Title: Renal supportive care, palliative care and end of life care: Perceptions of similarities, differences and challenges across Australia and New Zealand.

Short running title: Palliative and renal supportive care views

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Abstract

Renal supportive care (RSC) is an approach integrating nephrology and palliative care to improve quality of life for people with chronic kidney disease (CKD). RSC practice varies across services; therefore, understanding clinicians' perspectives is important to the evolution and definition of RSC.

Aim:

To understand renal clinicians' views and experiences of RSC, palliative care and end-of-life care.

Method:

A cross-sectional online survey was undertaken across Australia and New Zealand between February and May 2018. Participants were asked about end-of-life care, RSC, palliative care and an ideal model of RSC.

Results:

Estimated response rate 13% included 382 clinicians; doctors (32%), nurses (68%); of whom 84% access specialist palliative care and 59% RSC. A lack of agreed treatment goals (86%) and late or rushed treatment decision making (85%) was associated with challenging end-of-life experiences.

Variable concepts of RSC were described, with RSC being considered the same as: usual care for all CKD patients (40%), conservative (30%) or palliative care (22%). The term RSC was generally distinct from (77%) and more acceptable than palliative care (80%) with preferential RSC referral for symptoms (86% vs 69%, $p < 0.01$) and complex treatment decision making (82% vs 58%, $p < 0.01$). Aspirations for RSC included improving symptoms and quality of life (89%), with an ideal model comprising: symptom management (98%), improved nephrology and community service integration (96%) and clinician education (94%).

Conclusions:

This study revealed challenges for renal clinicians in providing end-of-life care and variation of views and experiences of RSC. It represents opportunities to develop RSC aligned with clinician priorities to improve patient care.

Key Words: Renal Supportive Care, Palliative Care, End-of-life care
Clinicians, Service Development

Background

Renal supportive care (RSC), also known as Kidney Supportive Care or Renal Palliative Care is a clinical approach aiming to improve quality of life for patients with advanced chronic kidney disease (CKD) through integrating palliative care principles and expertise within existing renal services. RSC has developed in response to the significant needs of nephrology patients, which includes symptom burden, functional limitations, comorbidities, polypharmacy and associated reduced prognosis and caregiver burden ⁽¹⁻³⁾. Furthermore, dialysis for end stage kidney disease does not fully restore health and survival outcomes relative to the general population without advanced CKD. Given this context, current renal care for people having dialysis or managed without dialysis (conservative care) has been described as limited when addressing complex needs of elderly, frail, multi-morbid patients living with advanced illness ⁽⁴⁾.

The role of palliative care in renal medicine has long been advocated. In 2003, Poppel and colleagues detailed the challenges facing renal clinicians when caring for patients who cease dialysis - describing the ethical, physical and emotional issues raised and the potential for palliative care interventions to ease distress and improve quality of life ⁽⁵⁾. Since this time, the concept of RSC has been proposed, defined and further developed. In 2007, RSC was described as a dynamic and emerging concept involving the key attributes of: availability from diagnosis to death with discussions of prognosis and impact of disease; interdisciplinary approach with restorative care (maximising disease control and quality of life); family and carer support; and, effective communication to ensure informed choice and treatment

decision-making ⁽⁶⁾. More recently, key activities of RSC have been described as: shared decision making, maximising quality of life, symptom control, physical function and psychological, social and family support ^(7,8).

Despite the growing literature in this field, it is unclear how renal supportive care is understood in clinical practice in Australia and New Zealand and the perceptions of similarities, differences and relationships with palliative care. In Australia, a position statement in 2013 described the variation in RSC models of care, with RSC defined as the integration of renal and palliative medicine using the skills of both disciplines to ensure optimum nephrology care while adding a focus on symptom control, holistic physical and spiritual care and, when appropriate, facilitation of a good death ⁽⁹⁾. In 2015, a landmark multi-national “Kidney Disease Improving Global Outcomes” (KDIGO) consensus publication on renal supportive care defined the term RSC as separate to comprehensive conservative care (comprehensive care for patients which does not include dialysis or transplantation) and synonymous with palliative care “... an approach that improves health related quality of life of patients and their families facing the problem(s) associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems physical, psychosocial and spiritual” ^(1,10). Whether these descriptions have translated into practical aspects of care for renal clinicians in Australia and New Zealand is unknown. This study aimed to understand renal clinicians’ experiences and perspectives of renal supportive care,

palliative care and end-of-life care for patients with advanced renal disease across Australia and New Zealand.

Methodology

A survey seeking views on renal supportive care, palliative care and end-of-life care was developed based upon the palliative care referral questionnaire ⁽¹¹⁾ and adapted to include additional questions emerging from qualitative data exploring renal clinicians' views of palliative care and RSC conducted in Victoria, Australia. The survey was then piloted using 8 nephrologists, 3 advanced trainees and 10 renal nursing staff from a range of healthcare services, and experiences (peritoneal dialysis, haemodialysis, management, clinical nurse educators, and nurse practitioners). During the piloting process, written and verbal feedback was provided to investigators and language modifications were made iteratively to ensure clarity of intended message across both medical and nursing staff, readability and face validity prior to broader dissemination. The final survey is detailed in Appendix 1.

From February to May 2018, participants were recruited via a link in the main professional bodies; the Australian and New Zealand Society of Nephrology (ANZSN) and Renal Society of Australia (RSA) using online newsletters distributed twice 1 month apart. Subsequent phone contact was made to each participating renal unit from the ANZDATA registry ⁽¹²⁾ with emails including the survey link then distributed internally within each unit. A confidential online survey tool (Lime survey) was used and content included the following areas; clinician demographics (gender, years of practice, site of practice (state, region eg.

metropolitan or remote), access to services (RSC, specialist palliative care), definitions and referral considerations to RSC and specialist palliative care, issues raised in end-of-life care and views on an ideal model of RSC.

Anonymous data were collected and exported to excel for analysis. Statistical analysis was performed using SPSS and STATA version 15.1 software. Pearson Chi-square test was used for between group comparisons. Multiple ordered logistic regression models were fitted to examine any potential factors associated with referral practices. These models were adjusted for; gender, experience, role, state, site of practice. Multi-collinearity was examined through the variance inflation factor for each covariate. The study was approved by the institutional research and ethics committee (LNR/16/SVHM/116).

Results

Of the 442 clinicians who responded to the survey, 382 identified themselves as renal medical or nursing staff and completed the survey and therefore were included in the analysis, estimated response rate 13%. The group excluded (who specified their professional role) comprised, allied health professionals (24), dialysis technicians or health assistants (5), researchers (5), pharmacists (2) and general physicians (2). Most respondents described access to specialist palliative care (84%) and fewer with access to formal RSC services (59%), defined as a person or persons employed to provide RSC [Table 1].

End-of-life care experiences

End-of-life care, (defined as the final 12 months of life) was reported to be most challenging when there was lack of agreed treatment goals by the patient, family or treating team (86%), late or rushed treatment decision making by the family, patient or treating team (85%) and conversations about end-of-life were held too late (72%). Compared with doctors, nurses described less confidence with difficult conversations about end-of-life (31% vs 16%, $p<0.01$), less clarity regarding when to refer to specialist palliative care (61% vs 23%, $p<0.01$) and fewer psychological supports when caring for patients at end-of-life (53% vs 38%, $p<0.01$) (Figure 1).

Renal Supportive Care views

Most respondents were confident that they understood the concept of RSC (93%) and many clinicians (65%) used the term “renal supportive care” in clinical practice. Those who did not use the term “renal supportive care” were more likely to be nurses (26% vs 15%, $p<0.05$) and were less likely to have access to RSC services (16% vs 34%, $p<0.01$). There were no significant differences in views of RSC according to location, experience, or access to RSC services. The majority of clinicians described RSC as including; a focus on symptoms and quality of life (89%), active medical treatments (72%) and extending beyond care of dying patients (last weeks of life) (85%) (Figure 2).

Most clinicians perceived RSC as different to palliative care (77%) and the term was more acceptable for patients (80%). Despite pragmatic differences in health systems, these results were not significantly different across location (metropolitan vs regional) or across states or

territories. Few respondents (5%) viewed referral to RSC as involving a complete transfer of care to a separate service where they (clinicians) were no longer involved in the patient's care. Most (79%) agreed that it would be useful to have more defined triggers to refer to RSC, and some participants (55%) thought renal clinicians were themselves skilled in aspects of RSC provision.

There was also variation in experiences of certain RSC functions and activities (Figure 2). Close to equivalent responses both agreeing (40%) and disagreeing (46%) to the statement that RSC is the same as usual care for all CKD patients, and a significant minority of clinicians who viewed RSC as the same as conservative care (30%) or palliative care (22%).

Palliative Care views

Specialist palliative care services were viewed as facilitating improved patient quality of life (97%), and symptom relief (86%) (Figure 3). Again, there was variation in perceived roles and activities of specialist palliative care with equivalent groups agreeing and disagreeing to the statement "specialist palliative care is care when active CKD treatments have stopped." Significant subgroups of respondents viewed palliative care as only for dying patients in the last weeks of life (26%) and the same as renal supportive care (17%). Many (55%) participants agreed that all patients with advanced chronic kidney disease could benefit from specialist palliative care and 67% agreed that earlier referral would be beneficial.

Clinicians reported reluctance from patients and families or carers to hear about specialist palliative care was a barrier to palliative care referral and integration (45%), and 17% reported losing contact with the patient following referral.

Referral Patterns

Renal clinicians sampled would preferentially refer patients to RSC over specialist palliative care for symptom management, complex treatment decision making, clinical or functional decline with limited prognosis, but not when the patient was in the last weeks of life (Table 2).

In multivariate regression models, clinicians were significantly more likely to refer for symptom management to RSC if it was viewed as more acceptable than specialist palliative care (OR: 2.39 95% CI: 1.16, 4.9). Nurses were more likely to consider RSC referral than doctors for patients with; limited prognosis (OR: 4.65 95% CI: 1.60, 13.55), requests to stop dialysis (OR: 4.35 95% CI: 1.27, 14.88), inability to continue dialysis (OR: 3.98 95% CI: 1.33, 11.97), assistance with complex treatment decision making (OR: 2.77 95% CI: 1.25, 6.15) or clinical deterioration (OR: 2.69 95% CI: 1.01, 7.17). Other factors including gender, years of clinical experience and practice location did not significantly predict referral patterns.

Renal Supportive Care Models

Respondents detailed essential elements of the ideal model of RSC described in Figure 4. These priorities did not differ with access to RSC services, location or role (doctor or nurse).

Discussion

This study provided novel insights of the experiences of renal clinicians in Australia and New Zealand when caring for renal patients near end-of-life, and highlights areas of both consensus and variation of views and experiences. Based on these findings, this study has revealed a series of potential opportunities to facilitate service development and health care education to improve patient care. The authors have summarised areas of priority to develop renal supportive care in Table 3 and extended these results to include potential activities and measurable outcomes which could be adapted to service and context.

With respect to difficult end-of-life care experiences, there was uniformity across clinicians who identified late and rushed decision making or a lack of unity of treatment goals between patients, clinicians and families as most challenging. Timely recognition and discussions including about end-of-life care for deteriorating patients is a critical part of nephrology care, and in practice this is complex, frequently difficult and highly emotive ⁽¹³⁾. A recent qualitative study of 20 renal clinicians in the United Kingdom described end-of-life discussions as extremely challenging and their conduct was highly variable related to uncertainties of prognosis and an unclear sense of responsibility regarding who should initiate these conversations. Discussion of treatment goals were frequently initiated upon patient deterioration and withdrawal from dialysis and were often perceived as too late ⁽¹⁴⁾. This

provides opportunities to train and support clinicians to lead discussions about goals of care and advance care planning earlier to improve patient, family, caregiver and clinician experiences.

When considering RSC, most clinicians viewed it as valuable, integrated, and distinct from palliative care and would refer well before the final weeks of life. However, diversity was evident when respondents detailed current experiences of roles and activities of RSC. Similarly, while most clinicians viewed specialist palliative care as beneficial for patients in improving symptoms and quality of life and relevant for patients with non-malignant conditions, experiences of palliative care were also variable, especially regarding the perceived role and timing of palliative care when “active” treatments were continuing. This incongruity has been described in literature describing palliative care for non-malignant disease, where uncertainty of prognosis ⁽¹⁵⁾ and unclear boundaries of professional roles ⁽¹⁶⁾ may impede palliative care integration.

With these challenges in mind, opportunities to develop renal supportive services across Australia and New Zealand have been highlighted in this study. In particular the opportunity to develop services which provide consistent, measurable and transparent activities with the capacity to benchmark between services. Such services should as a priority, according to renal clinicians, include symptom management given the well-established significant symptom burden and resulting poor quality of life in patients with advanced renal disease ⁽¹⁷⁻¹⁹⁾. A recent cross sectional study described the utility of patient reported symptom measures used to directly inform clinical care in Australia and New Zealand and 65% of renal units

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routinely measured symptoms for patients with advanced renal disease ⁽²⁰⁾. Embedding consistent metrics of symptom measurement for patients in renal supportive care services could provide collaborative patient and service outcomes and research opportunities to improve understanding of how RSC improves quality of care.

Another component of renal supportive care service models described as a priority by renal clinicians was to focus on interdisciplinary care communication and coordination. Mosely described the renal patient's perspective of multiple interactions between nephrologists, general practitioners, emergency staff, renal, dialysis and community health care professionals and argued that communication and reimbursement models promote fragmentation of care and obscure optimal care outcomes ⁽²¹⁾. It is likely that healthcare intricacy and fragmentation has increased over time, evidenced by the cumulative treatment intensity described for older dialysis patients, especially in the final 12 months of life ⁽²²⁾. Therefore, health care policy and resource allocation to enable improved health care coordination as part of renal supportive care models could improve patient experience and care outcomes.

To improve quality of end-of-life care for renal patients, these results highlight the need to prioritise systems which facilitate early detection, communication and responses to clinical deterioration to address the challenges at end-of-life identified by clinicians. The systematic development of renal supportive care and palliative care in nephrology care could provide part of this response. In recent years, it has been suggested that policy frameworks

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underpinning the dialysis model of funding of nephrology care has resulted in limited attention even 'dis-incentives' to comprehensively addressing other patient needs, with system wide funding changes necessary to further integrate palliative and supportive care into nephrology ⁽²³⁾. A broad and systematic approach to RSC service development is required across Australia and New Zealand which addresses referral pathways, communication needs, support for clinicians and ongoing funding to further develop high quality, comprehensive and integrated care in advanced renal disease and end-of-life care.

A number of limitations exist for this study. These results have selection and response bias, as only clinicians (nurses and doctors) interested in this field responded. In addition to this, an estimated response rate of 13% was lower than other online surveys or alternative methods of data collection such as in person or paper based (24) and it is unknown how many clinicians from each service completed surveys. Therefore, these results may not reflect the views of all nephrologists and renal nurses in Australia and New Zealand. Yet, an important benefit of this study design was the anonymity an online survey provided, enabling clinicians to respond in privacy and without censure. What was known from these results was most respondents (58%) were from Victoria and Queensland; therefore, results were less likely to be representative of other regions sampled. Despite these limitations, this study has provided an understanding of the challenges facing renal clinicians when caring for patients near end-of-life and consensus in the opportunities to improve renal supportive care and palliative care service integration within nephrology care.

Conclusions

Renal supportive care was viewed as acceptable, incorporating active treatments and a valuable approach to assist in improving symptoms and quality of life for patients with advanced renal disease. Palliative care was viewed as a beneficial, important, distinct part of care for patients with advanced renal disease, more often associated with the final phase of life. An approach to service development must understand and work with these perceptions, and simultaneously educate clinicians about the potential role and benefits of these approaches. Also, future health services research needs to incorporate patient, care giver and consumer views and experiences to ensure truly patient centred models of care.

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Conflict of Interest

The authors declare no conflict of interests in preparing and writing this manuscript.

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Tables

Table 1. Demographic characteristics of participants and access to services

Legend

RSC- renal supportive care, SPC- specialist palliative care

Table 2. Referral Patterns

Reason for Referral	n (%) RSC agree	n (%) SPC agree	χ^2 p
Uncontrolled symptoms	255 (86%)	205 (69%)	p<0.01
Complex treatment decision making	240 (82%)	169 (58%)	p<0.01
Limited prognosis (less than 1 year)	273 (91%)	208 (70%)	p<0.01
Patient was dying (last weeks of life)	231 (76%)	290 (96%)	p<0.01
The patient wanted to stop renal replacement therapy	291 (94%)	268 (87%)	p=0.05
The patient could no longer continue renal replacement therapy	286 (93%)	273 (89%)	p=0.23
The patient or family/carer were no longer able to manage the physical care of the patient	219 (74%)	176 (59%)	p<0.01
There are few instances when I would consider referral to RSC / SPC	79 (31%)	69 (27%)	p<0.01

Legend

RSC – renal supportive care

SPC – specialist palliative care

Table 3: Clinician lead priorities to develop renal supportive care

Priority areas	Examples of RSC activities	Outcomes measured
Patient symptoms and quality of life guiding practice	<ul style="list-style-type: none"> • Routine measurement of patient experience including symptoms and quality of life • Provision of education and support for renal clinicians in symptom management 	<ul style="list-style-type: none"> • Referral indications for RSC services monitored and feedback to renal clinicians • Effect on symptom scores and quality of life of RSC interventions • Number of RSC education sessions per year and attendance
Healthcare service coordination and integration	<ul style="list-style-type: none"> • Multidisciplinary RSC team including Palliative care and Nephrology specialists embedded in RSC clinics • Communication and integration between nephrology units and community-based services, including general practice, palliative care services, pharmacies and allied health 	<ul style="list-style-type: none"> • RSC roles and activities articulated and documented • Key hospital and community health care services involved identified and included in communication across services • Patient experience of continuity of care across services evaluated
End of life care and planning	<ul style="list-style-type: none"> • Support for clinicians, patients and families available for complex treatment decision making • Dedicated clinic time for advance care planning discussions with patients, care givers and families 	<ul style="list-style-type: none"> • Treatment decision making and advance care planning discussions and directives documented • Patient based triggers for clinical deterioration and responses developed and monitored

Figure 1. The most challenging end-of-life experiences are associated with:

Figure 2. Views on Renal Supportive Care:
"From your experience RSC is..."

Legend

QOL – Quality of life

CKD – Chronic kidney disease

RSC – Renal supportive care

Figure 3: Views on Palliative Care

From your clinical experience, specialist palliative care (SPC) is...

Legend

CKD – Chronic kidney disease

SPC – Specialist palliative care

**Figure 4. Which of the following are essential features of an "ideal" Renal Supportive Care Service?
Responses of Renal Doctors and Nurses from Australia and New Zealand**

Legend

GPs – General practitioners

RSC – Renal supportive care

SPC – specialist palliative care

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