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How do patients and carers make sense of renal dietary advice? A qualitative exploration

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How do patients and carers make sense of renal dietary advice? A qualitative exploration

Abstract

Background: Dietary modification is an integral part of chronic kidney disease (CKD) management. However, adherence to the renal diet is often suboptimal.

Methods: The aims of this study were to (i) describe the experiences of patients with CKD and their carers in their process of interpreting and implementing renal dietary advice; (ii) to explore strategies they used to make sense of and apply renal diet information and (iii) to develop recommendations for improved clinical practice. To achieve these aims, individual semi-structured interviews with 26 patients and 10 carers were conducted, using interview questions guided by Sensemaking theory.

Findings: Six themes emerged from the data which did not differ according to CKD stage, geographic location or renal replacement therapy (RRT) type. The renal diet was perceived by patients and carers to be overwhelming, frustrating and emotionally demanding; as well as being complex and challenging. To help make sense of and apply renal dietary advice, participants highly valued the input of the dietitian; and patients believed that their carer support was important. Individual problem-solving strategies were developed by participants to help them make sense of the renal diet, and many of them expressed a desire for additional resources and/or support.

Conclusions: This study highlights that learning to make sense of renal diet information is an emotionally challenging journey for patients and carers. In addition to utilising the expertise of dietitians, carer support was perceived to be integral to learning and using renal dietary advice. The study describes a number of important problem-solving strategies utilised by patients and carers, as well as recommendations to help improve sensemaking and adherence to the renal diet.

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23 advice. The study describes a number of important problem-solving strategies utilised by
24 patients and carers, as well as recommendations to help improve sensemaking and adherence
25 to the renal diet.

1 **Keywords:** carer, chronic kidney disease, patient, qualitative exploration, renal diet

2

1 INTRODUCTION

2 A key part of the management of Chronic Kidney Disease (CKD) is dietary modification
3 because changes in diet can delay CKD progression (Palmer et al., 2017) and ameliorate the
4 complications of CKD (Chan and Johnson, 2011, Kang et al., 2017, Ortiz et al., 2014). Other
5 consequences of non-adherence to the dietary self-management recommendations include
6 potentially life threatening hyperkalemia (Pani, 2014, Vlaminck et al., 2001); pulmonary
7 oedema (Wong, 2014); bone demineralisation (Karavetian et al., 2014), neuromuscular
8 complications (Arnold et al., 2017), malnutrition (Obi, 2015) and an overall increase in
9 hospitalisations and mortality (Matteson, 2010). Successful dietary self-management and
10 adherence to the appropriate evidence based practice dietary recommendations (Chan and
11 Johnson, 2011, O'Connor and Kumar, 2012, Ash, 2014) help to reduce complications
12 (Denhaerynck et al., 2007, Arnold et al., 2017, Kalantar-Zadeh and Fouque, 2017) and
13 improve patient outcomes (Ash, 2006, Ash, 2014).

14

15 The dietary prescription for CKD is multifaceted, and the dietary prescription differs between
16 the different stages of CKD (Ash, 2014, Naylor et al., 2013, Kalantar-Zadeh and Fouque,
17 2017). When End Stage Kidney Disease (ESKD) is reached, the dietary prescription also
18 varies between the different renal replacement therapy options. (Ash et al., 2006).

19 Unfortunately, because of the multifaceted changes to the renal diet, patients with renal
20 disease are often faced with complex decisions about which foods they can or can't eat on a
21 regular basis. The complexity of the dietary prescription is further exacerbated, if the patient
22 has diabetes or takes warfarin, both of which require further dietary modifications. Because
23 of these challenges, the diet for people with CKD, inclusive of ESKD, is considered to be one
24 of the most complex, restrictive and challenging therapeutic diets (Hollingdale et al., 2008,
25 Biruete et al., 2017).

1 LITERATURE REVIEW

2 There is limited information about how patients learn and then apply the advice provided to
3 them about the renal diet. The research available is mostly qualitative in nature and
4 dominated by haemodialysis patients. In these studies, patients have reported that the renal
5 diet is difficult to understand and implement (Morris et al., 2015, Mayers, 2000, Meuleman et
6 al., 2014, Sutton et al., 2008, Hollingdale et al., 2008), yet few studies have explored why
7 this is the case. In one of the largest studies to date, 100 patients with CKD reported that they
8 preferred to learn about the renal diet from dietitians and valued receiving a range of patient
9 education resources (Sutton et al., 2008). However, this study did not explore their
10 experiences of learning, nor how they make sense of and apply renal diet information.
11 Similarly, research on how carers of CKD patients support learning and implementation of
12 the renal diet is also scarce. This is surprising given that in several quantitative studies, carer
13 and family support has been associated with higher dietary adherence (Lambert et al., 2017a);
14 better diet quality (Johansson et al., 2013, Thomas et al., 2001), lower interdialytic weight
15 gains (Ahrari et al., 2014, Kara et al., 2007, Kugler et al., 2005), and improved potassium and
16 phosphate levels (Ahrari et al., 2014, Saran et al., 2003, Cicolini et al., 2012).

17

18 AIM OF THE STUDY

19 Based on the paucity of evidence in this important area, the aims of this study were to: (i)
20 describe the experiences of patients with CKD and their carer with respect to interpreting and
21 implementing the renal diet; (ii) explore the strategies used by patients and carers to help
22 them make sense of, and apply renal diet information; and (iii) develop recommendations to
23 help improve the provision of dietetic education to patients with CKD.

24

25 METHODS

1 **Sample:** Invitations to participate were sent by mail to all adults with CKD who had attended
2 a renal dietitian (n=53) or predialysis educator (n=58) outpatient clinic appointment in the
3 [health district name removed for peer review purposes] between August to October 2016. In
4 addition, invitations were sent by mail to all patients in the Department of Renal Medicine
5 who were known to be undertaking peritoneal dialysis (n=40), in centre haemodialysis
6 (n=139), or were among the 50 most recent patients who had undergone kidney
7 transplantation in the same department. This recruitment strategy was chosen to ensure that a
8 diverse range of patient experiences were represented and that the perspectives of patients
9 from metropolitan, regional, and rural areas in the health district were included. Patients and
10 carers were excluded if they were under 18 years of age and if they were unable to be
11 interviewed in person or via phone during the study period. Interpreters were used for
12 participants who could not speak English (n=1). Interested participants were asked to contact
13 the main author, who was known to some of the participants as the renal dietitian, to arrange
14 an interview time.

15 **Data collection:** This qualitative study assumed a relativist ontological position and utilised
16 the ‘Sensemaking’ theoretical framework (Dervin and Foreman-Wernet, 2012) to construct
17 the semi-structured interview guide (shown in Table 1). The focus of ‘Sensemaking’ theory is
18 the exploration of how individuals fill the ‘gaps’ in their understanding when they encounter
19 situations or information that they do not understand (that is situations or information that
20 does not ‘make sense’). The emotions associated with the ‘Sensemaking’ process (Dervin,
21 1998), and the nature of the ‘help’ that is provided to the individual to facilitate
22 ‘Sensemaking’ (Godbold, 2013) are of particular interest. ‘Sensemaking’ theory can therefore
23 help to obtain useful information about how patients and their carers experience, learn and
24 use the dietary education provided to them about the renal diet.

25

1 The individual semi-structured interviews were conducted by the first author, either in person
2 at the renal unit of the patient's choice or via the telephone. Interviews with patient – carer
3 dyads were conducted at the same time. The semi-structured interview questions were not
4 pilot tested prior to data collection. However, prompt questions (shown in Table 1) were used
5 in all interviews to ensure that all participants were prompted in a similar manner. Participant
6 checking of the transcripts was invited but no participant wished to do so. Information
7 regarding patient demographics, stage of kidney disease and duration of renal replacement
8 therapy role were obtained directly from patients and carers during the interviews. Participant
9 recruitment ceased when no new concepts or themes were described by study participants in
10 subsequent interviews (i.e. data saturation was reached). This is in keeping with the literature
11 relating to data saturation in qualitative research that indicates data saturation is reached
12 when interviews contain abundant and repeated accounts of the same phenomenon of interest
13 (Malterud et al., 2016, Morse, 1995). This study was approved by the joint University of
14 [name of ethics committee removed for peer review purposes] (Application number
15 HE2016/314).

16
17 **Data analysis:** Interviews were audiotaped and transcribed verbatim for analysis. Dedoose
18 software was used to manage, store the coding index and code the data (Dedoose Version
19 7.5.9, 2017). In keeping with the Framework approach used to guide the thematic analysis
20 (Smith and Firth, 2011), line by line coding of the transcripts was conducted by each of the
21 authors, who formed their own initial codes. All authors then met to compare and refine these
22 codes (core concepts) and to organise them into the initial categories. These categories were
23 then further refined via an iterative discussion between the authors to produce the final
24 analytical framework. This analytical framework was then applied to the transcripts and
25 facilitated the identification of the main themes. This process was used to enhance study rigor

1 and to ensure that the analysis reflected the full range and breadth of data. Illustrative quotes
2 that best captured the essence of the main themes were identified by the main author and the
3 final quotations included in the final manuscript were agreed upon by all authors.

4

5 **FINDINGS**

6 Twenty-six patients with CKD and ten carers consented to participate in the study, which
7 included nine patient–carer dyads and one carer who participated in the study without the
8 patient (Carer of patient 4). Of the ten carers involved in this study, seven (70%) were
9 female. No other demographic data was collected on carers.

10

11 The majority of patients (n=21, 81%) reported that the dietitian was the first source of renal
12 diet information. Other details regarding the characteristics of the patient participants are
13 shown in Table 2. In brief, over half of the patient participants were undertaking a renal
14 replacement therapy (n=15, 58%) and were male (n=15, 58%). Their median age was 66
15 years (IQR: 62.75-76 years), with a wide age range (30-86 years). The geographic location of
16 patients was spread evenly across metropolitan (n=8), regional (n=10) and rural (n=8) areas.
17 For those patient participants undertaking a RRT, the majority (n=19, 73%) had more than 6
18 years' experience of the RRT; and five of them (19%) had undertaken more than one type of
19 RRT. Interview times ranged from 13 minutes to more than 1.5 hours, with a mean interview
20 length of 30 minutes.

21

22 The quotations included below have been abbreviated to preserve participant anonymity and
23 are cited as Patient (P) or Carer (C) (number), and stage of CKD or type of RRT (e.g.
24 CKD3b: CKD stage 3b; PD: peritoneal dialysis, KT: kidney transplant, HD: haemodialysis,).

25

1 The following six themes emerged from the data about how patients and carers experienced,
2 learned and used renal diet advice. Themes did not differ according to CKD stage, geographic
3 location or RRT type. The renal diet was perceived by patients and carers to be: (i) an
4 overwhelming, frustrating and emotional journey; as well as being (ii) complex and
5 challenging. To assist with using, applying and making sense of the renal diet advice,
6 participants stated that (iii) dietitian input is highly valued (iv); carer support is important;
7 and that they (v) develop problem solving strategies. However, participants also expressed
8 (vi) a desire for additional resources and/or support.

9

10 **Theme 1: An overwhelming, frustrating and emotional journey**

11 Both patients and carers felt that learning about the renal diet was an overwhelming,
12 frustrating and emotional journey. This was partly because many participants had minimal
13 knowledge of the purpose of the diet, and had a poor understanding of kidney disease more
14 broadly.

15 *“Diabetes I can understand. Heart I can understand. Kidneys I got no clue”*

16 *(P11, CKD3b)*

17 Patients and carers felt overwhelmed by the dietary information provided to them and
18 described it as being excessive, difficult to absorb, and too complex.

19 *“I went out (of the appointment) and my head was just ...spinning ...I was*

20 *unprepared and had no idea what to expect” (P10, CKD5)*

21 *“You had to be aware of so many different things...I was very overwhelmed”*

22 *(Carer P2, HD)*

23 Frustrations regarding the renal diet were attributed to: not receiving helpful advice;
24 perceiving that they had a limited range of foods to consume; receiving didactic advice with

1 no explanation or rationale; and/or receiving dietary advice that included foods or ingredients
2 unfamiliar to them.

3 *“I was frustrated with what I didn’t know... what the different vegetables or different*
4 *ingredients that I never ever cooked (with) were” (P16, CKD4)*

5 Learning how to balance the different components of the renal diet was another source of
6 frustration. The metaphor of a jigsaw puzzle, or juggling act, was used by some participants
7 to describe their experiences.

8 *“It is like a jigsaw puzzle and what was needed was for someone to say these are the*
9 *pieces and this is where we are going and how all the pieces go together” (P14,*
10 *CKD2)*

11 Participants also described feeling frustrated about receiving conflicting renal diet advice,
12 from many sources which included patient education sheets, other health practitioners (e.g.
13 doctors and nurses); family and friends; other CKD patients, and the internet. Participants
14 suggested that this conflicting advice contributed to their confusion and / or anxiety, and
15 often left them with more questions than answers.

16

17 In addition to feeling overwhelmed and frustrated, patients and carers described feeling
18 fearful about the renal diet. Patients feared that they would consume the ‘wrong’ food, and
19 carers feared that they would serve the ‘wrong’ food.

20 *“I am more relaxed now...but before it was ahhh ! I can’t do anything because of that*
21 *fear ...that I was going to do the wrong thing” (P21, HD)*

22 *“I want to do the right thing for him..... what happens if I do it wrong maybe he*
23 *could die (Carer P4, HD)*

1 From an emotional perspective, participants not only described a sense of fear about the renal
2 diet, but they also described experiencing a sense of loss about not being able to consume
3 their favourite foods or meals.

4 *“I grieved...I really did...I know that it would be nice to have that (a banana
5 smoothie) but I can’t” (P2, HD)*

6 Others perceived that their dietary restrictions contributed to social isolation.

7 *“People don’t realize (the diet) restricts the people who have CKD...of having a social
8 life and social life is what makes life. It is what gives you pleasure.” (Carer P13,
9 CKD4).*

10

11 **Theme 2: A complex and challenging diet**

12 Participants commonly used words such as ‘shell shocked’, ‘stunned’ or ‘surprised’ to
13 describe their initial reactions to learning about the complexity and challenges of the renal
14 diet. They were especially concerned about how they were going to incorporate renal dietary
15 restrictions into their regular diets, particularly if they were managing multiple therapeutic
16 diets simultaneously.

17 *“Which one (diet) do you stick to more... the one for his diabetes...or his kidney
18 disease ... his heart. ...Plus he is on warfarin...I have never been so confused in my
19 life!” (Carer P11, CKD3b)*

20

21 Many participants stated that the renal diet continued to remain complex and challenging
22 over time.

23 *“Even after all these years my brain is working all the time ...just trying desperately
24 to get things right (with the diet)” (P22, HD).*

1 Participants also stated that making sense of the renal diet was challenging when they were
2 presented with unfamiliar terms, such as ‘*low potassium*’ or ‘*low phosphate.*’ They described
3 their struggles with learning about the food sources of these electrolytes

4 *“Potassium is not on food labels... I have a chart with the (foods) to avoid ...but the*
5 *list is far from complete” (P12, CKD4)*

6

7 **Theme 3: Dietitian input is highly valued**

8 Overall, participants highly valued the input of the dietitian, feeling reassured and
9 empowered by their contact with the dietitian.

10 *“After I saw the dietitian, I was more relaxed... that I had been doing the right thing”*
11 *(P16, CKD4)*

12 They described it especially helpful and reassuring when dietitians explored their prior
13 knowledge and understanding about their renal diet, and would have appreciated advice
14 regarding possible slight deviations from the diet.

15 *“I would have liked to have known that it is all right to follow (the diet) in*
16 *moderation ...I was feeling very guilty all the time and I didn’t need to be”*
17 *(P17, HD)*

18 Access to the same dietitian during critical stages, such as during changes to the dietary
19 prescription because of changes to RRT, were also truly valued.

20 *“Coming back (to the same dietitian after transplant) was good ...I liked to speak to*
21 *(the dietitian)...who knew me already” (P23, KT)*

22 Participants suggested that the renal diet information sheets provided by the dietitian were
23 very useful.

24 *“She (the dietitian) gave me information sheets ...and they were very useful because*
25 *you would keep referring back to them” (P20, CKD4).*

1 However, some participants perceived that the information sheets did not contain adequate
2 practical advice, which in turn hindered their ability to apply the renal diet advice

3 *“I wanted more ...concrete information ...you (dietitians) all know what you are*
4 *doing, but I am learning to do something that is completely foreign to me you know”*
5 *(Carer P2, HD)*

6 *“I think (dietitians) guidelines are great ...but if you (patient) can't find a way to put*
7 *that guideline into action then it is worthless” (P9, CKD2)*

8 Some participants also felt that the dietetic advice and meal plans lacked individualisation,
9 and that this too hindered sense making.

10 *“I just feel like ...the advice is not personalised ...so more individualisation is*
11 *needed” (P19, KT)*

12 Aspects of individualisation that were considered essential for sense making included;
13 guidance about how to prioritise the multiple components of the diet, and in particular which
14 elements of the renal diet were most critical to follow. Furthermore, education regarding how
15 to make the diet palatable; how to adapt the diet for family meal events; and how to increase
16 diet variety were suggested. Participants expressed a desire for the dietitian to explicitly flag
17 or ‘signpost’ sources of good quality online information.

18 *“It would have been helpful if we had been given a list of good websites to look at”*
19 *(Carer P18, CKD4)*

20 **Theme 4: Carer support is important**

21 Patient participants described that it was essential for the carer to be present during the renal
22 diet education sessions, especially during the early stages.

23 *“If you are a patient who is just starting out and you have to learn about the diet*
24 *...don't do it without your spouse” (P7, PD)*

1 Carer support was perceived to strengthened dietary adherence and to assist with recall of
2 important concepts regarding the renal diet.

3 *“My (carer is important) because I really do need another set of ears (in the*
4 *appointment) to help me” (P20, CKD4)*

5 *“My (carer)... has learned it over time...she can hold it in her brain longer than I can*
6 *... I can't recall (information)” (P16, CKD4)*

7 **Theme 5: Developing problem solving strategies**

8 Participants described a range of problem solving strategies they used to help them interpret
9 and make sense of the renal diet. The six most common strategies described included: talking
10 with other patients; searching the internet; developing their own individualised resources;
11 using feedback from blood tests; as well as using technology and experimentation. They used
12 these strategies to determine appropriate meals for consumption, to adapt their own recipes,
13 to increase the palatability of the renal diet, and to determine if foods or meals not included
14 on renal diet sheets were considered ‘safe’ to eat. They applied these problem-solving skills
15 to learn more about food composition, as well as unfamiliar ingredients, foods and cuisines.

16 *“We have had to become foodies...because you have got to know what is in it”*
17 *(Carer P13, CKD4)*

18 Some participants created their own informal peer networks, and used these interactions to
19 discuss the challenges of the diet, and to obtain and share information, such as recipes, food
20 lists and menu ideas. They shared their menu ideas or food lists with family, friends or
21 colleagues to facilitate social eating occasions.

22 *“We gave the list to our (friends) and they try to avoid serving him things he can't*
23 *have” (Carer P13, CKD4).*

24 Searching for renal diet information on the internet was a strategy described by almost all
25 participants, regardless of their age, gender and/or stage of CKD. They searched online to

1 obtain additional practical information (such as recipes, food lists and meal ideas) and to fill
2 their renal diet knowledge gaps. The internet was described by many participants as the first
3 place they looked for information when told they needed to follow a special diet.

4 *“To figure out what to have for dinner, I have a Google look” (Carer P18, CKD4).*

5 Other participants stated that they searched online when the renal diet resources they were
6 given did not meet their information needs.

7 *“I resorted to Dr Google ... because ...the (renal diet information) pamphlets ...are
8 pretty vague ...it doesn't actually say don't eat these foods ...it says avoid ...so then
9 you are just not sure exactly where you stand” (Carer P6, PD)*

10 Another strategy used by participants was to construct their own renal diet resources, which
11 they adapted for their own needs and sometimes used to guide food choices when shopping
12 or during social outings.

13 *“I adapted the original (diet sheet) that the dietitian gave us...tweaked it”
14 (Carer P13, CKD4)*

15 Blood test results were frequently used as a problem-solving strategy to help determine how
16 successfully the patient was adhering to the renal diet.

17 *“The way we know we (are) doing the right thing (with the diet) ... if we weren't then
18 the blood tests would show” (Carer P23, KT)*

19 An additional strategy described by many participants, including those over the age of 65,
20 included the use of technology. They described using apps on their mobile devices (e.g.
21 phones, tablets) to monitor their dietary intake, to objectively gauge their adherence and to
22 assist with purchasing food at the supermarket or in restaurants.

23 *“This app makes it a lot easier to find out quickly (if) it (the food) is a problem for
24 me” (P10, HD)*

1 *“I (use) an app (to record) how much protein ... carbohydrates and my overall fluid*
2 *intake” (P9, CKD2)*

3 Finally, experimentation with the diet over time was another key strategy used by the
4 participants. Adherence to the diet was initially strict, however over time, participants began
5 to experiment and reintroduce foods back into the diet.

6 *“It is a matter of experimenting over a long time and testing what you can eat”*
7 *(P16, CKD4)*

8 **Theme 6: A desire for additional resources and/or support**

9 Despite valuing the expertise, advice and support of the dietitian, participants also expressed
10 a desire for a range of additional resources and support. These broadly included alterations to
11 the renal diet resources and access to peer support. Patients expressed a preference for
12 receiving resources that were easy to read and understand with illustrations which were
13 tailored to their individual learning styles:

14 *“Pictures and colours I remember ...and the potassium pyramid ...was helpful for me*
15 *...because I am a visual person” (P21, HD)*

16 They suggested that words such as ‘processed’ or ‘portion’ were vague and unhelpful.

17 *“I didn’t know on the diet sheet what was meant by processed meat ...well what is*
18 *processed meat? Everything is processed!” (P13, CKD4)*

19 Peer support was not only perceived to be a problem-solving strategy, but also a desirable
20 resource which almost all patients wanted to access, regardless of their age or stage of CKD.

21 *“To talk to another person that is not ...a professional but has the disease ...is a great,*
22 *great help” (P12, CKD4).*

23 *“It would have been helpful (to have access to a peer) because we had to struggle our*
24 *own way through it ...and sometimes I got disheartened” (Carer P13, CKD4)*

25

1 **DISCUSSION**

2 This qualitative study found that patients and carers described their experience as being
3 highly emotive, complex and challenging. They suggested however, that while carer support
4 is integral to the sense making process, so too is input from dietitians, which they highly
5 valued. To address gaps in understanding, patients and carers in this study developed their
6 own renal diet problem solving strategies and recommended additional support and resources
7 to further improve their understanding and application of the renal diet.

8

9 One of the key findings from this study was that there is a long lasting emotional impact that
10 results from receiving renal diet advice, and an ongoing emotional burden associated with
11 applying this advice. Similar to previous research (White and Grenyer, 1999, Lo et al., 2016,
12 Low et al., 2014, Morris et al., 2017), patients felt poorly equipped to deal with the
13 challenges and complexity of dietary changes required. Interestingly, the emotional
14 experience of carers was similar to that of patients. This finding appears to be novel in the
15 context of dietetic advice, but is similar to previous work by others investigating
16 psychological adaptation to self-management in CKD or other chronic illness contexts
17 (Marlow et al., 2016, Swallow et al., 2014, Boer et al., 2014, Telford et al., 2006, Sidell,
18 1997, Pitt et al., 2017). However, participants in this study also described moving on from
19 feeling overwhelmed and frustrated, to accepting that the diet was important to maintain their
20 health and developed strategies enabling them to apply the renal diet to their everyday lives.
21 These are important findings for clinicians because being attentive to the how a patient and
22 their carer may be feeling has been associated with positive clinical benefits (Rees et al.,
23 2017). Being attentive to the emotional state of patients and carers will also influence the
24 timing, content and teaching techniques used by clinicians in their renal diet education
25 (Ormandy, 2008).

1
2 Three factors were identified in this study as important facilitators of renal diet sensemaking.
3 The first was input from the dietitian, which is consistent with previous work where dietitians
4 were identified as a preferred and trustworthy source of renal diet information (Sutton et al.,
5 2008, Hollingdale et al., 2008). However, this study extends the evidence base by
6 highlighting that it is not only the dietary information that facilitates sensemaking about the
7 renal diet, but also the reassurance and empowerment that is provided. The importance of
8 carer support was the second facilitator to renal diet sensemaking identified in this study.
9 Carers facilitated and supported health decisions relating to the renal diet, and assisted with
10 learning when memory loss or information overload was experienced by the patient.
11 Furthermore, carers also assisted with shopping and meal planning decisions. These findings
12 suggest that to facilitate sensemaking for patients, it is important for dietetic services to be
13 attentive to meeting the renal diet information needs of carers (Pratt and Searles, 2017,
14 Verseput and Piccoli, 2017), by routinely inviting and involving them in education sessions
15 (Hollingdale et al., 2008). Specific carer training about the renal diet (such as cooking or
16 meal preparation classes) may also be of use, because it may help to reduce carer burden and
17 improve psychosocial outcomes for both patients and carers (Tong et al., 2008, Farmer et al.).
18 The third facilitator of renal diet sensemaking, identified in the current study, involved the
19 use of strategies to solve renal diet related problems. Some of these problem solving
20 strategies, concur with evidence in the literature, such as feedback from blood tests (Palmer et
21 al., 2015), and experimentation (Tovazzi and Mazzoni, 2012). However, using peers to assist
22 with sensemaking and as a source of practical renal diet advice; developing their own
23 individualised resources; and the use of online resources and technology to assist with
24 sensemaking are new findings. These findings also highlight the need for dietitians (or other
25 clinicians who may be responsible for providing dietary advice to patients with CKD) to be

1 vigilant about what their patients have learned from their peers, how they have individualised
2 their resources and which online resources/technologies they are using. Furthermore, since
3 the quality and accuracy of online renal diet information is highly variable (Lambert et al.,
4 2017b, Lambert et al., 2017c) we suggest that clinicians provide guidance about where to
5 locate accurate, reliable and good quality renal diet information, as well as useful and
6 appropriate forums or blogs for interested patients and carers.

7
8 The advantage of using Sensemaking theory to guide the semi-structured interview questions
9 is that it helped to identify complexity of the renal diet as a key barrier to sensemaking. This
10 is consistent with previous research which described patients' difficulties with understanding
11 the health information provided (Lambert et al., 2015, Sussmann, 2001, Kelly et al., 2017). In
12 addition to the complexity of the diet, patients and carers in the current study described
13 receiving renal diet information that was confusing and contradictory. Some of the
14 difficulties experienced by patients when interpreting messages on diet sheets, could be
15 attributed to the high level of cognitive impairment in patients with CKD (Lambert et al.,
16 2016); as well as low health literacy experienced among this patient population (Taylor et al.,
17 2017, Lambert et al., 2015). To address potential barriers to sensemaking and difficulties with
18 the interpretation and application of the renal diet that may be due to inadequate health
19 literacy, we recommend incorporating several rounds of teachback (Dinh et al., 2016) during
20 education sessions to evaluate recall, and to ascertain understanding of important or complex
21 concepts (Gibbs, 2017, Gibbs and Chapman-Novakofski, 2012, Dantic, 2014, Negarandeh et
22 al., 2013, Porter et al., 2016). Other strategies to address health literacy related barriers,
23 include using plain language for all verbal and written communications, which will assist
24 with patient empowerment (Loukanova et al., 2007), and adherence to recommendation
25 (Miller, 2016, Carrara and Schulz, 2017).

1

2 Other barriers identified by participants in this study, included perceptions that they had not
3 received adequate individualised practical dietary advice, and that they had difficulties
4 prioritising various components of the renal diet. These findings are similar to those
5 described by previous researchers (Sutton et al., 2008, Morris et al., 2017, Sussmann, 2001,
6 Meuleman et al., 2014, Palmer et al., 2015). However, what is novel about the present study
7 findings is that the use of ‘signposting’ could help to overcome these barriers. Signposting
8 could be used to structure dialogue enabling patients and carers to follow where the
9 conversation is going and why (The Center for Healthcare Communication, 2010, Kurtz et
10 al., 2003). Participants wanted clinicians to explicitly describe or ‘signpost’ elements of the
11 diet or dietary prescription that were considered important for them. Other information that
12 could be signposted included advice about how to eat out, how to include favourite foods,
13 how to combine and manage multiple diet prescriptions (for example the renal and diabetic
14 diet prescriptions), and when and where to go for further information. Further studies
15 evaluating the impact and efficacy of using signposting during patient education encounters
16 are required.

17

18 **IMPLICATIONS FOR PRACTICE**

19 Several recommendations were suggested by participants in the present study to facilitate
20 renal diet sensemaking. For instance, they suggested reassurance from the dietitian to confirm
21 and verify their understanding of important renal diet related concepts was important.

22 Participants also suggested that patient education resources be available in formats which
23 were easy to read and understand with illustrations to facilitate sensemaking. The evidence
24 substantiates that utilising these formats for patient education resources are particularly
25 effective, and have been shown to be superior to traditional methods of instruction (Pratt and

1 Searles, 2017, Verseput and Piccoli, 2017, Houts et al., 2006b, Peregrin, 2010, Houts et al.,
2 2006a).

3

4 Access to peers for support and to facilitate learning about the renal diet were suggested by
5 participants in the present study. Clinicians should therefore consider how to utilise the
6 expertise of peers, not only because it is important to patients (Meuleman et al., 2014, Patel et
7 al., 2005), but also because they are considered integral components of effective educational
8 interventions in patients with CKD (Lopez-Vargas et al., 2016). Other suggestions included a
9 desire for clinicians to provide a clear explanation and rationale for the dietary changes, as
10 well as providing guidance about how to manage multiple therapeutic diets (when
11 appropriate).

12

13 Another recommendation borne out of the present study findings is to ensure that renal
14 dietary advice is understandable and actionable. Clinicians, such as dietitians, could therefore
15 better support patients to translate information about the renal diet by utilising additional
16 strategies to promote sensemaking and to increase patient and carer knowledge and
17 understanding (Loukanova et al., 2007). This could be facilitated by using question prompt
18 sheets prior to and during the appointment (Sansoni et al., 2015, Lederer et al., 2016); and by
19 discussing appropriate information seeking practices with patients and carers (Bonner and
20 Lloyd, 2012). Reviewing the need for additional advice and education at an important renal
21 diet transition point, such as when commencing a new RRT, is also recommended. Moreover,
22 multifaceted methods of interaction, such as using both verbal and written communication
23 when delivering the information, in conjunction with phone follow up, and practical group
24 work or workshops should also be considered because these are effective methods for

1 empowering CKD patients and delivering educational interventions (Lopez-Vargas et al.,
2 2016).

3
4 There are a number of strengths to this research. For instance, purposive sampling from a
5 diverse pool of patients with CKD and their carers was used to ensure a wide range of
6 participant experiences and stages of CKD were included. Transcripts were examined by
7 three analysts working independently and the themes that emerged from the transcripts were
8 derived via a consensus process. Another strength of this research, was that the lead author,
9 who conducted the interviews, is an experienced renal dietitian thereby facilitating a richer
10 exploration of the topic. In addition to these strengths, there are several limitations which
11 need to be acknowledged. For instance, even though dietitians provided the majority of
12 dietary advice to participants in this study, it is important to recognise that the practice of
13 dietitians and the dietary guidelines used may differ in other countries where nurses or other
14 clinicians may provide dietary counselling. Another potential limitation is that the interviews
15 were conducted by a person known to some of the participants, which may introduce
16 response bias. We believe this has been minimised by using a semi-structured interview
17 question guide based on the Sensemaking theoretical framework (Dervin and Foreman-
18 Wernet, 2012) with internally consistent questions and prompts. Another limitation is that a
19 small number of patients from only one health district were included. Furthermore, patients
20 from culturally and linguistically diverse backgrounds, and those with early CKD or in the
21 very early stages of commencing RRT, were also underrepresented in this research.

22

23 **CONCLUSION**

24 Dietary modification is fundamental to the management of CKD. The findings from this
25 study highlight that the experience of learning to interpret and apply renal diet advice is

1 complex, challenging and accompanied by an ongoing emotional burden for patients and
2 carers. Patients and carers value the expertise of the dietitian, but also needed to develop a
3 range of their own problem-solving strategies, over time, to make sense of the renal dietary
4 advice. It is suggested that additional strategies be incorporated into the patient education and
5 counselling process to help future patients and carers to make sense of the renal diet.

6

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9 share their experiences and expertise. Their commitment to improve services for others is
10 greatly appreciated.

11

12 **Transparency Declaration**

13 The lead author affirms that this manuscript is an honest, accurate, and transparent account of
14 the study being reported. The reporting of this work is compliant with the COREQ
15 guidelines. The lead author affirms that no important aspects of the study have been omitted
16 and that any discrepancies from the study as planned have been explained.

17

18 **Author contributions**

19 KL: Responsible for conception and design of the study, recruitment, data collection, data
20 analysis and primary responsibility for writing the manuscript. JM and KM: Both contributed
21 to refinements in study design, thematic analysis, and reviewed and edited the manuscript.

22

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35

Table 1. Semi structured interview guide based on Sensemaking methodology.

<p>Describing an experience related to learning about the renal diet</p> <p>I would like you to think back to a time that really stands out in your mind, when you were provided with renal diet information. It might be the first time or might be another time. I want it to be a time that is memorable – good or bad.</p> <p>Can you describe that experience of receiving the dietary advice?</p> <p><i>Prompts:</i></p> <ol style="list-style-type: none"> a. <i>What was the reason you were given renal diet advice ?</i> b. <i>Who gave you the advice ?</i> c. <i>Where did you go to get the advice ?</i> d. <i>Was there anyone else there with you ?</i> e. <i>Were you given anything at the time to help you understand ? pamphlet ? diet sheet ?</i> f. <i>How did the experience make you feel ?</i>
<p>Describing aspects that facilitated or were barriers to sensemaking</p> <p>Was there any part of the experience of receiving the dietary advice that you found reassuring or helpful to you or your carer?</p> <p><i>Prompts:</i></p> <ol style="list-style-type: none"> a) <i>What information were you given ?In what format ?</i> b) <i>What were the consequences of being give this ?</i> c) <i>Did this (name the part) affect the way you followed your diet ?</i> d) <i>How did (name part or person giving that advice) help / facilitate (and how did that help ?)</i> e) <i>Was there anything that (name part or person giving that advice) did that hindered following the advice ? (and how did it do this ?)</i>
<p>Verbalizing the gaps and struggles regarding the sensemaking process</p> <p>What were the big questions that you were left with as a result of the dietary advice?</p> <p><i>Prompts</i></p> <ol style="list-style-type: none"> a. <i>What were you trying to figure out ?</i> b. <i>What did you struggle with ?</i> c. <i>Was there anything you were left trying to understand ?</i>
<p>Tapping into emotions associated with sense making</p> <p>How did this experience (of receiving the dietary information) make you feel?</p> <p><i>Prompts:</i></p> <ol style="list-style-type: none"> a. <i>What emotions did you have at the time?</i> b. <i>Was it related to the experience?</i> c. <i>What conclusions do you come to from this situation?</i> d. <i>How did you come to those conclusions ?</i>
<p>Recommendations and suggested solutions to improve sensemaking</p> <p>What feedback can you offer us so we can improve things? If you could wave a magic wand what would have helped you ?</p> <p><i>Prompts:</i></p> <ol style="list-style-type: none"> a) <i>What was missing from the renal diet advice experience that you had ?</i> b) <i>How did that stop you from following the advice ?</i> c) <i>Was there anything else that was limited, incomplete or not effective or not helpful ?</i> d) <i>What could make a difference?</i> e) <i>Was there anywhere else that you looked or talked to for renal diet advice ?</i> f) <i>Was there anyone else you talked to, to help you make sense of the advice?</i> g) <i>How did that help ? What did they do that helped you understand ?</i>

Table 2. Characteristics of patient participants in the study

	Number of patient participants N=26
Gender (male, %)	15 (58%)
Median (interquartile range) age in years	66.0 (62.75-76.0)
Age range of participants in years	30-86
Age category of participants	
30-39 years	2
40-49 years	0
50-59 years	3
60-69 years	9
70-79 years	9
80+ years	3
Marital status of participants	
Married / Defacto	21
Single	2
Widow	0
Divorced	3
Geographic location of participants	
Metropolitan	8
Regional	10
Rural	8
Stage of CKD / RRT modality	
Predialysis (CKD stage 4 or 5)	9
Hospital centre based hemodialysis	6
Home hemodialysis	2
Peritoneal dialysis	4
Kidney Transplant	3
Early CKD (CKD stage 1 or 2)	2
Have undertaken more than 1 type of RRT	5
Number of participants receiving diet advice in prior 6 months	8 (31%)
Median duration of RRT (years, interquartile range)	7 (5-11)
Years of RRT	
0-1 year	1
1-5	3
6-10	6
>10	5