Catheter lock solutions are instilled into central venous access systems to have certain effects in this location. These access systems can be either dialysis catheters, Hickman-type lines or port-a-cath systems. The latter are used mainly in parenteral nutrition and for the administration of medication in oncology patients. These access systems are approved as medical devices and are CE marked. The central venous access is inserted in the subclavian, jugular or femoral veins.

The use of Antimicrobial Lock Solutions have been recommended in the "Hygiene Guideline complementing the German Dialysis Standard" and in the Position statement of European Renal Best Practice (ERBP)**. Pure heparin solutions containing no antimicrobial agent do not meet this criterion. Antibiotics are associated with the development of resistancy which is a major drawback. Highly concentrated citrate solutions and taurolidine-citrate solutions are therefore conceivably useful in this application.

Highly concentrated citrate solutions (30% and 46.7%) cause major adverse effects such as cardiac arrests and embolisms that are a significant risk for the patient. TauroLock™ as an antimicrobial lock solution has proven useful in dialysis, oncology and parenteral nutrition for many years and has meanwhile become established in the prevention of catheter-related infections.

The requirements of antimicrobial catheter lock solutions:

What should they do and what can they do?

TauroLock™ prevents catheter infections:

TauroLock™ is safe: The concentration of 4% citrate in TauroLock™ is safe and efficient - according to the recommendation of the FDA [ref.: FDA Warning Letter, April 2003].

No hypocalcaemic effects are observed in contrast to highly concentrated citrate solutions (30%, resp. 46.7%) e.g. arrhythmia, cardiac arrest*, embolism**, fingering fingers and metallic taste***. TauroLock™ is biocompatible and non toxic. In contrast to highly concentrated citrate there is no protein precipitation if using TauroLock™****.

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Renal supportive care in conservatively managed patients with advanced chronic kidney disease: a qualitative study of the experiences of patients and their carers/families

Anna Hoffman, Shelley Tranter, Elizabeth Josland, Frank Brennan & Mark Brown
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Abstract
Renal supportive care (RSC) integrates palliative and renal medicine to help patients with chronic kidney disease (CKD) to live as well as possible. Although there have been many studies investigating the experiences of patients on renal replacement therapy, there is very little research investigating the experiences of those choosing conservative management. The aim of this study was to gain a greater understanding of the experiences of conservatively managed patients and their carers/families within the service. This qualitative, descriptive study was conducted using semi-structured interviews. Thematic analysis was used to analyse the interview transcriptions. This study was conducted in a major renal service in Sydney, Australia. Twelve patients and 11 carers were interviewed. Patient criteria were >65 years, had advanced kidney disease (eGFR<30) and had chosen conservative management. Family/carers of patients that met the inclusion criteria were also interviewed. Six themes emerged. Themes common to both groups were: an awareness of what was going on; informed decision making; feeling supported; and waiting for health to decline. Patients expressed a need to maintain normality in their lives. Carers discussed issues and difficulties of adjusting their lives to being a carer. Open and honest discussions, prognostic information and early involvement of palliative care are crucial to ensure patients and carers can make clear, informed decisions. Connection to the RSC service gives patients a peace of mind that there is someone to call for advice and support. Patients and carers felt that a RSC service provides an excellent system of management.

Keywords
Patient experience, carer experience, end-stage kidney disease, conservative, renal supportive care, palliative.

Background
Deciding how to manage patients with declining kidney function is difficult. Each year in Australia approximately 16,000 adults will develop chronic kidney disease (CKD) (Australian Bureau of Statistics, 2013) and the majority will choose a form of renal replacement therapy (RRT) to manage it (ANZDATA Registry, 2016). Research shows, however, that for elderly patients (>75 years) with high co-morbidity burdens, dialysis may not significantly enhance survival (Foote et al., 2016). For those patients that choose a non-dialysis, conservative...
Renal supportive care in conservatively managed patients with advanced chronic kidney disease: a qualitative study of the experiences of patients and their carers/families

pathway, alternative programs have been developed to support them as their kidney function declines (Josland et al., 2012; Noble et al., 2007; O’Connor & Kumar, 2012).

Renal supportive care (RSC) programs offer holistic management to advanced CKD patients and their families to reduce symptom burden, improve quality of life and provide support towards the end of life (Josland et al., 2012). Although there have been many studies investigating the experiences of patients on RRT, there is very little research investigating the experiences of those choosing conservative management for their CKD.

A number of studies have examined why patients chose not to have dialysis, or opted to withdraw from treatment (Ashby et al., 2005; Noble et al., 2008; Tonkin-Crine et al., 2015). The crucial elements in their decision were the desire not to burden others and the concern that dialysis would decrease their quality of life. The problem of prognostic uncertainty and a sense of abandonment were also prominently expressed. Themes that emerged from one UK study were “age and the inevitable”, “feeling well on medication”, and being a “burden or nuisance” (Johnston & Noble, 2012).

While there is substantial literature regarding the impact that RRT has on patients and their carers/families (Axelsson et al., 2015; Low et al., 2008; Tong et al., 2014), only two studies have comprehensively investigated the impact on carers/families of patients managed conservatively (Noble et al., 2012; Low et al., 2014). Noble et al. (2012) interviewed 19 carers of patients managed in a UK RSC service three-monthly until study end or the patient’s death. There were 61 interviews in total. The prominent theme “caring from diagnosis to death” was illustrated by three subthemes: 1) Caregiver’s plight: making sense of the disease and potential deterioration; 2) having to care indefinitely; and 3) avoiding talk of death. The researchers concluded that nurses must address the needs of the carers alongside the needs of the patients and that there is a requirement for further research on this topic. Low et al. (2014) interviewed 26 carers of people with ESKD being managed conservatively and found that they did not separate CKD decline from their loved one’s other medical issues. This study highlighted the importance of understanding the close relationship between CKD and the natural ageing process.

A formal RSC service commenced at the study hospital in Sydney in 2009 staffed by a palliative care physician and an RSC clinical nurse consultant (CNC). The service expanded in 2015 to include an RSC dietitian and an RSC social worker.

This study was undertaken to gain a greater understanding of the experiences of patients and their carers/families within the RSC service, to identify if the RSC service is meeting individual needs and to add knowledge to a relatively unexplored area. In the RSC clinic, measurement of symptom burden and quality of life are collected routinely and patient outcomes are monitored over time (Brown et al., 2015). The experiences of patients and their carers, however, were poorly understood and required further investigation.

Methods

This qualitative descriptive study was conducted in a major renal service in Sydney, Australia, between May 2015 and June 2016. There were two groups of participants. Group one comprised patients attending the RSC clinic with advanced CKD who had chosen conservative management, with the following inclusion criteria: >65 years of age, estimated glomerular filtration rate (eGFR) <30, ability to converse in English, and at least one prior RSC clinic appointment. The second group comprised people who identified as a carer/support person for a conservatively managed RSC clinic patient (> 65years, with an eGFR<30 and at least one clinic appointment).

Semi-structured participant interviews were conducted. The case study methodology was used to allow a thorough exploration of the experiences of patients and carers attending the RSC clinic. This approach was chosen as the researcher can obtain a holistic and meaningful understanding of the characteristics of real-life events affecting the participants (Crowe et al., 2011).

Patients and carers/family were provided with a participant information and consent form. Willing participants attended interviews conducted by the renal CNC. The renal CNC conducted the interviews as she was a skilled and experienced interviewer and, although may have had previous contact with the patients, was not currently involved in the ongoing care or clinical coordination of the patients. Interviews were scheduled to coincide with the patients and carers attending for RSC clinic appointments. The RSC social worker was available to ensure support for any adverse outcomes that may have arisen from discussing potentially sensitive topics (Elmir et al., 2011).

Patients and their carers/families were interviewed separately to enable free and open discussion. Interviews were conducted in a quiet clinic consultation room and included semi-structured questions. Interviews were taped and transcribed verbatim. Patient questions focused on their health, experiences at the RSC clinic, decision making, and whether their individual needs were being addressed. Questions for carers focused on their role as a carer, the level of care they provided and any challenges they faced. There was consensus from the RSC clinicians on the questions used and no modifications were made during the interview schedule. Where possible, a follow-up interview was conducted six months after the initial interview. The second interviews were conducted to ascertain any changes experienced during the trajectory of the patient’s disease. The same questions were repeated at the second interview. Question 1 related to his/her initial decision not to have dialysis and patients were asked if there were any changes or regrets regarding their choice.
Demographic data collected included age, eGFR, living arrangements, support provided by the carer/family and their relationship to the patient. Data analysis was carried out in Excel. Thematic analysis was used to analyse the interview transcriptions. This involved searching the data to find repeated patterns of meaning, coding the transcripts, and revising, defining and naming themes (Braun & Clarke, 2006).

Approval to conduct the study was obtained from the South Eastern Sydney Local Health District Research and Ethics Committee. HREC Ref No: 15/044(LNR/15/POWH/131)-30/5/2015.

Results
All interviews were transcribed verbatim. Transcriptions were repeatedly reviewed during the interview phase to analyse the data relating to individual participants. Recruitment continued until saturation of themes occurred and no new information was identified. Analysis was then conducted to examine themes between participants. Comments of interest were highlighted and coded. The codes were collated into potential themes and finally the themes were refined and named (Braun & Clarke, 2006).

There were 12 patient participants and 11 carers/family participants. The participants were interviewed at baseline and, where possible, again at six months. There were a total of 36 interviews conducted. Although there were 50 conservatively managed patients seen in the clinic during this period, many did not meet the inclusion criteria, thereby precluding them from the study. Some carers could not be interviewed as patients attended the clinic alone.

Patient participants
The average age of the patient participants was 84 years (range 77–91 years). There were six males and six females. Two lived alone, eight with their spouse/partner and two with their daughters in the family home. At first interview, the average eGFR was 14.6 ml/min/1.73m² with a range of 4–27 ml/min/1.73m² (Table 1). Nine follow-up interviews were conducted: two patient participants had deceased before the second interview was scheduled (participants 5 and 9) and one patient did not have an appointment scheduled in the study period (participant 12). Average eGFR at the second interview was 12.6 ml/min/1.73m². Initial interviews took on average 17 minutes to complete (range: 11–24 minutes). Follow-up interviews were generally shorter, with an average of 13 minutes (range: 7–26 minutes).

Carer/family participants
There were 11 participants in the carer/family group: seven females and four males. There were four daughters and one son; the remaining six participants were spouses. Eight carers/family lived with the patient (2 of whom were daughters) and 3 children of the patients lived in separate homes. The average age of participants was 69 years, with a range of 42–89 years (Table 2). The average length of the initial interview was 20 minutes (range: 12–42 minutes). Four follow-up interviews were

<table>
<thead>
<tr>
<th>Patient</th>
<th>Sex</th>
<th>Age</th>
<th>eGFR (1st interview)</th>
<th>1st interview time (mins)</th>
<th>Marital status</th>
<th>Country of birth</th>
<th>Lives with</th>
<th>Lives where</th>
<th>eGFR (2nd interview)</th>
<th>2nd interview time (mins)</th>
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<td></td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>82</td>
<td>14</td>
<td>22</td>
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<td>Australia</td>
<td>Partner</td>
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<tr>
<td>3</td>
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<td>15</td>
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<td>Alone</td>
<td>In family home</td>
<td>13</td>
<td>20</td>
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</tr>
<tr>
<td>5</td>
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<td>16</td>
<td>Widowed</td>
<td>Australia</td>
<td>Daughters</td>
<td>In family home</td>
<td>3*</td>
<td>Deceased before 2nd interview</td>
<td></td>
</tr>
<tr>
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<td>12</td>
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<td>Wife</td>
<td>In family home</td>
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<tr>
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<tr>
<td>11</td>
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<td>16</td>
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<td>Australia</td>
<td>Wife</td>
<td>In family home</td>
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<tr>
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<td>F</td>
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<td>14</td>
<td>12</td>
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<td>Australia</td>
<td>Husband</td>
<td>In family home</td>
<td>18</td>
<td>13</td>
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</tbody>
</table>

*eGFR closest to date of death
conducted with an average time of 17 minutes (range: 9–26 minutes). Three carers did not have follow-up interviews as the patient died before the second interview was scheduled. Other interviews were not conducted due to different carers attending follow-up appointments, the unavailability of interviewer, or no appointment scheduled within study period.

Interview findings

Analysis of the interviews uncovered four common themes between patients and carers as well as one theme unique to patient and carer groups. In examining both groups we get a better understanding of their shared experiences and the social and emotional issues that can impact on their experience.

Shared themes

Theme 1: Awareness of what is going on

All patients and their carers were well informed and able to articulate the reasons why they were in the RSC program. They knew about their underlying kidney disease, reasons why dialysis was not the best option and what was currently occurring with their CKD management. Two patients explained openly that their advanced CKD was terminal and that they were nearing their end of life.

“I am dying because I am 82. I have kidney problems and I am coming to this clinic. I have asked the kidney doctor but he couldn’t tell me how long. I have pre-paid my funeral. I come to the clinic to get support because I am dying of kidney problems.” (Patient 9)

“My dad is at the end stage of his kidney disease. He’s towards the end and as time goes on he will deteriorate … he is close to passing away.” (Carer 9)

Theme 2: Informed decision making

Following on from theme 1, as patients were aware of their health condition this enabled them to be fully involved in the decision making about their care. Patients and carers expressed that they were comfortable with the decision not to commence dialysis. This decision was made in consultation with their families and doctors. Decreased quality of life (Low et al., 2014) and not wanting to be a burden on other family members (Johnston & Noble, 2012) were the two prominent reasons expressed for choosing not to dialyse.

“The original doctor didn’t want her to do dialysis due to age, frailty and trauma. She wouldn’t be able to do home-based dialysis. She has trouble gripping things with the arthritis in her hands. She is comfortable with that. She spoke to a few people and I think the trauma of coming here 3–4 times a week would be more traumatic.” (Carer 3)

“I didn’t want dialysis … I would be just getting over one day and then have to come in and do it again. It affects your quality of life. I am comfortable with the decision not to have dialysis.” (Patient 8)

<table>
<thead>
<tr>
<th>Carer</th>
<th>Sex</th>
<th>Age</th>
<th>Marital status</th>
<th>Country of birth</th>
<th>Lives with</th>
<th>Lives where</th>
<th>1st interview time (mins)</th>
<th>2nd interview time (mins)</th>
<th>Comments</th>
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<td>Australia</td>
<td>Wife (spouse of P1)</td>
<td>In family home</td>
<td>42</td>
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<td>Alone (daughter of P4)</td>
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<td>Australia</td>
<td>Husband (spouse of P6)</td>
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<td>15</td>
<td>9</td>
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<tr>
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<td>Australia</td>
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<td>17</td>
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<tr>
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<td>82</td>
<td>Married</td>
<td>Australia</td>
<td>Husband (spouse of P9)</td>
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<td>Mother moved in to other daughter’s house prior to second interview</td>
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<td>Husband (spouse of P11)</td>
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<tr>
<td>11</td>
<td>M</td>
<td>85</td>
<td>Married</td>
<td>Australia</td>
<td>Wife (spouse of P12)</td>
<td>In family home</td>
<td>14</td>
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</table>
They also felt there was thorough and co-ordinated care between their primary physician and their specialist(s). Some participants had previously attended the Renal Options Clinic to discuss treatment options and felt they were making an informed decision not to pursue dialysis.

**Theme 3: Feeling supported**

Feeling supported is an essential component of RSC (Noble et al., 2007). All patients stated they were well supported at home and infrequently attended the clinic on their own. Those that lived alone (two) had the support of regular visits from their children. All patients and carers felt supported by the RSC service. They expressed that the service gave them peace of mind that, not only were their medical needs being met, but there is someone to call for emotional support and advice. Carers especially appreciated having the additional support for practical issues that arose as their parent/partner’s health declined.

> I think it [RSC Clinic] is excellent. It gives you peace of mind that someone is looking after you. (Patient 1)

> She felt until she came to the clinic that previous doctors hadn’t explained a lot. She’s a lot happier now. (Carer 3)

Communication between the RSC team and the patients’ other health care providers (specialists and general practitioners) made patients feel there was thorough co-ordination of their care.

**Theme 4: Waiting**

The concept of “waiting” arises from the patients’ and carers’ understanding and acceptance of the progression of CKD (Low et al., 2014; Tong et al., 2014). Some patients talked about waiting to die or at least waiting for their health to decline. Some tried to put waiting for “it to end” out of their minds, while others were waiting for the day but were not sure when it would be. Most saw waiting to die as a normal part of the ageing process and accepted this inevitable component of the life of an elderly person.

> We have ordered our niche in the wall — all the funeral plans organised … [The person at the cemetery] told me with great emphasis that my spot will be looking over the garden. I said to her — do you think that I will be enjoying that? (Patient 12)

> I’ve thought about getting part-time work, but I don’t know if he’s going to last a year or 2 years … I think about the next time I get a full wage is when he is gone. I think about that sometimes. After he goes then I’ll think about it, but at the moment he is number one. (Carer 1)

There was also an acceptance and understanding from carers that, due to their age and their renal disease, that the life of their loved one was limited (Johnston & Noble, 2012). Although this was somewhat difficult to discuss, they expressed the need to be prepared. As mentioned in theme 3, being connected to the RSC service gave them reassurance that there was someone to call to guide them through the practicalities of end of life care.

> What options do we have? Whether to take her to a home or palliative care hospital? It is in the back of my head. It is just a matter of time. She is doing OK, but she won’t get better. (Carer 7)

**Theme unique to patient participants**

**Theme 5: Striving to be normal**

Participants were asked about their current physical and mental health and all responded that they were tired and lacked energy. Despite these symptoms, they were determined to attempt activities of daily living to a similar degree they had done prior to their health decline. Not only to maintain their independence, but to avoid becoming dependent on others (Tong et al., 2014). This caused some frustration as their CKD advanced. Increased tiredness and weakness meant that they weren’t able to perform these tasks as well as they had previously. Although energy levels fluctuated, they recognised that part of the issue was that they were “just getting old”.

> … then I get up of a morning and I shower (myself) and make myself look presentable for the start of the day and then I sit down in a chair in the bedroom and then when I feel OK I get up and make the bed and that’s an effort, a real effort. Occasionally now I am not worrying to make it but I hate to see it not made. (Patient 1)

> I was full of energy before. I still try to do everything. (Patient 4)

**Patient participant follow-up interviews**

The themes evident from the analysis of initial interview transcripts were explored further in follow-up interviews. When participants were asked about their current physical and mental health, all but one had experienced a decline but not necessarily related to the outcomes of advanced CKD. The participants remained tired and lacked energy and had become more frail, experiencing falls and mobility issues. Most had other health issues troubling them, including back pain, minor surgical procedures such as cataract surgery, prostate issues and other age-related health concerns. Two participants died in the six-month period.

The concept of “waiting to die” was also explored further. Patients were asked why they thought the experience of natural ageing and increased frailty differed to their experiences. The common theme expressed was, that although they recognised they were elderly with limited time, the difference was knowing there was an end point. Having a terminal disease was different to the abstract concept of death that came with natural ageing.
Themes unique to carer/family participants

Theme 6: Adjusting to the role as a carer

The declining health of patients has a huge impact on the life of their carers (Axelsson et al., 2015). In this study there were two distinct groups of carers: spouses/partners (six) and children (five) and the experiences of these two groups were quite different. The adjustments experienced by spouses had two main dimensions. Firstly, watching their long-term partner decline with an uncertain prognosis was difficult; however, most stated they were able to express their fears with each other. Open discussions helped ease anxiety about the unknown future. Secondly, caring for their spouse while managing their own health issues — many described this as looking after each other, both physically and emotionally. Older partners with their own health issues also had to rely on the wider family network and community support services to help with activities of daily living.

We have our tears when we talk about things, but it eases the stress. (Carer 2)

Adjustments made to care for parents had a large impact on the lives of their children. There were increasing demands placed on them as the health of their parent declined. Where the parents were still independent, children lived independently and provided assistance in transport (for appointments/shopping). Others had their parents living with them, and one child gave up full-time work to become a carer. All children talked about increased stress in juggling their own lives with the additional care needs of their parent. This was more acute for children who lived with their parents as they described their lives as being “put on hold” — having little social interaction with their peers while they focused on their caring role. Support from the RSC team helped them to manage this situation.

Both spouses and children stated that they did not see their caring role as being anything remarkable. They saw it as an extension of what they have always done (in the case of spouses) or what needs to be done to care for their parents (in the case of children).

Carer participant follow-up interviews

Four follow-up interviews were conducted with carers. Themes discussed in previous interviews were explored in more depth. There were no changes to their roles as a carer; however, two participants commented that they had noticed a decline in health of the patient and the concept of “waiting” was more prominent. They expressed appreciation of the support they received by the RSC team.

Discussion

This study examined the experiences of patients and their carers/family attending an RSC service to obtain a deeper understanding of their shared experiences. This study was also able to explore the social and emotional issues that can impact on experiences.

The participants were aware of what is going on with their health and claimed they had made an informed decision in choosing conservative management for their advanced CKD. In our large renal service (with an established RSC service), CKD patients are identified early where possible and undergo rigorous discussions regarding renal treatment options. Open and honest discussions with both patients and family are conducted within the Renal Options Clinic, during nephrologist appointments and in the RSC clinic. Patients can then make a clear, informed decision as to what treatment pathway they would like to pursue. Prognostic information and early involvement of palliative care are important in assisting patients to make informed choices (Ashby et al., 2005). As seen in a number of other studies, this research shows that “quality of life” and not wanting to be a “burden on family” were the predominant reasons that patients chose a conservative pathway. Carers also agreed that undertaking dialysis treatments would be too much of a strain on the patient (Johnston & Noble, 2012; Tonkin-Crine et al., 2015).

Good communication processes in the renal service ensure that patients feel supported and their wishes are respected. Family and significant others are involved from the onset of discussions. Advance care planning is discussed and completed at the earliest opportunity. Information is provided to help patients make an informed consent to treatment options. There is as much emphasis placed on ensuring that the decision not to pursue dialysis is the right course of action as there is ongoing discussions and support for potential RRT. It is suggested that renal services need to make this switch to accommodate the growing number of frail, elderly people for whom dialysis may not be indicated (Morton et al., 2012).

Waiting is a common theme in the aged care and oncology literature (Tan et al., 2014; Tong et al., 2014). The majority of patients in this study, however, viewed their health, including their CKD, as part of the natural ageing process. Because of this, they try to maintain normality in life. While “waiting” for a change in their health they strive to be normal. This is a theme that reoccurs in the literature regarding people on dialysis — holding on to what they had and adapting by living in the present (Da Silva-Gane & Farrington, 2014; Johnston & Noble, 2012).
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Difficulties for carers adjusting to the declining health of their family are not uncommon to the issues faced by carers caring for frail, older people (Low et al., 2014; Low et al., 2008). Similar to the carers in the study of Noble, Kelly et al., (2012) the uncertainty in determining prognosis increased the anxiety of carers as they worried about the rate of health decline and feared a rapid change. The connection to the RSC service gave them all peace of mind that there is someone to call for advice and support when end of life is near. In general, patients and carers felt that the RSC service staff provide an excellent service.

Study limitations
There was a potential for research bias as one of the researchers was a nurse familiar to the patients. To minimise the impact of this bias, transcripts were de-identified prior to thematic analysis. This study was also undertaken in a single unit so findings may not be transferable to other populations.

Conclusion
This study aimed to gain a greater understanding of the experiences of patients and their carers/families within the RSC service and to identify if the RSC service is meeting individual needs. Six themes were uncovered, four common to both patients and carers and two unique to each group. Common themes were: an awareness of what was going on; informed decision making; feeling supported; and waiting for a decline in health. Patients expressed a need to maintain normality in their lives. Carers discussed the issues and difficulties of adjusting their lives to being a carer. In examining the experiences of the two groups, we were able to gain a deeper understanding of the shared experiences of patients and their carers and the social and emotional issues they face. Open and honest discussions, prognostic information and early involvement of palliative care are crucial to ensure patients and carers can make clear, informed decisions. Connection to the RSC service gave patients peace of mind that there is someone to call for advice and support.

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