The information needs of older people who choose supportive care over dialysis: a case study approach

Jacqui Moustakas, Paul N Bennett & Shelley Tranter

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Abstract

Background
Supportive care is increasingly being viewed as an appropriate alternative option to dialysis or transplantation for older people with advanced chronic kidney disease (ACKD). The purpose of this study was to explore the information needs of older people with ACKD who choose supportive care as their treatment.

Methods
A case study approach using semi-structured interviews and medical case note review methods was used to explore the information needs of six older people receiving supportive care.

Results
The majority of the information the participants had recalled receiving placed a greater emphasis on dialysis over supportive care. Although they did not want dialysis, they were not clear on what supportive care meant or whether they had a supportive care plan. Participants perceived they had never been given specific information about supportive care. Medical case note review revealed infrequent and non-systematic documentation in medical case notes.

Conclusions
In the absence of a formal nephrology supportive care program, information may be provided in an unplanned, non-systematic approach to older people and their families who choose supportive care.

Keywords
Advanced chronic kidney disease, patient education, older people, supportive care, dialysis.

Background
Once people reach advanced chronic kidney disease (ACKD) they are required to make a choice between: (a) renal replacement therapy (RRT) in the form of either kidney transplantation, haemodialysis or peritoneal dialysis; or (b) supportive care. A supportive approach of care is appropriate for all people with chronic kidney disease (CKD), but the general understanding is that supportive care is the treatment provided to people who decide not to receive RRT. The aim of supportive care is to provide comprehensive care and complete management of increasing uraemic symptoms, pain management and psychological support of both the person with ACKD and their family (Jassal, Kelman, & Watson, 2011).

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The term supportive care has been increasingly embraced by renal clinicians (Berzoff, Swantkowski, & Cohen, 2008) as the term implies active treatment with positive implications rather than palliation, which may imply that death is immediately imminent (Davison & Jhangri, 2010). Other nomenclature such as non-dialysis care (Jassal et al., 2011), non-dialytic care (Noble & Rees, 2006; Wong, McCarthy, Howse, & Williams, 2007), conservative management (Abdel-Rahman & Holley, 2010; Murtagh et al., 2007), maximum conservative management (Carson, Juszczak, Davenport, & Burns, 2009) and palliative care (Harrison & Watson, 2011) have been used. The term supportive care can be differentiated from the terms (a) palliative care, which to many people has an association with imminent or immediate death, or (b) conservative management, which may imply limited or non-active treatment (Noble, Kelly, Rawlings-Anderson, & Meyer, 2007). Yet, supportive care does embrace and incorporate all aspects associated with the principles of palliative care. A supportive care approach without dialysis can be a positive way to provide complete care for patients and their significant friends and family (Brown et al., 2013).

Supportive care is increasingly being discussed as a treatment option because of the increasing number of older people with multiple comorbidities with ACKD (Noble, 2008). Comorbidities include coronary and peripheral vascular disease, cerebrovascular disease and decreased cognitive function (Chambers, Germain, & Brown, 2006; Murray et al., 2006; Stevens, Viswanathan, & Weiner, 2010), increased frailty and falls (Jassal & Watson, 2009). These comorbidities impact negatively on their survival and quality of life (QOL). Life quality is a major factor associated with people’s decision to choose supportive care (Ellam, El-Kossi, Prasanth, El-Nahas, & Khwaja, 2009) and can guide the health care team in an individual person’s challenging decision for supportive care over RRT (Clement, Chevalet, Rodat, Ould-Aoudia, & Berger, 2005; Ellam et al., 2009). Those with multiple comorbidities who have chosen not to have RRT have maintained a satisfactory QOL (De Biase et al., 2008).

In Australia, dialysis and renal supportive care patients who encounter high symptom burden have historically been managed by renal clinics on an ad hoc basis with referral to the palliative care team only occurring in the last few weeks of life. However, there has been an increase in interest in formal renal supportive care programs (Brown et al., 2013). These renal supportive care programs have recognised official links with palliative care services and provide collaborative care to patients who choose supportive care (Josland, Brennan, Anastasiou, & Brown, 2012).

The decision to choose supportive care or RRT may be influenced by the type and amount of information that is provided along with the context (Visser et al., 2009). However, the information provided to older people with ACKD regarding making choices about end-of-life care issues is limited (Berzoff et al., 2008; Davison, 2010). To assist in understanding the most appropriate educational resources and practices for supportive care decision making, current accepted educational resources and practices need reviewing as it is not known if they are written at an appropriate level or contain relevant information to people making these choices. To assist in these practice reviews all members of the multidisciplinary team (nurses, doctors, social workers, dieticians and psychologists) can be included, with the patient being the central decision-maker.

In the 2013 Australia and New Zealand Society of Nephrology Renal Supportive Care and Palliative Care Position Statement a key recommendation for research is to explore “methods of communication of prognosis and factors affecting decision-making” (Crail, Walker, Brown, & Renal Supportive Care working, 2013, p. 399). What is not clear are what the best information strategies are and how health care services can improve these strategies. Thus, it was the aim of this study to explore the education and information needs of people who have chosen supportive care.

**Method**

A case study methodology was used for this study including both qualitative and quantitative data, encouraging an in-depth exploration of many aspects of complex issues in real-life settings (Crowe et al., 2011). Methods used were semi-structured interview and medical case note analysis. The study was conducted at two major metropolitan hospitals in Sydney, Australia, with approval provided by the Human Research Ethics Committee of both the health service and affiliated University. This research was performed in accordance with the Australian National Health and Medical Research Council Guidelines (2009).

**Participants**

Purposeful sampling was undertaken in order to invite participants who had chosen supportive care. Participants were aged between 73 and 87 years old, consisting of 4 males and 2 females. Their estimated glomerular filtration rate (eGFR) ranged from 12 to 15 ml/min/1.73m². All participants requested to be interviewed in their own home. All participants were married and had their spouse present, with one also having their daughter at the interview. All participants had been managed by a nephrologist for longer than three months.

**Data collection and analysis**

Semi-structured interviews were conducted by the principal investigator who had no existing relationship with the
participants. The interview facilitated exploration of topics surrounding supportive care, background knowledge of the participant’s kidney disease, information received regarding kidney disease, the effect on family or social life, any services used or required, and what they understood about supportive care and their future (Table 1). The semi-structured nature of the interviews allowed the interviewer flexibility to ask additional probing questions to explore participant responses in greater depth. All interviews were digitally recorded and transcribed verbatim prior to analysis. Case notes were searched and all recorded notations relating to ACKD treatment options were documented.

Table 1: Semi-structured interview questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Example</th>
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<tr>
<td>1. Tell me about your kidney disease; how long have you known you have had kidney disease?</td>
<td>… yeah I read it all, well I’d hate them to waste their time if I wasn’t going to read it, a bit stupid [laughing] (Mrs E)</td>
</tr>
<tr>
<td>2. Who have you seen in regard to your kidney disease? This includes doctors, nurses, dieticians, social workers etc.</td>
<td>Other participants revealed that they had received limited information which was contradicted in their medical case notes where it was documented that their nephrologist had spoken to them about supportive care and the future of their treatment, albeit in differing terminology.</td>
</tr>
<tr>
<td>3. What information have you received?</td>
<td>I have otherwise had a very long discussion with Mr D and for his decision for conservative management, likely symptoms that will arise in the future and the requirement that he should ask for the Community Services early if he has any worsening symptoms. (Case Note #5)</td>
</tr>
<tr>
<td>4. What good or bad experiences have you had in relation to your care of your kidney disease?</td>
<td>One participant stated that he had received formal education on supportive care from his nephrologist, while others stated it had come from a renal nurse. Some stated they had only limited information as exemplified by Mr D.</td>
</tr>
<tr>
<td>5. Has your kidney disease affected your social life? In what way?</td>
<td>… and we haven’t had any more information about managing any kidney failure since then. (Mr D)</td>
</tr>
<tr>
<td>6. Has your kidney disease affected your family life? In what way?</td>
<td>Other participants revealed that they had received limited information which was contradicted in their medical case notes where it was documented that their nephrologist had spoken to them about supportive care and the future of their treatment, albeit in differing terminology.</td>
</tr>
<tr>
<td>7. What services do you receive? Or what services would you like to receive?</td>
<td>I have otherwise had a very long discussion with Mr D and for his decision for conservative management, likely symptoms that will arise in the future and the requirement that he should ask for the Community Services early if he has any worsening symptoms. (Case Note #5)</td>
</tr>
<tr>
<td>8. What is your understanding of supportive care?</td>
<td>One participant stated that he had received formal education on supportive care from his nephrologist, while others stated it had come from a renal nurse. Some stated they had only limited information as exemplified by Mr D.</td>
</tr>
<tr>
<td>9. What do you understand about the future?</td>
<td>Other participants revealed that they had received limited information which was contradicted in their medical case notes where it was documented that their nephrologist had spoken to them about supportive care and the future of their treatment, albeit in differing terminology.</td>
</tr>
<tr>
<td>10. Is there anything that the staff in the hospital can do to make it easier for you?</td>
<td>I have otherwise had a very long discussion with Mr D and for his decision for conservative management, likely symptoms that will arise in the future and the requirement that he should ask for the Community Services early if he has any worsening symptoms. (Case Note #5)</td>
</tr>
<tr>
<td>11. Is there any information that we can provide to your carer?</td>
<td>Other participants revealed that they had received limited information which was contradicted in their medical case notes where it was documented that their nephrologist had spoken to them about supportive care and the future of their treatment, albeit in differing terminology.</td>
</tr>
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</table>

The transcripts were analysed using Braun and Clarke’s (2006) six-step qualitative thematic analysis methods to code themes. Codes were created and themes extracted from the transcribed interviews. Once all data were examined, themes and subthemes were mapped to create a thematic map of analysis. Each theme was then named, and a clear definition was generated by detailing the specific characteristics of each theme.

Results

Findings from the analysis and both the semi-structured interviews and medical case notes revealed four overarching themes relevant to supportive care information: dialysis information but not supportive care information; no to hospital dialysis, yes to living at home; importance of partners and family; and maintaining independence.

Dialysis information but not supportive care information

The participants chose supportive care by default by declining RRT. It was not clear to participants the specific information they received relating to supportive care. Most information provided by clinicians appeared to be about the advantages and disadvantages of dialysis. All participants had been informed by their nephrologist that they could have dialysis if they wished.

According to the participants the information they received differed markedly. Some had received individual sessions by a senior renal nurse whilst they were in hospital. All participants had been given written material about dialysis; some had read the material whilst others did not.

… yeah I read it all, well I’d hate them to waste their time if I wasn’t going to read it, a bit stupid [laughing] (Mrs E)

One participant stated that he had received formal education on supportive care from his nephrologist, while others stated it had come from a renal nurse. Some stated they had only limited information as exemplified by Mr D.

…and we haven’t had any more information about managing any kidney failure since then. (Mr D)
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They believed that hospital dialysis involved potential infections and perceived pain. They chose not to dialyse but live their remaining time at home. Participants explained that going to the hospital for dialysis would be time-consuming and take away time that could be spent with their families or undertaking the activities they enjoyed in life.

Like 3 days a week you’re there for nearly 24/7 and what sort of a life is that? (Mrs E)

The participants also thought they were old and that the limited time left should be spent at home and not in hospital.

… no, that’s, that’s the clue, it’s the age. If I was 60 or 50 perhaps I would think about it. (Mrs E)

… well the reason I chose it is that, well I am 84 now and I was about 80 when I made the decision, I think you are getting a bit too old. And I think you know why bother? (Mr D)

Some participants had their own life experiences of seeing people on dialysis in hospitals.

Because I am a man who worked in the medical field and have seen a few patients who have taken kidney dialysis and have ended up with contamination and formation of access and things like that and suffering very badly I decided not to undergo kidney dialysis. (Mr A)

All participants chose to continue to live their life at home, which meant different things to each of them. The common element was not changing what they do on a daily basis and not having to adjust their life to a medical treatment.

All participants were optimistic in their time frame of living a few more years with their families at home, not on dialysis in the hospital. Mrs E, when discussing how often she saw her nephrologist, believed that “having long gaps between appointments” was a good sign. She believed this meant that her nephrologist expected her to be alive in the future.

No participants mentioned any discussion about advanced care directives (ACD) or had any formal ACD written in their notes or filed at home.

Importance of partners and families

All participants had spouses, with five participants having children and grandchildren. Family members were included in the decision of choosing supportive care. All of the participants and partners showed concern for each other.

That’s why I stay beside her day and night. Even myself, I don’t like to go by myself somewhere, even without her. Doesn’t matter where. (Mrs C’s husband)

All participants had discussed their decision not to pursue dialysis with their partners. The five participants who had children had also discussed it with their children and the participants stated the children were supportive of their decision. There were no opposing or conflicting thoughts. Though Mr E specifically stated it was Mrs E’s decision to make, he was supportive.

It’s her decision. Quite honestly I think it is a sound decision of hers. It’s a sensible one, and I’m inclined to agree with it. I know if it was my position I would do exactly the same thing. So, I’m happy with it. (Mrs E’s husband)

Even when partners were worried about how the other will cope when one dies from their kidney disease, they remained supportive. This was confirmed in the medical case note review where the social worker had documented the support regarding the decision to choose supportive care, despite the fact Mr A was worried how his wife would cope without him.

Throughout the interviews, each participant talked about their partners and how they worried about them and their health. It concerned them all. When the participants were given a finite time to live, it appeared to worry the partners more than the participants. Thus, the family and the participant were critical consumers of the healthcare information in the decision-making process.

Maintaining independence

The participants were keen to remain as independent as possible, with only some requiring minimal care or help in the home.

Community services do come and help certain activities. So far she is able to manage, so we are just trying to prolong the way we are. (Mr A)

Others were keen to inform the interviewer that they were entirely independent. They declined offers of any services and wanted to rely on themselves and their family for support. They stated they would ask for help when needed, but not yet.

Discussion

Through semi-structured interviews and case note analysis, this study confirmed the variation in supportive care journeys while also revealing similarities relevant to the supportive information goals of this study. This study confirmed that in-depth end-of-life care discussions did not seem to be systematically conducted with people suffering ACKD. Surprisingly, there was
a lack of educational information relating to advance directives, which was shown in the results with no participant having had an advance directive in their medical notes.

The participants had limited recollection of the information that had been provided regarding the treatment of their ACKD. They remembered being given education about dialysis and transplantation, but believed they had not been informed about supportive care. This finding contrasts with a previous United Kingdom study where patients who chose supportive care remembered the information given to them (Johnston & Noble, 2012). The participants in the Johnston and Noble study came from a CKD clinic where the same clinicians saw the patients regularly on a two-month basis, reviewing their symptoms in depth and talking about the progression of their renal disease and what they wanted. In comparison, the participants in this study saw different nephrologists and nurses for information. This has implications in that the education given to them may not be appropriate or maybe they are not recalling it consistently (Brunori, 2012).

Importantly, the cognition of this cohort may present a challenge to whether information is really synthesised in the normal education sessions (Sorensen et al., 2012). Cognitive impairment impacts on the older person’s ability to recall information when being educated, but all dialysis patients’ cognition needs assessment. Renal services need to conduct cognitive assessments of their patients to ascertain how information should be provided. This impaired cognition requires clinicians and educators to change the way education is provided.

Older people were focused on living their remaining time at home without the disturbance of dialysis and hospital visits, problems with transport or the possible infections associated with dialysis. They wanted to maintain their QOL, which meant to them staying at home and living day to day with their families. QOL is a complex concept that has different philosophical, political and health-related definitions (Fallowfield, 2009). As an older person commencing dialysis, there is a potential loss of independence (Brunori, 2012), although anyone’s independence may be decreased when commencing dialysis. This study’s findings showed that the older people believed their QOL would deteriorate if they went onto dialysis. Information from supportive care programs (focusing on symptom management, psychological support of patient and family and ACD planning) may need to focus on maintaining independence and contextually relevant strategies are required.

Limitations
A limitation of this study is that it was a small study of six participants for a master’s thesis project. Therefore, saturation of data collected was not tested. A further aspect of the study was that all participants had supportive families and family members present at the interview. The results may have been different from older people without supportive families. This study was from a unit where there were no formal renal palliative links during the study period. The results may be different from a unit where people were supported by a specific palliative care or supportive care program.

Conclusion
Older people with ACKD require information to support their independence and maintain their QOL. Older patients who chose supportive care had a limited understanding of health service strategies to support them. Their recall of formal information provided by their renal service was also limited. This study confirmed the gaps in supportive care information provision when there is no formal renal supportive care program.

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