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Likelihood that Expectations of Informal Care will be Met at Onset of Caregiving Need

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Abstract:

 Aging 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 factors that impact that likelihood.

Methods: Community dwelling respondents from bi-annual repeated assessments (2006-2010) of the Health and Retirement Study (HRS) over age 65 who expressed a caregiving expectation prior to **need** were included in the final analytic sample (n=1,352). 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 a 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 counseling individuals regarding the need to plan for additional LTC services.

Strengths and Weaknesses of the 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 care giving decisions are not available in this data, and future research would benefit from qualitative work which 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.

Background

The majority of Americans underestimate their future need for long term services and supports (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 funds are readily available to assist with LTSS financing. Robison et al. 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 post-acute or skilled nursing services), and

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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 leaves individuals at risk for unmet care needs and poor personal outcomes.

The number of Americans with LTC needs is large and expanding rapidly at a time in United States history when access to trained caregiving personnel and public financial resources are 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] Informal caregivers are often unprepared or unavailable to provide care, leaving an individual to become dependent upon 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 Shippee (2015) 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 upon 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 long term care 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 amongst other siblings.[12] Available literature also shows that mothers demonstrate

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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 bi-annual repeated assessments (2002-2010)

of the Health and Retirement Study (HRS). The HRS is sponsored by the National

Institute on Aging (grant number NIA U01AG009740) and is conducted by the University

of Michigan. It is a longitudinal study of a representative sample of about 20,000

Americans over the age of 50. Use of this data was approved by the Institutional Review

Board at the author institution, and authors have no competing interests to declare.

Among large scale studies designed to assess respondents' trajectories toward 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 that 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.

Analytic sample

The sample included all community-dwelling HRS respondents over age 65 in survey years 2002-2008 who were independent in their ADL tasks in their initial interview (n=9,546). Respondents who completed the initial interview by proxy and therefore did not express an expected caregiver were not included in the sample. Of those 9,546 respondents, 1,670 (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, 1,352 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 analytic sample (n=1,352). To address the proposed research objectives, only respondents who expressed a caregiving expectation and later developed a caregiving need were included in the analysis. Characteristics of the analytic 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.

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For each respondent that 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 to the list of expected caregivers provided by the respondent at the assessment most proximal and prior to 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. 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 upon empirical findings from previous research, and were taken from the HRS survey. Determination of predictor variables was guided by Andersen's model of health behavior 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 Long Term Care (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 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 1,670 respondents who developed a caregiving need the majority (n=1,352, 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 percent of caregiving expectations most proximal to the development of a caregiving need were stated at the biennial assessment that occurred two years before the onset of need. For 18% of the analytic 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.

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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. 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 number of ADL deficits was accounted for in the model. The interaction between gender and marital status was significant, meaning that married males had a significantly greater chance of having caregiving expectations met, and married females 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 which go unmet. Model results are displayed in Table 2.

Change Models

Change in a 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

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unmet expectations. 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 females were more strongly affected by either becoming or remaining unmarried. Race, gender and ADL's 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 nonsignificant. Model results are displayed in Table 3.

Discussion

Aging 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 under-estimation of their future need for care and the resources that will be available to meet those needs. Over-expectation 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 internalized expectations of care. Thirty percent of our sample for whom expectations of care were unmet were living without necessary care. Paid,

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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 utilization for falls and injuries, hospitalization, 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 is vital for 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. Long-term care expenses are a leading source of catastrophic medical costs

that can result in the exhaustion of personal resources and reliance upon public

financing (primarily Medicaid) for care.[8] Rates of personal protection through the

purchase of long-term care 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 toward community care and avoidance of nursing home placement, more

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investigation into the services needed to support expectations of informal care are

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 psycho-social 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 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 realized would enhance these findings. Additionally, future research would

benefit from examining the adverse healthcare utilization consequences of unmet

caregiving expectations and what strategies are pursued to access care by individuals

when expectations of care are unrealized. Understanding utilization 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 toward those most vulnerable, and inform resource

planning among policy makers.

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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 United States currently lacks a comprehensive plan to address the LTC needs of the aging 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.

List of Abbreviations

LTC= Long Term Care

HRS= Health and Retirement Study

LTSS= Long Term Services and Supports

Declarations

Ethics and Consent Statement: This analysis utilized only de-identified secondary data and was approved as Exempt by the IRB of author institution.

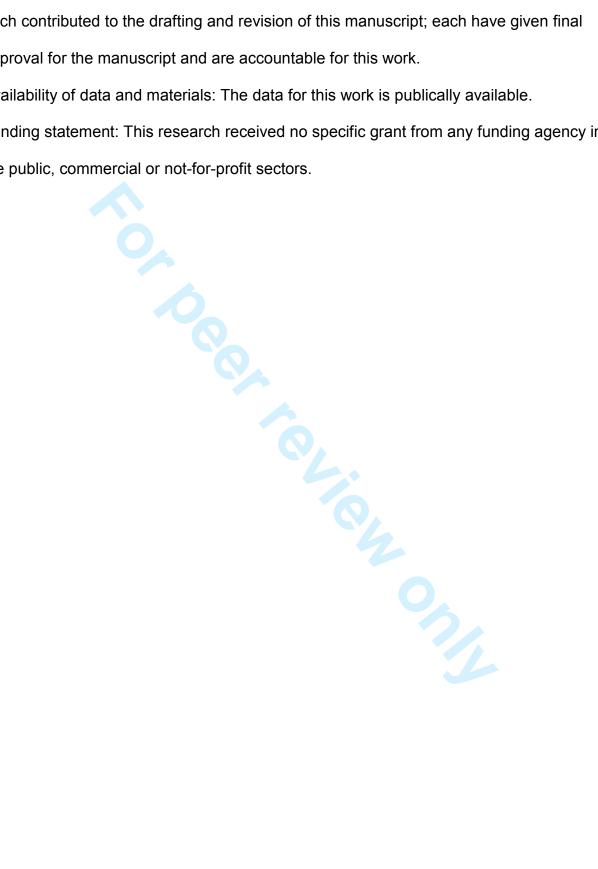Conflict of Interests: The authors declare they have no conflict of interests.

Author Contribution: KA, ZH and LS each made substantial contribution to the development of the research questions and the design of the analysis. KA, ZH and LS

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each contributed to the drafting and revision of this manuscript; each have given final

approval for the manuscript and are accountable for this work.

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Table 1. Baseline Characteristics of Analytic Sample (n=1, 352)

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
ADLs at Onset	2	1-6
Education in Years	11.39	0-17
LTC Insurance	11%	
Married	63%	
Female	61%	
White Race	82%	

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Table 2. Predictor Variables at Baseline and Likelihood for Met Expectations (n=1,352)

Variable	Estimate	P-Value	Odds Ratio	95% CL Lower	95% CL Upper
Intercept	5.2807	<.0001			
Age	-0.0690	<.0001	0.933	0.916	0.951
Living Child	-0.0974	0.4029	0.907	0.521	1.299
Self-Rate 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	<.0001	0.763	0.707	0.824
LTC Insurance	-0.0356	0.7328	0.965	0.619	1.402
Married	0.5619	<.0001	3.077[+]	1.866[+]	5.072[+]
Female	0.0099	0.9468	1.916[&]	1.181[&]	3.108[&]
Female*Married	-0.6402	<.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

+ Odds ratio of married vs unmarried for males. & Odds ratio of female vs male for unmarried. # Odds ratio of married vs unmarried for females.

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Table 3. Change in Predictor Variables and Likelihood for Met Expectations

(n=1,352)

	Estimate	P-Value	Odds Ratio	95% CL Lower Bound	95 % CI Upper Bound
Intercept	2.1305	<.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	<.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	<.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	<.0001	0.060[+]	0.025[+]	0.141[+]
Continued as Unmarried	-1.5658	<.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 males. # Still unmarried vs still married for males. & Female vs male for still married. ++ No longer married vs still married for females. ## Still unmarried vs still married for females.

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STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Likelihood that Expectations of Informal Care will be Met at Onset of Caregiving Need: A Retrospective Study of Older Adults in the United States

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Likelihood that Expectations of Informal Care will be Met at Onset of Caregiving Need: a retrospective study of older adults in the United States

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Abstract:

 Aging 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 factors that impact that likelihood.

Methods: Community dwelling respondents from bi-annual repeated assessments (2006-2010) of the Health and Retirement Study (HRS) over age 65 who expressed a caregiving expectation prior to need were included in the final analytic sample (n=1,352). 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 a 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 counseling individuals regarding the need to plan for additional LTC services.

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Strengths and Weaknesses of the 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 care giving decisions are not available in this data, and future research would benefit from qualitative work which 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.

Background

     The majority of Americans underestimate their future need for long term services and supports (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 funds are readily available to assist with LTSS financing. Robison et al. 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 post-acute or skilled nursing services), and

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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 leaves individuals at risk for unmet care needs and poor personal outcomes.

The number of Americans with LTC needs is large and expanding rapidly at a time in United States history when access to trained caregiving personnel and public financial resources are 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] Informal caregivers are often unprepared or unavailable to provide care, leaving an individual to become dependent upon 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 Shippee (2015) 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 upon 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 long term care 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 amongst other siblings.[12] Available literature also shows that mothers demonstrate

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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 bi-annual repeated assessments (2002-2010)

of the Health and Retirement Study (HRS). The HRS is sponsored by the National

Institute on Aging (grant number NIA U01AG009740) and is conducted by the University

of Michigan. It is a longitudinal study of a representative sample of about 20,000

Americans over the age of 50. Use of this data was approved by the Institutional Review

Board at the author institution, and authors have no competing interests to declare.

Among large scale studies designed to assess respondents' trajectories toward 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

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as eating or dressing. It is assumed in the data that if the respondent has a spouse that 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.

Analytic sample

The sample included all community-dwelling HRS respondents over age 65 in survey years 2002-2008 who were independent in their ADL tasks in their initial interview (n=9,546). Respondents who completed the initial interview by proxy and therefore did not express an expected caregiver were not included in the sample. Of those 9,546 respondents, 1,670 (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, 1,352 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 analytic sample (n=1,352). To address the proposed research objectives, only respondents who expressed a caregiving expectation and later developed a caregiving need were included in the analysis. Characteristics of the analytic 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.

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For each respondent that 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 to the list of expected caregivers provided by the

respondent at the assessment most proximal and prior to 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/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 upon empirical findings from previous research, and were taken

from the HRS survey. Determination of predictor variables was guided by Andersen's

model of health behavior 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 Long Term Care (LTC) insurance), and

respondent health and functional status reflecting potential need for care (cognitive

score, number of ADL deficits, self-rated health).

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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 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 1,670 respondents who developed a caregiving need the majority (n=1,352, 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 percent of caregiving expectations most proximal to the development of a caregiving need were stated at the biennial assessment that occurred two years before the onset of need. For 18% of the analytic 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.

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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 number of ADL deficits was accounted for in the model. The interaction between gender and marital status was significant, meaning that married males had a significantly greater chance of having caregiving expectations met, and married females 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 which go unmet. Model results are displayed in Table 2.

Change Models

Change in a number of predictor variables influenced the likelihood of unmet expectations. The more years that had passed between the expressed expectation and

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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. 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 females were more strongly affected by either becoming or remaining unmarried. Race, gender and ADL's 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 nonsignificant. Model results are displayed in Table 3.

Discussion

Aging 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 under-estimation of their future need for care and the resources that will be available to meet those needs. Over-expectation 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

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would benefit from future exploration. [13] Individuals may suffer emotional upset when loved ones fail to meet internalized expectations of care. Thirty percent 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 utilization for falls and injuries, hospitalization, 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 is vital for 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. Long-term care expenses are a leading source of catastrophic medical costs that can result in the exhaustion of personal resources and reliance upon public financing (primarily Medicaid) for care. [8] Rates of personal protection through the purchase of long-term care 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.

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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 toward community care and avoidance of nursing home placement, more investigation into the services needed to support expectations of informal care are 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 psycho-social 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 realized would enhance these findings. Additionally, future research would benefit from examining the adverse healthcare utilization consequences of unmet caregiving expectations and what strategies are pursued to access care by individuals when expectations of care are unrealized. Understanding utilization patterns (hospital,

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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 toward 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

United States currently lacks a comprehensive plan to address the LTC needs of the

aging 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.

List of Abbreviations

LTC= Long Term Care

HRS= Health and Retirement Study

LTSS= Long Term Services and Supports

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Declarations

Ethics and Consent Statement: This analysis utilized only de-identified secondary data and was approved as Exempt by the IRB of author institution.

Conflict of Interests: The authors declare they have no conflict of interests.

Author Contribution: KA, ZH and LS each made substantial contribution to the development of the research questions and the design of the analysis. KA, ZH and LS each contributed to the drafting and revision of this manuscript; each have given final approval for the manuscript and are accountable for this work.

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.

Funding statement: This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

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Table 1. Baseline Characteristics of Analytic Sample (n=1, 352)

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

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Table 2. Predictor Variables at Baseline and Likelihood for Met Expectations (n=1,352)

Variable	Estimate	P-Value	Odds Ratio	95% CL Lower	95% CL Upper
Intercept	5.2807	<.0001			
Age	-0.0690	<.0001	0.933	0.916	0.951
Living Child	-0.0974	0.4029	0.907	0.521	1.299
Self-Rate 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	<.0001	0.763	0.707	0.824
LTC Insurance	-0.0356	0.7328	0.965	0.619	1.402
Married	0.5619	<.0001	3.077[+]	1.866[+]	5.072[+]
Female	0.0099	0.9468	1.916[&]	1.181[&]	3.108[&]
Female*Married	-0.6402	<.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

+ Odds ratio of married vs unmarried for males. & Odds ratio of female vs male for unmarried. # Odds ratio of married vs unmarried for females.

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Table 3. Change in Predictor Variables and Likelihood for Met Expectations

(n=1,352)

	Estimate	P-Value	Odds Ratio	95% CL Lower Bound	95 % Cl Upper Bound
Intercept	2.1305	<.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	<.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	<.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	<.0001	0.060[+]	0.025[+]	0.141[+]
Continued as Unmarried	-1.5658	<.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 males. # Still unmarried vs still married for males. & Female vs male for still married. ++ No longer married vs still married for females. ## Still unmarried vs still married for females.

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STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found P. 1-2 of title pages
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported P. 1-2 of manuscript
Objectives	3	State specific objectives, including any prespecified hypotheses P. 3
Methods		
Study design	4	Present key elements of study design early in the paper P.3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection P.3-4
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants P.4
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable P.4-5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group P.4-5
Bias	9	Describe any efforts to address potential sources of bias P.4-5
Study size	10	Explain how the study size was arrived at P.4-5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why P.6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses P.6 all of the above as applicable
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed P 4-6
		(b) Give reasons for non-participation at each stage P.4-6
		(c) Consider use of a flow diagram Not appropriate for this analysis
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders P. 6, Table 1
		(b) Indicate number of participants with missing data for each variable of interest P.4, P. 6-7
Outcome data	15*	Report numbers of outcome events or summary measures P.7
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period P.7-8, Tables 2 & 3 for all of the above categories

| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses P. 8 |

Discussion

Key results	18	Summarise key results with reference to study objectives P.8
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias P.10
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence P.9-10
Generalisability	21	Discuss the generalisability (external validity) of the study results P.8-10

Other information

| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based P. 12 |

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.