

RESEARCH LETTER

Psychological Health in Young Adults With Kidney Failure: A 5-Year Follow-up of the SPEAK Study



To the Editor:

The psychosocial impact of kidney failure in young adults is implicated in the observed high risk of transplant loss¹ and death² in this group. In the Surveying Patients Experiencing Young Adult Kidney Failure (SPEAK) study, a cross-sectional investigation of psychosocial health among young adults in the United Kingdom aged 16-30 years receiving kidney replacement therapy, we reported worse psychosocial health outcomes among this group than in the age-matched general population.³ Using a General Health Questionnaire-12 score cutoff of ≥ 4 of 12, 31% of young adults had evidence of psychological morbidity compared with 15% among the general population. The specific nature of this psychological morbidity remains unknown, and to our knowledge, there have been no longitudinal studies investigating psychosocial outcomes as this group matures and becomes older. To

address this, we undertook the SPEAK-2 study: the 5-year follow-up of the original SPEAK study.

Details of the study population and methods are presented in [Item S1](#). Briefly, individuals recruited to the SPEAK study were invited to complete a revised online survey between June 2020 and January 2021. This included the General Health Questionnaire-12 as well as specific scales to measure symptoms of depression and anxiety: the Patient Health Questionnaire-9 and the Generalized Anxiety Disorder-7 scales, respectively. Patient Health Questionnaire-9 scores of ≥ 10 of 27 were consistent with symptoms of at least moderate depression. Generalized Anxiety Disorder-7 scores of ≥ 10 of 21 were consistent with symptoms of at least moderate generalized anxiety disorder. Differences in the baseline characteristics of respondents to SPEAK and SPEAK-2 were analyzed using Pearson's chi-squared test. Generalized Anxiety Disorder-7 and Patient Health Questionnaire-9 outcomes are reported descriptively. Ethical approval for the study was granted by the Health Research Authority Research Ethics Committee—Brent, reference 20/LO/0534.

Table 1. Comparison of the Demographic Characteristics, KRT Modality, and GHQ-12 Scores of Respondents to the SPEAK-2 Versus SPEAK Studies

Characteristics	SPEAK-2 study (n = 158) n (proportion)	SPEAK study (n = 467) n (proportion)	P value
Sex	152	466	0.14
Male sex	70 (46%)	248 (53%)	
Age band	157	496	
<21 y	6 (4%)	105 (21%)	
21 to <26 y	29 (18%)	156 (31%)	
26 to <31 y	54 (34%)	235 (47%)	
≥ 31 y	68 (43%)		
Median age (y)	30.4	25.7	
Ethnicity	157	444	0.03
White	145 (92%)	368 (83%)	
Asian	6 (4%)	48 (11%)	
Black	4 (3%)	17 (4%)	
Other	2 (1%)	11 (2%)	
Index of multiple deprivation quintile (1 = least deprived; 5 = most deprived)	130	496	0.08
1	21 (16%)	85 (17%)	
2	21 (16%)	104 (21%)	
3	31 (24%)	80 (16%)	
4	21 (16%)	122 (25%)	
5	36 (28%)	105 (21%)	
Current KRT modality	148	465	<0.001
Hemodialysis	16 (11%)	113 (24%)	
Kidney transplant	131 (89%)	323 (70%)	
Peritoneal dialysis	1 (1%)	29 (6%)	
GHQ-12	142	403	
Score of ≥ 4 of 12 suggesting probable psychological disturbance or mental ill health	63 (44%)	134 (33%)	0.02

Note: Data are presented as number and proportion (%). Not all percentages may total to 100 due to rounding. N reported for each characteristic represents the number of respondents for whom data were available. Demographic data for SPEAK study respondents are excluding subsequent SPEAK-2 respondents. Abbreviations: GHQ-12, General Health Questionnaire-12; KRT, kidney replacement therapy; SPEAK, Surveying Patients Experiencing Young Adult Kidney Failure.

Table 2. Psychological Health Survey Results of the SPEAK-2 Study by Current KRT Modality and Overall

Modality	GHQ-12 score $\geq 4/12$ (n = 142)	PHQ-9 score $\geq 10/27$ (n = 122)	GAD-7 score $\geq 10/21$ (n = 121)
	Proportion (95% confidence interval)	Proportion (95% confidence interval)	Proportion (95% confidence interval)
Kidney transplant	41% (33%-50%)	37% (28%-46%)	32% (23%-41%)
Dialysis	71% (44%-98%)	67% (35%-98%)	58% (26%-91%)
Overall	44% (36%-53%)	40% (31%-49%)	35% (26%-43%)

Note: Hemodialysis and peritoneal dialysis were combined to account for only 1 SPEAK-2 participant receiving peritoneal dialysis. Scale author recommendations were used for handling of missing data.

Abbreviations: GAD-7, Generalized Anxiety Disorder-7; GHQ-12, General Health Questionnaire-12; KRT, kidney replacement therapy; PHQ-9, Patient Health Questionnaire-9; SPEAK-2, Surveying Patients Experiencing Young Adult Kidney Failure.

We obtained data from 158 individuals (18%; see Fig S1). Those who responded to SPEAK-2 were more likely have a functioning kidney transplant and more likely to be White (Table 1). There was no association between baseline General Health Questionnaire-12 score and response to SPEAK-2 ($P = 0.1$). The proportion of respondents with General Health Questionnaire-12 scores of $\geq 4/12$ increased from 33% to 44% (Table 2). Delineating the nature of psychological morbidity, we found that 40% of respondents had Patient Health Questionnaire-9 scores consistent with at least moderate depression and 35% of respondents had Generalized Anxiety Disorder-7 scores consistent with at least moderate generalized anxiety disorder. Dialysis recipients had worse scores.

Our findings suggest an increased burden of psychological morbidity as young adults with kidney failure age and mature, particularly among dialysis recipients. The reasons for this are unclear. Qualitative studies have explored the psychosocial impact of kidney failure in young adults, with themes of difference and desire for normality, thwarted or moderated dreams and ambitions, and uncertainty and liminality characterizing the lived experience in this group.⁴ Therefore, our findings could represent a long-lasting, pervasive impact of kidney failure in young adulthood upon subsequent life participation. Our findings also characterize the nature of psychological morbidity, with 40% and 35% of respondents having evidence of depression and anxiety, respectively. Although our estimate for the prevalence of depression overlaps with the meta-analytical prevalence of depression among all adults with kidney disease of 34% (95% confidence interval, 31.9%-36.2%),⁵ >90% of individuals in this meta-analysis were receiving dialysis and had higher rates of depression than those seen among transplant recipients. In contrast, 89% of SPEAK-2 respondents had a transplant. Therefore, we may have underestimated the true prevalence of depression. Further longitudinal follow-up will elucidate how the mental health of individuals with kidney failure evolves over their life course.

The survey was conducted during the coronavirus disease 2019 pandemic, and the extent to which this contributed to psychological morbidity is unclear. Psychological health among participants of a longitudinal study of UK households did deteriorate early during the

pandemic.⁶ However, this largely returned to prepandemic levels by October 2020, approximately when our survey was active.⁷ This implicates other factors in the observed persistence of poorer outcomes among respondents. One reason could be the impact of shielding, which applied to all dialysis and transplant recipients in the United Kingdom until April 2021 and, in qualitative studies of other high-risk patient groups, had a subjective negative mental health impact.⁸ Longitudinal comparison with the age-matched general population may clarify the true extent and duration of the impact of the pandemic.

There are important limitations to this study. Our response rate was low, particularly among dialysis recipients, which may have introduced bias and limited the generalizability of our findings, as evidenced by broad confidence intervals. The low response rate also meant that we could not analyze the impact of changes in kidney replacement therapy modality on psychosocial health, which may be confounding outcomes.

In conclusion, we characterize a considerable burden of depression and anxiety symptomology among young adults with kidney failure as they age. Further longitudinal follow-up is vital to clarify the impact of the coronavirus disease 2019 pandemic. However, given the known negative impact of poor mental health on adherence, mental well-being,⁹ and employment,¹⁰ our findings highlight the urgent need for expanded mental health screening, prevention, and treatment for this vulnerable group.

Mohammed Al-Talib, MBBS, Fergus J. Caskey, MD, Carol Inward, MB BCH, Yoav Ben-Shlomo, PhD, and Alexander J. Hamilton, PhD

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Figure S1: Flowchart of recruitment to the SPEAK-2 study.

Item S1: Detailed study design and analytical methods.

ARTICLE INFORMATION

Authors' Affiliations: Department of Population Health Sciences, University of Bristol, Bristol, United Kingdom (MAT, FJC, YBS, AJH); Richard Bright Renal Unit, Southmead Hospital, North

Bristol NHS Foundation Trust, Bristol, United Kingdom (MAT, FJC); Bristol Royal Hospital for Children, University Hospitals Bristol and Weston NHS Foundation Trust, Bristol, United Kingdom (CI); and Exeter Kidney Unit, Royal Devon and Exeter Hospital, Exeter, United Kingdom (AJH).

Address for Correspondence: Mohammed Al-Talib, MBBS, Department of Population Health Sciences, University of Bristol Medical School, Canynge Hall, 39 Whatley Road, Bristol BS65EH, United Kingdom. Email: Mohammed.al-talib@bristol.ac.uk

Authors' Contributions: Research idea and study design: MAT, FJC, CI, YBS, AJH; data acquisition: MAT, AJH; data analysis/interpretation: MAT, FJC, CI, YBS, AJH; statistical analysis: MAT, AJH, YBS; manuscript drafting: MAT; manuscript review and editing: MAT, FJC, CI, YBS, AJH; supervision or mentorship: FJC, CI, YBS, AJH. Each author contributed important intellectual content during manuscript drafting or revision and agrees to be personally accountable for the individual's own contributions and to ensure that questions pertaining to the accuracy or integrity of any portion of the work, even one in which the author was not directly involved, are appropriately investigated and resolved, including with documentation in the literature if appropriate.

Support: This study was funded by a Bristol Health Research Charity (Charity number: 248189) Clinical Research Fellowship (RF08). MAT was funded by an National Institute for Health and Care Research Academic Clinical Fellowship (ACF-2020-25-006). The views expressed in this publication are those of the authors and not necessarily those of National Institute for Health and Care Research, National Health Service, or the UK Department of Health and Social Care. The funders of this study had no role in study design; collection, analysis, and interpretation of data; writing of the report; and the decision to submit the report for publication.

Financial Disclosure: The authors declare that they have no relevant financial interests.

Peer Review: Received November 21, 2022, as a submission to the expedited consideration track with 3 external peer reviews. Direct editorial input from the Statistical Editor and the Editor-in-Chief. Accepted in revised form February 5, 2023.

Publication Information: © 2023 The Authors. Published by Elsevier Inc. on behalf of the National Kidney Foundation, Inc. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>). Published online April 6, 2023 with doi [10.1016/j.xkme.2023.100637](https://doi.org/10.1016/j.xkme.2023.100637)

REFERENCES

1. Pankhurst T, Evison F, Mytton J, Williamson S, Kerecuk L, Lipkin G. Young adults have worse kidney transplant outcomes than other age groups. *Nephrol Dial Transplant*. 2020;35(6):1043-1051. doi:[10.1093/ndt/gfaa059](https://doi.org/10.1093/ndt/gfaa059)
2. Hamilton AJ, Casula A, Ben-Shlomo Y, Caskey FJ, Inward CD. The clinical epidemiology of young adults starting renal replacement therapy in the UK: presentation, management and survival using 15 years of UK Renal Registry data. *Nephrol Dial Transplant*. 2018;33(2):356-364. doi:[10.1093/ndt/gfw444](https://doi.org/10.1093/ndt/gfw444)
3. Hamilton AJ, Caskey FJ, Casula A, Ben-Shlomo Y, Inward CD. Psychosocial health and lifestyle behaviors in young adults receiving renal replacement therapy compared to the general population: findings from the SPEAK study. *Am J Kidney Dis*. 2019;73(2):194-205. doi:[10.1053/j.ajkd.2018.08.006](https://doi.org/10.1053/j.ajkd.2018.08.006)
4. Bailey PK, Hamilton AJ, Clissold RL, et al. Young adults' perspectives on living with kidney failure: a systematic review and thematic synthesis of qualitative studies. *BMJ Open*. 2018;8(1):e019926. doi:[10.1136/bmjopen-2017-019926](https://doi.org/10.1136/bmjopen-2017-019926)
5. Palmer S, Vecchio M, Craig JC, et al. Prevalence of depression in chronic kidney disease: systematic review and meta-analysis of observational studies. *Kidney Int*. 2013;84(1):179-191. doi:[10.1038/ki.2013.77](https://doi.org/10.1038/ki.2013.77)
6. Pierce M, Hope H, Ford T, et al. Mental health before and during the COVID-19 pandemic: a longitudinal probability sample survey of the UK population. *Lancet Psychiatry*. 2020;7(10):883-892. doi:[10.1016/S2215-0366\(20\)30308-4](https://doi.org/10.1016/S2215-0366(20)30308-4)
7. Pierce M, McManus S, Hope H, et al. Mental health responses to the COVID-19 pandemic: a latent class trajectory analysis using longitudinal UK data. *Lancet Psychiatry*. 2021;8(7):610-619. doi:[10.1016/S2215-0366\(21\)00151-6](https://doi.org/10.1016/S2215-0366(21)00151-6)
8. Sloan M, Gordon C, Lever E, et al. COVID-19 and shielding: experiences of UK patients with lupus and related diseases. *Rheumatol Adv Pract*. 2021;5(1):rkab003. doi:[10.1093/rap/rkab003](https://doi.org/10.1093/rap/rkab003)
9. Hamilton AJ, Caskey FJ, Casula A, Inward CD, Ben-Shlomo Y. Associations with wellbeing and medication adherence in young adults receiving kidney replacement therapy. *Clin J Am Soc Nephrol*. 2018;13(11):1669-1679. doi:[10.2215/CJN.02450218](https://doi.org/10.2215/CJN.02450218)
10. Kirkeskov L, Carlsen RK, Lund T, Buus NH. Employment of patients with kidney failure treated with dialysis or kidney transplantation—a systematic review and meta-analysis. *BMC Nephrol*. 2021;22(1):348. doi:[10.1186/s12882-021-02552-2](https://doi.org/10.1186/s12882-021-02552-2)