


ORIGINAL ARTICLE

Characterising patients and clinician experiences in comprehensive conservative care for kidney failure in Northern Queensland

Gheed Al Maraee,¹ Venkat Vangaveti¹ and Andrew Mallett ^{1,2,3,4}

¹College of Medicine and Dentistry, James Cook University, and ²Department of Renal Medicine, Townsville University Hospital, Townsville, and ³Institute for Molecular Bioscience, and ⁴Faculty of Medicine, The University of Queensland, Brisbane, Queensland, Australia

Key words

comprehensive conservative care, kidney supportive care, treatment options, prognostication.

Correspondence

Andrew Mallett, Department of Renal Medicine, Townsville University Hospital, Townsville, Qld. 4029, Australia.
Email: andrew.mallett@health.qld.gov.au

Received 15 August 2022; accepted 31 October 2022.

Abstract

Background: Comprehensive conservative care (CCC) is an emerging treatment option in kidney failure (KF), but its implementation has been restricted by a limited understanding of KF populations, outcomes and clinician experiences.

Aims: This pilot study aimed to investigate the characteristics of patients who are opting for (CCC) in North Queensland, Australia. It also aimed to highlight clinician factors impacting treatment discussions.

Methods: It was an observational study facilitated through an online cross-sectional survey to nephrologists, nephrology advanced trainees and nurse practitioners working across North Queensland.

Results: Study participants disagreed with the statement that patients commencing dialysis are more likely to have cardiac co-morbidities (46.7%), diabetes (40.0%), stroke (60.0%), liver disease (60.0%), chronic lung disease (53.3%), cognitive impairment (60.0%) and use of mobility aids (80.0%) than those commencing CCC. Conversely, they agreed that patients commencing dialysis are more likely to be independent (66.7%) and living in their private residence (40.0%). The median frailty score in patients choosing dialysis was 3.0 (interquartile range (IQR) 2.8–3.3), while that of patients selecting CCC was 4.5 (IQR 3.8–7.0). Our participants were aware of at least one clinical prognostication tool, and the one most frequently used was the ‘Surprise Question’ (46.2%, $n = 6$). Overall, our participants demonstrated low confidence (median 8.0%, IQR 6.0–8.0%) in facilitating CCC discussions.

Conclusion: Patients who are highly co-morbid and frail and have functional impairment are suitable candidates for CCC. More focus needs to be placed on objective prognostication of patients and the upskilling of clinicians to advocate for, and deliver, CCC.

Introduction

The incidence of dialysis-treated kidney failure (KF) has almost doubled in Australia over the last decade.¹ This applies across all age groups, including the frail and elderly.² However, emerging literature suggests that the burden of kidney replacement therapy (KRT) in the vulnerable elderly, those with multiple co-morbidities and functional and social limitations, outweighs its survival

benefits.^{3–6} Indeed, KRT in those aged over 75 years has been associated with more frequent hospitalisations, functional decline and dependence.^{3–6} Consequently, this patient demographic is exposed to a relatively more aggressive treatment trajectory than those suffering from other life-threatening illnesses.^{7–9} In this context, effort has been made to offer a treatment approach that is both active and sensitive to the needs of the elderly and frail. This is captured in the emerging paradigm known as comprehensive conservative care (CCC) and its practical application in nephrology in kidney supportive care (KSC) clinics.

CCC focuses on conserving quality rather than longevity of life.^{5,10–12} It is distinguished from palliative care in

AM is a recipient of a Queensland Health Advancing Clinical Research Fellowship. All other co-authors do not have any disclosures.

that it involves active disease management, symptom control and dietary advice to slow progression of disease, as well as endorsing advanced care planning.^{5,6,13,14} For instance, it involves active treatment of anaemia and fluid and electrolyte disturbances.^{10,11} Therefore, it is seen as a reasonable alternative to KRT in the elderly and frail patient cohort.¹⁵ Despite this, there appears to be a host of patient and physician barriers preventing the equal discussion of CCC alongside KRT in patients with KF.¹⁵ This is coupled by a lack of resources to facilitate CCC discussions, an area of research which is particularly lacking.^{8,9} These barriers could stem from current gaps in knowledge, including a need to better understand KF populations and outcomes, a need to evaluate clinician experiences and to appreciate the system-level resources and supports available in the Australian setting. To this end, a pilot survey was conducted across North Queensland, Australia, to describe and understand local clinicians' experience with CCC and dialysis to address these knowledge gaps and how they apply in the regional and rural Australian setting.

Methods

Study design

This was a descriptive, cross-sectional survey study distributed to nephrology-based clinicians in North Queensland from October to December 2021. The survey adopted a mixed format with demographic questions, a Likert scale, confidence scale and attitude and knowledge questions (see Appendix S1). It also incorporated a modified version of the 9-point Canadian Clinical Frailty Scale (CFS) for evidence-based assessment of frailty.^{16,17}

Study participants: sampling and recruitment

The target sample for this study was nephrologists, advanced trainees in nephrology and nurse practitioners currently practising in the regional and rural settings of North Queensland hospitals and nephrology clinics. All eligible clinicians across Townsville, Cairns, Mackay and Mount Isa were invited to partake in the survey. This included both male and female participants, with no limitations on age. Basic Physician Trainees who rotate between departments and registered nurses who do not practise autonomously were excluded from this study.

The sample size of eligible clinicians was 30, and they were all recruited for voluntary completion of the survey via an email from the Professor of Medicine in Townsville as part of engaging colleagues in a proposed North Queensland Kidney Research Consortium. Following this, participants received reminder emails on a second-

weekly basis to encourage input. Participants did not receive remuneration for completing the survey.

Data collection procedure

The data were collected using a cross-sectional survey distributed online via the platform REDCap. Data from the survey were stored on the James Cook University (JCU) Microsoft OneDrive, the investigator's private computer, a hard drive and a USB drive, while the project was active. Data will be retained by the primary investigator on a hard drive and USB drive for 5 years as per the JCU protocol.

Data analysis

The data collected were categorical, ordinal and nominal and were extracted directly from REDCap and downloaded for analysis using IBM SPSS Statistical Software (Version 26.0; IBM Corp., Armonk, NY, USA). The data were analysed using descriptive statistics, predominantly looking at frequencies of numerical data and chi-square testing for categorical data. Due to the predicted small sample size, data were regrouped into broader categories before analysis. Results were then presented with measures of central tendency and variance. As this was an observational study, relationships between variables were statistically insignificant and hence inferential statistics were not carried out.

Ethical considerations

Ethical approval was obtained from the James Cook University Human Research Ethics Committee (HREC) (application ID H8570) as per the National Statement on Ethical Conduct in Human Research (2007) – updated 2018.¹⁸

Results

Participant demographics

This survey was distributed to 30 participants across the involved sites in North Queensland. The total response rate was 70%. The experience of participants in working as full-time clinicians in nephrology ranged from less than 1 year to 25 years (median 7, interquartile range (IQR) 2.0–19.5 years). Their work was predominantly based in regional settings (68.4%; 13/19), as defined by a Modified Monash Model (MM) score of 2–3. A smaller portion of participants were equally distributed between metropolitan (MM1) (15.8%; 3/19) and rural (MM4–7) (15.8%; 3/19) settings. Most participants worked in the

public sector (78.9%; 15 out of 19), while 15.8% (3/19) worked both publicly and privately. Only 5.3% (1/19) worked exclusively in the private sector. 68.4% (13/19) of our participants had access to a palliative care team, with 73.3% (11/15) having an inpatient team, 73.3% (11/15) having a consult liaison service and 60.6% (9/15) having access to community palliative care services. However, most participants did not have access to a multi-disciplinary kidney supportive care team that facilitated conservative management (66.7%, 12/18).

Observed patient demographics

Participants disclosed that their patients commencing dialysis are qualitatively younger (median age group 51–60 years) than their patients who choose to commence conservative management (median age group 71–80 years). They were also asked about their patients' co-morbidities, functional status and socioeconomic determinants. Fifteen participants responded to these questions, with responses ranging from 'strongly agree' to 'strongly disagree'. Results were regrouped into three variables: 'agree', 'uncertain' and 'disagree' and can be found in Figure 1.

Results revealed that most of the participating clinicians (46.7%; 7/15) disagreed with the idea that their patients commencing KRT are more likely to have cardiac co-morbidities than those who choose CCC. The same was found for diabetes (40.0%; 6/15), stroke (60.0%; 9/15), liver disease and cirrhosis (60.0%; 9/15), chronic lung disease (53.3%; 8/15), cognitive impairment (60.0%; 9/15), use of mobility aids (80.0%; 12/15) and completion of an Advance Health Directive or Acute Resuscitation Plan (73.3%; 11/15).

In contrast, most participants agreed with the idea that their patients commencing KRT are more likely to be independent with activities of daily living (66.7%; 10/15) and are more likely to be living in their own private residence (40.0%; 6/15). They also largely agreed with 'my patients who choose KRT are more likely to have a hospitalised death than those who choose conservative management' (53.3%; 8/15).

Subanalyses of responses based on the degree of clinician experience (less than 10 years vs 10 or more years) were predominantly skewed in the same direction. The exceptions were 3 out of the 13 questions and related to the likelihood of patients having cardiovascular co-morbidities, diabetes or being from a non-English-speaking background. Please refer to Figure 1 for the full results. The results of the Likert scale overall suggest that from clinicians' experiences, patients who undertake CCC tend to have a higher co-morbidity burden, are more functionally impaired and are less likely to be living independently than those opting for KRT.

Frailty was then examined. In the question regarding the frailty of patients on KRT, the median frailty score was 3.0 (IQR 2.8–3.3). This meant 'Their medical problems are well managed; however they do not exercise', which was adapted from the CFS's 'Managing Well'. Meanwhile, the median score for patients who choose to commence CCC was 4.5 (IQR 3.8–7.0). This falls between the descriptions 'their symptoms limit their activity; however they manage their activities of daily living independently' and 'they depend on others for ADLs, which require higher-order thinking'. These correspond with 'living with very mild frailty' and 'living with mild frailty' on the CFS. These results demonstrate that our clinicians reported a higher median frailty score for their patients opting for CCC than those who commence KRT.

Clinical practice

In the last section of the survey, participants were asked about their experience with CCC in clinical practice. Thirteen participants responded to this section of the survey. These respondents indicated the most common reason patients switched from KRT to CCC as being the 'inability to tolerate dialysis' (6 out of 13). Most agreed that CCC should be routinely discussed with all patients (92.3%; 12 out of 13), and all agreed that CCC is 'an active treatment option'. However, participants did not notice an increase in the uptake of CCC throughout their years of practice (69.2%; 9 out of 13). A subanalysis looking into changes in uptake of CCC based on clinician experience (less than 10 years vs 10 or more years) demonstrated that despite years in practice, there has not been an increase in the uptake of CCC. Moreover, confidence levels in having discussions about CCC were profoundly low in this study group (median 8.0% confidence, IQR 6.0–8.0%). The reasons behind this were not immediately clear nor identified, though we speculate they may include clinician factors, patient factors, local health service factors, combinations of these or others that are not immediately clear. Further focused research to explore this reported low level of confidence is indicated, especially in order to enable the delivery of CCC and future KSC services.

Respondents were aware of several clinical assessment tools available in clinical practice (see Fig. 2): 92.3% know of the 'Surprise Question' (12 out of 13), 61.5% know 'The Karnofsky Performance Score' (8 out of 13), 61.5% know the 'Australian-modified Karnofsky Performance Status' (8 out of 13), 76.9% know of the 'Clinical Frailty Scale' (10 out of 13), 53.8% know the 'Charlson Comorbidity Index' (7 out of 13), and 76.9% know the 'Palliative Care Outcome Scale for end-stage renal disease' (10 out of 13). None of the respondents to this question voted 'none of the above'.

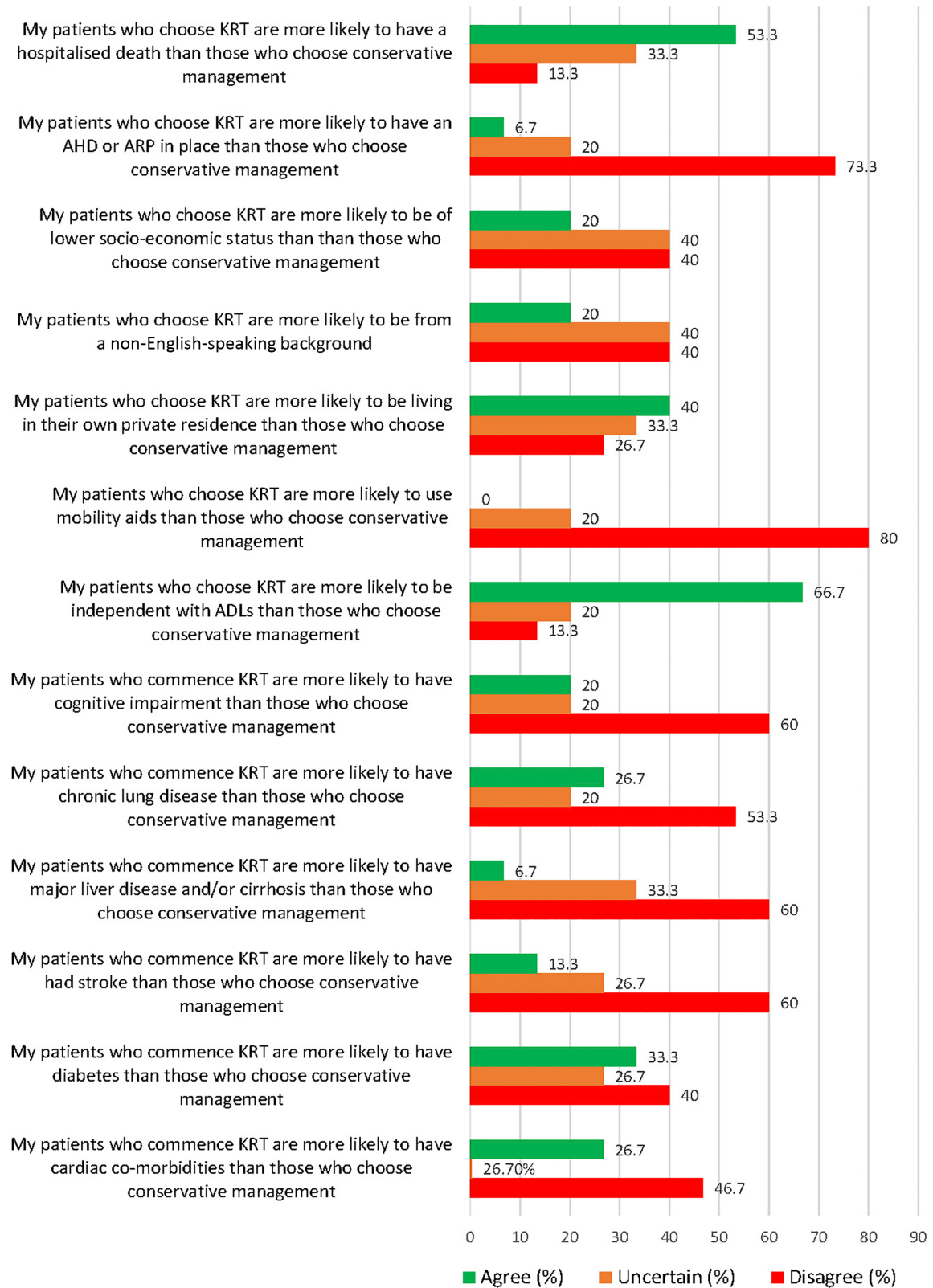


Figure 1 Patient characteristics as observed by clinicians.

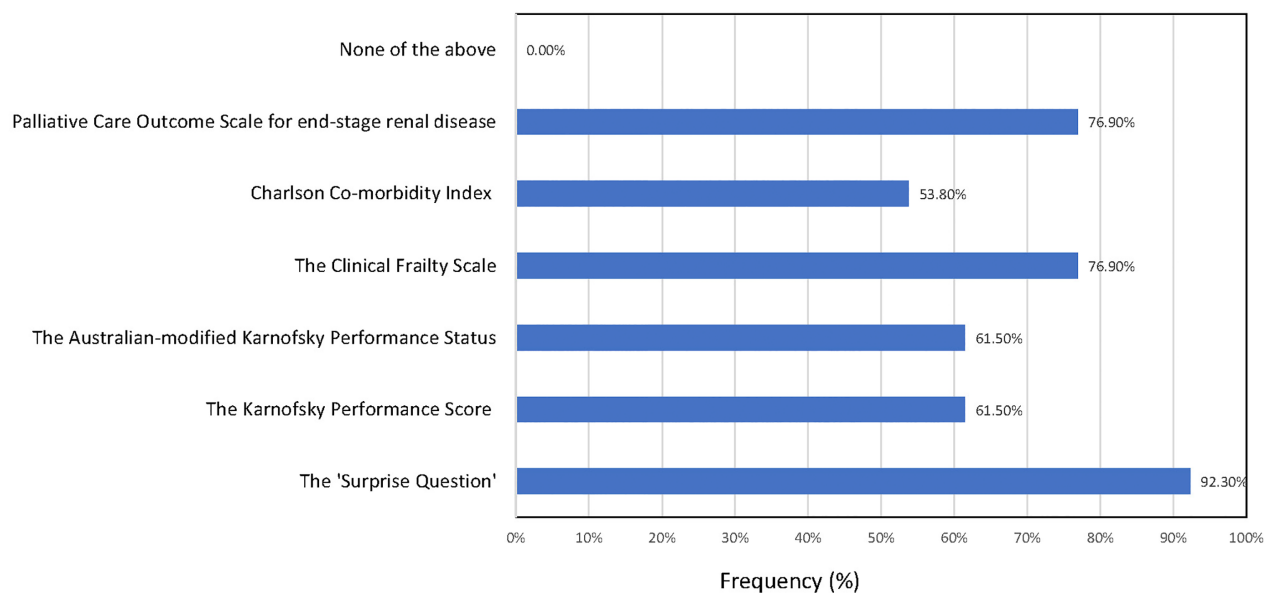


Figure 2 Prognostication tools that renal clinicians were aware of in north QLD.

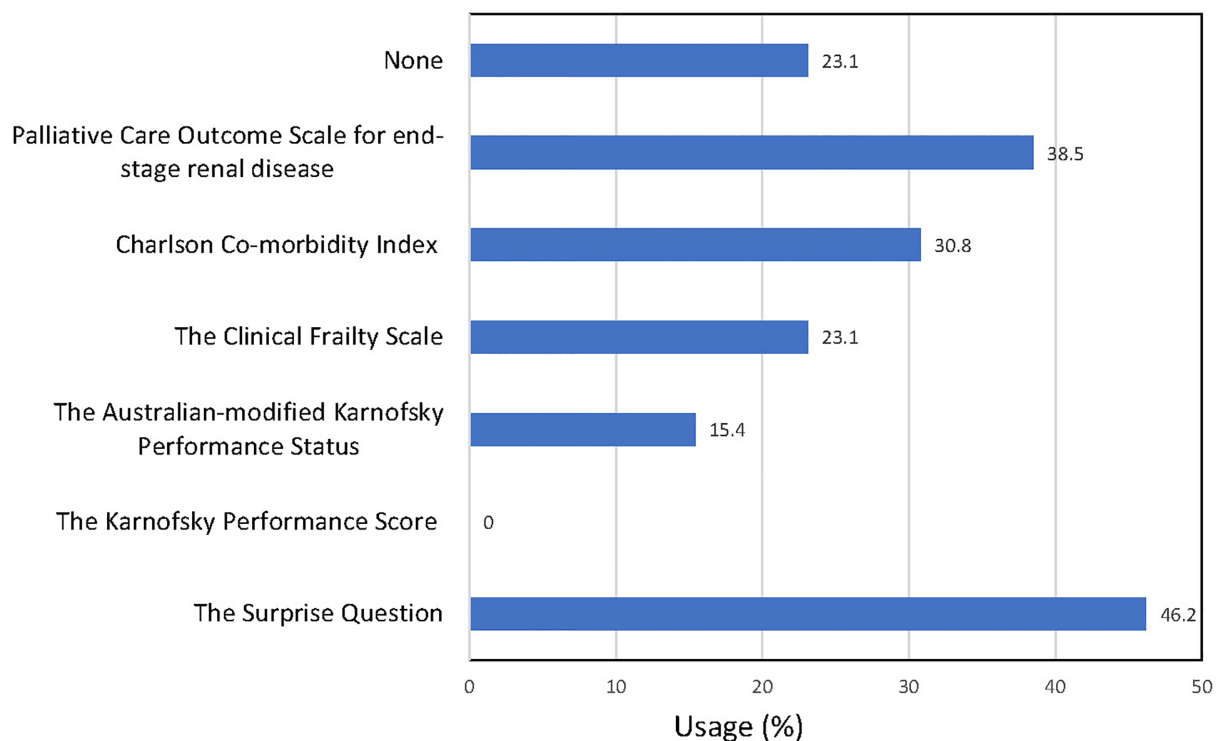


Figure 3 Prognostication tools actually implemented in everyday practice.

When asked about which clinical assessment tools from this list they used in clinical practice, the commonest response was the 'Surprise Question' (46.2%; 6 out of 13), followed by the 'Palliative Care Outcome Scale for end-stage renal disease' (38.5%, $n = 5$), then

the 'Charlson Comorbidity Index' (30.8%; 4 out of 13). Three participants stated that they do not use any scoring systems in clinical practice (23.1%; 3 out of 13). See Figure 3 for full results. These results demonstrate that there is a wide variety of tools available to assist in

decision-making, but they do not explain the participants' low confidence levels in navigating discussions around CCC in clinical practice.

Discussion

CCC has emerged as an important treatment alternative for patients whose risk of morbidity from dialysis outweighs the benefits.^{19,20} Our study confirmed that North Queensland-based clinicians believed that their conservatively managed patients were more elderly, frail, co-morbid and dependent than those choosing dialysis, which is consistent with previous quantitative research.^{6,9,21} Indeed, a previous study of Dutch nephrologists demonstrated that 'co-morbidities' was given a 9/10 on a scale of importance in dialysis decision-making, with 1 being not important at all and 10 being very important.²² Other factors noted to be important were cognitive impairment (10/10), impairment in activities of daily living (8/10) and impairment with mobility (7/10).²² Our study adds to these findings by demonstrating that, as per our participating clinicians' observations, patients undertaking CCC are more likely to have cardiovascular disease, diabetes, stroke, liver disease and cirrhosis, chronic lung disease and cognitive impairment and be functionally impaired than those undergoing dialysis.

This study also demonstrated that, based on the CFS, clinicians allocated a higher frailty score to those selecting CCC in comparison to dialysis at the time of treatment decision-making (median score 4.50 vs 3.00). Literature comparing the frailty of patients selecting dialysis versus CCC is scarce, and to our knowledge, this is the first study that utilised the CFS. One study by Teruel *et al.* demonstrated that patients opting for dialysis scored lower on the Charlson Comorbidity Index than those choosing CCC ($P < 0.001$).²³ Other qualitative studies elicited from patients undertaking CCC that poor physical fitness was a barrier to selecting dialysis and they preferred not to extend (their) life' if dialysis imposed a physical burden.^{24,25} It can be surmised from these studies that frailty has a role to play in suitability for dialysis. Our study provides further novel but inconclusive results regarding the role of the CFS in frailty scoring, due to the fact that not all participating clinicians were familiar with, or applied, the CFS in clinical practice. Further research is required to define the role of frailty scoring in KF decision-making.

Our participants were aware of at least one clinical assessment tool in clinical practice but did not universally apply them in treatment decision-making. This could explain, in part, why our clinicians have not observed an increase in the uptake of CCC over the last decade. This could be addressed by streamlining the availability of supported prognostication tools in the dialysis selection process. Another factor which could be contributing to the

lack of increase in uptake is the low level of confidence our clinicians demonstrated in navigating CCC discussions (median 8% confidence, IQR 6–8%). Previous literature showed that areas with few or no renal departments offering conservative management generally rely on primary care physicians to provide these services.²⁶ In one Canadian report, 40% of patients with stage 5 CKD who were not undergoing dialysis had not seen a nephrologist in a 2-year period.²⁷ This could explain the low confidence rates in our regional and rural nephrology-specific cohort in whom two thirds did not have access to kidney supportive care services (66.7%), which is a service specialised in delivering CCC and upskilling clinicians in this domain. Further research is required to compare this cohort with metropolitan-based colleagues that have greater access to kidney supportive care services.

This is the first Australia-based study looking into clinician experiences with patients who are opting for CCC, producing a comparison based on the CFS and delineating clinician factors that may be encouraging or precluding patient participation in CCC. There was a high response rate, 70%, amongst our participants. However, this study was limited by the small cohort of clinicians in North Queensland ($n = 30$). In this setting, causal relationships were less likely to be observed. Therefore, the results of this study are descriptive and provide grounds for further analytical research.

Conclusion

In conclusion, nephrology-based clinicians in North Queensland described their conservatively managed patients as more co-morbid and dependent than patients choosing dialysis. They also assigned a higher median frailty score to this patient cohort, though not all participants were familiar with the CFS used to assess frailty in our survey. Importantly, our cohort lacked both confidence in discussing conservative management and the universal access to infrastructure by which this service could be provided. Further emphasis needs to be placed on upskilling clinicians, and this may call for increased access to KSC services in regional and rural Queensland to support less aggressive treatment options in an ageing Australian population and to rationalise overall healthcare expenditure.

Acknowledgements

The authors would like to gratefully acknowledge all of the kidney health clinicians across northern Queensland who participated in this study. Open access publishing facilitated by James Cook University, as part of the Wiley - James Cook University agreement via the Council of Australian University Librarians.

References

- AIHW. Chronic Kidney Disease. AIHW Website. Published 2020. Available from URL: <https://www.aihw.gov.au/reports/chronic-kidney-disease/chronic-kidney-disease/contents/how-many-australians-have-chronic-kidney-disease>
- ANZDATA. ANZDATA 43rd Annual Report 2020. Data to 2019. ANZDATA Website. Published 2021. Available from URL: <https://www.anzdata.org.au/report/anzdata-43rd-annual-report-2020-data-to-2019/>
- Okamoto I, Tonkin-Crine S, Rayner H, Murtagh FEM, Farrington K, Caskey F *et al*. Conservative care for ESRD in the United Kingdom: a national survey. *Clin J Am Soc Nephrol* 2015; **10**: 120–6.
- Kwok W-H, Yong S-P, Kwok O-L. Outcomes in elderly patients with end-stage renal disease: comparison of renal replacement therapy and conservative management. *Hong Kong J Nephrol* 2016; **19**: 42–56.
- Hussain JA, Mooney A, Russon L. Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease. *Palliat Med* 2013; **27**: 829–39.
- Murtagh FEM, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris FE. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol Dial Transpl* 2007; **22**: 1955–62.
- O'Riordan J, Noble H, Kane PM, Smyth A. Advance care plan barriers in older patients with end-stage renal disease: a qualitative nephrologist interview study. *BMJ Support Palliat Care* 2020; **10**: e39–9.
- Verberne WR, Geers AB, Jellema WT, Vincent HH, van Delden JJ, Bos WJ. Comparative survival among older adults with advanced kidney disease managed conservatively versus with dialysis. *Clin J Am Soc Nephrol* 2016; **11**: 633–40.
- Chandna SM, Da Silva-Gane M, Marshall C, Warwicker P, Greenwood RN, Farrington K. Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy. *Nephrol Dial Transplant* 2011; **26**: 1608–14.
- Alston H, Burns A. Conservative care of the patient with end-stage renal disease. *Clin Med* 2015; **15**: 567–70.
- Koncicki HM, Swidler MA. Decision making in elderly patients with advanced kidney disease. *Clin Geriatr Med* 2013; **29**: 641–55.
- Seow YY, Cheung YB, Qu LM, Yee ACP. Trajectory of quality of life for poor prognosis stage 5D chronic kidney disease with and without dialysis. *Am J Nephrol* 2013; **37**: 231–8.
- Davison SN, Levin A, Moss AH, Jha V, Brown EA, Brennan F *et al*. Executive summary of the KDIGO controversies conference on supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney Int Rep* 2015; **88**: 447–59.
- Schmidt RJ, Landry DL, Cohen L, Moss AH, Dalton C, Nathanson BH *et al*. Derivation and validation of a prognostic model to predict mortality in patients with advanced chronic kidney disease. *Nephrol Dial Transplant* 2019; **34**: 1517–25.
- Verberne WR, Konijn WS, Prantl K, Dijkers J, Roskam MT, van Delden J *et al*. Older patients' experiences with a shared decision-making process on choosing dialysis or conservative care for advanced chronic kidney disease: a survey study. *BMC Nephrol* 2019; **20**: 264.
- Dalhousie University. Clinical Frailty Scale. Dalhousie University Website. Available from URL: <https://www.dal.ca/sites/gmr/our-tools/clinical-frailty-scale.html>
- Church S, Rogers E, Rockwood K, Theou O. A scoping review of the clinical frailty scale. *BMC Geriatr* 2020; **20**: 393.
- NHMRC. The National Statement on Ethical Conduct in Human Research (2007) – Updated 2018. Published 2018. NHRMC Website. Available from URL: <https://www.jcu.edu.au/jcu-connect/ethics-and-integrity/human-ethics>
- Brown SC, Masterson R. ANZSN Renal Supportive Care Guidelines 2013. *Nephrol Ther* 2013; **18**: 401–54.
- Fassett RG, Robertson IK, Mace R *et al*. Palliative care in end-stage kidney disease. *Nephrology* 2011; **16**: 4–12.
- Reindl-Schwaighofer R, Kainz A, Kammer M, Dumfarth A, Oberbauer R. Survival analysis of conservative vs. dialysis treatment of elderly patients with CKD stage 5. *PLoS One* 2017; **12**: e0181345.
- van Loon IN, Boereboom FT, Bots ML, Verhaar MC, Hamaker ME. A national survey on the decision-making process of dialysis initiation in elderly patients. *Neth J Med* 2015; **73**: 227–35.
- Teruel JL, Burguera Vion V, Gomis Couto A, Rivera Gorrin M, Fernández-Lucas M, Rodríguez Mendiola N *et al*. Elección de tratamiento conservador en la enfermedad renal crónica. *Nefrología* 2015; **35**: 273–9.
- Chanouzas D, Ng KP, Fallouh B, Baharani J. What influences patient choice of treatment modality at the pre-dialysis stage? *Nephrol Dial Transplant* 2012; **27**: 1542–7.
- Han E, Haldane V, Koh JJK, Quek RYC, Ozdemir S, Finkelstein EA *et al*. Perspectives on decision making amongst older people with end-stage renal disease and caregivers in Singapore: a qualitative study. *Health Expect* 2019; **22**: 1100–10.
- Tam-Tham H, Thomas CM. Does the evidence support conservative Management as an alternative to dialysis for older patients with advanced kidney disease? *Clin J Am Soc Nephrol* 2016; **11**: 552–4.
- Canadian Medical Association. Kidney - Strategic Clinical Network. Prevalence of Severe Kidney Disease and Use of Dialysis and Transplantation Across Alberta from 2004 – 2013, Alberta Annual Kidney Care Report. 2015. Alberta, Canada. <https://www.albertahealthservices.ca/assets/about/scn/ahs-scn-kh-annual-kidney-care-2015.pdf> (accessed 19th November 2022).

Supporting Information

Additional supporting information may be found in the online version of this article at the publisher's web-site:

Appendix S1. Supporting Information.