



## Dietary and Fluid Restrictions in CKD: A Thematic Synthesis of Patient Views From Qualitative Studies

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**Background:** Managing the complex fluid and diet requirements of chronic kidney disease (CKD) is challenging for patients. We aimed to summarize patients' perspectives of dietary and fluid management in CKD to inform clinical practice and research.

**Study Design:** Systematic review of qualitative studies.

**Setting & Population:** Adults with CKD who express opinions about dietary and fluid management.

**Search Strategy & Sources:** MEDLINE, EMBASE, PsycINFO, CINAHL, Google Scholar, reference lists, and PhD dissertations were searched to May 2013.

**Analytical Approach:** Thematic synthesis.

**Results:** We included 46 studies involving 816 patients living in middle- to high-income countries. Studies involved patients treated with facility-based and home hemodialysis (33 studies; 462 patients), peritoneal dialysis (10 studies; 112 patients), either hemodialysis or peritoneal dialysis (3 studies; 73 patients), kidney transplant recipients (9 studies; 89 patients), and patients with non-dialysis-dependent CKD stages 1 to 5 (5 studies; 80 patients). Five major themes were identified: preserving relationships (interference with roles, social limitations, and being a burden), navigating change (feeling deprived, disrupting held truths, breaking habits and norms, being overwhelmed by information, questioning efficacy, and negotiating priorities), fighting temptation (resisting impositions, experiencing mental invasion, and withstanding physiologic needs), optimizing health (accepting responsibility, valuing self-management, preventing disease progression, and preparing for and protecting a transplant), and becoming empowered (comprehending paradoxes, finding solutions, and mastering change and demands).

**Limitations:** Limited data in non-English languages and low-income settings and for adults with CKD not treated with hemodialysis.

**Conclusions:** Dietary and fluid restrictions are disorienting and an intense burden for patients with CKD. Patient-prioritized education strategies, harnessing patients' motivation to stay well for a transplant or to avoid dialysis, and viewing adaptation to restrictions as a collaborative journey are suggested strategies to help patients adjust to dietary regimens in order to reduce their impact on quality of life.

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**INDEX WORDS:** Chronic kidney disease (CKD); renal replacement therapy (RRT); dialysis; kidney transplant; diet; fluid management; treatment adherence; qualitative research; thematic synthesis; patient-centered care; patient perspective.

Chronic kidney disease (CKD) causes water, sodium, potassium, and phosphorus retention, which contributes to cardiovascular events, intradialysis symptoms, breathlessness, and edema. Obesity is a risk factor for end-stage kidney disease,<sup>1</sup> while malnutrition is endemic in people with advanced CKD and is associated with mortality.<sup>2</sup> However, adherence to dietary regimens in CKD is

challenging due to the burden of constant choices about food and drink, the adaptation to complex eating patterns, existing cultural practices, and the competing demands of CKD and related illnesses.<sup>3-6</sup>

Guidelines recommend that people with CKD receive dietary advice to intervene in salt, phosphate, potassium, and protein intake and emphasize the importance of dietary counseling.<sup>7</sup> While dietary

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interventions are considered central to the management of CKD, health professionals cite insufficient time to implement recommendations,<sup>8</sup> and inclusion of patient experiences and perceptions of dietary treatment in CKD guidelines is limited.<sup>7</sup>

We aimed to summarize patients' perspectives and choices of dietary and fluid management in CKD provided in existing qualitative studies to inform clinical practice and research.

## METHODS

We conducted this review using the ENTREQ (Enhancing Transparency in Reporting the Synthesis of Qualitative Research) framework.<sup>9</sup>

### Selection Criteria and Literature Search

We included qualitative data for adults 18 years or older who had CKD and who expressed opinions about diet or fluid management. We included CKD stages 1 to 5, kidney transplant recipients (5T), and people treated with dialysis (5D).<sup>7</sup>

### Data Sources and Searches

Electronic databases (MEDLINE, EMBASE, PsycINFO, CINAHL [Cumulative Index to Nursing and Allied Health Literature], and Google Scholar), reference lists of included studies, and PhD dissertations were searched to May 7, 2013 (Item S1, available as online supplementary material). Two authors (S.C.P. and G.F.M.S.) screened all records and discarded those that were not eligible. The full text of the remaining citations then was examined to identify qualitative data.

### Comprehensiveness of Reporting

S.C.P. and C.S.H. independently assessed the comprehensiveness of reporting using the COREQ (Consolidated Criteria for Reporting Qualitative Research) framework.<sup>10</sup>

## Synthesis of Findings

We identified descriptive themes in primary data and used thematic synthesis to generate analytical themes, which are a higher level of abstraction of concepts, understandings, or hypotheses.<sup>11</sup> We imported text of each primary source into HyperRESEARCH (ResearchWare Inc). One author (S.C.P.) performed line-by-line coding, conceptualized the data, and inductively identified concepts relating to patient perspectives, experiences, and values. Similar concepts were grouped into themes and subthemes. Conceptual linkages between themes were used to generate a thematic schema. To ensure that coding captured the relevant ideas and reflected data from the primary studies, researcher triangulation was done in which 2 authors (S.C.P. and A.T.) discussed the primary themes and analytical framework. Revisions of the themes and concepts were discussed, and these were incorporated into the final synthesis.

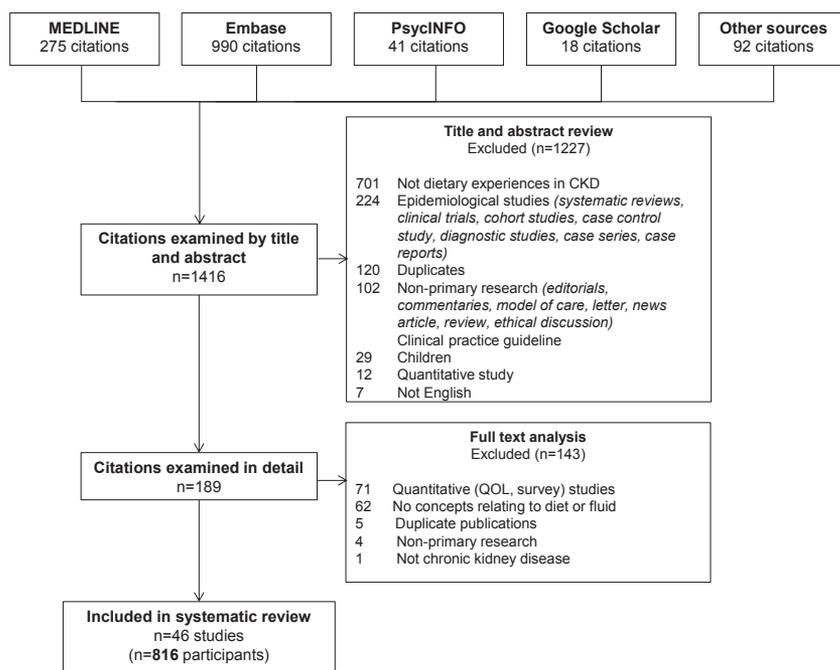
## RESULTS

### Characteristics of Studies

Forty-six studies (involving 816 patients) were included (Fig 1; Table 1). Studies involved patients treated with facility-based and home hemodialysis (33 studies; 462 patients), peritoneal dialysis (10 studies; 112 patients), either hemodialysis or peritoneal dialysis (3 studies; 73 patients), kidney transplant recipients (9 studies; 89 patients), and patients with non-dialysis-dependent CKD stages 1 to 5 (5 studies; 80 patients). The comprehensiveness of study reporting was variable (Table 2).

### Synthesis

Five major themes conceptualized patients' experiences: preserving relationships, navigating change, fighting temptation, optimizing health, and becoming



**Figure 1.** Results of search strategy and identification of publications included in the review. Abbreviations: CKD, chronic kidney disease; QOL, quality of life.

Table 1. Characteristics of Included Studies

Study	Country	N	Age Range (y)	Treatment or Condition	Methodology <sup>a</sup>	Data Collection	Analysis <sup>a</sup>	Principal Experiences Explored
Munakata <sup>50</sup> (1982)	JP	23	NS	Outpatient HD	NS	Interviews	NS	Self-care behaviors for diet
Hume <sup>4</sup> (1984)	CA	25	29-79	PD	NS	Interviews	NS	Dietary adherence
Berg <sup>3</sup> (1989)	US	23	17-78	HD	NS	Interviews	NS	Knowledge and choices about foods
Beer <sup>36</sup> (1995)	UK	12	22-64	HD, PD, Tx	Exploratory	Interviews	Thematic analysis	Body image with ESKD and after Tx
Bordelon <sup>12</sup> (1997)	US	20	NS	HD	Naturalistic enquiry	Interviews	NS	Empowerment of dialysis patients within community of care
Fisher <sup>17</sup> (1998)	UK	10	24-62	HD, PD, Tx	Exploratory	Interviews	Inductive approach	Quality of life before and after kidney Tx
Ndlovu <sup>51</sup> (1998)	ZA	14	19-48	Tx	Exploratory	Interviews	Thematic analysis	Kidney Tx viewed by African recipients
Bass <sup>23</sup> (1999)	US	13	40-69	HD, PD	Exploratory	Focus groups	Content analysis	Quality of life
Costello <sup>13</sup> (1999)	US	11	45-78	HD	NS	Focus groups	NS	Adaptation to ESKD/chronic illness
Mayers <sup>28</sup> (2000)	US	5	22-50	HD	Phenomenology	Interviews	Constant comparative method	Dietary restrictions
Sussman <sup>30</sup> (2001)	UK	8	20-68	HD	Exploratory	Interviews	Thematic analysis	Dietary restrictions
King <sup>22</sup> (2002)	UK	20	36-69	CKD	Phenomenology	Interviews	Template analysis	Adaptation to diabetic renal disease
Giles <sup>52</sup> (2003)	CA	4	NS	Home HD	Phenomenology	Interviews	Thematic analysis	ESKD and home HD technology
Martin-McDonald <sup>53</sup> (2003)	AU	10	22-68	HD, PD	Narrative	Interviews	Thematic continua	Dialysis
Polaschek <sup>54</sup> (2003)	NZ	6	20-60	Home HD	Critical interpretive approach	Interviews	Thematic analysis	Home HD
Pradel <sup>55</sup> (2003)	US	13	30-72	Tx (including potential recipients)	Phenomenology	Focus groups	Phenomenologic analysis	Before and after kidney Tx
Curtin <sup>34</sup> (2004)	US	18	33-86	PD	Exploratory/descriptive	Interviews	Thematic analysis	PD
Dekkers <sup>56</sup> (2005)	NL	7	55-82	HD	NS	Interviews	Phenomenologic analysis	ESKD
Al-Arabi <sup>21</sup> (2006)	US	80	NS	HD	Naturalistic enquiry	Interviews	Constant comparative method	Quality of life
Polaschek <sup>57</sup> (2007)	NZ	20	24-77	Home HD, PD	Interpretivist	Interviews	Thematic analysis	Home dialysis
Russ <sup>58</sup> (2007)	US	43	70-93	HD	Exploratory	Interviews	Grounded theory	Discontinuing treatment
Hollingdale <sup>20</sup> (2008)	UK	20	NS	CKD, HD	Exploratory	Focus groups	Framework method	Conceptualization of diet

(Continued)

Table 1 (Cont'd). Characteristics of Included Studies

Study	Country	N	Age Range (y)	Treatment or Condition	Methodology <sup>a</sup>	Data Collection	Analysis <sup>a</sup>	Principal Experiences Explored
Duffy <sup>59</sup> (2009)	US	10	28-48 <sup>b</sup>	Tx	Phenomenology	Interviews	Inductive thematic approach	Sibling relationships during living donor kidney Tx
Fex <sup>60</sup> (2009)	SE	6	37-83	Home HD, PD	Phenomenology	Interviews	Phenomenologic analysis	Advanced medical technology at home
Namiki <sup>61</sup> (2010)	AU	4	60-75	Home HD	Exploratory	Interviews	Thematic analysis	Home HD for older people
Sinclair <sup>14</sup> (2009)	AU	7	39-82	HD	NS	Interviews	Thematic analysis	Interdialytic weight gain
Tong <sup>18</sup> (2009)	AU	63	20-78	CKD, HD, Tx	NS	Focus groups	Thematic analysis	CKD
Ford-Anderson <sup>33</sup> (2010)	US	22	NS	HD	NS	Open-ended survey questions	Content analysis	Adherence to HD regimen
Ismail <sup>26</sup> (2010)	NL	50	27-74	Dialysis	NS	Focus groups	Thematic analysis	Living donor kidney Tx among ethnic minorities
Smith <sup>29</sup> (2010)	US	19	28-82	HD	NS	Focus groups	Content analysis	Self-care and adherence to fluid restrictions
Cases <sup>62</sup> (2011)	UK	6	48-74	Home HD	NS	Interviews	Phenomenologic analysis	Home HD
de Brito-Ashurst <sup>19</sup> (2011)	UK	20	NS	CKD	NS	Focus groups, vignettes, food diaries	Thematic analysis	Traditional and current diets and beliefs
Humphreys <sup>35</sup> (2011)	US	10	39-64	HD	NS	Interviews	Grounded theory	Kidney Tx evaluation for African American patients
Lai <sup>32</sup> (2012)	SG	13	39-63	HD	NS	Interviews	Phenomenologic analysis	Dialysis treatment
Lam <sup>5</sup> (2012)	CN	36	35-76	CAPD	Explanatory sequential design	Interviews	Content analysis	Treatment adherence
Rygh <sup>63</sup> (2012)	NO	11	23-82	Home HD, PD	NS	Interviews	Inductive thematic approach	Home dialysis
Stanfill <sup>27</sup> (2012)	US	7	41-60+	Tx	NS	Focus groups	Iterative thematic analysis	Weight gain after kidney Tx
Tovazzi <sup>25</sup> (2012)	IT	12	37-77	HD	NS	Interviews	Phenomenologic analysis	Restricted fluid intake and adherence
Urstad <sup>64</sup> (2012)	NO	16	26-67	Tx	NS	Interviews	Thematic analysis	Education following kidney Tx
Walker <sup>6</sup> (2012)	UK	9	63-93	CKD	Exploratory	Interviews	Thematic analysis	Transition to CKD
Bennett <sup>24</sup> (2013)	AU	9	29-67	HD	Visual image communication	Interviews	Thematic analysis	Adherence to fluid restrictions
Griva <sup>15</sup> (2013)	SG	37	NS	HD	Exploratory	Interviews, focus groups	Inductive thematic approach	Treatment adherence

(Continued)

**Table 1 (Cont'd).** Characteristics of Included Studies

Study	Country	N	Age Range (y)	Treatment or Condition	Methodology <sup>a</sup>	Data Collection	Analysis <sup>a</sup>	Principal Experiences Explored
Karamanidou <sup>31</sup> (2013)	UK	7	32-68	HD	Phenomenology	Interviews	Phenomenologic analysis	Illness, prescribed treatment and adherence
Krespi Boothby <sup>16</sup> (2013)	NS	16	23-77	HD	NS	Interviews	Template analysis	Dietary and/or fluid restrictions
Theofilou <sup>65</sup> (2013)	GR	10	NS	HD	NS	Interviews	Phenomenologic analysis	HD
Xi <sup>66</sup> (2013)	CA	10	38-57	Quotidian dialysis	Phenomenology	Interviews	Iterative thematic analysis	Quotidian dialysis

Abbreviations and definitions: AU, Australia; CA, Canada; CAPD, continuous ambulatory peritoneal dialysis; CKD, chronic kidney disease; CN, China; Constant comparative method, breaks the data into discrete phenomena and coding into categories; Content analysis, deductive methodology that involves identification of codes prior to searching for their occurrence in the data; Critical interpretivist approach/methodology, analytically disclosing meaning-making practices of people; ESKD, end-stage kidney disease; Ethnography, to discover and describe individual social and cultural groups; Explanatory sequential design; collecting qualitative data to explore a phenomenon followed by collection of quantitative data to test an emergent theory or framework; Framework method, identifies commonalities and differences in qualitative data, before focusing on relationships between different parts of the data, thereby seeking to draw descriptive and/or explanatory conclusions clustered around themes; GR, Greece; Grounded theory; discovery of theory through analysis of data; Iterative approach; similar to thematic analysis; HD, hemodialysis; IT, Italy; JP, Japan; Naturalistic enquiry, seeking to describe, understand or interpret daily life experiences and structures; NL, Netherlands; NO, Norway; NS, not stated; NZ, New Zealand; PD, peritoneal dialysis; Phenomenology, to study peoples' understanding and interpretations of their experiences in their own terms and emphasizing these as explanations for their actions; SE, Sweden; SG, Singapore; Template analysis; development of a coding template from a priori codes expected to be relevant to the analysis, which are modified or dispensed with if they are not relevant to the actual data examined; Thematic analysis, concepts and theories are inductively derived from the data; Tx, transplant(ation); UK, United Kingdom; US, United States; ZA, South Africa.

<sup>a</sup>As reported by authors.

<sup>b</sup>Age at time of kidney transplantation.

**Table 2.** Comprehensiveness of Reporting Assessment

Reporting Criteria	References of Studies Reporting Each Criterion	No. (%)
Characteristics of research team		
Interviewer or facilitator identified	4-6, 12, 16, 17, 26, 28, 29, 34, 35, 51, 53, 54, 57-60, 66	19 (41%)
Occupation	4-6, 12, 16, 17, 19, 24, 28, 34, 35, 53, 54, 57, 59, 60	16 (35%)
Experience or training in qualitative research	5, 12, 15, 20, 23, 24, 26, 55	8 (17%)
Research team relationship with participants		
Relationship established prior to study commencement	4, 12, 20, 24, 26, 35, 36, 59, 63	9 (20%)
Participant selection		
Selection strategy	4-6, 12-19, 22-29, 32-36, 51-55, 57, 59-61, 63, 64, 66	36 (78%)
Method of approach or recruitment	4, 5, 12, 15, 16, 18, 21, 24, 26-28, 30, 32-36, 51-55, 57, 59, 60, 62-64	28 (61%)
Sample size	3-6, 12-36, 50-66	100%
No./reasons for nonparticipation	5, 13-16, 18, 22, 27, 31, 33, 51, 55, 63	13 (28%)
Setting		
Venue of data collection	3-6, 12, 15, 16, 18-21, 23-31, 33-36, 51-54, 56-66	39 (85%)
Presence of nonparticipants (eg, clinical staff)	5, 16-18, 20, 21, 23-25, 29-31, 35, 56, 63-66	18 (39%)
Description of sample	3-6, 12-20, 22-36, 51-53, 55-66	43 (93%)
Data collection		
Questions, prompts, or topic guide	5, 12-18, 20, 21, 23, 24, 26-36, 53, 55, 56, 58, 59, 62-66	33 (72%)
Repeat interviews/observations	12, 18, 19, 24, 26, 27, 34, 35, 52-59, 61, 62	18 (39%)
Audio/visual recording	5, 6, 12, 13, 15-36, 51, 52, 54-57, 59-66	40 (87%)
Field notes	5, 6, 12, 18, 19, 21, 26, 27, 35, 51, 54, 55, 61, 63, 66	15 (33%)
Duration of data collection	3, 5, 6, 13-17, 19, 23-27, 29-32, 34-36, 51-54, 56-58, 60, 62-66	34 (74%)
Protocol for data preparation and transcription	5, 6, 12, 13, 15, 16, 18-24, 26, 27, 29-32, 34-36, 52, 55, 59-66	32 (70%)
Data (or theoretical) saturation	5, 6, 15, 16, 27-29, 32, 34, 66	10 (22%)
Data analysis		
Researcher/expert triangulation	5, 6, 13, 15, 18, 21-27, 29, 31, 32, 34, 35, 55, 62-66	23 (50%)
Derivation of themes or findings	5, 6, 12-36, 52-66	42 (91%)
Use of software	15, 18, 19, 26, 29, 33, 35, 36, 55, 59	10 (22%)
Participant feedback on findings	12, 13, 21, 27, 28, 34, 35, 53, 61, 62	10 (22%)
Reporting		
Participant quotations or raw data provided	3, 5, 6, 12-35, 50, 52-56, 58, 59, 61-66	41 (89%)
Range and depth of insight into participant perspectives	5, 6, 12-20, 22, 24-36, 51-66	41 (89%)

empowered (Table 3; Fig 2). Quotations to illustrate each theme are provided in Table 4.

### Preserving Relationships

*Interference with roles (23 studies).* Patients, principally those receiving dialysis, experienced challenges to their roles with others. They felt infantilized and scolded about their diet. Family members policed their diet intake<sup>12,13</sup> and searched for food they thought that patients had hidden.<sup>12</sup> Patients receiving dialysis resented unsolicited advice, particularly in social situations.<sup>13</sup> Some patients felt patronized by medical staff for not following food advice<sup>12</sup> and others told of eating restricted foods in secret to avoid being lectured by clinicians.<sup>5,14</sup>

*Social limitations (14 studies).* Food and fluid management stopped many dialysis patients from

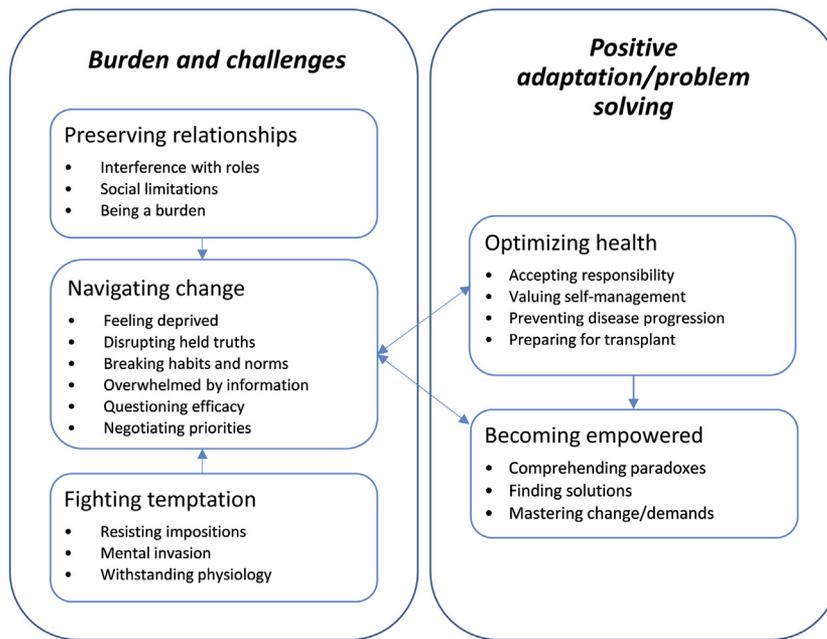
socializing. It became too difficult to explain food restrictions to others for fear of “social stigma”<sup>15</sup> or that refusing food or drink would offend their hosts.<sup>14-16</sup> Some preferred not to be with others because eating restrictively drew attention to their disease<sup>15,17</sup> and they became “afraid of seeing people.”<sup>5</sup> After declining invitations previously, some subsequently were excluded from social occasions.<sup>5</sup> Some patients decided to eat and drink normally in social situations and “pay for it” later with symptoms due to fluid overload or itch.<sup>5,15,18</sup> For first-generation immigrants from Bangladesh in the United Kingdom, dietary changes were embarrassing because reducing intake of some foods, including salt, could be interpreted as a sign of poverty.<sup>19</sup>

*Being a burden (11 studies).* Some patients receiving dialysis depended on family for preparing

**Table 3.** Studies Contributing to Each Theme by Reference Number

Themes	50	4	36	3	12	17	51	23	13	28	30	22	52	53	54	55	34	56	21	57	58	20	59	60	14	18	33	26	61	29	62	19	35	32	5	63	27	25	64	6	24	15	31	16	65	66					
<b>Preserving relationships</b>																																																			
Interference with roles	•	•		•	•	•			•	•	•	•	•		•						•	•				•	•				•	•					•		•	•	•	•	•	•							
Social limitations	•	•							•																	•	•				•	•						•		•	•	•	•	•	•						
Being a burden						•			•	•		•							•							•														•		•	•	•	•						
<b>Navigating change</b>																																																			
Feeling deprived	•	•						•	•	•	•	•								•	•					•	•	•			•	•																•			
Disrupting held truths							•		•	•																•		•																							
Breaking habits/norms	•						•	•	•	•	•									•						•	•																								
Overwhelmed by information			•						•	•	•	•	•													•																									
Questioning efficacy	•						•		•	•																•																									
Negotiating priorities		•					•	•	•											•	•	•	•				•	•																							
<b>Fighting temptation</b>																																																			
Resisting impositions		•		•						•	•	•	•		•																																				
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<b>Optimizing health</b>																																																			
Accepting responsibility	•	•					•																			•	•	•																							
Valuing self-management	•	•						•			•	•														•	•	•	•																						
Preventing CKD progression		•																								•																									
Preparing for and protecting transplant		•	•																																																
<b>Becoming empowered</b>																																																			
Comprehending paradoxes	•	•						•	•	•	•	•														•	•	•																							
Finding solutions		•							•	•	•															•	•	•																							
Mastering change and demands	•	•						•	•	•	•	•														•	•	•																							

Abbreviation: CKD, chronic kidney disease.



**Figure 2.** Conceptual framework for understanding patient's experiences of diet and fluid restrictions in chronic kidney disease.

meals in accordance with their dietary restrictions. They felt guilty that family members had to adopt the restrictive renal diet.<sup>20</sup> Some female Bangladeshi patients were concerned that if they omitted salt from meals their families would resent them,<sup>19</sup> while some patients chose to be vigilant about their dietary regimen to stay well and avoid becoming a burden to their family or wasting their nurses' and doctors' time.<sup>14</sup>

### **Navigating Change**

*Feeling deprived (27 studies).* In addition to experiencing severe illness, diet and fluid restrictions were perceived as a further deprivation. Patients viewed diet recommendations as externally imposed and more difficult to accept than if they had been a personal choice.<sup>5,13,15,21,22</sup> Patients spoke about having life's pleasures removed and how food had become bland and tasteless.<sup>12,13,21,23</sup> Some patients receiving dialysis described their restrictions using nihilistic or violent terms, such as "having no life at all,"<sup>24</sup> "having a meaningless existence,"<sup>5</sup> or as like being a prisoner, being condemned to death, or being tied up.<sup>25</sup> Some anticipated they would "live again; feel reborn!...and enjoy life again after receiving a kidney transplant!"<sup>26</sup> while those who have received a kidney transplant expressed delight at the freedom from their dietary restrictions: "I was excited about eating something I hadn't eaten in a while."<sup>27</sup>

*Disrupting held truths (12 studies).* Dietary restrictions were counterintuitive and disorienting. Dietary advice contradicted a "healthy diet"<sup>20</sup> and patients felt lethargic, malnourished, and starved if they followed the diet as instructed.<sup>5</sup> Some patients from an ethnic minority thought that recommended

diets did not consider traditional foods, with one patient from Barbados in the United States suggesting "something could be done to help put some back home foods on the list and let the dieticians learn about our foods...."<sup>28</sup>

*Breaking habits and norms (21 studies).* Patients were angry about having to take on a new food and liquid regimen in addition to changes to their daily schedules and recreational activities imposed by CKD. Some patients receiving dialysis were ambivalent about the transformation of so many aspects of their lives that were previously worry free.<sup>25</sup> Patients admitted forgetting the dietary recommendations, particularly when they had a change or a break in their routine.<sup>15</sup>

*Overwhelmed by information (18 studies).* When learning about diet management, patients described being "bombed" with information<sup>23</sup> that sometimes was not relevant to their cultural background or existing food preferences<sup>19</sup>; "[the clinicians] speak in a Latin tongue...and...just jibber, jibber, jibber."<sup>29</sup> Patients spoke of listed permissible foods as being unfamiliar to them.<sup>28</sup> Comorbid conditions (diabetes and heart disease) led to conflicting advice.<sup>20</sup> Patients reported not understanding the advice, when they were still in "emotional turmoil" after learning about their CKD diagnosis or just having had a dialysis catheter implanted.<sup>5</sup> Patients "preferred to receive advice from a renal dietician who could support the rules with a clear rationale and practical advice to help them implement any changes."<sup>20</sup> Kidney transplant recipients expressed a lack of knowledge about appropriate ways to follow dietary freedoms in a healthy way.<sup>27</sup>

**Table 4.** Illustrative Quotations From Participants in Primary Studies, by Theme

Theme	Quotations
<b>Preserving Relationships</b>	
Interference with roles	<p>"My kids accept it. They watch over me, you'd be surprised how they watch over. Family, you go out to eat with them and you order something, they say, 'You can't eat that'.<sup>#13</sup></p> <p>"When I come in to treatment I will be looking at my tech like 'What is she going to say about me having all this fluid on?' I kind of look at her and see the look that she gives me like, 'Boy, you better stop that'.<sup>#14</sup></p> <p>"You can't be sneaky. My son knows the routine: what type of medications I take, what I should be eating, and the like. I still like cashews. My husband and son look in all of my hiding places and find them...they always know when I'm eating them."<sup>#12</sup></p>
Social limitations	<p>"No, it means that, you know, sometimes you go to someplace to eat and there's all this food laying around and you realize that if you don't eat, you know, you're either gonna not eat anything and/or, you know, offend somebody...Probably stuff I shouldn't eat, you know, but I'll eat it anyway just because he cooked it up for me you know."<sup>#3</sup></p> <p>"People will think we are very poor and can't afford salt. They will think we are starving and have no money."<sup>#9</sup></p> <p>"I don't have any social life now, although I could do but I don't trust myself to go to dinners or cocktail parties because of drinking and eating. I don't know what they are going to serve me up you know, could be very salty. So I dodge all this stuff. Far better you eat at home. You know that there is no salt in it."<sup>#6</sup></p>
Being a burden	<p>"I want to have better health. I don't want to eat indiscriminately. If I do so, I'd suffer. It's okay if I can die, but I'd be a burden to others if I don't die. ...I'd be a burden for the young [my children] because they'd have to come and visit me often. That would be a trouble."<sup>5</sup></p> <p>"With the fluid restriction, I think if I'm going to come here four hours, three times a week, and go home and drink what I want, eat what I want, then it's a complete waste of time. I'm wasting the nurses' time, I'm wasting the doctors' time, and I'm wasting my time, so while I'm on dialysis, I try to do the right thing."<sup>#14</sup></p>
<b>Navigating Change</b>	
Feeling deprived (dealing with loss)	<p>"It's not an easy diet by any means...its affects life's little pleasures."<sup>23</sup></p> <p>"Lots of changes...Well, my diet. It took away all my goodies."<sup>13</sup></p> <p>"Quitting isn't the most difficult. It's not being allowed to eat for the long term that's difficult. It's adhering to the dietary restrictions in every meal that's difficult. If you give me a time frame, such as telling me not to eat it for 1 month, that would be easy. If you say I'm not allowed to eat it for my whole life, that'd be difficult."<sup>6</sup></p> <p>"If I am going to live thirsty, I don't want to live."<sup>24</sup></p>
Disrupting held truths	<p>"I always tell dieticians that the dietary restrictions would make people starve. There are so many foods that I should eat just a little. ...If I do as instructed by the dieticians, I'd die from starving."<sup>5</sup></p> <p>"I found my diet has been quite difficult...of all the healthy food I've been cooking it has had to stop."<sup>20</sup></p>
Breaking habits and norms	<p>"...it's a new life, an entire different life, new food, new intake of liquid and everything. Everything is different."<sup>#3</sup></p> <p>"I feel cross being where I am at because I can't live my normal life like I used to. I can't just drink whatever I want to drink whenever I want to drink it..."<sup>#4</sup></p>
Overwhelmed by information	<p>"It's confusing. ...the funniest thing is that they asked me what I ate because I didn't have any potassium. I told them I didn't eat those foods because they asked me not to eat them. They said I didn't have any potassium at all, and asked me to eat bananas because bananas contain potassium. Later, I had another blood test, after which they told me to stop eating bananas and eat like normal."<sup>5</sup></p> <p>"It is hard to know what to eat. They say less vegetables and fruits...I try to not eat soya beans no nuts...still high...still itchy...where am I going wrong?"<sup>#15</sup></p> <p>"I was so confused at the beginning but over years I learnt..."<sup>#15</sup></p>
Questioning efficacy	<p>"Not eating the foods before me doesn't mean that my test results would be better than if I ate them. With experience, you'd know and you'd continue eating."<sup>5</sup></p> <p>"Well the food they tell you to eat, it have no substance. It make you feel so weaky, weaky. If you could eat some of your back home food, maybe you could have a little strength in your body."<sup>28</sup></p> <p>"Doctors always tell me to follow restrictions more strictly whenever there's a problem. If that's always the case, anyone can be a doctor."<sup>5</sup></p>
Negotiating priorities	<p>"Half an hour I regret it but it happens again and again, and I struggle with that, and it becomes like a struggle between life and death."<sup>24</sup></p> <p>"I like to drink lots of water, even before I started dialysis. I try my best, but at the end of the day I'll be dead anyway."<sup>24</sup></p>

(Continued)

**Table 4 (Cont'd).** Illustrative Quotations From Participants in Primary Studies, by Theme

Theme	Quotations
	<p><i>"I have the choice. I can choose to survive for 2 or 3 more years; I have to restrict my diet. I can also choose to neglect it if I don't want to survive. That's simple. If I want to be able to eat for a longer time, I should adhere to dietary restrictions. If not, I may as well choose to eat whatever I like. I'd suffer if I don't adhere to dietary restrictions. I wouldn't die immediately if I don't adhere, but it'd be even worse if I'm like half dead."<sup>5</sup></i></p>
	<p><b><u>Fighting Temptation</u></b></p>
Resisting impositions	<p><i>"Just name anything, and you'd find out that I shouldn't eat it. There're too many foods that I shouldn't eat... It'd be impossible to refrain from eating those foods altogether, because there're too many of them. The list occupied four sheets of A4-sized paper, so you know how many there actually are."<sup>5</sup></i></p> <p><i>"My son says, 'Mama, that's not good.' But I say, 'I'm 72, I'm going to eat what I want.' It's not going to get better anyway. I'm so tired."<sup>58</sup></i></p> <p><i>"I was getting fed up of being told off, but I know she (the dietician) was doing good. Mum told me off about the diet and not sticking to it as well. It made me feel even more depressed so that I wanted to have something else."<sup>30</sup></i></p>
Mental invasion	<p><i>"And when I drink, I just don't like myself. When I have the water in my mouth then I don't want to swallow. You know when you are making love and you want to stop half way, how many people can control that. So when I have that water in my mouth it's like something is holding my hand, maybe God, and then I give up and I say, oh well I'll have it all."<sup>24</sup></i></p> <p><i>"I fail to resist, I am always thirsty, and my thoughts remain always fixed upon thirst and water.... I can't resist, I can't find a way to avoid the drinking need; my thoughts are always fixated on the bottle, and I am always close to the fridge."<sup>25</sup></i></p> <p><i>"It's like fighting nature all the time because you want to drink all the time. You have to have a really strong will to do that.... I get to the stage where I fantasize about it...."<sup>14</sup></i></p>
Withstanding physiologic needs	<p><i>"I think I will succeed in reducing fluid although I do not yet succeed in understanding: is not drinking beneficial for my body? Dehydration also derives from the fact that one doesn't drink. Do I have a problem with dehydration or not? Do you have this type of problem with your physiology?"<sup>25</sup></i></p> <p><i>"I get so tired when I cut down on water."<sup>50</sup></i></p>
	<p><b><u>Optimizing Health</u></b></p>
Accepting responsibility	<p><i>"I've taken actions such as being educated about dialysis, to take responsibility for my health and diet and I never miss my medications."<sup>12</sup></i></p> <p><i>"I love my food too and er.... I learnt the hard way, you know, er, phosphates itching and you soon get fed up with that and learn the hard way if you like."<sup>20</sup></i></p> <p><i>"Every time I have follow-up, I ask the nurse to write them [the laboratory results] down for me as a reference, and tell me whether my sodium and phosphorus levels are high. If my sodium or potassium level is high, the doctor would warn me, and I'd adhere to dietary restrictions. ...that's for my own reference, so I know how I should eat."<sup>5</sup></i></p>
Valuing self-management	<p><i>"If your attitude is right, I've got a, I've got a problem. I have a renal disease, but there's ways around it. I can go to dialysis, and if . . . I stick to the diet, and I do my treatment, and I take the medication, er, I can make a better quality of life for myself."<sup>62</sup></i></p> <p><i>"I oftentimes just think about me and what I need to do for me. Who is going to stop you from doing for you? Nobody. Help yourself."<sup>29</sup></i></p> <p><i>"...I don't have the prospect of a transplant, so I have to stay as well as possible. If I carry a regular weight I can hope to live another 10 years. This is the principal factor: to stay well with oneself, individual well-being."<sup>25</sup></i></p>
Preventing disease progression	<p><i>"I am very keen on controlling this quite fast, if I can, to avoid dialysis."<sup>20</sup></i></p>
Preparing for and protecting a transplant	<p><i>"I'm on the waiting list for a kidney transplant. Therefore, I must keep myself healthy. This is to ensure that when the hospital calls and tells me that there are kidneys for me, be immediately fit to undergo the operation. If my body can't tolerate the surgery or if I don't feel well when the hospital calls, I won't be allowed to undergo the surgery. I'll miss the chance then. That would be a pity because we've to wait for a very long time for a transplant."<sup>5</sup></i></p>
	<p><b><u>Becoming Empowered</u></b></p>
Comprehending paradoxes	<p><i>"Well, I found it hard, what made it difficult for me was just getting myself adjusted to the regulations and so forth. Having to do things that had to be done. Of course, like, it was hard but then, all of a sudden, it became so customary, I more or less got used to it...I have found that you have to, because of the dialysis, you have to adjust yourself to the situation. Therefore, it automatically becomes more or less customary."<sup>13</sup></i></p>

(Continued)

**Table 4 (Cont'd).** Illustrative Quotations From Participants in Primary Studies, by Theme

Theme	Quotations
Finding solutions	<p>"It's hard because I've to refer to it all the time. There're so many foods that I shouldn't eat. Now I've begun to get used to it."<sup>5</sup></p> <p>"I used to have a problem with potassium, but I think the dialyzers today are better and have largely solved that problem. I look at the blood work, and feel that the more I know the better I can juggle my diet."<sup>12</sup></p> <p>"That's when the nurses are really, really good at coming up with suggestions, alternatives and stuff like that. We had one patient that only ate like frozen meals. He didn't cook, he only had a microwave. And he would go and buy brands of, like, you know, those frozen TV dinners and that was basically his only source of nutrition. So, his primary nurse contacted the company to find out how much fluid they were putting in the gravy, how much potassium, how much sodium, how much whatever whatever each of his favorite meals was. And they, the company actually sent packets describing all of that so that the patient had a little library, like knowing which foods were high in phosphorous, potassium or sodium and that kind of stuff. So, that helped the patient adjust. Those sorts of things would help the patient adjust."<sup>13</sup></p>
Mastering change and demands	<p>"I don't know how you get people to stay on diets because it's all got to come from inside them and they've got to really want to do it and really, well, they've got to look after their health."<sup>30</sup></p> <p>"I've worked out what I can and can't do in certain stages of the dialysis cycle. So I just work around that."<sup>14</sup></p>

*Questioning efficacy (17 studies).* Patients believed that taking the advice about food and fluid was a personal choice.<sup>5</sup> Some patients had a sense that restrictions had few immediate or longer term benefits or even caused harm,<sup>18</sup> or alternatively that the dialysis could compensate for any excessive intake.<sup>29</sup> For this reason, some returned to a regular food or fluid intake<sup>28</sup> or lacked faith in doctors who advised strict restrictions because patients considered them unnecessary.<sup>5</sup>

*Negotiating priorities (23 studies).* Patients struggled with making choices between getting pleasure from food and fluid versus staying in control and keeping well. Some spoke about "cheating" on their diets by learning how to get away with eating treats in moderation.<sup>12,13</sup> "It isn't though I don't ever cheat on my diet, everyone does. I cheat in a way that I know from experience will be safe for me."<sup>12</sup> They tested the boundaries of dietary restrictions: "I try my best to adhere to dietary restrictions. I only eat a little bit in secret when I really can't refrain... But I don't do that often."<sup>5</sup> Others perceived there was no choice other than to stick to the diet.<sup>5,22</sup>

### **Fighting Temptation**

*Resisting impositions (15 studies).* For some patients, the dietary and fluid advice was seen as unreasonable. One described having a list of "forbidden foods" that occupied "four sheets of A4-sized paper" and was impossible to incorporate into daily life.<sup>5</sup> Consuming food in restricted amounts was unfeasible and impractical. "When I eat banana, I've to eat just half. Where do I put the remaining half then? It'd be better to eat the remaining half as well."<sup>5</sup> Some saw the dieticians' role as ideally not to impose change but to support patients in their adaptation to new diet and fluid habits.<sup>30</sup>

*Mental invasion (14 studies).* Some patients receiving hemodialysis were tormented by unrelenting

thoughts of food and drink.<sup>31</sup> Compulsive thoughts about fluid provoked "mirages" that made them look for water even when it was not present<sup>32</sup> or experience "visions...such as a mountain with fresh water gushing forth."<sup>25</sup> Patients would consider the need to drink as "stronger than me," describing themselves as "tortured,"<sup>14</sup> "fixated,"<sup>25</sup> "obsessed,"<sup>14</sup> or "addicted."<sup>24,25</sup> Thirst was distressing<sup>4</sup> and for some could never be satiated.<sup>33</sup>

*Withstanding physiologic needs (15 studies).* Food and fluid were seen as physical needs that were "indispensable elements for life."<sup>25</sup> Patients could not conceive of how medical advice leading to dehydration could be beneficial.<sup>25</sup> Some recipients of a kidney transplant found it impossible to control their appetites: "the larger the dose of prednisone, my appetite just got bigger and bigger," while another mentioned that he "never got full."<sup>27</sup> Dietary restrictions were both "fighting nature" and "fighting against themselves" against thirst or appetite.<sup>14</sup>

### **Optimizing Health**

*Accepting responsibility (22 studies).* Adherence to diet and fluid restrictions became more manageable when patients learned to accept responsibility for their treatment and recognized the potential consequences of their behavior on their future health. Some learned to cope better over time and by being "grown up" and simply accepting what they had to tolerate.<sup>31</sup> Some accepted that food and fluid changes were "part of the deal,"<sup>14</sup> and having taken charge, no longer allowed diet to be a dominating concern in their lives.<sup>20</sup>

*Valuing self-management (31 studies).* For some patients, diet and fluid advice was part of the suite of specific actions they could do to care for themselves<sup>12</sup> to feel better.<sup>5</sup> Some wanted to tell other patients to persevere on diet and fluid advice to improve quality

of life based on their own critical experiences, such as severe fluid overload.<sup>25,29</sup> Some patients gained confidence in their own dietary strategies by regulating their diet according to blood test results<sup>6</sup>: “I’ve kept my chemistries at a level and I know that if it goes up, I know how to bring it down.”<sup>34</sup>

*Preventing CKD progression (5 studies).* Some patients sought comprehensive guidance about how to prevent the progression of their disease<sup>18</sup> and wished in hindsight that they had taken more heed of dietary advice if they had known it might have slowed down the rate of their CKD progression.

*Preparing for and protecting a transplant (8 studies).* Some patients receiving dialysis harnessed the prospect of receiving a transplant as motivation to keep themselves healthy,<sup>5,13,21</sup> while viewing not getting a transplant as equivalent to giving up hope.<sup>13</sup> Some African American patients receiving dialysis believed that weight loss was difficult if not impossible while on dialysis therapy and were angry that they might be excluded from getting a transplant without weight loss.<sup>35</sup> Kidney transplant recipients refrained from foods they feared might cause transplant rejection.<sup>36</sup>

### ***Becoming Empowered***

*Comprehending paradoxes (21 studies).* Through a process of adaptation and negotiation, patients learned how to incorporate complicated dietary ideals into their lives.<sup>3</sup> By adjusting to the counterintuitive idea that many “healthy” foods were now off limits and making decisions based on how their symptoms responded to their choices, patients learned to navigate through complex clinical instructions until it became second nature.<sup>13</sup> Once they had “grappled” with the many adjustments needed to adapt to dialysis treatment, some felt confident to share their experiences with their peers.<sup>12</sup>

*Finding solutions (23 studies).* Some dialysis patients used practical responses to cope with dietary restrictions, such as buying cookbooks and learning to read nutritional labels to identify sodium-free products.<sup>12</sup> They developed libraries of foods that were high in potassium, phosphorus, and sodium<sup>19</sup> and valued regular contact with renal dieticians and their peers to consolidate their learning and build confidence.<sup>15</sup> Patients believed that the person who did the shopping and cooking for their household also should be invited to attend education sessions. They expressed a preference for a repeated problem-solving approach rather than didactic teaching methods when learning how to manage their food and fluid intake.<sup>20</sup>

*Mastering change and demands (25 studies).* Gaining and keeping control of diet and fluid was one way of finding meaningful ways to stay alive and feel good and that surviving their chronic disease was

worth the effort. They saw that quality of life “was within their own reach and under their control.”<sup>21</sup>

## **DISCUSSION**

In this review, we found that dietary and fluid management is a disorienting challenge and intense burden for patients when adapting to and coping with different stages of CKD. The substantial number and complexity of restrictions on food and fluid exacerbates the decreased quality of life caused by CKD and has a profound impact on patients’ relationships with others. Patients experience unresolved conflict between their medical team, which advocates strongly for a narrow window of diet and fluid choices on the basis of “improved health,” and their own sense of well-being, which is undermined by what they perceive as an unrealistic and unpalatable diet devoid of taste and interest. Studies reveal that patients avoid social situations and are overwhelmed by a confusing array of advice that seems contrary to their normal cultural beliefs and is difficult to implement fully. In sparse data, kidney transplant recipients find it difficult to readjust to normal eating patterns and cope with an increased appetite despite considerable relief at renewed freedom from restrictions. Thus, some fear their lack of knowledge about diet may contribute to transplant rejection. Patients indicate that information about appropriate diet management frequently is difficult to comprehend due to reliance on didactic one-off education sessions and thus prefer multiple problem-solving and collaborative approaches to learning in partnership with their dieticians and families. Some patients find feedback from blood tests helpful in their own self-management. This review finds that over time, individual patients draw on the strength of achieving incremental dietary changes, motivations of a future kidney transplant, slowing CKD progression, or feeling better as ways of sustaining dietary and fluid recommendations in their lives.

This thematic integration from studies across a range of clinical and cultural contexts highlights 3 potential factors that might be relevant to helping patients learn and incorporate dietary restrictions. Our review suggests that: (1) approaches to education, (2) harnessing patient motivation, and (3) identifying adaptation as a journey might be ways of helping patients adapt positively to dietary recommendations.

Patients desire knowledge about diet and fluid but may be counseled at a difficult time, such as when they are adapting to dialysis or transplantation or comprehending a diagnosis. For diabetes, patients who receive dietary counseling soon after diagnosis with consultation offered every 3 months and monthly nursing support show improved glycemic control, lower body weight, and less use of diabetes drugs,

suggesting that continued support over the months after diagnosis is helpful to generate meaningful dietary changes in other settings and possibly is applicable to CKD.<sup>37</sup> This also aligns with the preference of patients with CKD to form an alliance with their clinical team rather than feeling they are being scolded or patronized for not adhering to advice.

Partners and families are important sources of support who can shop for appropriate foods and make food palatable, as well as “take on the stress and concern of planning meals.”<sup>20</sup> This review suggests that caregivers might be involved routinely in dietary education because involvement of caregivers in nutrition counseling improves recall on messages about foods and food preparation information.<sup>38</sup> Advice about reading nutritional labels and building a personal library of foods to minimize or avoid relevant to cultural practices are helpful for patients in this review. In addition, the opportunity for patients to learn about and respond to regular blood test results aligns with existing data showing that patients with diabetes experience improved glycemic control in response to immediately available blood results.<sup>39</sup> Patient experiences in our review also are supported by evidence showing that education to avoid foods high in phosphorus additives at the time when patients purchase groceries or go to a fast food restaurant lowers serum phosphorus levels.<sup>40</sup>

Some patients prefer group education sessions in which they can support each other and discuss their concerns and find solutions. Patients favor problem-based learning on multiple occasions to build their confidence and gradually adapt to diet changes. This preference is supported by CKD data showing that individualized fortnightly dietary counseling with ongoing follow-up is more effective than written materials<sup>41</sup> and a nonrandomized study showing that regular 6-monthly dietetic review and intensive follow-up targeted to specific nutritional parameters is associated with improved nutrition, serum potassium and phosphorus levels, and fluid overload.<sup>42</sup>

This review indicates that kidney transplant recipients need ways to manage their increased appetite and advice to stay well and be reassured about their dietary approaches and the risk of transplant rejection. To support this need, a small exploratory study showed that body weight increased by ~6% in the first months after transplantation without measurable changes in dietary intake.<sup>43</sup> While regular dietary consultations and multidisciplinary care–modified dietary patterns might slow weight gain,<sup>44</sup> effects of lifestyle modification on patient-relevant outcomes in solid-organ transplantation are lacking.<sup>45</sup> Patients with earlier stages of CKD wish to address dietary approaches specifically targeted at preventing CKD progression, which aligns with evidence showing that

patients prioritize diet as an intervention to prevent CKD progression when asked.<sup>46</sup>

Patients often find changing their diet and fluid habits unacceptable because they view the restrictions as externally imposed and additional to other losses associated with CKD. Once patients experienced an increased sense of responsibility for food and fluid management as “part of the deal,” they became empowered and the dietary changes were much less important to their lives. Therefore, the key experiences of patients in this review might be used to inform decisional balance activity (patients and health workers exploring the pros and cons of changing and not changing health practices)<sup>47</sup> to help assist patients to incorporate dietary changes by better articulating the perceived benefits of change (feeling better; hope for better CKD, dialysis, and transplantation outcomes; and reducing burden to others) and costs of not changing (fluid overload, itch, and not gaining self-management) against their reasons to remain the same (inadequate information and understanding, ambivalence over efficacy, unsustainability of the changes needed, and competing priorities in CKD). Some patients who had found internal motivation to sustain dietary adjustments were keen to tell their peers about what they had learned so that others might shorten the time it took to adopt the restrictions. Meeting patient peers to discuss care has been suggested previously in the setting of CKD as inspirational and a “powerful and persuasive method for patients to gain knowledge about their treatment options” and may be widely applicable for people with CKD who face treatment that is complex and demanding and has been shown to have a positive influence on diet self-management in other settings.<sup>48,49</sup>

While we conducted a thematic synthesis drawing on a broad and comprehensive search of the literature, considering a coding and analytical framework agreed between multiple researchers, and evaluating the comprehensiveness of reporting in primary studies, this review has limitations that need to be considered. First, we did not include non-English research, and while studies were situated within different cultural settings or reflected on the impact of culture on patient experiences, we cannot infer the applicability of our findings to all cultural and clinical contexts. Because studies including patients treated by facility hemodialysis dominated the primary literature, the experiences of kidney transplant recipients, home dialysis patients, and those with non-dialysis-dependent CKD may have been underestimated. All studies were conducted in middle- and high-income countries, and conclusions may not be appropriate for patients in low-income regions.

In conclusion, dietary and fluid restrictions have a powerful negative impact on the experiences of patients with CKD that require time for adaptation and

patient- and family-centered care. The burden of dietary and fluid management may be alleviated through new approaches to patient education, harnessing patient motivations for change, and viewing adaptation to dietary and fluid management as a collaborative journey for patients, families, peers, and clinicians.

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### SUPPLEMENTARY MATERIAL

Item S1: Search strategies.

Note: The supplementary material accompanying this article (<http://dx.doi.org/10.1053/j.ajkd.2014.09.012>) is available at [www.ajkd.org](http://www.ajkd.org).

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