

## Social Networks of Self-care and Perceived Treatment Burden Among Patients on In-Center Hemodialysis



Mi-Kyung Song, Sudeshna Paul, Laura Plantinga, Carrie Henry, and Linda Turberville-Trujillo

**Background:** Dialysis patients manage not only the demand of dialysis but also other complex chronic conditions. These individuals may draw upon personal and social resources to cope with the demands of self-management and care coordination. This study was designed to describe social networks for self-management and care coordination among hemodialysis patients and explore the association between network characteristics and perceived treatment burden.

**Study Design:** A cross-sectional study using social network analysis.

**Setting & Participants:** 20 patients from an outpatient dialysis center.

**Factors:** Social network characteristics (eg, size and connectivity) and perceived treatment burden.

**Measurements/Outcomes:** Participants completed a battery of questionnaires, including the Patient Experience With Treatment and Self-management Questionnaire (measuring perceived treatment burden) and a social network survey asking the respondent to name up to 5 people to whom he or she turned for help with self-care and care coordination tasks and their characteristics and relationships.

**Results:** Participants were aged 53.4 years on average, half were women, and 18 were African Americans. On average, network size was 3.1 members, most of whom were women and family members. 7 patient networks included at least 1 health care provider. The clustering coefficient (the overall connection between members) was 0.54, suggesting that not all members within the patient's network were connected with each other. Multimorbidity was not associated with treatment burden domain scores, but greater network connectivity was associated with lower treatment-related financial burden ( $r = -0.61$ ).

**Limitations:** The small sample was racially homogeneous and precluded controlling for potential confounding factors.

**Conclusions:** Dialysis patients used networks of people to manage self-care and coordination tasks, but interconnectedness between members of individual patients' networks was limited, which might negatively affect their perceived treatment burden. The social context of dialysis patients could play an important role in their illness management and treatment burden and calls for future research.

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With the growing tendency to shift illness management responsibilities from health care settings to home, patients and their informal caregivers must adapt to complex self-management in their everyday lives.<sup>1</sup> This is hard work and yet often invisible.<sup>2</sup> End-stage renal disease

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(ESRD) is an exemplary medical condition that requires complex management because it is never a single disease but is accompanied by other chronic conditions, such as diabetes (>50%), coronary artery disease (42%), congestive heart failure (40%), and peripheral vascular disease (23%).<sup>3</sup> Patients with ESRD must manage not only the demands of dialysis but also multiple chronic conditions and associated symptoms.<sup>4</sup> These patients are required to receive ongoing life-sustaining treatment, follow complex regimens set by health care providers, and navigate increasingly fragmented health care systems.<sup>5</sup> The combined "workload" of these complex self-management activities and its impact on the individual's well-being is known as treatment burden.<sup>1,2,6-8</sup> Shah et al<sup>9</sup> found that perceived treatment burden, measured by an overall rating scale, was the highest among patients with ESRD compared

with other chronic conditions with complex self-management demands, including celiac disease, diabetes, congestive heart failure, and irritable bowel syndrome.

To cope with the demands of self-management and care coordination, patients with multiple complex chronic conditions draw upon a range of personal and social resources.<sup>10</sup> However, the extent of such resources that patients on dialysis therapy mobilize to manage self-care and care coordination demands is largely unknown. For example, who are the members of dialysis patients' networks for self-management and care coordination? What are their characteristics? Are they all family members or are any care providers involved, such as dialysis care providers? Are there certain aspects of care centralized with a certain family member? Are the patient's network characteristics associated with perceived treatment burden?

Addressing these questions is important because the choice of approaches to optimizing the support for self-management and care coordination is likely to be tied to the specific circumstances and constraints of a given setting or patient population.<sup>11</sup> Therefore, the purposes of this study were to: (1) solicit social networks for self-management and care coordination among patients on dialysis therapy, (2) examine the variation of network

characteristics, and (3) explore the associations between network characteristics (eg, network structure and composition) and perceived treatment burden.

## METHODS

### Study Design

We conducted a cross-sectional study using a social network analysis approach to explore the relationships between social network structure (eg, size, density, and interconnectedness) and the individual's health outcomes.<sup>12</sup> We used egocentric social network analysis, in which each informant (a dialysis patient in this study) is asked to identify the members of his or her network and describe their characteristics and relationships.<sup>12,13</sup>

### Setting and Participants

From April 2018 to June 2018, participants were recruited from a large outpatient dialysis center in Atlanta, GA, in the United States. Approximately 340 adults were receiving dialysis care at the center during the study period, which provides in-center hemodialysis, nocturnal hemodialysis, and home dialysis programs. Of those, 211 were receiving in-center hemodialysis. The care team for in-center hemodialysis included 1 charge nurse manager; 2 social workers; 2 dietitians; 7 rounding physicians, including 1 medical director; and 1 advanced nurse practitioner who also manages patients at 2 other outpatient dialysis centers.

Patients were eligible for the study if they were 18 years or older, had been receiving in-center hemodialysis for at least 3 months, had at least 1 chronic condition other than ESRD (documented in the problem list in the medical record) and had been admitted to a hospital in the past 12 months (and thus likely to experience a high demand of self-management and care coordination tasks and activities), and were able to speak English fluently. Patients were excluded if they had uncompensated hearing impairment or were too ill to participate in an hour-long data collection session. One hundred eight patients met the criteria and were referred to the research team by a care provider.

To obtain a sample of 20 patients from the referrals, we used computer-generated random numbers to approach potential participants during their dialysis treatment for written consent. Twenty-one patients were approached; of those, 1 declined and 20 provided written consent. The Emory University Institutional Review Board approved the study protocol (IRB00102541).

### Data Sources/Measurement

A trained data collector conducted an hour-long in-person data collection interview with each participant while the participant was receiving dialysis at the center. At completion, participants received a \$30 gift card. Participants' clinical characteristics, including comorbid conditions and months on dialysis therapy, were abstracted from

the medical records. Data collection from participants included the following information.

The Sociodemographic Profile included age, sex, race/ethnicity, marital status, religious affiliation, education, and household income. To measure treatment burden, we used the Patient Experience With Treatment and Self-management (PETS) Questionnaire, a comprehensive patient-reported measure of treatment burden.<sup>8</sup> The PETS included a total of 60 items with 14 domains asking a respondent about the level of difficulty obtaining and understanding medical information about his or her health problems; performing self-care activities/tasks such as medication taking, medical appointments, monitoring health, diet, and exercise or physical therapy; using medical devices to deliver medicine, monitor a health condition, or treat a health problem; and the burdens on relationships with others, financial difficulty, and care coordination difficulty. PETS has demonstrated good reliability and validity when tested with various patient populations with multiple chronic conditions.<sup>8,14</sup> Raw subscale scores were transformed into standardized (0-100) scale scores, with higher scores indicating greater burden in each domain.

The Social Network Survey began with name generator, in which the respondent (ego; the person of interest) was asked to think of the people (alters) to whom he or she turned for actual help or for information and advice to do self-care tasks or activities and coordination of any medical care during the past 6 months. These people could be the respondent's family members, other relatives, friends, or care providers at the dialysis center or outside the dialysis center. Self-management or self-care was defined as all the tasks and activities an individual does outside of the dialysis center for his or her health problems or illnesses to stay as healthy as possible, such as taking medicine and monitoring physical and emotional symptoms, blood pressure, blood glucose levels, fluid intake, and diet or exercise.<sup>8</sup> Coordination of care was defined as activities to connect dots related to a person's health care needs, such as coordinating his or her medical appointments, communicating with multiple care providers, or managing medicines prescribed by different physicians.<sup>15</sup> After explaining the definitions of self-management and coordination of care and providing examples, we asked the respondent to name up to 5 people. We limited the list of network members to 5 after considering subject burden associated with egocentric social network survey completion, given that the number of pairs increases exponentially with the number of network members.<sup>12</sup>

After listing up to 5 alters, the ego was asked to provide: (1) sociodemographic information about each alter, including age (best guess was allowed), sex, race/ethnicity, the relationship to the participant (eg, family member, nephrologist, or primary care provider), adopted from the General Social Survey<sup>13</sup>; (2) the information about tasks and activities with which each alter helped, the frequency of interaction, and the importance of the help

provided by each alter; and (3) information about whether each pair of 2 alters was communicating with each other for the ego's care needs. Ties between alters were assessed using a rating: 1 = "in contact all the time," 2 = "sometimes if needed," 3 = "rarely," 4 = "not connected," and 5 = "don't know."

### Statistical Analysis

Responses about alters collected from each patient (ego) were reconciled to construct the egocentric network of each ego. A connection or tie between alters was assumed when the rating of ties between alters was 1 or 2 (ie, the 2 alters in a pair were in contact all the time or sometimes).

We computed structural properties of the networks, including density, defined by the proportion of connections among all pairs of individuals, and the clustering coefficient, defined by the proportion of connections among all alter pairs. In addition, we described the composition of each network by proportion of characteristics (eg, age, sex, race, education, relationship, and roles in self-care or care coordination activities) observed. The diversity of the network was measured by aggregating the different types of alter characteristics present in the network. For example, the number of different race groups represented in the ego's network was used as a measure of alter race diversity.

We explored preliminary associations between network structure and composition measures and patients' perceived treatment burden (PETS domains) using Pearson or Spearman rank correlation coefficients, as appropriate. For comparing network measures by categorical variables, we used *t* tests or analysis of variance. In all cases, we constructed bootstrap confidence intervals (CIs) to account for small sample sizes and potential deviations from normality. Data management and statistical analyses were performed in SPSS, version 23 (IBM Corp), and R, version 3.5 (R Core Team).

## RESULTS

### Participant Characteristics and Experiences With Self-management and Care Coordination

Participants' mean age was 53.4 (standard deviation [SD] = 13.5) years, 10 (50%) were women, and 18 (90%) were African American (Table 1). On average, participants were on dialysis therapy for 6.5 years and 13 (65%) were managing at least 2 chronic conditions in addition to ESRD.

In response to the PETS, 3 participants reported that no health care provider told them about diet, including what to eat or avoid given their illnesses, and 7 reported receiving no recommendations about exercise or physical therapy specifically for their health problems. Of the 14 PETS treatment burden domain scores, the highest mean scores were for difficulties performing self-care activities related to diet (56.2) and exercise (49.4), financial

**Table 1.** Characteristics of Participants on In-Center Hemodialysis Therapy

Characteristics	
Male sex	10 (50.0%)
Age, y	53.4 (13.5), 28-82
Race	
Black or African American	18 (90.0%)
White or Caucasian	1 (5.0%)
American Indian/Native American	1 (5.0%)
Marital status	
Never married	11 (55.0%)
Widowed or separated	5 (25.0%)
Currently married	4 (20.0%)
Education level	
<High school	4 (20.0%)
High school	7 (35.0%)
>High school	7 (35.0%)
Gross annual household income	
<\$20,000	12 (60.0%)
\$20,000-\$29,999	2 (10.0%)
\$30,000-\$49,999	6 (30.0%)
Months on dialysis	78.9 (65.1), 10 mo-24 y
Vascular access type	
Arteriovenous fistula	5 (25.0%)
Graft	8 (40.0%)
Catheter	7 (35.0%)
Comorbid condition	
Hypertension	19 (95.0%)
Diabetes	7 (35.0%)
HIV*/AIDS	4 (20.0%)
Congestive heart failure	2 (10.0%)
Peripheral vascular disease	2 (10.0%)
Connective tissue disorder	2 (10.0%)
Ulcer disease	2 (10.0%)
Liver disease	1 (5.0%)
Multiple chronic conditions	
1 in addition to ESRD	7 (35.0%)
2 in addition to ESRD	9 (45.0%)
3-4 in addition to ESRD	4 (20.0%)

Note: N = 20. Values expressed as number (percent), mean (standard deviation), or mean (standard deviation), range.

Abbreviations: ESRD, end-stage renal disease; HIV\*, human immunodeficiency virus positive.

difficulty (44.0), difficulty getting health care services (40.2), physical and mental exhaustion (38.0), and monitoring health (37.5).

### Network Characteristics

Table 2 presents network composition and structure. A total of 62 alters were listed by the 19 participants; 1 participant had no alter. On average, network size was 3.1 alters (SD = 1.6; range, 0-5) with a mean of 5.6 ties/connections per ego (SD = 4.1; range, 0-15). Of 62 ego-alter ties, 54 (87%) were rated as being moderately or more important (a rating  $\geq 5$  on a 10-point scale), of whom 27 (43.5%) were rated as "extremely important (= 10)." Fifty-seven (91.9%) ties interacted for 6 months

**Table 2.** Network Characteristics

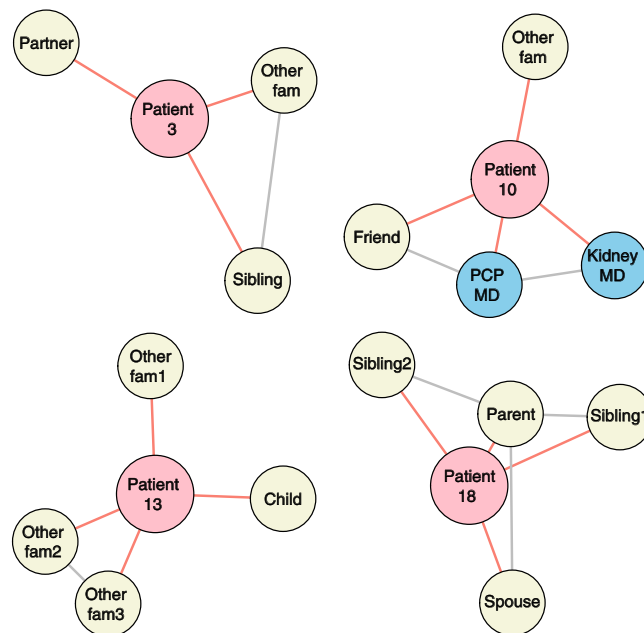
Characteristics	
Network structure	
Network size	4.10 (1.62)
Total no. of ties/connections	5.55 (4.07)
Network density	0.79 (0.18)
Clustering coefficient	0.54 (0.34)
Network composition	
Proportion of alters who are female	0.71 (0.25)
Proportion of alters who are African American	0.86 (0.22)
Proportion of alters aged < 40 y	0.31 (0.25)
Proportion of alters aged ≥ 40 to <60 y	0.49 (0.32)
Proportion of alters aged ≥ 60 y	0.21 (0.24)
Proportion of alters who are family caregivers	0.76 (0.34)
Spouse	0.10 (0.24)
Partners	0.04 (0.11)
Parents	0.05 (0.14)
Siblings	0.08 (0.17)
Children	0.15 (0.21)
Proportion of alters who are health care professionals	0.24 (0.34)
Proportion of alters who are dialysis providers	0.16 (0.26)
Proportion of alters in the same age group as ego	0.23 (0.30)
Proportion of alters of same sex as ego	0.49 (0.36)

Note: N = 20. Values expressed as mean (standard deviation). Network size indicates number of nodes in the network including ego. Network density indicates total number of ties/total number of pairs. For example, if an ego has 2 alters in his or her network, the total number of possible pairs, including the ego, is 3. If one of the pairs is not connected such that the ego knows the 2 alters but the 2 alters are total strangers and thus not connected, network density is 66.7% (2/3). Clustering coefficient indicates number of ties between alters/total number of alter pairs for ego.

or longer; of those, 46 (74.2%) interacted for more than a year.

Network members were mostly women, African Americans, and family members of participants (first-order relatives; eg, parents, spouses, siblings, and children). Three participants' networks included at least 1 friendship tie. The proportion of alters who were health care professionals, including dialysis care providers, was low. Of the 20 networks, 7 included at least 1 health care provider (mostly a nephrologist): an average of 0.2 health care professional ties per ego. Of those, 2 networks included nonphysician dialysis care providers (eg, dietician or registered nurse). Figure 1 shows a few examples of the networks, demonstrating variations in network structure and composition in this sample. All 20 networks are shown in Figure S1.

Network density (the proportion of potential connections among members in a network that are actual connections) was 79% on average (SD = 18%; range, 50%-100%). The clustering coefficient (the degree to which 2 people tend to share the same social connections, or a metric of the overall connection between alters) was 0.54 (SD = 0.34). That is, with a few exceptions, not all members within the network were connected with each other.



**Figure 1.** Examples of patients' egocentric networks. Circles denote nodes and lines denote ties or relationships between the nodes. Beige and blue circles represent family (fam) and professional caregivers, respectively. Red lines indicate relationship initiated from the patient and grey lines indicate relationships between the members as perceived by the patient. Abbreviation: PCP, primary care provider.

### Network Members' Involvement in Self-care and Care Coordination Activities

On average, 47% (SD = 34%, interquartile range [IQR] = 20%-67%) of alters in the network were engaged in organizing and refilling medicines, 51% (SD = 36%, IQR = 20%-80%) assisted with monitoring health (eg, checking blood pressure or blood glucose level), 50% (SD = 38%, IQR = 20%-100%) helped the patient understand medical information, 39% (SD = 39%, IQR = 0%-75%) assisted with tracking fluids and food intakes, and 25% (SD = 37%, IQR = 0%-50%) helped the patient exercise.

For assistance with care coordination tasks of patients, on average, 38% (SD = 36%, IQR = 0%-60%) of network members were involved in scheduling or tracking appointments. Specifically, 29% (SD = 30%, IQR = 0%-50%) assisted with keeping appointments with multiple providers, and 38% (SD = 37%, IQR = 0%-60%) were involved in making specialist appointments for patients. In addition, 48% (SD = 36%, IQR = 20%-100%) and 44% (SD = 38%, IQR = 0%-80%) of network members were involved in taking the patient to medical appointments and communicating with different providers, respectively.

### Relationships Among Participant and Network Characteristics and Treatment Burden

Older participants tended to have a larger network (correlation between age and network size,  $r = 0.41$ ; CI, 0.08-0.68), and those with 2 or more comorbid conditions



were more likely to have health care professionals in their network compared with those with 1 additional comorbid condition (33% vs 9%).

Of participants' sociodemographic and clinical characteristics, only the ego's education (years of formal education completed) was negatively associated with the burden related to medications ( $r = -0.45$ ; CI,  $-0.8$  to  $0.20$ ) and the difficulty performing self-care activities related to exercise or physical therapy ( $r = -0.71$ ; CI,  $-0.92$  to  $-0.18$ ). The number of other chronic conditions was not associated with treatment burden domain scores. Between network characteristics and treatment burden domain scores, network density was positively correlated with the burden related to medications ( $r = 0.54$ ; CI,  $0.16$  to  $0.79$ ) and inversely correlated with financial burden ( $r = -0.46$ ; CI,  $-0.80$  to  $-0.05$ ). Clustering coefficient (the level of network connectivity for the patient) was inversely correlated with the financial difficulties associated with medical expenses ( $r = -0.65$ ; CI,  $-0.88$  to  $-0.34$ ).

## DISCUSSION

In this study, we explored networks for self-management and care coordination among dialysis patients who manage multiple complex chronic conditions, including ESRD, and the association of the network characteristic with their perceived treatment burden in multiple domains. Patients in the study experienced substantial treatment burden, and burden scores were much higher than what have been reported in patient populations with other chronic conditions.<sup>8</sup> In particular, treatment burden related to financial difficulties was one of the top 3 highest domain scores, suggesting that financial distress ("financial toxicity") associated with illness management is not unique to cancer populations.<sup>16,17</sup>

We found that patients in our study have 3 members on average in their networks who play various roles in self-management tasks for the patient, and network size might likely be larger for those with more than 2 comorbid conditions. However, as shown in the network density and clustering coefficient, not all alters in the network were connected with each other (clustering coefficient) and thus the patient (ego) would be responsible for communication among certain network members, such as relaying messages from health care professionals to family members or vice versa. Those networks may lack efficiency in meeting the patient's self-management and care coordination needs without the patient him- or herself functioning as a "quarterback."

This finding is similar to a recent study by Andersson and Monin<sup>18</sup> in which caregiving networks were larger with a higher number of coexisting chronic conditions, but larger caregiving networks could serve to undermine care-recipients' well-being as morbidity increases. The finding that the clustering coefficient was inversely

correlated with financial difficulties suggests the potential impact of network structure on a patient's well-being and other health outcomes. It is possible that well-connected networks may work to pool resources for the patient to ease the financial difficulties, but the role of networks in perceived treatment burden calls for future studies.

Corbin and Strauss,<sup>19</sup> in their seminal work on chronic illness management at home, noted that technological advances in the diagnosis and treatment of chronic illnesses have made the "work" of managing chronic conditions increasingly specialized and complex for patients and informal caregivers. Although many studies have demonstrated the importance of patient activation as one of the components in the management of multiple chronic conditions using the Chronic Care Model,<sup>20</sup> our findings shed a new light on complex chronic illness management in that connectivity and interdependence of the individuals in a group or network, that is, their social context, may play a significant role in chronic illness management.

We found an average of 0.2 health care professional ties per ego, which is lower than what we hoped to observe given the substantial time that patients on in-center hemodialysis therapy spend in a dialysis center (every other day, 4-6 hours each time). Under the current dialysis care model, a nephrologist and dialysis nurse conduct weekly rounds with patients in the dialysis center, and the dietician and social worker assess patients on a monthly basis. In addition, the nephrologist, dialysis nurse, dietician, and social worker meet monthly at an interdisciplinary meeting to review the patient's laboratory test results and clinical care plans. Although there is growing recognition regarding the need to implement a comprehensive multidisciplinary care model (eg, medical homes) in dialysis centers to improve care coordination and quality of life for hemodialysis patients,<sup>21</sup> patients in our sample did not perceive themselves as being assisted by dialysis care providers in self-management and care coordination tasks.

Our study was a pilot study to explore dialysis patients' social networks for self-care and care coordination activities and perceived treatment burden and generate hypotheses regarding the structure and function of those networks. Thus, our study has several limitations. Our sample was small and more racially homogeneous than we desired. The small sample size precluded controlling for potential confounding factors. For example, other than the number of comorbid conditions, we do not know why certain egos were able to include a health care provider in their networks and why some were not. The study sample was recruited from 1 dialysis center in 1 geographical area and also no other dialysis modalities (eg, home dialysis) were included, for which the networks and their function may differ from those of our sample. Our study used the egocentric approach to social network, illustrating partial networks of patients. We do not know whether any tie between the ego and an alter was bidirectional (the alters identify themselves as the ego's network members for

self-care and care coordination activities). However, in an egocentric social network, any alter nominated by the ego is assumed to be a valid tie. Strength of ties between ego-alter pairs was not used in the analysis due to our small sample size but will be important in future work. Our name generator to enumerate 5 members was exploratory in that it did not specifically ask the patient to think about people in each type of relationships (eg, family members vs health care providers). This method of name generator is subject to recall bias.

Future work should involve larger-scale studies identifying network-level determination of treatment burden and potential confounding factors and evaluating network changes over time and their impact on chronic illness management. Findings from such work to articulate mechanisms by which networks have effects<sup>22</sup> could potentially lead to developing interventions on the structure and composition of the networks to improve effectiveness and efficiency in assisting patients' self-care and care coordination activities.

## SUPPLEMENTARY MATERIAL

### Supplementary File (PDF)

**Figure S1:** The patient egocentric networks of all 20 participants.

## ARTICLE INFORMATION

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