



# Dementia Care Among United States Dialysis Providers: A Mixed Methods Study Evaluating Clinician Comfort and Knowledge

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**Rationale & Objective:** Given the high burden of dementia in dialysis patients, the dialysis workforce needs to be prepared to provide high-quality, person-centered dementia care. We explored comfort with and knowledge of dementia among US dialysis care providers.

**Study Design:** Web-based survey.

**Setting & Participants:** Emails were sent to National Kidney Foundation and National Association of Nephrology Technicians/Technologists membership listservs (September 26, 2022–October 22, 2022). In total, 1,121 respondents had complete data for analysis (57%, 35–49 years; 62% female; 62%/22% White/African American) including 81 physicians, 61 advanced practice providers, 230 nurse managers, 260 nurses, 202 social workers, 195 dietitians, and 86 dialysis patient care technicians.

**Exposures:** Provider role, age, tenure, self-reported gender, previous dementia training, and awareness of dementia guidance.

**Outcomes:** Dementia Knowledge (assessed using Dementia Knowledge Assessment Scale [DKAS; score range, 0–25]).

**Analytic Approach:** Characteristics of respondents, comfort with dementia care, and dementia knowledge were summarized and tabulated overall and by role. Robust regression was used to obtain coefficients confidence intervals for the associations between

characteristics and DKAS scores, adjusting for role and tenure. Free-text responses to an open-ended question about treating patients with dementia or cognitive impairment were analyzed using thematic analysis.

**Results:** Dementia knowledge among US dialysis providers may be limited (overall DKAS score = 17; range, 13–21 across roles), despite most reporting knowing when patients had dementia (97%) and receiving training in dementia care (62%). Further, training may be inadequate: those who reported receiving dementia training had lower DKAS scores than those who reported not receiving training ( $\beta$ ,  $-3.9$ ; 95% CI,  $-4.4$  to  $-3.4$ ). Thematic analysis of open-ended responses suggested that the impact of dementia on dialysis care and management and treatment beyond dialysis care are challenging for providers.

**Limitations:** Data were self-reported and limited information was gathered about quality, content, and timing of dementia training received.

**Conclusion:** Many US dialysis care providers had suboptimal dementia knowledge, despite reporting being comfortable with providing dementia care and reporting they received prior training. Qualitative findings indicate complexity among providers regarding comfort with and knowledge of treating patients with cognitive impairment. Targeted training for the dialysis workforce in dementia knowledge and best practices for person-centered dementia care is warranted.

Complete author and article information provided before references.

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The public health burden of Alzheimer disease and related dementias (AD/ADRDs) has been well-documented. Although AD/ADRDs are common, precursory mild cognitive impairment (MCI) is even more common, with approximately 20% of those aged 50 years or older living with MCI and a lifetime risk of about 2 in 3.<sup>1,2</sup> People receiving dialysis have a particularly high burden of AD/ADRD (13%–16% with diagnosed dementia 5 years after dialysis start).<sup>3</sup> MCI, whether because of uremia or a precursor to AD/ADRD, is also extremely common among these patients, with >70% experiencing mild to severe cognitive impairment.<sup>4</sup>

The interdisciplinary US dialysis workforce primarily manages patients (>540,000 in 2021) in free-standing outpatient facilities.<sup>5</sup> The complexity of care needs—physical, social, and behavioral—among those with

dementia accounts for disproportionate amounts of dialysis provider time.<sup>6</sup> Therefore, it is important to aim for a welcoming workplace environment with consistent, engaged staffing.<sup>7–10</sup>

Importantly, in-center hemodialysis typically occurs in a very “dementia unfriendly” environment, with noise, constant activity, frequent staff turnover, and the requirement to remain still for extended periods.<sup>11</sup> These components of dialysis care are likely to cause confusion and distress in patients with MCI or AD/ADRD.<sup>11</sup> Despite this, current US<sup>12</sup> and international<sup>13</sup> clinical guidelines for dialysis care do not address AD/ADRD and MCI, except in the context of the decision to start dialysis.<sup>14</sup> Although there is evidence of the overlap between dementia and dialysis treatment, little is known about the comfort and level of knowledge that dialysis providers have regarding

### PLAIN-LANGUAGE SUMMARY

There is a high burden of mild cognitive impairment and dementia in the US in-center hemodialysis setting. Although the prevalence of dementia is increasing, little is known about the readiness for the interdisciplinary team to provide person-centered, dementia-friendly patient care. Examining data from a US web-based survey, we found that providers felt confident in knowing when a patient had cognitive impairment, but less than two-thirds reported receiving training about dementia. Further, those who received training about dementia or had awareness of dementia guidelines had lower scores for dementia knowledge. This information can be used to develop training and guidance for interdisciplinary team to reduce staff burden and improve quality of care for patients living with cognitive impairment.

caring for their patients with dementia and MCI. This study fills this gap by examining the comfort with and knowledge of US dialysis care providers with respect to dementia and its care; secondarily, we examined the association between dementia knowledge and characteristics such as clinic tenure, role, and previous dementia training.

## METHODS

### Study Design

A cross-sectional survey including items related to comfort with providing care to patients with dementia or cognitive impairment, dementia knowledge, and demographics (Item S1) was distributed by using an anonymized REDCap<sup>15</sup> link to National Kidney Foundation (NKF) and National Association of Nephrology Technicians/Technologists (NANT) members. Participants were recruited by using direct emails soliciting active dialysis care providers, which were sent to membership listservs by using NKF (including 2,322 physicians, 1,753 advanced practice providers [APPs], 5,295 nurses, 2,013 social workers, 5,006 dietitians, 1,172 dialysis patient care technicians [PCTs], and 7,483 other) and NANT (2,342 dialysis PCTs). Emails were sent to the full NKF membership twice, with one additional direct invitation to physicians and APPs. NANT members received information about the survey on 4 occasions. All participants received a \$10 e-gift card. There were 1,561 (1,471 and 90 for the NKF and NANT versions, respectively) clicks on the survey link; of these, 1,291 (1,224 and 67 for the NKF and NANT versions, respectively) completed the survey (82.7% overall completion rate; completion dates: September 26, 2022–October 22, 2022). Of the 1,291 respondents, 1,240 (96.0%) were actively working in dialysis care as physicians, APPs, nurse managers, registered nurses, licensed vocational nurses (LVNs)/licensed practical nurses (LPNs),

social workers, dietitians, or dialysis PCTs and were included. Among the 13 excluded, 9 (69.2%) listed roles as administrators/managers/directors, administrative assistants, or educators. Respondents who did not complete all items of the Dementia Knowledge Assessment Scale (DKAS)<sup>16,17</sup> (n=119) were excluded, leaving 1,121 respondents including 81 physicians, 61 APPs, 230 nurse managers, 260 nurses, 202 social workers, 195 dietitians, and 86 dialysis PCTs for primary analyzes. The Emory University Institutional Review Board reviewed the study and determined it to be exempt.

### Variables

#### Comfort With Dementia and Cognitive Impairment and Related Care

The following Likert-scale items (responses: strongly agree, agree, disagree, and strongly disagree) were developed ad hoc and used to assess comfort with dementia and cognitive impairment and their care: “I know when my patients are cognitively impaired or have dementia”; “I am aware of current guidance in caring for patients with dementia or cognitive impairment”; “I regularly speak to caregivers of patients with dementia or cognitive impairment”; “Our facility provides excellent care for patients with dementia or cognitive impairment”; “I have received specific training in how to care for patients with dementia or cognitive impairment”; and “I would like to learn more about how to identify and care for dementia or cognitive impairment in patients receiving dialysis.” Except for the last item, these items were not specific to the dialysis setting (Item S1).

#### Dementia Knowledge

The DKAS<sup>16,17</sup> was used to assess knowledge of dementia. The DKAS includes 25 true/false items and scores (unweighted total number of correct answers) can range from 0 (worst knowledge) to 25 (best knowledge). The DKAS also provides 4 subscale scores (“causes and characteristics,” “communication and behavior,” “care considerations,” and “risks and health promotion”) that are the sum of the related items (Table S1). The DKAS is a general knowledge scale that does not ask specifically about the dialysis setting.

#### Other Variables

Respondents were also asked about individual characteristics age at survey, gender, race, ethnicity, education, and work characteristics (types and US state/territory of facility, tenure [time in current role], work hours, patient caseload, receipt of formal dialysis training [defined as any training not including on-the-job training, such as classroom training], and certification(s)) to characterize the sample population (Table S1).

#### Statistical Analysis

Characteristics of respondents, comfort with dementia care, and dementia knowledge were summarized and tabulated

overall and by role.  $\chi^2$ , rank sum, and equality-of-medians tests were used to compare outcome variables across categories, as appropriate. In secondary analyses, robust regression was used to obtain coefficients ( $\beta$ s) and 95% confidence intervals (CIs) for the associations between characteristics and DKAS scores, with adjustment for role and tenure. Complete case analysis was used. Statistical analyses were performed using Stata v. 17.0 (Stata Corporation).

### Qualitative Analysis

Free-text responses to the item “What are some other comments you have regarding patients who receive dialysis and show signs of dementia or cognitive impairment?” We received 340 (27%) individual responses with enough detail to analyze. These were analyzed using a combination of inductive and deductive thematic analysis.<sup>18</sup> We created an initial codebook based on the survey, which was modified and further refined as coding progressed. All responses were read individually and coded based on relevant phrases, words, or patterns central to the aims of this study. Final themes were identified by comparing text within and across codes and by comparing to domains on the survey. NVivo 12 (QSR International) was used to manage data and conduct analysis of the qualitative data.

## RESULTS

### Characteristics of Respondents

A majority (57.1%) of the survey respondents were 35-49 years old and women (62.4%). Physicians (67.5%) and LVN/LPNs (72.6%) were more likely than other providers to be men (Table 1). Overall, 62.3%, 22.0%, and 9.4% of participants reported White, African American, and Asian race, respectively; 11.8% reported Hispanic ethnicity (Table 1). Half of the respondents had been in their current role for at least 5 years. Just more than half (55.3%) reported providing care in a for-profit clinic, and the majority (64.1%) reported working in a free-standing outpatient dialysis clinic. LVN/LPNs were most likely to report providing care in government/Veterans Affairs centers. Overall and across all roles, participants reported working  $\geq 40$  hours per week. The median number of patients/day was 15 with social workers reporting the highest median per day (40 patients) and LVNs/LPNs reporting the lowest (5 patients).

### Provider Comfort With Cognitive Impairment and Dementia

Overall, respondents indicated they agreed or strongly agreed with items assessing comfort with dementia and cognitive impairment with the lowest endorsement of receiving training related to dementia and cognitive impairment (Fig 1). Nearly all respondents (96.5%) indicated agreement with knowing when their patient had cognitive impairment or dementia. The majority agreed or strongly agreed with statements about awareness of

guidance in caring for patients with dementia (79.5%), speaking with caregivers of patients with dementia (87.8%), and working at a facility that provides excellent care for patients with dementia (86.6%). Regarding training, 61.7% of respondents agreed or strongly agreed they had received specific training for caring for patients with dementia, and 94.7% reported wanting to learn more about dementia and cognitive impairment (Table 2). LVNs/LVPs had the highest level of agreement across all questions. Physicians indicated the least agreement on knowing when their patients were cognitively impaired (92.5%), working at a facility that provides excellent care for patients with dementia (77.5%), and wanting to learn more about how to identify and care for people living with cognitive impairment or dementia (86.4%). Dietitians were least likely to agree that they were aware of current guidance (60.0%) or had received training about dementia or cognitive impairment (29.4%). PCTs were the least likely to agree that they regularly speak to caregivers of patients with dementia (73.3%) (Table 2).

### Dementia Knowledge and Its Correlates

Among this sample, Cronbach's alpha for the 25 DKAS items ( $\alpha = 0.79$ ,  $n=1,121$ ) indicated acceptable internal consistency for the scale in this sample. Median DKAS scores significantly differed across roles on the overall scale (Fig 2) and each subscale (Fig 3). On the overall scale (median interquartile range [IQR] score 17 out of 25, 68.0% correct), dietitians had the highest median IQR score (21 out of 25, 84.0% correct), whereas nurse managers/clinic coordinators had the lowest median IQR score (13 out of 25, 52.0% correct). Within the 4 subscales, respondents had the lowest median score on the “causes and characteristics” subscale (4 out of 7, 57.1% correct responses) and the highest median score on the “care considerations” subscale (6 out of 6, 100% correct responses). There was also variability across roles on the subscales with the greatest variability across groups on the “causes and consequences subscale,” whereas the “communication and behavior” and “care considerations” subscales had consistently high median IQR scores with all groups having median IQR ranges at 5 or 6 (out of 6).

Table 3 shows the associations of the DKAS with select demographic characteristics and 2 items regarding dementia-specific training and awareness of dementia guidance from the comfort items described previously. Independent of role, being 50 years and older ( $\beta$ , 2.42; 95% CI, 1.72-3.11), women ( $\beta$ , 4.07; 95% CI, 3.59-4.55) or having clinic tenure of 1-5 years ( $\beta$ , 1.25; 95% CI, 0.53-1.97) or more than 5 years ( $\beta$ , 3.16; 95% CI, 2.45-3.87) were statistically significantly associated with higher DKAS scores. Conversely, endorsing having received dementia-specific training ( $\beta$ , -3.88; 95% CI, -4.36 to -3.40) and reporting being aware of current dementia guidance ( $\beta$ , -2.43; 95% CI, -3.01 to -1.85) were both statistically significantly associated with lower DKAS

**Table 1.** Characteristics of US Dialysis Care Providers Responding to the Survey, Overall and by Role

Characteristic	Overall	Role							
		Physician	APP	NM/CC	RN	LVN/LPN	Social Worker	Dietitian	PCT
No. of Emails <sup>a,b</sup>	22,380	2,322	1,753	5,299 <sup>c</sup>	5,299	5,299	2,013	5,006	2,343
Response, N	1,121	81	67	230	153	107	202	195	86
Demographics									
Age, y, n (%) (N=1,115)									
18-34	202 (18.1%)	12 (15.0%)	12 (18.1%)	38 (16.6%)	32 (20.9%)	9 (8.4%)	38 (18.9%)	44 (22.8%)	17 (19.8%)
35-49	637 (57.1%)	46 (57.5%)	34 (51.5%)	154 (67.3%)	84 (54.9%)	96 (89.7%)	107 (53.2%)	80 (41.5%)	36 (41.9%)
≥50	276 (24.8%)	22 (27.5%)	20 (30.3%)	37 (16.1%)	37 (24.2%)	2 (1.9%)	56 (27.9%)	69 (35.8%)	33 (38.4%)
Gender, <sup>d</sup> n (%) (N=1,104)									
Female	689 (62.4%)	26 (32.5%)	47 (71.2%)	96 (42.7%)	89 (59.6%)	29 (27.4%)	158 (79.4%)	176 (91.7%)	68 (81.0%)
Male	415 (37.6%)	54 (67.5%)	19 (28.8%)	129 (57.3%)	63 (41.5%)	77 (72.6%)	41 (20.6%)	16 (8.3%)	16 (19.1%)
Race, <sup>e</sup> n (%) (N=1,082)									
Asian	102 (9.4%)	11 (14.9%)	5 (7.9%)	24 (10.6%)	22 (14.6%)	10 (9.4%)	10 (5.1%)	14 (7.5%)	6 (8.0%)
African American	238 (22.0%)	13 (17.6%)	11 (17.5%)	68 (30.1%)	45 (29.8%)	16 (15.0%)	51 (25.8%)	16 (8.5%)	18 (24.0%)
White	674 (62.3%)	46 (62.2%)	44 (69.8%)	111 (49.1%)	70 (46.4%)	74 (69.2%)	127 (64.1%)	155 (82.5%)	47 (62.7%)
Other	69 (6.4%)	4 (5.4%)	4 (6.4%)	22 (9.7%)	15 (9.9%)	7 (6.5%)	9 (4.6%)	3 (1.6%)	5 (6.7%)
Ethnicity, n (%) (N=1,067)									
Hispanic	126 (11.8%)	6 (8.1%)	7 (11.9%)	32 (14.8%)	19 (13.0%)	5 (4.7%)	29 (14.6%)	17 (9.1%)	11 (13.8%)
Not Hispanic	941 (87.2%)	68 (91.9%)	52 (88.1%)	185 (85.3%)	127 (87.0%)	101 (95.3%)	170 (85.4%)	169 (90.9%)	69 (86.3%)
Work characteristics									
Time in current role, n (%) (N=1,115)									
<1 y	144 (12.9%)	5 (6.3%)	10 (15.2%)	42 (18.4%)	17 (11.2%)	6 (5.6%)	38 (18.8%)	23 (11.8%)	3 (3.5%)
1-5 y	412 (37.0%)	27 (34.2%)	27 (40.9%)	95 (41.7%)	67 (44.1%)	32 (29.9%)	83 (41.1%)	60 (30.8%)	21 (24.4%)
>5 y	559 (50.1%)	47 (59.5%)	29 (43.9%)	91 (39.9%)	68 (44.7%)	69 (64.5%)	81 (40.1%)	112 (57.4%)	62 (72.1%)
Type of dialysis facility(ies), <sup>f</sup> n (%) (N=1,121)									
Free-standing outpatient	718 (64.1%)	48 (59.3%)	45 (67.2%)	108 (47.0%)	87 (56.9%)	22 (20.6%)	166 (82.2%)	174 (89.2%)	68 (79.1%)
Outpatient, hospital-based	412 (36.8%)	28 (34.6%)	22 (32.8%)	133 (57.8%)	57 (37.3%)	92 (86.0%)	46 (22.8%)	20 (10.3%)	14 (16.3%)
Inpatient	221 (19.7%)	38 (46.9%)	22 (32.8%)	35 (15.2%)	40 (26.1%)	41 (38.3%)	15 (7.4%)	14 (7.2%)	16 (18.6%)
Dialysis organization, n (%) (N=1,077)									
For-profit	595 (55.3%)	34 (43.6%)	38 (60.3%)	81 (35.5%)	76 (52.1%)	22 (20.6%)	142 (72.1%)	144 (78.3%)	58 (78.4%)
Not-for-profit	314 (29.2%)	29 (37.2%)	19 (30.2%)	108 (47.4%)	47 (32.2%)	15 (14.0%)	47 (23.7%)	36 (19.6%)	13 (17.6%)
Government/VA	168 (15.6%)	15 (19.2%)	6 (9.5%)	39 (17.1%)	23 (15.8%)	70 (65.4%)	8 (4.1%)	4 (2.2%)	3 (4.1%)

(Continued)

**Table 1 (Cont'd).** Characteristics of US Dialysis Care Providers Responding to the Survey, Overall and by Role

Characteristic	Overall	Role								
		Physician	APP	NM/CC	RN	LVN/LPN	Social Worker	Dietitian	PCT	
Hours worked per week, n (%) (N=1,119)										
<30	133 (11.9%)	10 (12.4%)	7 (10.5%)	38 (16.5%)	18 (11.9%)	7 (6.5%)	23 (11.4%)	27 (13.9%)	3 (3.5%)	
30-39	378 (33.8%)	27 (33.3%)	17 (25.4%)	123 (53.5%)	58 (38.4%)	31 (29.0%)	63 (31.2%)	45 (23.1%)	14 (16.3%)	
≥40	608 (54.3%)	44 (54.3%)	43 (64.2%)	69 (30.0%)	75 (49.7%)	69 (64.5%)	116 (57.4%)	123 (63.1%)	69 (80.2%)	
Number of dialysis patients seen per day, <sup>9</sup> median (IQR) (N=985)	15 (6-40)	17 (10-30)	20 (10-40)	8 (3-16)	10.5 (4-24)	5 (4-5)	40 (15-60)	36 (20-55)	10 (8-15)	
US region, n (%) (N=1,095)										
Northeast	202 (18.5%)	19 (24.4%)	15 (23.4%)	38 (17.4%)	27 (17.9%)	17 (15.9%)	40 (20.0%)	35 (18.3%)	11 (12.8%)	
South	433 (39.5%)	21 (26.9%)	23 (35.9%)	82 (37.6%)	53 (35.1%)	48 (44.9%)	81 (40.5%)	83 (43.5%)	42 (48.8%)	
Midwest	228 (20.8%)	9 (11.5%)	12 (18.8%)	37 (17.0%)	33 (21.9%)	18 (16.8%)	50 (25.0%)	44 (23.0%)	25 (29.1%)	
West	232 (21.2%)	29 (37.2%)	14 (21.9%)	61 (28.0%)	38 (25.2%)	24 (22.4%)	29 (14.5%)	29 (15.2%)	8 (9.3%)	

Abbreviations: APP, advanced practice provider; IQR, interquartile range (25<sup>th</sup>, 75<sup>th</sup> percentiles); LVN/LPN, licensed vocational nurse/licensed practical nurse; NM/CC, nurse manager/clinic coordinator; PCT, patient care technician; RN, registered nurse; VA, Veterans Affairs.

<sup>a</sup>Total emails sent includes groups and individuals that were not included in the analysis because they listed roles as administrators/managers/directors, administrative assistants, educators, or indicated they were not currently working in a dialysis clinic. Therefore, the totals of each role do not equal the total of emails sent.

<sup>b</sup>Does not account for sharing on social media, through presentations, or duplicates on the listservs.

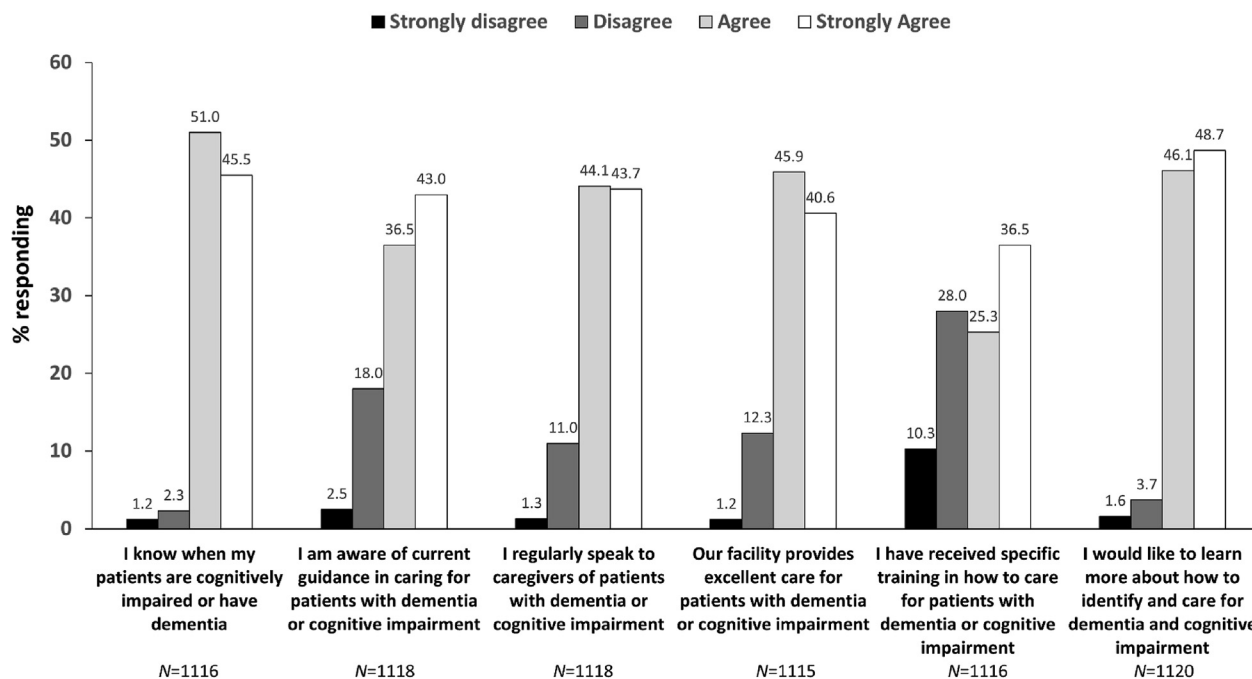
<sup>c</sup>Membership records only include one heading for "nurse." It is not possible to determine credentials or role from the listserv. The same number is presented for all nurse groups and response N is based on self-identified role.

<sup>d</sup>Excluding n=1 nonbinary individual to protect identity.

<sup>e</sup>Totals may be >100% because participants could pick multiple categories. Other includes American Indian/Alaskan Native, Hawaiian/Pacific Islander.

<sup>f</sup>Totals may be >100% because participants could pick multiple categories: outpatient free-standing and outpatient hospital-based (n = 97, 8.7%); outpatient free-standing and inpatient (n = 34, 3.0%); outpatient hospital-based and inpatient (n = 66, 5.9%); all 3 categories (n = 20, 1.8%).

<sup>g</sup>For physicians, median number of patients per week is presented.



**Figure 1.** Distribution of responses regarding comfort with dementia and cognitive impairment and its care among US dialysis care providers.

scores, also independent of role. Additional adjustment for tenure (time in current role) attenuated the estimates somewhat, but the associations generally remained similar and statistically significant (Table 3).

### Themes Identified From Open-Ended Responses

Of the 340 analyzable responses, nurse managers/clinic coordinators provided the most (19.9%) responses, followed by using LVN/LPNs (18.3%), social workers (16.7%), dietitians (15.8%), and registered nurses (10.1%). Physicians, APPs, and PCTs all provided fewer than 10% of the comments (7.6%, 6.9%, and 4.7%, respectively). Two-thirds (66.3%) of responses were provided by those who had worked in dialysis for more than 5 years, and just under half (47.0%) worked in for-profit dialysis centers. More than half (57.7%) of the respondents to the open-ended question were women, and nearly two-thirds (62.2%) were 35–49 years old. These characteristics mirrored the characteristics of individuals who completed the full survey.

We identified 2 overarching themes – impact of dementia on dialysis care and management and treatment beyond dialysis care, as well as multiple subthemes (illustrative quotes are included in Table 4).

### Impact of Dementia on Dialysis Care

Within our first overarching theme, we identified 6 subthemes:

1. Recognizing dementia: Survey respondents noted difficulty recognizing dementia among their patients,

especially in the initial stages, because of patients masking or downplaying symptoms, displaying cognitive issues but not yet being diagnosed, and lack of communication with family members. They also noted that symptoms of dementia are often confused with other symptoms or medical conditions.

2. Family involvement: Family involvement in care was mentioned as necessary for positive dialysis outcomes and efficient patient care, including their presence during dialysis treatment if possible. They also wrote that families may be in denial of dementia diagnosis and express frustration and encourage better communication with dialysis staff. Respondents noted that treatment can be difficult for patients living with dementia, but families often refuse to stop treatments.
3. Confusion: Respondents indicated that patients known to have dementia could experience confusion or disorientation that could negatively affect how they experience the dialysis process. Examples included how patients with dementia seem unaware of the environment and the things around them, experience paranoia or delirium, or do not fully understand the dialysis process.
4. Importance of routine and repetition: Providers noted a need for understanding and patience when working with patients with dementia during dialysis treatment. They wrote that having a consistent routine, being compassionate, and staying positive were helpful with reducing confusion and keeping patients calm and comfortable during treatment.
5. Safety concerns: Providers expressed concern for their own and their patients' safety. They noted that patients

**Table 2.** Reported Comfort With Dementia/Cognitive Impairment and its Care Among US Dialysis Care Providers, by Role

Item	No. (%) Responding Agree or Strongly Agree With Survey Item								
	Overall	Physician	APP	NM/CC	RN	LVN/LPN	Social Worker	Dietitian	PCT
I know when my patients are cognitively impaired or have dementia (N = 1,116)	1,077 (96.5%)	74 (92.5%)	65 (98.5%)	223 (97.4%)	148 (96.7%)	105 (99.1%)	194 (96.1%)	185 (95.4%)	83 (96.5%)
I am aware of current guidance in caring for patients with dementia or cognitive impairment (N = 1,118)	889 (79.5%)	54 (67.5%)	52 (77.6%)	205 (89.1%)	121 (79.1%)	105 (99.1%)	165 (82.1%)	117 (60.0%)	70 (81.4%)
I regularly speak to caregivers of patients with dementia or cognitive impairment (N = 1,118)	981 (87.8%)	64 (80.0%)	58 (86.6%)	206 (90.0%)	127 (83.0%)	107 (100%)	181 (89.6%)	175 (90.2%)	63 (73.3%)
Our facility provides excellent care for patients with dementia or cognitive impairment (N = 1,115)	965 (86.6%)	62 (77.5%)	52 (77.6%)	214 (93.9%)	130 (85.0%)	107 (100%)	169 (83.7%)	159 (82.8%)	72 (83.7%)
I have received specific training in how to care for patients with dementia or cognitive impairment (N = 1,116)	689 (61.7%)	51 (63.0%)	41 (61.2%)	188 (82.5%)	93 (61.6%)	105 (98.1%)	114 (56.4%)	57 (29.4%)	40 (46.5%)
I would like to learn more about how to identify and care for dementia and cognitive impairment (N = 1,120)	1,061 (94.7%)	70 (86.4%)	61 (91.0%)	225 (97.8%)	144 (94.1%)	107 (100%)	195 (96.5%)	181 (92.8%)	78 (91.8%)

Abbreviations: APP, advanced practice provider; LVN/LPN, licensed vocational nurse/licensed practical nurse; NM/CC, nurse manager/clinic coordinator; PCT, patient care technician; RN, registered nurse.

with dementia were difficult to care for during dialysis treatment because of restlessness, pulling out needles, refusing care, or issues with listening and speaking, which require prolonged attention that staff felt they cannot provide. They also noted concerns for staff safety and difficulty in managing negative behaviors to maintain a safe environment.

- Care team training: Respondents noted the importance of a diverse care team that involves medical staff, caregivers, and family to ensure patients with dementia receive diligent support. They noted that better staff resources, education, and training as well as consistent caregiver/guardian involvement can help provide patients with the direct care they need and improve their quality of life.

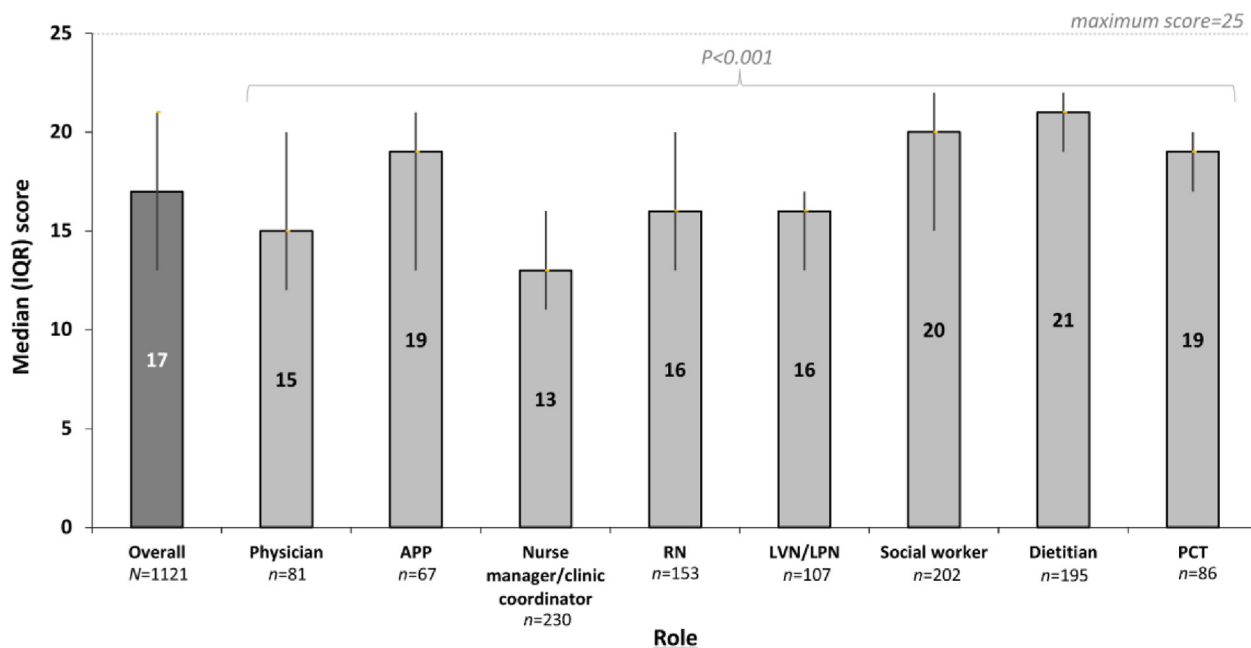
### Management and Treatment Beyond Dialysis Care

Although most of the text responses related to caring for patients in the clinic setting, respondents volunteered perceptions of factors beyond their scope that would improve the quality of life for their patients living with dementia, which might improve their own work environment. Two subthemes emerged from the data related to this theme:

- Early and accurate diagnosis and treatment: Respondents noted that an early diagnosis can improve the quality of life for those affected by using cognitive impairment. They noted that a medical diagnosis is necessary and would be beneficial for advising treatment options and improving their ability and comfort to care for patients. Additionally, respondents commented that appropriate medications for symptoms and ongoing medication management was important for preserving function.
- Importance of physical and mental well-being: One of the most common responses was the importance of incorporating physical exercise to improve physical and mental health outcomes to “fight the disease.” They also wrote patients with dementia should follow a healthy diet but noted challenges to adherence to diet/fluid restrictions related to dialysis treatment. Respondents stated there needed to be more attention paid to the mental well-being of people living with dialysis and dementia to reduce anxiety.

## DISCUSSION

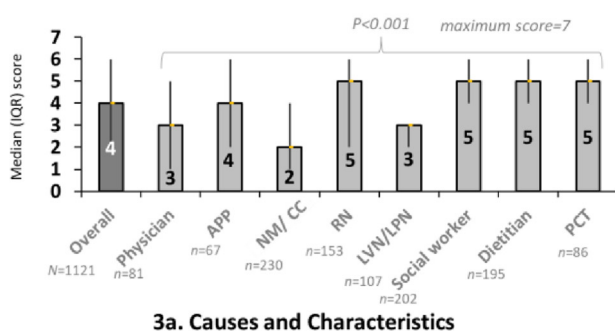
In this survey of NKF and NANT members, we found variability in comfort and knowledge of dementia across roles among US dialysis care providers. Most participants indicated high levels of awareness of guidelines and comfort when working with patients with cognitive impairment or dementia while simultaneously noting lower levels of receiving training related to cognitive impairment. Importantly, >90% of respondents across roles, except for physicians, wanted more training around identifying and treating patients with dementia. Dementia



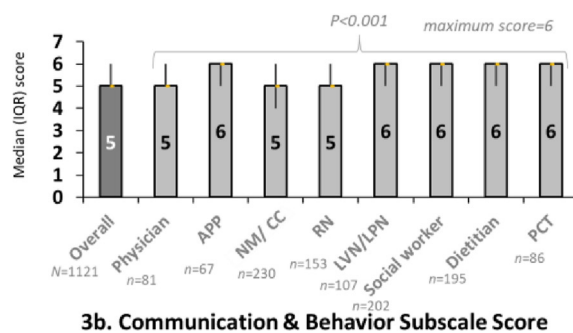
**Figure 2.** Dementia Knowledge Assessment Scale scores, overall and by role at dialysis facility. Range of scores = 0-25. Higher scores indicate better knowledge. Abbreviations: IQR, interquartile range; APP, advanced practice provider; RN, registered nurse; LVN/LPN, licensed vocational nurse/licensed practical nurse; PCT, patient care technician.

knowledge, based on the DKAS, also varied greatly by role and across the 4 subscales and was inversely correlated with self-reported receipt of specific training.

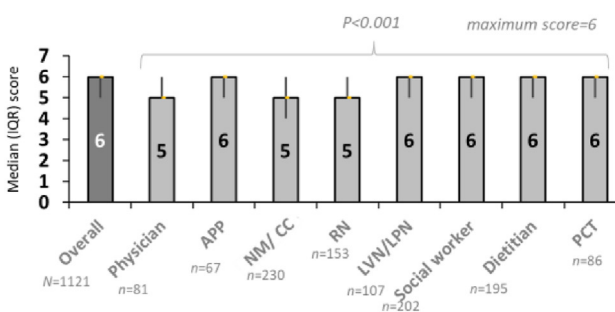
Understanding comfort and knowledge around dementia is essential, because dialysis providers provide extensive one-on-one care and might be the first to notice



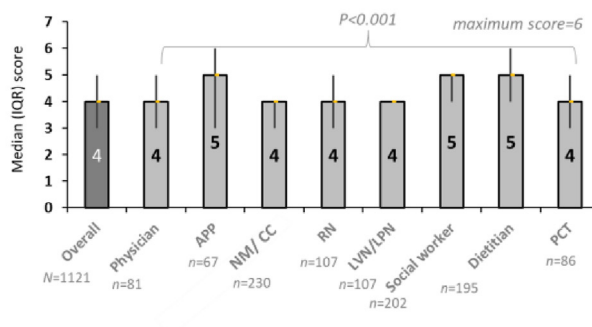
**3a. Causes and Characteristics**



**3b. Communication & Behavior Subscale Score**



**3c. Care Considerations**



**3d. Risk & Health**

**Figures 3.** Dementia Knowledge Assessment Subscale scores, overall and by role at dialysis facility. Range of scores = 0-6 or 0-7, depending on subscale. Higher scores indicate better knowledge. Abbreviations: IQR, interquartile range; APP, advanced practice provider; NM/CC, nurse manager/clinic coordinator; RN, registered nurse; LVN/LPN, licensed vocational nurse/licensed practical nurse; PCT, patient care technician.



**Table 3.** Association of Dementia Knowledge Assessment Scale With Select Characteristics

Characteristic	Difference in Score (95% CI) <sup>a</sup>		
	Unadjusted	Adjusted for Role	Adjusted for Role and Tenure
Age, y			
18-34	1.00 (ref)	1.00 (ref)	1.00 (ref)
35-49	-0.72 (-1.41 to -0.03)	-0.04 (-0.65 to 0.57)	-0.71 (-1.32 to -0.09)
≥50	2.78 (1.99-3.58)	2.42 (1.72-3.11)	1.27 (0.53-2.00)
Gender			
Male	1.00 (ref)	1.00 (ref)	1.00 (ref)
Female	5.43 (4.98-5.88)	4.07 (3.59-4.55)	3.70 (3.22-4.17)
Time in current role (tenure)			
<1 y	1.00 (ref)	1.00 (ref)	-
1-5 y	1.27 (0.43-2.11)	1.25 (0.53-1.97)	-
>5 y	3.39 (2.58-4.20)	3.16 (2.45-3.87)	-
Reported receiving dementia-specific training			
No	1.00 (ref)	1.00 (ref)	1.00 (ref)
Yes	-4.96 (-5.42 to -4.51)	-3.88 (-4.36 to -3.40)	-3.53 (-3.99 to -3.07)
Reported being aware of current dementia guidance			
No	1.00 (ref)	1.00 (ref)	1.00 (ref)
Yes	-3.55 (-4.18 to -2.91)	-2.43 (-3.01 to -1.85)	-2.24 (-2.80 to -1.68)

<sup>a</sup>From robust regression.

changes or be affected by patients' dementia behavior or symptoms. Previous research has shown that the dialysis work environment is not conducive to treating patients living with dementia<sup>11</sup> and that this work environment also contributes to staff burnout.<sup>19</sup> Therefore efforts should be made to create a workplace that is welcoming<sup>7</sup> and a dialysis workforce that is consistent,<sup>8-10</sup> engaged, and not overwhelmed<sup>20,21</sup> or burned out<sup>19,22</sup> to promote competency in providing necessary person-centered care for dialysis-treated adults with dementia.<sup>23</sup>

Given the variation in comfort and knowledge by role, as well as the negative association of receiving training with scores on the DKAS, findings suggest that it is imperative to provide opportunities for education and training in dementia care for all providers working in US dialysis centers. The negative association also suggests that the existing trainings are likely inadequate to meet the needs of this interprofessional care team. Improved access to high-quality, interactive, competency-based dementia education is necessary to better support both workers and patients.

This study indicates that dementia knowledge among US dialysis providers is limited. Although existing studies of dementia knowledge among dialysis providers are scant, these findings are consistent with previous studies involving providers in other contexts.<sup>24-28</sup> Across most contexts and disciplines, there are gaps in knowledge and training about dementia, and these scores improve with training.<sup>29</sup> Consequently, the identification and care for people living with dementia, especially those who are living with additional chronic conditions and who have complex care needs, such as patients receiving dialysis, can be impacted.

Among survey participants, nurse managers and physicians showed lower overall scores on dementia knowledge than all other groups and nurse managers scored the lowest on the "causes and characteristics" subscale. This might be because their roles in the in-center hemodialysis setting involves supervisory tasks rather than day-to-day, hands-on care of patients.<sup>30</sup> This distance from daily care coupled with existing knowledge gaps<sup>25</sup> might explain larger gap between nurse managers and those occupying other roles in the dialysis setting. Additionally, physicians are likely the furthest removed from their initial training. These differences did not persist across the other subscales.

As the burden of AD/ADRD among people receiving dialysis increases, the need for training will only become more important. Dialysis providers of all roles will face the increasing complexity of treating patients with MCI or AD/ADRD and increasing knowledge, competency, and self-efficacy in caring for patients with dementia can improve care and potentially improve workplace satisfaction among dialysis providers. Overall and regardless of role, there is a need for training about dementia, especially the "causes and characteristics" domain. Understanding the clinical and social context of the disease for their patients is likely to improve the empathy, creative problem-solving, and communication necessary to better support people living with dementia and their care partners to manage their dialysis treatment in the larger context of their conditions and their life.<sup>31</sup>

Our study has some limitations. Given we used anonymous surveys with multiple methods of recruitment, we cannot calculate a response rate or assess potential selection bias because we do not have a reliable denominator.

**Table 4.** Illustrative Quotes

Theme	Illustrative Quote 1	Illustrative Quote 2
<b>Impact of Dementia on Clinical Care</b>		
Recognizing dementia	"It's hard during dialysis as patients can slowly slip into dementia and can trick the staff that everything is normal for a while. Some patients don't want staff to contact their families for help with meds and other things." Dietitian	"It is hard to diagnose or understand when a patient is showing signs of dementia/cognitive impairment. It is often mistaken for poor adherence." Dietitian
Family involvement	"Family involvement is so important and establishing a main point of contact to avoid confusion and efficient patient care updates is helpful." Social worker	"For some patients with dementia, it truly seems a tortuous treatment for them. Dialysis to keep the person alive seems too burdensome for the patient, and more for the psychological needs of the family member." Social worker
Confusion	"It is very difficult and heartbreaking working with patients with dementia who are very confused as to why they are treated with dialysis as they no longer comprehend their own health." Social worker	"It is difficult for patients with dementia or cognitive impairment to understand dialysis and why they have to have it. It is hard for them to be stuck with needles and have to sit still for several hours at a time." Registered nurse
Importance of routine and repetition	"Being patient and providing a calm explanation on the dialysis process each time they ask is observed to be comforting...." Social worker	"Needing to provide frequent reminders of educational points and guidance." Dietitian
Safety concerns	"It can be difficult to dialyze these patients as they can become combative, restless." Nurse manager/clinic coordinator	"I fear for their care when they do not understand and pull at the needles and blood lines." Patient care technician
Care team training	"I feel all clinic staff could benefit from more education/training." Social worker	"Better staff education, training, and direction is needed. Support of the dialysis for patients with dementia is lacking." Nurse manager/clinic coordinator
<b>Management and Treatment Beyond Clinical Care</b>		
Early and accurate diagnosis and treatment	"Dementia diagnosed early helps both the person and family members to learn about the disease, set realistic expectations and plan for their future together." Licensed vocational/practical nurse	"Medications to make the patient comfortable and less anxious during dialysis are important." Dietitian
Importance of physical and mental well-being	"It's better to encourage patients to exercise so that the body can be fit to fight the disease." Licensed vocational/practical nurse	"Mental health care should be given priority." Physician

Further, our results may not be generalizable to all US dialysis providers. Additionally, all data are self-reported; therefore, there is the possibility of misclassification, particularly because of social desirability bias. It is also possible that respondents may have answered incorrectly that vascular dementia is the most common form of dementia if they were considering only patients receiving dialysis. However, many respondents answered correctly that Alzheimer is the most common form of dementia overall; therefore, there is an opportunity to not only better understand the presentations and experiences of the range of dementia types and severity in the dialysis setting but also to create trainings that are useful in this setting. Based on the limited information gathered about training received and awareness of current guidelines around AD/ADRD, the quantity, content, or timing of these experiences are unclear and therefore should be interpreted with caution. Given the limited knowledge about dementia in the dialysis setting, this study alone cannot cover the range of concerns for individuals caring for patients receiving dialysis who might also experience dementia. Further, although we received numerous qualitative responses that will help guide future studies and training, not all groups had equal representation. Additional mixed methods

studies are needed to ensure representation and allow for in-depth understanding of patient and provider experiences. Opportunities remain for more in-depth discussions with dialysis providers and development of training and guidance about concerns and needs when working with patients with dementia receiving dialysis.

To our knowledge, this is the first study to examine interdisciplinary dialysis provider comfort with and knowledge of treating patients receiving dialysis and living with dementia or cognitive impairment. This study was an important first step in understanding the level of dementia knowledge among the dialysis inter-professional care team. Findings from this study, specifically who on the dialysis care team and what domains of dementia knowledge to target, can inform the development of quality improvement projects in the dialysis setting, as well as the development and implementation of dementia education and potential interventions tailored to the in-center hemodialysis setting that address the types and severity of dementia among people receiving dialysis. State-of-the-art dementia education that is high-quality, interactive, and competency-based is needed to support workers to use person-centered strategies to improve the dialysis experience and quality of

care of people living with dementia in collaboration with their care partners.

## SUPPLEMENTARY MATERIALS

### Supplementary File (PDF)

**Item S1:** Relevant survey items.

**Table S1:** Percentage Answering Individual Items on the Dementia Knowledge Assessment Scale Correctly, Overall and by Role.

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