

Research Article

Shared Care Networks Assisting Older Adults: New Insights From the National Health and Aging Trends Study

Mengyao Hu, PhD,*^{ORCID} Vicki A. Freedman, PhD^{ORCID} Sarah E. Patterson, PhD^{ORCID} and Nora Lewis, HS

Institute for Social Research, University of Michigan, Ann Arbor, Michigan, USA.

*Address correspondence to: Mengyao Hu, PhD, Institute for Social Research, University of Michigan, 426 Thompson Street, Ann Arbor, MI 48104-1248, USA. E-mail: maggiehu@umich.edu

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Abstract

Background and Objectives: Caregiving research often assumes older adults receiving care have a primary caregiver who provides the bulk of care. Consequently, little is known about the extent to which care responsibilities are shared more evenly within a care network, the characteristics associated with sharing, or the consequences for meeting older adults' care needs.

Research Design and Methods: We analyze a sample of U.S. older adults receiving care from the 2011 National Health and Aging Trends Study ($n = 2,398$). Based on variables reflecting differences in care hours, activities, and care provided by the whole network, we create network typologies for those with two or more caregivers ($n = 1,309$) using K-means cluster analysis. We estimate multinomial and logistic regression models to identify factors associated with network type and the association between type and unmet needs. We conduct analyses overall and for older adults living with and without dementia.

Results: Analyses reveal four network types: Small, low-intensity shared care network (SCN); large, moderate-intensity SCN; small, low-intensity primary caregiver network (PCN); and moderate-sized, high-intensity PCN. Among all older adults receiving care, 51% have a sole caregiver, 20% have an SCN with no primary caregiver, and 29% have a PCN. Among older adults with dementia receiving intense care, unmet needs are lower among those with an SCN (vs. PCN).

Discussion and Implications: Findings underscore that the primary caregiver construct, although common, does not apply to a substantial share of care networks. Moreover, having an SCN when needs are high may be beneficial to meeting older adult's needs.

Keywords: Caregiver networks, Dementia, Unmet need

Research on caregiving for older adults often uses the concept of primary caregiver to characterize the individual providing the bulk of care, both in terms of time spent and tasks undertaken, during an illness or end-of-life experience. Some of the earliest uses of “primary” or “principal” caregiver can be traced to writings from the early 1980s describing the role of the family in caring for an older adult (Brody, 1981; Cantor, 1983; Horowitz, 1985; Johnson,

1983; Soldo & Myllyluoma, 1983; Stoller, 1983). Since that time, the primary caregiver construct has figured prominently in the caregiving literature (Aguila et al., 2019; Allen et al., 2012; Amjad et al., 2021; Liu et al., 2021; Stephens et al., 1991; Szinovacz & Davey, 2007; Wolff & Kasper, 2006; Wolff et al., 2018).

Measurement of the primary caregiver construct varies. Studies ask older adults to identify their primary caregiver

(e.g., Bullock et al., 2003; Li & Dai, 2019), ask caregivers if they consider themselves primary (e.g., Lilly et al., 2010; Sims-Gould & Martin-Matthews, 2007; Waite et al., 2019), and use objective measures, such as reports of time spent on care tasks or number of tasks (e.g., Gaugler et al., 2000; Lima et al., 2008; Marcum et al., 2020; Russell, 2004; Sayegh & Knight, 2011). Yet, neither the measures of primary caregiver nor the construct itself have been well validated (see Lilly et al., 2010, for a notable exception).

Indeed, underlying much of the research on primary caregivers is a premise that a single caregiver is unique among a set of potential or actual caregivers. However, both theoretical models and empirical results call into question this assumption. For example, Riley's latent kin matrix theory focuses on how a person needing care may call upon different caregivers depending on need, timing, and availability (Riley, 1983; Riley & Riley, 1996), suggesting a single primary caregiver may not always be the dominant model. Qualitative studies suggest that adult children often share care by taking turns or shifting and sharing caregiving roles (Ingersoll-Dayton et al., 2003; Lingler et al., 2008; Matthews & Rosner, 1988). Keith (1995) describes a special case of care sharing referred to as a "partnership" structure in which two caregivers contribute relatively equitably to caregiving work. Other studies have uncovered a division of labor among adult children that equalizes as care needs of an older parent increase (Davey & Szinovacz, 2007; Lin & Wolf, 2020; Wolf et al., 1997) and suggest that shared care may be especially common for those living with dementia (Marcum et al., 2020; Spillman et al. 2020).

Yet, national estimates of the extent to which caregivers to older adults share care responsibilities somewhat evenly (a "shared care network" or SCN) are lacking. Moreover, factors that are associated with having an SCN versus primary caregiver network (PCN) have not been identified, nor have implications of network type for adequately meeting older adults' daily needs been explored. With respect to the latter, unmet care needs of older adults have been used as a proxy for inadequate care (Allen & Mor, 1997; Beach & Schulz, 2017; Desai et al., 2001), with higher unmet needs linked to dementia and other high-need/high-cost conditions (Beach et al., 2020). Sharing care may lead to better outcomes for the older adult if caregivers support one another; alternatively, if SCNs are more likely to experience friction, needs may go unmet. To date, the relationships among dementia, network type, and unmet needs remain largely unexplored.

We advance this area of research by exploring the prevalence, characteristics, and outcomes associated with having an SCN, for older adults aged 65 and older, overall and by the presence of dementia. We use the National Health and Aging Trends Study (NHATS), a national study of older adults in the United States that identifies all caregivers, their hours, and tasks. Unlike prior analyses of NHATS that have gone beyond the focus on a single primary caregiver

to examine multiple actual or potential caregivers (e.g., Lin & Wolf, 2020; Spillman et al., 2020), we create a set of care network typologies and then examine the following questions:

- (1) How often do older adults have an SCN, in which care is shared relatively evenly among at least two caregivers, versus a PCN, in which one caregiver provides the bulk of care?
- (2) What characteristics are associated with having an SCN versus PCN? and,
- (3) Is network type (SCN vs. PCN) associated with older adults' unmet needs?

For each question, we explore whether findings vary by whether the care recipient has dementia.

Data and Methods

Data and Analytic Samples

Begun in 2011, NHATS is a nationally representative panel study of older adults' aged 65 and older living in the contiguous United States. The sample was drawn from the Medicare enrollment file, which includes approximately 96% of U.S. older adults. NHATS uses a stratified three-stage sample design and oversamples individuals at older ages and Black individuals (Montaquila et al., 2012). In total, 8,245 respondents participated in Round 1 (71% response rate).

We analyze the subset of cases who completed a sample person (SP) interview living in settings other than nursing homes ($n = 7,609$; including 7.7% proxy respondents who answered for SPs unable to answer for themselves). We focus our analysis on older adults ($n = 2,398$) who received help in 2011 with at least one of 12 activities in the domains of self-care, mobility, or household activities, the latter for health or functioning reasons, and the subset ($n = 1,309$) who had two or more caregivers who helped with at least one self-care, mobility, or household activity (excluding those who provided services on behalf of a residential care provider). Note that older adults who only received care from staff persons at the place they resided were excluded from the analytic sample because the number of hours of help received from these caregivers was not collected in NHATS.

Measures

Caregivers

NHATS participants were asked to report who helped with each of the 12 activities. For each helper, respondents were asked to report days in the last month (or, if they helped on a regular schedule, days per week) and hours per day. From this information, we constructed hours of help in the last month for each caregiver. Cases missing hours were imputed using an algorithm developed by Freedman et al. (2014).

The individuals providing the most and second most (and, if relevant, third most) hours in the last month were then designated as the primary and secondary (and tertiary) caregivers, respectively. When caregivers had the same number of hours, number of care activities was used to break the tie.

Care networks

We used four variables to characterize care networks, two representing the distance between primary and secondary caregivers and two representing the care provided by the network as a whole. First, we constructed the percentage gap in hours of care between primary and secondary caregivers as a percentage of the primary caregiver's hours. Second, we constructed the gap in the number of activities between the primary and secondary caregivers. Third, we constructed the total number of hours of help received by the older adult, summed across all caregivers. Finally, we counted the number of caregivers for each older adult. For older adults with three or more caregivers, we also constructed the percentage gap in hours of care and the gap in number of activities between secondary and tertiary caregivers.

Older adults' unmet needs

NHATS asks about adverse consequences in the last month occurring as the result of unmet needs. For each self-care, mobility, and household activity, older adults who reported receiving help every time the activity occurred were asked whether the consequence occurred in the last month because there was no one there to help. Those who reported difficulty but did not receive help every time the activity occurred were asked whether the consequence occurred because it was too difficult to do the activity by themselves. Specifically, respondents were asked if they had to stay in bed, were unable to go places in their home or building, were unable to leave their home or building, went without eating, went without showering/bathing/washing up, accidentally wet or soiled their clothes, went without getting dressed, went without clean clothes, went without groceries or personal items, went without a hot meal, went without handling bills or banking matters, and made a mistake in taking their medications. A summary indicator was constructed reflecting whether older adults experienced any unmet need.

Dementia and covariates

We used the NHATS' probable dementia classification (Kasper et al., 2013) to stratify analyses. NHATS classifies as having probable dementia individuals who report a diagnosis of Alzheimer's disease or dementia, those who score 2 or more on an informant dementia screen, and those who score on a series of cognitive tests 1.5 standard deviation (SD) below the mean in at least two domains (memory, orientation, and executive functioning). Other covariates used

as control variables in models included the older adult's age, gender (male and female), race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, and others), educational level, marital status, number of children, whether they have one or more children living in the household, whether they live in a residential care setting, and whether a proxy respondent completed the interview. All covariates were obtained from the Round 1 (2011) NHATS interview.

Analyses

To characterize care network types, we performed both hierarchical and k-means cluster analysis using the four care network variables (percentage gap in hours and gap in activities between primary and secondary caregivers, number of hours, and number of caregivers). In data preprocessing, these variables were normalized using *z*-scores. We first performed hierarchical clustering using a Euclidean distance function with the proximity between groups of variables measured using Ward's method. A dendrogram was plotted to depict the similarity in relationships among all older adults. To determine the number of meaningful clusters, we also used several clustering diagnostics, including cubic clustering criterion, R-squared scores, semipartial R-squared scores, root-mean square standard deviation, and between cluster sum of squares (see [Supplementary Figures 1–4](#)). After determining the optimal number of clusters, *g*, in hierarchical clustering, we performed k-means clustering specifying *g* number of clusters (Husson et al., 2011). Means of the standardized variables were used as the initial seeds of k-means. For older adults with three or more caregivers, we replicated the analysis using the four care network variables and the two additional care gap variables (between secondary and tertiary caregivers).

To examine characteristics related to clusters (hereafter, network type), we conducted bivariate tests to determine whether older adults' characteristics were associated with network type, including chi-square tests for categorical measures and analyses of variance (ANOVAs) for continuous measures. We also performed weighted multinomial logistic regression, overall and stratified by dementia status, to predict network type membership using older adults' characteristics.

Finally, we estimated logistic regression models to determine if network type was associated with older adults' unmet needs, for all older adults and stratified by dementia status. All models controlled for older adult's characteristics and were weighted and account for NHATS' complex sample design.

Results

[Table 1](#) shows the weighted distribution for baseline characteristics for the subset of older adults who received care in 2011 from one or more ($n = 2,398$), at least two

Table 1. Baseline Sociodemographic and Care Characteristics of the National Health and Aging Trends Study 2011 Cohort, by Number of Caregivers

Characteristics	Any caregivers	At least two caregivers	At least three caregivers
	<i>N</i> = 2,398	<i>n</i> = 1,309	<i>n</i> = 630
Hour care gap (%) between			
Primary and secondary, %		59.0	55.1
Secondary and tertiary, %			46.5
Activity gap (#) between			
Primary and secondary		1.9	1.8
Secondary and tertiary			0.8
Hours of help received care from all caregivers last month	163	213	258
Number of activities received care	4.8	5.7	6.5
Number of caregivers, %			
1	51.0		
2	25.8	52.6	
3	13.6	27.8	58.6
4+	9.6	19.6	41.4
Has probable dementia, %	29.7	36.1	39.1
Age, %			
65–69	15.9	12.6	15.4
70–74	16.0	12.0	10.1
75–79	18.6	18.8	18.5
80–84	19.8	22.7	20.6
85–89	18.5	20.5	21.8
90+	11.2	13.4	13.7
Female, %	67.9	72.3	72.6
Race/ethnicity, %			
White, non-Hispanic	74.5	69.8	68.3
Black, non-Hispanic	10.3	13.1	13.2
Hispanic	11.0	11.7	12.2
Others	4.2	5.4	6.3
Education, %			
Below high school	34.4	39.2	40.7
High school graduates	51.3	47.9	46.1
College and above	14.2	12.9	13.2
Marital status, %			
Married or with a partner	45.4	37.1	38.3
Separated or divorced	10.2	11.3	11.1
Widowed	40.4	47.1	47.4
Never married	4.0	4.4	3.2
Number of children	3.1	3.3	3.5
Have children in household, %	26.1	34.5	35.5
Residential care resident, %	13.4	11.7	8.4
Proxy respondent, %	18.0	23.2	25.5

Notes: Caregivers who provided at least one of the 12 care-related activities are included, and those who are staff person at the place sample person (SP) lives/lived (op1relatshp = 37) are excluded.

(*n* = 1,309), and at least three (*n* = 630) caregivers. About half (51.0 %) of older adults who received care in 2011 had only one caregiver, about a quarter (25.8%) had two caregivers, and 23.2% had three or more caregivers.

Among older adults with at least two caregivers, the average percentage gap in hours between the primary and the secondary caregiver was 59.0%, and the average gap in activities was 1.9. Networks of two or more provided on

average 213 hours/month of care and helped with an average of 5.7 activities. About half of this group had exactly two caregivers, and 36.1% had dementia.

Networks with at least three caregivers had smaller average gaps between secondary and tertiary caregivers (46.5% in hours and 0.8 in activities) than between primary and secondary caregivers (55.1% in hours and 1.8 in activities). They also provided more total hours of care

(258 on average) and helped with more activities (6.5) than networks with two or more caregivers. Nearly four in 10 in this group had dementia.

Based on various diagnostic metrics (see [Supplementary Figure 2](#)), the four-cluster solution was selected. [Table 2](#) presents the size, profile, and characteristics of each network type overall and by dementia status. We describe the network types as follows: (a) Small, low-intensity SCN, where there is not a clear primary caregiver (hours gap = 23.3%, activity gap = 0.6), the network size is relatively small (2.4) and the intensity of care is relatively low (89 hr); (b) small, low-intensity PCN, where there is a clear primary caregiver (hours gap = 80.7%) in a relatively small network (2.4) with relatively low hours of care (122 hr); (c) large, moderate-intensity SCN, where there is no clear primary caregiver (hour gap = 42.8%, activity gap = 0.1), the network size is large (4.9), and intensity of care moderate (234 hr); and (d) moderate-sized, high-intensity PCN, where there is a primary caregiver (hour gap = 77.1%, activity gap = 4.4), network size is 2.9, and hours are high (830 hr). Similar cluster profiles are found in the stratified analysis by dementia status, except that the activity gap between primary and secondary caregivers and total hours of care for those with dementia are higher than those without dementia.

Among older adults with one or more caregiver, 51% have a sole caregiver, 20% have an SCN with no primary caregiver, and 29% have a PCN (see [Supplementary Table 1](#)). For both those with and without dementia, about one out of five networks had a shared care arrangement (22.8% vs. 19.2%); however, there are differences for those with and without dementia in the percentages with a sole caregiver (40.5% vs. 55.5%) and PCN (36.7% vs. 25.4%). Among older adults with two or more caregivers, SCN comprised 41.4% of networks; this share was similar for those with and without dementia.

Remaining characteristics for each network type overall and by dementia status are presented in [Supplementary Tables 2 and 3](#). Focusing on those with an SCN, care is most commonly shared between adult children (e.g., for those with and without dementia, combined 33.2% for small, low-intensity SCN and 31.6% for large, moderate-intensity SCN). For those with small, low-intensity PCN, an adult child is a primary caregiver most often (about 42%–45% of the time). However, for those with moderate-sized, high-intensity PCN, the most common arrangement differs by the presence of dementia: among those with dementia, 52.7% have an adult child serving as a primary caregiver; among those without dementia, 57.6% have a spouse in this role.

[Table 3](#) presents multinomial logit model coefficients, with the most common network type—small, low-intensity PCN—as the omitted outcome. Among all older adults with at least two caregivers, those who were female, with more children, and with more than a high school education were significantly more likely to be in the large, moderate-intensity SCN. In addition, those who were widowed were

Table 2. Cluster Size, Profile, and Characteristics by Dementia Status for Older Adults With Two or More Caregivers.

Cluster size and profile	Overall (n = 1,309)				Dementia (n = 520)				No dementia (n = 789)			
	Cluster 1	Cluster 2	Cluster 3	Cluster 4	Cluster 1	Cluster 2	Cluster 3	Cluster 4	Cluster 1	Cluster 2	Cluster 3	Cluster 4
Cluster size (Weighted percentage)	358 (28.7)	608 (46.5)	175 (12.7)	168 (12.2)	115 (22.2)	206 (41.0)	86 (16.2)	113 (20.7)	243 (32.4)	402 (49.6)	89 (10.7)	55 (7.4)
Network cluster profiles												
Hour gap (%)	23.3	80.7	42.8	77.1	22.8	80.6	41.7	74.9	23.4	80.7	43.8	80.5
Activity gap (#)	0.6	2.5	0.1	4.4	0.4	3.4	0.0	4.3	0.6	2.1	0.1	4.6
Hours of help	89	122	234	830	132	152	288	841	72	108	189	812
Number of caregivers	2.4	2.4	4.9	2.9	2.4	2.4	5.0	2.9	2.4	2.4	4.8	2.8

Notes: Cluster 1 = small, low-intensity shared care network; Cluster 2 = small, low-intensity primary caregiver network; Cluster 3 = large, moderate-intensity shared care network; Cluster 4 = moderate-size, high-intensity primary caregiver network.

Table 3. Coefficients From Multinomial Logit Models Predicting Network Typology Membership, Overall and by Dementia Status^a

Older adults' characteristics	Overall (n = 1,283)				Dementia (n = 500)				No dementia (n = 783)			
	Cluster 1	Cluster 3	Cluster 4		Cluster 1	Cluster 3	Cluster 4		Cluster 1	Cluster 3	Cluster 4	
Age	-0.01	0.02	0.02		-0.03	0.02	0.01		0.00	0.01	0.01	
Female	0.21	0.73*	-0.36		0.72*	0.59	0.13		0.00	1.04*	-0.79	
Race/ethnicity												
Black	-0.10	0.04	0.03		0.51	-0.08	0.00		-0.33	0.12	-0.08	
Hispanic	0.26	0.40	0.12		0.56	-0.15	-0.18		0.13	0.80	0.37	
Others	0.72*	0.59	0.42		0.82	0.75	-0.35		0.61	-0.15	1.32	
White (ref.)												
Education												
High school	0.02	0.37	-0.02		-0.29	0.21	-0.20		0.08	0.60	0.15	
Above high school	0.39	0.66*	-0.16		-0.23	-0.01	-0.03		0.52	1.26**	-0.22	
Below high school (ref.)												
Marital status												
Separated or divorced	0.70	0.05	-0.78		-1.18	-1.43	-1.91**		1.29**	0.73	-0.03	
Widowed	0.34	-0.38	-0.88***		0.12	-0.34	-0.79*		0.40	-0.36	-1.04**	
Never married	0.53	-0.52	-0.90		-0.06	-0.38	-1.60*		0.73	-0.80	-0.19	
Married (ref.)												
Number of children	0.03	0.17**	0.05		-0.05	0.25**	0.12		0.05	0.15**	0.01	
Have children in household	-0.24	-0.03	0.60*		0.07	0.38	1.04**		-0.38	-0.40	-0.25	
Residential care resident	0.28	-0.49	-1.03		0.52	-0.76	-1.09		0.31	-0.45	-2.01	

Notes: Cluster 1 = small, low-intensity shared care network; Cluster 3 = large, moderate-intensity shared care network; Cluster 4 = moderate-size, high-intensity primary caregiver network.

^aOmitted category: small, low-intensity primary caregiver network.

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

Table 4. Coefficients From Logistic Regression Models Predicting Any Unmet Need, Overall and by Dementia Status

Variable	Overall	Dementia	No dementia
	(<i>n</i> = 1,279)	(<i>n</i> = 499)	(<i>n</i> = 780)
Network typology			
1 Small, low-intensity SCN	-0.38*	-0.61*	-0.33
2 Small, low-intensity PCN (ref.)			
3 Large, moderate-intensity SCN	0.43	-0.12	0.71
4 Moderate-size, high-intensity PCN	0.69**	0.71*	0.22
Age	-0.02	-0.01	-0.02
Female	-0.11	-0.02	-0.15
Race/ethnicity			
Black	-0.01	-0.06	-0.03
Hispanic	0.42	0.30	0.45
Others	-0.21	-0.14	-0.28
White (ref.)			
Education			
High school	-0.30*	-0.50*	-0.22
Above high school	-0.26	0.36	-0.49*
Below high school (ref.)			
Marital status			
Separated or divorced	0.27	-0.42	0.50
Widowed	-0.02	-0.16	0.07
Never married	-0.18	-0.04	-0.22
Married (ref.)			
Number of children	-0.06*	-0.04	-0.06
Have children in household	0.02	0.36	-0.16
Residential care resident	0.25	0.25	0.26

Notes: SCN = shared care network; PCN = primary caregiver network.

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

less likely, and those with children in the household were more likely to have a moderate-sized, high-intensity PCN. These patterns were similar for those without dementia. Among those with dementia, gender, marital status, number of children, and having children in the household were related to the type of network.

Table 4 shows the associations between the type of network and having any unmet needs. Among all older adults with at least two caregivers, those with a moderate-sized, high-intensity PCN were more likely to have unmet needs than those with a small, low-intensity PCN. Those with a small, low-intensity SCN were less likely to have unmet needs than those with a small, low-intensity PCN.

Focusing on the stratified results, three points are noteworthy. First, among those with dementia, those with a small, lower-intensity SCN were less likely to have unmet needs than those with a small, lower-intensity PCN. Second, those with a large, moderately intense SCN were less likely to have unmet needs than those with a moderately sized

network, high-intense PCN (-0.12 vs. 0.71; $p < .05$ for difference; not shown). Third, among those without dementia, there are no significant differences between PCN and SCN groups.

Finally, we explored network types among those with at least three caregivers (see Table 5). Again, four types were identified, although they did not vary much by network size (range: 3.3–4.3). The first two network types were both low-intensity, but the first (33.1%) was labeled low-intensity SCN (percentage hour gap between primary and secondary = 22.9%, activity gap = 1.0), whereas the second (40.7%) had more substantial gaps between primary and secondary (hour gap = 77.2%; activity gap = 2.7) and was therefore labeled low-intensity PCN. The third network type, moderate-intensity SCN (14.2%), did not have a clear primary caregiver (percentage hour gap = 47.9%; activity difference = -2.1, suggesting the secondary caregiver helped with more activities than the first). However, the two caregivers helping most helped substantially more than the rest of the caregivers in the network (hour gap between secondary and tertiary is 64.1%; activity gap is 5.0). A final network type (12.0%) was labeled high-intensity PCN. In total, about 52.7% (40.7% + 12.0%) of older adults with three or more caregivers had a primary caregiver in their network and the remaining about 47.3% had a network better described as an SCN.

Focusing on the stratified results, those with dementia were more likely than those without to be assisted by more intense networks (37.4% vs. 19.1%). Almost twice as many older adults with dementia (relative to those without) had a network classified as a moderate-intensity SCN in which two partners shared care evenly and more than other caregivers (18.8% vs. 11.3%).

Discussion

In this study, we identified care network types of older adults to explore the salience of the primary caregiver concept. We found that 51% of older adults have a sole caregiver, 20% have a shared network with no primary caregiver, and 29% have a network with a clearly identifiable primary caregiver. Our finding that half of older adults receiving assistance had only one caregiver is higher than a previously published estimate based on NHATS of 37% (Kasper et al. 2015). Differences are attributable to the less restrictive definition of helper in the Kasper et al. (2015) analysis, which also included, for example, transportation. Irrespective of these differences, we suggest the term *sole* rather than *primary* caregiver may be a better semantic fit for this group, because the term *primary* implies that an individual is providing the bulk of care among a set of caregivers.

Among older adults with two or more caregivers, four out of 10 had a care arrangement in which two caregivers—most often two adult children—more evenly shared primary responsibility for care. Among those with three or more caregivers, nearly half had an SCN, and a subset of

Table 5. Cluster Size and Profile by Dementia Status for Older Adults With Three or More Caregivers

Cluster size and profile	Overall (n = 630)				Dementia (n = 269)				No dementia (n = 361)			
	Cluster 1	Cluster 2	Cluster 3	Cluster 4	Cluster 1	Cluster 2	Cluster 3	Cluster 4	Cluster 1	Cluster 2	Cluster 3	Cluster 4
	(33.1)	(40.7)	(14.2)	(12.0)	(30.5)	(32.1)	(18.8)	(18.6)	(34.7)	(46.2)	(11.3)	(7.8)
Cluster size	196	256	98	80	72	81	60	56	124	175	38	24
(Weighted percentage)	(33.1)	(40.7)	(14.2)	(12.0)	(30.5)	(32.1)	(18.8)	(18.6)	(34.7)	(46.2)	(11.3)	(7.8)
Network cluster profiles												
Hour care gap (%) between												
Primary and secondary	22.9	77.2	47.9	77.6	22.3	75.9	52.5	75.3	23.3	77.7	43.0	81.2
Secondary and tertiary	34.9	48.0	64.1	52.4	35.2	50.5	63.9	55.8	34.8	46.8	64.2	47.2
Activity gap (#) between												
Primary and secondary	1.0	2.7	-2.1	5.8	1.2	3.8	-1.9	5.4	0.9	2.2	-2.3	6.3
Secondary and tertiary	0.0	0.2	5.0	0.3	-0.2	0.4	5.3	0.3	0.1	0.1	4.6	0.2
Hours of help	124	143	394	853	188	179	464	902	88	127	319	779
Number of caregivers	3.8	3.3	4.3	3.7	4.0	3.4	4.3	3.8	3.7	3.3	4.3	3.7

Notes: Cluster 1 = low-intensity shared care network; Cluster 2 = low-intensity primary caregiver network; Cluster 3 = moderate-intensity shared care network; Cluster 4 = high-intensity primary caregiver network.

14% had two caregivers who contributed similar amounts at levels much greater than other caregivers. The latter situation is similar to the “partnership” structure described in Keith (1995), which can be viewed as a special type of shared care arrangement. These findings support theoretical writings that emphasize multiple caregivers within a latent kin network may work together to meet an older adult’s care needs (Riley, 1983; Riley & Riley, 1996).

We also found that distributions across sole, SCN, and PCN differed for older adults living with and without dementia, but the share with SCN was similar—about one in five—for both groups. This finding differs from previous studies documenting more task sharing within specific domains of care (self-care/mobility and household activities) for older adults with (vs. without) dementia (Spillman et al., 2020). Our approach differs in that we count as sharing situations in which caregivers take on different domains of activities (e.g., bathing vs. meal preparation), take on different assignments within a domain (e.g., shopping vs. meal preparation), and jointly take on the same activity (alternating meal preparation); in contrast, Spillman et al. (2020) define sharing using the latter two categories.

We also find that among older adults with dementia, those with an SCN were less likely to have unmet needs than those in similarly sized networks with a PCN, but this finding did not hold for older adults without dementia. By linking network characteristics to unmet need, these findings are an advance over previous studies that have mainly focused on care recipients (Beach & Schulz, 2017) in shaping unmet need.

This study has several limitations. First, our focus has been on outcomes related to the older adult in the form of unmet needs. How network type and a caregiver’s position in the network relate to caregiver outcomes is a fruitful area for future research. Second, this study focused on differences by the presence of dementia, and sample size constraints precluded exploration of intersectionality between dementia and other care recipient factors, such as gender, race, and ethnicity. Nor were we able to introduce more details about the members of the care network, such as distance from the care recipient or family and work-related time demands or preferences, and how these characteristics shape network type and outcomes. Third, this study evaluates care network types for older adults aged 65 and older in 2011, when the leading edge of the baby boom generation was just entering late life. Given impending changes in education and family structure as the baby boom generation ages, replication of this analysis with more recent rounds of NHATS is an important next step. Fourth, these cross-sectional descriptive findings may mask more complex underlying processes. For instance, older adults with advanced dementia who require 24-hr care may have more unmet needs not attributable to having a PCN per se, but to the much higher hours of assistance required. Future research should draw upon the types of networks identified here to sort out how

care needs and SCN and PCN evolve and their relative importance in shaping met and unmet needs. Fifth, other research (Spillman et al., 2020) has highlighted additional aspects of caregiver networks, including the fraction helping with just one versus multiple domains of activities (specialist vs. generalist). Our approach also does not characterize the intensity or predictability of the timing of particular tasks. Findings may also be sensitive to the types of activities used to identify helpers and measures used to form care typologies. Future studies should consider alternative definitions of care sharing to determine the robustness of these findings.

Despite these limitations, this study has implications for practices aimed at improving care for older adults and related research. Our descriptive findings suggest that for older adults with dementia, having an SCN may help address needs better than having a PCN. This finding is consistent with previous studies that have demonstrated that the social support network mediates outcomes for both older adults and those who care for them (Roth et al., 2005). Yet programs to address care recipient and caregiver needs often focus on a primary or single caregiver. A recent review of caregiver interventions found that only four of 46 studies included more than one caregiver (Wiegelmann et al., 2021), perhaps because of the challenges of recruiting multiple caregivers. Notwithstanding this challenge, our findings lay the groundwork for additional experimental designs that might evaluate the effect of shifting to a shared care arrangement.

In addition, our findings have implications for recent calls to enhance the training of family caregivers (Administration for Community Living, 2019) and remove barriers for interacting with the paid health care system (Schulz et al., 2018). Prior studies suggest that additional training of family caregivers is needed, whether following a health care encounter or in conjunction with home health care (Burgdorf et al., 2021, 2022), alongside changes in processes, such as providing caregivers access to patient's medical records when patients are seriously ill (Schulz et al., 2018). Attempts to improve training and remove structural and process barriers should take into account the sizable extent of care sharing.

Finally, recent research has highlighted that caregivers (and not just recipients) are embedded within their own support networks, which vary in size and structure (Friedman & Kennedy, 2021). Our findings echo the value of studying caregivers' networks rather than focusing solely on the experience of individual caregivers and raises the additional question as to whether caregivers embedded in SCN are better supported than those who take on primary responsibility for a family member. More generally, this study underscores that the primary caregiver construct, although common, does not apply to a substantial share of care networks, and in doing so highlights the value of collecting information from the full care network in surveys of older adults and those who assist them.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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Conflict of Interest

None declared.

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References

- Administration for Community Living, U.S. Department of Health and Human Services. (2019). *Raise family caregiving advisory council*. <https://acl.gov/programs/support-caregivers/raise-family-caregivers-advisory-council>
- Aguila, E., López-Ortega, M., & Angst, S. (2019). Do income supplemental programs for older adults' help reduce primary caregiver burden? Evidence from Mexico. *Journal of Cross-Cultural Gerontology*, 34(4), 385–402. doi:10.1007/s10823-019-09374-8
- Allen, S. M., Lima, J. C., Goldscheider, F. K., & Roy, J. (2012). Primary caregiver characteristics and transitions in community-based care. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 67(3), 362–371. doi:10.1093/geronb/gbs032
- Allen, S. M., & Mor, V. (1997). The prevalence and consequences of unmet need: Contrasts between older and younger adults with disability. *Medical Care*, 35, 1132–1148. doi:10.1097/00005650-199711000-00005
- Amjad, H., Mulcahy, J., Kasper, J. D., Burgdorf, J., Roth, D. L., Covinsky, K., & Wolff, J. L. (2021). Do caregiving factors affect hospitalization risk among disabled older adults? *Journal of the American Geriatric Society*, 69(1), 129–139. doi:10.1111/jgs.16817
- Beach, S. R., & Schulz, R. (2017). Family caregiver factors associated with unmet needs for care of older adults. *Journal of the American Geriatrics Society*, 65(3), 560–566. doi:10.1111/jgs.14547
- Beach, S. R., Schulz, R., Friedman, E. M., Rodakowski, J., Martsolf, R. G., & James, A. E. (2020). Adverse consequences of unmet needs for care in high-need/high-cost older adults. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 75(2), 459–470. doi:10.1093/geronb/gby021
- Brody, E. (1981). "Women in the middle" and family help to older people. *Gerontologist*, 21(5), 471–480. doi:10.1093/geront/21.5.471
- Bullock, K., Crawford, S. L., & Tennstedt, S. L. (2003). Employment and caregiving: Exploration of African American caregivers. *Social Work*, 48(2), 150–162. doi:10.1093/sw/48.2.150

- Burgdorf, J. G., Arbaje, A. I., Stuart, E. A., & Wolff, J. L. (2021). Unmet family caregiver training needs associated with acute care utilization during home health care. *Journal of the American Geriatrics Society*, 69(7), 1887–1895. doi:10.1111/jgs.17138
- Burgdorf, J. G., Wolff, J. L., Chase, J. A., & Arbaje, A. I. (2022). Barriers and facilitators to family caregiver training during home health care: A multi-site qualitative analysis. *Journal of the American Geriatrics Society*, 70(5), 1325–1335. doi:10.1111/jgs.17762
- Cantor, M. H. (1983). Strain among caregivers: A study of experience in the United States. *Gerontologist*, 23(6), 597–604. doi:10.1093/geront/23.6.597
- Davey A., Szinovacz M. E. (2007). Division of care among adult children. In M. E. Szinovacz & A. Davey (Eds.), *Caregiving contexts: Cultural, familial, and societal implications* (pp. 133–159). Springer Publishing Company.
- Desai, M. M., Lentzner, H. R., & Weeks, J. D. (2001). Unmet need for personal assistance with activities of daily living among older adults. *Gerontologist*, 41(1), 82–88. doi:10.1093/geront/41.1.82
- Freedman, V. A., Spillman, B. C., & Kasper, J. (2014). Hours of care in rounds 1 and 2 of the National Health and Aging Trends Study. *NHATS Technical Paper #7*. Available at www.NHATS.org. Johns Hopkins University School of Public Health.
- Friedman, E. M., & Kennedy, D. P. (2021). Typologies of dementia caregiver support networks: A pilot study. *Gerontologist*, 61(8), 1221–1230. doi:10.1093/geront/gnab013
- Gaugler, J. E., Leitsch, S. A., Zarit, S. H., & Pearlin, L. I. (2000). Caregiver involvement following institutionalization: Effects of preplacement stress. *Research on Aging*, 22(4), 337–359. doi:10.1177/0164027500224002
- Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. *Gerontologist*, 25(6), 612–617. doi:10.1093/geront/25.6.612
- Husson, F., Lê, S., & Pagès, J. (2011). *Exploratory multivariate analysis by example using R* (Vol. 15). CRC Press. doi:10.1201/b21874
- Ingersoll-Dayton, B., Neal, M. B., Ha, J. H., & Hammer, L. B. (2003). Collaboration among siblings providing care for older parents. *Journal of Gerontological Social Work*, 40(3), 51–66. doi:10.1300/j083v40n03_05
- Johnson, C. L. (1983). Dyadic family relations and social support. *Gerontologist*, 23(4), 377–383. doi:10.1093/geront/23.4.377
- Kasper, J. D., Freedman, V. A., & Spillman, B. (2013). Classification of persons by dementia status in the national health and aging trends study. *Technical Paper #5*. Available at www.NHATS.org. Johns Hopkins University School of Public Health
- Kasper, J. D., Freedman, V. A., Spillman, B. C., & Wolff, J. L. (2015). The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs*, 34(10), 1642–1649. doi:10.1377/hlthaff.2015.0536
- Keith, C. (1995). Family caregiving systems: Models, resources, and values. *Journal of Marriage and the Family*, 57(1), 179–189. doi:10.2307/353826
- Li, M., & Dai, H. (2019). Determining the primary caregiver for disabled older adults in mainland China: Spouse priority and living arrangements. *Journal of Family Therapy*, 41(1), 126–141. doi:10.1111/1467-6427.12213
- Lilly, M. B., Laporte, A., & Coyte, P. C. (2010). Do they care too much to work? The influence of caregiving intensity on the labour force participation of unpaid caregivers in Canada. *Journal of Health Economics*, 29(6), 895–903. doi:10.1016/j.jhealeco.2010.08.007
- Lima, J. C., Allen, S. M., Goldscheider, F., & Intrator, O. (2008). Spousal caregiving in late midlife versus older ages: Implications of work and family obligations. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 63(4), S229–S238. doi:10.1093/geronb/63.4.s229
- Lin, I. F., & Wolf, D. A. (2020). Division of parent care among adult children. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 75(10), 2230–2239. doi:10.1093/geronb/gbz162
- Lingler, J. H., Sherwood, P. R., Crighton, M. H., Song, M. K., & Happ, M. B. (2008). Conceptual challenges in the study of caregiver–care recipient relationships. *Nursing Research*, 57(5), 367–372. doi:10.1097/01.NNR.0000313499.99851.0c
- Liu, Y., Li, H., Wu, B., Liu, X., Chen, H., Jin, H. Y., & Wu, C. (2021). Association between primary caregiver type and mortality among Chinese older adults with disability: A prospective cohort study. *BMC Geriatrics*, 21(1), 1–9. doi:10.1186/s12877-021-02219-5
- Marcum, C. S., Ashida, S., & Koehly, L. M. (2020). Primary caregivers in a network context. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 75, 125–136. doi:10.1093/geronb/gbx165
- Matthews, S. H., & Rosner, T. T. (1988). Shared filial responsibility: The family as the primary caregiver. *Journal of Marriage and the Family*, 50, 185–195. doi:10.2307/352438
- Montaquila, J., Freedman, V. A., Edwards, B., & Kasper, J. D. (2012). National health and aging trends study round 1 sample design and selection. *NHATS Technical Paper #1*. Johns Hopkins University School of Public Health. Available at www.NHATS.org
- Riley, M. W. (1983). The family in an aging society: A matrix of latent relationships. *Journal of Family Issues*, 4(3), 439–454. doi:10.1177/019251383004003002
- Riley, M. W., & Riley, J. W. (1996). Generational relations: A future perspective. In T. K. Hareven (Ed.), *Aging and generational relations: Life-course and cross-cultural perspectives* (pp. 283–291). Aldine de Gruyter. doi:10.1515/9783110875522.526
- Roth, D. L., Mittelman, M. S., Clay, O. J., Madan, A., & Haley, W. E. (2005). Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychology and Aging*, 20(4), 634. doi:10.1037/0882-7974.20.4.634
- Russell, R. (2004). Social networks among elderly men caregivers. *Journal of Men's Studies*, 13(1), 121–142. doi:10.3149/jms.1301.121
- Sayegh, P., & Knight, B. G. (2011). The effects of familism and cultural justification on the mental and physical health of family caregivers. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 66(1), 3–14. doi:10.1093/geronb/gbq061
- Schulz, R., Beach, S. R., Friedman, E. M., Martsolf, G. R., Rodakowski, J., & James III, A. E. (2018). Changing structures and processes to support family caregivers of seriously ill patients. *Journal of Palliative Medicine*, 21(S2), S-36. doi:10.1089/jpm.2017.0437
- Sims-Gould, J., & Martin-Matthews, A. (2007). Family caregiving or caregiving alone: Who helps the helper? *Canadian Journal on*

- Aging/La Revue Canadienne Du Vieillessement*, 26(S1), 27–45. doi:10.3138/cja.26.suppl_1.027
- Soldo, B., & Myllyluoma, J. (1983). Caregivers who live with dependent elderly. *Gerontologist*, 23, 605–611. doi:10.1093/geront/23.6.605
- Stephens, M. A. P., Kinney, J. M., & Ogrocki, P. K. (1991). Stressors and well-being among caregivers to older adults with dementia: The in-home versus nursing home experience. *Gerontologist*, 31(2), 217–223. doi:10.1093/geront/31.2.217
- Spillman, B. C., Freedman, V. A., Kasper, J. D., & Wolff, J. L. (2020). Change over time in caregiving networks for older adults with and without dementia. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 75(7), 1563–1572. doi:10.1093/geronb/gbz065
- Stoller, E. P. (1983). Parental caregiving by adult children. *Journal of Marriage and Family*, 45, 851–858. doi:10.2307/351797
- Szinovacz, M. E., & Davey, A. (2007). Changes in adult child caregiver networks. *Gerontologist*, 47(3), 280–295. doi:10.1093/geront/47.3.280
- Waite, L. J., Cagney, K. A., Dale, W., Huang, E., Laumann, E. O., McClintock, M. K., O’Muircheartaigh, C. A., Schumm, L. P., & Cornwell, B. (2019). National Social Life, Health, and Aging Project (NSHAP): Round 2 and partner data collection, 2010–2011. *Inter-university Consortium for Political and Social Research*. doi:10.3886/ICPSR34921.v4
- Wiegelmann, H., Speller, S., Verhaert, L. M., Schirra-Weirich, L., & Wolf-Ostermann, K. (2021). Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia—A systematic literature review. *BMC Geriatrics*, 21(1), 1–17. doi:10.1186/s12877-021-02020-4
- Wolf, D. A., Freedman, V., & Soldo, B. J. (1997). The division of family labor: Care for elderly parents. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 52, 102–109. doi:10.1093/geronb/52b.special_issue.102
- Wolff, J. L., & Kasper, J. D. (2006). Caregivers of frail elders: Updating a national profile. *Gerontologist*, 46(3), 344–356. doi:10.1093/geront/46.3.344
- Wolff, J. L., Mulcahy, J., Huang, J., Roth, D. L., Covinsky, K., & Kasper, J. D. (2018). Family caregivers of older adults, 1999–2015: Trends in characteristics, circumstances, and role-related appraisal. *Gerontologist*, 58(6), 1021–1032. doi:10.1093/geront/gnx093