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ORIGINAL ARTICLE

Patient priorities in dialysis

"What matters to you?": The relevance of patient priorities in dialysis care for assessment and clinical practice

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Abstract

Background: Dialysis patients are confronted with numerous, complex problems, which make it difficult to identify individual patient's most prominent problems. The objectives of this study were to (1) identify dialysis patients' most prominent problems from a patient perspective and (2) to calculate disease-specific norms for questionnaires measuring these problems.

Methods: One hundred seventy-five patients treated with hemodialysis or peritoneal dialysis completed a priority list on several domains of functioning (e.g., physical health, mental health, social functioning, and daily activities) and a set of matching questionnaires assessing patient functioning on these domains. Patient priorities were assessed by calculating the importance ranking of each domain on the priority list. Subsequently, disease-specific norm scores were calculated for all questionnaires, both for the overall sample and stratified by patient characteristics.

Results: Fatigue was listed as patients' most prominent problem. Priorities differed between male and female patients, younger and older patients, and home and center dialysis patients, which was also reflected in their scores on the corresponding domains of functioning. Therefore, next to general norm scores, we calculated corrections to the general norms to take account of patient characteristics (i.e., sex, age, and dialysis type).

Conclusions: Results highlight the importance of having attention for the specific priorities and needs of each individual patient. Adequate disease-specific, norm-based assessment is not only necessary for diagnostic procedures but is an essential element of patient-centered care: It will help to better understand and respect individual patient needs and tailor treatment accordingly.

1 | INTRODUCTION

End-stage kidney disease (ESKD) and dialysis treatment have a large impact on a patient's life. Many patients experience a large number of disabilities and suffer from a range of problems, such as fatigue, itch, pain, depression, anxiety, social difficulties, and a decreased sense of independence.[1–3] Because of the wide variety of problems dialysis patients face, clinicians are confronted with the difficulty to identify patients' most prominent problems.[4,5] By this, we mean problems that individual patients consider to require extra attention and that are more prominently present in comparison to other dialysis patients.

In order for clinicians to treat these problems, the first step is to identify what patients themselves see as their most prominent problems. The second step is to timely screen for these problems using patient-reported outcome measures (PROMs).[6,7] With respect to interpretation, use of adequate disease-specific norms is vital. Unfortunately, disease-specific norms are hardly available for dialysis patients. This is especially problematic considering the high heterogeneity of the population[8] and the fact that generic norms will simply fall short to the complexity of ESKD.

The objectives of the current study were (1) to identify dialysis patients' most prominent problems from a patient perspective and (2) to calculate disease-specific norms for questionnaires measuring a wide variety of domains—including physical health, mental health, social functioning, and daily activities—and supply corrections to the general norms to account for patient characteristics (sex, age, and dialysis modality). Resultantly, this will aid clinicians in classifying symptom severity and personalizing treatment for each individual patient.

2 | METHODS

2.1 | Participants and procedure

As part of a larger prospective study, hemodialysis and peritoneal dialysis patients were recruited from several Dutch hospitals and dialysis centers: Radboud university medical center, Nijmegen; VieCuri Medical Center, Venlo; Jeroen Bosch Hospital, Den Bosch; Ravenstein Dialysis Centre, Ravenstein; Bernhoven Hospital, Uden; Canisius Wilhelmina Hospital, Nijmegen. All patients provided written informed consent prior to participation. Recruitment took place from November 2013 through June 2015. Exclusion criteria were as follows: not being fluent in Dutch language, serious comorbid physical (life expectancy <6 months) or psychiatric problems, recent major life events, and cognitive problems that would interfere with completing the questionnaires.

In total, 365 patients were screened for participation. Ninety-five patients were excluded due to cognitive problems, language difficulties, or recent major life events. Of the remaining 270 patients, a sample of 175 patients completed the priority list and additional questionnaires (response rate: 65%). The current study focused on the baseline data of these patients.

The Medical Research Ethics Committee region Arnhem-Nijmegen decided that the study did not fall within the scope of the Medical Research Involving Human Subjects Act. Research was conducted in accordance with the Helsinki Declaration.

2.2 | Measures

2.2.1 | Patient characteristics

Patient characteristics were assessed with a general checklist supplemented with data extracted from medical files. A trained nurse specialist (RJ) determined the Charlson Comorbidity Index score based on patients' medical files.

2.2.2 | Priority list most prominent problems

The priority list contained 18 domains involving physical health, mental health, social functioning, and daily activities. Out of these 18 domains, patients were asked to choose three domains they considered most relevant.

2.2.3 | Physical health

The physical health composite score of the RAND Short Form-36 Health Status Inventory (RAND SF 36)[9] was used to assess physical health-related quality of life (HRQOL; Cronbach's $\alpha = 0.91$). In addition, using the subscales of the RAND SF 36, physical functioning (Cronbach's $\alpha = 0.92$), pain (Cronbach's $\alpha = 0.81$), and general health (Cronbach's $\alpha = 0.76$) were assessed. The Hays norm-based scoring algorithm was applied, transforming raw scores into *T*-scores ($M = 50 \pm 10$ in the general population).[9] In addition, we assessed the average amount of experienced pain with an 11-point Visual Analogue Scale (VAS; 0 = *no pain*, 10 = *worst pain ever*). Fatigue was measured with the subjective experience of fatigue subscale of the Checklist Individual Strength (CIS; Cronbach's $\alpha = 0.92$)[10] and an 11-point VAS to assess the average amount of experienced fatigue (0 = *no fatigue*, 10 = *worst fatigue ever*). Sleep problems were assessed with the Medical Outcomes Study (MOS) Sleep Scale[11] including the domains (1) sleep disturbance, (2) sleep adequacy, (3) sleep quantity, (4) somnolence, (5) snoring, and (6) shortness of breath or headache. For a summary of sleeping problems, the MOS Sleep Scale includes a nine-item Sleep Problem Index, with higher scores indicating more sleep problems (Cronbach's $\alpha = 0.86$).

Itch was measured with a subscale of the Impact of Chronic Skin Disease on Daily Life (IDSL).[12] One of the items measured the average amount of experienced itch using an 11-point VAS (0 = *no itching*, 10 = *worst itching ever*). We assessed the complete four-item subscale (Cronbach's $\alpha = 0.80$) and, separately, the VAS.

2.2.4 | Mental health

The mental health composite score of the RAND SF 36[9] was used to measure mental HRQOL (Cronbach's $\alpha = 0.86$). Using the subscales of the RAND SF 36, emotional well-being (Cronbach's $\alpha = 0.79$) and vitality (Cronbach's $\alpha = 0.70$) were assessed. The Hospital Anxiety and Depression Scale (HADS)[13] was used to assess anxiety (Cronbach's $\alpha = 0.83$) and depression (Cronbach's $\alpha = 0.76$).

2.2.5 | Social functioning

We used the subscale social functioning of the RAND SF 36[9] to assess social functioning (Cronbach's $\alpha = 0.78$).

2.2.6 | Daily activities

Limitations in daily activities were assessed with the subscales role limitations due to physical problems (Cronbach's $\alpha = 0.85$) and role limitations due to emotional problems (Cronbach's $\alpha = 0.93$) of the RAND SF 36.[9]

2.3 | Statistical analyses

First, the descriptives of the patient characteristics were calculated.

Second, we assessed the priority list in which patients listed their top three of domains they considered most relevant. We used frequency tables to calculate the ranking of the domains that patients listed in their top three. We calculated rankings based on the results of the overall sample and categorized by patient characteristics (sex, age, and dialysis type).

Third, the descriptives and the internal consistency of the questionnaires assessing several domains of functioning were calculated. We calculated the means and standard deviations (SDs) for the overall sample and categorized by patient characteristics.

Fourth, we calculated zero-order correlations between patient characteristics and domains of functioning. Correlation coefficients above 0.10, 0.30, and 0.50 were interpreted as small, medium, and large.[14]

Fifth, norm scores of questionnaires measuring the domains of functioning were calculated. The norms include cut-off scores for mild, moderate, and severe symptoms, which were calculated by using SD-derived norm calculations.[15,16] Dependent on the direction of the scale, we calculated cut-off scores for mild symptoms by either adding or subtracting 0.5 SD to/from the mean in our sample (i.e., added when higher scores indicate worse functioning and subtracted when higher scores indicate better functioning). We added or subtracted 1 SD to/from the mean to calculate cut-off scores for severe symptoms. Cut-off scores for moderate symptoms are in between these values. In addition, we used the means of the subgroups categorized by patient characteristics to calculate corrections to the general norms. Due to incidental missing values, sample size varies per analysis.

SPSS 23.0 (IBM, Armonk, NY, USA) was used to perform the statistical analyses.

3 | RESULTS

3.1 | Participant characteristics

Patient characteristics are found in Table 1 and are comparable to demographics of Dutch dialysis patients (RENINE annual report).[17] Participants had a high degree of comorbidity as shown by a mean Charlson Comorbidity Index of 5.4 ± 1.8 (range, 0–9), mainly consisting of cardiovascular diseases, pulmonary diseases, and diabetes.

Compared to patients treated with peritoneal dialysis or home hemodialysis, patients treated with in-center hemodialysis were older (70.2 ± 13.3 vs. 61.8 ± 17.4 years; $P = 0.01$) and had a higher Charlson Comorbidity score (5.7 ± 1.7 vs. 4.4 ± 1.9; $P < 0.001$). Sex and albumin level were not statistically different between different dialysis modalities. Age, albumin level, and Charlson Comorbidity scores did not differ between sexes. Higher age was associated with higher Charlson Comorbidity scores ($r = 0.81$; $P < 0.001$).

The participants in the study did not differ in age, sex, or dialysis type from patients who either were excluded or declined to participate.

3.2 | Priority list of most prominent problems

Figure 1 shows the top 5 problems that patients considered most relevant, for the overall sample and categorized by sex, age, and dialysis type. Fatigue was the most listed domain—59% of the patients listed fatigue in their top 3 of most prominent problems. Mobility was the second most listed domain (36%), followed by dependence upon others (25%), hobbies (24%), and sleeping problems (21%).

TABLE 1 Patient characteristics

Age, year	68.4 ± 14.7
Male sex	101 (57.7%)
Type of dialysis	
Center hemodialysis (day/night)	137 (78.3%)
Home hemodialysis	17 (9.7%)
Peritoneal dialysis	21 (12.0%)
Dialysis vintage, months	57.4 ± 53.1
Albumin level, mg/dl	33.6 ± 3.9
Charlson Comorbidity Index	5.4 ± 1.8

Notes: $n = 175$; values for categorical variables are given as count (proportion); values for continuous variables are given as mean ± standard deviation.

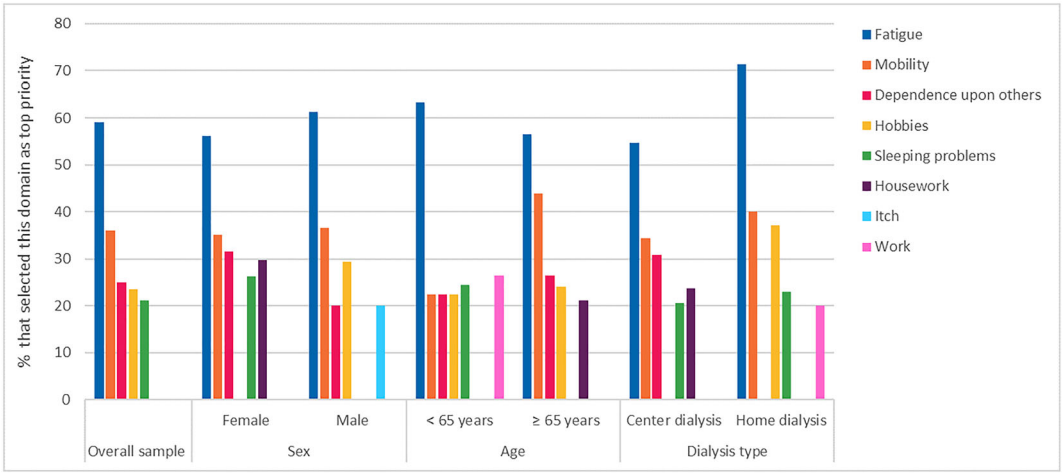

FIGURE 1 Top 5 of problems patients consider to be most relevant, ordered from most to least prominent for the overall sample and categorized by sex, age, and dialysis type. In the age category <65 years, a top 6 is shown because of equal scores for mobility, dependence upon others, and hobbies (fourth place) [Color figure can be viewed at wileyonlinelibrary.com]

Both men and women listed fatigue and mobility as their most prominent problems. In comparison to women, men placed more importance on hobbies (third vs. sixth place) and itch (fourth vs. ninth place), while women placed more importance on housework (fourth vs. 12th place).

To assess possible age differences, we categorized age into below 65 years ($n = 59$) and 65 years or older ($n = 116$). In comparison to patients aged 65 years or older, patients aged below 65 years rated work (second vs. 14th place) and sleeping problems (third vs. sixth place) as more important, while older patients placed more importance on mobility (second vs. fourth place).

To assess possible differences in dialysis type, we categorized the different types of dialysis into either "center dialysis" (e.g., in-center hemodialysis at day or night; $n = 137$) or "home dialysis" (e.g., peritoneal dialysis or home hemodialysis; $n = 38$). In comparison to patients treated with home dialysis, patients treated with center dialysis placed more importance on dependence upon others (third vs. 11th place) and housework (fourth vs. 11th place), whereas home dialysis patients rated hobbies (third vs. sixth place) and work (fifth versus 12th place) as more important.

For a complete listing of priorities of the overall sample and categorized by patient characteristics, see Table S1.

3.3 | Descriptive analysis of domains of functioning

Table 2 shows the means and SDs of the assessed domains of functioning, specified for the overall sample and categorized by sex, age, and dialysis type. When we compared the current sample's scores to the general population, we found our sample to report worse functioning on the domains physical health, social functioning, and daily activities. Patients' mental health was similar or slightly worse in comparison to the general population.[18–22] Current sample's scores were comparable to other dialysis populations (Table S2).[20,23,24]

3.4 | Associations of patient characteristics with domains of functioning

See Table 2 for an overview of the domains of functioning and significant differences between patient characteristics. In comparison to men, women reported a lower HRQOL as shown by their lower scores on the physical ($P = 0.002$) and mental health composite ($P = 0.03$) and the subscales physical functioning ($P = 0.01$), general health ($P = 0.004$), emotional well-being ($P = 0.03$), social functioning ($P = 0.001$), and role limitations due to physical problems ($P = 0.002$). In addition, women reported more fatigue ($P = 0.02$), sleep disturbance ($P = 0.02$), and anxiety ($P = 0.01$). No differences were found for other domains ($P \geq 0.07$).

In comparison to patients aged below 65 years, older patients reported worse physical functioning ($P = 0.004$), higher scores on the mental health composite ($P = 0.047$), a better emotional well-being ($P = 0.03$), more vitality ($P = 0.001$), a lower Sleep Problem Index ($P = 0.02$), more adequate sleep ($P = 0.001$), and less fatigue ($P = 0.04$). Age groups did not differ in other domains (P values ≥ 0.06). Similar results were observed with age as continuous variable instead of dichotomous. In comparison to patients treated with home dialysis, patients treated with center dialysis scored worse on physical functioning ($P = 0.03$) and emotional well-being ($P = 0.046$), but no differences were found for other domains (P values ≥ 0.09). Albumin level was not related to any of the assessed domains of functioning.

Based on these associations, we decided to include corrections to the general norms to adjust for sex, age, and dialysis type. Charlson

TABLE 2 Descriptive analysis of domains of functioning as shown by the means and standard deviations, specified for the overall sample and categorized by sex, age, and dialysis type

Domain of functioning	Overall sample	Sex		Age		Dialysis type	
		Female	Male	<65 years	≥65 years	Center dialysis	Home dialysis
	n = 150–174	*n* = 62-74	*n* = 88–101	*n* = 53–59	*n* = 94–116	*n* = 115–136	*n* = 32–38
Physical health							
Physical health composite score (RAND SF 36; *T*-score)	36.3 ± 10.4	**33.2 ± 9.0**	**38.4 ± 10.9**	36.2 ± 10.3	36.3 ± 10.6	35.5 ± 10.3	38.7 ± 10.6
Physical functioning	34.3 ± 12.0	**31.5 ± 11.7**	**36.3 ± 11.8**	**37.9 ± 11.3**	**32.4 ± 11.9**	**33.2 ± 11.9**	**38.1 ± 11.6**
Pain	47.0 ± 12.0	45.0 ± 12.0	48.4 ± 11.8	45.1 ± 12.9	47.9 ± 11.4	46.5 ± 12.0	48.8 ± 11.8
General health	35.8 ± 8.8	**33.6 ± 7.1**	**37.4 ± 9.6**	34.8 ± 8.3	36.3 ± 9.0	35.2 ± 8.2	37.7 ± 10.4
Experienced pain last 4 weeks (VAS)	3.4 ± 2.9	3.9 ± 3.0	3.1 ± 2.8	3.7 ± 3.0	3.3 ± 2.9	3.6 ± 2.8	2.7 ± 3.1
Fatigue (CIS)	35.4 ± 13.2	**38.2 ± 13.0**	**33.5 ± 13.1**	37.9 ± 12.1	34.2 ± 13.7	35.2 ± 13.3	36.4 ± 13.0
Experienced fatigue last 4 weeks (VAS)	5.4 ± 2.7	5.6 ± 2.7	5.2 ± 2.8	**5.9 ± 2.5**	**5.1 ± 2.8**	5.3 ± 2.7	5.7 ± 2.9
Sleep Problem Index (MOS Sleep Scale)	34.8 ± 20.1	38.2 ± 20.2	32.5 ± 19.7	**40.3 ± 22.5**	**32.0 ± 18.1**	34.7 ± 19.9	35.4 ± 20.7
Sleep disturbance	38.2 ± 26.2	**43.7 ± 27.4**	**34.2 ± 24.7**	43.3 ± 28.9	35.6 ± 24.4	38.6 ± 26.1	36.8 ± 27.0
Sleep adequacy	61.5 ± 28.8	58.8 ± 27.9	63.5 ± 29.4	**50.5 ± 30.6**	**67.3 ± 26.1**	63.1 ± 27.3	56.1 ± 33.3
Sleep quantity, hrs.	6.6 ± 1.7	6.7 ± 1.7	6.5 ± 1.7	6.4 ± 1.8	6.7 ± 1.6	6.6 ± 1.7	6.5 ± 1.7
Somnolence	40.5 ± 20.5	39.3 ± 20.0	41.4 ± 21.0	38.4 ± 19.8	41.6 ± 20.9	40.3 ± 20.3	41.1 ± 21.8
Snoring	33.9 ± 32.2	33.5 ± 31.4	34.2 ± 32.9	37.0 ± 32.8	32.3 ± 31.9	33.5 ± 31.7	35.6 ± 34.4
Shortness of breath or headache	14.8 ± 23.8	17.2 ± 24.7	13.0 ± 23.0	17.6 ± 24.7	13.3 ± 23.2	15.8 ± 24.7	11.1 ± 20.1
Itch (ISDL)	6.7 ± 3.5	7.1 ± 3.6	6.4 ± 3.4	6.5 ± 3.5	6.8 ± 3.5	6.6 ± 3.3	7.3 ± 4.0
Experienced itch last 4 weeks (VAS)	3.6 ± 2.7	3.8 ± 2.8	3.4 ± 2.7	3.4 ± 2.7	3.7 ± 2.8	3.5 ± 2.7	3.8 ± 2.8
Mental health							
Mental health composite score (RAND SF 36; *T*-score)	44.9 ± 10.2	**42.8 ± 9.3**	**46.4 ± 10.6**	**42.7 ± 10.6**	**46.1 ± 9.8**	44.4 ± 10.5	46.8 ± 8.8
Emotional well-being	49.0 ± 9.9	**47.1 ± 9.5**	**50.3 ± 10.1**	**46.6 ± 10.5**	**50.1 ± 9.5**	**48.1 ± 10.2**	**51.8 ± 8.5**
Vitality	45.7 ± 9.2	44.7 ± 9.2	46.5 ± 9.2	**42.4 ± 8.3**	**47.4 ± 9.2**	45.9 ± 9.0	45.2 ± 9.9
Anxiety (HADS)	4.2 ± 3.7	**5.1 ± 3.8**	**3.5 ± 3.5**	4.7 ± 4.0	3.9 ± 3.6	4.3 ± 3.8	3.7 ± 3.3
Depression (HADS)	5.7 ± 3.7	5.6 ± 3.3	5.7 ± 3.9	5.6 ± 4.2	5.7 ± 3.4	5.8 ± 3.5	5.1 ± 4.2

(Continues)

TABLE 2 (Continued)

Domain of functioning	Overall sample	Sex		Age		Dialysis type	
		Female	Male	<65 years	≥65 years	Center dialysis	Home dialysis
	$n = 150$–174	$n = 62$–74	$n = 88$–101	$n = 53$–59	$n = 94$–116	$n = 115$–136	$n = 32$–38
Social functioning							
Social functioning (RAND SF 36)	40.9 ± 12.7	**37.2 ± 11.7**	**43.6 ± 12.8**	40.8 ± 12.5	40.9 ± 12.9	40.2 ± 12.8	43.2 ± 12.2
Daily activities							
Role limitations due to physical problems (RAND SF 36; *T*-score)	37.8 ± 12.1	**34.4 ± 10.7**	**40.1 ± 12.4**	37.6 ± 11.4	37.9 ± 12.5	37.2 ± 12.2	40.0 ± 11.5
Role limitations due to emotional problems (RAND SF 36; *T*-score)	44.7 ± 14.6	43.1 ± 15.0	45.8 ± 14.2	45.7 ± 14.2	44.1 ± 14.8	43.6 ± 15.3	48.3 ± 10.9

Note: Sample sizes vary per analysis due to incidental missing values. Values are given as mean ±standard deviation. Values in **bold** indicate a significant difference between the categories ($P < 0.05$).
Abbreviations: CIS, Checklist Individual Strength; HADS, Hospital Anxiety Depression Scale; ISDL, Impact of Chronic Skin Disease on Daily Life; MOS Sleep Scale, Medical Outcomes Study Sleep Scale; RAND SF 36, RAND Short Form-36 Health Status Inventory; VAS, 11-point Visual Analogue Scale.

Comorbidity was not taken into account because of its strong correlation with age ($r = 0.81$; $P < 0.001$) and only weak correlations with some domains of functioning (r values ≤ 0.29).

3.5 | Norm scores questionnaires domains of functioning

Table 3 shows the norm scores of the questionnaires measuring domains of functioning including corrections to adjust for sex, age, and dialysis type. Using these corrections, it is possible to classify symptom severity in an individual patient in comparison to similar dialysis patients (see Table 3 for a calculation model).

4 | DISCUSSION

To get a better understanding of individual needs, disease-specific norm scores were calculated for questionnaires measuring commonly reported problems and included corrections to the general norms to adjust for patient characteristics. Adequate, disease-specific norms are indispensable in making a good evaluation of a patient's health in comparison to similar patients and show which aspects of patients' functioning require extra attention. Moreover, knowing what patients consider important aids clinicians in screening procedures and tailoring treatment to individual patient needs.

Fatigue was rated as patients' explicit number one priority regardless of sex, age, or dialysis type. This is consistent with earlier findings[25] and was also reflected in patients' high fatigue and low vitality scores and frequent sleeping problems. Fatigue in dialysis patients is a highly prevalent, complicated phenomenon with multiple causes.[26] As fatigue itself is an inherent part of dialysis treatment that cannot be prevented, focusing on teaching patients to better cope with fatigue could be highly valuable. Psychosocial interventions have shown to be effective in dialysis patients, especially when they include stress-management and relaxation techniques.[27] Additionally, patients with multiple sclerosis,[28] cancer,[29] rheumatoid arthritis,[30] and chronic fatigue syndrome[31] struggling with fatigue are found to benefit from cognitive behavioral therapy.

We observed numerous differences in patient characteristics, both in priorities and functioning. With regard to sex, women reported poorer functioning in physical, mental, and social domains and indicated more difficulties in daily activities. This is in line with previous observations in the dialysis population where women, compared to men, reported a lower HRQOL, a higher symptom burden, and more symptoms of depression and anxiety.[32] Regarding age, we found younger patients—despite better physical functioning—to report more sleeping problems and a poorer mental health compared to patients aged 65 years or older. Taking into account that younger patients rated both sleeping problems and work as top priorities, it is likely that work responsibilities or the inability to work are important causes of distress. This finding is supported by previous research showing retirement to be associated with a substantial decrease of

TABLE 3 Norm scores for questionnaires measuring domains of functioning, including correction factors for sex, age, and dialysis type

	Sex		Age		Dialysis type			
Domain of functioning	Female	Male	<65 years	≥65 years	Center dialysis	Home dialysis	Norm scores	
Physical health								
Physical health composite score (RAND SF 36)	+3.1	−2.1	+0.1	0.0	+0.8	−2.4	Mild:	>31.1
							Moderate:	31.1–25.9
							Severe:	<25.9
Physical functioning	+2.8	−2.0	−3.6	+1.9	+1.2	−3.8	Mild:	>28.3
							Moderate:	28.3–22.3
							Severe:	<22.3
Pain	+2.0	−1.4	+1.9	−0.9	+0.5	−1.8	Mild:	>41.0
							Moderate:	41.0–35.0
							Severe:	<35.0
General health	+2.2	−1.6	+1.0	−0.0.5	+0.6	−1.9	Mild:	>31.4
							Moderate:	31.4–27.0
							Severe:	<27.0
Experienced pain last 4 weeks (VAS)	−0.5	+0.3	−0.3	+0.1	−0.2	+0.7	Mild:	<4.9
							Moderate:	4.9–6.3
							Severe:	>6.3
Fatigue (CIS)	−2.8	+1.9	−2.5	+1.2	+0.2	−1.0	Mild:	<42.0
							Moderate:	42.0–48.6
							Severe:	>48.6
Experienced fatigue last 4 weeks (VAS)	−0.2	+0.2	−0.5	+0.3	+0.1	−0.3	Mild:	<6.8
							Moderate:	6.8–8.1
							Severe:	>8.1
Sleep Problem Index (MOS Sleep Scale)	−3.4	+2.3	−5.5	+2.8	+0.1	−0.6	Mild:	<44.9
							Moderate:	44.9–54.9
							Severe:	>54.9
Sleep disturbance	−5.5	+4.0	−5.1	+2.6	−0.4	+1.4	Mild:	<51.3
							Moderate:	51.3–64.4
							Severe:	>64.4
Sleep adequacy	+2.7	−2.0	+11.0	−5.8	−1.6	+5.4	Mild:	>47.1
							Moderate:	47.1–32.7
							Severe:	<32.7
Sleep quantity, hrs.	−0.1	+0.1	+0.2	−0.1	0.0	+0.1	Mild:	>5.8
							Moderate:	5.8–4.9
							Severe:	<4.9
Somnolence	+1.2	−0.9	+2.1	−1.1	+0.2	−0.6	Mild:	<50.8
							Moderate:	50.8–61.0
							Severe:	>61.0
Snoring	+0.4	−0.3	−3.1	+1.6	+0.4	−1.7	Mild:	<50.0
							Moderate:	50.0–66.1
							Severe:	>66.1
Shortness of breath or headache	−2.4	+1.8	−2.8	+1.5	−1.0	+3.7	Mild:	<26.7
							Moderate:	26.7–38.6
							Severe:	>38.6

(Continues)

TABLE 3 (Continued)

Domain of functioning	Sex		Age		Dialysis type		Norm scores	
	Female	Male	<65 years	≥65 years	Center dialysis	Home dialysis		
Itch (ISDL)	−0.4	+0.3	+0.2	−0.1	+0.1	−0.6	Mild:	<8.5
							Moderate:	8.5–10.2
							Severe:	>10.2
Experienced itch last 4 weeks (VAS)	−0.2	+0.2	+0.2	−0.1	+0.1	−0.2	Mild:	<5.0
							Moderate:	5.0–6.3
							Severe:	>6.3
Mental health								
Mental health composite score (RAND SF 36)	+2.1	−1.5	+2.2	−1.2	+0.5	−1.9	Mild:	>39.8
							Moderate:	39.8–34.7
							Severe:	<34.7
Emotional well-being	+1.9	−1.3	+2.4	−1.1	+0.9	−2.8	Mild:	>44.1
							Moderate:	44.1–39.1
							Severe:	<39.1
Vitality	+1.0	−0.8	+3.3	−1.7	−0.2	+0.5	Mild:	>41.1
							Moderate:	41.1–36.5
							Severe:	<36.5
Anxiety (HADS)	−0.9	+0.7	−0.5	+0.3	−0.1	+0.5	Mild:	<6.0
							Moderate:	6.0–7.9
							Severe:	>7.9
Depression (HADS)	+0.1	0.0	+0.1	0.0	−0.1	+0.6	Mild:	<7.6
							Moderate:	7.6–9.4
							Severe:	>9.4
Social functioning								
Social functioning (RAND SF 36)	+3.7	−2.7	+0.1	0.0	+0.7	−2.3	Mild:	>34.6
							Moderate:	34.6–28.2
							Severe:	<28.2
Daily activities								
Role limitations due to physical problems (RAND SF 36)	+3.4	−2.3	+0.2	−0.1	+0.6	−2.2	Mild:	>31.8
							Moderate:	31.8–25.7
							Severe:	<25.7
Role limitations due to emotional problems (RAND SF 36)	+1.6	−1.1	−1.0	+0.6	+1.1	−3.6	Mild:	>37.4
							Moderate:	37.4–30.1
							Severe:	<30.1

Note: Cut-off scores for mild symptoms are calculated by either adding or subtracting 0.5 SD to/from the mean in our sample, depending on the direction of the scale. Cut-off scores for severe symptoms are calculated by adding or subtracting 1 SD to/from the mean in our sample. Cut-off scores for moderate symptoms are in between these values. Individual measured scores in the different questionnaires are corrected with norm scores from this table in order to determine if the individual has mild, moderate of severe problems in that domain. Example: an individual score of 31.0 on the physical health composite score of a male patient aged 58 treated with center HD will be corrected to 26.6 (31.0–2.1 [correction male] − 2.4 [correction center dialysis] + 0.1 [correction < 65 years] = 26.6), which can be interpreted as moderate problems on this domain.

Abbreviations: CIS, Checklist Individual Strength; HADS, Hospital Anxiety Depression Scale; ISDL, Impact of Chronic Skin Disease on Daily Life; MOS Sleep Scale, Medical Outcomes Study Sleep Scale; RAND SF 36, RAND Short Form-36 Health Status Inventory; VAS, 11-point Visual Analogue Scale.

fatigue and depressive symptoms, in particular among patients with a chronic disease.[33] With respect to dialysis type, especially in center dialysis patients' dependence was seen as a major problem rating it as their third priority, whereas patients treated at home rated dependence only as their 11th priority. This difference is probably the result of inherent differences in disease severity between these dialysis modalities and the fact that home dialysis offers greater autonomy and flexibility to fit dialysis into normal daily life.[34]

All of these differences in priorities and functioning—either related to sex, age, or dialysis type—highlight the importance of having attention for the specific needs of each individual patient. These results are in line with earlier suggestions stating that the nephrology community should better recognize and understand the uniqueness of each individual's experience with ESKD. In turn, this will lead to better patient-centered care and better HRQOL.[35] Patient-centered care involves understanding and respecting individual patients' values, preferences, and needs and offering timely, tailored management of symptoms. Taking the patient's experience into account is linked to better satisfaction and perceived quality of care[36] and better health outcomes in a range of diseases.[37]

A specific strength of this study is the inclusion of the patient perspective by asking patients themselves for their opinion on priorities. Another strength is the calculation of disease-specific cut-off scores indicating symptom severity for a variety of health domains and the possibility to correct for patient characteristics. This strategy allows clinicians to detect remarkably high or low scores in an individual patient in comparison to patients similar in sex, age, and dialysis type. In addition, we selected multiple questionnaires per construct to offer clinicians some flexibility. We selected both questionnaires that can be answered in a short period of time to get quick, global insight in a problem, and longer questionnaires for more detail.

A limitation of the study is the relatively small sample size. For more robust calculations of the disease-specific norms, we would ideally prefer a larger sample, especially for the calculation of the corrections per patient characteristic. Although our data should be interpreted with caution, this study offers a first step into more norm-based screening methods in the dialysis population. Moreover, our sample is likely to be a good reflection of the Dutch dialysis population as shown by the high similarity with the national statistics (RENINE annual report).[17] Note, however, that since this is a Dutch population, the results may not generalize to dialysis populations in other countries.

Despite the need for further research, our results provide some practical suggestions to optimize personalized health care in dialysis care. The following four steps are advised: (1) patients complete short regular screening questionnaires as part of routine care; (2) clinicians interpret the scores using disease-specific norms and correction factors; (3) during consultation, the clinician provides feedback on patients' scores; and (4) depending on the outcomes, personalized treatment strategies can be offered. This could include personalized psychosocial treatment, but also adjustment of dialysis care itself.[38] Dialysis prescription, for example, is directly related to health outcomes such as HRQOL and mortality. Especially with regard to pill burden and polypharmacy (i.e., using multiple medications), tailoring could help to decrease the risk of adverse effects.[38–41] By performing these four steps, clinicians are able to closely monitor patients' health while contributing to efficient and patient-centered care.[6,42,43] Providing feedback on the screening results is highly valued by patients[43] and can be the starting point of discussing priorities for improvement. Ultimately, the screening results and patients' priorities form the basis of tailoring treatment to individual patient needs. Tailored psychosocial treatment is found successful in different chronic conditions[30,42,44] making it likely to be beneficial to dialysis patients as well.

5 | CONCLUSION

In summary, while using a patient perspective, the current study evaluated patients' most prominent problems and calculated norm scores for several questionnaires measuring these problems. Fatigue was patients' explicit number one priority. Regarding other domains of functioning, responses on the priority lists were quite heterogeneous when we categorized the results by sex, age, and dialysis type. These differences were reflected in the results on functioning as well. Resultantly, to get a better understanding of individual needs, these patient characteristics were incorporated as correction factors to the general norms. Adequate assessment is an essential element of patient-centered care and will help to better understand and respect individual patient needs and guide treatment accordingly.

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SUPPORTING INFORMATION

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