

A Multinational, Multicenter Study Mapping Models of Kidney Supportive Care Practice



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Introduction: Kidney supportive care (KSC) integrates kidney and palliative care to improve quality of life for people with chronic kidney disease (CKD). Despite increasing interest and global advocacy to integrate KSC into kidney care, evidence to guide optimal care delivery is limited.

Methods: This observational cross-sectional study used an online survey to describe current KSC models in Australia, Aotearoa-New Zealand, and the UK.

Results: Between April and December 2022, 114 nephrology units responded (response rate 67%), with 66% having a dedicated KSC service (UK, 74%; Australia, 58%; and New Zealand, 67%). Many different health care professionals worked in KSC services with diversity in clinical resources and activities between units and across countries. Overall, funding for KSC services was low, with a median full time equivalent (FTE) per unit (standardized per 100 people receiving hemodialysis [HD]) of 0.51 (interquartile range [IQR], 0.17–1.05) and 4 units provided a service without allocated funding. The scope of KSC service was wide-ranging and prioritized activities included symptom management, psychological support, complex future treatment planning and discussion, and care coordination. There were no significant differences between countries in terms of location of care provision, frequency of review, referral patterns or discharge rates; however, there was variation described within countries.

Conclusion: Models of KSC vary markedly across kidney units and between countries. Despite this variation, there was consistency in terms of clinical priorities which were person-centered and focused on physical and psychosocial well-being. Further research is required to evaluate the effectiveness of KSC provision, alongside improved funding methods to ensure sustainable and equitable KSC delivery.

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KEYWORDS: chronic kidney disease; kidney failure; kidney supportive care; models of care; palliative care; quality of life

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KSC is an approach to care that aims to improve the quality of life for people for whom kidney disease, either directly or indirectly, substantially impacts their well-being, treatment options, or access to care.^{1,2} KSC was developed in response to the complex physical and psychosocial needs of individuals that may not be fully met by traditional models of kidney care.^{3,4} Globally,

an increasing proportion of people with CKD are elderly and live with multiple long-term conditions, which are associated with worse morbidity and mortality outcomes.^{5–8} This population can often experience high symptom burden, functional limitations, and shortened life expectancy, whether or not they initiate kidney replacement therapy (KRT).² A comprehensive approach dedicated to addressing unmet needs by integrating palliative care practices into kidney care is essential.⁹ KSC aims to achieve this with an emphasis on shared decision-making, advance care planning, family and caregiver support, and early identification and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual

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problems.^{10,11} KSC is a key component of integrated care for people with CKD and can be delivered through the continuum of an individual's illness, concurrently with treatments for kidney disease and comorbidities, including KRT.^{1,12,13}

Despite cumulative recognition of the importance of KSC, clinicians' perceptions of it vary, and there is limited data describing the way this care is delivered, and standards of care have not yet been established.^{14,15} Variation in KSC provision, in terms of who is providing and receiving this care and how clinical services are applied in practice, may be expected between different populations and settings. However, marked variation can indicate a lack of evidence or consensus to guide clinical practice with the potential for distinct inequities in health care provision.¹⁶ In order to develop global and equitable KSC models that are integrated as part of comprehensive kidney care,¹⁷ research is required to understand current clinical practice to then evaluate the effectiveness of KSC models in different contexts. This study aimed to describe current models of KSC for adults across 3 countries, namely Australia, New Zealand, and the UK. The UK Conservative Kidney Management (CKM) practice patterns have been described previously, whereby CKM describes care for people with kidney failure that focuses predominantly on providing KSC to promote quality of life but does not include KRT.^{1,18} Nevertheless, to our knowledge, this is the first time KSC clinical data have been collected in Australia and New Zealand, and compared across countries.

METHODS

An observational, cross-sectional study design was used to describe models of KSC for adults. This was part of a larger project that also explored pharmacological symptom management in CKD (to be reported separately). Before study commencement, institutional ethics approval was obtained (HREC 2021/851, University of Sydney). An online survey capturing relevant clinical practice data was developed by kidney care clinicians working in Australia (4), New Zealand (1) and the UK (3), using the Research Electronic Data Capture application hosted by the University of Sydney (full survey available in the [Supplementary Material](#)). In March 2022, the survey was piloted with doctors and nurses from 4 KSC services. Written feedback was obtained to ensure readability, feasibility, and face-validity prior to the dissemination of the final survey.

The final survey was adapted according to participant country of practice and clinical relevance ([Supplementary Table S3](#)). Participants were asked

whether their unit had a KSC service, defined as "an individual or team dedicated to the management of symptoms and quality of life issues among those with advanced kidney disease." If units did have a KSC service, they were asked about the key features of their KSC model, which, for the purpose of this study, were defined as follows: (i) service structures (resources both clinical and financial, referral criteria and patient numbers, discharge rates, the clinical features of people receiving KSC, and location and modality of care provision), and (ii) service activities (perceived clinical roles, patient assessment tools, and other activities, including research).

Kidney units in Australia and New Zealand were identified via the Australia and New Zealand Dialysis and Transplant registry.¹⁹ UK National Health Service units were identified and invited by the UK Kidney Association. Information about the size of responding units was obtained from Australia and New Zealand Dialysis and Transplant registry and UK Kidney Association. Heads of units (or heads of KSC services, where known) were contacted directly via email with an invitation to complete the survey, including a center-specific survey link. Links could be shared between staff to permit contributions from multiple clinicians, with only 1 response accepted per unit. A participant information sheet was included at the beginning of the survey and consent was implied by completion of a survey. Recruitment and survey responses occurred between April and December 2022.

Questions employed categorical options, Likert scales, and free-text responses. Free-text responses were summarized descriptively. Numerical responses were analyzed descriptively, using the number of responses to each question as the denominator. This differed by question, as is indicated throughout the results. Numbers of individuals receiving CKM or KSC, KSC referrals, and FTE funding were standardized to 100 prevalent individuals receiving HD to enable comparison. Between-category comparisons were made using Fisher exact test or Kruskal-Wallis test (as appropriate for categorical or continuous dependent variables). *P*-values <0.05 were considered strong evidence of nonchance effects, with no adjustment made for multiple testing. To prevent repetition in the results, between-country differences can be assumed not to have reached the 0.05 level, unless stated otherwise. Data were analyzed using Stata 17.0 (StataCorp. College Station, TX).

RESULTS

A total of 171 units were invited to complete the survey, with 114 (67%) responses received (Australia, 58/

Table 1. Overview of kidney care units participating in the survey

Clinical features of service provision	Australia	New Zealand	United Kingdom	All countries
No. of all kidney units	104 ^a	12	70	193
No. of contacted kidney units (%)	89 (86)	12 (100)	70 (100)	171 (89)
No. of responding units (%)	58 (65)	7 (58)	49 (70)	114 (67)
No. of units with a KSC service (%)	26 (58)	4 (67)	34 (74)	64 (66)
All responding units				
Median no. CKM pts/unit (IQR)	50 (20–87)	25 (25–50)	55.5 (37.5–100)	50 (25–95)
Median no. of facility hemodialysis patients/unit (IQR)	96 (58–215)	129 (43–283)	349 (189–501)	190 (76–369)
Units with a dedicated KSC service				
No. of responding units	23	4	33	60
Median no. of CKM pts/unit (IQR)	70 (46–138)	25 (24–39)	64 (30–100)	62 (30–100)
Median no. of facility hemodialysis pts/unit (IQR)	198.5 (112–280)	280.5 (171–390)	360.5 (184–529)	276.5 (156.5–460.5)
Units without a KSC service				
No. of responding units	16	1	10	27
Median no. CKM pts/unit (IQR)	20 (5–55)	50 ^b	50 (41–64)	43 (15–55)
Median no. of facility hemodialysis pts/unit (IQR)	57 (35–120)	32 (21–43)	316.5 (190.5–417)	136 (43–225)

CKM, Conservative Kidney Management; IQR, interquartile range; KSC, kidney supportive care; No., number; pts, patients.

^aNote: There is not a 1:1 correspondence between nephrology services and hemodialysis units in Australia; 58 responses were received which represented 50 of 104 adult units listed by the Australia and New Zealand Dialysis and Transplant registry.

^bOnly 1 respondent from New Zealand that was without a KSC service provided number of CKM patients.

89 [65%]; New Zealand, 7/12 [58%]; and UK, 49/70 [70%]) (Table 1). There was no statistically significant difference in response rate between countries ($P = 0.92$). Most respondents were nephrologists (55/76 [72%]), followed by nurses (37/76 [49%]), palliative care physicians (4/76 [5%]), or other health care professionals (5/76 [7%]). Most survey responses (54/76 [71%]) were provided by a single clinician. Of the units 66% (64/97) reported having a KSC service (Australia, 26/45 [58%]; New Zealand, 4/6 [67%]; and UK, 34/46 [74%]).

KSC Models KSC Services Structures

Clinical Resources. Among 56 responses (Australia, 21; New Zealand, 4; and UK, 31), a wide variety of clinician groups were involved in the delivery of KSC across the 3 countries (Figure 1). Most KSC clinical teams included a nephrologist (48/56 [86%]), a dietitian (41/56 [73%]), a specialist KSC nurse (39/56 [70%]) and a social worker (36/56 [64%]), and 45% (25/56) included a palliative care physician. Of the KSC services, 25% (14/56) had nephrology trainees, 13% (7/56) had palliative care trainees, and only 1 unit (2%) had a geriatrician. Nephrologists were almost always part of the KSC team in the UK (30/31 [97%]), compared with 71% (15/21) and 75% (3/4) of Australian and New Zealand units, respectively ($P = 0.02$). Most Australian KSC teams included a social worker (18/21 [86%]) in comparison to only half of UK (16/31 [52%]) and New Zealand (2/4 [50%]) units ($P = 0.03$).

Among 54 responding units (Australia, 20; New Zealand, 4; and UK, 30), FTE for KSC provision (standardized/100 people receiving HD) was low, with a

median per-center FTE of 0.51 staff members (IQR, 0.17–1.05). The percentage of units with the following clinicians providing KSC without funding is listed: nephrologists, (45% units [19/43]); dietitians, (50% units [19/38]); social workers, (44% units [19/43]); and palliative care physicians, (33% units [8/24]). Of note, larger KSC teams (defined by median number of KSC encounters >500/yr) were more likely to have more dedicated KSC FTE funding (per 100 people receiving HD) (median, 0.95; IQR, 0.25–1.52; $n = 17$) compared with smaller KSC teams (median, 0.31; IQR, 0.17–0.62; $n = 29$) ($P < 0.01$).

Funding Sources. In Table 2, we illustrate the origin of financial resources for KSC services (50 responses: Australia, 18; New Zealand, 4; and UK, 28). Most funding came from nephrology departments (28/50 [56%]) or from the parent hospital (12/30 [40%]). Most UK and New Zealand units received KSC funding from only 1 source (25/28 [89%] and 3/4 [75%], respectively) whereas half of Australian units (9/18) received funding from 2 sources.

KSC Referrals. Among 55 responses (Australia, 21; New Zealand, 4; and UK, 30), most KSC services (39/55 [71%]) reported having referral criteria, but the specific referral indicators varied between units. Thirty-eight units described their referral criteria (or suitable reasons for referral) via free-text responses, which were subsequently categorized. The most common criteria for referral were for symptom management in dialysis and nondialysis individuals (19/38 [50%]) and referral for provision of CKM (16/38 [42%]). Other referral indicators included presence of advanced CKD (14/38 [37%]), requirement for discussion of or planning for dialysis withdrawal (14/38 [37%]), requirement for

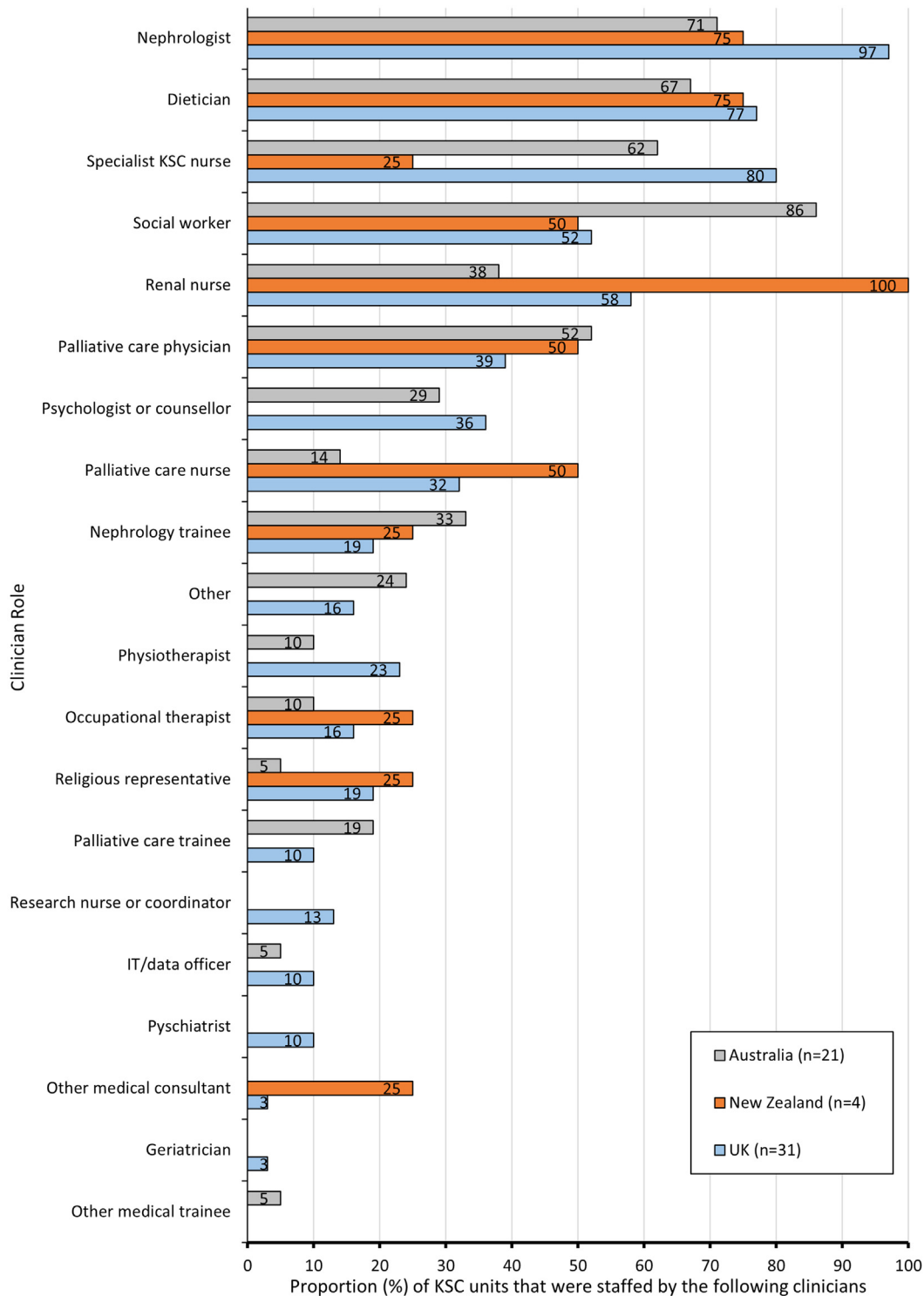


Figure 1. Clinicians involved in KSC provision across countries. Responses from 56 (88%) of 64 units with a KSC service that responded to this question. IT, information technology; KSC, kidney supportive care; UK, United Kingdom.

support in cases of frailty, deterioration, or life-limiting comorbidities (10/38 [26%]), provision of end-of-life care (9/39 [23%]), advance care planning (9/39 [23%]), KRT or CKM decision making (9/39 [23%]), and psychosocial or carer support (5/38 [13%]). Most units reported accepting referrals for any individual with advanced CKD or kidney failure, regardless of KRT

modality. However, in a minority of units, certain groups were viewed as not eligible for referral; these are individuals with predialysis CKD (7/52 [13%]), those receiving dialysis (5/52 [10%]), and transplant recipients (5/52 [10%]).

Almost all units accepted KSC referrals from nephrologists or nephrology trainees (36/37 [97%]),

Table 2. Funding sources for kidney supportive care services

Funding sources	Australia	New Zealand	United Kingdom	All
No. of responding units	18	4	28	50
No. of units (%) receiving funding from:				
Parent hospital	4 (22)	0	9 (32)	13 (26)
Nephrology department	8 (44)	3 (75)	17 (61)	28 (56)
Palliative care department	1 (6)	0	0	1 (2)
Both nephrology and palliative care departments	1 (6)	1 (25)	2 (7)	4 (8)
Primary care	0	0	1 (4)	1 (2)
Local health department	4 (22)			
Medicare claims (private funding)	2 (11)			
Direct from the state health department	5 (28)			
Clinical trials	1 (6)	0	0	1 (2)

No., number.

followed by referrals from nurse specialists (23/37 [62%]), palliative care physicians or trainees (21/37 [57%]), other physicians (21/37 [57%]), nursing staff (20/37 [54%]), and general practitioners (18/37 [49%]). Of the responding units with a KSC service, those in Australia and the UK received an estimated median of 60 new referrals annually (Australia: IQR, 48–116 [$n = 20$]; UK: IQR, 25–130 [$n = 26$]), whereas units in New Zealand received a median of 25 referrals annually (IQR, 6–72; $n = 3$). When standardized per 100 people receiving HD, the median number of annual referrals was significantly higher in Australia (30; IQR, 22–58; $n = 20$) than in the UK (13; IQR, 10–31; $n = 26$) or New Zealand (9; IQR, 9.0–14.5; $n = 3$) ($P < 0.01$).

Discharges. Most KSC services cared for individuals until the end of their lives; with few discharges back to other care providers (42 responses: Australia, 17; New Zealand, 2; and UK, 23). Of the KSC services, 88% (37/42) discharged an estimated 10% or fewer individuals to the care of general practitioners, and 93% (40/43) discharged an estimated 10% or fewer individuals back to the care of their nephrologists, with almost two-thirds (28/43, 65%) retaining all patients.

Patient Numbers. KSC services in Australia and the UK reviewed a similar number of people per year: median of 275 persons (IQR, 180–572; $n = 20$) and median of 240 persons (IQR, 131–450; $n = 28$) respectively, compared to a median of 25 persons per year (IQR, 12–288) by units with a KSC service in New Zealand ($n = 3$) (Supplementary Table S1). After adjusting these values to estimated center size, the number seen per year was greater in Australia (median of 170 patients/100 people receiving HD [IQR, 70–370]), compared to 95 [IQR, 22–183] and 19 [IQR, 9–58] in the UK and New Zealand, respectively ($P = 0.02$). Similarly, KSC services in Australian units conducted a greater total number of reviews per year compared to

UK and New Zealand units: median of 552 reviews (IQR, 300–1500; $n = 19$) compared to 360 reviews per annum (IQR, 240–600; $n = 25$) and 156 reviews per year (IQR, 12–360, $n = 3$), respectively.

Patient Characteristics. Individuals cared for by KSC services tended to be elderly (estimated 46% aged >80 years), with a majority receiving CKM (Australia, 50%; New Zealand, 95%; and UK, 60%) (Supplementary Table S2). Few individuals with a kidney transplant were reviewed as part of KSC services (median of 2% of all persons reviewed).

Responding units estimated that three-quarters of CKM individuals seen by their KSC service had an advanced care plan (median of 73%; IQR, 30–90; $n = 37$), compared with a median of only 40% of dialysis recipients (IQR, 15–60; $n = 33$), 12% of predialysis individuals (IQR, 0–50), and 4% of kidney transplant recipients (IQR, 0–35; $n = 28$).

Location and Modality of KSC Service Delivery. Among 47 responses (Australia, 19; UK, 25; and New Zealand, 3), the majority of units provided KSC services in outpatient clinics (43/47 [91%]) and via telehealth (43/47 [91%]), inpatient reviews (36/47 [77%]), home visits (33/47 [70%]), and reviews at dialysis units (32/47 [68%]). Forty-five percent provided a service at residential care or nursing home facilities (21/47). Over two-thirds (37/54 [69%]) reported regular dedicated KSC outpatient clinics. KSC clinics most frequently occurred on a weekly basis (14/37 [38%]), followed by twice-weekly (4/37 [11%]) or twice-monthly (4/37 [11%]).

The proportion of KSC services delivered at each location, as determined by the proportion of total patient encounters per year, is shown in Figure 2. Units in New Zealand delivered a greater proportion of their KSC service via clinics (median of 83%; IQR, 69–100; $n = 3$) compared with units in Australia (median of 19%; IQR, 17–43; $n = 19$) and in the UK, (median of 33%; IQR, 10–46; $n = 21$) ($P < 0.01$). In contrast, Australian units delivered a greater proportion of their care in the inpatient setting (median, 21%; IQR, 10–25; $n = 18$) compared with units in New Zealand (median of 8%; $n = 1$) and in the UK (median of 9%, IQR, 7–14; $n = 17$) ($P < 0.01$). Units in the UK had the greatest proportion of KSC home visits (median of 19%; IQR, 10–30; $n = 21$) compared to units in Australia (median of 8%, IQR, 2–17; $n = 11$) and New Zealand (median of 8%; $n = 1$) ($P < 0.05$).

KSC Activities

KSC Clinical Roles. Respondents described a variety of clinical roles for KSC services (Figure 3). Overall, among the 59 responding units (Australia, 22; New Zealand, 4; and UK, 33), the 5 activities that were most commonly

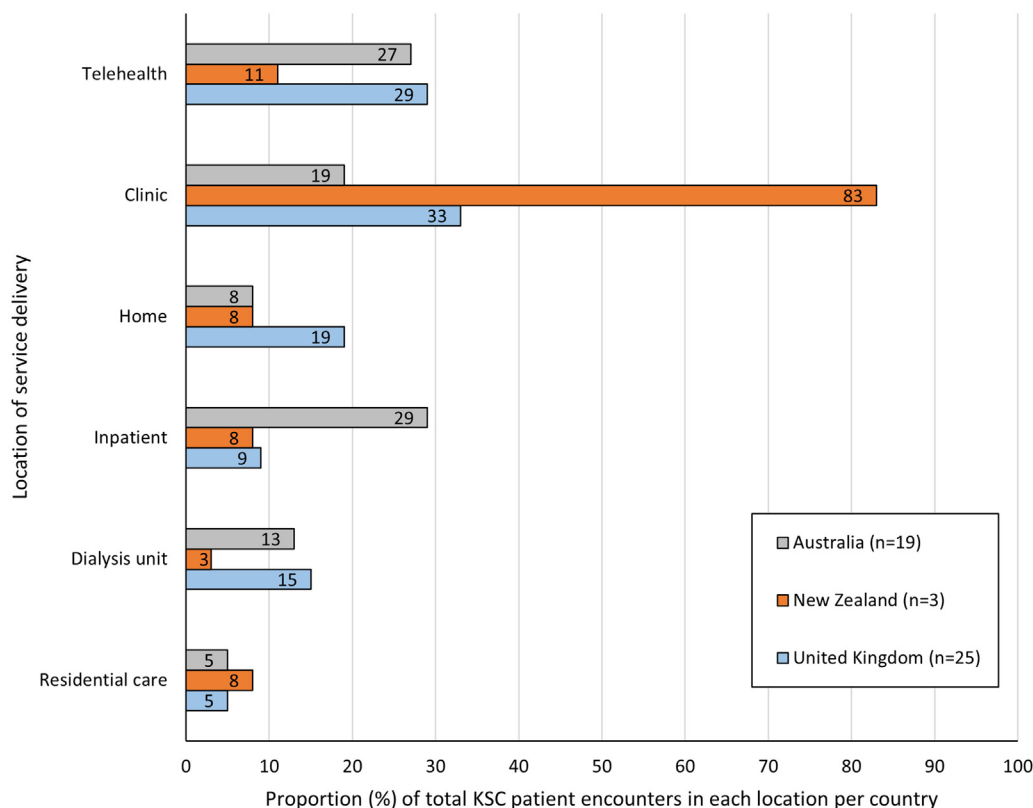


Figure 2. Kidney supportive care patient encounters by location. Proportions include only units who deliver a service in that location. Number of units (out of 47 responding units): telehealth, 33; residential care, 21; dialysis unit, 32; clinic, 43; inpatient, 36; and home, 33. KSC, kidney supportive care.

described as primary roles were introduction to KSC (81%), symptom management (80%), introduction to palliative care (73%), advance care planning (71%), and care coordination with general practitioners and community services (70%). In addition, many respondents viewed the management of chronic complications of advanced kidney disease as primary roles of their KSC service, including anemia and metabolic bone disease management (44%) and the provision of interventions to slow the progression of CKD (44%). Interestingly, KSC services with nephrologists were more likely to consider management of the metabolic/bone-mineral complications of CKD to be a primary role of KSC ($P = 0.029$). There was also some evidence that services staffed with nephrologists or specialist KSC nurses were more likely to consider interventions to slow progression of CKD to be a primary role ($P = 0.056$ and $P = 0.038$, respectively). Conversely, units staffed with palliative care physicians were more likely to consider end-of-life care as a primary role compared to those without palliative care physicians ($P < 0.01$).

Differences in responses of the perceived clinical activities of KSC were found between countries. In Australia, a minority of responding units (5/22 [23%]) perceived initiating interventions to slow CKD

progression to be a primary role of KSC compared with more than half of responding units across New Zealand (3/4 [75%]) and the UK (18/33 [55%]) ($P = 0.01$). Similarly, only 14% of Australian units (3/22) regarded the management of CKD complications as a primary role, compared with most units in New Zealand (3/4 [75%]) and the UK (20/33 [61%]) ($P < 0.01$).

Use of Standardized Assessments. There was considerable heterogeneity regarding the use of patient-reported and carer-reported measures, and measures of nutrition, function, and frailty tools by KSC services (48 responses: Australia, 17; New Zealand, 4; and UK, 27) (Table 3). Overall, a majority (72%) of responding units reported routine use of patient-reported outcome measures and patient-reported experience measures, most commonly the integrated palliative care outcome scale-renal (58% [28/48]), the palliative outcome scale symptom-renal (21% [10/48]), and the UK Kidney Association patient experience survey (19% [9/48]). A substantial minority of units routinely used the Euro-Qol-5-dimension questionnaire (31% [15/48]) (assesses quality of life); and the Rockwood frailty index (42% [20/48]). Free-text responses commonly described the use of the screening tools at every clinic visit or at 3 to 6-month intervals, which is likely to represent an equivalent period.

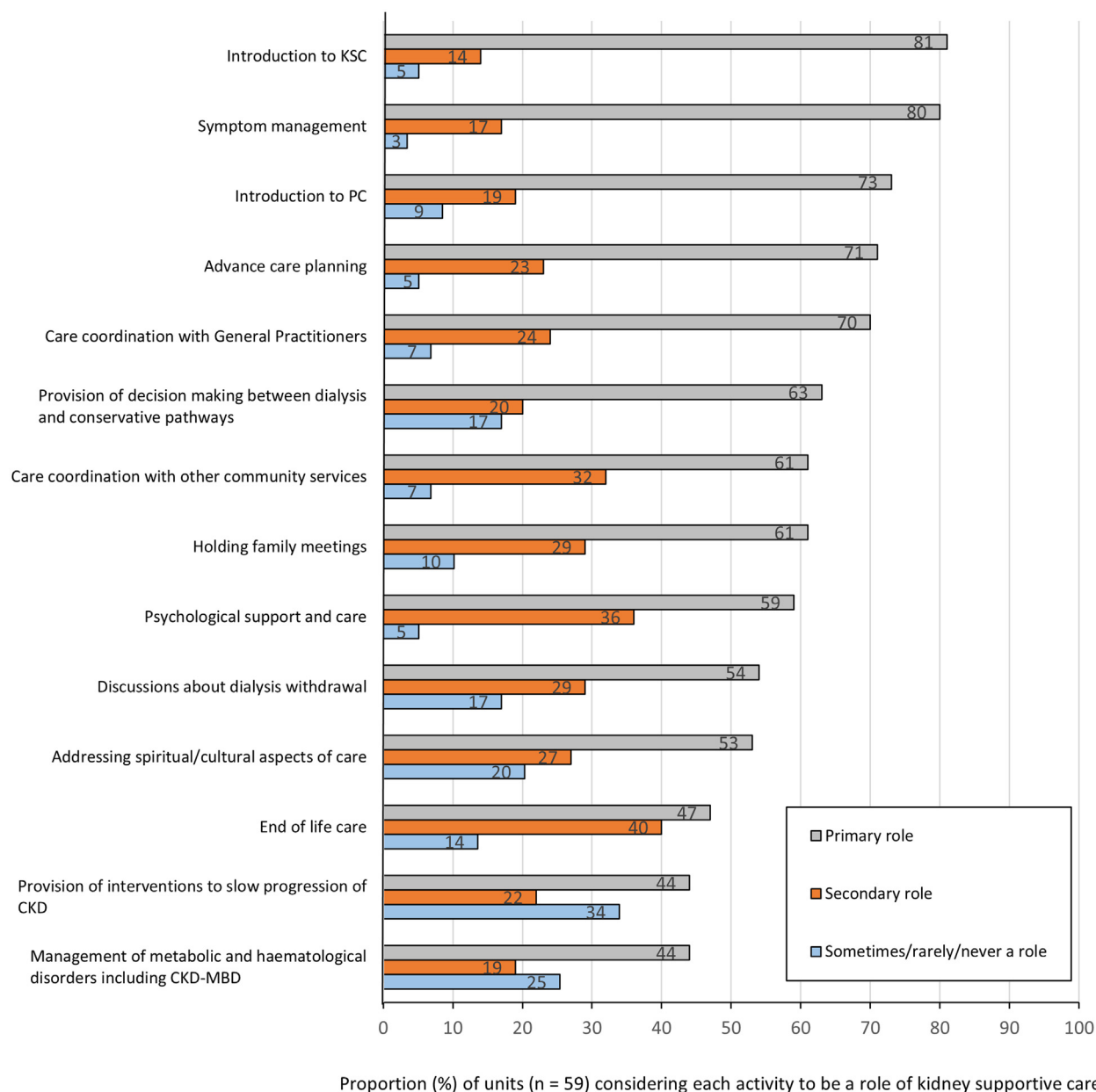


Figure 3. Perceived scope of kidney supportive care. CKD, chronic kidney disease; CKD MBD, chronic kidney disease metabolic bone disease; KSC, kidney supportive care; PC, palliative care. Primary role: a core activity led by the KSC. Secondary role: an activity whose primary responsibility typically remains with other health care providers or support services but to which the KSC service routinely contributes.

Other KSC Activities. Regarding other clinical KSC activities, 59% (30/51) of responding units (Australia, 18; New Zealand, 4; and UK, 29) reported conducting regular multidisciplinary meetings (defined as scheduled case management meetings without the individual present). Of the units, 48% (25/52) (Australia, 18; New Zealand, 4; and UK, 30) reported involvement in clinical research activities in the last 12 months, which included qualitative research (14/25 [56%]), retrospective observational and prospective interventional studies (including randomized studies; 9/25 each [36%]), and prospective observational studies

(8/25 [32%]). Free-text responses were used to capture additional activities undertaken by the KSC team. Responses included providing KSC advice to other clinicians; educational activities for peers and colleagues, patients, and carers; offering bereavement and caregiver support; assessing frailty; and providing social service guidance for patients and caregivers regarding social and financial support.

Units Without a Dedicated KSC Service. Of the responding units, 34% (33/97) (Australia, 19; New Zealand, 2; and UK, 12) did not report having a

Table 3. Routine use of patient and carer reported measures, and measures of nutrition, function, and frailty

Measures	Australia, n (%)	New Zealand, n (%)	United Kingdom, n (%)	Total	P-value
Responding units	17	4	27	48	
Symptom measures					
IPOS-renal	15 (88)	3 (75)	10 (37)	28 (58)	<0.01
POS-S	2 (12)	1 (25)	7 (26)	10 (21)	0.48
Other	0 (0)	0 (0)	3 (11.1)	3 (6)	0.44
HRQOL measures					
EQ5D	9 (53)	0 (0)	6 (22)	15 (31)	0.04
KDQOL-36	2 (12)	0 (0)	0 (0)	2 (4)	0.28
KDQOL-SF	1 (6)	0 (0)	0 (0)	1 (2)	0.44
SF-36	1 (6)	1 (25)	1 (4)	3 (6)	0.27
Other	0 (0)	1 (25)	2 (7)	3 (6)	0.17
Patient reported experience measures					
UKKA patient experience survey	1 (6)	0 (0)	9 (33)	10 (21)	0.06
Other patient experience survey	3 (18)	0 (0)	6 (22)	9 (19)	0.87
Carer experience survey	5 (29)	0 (0)	3 (11)	8 (17)	0.27
Function and frailty measures					
Karnofsky performance scale	11 (65)	0 (0)	5 (19)	16 (33)	<0.01
Rockwood clinical frailty scale	4 (23)	0 (0)	16 (59)	20 (42)	0.01
Other	0 (0)	0 (0)	3 (11)	3 (6)	0.44
Nutrition measures					
SGA	7 (41)	3 (75)	5 (19)	15 (31)	0.03
Short patient generated-SGA	5 (29)	0 (0)	1 (34)	6 (13)	0.04
Full patient generated-SGA	2 (12)	0 (0)	0 (0)	2 (4)	0.28
Other	0 (0)	0 (0)	3 (11)	3 (6)	0.44

EQ5D, EuroQOL 5 dimensions; HRQOL, Health related quality of life; IPOS-renal, Integrated palliative outcome scale-renal; KDQOL-36, Kidney disease quality of life-36; KDQOL-SF, Kidney disease quality of life-short form; POS-S, Palliative care outcome scale-symptom, PREMs, Patient reported experience measures; SF-36, Short form-36; SGA, Subjective global assessment; UKKA, United Kingdom kidney association.

dedicated KSC service. KSC activities in units without a dedicated service were delivered by a variety of clinicians, including nephrologists as part of their general nephrology care (30/33 units [91%]), community palliative care staff (24/33 [73%]), unit nurses (17/33 [52%]), general practitioners (17/33 [52%]), and specialist palliative care clinicians (15/33 [45%]). Units without a dedicated KSC service tended to care for fewer people receiving CKM (median of 43; IQR, 15–55; $n = 26$) compared with units with a dedicated KSC team (median of 62; IQR, 30–100; $n = 60$; $P < 0.01$). However, when adjusted per 100 people receiving HD, there was no difference in the number of people reported as receiving CKM by the presence or absence of a KSC team. There were similarly low discharge rates in units with and without KSC services. Slightly less than half ($n = 11/24$ [46%]) of units without a dedicated KSC service did not discharge any CKM recipients from

Table 4. Reasons for and against developing kidney supportive care services in units where kidney supportive care was not already present

Quotations in favor of developing KSC	Quotations against developing KSC
"Dedicating staff to this area of care would enhance patient experience and improve the timeliness of decision making." Role unknown	"Not enough demand for this." Nephrologist
"Kidney supportive care requires multi-faceted input by multi professional team. This is not factored in at the moment." Nephrologist	"I think nephrologists are generally pretty good at looking after the whole patient. I strongly believe that most dialysis is palliative care unless the patients are on the active transplant list." Role unknown
"North West Queensland Indigenous populations who are usually medically complex with high symptom burden need specific cultural attention to manage on CKD pathways." Nephrologist	"I don't think it's necessary" Nephrologist
"Supportive care is provided on an ad hoc basis and is ... quite a fragmented service." Nurse	"It's a small private unit. Physicians are treating their patients individually." Nephrologist

CKD, chronic kidney disease; KSC, kidney supportive care.

their service to their general practitioners and the majority (19/24 [79%]) discharged 10% or fewer individuals.

Of 31 responding units who did not have a dedicated KSC team, 22 (71%) were interested in developing a service. Free-text responses that described reasons for needing KSC services developed included a clear demand due to a growing number of individuals who could benefit from such care; a perception that KSC would provide a better service and care coordination with dedicated staffing and resourcing, and the opportunity to provide more culturally adapted care (Table 4). Of the 9 units not interested in creating a dedicated KSC service, reasons included a perceived lack of demand (especially in small and/or private units); established input from palliative care which was meeting KSC needs; and a belief that nephrologists could provide KSC through existing CKD clinics (Table 4).

DISCUSSION

This study has described the service structures and activities forming KSC models of care across Australia, New Zealand, and the UK. In addition, it has highlighted the variation in clinical scope within and between these countries. Over a third of units did not have dedicated KSC services, and those that often adopted different models and offered different care elements. Despite this variation, it was evident that all KSC services had person-centered clinical priorities, focusing on symptom management, complex future

treatment planning and discussion, and psychosocial support for individuals and families. These results are consistent with the key areas of KSC proposed by the “Kidney Disease Improving Global Outcomes” Controversies Conference on Supportive Care in Chronic Kidney Disease in 2015.¹

Two main models of KSC were identified as follows: some KSC services reported integrating KSC into preexisting kidney care services (as an integrated clinic, for instance) resulting in kidney clinicians providing kidney care and KSC simultaneously; whereas other units had a separate KSC service with separate, multidisciplinary clinics. Multiple factors are likely to contribute to the variation in KSC models of care. This may be partly explained by differences in sources of funding across locations. Smaller or privately funded kidney units may have been less able to fund or develop a KSC service, and other institutions could be relying on unfunded work performed by clinicians in addition to their other clinical roles. Apart from differential funding, other factors underpinning KSC models may include the clinical skill and capacity of local teams, and clinician or patient preferences.¹⁶ The unique experiences and attitudes of kidney clinicians at each unit are likely to influence the prioritization of developing a KSC model of care, consistent with a previous study describing CKM in the UK.¹⁸

This study also provided insights into CKM across the 3 countries, suggesting higher levels of CKM provision in Australia and New Zealand than in the UK. However, it is unclear whether reporting centers comparably defined and quantified conservatively managed individuals. Further work to reliably capture the care of all individuals receiving specialist kidney care is required. Some renal registries have begun to include people with CKD stage 4/5 as well as those receiving KRT, but this is not yet widespread, and differentiating those receiving CKM from others who have not yet initiated a plan to start KRT is difficult.²⁰

The ideal KSC model is currently unknown and is unlikely to take 1 form. Future research assessing patient experience and outcomes with different KSC models, for instance in the form of ethical randomized controlled trials, would help determine evidence-based recommendations for KSC delivery that are sensitive to the resources, funding, and needs of individual kidney units and their patients. What was consistently described in this study was the commitment to continue to provide individualized care for people in KSC services throughout the continuum of their illness until death. KSC was first described as end-of-life care for kidney patients, including pain and symptom management, hospice care, and dialysis cessation,^{21,22}

and now appears to be far more dynamic and perceived more broadly, is accessible for diverse groups, including those receiving KRT, and involves multiple aspects of care, including education, research, geriatric care, and community health care integration. Although, half of respondents indicated that spiritual and/or cultural care was a priority for their unit, only 14% of units had a religious representative as a member of their team. The role of KSC services in providing or coordinating access to spiritual care is likely to vary widely, and further research understanding its role and benefit in KSC is warranted.

The development of KSC services requires adequate funding to provide holistic, person-centered and multidisciplinary care. At present, KSC is developing variably and is potentially restricted by other kidney health priorities or funding, which risks inadequate care provision and the sustainability of some services. Further work to ensure global consensus of priority clinical and research outcomes with systems of embedded data collection is needed, with a particular focus on patient and caregiver well-being. For kidney units that do not currently have a dedicated KSC service, initial steps for development could include an assessment of unmet palliative care needs, such as symptom management, quality of life, shared decision making, advanced care planning, and spiritual aspects of care. This is consistent with the call for improved processes of information on KSC metrics, prognosis and well-being for kidney patients described by the International Society of Nephrology global consensus publication in 2020.¹³ Further, as part of a 5 to 10 year strategy to improve safe, sustainable and equitable access to kidney care worldwide, the International Society of Nephrology has recently published consensus definitions of KSC and CKM and developed a “Kidney Supportive Care and CKM Curriculum” to educate health care professionals on the principles and provision of CKM and KSC.^{1,23} National KSC guidelines and service development documents have also been produced in Australia and South Africa.^{24,25} Units wishing to develop a KSC service would benefit from engagement with these materials. In addition, units would also benefit from research in the training and qualification of KSC staff and communication between KSC and broader nephrology services and social or cultural support services. Future work that collaborates across services and countries to measure patient experiences of KSC interventions such as symptom burden, quality of life, decision-making processes, clinician and caregiver stress, and care coordination could further the systematic evaluation of KSC services and foster improvements in integration and delivery of this important element of kidney care.

Strengths and Limitations

This is the first study to explore and compare KSC activity and resourcing in Australia, New Zealand, and the UK and achieved a good response rate. However, survey responses were self-reported, sometimes incomplete and estimated by individual clinicians willing to complete a questionnaire; therefore, findings may differ from nonresponding units. New Zealand units had a small sample size, which limits interpretation of KSC activity and services across the country. A vital component of KSC is spiritual care; however, insufficient data were collected to describe its role within KSC. This represents an important area of future work. In addition, an essential component of KSC is patient experience, which was not captured by this survey and is required for future studies. The relationship between mainstream specialist palliative care services and KSC was not explored. This is an important future research question because this may help explain the variation found in KSC services. Finally, this survey only captures data in 3 countries that are known to have established KSC services. To understand global practices, this survey could be utilized in other countries and we would welcome collaboration in this endeavor. Countries interested in conducting a similar study should contact the corresponding author.

Conclusion

This study shows that KSC activity in Australia, New Zealand, and the UK is widely and variably applied and resourced and despite this, has maintained clinical priorities of improving patient experiences of health, well-being, and quality of life. Global consensus guidelines detailing KSC clinical activities and outcome measurement would aid development of more consistent methods of care provision and data collection. Future work must also highlight the benefit of KSC for patients, clinicians, and hospital services to enable ongoing development of equitable and sustainable KSC provision.

DISCLOSURE

All the authors declared no competing interests.

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DATA AVAILABILITY STATEMENT

Deidentified data are available on request. Proposals should be directed to Brendan Smyth (brendan.smyth@sydney.edu.au) and will be reviewed by the authors. Requests to access data to undertake hypothesis-driven research will not be unreasonably withheld. Data requesters will need to sign a data access agreement and to confirm that data will only be used for the agreed purpose for which access was granted.

SUPPLEMENTARY MATERIAL

[Supplementary File \(PDF\)](#)

Table S1. Number of patients reviewed by units with dedicated kidney supportive care services.

Table S2. Demographics of kidney supportive care patients, by median proportion.

Table S3. Differences between Australian, New Zealand and United Kingdom versions of the survey.

Copy of RedCap Survey of Kidney Supportive Practices.

CROSS Checklist.

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