

The Impact of Care Partners on the Mobility of Older Adults Receiving Hemodialysis



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Rationale & Objective: Many older adults receiving hemodialysis have mobility limitations and rely on care partners, yet data are sparse regarding the support provided by care partners. Our aim was to examine how care partners support the mobility of an older adult receiving hemodialysis.

Study Design: Qualitative study.

Setting & Participants: Using purposive sampling, we recruited persons aged 60 years or more receiving maintenance hemodialysis and care partners aged 18 years or more who were providing support to an older adult receiving hemodialysis. We conducted in-person semi-structured interviews about mobility with each individual.

Analytical Approach: We conducted descriptive and focused coding of interview transcripts and employed thematic analysis. Our outcome was to describe perceived mobility supports provided by care partners using qualitative themes.

Results: We enrolled 31 older adults receiving hemodialysis (42% women, 68% Black) with a mean age of 73 ± 8 years and a mean dialysis

duration of 4.6 ± 3.5 years. Of these, 87% of patients used assistive devices and 90% had care partners. We enrolled 12 care partners (75% women, 33% Black) with a mean age of 54 ± 16 years. From our patient and care partner interviews, we found three themes: (1) what care partners see, (2) what care partners do, and (3) what care partners feel. Regarding what they see, care partners witness a decline in patient mobility. Regarding what they do, care partners guide and facilitate activities and manage others who also assist. Regarding what they feel, care partners respect the patient's autonomy but experience frustration and worry about the patient's future mobility.

Limitations: Modest sample size; single geographic area.

Conclusions: In older adults receiving hemodialysis, care partners observe a decline in mobility and provide support for mobility. They respect the patient's autonomy but worry about future mobility losses. Future research should incorporate care partners in interventions that address mobility in older adults receiving hemodialysis.

Complete author and article information provided before references.

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Mobility is the ability to move from one place to another safely and reliably,¹ and conceptually includes tasks such as ambulation, self-care, and attending social activities. Mobility is fundamental to a sense of independence and self-worth.² Yet, 57% of older adults receiving hemodialysis have limitations in mobility,³ and thus require assistance in some way for tasks involving mobility.

Prior studies have documented that care partners often provide hands-on assistance with self-care activities, such as bathing.⁴ But other than direct care, we lack information about the additional ways by which care partners may support the mobility of an older adult receiving hemodialysis. As greater social support is associated with better long-term outcomes for persons receiving hemodialysis, including lower mortality,⁵⁻⁷ we suspect that care partners provide support that is more sophisticated and multifaceted than previously recognized.

To appropriately address mobility limitations in older adults receiving hemodialysis, we need an in-depth understanding of how care partners support mobility. This knowledge will ensure that efforts to improve mobility for older adults receiving hemodialysis are comprehensive and person-centered. Our aim for this study was to qualitatively investigate how care partners support the mobility of

an older adult receiving hemodialysis, using the experiences of patients and care partners.

METHODS

Study Sample

We used purposive sampling to recruit both 1) older adults receiving hemodialysis (patients) and 2) the care partners of an older adult receiving hemodialysis. We recruited both patients and care partners because we wished to have the full context of how mobility support is provided by care partners. Fig 1 details the flow of participants into the study. Between May 2019 and March 2020, we used referrals from primary care physicians and nephrologists in a single urban area to identify older adults who were English-speaking, receiving in-center hemodialysis, and aged 60 years or more. Nursing home residents and persons who are unable to give informed consent were excluded. Referring clinicians were not required to notify potential participants about the referral. Eighty older adults receiving hemodialysis were contacted. They received introductory letters regarding the study with an opt-out option, which were mailed or distributed in person at the dialysis facility. We then contacted potential participants via telephone or approached them in person at the dialysis facility to gauge interest.

PLAIN-LANGUAGE SUMMARY

Many older adults receiving hemodialysis have trouble walking, and they often rely on care partners to support their mobility. However, we know very little about how care partners specifically provide help. We talked to 31 older patients receiving hemodialysis and 12 of their care partners to find out how care partners assist patients with mobility. We found that care partners observe a decline in patient mobility, manage and facilitate mobility tasks, and feel frustrated and often worry about the patient's future mobility. As they are a crucial support for the mobility of patients, care partners should be incorporated into any future therapies targeting the mobility of older adults receiving hemodialysis.

From May 2019 to March 2020, we used referrals from either patient participants or from clinicians to identify 26 potential care partner participants. Inclusion criteria for care partners were age 18 or older, English-speaking, and regularly supporting an older adult receiving hemodialysis with assistance for personal needs, household chores, finances, or other needs.⁸ Both informal (unpaid) and formal (paid) care partners were eligible. Of note, eligibility did not require that the patient supported by the care partner also be enrolled. Subsequently, an opt-out letter was mailed or given directly to the care partner, which was followed up with a telephone call or an in-person visit at the dialysis center to determine interest.

Because of the coronavirus disease 2020 pandemic, recruitment was curtailed in March 2020. Although we considered continuing telephonic contact, we lacked institutional review board approval for telephonic informed consent and equipment to record telephonic interviews.

Participants received a \$50 incentive. We performed the study in adherence to the Declaration of Helsinki and with approvals from the institutional review boards at Boston University (H-38465) and Stanford University (IRB-58910). All participants provided written informed consent. We followed the Consolidated Criteria for Reporting Qualitative Research guidelines (Item S1).⁹

Study Setting and Assessment

For both the patient and care partner participants, a single in-person assessment was conducted, usually in the participant's home, unless otherwise requested. If the assessment occurred outside the home, it was typically performed in a private meeting space available to the researchers.

Comorbid Conditions and Care Partner Characteristics

Participants were queried on specific conditions using both medical and colloquial terms when appropriate (eg, hypertension and high blood pressure). For arthritis, both

degenerative and autoimmune forms were included in this category. We assessed vision problems, hearing problems, and the use of assistive devices by self-report or evidence of appropriate devices (eg, wearing glasses and/or hearing aid and/or wheelchair use). Height and weight were directly measured. Patient participants were queried about their dialysis history and the presence of a care partner.⁸ Care partner participants self-reported the type of relationship they had (e.g., family, friend) with the older adult receiving hemodialysis.

Modified Caregiver Strain Index

To characterize care partner burden, we administered the Modified Caregiver Strain Index (MCSI) to the care partner participants. The MCSI comprises 13 statements regarding the perceived frequency of common caregiving challenges, such as disturbed sleep and financial strain.¹⁰ Respondents denoted the frequency of difficulties on a regular basis, sometimes, or not at all. The MCSI is scored from 0 to 26, with higher scores representing greater caregiving burden.¹⁰ The MCSI has been widely used in caregiving studies of older adults.¹¹

Participant Interviews

From June 2019 to March 2020, we conducted semi-structured interviews with 31 patients and 12 care partners. The interviews lasted between 60 and 90 minutes. CKL or JS conducted the interviews; typically one or two other study members were present for technical assistance or training purposes. The study purpose and professional background of each investigator were shared at the beginning of the interview. Unless requested otherwise, the participants were interviewed

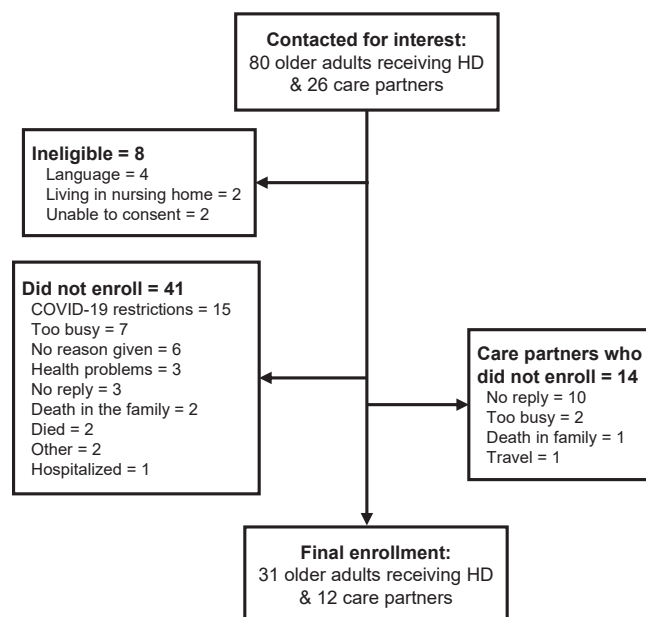


Figure 1. Participant flow diagram. Abbreviation: HD, hemodialysis.

Table 1. Characteristics of Study Sample

Characteristic	Older Adults Receiving Hemodialysis (N=31)	Care Partners (N=12)
Male	18 (58%)	3 (25%)
Age (years)	72.5 ± 8.1	53.8 ± 15.7
Race		
White	8 (26%)	6 (50%)
Black	21 (68%)	4 (33%)
Asian	2 (6%)	2 (17%)
Education		
Completed high school or less	16 (52%)	1 (8%)
Some college education or higher	15 (48%)	11 (92%)
Comorbidities		
Hypertension	27 (87%)	3 (25%)
Diabetes	20 (65%)	1 (8%)
Myocardial infarction	15 (48%)	1 (8%)
Stroke	8 (26%)	0
Smoker	6 (19%)	0
Arthritis	13 (42%)	3 (25%)
Depression	12 (39%)	2 (17%)
Hearing problems	8 (26%)	0
Vision problems	25 (81%)	10 (83%)
Years on dialysis	4.6 ± 3.5	N/A
Uses assistive device	27	0
Cane	9	0
Walker	14	0
Wheelchair	4	0
Care partner specific characteristics		
Relationship to older adult receiving hemodialysis		
Spouse/domestic partner	N/A	2 (17%)
Adult child	N/A	4 (33%)
Sibling	N/A	1 (8%)
Other relative	N/A	4 (33%)
Professional (e.g., case manager, social worker)	N/A	1 (8%)
Hours per week spent in caregiving	N/A	14.5 (7.0, 46.5)
Employed	N/A	8 (67%)
Modified Caregiver Strain Index score	N/A	9.1 ± 3.8

Note: Data reported as N (%), mean ± standard deviation, or median (25th, 75th percentile).
Abbreviation: N/A, not applicable.

alone. We used an interview guide that we developed on the basis of the literature (Item S2). During the interviews, we asked additional questions on the basis of the responses to the interview guide prompts. Within 24 hours, field notes were recorded, including whether the interview guide questions required revision. Ultimately, no revisions to the interview guide were needed. The interviews were audiotaped and professionally transcribed. Transcripts were deidentified using alphanumeric labels.

Analytical Approach

Quantitative

Descriptive analyses of the demographic and clinical characteristics of the sample, including the MCSI, were performed and reported to characterize the sample and establish a context for the qualitative analyses.

Qualitative

Consistent with the concept of reflexivity,¹² we acknowledge the influence of researcher training and standpoint on the analysis. Analysis was performed by five investigators; their backgrounds and roles included geriatric medicine (CKL, principal investigator), medical sciences (DL, project manager; KW, research assistant), and research administration (JS, project manager). Of the five investigators, three have advanced degrees (CKL, DL, and KW) and two have previously conducted qualitative research (CKL and JS). Three investigators (CKL, DL, and JS) had collaborated previously. As such, the data analytic approach was informed with a focus on clinical geriatrics and medical science, with a pragmatic interest in improving the well-being of older patients and their care partners.

We employed thematic analysis for data analysis because this approach has flexibility and accommodates unanticipated

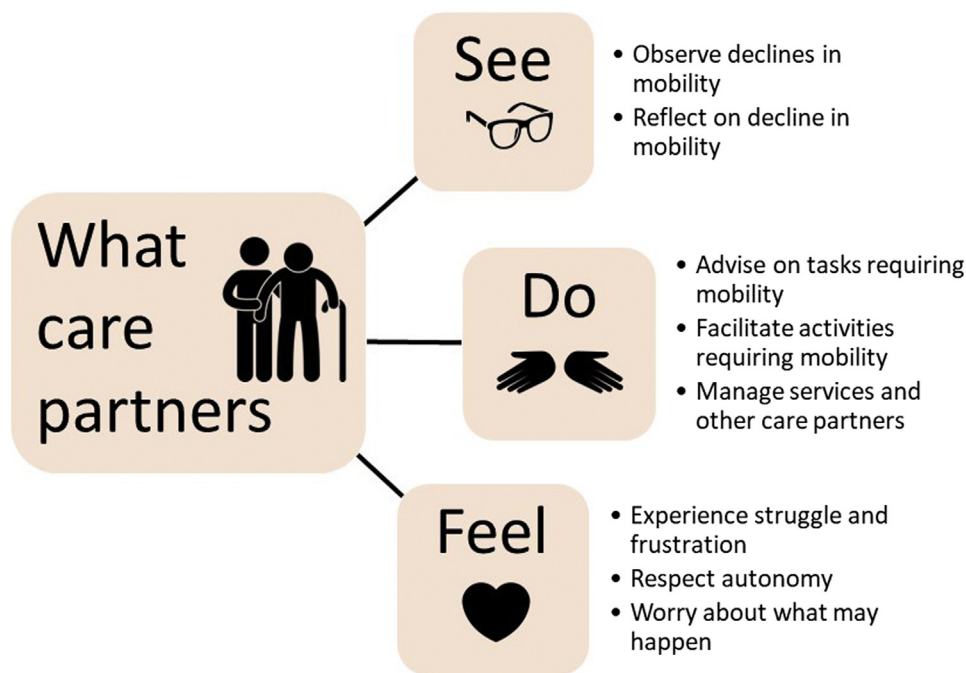


Figure 2. Themes and subthemes regarding the impact of care partners on the mobility of an older adult receiving hemodialysis.

insights.¹³ After the initial review (eg, familiarization), three investigators (CKL, DL, and KW) used descriptive and focused coding to categorize individual sentences into specific codes.¹⁴ We commenced coding with the first interview and continuously thereafter. We first employed a deductive approach using the interview guide to formulate the initial codes, followed by inductive analysis for codes that were not related to an explicit interview guide topic. Coding discrepancies were resolved with iterative deliberation until consensus was reached. We refined the codebook weekly and evaluated interrater reliability with 11 of the patient transcripts and three of the care partner transcripts. Data saturation was reached when no new codes emerged and the codebook was finalized (Item S3).^{15,16} We used the same codebook for both the patient and care partner transcripts, which were coded together.

Investigators CKL, DL, and JS then reviewed all the codes pertaining to care partners for major themes. Discrepancies regarding themes were resolved with iterative deliberation until consensus was reached. Three exemplar quotes were selected to illustrate each subtheme; whenever feasible, quotes from both patient and care partner participants were included to showcase diversity in experiences. We established trustworthiness using triangulation with the participation of multiple investigators during analysis, reflexivity as related to investigator biases, and maintenance of an audit trail.¹⁷⁻¹⁹ When needed, we solicited input from JM regarding our procedures for coding and thematic analysis. NVivo 11 (QSR International, Inc) facilitated analysis. Transcripts and coded data were not returned to the participants for comment.

RESULTS

Characteristics of Study Sample

Characteristics of the 31 older adults receiving hemodialysis and 12 care partners are presented in Table 1. Among the patient participants, 58% were men and 68% were Black with a mean age of 72 years. Furthermore, about half (48%) had attended college, most had hypertension (87%), and the majority (65%) had diabetes. On average, patient participants had been receiving dialysis for 4.6 years, and the majority (87%) required an assistive device for mobility. Most (90%) patient participants reported having a care partner.

Among care partner participants, 75% were women, 33% were Black, and they had a mean age of 53 years. The majority (92%) had a college education, 25% had hypertension, and 8% had diabetes. Eleven of the care partner participants were related to the older adult receiving hemodialysis. Most (67%) were employed, and on average, they spent 43.7 hours per week on caregiving responsibilities. The mean MCSI score was 9.1 points. Recorded MCSI scores ranged from 0 to 15 points.

Themes Regarding the Impact of Care Partners on the Mobility of an Older Adult Receiving Hemodialysis

From our interviews with the patient and care partner participants, three major themes emerged: (1) what care partners *see*, (2) what care partners *do*, and (3) what care partners *feel*. Each theme had related subthemes, illustrated

Table 2. Themes, Subthemes, and Exemplar Quotes Regarding Impact of Care Partners on the Mobility of an Older Adult Receiving Hemodialysis

Subtheme	Participant Quotations
Theme 1: What care partners see	
Observe declines in mobility	<p>Before we could walk, and we could walk and talk at the same time at a fair clip. I'm generally a fast walker, but I would slow down for her, and we could walk as I did in the past year, and it wouldn't be a problem. We can't do that now. She's a lot slower. She gets tired easily. -Care partner participant 11</p> <p>To a point where, even walking—he lives...very close to [supermarket name]. Walking from his apartment to [supermarket name], having seeing him stop 6 times, gasping for air. Seeing his legs turn to like, literally, noodles, like they would just wither from under him and he'd have to sit down and sort of catch his breath, those types of things. It felt like it was fairly drastic...it almost seems like a roller coaster ride. There's some days where I feel like he's running down the hallway, and then there's other days where he just seems like he's so frail and so weak. We talked a little bit about—that's sort of the progression that I've seen over those last—especially, after he started dialysis, he was just seeing his leg get very weak from under him. -Care partner participant 12</p> <p>That's when I knew that we had to step in. She couldn't walk good. She wasn't taking care of the house because she was in pain. She was very weak all the time, which is not like my grandmother. She wasn't doing all the normal things that she would do, especially the cleaning. My grandmother's a very clean person. The bathroom was a mess. She wasn't cooking for herself. That's how I knew, okay, something's really wrong. It was gradual. it took her a while for her body to adjust to the dialysis.... I feel like it was almost half a year. Even she would complain about it, "When is this going to end? When is the vomiting going to end? The weakness." -Care partner participant 1</p>
Reflect on decline in mobility	<p>Should I not help her as much as I do? It's hard. I know. 'Cause I'll say, "What do you need? I'll get it." I'll get up and get her insulin. I'll get her a cup of tea. Because it's so hard for her to get up and stand, it's just painful for her. I want to help her, but I don't know if I'm hurting her by doing her walking for her. -Care partner participant 7</p> <p>I never know how he's feeling ...I'm always saying to him, "What's wrong? What's wrong?" I don't know. I just don't know how bad it is. -Care partner participant 9</p> <p>She'll go so far but she won't do everything for me because she knows that I need to do certain parts of it myself. She will go so far, you know? -Patient participant 16</p>
Theme 2: What care partners do	
Advise on tasks requiring mobility	<p>If somebody's asking me...asking me to come over there and take her to go shopping, and it's a bad day and I'm getting ready to get up and go struggle to do it, she [care partner] turns around and tells me, "[Patient participant name], she can go another day. You're not in the best of shape. Just rest today," or, "If I got some time, I'll take her." You know what I mean? She helps me out in those ways. -Patient participant 16</p> <p>I asked her last night if she wanted to get a chair lift that she'd sit in and slide up. She said, "No." Again, she's just—which, I think it's good to some degree because I think it will force her to walk. -Care partner participant 7</p> <p>She'll be trying to pick up a 20 pound bag of rice and she'll be struggling with it. I'll go and grab the rice and pick it up for her. I keep telling her all the time, "Nana, if you need help, just say so. I don't expect you to pick up 40 pounds of rice. That's ridiculous." -Care partner participant 1</p>
Facilitate activities requiring mobility	<p>Behind the porch, we have land so we can do the garden. In summer we do a garden. We don't have time, but we try to do it so please her. Make her happy. After breakfast, if it's summer, I have her go outside to the porch, so she walk back and forth....Sunday we go to the church, keep her busy. She's so happy on Sunday. Sunday we all go to the have breakfast, the whole family, at 7:00, and we go to the church at 8:30. After the church, church is an hour, so it'll be 9:30, 10:00. We take her back home for lunch. After that we take her to the market. We get our food or- We go to the [supermarket]. That's bigger, so I can put her in the wheelchair, go around. She loves it. -Care partner participant 4</p> <p>We tried taking in turns to take him for a walk. He doesn't want to leave the apartment. -Care partner participant 8</p> <p>Well, my son will bring me the ingredients, and I'll put 'em together. -Patient participant 2</p>

(Continued)

Table 2 (Cont'd). Themes, Subthemes, and Exemplar Quotes Regarding Impact of Care Partners on the Mobility of an Older Adult Receiving Hemodialysis

Subtheme	Participant Quotations
Manage services and other care partners	<p>My wish, if I can have the patience—because they ask you thousands of requests—because I wish I can have—how do you call it?—the place where my mother can go with wheelchair. Ramp. A ramp, because there is a time—because I would love my mother to stay with me forever, but there is a time, I know, and when she is sick, she cannot—hard for her to take the stairs, but if I have a ramp in the house, it would be so easy for her to walk by, even to—because the ramp is going to be hers, basically. It will be more easy go back and forth on the ramp, either to sit to see what she's doing right now. This is one of the thing I will do, but then I start to process, the extra thousands of people, and I always give up. I feel like it is just too much on me. -Care partner participant 2</p> <p>When we see him do any form of physical therapy, we see him get strength back. Then, once he gets back home, he falls off that regimen of physical therapy, and it goes right back down again. So, that's hard. We try to keep him in some form of physical therapy. I've been talking with [name of dialysis facility], just to see if they could get them into some sort of consistent outpatient physical therapy. We're working on that piece of it. -Care partner participant 12</p> <p>He [my son] took me to [supermarket name] or something like that. And the only way that happened, my daughter had to put her 2 cents in too with it. "You better do it or else." -Patient participant 8</p>
Theme 3: What care partners feel	
Experience struggle and frustration	<p>I have to request for vacation from him... I have to be strong. Otherwise, he will be in bed all the time. -Care partner participant 6</p> <p>There's some days where I noticed, if I don't get the sleep or if I don't wake up earlier enough and everything throughout the given day just keeps happening, that I do at times feel overwhelmed. -Care partner participant 5</p> <p>I would keep bothering her, asking her, "What do I do now? What do I do now?" She would keep saying to me, "I'm not a doctor and stop bothering me. I don't want to hear about it." ...I can understand how she was, but she was going out of her mind. She kept saying, "I'm going to leave you, I'm going to leave you," and that sort of thing. -Patient participant 25</p>
Respect autonomy	<p>She was completely, completely, completely dependent, completely. I couldn't imagine what that feels like, going from doing everything by yourself to not even being able to put your own clothes on. -Care partner participant 1</p> <p>Because there's maybe some things I'd want to insist on, but because she's my mother, sometimes it makes it a little harder to, I guess, do what I feel is right at that given moment of time. Sometimes, there is that conflict, and then there's the times where I don't want to push too hard because I'm her son. -Care partner participant 5</p> <p>He'll tell you what you want to hear, but then the reality is—but that's not the reality. How far do you push to get him to do the things that he needs to do? It's hard. It's really hard, but still respect him. -Care partner participant 10</p>
Worry about what may happen	<p>Every day, I never know what's going to happen...when he goes to bed at night, he has a hard time getting in and getting out of the bed. He groans, and I don't know how bad it is because of the groan because he groans a lot because of getting up and sitting down...I never know how he's feeling, and it's frightening to me when I hear him. I'm always saying to him, "What's wrong? What's wrong?" I don't know. ... it's very upsetting. I just don't know how bad it is. I'm going to take care of him the best I can. -Care partner participant 9</p> <p>She's petrified of falling. The wet leaves, she called me yesterday and said, "How cold is it out? Is it icy? Do you think I can go to the gym?" I said, "Oh, God. I'm going to answer that one, and if I'm wrong, and she slips....I don't lock the door when I leave in case there needs to be a wellness check." -Care partner participant 7</p> <p>She always have her ears open and before I know, she was down here, grandma, what's the matter, what's the matter, you fell? And, she picked me up, took me to the bed and everything, but everything was okay after. -Patient participant 2</p>

Note: Quotes have been edited for clarity.

in Fig 2. We listed the exemplar quotes highlighting these themes and subthemes in Table 2.

Theme 1: What Care Partners See

Multiple care partner participants recounted watching the mobility change in the older adult receiving hemodialysis. A subtheme was that care partners observed a decline in mobility over time. For example, one care partner noted that the patient's walking had become progressively slower. Two care partners saw weakness and fatigue develop, making it difficult for the patients to accomplish previously routine tasks. Both care partners observed how these changes occurred after hemodialysis initiation.

These observations prompted care partner participants to reflect on the implications of these changes, which emerged as the second subtheme. At times, this reflection motivated specific actions by the care partner. For example, a care partner described how she constantly inquired about the needs of the patient to ensure that she provided enough assistance. Another care partner worried about how assistance might actually be harmful rather than helpful. A patient participant stated that he suspected that his care partner indirectly encouraged mobility by choosing to only assist with certain tasks.

Theme 2: What Care Partners Do

A second theme was what care partner participants did to assist the mobility of the patients, as shown by the exemplar quotes in Table 2. One subtheme was how care partners advised on tasks requiring mobility, whether solicited or unsolicited. Notably, a care partner anguished over giving incorrect guidance and causing potential harm. A patient participant recognized that his care partner would advocate on his behalf when certain tasks were beyond his capabilities.

Another subtheme was that care partner participants facilitated opportunities to maintain mobility. A care partner described how their family maintained a garden to encourage the patient to walk. They also took the patient on outings to church and the grocery store. Another care partner described how she and other care partners worked together to encourage the patient to walk more. A patient participant who enjoyed cooking but had difficulty with ambulation described how her care partner brought ingredients to her so she could still cook.

A third subtheme that emerged was that care partners managed other people and services that assisted with mobility, including other care partners. For example, one care partner spoke about lobbying for a handicap ramp and another cited advocating for physical therapy. One patient participant recounted that her adult daughter/care partner admonished the other siblings into taking her grocery shopping.

Theme 3: What Care Partners Feel

The loss of mobility caused emotional distress for both patient and care partner participants. Notably, several patient and care partner participants became tearful when

describing their experiences. One subtheme that emerged was the frustration of care partners with caregiving responsibilities. As described in Table 2, one care partner felt that she needed to request respite from the patient and felt that the patient's mobility relied entirely on their shoulders. Another care partner described feeling overwhelmed, especially when the care partner was inadequately rested. A patient participant recounted how his constant queries for assistance and advice caused his care partner to voice discontent with their relationship.

The second subtheme was that care partner participants respected the autonomy of the older adult receiving hemodialysis. Recognizing that mobility represents independence, care partners sympathized with the emotional devastation caused by losses in mobility. Being a relative, especially a child, reinforced the importance to care partners of maintaining respect for the patients' autonomy. Care partners described how different perceptions of the mobility losses by the care partner and patient complicated their efforts to respect autonomy. One care partner described how the patient would verbally agree to a precaution but then not comply. Care partners experienced a tension between the desire to respect autonomy and the support they provided for mobility.

The final subtheme was that care partner participants worried about safety. Care partners expressed fears of injury when the patient undertook a task requiring mobility, such as getting into bed. Care partners were concerned about leaving the patient alone for any period of time. One care partner did not lock the front door should emergency personnel need to enter. As such, a patient participant described how her care partner was always vigilant and responsive to her needs.

DISCUSSION

In this study investigating how care partners support the mobility of an older adult receiving hemodialysis using qualitative input from patients and care partners, we found three major themes: what care partners *see*, what care partners *do*, and what care partners *feel*. Regarding what care partners *see*, we found the following subthemes: care partners (1) observed a decline in mobility in the older adult receiving hemodialysis, and (2) reflected on the downstream implications of the losses in mobility. For the theme of what care partners *do*, we found the following subthemes: care partners advised the patient about mobility limitations, facilitated activities requiring mobility, and managed other care partners and services involved with mobility. Finally, for the theme of what care partners *feel*, we found subthemes that care partners experienced struggles and frustration. Although they prioritized and respected the autonomy of the older adult receiving hemodialysis, care partners constantly worried about the future of the older adult receiving hemodialysis.

The care partners in our sample were predominantly women and typically family members. This is consistent with prior studies of care partners, including a study by Belasco et al²⁰ in which the investigators focused on care partners of older adults receiving hemodialysis, as well as a systematic review by Gilbertson et al²¹ of 61 studies of care partners of adults of all ages receiving dialysis. In terms of our qualitative results, our findings complement prior work. A systematic review of seven studies by Van Hoang et al found that care partners often struggled with their responsibilities and feared for the future,⁴ similar to our results that care partners experienced frustration and worried about future declines in mobility. Beanlands et al²² studied 37 care partners of adults receiving dialysis and described how care partners continually appraised the activities of the patients, coached them in these activities, and advocated in medical settings on their behalf. These results align with our finding that care partners advised and facilitated activities requiring mobility. While these prior studies examined the broad range of responsibilities borne by care partners, our study focused specifically on the responsibilities linked to mobility issues. Although the limited mobility of older adults receiving hemodialysis has been previously documented,²³⁻²⁶ to our knowledge, the impact of this limited mobility on care partner responsibilities has not been previously explored.

As future studies examine ways to improve the mobility of older adults receiving hemodialysis, our results highlight the need to include care partners in these endeavors, including studies developing interventions to improve mobility. Potentially, care partners could be integrated in three ways. First, care partners could be incorporated into the mobility assessments. In other fields, such as dementia research, care partner observations are used in assessment tools.²⁷ Second, care partners could assist in intervention delivery. In a study of stroke survivors, a care partner-supervised physical activity program improved the mobility of the stroke survivors.²⁸ Finally, care partners could participate in the intervention alongside the patient. This last approach would likely benefit both the older adult receiving hemodialysis and the care partner. A systemic review of six physical activity interventions for patient-care partner dyads found that these interventions improved the psychosocial health of the care partner.²⁹

Our study found that care partners advise and manage the mobility limitations of older adults receiving hemodialysis. In essence, they coordinate the care needed to address mobility limitations. This may in part explain the results of the Dialysis Outcomes and Practice Patterns Study, which found less social support was associated with more limitations in mobility.³⁰ This finding aligns with broader data on all care partners; the 2020 US National Caregiver Alliance report found that 56% of care partners included advocacy with providers and outside services/agencies as a responsibility.⁸ Yet, care partners of persons receiving hemodialysis report they feel their role is often overlooked in the clinical care plan.³¹

Notably, others have shown that less social support is also associated with worse mortality among dialysis-dependent adults.^{6,7} To address this disconnect, employing models of kidney care that incentivize care coordination, such as those within the Kidney Care Choices model,³² may be one potential solution. As we and others have shown, care partners already do the work of managing the care required; thus, these models could provide additional means to support care partners and the crucial care they provide.

Finally, although our sample size of care partners was limited, our finding that care partners spent an average of 43 hours a week in caregiving responsibilities merits comment. Although Belasco et al²⁰ found a greater commitment of 70 hours a week in Brazilian care partners, the amount of 43 hours weekly remains sobering and is the equivalent of full-time employment in the United States. Moreover, in the care partner sample, we found a mean Modified Caregiver Strain Index score of 9, which signifies moderate care burden, consistent with other studies.^{20,33-35} Given this evidence, it is not surprising that a systemic review reported that up to 55% of care partners for persons receiving dialysis have symptoms of depression.²¹ Our study adds to the evidence that care partners provide an immense amount of care and support to patients receiving hemodialysis, which may be detrimental to their own health. Given the significant time commitment, we suspect that there are likely negative impacts on the other responsibilities of care partners. For example, a survey of U.S. care partners found that 61% of care partners reported altering their work schedules to accommodate caregiving responsibilities; 10% of care partners have given up working entirely.⁸

Our study had several limitations. Because the coronavirus disease pandemic affected recruitment, our sample size was modest. We also did not mandate participation of both the patient and their care partner. Although a focus on only patient-care partner dyads may have generated additional insights, we chose a priori against this approach to ensure a broad range of care partner experiences. For example, two of the care partner participants in the study supported non-English-speaking patients. As English fluency was part of the eligibility criteria for both patients and care partners, if we had mandated dyad participation, these care partners would have not been enrolled. Finally, the majority of care partner participants were white, which differed from the patient sample. We acknowledge that this resulting bias, coupled with the recruitment of individuals from a single geographic area, may limit the transferability of our findings.

Our study had several strengths. Our focus was on care partners of older adults receiving hemodialysis. Most prior studies have not exclusively focused on older patients per se, despite evidence demonstrating that older adults make up the majority of persons receiving hemodialysis in the United States.³⁶ By using qualitative methodology, we captured nuanced information about care partners and their experiences and incorporated their words directly

into our results. This aligns with the nephrology community's priority of incorporating the input of patients and care partners into research efforts.^{37,38}

In our study exploring how care partners address mobility limitations in older adults receiving hemodialysis, we found three major themes: what care partners *see*, what care partners *do*, and what care partners *feel*. Overall, care partners observed a mobility decline in the older adult receiving hemodialysis. Although care partners did their best to assist with these mobility changes, they found such responsibilities emotionally difficult. In the United States, a recent emphasis on new models of care delivery for those receiving dialysis may be an opportunity to develop interventions to support care partners and the vital role they play in the care of older adults receiving hemodialysis.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Item S1: COREQ checklist.

Item S2: Interview guides for patient and care partner participants.

Item S3: Codebook.

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