counties); Rhode Island (three hospital-based clinics and three private oncology practices); and New York City (the Memorial Sloan Kettering Cancer Center). Patient eligibility criteria were selected to identify patients with at least a six-month survival prognosis, but who were likely to experience functional impairments due to treatment complications or disease progression. Criteria were 21 years of age or older with nonlocalized, recurrent, or inoperable cancer, and solid tumors of the gastrointestinal tract, genital-urinary organs, breast, lung (all stages), or head and neck as primary disease sites. In addition, patients with Hodgkins disease or non-Hodgkins lymphoma were included.

Eligible patients were identified at the offices and outpatient clinics of participating physicians and hospitals upon initiation of a course of treatment. Eligible patients were mailed a letter informing them of the study and asking for their participation. They were contacted by research interviewers shortly after treatment initiation to increase the

likelihood that the interviews would take place while the patients were still undergoing treatment. All but 45 (7.3 percent) patients were either in the midst of a course of treatment or had ended treatment within 14 days before their interview. A random half of patients were recontacted for a follow-up interview at three months postbaseline, and the remainder of the sample at six months postbaseline. This article presents the results of analyses of patients' needs and unmet needs reported in the baseline interview.¹

Ninety-two (14.6 percent) of the final baseline number of patients were "too ill" to respond to the telephone interview, and a proxy respondent was identified to serve as an informant about the patient's condition (three-quarters of the time this was a spouse or family member). Proxy respondents were in a good position to characterize patients' functioning, the presence of symptoms, and patients' dependence in daily activities. However, proxy respondents were not asked subjective questions about the resiliency of patients' informal support systems. Additionally, questions about whether patients had unmet needs might not have been interpreted in the same way by proxies as by patients. Consequently, analyses of patients' unmet needs exclude proxy data.

DEPENDENT VARIABLES

As part of the initial interview, we asked patients about assistance received with specific tasks, based on the Index of Activities of Daily Living (ADL) (Katz and Akpom 1976), and on the Scale for Instrumental Activities of Daily Living (IADL) (Lawton 1971). We categorized individual activities into three domains, based on implications for service delivery: personal activities (bathing and dressing, combined into one question), instrumental activities (meal preparation, light housekeeping, heavy housekeeping, shopping), and transportation (to the doctor and for general purposes).

Need for Assistance

We classified patients who reported either having help with a task due to illness, or who reported having difficulty performing a task by themselves, as having need for assistance in that domain of activities. For example, a patient who reported receiving help with cooking because of illness and/or the side effects of treatment was classified as having need for assistance in the domain of instrumental activities (although a patient who reported that he had always received help was not classified as needing assistance).

Unmet Need

Similarly, we classified patients who reported needing more help than they were getting as having unmet need for assistance in that domain.

INDEPENDENT VARIABLES

The form, definitions, and sample means of all independent variables are presented in Table 1. These variables represent constructs which prior research has shown to be related to cancer patients' needs for assistance or unmet need. The variables of interest were selected a priori for modeling these two types of outcomes. Empirical analyses were conducted on the current data set to refine the functional form of the various independent variables. In modeling need for assistance, we selected disease-related independent variables most likely to indicate potential compromise in patients' functioning. It was our intent to test a number of indicators that would be readily available to medical staff for purposes of identifying patients who might be in need of referral for service programs. Operationalization of these indicators in their selected form is explained below.

We expected that duration of disease would have an effect on patient functioning and that, in particular, patients who had lived with their disease for a year or more would manifest the cumulative, debilitating effect of treatment and disease progression. We also expected that patients with metastatic disease, that is, cancer that had spread beyond the organs of origin, were further along the disease course than patients with localized or regional cancer and thus were more likely to experience the need for help with daily activities. Since radiation treatment is administered five days a week for several weeks at a time while chemotherapy is often administered in single doses separated by weeks of "down time," we expected that radiation would have a cumulative effect on patients, resulting in greater functional impairment than that experienced by patients receiving chemotherapy.

The additive impact of cancer plus at least one other chronic illness was expected to result in greater need for assistance at home than would occur for patients without other chronic conditions. Finally, after consultation with clinicians, we decided that patients who reported three or more symptoms in the two weeks before interview, those who reported spending at least one day in bed, and those who reported restricting normal activities for the entire two-week period before the baseline interview were more likely to need help with daily activities than less compromised patients.

We examined the effect of morbidity and patients' informal sup-

Table 1: Independent Variables Used in Analyses

<i>Variable*</i>	<i>Definition</i>	<i>Sample Distribution (%)</i>
<i>Patient Demographics</i>		
Female	Patient sex is female.	54
Age 65+	Patient age is over 65.	43
Low income	Patient received or applied for one of the following: General Public Assistance, food stamps, Medicaid, or Social Security Disability Income.	21
<i>Disease Indicators</i>		
Disease duration > 12 months	Patient was diagnosed with cancer over one year ago.	38
Metastases	Patient's disease is at the most advanced stage.	59
Radiation	Patient is undergoing radiation treatment (otherwise patient is receiving chemotherapy).	57
3+ Symptoms	Patient reported three or more symptoms in the two weeks before the interview.	32
Bed days	Patient reported at least one bed day in the two weeks before the interview.	31
Activity restricted every day	Patient reported cutting down on normal activities every day in the two weeks before the interview.	40
Other health condition(s)	Patient reported at least one other chronic illness in addition to cancer.	65
<i>Social Support: Characteristics</i>		
Married	Patient is currently married.	70
Living alone	Patient is currently residing alone.	14
0-3 Helpers	Patient reported having zero to three people to turn to for help.	24
Children living nearby	Patient's adult child(ren) live within one hour's drive.	50
Low resiliency	Patient reported being not at all or only somewhat confident of family/friends' ability to personally provide help.	17

*All of the above variables are dichotomous (coded 1,0). The definition indicated applies to values 1 (0 otherwise).

port system characteristics on reported unmet need only for patients who responded to interview questions themselves and who had need for assistance in each domain. Since we restricted the sample to those in need, only the more immediate indicators of physiological status (number of symptoms and days of restricted activity) were included in the models. We selected social support variables that, as suggested in research literature on informal systems of care, may affect the adequacy of assistance received (Guadagnoli and Mor 1991; Noelker and Wallace 1985; Treas 1977). In particular, patients who are married or living with others, or both, are less likely to have unmet need for help than patients who are unmarried or living alone. Since adult children are the primary providers of informal care to disabled parents (U.S. Congress 1987; Brody 1981), patients whose children live nearby are expected to have less unmet need than patients without children living nearby.

Given the multiplicity of daily living needs that dependent patients have, we expected that patients with small informal care networks would be more likely to have unmet need than patients with larger networks. In this sample, only 24 percent of patients reported three or fewer helpers; we therefore considered three as an appropriate cutoff point, indicating a small helping network. Finally, patients who reported no (or low) confidence in the ability of helpers to provide care (low resiliency) were expected to be at greater risk of unmet need than were patients with more confidence in their helping network.

In addition to the disease and social support indicators just described, we included patient age, sex, and socioeconomic status as demographic variables likely to influence both need and unmet need. We selected age 65 as a cutoff point, since almost all Americans over age 65 are Medicare recipients and are eligible for a variety of home health services. Since approximately one-quarter of the patient sample (27 percent) refused to supply information concerning household income, we created an indicator variable of patients' likely income status based on whether they had applied for Medicaid, General Public Assistance, food stamps, or Disability Income (whether received or pending). All of these programs have eligibility tests of income and assets and, as such, application for at least one program may be a better indicator of available resources than income by itself in this mixed age and employment status sample. Measures such as this have proved to be a risk factor for poor access to health care in numerous

areas of medical and health services research (Davis and Rowland 1983).

ANALYTIC APPROACH

We first calculated the bivariate odds ratios of the likelihood of having need (and, separately, of having unmet need) as a function of the independent variables described in Table 1. Logistic regression analyses were then conducted to identify determinants of patient need for assistance in each domain, controlling for all factors simultaneously. Given the salience of proxy status to the characterization of patients' needs, we conducted multivariate analyses both with and without an indicator of proxy status separately for those without a proxy to determine whether proxy status influenced the pattern of observed relationships.

Unmet need was examined separately in the instrumental and transportation domains among patients who reported need. We used logistic regression to model unmet need after excluding those patients with a proxy respondent. No analyses were conducted of unmet need for personal care assistance since only a small number of patients had a need in this area and many of them had a proxy respondent. All variables hypothesized to have an effect were included in the models.

Phi coefficients for dichotomous variables were calculated to check for problems of multicollinearity among independent variables entered into multivariate analyses. The average inter-item phi coefficient for the clinical and morbidity variables is .12. The largest correlation (.37) was between disease duration and the presence of metastases. The average inter-item phi coefficient for the sociodemographic and support variables was .11. Except for the expected correlation between marital status and living alone (.67), all other coefficients were below .36.

To examine the possibility of "overmodeling" the data, particularly in the unmet need analyses based on a relatively small sample, we tested the stability of the multivariate adjusted odds ratios with a bootstrap sampling technique to estimate the coefficients derived from conducting 100 replications of each logistic regression model. For each replication, we drew the requisite number of cases per model by sampling with replacement (e.g., cases could be represented more than once). The variance and standard error of each regression coefficient was averaged over all replications as a means of determining the stability of the observed effects to changes in sample composition.

RESULTS

A total of 1,004 eligible patients were identified at participating outpatient offices and clinics, and 629 (62.6 percent) of these agreed to participate and completed the initial patient interview. Patient refusal or family refusal to allow access to the patient were the primary reasons for nonparticipation ($N = 226$; 22.5 percent). Physicians refused access to an additional 33 (3.3 percent) patients, 31 (3.1 percent) died before contact, and interviewers were unable to reach 85 (8.5 percent) patients within the designated time frame, largely due to scheduling conflicts.

There were no significant differences between participants and nonparticipants in terms of age, sex, cancer type, or stage of disease at treatment initiation. However, refusals and scheduling conflicts were more prevalent in New York ($p < .001$). In addition, patients initiating a course of chemotherapy were more likely to participate in the study than patients initiating a course of radiation treatment ($p < .05$).

Ninety-two (14.6 percent) of the 629 initial interviews were completed by proxy respondents. Of these, 83.9 percent were patients' spouses, children, or other relatives. As expected, patients with proxy respondents had more bed days, more reduced-activity days, and greater likelihood of receiving radiation, presumably for palliative rather than adjuvant purposes. Proxy respondents were also more common for patients over age 65 and among men. Proxy and self-reporting patients did not have different numbers of helpers or children nearby nor were they different with respect to disease parameters (metastases or the presence of comorbidities).

SAMPLE DESCRIPTION

Table 1 describes the distribution of the sample on variables used in our analyses. Just over half (54 percent) of the sample is female and 43 percent is over 65 years of age. Slightly more than one-fifth of the patients (21 percent) report having applied for some form of public assistance, and are thus considered to have low income. Consistent with the demographics in Rhode Island and Central Pennsylvania, the vast majority of patients in the sample are white (94 percent; data not shown).

The sample has approximately equal representation of lung and breast cancer patients (22 percent and 23 percent, respectively), as well as patients with solid tumors of the gastrointestinal tract and genital-

urinary organs (20 percent each; data not shown). Eight percent of the sample have cancers of the head and neck, and 6 percent are diagnosed with Hodgkins disease or non-Hodgkins lymphoma. The majority of patients (59 percent) have metastatic disease, and over one-third (38 percent) were diagnosed a year prior to study entry. Nearly two-thirds (65 percent) report a chronic disease in addition to cancer. Reported symptom experience, days spent in bed, and days of decreased activity suggest a fairly high level of morbidity in this sample in the two weeks before interview, a period during which all were undergoing cancer treatment.

The majority of patients have some source of informal help. Only 14 percent live alone, and only 17 percent report little confidence that they can rely on their helpers to provide care. The majority of respondents (70 percent) are married, and half report that they have children living nearby.

Characterizing Need for Assistance

Approximately half of the sample reported a need for assistance with instrumental tasks (50.9 percent); a slightly higher proportion reported needing help with transportation (58.3 percent); and 14 percent of the patients reported needing help with personal care. Phi coefficients reveal moderate associations between the three domains of need (.25 to .35). The relationship between the need for assistance in each domain and independent variables was examined using bivariate odds ratios, which are present in Table 2. Statistically significant associations are those whose 95 percent confidence intervals do not include 1.0.

Patients with significant morbidity (three or more symptoms, one or more days in bed, and restricted activity every day) have increased odds of needing assistance in all three domains of activities. Metastatic patients are nearly three times as likely to need help with personal activities than are patients with regional or local disease, and are 1.5 times as likely to need help with instrumental tasks. Presence of another chronic illness increases the likelihood of need in all three domains, although the effect is stronger in the personal care and transportation domains than for household management tasks. Duration of illness also increases the odds of needing help, but the confidence intervals include 1.0 for all domains of need. Finally, patients initiating a course of radiation therapy have lower odds of needing help with instrumental tasks and transportation than do chemotherapy patients.

While older patients (65+) are nearly twice as likely to report a need for personal care, they are less likely to need help with instrumen-

Table 2: Bivariate Odds Ratios (with 95 percent Confidence Intervals) of Having Need by Selected Illness-Related and Sociodemographic Characteristics (N = 629)

<i>Domain</i>	<i>Personal</i>	<i>Instrumental</i>	<i>Transportation</i>
Percent with need	13.7%	50.9%	58.3%
Disease duration > 12 months	1.31 (0.81,2.11)	1.38 (0.99,1.92)	1.10 (0.78,1.54)
Metastases	2.79 (1.67,4.66)	1.59 (1.15,2.19)	1.21 (0.88,1.67)
Radiation (versus chemotherapy)	1.27 (0.80,2.03)	0.71 (0.51,0.97)	0.68 (0.49,0.95)
3+ Symptoms	1.86 (1.17,2.97)	2.60 (1.82,3.71)	2.32 (1.61,3.35)
Activity restricted every day	6.40 (3.76,10.89)	2.97 (2.11,4.16)	2.40 (1.70,3.39)
Bed days	3.90 (2.44,6.24)	2.52 (1.73,3.62)	3.41 (2.29,5.08)
Other health conditions	1.68 (1.01,2.82)	1.28 (0.92,1.78)	1.80 (1.29,2.53)
Age 65+	1.70 (1.07,2.68)	0.64 (0.46,0.88)	0.88 (0.63,1.21)
Female	0.98 (0.62,1.55)	4.10 (2.93,5.74)	1.57 (1.31,2.17)
Low income	2.16 (1.30,3.58)	1.80 (1.20,2.69)	1.88 (1.23,2.86)

tal tasks than are younger patients. Women are four times more likely than men to report needing assistance with instrumental tasks and twice as likely to report needing transportation help. Finally, low-income patients are approximately twice as likely as other patients to have need in all domains.

Table 3 presents the results of regressing independent variables onto need for assistance in each domain. Physiological factors were most strongly related to need for assistance in all three domains. Those with daily activity restriction in the prior two weeks were more than four times as likely to need assistance with personal care tasks than were those less restricted (adjusted odds ratio (AOR) 4.56). Patients reporting bed days in the prior two weeks were approximately twice as likely to need assistance in all domains. Metastatic disease also increased patients' odds of needing help, although the presence of another chronic disease increased only the likelihood of need for transportation.

Table 3: Adjusted Odds Ratios of Having Need for Assistance within Activity Domain

<i>Domain</i>	<i>Personal</i>	<i>Instrumental</i>	<i>Transportation</i>
Disease duration > 12 months	1.10 (0.61,1.97)	1.03 (0.67,1.57)	0.95 (0.64,1.43)
Metastases	2.21 (1.18,4.13)	1.65 (1.08,2.52)	0.99 (0.67,1.49)
Radiation (versus chemotherapy)	1.37 (0.77,2.44)	0.89 (0.59,1.35)	0.69 (0.47,1.03)
3+ Symptoms	1.44 (0.80,2.58)	1.72 (1.12,2.66)	1.48 (0.97,2.26)
Activity restricted every day	4.56 (2.50,8.34)	2.66 (1.76,4.01)	1.86 (1.26,2.75)
Bed days	2.39 (1.36,4.22)	1.64 (1.06,2.55)	2.57 (1.65,4.02)
Other health conditions	1.01 (0.54,1.90)	1.30 (0.86,1.97)	1.88 (1.27,2.78)
Age 65+	2.15 (1.17,3.94)	0.82 (0.54,1.25)	1.12 (0.75,1.66)
Female	1.10 (0.64,1.89)	5.19 (3.49,7.72)	1.61 (1.11,2.33)
Low income	2.27 (1.22,4.21)	1.51 (0.92,2.47)	1.45 (0.89,2.33)

Social factors increased the odds of needing assistance. Older patients, and patients with low income, were twice as likely to have need for assistance with personal care than were other patients. While gender was unrelated to need for personal care assistance, women were more than five times as likely to need help with instrumental tasks than were men, and were 1.6 times more likely to need transportation assistance than were men. Patients classified as low income were somewhat more likely (AOR 1.51) to need help with instrumental tasks, than were those who had not applied for public support.

Given the consensus of research findings concerning proxies' tendency to overreport patients' functional impairment (Rothman, Hedrick, Bulcroft, et al. 1991; Farrow and Samet 1990; Magaziner et al. 1988; Rubenstein et al. 1984), a dummy variable (0,1) was added to these models to determine if effects were unduly inflated by proxy report. Patients with proxy respondents were 3.6 times more likely to need personal care (95 percent confidence interval (CI): 1.90, 7.08), 1.5 times more likely to report need for help with instrumental tasks (CI: 0.83, 2.83), and 1.8 times more likely to report needing help with

transportation (CI: 0.99, 3.38), controlling for all other factors. However, inclusion of a dummy variable for proxy status did not alter the magnitude, nor the level of statistical significance of the regression coefficients reported in Table 3. Thus, having a proxy respondent contributes to reports of need over and above the effects of morbidity and social factors; however, it does not appear to confound analytic results.

Characterizing Unmet Need

Levels of reported unmet need among nonproxy patients with need for instrumental and transportation assistance are presented in Table 4, along with bivariate odds ratios. Around one-third (32.7 percent) of patients needing help with instrumental tasks reported insufficient help; and 16 percent of patients needing assistance with transportation reported that they could use more help. The correlation between these two domains of unmet need is .39, but as can be seen in Table 4, they relate in a somewhat different manner with independent variables selected for analysis.

Among patients needing assistance in one of these areas, the most severely disabled patients (daily activity restriction) are about twice as likely as less impaired patients to have an unmet need for both instrumental activities and transportation. Similarly, patients with three or more symptoms are significantly more likely to have unmet need for transportation than are those with fewer symptoms.

Social factors, particularly indicators of support, are also related to both measures of unmet need. Older patients (over age 65) are approximately half as likely to have unmet need with both instrumental activities and transportation as are younger patients. Low-income patients are three times more likely to have unmet need for transportation than are patients with higher income. Patients with smaller helping networks or who do not perceive their network as resilient have significantly increased odds of having unmet need for assistance with instrumental activities and transportation. Consistent with this pattern of findings, patients whose children live nearby are less than half as likely to report inadequate assistance in both of these areas of activities than patients without children nearby.

When all factors included in bivariate analyses are simultaneously entered into logistic regression equations, we find that physiological as well as social factors remain significantly related to the presence of unmet need. Daily activity restriction more than doubles the odds of inadequate assistance in both the instrumental activities and the trans-

Table 4: Bivariate Odds Ratio (with 95 percent Confidence Intervals) of Having Unmet Need among Those with Need by Selected Illness-Related and Sociodemographic Characteristics

<i>Domain</i>	<i>No Proxy</i>	
	<i>Instrumental</i>	<i>Transportation</i>
Number with need	272	306
Percent with unmet need	32.7%	16.0%
3+ Symptoms	1.69 (1.01,2.82)	1.87 (1.01,3.46)
Activity restricted every day	2.51 (1.49,4.24)	1.86 (1.00,3.44)
Age 65+	0.62 (0.36,1.09)	0.52 (0.26,1.03)
Female	0.74 (0.41,1.32)	1.40 (0.72,2.70)
Low income	1.29 (0.73,2.30)	3.29 (1.73,6.26)
Married	0.89 (0.52,1.51)	0.61 (0.32,1.14)
Living alone	1.14 (0.59,2.20)	1.75 (0.82,3.74)
0-3 Helpers	1.79 (1.03,3.13)	1.93 (1.00,3.74)
Low resiliency	2.54 (1.38,4.69)	5.98 (2.98,11.98)
Children living nearby	0.45 (0.27,0.75)	0.40 (0.25,0.77)

portation areas (see Table 5). After controlling for restricted activity, patients with many symptoms were not more likely to have unmet needs than were those with fewer symptoms.

The perceived resiliency of the social support network was strongly related to the presence of unmet need in the multivariate model. Patients reporting that their support networks were not resilient were over twice as likely to have unmet needs for instrumental tasks and over seven times as likely to have unmet needs for transportation than were patients who perceived their support networks to be more resilient. After controlling for this perception, the size of the helping network was not related to unmet need. (Separate analyses conducted in which the perceptual question was excluded revealed a strong rela-

Table 5: Adjusted Odds Ratios of Having Unmet Need among Patients with Need

<i>Domain</i>	<i>Instrumental</i>	<i>Transportation</i>
Number with need	272	306
Percent with unmet need	32.7%	16%
3+ Symptoms	1.40 (0.78,2.51)	0.94 (0.43,2.03)
Activity restricted every day	2.70 (1.51,4.85)	2.45 (1.15,5.23)
Age 65+	0.55 (0.28,1.09)	0.48 (0.19,1.20)
Female	0.70 (0.35,1.39)	1.87 (0.80,4.35)
Low income	1.05 (0.53,2.07)	2.85 (1.29,6.32)
Married	0.76 (0.34,1.70)	0.71 (0.24,2.10)
Living alone	0.93 (0.35,2.50)	0.81 (0.22,3.03)
0-3 Helpers	1.30 (0.64,2.63)	0.80 (0.31,2.09)
Low resiliency	2.37 (1.12,5.07)	7.36 (2.95,18.40)
Children living nearby	0.40 (0.22,0.72)	0.31 (0.13,0.70)

tionship between unmet need and small network size, controlling for the other physiological and sociodemographic factors.)

Older patients are half as likely to report unmet need for assistance with instrumental tasks and transportation, although the confidence intervals include 1.0. Patients with low income are at nearly three times the risk for unmet need with transportation, after controlling for other factors although this factor is unrelated to unmet need for help with instrumental tasks. Finally, patients with children living nearby have substantially reduced odds of unmet need for help with instrumental tasks and transportation, even controlling for perceived resiliency.

Bootstrap Sampling Estimation

All multivariate models presented in Tables 3 and 5 were replicated 100 times using the bootstrap technique described in the methods section of

this article. Results indicate that our estimates are well within one standard error of the mean coefficient for each independent variable based on 100 replications of the model. This was equally true for models with relatively small numbers of cases (e.g., $N = 272$). Although this does not correct for the nonrepresentative nature of our sample, it does validate the stability of estimates for this population.

DISCUSSION

We examined the association between demographic and disease/treatment-related factors and the need for assistance with personal care, instrumental tasks (shopping, housework, cooking), and transportation in a sample of cancer patients undergoing outpatient treatment. Additionally, we investigated the importance of the social support resources available to patients in predicting unmet need for assistance among those with need, controlling for potentially confounding physiological and demographic factors in logistic regression.

Not surprisingly, physiological and disease factors were strongly related to need for assistance in all domains. Measures of morbidity at the time of interview are particularly salient, as is metastatic disease, an indicator that patients are approaching cancer's terminal phase. However, neither length of time since the patient's diagnosis nor the type of treatment that the patient is receiving differentiates patients' experience of need. Comorbidity increases patients' need for help with transportation, possibly due to the multiplicity of physicians involved in treating patients' multiple chronic illnesses.

Female patients are much more likely than male patients to report need in the areas of instrumental activities and transportation. This may be partly explained by our definition of need. Since many male patients in this sample attributed assistance received to non-illness-related factors, such as gender role responsibilities, they were classified as not needing help with these tasks due to their illness. To the extent that some of these men were actually physically unable to perform these activities, assistance needs among male patients may have been underestimated (Allen et al. 1990). The measurement of the impact of illness and its treatment on men's need for assistance is therefore confounded by gender roles. It is likely that women are not more likely to need assistance than men, controlling for other factors.

The significant association of our indicator of low income with need for assistance in all areas is less easily explained. It may be indicative of poorer health status among low-income patients, although

the fact that it retains a significant association even after controlling for more direct health status measures suggests that other factors may be involved. It is possible that the combination of disease and limited financial resources has a cumulative effect on access to health care treatment, which in turn affects patients' health status. Many researchers have observed income, race, and other social biases in access to care as well as health status outcomes that might be reflected in these data (Weissman and Epstein 1989; Ries and Brown 1991; Dayal et al. 1987; Samet, Hunt, Key, et al. 1986; Satariano, Bell, and Swanson 1986).

Morbidity is important in predicting unmet need among patients with need, suggesting that the more illness interferes with patients' ability to perform tasks themselves, the greater the likelihood that some needs will go unmet. The relationship of low income to unmet need for transportation is also understandable. Patients with higher incomes can always resort to calling a taxi if informal resources fail them. This option may not be available to those in financial need.

The observed trend for persons over 65 to be less likely to have unmet need may be indicative of the competing demands that are characteristic of an earlier phase of the life course. For example, an elderly patient may be content with a neighbor's assistance with shopping on a weekly basis, while a younger person may require more than occasional assistance and report unmet need for transportation. Younger impaired cancer patients, facing the multiple responsibilities inherent in life's mid course, may have young children who require more assistance than they are able to offer. The helping resources available to these patients may be elderly parents, who are limited in their ability to take over multiple tasks, or peers, who themselves are compromised as helpers, given the nature of their own responsibilities. Our finding that younger patients have a greater vulnerability to inadequate assistance confirms the earlier work of Houts and his colleagues (Houts, Yasko, Kahn, et al. 1986).

Marital status has only a small protective effect against unmet need for assistance with household activities or transportation when other social support factors are considered. Rather, it is the patient's perception of the resiliency of the helping network to continue providing care that has the strongest protective effect. This suggests that the multiplicity of daily tasks and errands with which the cancer patient requires assistance may lead to strain on the informal system, as helpers struggle to meet their own responsibilities. The presence of adult children nearby appears to decrease the likelihood of unmet need in these areas, probably because geographical nearness facilitates availability for errands, rides to appointments, and so forth. Further, the

size of patients' helping networks appears to influence the likelihood of unmet need over and above the effect of children living in the area when we substitute network size for perceived resiliency. Clearly, such structural features of the patient's support network are related to its effectiveness in meeting assistance needs.

It is evident from this investigation that the proportion of cancer patients undergoing outpatient treatment who are impaired in daily functioning is high, and that the proportion of impaired patients who have insufficient help in meeting their needs is substantial, ranging from 16 percent to 33 percent across task areas in this sample. By excluding patients who were not yet experiencing need for help, we were able to isolate network characteristics that are most indicative of unmet need in each area of daily activities. Two important lessons to be learned from this study are the complexity of the dynamics of meeting patients' needs, and the fact that the sufficiency of patients' resources to meet their need for help in one area does not guarantee that all needs will be adequately met.

Limitations

Every attempt was made to recruit all patients who met eligibility criteria at participating outpatient clinics and physicians' offices. However, the nonresponse rate was sufficiently high to cause concern about the representativeness of the interviewed sample. Unfortunately, high refusal rates (22.5 percent in this study) are unavoidable in populations of patients who are very ill. Cancer, in particular, is a disease whose diagnosis and treatment are traumatic for the patient and the family. For some of these people, participation in research in the midst of cancer treatment is too much of an intrusion at a difficult time. Physicians refused access to their patients only when the patients were very sick or when their willingness to continue treatment was questionable, largely because of the associated toxicity. Additionally, many of the scheduling difficulties that research staff experienced were due to delay of the interview by patients and family members, until the patients were either too sick to be interviewed or had passed beyond the protocol time frame.

Eligible patients who were undergoing a course of radiation treatment were more likely not to participate in the study than patients undergoing chemotherapy. We found that 46 percent of radiation patients, versus 33 percent of chemotherapy patients, reported restricting activities every day of the two weeks before the interview, suggesting that radiation might have a greater fatiguing effect than

chemotherapy. Yet neither need nor unmet need differed as a function of treatment type when other factors were controlled. Our data suggest that the greater fatigue associated with radiation was counterbalanced by a higher level of symptom experience among chemotherapy patients.

It is possible that the exhausting and disruptive nature of daily visits to an outpatient radiation treatment center discourages patients and their families from volunteering for a lengthy interview survey. This interpretation is supported by a study that reported a high level of distress associated with undergoing adjuvant radiation treatment that was not observed with adjuvant chemotherapy (Silberfarb, Maurer, and Crouthamel 1980). If psychological distress were an outcome of this study, results could be biased by underrepresentation of radiation patients. However, there is no evidence to suggest that our estimates of need and unmet need are biased due to the higher nonparticipation rates of radiation patients.

Finally, the nonresponse rates, and particularly the refusal rates, experienced in our study are comparable to rates reported in similar populations of newly diagnosed cancer patients (McDuffie, Klaassen, and Dosman 1991) and those undergoing treatment (Mor, Guadagnoli, and Rosenstein 1991), as well as the rates observed in general population surveys (Wagner, Koepsell, Anderman, et al. 1991). It is likely that our estimates of need and unmet need in the population are lowered by nonresponse for all the reasons just discussed. To the extent that the relationships between independent and outcome variables are biased by such an underestimate, the effects are dampened. The "true" effects of the observed factors may be substantially stronger in a sicker sample. This would be true for both the physiological as well as the social support factors, since increased impairment appears to exacerbate inadequacies in patients' support networks.

The underrepresentation of racial minorities in this sample prohibits an examination of the influence of race on the impact of the dehospitalization of cancer treatment. As expected, representation of nonwhites was much higher in New York (15 percent) than in Rhode Island (1 percent) and Pennsylvania (3 percent), where minorities comprise a much smaller proportion of the adult population. To the extent that the treatment settings participating in the study underrepresent minorities living in their catchment areas, it is likely that the effect of our low-income proxy is underestimated. Past research has repeatedly shown that minorities are less likely to receive optimal cancer treatment (Satariano, Bell, and Swanson 1986; Samet, Hunt, Key,

et al. 1986). Therefore, it is entirely conceivable that they would be underrepresented in many settings where advanced cancer is treated.

As we discussed in the results section of this article, there was an effect of proxy response, even after controlling for other measures of morbidity, on estimates of need. However, since the primary reason for a proxy respondent in a study of this nature is that the patient is too ill to complete the interview him/herself, it is unlikely that estimates of need are substantially inflated by the fact that 15 percent of the sample had proxies respond to interview questions for them.

Policy Implications

In this article, we have attempted to highlight the implications of shifting cancer treatment from inpatient to outpatient settings, including patients' homes. In some sense this shift in locus of care is but another step in the initiative to disseminate state-of-science treatment protocols to the community, where a maximum number of cancer patients will have access to the best that current technology has to offer. This initiative dates back to the National Cancer Act of 1971, which stressed the dissemination of new treatments for use by community physicians (Kaluzny, Ricketts, Warnecke, et al. 1989). Since that time, controlled trials testing the efficacy of new protocols have expanded beyond specialty cancer centers and university hospitals to community hospitals and group practices, where physicians see the majority of patients.

Added to the national incentive to disseminate the practice of state-of-science treatment protocols to the community is the incentive to control health care costs, best exemplified by the introduction of a prospective payment system for reimbursement under Medicare in 1983. This combination of incentives has resulted in the administration of increasingly complex treatment protocols to ever larger numbers of cancer patients, most of whom now return home to cope with treatment-induced toxicity.

We have learned from past lessons with the mentally ill that the dehospitalization of care can result in inadequacies of care if supportive mechanisms are not present to counterbalance the loss of "protection" afforded by an inpatient setting (Mechanic and Rochefort 1990; Brown 1985). Our main goal in presenting the results of this study is to advance a better understanding of the factors that contribute to reports of need and unmet need for help during outpatient cancer treatment in order to facilitate patient monitoring in the community. One possible locale for monitoring that is both appropriate and feasible is the outpatient clinic or physician's office, where staff can gather relevant infor-

mation concerning available sources of informal help during intake interviews, thus anticipating potential difficulties even before assistance is actually needed. Adequacy of the care received at home could thus be monitored, along with patient health status and toxic reactions to treatment. Providers' familiarity with patient and disease characteristics likely to signal high levels of need and unmet need would enable them to identify patients at risk and to direct them to proper channels for education, assistance, or both.

From a social policy perspective, resource allocation requires a basis for ranking needs and forces consideration of such questions as, Can we reasonably expect all needs to be met? Is inadequate assistance with instrumental activities as important as an unmet need for assistance with transportation to treatment, which might compromise adherence to the treatment regimen? Can families, who provide almost all of the care to patients, continue to cope with meeting patients' needs at home or are breakdowns of the support network to be expected?

As current trends toward outpatient cancer therapy continue, policymakers must give weight to these issues. Policy initiatives to dehospitalize cancer treatment will be successful only to the extent that the health status of cancer patients, their ability to comply with treatment regimens, and the resiliency of their support network are not unduly adversely affected by the move from the hospital to the home.

NOTE

1. Longitudinal change in needs among the sample of patients ($N = 434$) who participated in both the initial and the follow-up interview is reported in: V. Mor, S. Allen, P. Houts, and K. Siegel. "The Changing Needs of Cancer Patients at Home: A Longitudinal View." *Cancer* 69, no. 3 (1992): 829-38.

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