Patient satisfaction with haemodialysis care: An international survey

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Patient satisfaction with haemodialysis care: An international survey

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Abstract

Objectives

To evaluate patient experiences of specific aspects of haemodialysis care across several countries

Design

Cross-sectional survey using the Choices for Healthy Outcomes in Caring for End-Stage Renal Disease (CHOICE) questionnaire

Setting

Haemodialysis clinics within a single provider in Europe and South America

Participants

2748 adults treated in haemodialysis

Primary and secondary outcomes

The primary outcome was patient satisfaction with overall care. Secondary outcomes included patient experiences of individual aspects of dialysis care

Results

2145 (78.1%) adults responded to the questionnaire. Fewer than half (46.5% [95% confidence interval, 44.5 to 48.6]) rated their overall care as excellent. Global perceptions of care were uninfluenced by most respondent characteristics except age and depressive symptoms; older respondents were less critical of their care (adjusted odds ratio for excellent rating 1.44 [1.01-2.04]) and those with depressive symptoms were less satisfied (0.56 [0.44 to 0.71]). Aspects of care that respondents most frequently ranked as excellent were staff attention to dialysis vascular access (54 [52-56]%), caring of nurses (53 [51-55]%), staff responsiveness to pain or discomfort (51 [49-53]%), caring, helpfulness and sensitivity of dialysis staff (50 [48-52]%), and ease of reaching dialysis staff by telephone (48 [46-50]%). The aspects of care least frequently ranked as excellent were information provided when choosing a dialysis modality (23 [21-25]%), ease of seeing a social worker (28 [24-

32]%), information provided about dialysis (34 [32-36]%), accuracy of information from nephrologist (for example, about prognosis or likelihood of a kidney transplant) (37 [35-39]%), and accuracy of nephrologists' instructions (39 [36-41]%).

Conclusion

Haemodialysis patients are least satisfied with the complex aspects of care. Patients' expectations for accurate information, prognosis, the likelihood of kidney transplantation and their options when choosing dialysis treatment need to be considered when planning healthcare research and healthcare practices.

Article summary

Strengths and limitations of this study

- The study is based on a large multinational survey of patients with chronic kidney failure needing treatment with long-term dialysis. There were no specific exclusions other than refusal or inability to complete the survey questions

- This study adds knowledge across a large cohort of the specific aspects of dialysis care that fewer patients find satisfactory

- The limitations were the lack of data about the health service characteristics that might have contributed to patient experiences as well as linkages to patient relevant outcomes

Introduction

Patients treated with haemodialysis experience mortality rates approaching 15-20% each year[1] and have profoundly impaired quality of life,[2 3] contributed to by severe symptoms of fatigue, low appetite, pain, sleep disorders, anxiety, nausea, and restless legs.[4] While interventions in haemodialysis trials and healthcare regulations have largely focused on biomarker endpoints and quantitative outcomes (mortality and cardiovascular events) to evaluate care, dialysis patients value normalization of their lives, economic efficiency in healthcare, and how their personal preferences are met, including reducing dietary and travel restrictions.[5 6] This mismatch in patient, provider and research priorities has resulted in clinical research and practice that have not improved patient-centred outcomes for dialysis patients[7-11] and consumed considerable resources.[12]

Given that patients treated with in-centre haemodialysis attend dialysis care at least three times per week for several hours each time, their experiences of dialysis care are likely to have an important impact on living with chronic illness.[3 13] By contrast, health funders have traditionally used only clinical performance indicators such as anaemia, blood pressure, nutrition, dialysis vascular access and adequacy of solute removal to evaluate and allocate reimbursement for dialysis provision.[14-17] While improving patient satisfaction with dialysis treatment has the potential to increase quality of life and improve patient-level outcomes, data to inform this objective are scarce.[18 19] Studies indicate that healthcare delivery in the latter stages of chronic kidney disease such as predialysis nephrology care, multidisciplinary management, psycho-education interventions and prognosis communication may improve quantitative health outcomes in the dialysis setting, but there is little information on the effects of these strategies on outcomes relevant to patients, that include symptoms, function and quality of life.[20-24] In addition, evaluations of patient experiences of haemodialysis care are available and can shape our knowledge about what patients value, but in existing studies smaller population sizes within single countries limit the power to adjust for case-mix[19] and perceptions of care are limited to global scores which may restrict our understanding of

the contributions of specific, and potentially modifiable, aspects of care on overall patient experience.[18]

Greater understanding of how patients experience all facets of long-term dialysis is needed to inform the design of large-scale trials which evaluate targeted healthcare strategies to improve the lives of dialysis patients in ways they value. Accordingly, we aimed, for the first time, to describe patient satisfaction with haemodialysis care in a large multi-national cohort to assess patients' experiences of haemodialysis care while accounting for clinical and demographic characteristics.

Methods

Participants

We used data from Diaverum, a network which provides renal care including long-term in-centre haemodialysis treatment for more than 20,000 patients in Europe and South America and surveys patients at least annually about their satisfaction with care. We conducted a cross-sectional analysis of routinely-gathered survey data collected in 2008. We selected a convenience sample of 15% of patients in the network from clinics that were willing to contribute. Data were included for selected patients who were aged 18 years or older and treated with haemodialysis between January and June 2008 in centres located in Europe (Hungary, Italy, Poland, and Portugal) and South America (Argentina). All clinical centres were managed during the study period according to the same standards of care. Of the 2748 patients selected (Argentina, n=670; Hungary, n=683; Italy, n=880; Poland, n=477; Portugal, n=38), 2145 (78.1%) responded and 1846 (67.2%) provided complete responses to all questions. We obtained ethics approval to analyse routinely-gathered clinical data from the University of Sydney Human Research Ethics Committee (project number 2013/031). The study was conducted according to the requirements of the Declaration of Helsinki.

Key measures

We collected data from patient responses to the Choices for Healthy Outcomes In Caring for End-stage kidney disease (CHOICE) questionnaire, which evaluates satisfaction with dialysis treatment (see the **eAppendix** for the full survey).[25] The CHOICE questionnaire was originally developed by Rubin and colleagues using a focus group of long-term in-centre haemodialysis and home-based peritoneal dialysis patients to identify aspects of dialysis care most important to them. The items identified were then ranked by a larger number of long-term dialysis patients to identify the top 25 items they considered extremely important. The questionnaire asks 20 questions about patients' experiences relating to these different aspects of dialysis care on a 5-point Likert scale (poor, fair, good, very good, excellent). In addition, three questions ask patients to rate the overall quality of their care (poor, fair, good, very good, excellent, or not applicable), how much about their care could be better (many things, a few things, one or two things, and nothing could be better at all), and whether they would recommend their care service to others who may need dialysis care (definitely not, probably not, not sure, probably yes, and definitely yes) (**eTable 1)**. In addition, we summarized measures of key performance indicators for dialysis within each country (**eTable 2**) for the two quarters in which satisfaction data were collected and reported these as overall performance scores for each participating country.

In the present analysis, the question "How easy is it to meet the social worker when you want to?" was only included in the annual survey in Hungary and the two global questions about care "Thinking about your dialysis care overall, how much could be better?" and "Would you recommend your dialysis centre to a friend or relative who needs dialysis?" were omitted in the annual survey of Italian patients.

Surveys were provided to patients by dialysis clinical staff during routine dialysis care. Patients self-completed the questionnaires anonymously during a dialysis session and data were de-identified. We then linked survey data to concurrent demographic, clinical, and laboratory information in a clinical database using a unique patient identifier; additional data were provided where necessary by the treating physician on a standardized case report form. We used questionnaires in the patients' native language after translation and linguistic validation by the MAPI Institute (http://www.mapi-institute.com).

Analysis

We considered a response to the survey as complete when interpretable answers were provided for all survey questions and partially complete when one or more answers was missing. We used chi-square tests and Mann-Whitney U tests to compare the characteristics of patients who responded to the survey with those who did not. The primary outcome of interest was the proportion of respondents who evaluated their overall care as 'excellent'. We also estimated the proportion of respondents who evaluated each separate dimension of care as 'excellent'. To account for the multilevel nature of the data (patients clustered within countries) and to control simultaneously for the possible confounding effects of the different variables, we used multivariate multilevel logistic regression models.[26 27] We constructed clustering and case-mix adjusted models that controlled for the following potential confounding variables: age, gender, education level, occupational status, marital status, distance to travel to the dialysis centre, kidney transplant waiting list status, comorbid conditions (diabetes mellitus, hypertension, cardiovascular event), depression score, cause of end-stage kidney disease, duration of dialysis per session, dialysis dose, adequacy of dialysis, and serum values of haemoglobin and phosphorus. We performed multilevel logistic regression using the SAS language macro routine Proc GLIMMIX (SAS Institute Inc., Cary, NC; Release 9·1, 2002-2003; http://www.sas.com).

Results

Characteristics of patients in the network and respondents to questionnaire

Respondents were younger and lived closer to their dialysis center than non-respondents (**Table 1**). Questionnaire response rates differed by country; patients in Portugal were most likely to respond to the survey (97.4%), with decreasing response rates in Argentina (81.9%), Hungary (81.4%), Poland

(74.4%), and Italy (73.6%). Overall, respondents were 61.0 ± 15.5 years, most were men (55.5%), 40.2% had 6 to 8 years of school education, and about half had depressive symptoms according to the Center for Epidemiological Studies-Depression (CES-D) Scale (score of 18 of above). Two-thirds of respondents were married (60.8%), most were unemployed (68.8%), and a minority had previously received a kidney transplant (6.9%).

Survey responses

Fewer than half of respondents rated their overall care as excellent (1057/2271; 46.5% [95% confidence interval (CI), 44.5 to48.6%]) and about three-quarters rated their care as excellent or very good (1783/2271; 78.5% [CI 76.8 to 80.2%]) (**Figure 1**). The proportion rating their overall care as excellent was lowest in Poland (13.7%), with an increasing proportion in Argentina (30.3%), Italy (61.2%), Hungary (63.5%), and Portugal (83.8%) (**eTable 1**).

Table 2 shows the association between respondent characteristics and the proportion rating haemodialysis care as excellent. In analyses clustered by country and controlled for demographic and clinical variables, older respondents were more likely to consider care excellent (adjusted odds ratio [AOR] for those 70 years or older, 1.44 [CI, 1.01 to 2.04] compared with those aged 18 to 49 years) and those with depressive symptoms were less likely to consider that care met excellent standards (AOR, 0.56 [CI, 0.44 to 0.71]). Gender, education, marital status, comorbidity (including diabetes and cardiovascular disease) and the time spent on dialysis each week were not associated with perspectives of overall care.

Figure 1 shows the proportion of respondents who considered that nothing about their care could be better and **eTable 3** provides responses according to clinical, demographic and treatment-based characteristics. Overall, about one-third of respondents considered that nothing about their care could be better (486/1477; 32.9% [CI, 30.6% to 35.3%]). Respondents aged 70 years or older (AOR, 2.20 [CI, 1.47 to 3.31]) and those living further away from their dialysis centre (AOR, 1.39 [CI, 1.04 to 1.85]) were more likely to consider that no aspect of their care required improvement. In the four countries in which this question was asked (Argentina, Hungary, Poland, and Portugal), compared with Argentina, patients in Hungary (AOR, 1.37 [CI, 1.06 to 1.77]) and Poland (AOR, 1.82 [CI, 1.37 to 2.42]) were more likely to consider than nothing about their care needed to be changed.

In the four countries in which the question “would you recommend your dialysis centre to a friend or relative who needed dialysis” was asked, 1022 of 1587 respondents (64.4% [CI, 62.0 to 66.7%]) would definitely recommend their dialysis centre. Older respondents (AOR, 1.84 [CI, 1.24-2.74]) and those living further from their dialysis centre (AOR, 1.37 [CI, 1.03-1.83]) were more likely to recommend their dialysis centre to others for care, whereas those with depressive symptoms were less likely to recommend their care to others (AOR, 0.67 [CI, 0.51 to 0.87]) (**eTable 4**). Compared to Argentina, strong recommendations would more likely be made by respondents in Hungary (AOR 2.38 [CI 1.84-3.07]) and Portugal (AOR 28.2 [CI 3.84-207.39]).

The five items that respondents rated most frequently as excellent were “attention of staff to cleanliness of the dialysis vascular access site” (54% ranked as excellent), “caring and helpfulness of nurses” (53%), “response of staff to pain or discomfort” (51%), “caring, helpfulness and sensitivity of dialysis staff” (50%), and “ease of reaching staff by telephone” (48%) (**Figure 1**). The five items rated least frequently by respondents as excellent were “the amount of information when choosing dialysis modality”(23%), “the ease of seeing a social worker when needed” (28%), “amount of information from dialysis staff” (34%), “accuracy of information from nephrologist including prognosis and likelihood of getting a kidney transplant” (37%), and “accuracy of instructions from nephrologist” (39%). In general, the amount of caring and concern shown by staff, particularly by nurses, and the ability of patients to contact dialysis staff were ranked highly, whereas the amount and delivery of information about treatment choices and prognosis as well as access to social worker staff and nephrologists were ranked lowest.

A composite measure of key performance indicators were similar in the included countries during the recruitment period (in descending order with a higher value indicating higher performance:

Hungary 1535, Portugal 1551, Italy 1543, Poland 1381, and Argentina 1303) and were associated with the proportion of respondents reporting excellent overall care (for each unit increase in performance score, the proportion of respondents who ranked care as excellent increased by 0.21% (95% CI -0.02% to 0.44%).

Discussion

We report the largest study of patient satisfaction with dialysis care to date and identify specific deficits in long-term dialysis care across several countries. Most respondents viewed their overall dialysis care as below excellent and needing improvement. Specifically, while the majority of respondents approved of the more technical aspects of dialysis treatment (attention to the cleanliness of the dialysis vascular access site, caring and helpfulness of nurses and dialysis staff, and attention by staff to immediate needs (pain, discomfort, sterile procedures)), a minority were satisfied with the more complex and integrated components of care. These were the accuracy and amount of information given by staff to patients about their dialysis treatment, prognosis and making choices between peritoneal dialysis and haemodialysis in addition to support from social worker staff. Older respondents were generally less critical of their haemodialysis care, while those with depressive symptoms were less frequently satisfied. Other demographic and clinical features did not reliably influence perceptions of overall care and country of treatment had inconsistent effects on satisfaction. Better dialysis care performance scores were associated with higher overall patient satisfaction.

Our patients' perspectives together with other similar studies from the United States[19] and The Netherlands[18] emphasise that deficiencies in dialysis care are consistently found and need to be considered specifically when conducting research to improve dialysis patient outcomes. This is particularly relevant as existing interventions in the dialysis setting, including anaemia management,[7] control of phosphorus[28] and parathyroid hormone levels,[29] dialysis dose and flux,[9] and starting dialysis earlier[8] have not improved patient-wellbeing despite evaluation in thousands of patients. Our respondents, consistent with the findings of others,[30-32] report specifically receiving inadequate information about their illness journey and as well as their dialysis treatment options. In our and other chronic diseases settings, patients report needing more information about the causes and progression of their disease, disease symptoms and their impact, and social and financial support.[33] [34]Patients, often due to the competing demands of daily life, rely on healthcare professional to initiate discussions about care planning and not having future-oriented conversations reduces patients' capacity for hope.[35] Patients perceive poor communication as reflecting secrecy, misinformation and insensitivity. Subsequently, inadequate information reduces the ability of patients and their families to care for themselves and induces worry.[33] While education strategies increase patients' willingness to choose self-care dialysis,[23] the wider effect of educational interventions in the dialysis setting that answer unmet questions about disease trajectory and treatment choices with the aim of improving patient experiences of end-stage kidney disease are not well understood and warrant larger-scale trials. Research in other settings suggest specific interventions to improve information provision, such as training and support for healthcare staff in communication and basic counseling, and overcoming barriers to good communication including addressing time pressures and understaffed environments and considering innovative non-written methods might be appropriate complex strategies for trials in the dialysis setting.[33]

This study indicates most patients in dialysis settings want more accurate information about their prognosis, in line with experiences of other dialysis patients and those who have cancer.[35 36] Accurate prognostic information empowers patients;[37] when discussions about prognosis do not occur, patients and their families may (incorrectly) fear the worst. For dialysis patients in our study, the information they receive about prognosis is frequently unsatisfactory including specifically understanding their chances of receiving a kidney transplant and their survival. Physicians in other medical specialties similarly provide insufficient information about prognosis[38] and infrequently check their patients' understanding during consultations.[39] Physicians commonly find disclosing prognosis stressful and desire more training and guidance for this aspect of clinical practice.[40] Our findings suggest that meeting patients' expectations about information is an important but potentially neglected aspect of dialysis care and is consistent with data showing that patients are infrequently involved in discussions about prognosis and likelihood of transplantation.[32] The effect of increased clinician training in prognosis provision about survival and transplantation could form the basis of a testable strategy in future health services research in dialysis.

The patient-centred movement in healthcare ('nothing about me without me')[41] has engendered considerable data on the issues of most importance to patients and their families to highlight the mismatch between patients' values and the outcomes routinely measured in research and clinical practice, including for patients with advanced kidney disease.[5 42] While landmark trials in nephrology over the past three decades have measured treatment effectiveness using biomarker levels and major cardiovascular events and survival, emerging data show that patients are frequently willing to forgo survival in exchange for fewer restrictions on their daily life, and prioritize collaborative research aimed at improving the way they feel, function, and survive.[5 6] In addition, contemporary studies of communication and educational strategies as well as complex healthcare service changes in dialysis have used similarly quantitative outcomes to assess treatment effectiveness, which have included urgent dialysis start, vascular access processes, and survival.[20 21 43] We suggest that, in line with patient-centred data, trials of communication or education for dialysis patients might consider aspects of quality of life valued by patients as key outcomes for assessing effectiveness.

Notably, patient satisfaction was largely unrelated to most clinical or demographic patient characteristics despite a large sample size and similar to other studies in the US and The Netherlands, suggesting that lower satisfaction of many aspects of dialysis care is a global patient experience. Older patients in this study rated their overall care more highly, consistent with a recent study of patient perceptions of dialysis care in The Netherlands,[18] and of studies of patient satisfaction across health services more generally,[44 45] despite evidence that older patients may actually receive lower quality care.[46] In contrast, depressive symptoms markedly reduced satisfaction in this study, (even when controlling for markers of health status and comorbidity); similar findings have been reported in other settings.[47] Those with depressive symptoms voluntarily ration the time they have with medical staff, which may in turn impair patient-clinician communication and serve to decrease their satisfaction with care overall.[47]

Limitations of the study

Although we provide considerable satisfaction data for dialysis patients in several countries, our analysis should be interpreted in light of the study limitations. First, we did not evaluate in detail the influence of healthcare systems in which the dialysis clinics were situated (including features such as staffing-levels[48] or number of beds[49]) on patient satisfaction, although we did find an association between overall satisfaction and global clinical performance. While interpersonal relations with healthcare workers are the most frequently mentioned by patients when asked to rate their care, contextual factors relating to conditions of medical services are also described commonly by patients and often lead to negative comments about healthcare.[50] Second, we took a quantitative approach to assessing patients' perceptions, which may be suboptimal for understanding the full range of feelings, values and experiences of receiving dialysis care. In addition, satisfaction and dissatisfaction may not simply be alternative ends of a single spectrum of perception and may in fact exist side-by-side within a patient experience of care.[51] Third, we did not capture satisfaction with a specific healthcare event and surveyed patients who had been treated with dialysis for 3 years on average. The potential lag between pivotal patient experiences and the survey may have introduced recall bias.[52] Fourth, we did not capture longitudinal data to determine any association between perceptions of care and health-related behaviour and outcomes including healthcare utilization, quality of life, or survival. Finally, the findings in this study may not be applicable to other dialysis settings including peritoneal dialysis or home-based haemodialysis care.

Implications of the study

As measures of patient experience are distinctive indicators of health care quality,[52] our analysis suggests several strategies might improve care for patients in the later stages of chronic kidney disease. First, patients need better information about their choices of treatment for end-stage kidney disease including dialysis modalities. A recent systematic review suggests this is optimally provided when the glomerular filtration rate falls below 30 ml/min per 1.73 m ^{2} and well in advance of preparations for dialysis vascular access.[30] Second, formal care strategies that provide patients with information about prognosis and the impact of end-stage kidney disease and its treatments on their life earlier in the course of kidney disease need to be developed and assessed. Current practices for assessing and discussing prognosis are manifestly inadequate[35] and our present reliance on individual physicians to initiate such discussions is not meeting the needs of our patients. Third, better delivery of information about dialysis from both nephrologists and dialysis staff is expected by patients and greater understanding of the information that patients need and optimal mode(s) of delivery may improve care.

Conclusion

This large study of patient satisfaction with different aspects of long-term haemodialysis care suggests that patients' needs are not being fully met. The findings suggest that meeting patient expectations about information on dialysis choices and prognosis may be critical for improving patient experiences of long-term dialysis care and can form the basis for future healthcare services research in the dialysis setting.

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Competing interests

GS is Senior Vice-President of Scientific Affairs at Diaverum. JH is Senior Vice President Medical Operations - Chief Medical Officer of Diaverum. MR, CW, EC, RG, JNF, MT, ML, AB-S, and JD are employees of Diaverum. SP receives a fellowship from the Consorzio Mario Negri Sud, Italy from provided by an unrestricted educational grant from Amgen Dompé. SP is a 2012 L'Oreal UNESCO For Women in Science Australia and New Zealand Fellow.

Ethical approval

We obtained ethics approval for the analyses of routinely collected data from the University of Sydney Human Research Ethics Committee on 27 February 2013. The authorized personnel are Allison Tong, Jonathan Craig and Giovanni Strippoli. The project number for approval was 2013/031 and included approval of the satisfaction survey, the data custodian (Diaverum) and the survey data dated January 2008.

Author contributions

SP designed the study, interpreted data analysis, wrote the first draft and revised the paper. GdB designed the data analysis, cleaned and analyzed data, and drafted and revised the paper. JCC assisted with study design, interpreted the data analysis, and drafted and revised the paper. AT interpreted the data analysis, and drafted and revised the paper. MT assisted with data collection tools, interpreted the data analysis, and drafted revised the paper. FP interpreted the data analysis, and revised the paper. MR monitored data collection for the whole study, assisted with data collection and cleaning, and interpreted the data analysis, and revised the paper. JH and CW interpreted the data analysis, and revised the paper. EC, RG, JNF, MT, ML, AB-S, and JD assisted with data collection, and interpreted the data analysis, and revised the paper. GFMS designed the study and data collection tools, monitored data collection for the whole study, interpreted the data analysis, and drafted and revised the paper. He is the guarantor. All authors had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Presentation as abstract

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Data sharing statement

None available

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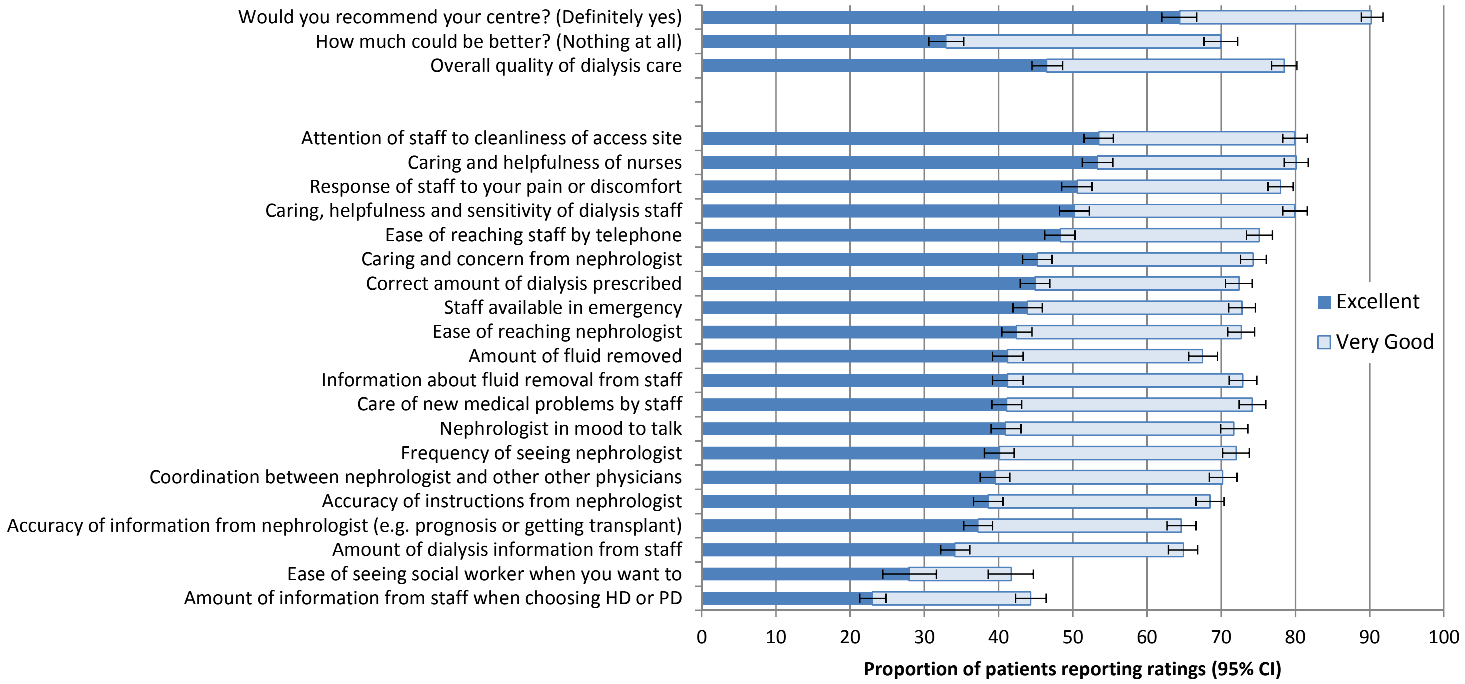
Figure Legends

Figure 1 Probabilities of excellent or very good ratings of overall care by dialysis patients

Figure 1 Probabilities of excellent or very good ratings of overall care by dialysis patients



Tables

Table 1 | Characteristics of participants who responded and those who did not respond to satisfaction survey

Characteristic	Complete or partial response to survey (n=2145)	No response to survey (n=603)	P value
Age, *years*	61.0 (15.5)	62.7 (14.8)	0.04
Gender , *n (%) male*	1190 (55.5)	314 (52.1)	0.14
Highest school education			
≤ 5 years	847 (42.1)	238 (41.6)	0.82
>5 years	1163 (57.9)	334 (58.4)	
Depression score (Center for Epidemiological Studies-Depression Scale)			
< 18	947 (49.6)	67 (46.7)	0.25
≥ 18	963 (50.4)	83 (55.3)	
Married	1303 (60.8)	377 (62.5)	0.43
Living alone	275 (13.0)	97 (16.2)	0.04
Distance of housing from dialysis unit			0.001
< 20 kilometres	1540 (73.1)	392 (65.8)	
> 20 kilometres	567 (26.9)	204(34.2)	
Active on waiting list for transplant	309 (14.4)	72 (11.9)	0.12
Previous kidney transplant	148 (6.9)	28 (4.7)	0.05
Employment			0.002
Employed	331 (15.7)	76 (12.9)	
Unemployed	1451 (68.8)	450 (76.1)	
Receiving benefit/pension	328 (15.6)	65 (11.0)	
Comorbid conditions			
Diabetes mellitus	486 (23.5)	146 (25.1)	0.42
Hypertension	1347 (68.5)	376 (70.3)	0.65
Prior cardiovascular event	472 (22.0)	124 (20.6)	0.45
Time on dialysis, *months*	37.3 (16.3-70.9)	36.0 (17.0-75.7)	0.69
Dialysis treatment time, *minutes per session*	235.9 (20.5)	234.3 (23.5)	0.35
Dialysis adequacy, *single pool Kt/V*	1.6 (0.3)	1.5 (0.3)	0.02
Interdialytic weight gain, *kg*	2.29 (1.03)	2.37 (1.09)	0.16
Serum values			
Haemoglobin, *g/l*	11.0 (1.4)	11.0 (1.3)	0.31
Systolic blood pressure, *mmHg*	130.0 (18.0)	128.4 (17.3)	0.07
Serum albumin, *g/l*	3.9 (0.5)	3.9 (0.5)	0.73
Serum phosphorus, *mmol/l*	4.6 (1.4)	4.6 (1.4)	0.69
Serum ferritin, *µg/l*	430 (242-660)	409 (242-672)	0.71
Serum parathyroid hormone, *pmol/l*	282 (162-481)	287 (167-530)	0.23
Antidepressant medication	113 (5.3)	26 (4.3)	0.34
Anxiolytic medication	291 (13.6)	86 (14.3)	0.66
Country			<0.0001
Argentina	549 (81.9)	121 (18.1)	
Hungary	556 (81.4)	127 (18.6)	
Italy	648 (73.6)	232 (26.4)	
Poland	355 (74.4)	122 (25.6)	
Portugal	37 (97.4)	1 (2.6)	

Data are expressed as mean (SD), number (%), or median (25th percentile, 75th percentile). Kt/V refers to the clearance of urea and is a measure of the amount of dialysis received.

Table 2 | Proportion of patients who gave an excellent rating to overall haemodialysis care according to patient characteristics

Characteristic	Excellent rating N (%)	Other rating N (%)	Unadjusted odds ratio	Clustering and case-mix adjusted odds ratio
Age				
18-49 years	183 (19.1)	300 (28.1)	1.00 (reference)	1.00
50-59 years	146 (15.3)	215 (20.1)	1.11 (0.84-1.47)	1.01 (0.70-1.44)
59-69 years	221 (23.1)	218 (20.4)	1.66 (1.28-2.16)	1.18 (0.82-1.69)
≥70 years	406 (42.5)	335 (31.4)	1.99 (1.57-2.51)	1.44 (1.01-2.04)
Male gender	466 (46.1)	483 (43.1)	1.13 (0.95-1.34)	1.12 (0.88-1.44)
Highest school education				
≤5 years	465 (49.0)	375 (35.8)	1.72 (1.44-2.06)	0.95 (0.74-1.21)
>5 years	485 (51.1)	673 (64.2)	1.00 (reference)	1.00
Occupational status				
Employed	120 (12.0)	209 (19.0)	0.59 (0.46-0.75)	0.79 (0.56-1.12)
Unemployed or pension	876 (88.0)	893 (81.0)	1.00	1.00
Married	601 (59.4)	693 (61.8)	0.91 (0.76-1.08)	0.86 (0.67-1.10)
Distance of housing from dialysis unit				
<20 kilometres	741 (73.9)	792 (72.5)	1.00	1.00
>20 kilometres	262 (26.1)	300 (27.5)	0.93 (0.77-1.13	1.18 (0.91-1.54)
Waiting list for kidney transplant	131 (13.0)	176 (15.7)	0.80 (0.63-1.02)	0.80 (0.56-1.14)
Comorbid conditions				
Diabetes mellitus	249 (25.4)	233 (21.6)	1.24 (1.01-1.52)	1.38 (0.78-2.46)
Prior cardiovascular event	248 (24.5)	220 (19.6)	1.33 (1.08-1.63)	0.89 (0.63-1.26)
Center for Epidemiological Studies-Depression Scale score				
<18	472 (52.5)	472 (47.2)	1.00 (reference)	1.00 (reference)
≥18	427 (47.5)	527 (52.8)	0.81 (0.68-0.97)	0.56 (0.44-0.71)
Dialysis adequacy, *single pool Kt/V*				
<1.4	202 (20.6)	245 (22.2)	1.00 (reference)	1.00
≥1.4	778 (79.4)	856 (77.8)	1.10 (0.89-1.36)	1.11 (0.83-1.49)
Serum phosphorus, mmol/l				
<1.45	516 (51.5)	509 (45.9)	1.00 (reference)	1.00
≥1.45	486 (48.5)	601 (54.1)	0.80 (0.67-0.95)	0.96 (0.76-1.23)
Haemoglobin, g/l				
<110	476 (47.6)	537 (48.2)	1.00 (reference)	1.00
≥110	525 (52.4)	578 (51.8)	1.02 (0.86-1.22)	0.90 (0.71-1.14)
Albumin, g/dl				
<3.8	371 (37.8)	369 (33.7)	1.00 (reference)	1.00
3.8-4.0	277 (28.2)	324 (29.6)	0.85 (0.69-1.05)	1.07 (0.80-1.42)
≥4.1	333 (33.9)	401 (36.6)	0.83 (0.67-1.01	0.78 (0.58-1.05)
Systolic blood pressure, mmHg				
≤120	270 (27.2)	353 (32.1)	1.00 (reference)	1.00
121-140	404 (40.6)	441 (40.0)	1.20 (0.97-1.47)	0.89 (0.67-1.19)
≥140	320 (32.2)	307 (27.9)	1.36 (1.09-1.70)	1.03 (0.76-1.40)
Country				
Poland	48 (4.8)	303 (27.0)	0.09 (0.07-0.13)	-
Argentina	172 (17.0)	372 (33.2)	0.28 (0.22-0.35)	-
Italy	405 (40.1)	242 (21.6)	1.00 (reference)	-
Hungary	355 (35.1)	198 (17.7)	1.07 (0.85-1.36)	-
Portugal	31 (3.1)	6 (0.5)	3.09 (1.27-7.51)	-

Clustering and case-mix adjusted model controlled for age, gender, education level, occupational status, marital status, distance from dialysis centre, activity on transplant waiting list, comorbid conditions (diabetes, hypertension, cardiovascular event) depression score, cause of end-stage kidney disease, duration of dialysis per session and dialysis dose, dialysis adequacy (Kt/V), serum values (haemoglobin; phosphorus) and country.

Supplement

eAppendix CHOICE Satisfaction Questionnaire

We want your opinion on the quality of the medical care you receive for your dialysis treatment. Please choose the answer than best reflects your views for each of the questions below. There is no right or wrong answer. We want your opinions.

	Please rate the following *(Fill in the corresponding circle on each line):*	**Poor**	**Fair**	**Good**	**Very Good**	**Excellent**	**Not Applicable to me**
1.	How easy is it to reach the kidney doctor	○	○	○	○	○	○
2.	The nephrologist's caring and concern about you	○	○	○	○	○	○
3.	How often the nephrologist sees you	○	○	○	○	○	○
4.	How often the nephrologist is in a mood to talk with patients	○	○	○	○	○	○
5.	How accurate the nephrologist is about information like your chance of doing well or of getting a transplant	○	○	○	○	○	○
6.	How accurate the nephrologist's instructions to you are	○	○	○	○	○	○
7.	How well the nephrologist makes sure the amount of dialysis you are getting is just right for you	○	○	○	○	○	○
8.	How well the nephrologist and other doctors you see coordinate with each other	○	○	○	○	○	○
9.	How easy it is to reach your dialysis center by telephone	○	○	○	○	○	○
10.	How much attention doctors and nurses pay to cleanliness when they work with your IV or access site	○	○	○	○	○	○
11.	How helpful and caring the nurses at your dialysis center are	○	○	○	○	○	○
12.	How sensitive, helpful, and caring your dialysis center staff are	○	○	○	○	○	○
13.	How well your dialysis center staff responds when you say you are in pain or uncomfortable	○	○	○	○	○	○
14.	The number and kind of staff available to help you in an emergency	○	○	○	○	○	○
15.	How much information you are being given about dialysis	○	○	○	○	○	○
16.	The amount of information you are being given to help you choose between hemodialysis and peritoneal dialysis	○	○	○	○	○	○
17.	How much information you are given about the amount of fluid to take in and take off	○	○	○	○	○	○
18.	How much fluid is removed during your dialysis session	○	○	○	○	○	○
19.	How easy it is to meet the social worker when you want to	○	○	○	○	○	○
20.	How well new medical problems taken care of by the dialysis center staff when they arise	○	○	○	○	○	○
21.	How would you rate the quality of care you have received as a dialysis patient, overall	○	○	○	○	○	○

22. Thinking about your dialysis care overall, how much could be better

Many things	A few things	One or two tings	Nothing could be better at all
○	○	○	○

22. Would you recommend your dialysis center to a friend or relative who needs dialysis

Definitely not	Probably not	Not sure	Probably yes	Definitely yes
○	○	○	○	○

Thank you for completing this survey. Please put your survey in the envelope, seal it, and give it to the clinic coordinator.

eTable 1 | Percentage of patients who rated care as excellent overall and according to country

Satisfaction Domain and Item	Overall cohort	Italy	Argentina	Hungary	Poland	Portugal
Nephrologist						
1. Ease of reaching	983/2316	375 (54.1)	159 (26.3)	351 (58.7)	69 (18.0)	29 (78.4)
2. Caring and concern	1049/2321	426 (61.2)	151 (24.9)	365 (61.0)	76 (19.8)	31 (83.8)
3. Frequency of seeing	928 /2316	395 (56.8)	121 (20.0)	320 (53.8)	64 (16.7)	28 (75.7)
4. In mood to talk	945/2308	414 (59.8)	121 (21.8)	297 (50.0)	74 (19.3)	29 (78.4)
5. Accuracy of information	851/2286	343 (50.4)	105 (17.4)	331 (56.5)	45 (11.8)	27 (73.0)
6. Accuracy of instructions	889/2302	359 (52.3)	111 (18.4)	340 (57.4)	52 (13.6)	27 (75.0)
7. Correct amount of dialysis	1030/2295	479 (68.6)	100 (17.0)	375 (63.6)	48 (12.6)	28 (75.7)
8. Coordination with other physicians	909/2302	397 (57.2)	147 (24.5)	285 (48.4)	53 (13.8)	27 (73.0)
Dialysis Staff						
9. Ease of reaching staff	1110/2299	458 (66.1)	143 (23.9)	428 (72.4)	51 (13.4)	30 (81.1)
10. Attention to cleanliness of access	1235/2308	487 (69.9)	196 (23.7)	452 (76.2)	69 (18.1)	31 (83.8)
11. Caring of nurses	1238/2321	470 (67.2)	214 (35.3)	449 (75.3)	74 (19.3)	3 (83.8)
12. Caring of staff	1166/2322	442 (63.1)	193 (31.8)	423 (71.1)	77 (20.2)	31 (83.8)
13. Response to pain	1162/2298	492 (71.1)	192 (32.1)	408 (68.5)	40 (10.7)	30 (81.1)
14. Staff available in emergency	1001/2281	448 (64.9)	116 (19.6)	375 (63.7)	33 (8.9)	29 (78.4)
15. Amount of dialysis information	776/2273	303 (44.4)	90 (15.3)	321 (53.8)	34 (9.2)	28 (75.7)
16. Amount of information on	513/2230	175 (26.5)	70 (12.0)	229 (39.5)	12 (3.3)	27 (73.0)
17. Information about fluid removal	1041/2268	441 (63.4)	127 (21.8)	412 (70.0)	35 (9.6)	26 (70.3)
18. Amount of fluid removed	917/2226	421 (60.7)	80 (14.3)	367 (62.3)	22 (6.3)	27 (73.0)
19. Ease of seeing social worker*	162/585	-	-	162 (27.7)	-	-
20. New medical problems	927/2256	375 (54.6)	148 (25.7)	355 (60.0)	20 (5.5)	29 (78.4)
Overall Ratings						
21. Quality of dialysis care	1057/2271	424 (61.2)	177 (30.3)	375 (63.5)	50 (13.7)	31 (83.8)
22. How much could be better? **	518/1575	-	162 (27.7)	201 (34.1)	148	7 (20.6)
23. Would you recommend your center? **	1022/1587	-	330 (56.5)	433 (73.9)	223	36 (97.3)

*Question 19 was present only in the Hungarian version of the survey
**Questions 22 and 23 were not included in the Italian version of the questionnaire

eTable 2 | Key performance indicators

Key performance indicators
Kt/V ≥ 1.4
Albumin ≥ 35 g/l
nPCR ≥ 1.0 g/kg/day
Haemoglobin ≥ 10.0 and ≤ 12.0 g/dl
Ferritin ≥ 200 and ≤ 500 ng/ml
Phosphorus ≥3.5 and ≤5.5 mg/dl
Calcium by phosphorus product <55 mg^2/dl^2
Parathyroid hormone ≥150 pg/ml and ≤ 300 pg/ml
Mean arterial pressure <105 mmHg
Interdialytic weight gain <4 %
Arteriovenous fistula

eTable 3 | Percentage of patients who reported that nothing about care could be better according to patient and centre characteristics

Characteristic	Excellent rating N (%)	Other rating N (%)	Unadjusted odds ratio	Clustering and case-mix adjusted odds ratio
Age				
18-49 years	91 (19.6)	293 (31.1)	1.00 (reference)	1.00
50-59 years	79 (17.0)	205 (21.8)	1.24 (0.87-1.76)	1.14 (0.76-1.71)
59-69 years	112 (24.1)	208 (22.1)	1.73 (1.25-2.41)	1.40 (0.94-2.10)
≥70 years	182 (39.2)	235 (25.0)	2.49 (1.84-3.38)	2.20 (1.47-3.31)
Male gender	232 (47.7)	431 (43.5)	1.19 (0.95-1.48)	1.29 (0.97-1.72)
Highest school education				
≤5 years	176 (40.3)	334 (36.1)	1.20 (0.95-1.51)	1.17 (0.87-1.57)
>5 years	261 (59.7)	592 (63.9)	1.00 (reference)	1.00
Occupational status				
Employed	65 (13.7)	181 (18.6)	0.70 (0.51-0.95)	0.86 (0.57-1.30)
Unemployed or pension	409 (86.3)	792 (81.4)	1.00	1.00
Married	289 (59.5)	583 (58.8)	1.03 (0.82-1.28)	1.19 (0.90-1.58)
Distance of housing from dialysis unit				
<20 kilometres	302 64.5)	695 (71.4)	1.00	1.00
>20 kilometres	166 (35.5)	279 (28.6)	1.37 (1.08-1.73)	1.39 (1.04-1.85)
Waiting list for kidney transplant	66 (13.6)	170 (17.2)	0.76 (0.56-1.03)	1.11 (0.75-1.65)
Comorbid conditions				
Diabetes mellitus	122 (26.1)	226 (23.7)	1.13 (0.88-1.46)	1.24 (0.67-2.30)
Prior cardiovascular event	110 (22.6)	213 (21.5)	1.07 (0.82-1.39)	0.94 (0.67-1.31)
Center for Epidemiological Studies-Depression Scale score				
<18	243 (54.1)	448 (49.0)	1.00 (reference)	1.00 (reference)
≥18	206 (45.9)	467 (51.0)	0.81 (0.65-1.02)	0.81 (0.62-1.06)
Dialysis adequacy, *single pool Kt/V*				
<1.4	94 (19.7)	202 (20.8)	1.00 (reference)	1.00
≥1.4	384 (80.3)	769 (79.2)	1.07 (0.82-1.41)	1.18 (0.82-1.69)
Serum phosphorus, mmol/l				
<1.45	258 (53.4)	510 (52.0)	1.00 (reference)	1.00
≥1.45	225 (46.6)	471 (48.0)	0.94 (0.76-1.17)	1.05 (0.79-1.39)
Haemoglobin, g/l				
<110	229 (47.3)	530 (53.8)	1.00 (reference)	1.00
≥110	255 52.7)	455 (46.2)	1.30 (1.04-1.61)	1.27 (0.96-1.66)
Albumin, g/dl				
<3.8	161 (33.5)	316 (32.5)	1.00 (reference)	1.00
3.8-4.0	145 (30.2)	281 (28.9)	1.01 (0.77-1.33)	0.91 (0.65-1.28)
≥4.1	175 (36.4)	374 (38.5)	0.92 (0.71-1.19)	0.81 (0.57-1.15)
Systolic blood pressure, mmHg				
≤120	156 (32.5)	300 (31.0)	1.00 (reference)	1.00
121-140	193 (40.2)	373 (38.5)	1.00 (0.77-1.29)	0.98 (0.71-1.36)
≥140	131 (27.3)	296 (30.6)	0.85 (0.64-1.13)	0.88 (0.62-1.26)
Country				
Italy	-	-	-	-
Portugal	7 (1.4)	27 (2.7)	0.69 (0.29-1.61)	-
Argentina	148 (30.4)	392 (39.6)	1.00 (reference)	-
Hungary	188 (38.7)	364 (36.7)	1.37 (1.06-1.77)	-
Poland	143 (29.4)	208 (21.0)	1.82 (1.37-2.42)	-

Clustering and case-mix adjusted model controlled for age, gender, education level, occupational status, marital status, distance from dialysis centre, activity on transplant waiting list, comorbid conditions (diabetes, hypertension, cardiovascular event) depression score, cause of end-stage kidney disease, duration of dialysis per session and dialysis dose, dialysis adequacy (Kt/V), serum values (haemoglobin; phosphorus) and country.

eTable 4 | Percentage of patients who would recommend their dialysis center to a friend or relative who needed dialysis care according to patient and center characteristics

Characteristic	Excellent rating N (%)	Other rating N (%)	Unadjusted odds ratio	Clustering and case-mix adjusted odds ratio
Age				
18-49 years	216 (23.4)	170 (34.8)	1.00	1.00
50-59 years	191 (20.7)	96 (19.5)	1.57 (1.14-2.15)	1.34 (0.93-1.94)
59-69 years	222 (24.1)	99 (20.2)	1.76 (1.29-2.41)	1.36 (0.93-1.99)
≥70 years	294 (31.8)	124 (25.4)	1.87 (1.40-2.50)	1.84 (1.24-2.74)
Male	438 (45.2)	229 (44.5)	1.03 (0.83-1.28)	0.97 (0.73-1.28)
Highest school education				
≤5 years	363 (40.6)	151 (31.7)	1.47 (1.16-1.86)	1.15 (0.86-1.54)
>5 years	532 (59.4)	325 (68.3)	1.00	1.00
Occupational status				
Employed	155 (16.3)	90 (17.9)	0.89 (0.67-1.19)	1.17 (0.81-1.68)
Unemployed or pension	796 (83.7)	413 (82.1)	1.00	1.00
Married	581 (60.0)	299 (58.1)		1.06 (0.81-1.39)
Distance of housing from dialysis unit				
<20 kilometres	633 (66.8)	370 (73.6)	1.00	1.00
>20 kilometres	314 (33.2)	133 (26.4)	1.38 (1.09-1.75)	1.37 (1.03-1.83)
Waiting list for kidney transplant	152 (15.7)	86 16.7)	0.93 (0.70-1.24)	1.01 (0.70-1.45)
Comorbid conditions				
Diabetes mellitus	240 (25.8)	112 (22.5)	1.20 (0.93-1.55)	1.52 (0.78-2.94)
Prior cardiovascular event	234 (24.2)	92 (17.9)	1.46 (1.12-1.92)	1.21 (0.85-1.71)
Center for Epidemiological Studies-Depression Scale score				
<18	475 (53.1)	214 (45.2)	1.00	1.00
≥18	420 (46.9)	260 (54.9)	0.73 (0.58-0.91)	0.67 (0.51-0.87)
Dialysis adequacy, *single pool Kt/V*				
<1.4	181 (19.13)	114 (22.4)	1.00	1.00
≥1.4	765 (80.9)	395 (77.6)	1.22 (0.94-1.59)	1.11 (0.79-1.56)
Serum phosphorus, mmol/l				
<1.45	532 (55.4)	242 (47.5)	1.00	1.00
≥1.45	429 (44.6)	267 (52.5)	0.73 (0.59-0.91)	1.09 (0.83-1.43)
Haemoglobin, g/l				
<110	485 (50.4)	276 (53.8)	1.00	1.00
≥110	477 (59.6)	237 (46.2)	1.15 (0.92-1.42)	0.95 (0.73-1.24)
Albumin, g/dl				
<3.8	294 (30.9)	186 (36.7)	1.00	1.00
3.8-4.0	287 (30.2)	140 (27.6)	1.30 (0.99-1.70)	1.29 (0.93-1.80)
≥4.1	370 (38.9)	181 (35.7)	1.29 (1.00-1.67)	1.00 (0.70-1.42)
Systolic blood pressure. mmHg				
≤120	295 (31.2)	167 (32.8)	1.00	1.00
121-140	381 (40.2)	183 (36.0)	1.18 (0.91-1.53)	0.81 (0.59-1.11)
≥140	271 (28.6)	159 (31.2)	0.96 (0.73-1.27	0.70 (0.50-0.99)
Country				
Italy	-	-	-	
Portugal	36 (3.7)	1 (0.2)	28.23 (3.84-207.39)	-
Argentina	306 (31.6)	240 (46.6)	1.00	-
Hungary	412 (42.5)	136 (26.4)	2.38 (1.84-3.07)	-
Poland	215 (22.2)	138 (26.8)	1.22 (0.93-1.60)	-

Clustering and case-mix adjusted model controlled for age, gender, education level, occupational status, marital status, distance from dialysis centre, activity on transplant waiting list, comorbid conditions (diabetes, hypertension, cardiovascular event) depression score, cause of end-stage kidney disease, duration of dialysis per session and dialysis dose, dialysis adequacy (Kt/V), serum values (haemoglobin; phosphorus) and country.

Medical committee who participated to the study contributing to enrolment of patients

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STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	**Recommendation**	**Page reference**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	5-7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5-7
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5-6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-7
Bias	9	Describe any efforts to address potential sources of bias	7
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	7
		(*b*) Describe any methods used to examine subgroups and interactions	7
		(*c*) Explain how missing data were addressed	Not done
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	5-6
		(*e*) Describe any sensitivity analyses	None
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	p 5, 8 Table 1
		(b) Give reasons for non-participation at each stage	5, 8
		(c) Consider use of a flow diagram	Table provided
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1
		(b) Indicate number of participants with missing data for each variable of interest	eTable 1
Outcome data	15*	Report numbers of outcome events or summary measures	eTable 1

	Item No	Recommendation	Page reference
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Table 2, eTable 3, eTable 4
		(*b*) Report category boundaries when continuous variables were categorized	Throughout
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Not applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Not done
Discussion			
Key results	18	Summarise key results with reference to study objectives	10-11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	13
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	10-13
Generalisability	21	Discuss the generalisability (external validity) of the study results	13
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	15

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Patient satisfaction with in-centre haemodialysis care: An international survey

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Patient satisfaction with in-centre haemodialysis care: An international survey

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Abstract

Objectives

To evaluate patient experiences of specific aspects of haemodialysis care across several countries

Design

Cross-sectional survey using the Choices for Healthy Outcomes in Caring for End-Stage Renal Disease (CHOICE) questionnaire

Setting

Haemodialysis clinics within a single provider in Europe and South America

Participants

2748 adults treated in haemodialysis

Primary and secondary outcomes

The primary outcome was patient satisfaction with overall care. Secondary outcomes included patient experiences of individual aspects of dialysis care

Results

2145 (78.1%) adults responded to the questionnaire. Fewer than half (46.5% [95% confidence interval, 44.5 to 48.6]) rated their overall care as excellent. Global perceptions of care were uninfluenced by most respondent characteristics except age and depressive symptoms; older respondents were less critical of their care (adjusted odds ratio for excellent rating 1.44 [1.01-2.04]) and those with depressive symptoms were less satisfied (0.56 [0.44 to 0.71]). Aspects of care that respondents most frequently ranked as excellent were staff attention to dialysis vascular access (54 [52-56]%), caring of nurses (53 [51-55]%), staff responsiveness to pain or discomfort (51 [49-53]%), caring, helpfulness and sensitivity of dialysis staff (50 [48-52]%), and ease of reaching dialysis staff by telephone (48 [46-50]%). The aspects of care least frequently ranked as excellent were information provided when choosing a dialysis modality (23 [21-25]%), ease of seeing a social worker (28 [24-

32]%), information provided about dialysis (34 [32-36]%), accuracy of information from nephrologist (for example, about prognosis or likelihood of a kidney transplant) (37 [35-39]%), and accuracy of nephrologists' instructions (39 [36-41]%).

Conclusion

Haemodialysis patients are least satisfied with the complex aspects of care. Patients' expectations for accurate information, prognosis, the likelihood of kidney transplantation and their options when choosing dialysis treatment need to be considered when planning healthcare research and healthcare practices.

Article summary

Strengths and limitations of this study

- The study is based on a large multinational survey of patients with chronic kidney failure needing treatment with long-term dialysis. There were no specific exclusions other than refusal or inability to complete the survey questions

- This study adds knowledge across a large cohort of the specific aspects of dialysis care that fewer patients find satisfactory

- The limitations were the lack of data about the health service characteristics that might have contributed to patient experiences as well as linkages to patient relevant outcomes

Introduction

Patients treated with haemodialysis experience mortality rates approaching 15-20% each year[1] and have profoundly impaired quality of life,[2 3] contributed to by severe symptoms of fatigue, low appetite, pain, sleep disorders, anxiety, nausea, and restless legs.[4] While interventions in haemodialysis trials and healthcare regulations have largely focused on biomarker endpoints and quantitative outcomes (mortality and cardiovascular events) to evaluate care, dialysis patients value normalization of their lives, economic efficiency in healthcare, and how their personal preferences are met, including reducing dietary and travel restrictions.[5 6] This mismatch in patient, provider and research priorities has resulted in clinical research and practice that have not improved patient-centred outcomes for dialysis patients[7-11] and consumed considerable resources.[12]

Given that patients treated with in-centre haemodialysis attend dialysis care at least three times per week for several hours each time, their experiences of dialysis care are likely to have an important impact on living with chronic illness.[3 13] By contrast, health funders have traditionally used only clinical performance indicators such as anaemia, blood pressure, nutrition, dialysis vascular access and adequacy of solute removal to evaluate and allocate reimbursement for dialysis provision.[14-17] While improving patient satisfaction with dialysis treatment has the potential to increase quality of life and improve patient-level outcomes, data to inform this objective are scarce.[18 19] Studies indicate that healthcare delivery in the latter stages of chronic kidney disease such as predialysis nephrology care, multidisciplinary management, psycho-education interventions and prognosis communication may improve quantitative health outcomes in the dialysis setting, but there is little information on the effects of these strategies on outcomes relevant to patients, that include symptoms, function and quality of life.[20-24] In addition, evaluations of patient experiences of haemodialysis care are available and can shape our knowledge about what patients value, but in existing studies smaller population sizes within single countries limit the power to adjust for case-mix[19] and perceptions of care are limited to global scores which may restrict our understanding of

the contributions of specific, and potentially modifiable, aspects of care on overall patient experience.[18]

Greater understanding of how patients experience all facets of long-term dialysis is needed to inform the design of large-scale trials which evaluate targeted healthcare strategies to improve the lives of dialysis patients in ways they value. Accordingly, we aimed, for the first time, to describe patient satisfaction with haemodialysis care in a large multi-national cohort to assess patients' experiences of haemodialysis care while accounting for clinical and demographic characteristics.

Methods

Participants

We used data from Diaverum, a network which provides renal care including long-term in-centre haemodialysis treatment for more than 20,000 patients in Europe and South America and surveys patients at least annually about their satisfaction with care. We conducted a cross-sectional analysis of routinely-gathered survey data collected in 2008. We selected a convenience sample of 15% of patients in the network from clinics that were willing to contribute. Data were included for selected patients who were aged 18 years or older and treated with haemodialysis between January and June 2008 in centres located in Europe (Hungary, Italy, Poland, and Portugal) and South America (Argentina). All clinical centres were managed during the study period according to the same standards of care. Of the 2748 patients selected (Argentina, n=670; Hungary, n=683; Italy, n=880; Poland, n=477; Portugal, n=38), 2145 (78.1%) responded and 1846 (67.2%) provided complete responses to all questions. We obtained ethics approval to analyse routinely-gathered clinical data from the University of Sydney Human Research Ethics Committee (project number 2013/031). The study was conducted according to the requirements of the Declaration of Helsinki. The mean age and gender composition of our cohort is similar to prevalent patients treated with kidney replacement therapy in Europe.[25]

Key measures

We collected data from patient responses to the Choices for Healthy Outcomes In Caring for End-stage kidney disease (CHOICE) questionnaire, which evaluates satisfaction with dialysis treatment (see the **eAppendix** for the full survey).[26] The CHOICE questionnaire was originally developed by Rubin and colleagues using a focus group of long-term in-centre haemodialysis and home-based peritoneal dialysis patients to identify aspects of dialysis care most important to them. The items identified were then ranked by a larger number of long-term dialysis patients to identify the top 25 items they considered extremely important. The questionnaire asks 20 questions about patients' experiences relating to these different aspects of dialysis care on a 5-point Likert scale (poor, fair, good, very good, excellent). In addition, three questions ask patients to rate the overall quality of their care (poor, fair, good, very good, excellent, or not applicable), how much about their care could be better (many things, a few things, one or two things, and nothing could be better at all), and whether they would recommend their care service to others who may need dialysis care (definitely not, probably not, not sure, probably yes, and definitely yes) (**eTable 1)**. In addition, we summarized measures of key performance indicators for dialysis within each country (**eTable 2**) for the two quarters in which satisfaction data were collected and reported these as overall performance scores for each participating country.

In the present analysis, the question "How easy is it to meet the social worker when you want to?" was only included in the annual survey in Hungary and the two global questions about care "Thinking about your dialysis care overall, how much could be better?" and "Would you recommend your dialysis centre to a friend or relative who needs dialysis?" were omitted in the annual survey of Italian patients.

Surveys were provided to patients by dialysis clinical staff during routine dialysis care. Patients self-completed the questionnaires anonymously during a dialysis session and data were de-identified. We then linked survey data to concurrent demographic, clinical, and laboratory information in a clinical database using a unique patient identifier; additional data were provided where necessary by the treating physician on a standardized case report form. We used questionnaires in the patients' native language after translation and linguistic validation by the MAPI Institute (http://www.mapi-institute.com).

Analysis

We considered a response to the survey as complete when interpretable answers were provided for all survey questions and partially complete when one or more answers was missing. We used chi-square tests and Mann-Whitney U tests to compare the characteristics of patients who responded to the survey with those who did not. The primary outcome of interest was the proportion of respondents who evaluated their overall care as 'excellent'. We also estimated the proportion of respondents who evaluated each separate dimension of care as 'excellent'. To account for the multilevel nature of the data (patients clustered within countries) and to control simultaneously for the possible confounding effects of the different variables, we used multivariate multilevel logistic regression models.[27 28] We constructed clustering and case-mix adjusted models that controlled for the following potential confounding variables: age, gender, education level, occupational status, marital status, distance to travel to the dialysis centre, kidney transplant waiting list status, comorbid conditions (diabetes mellitus, hypertension, cardiovascular event), depression score, cause of end-stage kidney disease, duration of dialysis per session, dialysis dose, adequacy of dialysis, and serum values of haemoglobin and phosphorus. We performed multilevel logistic regression using the SAS language macro routine Proc GLIMMIX (SAS Institute Inc., Cary, NC; Release 9·1, 2002-2003; http://www.sas.com).

Results

Characteristics of patients in the network and respondents to questionnaire

Respondents were younger and lived closer to their dialysis centre than non-respondents (**Table 1**). Questionnaire response rates differed by country; patients in Portugal were most likely to respond to the survey (97.4%), with decreasing response rates in Argentina (81.9%), Hungary (81.4%), Poland (74.4%), and Italy (73.6%). Overall, respondents were 61.0 ± 15.5 years, most were men (55.5%), 40.2% had 6 to 8 years of school education, and about half had depressive symptoms according to the Center for Epidemiological Studies-Depression (CES-D) Scale (score of 18 of above). Two-thirds of respondents were married (60.8%), most were unemployed (68.8%), and a minority had previously received a kidney transplant (6.9%).

Survey responses

Fewer than half of respondents rated their overall care as excellent (1057/2271; 46.5% [95% confidence interval (CI), 44.5 to48.6%]) and about three-quarters rated their care as excellent or very good (1783/2271; 78.5% [CI 76.8 to 80.2%]) (**Figure 1**). The proportion rating their overall care as excellent was lowest in Poland (13.7%), with an increasing proportion in Argentina (30.3%), Italy (61.2%), Hungary (63.5%), and Portugal (83.8%) (**eTable 1**).

Table 2 shows the association between respondent characteristics and the proportion rating haemodialysis care as excellent. In analyses clustered by country and controlled for demographic and clinical variables, older respondents were more likely to consider care excellent (adjusted odds ratio [AOR] for those 70 years or older, 1.44 [CI, 1.01 to 2.04] compared with those aged 18 to 49 years) and those with depressive symptoms were less likely to consider that care met excellent standards (AOR, 0.56 [CI, 0.44 to 0.71]). Gender, education, marital status, comorbidity (including diabetes and cardiovascular disease) and the time spent on dialysis each week were not associated with perspectives of overall care.

Figure 1 shows the proportion of respondents who considered that nothing about their care could be better and **eTable 3** provides responses according to clinical, demographic and treatment-based characteristics. Overall, about one-third of respondents considered that nothing about their care could be better (486/1477; 32.9% [CI, 30.6% to 35.3%]). Respondents aged 70 years or older (AOR, 2.20 [CI, 1.47 to 3.31]) and those living further away from their dialysis centre (AOR, 1.39 [CI, 1.04 to 1.85]) were more likely to consider that no aspect of their care required improvement. In the four countries in which this question was asked (Argentina, Hungary, Poland, and Portugal), compared with Argentina, patients in Hungary (AOR, 1.37 [CI, 1.06 to 1.77]) and Poland (AOR, 1.82 [CI, 1.37 to 2.42]) were more likely to consider than nothing about their care needed to be changed.

In the four countries in which the question "would you recommend your dialysis centre to a friend or relative who needed dialysis" was asked, 1022 of 1587 respondents (64.4% [CI, 62.0 to 66.7%]) would definitely recommend their dialysis centre. Older respondents (AOR, 1.84 [CI, 1.24-2.74]) and those living further from their dialysis centre (AOR, 1.37 [CI, 1.03-1.83]) were more likely to recommend their dialysis centre to others for care, whereas those with depressive symptoms were less likely to recommend their care to others (AOR, 0.67 [CI, 0.51 to 0.87]) (**eTable 4**). Compared to Argentina, strong recommendations would more likely be made by respondents in Hungary (AOR 2.38 [CI 1.84-3.07]) and Portugal (AOR 28.2 [CI 3.84-207.39]).

The five items that respondents rated most frequently as excellent were "attention of staff to cleanliness of the dialysis vascular access site" (54% ranked as excellent), "caring and helpfulness of nurses" (53%), "response of staff to pain or discomfort" (51%), "caring, helpfulness and sensitivity of dialysis staff" (50%), and "ease of reaching staff by telephone" (48%) (**Figure 1**). The five items rated least frequently by respondents as excellent were "the amount of information when choosing dialysis modality"(23%), "the ease of seeing a social worker when needed" (28%), "amount of information from dialysis staff" (34%), "accuracy of information from nephrologist including prognosis and likelihood of getting a kidney transplant" (37%), and "accuracy of instructions from nephrologist" (39%). In general, the amount of caring and concern shown by staff, particularly by nurses, and the ability of patients to contact dialysis staff were ranked highly, whereas the amount and delivery of information about treatment choices and prognosis as well as access to social worker staff and nephrologists were ranked lowest.

A composite measure of key performance indicators were similar in the included countries during the recruitment period (in descending order with a higher value indicating higher performance: Hungary 1535, Portugal 1551, Italy 1543, Poland 1381, and Argentina 1303) and were associated with the proportion of respondents reporting excellent overall care (for each unit increase in performance score, the proportion of respondents who ranked care as excellent increased by 0.21% (95% CI -0.02% to 0.44%).

Discussion

We report the largest study of patient satisfaction with dialysis care to date and identify specific deficits in long-term dialysis care across several countries. Most respondents viewed their overall dialysis care as below excellent and needing improvement. Specifically, while the majority of respondents approved of the more technical aspects of dialysis treatment (attention to the cleanliness of the dialysis vascular access site, caring and helpfulness of nurses and dialysis staff, and attention by staff to immediate needs (pain, discomfort, sterile procedures)), a minority were satisfied with the more complex and integrated components of care. These were the accuracy and amount of information given by staff to patients about their dialysis treatment, prognosis and making choices between peritoneal dialysis and haemodialysis in addition to support from social worker staff. Older respondents were generally less critical of their haemodialysis care, while those with depressive symptoms were less frequently satisfied. Other demographic and clinical features did not reliably influence perceptions of overall care and country of treatment had inconsistent effects on satisfaction. Better dialysis care performance scores were associated with higher overall patient satisfaction.

Our patients’ perspectives together with other similar studies from the United States[19] and The Netherlands[18] emphasise that deficiencies in dialysis care are consistently found and need to be considered specifically when conducting research to improve dialysis patient outcomes. This is particularly relevant as existing interventions in the dialysis setting, including anaemia management,[7] control of phosphorus[29] and parathyroid hormone levels,[30] dialysis dose and flux,[9] and starting dialysis earlier[8] have not improved patient-wellbeing despite evaluation in thousands of patients. Our respondents, consistent with the findings of others,[31-33] report specifically receiving inadequate information about their illness journey and as well as their dialysis treatment options. In our and other chronic diseases settings, patients report needing more information about the causes and progression of their disease, disease symptoms and their impact, and social and financial support.[34] [35]Patients, often due to the competing demands of daily life, rely on healthcare professional to initiate discussions about care planning and not having future-oriented conversations reduces patients’ capacity for hope.[36] Patients perceive poor communication as reflecting secrecy, misinformation and insensitivity. Subsequently, inadequate information reduces the ability of patients and their families to care for themselves and induces worry.[34] While education strategies increase patients’ willingness to choose self-care dialysis,[23] the wider effect of educational interventions in the dialysis setting that answer unmet questions about disease trajectory and treatment choices with the aim of improving patient experiences of end-stage kidney disease are not well understood and warrant larger-scale trials. Research in other settings suggest specific interventions to improve information provision, such as training and support for healthcare staff in communication and basic counselling, and overcoming barriers to good communication including addressing time pressures and understaffed environments and considering innovative non-written methods might be appropriate complex strategies for trials in the dialysis setting.[34]

This study indicates most patients in dialysis settings want more accurate information about their prognosis, in line with experiences of other dialysis patients and those who have cancer.[36 37]

Accurate prognostic information empowers patients;[38] when discussions about prognosis do not occur, patients and their families may (incorrectly) fear the worst. For dialysis patients in our study, the information they receive about prognosis is frequently unsatisfactory including specifically understanding their chances of receiving a kidney transplant and their survival. Physicians in other medical specialties similarly provide insufficient information about prognosis[39] and infrequently check their patients' understanding during consultations.[40] Physicians commonly find disclosing prognosis stressful and desire more training and guidance for this aspect of clinical practice.[41] Our findings suggest that meeting patients' expectations about information is an important but potentially neglected aspect of dialysis care and is consistent with data showing that patients are infrequently involved in discussions about prognosis and likelihood of transplantation.[33] The effect of increased clinician training in prognosis provision about survival and transplantation could form the basis of a testable strategy in future health services research in dialysis.

The patient-centred movement in healthcare ('nothing about me without me')[42] has engendered considerable data on the issues of most importance to patients and their families to highlight the mismatch between patients' values and the outcomes routinely measured in research and clinical practice, including for patients with advanced kidney disease.[5 43] While landmark trials in nephrology over the past three decades have measured treatment effectiveness using biomarker levels and major cardiovascular events and survival, emerging data show that patients are frequently willing to forgo survival in exchange for fewer restrictions on their daily life, and prioritize collaborative research aimed at improving the way they feel, function, and survive.[5 6] In addition, contemporary studies of communication and educational strategies as well as complex healthcare service changes in dialysis have used similarly quantitative outcomes to assess treatment effectiveness, which have included urgent dialysis start, vascular access processes, and survival.[20 21 44] We suggest that, in line with patient-centred data, trials of communication or education for dialysis patients might consider aspects of quality of life valued by patients as key outcomes for assessing effectiveness.

Notably, patient satisfaction was largely unrelated to most clinical or demographic patient characteristics despite a large sample size and similar to other studies in the US and The Netherlands, suggesting that lower satisfaction of many aspects of dialysis care is a global patient experience. Older patients in this study rated their overall care more highly, consistent with a recent study of patient perceptions of dialysis care in The Netherlands,[18] and of studies of patient satisfaction across health services more generally,[45 46] despite evidence that older patients may actually receive lower quality care.[47] In contrast, depressive symptoms markedly reduced satisfaction in this study, (even when controlling for markers of health status and comorbidity); similar findings have been reported in other settings.[48] Those with depressive symptoms voluntarily ration the time they have with medical staff, which may in turn impair patient-clinician communication and serve to decrease their satisfaction with care overall.[48] Notably, in other chronic disease settings, patient satisfaction is increased in association with better patient-clinician interaction and support for patient self-management[49] and high levels of patient satisfaction for interpersonal skills, technical quality and access to care can be present in chronic illness settings such as diabetes mellitus and rheumatoid arthritis.[50]

Limitations of the study

Although we provide considerable satisfaction data for dialysis patients in several countries, our analysis should be interpreted in light of the study limitations. First, we did not evaluate in detail the influence of healthcare systems in which the dialysis clinics were situated (including features such as staffing-levels[51] or number of beds[52]) on patient satisfaction, although we did find an association between overall satisfaction and global clinical performance. While interpersonal relations with healthcare workers are the most frequently mentioned by patients when asked to rate their care, contextual factors relating to conditions of medical services are also described commonly by patients and often lead to negative comments about healthcare.[53] Second, we took a quantitative approach to assessing patients' perceptions, which may be suboptimal for understanding the full range of feelings, values and experiences of receiving dialysis care. In addition, satisfaction and dissatisfaction may not simply be alternative ends of a single spectrum of perception and may in fact exist side-by-side within a patient experience of care.[54] Third, we did not capture satisfaction with a specific healthcare event and surveyed patients who had been treated with dialysis for 3 years on average. The potential lag between pivotal patient experiences and the survey may have introduced recall bias.[55] Fourth, we did not capture longitudinal data to determine any association between perceptions of care and health-related behaviour and outcomes including healthcare utilization, quality of life, or survival. Finally, the findings in this study may not be applicable to other dialysis settings including peritoneal dialysis or home-based haemodialysis care and regional settings outside our survey countries including many USA, European and United Kingdom dialysis settings. In addition, the study survey predates more widespread use of haemodiafiltration which may be associated with greater haemodynamic stability during dialysis therapy and different levels of patient satisfaction.

Implications of the study

As measures of patient experience are distinctive indicators of health care quality,[55] our analysis suggests several strategies might improve care for patients in the later stages of chronic kidney disease. First, patients need better information about their choices of treatment for end-stage kidney disease including dialysis modalities. A recent systematic review suggests this is optimally provided when the glomerular filtration rate falls below 30 ml/min per 1.73 m^2 and well in advance of preparations for dialysis vascular access.[31] Second, formal care strategies that provide patients with information about prognosis and the impact of end-stage kidney disease and its treatments on their life earlier in the course of kidney disease need to be developed and assessed. Current practices for assessing and discussing prognosis are manifestly inadequate[36] and our present reliance on individual physicians to initiate such discussions is not meeting the needs of our patients. Third, better delivery of information about dialysis from both nephrologists and dialysis staff is expected by patients and greater understanding of the information that patients need and optimal mode(s) of delivery may improve care.

Conclusion

This large study of patient satisfaction with different aspects of long-term haemodialysis care suggests that patients' needs are not being fully met. The findings suggest that meeting patient expectations about information on dialysis choices and prognosis may be critical for improving patient experiences of long-term dialysis care and can form the basis for future healthcare services research in the dialysis setting.

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Competing interests

GS is Senior Vice-President of Scientific Affairs at Diaverum. JH is Senior Vice President Medical Operations - Chief Medical Officer of Diaverum. MR, CW, EC, RG, JNF, MT, ML, AB-S, and JD are employees of Diaverum. SP receives a fellowship from the Consorzio Mario Negri Sud, Italy from provided by an unrestricted educational grant from Amgen Dompé. SP is a 2012 L'Oreal UNESCO For Women in Science Australia and New Zealand Fellow.

Ethical approval

We obtained ethics approval for the analyses of routinely collected data from the University of Sydney Human Research Ethics Committee on 27 February 2013. The authorized personnel are Allison Tong, Jonathan Craig and Giovanni Strippoli. The project number for approval was 2013/031 and included approval of the satisfaction survey, the data custodian (Diaverum) and the survey data dated January 2008.

Author contributions

SP designed the study, interpreted data analysis, wrote the first draft and revised the paper. GdB designed the data analysis, cleaned and analyzed data, and drafted and revised the paper. JCC assisted with study design, interpreted the data analysis, and drafted and revised the paper. AT interpreted the data analysis, and drafted and revised the paper. MT assisted with data collection tools, interpreted the data analysis, and drafted revised the paper. FP interpreted the data analysis, and revised the paper. MR monitored data collection for the whole study, assisted with data collection and cleaning, and interpreted the data analysis, and revised the paper. JH and CW interpreted the data analysis, and revised the paper. EC, RG, JNF, MT, ML, AB-S, and JD assisted with data collection, and interpreted the data analysis, and revised the paper. GFMS designed the study and data collection tools, monitored data collection for the whole study, interpreted the data analysis, and drafted and revised the paper. He is the guarantor. All authors had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Presentation as abstract

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Data sharing statement

None available

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Figure Legends

Figure 1 Probabilities of excellent or very good ratings of overall care by dialysis patients

Tables

Table 1 | Characteristics of participants who responded and those who did not respond to satisfaction survey

Characteristic	Complete or partial response to survey (n=2145)	No response to survey (n=603)	P value
Age, *years*	61.0 (15.5)	62.7 (14.8)	0.04
Gender , *n (%) male*	1190 (55.5)	314 (52.1)	0.14
Highest school education			
≤ 5 years	847 (42.1)	238 (41.6)	
>5 years	1163 (57.9)	334 (58.4)	0.82
Depression score (Center for Epidemiological Studies-Depression Scale)			
< 18	947 (49.6)	67 (46.7)	0.25
≥ 18	963 (50.4)	83 (55.3)	
Married	1303 (60.8)	377 (62.5)	0.43
Living alone	275 (13.0)	97 (16.2)	0.04
Distance of housing from dialysis unit			0.001
< 20 kilometres	1540 (73.1)	392 (65.8)	
> 20 kilometres	567 (26.9)	204(34.2)	
Active on waiting list for transplant	309 (14.4)	72 (11.9)	0.12
Previous kidney transplant	148 (6.9)	28 (4.7)	0.05
Employment			0.002
Employed	331 (15.7)	76 (12.9)	
Unemployed	1451 (68.8)	450 (76.1)	
Receiving benefit/pension	328 (15.6)	65 (11.0)	
Comorbid conditions			
Diabetes mellitus	486 (23.5)	146 (25.1)	0.42
Hypertension	1347 (68.5)	376 (70.3)	0.65
Prior cardiovascular event	472 (22.0)	124 (20.6)	0.45
Time on dialysis, *months*	37.3 (16.3-70.9)	36.0 (17.0-75.7)	0.69
Dialysis treatment time, *minutes per session*	235.9 (20.5)	234.3 (23.5)	0.35
Dialysis adequacy, *single pool Kt/V*	1.6 (0.3)	1.5 (0.3)	0.02
Interdialytic weight gain, *kg*	2.29 (1.03)	2.37 (1.09)	0.16
Serum values			
Haemoglobin, *g/l*	11.0 (1.4)	11.0 (1.3)	0.31
Systolic blood pressure, *mmHg*	130.0 (18.0)	128.4 (17.3)	0.07
Serum albumin, *g/l*	3.9 (0.5)	3.9 (0.5)	0.73
Serum phosphorus, *mmol/l*	4.6 (1.4)	4.6 (1.4)	0.69
Serum ferritin, *μg/l*	430 (242-660)	409 (242-672)	0.71
Serum parathyroid hormone, *pmol/l*	282 (162-481)	287 (167-530)	0.23
Antidepressant medication	113 (5.3)	26 (4.3)	0.34
Anxiolytic medication	291 (13.6)	86 (14.3)	0.66
Country			<0.0001
Argentina	549 (81.9)	121 (18.1)	
Hungary	556 (81.4)	127 (18.6)	
Italy	648 (73.6)	232 (26.4)	
Poland	355 (74.4)	122 (25.6)	
Portugal	37 (97.4)	1 (2.6)	

Data are expressed as mean (SD), number (%), or median (25th percentile, 75th percentile). Kt/V refers to the clearance of urea and is a measure of the amount of dialysis received.

Table 2 | Proportion of patients who gave an excellent rating to overall haemodialysis care according to patient characteristics

Characteristic	Excellent rating N (%)	Other rating N (%)	Unadjusted odds ratio	Clustering and case-mix adjusted odds ratio
Age				
18-49 years	183 (19.1)	300 (28.1)	1.00 (reference)	1.00
50-59 years	146 (15.3)	215 (20.1)	1.11 (0.84-1.47)	1.01 (0.70-1.44)
59-69 years	221 (23.1)	218 (20.4)	1.66 (1.28-2.16)	1.18 (0.82-1.69)
≥70 years	406 (42.5)	335 (31.4)	1.99 (1.57-2.51)	1.44 (1.01-2.04)
Male gender	466 (46.1)	483 (43.1)	1.13 (0.95-1.34)	1.12 (0.88-1.44)
Highest school education				
≤5 years	465 (49.0)	375 (35.8)	1.72 (1.44-2.06)	0.95 (0.74-1.21)
>5 years	485 (51.1)	673 (64.2)	1.00 (reference)	1.00
Occupational status				
Employed	120 (12.0)	209 (19.0)	0.59 (0.46-0.75)	0.79 (0.56-1.12)
Unemployed or pension	876 (88.0)	893 (81.0)	1.00	1.00
Married	601 (59.4)	693 (61.8)	0.91 (0.76-1.08)	0.86 (0.67-1.10)
Distance of housing from dialysis unit				
<20 kilometres	741 (73.9)	792 (72.5)	1.00	1.00
>20 kilometres	262 (26.1)	300 (27.5)	0.93 (0.77-1.13	1.18 (0.91-1.54)
Waiting list for kidney transplant	131 (13.0)	176 (15.7)	0.80 (0.63-1.02)	0.80 (0.56-1.14)
Comorbid conditions				
Diabetes mellitus	249 (25.4)	233 (21.6)	1.24 (1.01-1.52)	1.38 (0.78-2.46)
Prior cardiovascular event	248 (24.5)	220 (19.6)	1.33 (1.08-1.63)	0.89 (0.63-1.26)
Center for Epidemiological Studies-Depression Scale score				
<18	472 (52.5)	472 (47.2)	1.00 (reference)	1.00 (reference)
≥18	427 (47.5)	527 (52.8)	0.81 (0.68-0.97)	0.56 (0.44-0.71)
Dialysis adequacy, *single pool Kt/V*				
<1.4	202 (20.6)	245 (22.2)	1.00 (reference)	1.00
≥1.4	778 (79.4)	856 (77.8)	1.10 (0.89-1.36)	1.11 (0.83-1.49)
Serum phosphorus, mmol/l				
<1.45	516 (51.5)	509 (45.9)	1.00 (reference)	1.00
≥1.45	486 (48.5)	601 (54.1)	0.80 (0.67-0.95)	0.96 (0.76-1.23)
Haemoglobin, g/l				
<110	476 (47.6)	537 (48.2)	1.00 (reference)	1.00
≥110	525 (52.4)	578 (51.8)	1.02 (0.86-1.22)	0.90 (0.71-1.14)
Albumin, g/dl				
<3.8	371 (37.8)	369 (33.7)	1.00 (reference)	1.00
3.8-4.0	277 (28.2)	324 (29.6)	0.85 (0.69-1.05)	1.07 (0.80-1.42)
≥4.1	333 (33.9)	401 (36.6)	0.83 (0.67-1.01	0.78 (0.58-1.05)
Systolic blood pressure, mmHg				
≤120	270 (27.2)	353 (32.1)	1.00 (reference)	1.00
121-140	404 (40.6)	441 (40.0)	1.20 (0.97-1.47)	0.89 (0.67-1.19)
≥140	320 (32.2)	307 (27.9)	1.36 (1.09-1.70)	1.03 (0.76-1.40)
Country				
Poland	48 (4.8)	303 (27.0)	0.09 (0.07-0.13)	-
Argentina	172 (17.0)	372 (33.2)	0.28 (0.22-0.35)	-
Italy	405 (40.1)	242 (21.6)	1.00 (reference)	-
Hungary	355 (35.1)	198 (17.7)	1.07 (0.85-1.36)	-
Portugal	31 (3.1)	6 (0.5)	3.09 (1.27-7.51)	-

Clustering and case-mix adjusted model controlled for age, gender, education level, occupational status, marital status, distance from dialysis centre, activity on transplant waiting list, comorbid conditions (diabetes, hypertension, cardiovascular event) depression score, cause of end-stage kidney disease, duration of dialysis per session and dialysis dose, dialysis adequacy (Kt/V), serum values (haemoglobin; phosphorus) and country.

Patient satisfaction with in-centre haemodialysis care: An international survey

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Abstract

Objectives

To evaluate patient experiences of specific aspects of haemodialysis care across several countries

Design

Cross-sectional survey using the Choices for Healthy Outcomes in Caring for End-Stage Renal Disease (CHOICE) questionnaire

Setting

Haemodialysis clinics within a single provider in Europe and South America

Participants

2748 adults treated in haemodialysis

Primary and secondary outcomes

The primary outcome was patient satisfaction with overall care. Secondary outcomes included patient experiences of individual aspects of dialysis care

Results

2145 (78.1%) adults responded to the questionnaire. Fewer than half (46.5% [95% confidence interval, 44.5 to 48.6]) rated their overall care as excellent. Global perceptions of care were uninfluenced by most respondent characteristics except age and depressive symptoms; older respondents were less critical of their care (adjusted odds ratio for excellent rating 1.44 [1.01-2.04]) and those with depressive symptoms were less satisfied (0.56 [0.44 to 0.71]). Aspects of care that respondents most frequently ranked as excellent were staff attention to dialysis vascular access (54 [52-56]%), caring of nurses (53 [51-55]%), staff responsiveness to pain or discomfort (51 [49-53]%), caring, helpfulness and sensitivity of dialysis staff (50 [48-52]%), and ease of reaching dialysis staff by telephone (48 [46-50]%). The aspects of care least frequently ranked as excellent were information provided when choosing a dialysis modality (23 [21-25]%), ease of seeing a social worker (28 [24-

32]%), information provided about dialysis (34 [32-36]%), accuracy of information from nephrologist (for example, about prognosis or likelihood of a kidney transplant) (37 [35-39]%), and accuracy of nephrologists' instructions (39 [36-41]%).

Conclusion

Haemodialysis patients are least satisfied with the complex aspects of care. Patients' expectations for accurate information, prognosis, the likelihood of kidney transplantation and their options when choosing dialysis treatment need to be considered when planning healthcare research and healthcare practices.

Article summary

Strengths and limitations of this study

- The study is based on a large multinational survey of patients with chronic kidney failure needing treatment with long-term dialysis. There were no specific exclusions other than refusal or inability to complete the survey questions

- This study adds knowledge across a large cohort of the specific aspects of dialysis care that fewer patients find satisfactory

- The limitations were the lack of data about the health service characteristics that might have contributed to patient experiences as well as linkages to patient relevant outcomes

Introduction

Patients treated with haemodialysis experience mortality rates approaching 15-20% each year[1] and have profoundly impaired quality of life,[2 3] contributed to by severe symptoms of fatigue, low appetite, pain, sleep disorders, anxiety, nausea, and restless legs.[4] While interventions in haemodialysis trials and healthcare regulations have largely focused on biomarker endpoints and quantitative outcomes (mortality and cardiovascular events) to evaluate care, dialysis patients value normalization of their lives, economic efficiency in healthcare, and how their personal preferences are met, including reducing dietary and travel restrictions.[5 6] This mismatch in patient, provider and research priorities has resulted in clinical research and practice that have not improved patient-centred outcomes for dialysis patients[7-11] and consumed considerable resources.[12]

Given that patients treated with in-centre haemodialysis attend dialysis care at least three times per week for several hours each time, their experiences of dialysis care are likely to have an important impact on living with chronic illness.[3 13] By contrast, health funders have traditionally used only clinical performance indicators such as anaemia, blood pressure, nutrition, dialysis vascular access and adequacy of solute removal to evaluate and allocate reimbursement for dialysis provision.[14-17] While improving patient satisfaction with dialysis treatment has the potential to increase quality of life and improve patient-level outcomes, data to inform this objective are scarce.[18 19] Studies indicate that healthcare delivery in the latter stages of chronic kidney disease such as predialysis nephrology care, multidisciplinary management, psycho-education interventions and prognosis communication may improve quantitative health outcomes in the dialysis setting, but there is little information on the effects of these strategies on outcomes relevant to patients, that include symptoms, function and quality of life.[20-24] In addition, evaluations of patient experiences of haemodialysis care are available and can shape our knowledge about what patients value, but in existing studies smaller population sizes within single countries limit the power to adjust for case-mix[19] and perceptions of care are limited to global scores which may restrict our understanding of

the contributions of specific, and potentially modifiable, aspects of care on overall patient experience.[18]

Greater understanding of how patients experience all facets of long-term dialysis is needed to inform the design of large-scale trials which evaluate targeted healthcare strategies to improve the lives of dialysis patients in ways they value. Accordingly, we aimed, for the first time, to describe patient satisfaction with haemodialysis care in a large multi-national cohort to assess patients' experiences of haemodialysis care while accounting for clinical and demographic characteristics.

Methods

Participants

We used data from Diaverum, a network which provides renal care including long-term in-centre haemodialysis treatment for more than 20,000 patients in Europe and South America and surveys patients at least annually about their satisfaction with care. We conducted a cross-sectional analysis of routinely-gathered survey data collected in 2008. We selected a convenience sample of 15% of patients in the network from clinics that were willing to contribute. Data were included for selected patients who were aged 18 years or older and treated with haemodialysis between January and June 2008 in centres located in Europe (Hungary, Italy, Poland, and Portugal) and South America (Argentina). All clinical centres were managed during the study period according to the same standards of care. Of the 2748 patients selected (Argentina, n=670; Hungary, n=683; Italy, n=880; Poland, n=477; Portugal, n=38), 2145 (78.1%) responded and 1846 (67.2%) provided complete responses to all questions. We obtained ethics approval to analyse routinely-gathered clinical data from the University of Sydney Human Research Ethics Committee (project number 2013/031). The study was conducted according to the requirements of the Declaration of Helsinki. The mean age and gender composition of our cohort is similar to prevalent patients treated with kidney replacement therapy in Europe.[25]

Key measures

We collected data from patient responses to the Choices for Healthy Outcomes In Caring for End-stage kidney disease (CHOICE) questionnaire, which evaluates satisfaction with dialysis treatment (see the **eAppendix** for the full survey).[26] The CHOICE questionnaire was originally developed by Rubin and colleagues using a focus group of long-term in-centre haemodialysis and home-based peritoneal dialysis patients to identify aspects of dialysis care most important to them. The items identified were then ranked by a larger number of long-term dialysis patients to identify the top 25 items they considered extremely important. The questionnaire asks 20 questions about patients' experiences relating to these different aspects of dialysis care on a 5-point Likert scale (poor, fair, good, very good, excellent). In addition, three questions ask patients to rate the overall quality of their care (poor, fair, good, very good, excellent, or not applicable), how much about their care could be better (many things, a few things, one or two things, and nothing could be better at all), and whether they would recommend their care service to others who may need dialysis care (definitely not, probably not, not sure, probably yes, and definitely yes) (**eTable 1)**. In addition, we summarized measures of key performance indicators for dialysis within each country (**eTable 2**) for the two quarters in which satisfaction data were collected and reported these as overall performance scores for each participating country.

In the present analysis, the question "How easy is it to meet the social worker when you want to?" was only included in the annual survey in Hungary and the two global questions about care "Thinking about your dialysis care overall, how much could be better?" and "Would you recommend your dialysis centre to a friend or relative who needs dialysis?" were omitted in the annual survey of Italian patients.

Surveys were provided to patients by dialysis clinical staff during routine dialysis care. Patients self-completed the questionnaires anonymously during a dialysis session and data were de-identified. We then linked survey data to concurrent demographic, clinical, and laboratory information in a clinical database using a unique patient identifier; additional data were provided where necessary by the treating physician on a standardized case report form. We used questionnaires in the patients' native language after translation and linguistic validation by the MAPI Institute (http://www.mapi-institute.com).

Analysis

We considered a response to the survey as complete when interpretable answers were provided for all survey questions and partially complete when one or more answers was missing. We used chi-square tests and Mann-Whitney U tests to compare the characteristics of patients who responded to the survey with those who did not. The primary outcome of interest was the proportion of respondents who evaluated their overall care as 'excellent'. We also estimated the proportion of respondents who evaluated each separate dimension of care as 'excellent'. To account for the multilevel nature of the data (patients clustered within countries) and to control simultaneously for the possible confounding effects of the different variables, we used multivariate multilevel logistic regression models.[27 28] We constructed clustering and case-mix adjusted models that controlled for the following potential confounding variables: age, gender, education level, occupational status, marital status, distance to travel to the dialysis centre, kidney transplant waiting list status, comorbid conditions (diabetes mellitus, hypertension, cardiovascular event), depression score, cause of end-stage kidney disease, duration of dialysis per session, dialysis dose, adequacy of dialysis, and serum values of haemoglobin and phosphorus. We performed multilevel logistic regression using the SAS language macro routine Proc GLIMMIX (SAS Institute Inc., Cary, NC; Release 9·1, 2002-2003; http://www.sas.com).

Results

Characteristics of patients in the network and respondents to questionnaire

Respondents were younger and lived closer to their dialysis cent~~er~~re than non-respondents (**Table 1**). Questionnaire response rates differed by country; patients in Portugal were most likely to respond to the survey (97.4%), with decreasing response rates in Argentina (81.9%), Hungary (81.4%), Poland (74.4%), and Italy (73.6%). Overall, respondents were 61.0 ± 15.5 years, most were men (55.5%), 40.2% had 6 to 8 years of school education, and about half had depressive symptoms according to the Center for Epidemiological Studies-Depression (CES-D) Scale (score of 18 of above). Two-thirds of respondents were married (60.8%), most were unemployed (68.8%), and a minority had previously received a kidney transplant (6.9%).

Survey responses

Fewer than half of respondents rated their overall care as excellent (1057/2271; 46.5% [95% confidence interval (CI), 44.5 to48.6%]) and about three-quarters rated their care as excellent or very good (1783/2271; 78.5% [CI 76.8 to 80.2%]) (**Figure 1**). The proportion rating their overall care as excellent was lowest in Poland (13.7%), with an increasing proportion in Argentina (30.3%), Italy (61.2%), Hungary (63.5%), and Portugal (83.8%) (**eTable 1**).

Table 2 shows the association between respondent characteristics and the proportion rating haemodialysis care as excellent. In analyses clustered by country and controlled for demographic and clinical variables, older respondents were more likely to consider care excellent (adjusted odds ratio [AOR] for those 70 years or older, 1.44 [CI, 1.01 to 2.04] compared with those aged 18 to 49 years) and those with depressive symptoms were less likely to consider that care met excellent standards (AOR, 0.56 [CI, 0.44 to 0.71]). Gender, education, marital status, comorbidity (including diabetes and cardiovascular disease) and the time spent on dialysis each week were not associated with perspectives of overall care.

Figure 1 shows the proportion of respondents who considered that nothing about their care could be better and **eTable 3** provides responses according to clinical, demographic and treatment-based characteristics. Overall, about one-third of respondents considered that nothing about their care could be better (486/1477; 32.9% [CI, 30.6% to 35.3%]). Respondents aged 70 years or older (AOR, 2.20 [CI, 1.47 to 3.31]) and those living further away from their dialysis centre (AOR, 1.39 [CI, 1.04 to 1.85]) were more likely to consider that no aspect of their care required improvement. In the four countries in which this question was asked (Argentina, Hungary, Poland, and Portugal), compared with Argentina, patients in Hungary (AOR, 1.37 [CI, 1.06 to 1.77]) and Poland (AOR, 1.82 [CI, 1.37 to 2.42]) were more likely to consider than nothing about their care needed to be changed.

In the four countries in which the question “would you recommend your dialysis centre to a friend or relative who needed dialysis” was asked, 1022 of 1587 respondents (64.4% [CI, 62.0 to 66.7%]) would definitely recommend their dialysis centre. Older respondents (AOR, 1.84 [CI, 1.24-2.74]) and those living further from their dialysis centre (AOR, 1.37 [CI, 1.03-1.83]) were more likely to recommend their dialysis centre to others for care, whereas those with depressive symptoms were less likely to recommend their care to others (AOR, 0.67 [CI, 0.51 to 0.87]) (**eTable 4**). Compared to Argentina, strong recommendations would more likely be made by respondents in Hungary (AOR 2.38 [CI 1.84-3.07]) and Portugal (AOR 28.2 [CI 3.84-207.39]).

The five items that respondents rated most frequently as excellent were “attention of staff to cleanliness of the dialysis vascular access site” (54% ranked as excellent), “caring and helpfulness of nurses” (53%), “response of staff to pain or discomfort” (51%), “caring, helpfulness and sensitivity of dialysis staff” (50%), and “ease of reaching staff by telephone” (48%) (**Figure 1**). The five items rated least frequently by respondents as excellent were “the amount of information when choosing dialysis modality”(23%), “the ease of seeing a social worker when needed” (28%), “amount of information from dialysis staff” (34%), “accuracy of information from nephrologist including prognosis and likelihood of getting a kidney transplant” (37%), and “accuracy of instructions from nephrologist" (39%). In general, the amount of caring and concern shown by staff, particularly by nurses, and the ability of patients to contact dialysis staff were ranked highly, whereas the amount and delivery of information about treatment choices and prognosis as well as access to social worker staff and nephrologists were ranked lowest.

A composite measure of key performance indicators were similar in the included countries during the recruitment period (in descending order with a higher value indicating higher performance: Hungary 1535, Portugal 1551, Italy 1543, Poland 1381, and Argentina 1303) and were associated with the proportion of respondents reporting excellent overall care (for each unit increase in performance score, the proportion of respondents who ranked care as excellent increased by 0.21% (95% CI -0.02% to 0.44%).

Discussion

We report the largest study of patient satisfaction with dialysis care to date and identify specific deficits in long-term dialysis care across several countries. Most respondents viewed their overall dialysis care as below excellent and needing improvement. Specifically, while the majority of respondents approved of the more technical aspects of dialysis treatment (attention to the cleanliness of the dialysis vascular access site, caring and helpfulness of nurses and dialysis staff, and attention by staff to immediate needs (pain, discomfort, sterile procedures)), a minority were satisfied with the more complex and integrated components of care. These were the accuracy and amount of information given by staff to patients about their dialysis treatment, prognosis and making choices between peritoneal dialysis and haemodialysis in addition to support from social worker staff. Older respondents were generally less critical of their haemodialysis care, while those with depressive symptoms were less frequently satisfied. Other demographic and clinical features did not reliably influence perceptions of overall care and country of treatment had inconsistent effects on satisfaction. Better dialysis care performance scores were associated with higher overall patient satisfaction.

Our patients' perspectives together with other similar studies from the United States[19] and The Netherlands[18] emphasise that deficiencies in dialysis care are consistently found and need to be considered specifically when conducting research to improve dialysis patient outcomes. This is particularly relevant as existing interventions in the dialysis setting, including anaemia management,[7] control of phosphorus[29] and parathyroid hormone levels,[30] dialysis dose and flux,[9] and starting dialysis earlier[8] have not improved patient-wellbeing despite evaluation in thousands of patients. Our respondents, consistent with the findings of others,[31-33] report specifically receiving inadequate information about their illness journey and as well as their dialysis treatment options. In our and other chronic diseases settings, patients report needing more information about the causes and progression of their disease, disease symptoms and their impact, and social and financial support.[34] [35]Patients, often due to the competing demands of daily life, rely on healthcare professional to initiate discussions about care planning and not having future-oriented conversations reduces patients' capacity for hope.[36] Patients perceive poor communication as reflecting secrecy, misinformation and insensitivity. Subsequently, inadequate information reduces the ability of patients and their families to care for themselves and induces worry.[34] While education strategies increase patients' willingness to choose self-care dialysis,[23] the wider effect of educational interventions in the dialysis setting that answer unmet questions about disease trajectory and treatment choices with the aim of improving patient experiences of end-stage kidney disease are not well understood and warrant larger-scale trials. Research in other settings suggest specific interventions to improve information provision, such as training and support for healthcare staff in communication and basic counselling, and overcoming barriers to good communication including addressing time pressures and understaffed environments and considering innovative non-written methods might be appropriate complex strategies for trials in the dialysis setting.[34]

This study indicates most patients in dialysis settings want more accurate information about their prognosis, in line with experiences of other dialysis patients and those who have cancer.[36 37]

Accurate prognostic information empowers patients;[38] when discussions about prognosis do not occur, patients and their families may (incorrectly) fear the worst. For dialysis patients in our study, the information they receive about prognosis is frequently unsatisfactory including specifically understanding their chances of receiving a kidney transplant and their survival. Physicians in other medical specialties similarly provide insufficient information about prognosis[39] and infrequently check their patients' understanding during consultations.[40] Physicians commonly find disclosing prognosis stressful and desire more training and guidance for this aspect of clinical practice.[41] Our findings suggest that meeting patients' expectations about information is an important but potentially neglected aspect of dialysis care and is consistent with data showing that patients are infrequently involved in discussions about prognosis and likelihood of transplantation.[33] The effect of increased clinician training in prognosis provision about survival and transplantation could form the basis of a testable strategy in future health services research in dialysis.

The patient-centred movement in healthcare ('nothing about me without me')[42] has engendered considerable data on the issues of most importance to patients and their families to highlight the mismatch between patients' values and the outcomes routinely measured in research and clinical practice, including for patients with advanced kidney disease.[5 43] While landmark trials in nephrology over the past three decades have measured treatment effectiveness using biomarker levels and major cardiovascular events and survival, emerging data show that patients are frequently willing to forgo survival in exchange for fewer restrictions on their daily life, and prioritize collaborative research aimed at improving the way they feel, function, and survive.[5 6] In addition, contemporary studies of communication and educational strategies as well as complex healthcare service changes in dialysis have used similarly quantitative outcomes to assess treatment effectiveness, which have included urgent dialysis start, vascular access processes, and survival.[20 21 44] We suggest that, in line with patient-centred data, trials of communication or education for dialysis patients might consider aspects of quality of life valued by patients as key outcomes for assessing effectiveness.

Notably, patient satisfaction was largely unrelated to most clinical or demographic patient characteristics despite a large sample size and similar to other studies in the US and The Netherlands, suggesting that lower satisfaction of many aspects of dialysis care is a global patient experience. Older patients in this study rated their overall care more highly, consistent with a recent study of patient perceptions of dialysis care in The Netherlands,[18] and of studies of patient satisfaction across health services more generally,[45 46] despite evidence that older patients may actually receive lower quality care.[47] In contrast, depressive symptoms markedly reduced satisfaction in this study, (even when controlling for markers of health status and comorbidity); similar findings have been reported in other settings.[48] Those with depressive symptoms voluntarily ration the time they have with medical staff, which may in turn impair patient-clinician communication and serve to decrease their satisfaction with care overall.[48] Notably, in other chronic disease settings, patient satisfaction is increased in association with better patient-clinician interaction and support for patient self-management[49] and high levels of patient satisfaction for interpersonal skills, technical quality and access to care can be present in chronic illness settings such as diabetes mellitus and rheumatoid arthritis.[50]

Limitations of the study

Although we provide considerable satisfaction data for dialysis patients in several countries, our analysis should be interpreted in light of the study limitations. First, we did not evaluate in detail the influence of healthcare systems in which the dialysis clinics were situated (including features such as staffing-levels[51] or number of beds[52]) on patient satisfaction, although we did find an association between overall satisfaction and global clinical performance. While interpersonal relations with healthcare workers are the most frequently mentioned by patients when asked to rate their care, contextual factors relating to conditions of medical services are also described commonly by patients and often lead to negative comments about healthcare.[53] Second, we took a quantitative approach to assessing patients' perceptions, which may be suboptimal for understanding the full range of feelings, values and experiences of receiving dialysis care. In addition, satisfaction and dissatisfaction may not simply be alternative ends of a single spectrum of perception and may in fact exist side-by-side within a patient experience of care.[54] Third, we did not capture satisfaction with a specific healthcare event and surveyed patients who had been treated with dialysis for 3 years on average. The potential lag between pivotal patient experiences and the survey may have introduced recall bias.[55] Fourth, we did not capture longitudinal data to determine any association between perceptions of care and health-related behaviour and outcomes including healthcare utilization, quality of life, or survival. Finally, the findings in this study may not be applicable to other dialysis settings including peritoneal dialysis or home-based haemodialysis care and regional settings outside our survey countries including many USA, European and United Kingdom dialysis settings. In addition, the study survey predates more widespread use of haemodiafiltration which may be associated with greater haemodynamic stability during dialysis therapy and different levels of patient satisfaction.

Implications of the study

As measures of patient experience are distinctive indicators of health care quality,[55] our analysis suggests several strategies might improve care for patients in the later stages of chronic kidney disease. First, patients need better information about their choices of treatment for end-stage kidney disease including dialysis modalities. A recent systematic review suggests this is optimally provided when the glomerular filtration rate falls below 30 ml/min per 1.73 m^2 and well in advance of preparations for dialysis vascular access.[31] Second, formal care strategies that provide patients with information about prognosis and the impact of end-stage kidney disease and its treatments on their life earlier in the course of kidney disease need to be developed and assessed. Current practices for assessing and discussing prognosis are manifestly inadequate[36] and our present reliance on individual physicians to initiate such discussions is not meeting the needs of our patients. Third, better delivery of information about dialysis from both nephrologists and dialysis staff is expected by patients and greater understanding of the information that patients need and optimal mode(s) of delivery may improve care.

Conclusion

This large study of patient satisfaction with different aspects of long-term haemodialysis care suggests that patients' needs are not being fully met. The findings suggest that meeting patient expectations about information on dialysis choices and prognosis may be critical for improving patient experiences of long-term dialysis care and can form the basis for future healthcare services research in the dialysis setting.

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Competing interests

GS is Senior Vice-President of Scientific Affairs at Diaverum. JH is Senior Vice President Medical Operations - Chief Medical Officer of Diaverum. MR, CW, EC, RG, JNF, MT, ML, AB-S, and JD are employees of Diaverum. SP receives a fellowship from the Consorzio Mario Negri Sud, Italy from provided by an unrestricted educational grant from Amgen Dompé. SP is a 2012 L'Oreal UNESCO For Women in Science Australia and New Zealand Fellow.

Ethical approval

We obtained ethics approval for the analyses of routinely collected data from the University of Sydney Human Research Ethics Committee on 27 February 2013. The authorized personnel are Allison Tong, Jonathan Craig and Giovanni Strippoli. The project number for approval was 2013/031 and included approval of the satisfaction survey, the data custodian (Diaverum) and the survey data dated January 2008.

Author contributions

SP designed the study, interpreted data analysis, wrote the first draft and revised the paper. GdB designed the data analysis, cleaned and analyzed data, and drafted and revised the paper. JCC assisted with study design, interpreted the data analysis, and drafted and revised the paper. AT interpreted the data analysis, and drafted and revised the paper. MT assisted with data collection tools, interpreted the data analysis, and drafted revised the paper. FP interpreted the data analysis, and revised the paper. MR monitored data collection for the whole study, assisted with data collection and cleaning, and interpreted the data analysis, and revised the paper. JH and CW interpreted the data analysis, and revised the paper. EC, RG, JNF, MT, ML, AB-S, and JD assisted with data collection, and interpreted the data analysis, and revised the paper. GFMS designed the study and data collection tools, monitored data collection for the whole study, interpreted the data analysis, and drafted and revised the paper. He is the guarantor. All authors had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Presentation as abstract

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Data sharing statement

None available

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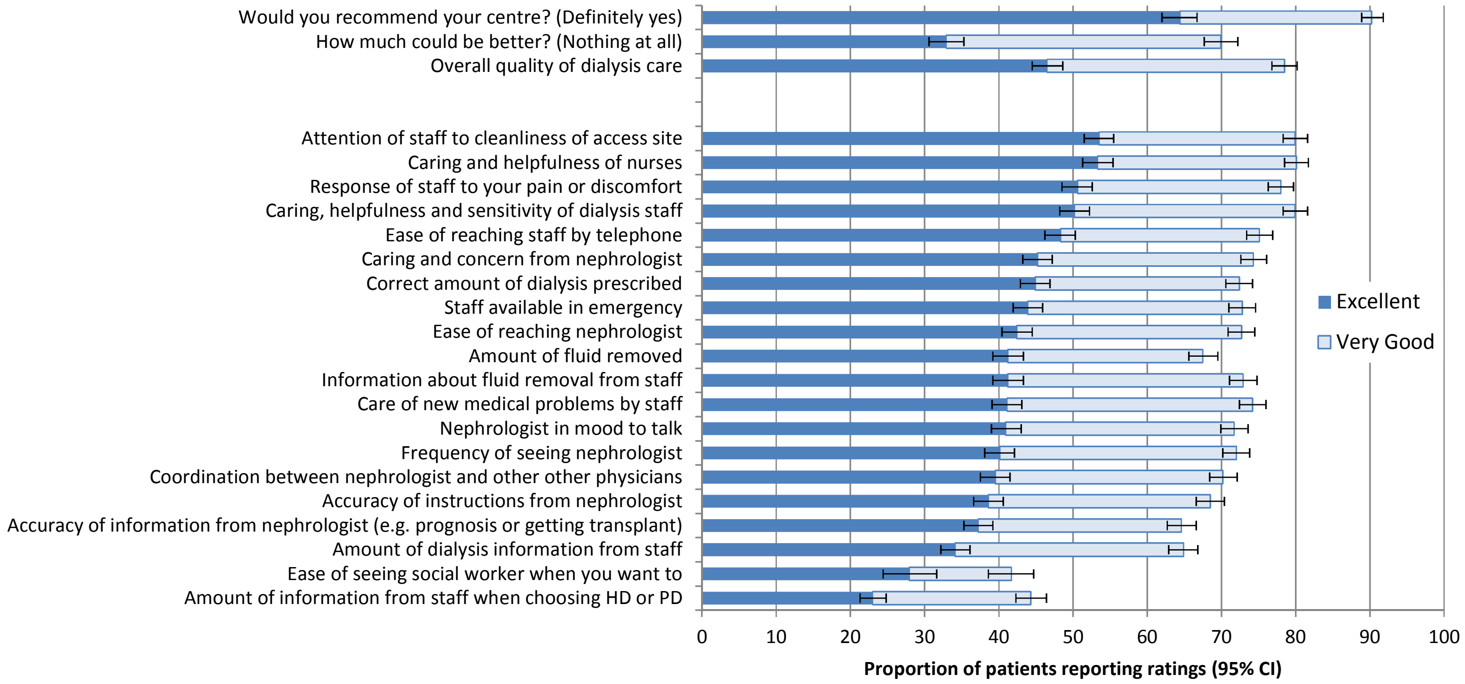
Figure Legends

Figure 1 Probabilities of excellent or very good ratings of overall care by dialysis patients

Figure 1 Probabilities of excellent or very good ratings of overall care by dialysis patients



Tables

Table 1 | Characteristics of participants who responded and those who did not respond to satisfaction survey

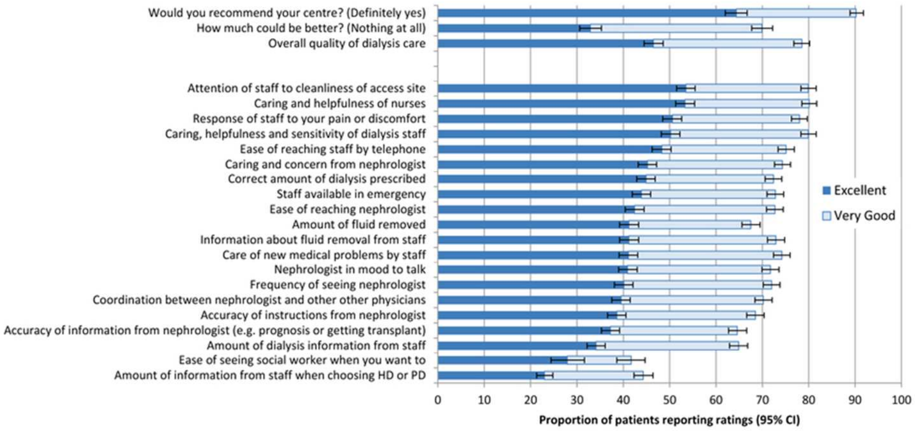
Characteristic	Complete or partial response to survey (n=2145)	No response to survey (n=603)	P value
Age, *years*	61.0 (15.5)	62.7 (14.8)	0.04
Gender , *n (%) male*	1190 (55.5)	314 (52.1)	0.14
Highest school education			
≤ 5 years	847 (42.1)	238 (41.6)	0.82
>5 years	1163 (57.9)	334 (58.4)	
Depression score (Center for Epidemiological Studies-Depression Scale)			
< 18	947 (49.6)	67 (46.7)	0.25
≥ 18	963 (50.4)	83 (55.3)	
Married	1303 (60.8)	377 (62.5)	0.43
Living alone	275 (13.0)	97 (16.2)	0.04
Distance of housing from dialysis unit			0.001
< 20 kilometres	1540 (73.1)	392 (65.8)	
> 20 kilometres	567 (26.9)	204(34.2)	
Active on waiting list for transplant	309 (14.4)	72 (11.9)	0.12
Previous kidney transplant	148 (6.9)	28 (4.7)	0.05
Employment			0.002
Employed	331 (15.7)	76 (12.9)	
Unemployed	1451 (68.8)	450 (76.1)	
Receiving benefit/pension	328 (15.6)	65 (11.0)	
Comorbid conditions			
Diabetes mellitus	486 (23.5)	146 (25.1)	0.42
Hypertension	1347 (68.5)	376 (70.3)	0.65
Prior cardiovascular event	472 (22.0)	124 (20.6)	0.45
Time on dialysis, *months*	37.3 (16.3-70.9)	36.0 (17.0-75.7)	0.69
Dialysis treatment time, *minutes per session*	235.9 (20.5)	234.3 (23.5)	0.35
Dialysis adequacy, *single pool Kt/V*	1.6 (0.3)	1.5 (0.3)	0.02
Interdialytic weight gain, *kg*	2.29 (1.03)	2.37 (1.09)	0.16
Serum values			
Haemoglobin, *g/l*	11.0 (1.4)	11.0 (1.3)	0.31
Systolic blood pressure, *mmHg*	130.0 (18.0)	128.4 (17.3)	0.07
Serum albumin, *g/l*	3.9 (0.5)	3.9 (0.5)	0.73
Serum phosphorus, *mmol/l*	4.6 (1.4)	4.6 (1.4)	0.69
Serum ferritin, *µg/l*	430 (242-660)	409 (242-672)	0.71
Serum parathyroid hormone, *pmol/l*	282 (162-481)	287 (167-530)	0.23
Antidepressant medication	113 (5.3)	26 (4.3)	0.34
Anxiolytic medication	291 (13.6)	86 (14.3)	0.66
Country			<0.0001
Argentina	549 (81.9)	121 (18.1)	
Hungary	556 (81.4)	127 (18.6)	
Italy	648 (73.6)	232 (26.4)	
Poland	355 (74.4)	122 (25.6)	
Portugal	37 (97.4)	1 (2.6)	

Data are expressed as mean (SD), number (%), or median (25th percentile, 75th percentile). Kt/V refers to the clearance of urea and is a measure of the amount of dialysis received.

Table 2 | Proportion of patients who gave an excellent rating to overall haemodialysis care according to patient characteristics

Characteristic	Excellent rating N (%)	Other rating N (%)	Unadjusted odds ratio	Clustering and case-mix adjusted odds ratio
Age				
18-49 years	183 (19.1)	300 (28.1)	1.00 (reference)	1.00
50-59 years	146 (15.3)	215 (20.1)	1.11 (0.84-1.47)	1.01 (0.70-1.44)
59-69 years	221 (23.1)	218 (20.4)	1.66 (1.28-2.16)	1.18 (0.82-1.69)
≥70 years	406 (42.5)	335 (31.4)	1.99 (1.57-2.51)	1.44 (1.01-2.04)
Male gender	466 (46.1)	483 (43.1)	1.13 (0.95-1.34)	1.12 (0.88-1.44)
Highest school education				
≤5 years	465 (49.0)	375 (35.8)	1.72 (1.44-2.06)	0.95 (0.74-1.21)
>5 years	485 (51.1)	673 (64.2)	1.00 (reference)	1.00
Occupational status				
Employed	120 (12.0)	209 (19.0)	0.59 (0.46-0.75)	0.79 (0.56-1.12)
Unemployed or pension	876 (88.0)	893 (81.0)	1.00	1.00
Married	601 (59.4)	693 (61.8)	0.91 (0.76-1.08)	0.86 (0.67-1.10)
Distance of housing from dialysis unit				
<20 kilometres	741 (73.9)	792 (72.5)	1.00	1.00
>20 kilometres	262 (26.1)	300 (27.5)	0.93 (0.77-1.13	1.18 (0.91-1.54)
Waiting list for kidney transplant	131 (13.0)	176 (15.7)	0.80 (0.63-1.02)	0.80 (0.56-1.14)
Comorbid conditions				
Diabetes mellitus	249 (25.4)	233 (21.6)	1.24 (1.01-1.52)	1.38 (0.78-2.46)
Prior cardiovascular event	248 (24.5)	220 (19.6)	1.33 (1.08-1.63)	0.89 (0.63-1.26)
Center for Epidemiological Studies-Depression Scale score				
<18	472 (52.5)	472 (47.2)	1.00 (reference)	1.00 (reference)
≥18	427 (47.5)	527 (52.8)	0.81 (0.68-0.97)	0.56 (0.44-0.71)
Dialysis adequacy, *single pool Kt/V*				
<1.4	202 (20.6)	245 (22.2)	1.00 (reference)	1.00
≥1.4	778 (79.4)	856 (77.8)	1.10 (0.89-1.36)	1.11 (0.83-1.49)
Serum phosphorus, mmol/l				
<1.45	516 (51.5)	509 (45.9)	1.00 (reference)	1.00
≥1.45	486 (48.5)	601 (54.1)	0.80 (0.67-0.95)	0.96 (0.76-1.23)
Haemoglobin, g/l				
<110	476 (47.6)	537 (48.2)	1.00 (reference)	1.00
≥110	525 (52.4)	578 (51.8)	1.02 (0.86-1.22)	0.90 (0.71-1.14)
Albumin, g/dl				
<3.8	371 (37.8)	369 (33.7)	1.00 (reference)	1.00
3.8-4.0	277 (28.2)	324 (29.6)	0.85 (0.69-1.05)	1.07 (0.80-1.42)
≥4.1	333 (33.9)	401 (36.6)	0.83 (0.67-1.01	0.78 (0.58-1.05)
Systolic blood pressure, mmHg				
≤120	270 (27.2)	353 (32.1)	1.00 (reference)	1.00
121-140	404 (40.6)	441 (40.0)	1.20 (0.97-1.47)	0.89 (0.67-1.19)
≥140	320 (32.2)	307 (27.9)	1.36 (1.09-1.70)	1.03 (0.76-1.40)
Country				
Poland	48 (4.8)	303 (27.0)	0.09 (0.07-0.13)	-
Argentina	172 (17.0)	372 (33.2)	0.28 (0.22-0.35)	-
Italy	405 (40.1)	242 (21.6)	1.00 (reference)	-
Hungary	355 (35.1)	198 (17.7)	1.07 (0.85-1.36)	-
Portugal	31 (3.1)	6 (0.5)	3.09 (1.27-7.51)	-

Clustering and case-mix adjusted model controlled for age, gender, education level, occupational status, marital status, distance from dialysis centre, activity on transplant waiting list, comorbid conditions (diabetes, hypertension, cardiovascular event) depression score, cause of end-stage kidney disease, duration of dialysis per session and dialysis dose, dialysis adequacy (Kt/V), serum values (haemoglobin; phosphorus) and country.



Probabilities of excellent or very good ratings of overall care by dialysis patients
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Supplement

eAppendix CHOICE Satisfaction Questionnaire

We want your opinion on the quality of the medical care you receive for your dialysis treatment. Please choose the answer than best reflects your views for each of the questions below. There is no right or wrong answer. We want your opinions.

Please rate the following *(Fill in the corresponding circle on each line):*	Poor	Fair	Good	Very Good	Excellent	Not Applicable to me
1. How easy is it to reach the kidney doctor	○	○	○	○	○	○
2. The nephrologist's caring and concern about you	○	○	○	○	○	○
3. How often the nephrologist sees you	○	○	○	○	○	○
4. How often the nephrologist is in a mood to talk with patients	○	○	○	○	○	○
5. How accurate the nephrologist is about information like your chance of doing well or of getting a transplant	○	○	○	○	○	○
6. How accurate the nephrologist's instructions to you are	○	○	○	○	○	○
7. How well the nephrologist makes sure the amount of dialysis you are getting is just right for you	○	○	○	○	○	○
8. How well the nephrologist and other doctors you see coordinate with each other	○	○	○	○	○	○
9. How easy it is to reach your dialysis center by telephone	○	○	○	○	○	○
10. How much attention doctors and nurses pay to cleanliness when they work with your IV or access site	○	○	○	○	○	○
11. How helpful and caring the nurses at your dialysis center are	○	○	○	○	○	○
12. How sensitive, helpful, and caring your dialysis center staff are	○	○	○	○	○	○
13. How well your dialysis center staff responds when you say you are in pain or uncomfortable	○	○	○	○	○	○
14. The number and kind of staff available to help you in an emergency	○	○	○	○	○	○
15. How much information you are being given about dialysis	○	○	○	○	○	○
16. The amount of information you are being given to help you choose between hemodialysis and peritoneal dialysis	○	○	○	○	○	○
17. How much information you are given about the amount of fluid to take in and take off	○	○	○	○	○	○
18. How much fluid is removed during your dialysis session	○	○	○	○	○	○
19. How easy it is to meet the social worker when you want to	○	○	○	○	○	○
20. How well new medical problems taken care of by the dialysis center staff when they arise	○	○	○	○	○	○
21. How would you rate the quality of care you have received as a dialysis patient, overall	○	○	○	○	○	○

22. Thinking about your dialysis care overall, how much could be better

Many things	A few things	One or two tings	Nothing could be better at all
○	○	○	○

22. Would you recommend your dialysis center to a friend or relative who needs dialysis

Definitely not	Probably not	Not sure	Probably yes	Definitely yes
○	○	○	○	○

Thank you for completing this survey. Please put your survey in the envelope, seal it, and give it to the clinic coordinator.

eTable 1 | Percentage of patients who rated care as excellent overall and according to country

Satisfaction Domain and Item	Overall cohort	Italy	Argentina	Hungary	Poland	Portugal
Nephrologist						
1. Ease of reaching	983/2316	375 (54.1)	159 (26.3)	351 (58.7)	69 (18.0)	29 (78.4)
2. Caring and concern	1049/2321	426 (61.2)	151 (24.9)	365 (61.0)	76 (19.8)	31 (83.8)
3. Frequency of seeing	928 /2316	395 (56.8)	121 (20.0)	320 (53.8)	64 (16.7)	28 (75.7)
4. In mood to talk	945/2308	414 (59.8)	121 (21.8)	297 (50.0)	74 (19.3)	29 (78.4)
5. Accuracy of information	851/2286	343 (50.4)	105 (17.4)	331 (56.5)	45 (11.8)	27 (73.0)
6. Accuracy of instructions	889/2302	359 (52.3)	111 (18.4)	340 (57.4)	52 (13.6)	27 (75.0)
7. Correct amount of dialysis	1030/2295	479 (68.6)	100 (17.0)	375 (63.6)	48 (12.6)	28 (75.7)
8. Coordination with other physicians	909/2302	397 (57.2)	147 (24.5)	285 (48.4)	53 (13.8)	27 (73.0)
Dialysis Staff						
9. Ease of reaching staff	1110/2299	458 (66.1)	143 (23.9)	428 (72.4)	51 (13.4)	30 (81.1)
10. Attention to cleanliness of access	1235/2308	487 (69.9)	196 (23.7)	452 (76.2)	69 (18.1)	31 (83.8)
11. Caring of nurses	1238/2321	470 (67.2)	214 (35.3)	449 (75.3)	74 (19.3)	3 (83.8)
12. Caring of staff	1166/2322	442 (63.1)	193 (31.8)	423 (71.1)	77 (20.2)	31 (83.8)
13. Response to pain	1162/2298	492 (71.1)	192 (32.1)	408 (68.5)	40 (10.7)	30 (81.1)
14. Staff available in emergency	1001/2281	448 (64.9)	116 (19.6)	375 (63.7)	33 (8.9)	29 (78.4)
15. Amount of dialysis information	776/2273	303 (44.4)	90 (15.3)	321 (53.8)	34 (9.2)	28 (75.7)
16. Amount of information on	513/2230	175 (26.5)	70 (12.0)	229 (39.5)	12 (3.3)	27 (73.0)
17. Information about fluid removal	1041/2268	441 (63.4)	127 (21.8)	412 (70.0)	35 (9.6)	26 (70.3)
18. Amount of fluid removed	917/2226	421 (60.7)	80 (14.3)	367 (62.3)	22 (6.3)	27 (73.0)
19. Ease of seeing social worker*	162/585	-	-	162 (27.7)	-	-
20. New medical problems	927/2256	375 (54.6)	148 (25.7)	355 (60.0)	20 (5.5)	29 (78.4)
Overall Ratings						
21. Quality of dialysis care	1057/2271	424 (61.2)	177 (30.3)	375 (63.5)	50 (13.7)	31 (83.8)
22. How much could be better? **	518/1575	-	162 (27.7)	201 (34.1)	148	7 (20.6)
23. Would you recommend your center? **	1022/1587	-	330 (56.5)	433 (73.9)	223	36 (97.3)

*Question 19 was present only in the Hungarian version of the survey
**Questions 22 and 23 were not included in the Italian version of the questionnaire

eTable 2 | Key performance indicators

Key performance indicators
Kt/V ≥ 1.4
Albumin ≥ 35 g/l
nPCR ≥ 1.0 g/kg/day
Haemoglobin ≥ 10.0 and ≤ 12.0 g/dl
Ferritin ≥ 200 and ≤ 500 ng/ml
Phosphorus ≥3.5 and ≤5.5 mg/dl
Calcium by phosphorus product <55 mg^2/dl^2
Parathyroid hormone ≥150 pg/ml and ≤ 300 pg/ml
Mean arterial pressure <105 mmHg
Interdialytic weight gain <4 %
Arteriovenous fistula

eTable 3 | Percentage of patients who reported that nothing about care could be better according to patient and centre characteristics

Characteristic	Excellent rating N (%)	Other rating N (%)	Unadjusted odds ratio	Clustering and case-mix adjusted odds ratio
Age				
18-49 years	91 (19.6)	293 (31.1)	1.00 (reference)	1.00
50-59 years	79 (17.0)	205 (21.8)	1.24 (0.87-1.76)	1.14 (0.76-1.71)
59-69 years	112 (24.1)	208 (22.1)	1.73 (1.25-2.41)	1.40 (0.94-2.10)
≥70 years	182 (39.2)	235 (25.0)	2.49 (1.84-3.38)	2.20 (1.47-3.31)
Male gender	232 (47.7)	431 (43.5)	1.19 (0.95-1.48)	1.29 (0.97-1.72)
Highest school education				
≤5 years	176 (40.3)	334 (36.1)	1.20 (0.95-1.51)	1.17 (0.87-1.57)
>5 years	261 (59.7)	592 (63.9)	1.00 (reference)	1.00
Occupational status				
Employed	65 (13.7)	181 (18.6)	0.70 (0.51-0.95)	0.86 (0.57-1.30)
Unemployed or pension	409 (86.3)	792 (81.4)	1.00	1.00
Married	289 (59.5)	583 (58.8)	1.03 (0.82-1.28)	1.19 (0.90-1.58)
Distance of housing from dialysis unit				
<20 kilometres	302 64.5)	695 (71.4)	1.00	1.00
>20 kilometres	166 (35.5)	279 (28.6)	1.37 (1.08-1.73)	1.39 (1.04-1.85)
Waiting list for kidney transplant	66 (13.6)	170 (17.2)	0.76 (0.56-1.03)	1.11 (0.75-1.65)
Comorbid conditions				
Diabetes mellitus	122 (26.1)	226 (23.7)	1.13 (0.88-1.46)	1.24 (0.67-2.30)
Prior cardiovascular event	110 (22.6)	213 (21.5)	1.07 (0.82-1.39)	0.94 (0.67-1.31)
Center for Epidemiological Studies-Depression Scale score				
<18	243 (54.1)	448 (49.0)	1.00 (reference)	1.00 (reference)
≥18	206 (45.9)	467 (51.0)	0.81 (0.65-1.02)	0.81 (0.62-1.06)
Dialysis adequacy, *single pool Kt/V*				
<1.4	94 (19.7)	202 (20.8)	1.00 (reference)	1.00
≥1.4	384 (80.3)	769 (79.2)	1.07 (0.82-1.41)	1.18 (0.82-1.69)
Serum phosphorus, mmol/l				
<1.45	258 (53.4)	510 (52.0)	1.00 (reference)	1.00
≥1.45	225 (46.6)	471 (48.0)	0.94 (0.76-1.17)	1.05 (0.79-1.39)
Haemoglobin, g/l				
<110	229 (47.3)	530 (53.8)	1.00 (reference)	1.00
≥110	255 52.7)	455 (46.2)	1.30 (1.04-1.61)	1.27 (0.96-1.66)
Albumin, g/dl				
<3.8	161 (33.5)	316 (32.5)	1.00 (reference)	1.00
3.8-4.0	145 (30.2)	281 (28.9)	1.01 (0.77-1.33)	0.91 (0.65-1.28)
≥4.1	175 (36.4)	374 (38.5)	0.92 (0.71-1.19)	0.81 (0.57-1.15)
Systolic blood pressure, mmHg				
≤120	156 (32.5)	300 (31.0)	1.00 (reference)	1.00
121-140	193 (40.2)	373 (38.5)	1.00 (0.77-1.29)	0.98 (0.71-1.36)
≥140	131 (27.3)	296 (30.6)	0.85 (0.64-1.13)	0.88 (0.62-1.26)
Country				
Italy	-	-	-	-
Portugal	7 (1.4)	27 (2.7)	0.69 (0.29-1.61)	-
Argentina	148 (30.4)	392 (39.6)	1.00 (reference)	-
Hungary	188 (38.7)	364 (36.7)	1.37 (1.06-1.77)	-
Poland	143 (29.4)	208 (21.0)	1.82 (1.37-2.42)	-

Clustering and case-mix adjusted model controlled for age, gender, education level, occupational status, marital status, distance from dialysis centre, activity on transplant waiting list, comorbid conditions (diabetes, hypertension, cardiovascular event) depression score, cause of end-stage kidney disease, duration of dialysis per session and dialysis dose, dialysis adequacy (Kt/V), serum values (haemoglobin; phosphorus) and country.

eTable 4 | Percentage of patients who would recommend their dialysis center to a friend or relative who needed dialysis care according to patient and center characteristics

Characteristic	Excellent rating N (%)	Other rating N (%)	Unadjusted odds ratio	Clustering and case-mix adjusted odds ratio
Age				
18-49 years	216 (23.4)	170 (34.8)	1.00	1.00
50-59 years	191 (20.7)	96 (19.5)	1.57 (1.14-2.15)	1.34 (0.93-1.94)
59-69 years	222 (24.1)	99 (20.2)	1.76 (1.29-2.41)	1.36 (0.93-1.99)
≥70 years	294 (31.8)	124 (25.4)	1.87 (1.40-2.50)	1.84 (1.24-2.74)
Male	438 (45.2)	229 (44.5)	1.03 (0.83-1.28)	0.97 (0.73-1.28)
Highest school education				
≤5 years	363 (40.6)	151 (31.7)	1.47 (1.16-1.86)	1.15 (0.86-1.54)
>5 years	532 (59.4)	325 (68.3)	1.00	1.00
Occupational status				
Employed	155 (16.3)	90 (17.9)	0.89 (0.67-1.19)	1.17 (0.81-1.68)
Unemployed or pension	796 (83.7)	413 (82.1)	1.00	1.00
Married	581 (60.0)	299 (58.1)		1.06 (0.81-1.39)
Distance of housing from dialysis unit				
<20 kilometres	633 (66.8)	370 (73.6)	1.00	1.00
>20 kilometres	314 (33.2)	133 (26.4)	1.38 (1.09-1.75)	1.37 (1.03-1.83)
Waiting list for kidney transplant	152 (15.7)	86 16.7)	0.93 (0.70-1.24)	1.01 (0.70-1.45)
Comorbid conditions				
Diabetes mellitus	240 (25.8)	112 (22.5)	1.20 (0.93-1.55)	1.52 (0.78-2.94)
Prior cardiovascular event	234 (24.2)	92 (17.9)	1.46 (1.12-1.92)	1.21 (0.85-1.71)
Center for Epidemiological Studies-Depression Scale score				
<18	475 (53.1)	214 (45.2)	1.00	1.00
≥18	420 (46.9)	260 (54.9)	0.73 (0.58-0.91)	0.67 (0.51-0.87)
Dialysis adequacy, *single pool Kt/V*				
<1.4	181 (19.13)	114 (22.4)	1.00	1.00
≥1.4	765 (80.9)	395 (77.6)	1.22 (0.94-1.59)	1.11 (0.79-1.56)
Serum phosphorus, mmol/l				
<1.45	532 (55.4)	242 (47.5)	1.00	1.00
≥1.45	429 (44.6)	267 (52.5)	0.73 (0.59-0.91)	1.09 (0.83-1.43)
Haemoglobin, g/l				
<110	485 (50.4)	276 (53.8)	1.00	1.00
≥110	477 (59.6)	237 (46.2)	1.15 (0.92-1.42)	0.95 (0.73-1.24)
Albumin, g/dl				
<3.8	294 (30.9)	186 (36.7)	1.00	1.00
3.8-4.0	287 (30.2)	140 (27.6)	1.30 (0.99-1.70)	1.29 (0.93-1.80)
≥4.1	370 (38.9)	181 (35.7)	1.29 (1.00-1.67)	1.00 (0.70-1.42)
Systolic blood pressure. mmHg				
≤120	295 (31.2)	167 (32.8)	1.00	1.00
121-140	381 (40.2)	183 (36.0)	1.18 (0.91-1.53)	0.81 (0.59-1.11)
≥140	271 (28.6)	159 (31.2)	0.96 (0.73-1.27	0.70 (0.50-0.99)
Country				
Italy	-	-	-	
Portugal	36 (3.7)	1 (0.2)	28.23 (3.84-207.39)	-
Argentina	306 (31.6)	240 (46.6)	1.00	-
Hungary	412 (42.5)	136 (26.4)	2.38 (1.84-3.07)	-
Poland	215 (22.2)	138 (26.8)	1.22 (0.93-1.60)	-

Clustering and case-mix adjusted model controlled for age, gender, education level, occupational status, marital status, distance from dialysis centre, activity on transplant waiting list, comorbid conditions (diabetes, hypertension, cardiovascular event) depression score, cause of end-stage kidney disease, duration of dialysis per session and dialysis dose, dialysis adequacy (Kt/V), serum values (haemoglobin; phosphorus) and country.

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STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Page reference
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	5-7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5-7
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5-6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-7
Bias	9	Describe any efforts to address potential sources of bias	7
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	7
		(*b*) Describe any methods used to examine subgroups and interactions	7
		(*c*) Explain how missing data were addressed	Not done
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	5-6
		(*e*) Describe any sensitivity analyses	None
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	p 5, 8 Table 1
		(b) Give reasons for non-participation at each stage	5, 8
		(c) Consider use of a flow diagram	Table provided
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1
		(b) Indicate number of participants with missing data for each variable of interest	eTable 1
Outcome data	15*	Report numbers of outcome events or summary measures	eTable 1

	Item No	Recommendation	Page reference
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Table 2, eTable 3, eTable 4
		(*b*) Report category boundaries when continuous variables were categorized	Throughout
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Not applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Not done
Discussion			
Key results	18	Summarise key results with reference to study objectives	10-11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	13
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	10-13
Generalisability	21	Discuss the generalisability (external validity) of the study results	13
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	15

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.