The Kidney Supportive Care program: Characterisation of patients referred to a new model of care for advanced chronic kidney disease

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ABSTRACT

Objectives: For many people with advanced kidney disease, their physical, psychological and emotional needs remain unmet. Kidney supportive care, fully integrating specialist kidney and palliative care teams, responds to the emotional and symptom distress in this cohort who may be on a non-dialysis care pathway or on dialysis and approaching end of life. We aimed to analyse and describe the operation and patient characteristics of a new kidney supportive care program (KSCp).

Methods: A multidisciplinary KSCp was introduced through a tertiary hospital in Brisbane, Australia. Operational information and characteristics of referred patients were collected from internal databases and electronic medical records and analysed descriptively. Patient data were collected using validated instruments to assess symptom burden, health-related quality of life, health state, functional status and performance at clinic entry and analysed descriptively.

Results: 129 people with advanced kidney disease were referred to the KSCp within the first year (median age 74 (range 27.7–90.5), 48.1% female, median Charlson Co-morbidity Index score 7 (interquartile range 6–8) and mean IPOS-Renal score 19.6±9.8). 59% were currently receiving dialysis. The leading reason for referral was symptom management (37%). While quality of life and health state varied considerably among the cohort, in general these parameters were well below population norms.

Conclusions: Results indicate that patients referred to the KSCp were those with a strong need for a patient-centred, integrated model of care. Shifting focus to co-ordinated, multidisciplinary care rather than discrete specialty silos appears key to addressing the challenging clinical problems in end-of-life care.

INTRODUCTION

Kidney disease is a major and growing public health burden worldwide. Chronic kidney disease (CKD) is common, affecting ~10% of the Australian population.[1] It is more common with increasing age and conflates the risk of other chronic diseases such as cardiovascular disease.[2 3] Advanced stages of CKD are associated with increased risk of premature death [2] and a considerable burden of physical, emotional and social symptoms. This burden can be further compounded by dialysis. Although there is significant variability in patients' experiences, dialysis is associated with a high prevalence and severity of symptoms (reviewed in [4]) in addition to restrictive lifestyle modifications. Withdrawal from dialysis is now the most common cause of death in the Australian dialysis population >75 years.[5]

The needs of people with end stage kidney disease (ESKD) include the management of their symptoms, psychosocial support for themselves and their families and planning for when their health circumstances worsen.[6] These needs are complicated by the complex and heterogeneous characteristics of these people (e.g. age, co-morbidities, CKD stage) and often remain unmet due to factors such as a lack of appropriate resources and fragmentation of care.[6 7] A dedicated person-centred pathway is needed to address the challenges experienced by this vulnerable patient population.

Kidney supportive care is an active treatment pathway that specifically addresses factors influencing quality of life of people with advanced kidney disease and their families.[8 9] It complements (without supplanting) the traditional biomedical model of care practiced by kidney specialists. Kidney supportive care focuses on the existential experience of the patient, family and/or carer, as well as their expectations, preferences and decision-making around the complex healthcare options during the advanced stages of CKD.[10] A further focus is managing the multidimensional symptom burden that affects health-related quality of life.[11-13] These are highly specific skill sets that, while fitting most closely with the specialty of palliative care, also need kidney-specific expertise.

It is important to note that "supportive care" in a kidney context is, on occasion, used as synonymous with conservative management of ESKD (as opposed to kidney replacement therapy (KRT)). Here, however, we follow the guidelines specified by KDIGO (Kidney Disease: Improving Global Outcomes),[10] using the term "supportive care" to indicate integrated kidney and palliative medicine. This encompasses both conservative management and the care of individuals receiving KRT who require help with symptom management, decision-making and/or advance care planning.

While kidney supportive care has been established in other parts of Australia, prior to 2016, there was no structured kidney supportive care pathway in Queensland, a state with an ageing population and a high prevalence of people treated with dialysis (496 per million population).[5] The KSC program (KSCp) was introduced into the Metro North Hospital and Health Service (MNHHS), Queensland, covering a catchment from the Brisbane central business district to Kilcoy (74km to the northwest), in February 2016 in response to the unmet need most evident in those stopping dialysis. We describe in detail the model of care of the KSCp as well as characteristics of KSCp patients, their transition through the model and outcomes of the first 12 months of the service's operation.

MATERIALS AND METHODS

The Kidney Supportive Care program: Clinical model

The KSCp is an integrated pathway of care with elements of both kidney and palliative skill sets and practices. The team is jointly led by a specialist in palliative medicine and an advanced practice nurse (a specialist kidney clinical nurse consultant (CNC)) who case manages the patients, and also consists of an advanced medical trainee in nephrology, a kidney pharmacist and a social worker with expertise in renal medicine and end of life care. The program is patient-centred with a focus on shared decision making with patients and carers, exploration of patient experiences and the provision of supportive care appropriate to individual symptom burden. The purpose of the program, its structure and work flows were endorsed by MNHHS executives and leadership teams in the kidney and palliative medicine services.

Patient population

Those referred to the KSCp have advanced stages of CKD and meet one or more of the following requirements: 1) have symptom distress; 2) have already decided or who have been medically advised not to have KRT or need to make a decision about whether to commence KRT; 3) are already receiving KRT and have significant co-morbidities, a new diagnosis of a second life-limiting disease, advanced age or a need for education around ceasing KRT.

Referral process

Patients are referred into the KSCp by their treating nephrologists or, with prior approval of the nephrologist, by other members of the kidney multidisciplinary team (Figure 1). The criteria and patient flow in Figure 1, including entry into the KSCp and exit, were agreed during stakeholder engagement meetings. The CNC triages the referral and is the first point of contact with the patient. Where the patient consultation is as an outpatient, the CNC works with administrative staff to organise an appointment at a KSCp clinic. If the person referred is an inpatient, the CNC in-reaches, meeting the person and their family to introduce the program and to discuss pathways of care. The CNC out-

reaches into the four dialysis facilities distributed across MNHHS. Throughout contact with the KSCp the patient's original nephrologist remains as the named treating consultant, in line with the KSCp's aim to be a value-add program.

Roles of the multidisciplinary KSCp team members

The multidisciplinary team work together towards a common goal of providing optimal care for the patients. See Supplementary File 1 for a detailed description of each role.

Clinic operational flow

Outpatient consultations take place in clinics conducted weekly in a community health centre. The team meets prior to the start of the outpatient clinic to briefly discuss relevant background information for each patient. This includes prioritising and sequencing consultations with differing team members depending on patients' individual needs The CNC takes the lead in this clinical briefing. On arrival, patients (with or without the assistance of a carer or family member) complete relevant health questionnaires. Patients are typically seen first by the CNC who confirms or re-triages the sequencing based on the consultation and the results of the health questionnaires.

Consultations with the CNC, pharmacist and social worker are typically of 30 minutes duration. Medical consultations are 60 minutes for new patients and 45 minutes for reviews. Generally, new patients are seen by the palliative medicine consultant while review patients are seen by the kidney advanced trainee; this may differ, however, based on individual patient needs. Additionally, complex patients may be jointly seen by two or more members of the MDT to reduce the burden on the patient, support an integrated treatment plan and aid in the training of the advanced trainee.

The team re-assembles post-clinic to case conference. Decisions are made on who will progress emergent issues, changes in medications and any decisions patients have made about treatment options or advance care planning. A multidisciplinary care plan derived from the case conference and the clinicians' notes is completed by the CNC using a template adapted by the Palliative and Supportive Care service from the Gold Standards Framework [14] for use by the KSCp. This is received by each

patient's nephrologist, general practitioner, other kidney team members (e.g. dialysis nurses) and any other relevant healthcare providers within days. Appropriate referral to specialist community and palliative care services and other health agencies (e.g. aged care services) are responsive to patients' needs. Completed Advance Care Plans and other documents are processed by an administrative officer and, where applicable, recorded in the patients' clinical record.

Subsequent appointments are based on each patient's needs, which are determined individually by any member of the team and collectively in collaboration with the patient and/or carer.

Outside clinic hours

Team members, individually or together, in-reach to patients admitted to hospital and out-reach into dialysis facilities. The sequencing of consultations becomes resource sensitive: access to all members of the KSCp team is reliant on patient location. Case conferencing may occur virtually or with a smaller group if not all team members can be present. The consultations are more likely to reflect acute health events, are important in continuity of care, are points of patient advocacy of their elected preferences and assist the health system in delivering the services the patients expect.

The CNC case manages patients between clinic visits, is the first point of contact for emergent calls during working hours and is the key communication channel in the team.

Evaluation of the KSCp

Ethical approval

The implementation of the KSCp was evaluated using implementation science methodology as a collaboration between the KSCp clinicians and university academics. Approval from the Human Research Ethics Committee of the Royal Brisbane and Women's Hospital was granted (reference no. HREC/16/QRBW/208). In lieu of individual consent, approval to use clinical data for research purposes was granted under the Public Health Act 2005 by the Queensland Department of Health (reference no. RD006421).

Clinical data

Data collection

A range of clinical data is collected and recorded in patients' clinical charts as part of the detailed patient assessment and monitoring of progress (e.g. symptoms, quality of life), and to aid in making clinical decisions on when additional interventions (e.g. referral to community palliative care services, psychological support) are needed. This includes 1) demographic data, 2) co-morbidities using the Charlson Co-morbidity Index [15], 3) symptom burden recorded by the patient self-scoring the Integrated Palliative care Outcome Scale Renal (IPOS-Renal) questionnaire [16] and 4) health-related quality of life (HRQoL) using the 36-Item Short Form Health Survey version 2 (SF-36v2) [17] questionnaire. Patients' function and performance are assessed by the CNC using the Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) scale [18] and the Australia-modified Karnofsky Performance Scale (AKPS),[19] respectively. If clinically indicated, anxiety and depression are assessed by the CNC using the Hospital Anxiety and Depression Scale.[20] The team also measure carer burden using the Caregiver Strain Index [21] which is completed by patients' carers (if applicable). These data are all used in the clinical management of the patient and are usual care in the KSCp.

Data analysis

The scores for symptom burden, co-morbidity, function, performance, caregiver strain and physical and mental components of HRQoL were calculated according to the protocols of the respective instruments. For symptom burden, results were expressed as number of symptoms per patient, total score, frequency of individual symptoms (prevalence) and mean score per individual symptom (severity). Mean severity score per symptom was calculated at an individual level by dividing total score by the number of symptoms per patient. As the IPOS-Renal questionnaire has been not previously validated for use in people with pre-terminal kidney disease, internal consistency

(reliability) and convergent validity were assessed by calculating Cronbach's alpha and by determining correlation with HRQoL in the physical and mental domains.

Health state utility scores were calculated from the SF-36v2 questionnaire using the SF-6D algorithm [22] and Australian preference weights.[23]

Results were analysed descriptively. The distribution of data was determined using the Shapiro-Wilk normality test. Where distribution was normal, results were expressed as mean ± SD and non-normally distributed data results were expressed as median (interquartile range), unless otherwise stated. For HRQoL, mental domain data were normally distributed and physical domain data were not; for consistency of display, both were expressed as mean ± SD but a non-parametric (i.e. more conservative) test was used for significance testing. Frequency results were expressed as percentages.

For the physical and mental components of the HRQoL, mean values were compared to the instrument's inbuilt norms [17] using one-sample t-tests. A two-tailed Wilcoxon matched-pairs signed rank test was used for the within-group comparisons. P values <0.05 were considered statistically significant. Statistical analyses were performed using GraphPad Prism (v.7.0, GraphPad Prism Software, San Diego, CA, USA).

RESULTS

Referrals to the KSCp

Over the first 12 months of operation, 129 patients (48.1% female, 51.9% male) were referred to the program. The main reason for referral was symptom management (37%); other reasons included conservative management (17%), decision-making around dialysis options (11%) and advance care planning (7%). Almost a third (29%) were referred for more than one reason. The mean number of appointments per patient was 2.1±1.4, and mean time between appointments was 8.2±5.6 weeks. One patient was seen by the KSCp team as an inpatient and seven (5%) were seen in a dialysis unit while receiving dialysis; the remainder attended appointments at the outpatient clinic.

Patient demographics

Patient demographics are presented in Table 1. The median age of patients at referral was 74 years (range 27.7–90.5). The majority of patients were born in Australia (78%), with 8% born in the UK and the remainder immigrants from a range of countries. Among those born in Australia, six patients (6%) identified as indigenous Australian. The most common occupation in the group was pensioner (40%) followed by retired (28%). The most common relationship status was married (46%). 22 caregivers completed the Caregiver Strain Index at baseline, with a mean score of 4.7±3.9. Five caregivers (23%) reported a score of >7, representing a high level of stress.

Table 1: Demographic characteristics of KSCp patients

		n	%
Sex	female	62	48
	male	67	52
Occupation	pensioner	52	40
	retired	36	28
	home duties	21	16
	employed	6	5
	unemployed	3	2
	not stated	21	16
Relationship status	married	59	46
	widowed	23	18

	divorced	21	16
	never married	15	12
	separated	5	4
	de facto	4	3
	not stated	3	2
*Reason for referral**	symptom management	50	39
	conservative management	22	17
	decision-making	14	11
	advance care planning	9	7
	more than one reason	37	29

*More than one reason for referral was possible

Clinical characteristics

Over half of the referred patients were on dialysis (either peritoneal dialysis or haemodialysis) at the time of referral (59%). The distribution of treatment pathways at referral is shown in Figure 2A. Most patients were either in CKD stage 5 (34%) or 5D (55%) and the remaining 11% were referred while in CKD stage 4 (Figure 2B). For those not on dialysis, the median estimated glomerular filtration rate (eGFR) was 12 (10–14) mL/min/1.73m^2 (Figure 2C). At initial KSCp visit, there was a median Charlson Co-morbidity Index score of 7 (6–8) (Figure 2D). This indicates a high risk of mortality, with a previous study finding that scores $\geq$5 were associated with a mortality rate of 85% after 1 year [24]. 70% of patients had a functional level (RUG-ADL) score of 4, representing the status of independence with activities of daily living, although the scores ranged from 4 to 18 (the maximal end of the scale, representing full assistance needed) (Figure 2E). The median performance score (AKPS) was 60 (range 40–80), with 60 representing the status "able to care for most needs, but requires occasional assistance" (Figure 2F).

Patient-reported outcomes at baseline

Symptom burden

The Cronbach's alpha of the IPOS-Renal questionnaire was 0.80, indicating high reliability. Symptom burden was shown to be significantly negatively correlated with physical (−0.428, p=0.002) and mental

(−0.401, p=0.004) HRQoL, indicating that the IPOS-Renal is valid for this patient population. The mean number of symptoms reported per patient at baseline was 10.0±3.8 and the mean overall symptom score was 19.6±9.8, giving a mean severity score per symptom of 2.0. This corresponds with a moderate level of severity, and accords with a previous study in people with stage 5 CKD not receiving dialysis [25]. The most prevalent symptoms reported by patients were weakness/fatigue (90%), pain (82%), poor mobility (80%) and drowsiness (74%). Symptoms varied in reported severity, with weakness, pain, poor mobility, drowsiness and difficulty sleeping the five most severe symptoms. Prevalence and severity of all reported symptoms are shown in Figure 3A and 3B, respectively.

Health-related quality of life and health state utility

The mean HRQoL scores for the physical (31.1±9.0) and mental (42.3±12.5) component summary scales in the KSCp cohort were significantly below the norms for the SF-36v2 (50; p<0.0001 for both comparisons) (Figure 3C). Within the KSCp cohort, physical quality of life was significantly lower than mental quality of life (p<0.0001). There was considerable variation in health state among patients, with a mean health utility score of 0.17±0.26 (Figure 3D). Scores ranged from 0.82, representing robust health, to -0.36, representing a state of health considered worse than death.

DISCUSSION

For the 12-month period prior to the commencement of the KSCp, between February 2015 and January 2016, internal hospital data showed only 27 kidney referrals to the specialist Palliative and Supportive Care service within the Royal Brisbane and Women's Hospital, the main hub of MNHHS. A significant proportion of patients with ESKD—whether on a KRT or non-KRT pathway—died without receiving specialist palliative care. Their expectations, as expressed in advance care plans, were unknown. The 129 referrals to the KSCp in its first 12 months after January 2016 exceeded predicted numbers. This substantial increase demonstrates that the pathway meets a need within the hospital and health service. Although the leading reason for referral was symptom management, a considerable proportion of KSCp patients were referred for more than one reason, highlighting the complexity of care requirements for many people with advanced CKD. The spread of reasons for referral demonstrates the need for a mix of skill sets and the rationale for an integrated kidney and palliative multidisciplinary care team.

While the need for kidney supportive care is clear, how best to service this need is not. Health services in Australia [26] and internationally [27-30] have implemented kidney supportive care programs that differ in focus, design and resourcing. A comparison of published models is shown in Table 2. These services are at the forefront of recognising that this pathway represents the routine clinical care of the future.[31] The KSCp model presented here accepts referrals for both patients receiving KRT and those not receiving KRT, a point of differentiation from some other models, which may focus primarily on one group or the other. The KSCp has porous boundaries where patients enter, exit and re-enter depending on their time-dependent healthcare needs and decisions. The KSCp is designed to be activated when the patient triggers one of the referral criteria. Patients in the KSCp may therefore be at a relatively early stage in their disease trajectory. Patients are able to articulate, document and implement their healthcare wishes in a considered time frame and while still in relatively good health. We advocate using the term "supportive care" rather than "palliative care" to signal that this is an

active treatment pathway. Use of this term has also been shown to encourage early referral by healthcare providers.[32]

Table 2: Comparison of published models of kidney supportive care programs

	Poppel et al.	Brown et al.	Chao et al.	Rak et al.	Purtell et al.
Year	2003	2013	2015	2016	2018
Country	USA	Australia	Taiwan	USA	Australia
Outpatient clinic	-	x	-	-	x
Home visits	-	-	x	x	-
Multidisciplinary team	x	x	x	x	x
Nurse	x	x	x	x	x
Nephrologist/trainee	x	x	unclear	x	x
Palliative medicine specialist	x*	x	x	x	x
Dietician	-	x	x	-	-
Social worker	x	x	x	x	x
Pharmacist	-	-	x	-	x
Psychologist	-	-	x	-	-
Bioethicist	-	-	-	x	-
Patients receiving dialysis	x	-	x**	x	x
Patients receiving conservative care	-	x	x	x	x

*only for education of other clinicians
** only upon decision to withdraw from dialysis

The composition of the multidisciplinary team and their assembly into a single unit differentiates the KSCp from some models established elsewhere. The team uses immediate case conferencing, supervised advanced trainee consultations and flexibility of sequencing to meet the needs of the patients. Team members may conduct conjoint instead of individual consultations when patients become fatigued and need to return home early.

There are several strengths of this model. Firstly, it is meeting the needs of a highly vulnerable cohort of patients. They experience advanced clinical handover in the sequence of consultations, ensuring continuity of care throughout the entire clinical encounter that minimises repetition. Secondly, the model includes a pharmacist who provides specialist input into the quality use of medicines, reducing potential polypharmacy interactions in patients at high risk of medication misadventure. Thirdly the model is training the health providers, including nephrologists, of the future. We observe the team evolving from the initial multidisciplinary functioning of the new team (i.e. discrete specialty and discipline silos) into a more mature team operating as an interdisciplinary model of care. The additional value of this change is greater flexibility of care delivery through the integration of disciplinary roles and skill, cooperation and communication.[33]

We observed that patients referred to the KSCp had a heavy burden of symptoms. This was the most common reason for referral by nephrologists, reflecting a pragmatic recognition of patient distress not met by nephrology skill sets that are, predominantly, biometrically oriented. High symptom burden in people with advanced CKD, regardless of CKD stage or KRT modality, is well known.[25 34-36] Brennan et al. used, as in the current study, the IPOS-Renal, albeit in an older cohort of patients with advanced CKD not receiving dialysis, finding similarly high total symptom scores and mean severity scores per symptom. [25] Murtagh et al. have previously reported symptom burden in people with stage 5 CKD not receiving KRT using the Memorial Symptom Assessment Scale-Short Form (MSAS-SF).[34] As in the current study, shortness of breath, drowsiness and lack of energy (fatigue) were among the five most prevalent symptoms, with itch being less prevalent in our study (55% compared to 74%). Symptoms are, however, multidimensional and, to be clinically useful, ought to be assessed

for severity, distress and frequency. Almutary et al., using the CKD Symptom Burden Index (which assesses 32 symptoms) showed that in CKD stages 4 and 5 fatigue (weakness or tiredness), bone or joint pain and decreased interest in sex were the more problematic physical symptoms.[36] Psychological symptoms (feeling sad, worried and depressed) were more burdensome for those not receiving dialysis. In our patient group, weakness (fatigue), pain and poor mobility were the most severe symptoms. Further comparisons cannot be made due to the different instruments used and that the IPOS-Renal does not assess symptom distress and frequency. Future analyses will track changes in overall and individual symptom scores over time.

Self-reported HRQoL and the extrapolated health state scores varied considerably among the cohort, in line with the principle of accepting the referral of patients with a wide range of function and performance capabilities and co-morbid statuses. Some individuals reported HRQoL scores above the reference population mean and a health state towards the high end of the scale, but most reported poor HRQoL. Health state utility values were below those previously reported in similar populations.[37 38] While this reflected the poor health status of the KSCp patients, it has to be considered that SF-6D is known to generate preference scores that are lower than those elicited using other instruments.[38 39] Still, the spread of HRQoL values reported in KSCp patients highlights the need for personalised care for people with advanced CKD, as those with different health circumstances may have different priorities and requirements.

The establishment of a kidney supportive care pathway in Brisbane and subsequent referrals to it in its first year underline the presence of a population requiring care pathways other than dialysis and transplantation. While previous work has shown promising effects associated with supportive care for people with advanced CKD [40], the outcomes for KSCp patients over time (including changes in symptom burden and HRQoL), as well as health economic analyses (including hospital utilisation), will be key to evaluating the impact of this program.

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FIGURE LEGENDS

Figure 1:

Schematic representation of patient flow into and out of the kidney supportive care program.

Figure 2:

Baseline characteristics of patients referred to the KSCp. **A**) CKD management pathway at referral; **B**) CKD stage; **C**) eGFR; **D**) Co-morbidity score; **E**) Function; **F**) Performance. Data expressed as median (interquartile range) (**C**, **D** and **F**) or median (range) (**E**). Abbreviations: AKPS, Australia-modified Karnofsky Performance Scale; CCI, Charlson Co-morbidity Index; CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate; HD, haemodialysis; PD, peritoneal dialysis; RUG-AGL, Resource Utilisation Groups – Activities of Daily Living Scale.

Figure 3:

A) Prevalence of individual patient-reported symptoms; **B**) Severity of individual patient-reported symptoms; **C**) Patient-reported physical and mental health-related quality of life and **D**) Health state of KSCp patients at initial visit. Data expressed as percentage of patients (A) and mean ± SD (B, C, D). Dashed line indicates the survey norm and dotted lines indicate mean scores. Abbreviation: IPOS, Integrated Palliative care Outcomes Scale; SF-36, 36-Item Short Form Health Survey. ****, $p < 0.0001$.