

Unmet Need for Personal Assistance With Activities of Daily Living Among Older Adults

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Purpose: This study examined the prevalence, correlates, and negative consequences of unmet need for personal assistance with activities of daily living (ADLs) among older adults. **Design and Methods:** The authors analyzed cross-sectional data from the 1994 National Health Interview Survey's Supplement on Aging. Data were weighted to be representative of the noninstitutionalized population aged 70 years and older. **Results:** Overall, 20.7% of those needing help to perform 1 or more ADLs (an estimated 629,000 persons) reported receiving inadequate assistance; for individual ADLs, the prevalence of unmet need ranged from 10.2% (eating) to 20.1% (transferring). The likelihood of having 1 or more unmet needs was associated with lower household income, multiple ADL difficulties, and living alone. Nearly half of those with unmet needs reported experiencing a negative consequence (e.g., unable to eat when hungry) as a result of their unmet need. **Implications:** Greater, targeted efforts are needed to reduce the prevalence and consequences of unmet need for ADL assistance in elderly persons.

Key Words: Elderly persons, ADLs, Disability, Living arrangements

Many elderly persons living in the community have difficulty performing basic activities of daily living (ADLs), such as eating, walking, and toileting. Often, individuals are able to overcome such difficulties through the use of assistive devices (see, e.g., Hartke, Prohaska, & Furner, 1998; Manton, Corder, & Stallard, 1993; Verbrugge, Rennert, & Madans, 1997). In many instances, however, disabled elderly persons need help from others (i.e., personal assistance) to perform ADLs (Norburn et al., 1995). If the need for as-

sistance goes unmet, older adults may be at risk for a variety of adverse outcomes, including increased health services utilization and depression (Allen & Mor, 1997) as well as institutionalization (Chenier, 1997; Tennstedt, McKinlay, & Kasten, 1994). Current estimates of need and unmet need for ADL personal assistance may serve as an indicator of future need for long-term care services (Tennstedt et al., 1994).

To help reduce the burden of unmet need and to facilitate the development and targeting of in-home and community-based services, it is important that we determine the prevalence and correlates of unmet need for personal assistance with ADLs. To date, however, few population-based studies have sought to address this issue. Analyzing data from the 1984 National Long-Term Care Survey (NLTCs), Manton (1989) found that, among community-dwelling older adults with chronic disability, the prevalence of unmet need for ADL assistance ranged from 1.4% (eating) to 27.9% (toileting). Overall, more than a third (34.6%) of the disabled population aged 65 years and older reported an unmet need for assistance with one or more ADLs. Prevalence of unmet need was strongly associated with increasing age and level of disability.

Using different definitions of disability, need, and unmet need, Allen and Mor (1997) conducted a telephone survey of disabled adults in Springfield, Massachusetts, and found that the prevalence of unmet need for assistance with ADLs ranged from 4.3% (eating) to 22.6% (bathing) among those aged 65 and older. Unmet need was significantly more likely among persons with two or fewer reliable helpers and among those who were more severely impaired. The authors also found that a substantial proportion of elderly persons with unmet needs experienced serious, negative consequences as a result of receiving inadequate personal assistance. In another study of disabled elderly persons (aged 70 years and older) in Massachusetts, Tennstedt and colleagues (1994) reported that less than 10% of respondents had an unmet need for assistance with personal care ADLs and that the likelihood of unmet need was significantly associated with level of disability.

From a national policy and planning perspective, these previous findings are somewhat limited insofar

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as they are based on older data or on data from a limited geographic region. In contrast, in the present study we used recent data from a nationally representative sample of older adults to address the following objectives: (a) to derive estimates of need and unmet need for ADL personal assistance; (b) to identify correlates of unmet need; and (c) building on the work of Allen and Mor (1997), to examine the prevalence and correlates of negative consequences of unmet need for ADL assistance.

Methods

Data Source and Analytic Sample

Data for these analyses come from the Second Supplement on Aging (SOA II) to the 1994 National Health Interview Survey (NHIS), conducted by the National Center for Health Statistics (NCHS) in collaboration with the National Institute on Aging. Covering a broad range of health topics, the NHIS is a household survey that is administered annually to a multistage probability sample of the civilian, noninstitutionalized population of the United States (Massey, Moore, Parsons, & Tadros, 1989). Approximately 1 year after the 1994 NHIS was conducted, household members aged 70 years and older were recontacted, and 9,447 of these individuals completed the SOA II (NCHS, 1998). Reflecting the U.S. population aged 70 and older in 1995, the weighted SOA II sample had a mean age of 77.3 years and was 60% female and 90% White.

Trained interviewers from the U.S. Bureau of the Census collected SOA II data through face-to-face, in-home interviews. Assisted and proxy interviews (6% and 11%, respectively) were allowed for elderly persons who were unable to participate on their own because of illness or impairment. Data were collected on various aspects of health and well-being in later life, such as sociodemographic characteristics, living arrangements, and measures of physical health and functioning, including ADLs.

The SOA II interview included a series of questions about seven ADLs: (a) bathing or showering; (b) dressing; (c) eating; (d) getting in and out of bed or chairs (i.e., transferring); (e) walking; (f) getting outside; and (g) using the toilet, including getting to the toilet (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963). For each ADL, respondents were first asked whether

or not, because of a health or physical problem, they had any difficulty performing the activity (by themselves and without using special equipment). For the purposes of this study, we defined disability as difficulty performing ADLs. The prevalence of ADL disability ranged from 2.5% (eating) to 23.9% (walking). Overall, nearly 30% of all persons aged 70 and older reported difficulty performing one or more ADLs. Excluding individuals who reported no difficulty performing ADLs (see Figure 1), we focused the analyses of this study on older adults with ADL disabilities.

Personal Assistance With ADLs

After asking respondents whether they had difficulty performing individual ADLs, interviewers asked study participants whether or not they received assistance from another person when performing a given activity, and whether or not they needed (or needed more) personal assistance. Personal assistance was defined as either hands-on help or supervisory/standby help. On the basis of the answers to these questions, we categorized disabled respondents as having no need, met need, or unmet need for personal assistance with ADLs (see Figure 1). As Figure 1 illustrates, individuals were categorized as having no need for personal assistance with a given ADL if they reported having difficulty performing the activity, but not receiving and not needing personal assistance. Respondents were categorized as having a met need if they reported having difficulty and receiving personal assistance, but not needing more assistance. Those who reported having difficulty and needing more personal assistance than they were receiving, if any, were categorized as having an unmet need.

Negative Consequences of Unmet Need

For four of the seven ADLs, the SOA II interviewers asked respondents whether or not they had experienced (during the past month) any negative consequences as a result of inadequate personal assistance. For example, respondents who reported experiencing either (a) discomfort because they were not able to bathe as often as they would have liked or (b) a burn or scald caused by bathing with water that was too hot were regarded as having experienced a negative consequence of unmet need for personal assistance with bathing/showering. Similar sorts of questions were asked for dressing, eating, and toileting (see Table 1).

Respondents who reported difficulty walking were asked how often they moved around their house/apartment. Multiple-choice answers ranged from "whenever [I] want" to "not often enough even to use the bathroom." Those who reported mobility restriction (i.e., something other than "whenever [I] want") were categorized as having had a negative consequence of unmet need for personal assistance with walking. In the SOA II interview, questions regarding negative consequences of unmet need were not asked for the remaining two ADLs, that is, transferring and getting outside.

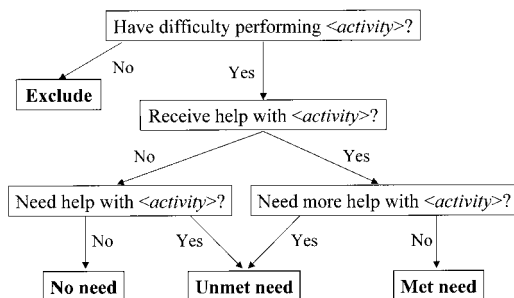


Figure 1. Determination of personal assistance need status for activities of daily living.

Table 1. Questions Used to Assess Negative Consequences of Unmet Need for Personal Assistance With Activities of Daily Living

Bathing/showering	
1.	During the past month, did you experience discomfort because you were not able to bathe as often as you would have liked?
2.	During the past month, did you experience a burn or scald caused by bathing with water that was too hot?
Dressing	
1.	During the past month, did you experience discomfort because you were not able to change your clothes as often as you would have liked because you did not have help?
Eating	
1.	During the past month, were there times you were unable to eat when you were hungry because no one was available to help you eat?
Walking	
1.	How often do you move around your [house/apartment/room]? Would you say (1) whenever you want, (2) often enough to stretch and have a change of scenery now and then, (3) often enough to take care of toileting needs but not much more than that, or (4) not often enough even to use the bathroom?
Toileting	
1.	During the past month, did you experience discomfort because you did not have help getting to the bathroom or changing soiled clothing as often as you needed to?
2.	During the past month, did you wet or soil yourself because you did not have help getting to the bathroom, using a bed pan or using a commode?

Potential Correlates

Sociodemographic characteristics, number of chronic conditions, and level of ADL disability were considered as potential correlates of unmet need and negative consequences of unmet need for personal assistance with ADLs. Specifically, we included the following sociodemographic variables in the analysis: sex, age (70–74, 75–79, 80–84, ≥ 85 years), race (White, Black, or other), education (< 12 or ≥ 12 years), annual household income ($< \$20,000$ or

$\geq \$20,000$), and living arrangements (alone or not alone).

Respondents reported whether or not they had ever had (a) a broken hip; (b) osteoporosis; (c) diabetes; (d) arthritis; (e) chronic bronchitis or emphysema; (f) asthma; (g) hypertension; (h) heart disease (including coronary heart disease, angina, heart attack or myocardial infarction); (i) any other heart disease; (j) a stroke or cerebrovascular accident; or (k) cancer. We calculated a summary score and categorized respondents as having had zero to one, two to three, or four or more chronic conditions. Level of ADL disability was defined according to the number of ADLs an individual had difficulty performing (one to two, three to four, or five to seven ADLs). Because assisted and proxy interviews were allowed in SOA II data collection, our analyses also included a variable for respondent status (self, assisted, or proxy).

Data Analysis

Among persons with ADL difficulties, we determined the overall distribution of need (i.e., no need, met need, or unmet need) for personal assistance with ADLs. Then, focusing on those individuals who reported need (either met need or unmet need) for assistance, we reexamined level of unmet need. Next, we determined the proportion of individuals who had experienced a negative consequence as a result of their unmet need. Finally, chi-squared and logistic regression analyses (Agresti, 1990) were performed to identify correlates of both unmet need and negative consequences of unmet need for personal assistance with one or more ADLs. The multivariate analysis employed a backward elimination strategy (Kleinbaum, 1994). Odds ratios (ORs) with 95% confidence intervals (CIs) were calculated. We performed all analyses using SUDAAN (Shah, Barnwell, & Bieler, 1996) to take into account the survey's complex sample design; this allowed for appropriate variance estimation and weighting of the data.

Table 2. Prevalence of Need, Unmet Need, and Negative Consequences of Unmet Need for Personal Assistance With ADLs

ADL	Difficulty Performing ADL		Personal Assistance Need Status, Weighted % ^b			Unmet Need Among Those With Need, Weighted % ^c	Negative Consequences Among Those With Unmet Need, Weighted % ^d
	<i>n</i>	Weighted <i>n</i> ^a	No Need	Met Need	Unmet Need		
Eating	218	510,000	39.0	54.8	6.2	10.2	21.1
Toileting	578	1,277,000	44.5	45.7	9.7	17.6	50.6
Dressing	810	1,822,000	26.3	64.1	9.7	13.1	20.3
Transferring	1,054	2,403,000	59.7	32.2	8.1	20.1	— ^e
Getting outside	1,205	2,727,000	34.2	54.8	11.0	16.7	— ^e
Bathing/showering	1,285	2,918,000	30.2	58.1	11.7	16.7	42.1
Walking	2,195	4,980,000	66.2	27.4	6.4	18.9	39.7
Any ADL	2,746	6,233,000	51.3	38.6	10.1	20.7	47.6

Note: ADL = activity of daily living.

^aEstimated population *n*, rounded to the nearest thousand.

^bThe denominator is the weighted number who have difficulty performing ADL. Percentages may not sum to 100% due to rounding.

^cThe denominator is persons with need (either met need or unmet need) for ADL personal assistance. Using eating as an example, 6.2%/61.0% = 10.2%. Values may differ slightly due to rounding.

^dThe denominator is persons with unmet need for ADL personal assistance.

^eQuestions regarding negative consequences of unmet need were not asked for transferring and getting outside.

Table 3. Correlates of Unmet Need for Personal Assistance With One or More ADLs

Variable	Sample <i>n</i> With Need ^a	Weighted % With Unmet Need	Adjusted ^b Odds Ratio	95% Confidence Interval
Total	1,346	20.7		
Sex				
Male	429	16.8*		
Female	917	22.6		
Age (Years)				
70–74	320	17.9		
75–79	313	21.9		
80–84	312	23.5		
85+	401	20.1		
Race				
White	1,106	19.9		
Black	215	26.4		
Other	25	23.1		
Education (Years)				
<12	709	23.1*		
12+	571	17.7		
Household Income				
<\$20,000	765	25.0***	1.40	0.99–1.98
\$20,000+	488	15.0	1.00	
Living Arrangements				
Live alone	388	32.3***	2.13	1.36–3.35
Live with other(s)	935	16.2	1.00	
No. of Chronic Conditions				
0–1	236	17.6		
2–3	651	20.3		
4+	440	23.0		
No. of ADL Difficulties				
1–2	413	13.7***	1.00	
3–4	420	18.6	1.53	0.99–2.36
5–7	513	28.4	2.98	1.96–4.52
Respondent Status				
Self	690	23.2*	1.00	
Assisted	224	21.5	1.00	0.62–1.61
Proxy	421	16.3	0.66	0.45–0.97

Note: ADL = activity of daily living.

^aPersons with need (either met need or unmet need) for personal assistance with one or more ADLs; totals may not sum to 1,346 due to missing data.

^bEach variable is adjusted for the other variables listed in the model.

* $p < .05$; *** $p < .001$ for chi-squared test.

Results

As the results in Table 2 show, substantial numbers of older adults have difficulty performing basic activities of daily living; it is estimated that more than 6.2 million adults aged 70 and older had difficulty performing one or more ADLs in 1995. Among those who had difficulty performing individual ADLs, the prevalence of unmet need for assistance ranged from 6.2% for eating to 11.7% for bathing/showering. Considering only persons with need (either met need or unmet need) for assistance, estimates of unmet need ranged from 10.2% for eating to 20.1% for transferring. Overall, 48.7% of older adults with ADL difficulties (or an estimated 3 million persons aged 70 and older) reported needing some sort of personal assistance with one or more ADLs, and, of those individuals with need, 20.7% (or an estimated 629,000 persons) had an unmet need. Nearly half (47.6%) of respondents with an unmet need for ADL personal assistance reported experiencing a negative consequence as a result of their unmet need.

Correlates of unmet need for ADL personal assistance are presented in Table 3. Prevalence of unmet need did not significantly vary by age, race, or number of chronic conditions. After adjusting for other sample characteristics, neither sex nor education was independently associated with unmet need. In multivariate analysis, respondents whose annual household income was less than \$20,000, who lived alone, and who had difficulty performing an increasing number of ADLs were at increased risk of having an unmet need for personal assistance. In addition, participants with a proxy respondent were less likely to have unmet needs.

Table 4 presents correlates of negative consequences of unmet need for ADL personal assistance. The likelihood of experiencing negative consequences of unmet need was significantly associated with lower income and increasing level of ADL disability. None of the other sociodemographic and health status variables considered were associated with negative consequences.

Table 4. Correlates of Negative Consequences of Unmet Need for Personal Assistance With One or More ADLs

Variable	Sample <i>n</i> With Unmet Need ^a	Weighted % With Negative Consequences	Adjusted ^b Odds Ratio	95% Confidence Interval
Total	227	47.6		
Sex				
Male	59	51.9		
Female	168	46.1		
Age (Years)				
70–74	42	56.1		
75–79	56	49.4		
80–84	62	50.2		
85+	67	38.2		
Race				
White	172	45.1		
Black	51	50.7		
Other	4	100.0		
Education (Years)				
<12	136	44.7		
12+	78	48.8		
Household Income				
<\$20,000	156	54.0**	2.78	1.45–5.32
\$20,000+	60	32.6	1.00	
Living Arrangements				
Live alone	95	47.9		
Live with other(s)	130	48.3		
No. of Chronic Conditions				
0–1	29	49.1		
2–3	108	42.5		
4+	88	53.2		
No. of ADL Difficulties				
1–2	42	25.6**	1.00	
3–4	54	39.4	2.04	0.75–5.56
5–7	131	59.2	4.67	1.75–12.46
Respondent Status				
Self	125	49.0		
Assisted	40	40.2		
Proxy	61	49.1		

Note: ADL = activity of daily living.

^aPersons with unmet need for personal assistance with one or more ADLs; totals may not sum to 227 due to missing data.

^bEach variable is adjusted for the other variable listed in the model.

***p* < .01 for chi-squared test.

Discussion

Using data from a nationally representative sample of community-dwelling elderly persons, we found that approximately 3 million persons aged 70 and older needed personal assistance to perform one or more ADLs in 1995. Overall, fully one fifth of those needing help reported receiving inadequate assistance, half of whom had recently experienced a negative consequence as a result of their unmet need. Low-income elderly persons and those with multiple ADL difficulties were at increased risk for both having an unmet need and experiencing a negative consequence as a result. Those who lived alone were more than twice as likely to have unmet needs, though no more likely to report negative consequences.

It is difficult to compare estimates of unmet need for ADL assistance across studies, because of considerable differences in study methods; sample characteristics; and definitions of disability, need, and unmet need. Whether we use all persons reporting

difficulty performing a given ADL or only those needing assistance as the denominator, our estimates of unmet need differ from those previously reported (Allen & Mor, 1997; Manton, 1989; Tennstedt et al., 1994). For most ADLs, we found higher rates of unmet need for assistance than either Manton (1989) or Tennstedt and colleagues (1994). This may be explained, at least in part, by our more comprehensive definition of unmet need: Whereas the two earlier studies asked only respondents receiving no help at all whether or not they needed help, we additionally asked those receiving some help whether or not they needed more help (similar to Allen & Mor, 1997). Moreover, the relatively low rates of unmet need reported by Tennstedt and colleagues (1994) may reflect the fact that their analysis focused on a select subsample of study participants who were still alive and community-dwelling 2 years following baseline interview. The higher rates of unmet need reported by Allen and Mor (1997) may, in part, be attributed to their assessment of need in the past month (1-

month period prevalence) as opposed to need at the present time (point prevalence).

Consistent with other studies (Allen & Mor, 1997; Manton, 1989; Tennstedt et al., 1994), on the other hand, was the finding that level of ADL disability (defined as the number of ADLs an individual had difficulty performing) was the strongest predictor of unmet need. The positive association between severity of disability and prevalence of unmet need for assistance likely reflects the fact that elderly persons with more ADL difficulties require more personal care, thereby increasing the likelihood that caregivers will not be able to satisfy all needs. The importance of the observed association between level of ADL disability and prevalence of unmet need is underscored by findings that increased disability and caregiver burden often precipitate the transition from community living to institutionalization (Chenier, 1997).

In this study, we also found that disabled elderly persons whose annual household income was less than \$20,000 were more likely to report receiving inadequate personal assistance with ADLs. Although Tennstedt and colleagues (1994) did not find an association between income and unmet need, Allen and Mor (1997) reported that the number of routine expenses one could not afford (a proxy for income) was positively associated with the number of unmet ADL needs (OR = 1.14, 95% CI = 0.99-1.30). Similarly, in a study of cancer outpatients (Siegel, Raveis, Houts, & Mor, 1991), unmet needs were significantly more likely among those eligible for Medicaid or public assistance. In these data, we did not find an association between insurance status and unmet need. More than 95% of the sample had Medicare; in addition, 21% had Medicaid and 64% had private insurance. Prevalence of unmet need for personal assistance with one or more ADLs did not differ according to presence or absence of Medicaid (21.2% vs. 20.6%, respectively, $p = .84$) or presence or absence of private insurance (19.8% vs. 23.0%, respectively, $p = .23$). These data suggest that elderly persons living in lower income households are less likely to be able to pay for formal care when the level of informal caregiving is insufficient. There is longitudinal evidence that increased access to formal in-home services may contribute to continued community living among disabled elderly persons (Tennstedt, Crawford, & McKinlay, 1993b).

Older adults with multiple ADL difficulties and limited financial resources were at increased risk for not only having unmet needs but also experiencing negative consequences of unmet needs. It is of great concern that nearly half of those with unmet needs experienced one or more negative consequences, because many of the negative consequences (such as not being able to eat when hungry and experiencing a burn or scald when bathing) had the potential to seriously threaten the health and safety of those with unmet needs.

Our finding that older adults who lived alone were twice as likely as those who lived with others to report an unmet need for personal assistance is con-

sistent with an extensive body of literature on instrumental social support (e.g., Langford, Bowsher, Maloney, & Lillis, 1997) and informal caregiving (e.g., Robinson, 1997). As expected, in the majority of cases, a disabled respondent's spouse or child was the primary caregiver. A more detailed analysis of household composition, marital status, and availability of children supported the findings of Chappell (1991) and Tennstedt, Crawford, and McKinlay (1993a) that coresidence is often more important than kinship tie per se in determining patterns of informal care and use of formal services. The fact that those who live alone are especially vulnerable to having unmet needs is important in light of the fact that, over time, an increasing proportion of the oldest-old, particularly women, are living alone (U.S. Bureau of the Census, 1996).

We also found that participants with a proxy respondent were less likely to have unmet needs. Although we believe this likely reflects the fact that those with an available proxy are more likely to need and, indeed, receive personal assistance with ADLs, the association may stem from proxies' greater unwillingness to report unmet need, fearing that doing so would negatively reflect on their own caregiving adequacy. To the extent that the latter is true, unmet need for ADL personal assistance would be underestimated. Notably, the same correlates of unmet need and negative consequences of unmet need were found when we restricted the sample to self-respondents only.

Although the majority of older adults who have difficulty performing basic ADLs have either no need or met need for personal assistance, a substantial proportion of disabled elderly persons continue to have unmet needs and experience negative consequences as a result. Most of the assistance that a community-dwelling elderly person receives is provided informally by family caregivers; in some instances, this care is supplemented by formal services. Because individuals whose needs for assistance go unmet may be at risk for a variety of adverse outcomes, it is important that the likelihood of having unmet needs be minimized. Greater, targeted efforts are needed to identify at-risk older persons living in the community and to provide services (e.g., home care, community-based services, assistive devices, and residential modifications) that may reduce the burden of unmet need. In the present study, we identified broad socio-demographic and health status factors associated with unmet need and negative consequences of unmet need for ADL personal assistance. Further studies are needed to identify and overcome specific barriers to receiving help and services (e.g., inability to pay and lack of accessibility or availability in one's area). Future work should consider the effectiveness of targeting potentially vulnerable populations, such as older adults living in low-income housing or poor rural communities.

Follow-up data are currently being collected on SOA II respondents. In future studies, we will be able to examine the longitudinal effects of having unmet

needs for ADL personal assistance in terms of outcomes such as functional decline, medical visits, hospitalizations, institutionalization, and mortality.

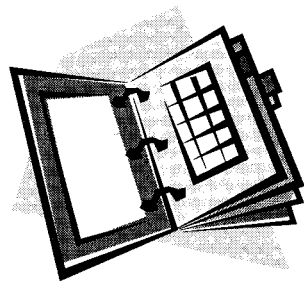
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