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EXAMINING PATIENT DISTRESS AND UNMET NEED FOR SUPPORT ACROSS UK RENAL UNITS WITH VARYING MODELS OF PSYCHOSOCIAL CARE DELIVERY: A CROSS-SECTIONAL SURVEY STUDY.

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**EXAMINING PATIENT DISTRESS AND UNMET NEED FOR SUPPORT ACROSS UK RENAL
UNITS WITH VARYING MODELS OF PSYCHOSOCIAL CARE DELIVERY: A CROSS-SECTIONAL
SURVEY STUDY.**

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ABSTRACT

Objective

To examine in-centre haemodialysis (ICHD) patients' emotional distress and perceived need for support across UK renal units with varying models of psychosocial service provision.

Design

The study used a cross-sectional survey design. Univariate and multivariate logistic regression were used to examine patient distress, as captured by the Distress Thermometer, and need for support, across different renal units.

Setting

Seven renal units across England, Wales and Scotland. The units were purposively selected so that varying workforce models of renal psychosocial services were represented.

Participants

In total, 752 patients were on dialysis in the participating centres on the days of data collection. All adult patients, who could understand English, and with capacity (as determined by the nurse in charge), were eligible to participate in the study. The questionnaire was completed by 509 patients, resulting in an overall response rate of 67.7%.

Outcome measures

The prevalence of distress and patient reported need for support.

Results

48.9% (95% Confidence Interval (CI): 44.5 – 53.4) of respondents were categorised as experiencing distress. A significant association between distress and models of renal psychosocial service provision was found ($\chi^2(6)=15.05$, $p = .019$). Multivariate logistic regression showed that patients in units with higher total psychosocial staffing ratios [odds ratio (OR) 0.65 (95% CI 0.47-0.89); $p=0.008$] and specifically higher social work ratios [OR 0.49 (95% CI 0.33-0.74; $p=0.001$) are less likely to experience distress, even after controlling for demographic variables. In addition, a higher patient-reported unmet need for support was

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3 found in units where psychosocial staffing numbers are low or non-existent ($\chi^2(6) = 37.80$,
4 $p < 0.0001$).
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7 **Conclusions**

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10 The novel findings emphasise a need for increased incorporation of dedicated renal
11 psychosocial staff into the renal care pathway. Importantly, these members of staff should be
12 able to offer support for psychological as well as practical and social care related issues.
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16 **KEY WORDS**

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19 Nephrology, Psychosocial Support Systems, Interdisciplinary Health Team, Psychological
20 distress, Health Workforce, Chronic Disease
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30 **STRENGTHS AND LIMITATIONS OF THIS STUDY**

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- 33 • This study is the first to investigate distress in renal patients across varying models of
34 psychosocial service delivery, providing a unique health systems research perspective.
 - 35 • This is a cross-sectional study, since a longitudinal panel study was not possible for
36 practical reasons.
 - 37 • Those from black and minority ethnic groups were under-represented in the
38 responses.
 - 39 • The overall response rate was high, which increases the probability that the findings
40 are representative of the patients in participating units.
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INTRODUCTION

Chronic Kidney Disease (CKD) is a worldwide public health problem, with increasing incidence and prevalence, high costs, and poor outcomes¹. The disease is typically progressive and can be divided into five stages of increasing severity, with treatments based on these stages. For a small, but significant percentage of people, CKD progresses to End-Stage Renal Disease (ESRD). At this stage, which is irreversible, the kidneys are no longer able to function and renal replacement therapy (RRT) – dialysis or transplantation – becomes necessary to maintain life^{2,3}. People with CKD often have a range of comorbid disorders. Some of these, such as hypertension and diabetes, are risk factors of the disease. Others, such as heart failure or chronic pulmonary disease, are often co-prevalent as a result of CKD or because of shared risk factors^{4,5}. Living with CKD, and especially ESRD, provides many ongoing physical, emotional, financial and/or social challenges throughout a patient's renal journey. These consequences of the disease and its comorbidities make patient access to expertise in medical, nursing, dietetic, pharmacological, psychological and social areas essential⁶.

In recent years, against a global backdrop of shortages in the nephrology workforce, there have been increasing calls for a change in the existing models of renal care to manage the demands of an increasing CKD burden. A collaborative care model, in which a greater share of the work is performed by allied health professionals (including psychosocial staff) is one of the proposed solutions⁷. Acceptance that a focus on the psychosocial needs of the patients should be included in comprehensive psychosocial care has grown in recent years⁸, yet this has not always translated into practice. Internationally, limited evidence suggests differences in the level and type of renal psychosocial care accessible to patients. A recent Europe-wide study found that multidisciplinary teams (defined as teams consisting of allied health professionals, e.g. expert nurses, dieticians and social workers) were routinely available to patients with CKD in only eight out of 17 studied countries⁹. In the US and Australia, renal dedicated social workers appear to be the point-person responsible for providing psychosocial care, although in both countries high caseloads and exceeded benchmarks were reported¹⁰⁻¹². US renal social workers are in a special position, since ESRD is the only disease

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3 for which Medicare's Conditions for Coverage Mandate requires a Masters-level trained social
4 worker on every interdisciplinary team¹³. A recent workforce report by Seekles et al.¹⁴ showed
5 that in the UK, over the past 15 years, a change in renal psychosocial staffing levels had taken
6 place. The number of (bachelor-level trained) renal social workers had reduced dramatically,
7 whilst renal psychologists and counsellors had grown in numbers. In the UK too,
8 recommended staff-to-patient ratios were far from being met. A general UK renal
9 psychosocial service provision model was lacking: most renal units incorporated different
10 psychosocial teams, made up of varying types and numbers of staff, while some units
11 completely lacked any form of dedicated psychosocial support¹⁵.

21 Currently, UK guidelines from the National Health Service (NHS) England¹⁶ and the National
22 Institute for Health and Care Excellence (NICE)³ vaguely state that haemodialysis (HD) patients
23 'must have access to' psychosocial services, without clarifying the type and number of staff
24 that should be accessible. This, and the large variety in models of service provision found,
25 reflects a lack of empirical studies on the delivery of psychosocial services that can inform
26 evidence-based staffing standards and regulations. This paper presents the findings of an
27 investigation that used the concept of distress – broadly defined as 'a multifactorial
28 unpleasant experience of a psychological (i.e., cognitive, behavioural, emotional), social,
29 spiritual, and/or physical nature'¹⁷ – to explore the association between in-centre
30 haemodialysis (ICHHD) patient distress, their perceived need for support and UK models of
31 renal psychosocial service delivery. Studies have found that distress can have a negative effect
32 on quality of life, health outcomes and costs, emphasising the importance of addressing
33 psychosocial issues in renal patients^{18–20}. The research question asked whether there is a
34 relationship between different UK models of renal psychosocial service delivery, self-reported
35 distress and need for support of ICHD patients. This investigation forms part of a larger,
36 nationwide mixed-methods study that aims to understand how renal psychosocial services
37 are delivered in the UK.

53 **METHODS**

56 **Participating renal units**

58 The study used a cross-sectional survey design and included in-centre haemodialysis (ICHHD)
59 patients from seven main renal units across England (n=3), Wales (n=2) and Scotland (n=2).

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3 The sites were purposively selected out of a total of 89 renal units, informed by the outcomes
4 of a recent renal psychosocial workforce mapping¹⁴, to ensure an inclusion of different
5 staffing ratios and models of psychosocial service provision. Ratios were calculated using the
6 number of ICHD patients from the latest UK Renal Registry²¹. Whilst many members of
7 psychosocial staff cover the whole range of RRT patients, including transplant patients, this
8 number was most appropriate since it links directly to the study population. Throughout this
9 paper, the units have been sorted based on their psychosocial staff-to-ICHD patient ratios,
10 with unit A having no renal dedicated psychosocial staff available and unit G having the best
11 ratio of staff available to its patients. Patients in in unit B have access to psychology services
12 only, whereas patients in unit C have access to a counsellor and welfare advisor. Patients in
13 units D, E, F and G have access to a social worker, in combination with either a psychologist,
14 counsellor or psychiatrist.

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16 On average, ratios of renal dedicated psychosocial staffing in the study sites are better than
17 ratios found across the UK. The average ratio of psychologists in this study is 1 Full-Time
18 Equivalent (FTE) per 248 dialysis patients, compared to an average of 1 FTE per 1044 patients.
19 For social workers, the average ratio in this study is 1 FTE per 156 dialysis patients, compared
20 to 1 FTE per 355 patients across the UK¹⁴. Comparison of overall staffing ratios was not
21 possible due to a lack of comparable data. Furthermore, only units B and D had a black and
22 minority ethnic (BME) population of a similar size as the overall UK dialysis population, whilst
23 the other units served predominantly or completely white populations.

24 25 26 **Patients and public involvement**

27 The study design was developed with input from patient representatives, who were asked to
28 comment on the appropriateness of the outcome measures and provide insight into the
29 expected burden and time required for participation. Patients were not involved in the
30 recruitment or further conduct of the study. The results will be disseminated to participants
31 and the wider renal units through Kidney Care UK's (KCUK) marketing channels (website,
32 posters) at the end of the project.

33 34 35 **Participants and recruitment**

36 All adult ICHD patients who could understand English, and with capacity (as determined by
37 the nurse in charge), were eligible to participate in the study. Data collection took place
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between March 2018 and July 2019. Renal unit staff at each Trust provided all eligible patients with a letter of invitation and an information sheet. The University research team would visit the unit one week later to distribute the questionnaires (with information sheets), which were to be completed by patients whilst on dialysis. Consent was assumed upon return of the completed questionnaire. To prevent selection bias, patients were allowed help with completion of the questionnaire.

Sample

The sample size was restricted by the number of patients dialysing in the renal units. In total, 752 patients were on dialysis in the participating centres on the days of data collection. Of these, 509 completed the questionnaire, resulting in an overall response rate of 67.7%. The response rates in participating units varied from 49.0% to 82.0%.

As can be seen in Table 1 **Error! Reference source not found.**, the majority of respondents were male and aged over 70 years old. This distribution of gender is similar to the general UK ICHD population, which is reported to consist for 61.9% of males. The median age of the general ICHD population is 67.5 years²¹. The study sample was almost entirely made up of people from the white ethnic group, which is different from the total ICHD population, in which this group makes up around 70 percent of patients ²¹. Furthermore, the majority of patients had been on dialysis for 6 months to three years, lived together with their partner or family and was retired.

Four respondents did not complete the DT, whilst others did not provide information on other questions, leading to varying numbers of missing data. Instead of using listwise deletion, which would have resulted in the loss of important information on some analyses, pairwise deletion was used to maximise the available data on an analysis by analysis basis.

Table 1: Respondent characteristics and proportion per sub-group

Characteristic	N	%
Total	509	100
<i>Main unit (psychosocial model)</i>		
Unit A (no staff)	64	12.6
Unit B (psychology)	65	12.8
Unit C (counselling + welfare advise)	98	19.3

Unit D (social work + psychology + counselling)	73	14.3
Unit E (social work + psychiatry)	104	20.4
Unit F (social work + psychology)	47	9.3
Unit G (social work + psychology)	58	11.4
<i>Sex</i>		
Male	311	61.1
Female	192	37.7
Missing	6	1.2
<i>Age Category</i>		
18-39	50	9.8
40-49	51	10.0
50-59	97	19.1
60-69	104	20.4
≥70	201	39.5
Missing	6	1.2
<i>Ethnicity</i>		
White	460	90.4
Other	42	8.3
Missing	7	1.4
<i>Time on Dialysis</i>		
<6 months	87	17.1
6 months to 3 years	193	37.9
3 to 5 years	91	17.9
>5 years	130	25.5
Missing	8	1.6
<i>Living situation</i>		
Living alone	147	29.7
Living together	349	70.3
Missing	13	2.6
<i>Employment situation</i>		
Employed	67	13.2

Unemployed	14	2.8
Unable to work	183	36.0
Retired	237	46.6
Missing	8	1.6

Ethical approval

Ethical approval was obtained from the University of Salford Ethics Committee, the West of Scotland Research Ethics Service and Health Research Authority in October 2017 (Ref 17/WS/0185). In addition, all Research and Development offices from the participating Trusts approved the study and confirmed their capability and capacity to host the research.

Measurements

The questionnaire used the NCCN Distress Thermometer (DT) and Problems Checklist¹⁷ as the instrument to measure distress. Although initially developed to screen for distress in oncology patients, the DT has been validated for use in the UK renal population²². It is a simple one-item screening tool, designed to be part of health professionals' daily practice, which asks patients to rate their distress on a 11-point Likert scale from zero (nothing) to ten (extreme). For analysis, distress was examined through a binary variable of distress 'caseness', with DT scores of ≥ 4 denoting distress¹⁷.

Patients indicated which issues were causing them distress by ticking a box on the Problem Checklist. The questionnaire included further tick-box questions to determine whether patients were currently in receipt of psychosocial support; and if not, whether they would like to receive this support. Information on sociodemographic characteristics (sex, age, ethnicity, living situation and employment situation) was captured using closed questions.

Data analysis methods

The prevalence of distress and 95% Confidence Intervals (CIs) were calculated using the cut-off score described in the measurements section. Univariate logistic regression was then applied to examine the associations between distress, study sites and demographic characteristics. Subsequently, multivariate logistic regression was used to identify whether study site, staffing ratios and further demographic variables served as predictors of distress.

All variables were entered simultaneously. Finally, univariate logistic regression was used to investigate the perceived need for support and prevalence of problem types across the study sites. All analysis were conducted using Stata Statistical Software: Release 14.2²³.

RESULTS

Overall, a distress score of ≥ 4 was observed in 247 out of 505 respondents, indicating that 48.9% (95% CI: 44.5 – 53.4) of ICHD patients were experiencing some form of distress. 25.7% (130 cases, 95% CI: 22.0-29.8) were identified as having mild to moderate distress (DT score 4-6). A DT score of ≥ 7 was observed for 117 cases, indicating that 23.2% of patients (95% CI: 19.6-27.1) across all study sites were experiencing severe distress.

Findings from univariate analyses (**Error! Reference source not found.2**) showed an association between distress and study site, with patients in units F and G less likely to be cases than in unit A, B and C. Further associations were found with age group and employment situation. Specifically, those aged 18-39, 40-49 and 50-59 and those patients who were unemployed or considered themselves unable to work were significantly more likely to be distressed than those aged 70 or above and retired.

Table 2. Summary of univariate logistic analyses for association between distress and demographic variables

Variable	Distress (DT ≥ 4) % (n)	OR (95% CI)	P-value	Likelihood-Ratio Chi2
Total (n=505)	48.9 (247)			
Main unit (n=505)				$\chi^2(6)=15.05, p = .019$
A	56.3 (36)	1.00	-	
B	56.3 (36)	1.00 (0.50-2.01)	1.00	
C	59.2 (58)	1.13 (0.60-2.14)	0.712	
D	48.0 (35)	0.72 (0.37-1.41)	0.332	
E	43.3 (45)	0.59 (0.32-1.11)	0.103	
F	34.1 (15)	0.40 (0.18-0.89)	0.025	
G	37.9 (22)	0.48 (0.23-0.98)	0.044	
Sex (n=499)				$\chi^2(1)=2.23, p = .135$
Male	46.3 (143)	1.00		

Female	53.2 (101)	1.32 (0.92-1.89)	0.136	
Age Category (n=499)				$\chi^2(4)=22.36, p<0.001$
18-39	60.0 (30)	2.46 (1.30-4.64)	0.005	
40-49	62.0 (31)	2.68 (1.41-5.07)	0.003	
50-59	61.9 (60)	2.66 (1.61-4.39)	<0.0001	
60-69	47.1 (49)	1.46 (0.90-2.36)	0.122	
≥70	37.9 (75)	1.00	-	
Ethnicity (n=498)				$\chi^2(1)=1.22, p = .269$
White	48.3 (220)	1.00	-	
Other	57.1 (24)	1.43 (0.76-2.71)	0.272	
Time on Dialysis (n=497)				$\chi^2(3)=2.99, p = .393$
<6 months	48.8 (42)	1.28 (0.74-2.22)	0.371	
6 months to 3 years	52.1 (100)	1.46 (0.93-2.30)	0.097	
3 to 5 years	51.1 (46)	1.40 (0.82-2.42)	0.216	
>5 years	42.6 (55)	1.00	-	
Living situation (n=492)				$\chi^2(1)=1.00, p = .316$
Living alone	52.1 (76)	1.00	-	
Living together	47.1 (163)	0.82 (0.56-1.21)	0.316	
Employment situation (n=497)				$\chi^2(3)=26.17, p <0.001$
Employed	42.4 (28)	1.14 (0.65-1.98)	0.649	
Unemployed	78.6 (11)	5.65 (1.54-20.83)	0.009	
Unable to work	61.2 (112)	2.43 (1.64-3.62)	<0.0001	
Retired	39.3 (92)	1.00	-	

DT: Distress Thermometer; OR: Odds Ratio; 95% CI: 95% confidence interval.

A multivariate logistic regression model (**Error! Reference source not found.3**) including renal unit and other demographic variables sex, age, ethnicity, time on dialysis, living situation and

employment situation was found to be a significant predictor of distress (LR $\chi^2(19)= 56.77, p < 0.0001$). The renal unit that patients belonged to significantly predicted distress, with being a patient in unit E ($\beta -0.718$) or F ($\beta -1.083$) significantly reducing the likelihood of distress compared to being a patient in unit A. Time on dialysis was also found to be a predictor of distress, with being on dialysis for a period of 3 to 5 years significantly increasing the likelihood of distress. Age group and employment situation were not found to be predictors.

Table 3: Multivariate regression model for predictors of distress including renal unit and demographic variables

Predictor	OR (95% CIs)	P-value
Constant	0.688 (0.32-1.47)	
Renal unit		
A	<i>reference</i>	
B	0.851 (0.40-1.82)	0.676
C	1.193 (0.60-2.36)	0.612
D	0.663 (0.32-1.38)	0.272
E	0.488 (0.25-0.97)	0.041
F	0.338 (0.14-0.84)	0.019
G	0.508 (0.23-1.10)	0.086
Sex		
Male	<i>reference</i>	
Female	1.268 (0.85-1.89)	0.241
Age Category		
18-39	2.186 (0.92-5.22)	0.078
40-49	2.173 (0.92-5.13)	0.077
50-59	1.809 (0.89-3.73)	0.108
60-69	1.179 (0.68-2.05)	0.560
≥ 70	<i>reference</i>	
Ethnicity		
White	<i>reference</i>	
Other	1.037 (0.48-2.22)	0.925
Time on Dialysis		
<6 months	1.509 (0.82-2.77)	0.183

6 months to 3 years	1.434 (0.88-2.34)	0.149
3 to 5 years	1.833 (1.01-3.34)	0.047
>5 years	<i>reference</i>	
Living situation		
Living alone	<i>reference</i>	
Living together	0.725 (0.48-1.10)	0.134
Employment situation		
Employed/in Education	0.560 (0.28-1.30)	0.194
Unemployed	4.058 (0.90-18.33)	0.069
Unable to work	1.791 (0.97-3.30)	0.061
Retired	<i>reference</i>	
No. of observations	488	

Further regression analysis was undertaken to provide more insight into the relationship between distress and psychosocial staffing ratios. Three similar multivariate logistic regression models were created, differing only by inclusion of either the total ratio of renal dedicated psychosocial staff, the ratio of renal social workers or the ratio of renal psychologists/counsellors (**Error! Reference source not found.**4). Whilst acknowledging the difference between psychologists and counsellors, it was decided to group these professions together in model 3 because of their low numbers. All models included the demographics sex, ethnicity, age, living situation, time on dialysis and employment situation as predictors.

The results were as follows:

- Model 1 (including total ratios of psychosocial staff): a collective significant effect was found, LR χ^2 (14)=47.68, $p < 0.0001$. Specifically, the ratio of total psychosocial staff was found to significantly predict distress, with higher ratios of staff leading to a lower likelihood of distress (β -.43, $p = 0.008$).
- Model 2 (including ratios of social work staff): This model also returned a significant result, predicting distress LR χ^2 (14)=52.57, $p < 0.0001$. A significant association was found between social worker ratios and distress, with likelihood of distress reducing as social worker ratios increased (β -.71, $p = 0.001$).

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- Model 3 (including ratios of psychology/counselling staff): Overall, the model significantly predicted distress, LR χ^2 (14)= 40.60, $p < 0.001$, but the ratio of psychology/counselling staff was not found to be a significant predictor (β -.13, $p = 0.706$).

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Table 4: Multivariate logistic regression models for predictors of distress including staff ratios and demographic variables

Predictor	Model 1		Model 2		Model 3	
	OR (95% CI)	P-value	OR (95% CI)	P-value	OR (95% CI)	P-value
Constant	0.69 (0.37-1.29)		0.66 (0.37-1.18)		0.468 (0.26-0.85)	
Total psychosocial staff ratio	0.65 (0.47-0.89)	0.008				
Social work ratio			0.49 (0.33-0.74)	0.001		
Psychology/counselling ratio					0.878 (0.45-1.73)	0.706
Sex						
Male <i>reference</i>						
Female	1.19 (0.81-1.76)	0.379	1.22 (0.83-1.80)	0.319	1.211 (0.82-1.79)	0.335
Age Category						
18-39	2.14 (0.91-5.04)	0.083	2.20 (0.93-5.21)	0.074	2.01 (0.86-4.72)	0.107
40-49	2.11 (0.91-4.92)	0.084	2.15 (0.92-5.02)	0.078	2.22 (0.95-5.15)	0.064
50-59	1.83 (0.90-3.72)	0.096	1.801 (0.88-3.67)	0.105	1.946 (0.96-3.95)	0.065
60-69	1.20 (0.70-2.08)	0.504	1.210 (0.70-2.09)	0.494	1.224 (0.71-2.10)	0.464
≥ 70 <i>reference</i>						
Ethnicity						
White <i>reference</i>						
Other	0.94 (0.45-1.96)	0.859	0.95 (0.45-2.00)	0.892	1.01 (0.48-2.10)	0.991
Time on Dialysis						
<6 months	1.58 (0.87-2.87)	0.137	1.51 (0.83-2.75)	0.180	1.68 (0.93-3.05)	0.086
6 months to 3 years	1.47 (0.91-2.39)	0.119	1.45 (0.89-2.36)	0.131	1.56 (0.96-2.52)	0.070

3 to 5 years	1.87 (1.04-3.37)	0.037	1.86 (1.02-3.35)	0.041	1.91 (1.09-3.42)	0.029
>5 years <i>reference</i>						
Living situation						
Living alone <i>reference</i>						
Living together	0.77 (0.51-1.16)	0.206	0.75 (0.49-1.13)	0.167	0.77 (0.51-1.16)	0.217
Employment situation						
Employed	0.61 (0.28-1.29)	0.190	0.61 (0.28-1.29)	0.190	0.64 (0.30-1.36)	0.244
Unemployed	3.49 (0.79-15.51)	0.100	3.76 (0.84-16.81)	0.084	3.41 (0.77-15.12)	0.106
Unable to work	1.68 (0.93-3.04)	0.088	1.71 (0.94-3.10)	0.080	1.64 (0.90-2.95)	0.104
Retired <i>reference</i>						
No. of observations	488		488		488	

43.4% of patients reported one or more practical issues, such as problems related to finances or housing and 60.9% of patients reported one or more emotional issues (such as depression or fears). 17.6% of respondents stated that they would like to receive support for their problems, but were not currently receiving any. Univariate analysis indicated that there were differences across units ($\chi^2(6) = 37.80$, $p < 0.0001$), with patients in units C, D, E, F and G significantly less likely to report an unmet need for support than patients in unit A and B (**Error! Reference source not found.**5). Of the people that reported a need for support, 75.9% were classed as distressed.

Table 5: Univariate logistic analysis of patients reporting a perceived unmet need for support per study site

Unit	% Unmet need for support (n)	Odds ratio (95% CI)	P-value
Total (n=499)	17.6 (88)		
A	35.5 (22)	1.00	
B	35.4 (23)	0.996 (0.48-2.06)	0.991
C	12.5 (12)	0.260 (0.12-0.58)	0.001
D	16.9 (12)	0.370 (0.17-0.83)	0.016
E	8.7 (9)	0.172 (0.073-0.41)	<0.001
F	13.9 (6)	0.295 (0.11-0.81)	0.017
G	6.9 (4)	0.135 (0.043-0.42)	0.001

DISCUSSION

Main findings

It was found that almost half (48.9%, 95% CI: 44.5 – 53.4) of all ICHD patients participating in this study experienced some form of distress, indicating the need for psychosocial support and services. In general, our results suggest that there is a significant relationship between the different UK models of renal psychosocial service delivery and ICHD patient distress. An association between distress and models of psychosocial service provision was found and the results indicated that psychosocial staff-to-patient ratios significantly predict distress in patients. Specifically, patients in units with higher total psychosocial staff ratios and higher social work ratios were less likely to experience distress, even after controlling for their sex, age, ethnicity, time on dialysis, living situation and employment status. Furthermore, differences across units were found in patients' reported unmet need for support, with patients in units with both practical (as provided by a social worker/welfare advisor) and emotional support (from a psychologist/counsellor) available significantly less likely to want (additional) support.

Strengths and limitations

The key limitation of this study is its cross-sectional nature. A longitudinal panel study that would measure patient's distress levels before and after receiving certain psychosocial services (or no such services) would have had a higher internal validity, however, such study was not possible for practical reasons. Due to the selection of study sites based on psychosocial service provision models, the average psychosocial staffing ratios in this study were higher than the overall UK renal psychosocial staffing ratios. Based on our findings, this suggests that we may have underestimated overall distress prevalence. However, importantly, one of the strengths of this study is the high response rate. Of relevance for the aim of exploring distress across different models of service provision, this increases the probability that the scores are representative of the patients in the participating units. Due to

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3 a lack of available data, it was not possible to examine these findings in the wider, unit-specific
4 context, including factors such as patients' access and use of general psychosocial services in
5 the hospital or community. However, in-depth qualitative research was completed with renal
6 staff to explore the wider process of psychosocial service delivery in each study site in a linked
7 component of this study (findings to be reported elsewhere).
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12 **Implications**

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15 This is the first study to explore distress across different models of renal psychosocial service
16 provision. Whilst the overall prevalence of distress was in line with estimates from other
17 studies that used self-reported measures for depression and anxiety^{8,19}, it is the difference in
18 prevalence across units that is of importance. Associations between distress and demographic
19 variables have been widely reported in other studies^{24,25}, however our result show that after
20 accounting for models of service provision, other demographic factors (apart from time on
21 dialysis) do not emerge as significant predictors of distress. This finding contradicts recently
22 published findings by Damery, Braun, Sein, et al. who reported no influence of service delivery
23 models on distress in their study²⁴. There are a couple of possible explanations for this
24 discrepancy: firstly, Damery et al. only compared prevalence of mild-to moderate distress,
25 leaving the prevalence of severe distress out of their analysis and excluding patients using
26 psychiatric services since CKD stage 5 from participation. In the context of psychosocial
27 service delivery, the current study took all levels of distress into account and did not exclude
28 those who were already receiving support. Secondly, whilst Damery et al. did not report staff-
29 to-patient ratios, only renal psychologists are mentioned, which appears to reflect little
30 variation in models of service provision across the participating units. Any differences in
31 staffing levels might have been too small to result in differences in patient distress. Finally,
32 there was no mention of the presence of renal social workers, whose availability plays an
33 important role in reducing patient distress, according to the current findings.
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51 The findings of this study are relevant for policy makers and practitioners in allocating
52 resources to the management of distress in renal patients and in the wider context of
53 psychosocial service delivery for those with long-term conditions. Not only does the evidence
54 presented here show that renal psychosocial staff play a role in reducing patient distress, the
55 results also highlight a higher patient-reported need for these services in hospitals where
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3 psychosocial staffing numbers are low or non-existent. This is in line with, Damery et al. who
4 found higher levels of need in units without renal psychologists available, compared to those
5 with renal psychologists available²⁴. Yet, psychosocial services have steadily reduced over the
6 last years ¹⁵, leaving patients having to look for support from services provided in the
7 community. The results could indicate that these services are inaccessible or unable to
8 provide the support patients want, leading to higher distress. Symptoms of distress can have
9 a negative effect on patient quality of life, medical outcomes and costs, through reduced
10 treatment-adherence and increased rates of mortality, hospitalisation and length of hospital
11 stay ^{18–20}. Therefore, the findings emphasise a need for increased numbers of integrated
12 psychosocial staff and a renal psychosocial care pathway, which, importantly, should include
13 practical as well as emotional support. Importantly, since multimorbidity in CKD patients is
14 high, these levels of unmet need might not be restricted to the renal population only, but
15 could reflect an issue in the wider context of service provision for patients living with long-
16 term conditions.
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30 Whilst further investigation into appropriate staffing levels is necessary and the wider number
31 of patients on all treatment modalities should be taken into account to determine these, the
32 findings could provide a first indication of the minimum ratios of psychosocial staff required.
33 The first participating unit with a dedicated social worker to have significantly lower distress
34 levels than a unit without any support, had a staffing ratio of 1 social worker per 142 ICHD
35 patients; the staffing ratio in the first unit with a dedicated psychologist to have significantly
36 lower distress levels was 1 psychologist per 532 ICHD patients.
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44 In addition to adequate staffing levels, another important aspect of a psychosocial care
45 pathway would be the identification of patients in need for support, which could be achieved
46 by screening for distress. It is essential that the focus of this screening is not only on detecting
47 clinically significant distress that could warrant a psychological intervention. Instead, for it to
48 identify patients that could benefit from any type of psychosocial service, screening processes
49 should bring patients to light who are experiencing distress, in the wider sense of the word,
50 and/or psychosocial issues. For example, practical problems (such as issues with social care
51 or transport) would not necessarily make a patient report distress that would meet the
52 criteria for a formal diagnosis of anxiety or depression. Yet, in order to solve these problems
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3 and prevent them from contributing to negative health outcomes, a patient might still require
4 support from a social worker. The use of the DT and Problem Checklist, already recommended
5 in US oncology care guidelines¹⁷, would allow for such a wide approach to screening and has
6 been found to be an acceptable tool in the renal population²². Still, even with this wide
7 approach to capturing distress, our results show that it cannot be assumed that distress
8 equals need for support. As such, any screening tool should always include a question that
9 captures a patient-reported need and want for psychosocial services.
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17 In conclusion, our findings support the incorporation of dedicated psychosocial support in the
18 renal care pathway. At a time of calls for the evaluation and restructuring of CKD care models
19 to improve outcomes and reduce the costs of care, the need for true integration of renal
20 psychosocial services in new models of care can no longer be ignored.
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26
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29

30 31 32 **COMPETING INTERESTS**

33
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36 National Institute of Health Research, and the British Renal Society, outside the submitted
37 work.
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43
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46 involvement in the data collection, analysis or writing of this manuscript.
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49 50 51 **AUTHORS' CONTRIBUTIONS**

52
53 MS and PO were involved in the design and data collection. MS and DK designed a data
54 analysis plan and MS undertook the data analysis under supervision and support from DK.
55 MS drafted the manuscript under supervision from PO and DK, who both completed
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3 revisions. All authors provided intellectual content of critical importance to the work
4 described and have read and approved the final manuscript.
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7 **DATA SHARING STATEMENT**

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10 The dataset used during the current study is available from the corresponding author on
11 reasonable request after completion of the wider project.
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For peer review only

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
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
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	9
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	9
Bias	9	Describe any efforts to address potential sources of bias	7
Study size	10	Explain how the study size was arrived at	7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	9
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	9
		(b) Describe any methods used to examine subgroups and interactions	9
		(c) Explain how missing data were addressed	7
		(d) If applicable, describe analytical methods taking account of sampling strategy	n/a
		(e) Describe any sensitivity analyses	n/a
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	7
		(b) Give reasons for non-participation at each stage	-
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	8
		(b) Indicate number of participants with missing data for each variable of interest	8
Outcome data	15*	Report numbers of outcome events or summary measures	10
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	10
		(b) Report category boundaries when continuous variables were categorized	10
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	12-15
Discussion			
Key results	18	Summarise key results with reference to study objectives	16
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	16
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	17
Generalisability	21	Discuss the generalisability (external validity) of the study results	16-17
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	19

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

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.

BMJ Open

EXAMINING PATIENT DISTRESS AND UNMET NEED FOR SUPPORT ACROSS UK RENAL UNITS WITH VARYING MODELS OF PSYCHOSOCIAL CARE DELIVERY: A CROSS-SECTIONAL SURVEY STUDY.

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Secondary Subject Heading:	Health services research, Mental health, Sociology
Keywords:	Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Nephrology < INTERNAL MEDICINE, MENTAL HEALTH, Dialysis < NEPHROLOGY, Depression & mood disorders < PSYCHIATRY, SOCIAL MEDICINE

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**EXAMINING PATIENT DISTRESS AND UNMET NEED FOR SUPPORT ACROSS UK RENAL
UNITS WITH VARYING MODELS OF PSYCHOSOCIAL CARE DELIVERY: A CROSS-SECTIONAL
SURVEY STUDY.**

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WORD COUNT

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ABSTRACT

Objective

To examine in-centre haemodialysis (ICHHD) patients' emotional distress and need for support across UK renal units with varying models of psychosocial service provision.

Design

The study used a cross-sectional survey design. Logistic regression analysis was used to examine patient distress, as captured by the Distress Thermometer, and need for support, across different renal units.

Setting

Seven renal units across England, Wales and Scotland. The units were purposively selected so that varying workforce models of renal psychosocial services were represented.

Participants

In total, 752 patients were on dialysis in the participating centres on the days of data collection. All adult patients, who could understand English, and with capacity (as determined by the nurse in charge), were eligible to participate in the study. The questionnaire was completed by 509 patients, resulting in an overall response rate of 67.7%.

Outcome measures

The prevalence of distress and patient reported need for support.

Results

The results showed that 48.9% (95% Confidence Interval (CI): 44.5 – 53.4) of respondents experienced distress. A significant association between distress and models of renal psychosocial service provision was found ($\chi^2(6)=15.05$, $p = .019$). Multivariable logistic regression showed that patients in units with higher total psychosocial staffing ratios [odds ratio (OR) 0.65 (95% CI 0.47-0.89); $p= .008$] and specifically higher social work ratios [OR 0.49 (95% CI 0.33-0.74; $p= .001$) were less likely to experience distress, even after controlling for demographic variables. In addition, a higher patient-reported unmet need for support was

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3 found in units where psychosocial staffing numbers are low or non-existent ($\chi^2(6) = 37.80, p <$
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5 0.001).

6 7 **Conclusions**

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10 The novel findings emphasise a need for increased incorporation of dedicated renal
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12 psychosocial staff into the renal care pathway. Importantly, these members of staff should be
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14 able to offer support for psychological as well as practical and social care related issues.

15 16 **KEY WORDS**

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18 Nephrology, Psychosocial Support Systems, Interdisciplinary Health Team, Psychological
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20 distress, Health Workforce, Chronic Disease

21 22 **STRENGTHS AND LIMITATIONS OF THIS STUDY**

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- 26 • This is the first study to investigate distress in renal patients across varying models of
27 psychosocial service delivery, providing a unique health systems research perspective.
 - 28 • The sample size of the study was large, with participants from seven renal units across
29 the UK.
 - 30 • The overall response rate was high, increasing the probability that the findings are
31 representative of the patients in participating units.
 - 32 • Those from black and minority ethnic (BAME) groups were under-represented in the
33 responses.
 - 34 • The cross-sectional study design provided a snapshot of distress in renal patients, but
35 future studies should consider a longitudinal panel study to capture changes in
36 distress over time, for individuals and groups of patients along the renal pathway.
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INTRODUCTION

Chronic kidney disease (CKD) is a worldwide public health problem, with increasing incidence and prevalence, high costs, and poor outcomes [1]. The disease is typically progressive and can be divided into five stages of increasing severity, with treatments based on these stages. For a small, but significant percentage of people, CKD progresses to end-stage renal disease (ESRD). At this stage, which is irreversible, the kidneys are no longer able to function and renal replacement therapy (RRT) – dialysis or transplantation – becomes necessary to maintain life [2,3]. According to the latest Renal Registry data, there were 64,887 patients receiving RRT in the UK at the end of 2017. Of these, 37.3% received in-centre haemodialysis (ICHHD), 5.4% received peritoneal dialysis, 2.0% dialysed at home and 55.2% had received a transplant [4]. People with CKD often have a range of comorbid disorders. Some of these, such as hypertension and diabetes, are risk factors of the disease. Others, such as heart failure or chronic pulmonary disease, are often co-prevalent as a result of CKD or because of shared risk factors [5,6]. Living with CKD, and especially ESRD, provides many ongoing physical, emotional, financial and/or social challenges throughout a patient's renal journey. These consequences of the disease and its comorbidities make patient access to expertise in medical, nursing, dietetic, pharmacological, psychological and social areas essential[7].

In recent years, against a global backdrop of shortages in the nephrology workforce, there have been increasing calls for a change in the existing models of renal care to manage the demands of an increasing CKD burden. A collaborative care model, in which a greater share of the work is performed by allied health professionals (including psychosocial staff) is one of the proposed solutions[8]. Acceptance that a focus on the psychosocial needs of the patients should be included in comprehensive psychosocial care has grown in recent years[9], yet this has not always translated into practice. Internationally, limited evidence suggests differences in the level and type of renal psychosocial care accessible to patients. A recent Europe-wide study found that multidisciplinary teams (defined as teams consisting of allied health professionals, e.g. expert nurses, dieticians and social workers) were routinely available to patients with CKD in only eight out of 17 studied countries[10]. In the US and Australia, renal dedicated social workers appear to be the point-person responsible for providing psychosocial care, although in both countries high caseloads and exceeded benchmarks were reported [11–13]. US renal social workers are in a special position, since ESRD is the only

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3 disease for which Medicare's Conditions for Coverage Mandate requires a Masters-level
4 trained social worker on every interdisciplinary team[14]. Generally, in the UK, while all
5 members of staff within the renal unit have a role in providing general psychosocial support,
6 the core specialist psychosocial professionals include a psychologist (clinical, counselling or
7 health), a counsellor or a psychotherapist, and/or a social worker. There are differences in
8 the training and expertise of these professionals. A psychologist will have undertaken a
9 minimum of six years of training to doctorate level and will mainly support patients with
10 diagnosed, complex mental health issues; a counsellor or psychotherapist will have a
11 minimum of an undergraduate diploma, but may have a bachelor's degree or postgraduate
12 qualifications and will support patients with emotional or behavioural issues; a renal social
13 worker will have a bachelor's degree in social work and/or a post-graduate social work
14 qualification and, broadly speaking, focuses on improving patients' quality of life and
15 functioning in society by connecting them to community and social care services. Whilst the
16 lines between these professions often seem blurred, it is important to recognise that these
17 roles are not interchangeable and each professional uses different, and sometimes
18 complementary, approaches to support patients. A recent workforce report by Seekles et al.
19 [15] showed that in the UK, over the past 15 years, a change in renal psychosocial staffing
20 levels had taken place. The number of renal social workers had reduced dramatically, whilst
21 renal psychologists and counsellors had grown in numbers. In the UK too, recommended staff-
22 to-patient ratios were far from being met. A general UK renal psychosocial service provision
23 model was lacking: most renal units incorporated different psychosocial teams, made up of
24 varying types and numbers of staff, while some units completely lacked any form of dedicated
25 psychosocial support[16].

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Currently, UK guidelines from the National Health Service (NHS) England[17] and the National Institute for Health and Care Excellence (NICE)[3] vaguely state that haemodialysis (HD) patients 'must have access to' psychosocial services, without clarifying the type and number of staff that should be accessible. This, and the large variety in models of service provision found, reflects a lack of empirical studies on the delivery of psychosocial services that can inform evidence-based staffing standards and regulations. This paper presents the findings of an investigation that used the concept of distress – broadly defined as 'a multifactorial unpleasant experience of a psychological (i.e., cognitive, behavioural, emotional), social,

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3 spiritual, and/or physical nature'[18] – to explore the association between ICHD patient's
4 distress, their perceived need for support and UK models of renal psychosocial service
5 delivery. Studies have found that distress can have a negative effect on quality of life, health
6 outcomes and costs, emphasising the importance of addressing psychosocial issues in renal
7 patients[19–21]. The research question asked whether there is a relationship between
8 different UK models of renal psychosocial service delivery, self-reported distress and need for
9 support of ICHD patients. This investigation forms part of a larger, nationwide mixed-methods
10 study that aims to understand how renal psychosocial services are delivered in the UK.
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19 **METHODS**

20 **Participating renal units**

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24 The study used a cross-sectional survey design and included ICHD patients from seven main
25 renal units across England (n=3), Wales (n=2) and Scotland (n=2). The sites were purposively
26 selected out of a total of 89 renal units, informed by the outcomes of a recent renal
27 psychosocial workforce mapping[15], to ensure an inclusion of different staffing ratios and
28 models of psychosocial service provision. Ratios were determined based on the number of
29 ICHD patients from the latest UK Renal Registry[4]. Whilst many members of psychosocial
30 staff cover the whole range of RRT patients, including transplant patients, this number was
31 most appropriate since it links directly to the study population. To obtain a numerical value
32 for ratios suitable for comparisons and analysis, the Full-Time Equivalent (FTE) of psychosocial
33 staff was divided by the number of ICHD patients in that unit, multiplied by 100. For example,
34 1 FTE social work per 100 patients would equate to a ratio of 1. Throughout this paper, the
35 units have been sorted based on their psychosocial staff-to-ICHD patient ratios, with unit A
36 having no renal dedicated psychosocial staff available and unit G having the highest ratio of
37 total psychosocial staff available to its patients. To protect the anonymity of the participating
38 renal units, exact characteristics that could lead to identification cannot be provided. Instead,
39 table 1 provides an overview of indicators of unit size, in addition to the psychosocial
40 provision model. As can be seen, all units have different models of psychosocial service
41 provision, apart from unit F and G, who differ in their staff-to-patient ratios.
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Table 1 Characteristics of participating renal units

Unit Name	No. ICHD patients	No. RRT patients	No. satellite units	Psychosocial staffing model
Unit A	0-250	501-750	6-8	No dedicated staff
Unit B	251-500	1001-1250	3-5	Psychology
Unit C	251-500	1001-1250	3-5	Counselling and welfare advice
Unit D	251-500	751-1000	3-5	Psychology, counselling & social work
Unit E	251-500	751-1000	3-5	Social work & psychiatry
Unit F	0-250	251-500	0-2	Psychology & social work
Unit G	0-250	0-250	0-2	Psychology & social work

On average, ratios of renal dedicated psychosocial staffing in the study sites are better than ratios found across the UK. The average ratio of psychologists in this study is 1 Full-Time Equivalent (FTE) per 248 dialysis patients, compared to an average of 1 FTE per 1044 patients. For social workers, the average ratio in this study is 1 FTE per 156 dialysis patients, compared to 1 FTE per 355 patients across the UK[15]. Comparison of overall staffing ratios was not possible due to a lack of comparable data. Furthermore, only units B and D had a black and minority ethnic (BAME) population of a similar size as the overall UK dialysis population, whilst the other units served predominantly or completely white populations.

Patients and public involvement

The study design was developed with input from patient representatives, who were asked to comment on the appropriateness of the outcome measures and provide insight into the expected burden and time required for participation. Patients were not involved in the recruitment or further conduct of the study. The results will be disseminated to participants and the wider renal units through Kidney Care UK's (KCUK) marketing channels (website, posters) at the end of the project.

Participants and recruitment

All adult ICHD patients who could understand English, and with capacity (as determined by the nurse in charge), were eligible to participate in the study. Data collection took place between March 2018 and July 2019. Renal unit staff at each Trust provided all eligible patients with a letter of invitation and an information sheet. The University research team would visit the unit one week later to distribute the questionnaires (with information sheets), which were to be completed by patients whilst on dialysis. Consent was assumed upon return of the

completed questionnaire. To prevent selection bias, patients were allowed help with completion of the questionnaire.

Sample

The sample size was restricted by the number of patients dialysing in the renal units. In total, 752 patients were on dialysis in the participating centres on the days of data collection. Of these, 509 completed the questionnaire, resulting in an overall response rate of 67.7%. Non-participants either refused to participate, were asleep, did not feel well enough to participate, did not speak English or lacked capacity. The response rates in participating units varied from 49.0% in unit F to around 82.0% in units D and G.

As can be seen in Table 2 **Error! Reference source not found.**, the majority of respondents were male and aged over 70 years old. This distribution of gender is similar to the general UK ICHD population, which is reported to consist for 61.9% of males. The median age of the general ICHD population is 67.5 years[4]. The study sample was almost entirely made up of people from the white ethnic group, which is different from the total ICHD population, in which this group makes up around 70 percent of patients [4]. Furthermore, the majority of patients had been on dialysis for 6 months to three years, lived together with their partner or family and was retired.

Four respondents did not complete the Distress Thermometer (DT), whilst others did not provide information on other questions, leading to varying numbers of missing data. Instead of using listwise deletion, which would have resulted in the loss of important information on some analyses, pairwise deletion was used to maximise the available data on an analysis by analysis basis.

Table 2: Respondent characteristics and proportion per sub-group

Characteristic	N	%
Total	509	100
<i>Main unit (psychosocial model)</i>		
Unit A (no staff)	64	12.6
Unit B (psychology)	65	12.8
Unit C (counselling + welfare advise)	98	19.3
Unit D (social work + psychology + counselling)	73	14.3

Unit E (social work + psychiatry)	104	20.4
Unit F (social work + psychology)	47	9.3
Unit G (social work + psychology)	58	11.4
<i>Sex</i>		
Male	311	61.1
Female	192	37.7
Missing	6	1.2
<i>Age Category</i>		
18-39	50	9.8
40-49	51	10.0
50-59	97	19.1
60-69	104	20.4
≥70	201	39.5
Missing	6	1.2
<i>Ethnicity</i>		
White	460	90.4
Other	42	8.3
Missing	7	1.4
<i>Time on Dialysis</i>		
<6 months	87	17.1
6 months to 3 years	193	37.9
3 to 5 years	91	17.9
>5 years	130	25.5
Missing	8	1.6
<i>Living situation</i>		
Living alone	147	29.7
Living together	349	70.3
Missing	13	2.6
<i>Employment situation</i>		
Employed	67	13.2
Unemployed	14	2.8

Unable to work	183	36.0
Retired	237	46.6
Missing	8	1.6

Ethical approval

Ethical approval was obtained from the University of Salford Ethics Committee, the West of Scotland Research Ethics Service and Health Research Authority in October 2017 (Ref 17/WS/0185). In addition, all Research and Development offices from the participating Trusts approved the study and confirmed their capability and capacity to host the research.

Measurements

The questionnaire used the US National Comprehensive Cancer Network's DT and Problems Checklist[18] as the instrument to measure distress. Although initially developed to screen for distress in oncology patients, the DT has been validated for use in the UK renal population [22]. It is a simple one-item screening tool, designed to be part of health professionals' daily practice, which asks patients to rate their distress on a 11-point Likert scale from zero (nothing) to ten (extreme). For analysis, distress was examined through a binary variable of distress 'caseness', with DT scores of ≥ 4 denoting distress [18]. Studies using the DT in renal care are limited, but a meta-analysis of studies in oncology patients found a good balance between pooled sensitivity (0.81, 95% Confidence Interval (CI): 0.79–0.82) and pooled specificity (0.72, 95 % CI: 0.71–0.72) at the cut-off score of 4 when comparing the DT to other diagnostic tools, such as the Hospital Anxiety and Depression Scale and Beck's Depression Inventory [23]. However, for the current study, this is less relevant since the DT was not used to identify patients with diagnosable mood disorders, but to determine the prevalence of distress defined as 'an unpleasant emotional state' and allow for comparisons across units. Distress, here, does not unambiguously refer to the same concept [24].

Patients indicated which issues were causing them distress by ticking a box on the Problem Checklist. The questionnaire included further tick-box questions, with the options yes or no, to determine whether patients were currently in receipt of psychosocial support; and if not, whether they would like to receive this support. Information on sociodemographic

characteristics (sex, age, ethnicity, living situation and employment situation) was captured using closed questions.

Data analysis methods

The prevalence of distress and 95% CIs were calculated using the cut-off score described in the measurements section. Univariate logistic regression was then applied to examine the associations between distress, study sites and demographic characteristics. Subsequently, multivariable logistic regression was used to identify whether study site, staffing ratios and further demographic variables served as predictors of distress. All variables were entered simultaneously. Finally, univariate logistic regression was used to investigate the perceived need for support and prevalence of problem types across the study sites. All analysis were conducted using Stata Statistical Software: Release 14.2 [25].

RESULTS

Overall, a distress score of ≥ 4 was observed in 247 out of 505 respondents, indicating that 48.9% (95% CI: 44.5 – 53.4) of ICHD patients were experiencing some form of distress. Mild-to-moderate distress (DT score 4-6) was identified in 25.7% of patients (130 cases, 95% CI: 22.0-29.8). A DT score of ≥ 7 was observed for 117 cases, indicating that 23.2% of patients (95% CI: 19.6-27.1) across all study sites were experiencing severe distress.

Findings from univariate analyses (**Error! Reference source not found.3**) showed an association between distress and study site, with patients in units F and G less likely to be cases than in unit A, B and C. Further associations were found with age group and employment situation. Specifically, those aged 18-39, 40-49 and 50-59 and those patients who were unemployed or considered themselves unable to work were significantly more likely to be distressed than those aged 70 or above and retired.

Table 3. Summary of univariate logistic analyses for association between distress and demographic variables

Variable	Distress (DT ≥ 4) % (n)	OR [95% CI]	P-value	LR Chi2
Total (n=505)	48.9 (247)			
Main unit (n=505)				$\chi^2 (6) = 15.05, p = .019$
A	56.3 (36)		-	
B	56.3 (36)	1.00 [0.50-2.01]	1.00	

C	59.2 (58)	1.13 [0.60-2.14]	.712	
D	48.0 (35)	0.72 [0.37-1.41]	.332	
E	43.3 (45)	0.59 [0.32-1.11]	.103	
F	34.1 (15)	0.40 [0.18-0.89]	.025	
G	37.9 (22)	0.48 [0.23-0.98]	.044	
Sex (n=499)				$\chi^2(1) = 2.23, p = .135$
Male	46.3 (143)			
Female	53.2 (101)	1.32 [0.92-1.89]	.136	
Age Category (n=499)				$\chi^2(4) = 22.36, p < .001$
18-39	60.0 (30)	2.46 [1.30-4.64]	.005	
40-49	62.0 (31)	2.68 [1.41-5.07]	.003	
50-59	61.9 (60)	2.66 [1.61-4.39]	<.001	
60-69	47.1 (49)	1.46 [0.90-2.36]	.122	
≥70	37.9 (75)		-	
Ethnicity (n=498)				$\chi^2(1) = 1.22, p = .269$
White	48.3 (220)		-	
Other	57.1 (24)	1.43 [0.76-2.71]	.272	
Time on Dialysis (n=497)				$\chi^2(3) = 2.99, p = .393$
<6 months	48.8 (42)	1.28 [0.74-2.22]	.371	
6 months to 3 years	52.1 (100)	1.46 [0.93-2.30]	.097	
3 to 5 years	51.1 (46)	1.40 [0.82-2.42]	.216	
>5 years	42.6 (55)		-	
Living situation (n=492)				$\chi^2(1) = 1.00, p = .316$
Living alone	52.1 (76)		-	
Living together	47.1 (163)	0.82 [0.56-1.21]	.316	

Employment situation (n=497)				$\chi^2(3) = 26.17, p < .001$
Employed	42.4 (28)	1.14 [0.65-1.98]	.649	
Unemployed	78.6 (11)	5.65 [1.54-20.83]	.009	
Unable to work	61.2 (112)	2.43 [1.64-3.62]	<.001	
Retired	39.3 (92)		-	

DT: Distress Thermometer; OR: Odds Ratio; 95% CI: 95% confidence interval, LR: Likelihood Ratio.

A multivariable logistic regression model (**Error! Reference source not found.**4) including renal unit and other demographic variables sex, age, ethnicity, time on dialysis, living situation and employment situation was found to be a significant predictor of distress (Likelihood Ratio (LR) $\chi^2(19) = 56.77, p < .001$). The renal unit that patients belonged to significantly predicted distress, with being a patient in unit E ($\beta -0.718$) or F ($\beta -1.083$) significantly reducing the likelihood of distress compared to being a patient in unit A. Time on dialysis was also found to be a predictor of distress, with being on dialysis for a period of 3 to 5 years significantly increasing the likelihood of distress. Age group and employment situation were not found to be predictors.

Table 4: Multivariable regression model for predictors of distress including renal unit and demographic variables

Predictor	B (se)	OR [95% CI]	p
Constant	0.176 (0.348)		
Renal unit			
A	<i>reference</i>		
B	-0.161 (0.387)	0.851 [0.40-1.82]	.676
C	0.176 (0.348)	1.193 [0.60-2.36]	.612
D	-0.411 (0.375)	0.663 [0.32-1.38]	.272
E	-0.718 (0.351)	0.488 [0.25-0.97]	.041
F	-1.083 (0.461)	0.338 [0.14-0.84]	.019
G	-0.678 (0.395)	0.508 [0.23-1.10]	.086
Sex			
Male	<i>reference</i>		
Female	0.237 (0.202)	1.268 [0.85-1.89]	.241

Age Category				
18-39	0.782 (0.444)	2.186 [0.92-5.22]	.078	
40-49	0.776 (0.439)	2.173 [0.92-5.13]	.077	
50-59	0.593 (0.369)	1.809 [0.89-3.73]	.108	
60-69	0.164 (0.282)	1.179 [0.68-2.05]	.560	
≥70	<i>reference</i>			
Ethnicity				
White	<i>reference</i>			
Other	0.0366 (0.388)	1.037 [0.48-2.22]	.925	
Time on Dialysis				
<6 months	0.411 (0.309)	1.509 [0.82-2.77]	.183	
6 months to 3 years	0.360 (0.249)	1.434 [0.88-2.34]	.149	
3 to 5 years	0.606 (0.305)	1.833 [1.01-3.34]	.047	
>5 years	<i>reference</i>			
Living situation				
Living alone	<i>reference</i>			
Living together	-0.321 (0.215)	0.725 [0.48-1.10]	.134	
Employment situation				
Employed/in Education	-0.511 (0.394)	0.560 [0.28-1.30]	.194	
Unemployed	1.401 (0.769)	4.058 [0.90-18.33]	.069	
Unable to work	0.583 (0.311)	1.791 [0.97-3.30]	.061	
Retired	<i>reference</i>			
N	488			

Further regression analysis was undertaken to provide more insight into the relationship between distress and psychosocial staffing ratios. Three similar multivariable logistic regression models were created, differing only by inclusion of either the total ratio of renal dedicated psychosocial staff, the ratio of renal social workers or the ratio of renal psychologists/counsellors (**Error! Reference source not found.5**). The difference between psychologists and counsellors should be acknowledged and emphasised, yet it was decided to group these professions together in model 3 so that counselling staff (only present in 2

units) could be taken into account. In the units that had renal social work available, ratios varied from 0.39 to 1.39. The variation in ratios for psychologists/counsellors was less; the ratios varied from 0.38 to 0.86. All models included the demographics sex, ethnicity, age, living situation, time on dialysis and employment situation as predictors.

The results were as follows:

- Model 1 (including total ratios of psychosocial staff): a collective significant effect was found, LR χ^2 (14)=47.68, $p < .001$. Specifically, the ratio of total psychosocial staff was found to significantly predict distress, with higher ratios of staff leading to a lower likelihood of distress (β -.43, $p = .008$).
- Model 2 (including ratios of social work staff): This model also returned a significant result, predicting distress LR χ^2 (14) = 52.57, $p < .001$. A significant association was found between social worker ratios and distress, with likelihood of distress reducing as social worker ratios increased (β -.71, $p = .001$).
- Model 3 (including ratios of psychology/counselling staff): Overall, the model significantly predicted distress, LR χ^2 (14) = 40.60, $p < .001$, but the ratio of psychology/counselling staff was not found to be a significant predictor (β -.13, $p = .706$). To note, a model including psychology ratios only showed similar, non-significant results.

Table 5 Multivariable logistic regression models for predictors of distress including staff ratios and demographic variables

Predictor	Model 1			Model 2			Model 3		
	B (se)	OR [95% CI]	p	B (se)	OR [95% CI]	p	B (se)	OR [95% CI]	p
Constant	-0.37 (0.32)			-0.41 (0.29)			-0.76 (0.30)		
Ratios									
Total psychosocial staff	-0.429 (0.16)	0.65 [0.47-0.89]	.008						
Social work				-0.706 (0.21)	0.49 [0.33-0.74]	.001			
Psychology/counselling							-0.126 (0.35)	0.878 [0.45-1.73]	.718
Sex									
Male <i>reference</i>									
Female	0.176	1.19	.379	0.199	1.22	.319	0.192	1.211	.335

	(0.120)	[0.81-1.76]		(0.20)	[0.83-1.80]		(0.20)	[0.82-1.79]	
Age Category									
18-39	0.759 (0.44)	2.14 [0.91-5.04]	.083	0.787 (0.44)	2.20 [0.93-5.21]	.074	0.700 (0.43)	2.01 [0.86-4.72]	.107
40-49	0.747 (0.43)	2.11 [0.91-4.92]	.084	0.763 (0.43)	2.15 [0.92-5.02]	.078	0.796 (0.43)	2.22 [0.95-5.15]	.064
50-59	0.600 (0.36)	1.83 [0.90-3.72]	.096	0.588 (0.36)	1.801 [0.88-3.67]	.105	0.665 (0.36)	1.946 [0.96-3.95]	.065
60-69	0.186 (0.28)	1.20 [0.70-2.08]	.504	0.191 (0.28)	1.210 [0.70-2.09]	.494	0.202 (0.28)	1.224 [0.71-2.10]	.464
≥70 <i>reference</i>									
Ethnicity									
White <i>reference</i>									
Other	-0.069 (0.38)	0.94 [0.45-1.96]	.859	-0.051 (0.38)	0.95 [0.45-2.00]	.892	0.004 (0.38)	1.01 [0.48-2.10]	.991
Time on Dialysis									
<6 mths	0.456 (0.31)	1.58 [0.87-2.87]	.137	0.412 (0.31)	1.51 [0.83-2.75]	.180	0.521 (0.30)	1.68 [0.93-3.05]	.086
6 mths to 3 yrs	0.388 (0.25)	1.47 [0.91-2.39]	.119	0.374 (0.25)	1.45 [0.89-2.36]	.131	0.445 (0.25)	1.56 [0.96-2.52]	.070
3 to 5 yrs	0.624 (0.30)	1.87 [1.04-3.37]	.037	0.618 (0.30)	1.86 [1.02-3.35]	.041	0.648 (0.30)	1.91 [1.09-3.42]	.029
>5 yrs <i>reference</i>									
Living situation									
Alone <i>reference</i>									
Together	-0.267 (0.21)	0.77 [0.51-1.16]	.206	-0.291 (0.21)	0.75 [0.49-1.13]	.167	-0.258 (0.21)	0.77 [0.51-1.16]	.217
Employment									
Employed	-0.506 (0.39)	0.61 [0.28-1.29]	.190	-0.509 (0.39)	0.61 [0.28-1.29]	.190	-0.450 (0.39)	0.64 [0.30-1.36]	.244
Unemployed	1.248 (0.76)	3.49 [0.79-15.5]	.100	1.323 (0.76)	3.76 [0.84-16.8]	.084	1.227 (0.76)	3.41 [0.77-15.1]	.106
Unable to work	0.520 (0.30)	1.68 [0.93-3.04]	.088	0.534 (0.30)	1.71 [0.94-3.10]	.080	0.492 (0.30)	1.64 [0.90-2.95]	.104
Retired <i>reference</i>									
N	488		488			488			

One or more practical issues (such as problems related to finances or housing) were reported by 43.4% of patients; 60.9% reported one or more emotional issues (such as depression or fears). It was found that 17.6% of respondents wanted to receive psychosocial support for their problems, but were not currently receiving any. Univariate analysis indicated that there were differences across units ($\chi^2(6) = 37.80, p < .001$), with patients in units C, D, E, F and G significantly less likely to report an unmet need for support than patients in unit A and B (**Error! Reference source not found.**6). Of the people that reported a need for support, 75.9% were classed as distressed.

Table 6: Univariate logistic analysis of patients reporting a perceived unmet need for support per study site

Unit	% Unmet need for support (n)	OR [95% CI]	<i>p</i>
Total (n=499)	17.6 (88)		
A	35.5 (22)		
B	35.4 (23)	0.996 [0.48-2.06]	.991
C	12.5 (12)	0.260 [0.12-0.58]	.001
D	16.9 (12)	0.370 [0.17-0.83]	.016
E	8.7 (9)	0.172 [0.073-0.41]	<.001
F	13.9 (6)	0.295 [0.11-0.81]	.017
G	6.9 (4)	0.135 [0.043-0.42]	.001

DISCUSSION

Main findings

It was found that almost half (48.9%, 95% CI: 44.5 – 53.4) of all ICHD patients participating in this study experienced some form of distress, indicating the need for psychosocial support and services. In general, our results suggest that there is a significant relationship between the different UK models of renal psychosocial service delivery and ICHD patient distress. An association between distress and models of psychosocial service provision was found and the results indicated that psychosocial staff-to-patient ratios significantly predict distress in patients. Specifically, patients in units with higher total psychosocial staff ratios and higher social work ratios were less likely to experience distress, even after controlling for their sex, age, ethnicity, time on dialysis, living situation and employment status. Furthermore, differences across units were found in patients reported unmet need for support, with patients in units with both practical (as provided by a social worker/welfare advisor) and emotional support (from a psychologist/counsellor) available significantly less likely to want (additional) support.

Strengths and limitations

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3 The key limitation of this study is its cross-sectional nature. A longitudinal panel study that
4 would measure patient's distress levels before and after receiving certain psychosocial
5 services (or no such services) would have had a higher internal validity, however, such study
6 was not possible for practical reasons. Due to the selection of study sites based on
7 psychosocial service provision models, the average psychosocial staffing ratios in this study
8 were higher than the overall UK renal psychosocial staffing ratios. Based on our findings, this
9 suggests that generalising these results to the whole ICHD population could underestimate
10 overall distress prevalence. Importantly, one of the strengths of this study is the high response
11 rate. Even the lowest response rate (in unit F) was still relatively high (49%), although
12 variability between the units was found. There is however no indication that response rate
13 variability affected the results, with the highest (unit G) and lowest (unit F) response rates
14 showing the lowest distress prevalence. Of relevance for the aim of exploring distress across
15 different models of service provision, this increases the probability that the scores are
16 representative of the patients in the participating units. To our knowledge, this is the first UK
17 study to show an impact of renal social worker staffing levels on patient distress. This is not
18 to say that renal psychologists and counsellors do not impact patient distress levels. The ratios
19 of psychological staff were much more equal across units than the social work ratios, which
20 could have contributed to the current findings. Further research could explore distress across
21 units that have notable differences in psychology staffing levels. Due to a lack of available
22 data, it was not possible to examine the current findings in the wider, unit-specific context,
23 including factors such as patients' access and use of general psychosocial services in the
24 hospital or community. However, in-depth qualitative research was completed with renal
25 staff to explore the wider process of psychosocial service delivery in each study site in a linked
26 component of this study (findings to be reported elsewhere).

47 **Implications**

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50 This is the first study to explore distress in ICHD patients across different models of renal
51 psychosocial service provision. Whilst the overall prevalence of distress was in line with
52 estimates from other studies that used self-reported measures for depression and anxiety
53 [9,20], it is the difference in prevalence across units that is of importance. Associations
54 between distress and demographic variables have been widely reported in other studies
55 [26,27], however our results show that after accounting for models of service provision, other

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3 demographic factors (apart from time on dialysis) do not emerge as significant predictors of
4 distress. This finding contradicts recently published findings by Damery, Braun, Sein, et al.
5 who reported no influence of service delivery models on distress in their study[26]. There are
6 a couple of possible explanations for this discrepancy: firstly, Damery et al. only compared
7 the prevalence of mild-to moderate distress, leaving the prevalence of severe distress out of
8 their analysis and excluding patients using psychiatric services since CKD stage 5 from
9 participation. In the context of psychosocial service delivery, the current study took all levels
10 of distress into account and did not exclude those who were already receiving support.
11 Secondly, whilst Damery et al. did not report staff-to-patient ratios, only renal psychologists
12 are mentioned, which appears to reflect little variation in models of service provision across
13 the participating units. Any differences in staffing levels might have been too small to result
14 in differences in patient distress. Finally, there was no mention of the presence of renal social
15 workers, whose availability plays an important role in reducing patient distress, according to
16 the current findings.
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30 The findings of this study are relevant for policy makers and practitioners in allocating
31 resources to the management of distress in renal patients and in the wider context of
32 psychosocial service delivery for those with long-term conditions. Not only does the evidence
33 presented here show that renal psychosocial staff play a role in reducing patient distress, the
34 results also highlight a higher patient-reported need for these services in hospitals where
35 psychosocial staffing numbers are low or non-existent. This is in line with Damery et al. who
36 found higher levels of need in units without renal psychologists available, compared to those
37 with renal psychologists available[26]. Yet, psychosocial services have steadily reduced over
38 the last years [16], leaving patients having to look for support from services provided in the
39 community. The results could indicate that these services are inaccessible or unable to
40 provide the support patients need, leading to higher distress. Further research is needed to
41 explore whether this is the case for the whole dialysis population, including patients on home
42 haemodialysis and peritoneal dialysis.
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55 Symptoms of distress can have a negative effect on patient quality of life, medical outcomes
56 and costs, through reduced treatment-adherence and increased rates of mortality,
57 hospitalisation and length of hospital stay [19–21]. Therefore, the findings emphasise a need
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3 for increased numbers of integrated psychosocial staff and a renal psychosocial care pathway,
4 which, importantly, should include practical as well as emotional support. However, the main
5 challenge to implementing psychosocial support is the lack of robust evidence to indicate
6 adequate psychosocial staffing levels. Whilst further investigation into appropriate staffing
7 levels is necessary and the wider number of patients on all treatment modalities should be
8 taken into account to determine these, the findings provide a first indication of the minimum
9 ratios of psychosocial staff required. The first participating unit with a dedicated social worker
10 to have significantly lower distress levels than a unit without any support, had a staffing ratio
11 of 1 social worker per 142 ICHD patients; the staffing ratio in the first unit with a dedicated
12 psychologist to have significantly lower distress levels was 1 psychologist per 532 ICHD
13 patients. For social work, this is still much higher than recommended staffing ratios of 1 full-
14 time worker per 70 HD patients, to allow access to both routine and complex social work
15 support for each patient as they move along the renal pathway. A further challenge to the
16 implementation of renal psychosocial services is ensuring that access to these services is
17 equitable across the country, not just based on a postcode lottery. This study highlighted
18 geographical differences in distress prevalence, related to access to renal dedicated
19 psychosocial services. In addition, it is important to consider the role that dialysis staff play in
20 the process of delivering psychosocial services. There is the expectation that dialysis staff
21 support patients who experience lower-level distress [28] and psychosocial staff are often
22 dependent on dialysis staff to inform, identify and refer patients in need for support to their
23 service. Yet, a recent study by Combes et al. [29] found that dialysis staff experience
24 significant barriers in identifying and responding to distress, related to skills and knowledge,
25 but also role perceptions.

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46 To relieve some of the dependence on dialysis staff, screening patients for distress could be
47 another way to identify patients in need. It is essential that the focus of this screening is not
48 only on detecting clinically significant distress that could warrant a psychological intervention.
49 Instead, for it to identify patients that could benefit from any type of psychosocial service,
50 screening processes should bring patients to light who are experiencing distress, in the wider
51 sense of the word, and/or psychosocial issues. For example, practical problems (such as issues
52 with social care or transport) would not necessarily make a patient report distress that would
53 meet the criteria for a formal diagnosis of anxiety or depression. Yet, in order to solve these
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3 problems and prevent them from contributing to negative health outcomes, a patient might
4 still require support from a social worker. The use of the DT and Problem Checklist, already
5 recommended in US oncology care guidelines [18], would allow for such a wide approach to
6 screening and has been found to be an acceptable tool in the renal population [22]. Still, even
7 with this wide approach to capturing distress, our results show that it cannot be assumed that
8 distress equals need for support. As such, any screening tool should always include a question
9 that captures a patient-reported need and want for psychosocial services.
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16 In conclusion, our findings support the incorporation of dedicated psychosocial support in the
17 renal care pathway. At a time of calls for the evaluation and restructuring of CKD care models
18 to improve outcomes and reduce the costs of care, the need for true integration of renal
19 psychosocial services in new models of care can no longer be ignored.
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50 **AUTHORS' CONTRIBUTIONS**

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53 MS and PO were involved in the design and data collection. MS and DK designed a data
54 analysis plan and MS undertook the data analysis under supervision and support from DK.
55 MS drafted the manuscript under supervision from PO and DK, who both completed
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3 revisions. All authors provided intellectual content of critical importance to the work
4 described and have read and approved the final manuscript.
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7 **DATA SHARING STATEMENT**

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10 The dataset used during the current study is available from the corresponding author on
11 reasonable request after completion of the wider project.
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For peer review only

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

Section/Topic	Item #	Recommendation	Reported on page #
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
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	9
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	9
Bias	9	Describe any efforts to address potential sources of bias	7
Study size	10	Explain how the study size was arrived at	7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	9
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	9
		(b) Describe any methods used to examine subgroups and interactions	9
		(c) Explain how missing data were addressed	7
		(d) If applicable, describe analytical methods taking account of sampling strategy	n/a
		(e) Describe any sensitivity analyses	n/a
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	7
		(b) Give reasons for non-participation at each stage	-
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	8
		(b) Indicate number of participants with missing data for each variable of interest	8
Outcome data	15*	Report numbers of outcome events or summary measures	10
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	10
		(b) Report category boundaries when continuous variables were categorized	10
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	12-15
Discussion			
Key results	18	Summarise key results with reference to study objectives	16
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	16
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	17
Generalisability	21	Discuss the generalisability (external validity) of the study results	16-17
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	19

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

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.