

Targeting Risk for Unmet Need: Not Enough Help Versus No Help at All

Julie C. Lima¹ and Susan M. Allen²

¹Population Studies and Training Center and ²Center for Gerontology and Health Care Research, Brown University.

Objectives. This study examined factors associated with unmet need for care among persons aged 18 and older who need help with daily living tasks. The analysis focused on two types of unmet need: not enough (or inadequate) help and no help at all.

Methods. The authors used multinomial logistic regression to examine differences between persons with long-term care needs who (a) had all their needs met; (b) received inadequate help; and (c) received no help at all. Data were from the Adult Followback to the National Health Interview Survey on Disability (NHIS-D) for 1994 and 1995.

Results. The determinants of inadequate care versus no care differed with respect to age, gender, level of impairment, and insurance status. Whereas age and gender were important in determining inadequate care, insurance coverage and availability of social support were key factors related to a situation of no care.

Discussion. The present study demonstrates that the characteristics of groups reporting inadequate care versus no care, and the factors associated with these situations, are quite different. Nevertheless, the most important demographic risk factors for both types of unmet need mirror demographic groups currently on the increase in the U.S. population.

APPROXIMATELY 35–43 million people in the United States have physical or mental disabilities (National Health Interview Survey, 1996). Twelve million require long-term care, most of which is provided informally in the community by family and friends (U.S. General Accounting Office, 1994). Given this strong reliance on informal community-based care, social factors such as family structure and gender relationships have important consequences for the adequacy of care required by persons who cannot meet daily living needs independently.

A study of 27 developed countries has indicated a universal reduction in mortality at advanced ages (80 and older) over the past decades. Currently, 50% of women and 33% of men die after the age of 80 (Kannisto, Lauritsen, Thatcher, & Vaupel, 1994). Decreasing mortality, however, does not necessarily lead to decreasing years of morbidity before death. Further, research has indicated that the majority of unmarried elderly persons who experience declines in health still live alone (Worobey & Angel, 1990). This trend may increase because there has been a premium given to independent living in recent decades and because rising divorce rates decrease the likelihood that a person will enter old age with a spouse (Crimmins & Ingegneri, 1990; Glenn, 1991; Kramarow, 1995). It is therefore imperative to target those at risk for unmet care needs if community living is to be maintained.

Although a critical problem of the aging population, community-based long-term care services are also important for working-aged adults with disabilities, a vulnerable and understudied population whose numbers can be expected to grow given increased rates of survival from previously fatal injuries and conditions (Guyer et al., 1999). Poor health reduces educational attainment, income, and employment po-

tential, contributing to the fact that younger people with disabilities are disproportionately living in poverty and are at risk for entering old age largely without financial assets (McCarty & Levine, 1999). Disability in younger years may also present barriers to marriage (Becker, 1991), potentially resulting in fewer options in terms of family and friends to provide long-term care assistance. In fact, some may not have anyone to care for them at all. Insight into the needs of this population may be helpful in planning to accommodate the frail elderly people of the future.

In summary, persons with disabilities who have long-term care needs and who live in the community are a vulnerable population, at risk for inadequate helping resources as well as no resources at all. Our purpose in this study was to examine differences in unmet need for care among persons aged 18 and older who require help with daily tasks. This study is unique in distinguishing between two types of unmet need—unmet need as a result of inadequate help and as a result of no help at all. Unmet need as a result of no help at all was measured in a most basic way—the absence of any help (paid or unpaid) when a person reported need for help with daily living needs. Inadequate help indicated that the person with a long-term care need did have someone to help out, but the help provided was inadequate to meet all needs. As we discuss later, there is reason to expect that factors associated with these caregiving situations are quite different.

The Concept of Unmet Need

Unmet need has been conceived as an important quality of life indicator (Kane & Boulton, 1998; Mor, Guadagnoli, & Rosenstein, 1991). When a person is in need of long-term

care services, a lack of sufficient care can have negative consequences that may compromise a person's safety in the community and impede the management of health problems. For instance, Allen and Mor (1997) found that persons with inadequate help with specific activities of daily living (ADLs) such as transferring from bed to chair were more likely to fall. Similarly, inadequate levels of assistance in instrumental activities of daily living (IADLs) such as shopping resulted in an inability for persons to fill prescriptions and buy medical supplies.

The concept of unmet need has been operationalized in several ways. Some studies defined unmet need as lack of access to formal health care services (Biegel, Petchers, Snyder, & Beisgen, 1989; M. Katz et al., 2000; Thomas & Payne, 1998; Vinton, Altholz, & Marcus, 1997). Others, including this study, concentrated less on the specific service needed and more on limitations in ADLs and IADLs and the availability or adequacy of assistance with these tasks (Allen & Mor, 1997; Montoya, Richard, Bell, & Atkinson, 1997; Sanson-Fisher et al., 2000). However, availability, in terms of whether a person in need has a caregiver or not, has seldom been distinguished from adequacy, in terms of whether caregivers are providing adequate help to meet care recipients' needs. Typically instances of inadequate care and the absence of care have been collapsed together. In fact, the situation of no care has been largely overlooked in long-term care research despite the fact that factors associated with no care are likely to differ from the situation of inadequate care (Williams, Lyons, & Rowland, 1997).

Supervisory care is another issue of unmet need that has been inadequately examined in the literature (Williams et al., 1997). Kane and Boulton (1998), however, stressed that care requirements may be greatly underestimated if these supervisory roles are not taken into consideration. Indeed, they often require more of a time commitment than just performing the task for the individual. In this study we took into account both hands-on and supervisory help in our assessment of needs.

Age, Gender, and Social Networks

Five million people requiring long-term care are between the ages of 18 and 65, and 96% of this age group receive their help outside of institutions, compared with 89% of the 7.3 million elderly persons and 88% of the 0.4 million children who require long-term care (U.S. General Accounting Office, 1994). Although it is known that most community-based long-term care is provided by family members, most of what is known about caregiving networks relates to frail elderly persons. Knowledge of caregiving situations for working-aged people with disability is confined to their use of formal services (Allen & Mor, 1998).

Research has shown that elderly people with disabilities rely primarily on their spouse and, particularly for women, on adult daughters (Stone, Cafferata, & Sangl, 1987). As we have discussed, these helping resources may be less available to younger than to older persons with disability. On the other hand, research has also shown a decline with age in the quantity and quality of networks (Turner & Marino, 1994), which may result in a lack of available caregivers for

older persons. Thus it is not clear whether the complete lack of care differs among older and younger persons with disability.

There may be differences, however, in the adequacy of care. Younger adults are more likely to be cared for by older family members, such as parents, who may themselves have health problems that limit their ability to care sufficiently for their disabled child. Younger adults who are married are more likely to have spouses who are in the work force, which decreases the time the spouse can spend in caregiving. Older persons with needs, on the other hand, are more likely to be cared for by their adult children or retired spouses. Their children may be more physically and financially able to provide help, and the retired spouse may be more available throughout the day. In fact, Allen and Mor (1997) found that among community-dwelling adults with disability, younger adults experienced more unmet need than older adults.

Gender roles may also have important consequences for the availability and adequacy of care for men and women. Women are more likely than men to care for ailing relatives, especially in the hands-on tasks such as dressing and toileting (Stone et al., 1987). The most important source of long-term care is a spouse. Although spouses are the most frequent caregivers to ailing persons, a gender difference exists in patterns of caregiving, with wives providing more hands-on (ADL) care, and also more help with tasks such as housework and cooking, than husbands (Miller & Cafasso, 1992).

Skills appropriate to the caregiving role are likely to be an outcome of gender role socialization; thus, whereas most women are competent in this arena, many (certainly not all) men are not. This incongruity between caregiving tasks and some men's skills was illustrated in Kaye and Applegate's (1990) study of 148 men who participated in caregiver support groups, the majority of whom were caring for their spouses. Caregiving men in this study reported feeling less competent in household management and personal care tasks than in more "masculine" tasks such as managing finances and providing transportation. Further, the nature of the tasks they performed themselves mirrored their self-rated feelings of competency (Kaye & Applegate, 1990). Possibly because of this, research has shown that inadequacy of care is higher among women than it is among men (Allen, 1994).

Although the adequacy of care may be less for women than for men who have caregivers, it is likely that women have more persons available to them from whom to seek help. Women have both larger and more supportive networks than men (Dykstra, 1990; Wellman, 1992). In a recent study, Allen, Goldscheider, and Ciambone (1999) examined gender roles, marital intimacy, and nomination of spouse as primary caregiver in a sample of people receiving outpatient treatment for cancer. According to this study, women are only one third as likely as men to name their husbands as primary caregivers, net of age, educational attainment, employment, and other factors. This findings suggests that women have more people to whom they turn for help, whereas men tend to rely solely on their wives. It has also been observed that women without a partner tend to get

more support from their nonkin relations than do men (Dykstra, 1990; Wellman, 1985). In fact, in a recent study Davey and colleagues (1999) found that elderly women in the United States are twice as likely as men to be receiving assistance. Men, particularly outside of marriage, therefore appear to be at elevated risk of going without care.

Not surprisingly, kin are the primary source of community-based care (Litwak & Szelenyi, 1969; Messeri, Silverstein, & Litwak, 1993; Stone et al., 1987; Wellman, 1992, 1998), and some kin relationships are more important than others. The parent-child relationship is the second strongest kin relationship, yielding only to the relationship between spouses (Rossi & Rossi, 1990). Relationships between siblings are next, followed by more distant relations. Obviously, persons who are not married cannot have a spouse (the most supportive tie) and are less likely to have children (the next strongest tie). Recent research has shown that unmarried elderly persons receiving community care have lower odds than married persons of having a helping network dominated by family members and higher odds of receiving help from friends and formal helpers, who may be less invested in providing care than family caregivers. Care from formal helpers may also be time limited and dictated by a job description. Finally, divorced or separated persons had the smallest networks of helpers, relative to widows and those who never married (Barrett & Lynch, 1999).

In summary, on the basis of the theoretical and empirical literature, we expected that age, gender, and marital status would have differential effects on the availability and adequacy of care received by persons with disabilities. For persons who have a caregiver, we expected that working-aged people with disability would be more likely than elderly persons to have inadequate care and that women would be more likely to have inadequate care than men. Finally, we expected that those who are not currently married, particularly the divorced, would be more likely to have inadequate care than those who are married, because they are likely to have a smaller pool of helpers to draw from, composed mainly of distant kin and nonkin.

Having no caregiver at all was expected to be associated particularly with marital status. That is, those who are not currently married would be more likely to have no help than those who are married. More specifically, the divorced or separated would be the most likely to have no help. We did not expect differences by age or gender in the complete absence of care. There are varying and distinct advantages to being old or young, or male or female, when it comes to obtaining some form of care, and we expected that these different effects would cancel each other out.

However, several interactions among age, gender, and marital status were expected. For instance, we expected that men would be more likely to have no caregiver if they are young and unmarried. Women who are married, however, were expected to be at higher risk for inadequate care. In addition, older women were expected to have the least unmet need because they have the most potential for support, especially married and widowed women. Finally, we expected that divorced men would be at greater risk than women for the complete absence of care.

METHODS

We examined the hypotheses stated previously using data collected in Phase II of the National Health Interview Survey on Disability for the years 1994 and 1995. The National Health Interview Survey is a continuing nationwide survey of the noninstitutionalized civilian population in the United States. The 1994 and 1995 versions of the National Health Interview Survey included a special section on disability that was used to obtain national estimates of various types of disability in the general population. It also served as a screening device to determine eligibility for a second phase of the survey. Phase II of the survey on disability consisted of four sections. One of the sections, the Adult Disability Followback Survey (DFS), was used here. This survey was conducted to obtain more extensive information about persons with disabilities on issues such as employment, use of services and benefits, transportation and personal assistance needs, housing characteristics, environmental barriers, and participation in social activities.

The study sample consisted only of noninstitutionalized persons in the DFS who reported receiving or needing help with at least one ADL or IADL due to a health problem. These two measures are widely used in disability research as measures of long-term care need. Help was defined as hands-on or supervisory help. It has been suggested that asking about the need for supervisory help captures a greater number of individuals with cognitive difficulties (Williams et al., 1997). Respondents were asked a number of questions regarding each of these activities. Of the 25,805 individuals in the DFS, 335 were institutionalized between the first and second phases of the disability supplement and were therefore eliminated. Of the remaining 25,470 respondents, 9,646 stated that they needed or received help with at least one ADL or IADL. Therefore, the analytic sample for this research consisted of these 9,646 respondents.

Measures

The measures of unmet need in this study were based on ADL and IADL limitations (S. Katz & Akpom, 1976; Lawton, 1971). ADLs are basic life activities, including bathing or showering, dressing, eating, getting in or out of bed/chairs, walking, getting outside, and using or getting to the toilet. IADLs refer to preparing your meals, shopping for groceries, managing money, using the telephone, doing heavy housework, doing light housework, getting to places, and managing medications. This survey asked whether or not a person had difficulty performing these activities and whether or not they received help. Help could be hands-on or supervisory. If they did not receive help of either sort, they were further asked if they needed help. If they did receive help, they were asked whether they needed more help.

On the basis of responses to the questions described previously, the dependent variable consisted of three levels. The first referred to persons who reported needing help and having enough help (no unmet need), the second to persons who received some help but reported needing more help (inadequate help), and the third to persons who needed help, but did not receive it from any source (no help at all).

The key independent variables included on the basis of theoretical importance were age, gender, and marital status. Also included to control for possible confounding were the number of ADL and IADL limitations, education level, race/ethnicity, poverty status, insurance status, number of people in the household, and type of respondent (self or proxy).

Age of the respondent was categorized to represent young adulthood (18–44), middle age (45–64), and retirement age (65 and older). Because most is known about elderly persons, they served as the reference category. Gender was a dichotomous variable, with female = 1 and male = 0. Finally, marital status consisted of four categories: currently married, divorced/separated, widowed, and never married. Currently married was the reference category because this status was expected to be lowest risk for both of the situations investigated, inadequate help or no help.

Because of data constraints, poverty status consisted of only two categories: at or above the poverty level and below the poverty level. Because those below the poverty level are at elevated risk of unmet need, at or above poverty was used as the reference group. Education level was included in the model as a second measure of socioeconomic status and was operationalized with four categories: less than high school, high school graduate (reference), some college, and college graduate. People educated beyond high school generally have greater social support as well as the resources to purchase care. Conversely, those with less than a high school education may have less access to care from either formal or informal sources (Turner & Marino, 1994).

Race/ethnicity consisted of four categories: White (reference), Black, Hispanic, and other. Contrary to past research on social support, recent studies have found that minorities have less social support than Whites (Hogan, Eggebeen, & Clogg, 1993; Roschelle, 1997).

Insurance status often reflects poverty status. Disabled persons, however, may be eligible for Medicaid because of the expenses associated with their health conditions (medically needy). Therefore, we included indicators of both insurance type and poverty status in the model. Insurance type is important because reimbursement for certain long-term care services is more likely to be provided under some reimbursement mechanisms (especially Medicare and Medicaid) than others. For instance, Medicare reimburses home health care after discharge from the hospital for a 30-day period. Therefore, this may (at least temporarily) reduce a person's unmet need. Medicaid, although limited, is considered to be the sole provider of long-term care services in general. Private insurance does not generally cover long-term care services (McCarty & Levine, 1999). Insurance status in this analysis consisted of seven mutually exclusive categories. Those who had no insurance were used as the reference group. The other six categories consisted of persons who had private insurance only; both Medicare and private insurance; Medicare and Medicaid; Medicare only; Medicaid only; or another type of public insurance (Indian Health Services, veterans' insurance, or other).

Numbers of ADL and IADL limitations were continuous variables, included in the model to control for severity of impairment. ADL limitations ranged from 0 to 7, and IADL

limitations ranged from 0 to 8. The nature of the conditions causing these limitations was not included because the complexity of categorizing the multiplicity of conditions and duration of each type typically reported by individuals with disabilities was beyond the scope of these analyses. The focus here was on impact of health conditions on functioning, rather than etiology of disability. However, it was known that respondents had been disabled for 12 or more months, the duration of time between the Phase I and Phase II surveys.

Type of respondent consisted of three categories: self or assisted response (reference), proxy response, and unknown. Finally, number of persons in the household was also a continuous variable included in the model as an indicator of caregiver availability, in addition to marital status. It was truncated at five or more persons, because only a small minority of respondents had a larger household size. Assistance to people with disability is also provided by geographically proximate kin outside of the household. However, although the numbers of living brothers, sisters, and parents were indicated in the data, geographic proximity was not. Preliminary analyses indicated that these indicators were not sensitive to study outcomes, and they were dropped from the final model.

Except for type of respondent, where nonresponse was 2.8%, nonresponse was minimal (<1%). Therefore, all nonresponse was excluded from the analysis for these variables. An indicator of nonresponse for type of respondent was included in the model. The final sample size was 9,605.

Analysis

Because of the categorical and nonordinal nature of the dependent variable, multinomial regression was used for the multivariate analyses. In addition, we conducted supporting analyses using multiple regression to determine factors associated with number of unmet needs among respondents classified as having inadequate care, that is, having a caregiver whose help was not sufficient to meet their needs. We provided a sampling weight for each observation to take into account oversampling by age, sex, and race, as well as loss to follow-up between Phases I and II. This weight was used for all analyses. In addition, use of the above analyses depended on simple random sampling. The sampling design was stratified, multistage, and clustered (National Health Interview Survey, 1996), and therefore, we used the SUDAAN statistical package (Shah, Barnell, & Bieler, 1996) to take this complex survey design into account.

RESULTS

Table 1 contains the weighted means and standard deviations for all variables. The first column describes the total sample, the second describes those with adequate help ($n = 7,495$), the third those with inadequate help ($n = 1,767$), and the fourth those with complete absence of help ($n = 343$).

Persons in the overall sample had an average of 2.0 ADL limitations and 2.4 IADL limitations. They were predominantly female. In addition, almost half were 65 and older. Most did not attend college. Unsurprisingly, the majority of the overall sample was White. Almost half of the sample

Table 1. Weighted Means and Standard Deviations of Noninstitutionalized Individuals in the 1994 and 1995 National Health Interview Adult Followback Survey Who Stated That They Had Difficulty With at Least One ADL or IADL by Type of Help Received ($N = 9,605$)

Variable	Total ($N = 9,605$)		All Needs Met ($n = 7,495$)		Partial Unmet Need ($n = 1,767$)		Complete Unmet Need ($n = 343$)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Number of ADL limitations (range = 0–7)	2.031	0.030	1.862	0.032	2.878	0.058	1.540	0.106
Number of IADL limitations (range = 0–8)	2.411	0.031	2.270	0.034	3.193	0.062	1.593	0.093
Sex								
Male	0.356	0.005	0.373	0.006	0.287	0.011	0.331	0.025
Female	0.644	0.005	0.627	0.006	0.714	0.011	0.669	0.025
Age								
18–44	0.234	0.005	0.230	0.006	0.257	0.011	0.207	0.022
45–64	0.301	0.005	0.299	0.006	0.292	0.012	0.389	0.030
65+	0.465	0.006	0.471	0.007	0.451	0.012	0.404	0.028
Completed Education								
Less than high school	0.412	0.006	0.411	0.007	0.430	0.012	0.362	0.026
High school	0.351	0.006	0.354	0.007	0.332	0.011	0.361	0.026
Some college	0.142	0.004	0.137	0.005	0.153	0.009	0.183	0.022
College grad/+	0.095	0.003	0.097	0.004	0.086	0.007	0.095	0.017
Race								
White	0.763	0.008	0.778	0.008	0.701	0.016	0.740	0.023
Black	0.132	0.006	0.121	0.006	0.172	0.013	0.156	0.020
Hispanic	0.071	0.004	0.068	0.004	0.086	0.007	0.065	0.013
Other	0.035	0.004	0.033	0.003	0.041	0.008	0.039	0.011
Marital Status								
Married	0.473	0.006	0.495	0.007	0.414	0.015	0.292	0.029
Widowed	0.258	0.005	0.233	0.006	0.278	0.012	0.261	0.025
Divorced/separated	0.141	0.004	0.125	0.005	0.180	0.011	0.295	0.028
Never married	0.128	0.005	0.127	0.005	0.128	0.009	0.152	0.019
Below poverty level	0.231	0.006	0.217	0.006	0.291	0.012	0.236	0.023
Insurance Coverage								
None	0.062	0.003	0.059	0.003	0.061	0.006	0.114	0.019
Private	0.197	0.005	0.201	0.006	0.172	0.010	0.229	0.028
Private and Medicare	0.354	0.007	0.368	0.008	0.308	0.013	0.290	0.026
Medicare and Medicaid	0.122	0.005	0.119	0.006	0.140	0.009	0.096	0.017
Medicare only	0.132	0.004	0.130	0.005	0.141	0.009	0.124	0.022
Medicaid only	0.111	0.004	0.103	0.004	0.146	0.009	0.115	0.020
Other	0.024	0.002	0.021	0.002	0.033	0.005	0.032	0.011
Number of Persons in Household	2.381	0.019	2.428	0.020	2.310	0.037	1.706	0.059
Proxy Report								
No	0.806	0.006	0.792	0.006	0.848	0.009	0.907	0.016
Yes	0.166	0.006	0.179	0.006	0.130	0.009	0.044	0.014
Missing	0.028	0.002	0.029	0.002	0.022	0.004	0.049	0.011

Note: ADL = activity of daily living; IADL = instrumental activity of daily living.

were married at the time of the survey. Almost a quarter of the sample were below the poverty line, but the vast majority had at least some form of insurance. On average, the sample lived in a household of 2.4 persons, and one fifth of the surveys were completed by proxy respondents.

Persons who had adequate help closely resembled the full sample. In general, they had slightly fewer ADL and IADL limitations and lived with a larger number of persons. Those with inadequate help appeared to have more limitations than those whose help was adequate to meet their needs. This group also had a higher representation of women, Blacks, and divorced persons. Finally, there was a higher representation of people living below the poverty level but fewer persons in their households.

Persons who reported a complete absence of help had fewer overall limitations than did those who had a caregiver. They appeared to be middle aged and more educated. Of note, this group contained a large number of divorced

and never married individuals. They lived with relatively fewer persons and appeared to have higher numbers of uninsured than the other groups.

Not Enough Help

The results of the multinomial logistic regression model are presented in Table 2. Overall, the results were as expected from prior research in terms of factors associated with inadequate help relative to those who had all their needs met. The three main independent variables of interest showed predicted results. In particular, when we controlled for other sociodemographic characteristics, those with inadequate help were approximately 40% more likely to be female than those whose needs were met ($OR = 1.42, p < .001$). Younger persons, aged 18–44, were one third more likely to have inadequate help than those 65 and older ($OR = 1.33, p < .05$). Finally, divorced or separated persons were

Table 2. Multinomial Regression of the Odds of Having Inadequate Help or No Help at All Versus Having Adequate Help When Help Is Needed for Noninstitutionalized Individuals in the 1994 and 1995 National Health Interview Adult Followback Survey Who Stated That They Had Difficulty With at Least One ADL or IADL ($n = 9,605$)

Variable	Inadequate Help vs Adequate Help		No Help at All vs Adequate Help	
	Odds Ratio	95% Confidence Interval	Odds Ratio	95% Confidence Interval
Intercept	0.149***	0.104–0.212	0.446*	0.224–0.889
Number of ADL Limitations (range = 0–7)	1.181***	1.145–1.218	1.017	0.947–1.091
Number of IADL Limitations (range = 0–8)	1.142***	1.102–1.183	0.808***	0.734–0.890
Sex (female)	1.424***	0.613–0.804	1.076	0.716–1.207
Age				
18–44	1.328*	1.067–1.653	0.952	0.578–1.567
45–64	0.957	0.797–1.149	1.092	0.734–1.624
65+ (reference)				
Completed Education				
Less than high school	1.040	0.906–1.193	0.894	0.675–1.185
High school (reference)				
Some college	1.159	0.965–1.392	1.197	0.847–1.692
College grad/+	1.041	0.845–1.281	0.842	0.543–1.306
Race				
White (reference)				
Black	1.381**	1.114–1.713	1.416*	1.020–1.966
Hispanic	1.383**	1.117–1.711	1.279	0.805–2.031
Other	1.455	0.965–1.392	2.052*	1.125–3.743
Marital Status				
Married (reference)				
Widowed	1.079	0.907–1.284	1.320	0.893–1.950
Divorced/separated	1.242*	1.017–1.517	2.515***	1.671–3.786
Never married	1.051	0.847–1.303	1.949**	1.260–3.016
Poverty				
At or above (reference) poverty level				
Below poverty level	1.134	0.966–1.331	0.778	0.560–1.081
Insurance Coverage				
None (reference)				
Private	0.921	0.700–1.211	0.626	0.374–1.046
Private and Medicare	0.802	0.599–1.073	0.317***	0.183–0.550
Medicare and Medicaid	0.879	0.644–1.199	0.328***	0.182–0.588
Medicare only	0.958	0.708–1.297	0.400**	0.225–0.712
Medicaid only	1.160	0.887–1.519	0.529*	0.309–0.905
Other	1.465	0.960–2.234	0.735	0.304–1.777
Number of Persons in Household	0.886***	0.835–0.939	0.503***	0.413–0.612
Proxy Report				
No (reference)				
Yes	0.516***	0.428–0.622	0.380**	0.202–0.713
Missing	0.623*	0.406–0.955	1.485	0.895–2.496
–2 log likelihood, <i>df</i>	941.83, 48			

Note: ADL = activity of daily living; IADL = instrumental activity of daily living.

* $p < .05$; ** $p < .01$; *** $p < .001$.

24% more likely to have inadequate help than married persons (OR = 1.24, $p < .05$).

The effects of the control variables were also as expected. There was an increase in risk for inadequate help with each additional ADL and IADL limitation by 18% and 14%, respectively ($p < .001$). Blacks and Hispanics were each 38% more likely to have inadequate help than Whites ($p < .01$). In contrast, there was an 11% reduction in risk for inadequate help for each person residing in the household with the individual requiring care (OR = 0.89, $p < .001$).

When we controlled for other variables, health insurance coverage did not affect whether or not a person had unmet need, given that they had a caregiver. Finally, proxy respondents were only approximately half as likely as self-respondents were to state that a person had inadequate help (OR = .52, $p < .001$).

No Help at All

The second set of estimates in Table 2 compares those who received no help with those whose needs were completely met. These results differed markedly from the first comparison described previously. There were neither gender nor age differences between those who did not get help and those whose needs were completely met, with other sociodemographic characteristics controlled. Marital differences, however, were much more pronounced. Persons who were divorced or separated were 2.5 times more likely to have no help (OR = 2.52, $p < .001$) and those who had never been married were almost twice as likely to lack help (OR = 1.95, $p < .01$) than persons who were currently married.

The effects of other control variables also differed from those in the first set of comparisons. Although there were no

differences in ADL limitations between those who had adequate help and those who had no help, those with more IADL limitations were actually 20% less likely to have no help than those with fewer IADL limitations ($OR = 0.81$, $p < .001$). In addition, insurance coverage was very important. Those with more than one type of health insurance, that is, private and Medicare or Medicare and Medicaid, were the least likely to lack a caregiver compared with those with no insurance ($ORs = 0.32$ and 0.33 , respectively; $p < .001$). Those with only Medicare ($OR = 0.40$, $p < .01$) or Medicaid ($OR = 0.53$, $p < .05$) were also less likely to lack care than those with no insurance. Having only private insurance or public insurance other than Medicaid or Medicare, however, did not improve the chances of having adequate care compared with those with no insurance at all.

Blacks ($OR = 1.42$, $p < .05$) and respondents of "other" races ($OR = 2.05$, $p < .05$) were significantly more likely than Whites to have no help at all, but Hispanics did not differ from Whites in this comparison. Not surprisingly, for each additional person in a disabled individual's household there was a 50% reduction in the risk of having no help at all; similarly, proxy respondents were only approximately one third as likely as self-respondents to report no care at all ($OR = .38$, $p < .01$).

Modeling the Extent of Inadequate Care

Although our primary focus in this study was to identify and differentiate risk factors for people with disability in two distinct situations—those who have help but help received is inadequate to meet all care needs and those who have no help at all—we recognized that it is useful to understand factors associated with extent of unmet need as well as unmet need per se. In this study, respondents classified as having inadequate care had as few as 1 unmet need or as many as 15. Therefore, a subanalysis consisting of ordinary least squares (OLS) regression for those classified as having inadequate care ($n = 1,767$) was conducted. The dependent variable had a possible range of 15 (7 ADLs and 8 IADLs). Factors associated with higher levels of unmet need were number of ADL and IADL limitations, number of people in the household of the care receiver, and Black or Hispanic race. However, no associations were observed between number of unmet needs and the three independent variables of theoretical interest to this research (i.e., gender, age, and marital status; data not shown).

Interactions

Expected interaction effects were tested in the multivariate model, including interactions between gender and age, gender and marital status, and marital status and age. Finally, a three-way interaction involving gender, age, and marital status was examined. In no case was an interaction significant, and interactions were dropped from the final model.

DISCUSSION

In this study we demonstrate the importance of distinguishing people with disability who receive inadequate care from those who receive no care at all. Clearly, these are two different groups, with people receiving no care character-

ized by less severity of impairment, lower levels of insurance coverage, and less informal support availability relative to people who have a caregiver but whose care is not enough to meet impairment-related needs. Further, our findings suggest that although several key factors resulting in situations of inadequate help and complete lack of help are the same, others are quite different.

Consistent with findings from research on people with cancer (Allen, 1994), we find that women with disability are more likely to report inadequate care than men, possibly because they are more likely to be cared for by male caregivers, who may not be familiar with female-associated tasks. However, given that gender roles are most likely to be operant among married couples, the lack of an interaction between gender and marital status in this study suggests that women may also have higher standards of care than men and are more likely to report their care is inadequate. For example, men with disability may be bothered less by undone housework and other household chores and thus less likely than women to associate a messy house with inadequate care. It may also be the case that a wife's frailty encourages a more equitable division of labor, a finding supported in a recent qualitative study examining the pathways through which an equitable division of household labor is attained (Risman & Johnson-Sumerford, 1998). Thus, although women are more likely than men to report unmet need, the effect is not stronger for married relative to unmarried women.

The finding that younger age is related to inadequate care in this national sample supports findings from a regional study of people with disability (Allen & Mor, 1997). As we have discussed, it is likely that the competing demands of caregivers of this age group, for example, paid work and young families, as well as health problems among caregiving parents, may partly explain the increased vulnerability of people disabled early in life to inadequate care. Further, services available through the Administration on Aging that may bolster the efforts of informal networks, such as Meals on Wheels and homemaker services, are not available to younger populations.

Although gendered expectations and stage of life course appear to have implications for receipt of adequate care, they are not important in determining whether a person with disability has a caregiver in the first place. The latter measure is more objective than the former; that is, one either has a caregiver or one does not. The necessarily subjective nature of rating one's care as inadequate suggests that the observed relationship between age and unmet need may be explained by cohort as well as life course differences. Younger people with disability may have views reflective of socialization during a period of national, if not individual, prosperity, which raises expectations for care and the quality of life with disability, relative to older cohorts who may have been socialized to expect less. Similarly, as discussed previously, women's expectations for care may be higher than men's, although access to a caregiver is not different by gender.

The crucial factor in determining whether or not one has a caregiver, given the need for help, is access, operationalized in this study by several indicators of social support

availability as well as insurance status. On the basis of knowledge of the size and composition of the social networks of the unmarried (Barrett & Lynch, 1999), it is not surprising that divorced, separated, and never married people with disability are at substantial risk of going without care when they experience declines in health. Further, greater dependence on formal care and nonkin helpers among those who do have help may explain why these groups are also at risk of inadequate care.

Similarly, living alone is a major risk factor for unmet need, as is evidenced by the substantial reduction in risk, particularly for a complete lack of care, when people with disability live with others. We see a similar effect of proxy interview status, because willingness to complete a research interview for someone suggests that the proxy is also likely to be available for other types of assistance. The reduction in risk for inadequate care should be noted with caution, however, because a proxy/helper may be reluctant to classify his or her own efforts as inadequate to meet a patient's needs.

All types of insurance coverage, with the exception of private coverage only, substantially reduce the risk of having no one to provide help, and the direction of the effect for private coverage is the same, although not statistically significant. Clearly, this is largely a problem of nonelderly people with disabilities, because coverage by Medicare is nearly universal among people aged 65 and older. People without insurance in this sample (11% among people reporting no care) may not yet be sufficiently disabled to qualify for public insurance, or they may not know that public insurance is an option for them.

Although insurance status appears protective of a "no care" situation, presumably by providing access to formal sources of assistance, it does not protect people with disability from inadequate care. Although intuitively it seems that some care must be better than none, the immediate negative consequences of unmet need—falling, for example—have been shown to occur among those with inadequate care as well as those with no care at all (Allen & Mor, 1997). As long-term care issues come under increasing scrutiny, policymakers need to think in terms of expanding the amount of care available under public reimbursement mechanisms such that it is sufficient to meet individual need and to reexamine eligibility criteria to ensure that allotted care is not too little, too late. For example, people lacking informal support systems who must decline to the point that they are eligible for Medicaid community-based waiver services may find that the services available to them are not sufficient to meet impairment-related needs. Institutions then become the only viable option for people in this situation.

The finding that people with more severe disability, that is, higher levels of ADL and IADL impairments, are more likely to report inadequate care is intuitive, suggesting that the more needs one has, the harder it is to meet them adequately. In contrast, there is no relation between ADL impairment and the situation of no care, and people with higher levels of IADL impairment are less likely to experience complete unmet need. These findings suggest that people with high levels of impairment simply cannot remain in the community for long without help, evidenced by the fact

that the average level of impairment in the group without caregivers is only half that of the group experiencing inadequate care. These people are likely at the beginning of a trajectory of functional decline. At some point such individuals either seek assistance from their families, perhaps waiting until they cannot manage on their own any longer, or from the social service system, or they are called to the attention of the system by health care providers, family, and friends.

Importantly, in this study we find that minorities are at a distinct disadvantage when compared with Whites in terms of getting their needs met. This supports the recent finding that minorities do not have stronger support networks than Whites (Roschelle, 1997). So, although the vast majority of nursing home residents are White, it can no longer be assumed that minorities are remaining in the community because they have adequate informal care. They are, in fact, at significantly elevated risk of having not enough care as well as no care at all.

The current study sheds light on important differences between the characteristics of people with disability who experience inadequate help for long-term care services and those who receive no care at all and the factors that are associated with these situations. It is striking that the most important demographic risk factors for both types of unmet need mirror demographic groups currently on the increase in the U.S. population. Increases in minority populations, in the numbers of men and women living with disabling conditions acquired early in life, and in the proportion of adults getting divorced or remaining single will increasingly call attention to the inadequacy of the long-term care system in place today.

The 1999 Olmstead decision (*L. C. by Zimring V. Olmstead*, 1997) requires states to provide services to persons with disabilities in community settings rather than institutions, if community-based services constitute reasonable accommodations. This landmark ruling challenges policymakers to expand the availability and coverage of existing community-based services and to develop new models of supportive care that enable the more vulnerable members of the population to maximize their independence and quality of life as community members.

ACKNOWLEDGMENTS

This research was supported by Grants R29 AG12449 from the National Institute on Aging and HD 07338-12 from the National Institute of Child Health and Human Development.

Address correspondence to Dr. Susan M. Allen, Center for Gerontology and Health Care Research, Brown University, Box G-B213, Providence, RI 02912. E-mail: Susan_Allen@Brown.edu

REFERENCES

- Allen, S. (1994). Gender differences in spousal caregiving and unmet need for care. *Journal of Gerontology: Social Sciences*, 49, S187-S195.
- Allen, S., Goldscheider, F., & Ciambone, D. (1999). Gender roles, marital intimacy, and nomination of spouse as primary caregiver. *The Gerontologist*, 39, 150-158.
- Allen, S., & Mor, V. (1997). The prevalence and consequences of unmet need: Contrasts between older and younger adults with disability. *Medical Care*, 35, 1132-1148.
- Allen, S., & Mor, V. (Eds.). (1998). *Living in the community with disability: Service needs, use, and systems*. New York: Springer.

- Barrett, A. E., & Lynch, S. M. (1999). Caregiving networks of elderly persons: Variation by marital status. *The Gerontologist*, 39, 695-704.
- Becker, G. (1991). *A treatise on the family*. Cambridge, MA: Harvard University Press.
- Biegel, D., Petchers, M., Snyder, A., & Beisgen, B. (1989). Unmet needs and barriers to service delivery for the blind and visually impaired elderly. *The Gerontologist*, 29, 86-91.
- Crimmins, E., & Ingegneri, D. (1990). Interaction and living arrangements of older parents and their children: Past trends, present determinants, future implications. *Research on Aging*, 12, 3-35.
- Davey, A., Femia, E., Shea, D., Zarit, S., Sundstrom, G., Berg, S., & Smyer, M. (1999). How many elders receive assistance? *Journal of Aging and Health*, 11, 199-220.
- Dykstra, P. (1990). Disentangling direct and indirect gender effects on the supportive network. In C. P. Knipscheer & T. C. Antonucci (Eds.), *Social network research: Substantive issues and methodological questions* (pp. 55-65). Amsterdam: Swets & Zeitlinger.
- Glenn, N. (1991). The recent trend in marital success in the United States. *Journal of Marriage and the Family*, 53, 261-270.
- Guyer, B., Hoyert, D., Martin, J., Ventura, S., MacDorman, M., & Strobino, D. (1999). Annual summary of vital statistics—1998. *Pediatrics*, 104, 1226-1246.
- Hogan, D., Eggebeen, D., & Clogg, C. (1993). The structure of intergenerational exchanges in American families. *American Journal of Sociology*, 98, 1428-1458.
- Kane, R., & Boulton, C. (1998). Defining the service needs of frail older persons. In S. Allen & V. Mor (Eds.), *Living in the community with disability: Service needs, use, and systems* (pp. 15-41). New York: Springer.
- Kannisto, V., Lauritsen, J., Thatcher, A. R., & Vaupel, J. (1994). Reductions in mortality at advanced ages: Several decades of evidence from 27 countries. *Population and Development Review*, 20, 793-810.
- Katz, M., Cunningham, W., Mor, V., Anderson, R., Kellogg, T., Zierler, S., Crystal, S., Stein, M., Cylar, K., Bozzette, S., & Shapiro, M. (2000). Prevalence and predictors of unmet need for supportive services among HIV-infected persons: Impact of case management. *Medical Care*, 38, 58-69.
- Katz, S., & Akpom, C. A. (1976). A measure of primary sociological functions. *International Journal of Health Services*, 6, 493-507.
- Kaye, L., & Applegate, J. S. (1990). *Men as caregivers to the elderly: Understanding and aiding unrecognized family support*. Lexington, MA: Lexington Books.
- Kramarow, E. (1995). Living alone among the elderly in the United States: Historical perspectives on household change. *Demography*, 32, 335-352.
- Lawton, M. P. (1971). The functional assessment of elderly people. *Journal of the American Geriatrics Society*, 19, 465-481.
- L. C. by Zimring V. Olmstead, 1997 U.S. Dist. LEXIS 3540 (N. D. Ga. Mar. 25, 1997).
- Litwak, E., & Szelenyi, I. (1969). Primary group structures and their functions: Kin, neighbors, and friends. *American Sociological Review*, 34, 465-481.
- McCarty, D., & Levine, H. (1999). Needs of people with chronic and disabling conditions. In M. Lillie-Blanton, R. M. Martinez, B. Lyons, & D. Rowland (Eds.), *Access to health care: Promises and prospects for low-income Americans* (pp. 61-72). Washington, DC: Kaiser Commission on Medicaid and the Uninsured.
- Messeri, P., Silverstein, M., & Litwak, E. (1993). Choosing optimal support groups: A review and reformulation. *Journal of Health and Social Behavior*, 34, 122-137.
- Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *The Gerontologist*, 32, 498-507.
- Montoya, I., Richard, A., Bell, D., & Atkinson, J. (1997). The analysis of unmet need for HIV services: The Houston Study. *Journal of Health Care for the Poor and Underserved*, 8, 446-460.
- Mor, V., Guadagnoli, E., & Rosenstein, R. (1991). Cancer patients' unmet support needs as a quality-of-life indicator. In D. Osoba (Ed.), *Effect of cancer on quality of life* (pp. 155-168). Boca Raton, FL: CRC Press.
- National Health Interview Survey on Disability, Phase 1, 1994 [electronic data file and documentation]. (1996). Hyattsville, MD: National Center for Health Statistics [Producer and Distributor].
- Risman, B., & Johnson-Sumerford, D. (1998). Doing it fairly: A study of postgender marriages. *Journal of Marriage and the Family*, 60, 23-40.
- Roschelle, A. (1997). *No more kin: Exploring race, class, and gender in family networks*. Thousand Oaks, CA: Sage.
- Rossi, A., & Rossi, P. (1990). *Of human bonding—Parent-child relations across the life course*. New York: Aldine De Gruyter.
- Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. *Cancer*, 88, 226-237.
- Shah, B., Barnell, B., & Bieler, G. (1996). *SUDAAN user's manual, release 7.0*. Research Triangle Park, NC: Research Triangle Institute.
- Stone, R., Cafferata, G., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. *The Gerontologist*, 27, 616-626.
- Thomas, C., & Payne, S. (1998). Home alone: Unmet need for formal support services among home health clients. *Home Health Care Services Quarterly*, 17, 1-20.
- Turner, R. J., & Marino, F. (1994). Social support and social structure: A descriptive epidemiology. *Journal of Health and Social Behavior*, 35, 193-212.
- U.S. General Accounting Office. (1994, November). *Long-term care: Diverse, growing population includes millions of all ages*. Washington, DC: Author.
- Vinton, L., Altholz, J., & Marcus, M. (1997). A survey of unmet needs of homebound elders. *Journal of Gerontological Social Work*, 27, 69-84.
- Wellman, B. (1985). Domestic work, paid work, and net work. In S. Duck & D. Perlman (Eds.), *Understanding personal relationships—An interdisciplinary approach* (pp. 159-191). London: Sage.
- Wellman, B. (1992). Which types of ties and networks provide what kinds of social support. *Advances in Group Processes*, 9, 207-235.
- Wellman, B. (1998). The place of kinfolk in personal community networks. In K. Hansen & A. Garey (Eds.), *Families in the U.S.—Kinship and domestic politics* (pp. 231-239). Philadelphia: Temple University Press.
- Williams, J., Lyons, B., & Rowland, D. (1997). Unmet long-term care needs of elderly people in the community: A review of the literature. *Home Health Care Services Quarterly*, 16, 93-119.
- Worobey, J., & Angel, R. (1990). Functional capacity and living arrangements of unmarried elderly persons. *Journal of Gerontology: Social Sciences*, 45, S95-S101.

Received August 31, 2000

Accepted March 30, 2001