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Original Article

End Stage Kidney Disease Patient Experiences of Renal Supportive Care in an Australian Teaching Hospital - A Qualitative Study

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Abstract

Context. Renal Supportive Care Services (RSCS) were introduced in Australia to provide patient-centred care with a focus on better symptom management and improved quality of life in end stage kidney disease (ESKD) patients managed with or without dialysis. While RSCS have demonstrated clinical benefits with reduced length of hospital stay and symptom burden, there is a gap in understanding the experience of patients referred to RSCS.

Objectives. To identify patient attitudes, beliefs, and perspectives on the RSCS.

Methods. Qualitative interviews were conducted with 20 participants from both dialysis and conservative treatment pathways. Transcripts were then thematically analysed and primary themes identified, which were reviewed with a stakeholder group that included doctors, nurses and allied health staff to provide triangulation.

Results. Patients perceived the RSCS as a provider of multidisciplinary, holistic and patient-centred care that, in addition, helped to ensure prognostic awareness and timely end-of-life care planning. This contributed to an overall sense of patient empowerment with healthcare decisions. This study identified three major themes: (1) Expectations of care; (2) Experience of care; and (3) Understanding patient needs.

Conclusion. The study found that RSCS support patient-centred and family-orientated initiatives in decision making and control over healthcare management. This is empowering for patients. Additional patient values, needs and wants from the RSCS were also identified and these could be addressed to improve the patient experience. Our findings support the ongoing use of RSCS to improve the experience of ESKD patients. *J Pain Symptom Manage* 2021;000:1–10. © 2021 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Renal supportive care, patient experience, end stage kidney disease, patient empowerment, continuity of care

Key Message

This article describes a qualitative study that uniquely investigated patient attitudes, beliefs and perspectives on Renal Supportive Care Services (RSCS).

This study showed there is a clear benefit for RSCS to be embedded within renal medicine services as they provide holistic care and ensure timely end-of-life care discussions.

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Introduction

Patients with advanced chronic kidney disease (CKD), whether undergoing dialysis or not, have described a symptom burden and impairment of quality of life similar to patients with terminal cancer.¹⁻⁴ Traditional measures of health focus on mortality and the progression from CKD into end stage kidney disease (ESKD).⁵ These measures do not adequately assess symptom burden of disease which can increase patient distress and negatively affect quality of life.⁵⁻⁷ Quality of life has been shown to be of higher value than quantity for patients living with ESKD.^{8,9}

The main aim of the establishment of RSCS was to focus on impaired quality of life and improve symptom burden.^{10,11} Renal supportive care (RSC) integrates specialist palliative care with usual nephrological care in order to manage symptomatology and provide planning for end-of-life discussions in a patient centred, holistic model of care.¹² Included in this multidisciplinary team is a palliative care physician, nephrologist, dietician, social worker and clinical nurse consultant (CNC). Prior research has shown the benefits of an integrative, multidisciplinary service like RSC in improving quality of life and symptom burden with or without dialysis.¹²⁻¹⁴ In addition, those who had access to an RSC-like service were less likely to be admitted to or die in hospital.¹⁵

At Royal Prince Alfred Hospital (RPAH), Sydney, Australia, patients are referred to RSC when they have elected a not-for-dialysis pathway (conservative) or are on dialysis and who require symptom management. Referral criteria includes, i) CKD patients who have chosen a not-for-dialysis pathway and have an eGFR ≤ 15 ml/min/1.73m², ii) chronic dialysis patients who require symptom management, and iii) CKD patients who have not commenced dialysis or remain undecided about their pathway and require symptom management. Once referred, patients are generally seen in the dedicated, multidisciplinary outpatient clinic. In addition, based on need, patients are also seen in the inpatient dialysis units or ward setting (Table 1). The inpatient experience is limited to the RSC medical and nursing members of the team as the allied health staff involvement is ward based.

The RSC CNC plays a vital role in RSC service delivery. The CNC is the main point of contact and is responsible for triaging and coordinating care and is available to patients, carers, and other healthcare professionals to provide ongoing information and address concerns about the service.

RSC is increasing across Australian hospitals and worldwide, however the patient experience of these services remains largely unknown. This is a single site, exploratory study looking to highlight this aspect of RSC in a major Australian teaching hospital. The aim of this qualitative study was to identify patient attitudes, beliefs, and perspectives on the RSCS to ensure that the service recognises and caters to individual patient need.

Methods

Study Design

This was a qualitative, semi-structured interview study.

Participant Selection

A convenience sample of participants were recruited from patients known to the RSCS. This included patients who were seen consecutively by the RSC team. Potential participants were identified from outpatient clinics, dialysis units and inpatient care by treating clinicians. Independent researcher (E.S.) approached potential participants, gained written consent after providing information on the study and answered any queries. Recruitment ceased once data saturation was reached (no new information over three consecutive interviews).¹⁶ A trained researcher (E.S.) conducted all 20 interviews.

Description of Clinic

Patients attend a multidisciplinary outpatient clinic which consists of a palliative care physician, a nephrology registrar, a dietician, a social worker and a CNC. At the clinic the patient is reviewed using established clinical outcome measures including the Integrative Palliative Outcome Scale - Renal (IPOS-R) and the Australia-

Table 1
Participant Characteristics

	Total n=20 (%)	Conservative n=8 (%)	HD ^a n=12 (%)
Mean age (SD ^b)	74.3 (11.8)	85.5 (4.4)	66.8 (8.6)
Gender			
Female	11 (55)	4 (36)	7 (64)
Male	9 (45)	4 (44)	5 (56)
Patient setting			
Inpatient	10 (50)	1 (10)	9 (90)
Outpatient	10 (50)	7 (70)	3 (30)

^a= haemodialysis;

^b= standard deviation

modified Karnofsky Performance Status (AKPS) and provided with an introduction to the service and ongoing advice ranging from diet, symptoms, advanced care planning to support services. Workflow practices and referral pathways are outlined in [Appendix 1](#).

Inclusion and Exclusion Criteria

Patients were eligible to be included in the study if they were: known to the RSCS; 18 years old or over; and assessed as CKD 5 or ESKD, managed with dialysis or conservative (non-dialysis) care. Patients were excluded if they were: not referred to the RSCS; less than 18 years of age; already receiving end-of-life care; or unable to answer questions in English.

Setting

This study was conducted at RPAH, in Sydney, Australia. RPAH is a major metropolitan teaching hospital with a large CKD programme, including transplantation, dialysis and conservative (non-dialysis) care pathways.

Data Collection

A semi-structured interview methodology was chosen for its ability to provide rich data. The interview questions were developed from the literature¹⁷⁻²⁰ with discussion amongst three expert clinicians who have significant experience in qualitative renal research. These experts helped guide the question focus on patient attitudes and beliefs.²¹ The interview guide can be found in [Appendix 2](#). The interviews were an average of 30 minutes duration and were conducted over an eleven-month period from August 2019 to June 2020. Interviews were audio-recorded and transcribed verbatim by an independent researcher (E.S.).

Analysis

A qualitative thematic analysis was conducted.²² Individual coding of an initial six transcripts was completed by three researchers (E.S., M.B., and R.P.) using inductive (response-based) methods to determine a preliminary coding framework, which was refined after reading a further six transcripts and organized into themes. The remaining transcripts were coded by one researcher (E.S.) using the final coding framework, which was modified as new themes were identified in the remaining transcripts. Sub-group (diagnosis based) differences were explored through the analyses. Differences among researchers' interpretations were resolved through discussion. Relevant quotes to illustrate the identified themes were extracted.

The data set and themes were scrutinized by a stakeholder group in lieu of patient participation due to a high level of participant attrition. This acted as a proxy for member-checking. This stakeholder group

included two registrars, one nephrologist, one dietitian, one social worker, one CNC, one nurse practitioner and two palliative care physicians who work closely with RSC patients.

Ethics

This study received ethics approval from Sydney Local Health District Ethics Review Committee (RPAH Zone) under Protocol X19-0167.

Results

Twenty four participants were recruited for the study. Eight participants (40%) were on the conservative treatment pathway and 12 (60%) were receiving maintenance hemodialysis (HD). Four patients declined to consent with the most common reason being wanting to undergo dialysis in peace ([Fig. 1](#)). Participant characteristics are provided in [Table 1](#).

Three themes were identified: 1) Expectations of care; 2) Experience of care; 3) Understanding patient needs ([Table 2](#)). Subthemes are listed below.

Theme 1: Expectations of Care

This theme focused on patients' expectations of care and the effect that had on their attitude. Four subthemes were identified regarding patient attitude when initially meeting with the RSCS. These were: 1) Level of patient understanding; 2) Procedural burden; 3) Trusting relationship; 4) Emotions around referral.

Level of Patient Understanding. Most HD patients did not understand the role of the RSCS. A few were aware that the team would address symptom burden. Some HD patients were worried about the name 'palliative care' and associated it with end-of-life care. Conversely, approximately half of the conservative patients had a good understanding of the RSCS. It was noted that full comprehension of these services took time. Despite differing levels of patient understanding, participants in both groups were unaware how the RSCS fit within their wider healthcare picture.

"It take me a while to understand the situation all in my head, you know what I mean?" (Male, 85, Conservative treatment pathway)

"... over time it sort of seeped in and made sense. Cause I mean at first, it's... just so overwhelming." (Female, 61, HD treatment pathway)

Procedural Burden. Patients with chronic conditions like ESKD need to attend a lot of appointments and procedures. A greater burden was experienced by patients in the HD treatment pathway where RSCS was initially seen as part of this appointment burden. However,

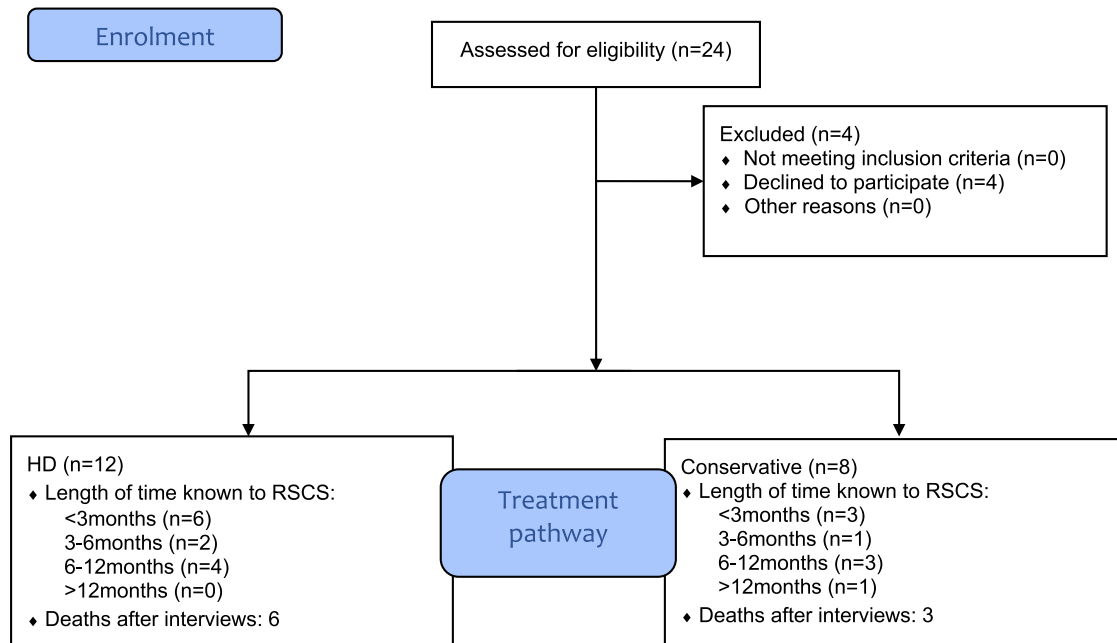


Fig. 1. Consort diagram illustrating patient enrolment and recruitment numbers including length of time known to RSCS for each treatment pathway.

over time with greater understanding of the RSCS benefit this sense of burden was alleviated. Patients felt each new referral or service seemed to blend in with another. This promoted a level of disengagement with their health and an acceptance of more appointments without trying to understand the referral in relation to their health.

“Just another doctor. You’ve got to remember that I’ve been going through the medical system for the last 10 or so years. . . the doctor could have been anyone for all I know.” (Male, 76, HD treatment pathway)

Regardless of treatment pathway, there was a close and reciprocal association between perceived appointment and procedural burden and the relationships patients had with both their renal and RSC doctors.

“My specialist, he was really good. He was easy to talk too. I felt that I could talk to him about anything and ask him about anything which was really good.” (Female, 62, HD treatment pathway)

Trusting Relationship. Patients generally felt that their RSC doctors were doing their best to provide the most up-to-date care they could. Patients expressed a sense of hope for improvement with doctors, while realizing there were limitations to what could be done. At times, the sense of trust was interrelated with the patient’s spiritual connections accepting finitude of their life and future.

“It’s as I said I trust doctors, I don’t know what medicine or whatever, so I trust them.” (Female, 89, Conservative treatment pathway)

“You see, I could leave a day or two or a month or a year or more years it depends on God.” (Female, 89, Conservative treatment pathway)

Emotions Around Referral. Patients felt hopeless, guilty, depressed and shared a sense of failure when they were first diagnosed with ESKD. This seemed to relate to an overall feeling of grief and loss. When referred to the RSCS, patients felt overwhelmed and scared. Some of those emotions were related to prior stereotypes associated with palliative care and dying. Others felt an uncertainty about palliative care and what to expect from the service.

“Well, they told me because your kidney is already 9% there is not much hope and the idea was, it was just a matter of time. Short time” (Male, 88, Conservative treatment pathway)

Theme 2: Experience of Care

The second theme related to the personal values of patients and how they aligned with their experience of care from the RSCS. Subthemes identified included: 1) Timely referral; 2) Continuity of care; 3) Prognostic awareness.

Timely Referral. The referral of patients to the RSCS was considered well timed from the patient perspective in

Table 2
Themes and Subthemes

Theme	Subthemes	Participant Examples
Expectations of care	(1) Level of patient understanding	“I had no idea what I was walking into or, or what, what would happen.” (Female, 62, HD treatment pathway) “I didn’t really expect, um, I didn’t know what to expect from palliative care. . . it was daunting at first but then later on it got clearer about what we can do.” (Female, 90, Conservative treatment pathway)
	(2) Procedural burden	“There’s so many people that came that I can’t even remember” (Male, 72, HD treatment pathway) “I don’t know, they’re [healthcare professionals] all the same. They’ve all been alright.” (Female, 82, Conservative treatment pathway)
	(3) Trusting relationship	“They’re good people. They’re caring, trying their best, they’re human.” (Female, 89, Conservative treatment pathway)
	(4) Emotions around referral	“I . . . freaked out actually, just hearing the [palliative care] name.” (Female, 46, HD treatment pathway) “It was my fault, I should have come earlier, I should have come.” (Male, 76, HD treatment pathway) “Well, they reckon my whole health system has broken down, everything is bad, there is nothing good” (Male, 88, Conservative treatment pathway)
Experience of care	(1) Timely referral	“The follow up is what I appreciated the most. With the kidney levels I’ve got at the moment, I’m really not in palliative care . . . but it’s great that I’m still here” (Female, 87, Conservative treatment pathway) “I think I got them at the right time. Oh, when I was in hospital, I got most of it [the care] yea, yea. Not just when the pain came on...” (Female, 59, HD treatment pathway)
	(2) Continuity of care	“I thought that they were all very helpful, not just the doctors but uh. . . everyone in that group was quite pleasant and there was the contact person, who has since moved on was extremely helpful and uh, she followed my health. . . and she knew when I was admitted to hospital at various times and checked up, so that was very good. I’m not sure she’s been replaced yet” (Female, 87, Conservative treatment pathway)
	(3) Prognostic awareness	“I don’t think they can do much more than what they have done or doing. I am very happy with the state that I am. From there on it’s all profit, if I die this afternoon or tomorrow then good luck to me.” (Male, 78, Conservative treatment pathway)
Understanding patient needs	(1) Holistic care	“But sometimes when you think it’s not all inclusive until somebody tells you a bit more about certain things” (Male, 88, Conservative treatment pathway)
	(2) Patient-centred care	They truly sort of gave me the sense that they, they cared about what was best for me and they sort of never tried to push anything onto to me” (Female, 62, HD treatment pathway)
	(3) Family involvement	“What sort of state is she [wife] in? If she doesn’t feel comfortable with what’s going on than the whole process is not so satisfactory. Kids need to understand their role is to help mum not to feel sorry for themselves. Once the family side of things is sorted then it’s how do you help me?” (Male, 76, HD treatment pathway)

the majority of cases. Few patients suggested the care should have been brought in earlier. Most patients were seen in the outpatient setting prior to admission. Thus, when patients were admitted to hospital, they had already established a therapeutic relationship with the RSC team and appreciated seeing a familiar face.

“The nurse was following my progress, so I didn’t have to ring up and say, ‘I’m in hospital.’ It was just sort of, ‘Hello.’ She was just there” (Female, 87, Conservative treatment pathway)

Continuity of Care. The role of the CNC is pivotal within the RSCs. When this integral person was no longer available, patients struggled. The loss of contact with the CNC due to resignation prompted an exacerbation of loss to follow up and created a fragmentation in the service, which made it hard for patients to get into contact with the RSC team with regards to appointments and services.

“The follow up with CNC was amazing I thought but you could see for yourself today that it was a pretty friendly and relaxed atmosphere. It wasn’t intimidating in any way, which I’m sure it could be.” (Female, 87, Conservative treatment pathway)

“When we thought they not calling us, what should we do?” (Male, 78, Conservative treatment pathway)

Prognostic Awareness. The transcripts revealed that RSC supported early understanding and acceptance of prognosis which in turn reduced patient anxiety. This indicated that patients could cope with information regarding their poor prognosis provided they have adequate ongoing support. This acceptance helped assist discussions around future care planning and wishes around place of death. Prognostic awareness, planning ahead and being able to support the family for life past their death was a major priority for all patients.

“Well, number one is acceptance, accept what is going to happen to me. . .but I expect at any moment life would end, who knows?” (Female, 89, Conservative treatment pathway)

Theme 3: Understanding Patient Needs

The third theme revolved around how services were provided to meet patients' needs. Three subthemes were identified which expressed parts of the RSCS that were indispensable: 1) Holistic care; 2) Patient-centred care; and 3) Family involvement.

Holistic Care. Each member of the multidisciplinary RSCS team was valued by the patient. The team provided information on a whole host of services, some of which patients were unaware. Patients and their families felt more secure to have a holistic-care team in place, reducing patient and family anxiety. Patients felt that they were able to effectively communicate their needs with the RSC team.

“I mean it's [RSCS] very important to me because I wasn't getting it before I didn't realise how important it was, but it's been really good now that I'm getting it.” (Female, 64, HD treatment pathway)

“I actually look forward too, to that once a month visit where. . . can sit down and talk through some stuff with them so yeah. . .” (Female, 62, HD treatment pathway)

Patient-Centred Care. Patients felt their circumstances were considered. For example, they appreciated the staff's thoughtfulness in seeing patients in haemodialysis to avoid requiring an extra appointment. Patients also valued the 'human factor' staff provided and a feeling of appreciation was expressed for the compassionate approach of the RSCS.

“They were there for me not ff-for them or you know just because it was their job.” (Female, 62, HD treatment pathway)

“They came to me, only because of cost, it costs me on average \$55 to come by uber, so I didn't want that. . . so I didn't have the means to come up all the way here so it's mainly financially why I didn't come into the clinic.” (Female, 46, HD treatment pathway)

Family Involvement. Patients appreciated being asked whether they would like their family to be included in their care discussions. This was useful when patients felt diffident in communicating their health issues with family. Most patients placed the needs of family over their own. Patients felt they could focus on their treatment and future care plans once their family's needs were met.

“Mainly they'll, they will involve my family if need be, if I say look, I want my daughter to be here for you to speak to her, they're good like that” (Female, 59, HD treatment pathway)

“Once the family side of things is sorted then it's how do you help me?” (Male, 76, HD treatment pathway)

Discussion

This study gives an in-depth view of how patients interact with RSCS and identifies the clinical significance of these services from the patients' perspectives. Patients were pleased to acknowledge that RSCS provided the foundational support for end-of-life care discussions and an ability to accept their finitude. The holistic care that RSCS provided helped contribute to an overall sense of empowerment with their healthcare decisions. In contrast, patients identified the areas that require more support from the RSCS, including a clearer understanding of how to access appointments and obtain further emotional support when dealing with the transition to end-of-life care.

As part of the holistic care of the RSCS, physical, psychosocial, and spiritual wellbeing are all addressed. The results of this study indicate that patients place a high value on their spiritual wellbeing with this intertwining with their ideals of death, which is consistent with the literature.²³ Past research identified that the spiritual aspect of patient care is often under-recognized in terminally ill patients which leads to poorer quality of life outcomes.²⁴⁻²⁷ Furthermore, studies have shown that involving the patient's spiritual beliefs provides for better comfort and quality of life outcomes.^{25,28,29}

In terms of psychosocial wellbeing, patients in this study described emotions relating to referral and diagnosis of ESKD that seemed to relate to a sense of grief and loss. ESKD patients experiencing grief and loss have increased rates of depression and reduced quality of life outcomes.^{30,31} This highlights the need for psychosocial support from the RSCS and suggests that a CKD/ESKD support group as part of further service development may be beneficial. Support groups have been shown to address feelings of isolation, increase knowledge of the patient's condition, increase confidence and empowerment and in general, improve quality of life.^{32,33} The importance of a central contact person like the CNC in this study to coordinate care has been documented in the literature as imperative for integrative models of care and to promote a sense of non-abandonment.³⁴

This study found that early referral times were associated with better patient understanding of the RSCS, improving opportunities to gain rapport and familiarity

with the team prior to decline in kidney function. It also facilitated early discussions around end-of-life care and acceptance of prognosis. This is similar to prior evidence where patient experiences were enhanced when discussions of prognostic uncertainty were shared between the clinician and patient.³⁵⁻³⁷ The literature also suggests that early referral improves quality of life, reduces depressive symptoms and aids in the time required to comprehend emotional impacts of terminal illness.³⁸⁻⁴²

In our study, patients were subjectively more likely to experience a better understanding and a reduced appointment and procedural burden when they had a good relationship with both their renal and RSC doctors. Prior research has also shown that patients are more likely to be satisfied with their care when they

have a good relationship with their doctor.⁴³ From our results, patients and families were comforted knowing a multidisciplinary team alongside their usual nephrologist was looking after them to provide holistic and patient-centred care. Our study also recognized the critical importance of family involvement and how this can aid conversations around prognostic awareness; similar to prior research.⁴⁴⁻⁴⁶

Overall, the themes of this study are linked by the overarching principle of patient empowerment. Where patients acknowledged the positive aspects of the RSCS they highlighted areas which empowered them to make decisions and take control over their health (Fig. 2). These themes included, trusting relationship, timely referral, prognostic awareness, holistic care, patient-centred care and family involvement. When continuity of

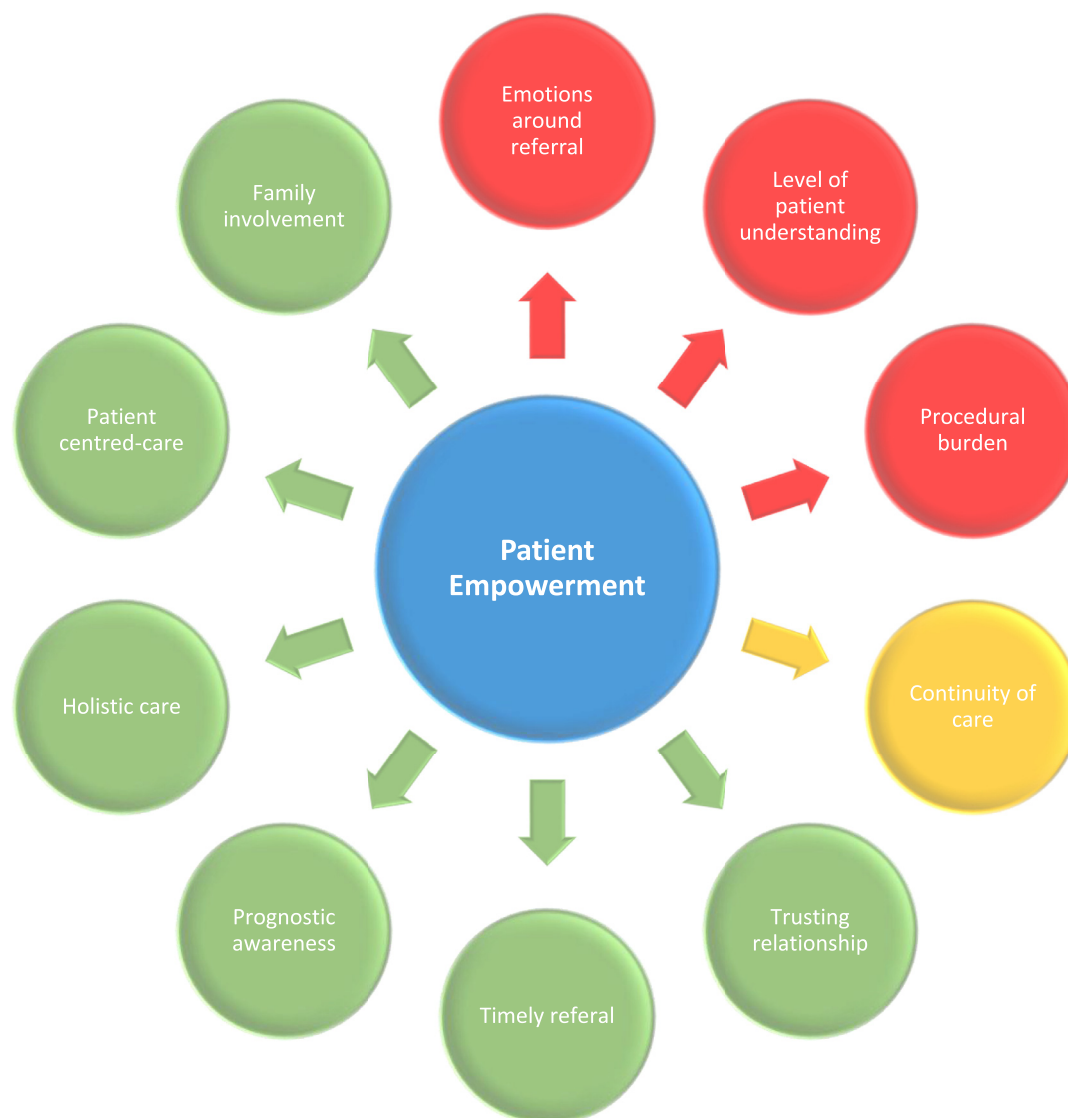


Fig. 2. Thematic schema from patient's experiences of the RSCS integrated into patient empowerment (green denotes areas of patient empowerment, yellow denotes area of improvement, red denotes areas that need further support initiatives) (For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article).

care was lost through the integral RSC CNC not being involved with patient care there was a sense of powerlessness for patients. The other themes that demonstrated this were, poor patient understanding, emotions around referral and procedural burden. Our study provides evidence in support of the literature in aspects of patient empowerment.⁴⁷ Interestingly, a recent study by Bristol et al.⁴⁸ indicated the interlinking nature of patient activation with patient empowerment. In their study, patients felt more engaged and activated with their healthcare after attending the RSC clinic. Furthermore, patients acted as ambassadors for their RSCS and talked about it with other patients whilst on dialysis. Similarly in our study, we emphasized that patients became more engaged overtime with improved understanding due to ongoing education and guidance from the RSCS. Thus the RSCS seems to embody the foundations of patient empowerment and can be integral to patient activation.

The limitations to this qualitative study include using a convenience sample, high patient attrition and excluding non-English speakers. Since this study was undertaken in a major Australian tertiary hospital, it does not reflect the services provided in rural areas. This study was not intended to be generalizable and other cohorts may respond differently.

Despite these factors, this patient population gave a comprehensible exploratory insight into our RSCS. Due to the novel model of care that the RSCS provides, this study delivers useful insight into service delivery from the patient's perspective. This research will help guide the discussion of future work, particularly in contextualizing these results on patient experience with future quantitative studies.

In conclusion, this study gives a unique insight into patient perspectives, beliefs and attitudes in receiving care from RSCS. Patients were empowered by the RSCS by gaining prognostic awareness, spiritual care integration and family involvement. Greater importance needs to be placed on further support integration, personalized knowledge acquisition and re-engaging patients with their healthcare. These identified areas will be used to refine our RSC clinic and patient interactions in the future. Our findings support the literature in encouraging the ongoing use of RSCS to improve the patient experience. Finally, this study provides potential stakeholders interested in creating RSCS the foundations of what patients may value in an integrative service delivery model.

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Disclosures

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Supplementary materials

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.jpainsymman.2021.12.024](https://doi.org/10.1016/j.jpainsymman.2021.12.024).

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