

## Together We Can Improve Outcomes in Kidney Failure: Examining Social Networks in Hemodialysis

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**K**idney failure is a life-changing disease with treatments that impose a significant burden not only for the patient, but also for the people who help care for the patient.<sup>1-3</sup> Social network theory defines a group of people

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who help the patient as members of the patient's social support network.<sup>4,5</sup> The members of a dialysis patient's social support network help the patient with multiple medications, dietary restrictions, financial assistance, and travel to medical appointments.<sup>5,6</sup> In their study, Song et al<sup>7</sup> set out to examine how a patient's social support network strength and structure are associated with that patient's perceived treatment burden. What is unique about Song et al is that they examined the role of each support network member and how these network members are interconnected. Previous research mainly studied the relationship between a patient and his or her primary support person<sup>1,3</sup> or patients' satisfaction with their social network.<sup>8</sup>

This research is particularly timely because robust social support networks are necessary for the treatment modalities with the best outcomes: kidney transplantation and home hemodialysis.<sup>9</sup> Transplantation is the best example of the importance of support networks because not only are most living kidney donors members of patients' social support networks, but also many transplantation centers require patients to have a social support network member to be placed on the transplant wait-list.<sup>10</sup> Most home hemodialysis programs require a social support network member as well.<sup>11</sup> Despite the crucial role of social support networks in the treatment of kidney failure, few studies have examined the strength and structure of these social support networks.<sup>10,12,13</sup>

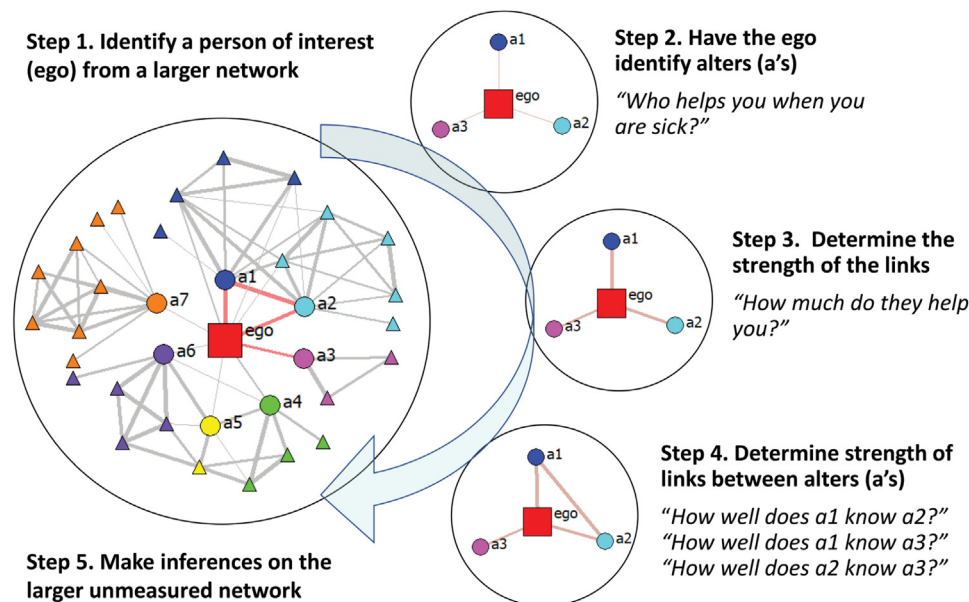
In this issue, Song et al<sup>7</sup> conducted a cross-sectional social network survey of a random sample of 20 in-center hemodialysis patients with high self-care and care coordination needs in a single hemodialysis center in Atlanta, GA, to assess patients' social support networks and perceived treatment burden. This survey, in addition to measuring the Patient Experience With Treatment and Self-management (PETS) questionnaire,<sup>14</sup> also asked patients to list as many as 5 people that "he or she could turn to for actual help or for information to do self-care tasks or activities and coordination of any medical care during the past 6 months."<sup>7</sup> Patient participants were then asked demographic information about the people listed, how often

they saw them, and what types of help they provided. Last, patient participants were asked how frequently these network members communicated with each other about the patient participant.

This is called an egocentric analysis, in which the participant who is surveyed is referred to as the ego and is asked about his or her perceptions of the relationships (referred to as ties) with the members of the networks (alters) and his or her perceptions of the alter-alter ties (Fig 1). The primary advantage of egocentric analysis is that data are collected from only 1 member of the network, compared to sociocentric analysis, in which all members of the network need to be surveyed.<sup>4</sup> Egocentric analysis is especially useful in the medical field when the primary interest is how a patient's outcome is dependent on the ego network and not the outcomes of other members of the network or the structure of the full network. These surveys still can be very time consuming because the number of questions about alter-alter relationships grows exponentially when asking about the number of alters ( $((n)(n-1))/2$ ). For this reason, Song et al limited the list to 5 network members.<sup>15</sup> Thus, this report reduced the patient's social network<sup>15</sup> to the few people who the patient perceived to help the most with medical self-care.

Study participants were 90% black and had dialysis vintages ranging from 10 months to 24 years. Participants named a mean of 3 people in their support networks. The composition or diversity of the patient social networks reflects gender roles and racial integration in the United States. Despite patient participants being 50% female, 71% of the network members were female. This reflects not only how women are the primary caregivers and support persons in our society, but may also explain why women donate kidneys more often than men.<sup>16</sup> Additionally, there was a lack of racial diversity among the networks.<sup>17</sup> In this predominantly black patient population, the social support networks were also predominantly black.

Song et al examined the strength and structure of the network and found that patient networks with higher clustering coefficients had less financial burden. The clustering coefficient is the proportion of alters in the patient's network who are connected to each other. In general, if an ego is strongly connected to an alter, that alter will have relationships with other alters connected to the ego.<sup>18</sup> Networks with high clustering coefficients are composed mostly of strong relationships, which are referred to as



**Figure 1.** Steps in an egocentric analysis. This figure has 4 panels describing the steps of an egocentric analysis. The first panel depicts a hypothetical network from an egocentric perspective. The ego is in the center, depicted by a red square. The ego is surrounded by circles that represent the ego's alters, and for easy reference in the article, they are labeled a1 through a7. Triangles represent the alter's alters, or in lay terms, "friends of friends." Pink lines represent the health support relationships studied by Song et al. Gray lines are the relationships not captured in the study. The thickness of the line is a measure of how strong the relationship is, with thicker lines representing stronger relationships. Song et al does not graphically represent the strength of the ties in their figure; however, they only analyze and represent the alter-alter relationships that can be characterized as strong because of the frequency of contact. The steps in an egocentric analysis are as follows. Step 1 is to identify the person of interest (ego) to survey. Step 2 is to ask the person to identify members of his or her social network (alters). This part of the survey is the list or name generator. Step 3 is the interpreter. The ego is asked about specifics of the relationship with that alter and demographic characteristics of the alter. Step 4 asks the ego to describe the relationship between the alters. In step 5, network data are complete, it can be analyzed, and inferences about the larger unmeasured network can be made. For example, the clustering coefficient for the 3 alters in the medical support network is 0.33, or 33% of the possible connections between alters exist, and when we examine the larger network of the 7 alters and their alters, this clustering coefficient is 0.27. It should be noted that this figure is constrained to 2 degrees of separation (2 links away from the ego) and that this network can be expanded outward. Furthermore, the average human social network is between 150 and 250 people. It is difficult to collect data for all these members with a survey and to graphically represent them. It has been repeatedly shown that despite the large number of network members, we usually interact with 5 to 10 on a regular basis.<sup>15</sup> This figure was created using Netdraw.<sup>22</sup>

strong ties. The clustering coefficient for the network ego, a1, a2, and a3 is 0.33 because only 33% of the connections between a1, a2, and a3 are present. Alters a1 and a2 in Figure 1 would be considered strong ties because they are connected to each other.

Financial burden may be decreased in highly clustered networks because there is more than one alter and these strongly tied alters pool their resources. Previous research has shown that highly clustered networks tend to have similar knowledge and reinforce attitudes and behaviors,<sup>18,19</sup> and patients who form highly clustered networks with other patients within the hemodialysis clinic complete more steps toward transplantation.<sup>13</sup>

Having network members who are not strongly clustered within the network may be important as well. These people, who are weak ties, tend to be connected to other social networks (alters a3 and a7 in Fig 1) and have novel information that the clustered members do not

have.<sup>12,17,18</sup> One study found that hemodialysis patients who had a network member who was outside of their strong family network were more likely to have accurate information about transplantation.<sup>12</sup>

The results of Song et al must be interpreted within the context of its limitations. This was a single-center study and surveyed only 20 patients. Although the random sample improves the ability to make inferences, the ability to generalize is limited. The major limitation of this study is that they limited the social network list generator to 1 question. Furthermore, the list generator question assessed multiple forms of support at once, which may have affected the results. Future research, for example, could ask patients to list the 5 people they rely on the most for advice, then list the 5 people who help with medical devices, and then 5 who help coordinate care. There will be overlap among these groups, and they can then ask about the people who only appear on all 3 lists or the top 2 from

each list without exponentially increasing the number of questions.<sup>4</sup>

We must interpret cautiously the results that only 35% of respondents had health care providers as part of their support network. Many patients may have perceived the medical advice, coordination of care, and arranging of transportation as part of the health care providers' job description and not identified them as a support network member. Nonetheless, Song et al found that patients with multiple comorbid conditions tended to have a health care provider as part of their network and older patients had more members of their support network. Intuitively this makes sense: when I am on dialysis rounds, I feel like I spend a lot more time coordinating care with my older comorbid patients and their caregivers than with my young and otherwise "healthy" patients. If researchers are interested in the role of health care providers in patients' support network, they can ask the patients to list the 3 to 5 health care providers they rely on and then ask about the providers' interactions with other members of the support network. How clustered the health care member is within the patient's support network may affect outcomes. For example, if the support network members never talk to the physician, the patient would be the sole conduit for information and may not always correctly relay the information.

Despite these limitations, Song et al provide an important and focused look into the structure of patients' closest self-care support networks, and the implications and methods of this study are generalizable to multiple domains of nephrology. There are still many areas to explore in the social networks of patients with end-stage renal disease (ESRD), including social networks within the hemodialysis clinics, because the staff and other patients have been shown to provide support.<sup>2,12,13</sup> Additionally, very little is known about the role of online social networks and social media.<sup>20</sup> A better understanding of patients' social networks is applicable to transplantation, home modalities, adherence, end-of-life care, and even detangling environmental versus inherited causes of kidney diseases.<sup>1,4</sup> Furthermore, this tool can help identify people at risk for poor outcomes from social isolation and for whom network-building interventions can be implemented.<sup>8,21</sup>

Based on the existing knowledge, it is reasonable to suggest that a social network survey be incorporated as part of the annual assessment of patients with ESRD. Even 40 years ago<sup>1</sup> it was apparent that treating the patient alone was not enough to improve outcomes in ESRD. Today, the analytic tools exist to research the role of social networks on health outcomes in nephrology, and the work of Song et al represents an important first step.

## ARTICLE INFORMATION

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