

Supplement Article: AD RD Care in Context

Conceptualizing and Operationalizing Collaboration Among Multiple Caregivers of Older Adults

Katrina R. Ellis, PhD, MPH, MSW,^{1,2,*} Athena Koumoutzis, MA,³ Jordan P. Lewis, PhD,^{4,5} Zhiyong Lin, PhD,^{5,6} Yuanjin Zhou, PhD,^{6,7} William J. Chopik, PhD,⁷ and Richard Gonzalez, PhD^{2,8}

¹School of Social Work, University of Michigan, Ann Arbor, Michigan, USA. ²Research Center for Group Dynamics, Institute for Social Research, University of Michigan, Ann Arbor, Michigan, USA. ³Department of Sociology and Gerontology, Miami University, Oxford, Ohio, USA. ⁴University of Minnesota Medical School, Duluth Campus, Duluth, Minnesota, USA. ⁵Department of Sociology, University of Texas at San Antonio, San Antonio, Texas, USA. ⁶Steve Hicks School of Social Work, the University of Texas at Austin, Austin, Texas, USA. ⁷Department of Psychology, Michigan State University, East Lansing, Michigan, USA. ⁸Department of Psychology, University of Michigan, Ann Arbor, Michigan, USA.

*Address correspondence to: Katrina R. Ellis, PhD, MPH, MSW, School of Social Work, University of Michigan, Room 3849, Ann Arbor, MI 48109-1382, USA. E-mail: kahe@umich.edu

Received: February 10, 2022; Editorial Decision Date: September 12, 2022

Decision Editor: Toni C. Antonucci, PhD

Abstract

Objectives: In many families, multiple caregivers support older adults living with dementia. Studying collaboration among caregivers requires consideration of conceptual and methodological issues that have not been fully explored. This study presents a framework for conceptualizing caregiver collaboration and an index that captures variation in collaboration among multiple caregivers within care networks.

Methods: We used data from the 2015 waves of the National Health and Aging Trends Study and National Study of Caregiving (NSOC) to operationalize collaboration among multiple caregivers ($N = 1,298$) of 552 care recipients ($M_{age} = 83.69$, $SD = 7.73$; 71.6% women; 47.9% possible/probable dementia; 38.9% people of color).

Results: The care collaboration index considered individual and overlapping contributions while controlling for the size of the care network (caregivers in network responding to NSOC survey) and total network size (number of caregivers in network) in the statistical model. Larger care networks enabled more collaboration, both in general and across most types of tasks ($\beta_s > 0.38$). Collaboration was greater among those caring for a Black or Hispanic care recipient, both in general and for household and medical/health tasks specifically ($\beta_s > 0.11$). Collaboration was also greater among those caring for recipients with probable dementia, both in general and for most tasks ($\beta_s > 0.11$) but not transportation-related tasks ($p = .219$).

Discussion: Results are examined in the context of care network dynamics and proposed mechanisms linking care collaboration to outcomes for caregivers and recipients. Strengths and limitations of our conceptualization and operationalization of collaboration are discussed.

Keywords: Alzheimer's disease, Caregiving, Collaboration, Social networks

It is estimated that in 2021, 6.2 million people in the United States will be living with Alzheimer's disease, the

most common cause of dementia, and this number is projected to increase to 12.7 million in 2050 ([Alzheimer's](#)

Association, 2020). Most individuals with dementia reside in communities with the support of friend or family caregivers (Hebert et al., 2013). While networks of individuals often share care responsibilities (Usita et al., 2004), few studies consider the conceptual and methodological implications of these care dynamics (Feld et al., 2006; Lingler et al., 2008). In this study, we present a framework for conceptualizing collaboration in care networks, operationalize collaboration, and examine variation in collaboration according to care network and care recipient characteristics.

Primary Caregivers Versus Care Networks

Dementia caregiving research and practice primarily focus on a single family/friend caregiver as the main or most important person providing informal care (Keith, 1995). There are concerns, however, that contributions and consequences of caregiving from other family members/friends are underestimated (Esandi et al., 2021; Keith, 1995). Multiple caregivers are often involved in supporting care recipients and are affected by the illness (Qualls, 2014). As such, more than one individual may self-identify as a primary caregiver because of their own perceptions of role fulfillment and caregiving demands (Marcum et al., 2020).

Individuals may also share care responsibilities due to the progression of dementia and the complex care requirements of older adults living with dementia (Gonçalves-Pereira et al., 2020; Koehly et al., 2015). Care networks vary in size and dynamics (Ponnala et al., 2018), their size typically increasing with greater care recipient needs (Andersson & Monin, 2018), particularly medical, mobility, or self-care tasks (Spillman et al., 2020), or ineffective coordination among caregivers (Andersson & Monin, 2018). A greater understanding of the collaboration that occurs within these networks, including factors that influence collaboration, is needed.

Collaboration in Care Networks

Collaboration has been studied across disciplines and settings with variations in its conceptualization. Drawing on literature from several fields, Bedwell and colleagues (2012) defined collaboration as “an evolving process whereby two or more social entities actively and reciprocally engage in joint activities aimed at achieving at least one shared goal” (p. 130). In line with this definition, this study conceptualizes collaboration in care networks as a process whereby two or more informal caregivers engage in activities to achieve the collective goal of care provision for an identified care recipient. Effective collaboration requires varying levels of coordination, which refers to how activities are completed. For example, caregivers may independently perform activities (e.g., one person drives the care recipient places, another handles finances), work together to complete an activity (e.g., each person administers medications), or sequence their efforts (e.g., one person schedules

appointments, another accompanies care recipient to appointments; Bedwell et al., 2012). Moreover, some care networks may include *specialist* caregivers who assist with a single domain of tasks and *generalist* caregivers who assist with multiple domains of tasks (Spillman et al., 2020). The process of collaboration can elicit positive feelings and amicable interactions but can also include the presence of negative feelings and interactions. To this end, many theories have also examined cooperation as an important attitudinal construct that can aid effective collaborations (Bedwell et al., 2012). While care networks low in coordination and cooperation could be viewed as working in collaboration given our definition, the care provided may be less effective and inefficient for care provision.

Collaborative care networks have been investigated via task-specific models that distinguish between the support provided to the care recipient, the proximity and availability of the caregiver(s), the fit between needed care assistance, and the length of commitment to caregiving (Litwak, 1985; Litwak et al., 1990; Messeri et al., 1993). Hierarchical and compensatory models emphasizing the relationship between the caregiver and recipient also explore this phenomenon (Cantor, 1979; Freedman & Spillman, 2014; Spillman et al., 2020). Despite the contributions of this body of research, we know relatively little about the collaborative processes among multiple caregivers in care networks, including potential routes to and circumstances surrounding collaboration. A collaboration-specific model, which centers the interdependent interactions of caregivers (vs a task-centered approach), may enhance understanding of this process.

Multilevel Conceptual Framework of Care Network Collaboration

We propose a multilevel conceptual framework to guide this area of research (see Figure 1) adapted from models of collaboration (Bedwell et al., 2012; Wood & Gray, 1991). The framework offers four key collaboration dimensions: context, preconditions, processes, and outcomes. The framework is centered on the work of the care network to identify and engage in tasks that serve the goal of providing care, ultimately contribute to caregiver, care recipient, and network-level health outcomes.

Context

Political (Dawson et al., 2020) and sociocultural (Knight & Sayegh, 2010) orientations to caregiving, social determinants of health (Young et al., 2020), and health across the life span affect resources and constraints at community, family, and care network levels. Norms within community and family contexts of caregivers and care recipients regarding communication, trust, reciprocity, and expectations of mutuality and interdependence likely influence care network functioning (Thomson et al., 2007) and may differ

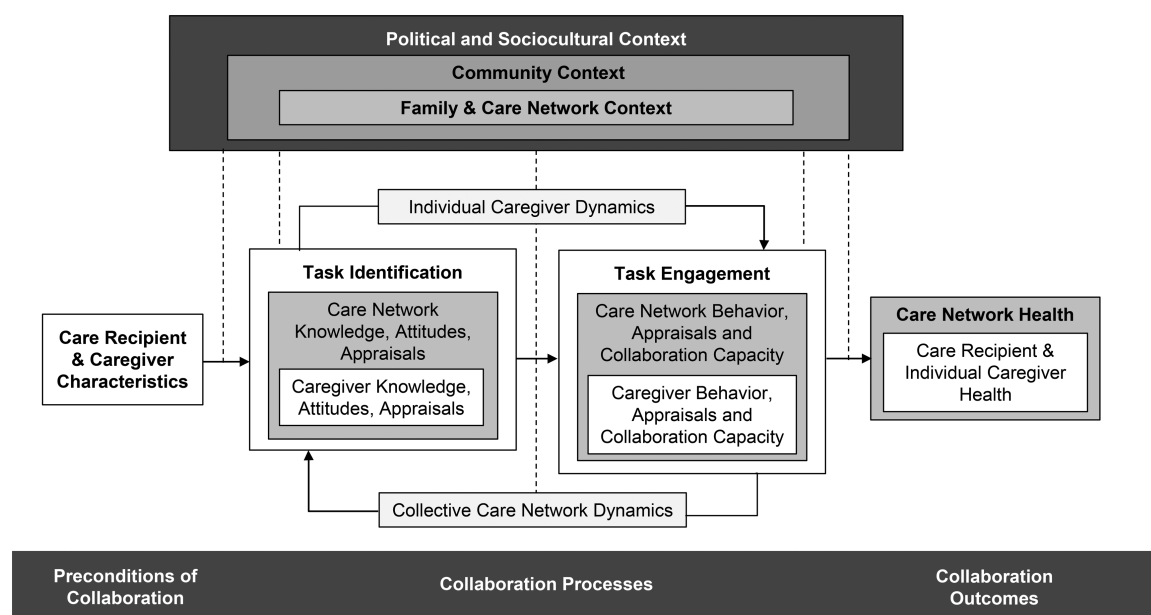


Figure 1. Conceptual model of collaboration among multiple caregivers.

depending on the relationships represented within a network (e.g., spouse vs neighbor vs adult child). Our model considers the broader family context as well as the care network context as key components, the latter of which is comprised of individual family/friend caregivers. Shared family history of caregiving and collaboration may also influence collaboration norms and expectations (Marek et al., 2015). Collectively, these elements set the stage for care network formation and functioning. The care network context includes several factors, such as network size, relationship composition (e.g., spousal, friend), geographic distance between the recipient and network members, time in caregiver/recipient roles, and density (e.g., familiarity and regularity of contact network members; Fast et al., 2004; Marcum et al., 2020). Gender composition is another feature of the care network—women tend to provide more hours of care and assist with more complex tasks than men (AARP & National Alliance for Caregiving, 2020).

Preconditions

Preconditions of collaboration define the boundaries of care needs and possibilities for care collaboration given the caregivers involved. These preconditions include sociodemographic characteristics of the care recipient and personal and health characteristics that necessitate care, including dementia status and functional abilities. Caring for someone with dementia is often more intensive and extensive compared to caring for someone without cognitive impairment (Friedman et al., 2015), and may lead to greater subjective burden (Karg et al., 2018) and physical difficulties (Parker et al., 2021). Caregiver-specific preconditions include sociodemographic characteristics and psychosocial factors, including an individual's previous caregiving

experience (Dilworth-Anderson et al., 2020). The social positionality of care recipients and caregivers, including issues of marginalization and racialized status, are also important to consider (Dilworth-Anderson et al., 2002).

Processes

Collaboration processes consist of task identification, task engagement, and individual and network dynamics underlying care provision. Task identification involves individual caregiver and care network knowledge of recipient needs and resources to meet those needs, attitudes regarding the completion of care tasks, and related cognitive appraisals (Hall et al., 2018). Task engagement involves the completion of tasks at the individual level and network level; individual caregivers might complete one or more care tasks in several domains, while network-level considerations involve how tasks are distributed across a network and overlap in the tasks of individual caregivers (Hall et al., 2018). Behaviors critical to the process of engagement include adaptation, information processing, leadership, and sense-making (Bedwell et al., 2012). Reappraisals within task engagement consist of perceived benefits of collaboration (e.g., personal gain, improved relationship quality) and costs (e.g., stress, strained social roles). Collaboration capacity refers to strengths and limitations of caregivers (individually) and care networks (collectively) that affect their ability to work together (Foster-Fishman et al., 2001). Finally, individual caregiver and collective care network dynamics facilitate or impede task identification and task engagement and include coordination, cooperation, maximization of network resources, relationship management, subjective assessments of fair share, communication, (dis-)agreements about tasks, and overall care.

Outcomes

The framework focuses on collaboration's influence on the health of the care recipient, individual caregivers, and the overall care network. Broader family health outcomes are also appropriate to consider as a collaboration outcome. Taken together, applying theories used to describe organizational behavior and investigating collaboration as the central phenomena of interest among care networks helps to delineate opportunities for research and intervention on an understudied issue.

Study Purpose

Before formally testing the full conceptual framework presented in [Figure 1](#), basic descriptive research that operationalizes collaboration is needed. We operationalized collaboration among care networks and provided an initial proof-of-concept examining variation in collaboration to identify contexts where collaboration is most needed and, potentially, most consequential for care recipient and caregiver outcomes. We built a measure of task overlap among care networks—a task engagement-related collaboration process—using multiple informants from a large study of care networks. We calculated individual care contributions, weighed by the number of care tasks required, and summed these contributions across individuals to yield a single, linear combination of collaboration for the care network.

We also examined whether care network size—a component of the care network context in our conceptual framework—and preconditions of collaboration (race/ethnicity and dementia status) were associated with observed collaboration. We hypothesized that, if more caregivers were present, the opportunities for task overlap within the care network would be greater. This intuition came from health services research demonstrating more collaboration among larger groups ([Stommel et al., 1995](#)). Whether racial or ethnic differences in collaboration would be seen was less clear. Because Black and Hispanic individuals are at higher risk for Alzheimer's disease and other chronic health conditions ([Barnes, 2008](#); [Barnes & Bennett, 2014](#)), and racial and ethnic disparities exist in the quality of medical care ([Mateo & Williams, 2021](#)), their care networks might engage in greater collaboration to meet mounting health needs and challenges. Other research suggests that caregiving might have similar consequences for families regardless of race/ethnicity ([Haley et al., 1995](#)). Thus, although we tested for racial or ethnic differences in collaboration, we had no formal or directional hypotheses. Finally, we hypothesized that collaboration would be higher among care networks caring for individuals with dementia because of the increased burden and associated physical costs accompanying this condition ([Ducharme et al., 2011](#)).

Method

Data and Sample

This study uses data from the 2015 National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC), two linked surveys of the nationally representative Medicare population aged 65 and older and their caregivers ([Freedman et al., 2019](#)). NHATS captures a detailed picture of daily functioning among older adults, types of help received, and service environments where they lived. NSOC surveys individuals identified from the NHATS helper roster as a family member or an unpaid helper, assisting with mobility, self-care support, household activities, transportation, banking, or medical activities ([Freedman et al., 2019](#)). Up to five eligible caregivers for each older adult completed telephone interviews. For older adults with more than five eligible helpers, five were selected at random.

Of 7,499 NHATS participants living in the community or in a residential care facility in 2015, 2,417 were included in the NSOC sampling frame (NHATS and NSOC participants were linked via a common ID variable; "spid"); 5,212 caregivers met eligibility criteria for the NSOC. NHATS participants did not provide contact information for 1,711 eligible caregivers, and 1,297 of the remaining 3,501 eligible caregivers could not be located or refused to respond, yielding a 67.2% first-stage response rate and a 63.0% second-stage response rate. In total, 2,204 caregivers of 1,458 older adults responded to the NSOC in 2015. We excluded 906 caregivers who were the single caregivers to the care recipient because collaboration cannot be assessed. The final sample includes 1,298 caregivers within 552 care networks: 397 include two caregivers, 120 include three caregivers, 31 include four caregivers, and 4 include five caregivers.

Measures

Caregiving tasks

We categorized caregiving tasks into five domains: household activities, medical care, mobility activities, transportation, and social service utilization. See [Supplementary Table 1](#) for a full list of caregiving tasks. As expected, Cronbach's alphas were related to the number of tasks in each group: household activities ($n = 3$ tasks; $\alpha = 0.56$), medical care ($n = 12$ tasks; $\alpha = 0.81$), mobility activities ($n = 4$ tasks; $\alpha = 0.64$), transportation ($n = 2$ tasks; $\alpha = 0.08$), and social service utilization tasks ($n = 4$ tasks; $\alpha = 0.48$). Cronbach's alpha for all tasks was 0.84.

Care collaboration index

We developed a care collaboration index for each care network. There are many different approaches to operationalizing how people might collaborate in caregiving. Most research has focused on *task*-related measures. Specifically,

these approaches involve an examination of tasks being done (e.g., do at least two people do one task? Does one person [vs many] tend to do most tasks?). In the current study, we instead focused on *caregivers* rather than tasks. This focus shifts the study of collaboration to a discussion of caregiver experiences, their reported share of the tasks, and potential overlaps in collaboration. Summaries and examples of task-focused operationalizations of care networks can be found elsewhere (Ali et al., 2022; Spillman et al., 2020). Our approach leverages a major strength of the NSOC data—each caregiver's report of their care—to create an omnibus measure of care collaboration across people that is largely agnostic regarding the specific tasks completed.

To characterize caregiving activities in terms of sharing tasks and care scope, we identified (1) the number of caregivers providing NSOC data in each network (i.e., care network size), (2) the total number of care tasks for each recipient, and (3) the number of tasks each individual caregiver engaged in within the network. For example, caregivers might undertake different tasks or jointly take on the same tasks within a domain. After calculating these three indicators, we divided the number of tasks each caregiver completed by the total number of care tasks for the recipient. We then summed these values across caregivers within the network to create the index score. This index is continuous such that higher numbers indicate more overlap in task completion; we computed an overall collaboration score for each network across all tasks and separate collaboration scores for the five task domains (see [Supplementary Table 2](#) for examples of care network collaboration and associated index scores).

Dementia status of care recipient

NHATS classified respondents into three groups—no dementia, possible dementia, and probable dementia—based on the self-reported diagnosis of dementia or Alzheimer's disease, an AD8 Dementia Screening Interview, and cognitive tests (Kasper et al., 2013). Cognitive tests assessed three domains of cognitive functioning: memory, orientation, and executive functioning. NHATS participants were classified as *probable dementia* if they (a) reported a diagnosis of dementia or Alzheimer's disease from a doctor, (b) scored 2 or more on the AD8 Dementia Screening Interview by proxies, or (c) scored ≤ 1.5 SD below the mean for self-respondents on at least two cognitive domains. Scores ≤ 1.5 SD below the mean in one cognitive domain indicated *possible dementia*.

Analytical Strategies

Using the care collaboration index, we estimated a series of regression models with weights to examine (1) whether care collaboration differed for older adults by key predictors and (2) if the association between care collaboration and predictors varied across the five domains of

care tasks. Our primary outcome was care collaboration (total and across the five domains). Our primary predictors were two indicators of network size, race/ethnicity (White, Black, Hispanic, Other), and dementia status (no dementia, possible dementia, and probable dementia). One indicator of network size (total network size) represented the total number of caregivers within a care recipient's network. The second indicator (care network size) represented the number of caregivers who responded to the NSOC and is the number of caregivers upon which the collaboration measure was built. Both size measures were included because the collaboration measure depends on the number of caregivers sampled (care network size), and the NSOC sampling frame is relatively agnostic to the broader care network because it can only sample up to five individuals. Controlling and not controlling for these size variables did not significantly affect the results, so we ultimately decided to keep them in the models.

We controlled for a set of sociodemographic characteristics and health conditions of care recipients. Demographic information was assessed by age (in years), gender (female = 1, male = 0), marital status (married/partnered = 1, widowed/divorced/never married = 0), and race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, and Other). To measure socioeconomic status, we used the highest educational attainment (i.e., less than high school, high school graduate, and some college but no degree, or college graduate) and total household income (a comprehensive measure of respondent earnings, spousal earnings, capital income, pensions and annuities, and other income; log-transformed). Health conditions of older adults were the number of chronic disease diagnoses (e.g., heart diseases, diabetes).

Results

Sample Characteristics

[Table 1](#) presents descriptive statistics of care recipient characteristics for the total sample and by care network size. Results indicate older adults cared for by multiple caregivers were relatively older (mean age = 84), most were women (72%), and more than 90% of them were either Black or White. Nearly half of care recipients had cognitive impairment or dementia. The total number of caregivers included in this study (care network size) was smaller than the number who actually aided care recipients (total network size).

Variation in Collaboration

As seen in [Table 2](#) (see Author Note 1), larger care networks reported more collaboration overall ($\beta = 0.62$, $p < .001$). Larger care networks reported more collaboration for household ($\beta = 0.52$, $p < .001$), medical/health care ($\beta = 0.38$, $p < .001$), mobility-related care ($\beta = 0.44$,

Table 1. Care Recipient and Care Network Demographics and Characteristics

	Care recipients (all; N = 522)	Care recipients by care network size		
		2-person (N = 397)	3-person (N = 120)	4- or 5-person (N = 35)
	Mean (SD) or %	Mean (SD) or %	Mean (SD) or %	Mean (SD) or %
Age	83.69 (7.73)	83.44 (7.78)	84.30 (7.44)	84.46 (8.14)
Gender (male)	28.40%	29.20%	27.50%	22.90%
Race/ethnicity				
White	61.10%	60.00%	64.10%	62.90%
Black	32.00%	32.90%	29.20%	31.40%
Hispanic	4.50%	5.10%	2.50%	5.70%
Other	2.40%	2.00%	4.20%	0.00%
Relationship status (partnered)	34.60%	34.80%	35.00%	31.40%
Education				
High school diploma or equivalent	62.90%	62.70%	63.90%	64.70%
Some college/associate's degree	20.60%	21.70%	17.60%	17.60%
Bachelor's degree	8.80%	7.90%	12.60%	5.90%
Graduate/professional degree	7.50%	7.70%	5.90%	11.80%
Income				
≤\$15,000	31.00%	30.00%	34.20%	31.40%
\$15,001–\$29,999	34.10%	34.30%	33.30%	34.30%
\$30,000–\$99,999	29.90%	29.50%	30.00%	34.30%
\$100,000+	5.10%	6.30%	2.50%	0.00%
Chronic illnesses	1.28 (1.68)	1.31 (1.72)	1.07 (1.48)	1.63 (1.85)
Dementia status				
No dementia	52.10%	50.60%	56.30%	54.30%
Possible	13.70%	13.90%	14.30%	8.60%
Probable	34.20%	35.40%	29.40%	37.10%
Care network size	2.35 (0.62)	2.00 (0.00)	3.00 (0.00)	4.11 (0.32)
Total network size	2.93 (1.49)	2.58 (1.36)	3.62 (1.42)	4.46 (1.29)
Collaboration indices				
Overall	1.48 (0.36)	1.34 (0.22)	1.73 (0.34)	2.19 (0.45)
Household	1.63 (0.56)	1.45 (0.37)	1.96 (0.57)	2.60 (0.81)
Medical/health	1.30 (0.44)	1.19 (0.37)	1.51 (0.43)	1.81 (0.53)
Mobility	1.46 (0.69)	1.25 (0.54)	1.84 (0.63)	2.57 (0.84)
Transportation	1.40 (0.81)	1.21 (0.69)	1.74 (0.81)	2.43 (0.98)
Social service utilization	0.69 (0.73)	0.63 (0.66)	0.74 (0.79)	1.22 (1.03)

Notes: Descriptive statistics for care recipients (all) and averages/percentages of care recipients with different-sized care networks (2-person, 3-person, and 4- or 5-person) are provided.

$p < .001$), and transportation-related ($\beta = 0.52$, $p < .001$), but not for social service utilization care tasks ($\beta = 0.10$, $p = .077$; see [Supplementary Tables 3–7](#) for full results by task domain). Total network size was not significantly associated with collaboration overall, or collaboration on household or medical/health care tasks ($ps > .469$). Total network size was associated with greater collaboration on mobility-related ($\beta = 0.12$, $p = .005$) and social service utilization tasks ($\beta = 0.11$, $p = .034$) and less collaboration on transportation-related tasks ($\beta = -0.19$, $p < .001$).

Relative to White care recipients, Black care recipients garnered more collaboration overall ($\beta = 0.11$, $p = .002$), for household tasks ($\beta = 0.19$, $p < .001$), and for medical/

health care tasks ($\beta = 0.11$, $p = .001$). Relative to White care recipients, care recipients in the “Other” race/ethnicity category garnered more collaboration overall ($\beta = 0.07$, $p = .027$) and collaboration for household tasks ($\beta = 0.08$, $p = .013$) and mobility tasks ($\beta = 0.04$, $p = .045$); care recipients in the “Other” race/ethnicity category garnered less collaboration for social service utilization tasks ($\beta = -0.08$, $p = .021$). Hispanic care recipients garnered more collaboration for household ($\beta = 0.05$, $p = .038$) and medical/health care tasks ($\beta = 0.05$, $p = .043$) compared to White care recipients. The Black, Hispanic, and “Other” groups largely did not differ from each other ($ps > .061$); the few exceptions were that Hispanic participants received less total collaboration relative to Black participants ($\beta = -0.05$,

Table 2. Regression Analyses Predicting Total Collaboration

	<i>b</i>	<i>SE</i>	β	<i>t</i>	<i>p</i>	95% confidence interval	
						LB	UB
Intercept	1.409	0.024		59.033	<.001	1.361	1.457
Total network size	0.005	0.010	0.020	0.486	.629	-0.015	0.025
Care network size	0.363	0.023	0.622	16.058	<.001	0.318	0.408
Race/ethnicity (White is reference)							
Black	0.081	0.025	0.105	3.236	.002	0.031	0.132
Hispanic	-0.006	0.034	-0.004	-0.188	.851	-0.075	0.062
Other	0.155	0.068	0.065	2.284	.027	0.019	0.291
Dementia status (no dementia is reference)							
Possible dementia	0.069	0.038	0.066	1.818	.075	-0.007	0.146
Probable dementia	0.142	0.028	0.186	5.046	<.001	0.085	0.198
Age	-0.005	0.002	-0.110	-3.185	.002	-0.008	-0.002
Male	0.016	0.031	0.020	0.518	.607	-0.046	0.078
Partnered	-0.076	0.033	-0.100	-2.300	.026	-0.142	-0.010
Chronic illness	0.003	0.006	0.013	0.433	.667	-0.010	0.016
Education	-0.008	0.005	-0.050	-1.659	.103	-0.019	0.002
Income	0.015	0.009	0.058	1.693	.097	-0.003	0.033

Notes: $R^2 = 0.484$. LB = Lower Bound; UB = Upper Bound.

$p = .018$). Also, “Other” recipients received more collaboration overall ($\beta = 0.07$, $p = .038$, compared to Hispanic participants) and on mobility tasks ($\beta = 0.05$, $p = .020$, compared to Black recipients; $\beta = 0.07$, $p = .024$, compared to Hispanic recipients) but less collaboration on social service utilization tasks ($\beta = -0.08$, $p = .038$, compared to Black recipients).

Relative to recipients without dementia, recipients with probable dementia garnered more collaboration overall ($\beta = 0.19$, $p < .001$), and for household ($\beta = 0.11$, $p < .001$), medical/health care ($\beta = 0.26$, $p < .001$), mobility-related ($\beta = 0.18$, $p < .001$), and social service utilization care tasks ($\beta = 0.16$, $p = .004$) but not transportation-related tasks ($p = .219$). Recipients with possible dementia garnered more collaboration for medical/health care tasks ($\beta = 0.11$, $p = .002$) but not in other domains or overall ($ps > .075$). Those with possible and probable dementia largely did not differ from each other on any of the collaboration variables ($ps > .060$). The only exceptions are that, compared to those with possible dementia, those with probable dementia garnered more collaboration overall ($\beta = 0.10$, $p = .041$) and for medical/health care tasks ($\beta = 0.11$, $p = .023$; see Author Note 2).

Discussion

Dementia is a progressive neurological condition. Increasing disability and mounting recipient needs translate into more caregiving demands (Schulz et al., 2020) and the sharing of caregiving responsibilities among individuals (Gonçalves-Pereira et al., 2020; Koehly et al., 2015). Previous research with multiple caregivers has examined issues such as tasks completed for recipients (Spillman et al., 2020), care

network types and structures (Ali et al., 2022; Friedman & Kennedy, 2021), caregiver burden (Xu et al., 2021), and recipient psychological well-being (Andersson & Monin, 2018). However, limited attention has been given to collaboration as a critical process among multiple caregivers. The current study aimed to add to this growing body of literature by presenting a conceptual framework to aid investigations of the context and drivers of collaboration among multiple caregivers and create an index that provides a measure of collaboration in care networks. Guided by our conceptual framework, we investigated how network size, an aspect of the care network context, and preconditions influenced observed collaboration. Findings indicated more collaboration among recipients with probable or possible dementia, which could reflect a lack of supportive resources for dementia care available to care networks and care recipients with unmet needs (Black et al., 2019). More collaboration was also observed in larger care network and among Black, Hispanic, or Other (non-White) care recipients.

Study findings highlight the importance of culturally informed care network interventions. Normative beliefs regarding kinship reciprocity and an obligation to provide care are often observed among Black, Hispanic, and other populations of color (Dilworth-Anderson et al., 2002). These values are not as commonly identified among White caregivers and may help explain the increased use of informal support among these groups (Dilworth-Anderson et al., 2002). National estimates indicate 76% of caregivers live with or within 20 min, with populations of color more likely to have live-in caregivers (AARP & National Alliance for Caregiving, 2020). Evidence suggests less reliance on formal caregiver support among populations of color can be attributed in part to past negative experiences and less

culturally responsive support (Navaie-Waliser et al., 2001). Health disparities that increase the likelihood and severity of needed care (Young et al., 2020) also contribute to racial/ethnic variation in care network collaboration and functioning.

Future work should test the proposed conceptual framework more fully (Figure 1), including examining how other characteristics of both caregivers and caregiver network influence collaboration. Research indicates caregiver demographic and contextual factors influence caregiver/recipient outcomes (Pearlin et al., 1990). For example, caregivers reporting incomes less than \$50,000/year are more likely to coreside with care recipients compared to caregivers reporting higher incomes (AARP & National Alliance for Caregiving, 2020b). Caregivers with fewer resources who coreside with their recipients may report more generalist caregiving functions such as assisting across multiple activities of daily living and instrumental activities of daily living needs due to their close proximity to the care recipient, which could influence collaboration within the network.

Additionally, the relational functioning of individuals involved within the care network can influence their ability to collaborate and subsequently, caregiver and care recipient outcomes. As proposed in the caregiver stress process model, family and social support systems can serve as either sources of strain or mediators of support–outcome associations (Pearlin et al., 1990). As such, communication patterns, roles and organization within the support network, subjective assessments of fair share, and motivation to provide care may predict how well a caregiver network functions (Esandi et al., 2021). Future studies should explore how these factors, which fall under collaboration processes in our framework (e.g., attitudes, appraisals), influence care network functioning and collaboration patterns. Moreover, given the use of cross-sectional data in the current study, future research should also examine whether collaboration increases over time in step with recipient needs or is influenced by other supportive resources.

Positive and negative feelings can arise within collaborative caregiving situations. It is possible that conflict or lack of coordination among caregivers results in larger caregiving networks. These larger network sizes might, in themselves, also be fraught with conflict, and with a lack of effective coordination, might hinder care recipient well-being (Andersson & Monin, 2018). Future studies should assess the bidirectional relationships between network size and collaborations. In addition, network dynamics such as how caregivers are added to and/or dropped from caregiving networks over time is an important area to consider that may influence caregiver behavior and beliefs about collaboration capacity.

Limitations and Future Directions

First, the operationalization of collaboration was a linear combination of tasks completed across caregivers. However, caregivers can also play *complementary* roles, where one

caregiver specializes in completing certain tasks, allowing another caregiver to dedicate efforts elsewhere. This complementary collaboration can occur both within (i.e., you order medications, and I care for a recipient's dental care) and across domains (i.e., you handle the medical/health tasks, and I will handle transportation). There are yet other illustrations and characterizations of caregiving collaboration that focus on particular (or sets of) tasks (e.g., some tasks are completed by at least two people, clusters of tasks done by some individuals and not others; Ali et al., 2022). Future work can explore additional ways to operationalize collaboration, such as examining the number of tasks shared by two or more caregivers, calculating a different measure of task overlap, and addressing the issue that the proposed collaboration score will be related to network size, which we controlled for. Subjective measures and network analysis measures that take a network measurement approach are promising directions.

It is necessary to take into account the broader context of the care network when operationalizing care network collaborations, as we articulated in Figure 1. Part of this consideration around how caregivers collaborate with each other are practical constraints, such as whether or not caregivers coreside with care recipients, live nearby, or coordinate their efforts from afar. Nearly 90% of caregivers live within 1 hr of the care recipient (AARP & National Alliance for Caregiving, 2020). As limited care network context data were collected in NSOC, we were not able to examine broader contexts of the care network, such as physical distance of caregivers from care recipients, time in caregiver/recipient roles, and closeness among care network members. For future research, we advocate for more contextual information of care network arrangements to be collected.

Second, when NHATS respondents listed more than five caregivers, five caregivers were randomly selected for participation. Among all eligible caregivers for NSOC, approximately half completed an interview. While the most active caregivers might respond to NSOC, and the number of NSOC respondents and nominated total care network members is correlated ($r = .388, p < .001$), the care collaboration captured in this study may only represent coordination among caregivers who are more selective with respect to the involvement in care tasks.

Third, there is a relative imbalance of care tasks across domains in the data, with most tasks related to medical/health management. Further, there are also tasks that share very close overlap that could be combined or consolidated in reasonable ways (e.g., making medical appointments and talking with medical providers probably overlap but other tasks can be ambiguous in how much they overlap). We thematically grouped the tasks into what we considered conceptually meaningful domains under the constraints of task information collected by NSOC. By operationalizing collaboration as an overlapped share of the task completion and controlling for some variables systematically related to the diversity of tasks (e.g., people with probable dementia likely require certain types of care that others do not), we partially accounted for this limitation.

Nevertheless, it is a practical constraint that needs to be addressed in future work. Additionally, future research incorporating additional caregiving tasks may be useful for investigating aspects of the conceptual framework related to task identification and engagement, including variation in domain-specific collaboration.

Lastly, NSOC focuses mostly on informal caregivers. It is expected, however, that mixed care networks—with informal and formal caregivers co-facilitating care—will support an increasing number of community-dwelling older adults in the coming years. Future studies should investigate preconditions, processes, and outcomes of collaboration when informal care networks function alongside formal paid care.

Conclusion

For progressive diseases like dementia, identification of the key factors influencing collaboration can be helpful for targeting barriers and facilitators to future care coordination needs. This work highlights several important conceptual and methodological considerations for future research, including novel methods of measuring collaboration. Research formally testing and refining conceptual frameworks of caregiving and comparing measures of collaboration is warranted.

Supplementary Material

Supplementary data are available at *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* online.

Author Notes

1. In the analyses presented here, we used survey weights and survey design variables to account for the complex survey design of NHATS (Round 5). Reported results are comparable to the unweighted results, with some minor shifts in the effect sizes of some predictors.
2. We ran a series of supplementary analyses in which we reran the main regression models while controlling for caregiver characteristics. Because the level of analysis is the care network, we controlled for the average age of the network members, and the percentage of the network that was: employed, married, male, and who were kin (i.e., relationship type). As seen in [Supplementary Tables 8–13](#), most findings were unchanged. The few substantive findings were that the effects for “Other” race for household, mobility, and social service utilization tasks became nonsignificant (their *p* values were close to .05 before this adjustment, and effect sizes were originally small); the Hispanic coefficient for medical/health tasks also became nonsignificant. All other dementia-related and racial/ethnic differences were unchanged. Among the most reliable predictors of collaboration among caregivers were that older caregiver networks collaborated

less for overall, household, medical/health, and mobility tasks (β s > 10.091); caregiving networks with a larger percentage of kin collaborated more for overall, household, medical/health, and mobility tasks (β s > 10.1021).

Funding

This work was supported by the Michigan Center for Contextual Factors in Alzheimer’s Disease (MCCFAD) [P30 AG059300], funded by the National Institute on Aging of the National Institutes of Health. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Conflict of Interest

None declared.

Author Contributions

All authors contributed to the planning, conceptualization, and writing of the manuscript.

References

- AARP & National Alliance for Caregiving. (2020). *Caregiving in the United States 2020*. <https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html>
- Ali, T., McAvay, G. J., Monin, J. K., & Gill, T. M. (2022). Patterns of caregiving among older adults with and without dementia: A latent class analysis. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 77(Supplement_1), S74–S85. doi:10.1093/geronb/gbab237
- Alzheimer’s Association. (2020). 2020 Alzheimer’s disease facts and figures. *Alzheimer’s & Dementia*, 16(3), 391–460. doi:10.1002/alz.12068
- Andersson, M. A., & Monin, J. K. (2018). Informal care networks in the context of multimorbidity: Size, composition, and associations with recipient psychological well-being. *Journal of Aging and Health*, 30(4), 641–664. doi:10.1177/0898264316687623
- Barnes, L. L. (2008). Perceived discrimination and mortality in a population-based study of older adults. *American Journal of Public Health*, 98(7), 1241. doi:10.2105/AJPH.2007.114397
- Barnes, L. L., & Bennett, D. A. (2014). Alzheimer’s disease in African Americans: Risk factors and challenges for the future. *Health Affairs*, 33(4), 580–586. doi:10.1377/hlthaff.2013.1353
- Bedwell, W. L., Wildman, J. L., DiazGranados, D., Salazar, M., Kramer, W. S., & Salas, E. (2012). Collaboration at work: An integrative multilevel conceptualization. *Human Resource Management Review*, 22(2), 128–145. doi:10.1016/j.hrmr.2011.11.007
- Black, B. S., Johnston, D., Leoutsakos, J., Reuland, M., Kelly, J., Amjad, H., Davis, K., Willink, A., Sloan, D., Lyketsos, C., & Samus, Q. M. (2019). Unmet needs in community-living persons with dementia are common, often non-medical and

- related to patient and caregiver characteristics. *International Psychogeriatrics*, 31(11), 1643–1654. doi:10.1017/S1041610218002296
- Cantor, M. H. (1979). Neighbors and friends: An overlooked resource in the informal support system. *Research on Aging*, 1(4), 434–463. doi:10.1177/016402757914002
- Dawson, W. D., Bangerter, L. R., & Splaine, M. (2020). The politics of caregiving: Taking stock of state-level policies to support family caregivers. *Public Policy & Aging Report*, 30(2), 62–66. doi:10.1093/ppar/praa005
- Dilworth-Anderson, P., Moon, H., & Aranda, M. P. (2020). Dementia caregiving research: Expanding and reframing the lens of diversity, inclusivity, and intersectionality. *Gerontologist*, 60(5), 797–805. doi:10.1093/geront/gnaa050
- Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980–2000). *Gerontologist*, 42(2), 237–272. doi:10.1093/geront/42.2.237
- Ducharme, F., Lévesque, L., Lachance, L., Kergoat, M.-J., & Coulombe, R. (2011). Challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer disease: A descriptive study. *International Journal of Nursing Studies*, 48(9), 1109–1119. doi:10.1016/j.ijnurstu.2011.02.011
- Esandi, N., Nolan, M., Canga-Armayor, N., Pardavila-Belio, M. I., & Canga-Armayor, A. (2021). Family dynamics and the Alzheimer's disease experience. *Journal of Family Nursing*, 27(2), 124–135. doi:10.1177/1074840720986611
- Fast, J., Keating, N., Otfinowski, P., & Derksen, L. (2004). Characteristics of family/friend care networks of frail seniors. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 23(1), 5–19. doi:10.1353/cja.2004.0003
- Feld, S., Dunkle, R. E., Schroepfer, T., Shen, H. W. (2006). Expansion of elderly couples' IADL caregiver networks beyond the marital dyad. *International Journal of Aging and Human Development*, 63(2), 95–113. doi:10.2190/cw8g-pb6b-ncgh-ht1m
- Foster-Fishman, P. G., Berkowitz, S. L., Lounsbury, D. W., Jacobson, S., & Allen, N. A. (2001). Building collaborative capacity in community coalitions: A review and integrative framework. *American Journal of Community Psychology*, 29(2), 241–261. doi:10.1023/A:1010378613583
- Freedman, V. A., Skehan, M. E., Hu, M., Wolff, J., & Kasper, J. D. (2019). *National Study of Caregiving I-III User Guide*. Baltimore: Johns Hopkins Bloomberg School of Public Health. <http://www.nhats.org>
- Freedman, V. A., & Spillman, B. C. (2014). Disability and care needs among older Americans. *Milbank Quarterly*, 92(3), 509–541. doi:10.1111/1468-0009.12076
- 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
- Friedman, E. M., Shih, R. A., Langa, K. M., & Hurd, M. D. (2015). US prevalence and predictors of informal caregiving for dementia. *Health Affairs*, 34(10), 1637–1641. doi:10.1377/hlthaff.2015.0510
- Gonçalves-Pereira, M., Zarit, S. H., Cardoso, A. M., Alves da Silva, J., Papoila, A. L., & Mateos, R. (2020). A comparison of primary and secondary caregivers of persons with dementia. *Psychology and Aging*, 35(1), 20–27. doi:10.1037/pag0000380
- Haley, W. E., West, C. A. C., Wadley, V. G., Ford, G. R., White, F. A., Barrett, J. J., Harrell, L. E., & Roth, D. L. (1995). Psychological, social, and health impact of caregiving: A comparison of Black and White dementia family caregivers and noncaregivers. *Psychology and Aging*, 10(4), 540–552. doi:10.1037/0882-7974.10.4.540
- Hall, K. L., Vogel, A. L., Huang, G. C., Serrano, K. J., Rice, E. L., Tsakraklides, S. P., & Fiore, S. M. (2018). The science of team science: A review of the empirical evidence and research gaps on collaboration in science. *American Psychologist*, 73(4), 532. doi:10.1037/amp0000319
- Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer disease in the United States (2010–2050) estimated using the 2010 census. *Neurology*, 80(19), 1778–1783. doi:10.1212/wnl.0b013e31828726f5
- Karg, N., Graessel, E., Randzio, O., & Pendergrass, A. (2018). Dementia as a predictor of care-related quality of life in informal caregivers: A cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. *BMC Geriatrics*, 18(1), 189. doi:10.1186/s12877-018-0885-1
- Kasper, J. D., Freedman, V. A., & Spillman, B. C. (2013). *Classification of persons by dementia status in the National Health and Aging Trends Study. Technical Paper #5*. Baltimore: Johns Hopkins University School of Public Health. <http://www.nhats.org>
- Keith, C. (1995). Family caregiving systems: Models, resources, and values. *Journal of Marriage and the Family*, 57(1), 179–189. doi:10.2307/353826
- Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: The updated sociocultural stress and coping model. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 65(1), 5–13. doi:10.1093/geronb/gbp096
- Koehly, L. M., Ashida, S., Schafer, E. J., & Ludden, A. (2015). Caregiving networks-using a network approach to identify missed opportunities. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 70(1), 143–154. doi:10.1093/geronb/gbu111
- 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
- Litwak, E. (1985). *Helping the elderly: The complementary roles of informal networks and formal systems*. Guilford Press.
- Litwak, E., Messeri, P., & Silverstein, M. (1990). The role of formal and informal groups in providing help to older people. *Marriage & Family Review*, 15(1–2), 171–193. doi:10.1300/J002v15n01_09
- Marcum, C. S., Ashida, S., & Koehly, L. M. (2020). Primary caregivers in a network context. *The Journal of Gerontology, Series B: Psychological Sciences and Social Sciences*, 75(1), 125–136. doi:10.1093/geronb/gbx165
- Marek, L. I., Brock, D. P., & Savla, J. (2015). Evaluating collaboration for effectiveness: Conceptualization and measurement. *American Journal of Evaluation*, 36(1), 67–85. doi:10.1177/1098214014531068
- Mateo, C. M., & Williams, D. R. (2021). Racism: A fundamental driver of racial disparities in health-care quality. *Nature Reviews Disease Primers*, 7(1), 20. doi:10.1038/s41572-021-00258-1

- Messeri, P., Silverstein, M., & Litwak, E. (1993). Choosing optimal support groups: A review and reformulation. *Journal of Health and Social Behavior*, 34(2), 122–137. doi:10.2307/2137239
- Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kuerbis, A. N., & Donelan, K. (2001). The experiences and challenges of informal caregivers: Common themes and differences among Whites, Blacks, and Hispanics. *Gerontologist*, 41(6), 733–741. doi:10.1093/geront/41.6.733
- Parker, L. J., Fabius, C., Rivers, E., & Taylor, J. L. (2021). Is dementia-specific caregiving compared with non-dementia caregiving associated with physical difficulty among caregivers for community-dwelling adults? *Journal of Applied Gerontology*, 41(6), 1074–1080. doi:10.1177/07334648211014352
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, 30(5), 583–594. doi:10.1093/geront/30.5.583
- Ponnala, S., Weiler, D. T., Gilmore-Bykovskiy, A., Block, L., Kind, A. J., & Werner, N. E. (2018). Towards an understanding of informal care networks of persons with dementia: Perceptions of primary caregivers. *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, 62(1), 561–562. doi:10.1177/1541931218621128
- Qualls, S. H. (2014). Family therapy with ageing families. In N. A. Pachana & K. Laidlaw (Eds.), *The Oxford handbook of clinical geropsychology* (pp. 710–732). Oxford University Press.
- Schulz, R., Beach, S. R., Czaja, S. J., Martire, L. M., & Monin, J. K. (2020). Family caregiving for older adults. *Annual Review of Psychology*, 71, 635–659. doi:10.1146/annurev-psych-010419-050754
- 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
- Stommel, M., Given, B. A., Given, C. W., & Collins, C. (1995). The impact of the frequency of care activities on the division of labor between primary caregivers and other care providers. *Research on Aging*, 17(4), 412–433. doi:10.1177/0164027595174003
- Thomson, A. M., Perry, J. L., & Miller, T. K. (2007). Conceptualizing and measuring collaboration. *Journal of Public Administration Research and Theory*, 19(1), 23–56. doi:10.1093/jopart/mum036
- Usita, P. M., Hall, S. S., & Davis, J. C. (2004). Role ambiguity in family caregiving. *Journal of Applied Gerontology*, 23(1), 20–39. doi:10.1177/0733464803253591
- Wood, D. J., & Gray, B. (1991). Toward a comprehensive theory of collaboration. *The Journal of Applied Behavioral Science*, 27(2), 139–162. doi:10.1177/0021886391272001
- Xu, J., Liu, P.-J., & Beach, S. (2021). Multiple caregivers, many minds: Family discord and caregiver outcomes. *Gerontologist*, 61(5), 661–669. doi:10.1093/geront/gnaa067
- Young, H. M., Bell, J. F., Whitney, R. L., Ridberg, R. A., Reed, S. C., & Vitaliano, P. P. (2020). Social determinants of health: Underreported heterogeneity in systematic reviews of caregiver interventions. *Gerontologist*, 60(Supplement_1), S14–S28. doi:10.1093/geront/gnz148