

BMJ Open Likelihood that expectations of informal care will be met at onset of caregiving need: a retrospective study of older adults in the USA

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ABSTRACT

Background Ageing adults are likely to expect informal caregiving assistance from a friend or family member, reflecting the reality that most long-term care (LTC) is provided by family and friends. The purpose of the study was to determine the likelihood that expectations of care will be unmet at the onset of functional disability, and the factors that impact that likelihood.

Methods Community-dwelling respondents from biannual repeated assessments (2006–2010) of the Health and Retirement Study over age 65 who expressed a caregiving expectation prior to need were included in the final analytical sample (n=1352). Logistic regression and change models were specified to address impact of variables on unmet expectations.

Results Expectations of care were unmet for almost one-third (32%) of the sample, among whom 30% were not receiving needed care. Unmet expectations were associated with being unmarried, older and having a higher number of ADL deficits. Change over time in the number of predictor variables influenced the likelihood of unmet expectations.

Conclusions Unplanned dependence on formal care systems and/or having unmet care needs places elders at risk of negative outcomes. Knowledge of factors that impact whether expected care is eventually received provides robust evidence for counselling individuals regarding the need to plan for additional LTC services.

BACKGROUND

The majority of Americans underestimate their future need for long-term services and support (LTSS).¹ Between 2010 and 2040 the number of Americans needing LTSS is projected to more than double to over 40 million,² and this may be an underestimate given current levels of disability risk among the middle-aged and young-old.³ Yet studies have shown that a sizeable proportion of Americans do not believe they will need LTSS in the future.^{1 4 5} The majority of Americans have not adequately planned for future LTSS needs.^{6 7} Planning in the absence of crisis is rare, and many Americans erroneously perceive that Medicare or other public

Strengths and limitations of this study

- Use of a large, representative data set allows for testing of the predictive value of personal expectations on likelihood that expected care will be received, a novel question that can inform personal discussions and policy decisions.
- The complex details surrounding caregiving decisions are not available in these data, and future research would benefit from qualitative work that supplements these findings.
- It is not clear whether those who did not receive care from the expected source but are receiving adequate care are satisfied with their informal caregiving arrangement, a significant limitation to the meaningful application of these findings.

funds are readily available to assist with LTSS financing. Robison *et al*⁵ found that 31% of surveyed middle-aged and older adults had no plans to finance their LTSS needs, 45% planned to rely on Medicare (which only funds limited postacute or skilled nursing services), and yet 90% planned to remain in their own home. Underestimation of future LTSS needs and overestimation of LTSS financing options, combined with little individual planning for LTSS, leave individuals at risk for unmet care needs and poor personal outcomes.

The number of Americans with long-term care (LTC) needs is large and expanding rapidly at a time in US history when access to trained caregiving personnel and public financial resources is diminishing. Demands of friends and family to provide LTC are common and will invariably increase in relation to predicted demographic and economic trends.^{8 9} The caregiver support ratio, defined as the number of adults aged 45–64 available to care for each person aged 80 and over, is expected to decrease from 7:1 in 2010 to 4:1 in 2030 and 3:1 in 2050.⁸



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Informal caregivers are often unprepared or unavailable to provide care, leaving an individual to become dependent on paid (formal) care services or face unmet care needs.^{10 11}

Despite the lack of overt planning for LTSS needs, people have expectations regarding living arrangements and caregiving when a need arises. Henning-Smith and Shippee¹ found that 73% of respondents to the National Health Interview Survey expected a family member to provide care, a significantly higher number of respondents than those who expected to rely on professional services or paid care for assistance. Research has also demonstrated that persons who expect to receive care from a family member are less likely to purchase LTC insurance, placing them at risk if the expected informal care is not provided.⁴

Previous researchers have shown that the parental expectations that a child will become their caregiver significantly predict selection of that particular child as caregiver among other siblings.¹² Available literature also shows that mothers demonstrate negative responses when caregiver preferences are unmet.¹³ As of yet, the frequency that expectations of informal care from any source will be met or unmet when need arises is unknown. It is also unclear what factors influence the likelihood that expectations for care will be met among a representative sample of older Americans. The current analyses address those gaps by using a large, nationally representative sample that expressed an expectation for care and later developed a caregiving need to answer the following research questions:

1. How often were caregiving expectations expressed prior to disability onset met at the time of caregiving need?
2. What individual and situational factors influenced that likelihood that expectations of care were met?

DESIGN AND METHODS

Data for this study were taken from biannual repeated assessments (2002–2010) of the Health and Retirement Study (HRS). It is a longitudinal study of a representative sample of about 20 000 Americans over the age of 50. Among large-scale studies designed to assess respondents' trajectories towards LTC needs, the HRS is unique in its inclusion of information about the respondents' expectations that a specific family member or friend will provide caregiving to the respondent when needed. Respondents are asked which of their family members or friends would be willing and able to provide needed help with personal care needs such as eating or dressing. It is assumed in the data that if the respondent has a spouse the spouse would be the primary caregiver, but respondents may report additional potential caregivers, allowing for the possibility that a current spouse may not be available or able to provide caregiving in the future.

Table 1 Baseline characteristics of analytical sample (n=1352)

Variable	Mean	Range
Age	81	67–104
Living children	3.5	0–20
Self-rated health	3 (fair)	1–5 (poor–excellent)
Cognitive score	9	0–10 (higher more intact)
Household income	\$38 390	\$0–\$726 768
Education in years	11.39	0–17
LTC insurance	11%	
Married	63%	
Female	61%	
White race	82%	
ADLs at baseline	0	0
ADLs at onset of caregiving need	2	1–6

ADL, activities of daily living; LTC, long-term care.

Analytical sample

The sample included all community-dwelling HRS respondents over age 65 in survey years 2002–2008 who were independent in their activities of daily living (ADL) tasks in their initial interview (n=9546). Respondents who completed the initial interview by proxy and therefore did not express an expected caregiver were not included in the sample. Of those 9546 respondents, 1670 (17%) developed an ADL deficit (dressing, walking, transfer mobility, bathing, eating or toileting) that required human help at a data collection point after their initial interview. Among those who developed a caregiving need, 1352 had expressed an expectation of care from a named friend or family member prior to the need for care. Only those respondents who expressed a caregiving expectation prior to need were included in the final analytical sample (n=1352). To address the proposed research objectives, only respondents who expressed a caregiving expectation and later developed a caregiving need were included in the analysis. The characteristics of the analytical sample are displayed in table 1.

Measurement and variables

Respondents' informal caregiving expectation was measured by their stated expectation of care from a named caregiver while still independently performing ADL tasks (prior to a need for care). An expectation could be stated at each biennial assessment. Onset of caregiving need was also assessed at each biennial assessment. For each respondent who newly reported the need for caregiving help from another person, it was noted who was providing the needed care. The list of actual caregivers was then compared by authors with the list of expected caregivers provided by the respondent at the assessment most proximal and prior to the development

of the caregiving need. If the respondent did not report an expectation of informal care in the assessment just prior to the onset of a caregiving need, the next prior assessment was considered, and so forth until the expectation most proximal to caregiving onset was identified.

The expectation was considered met if the respondent received care from their spouse or any other named caregiver. Care is defined as personal assistance with any ADL/instrumental activities of daily living (IADL) need. An expectation was considered unmet if none of the expected caregivers were actually providing care to the respondent, including situations when the respondent did not receive any needed care, received care from someone other than a spouse or expected caregiver, or received only paid care services. Predictor variables were selected based on empirical findings from previous research and were taken from the HRS survey. Determination of predictor variables was guided by Andersen's model of health behaviour, which describes predisposing, enabling and need characteristics that influence need for health-related services.¹⁴ The variables chosen include respondent demographic characteristics reflecting predisposing characteristics that increase need for care (age, race, education); family structure (marital status, number of living children) and economic predictors reflecting characteristics that enable acquisition of care (household income, having LTC insurance); and respondent health and functional status reflecting potential need for care (cognitive score, number of ADL deficits, self-rated health).

Analysis

A logistic regression model was fit to assess the relationship between the predictor variables and the binary outcome variable of whether or not caregiver expectations were met. A second logistic regression model was fit to assess the relationship between change over time in predictor variables and likelihood of met/unmet expectations. Potential predictor variables were assessed in turn in a simple logistic model, and the potential form of their relationship was explored using exploratory data analysis. Potential interactions were also tested. The best form of each predictor (as assessed by receiver operating characteristic (ROC) area under the curve) was then combined into the full models. A P value for an estimated effect in the full model below 0.05 was taken to be a statistically significant effect on the log odds of having expectations for care met.

RESULTS

Of the 1670 respondents who developed a caregiving need, the majority (n=1352, 81%) had expressed a caregiving expectation prior to onset of need. Adult child or child-in-law was the most frequently reported expected caregiver (48%), followed by spouse (35%). No other expected caregiver to recipient relationship occurred at more than 7% in this sample. Seventy-two per cent of caregiving expectations most proximal to the development of

a caregiving need were stated at the biennial assessment that occurred 2 years before the onset of need. For 18% of the analytical sample, the most recent statement of expectations was 4 years prior to caregiving need, and 7% expressed the most recent expectation of informal care was recorded 6 years prior to need. Only 3% of individuals expressed their most recent expectation 8 years prior to need.

Expectations of care were unmet for almost one-third (32%) of respondents who expressed an expectation of caregiving during an interview prior to developing a caregiving need. Among those whose caregiving expectations went unmet (n=427), 37% received only paid assistance, 33% received informal care from someone other than the expected caregiver and 30% were not receiving needed care. The average hours of help per day by caregiving status were 7.8 hours for those with unmet expectations, 7.2 hours for those with met expectations and 6.9 hours of care received from the expected caregiver. Unmet expectations were associated with being unmarried, older and having a higher number of ADL deficits. Unmet expectations were also associated with very high and very low self-rated health. Self-rated health had a quadratic relationship with met expectations; those in the middle (fair, good) had the highest rate of met expectations, while those with the lowest (poor) and highest (very good) were less likely to have their expectations met. The influence of cognitive impairment on unmet expectations became non-significant when the number of ADL deficits was accounted for in the model. The interaction between gender and marital status was significant, meaning that married men had a significantly greater chance of having caregiving expectations met, and married women were more likely to have unmet expectations. Number of living children, race, income and the presence of LTC insurance coverage were non-significant predictors of having caregiving expectations that go unmet. Model results are displayed in [table 2](#).

Change models

Change in the number of predictor variables influenced the likelihood of unmet expectations. The more years that had passed between the expressed expectation and onset of caregiving need (change in respondent age), change in marital status from married to unmarried (divorce or death of spouse) and remaining unmarried (in comparison to remaining married) were associated with an increased likelihood of unmet expectations. The magnitude of change in self-rated health (positive or negative) was associated with a decreased likelihood of unmet expectations. There was a significant interaction between female gender and change in marital status, meaning that women were more strongly affected by either becoming or remaining unmarried. Race, gender and ADLs at caregiving onset were entered into the model as control variables despite their static nature. Changes in cognition, loss of income and loss of LTC insurance were non-significant. Model results are displayed in [table 3](#).

Table 2 Predictor variables at baseline and likelihood for met expectations (n=1352)

Variable	Estimate	P value	OR	95% CI Lower bound	95% CI Upper bound
Intercept	5.2807	<0.0001			
Age	-0.0690	<0.0001	0.933	0.916	0.951
Living child	-0.0974	0.4029	0.907	0.521	1.299
Self-rated health	0.8511	0.0062			
Self-rate health ^{squared}	-0.1460	0.0029			
Cognitive score	0.0351	0.4133	1.036	0.952	1.126
Above-average income	0.2312	0.1669	1.260	0.908	1.749
ADLs at onset	-0.2707	<0.0001	0.763	0.707	0.824
LTC insurance	-0.0356	0.7328	0.965	0.619	1.402
Married	0.5619	<0.0001	3.077*	1.866*	5.072*
Female	0.0099	0.9468	1.916†	1.181†	3.108†
Female × married	-0.6402	<0.0001	0.855‡	0.613‡	1.193‡
White race	0.1283	0.1410	1.137	0.918	1.819
Education in years	0.0137	0.5046	1.014	0.974	1.056

*OR of married vs unmarried for men.

†OR of women vs men for unmarried.

‡OR of married vs unmarried for women.

ADL, activities of daily living; LTC, long-term care.

Table 3 Change in predictor variables and likelihood for met expectations (n=1352)

	Estimate	P value	OR	95% CI Lower bound	95% CI Upper bound
Intercept	2.1305	<0.0001			
Age increase (years)	-0.1075	0.0005	0.898	0.846	0.954
Living child	-0.1195	0.6091	0.887	0.561	1.403
Self-rated health change	0.2756	<0.0001	1.317	1.169	1.485
Cognitive score change	-0.0479	0.2131	0.953	0.884	1.028
Lost 10% or more of income	-0.0735	0.7485	0.929	0.593	1.456
ADLs at onset	-0.3034	<0.0001	0.738	0.682	0.799
No longer has LTC insurance	1.0224	0.0776	2.780	0.893	8.652
New LTC insurance	0.3986	0.457	1.499	0.524	4.286
Continued without LTC insurance	0.2591	0.2566	1.296	0.828	2.028
No longer married	-2.8181	<0.0001	0.060*	0.025*	0.141*
Continued as unmarried	-1.5658	<0.0001	0.209†	0.125†	0.350†
Female	-0.5588	0.0043	0.572‡	0.390‡	0.839‡
Female × no longer married	1.5832	0.0019	0.291§	0.173§	0.490§
Female × continued as unmarried	1.0948	0.0005	0.624¶	0.441¶	0.883¶
White race	0.1355	0.4252	1.145	0.821	1.598
Education in years	0.0257	0.1803	1.026	0.988	1.065

*No longer married vs still married for men.

†Still unmarried vs still married for men.

‡Women vs men for still married.

§No longer married vs still married for women.

¶Still unmarried vs still married for women.

ADL, activities of daily living; LTC, long-term care.

DISCUSSION

Ageing adults are likely to expect informal care from a family member, potentially to the detriment of their motivation to plan for formal care services. A critical barrier to effectively planning for LTC needs has been the gap in knowledge surrounding factors that influence the likelihood that expected informal care will be or will not be received. The findings from this analysis have important application in the development of LTC planning interventions that are realistic and reflect the situational context of individuals and families.

Americans have a documented underestimation of their future need for care and the resources that will be available to meet those needs. Overexpectation of care from friends and family members puts individuals at risk. Although a third of respondents with unmet expectations were receiving informal care from an unexpected source, disrupted care expectations may have negative emotional and interpersonal consequences that would benefit from future exploration.¹³ Individuals may suffer emotional upset when loved ones fail to meet internalised expectations of care. Thirty per cent of our sample for whom expectations of care were unmet were living without necessary care. Paid, formal care may have been unavailable, unaffordable or of poor quality. When needed care is not delivered, an individual is at significantly increased risk for emergency department utilisation for falls and injuries, hospitalisation, early mortality, poor quality of life and general health decline.^{15–18} Realistic expectations regarding the need for future care and the source of that needed care are vital to personal health.

The onset of caregiving need is a critical hinge in an individual's LTC needs trajectory. Persons who are older and highly ADL-dependent may overwhelm the capacity of the expected caregiver, resulting in use of paid or institutional services. When expectations of care are unmet, the impact goes beyond the individual and their informal caregivers and extends to financially limited public care delivery and payment systems. LTC expenses are a leading source of catastrophic medical costs that can result in the exhaustion of personal resources and reliance on public financing (primarily Medicaid) for care.⁸ Rates of personal protection through the purchase of LTC insurance are relatively low and have been projected to become even lower. It is estimated that only 11%–14% of Americans over age 65 have LTC insurance coverage.^{2,7,19}

Prior to this study what remained unclear was the predictive validity of individual expectations on actual receipt of care when need arises. It was found that expectations often went unmet, and that those most at risk to be underprepared for LTC needs (older, more disabled) were most likely to have unmet caregiving expectations. Disturbingly, almost a third (30%) of those with unmet needs reported receiving no care, this despite noting the need for human assistance at the time of interview. As public policy moves towards community care and avoidance of nursing home placement, more investigation into

the services needed to support expectations of informal care is warranted.

There are a number of limitations to this analysis, and the literature surrounding expectations of LTC would benefit from future studies that address these limitations. First, the HRS relies on respondent self-report information, and analyses were limited by the lack of availability of necessary variables in more recent survey years. Available data did not allow for a deeper exploration into the psychosocial effects of unmet expectations, the reasons why care needs were not met when expectations failed, or the individual response to those unmet needs and expectations. It was also not possible to examine whether the expected caregiver was providing care via a proxy paid caregiver, or providing other needed resources to the care recipient apart from direct assistance with ADL/IADL needs. Caregiver employment or parenthood status were also not included in the data or in our analyses. It should also be noted that individuals with advanced or severe dementia were likely non-responders to the survey and were less likely to be included in the sample.

Qualitative exploration into the context through which expectations develop and become realised would enhance these findings. Additionally, future research would benefit from examining the adverse healthcare utilisation consequences of unmet caregiving expectations and what strategies are pursued to access care by individuals when expectations of care are unrealised. Understanding utilisation patterns (hospital, nursing home, home and community-based care) that result from unmet caregiving expectations could provide clinicians with evidence about the relative importance of targeting LTC planning interventions towards those most vulnerable, and inform resource planning among policy makers.

CONCLUSION

This study provides evidence that many older adults are unprepared for the onset of caregiving needs and would benefit from evidence-based planning by professionals. Knowing the likelihood that expected care will be received promotes the ability for professionals to provide realistic, evidence-based care planning that potentially extends the functional capacity and quality of life for aged Americans and their caregivers. The USA currently lacks a comprehensive plan to address the LTC needs of the ageing population. Understanding the frequency and influences of unmet caregiving expectations provides needed information to link expectations to reality, and can be used to inform innovative solutions to care provision for the upcoming cohort of aged Americans.

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Competing interests None declared.

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Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The data for this work is publicly available. Information on how to access available data is located at <https://hrs.isr.umich.edu/data-products>.

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