

Informal Caregiving Networks of Older Adults With Dementia Superimposed on Multimorbidity: A Social Network Analysis Study

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Abstract

Background and Objectives: Caregiving is a social process and commonly involves more than a single caregiver, especially for older adults with multimorbidity, including dementia. This study was to characterize informal caregiving networks of older adults with dementia superimposed on multimorbidity (e.g., end-stage kidney disease) and to examine the relationships of network properties to outcomes of caregivers and older adults.

Research Design and Methods: An egocentric social network survey was conducted. Up to 3 family caregivers of older adults on dialysis who had moderate-to-severe irreversible cognitive impairment with or without a documented diagnosis of dementia were recruited from 11 dialysis centers in 2 states. Caregivers completed a social network survey about individuals providing caregiving to the older adult and measures of caregiving burden and rewards, depression, and financial hardship. Older adults' emergency department visits and hospital admissions during the past 12 months were abstracted from the medical records.

Results: A total of 76 caregiver informants of 46 older adults (78% Black) participated in the study. Of the 46 older adults, 65% had a multimember network (median size of 4). As the network density (the proportion of ties between members among all possible ties) increased, primary caregivers' financial hardship decreased whereas nonprimary caregivers' financial hardship increased. Further, for every 1-unit increase in mean degree (the average number of connections among members), there was a nearly fourfold increase in the odds of no hospital admission during the prior year for the older adult.

Discussion and Implications: The network dynamics of informal caregiving networks may have an impact on the well-being of caregivers and older adults with dementia, but confirmatory longitudinal studies are needed.

Keywords: Alzheimer's disease, Cognitive impairment, Family caregivers, Multiple chronic conditions

Translational Significance: Historically, caregiving research has been focused on a caregiver designated as the primary caregiver. Using an egocentric social network analysis approach, this study was to characterize the network of informal caregivers for older adults with dementia superimposed on multimorbidity. Caregiving commonly involved a multimember network rather than a primary caregiver alone, and network characteristics were associated with the well-being of caregivers and care recipients. The understanding of informal caregiving at the network level may help identify new strategies for alleviating caregiver burden, such as distribution of caregiving roles, and may ultimately improve the health outcomes of older adults with dementia.

Background and Objectives

Caregiving is defined as attending to another person's health needs and includes assistance with one or more activities of daily living (ADLs), such as bathing and dressing, as well as multiple instrumental activities of daily living (IADLs), such

as paying bills, shopping, and transportation (Alzheimer's Association, 2022; Gaugler et al., 2002). Although dementia is the single largest contributor to disability and increased care needs in the United States (Alzheimer's Association, 2022), the effect of dementia on caregiving and the caregiving

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burden in the context of multiple chronic conditions, including a complex chronic illness like end-stage kidney disease (ESKD), has been poorly characterized. Multiple chronic conditions affect three in four adults who are 65 years of age and older (Buttorff et al., 2017; Freid et al., 2012; Salive, 2013). The defining characteristics of multiple complex chronic conditions (Forum, 2012) include two or more coexisting chronic conditions that last at least 1 year; collective adverse effects on health status, function, or quality of life; require complex health care management and decision making; and compromise life expectancy or hinder self-management.

ESKD is an exemplary case of multiple complex chronic conditions because ESKD is never a single disease but a family of complex chronic conditions, such as diabetes and hypertension (the two most common underlying conditions for ESKD), coronary artery disease, and congestive heart failure (United States Renal Data System, 2021). Nearly one in five adults with ESKD are at least 65 years old (United States Renal Data System, 2021) who are on dialysis, living at home, and cared for by family members, typically a spouse or child (Ekelund & Andersson, 2010; Suri et al., 2011, 2014; United States Renal Data System, 2021). Although the numbers are increasing, less than 1% of older adults with ESKD are estimated to reside in nursing homes (Hall et al., 2013), and thus the burden of caregiving largely falls onto informal caregivers (Ekelund & Andersson, 2010; Gilbertson et al., 2019; Suri et al., 2011, 2014; Tong et al., 2008).

Caregiving in the context of complex multimorbidity most likely represents a network of people drawn from the social circles of the older adult and/or family caregivers and reflects the relative presence or absence of social capital to help them manage and cope with the demands of self-management and care coordination (Ridgeway et al., 2014; Valente, 2010). A social network is defined as “a specific set of linkages among a defined set of persons, with the additional property that the characteristics of these linkages as a whole be used to interpret the social behavior of the person involved” (Mitchell, 1969, p. 2). As such, a social network refers to the structure, such as ties in the overall network, size, nature of the ties (e.g., frequency and intensity of interactions), and functions that networks provide (e.g., tangible aid and services; Israel, 1982).

A growing body of literature demonstrates that caregiving is a social process and commonly involves more than a single caregiver, especially for older adults (Andersson & Monin, 2018; Friedman & Kennedy, 2021; Koehly et al., 2015; Marcum et al., 2018; Spillman et al., 2020). For example, Andersson and Monin (2018) reported that caregiving networks were larger for those with a higher number of coexisting chronic conditions. However, they also found that larger caregiving networks might serve to undermine care recipients' well-being as morbidity increases, suggesting that there may be ideal network characteristics to optimize care recipients' health and social outcomes. Notably, the Andersson study excluded individuals with dementia because the caregiving information was collected from the patient rather than the caregiver. Similarly, research has shown that older adults with dementia have larger caregiving networks involving more task sharing than those without dementia (Koehly et al., 2015; Spillman et al., 2020). These recent studies highlight the need for empirical data on caregiving that goes beyond primary caregivers to develop interventions and policy planning to impact

the community of caregivers. Furthermore, recognizing the established linkage between social networks and health (Chang et al., 2017; Smith & Christakis, 2008), informal caregiving networks are likely to influence caregivers' and care recipients' health outcomes, but no studies have investigated the relationships.

Yet historically caregiving research has been focused on an individual primary caregiver's characteristics and health status and has generally overlooked the role of social interactions in caregiving and these effects on the health outcomes of caregivers and care recipients. This is important because the focus on caregiving as primary caregiver–care recipient dyadic interactions may provide limited capturing of the demand for and supply of informal caregiving and incomplete estimates of the need or type of support and services. To begin to address these gaps, we conducted a social network analysis study to (a) characterize informal caregiving networks of older adults with dementia superimposed on ESKD with respect to network members and their characteristics (e.g., age, gender, relationship to the patient) and network properties (e.g., network size, diversity, density, and centrality); (b) examine the relationships between network properties and caregiver outcomes (overall self-rated health, depressive symptoms, perceived caregiving burden, and rewards of caregiving); and (c) examine the associations of the network properties to health care resource use for older adults (emergency department [ED] visits and hospital admissions) during the past year.

Research Design and Methods

Research Design

The study was a telephone-based egocentric social network survey. In an egocentric social network study, each informant is asked to identify the members of his or her network and their relationships (Smith & Christakis, 2008; Valente, 2010). For fuller descriptions of networks, we included the primary family caregivers (index informant) and up to two additional family caregiver informants identified from the index caregiver who plays an important role in caregiving (i.e., providing direct care and/or participating in decision making about care) for the older adult. We limited up to three informants because, after three, the number of new network members identified and their contributions to the caregiving network information tend to yield no new information (Koehly et al., 2015).

Setting and Participants

We first identified patients on hemodialysis who were 65 years old or older and had a diagnosis of dementia documented in the medical record from 11 free-standing dialysis centers in two states, GA and NC. Home dialysis was not considered because it would be very unlikely that those older adults would continue to dialyze at home after the diagnosis of dementia or with moderate-to-severe cognitive impairment. Because dementia is largely underdiagnosed for individuals with ESKD, we also asked the treating nephrologist or advanced practice nurse to identify older adults who were suspected of having dementia or irreversible moderate-to-severe cognitive impairment. To ensure the level of cognitive impairment to be moderate to severe (an MoCA [Montreal Cognitive Assessment] score <17; Nasreddine et al., 2005; Trzepacz et al., 2015), a trained research assistant

administered the MoCA after obtaining permission to do so from the primary caregiver listed in the medical record. Nursing home residents were excluded.

The primary/index caregiver (FCG1) was identified from the older adult's medical record. Eligible FCG1s met the following criteria: (1) 18 years or older; (2) a family member (either biological [e.g., a child] or nonbiological family member [e.g., a spouse] of the older adult, including significant others or partners); (3) provide direct care (assistance with ADLs, IADLs, self-care and care coordination tasks) and/or participate in decision making about care; (4) able to communicate in English; and (5) self-identify as "the primary caregiver" defined as having the primary responsibility for providing care and/or spending the most time providing care (as opposed to providing intermittent supplementary or complementary help to the care recipient; Schultz & Eden, 2016).

During the social network survey, FCG1 was asked to name up to five members of the caregiving network who provide direct care and/or participate in decision making about care. We contacted family caregivers from the list of network members provided by the FCG1 to enroll the second and third FCG (as applicable) if they met the criteria (1) through (4). Although nonfamily members (e.g., friends, neighbors) were counted as network members if enumerated by the FCG, they were not considered as potential FCG informants because these nonfamily caregivers would be unlikely to be involved in decision making about the care of the older adult.

Outcomes and Measurement

Social Network Survey

The survey included five components: (1) the FCG's sociodemographic information; (2) naming up to five family or nonfamily network members who participated in caregiving for at least 6 months; (3) sociodemographic information about each member, including age, gender, race/ethnicity, and relationships to the FCG (the informant's best guess was allowed; if there were family caregivers in the list, their contact information was obtained); (4) what caregiving role each network member plays, including the informant him- or herself; and (5) whether network members were in touch with each other via phone, text, or email (member connection).

Next, we contacted additional FCGs from the list of network members, who might be eligible to participate in the study. As done with the FCG1, the second and third FCG(s) were asked to enumerate up to five members of the caregiving network and completed the social network survey. Snowball sampling continued until up to two additional FCGs participated, or all referred FCGs refused to participate or could not be reached. Snowball sampling stopped if there were no other FCGs in the initial caregiving network enumerated by the FCG1.

Caregiver outcome measures

To assess *caregiver's overall health*, we used a four-point single scale ranging from "poor" (= 1) to "excellent" (= 4) in consideration of subject response burden, which is as valid, reliable, and sensitive as a multi-item scale (e.g., SF-36 Health Survey; Macias et al., 2015; Rohrer et al., 2009). *Caregiver burden* was measured using the 12-item version of the Zarit Burden Interview (ZBI-12; Bedard et al., 2001) that has been widely used (Cronbach's alpha = 0.92) and validated to measure the burden of caregiving. Each item is rated on a

five-point scale ranging from "never" (= 0) to "nearly always" (= 4). A summed score of 21 or higher suggests high burden. To assess *rewards of caregiving*, we used the Rewards of Caregiving Scale (Archbold & Stewart, 1996). The original scale (Cronbach's alpha > 0.80) includes 15 items with a five-point Likert-type scale ranging from "not at all" (= 0) to "a great deal" (= 4). Three items have been excluded because of a lack of relevance (e.g., "Does caring for him or her help you understand your own aging?"). Using the Center for Epidemiologic Studies—Depression Scale—Short Form (CES-D-SF; Andresen et al., 1994), we measured *caregiver symptoms of depression*. The CES-D-SF includes 10 items (Cronbach's alpha > 0.70; Mohebbi et al., 2018) that tap psychological depressive symptoms each with response options of 0 (rarely or less than once a week) to 3 (frequently or 5–7 days a week) with the higher scores indicating the presence of more symptomatology (Bosworth et al., 2001; Brown et al., 2005). Finally, we used the COMprehensive Score for financial Toxicity (COST) to measure financial hardship (de Souza et al., 2014, 2017). The COST (Cronbach's alpha = 0.92) was originally developed to assess financial hardship in cancer and has rapidly been adopted as the common measure of financial toxicity in chronic illness (de Souza et al., 2014, 2017). It measures the general financial situation and the impact of illness on financial situation and distress. The COST includes 11 items with response options from 0 (not at all) to 4 (very much) with higher scores indicating greater financial burden. Items 3 and 10 ("my illness") were revised to be appropriate for family caregiver respondents.

Older adults' ED visits and hospital admissions

We collected information about older adults' ED visits and hospital admissions during the past 12 months from the dialysis center's electronic medical record (EMR) system along with their clinical characteristics, including years on dialysis, diagnosis of dementia, and comorbid conditions that are currently treated and/or monitored.

The data collection with FCGs took about an hour. At completion, a \$30 gift card was mailed to each participant. The study protocol was approved by Emory and Wake Forest Institutional Review Boards.

Statistical Analysis

Individual and pairwise caregiver relationship information from multiple informants were reconciled, and the resulting caregiving networks for each older adult were visualized using the igraph package in R-4.2.0 based on the Fruchterman-Reingold layout algorithm (Fruchterman & Reingold, 1991). We computed several network measures (Crossley et al., 2015; Scott, 2017; Valente, 2010): network *size* (total number of members), *density* (proportion of connected pairs among all possible pairs of members), mean and maximum *degrees* (average and maximum number of connections a member has to the other network members), and maximum *betweenness centrality* (the proportion of times a member lies within the shortest path between other pairs of members).

For the descriptive analysis, we assumed undirected (i.e. all relationships are mutual) and used weights that corresponded to the strength of each relationship or helpfulness of assistance provided as described by O'Malley and Paul (2015). All FCGs were asked whether any pair of members named by them communicated with each other for caregiver care needs, on a scale ranging from 1 (= all the time) to 5 (=

not connected/don't know). Any pair of members that communicated at least sometimes or have a weight of less than or equal to 2, were classified as a connection or tie. To assess bivariate associations between the network measures and caregiving activities, and outcomes of caregivers and older adults with dementia, we computed Spearman's rho coefficients, a nonparametric measure of strength and direction between two variables, due to a lack of normality in some variables.

To account for the clustering of caregivers within the network, generalized estimating equations were used to model the relationships between network characteristics and caregiver outcomes after adjusting for caregiver characteristics (e.g., income, employment status, years of caregiving). An exchangeable correlation structure, where each caregiver pair was assumed equally correlated, was used to account for correlations between repeated measurements within each network. For binary outcomes, such as probability of any ED visits and hospital admissions during the previous 12-month period, we used logistic regression models to assess the effect of network properties after adjusting for older adults' characteristics, such as years on dialysis and number of comorbid conditions. All statistical tests were two sided with a 5% significance level. We used IBM SPSS Statistics (Version 27) and R-4.2.0 for the data analyses.

Results

Participants

Of 113 older adults who had a diagnosis or were suspected of dementia, 66 FCG1s (58.4%) consented for cognitive screening of the older adult and survey participation if eligible (see Figure 1 for details). Of those, 20 were excluded, leaving 46 FCG1s who first completed the survey. Of the 46, 16 (34.8%)

were singletons in which there was no individual involved in caregiving other than the FCG1. Of the remaining 30 multimember networks, in addition to 46 FCG1s, 30 additional FCGs (nonprimary) participated in the study, totaling 76 FCG informants.

Older adults were 73.9 years old (standard deviation [SD] = 12.5), 22 (47.8%) were male, 35 (77.8%) were Black, 24 (52.2%) completed high school, and 16 (34.8%) were currently married. Older adults were on dialysis for 4.2 years ($SD = 2.9$) and had 5 comorbid conditions (median) in addition to dementia. A dementia diagnosis was recorded for 24 (53.3%) in the EMR, but the date of diagnosis was available for 17 (46%). Of the 46 individuals, an MoCA was not administered to 22 patients (47.8%) because cognitive impairment was too severe.

A majority of FCG informants ($n = 39$, 51.3%) were a child of the older adult, woman ($n = 57$, 75%), Black ($n = 58$, 76.3%), and currently living with the older adult ($n = 42$, 55.3%). FCGs were involved in caregiving for the older adult for 7 years on average (Table 1). Compared to nonprimary FCGs, FCG1s were more likely to live with the older adult (69.6% vs 33.3%, $p = .002$), had a higher number of days of caregiving in the past week (median 7 vs 4 days, $p < .001$), and provided a higher number of IADLs assistance (median 10 vs 7.5, $p = .002$).

Characteristics of Informal Caregiving Networks

The average network size across 46 networks was 2.8 ($SD = 1.84$) with a maximum of 6. Within the 30 multimember networks, the median network size was 4. On average, the 30 multimember networks were composed of 69% ($n = 77$) women and 97% ($n = 110$) immediate family members or first-degree relatives. Three networks (10%) included at least one nonfamily member (e.g., friend). The mean caregiving years were higher in multimember networks compared to singletons ($M [SD] = 7.8 [6.7]$ vs $4.5 [4.0]$, $p = .04$).

Among the multimember networks, the network density was high ($= 0.9$), meaning that nearly all network members were connected with at least one other member. Centrality measures (mean degree, maximum degree, and maximum betweenness) indicate the importance of members in a network and inform who the "key" players are (Crossley et al., 2015). Figure 2 illustrates two examples of networks studied. In 27 multimember networks (90%), the FCG1 had the maximum degree and maximum betweenness, and thus was the most connected and central person in the network. Helping with IADLs was shared among a median of 81.7% of the network members whereas activities related to health monitoring and self-care activities were shared by 66.7%. A median of 50% of the network members shared the role and responsibility of care-related decision making and ADLs assistance each.

Of the 30 multimember networks, 19 networks (63.3%) were represented by at least 2 FCGs, including FCG1. To explore the potential advantage of interviewing additional FCG informants other than the FCG1, we compared the network properties of the 19 networks when using FCG1 data only versus when using all FCG informants for the network (Table 2). The numbers of network members, ties, and maximum degrees were significantly higher when including data from FCG1 and additional FCG informants compared to using FCG1 data only.

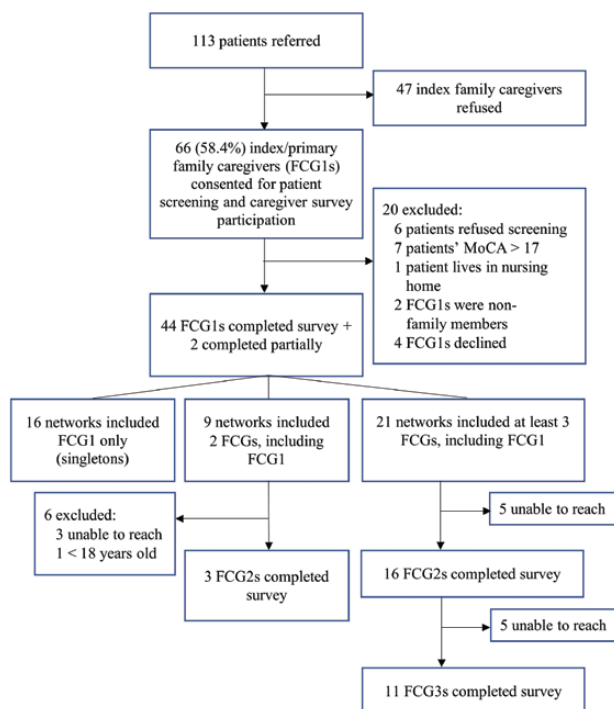


Figure 1. Study participant flow. FCG = family caregiver; MoCA = Montreal Cognitive Assessment score.

Table 1. Sociodemographic and Caregiving Characteristics of Family Caregiver Informants

Characteristics	Overall (N = 76)		Primary FCG (n = 46)		Nonprimary FCG (n = 30)	
	n (%)	M (SD); median, range	n (%)	M (SD); median, range	n (%)	M (SD); median, range
Sociodemographic						
Age, M (SD)	54.2 (14.5)		57.7 (13.2)		48.6 (15.8)	
Female, sex	57 (75.0)		37 (80.4)		20 (66.7)	
Race						
White	14 (18.7)		9 (19.6)		5 (17.2)	
Black	58 (77.3)		35 (76.1)		23 (79.3)	
Other	3 (0.04)		2 (4.3)		1 (3.4)	
Relationship to patient						
Spouse	11 (14.5)		11 (23.9)		0 (0.0)	
Child	39 (51.3)		23 (50.0)		16 (53.3)	
Child-in-law	1 (0.01)		0 (0.0)		1 (3.3)	
Relative	18 (23.7)		8 (17.4)		10 (33.3)	
Other	7 (0.1)		4 (8.7)		3 (10.0)	
Marital status if not patient's spouse						
Never married	20 (26.7)		9 (20.0)		20 (26.7)	
Married	31 (41.3)		21 (46.6)		31 (41.3)	
Widowed	10 (13.3)		8 (17.8)		10 (13.3)	
Separated or divorced	11 (14.7)		5 (11.1)		11 (14.7)	
Other	3 (4.0)		2 (4.4)		3 (4.0)	
Education level						
<High school	1 (1.3)		1 (2.2)		0 (0.0)	
High school	31 (40.8)		18 (39.1)		13 (43.3)	
College or higher	44 (57.9)		27 (58.7)		17 (56.7)	
Employment status						
Full time	29 (38.2)		19 (41.3)		10 (33.3)	
Part time	8 (10.5)		4 (8.7)		4 (13.3)	
Unemployed	9 (11.8)		3 (6.5)		6 (20.0)	
Retired	21 (27.6)		14 (30.4)		7 (23.3)	
Disabled/unable to work	8 (10.5)		6 (13.0)		2 (6.7)	
Other	1 (1.3)		0 (0.0)		1 (3.3)	
Household gross annual income						
<\$20,000	23 (30.3)		11 (23.9)		12 (40.0)	
\$20,000–\$30,000	10 (13.7)		8 (17.4)		2 (6.7)	
\$30,000–\$50,000	14 (19.2)		9 (19.6)		5 (16.7)	
≥\$50,000	26 (35.6)		15 (32.6)		11 (36.7)	
Living with patient	42 (63.6)		32 (69.6)		10 (33.3)	
Caregiving						
Years of caregiving		7.0 (6.8); 5, 0.3–33		6.7 (6.1); 5, 0.3–25		7.5 (7.8); 6, 0.5–33
Days of caregiving in the past week		5.0 (2.5); 7, 0–7		5.8 (2.1); 7, 0–7		3.9 (2.5); 4, 0–7
Total number of ADLs assistance		2.7 (2.4); 2, 0–7		2.8 (2.4); 2, 0–7		3.3 (2.6); 2.5, 0–7
Total number of IADLs assistance		8.2 (3.0); 9, 0–12		9.1 (2.4); 10, 4–12		6.8 (3.4); 7.5, 0–12

Notes: ADLs = activities of daily living; FCG = family caregiver; IADLs = instrumental activities of daily living; M = mean, SD = standard deviation.

Outcomes of Caregivers and Older Adults

Generally, the FCGs reported a good overall rating of current health ($M = 3.0$, $SD = 0.7$), mild caregiving burden ($M = 11.1$, $SD = 8.5$), high caregiving rewards ($M = 39.3$, $SD =$

9.0 ; possible range = 0–48), mild depressive symptom scores ($M = 7.3$, $SD = 6.0$; possible range = 0–30), and mild financial hardship ($M = 17.7$, $SD = 5.9$; possible range = 0–44). Compared to nonprimary FCGs, FCG1s perceived greater

financial hardship ($M [SD] = 15.3 [5.8]$ vs $19.4 [5.3]$, $p = .002$). On average, the total number of ED visits and hospital admissions over the past 12 months was 0.8 ($SD = 1.5$; median = 0, maximum = 6) and 1.6 ($SD = 1.3$; median = 1; maximum = 5), respectively.

Relationships Between Network Properties and Outcomes of Caregivers and Older Adults

Of the caregiver outcomes, univariate analysis showed that only the COST scores were associated with some network

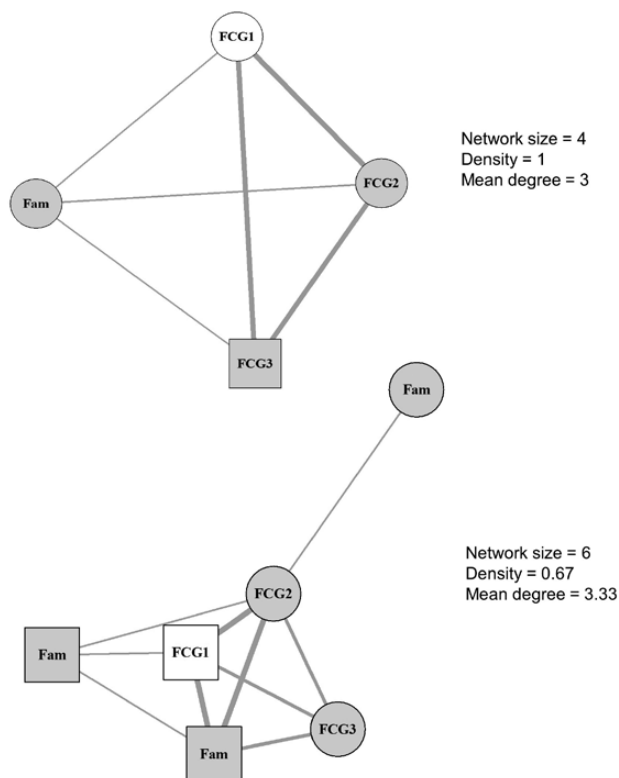


Figure 2. Examples of caregiving networks. FCG1 = Primary/index family caregiver informant; FCG2 = family caregiver informant 2; FCG3 = family caregiver informant 3; Fam = other family caregiver; circle = female; square = male; thicker line = stronger tie; network size = the total number of members; density = the proportion of connections or ties between members among all possible pairs of members; mean degree = the average number of connections a member has to the other network members.

properties. FCG1s' COST scores were inversely associated with the network density ($\rho = -0.37$, $p < .05$) but positively associated with the maximum betweenness ($\rho = 0.37$, $p < .05$). That is, the higher proportion of the members linked in the network, the less perceived financial hardship. However, the higher proportion of times the member was located on the shortest path between other members of the network, the greater perceived financial hardship.

Multivariate analyses showed the relationships among COST scores of FCG1s versus FCG2s and FCG3, and network properties (density and maximum betweenness). FCG1s' financial hardship decreased as the network density (overall member connection) increased but at the expense of increased nonprimary caregivers (FCG2 and FCG3)' COST scores (Figure 3). On the other hand, FCG1s' COST scores increased as the network's maximum betweenness increased but the FCG2's and FCG3's COST decreased. That is, because 90% of the time it was FCG1s who held the maximum betweenness in this sample, FCG1 was thought to play an authoritative and influential role in the network, the greater financial hardship experienced by the FCG1 whereas nonprimary caregivers' hardship was lessened. These relationships remained unchanged even after accounting for caregiving years, employment status, and annual income.

Although the network properties were not associated with years on dialysis, the number of comorbid conditions, the number of ED visits, or the number of hospital admissions showed an inverse correlation with the mean degree ($\rho = -0.47$, $p < .01$) and the maximum degree ($\rho = -0.43$, $p < .05$), meaning that the higher number of ties held by members was or the more members were directly connected in the network, the fewer hospital admissions. Accounting for years on dialysis, comorbid conditions, and age, multivariable logistic regression analysis showed that with every one-unit increase in mean degree and maximum degree, the odds of no hospital admission increase by 3.7 ($p = .03$) and 3.6 folds ($p = .04$), respectively. That is, the higher member connectivity, the lower odds of older adult's hospital admissions. These relationships remained unchanged after accounting for years on dialysis and comorbid conditions.

Discussion and Implications

We conducted an egocentric social network analysis study to describe informal caregiving networks of older adults with ESKD as an exemplar of multimorbidity who had

Table 2. Comparison of Network Properties Based on Primary Caregiver Informants (FCG1) Only Versus Primary and Additional Caregiver Informants (All FCGs; $n = 19$)

Network property	FCG1 only			All FCGs			<i>p</i>
	<i>M</i>	<i>SD</i>	Range	<i>M</i>	<i>SD</i>	Range	
Number of nodes/network members	3	1	2–5	4	2	2–6	.02
Number of ties	3	2	1–10	6	4	1–15	.03
Density	0.96	0.12	0.6–1	0.90	0.17	0.4–1	.41
Mean degree	1.78	0.87	1–4	2.74	1.18	1–5	.05
Maximum degree	2	1	1–4	3	2	1–5	.02

Notes: *p* Values are based on 1,000 bootstrap samples for *t* test. Density = the proportion of connections or ties between members among all possible ties; degree = the number of members the FCG is connected with. FCG = family caregiver; *M* = mean, *SD* = standard deviation

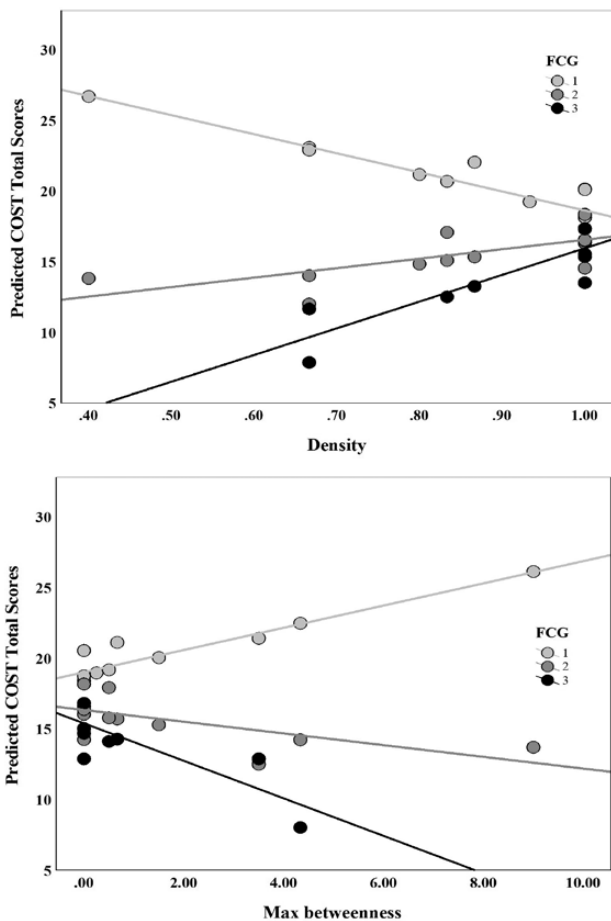


Figure 3. COST scores, network density, and maximum betweenness. COST = Comprehensive Score for Financial Toxicity, a measure of financial hardship; FCG = family caregiver. Density = the proportion of connections or ties between members among all possible ties, maximum betweenness = the proportion of times a member lies within the shortest path between other pairs of members. All graphs are based on multivariable models adjusted for covariates: caregiving years, income, and employment.

moderate-to-severe dementia, and to explore the linkage between caregiving network properties and health outcomes of informal caregivers and older adults. Of importance, our focus was on characterizing the structure and dynamics of informal caregiving networks of older adults with multimorbidity and dementia as opposed to social support networks for caregivers. We found that most of those older adults were cared for by multiple caregivers. In most networks, care-related decision-making or self-management activities (e.g., monitoring health, taking medications) for the older adult were distributed to a small subgroup within the network in which the primary caregiver might or might not be part of the subgroup. We also found that the primary caregivers' financial hardship decreased as the network density (overall member connection) increased but at the expense of increased nonprimary caregivers' financial hardship. On the other hand, the primary caregivers' financial hardship increased as the network's maximum betweenness increased but the nonprimary caregivers' financial hardship decreased. Because it was the primary caregiver who held the maximum betweenness in most networks in this sample, the more the primary caregiver played an authoritative role in the network, the financial

hardship experienced by the primary caregiver was greater whereas nonprimary caregivers' hardship was lessened. Furthermore, we found that the higher member connectivity, the lower odds of hospital admissions for the older adult.

Our findings expand the understanding of informal caregiving beyond the role of the primary caregiver, which also confirm previous study findings that caregiving commonly involves more than a single caregiver, especially for older adults (Andersson & Monin, 2018; Friedman & Kennedy, 2021; Koehly et al., 2015; Marcum et al., 2018; Spillman et al., 2020). In our sample, the mean year of caregiving was higher in multimember networks compared to singletons. Caregiving networks may grow larger as the caregiving demands increase over time; however, because our study was a cross-sectional study, we do not know whether singletons reflect the absence of social capital or lower caregiving demands.

The study sample of older adults with ESKD may be viewed as a unique population that differs from others. However, the nature of informal caregiving and caregiving burden among caregivers of adults with ESKD has been found to be similar to other populations, such as congestive heart failure and cancer (Ekelund & Andersson, 2010; Gilbertson et al., 2019; Suri et al., 2011, 2014; Tong et al., 2008). Our findings suggest that the interactions and influences among the individuals in the network may play an important role in the well-being of caregivers as well as the older adults. For example, caregivers' financial hardship may be offset by network dynamics, and caregiving network's cohesion may have meaningful implications for healthcare resource use for the older adults receiving dialysis. Given that the number of network members was not associated with any of the outcomes of caregivers or older adults, the findings suggest that it is not necessarily the size but the quality or function of the network that matters.

The social network approach is well aligned with the phenomenon of informal caregiving for older adults with dementia as it helps account for the group dynamics of a social network and explain how such network characteristics affect members' behaviors and well-being (Luke & Harris, 2007). We determined that assessing informal caregiving networks needed to be egocentric as opposed to sociocentric because there is no clearly defined boundary of a given caregiving network to generate a roster of network members until a caregiver of the older adult provides the information (Crossley et al., 2015). We found that our multi-informant approach, interviewing additional family caregiver informants other than the primary caregiver significantly increased most of the network properties, such as network size, connections, and maximum degree centrality, allowing for a fuller description of networks. However, because the approach is labor intensive and adds to the complexity in participant recruitment, future researchers may need to weigh the benefits and burdens when considering the approach for their research.

Our findings have several research and clinical and social service implications. The research implications mostly stem from our study's limitations. That is, although data-rich, our study included a small sample and used a cross-sectional study design. Second, although network members to be nominated by the caregiver informants could be other family members or nonfamily members as long as the person participated in caregiving activities for the older adult, the caregiver informants in the study were limited to either a biological or nonbiological family member. Third, in the

case where eligible FCG2 and/or FCG3 refused to participate in the study, the network measures were computed based on the information from FCG1, and thus it is possible that those networks might be in fact larger than what was described based on the FCG1 perspectives only. Given these limitations, the study findings may not be generalizable without caution. Although the fact that the study sample including predominantly Blacks is a strength given that Blacks have been underrepresented in research in general, future research should include longitudinal studies with a large, diverse (racially, socioeconomically, and geographically) sample to examine the formation and functioning of caregiving networks for older adults over time and to confirm the linkages between network properties and caregivers' and older adults' outcomes that we observed in the study.

Rarely do health care providers or social service providers assess who, other than the primary caregiver, are involved in caregiving for the older adult living at home, and what caregiving roles that they are playing. This assessment may be important because the primary caregiver may or may not be the one who is responsible for monitoring the older adult's health at home. Further, caregiver education in clinical settings may need to be directed beyond the primary caregiver. The understanding of informal caregiving at the network level may help identify new strategies for alleviating caregiver burden, such as distribution of caregiving roles, and may ultimately improve the health outcomes of older adults with dementia.

In summary, although the generality of the current results must be established by future research, the present study findings contribute to the body of evidence in dementia caregiving that has traditionally been focused on primary caregivers. Further, the study findings go beyond the current evidence of caregiving networks that has been limited to network size and composition and provide empirical data on potential relationships between network dynamics or functioning and the outcomes of caregivers and older adults with dementia.

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Conflict of Interest

Each author declares that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

Data Availability

Study data and analytic methods will be available to other researchers per request once the publication reporting the main findings has been published. The study was a one-time survey and thus was not pre-registered.

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