2018

Exploring the challenges to dietary selfmanagement adherence in end stage kidney disease: implications for clinical practice

Kelly Lambert

UNIVERSITY OF WOLLONGONG

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Exploring the challenges to dietary self-management adherence in end stage kidney disease: implications for clinical practice

A thesis submitted in fulfilment of the requirements for the award of the degree

Doctor of Philosophy

From

UNIVERSITY OF WOLLONGONG

By

KELLY LAMBERT
BSc (Nutr), MSc (Nutr Diet), Grad Cert Mgmt

School of Medicine in the Faculty of Science Medicine & Health

2018
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This research has been conducted with the support of an Australian Government Research Training Program Scholarship.
Declaration

I, Kelly Lambert, declare that this thesis is submitted in partial fulfilment of the requirements for the conferral of the degree Doctor of Philosophy, from the University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. This document has not been submitted for qualifications at any other academic institution.

Kelly Lambert

April 5, 2018
Verification

This statement verifies that the greater part of the work in this thesis is attributed to the candidate. Kelly Lambert contributed to the conception and design of studies in this thesis, undertook data collection and analysis, and prepared drafts of all manuscripts. The candidate was responsible for responding to editorial suggestions from co-authors and peer reviewers and facilitated submission of all manuscripts to the relevant peer reviewed journals. Further details of the contribution of co-authors can be found in each chapter and in Appendix 3.

Associate Professor Judy Mullan (Primary Supervisor)

Kelly Lambert (candidate)

5.4.2018
Abstract

Chronic Kidney Disease (CKD) is one of the most common chronic medical conditions worldwide. Dietary modification (also known as dietary self-management) is integral to preventing the progression of CKD and in managing the complications of end stage kidney disease (ESKD). Adherence to the renal diet is challenging, and strategies to improve dietary self-management, especially for ESKD patients, are limited.

This doctoral thesis is presented as a thesis by compilation, and the studies conducted were guided by the Health Literacy Skills Framework (HLSF) as the theoretical framework. The overarching aim of this thesis was to explore the issues associated with adherence to dietary self-management in adults with ESKD using the lens of health literacy. To achieve the aims, a sequential explanatory mixed methods approach was used and included four cross sectional quantitative studies, and two qualitative studies.

Chapter 1 includes background information and the results of an integrative review regarding dietary adherence in ESKD. The integrative review indicated that adherence to the overall renal diet was as low as 31.5%. The review also identified that adherence to individual elements of the renal diet varied greatly. In addition, the review highlighted that older patients, lower socioeconomic standing, limited access to social support and poor self-efficacy were consistently associated with poor adherence to dietary self-management.

Chapter 2 presents findings from a study investigating the cognitive capabilities of 155 adults with ESKD using the Modified Cognitive Assessment Tool. Cognitive impairment was found in approximately one third of the study participants, and deficits in areas such as executive function, attention, and memory were common. The extent of these deficits varied according to the stage of ESKD and type of renal replacement therapy undertaken by the patients.
Chapter 3 reports on a study which explored the health literacy skills of 153 adults with ESKD, using the Health Literacy Management Scale. The study identified that inadequate health literacy, especially in the domains relating to attending to one’s health needs and understanding health information were common among this patient cohort. Variations in the health literacy skills between the stages of ESKD were again apparent in this study.

Chapter 4 and Chapter 5 describe two studies that investigated the health literacy demand of renal diet information available online (i.e. websites, YouTube and renal diet apps), using the Patient Education Material Assessment Tool; the DISCERN tool; the Mobile Application Rating Scale and seven readability calculators. The accuracy of the online renal diet information was determined by utilising relevant evidence-based guidelines for the dietary management of kidney disease. The results of these studies indicated that the accuracy, understandability and actionability of renal diet information differs greatly between the online sources.

Chapter 6 outlines the main themes that emerged from the semi-structured interviews with 26 adults with ESKD and 10 carers. The aim of this study was to explore factors that impact on the comprehension of dietary self-management advice from the perspective of the patient and carer. Sensemaking theory was used to guide the interview questions. This study highlights that patients and carers find the renal dietary advice to be overwhelming, frustrating and emotionally challenging, even though they highly value the dietitian’s input. Some of the problem-solving strategies they utilised included talking with others, searching the internet, constructing individualised resources, using technology and blood test results to monitor dietary adherence. They also expressed a desire for additional resources and/or support to assist with renal diet sense making.

Chapter 7 describes the main themes that emerged from semi-structured interviews with 27 renal dietitians from Australia and New Zealand. The aim of this final study was to explore the experiences of dietitians and the strategies they use to provide dietary self-management advice to adults with ESKD. Sensemaking theory guided construction of the interview questions. Renal dietitians expressed feelings of frustration and described working in practice environments with limited resources.
Renal diet sense making was facilitated by dietitians demonstrating empathy and establishing a sense of trust. Common strategies used by renal dietitians to help patients make sense of the renal diet included clarifying ambiguities and conflicting information, as well as simplifying complex information.

Chapter 8 discusses the main findings of the thesis. The significance of these findings and the implications for clinical practice are also outlined. These include the need for the development of health literacy sensitive renal diet resources and for new models of dietetic care that are attentive to the cognitive capabilities and health literacy skills of patients and carers. It is anticipated that these alterations to clinical practice may facilitate improved understanding and adherence to the renal diet and dietary self-management.
Publications constituting this thesis

Published articles


Articles accepted for publication

**Lambert K, Mansfield K, Mullan J.** A qualitative exploration of the experiences of renal dietitians and how they help patients with kidney disease to understand the renal diet, *Nutrition and Dietetics,* Accepted for publication May 24, 2018, DOI: 10.1111/1747-0080.12443
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To Alex Koukomous, Lisa Mesiti and Paris Owen, formerly student dietitians, and now proud clinical dietitians, for their enthusiasm and willingness to help me with the studies detailed in Chapters 4 and 5.
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Sincerest thanks to the patients and carers who shared their experiences of living with end stage kidney disease. You will (probably) never read this thesis but I endeavour to keep working so that improvements in the care of others in the future is possible

Finally, thanks to my colleagues at the Department of Renal Medicine, Centre for Health Research Illawarra Shoalhaven Population, Research Central, Department of Clinical Nutrition, Illawarra Health and Medical Research Institute and the University of Wollongong Discipline of Nutrition and Dietetics for your enthusiasm, interest and willingness to support my past, present (and future) renal research endeavours
Dedication

To my favourite little people in the whole world: my children Aidan and Zoe.
To my parents for their ongoing and unwavering support of me and my crazy
endeavours (and babysitting when required)
To my long suffering and very patient husband, Mat 😊
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Travel Grants were also received from:

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- The Australian and New Zealand Society of Nephrology
- The Illawarra Shoalhaven Local Health District
- The University of Wollongong Faculty of Science Medicine and Health
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List of abbreviations

ANZDATA: Australia and New Zealand Dialysis and Transplant Registry
CI: Cognitive Impairment
CKD: Chronic Kidney Disease
COREQ: Consolidated Criteria for Reporting of Qualitative Research
eGFR: estimated Glomerular Filtration Rate
ESKD: End Stage Kidney Disease
HD: Haemodialysis
HeLMS: Health Literacy Management Scale
HLSF: Health Literacy Skills Framework
IQR: Interquartile Range
ISLHD: Illawarra Shoalhaven Local Health District
K: Potassium
KT: Kidney Transplant
MARS: Mobile Application Rating Scale
MoCA: Montreal Cognitive Assessment Tool
NDCKD: Non dialysing Chronic Kidney Disease
OR: Odds Ratio
PCKD: Poly Cystic Kidney Disease
PRE: Predialysis
PD: Peritoneal Dialysis
PO₄: Phosphate
PEMAT: Patient Education Material Assessment Tool
RRT: Renal Replacement Therapy
WHO: World Health Organisation
CHAPTER 1: Introduction

SECTION 1: Overview

1.1.1. Structure of the Thesis

Prior to reading this thesis, it is important for the reader to understand the context of the research and the position of the researcher. The research undertaken in this thesis was based on the researcher’s 19 years of experience in clinical practice, and a desire to better understand the complex factors that may influence adherence to the dietary recommendations for individuals with end stage kidney disease (ESKD). For the decade prior to the commencement of doctoral studies, the researcher was employed full time as a renal dietitian in the Illawarra Shoalhaven Local Health District of New South Wales, Australia. The opportunity to undertake formal research to examine the challenges to dietary adherence in adults with ESKD, and to explore the potential implications for clinical practice were considered integral to improving patient care.

1.1.2. Setting of the research

The Illawarra Shoalhaven Local Health District (ISLHD) of New South Wales, Australia (Figure 1.1.) services 390 000 residents in a 250 kilometre long coastal catchment area[^1]. The catchment area includes rural, regional and metropolitan areas.

In 2016, the ISLHD was considered the number one kidney disease ‘hotspot’ in Australia[^2], with a population prevalence of CKD (19.5%) that is double the national average. There are no private nephrologists in ISLHD and all nephrology medical care is provided by nephrologists located at the four public hospitals in the health district: Wollongong, Shellharbour, Shoalhaven, and Milton Ulladulla Hospital.
There were approximately 600 patients on a renal replacement therapy (RRT) in the ISLHD in 2017, with a similar demographic profile to the larger cohort of adults with ESKD undertaking RRT in Australia. Most ISLHD patients with ESKD undertaking a RRT were male, Caucasian and aged above 55 years of age. One third of these patients had diabetes as the primary cause of their renal disease. Additional details regarding the profile of these patients are shown in Appendix 4 and 5.

Renal dietitian services in the ISLHD are few, and only 1.4 full time equivalent renal dietitians service the ISLHD (including the position held by the researcher). The majority of the work in the position held by the researcher was to provide dietetic education and counselling to adults with stage 4 and stage 5 CKD i.e. predominantly those with ESKD. This includes those undertaking a RRT such as haemodialysis, peritoneal dialysis, or kidney transplantation; or those receiving renal supportive care.
1.1.3. Structure of the Thesis

This thesis is prepared according to the University of Wollongong guidelines for ‘Thesis by Compilation’ 5. The first chapter is divided into four sections and provides an introduction to the topic and thesis, an integrative literature review, and details of the theoretical framework and methodology. This is followed by six chapters outlining studies that explore factors that may impact on adherence to dietary self-management in ESKD. The focus of the discussion in the final chapter (Chapter 8) is to situate the findings of this thesis and outline potential changes required in clinical practice to improve patient care.

The integrative review in Chapter 1 and studies included in Chapters 2-7 are prepared in the format of journal articles. The integrative review and Chapters 2-5 have undergone peer review and been published during the candidature. Chapters 6 and 7 were undergoing peer review at the time of thesis submission, and were subsequently accepted for publication. To enhance the coherence of this thesis, an Executive Summary prefaces Chapters 2-7 to outline the relationships between chapters and with the overall thesis aims. Permission to reproduce the published chapters has been obtained from each journal and are shown in Appendices 6-10.

While all published articles were originally formatted according to the guidelines for each journal, the referencing in this thesis has been changed to Vancouver style for consistency within the thesis.
SECTION 2: Background

1.2.1 Overview of Chronic Kidney Disease

Chronic kidney disease (CKD) is a significant global public health problem. The worldwide age standardised prevalence of CKD is estimated to be 10.4% for men and 11.8% in women. Individuals with CKD experience a poorer quality of life and higher rates of morbidity. Cardiovascular comorbidities such as hypertension, vascular calcification, and left ventricular hypertrophy are particularly common and contribute to cardiovascular disease being the leading cause of death in adults with CKD worldwide.

The burden of disease attributed to CKD in Australia is similar to global figures, with approximately 10% of the Australian population having a diagnosis of CKD, and about 1 in 3 Australians are at risk of developing CKD. The main contributors to the development of CKD in Australia are diabetes mellitus, glomerulonephritis (inflammation of the kidneys) and hypertension. Other factors such as an ageing population and high rates of obesity also play an important role. CKD also imposes a significant financial burden on the Australian health system and contributes to one in every nine deaths in Australia.

Classification of Chronic Kidney Disease

CKD is defined using criteria developed by the Kidney Disease: Improving Global Outcomes Clinical Practice Group. These definitions have been adopted universally and classify CKD into five stages according to the degree of kidney function (measured using the estimated glomerular filtration rate, eGFR) and the amount of protein lost in the urine (known as proteinuria). Stage 1 and 2 CKD are considered to be the early stages of CKD and present few problems or side effects. At Stage 3 kidney function is reduced, and significant health issues begin to manifest. Kidney function is severely compromised at Stage 4 CKD and is often termed advanced kidney disease or the ‘predialysis’ stage.

When a patient reaches Stage 5 CKD (also known as End Stage Kidney Disease, ESKD), the complications are life limiting and eventually kidney function is no
longer able to sustain life. Table 1.2.1 outlines the stages and common complications of CKD in more detail.

Table 1.2.1. Overview of the classification of CKD and common complications

<table>
<thead>
<tr>
<th>Stage of CKD</th>
<th>eGFR</th>
<th>Complications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early stage CKD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 1</td>
<td>At least 90ml/min i.e. normal eGFR</td>
<td>There may be physical evidence of kidney damage visible on biopsy but without decreased eGFR. The patient is usually asymptomatic.</td>
</tr>
<tr>
<td>Stage 2</td>
<td>60-89 ml/min</td>
<td>There is physical evidence of kidney damage with some reduction in eGFR. Most patients are asymptomatic.</td>
</tr>
<tr>
<td>Moderate kidney disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 3a</td>
<td>45-59 ml/min</td>
<td>Kidney function is significantly reduced. Patients are often asymptomatic. Complications such as nocturia, cardiovascular disease, bone disease, fluid overload and anaemia develop.</td>
</tr>
<tr>
<td>Stage 3b</td>
<td>30-44 ml/min</td>
<td></td>
</tr>
<tr>
<td>Advanced kidney disease / predialysis stage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 4</td>
<td>15-29ml/min</td>
<td>Kidney function is significantly reduced. Blood levels of waste products increase and dysfunction in other organs occurs. Patients experience symptoms such as memory loss, insomnia, restless legs, skin itch, taste changes, fluid overload and may develop malnutrition.</td>
</tr>
<tr>
<td>End Stage Kidney Disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 5</td>
<td>&lt;15 ml/min</td>
<td>Kidney function is unable to sustain life. Symptoms and laboratory abnormalities are often severe.</td>
</tr>
</tbody>
</table>

1.2.2. Progression of CKD to ESKD

CKD is considered a largely preventable chronic disease because many of the risk factors that influence progression from Stage 1 and 2 CKD to ESKD are known to be modifiable. When early stage CKD risk factors are managed well, the risk of
progression to ESKD can be reduced by as much as 50%, and in some circumstances, CKD may even be reversible.\(^{21}\)

To reduce the risk of progression from Stage 1 and 2 CKD to ESKD, a three pronged approach is recommended.\(^{22}\) This approach involves adhering to dietary recommendations to manage coexisting conditions such as obesity and diabetes; avoiding the use of nephrotoxic medications (such as non steroidal anti inflammatory drugs); and using medications to reduce cardiovascular disease risk, control blood pressure and reduce proteinuria.\(^{23}\)

Unfortunately, approximately 2% of individuals with Early Stage CKD will progress to ESKD.\(^{24}\) In these circumstances, fluid and waste products accumulate in the blood and a range of medical complications develop. Complications usually include pulmonary oedema, renal anaemia,\(^{25}\) renal bone disease,\(^{26}\) and malnutrition.\(^{27}\)

### 1.2.3. Medical Management of ESKD

There are two main approaches to medically manage ESKD. One option is to undertake conservative or non-dialytic management. This management approach utilises palliative care principles to manage the symptom burden of ESKD until death.\(^{28}\) The second option is renal replacement therapy (RRT), which can be commenced to sustain life. RRT consists of either undergoing kidney transplantation or undertaking dialysis (haemodialysis or peritoneal dialysis). It is common in Australia for patients with ESKD to undertake peritoneal dialysis first and then to transfer over to haemodialysis after peritoneal dialysis is no longer effective.\(^{14}\) A small proportion of patients who have undergone dialysis may then also go on to receive a kidney transplant.\(^{14}\) The demand for commencing a RRT is increasing exponentially in both Australia\(^{20}\) and globally.\(^{29}\) Currently, there are just over 21 000 people in Australia receiving a renal replacement therapy, of which about 55% are undertaking dialysis.\(^ {14}\)

### 1.2.4. Self-Management of ESKD

In addition to medically managing ESKD, all patients with ESKD must also ‘self-manage’ a number of tasks related to their health. Self-management refers to the daily tasks that patients undertake to control the impact of the disease on their health.
According to Clark et al (1991) these self-management tasks are undertaken in collaboration with and guidance from the patient’s health care team.

Self-management increases in complexity as a patient progresses to ESKD. The complexity of these self-management tasks also varies according to the type of medical management chosen and where applicable, the type of RRT undertaken. For example, those who have undertaken a kidney transplant need to self-manage diet, physical activity, monitor clinical signs and conduct skin cancer surveillance (See Table 1.2.2).

**Table 1.2.2. Self-management tasks according to stage of CKD**

<table>
<thead>
<tr>
<th>CKD Stage 1 and 2</th>
<th>CKD Stage 3 and 4</th>
<th>End Stage Kidney Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Peritoneal Dialysis</td>
</tr>
<tr>
<td>Diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical activity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>May include medications</td>
<td>Medications</td>
<td>Erythropoeitin replacement therapy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>May include Erythropoeitin replacement therapy</td>
</tr>
<tr>
<td>Monitor clinical signs and symptoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home dialysis</td>
<td></td>
<td>May include home dialysis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sun protection and skin cancer surveillance</td>
</tr>
</tbody>
</table>

In general, for those with ESKD, self-management can be best summarised as a combination of taking responsibility for the management of a complex regimen of medications, self-monitoring clinical signs and symptoms, and undertaking regular physical activity. These tasks are summarised in Figure 1.2. Dietary modification is an essential component of the self-management of ESKD.
1.2.5. Dietary Self-Management of ESKD

Dietary modification (hereafter referred to as dietary self-management) is important at all stages of CKD. In the early stages of CKD, dietary self-management assists with control of risk factors (such as obesity and diabetes) and plays an essential part in preventing the progression of CKD to ESKD. However, as individuals progress to ESKD, dietary self-management increases in importance, and is used to manage the symptoms and complications associated with ESKD. Because dietary self-management is so critical in the latter stages of kidney disease, the focus of this thesis will be on dietary self-management at the predialysis stage (Stage 4 CKD) and in ESKD (Stage 5 CKD). For simplicity, from this point forward, the dietary self-management recommendations for both of these stages will be referred to as the dietary self-management recommendations for ESKD.

The dietary self-management recommendations provided to individuals with ESKD are constructed using evidence based clinical practice guidelines in conjunction with an individualised assessment. The dietary self-management recommendations are complex and require the individual to make modifications to a range of nutrients in their diet simultaneously. These include alterations to macronutrient intake (such as
energy (kilojoule), fluid and protein intake); as well as alterations to micronutrient intake (for example sodium, potassium, phosphate, vitamin C, B6, folate, B12 and zinc \(^{38,39}\)). Adding additional complexity to dietary self-management is the fact that the recommendations differ according to the type of RRT undertaken.

The dietary self-management recommendations for individuals with ESKD are considered by dietitians and patients to be challenging and restrictive, and the diet is often perceived by patients to be contradictory to typical healthy eating advice \(^{40}\). The dietary self-management recommendations for ESKD are summarised in generic terms in Table 1.2.3. and are adapted from evidence-based practice recommendations \(^{38,39,41}\). The italicised items in Table 1.2.3. are used to highlight the differences in the diet between the treatment options for ESKD.
Table 1.2.3. Summary of dietary self-management recommendations for ESKD

<table>
<thead>
<tr>
<th>Nutrient</th>
<th>Predialysis stage</th>
<th>Supportive care 46</th>
<th>HD</th>
<th>PD</th>
<th>Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sodium</td>
<td>Reduced sodium diet i.e. limit added salt and salty foods and condiments</td>
<td>Individualised based on symptoms and patient goals</td>
<td>Reduced sodium diet</td>
<td>Reduced sodium diet</td>
<td>Reduced sodium diet</td>
</tr>
<tr>
<td>Protein</td>
<td>Moderate protein diet Eat 1 serve of HBV protein daily</td>
<td>Moderate protein diet Eat 1 serve of HBV protein daily</td>
<td>High protein diet Eat &gt;2 serves of HBV protein daily</td>
<td>High protein diet Eat &gt; 2 serves of HBV protein daily</td>
<td>Moderate protein diet Eat 1 serve of HBV protein daily</td>
</tr>
<tr>
<td>Energy</td>
<td>Higher requirements than healthy people except if overweight</td>
<td>Individualised based on nutritional status, co-morbidities, physical function and activity levels</td>
<td>Higher requirements than healthy people except if overweight</td>
<td>Higher requirements than healthy people except if overweight</td>
<td>Individualised as per healthy people</td>
</tr>
<tr>
<td>Fat</td>
<td>No evidence-based guidance available</td>
<td>No evidence-based guidance available</td>
<td>Low saturated fat i.e. limit butter, cream, use lean meats and low-fat products</td>
<td>Low saturated fat i.e. limit butter, cream, use lean meats and low-fat products</td>
<td>Low saturated and total fat i.e. limit butter, cream, use lean meats and low-fat products</td>
</tr>
<tr>
<td>Fluid</td>
<td>Individualised based on blood pressure and symptoms</td>
<td>Individualised based on blood pressure and symptoms</td>
<td>Restricted usually to &lt;1000ml day</td>
<td>Individualised based on blood pressure and symptoms</td>
<td>Not restricted – aim for 2-3 litres per day minimum</td>
</tr>
<tr>
<td>K</td>
<td>If serum potassium is elevated, dietary restriction may be considered</td>
<td>Low potassium diet</td>
<td>No potassium restriction.</td>
<td>No potassium restriction.</td>
<td>No potassium restriction.</td>
</tr>
<tr>
<td>PO₄</td>
<td>Low phosphate diet if serum phosphate elevated</td>
<td>Individualised. Consider restriction in pruritus</td>
<td>Low phosphate diet</td>
<td>Restrict dairy to 1 serve daily</td>
<td>No phosphate restriction Aim for 4 serves of dairy products daily</td>
</tr>
<tr>
<td>Vitamins and minerals</td>
<td>No additional vitamin or mineral supplements usually required</td>
<td>No evidence-based guidance available</td>
<td>Extra vitamin C, folic acid, vitamin B6, selenium and zinc required due to dialysis losses</td>
<td>Extra vitamin C and pyridoxine required due to dialysis losses</td>
<td>No additional vitamin or mineral supplements usually required</td>
</tr>
</tbody>
</table>

Legend: HD: haemodialysis; K: Potassium; PO₄: Phosphate; PD: Peritoneal Dialysis; HBV: High biological value protein i.e. protein derived from meat, chicken, fish, eggs
1.2.6. Adherence to Dietary Self-Management Recommendations in ESKD

Successful dietary self-management in ESKD reduces medical complications\textsuperscript{37, 42, 43} and may improve life expectancy\textsuperscript{38, 41}. The consequences that result from non-adherence to the diet include potentially life threatening biochemical disturbances (such as hyperkalemia\textsuperscript{44, 45}); pulmonary oedema\textsuperscript{46}; bone demineralisation\textsuperscript{47}; neuromuscular complications such as neuropathy\textsuperscript{48}, malnutrition\textsuperscript{49} and an overall increase in hospitalisations and mortality\textsuperscript{50}. In the absence of a comprehensive review examining the barriers to dietary self-management adherence in ESKD, the following section, which is comprised of an integrative review, explores this topic in more detail.

The following section was published as:

References


SECTION 3: Literature Review

Title: An integrative review of the literature on dietary adherence in end stage kidney disease.

Authors:

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Kylie Mansfield, School of Medicine, Faculty of Science, Medicine and Health, University of Wollongong, New South Wales, Australia
An integrative review of the literature on dietary adherence in end stage kidney disease.

1.3.1. Abstract

**Background:** Dietary modification is an important component of the management of end stage kidney disease (ESKD). The diet for ESKD involves modifying energy and protein intake, and altering sodium, phosphate, potassium and fluid intake. There have been no comprehensive reviews to date on this topic. The aims of this integrative review were to (i) describe the methods used to measure dietary adherence (ii) determine the rate of dietary adherence and (iii) describe factors associated with dietary adherence in ESKD.

**Methods:** The Web of Science and Scopus databases were searched using the search terms ‘adherence’ and ‘end stage kidney disease’. Of the 787 potentially eligible papers retrieved, 60 papers of 24,743 patients were included in this review. Of these papers, 44 reported the rate of dietary adherence and 44 papers described factors associated with adherence.

**Results:** Most of the evidence regarding dietary adherence is derived from studies of hemodialysis patients (72% of patients). The most common method of measuring dietary adherence in ESKD was subjective techniques (e.g. food diaries or adherence questionnaires). This was followed by indirect methods (e.g. serum potassium, phosphate or interdialytic weight gain). The weighted mean adherence rate to ESKD dietary recommendations was 31.5% and 68.5% for fluid recommendations. Adherence to protein, sodium, phosphate, and potassium recommendations were highly variable due to differences in measurement methods used and were often derived from a limited evidence base. Socioeconomic status, age, social support and self-efficacy were associated with dietary adherence. However, factors such as taste, the impact of the diet on social eating occasions; and dietetic staffing also appear to play a role in dietary adherence.

**Conclusion:** Dietary adherence rates in people with ESKD are suboptimal. Further research is required on dietary adherence in patients with ESKD from different social, educational, economic and ethnic groups. This research may identify other factors which may impact upon adherence and could be used to inform the design of future strategies to improve dietary adherence. Future research that reports not just
the rate of adherence to individual components of the nutrient prescription but also the overall quality of the diet would be useful.

**Keywords:** Dietary adherence, self-management, end stage kidney disease, adherence, compliance, chronic kidney disease, dialysis; fluid restriction, potassium, phosphate
1.3.2. Background

The prevalence of Chronic Kidney Disease (CKD) is increasing rapidly\(^1\). Driven by an aging population and increasing rates of obesity, diabetes and hypertension, approximately 1 in 8 adults globally are known to have CKD\(^2\); and it is estimated that about 2% of these individuals with CKD will progress to End Stage Kidney Disease (ESKD)\(^3\). An appropriate diet can slow progression of CKD to ESKD\(^4\); ameliorate the complications of CKD and ESKD\(^5-8\), and increase survival\(^9,10\), making dietary modification a critical part of the management of CKD and ESKD\(^11\).

There is no standard renal diet. Instead, a progressive accumulation of dietary restrictions occurs as patients’ progress from CKD to ESKD. Typically, people with early CKD need to modify their intake of protein and sodium. In contrast, people with ESKD need to modify their intake of kilojoules; their fluid and protein intake; reduce their intake of minerals, such as sodium, potassium and phosphate; and potentially increase their intake of vitamins and minerals, such as vitamin C, B, folate, B12 and zinc\(^12\). Because of the large number of dietary modifications required, the diet for people with ESKD is considered by dietitians to be one of the most complex and restrictive therapeutic diets\(^13,14\). Adults with ESKD also perceive diet to be complicated and contradictory to typical healthy eating advice\(^15,16\). For example, fruits, vegetables and dairy products are often restricted in ESKD due to their potassium or phosphate content.

In addition to these challenges, the diets for people with CKD and ESKD (hereafter referred to as the renal diet for simplicity) also changes when patients commence or change the type of renal replacement therapy. For example, people receiving haemodialysis are routinely required to restrict dietary potassium intake, whereas those undertaking peritoneal dialysis are not\(^27\). These subtle differences in the renal diet prescription, combined with conflicting dietary advice between health professionals\(^16\), are often cited as an ongoing source of frustration, bewilderment and confusion for people with ESKD\(^16,17\). Given the challenges imposed by the renal diet, it is unsurprising that dietary adherence is often reported to be poor\(^18,19\).

Adherence, also used interchangeably with the term ‘compliance’, is frequently cited as: “the degrees to which patient behaviours coincide with the recommendations of
health care providers”

Previous researchers have investigated adherence to various ESKD treatment components, such as medications; phosphate binders; haemodialysis attendance, and peritoneal dialysis treatments. However, dietary adherence in people with ESKD is more complex and has not been explored in detail. The limited evidence that is available suggests that dietary adherence rates vary greatly between studies. It is also unclear if adherence varies between the individual nutrients modified in the dietary regimen for people with ESKD. A better understanding of dietary adherence in ESKD is critical because poor dietary adherence is associated with worse health outcomes. Improved knowledge and understanding of the issues associated with renal diet adherence may translate to improved dietary management strategies and improved health outcomes. Therefore, the aim of this integrative review is to provide a comprehensive summary of the evidence regarding dietary adherence in people with ESKD. The specific research questions posed in this integrative review were:

1. What methods have been used to measure dietary adherence in adults with ESKD?
2. What is the estimated rate of dietary adherence in adults with ESKD?
3. What factors are associated with dietary adherence in adults with ESKD?

1.3.3. Methods

Integrative reviews provide a comprehensive understanding of a complex phenomenon by synthesising qualitative and quantitative literature. To increase rigour, this integrative review utilised methodology described by previous authors. In brief, this methodology includes clearly delineating the focus of the research question/s, undertaking a well-defined literature search strategy, systematically evaluating studies and compiling a transparent collation of findings.

Literature Search

Comprehensive searches of the Web of Science and Scopus databases were conducted during April 2015. The key words ‘adherence’ and ‘end stage kidney disease’ were used to identify suitable peer reviewed journal articles. The corresponding MeSH terms and Boolean operators used to retrieve articles in these
searches are shown in Table 1.3.1. The reference lists of retrieved studies and review articles were also hand searched for additional relevant publications.

Table 1.3.1. Search terms used in integrative review of dietary adherence in ESKD

<table>
<thead>
<tr>
<th>Search term</th>
<th>MeSH terms used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adherence</td>
<td>adheren* OR non adheren* OR non-adheren* OR compliant* OR non compliant*</td>
</tr>
<tr>
<td>End stage kidney</td>
<td>end stage kidney failure OR end stage renal failure OR end stage renal disease</td>
</tr>
<tr>
<td>disease</td>
<td></td>
</tr>
</tbody>
</table>

Inclusion criteria

Studies considered eligible for inclusion were any experimental, observational or qualitative studies that included (i) human adults with ESKD (stage 4 or 5 CKD, conservatively managed or on any renal replacement therapy modality); (ii) reported either the rate of dietary adherence or examined factors associated with dietary adherence; (iii) reported the results in English and (iv) were available in full text. Editorials, practice guidelines, review articles, paediatric studies, studies not in English and studies not reporting the rate of dietary adherence were excluded from the analyses. Dates of publication were restricted to 2000-2015. This coincided with the release date of the first clinical practice guidelines for the nutritional management of chronic kidney disease.³¹

Data extraction

Extracted data from the eligible included studies were compiled into three summary tables to assist with interpretation and synthesis of the results. Table 1.3.2 is comprised of all studies included in this integrative review and contains a description of the salient features of each study. Table 1.3.3 contains the rates of adherence to the renal diet, and Table 1.3.4 summarises the rates of adherence. Table 1.3.5 outlines the factors associated with dietary adherence in ESKD.
1.3.4. Results

The number of potential articles relevant for review was 787 (see Figure 1.3.). An additional 85 articles were identified after hand searching the references. Following the removal of duplicates and irrelevant articles, a total of 60 articles were included in this review. Of the 60 Studies, 16 reported the rate of dietary adherence;

Figure 1.3. Flowchart illustrating selection of articles for review
28 studies reported both the rate of adherence and factors associated with adherence; and 16 studies only contained details regarding factors associated with adherence (Figure 1.3.1). For the final synthesis of findings, a total 44 articles reported the rate of dietary adherence, and 44 articles described factors associated with dietary adherence in ESKD.

A summary of the 60 studies included in this integrative review are shown in Table 1.3.2. Overall, a total of 24 743 adults with ESKD were studied, and sample sizes in the studies varied from 4 people to more than 7000. Most of these studies were conducted in Asia (17 studies, 28%) or the USA (16 studies, 27%), followed by studies conducted in the United Kingdom (9 studies, 15%) and Europe (8 studies, 13%) (Table 1.3.2). Two studies were transcontinental in nature involving the USA and Germany; as well as Europe, the USA and Japan. The majority of the data on dietary adherence was from studies involving people with ESKD undertaking haemodialysis (43 studies, 72%); followed by people undertaking peritoneal dialysis (7 studies, 12%). Only two studies included people with a kidney transplant (3%). More than half of all included studies were cross-sectional observational studies (n=31 studies, 52%), and only four studies (6%) were qualitative in nature.

Methods used to measure dietary adherence in ESKD

Of the 60 articles in this review, a range of approaches to measure dietary adherence were evident. These are summarised in Table 1.3.2 and can be broadly categorised into the use of subjective approaches (28 studies, 47%), indirect approaches (23 studies, 38%), and combination approaches (9 studies, 15%).

Subjective approaches

Of the 28 studies that used a subjective approach to measuring dietary adherence in ESKD, there were 15 variations of how this was conducted. These are shown in Table 1.3.2. The most common method described was the use of the Dialysis Diet and Fluid Non Adherence Questionnaire (DDFQ), a four item self-report instrument that probes the severity and duration of renal diet and fluid restriction non-adherence. This instrument has been demonstrated to be weakly correlated
indirect measures of dietary adherence including interdialytic weight gain, serum albumin, serum potassium and serum phosphate. The DDFQ was used as the only method to measure adherence in seven studies. Other common methods for collecting subjective information about dietary adherence included various iterations of food records such as 24 hour recalls, 3 day food recalls, 2 day food recalls, 3 day food records, and food frequency questionnaires. Other subjective methods included the use of stress scales relating to the diet or self-reported adherence.

**Indirect approaches**

There were 23 studies that used an indirect approach to measuring dietary adherence. Interdialytic weight gain (IDWG), which refers to the fluid gain in kilograms gained between haemodialysis sessions, was the most frequently reported indirect method for measuring dietary adherence (16 studies, Table 1.3.2). This was followed by 10 studies using blood tests to measure serum potassium, phosphate, albumin, or urea and urine collections to measure volume or sodium (2 studies). Ten studies used IDWG in isolation to measure adherence. Five studies used only blood tests to measure adherence.

**Combination approaches**

A combination approach was used in nine studies, with the combination of blood tests, the DDFQ, and IDWG being the most common (Table 1.3.2). This type of combination approach theoretically provides information regarding adherence to the overall renal diet, fluid intake and adherence to the low potassium and low phosphate components of the renal diet. Another common combination approach reported was the use of IDWG and food recalls or food records (3 studies).

**Estimated rates of dietary adherence in ESKD**

Details regarding the estimated rates of dietary adherence in ESKD were obtained from 44 studies (n=23 117 adults with ESKD). The rates of adherence from the 44 individual studies are shown in Table 1.3.3, and the weighted mean adherence rates for the various components of the dietary prescription for ESKD are summarised in Table 1.3.4. The weighted mean adherence rates ranged from 2.9% for fibre...
recommendations to 85.6% for adherence to the low potassium diet (Table 1.3.4). The overall rate of adherence to the renal diet was estimated to be 31.5%.

Attempts to compare dietary adherence rates within or between the various components of the renal diet are difficult. This is due to the highly heterogeneous nature of the study participants and the varying methods used to determine adherence. For example, as shown in Table 1.3.3, the gender balance of males in the studies varied from 35% to 71.7%. Studies also included cohorts with a known history of non-adherence, high rates of depression, high rates of malnutrition, or large numbers of highly illiterate adults with ESKD. Furthermore, studies varied according to whether participants were from a single centre, or were from large multicentre, and/or transcontinental studies. However, to provide some clarity regarding the estimated rates of dietary adherence, the four most frequently reported types of dietary adherence studies are discussed further in the following sections.

**Fluid restricted diets**

Fluid restrictions are recommended for people with ESKD and are used to prevent fluid overload and pulmonary oedema. Fluid restricted diets are typically in the range of 1000-1500ml of fluid per day. For those who have received a kidney transplant, fluid restrictions are not recommended and instead a higher fluid intake is suggested (usually > 3000ml per day). Most studies that report adherence to fluid recommendations in this review were conducted using people undertaking haemodialysis (24 studies), and IDWG was the most frequently used method of measuring adherence.

Overall, adherence rates to fluid recommendations varied from as low as 0% in a population known to be non-adherent to as high as 96.6%. The only two studies which examined adherence to fluid recommendations in people undertaking peritoneal dialysis, using the DDFQ to measure adherence found that the adherence rates were between 64-85%. In contrast, only one third of adults with a kidney transplant self-reported that they were adherent to fluid recommendations.
Low phosphate diets

Restriction of dietary phosphate intake is recommended for all adults with ESKD in an attempt to lower the deranged serum phosphate levels. Of the 15 studies that reported low phosphate diet adherence rates, the majority (13 studies) used serum phosphate to measure dietary adherence and found that rates varied between 43.5% - 84.5%. More than half of these studies reported an adherence rate of greater than 70%, with younger people having lower adherence rates (44.8%) when compared to older people (68.8%).

Two studies which measured low phosphate diet adherence used food recalls or food records to obtain data on dietary phosphate intake and neither study reported the proportion of inorganic to organic phosphate intake, an important emerging component of dietary phosphate management. In the only study retrieved that compared the rate of adherence to the low phosphate diet using two different methods, Elliott et al, found that adherence was 32.6% when using a self-report survey on adoption of the low phosphate diet (the Precaution Adoption Process Model tool), compared with an adherence rate of 43.8% using serum phosphate.

Low potassium diets

A low potassium diet is recommended for adults with ESKD, and is used to prevent the potentially fatal complication of chronic hyperkalemia. Serum potassium was the most frequently reported method for measuring adherence to the low potassium diet, and only one study used a food recall to determine low potassium dietary adherence. All 12 studies of low potassium diet adherence were conducted on in people undertaking haemodialysis, highlighting an obvious lack of research regarding low potassium diet adherence in those undertaking home haemodialysis and in those with CKD.

Overall renal diet adherence

One challenge of summarising the literature on renal diet adherence is the varying definitions used by previous researchers about what ‘renal diet’ adherence entails. For example, Baraz et al, defined adherence to the renal diet as serum creatinine, sodium, potassium, calcium, phosphate, albumin, urea and uric acid within acceptable limits. In contrast, Quan et al, defined renal diet adherence as
‘following the dietitian’s prescription’. Despite these differences, the reported adherence rates to the renal diet were relatively poor overall, with a weighted mean adherence rate of 31.5%. Only five of the eighteen cohorts studied achieved an adherence rate greater than 50% (38, 39, 56, 59, 76). The measurement tools used to determine renal diet adherence also varied, with five different methods used to describe renal diet adherence: serum measures (38, 39, 56, 59, 76), the DDFQ (33, 37-42), the 3 day food record (50), or a combination of measures including self-report (56, 76, 87, 88). Furthermore, four studies compared overall renal diet adherence using two different methods: the DDFQ and serum measures (76, 87, 88) or self-report and serum measures (56). The findings indicated that renal diet adherence varied in the same cohort of adults with ESKD by 8.9% (88) to 31% (56), suggesting that simply using different adherence measurement methods can also affect the adherence rate results.

**Factors reported to be associated with dietary adherence in adults with ESKD**

Adherence to medical treatment is a complex process influenced by many social, individual, cultural and environmental factors (83). This component of the integrative review utilised data from 44 studies. To assist with interpretation of the results, the factors reported to be associated with dietary adherence have been categorised according to the World Health Organisational (WHO) Multidimensional Adherence Model (89) and are shown in Table 1.3.5. The categories outlined in the WHO model (89) are (i) socioeconomic factors (ii) condition related factors (iii) therapy related factors (iv) health care team and system factors and (v) patient related factors.

**Socioeconomic factors**

Twenty four studies provided information on socioeconomic factors associated with dietary adherence. From these studies, age, gender and education level were the most frequently explored socioeconomic factors (Table 1.3.5). Older adults and individuals with a higher level of education were consistently associated with greater dietary adherence. Evidence regarding occupation level suggests that those who are not working are more likely to adhere to the renal diet. In contrast, results regarding the relationship between gender and dietary adherence were mixed. Overall, female gender was associated with greater dietary adherence to the renal diet in eight of
eleven studies. One of the few studies which reported the opposite result, that is, males were more likely to be adherent to the renal diet, came from the largest study cohort included in this integrative review with more than 7000 adults with ESKD.  

*Condition and therapy related factors*

Information on condition and therapy related factors associated with dietary adherence were obtained from 25 studies (Table 1.3.5). From these studies, most evidence supported an association between the length of time undertaking haemodialysis and poorer renal diet adherence. Reasons for this remain unexplored, but it is thought to be related to the practical challenge of managing the complex dietary modifications required for many years, and to the scale of modifications required to long standing behaviours.

The relationship between dietary knowledge and renal diet adherence is not clear and the evidence base comes from only 6 studies of less than 2000 adults with ESKD. Poor dietary knowledge was associated with suboptimal renal diet adherence in four studies. Provision of renal diet related practical skills and knowledge, such as learning food composition details, self-monitoring strategies or learning appropriate recipe modifications were found to be associated with greater renal diet adherence and were also highly valued by patients in the three qualitative studies. Factors such as receiving conflicting dietary advice from different health professionals, and the complexity of the diet were reported to be associated with poorer dietary adherence.

*Health care team and system factors*

Research on the relationship between the health care team and health care system factors on dietary adherence in ESKD is scarce, but of increasing academic interest. Evidence from nine studies suggests that the quality of the relationship between the patient and the health care professional is important (Table 1.3.5). For example, patients with EKSD who receive intensive education from experienced renal dietitians, or patients who received support from renal health professionals were more adherent to the renal diet. Furthermore, inadequate support or infrequent contact from renal dietitians was specifically found to impact negatively on dietary adherence. The main reason suggested by the authors for these
findings was inadequate staffing ratios 27,91. This is an important finding as staffing surveys of renal dietitians from the US 95, 96, UK 97, Asia 98 and Australia 99, 100 consistently report that renal dietitian staffing ratios are below evidence based practice recommendations.

*Patient related factors.*
Evidence for patient related factors was obtained from 25 studies with ESKD. Factors such as the presence of social and family support, and positive beliefs and attitudes towards the renal diet were frequently studied and found to be consistently associated with improved renal diet adherence. Patients who understood and valued the potential benefits of dietary modification 19, 34-36, 70, 92 were more adherent to the diet than those who felt the diet posed a burden 71. Self-efficacy refers to a person’s confidence to control their behaviour to achieve a goal 101. The impact of self-efficacy on dietary adherence was investigated in six studies, and these studies reported that adults exhibiting greater self-efficacy also experienced higher dietary adherence rates 68, 69, 71, 84, 88, 102.

The impact of the renal diet on social eating events was also a specific patient related factor identified with renal diet adherence in four studies 13, 19, 34, 35. Findings from the three qualitative studies 13, 34, 35 indicated several situational or contextual factors relating to social eating that impacted on dietary adherence. For example, dietary adherence was influenced by acceptance of the renal diet by family members or friends 13, 34. One study also reported that patients were not adherent to the diet to avoid ridicule from others or because foods adherent to the renal diet were not readily available when eating out 35.

Taste preferences (particularly for salt) were also reported as a barrier to renal diet adherence in several studies 34, 35, 88. For example, De Brito-Ashurst et al 34 reported perceptions that salt was a vital food ingredient and thus not possible to reduce in the diet without reducing palatability 34. Finally, depression appears to be an under researched area pertaining to renal diet adherence. This is surprising given the high prevalence of the disorder in patients with ESKD 103. Two studies explored the relationship between depression and renal diet adherence 49, 76, those who were depressed also exhibited worse dietary adherence. Similarly, those with greater
mental health 71 or adequate psychological coping skills 66 were more likely to adhere to the renal diet.

1.3.5. Discussion

Adherence to medical treatment is considered to be the most effective method for improving health outcomes 104. The intent of this integrative review was to synthesise the body of evidence regarding dietary adherence in adults with ESKD and identify the factors which influence dietary adherence. This review has yielded four key findings that can be used by clinicians and researchers to improve renal diet adherence.

The first key finding of this review was that research on dietary adherence in ESKD is dominated by studies using subjective self-reported information. Measurement of dietary adherence in ESKD is challenging, and unlike medication or dialysis related adherence studies, there is no ‘gold standard’ or single physiological marker exists that indicates a person is consuming the recommended ESKD diet prescription. Subjective methods such as diet recalls, food frequency questionnaires and diet records impose a significant subject burden in an unwell population. They are also known to be associated with problems of underreporting of dietary intake 105. Adherence questionnaires like the DDFQ 37 or the Renal Adherence Behaviour questionnaire 106 also assume patients have adequate cognitive capabilities and appropriate levels health literacy; as well as an adequate understanding of the diet to answer the questions appropriately. This is particularly problematic given that cognitive impairment and low health literacy are common in patients with ESKD 107-111. Consequently, subjective approaches should also be used with caution in those with ESKD.

The second key finding of this review is that indirect physiological measures (such as serum potassium, phosphate or interdialytic weight gain) have been used frequently to measure dietary adherence in ESKD. The obvious advantages of using serum markers are that they are relatively cheap, easy to obtain, and have a low patient burden. However, serum potassium and phosphate are strongly influenced by non-dietary factors such as residual renal function 112,113, constipation 114, adherence to prescribed medications 115,116, acid base balance 117 and time between treatments.
Making them unreliable and inaccurate markers of dietary adherence. Future studies of dietary adherence in ESKD should ideally attempt to use direct observation and immediate quantification of dietary intake to provide the most accurate data on dietary intake. However, limited staffing, finances, and the inability to monitor patients for long time periods, make this approach unlikely to be implemented. For pragmatic reasons it is therefore suggested that a combination of indirect measures (e.g. interdialytic weight gain, urine volume and sodium) and subjective methods (such as dietitian assisted dietary recalls) be used instead to increase the rigour of the information collected. Improved reporting of dietary outcomes in future studies is also needed and future research should include comprehensive details of dietary intake as well as reporting the rate of adherence. This approach has been used in several recent studies, and provides superior quality information that could then be used to guide future dietary adherence interventions.

This review provides clinicians with estimates of the rate of adherence to the renal diet and is the third important finding of this review. Attempts to compare the estimated dietary adherence rates to other components of the ESKD treatment regimen are challenging however, because the renal diet contains many components. Overall, the weighted mean adherence rates to fluid, phosphate, potassium and carbohydrate recommendations were similar to rates of adherence in other medical conditions. For example, it is estimated that 50-70% of patients are expected to be adherent to their therapy irrespective of the disease, prognosis or setting. Previous research in people with chronic diseases (such as diabetes, hypertension or ischemic heart disease) have also reported adherence rates of this magnitude. However, the low rate of adherence to the overall renal diet as well as to specific components such as energy, protein, sodium, total fat and fibre reported in this review suggests that designing interventions to improve dietary adherence in those with ESKD is required.

Interventions to improve adherence are proposed to have a greater impact on patient health than any further improvements in medical technologies and treatments.

The final important findings of this review were that there are several factors that are associated with good dietary adherence: older age; higher education levels; the
presence of social or family support; and high levels of self-efficacy. Several other unique factors such as taste, the impact of the diet on social eating occasions; and dietetic staffing also play a role in dietary adherence.

However, several factors impacting on dietary adherence in ESKD examined in this review warrant specific further discussion. For example, the relationship between renal diet knowledge and renal diet adherence requires further investigation. Previous studies of adherence in people with ESKD have demonstrated that knowledge was strongly associated with adherence to the ESKD treatment regimen.

However, in the present review, greater knowledge of the renal diet was not always associated with improved dietary adherence. This surprising finding is consistent with a recent systematic review on the relationship between dietary knowledge and dietary adherence in general, which also showed that in adults there was only a weak association. In other words, it appears that knowledge alone is not sufficient for optimal renal dietary adherence. Several emerging areas that may explain these findings include the possibility that individuals with ESKD may have lower levels of patient activation and patient engagement for undertaking the changes required when following the renal diet, and therefore further investigation of the reasons for these findings is clearly warranted.

The quality of the relationship between the patient and the health care provider was identified in this review as an important modifier of dietary adherence. In addition, recent evidence indicates that multidisciplinary care slows the rate of decline in renal function, suggesting that adherence rates may be better in patients treated by multidisciplinary teams. Further research exploring how this relationship impacts on dietary adherence is important and could be used to redesign dietary education strategies. Patients with kidney disease have expressed dissatisfaction with the information provided to them by health care providers in numerous studies. As a result, patients now use the internet to seek answers to the questions they feel are important to them. Whether this occurs with those seeking renal diet information remains unexplored, and the impact of ‘googling’ on dietary adherence is unknown. Similarly, frustrations have been expressed by patients about receiving contradictory dietary information, but how this impacts on dietary adherence is also unknown. The perceptions by patients and other staff about the role of the renal
dietitian should also be explored further. For example, patients are commonly referred to renal dietitians by medical staff to prevent disease progression or to control side effects. However, these are infrequently expressed motivators for attending dietitian appointments or for adhering to the diet. Instead, patients report consulting renal dietitians to either improve their quality of life, or to decrease the negative impact of the diet on social eating occasions.

The impact of factors such as health literacy and cognitive impairment on dietary adherence in ESKD also requires further exploration. The renal diet is acknowledged as one of the most complex diets to teach, understand and implement. The presence of cognitive impairment and low health literacy in patients with ESKD could contribute to the poor rates of dietary adherence reported in this review. Previous research has confirmed that health literacy skills and cognitive capabilities are important influences on other self-management abilities in patients with ESKD. It seems reasonable therefore, to assume that a poor understanding of the renal diet, poor quality patient education materials or poorly given instructions relating to the diet may lead to errors in the dietary self-management process and worsen health outcomes. Therefore, a better understanding of how these factors impact on dietary adherence is critical for preventing disease progression and further complications.

There are several areas for future research that are evident from this integrative review. For instance, due to the lack of studies on dietary adherence in patients with ESKD not undertaking dialysis, it is recommended that future research on dietary adherence should include this group of patients, as well as kidney transplant recipients. Future studies should also utilise a comprehensive dietitian assisted dietary assessment method such as a diet recall, diet record, FFQ or diet quality index. Exploring differences in adherence that may occur between non-dialysis and dialysis days; as well as the differences in adherence that may occur according to dialysis vintage, or in minority cultural groups are also important. Studies should also investigate differences in adherence to the renal diet according to gender and over time. This is an important area for future research because adherence to the renal diet requires continuous self-regulation and adherence would be expected to
vary day to day, as well as over time, between renal replacement therapy modalities and according to season 123, 155. Future research on renal diet adherence should also consider reporting the impact of the renal diet on overall diet quality 14, 156-158. The relationship between nutrient modification and overall diet quality is increasingly recognised as important and is known to influence the risk and development of chronic diseases such as kidney disease 159, 160. The use of indirect measures will not adequately capture these variations in quality, quantity and adherence 161. Further research examining how patients make sense of the renal diet, and how this may impact on adherence would also be useful and could be used to inform and guide practitioners about the content of future dietary education strategies and patient education resources.

Several recommendations for clinicians are also evident from this review. Additional support or alternative education and counselling strategies may be required to enhance dietary adherence in individuals who are male; younger; with lower education levels, and with inadequate social and family support. Patients that may be depressed have low self-efficacy and those with a long dialysis vintage may also be another target group for additional support from health professionals. Based on the findings of this review, advice from health professionals within renal units where possible should also be consistent and delivered utilising appropriate health literacy techniques 162, 163. Clinicians should also consider utilising or expanding upon the use of pragmatic and flexible dietary prescriptions (such as those described recently for individuals requiring a low protein diets 164-166 in an attempt to improve dietary adherence.

The strengths of this review include the exhaustive coverage of the topic using studies retrieved from a comprehensive search of two large databases and the retrieval of a large number of additional relevant articles from reference lists. There are also limitations relating to this review which need to be acknowledged. The grey literature was not searched and articles in languages other than English were not included. The search strategy used was based on MeSH terms, and alternative or additional search terms may have retrieved other relevant articles.
Conclusions

Dietary modification is an important component of the management of ESKD. Based on the findings of this review it is estimated that around one in three adults with ESKD are adherent to the renal diet and approximately two thirds of adults with ESKD adhere to recommendations regarding fluid. Uncertainty surrounds these results though due to wide variations in adherence rates between studies, and the use of methodological approaches with inherent flaws in reliability and accuracy. Adults found to be most likely to adhere to the renal diet includes females, older adults, and individuals with adequate family and social support and self-efficacy. This review has also highlighted that further research on dietary adherence is required in several cohorts with ESKD, such as kidney transplant recipients or those with ESKD not undertaking dialysis. Developing strategies to address the barriers identified in this review to dietary adherence in ESKD may improve health outcomes.

Competing interests

The authors declare that they have no competing interests.

Authors’ contributions

KL designed the review, conducted the analysis, and takes main responsibility for writing the article. JM and KM contributed to study design, analysis and interpretation.

Authors’ information

KL is an Advanced Accredited Practising Dietitian and Renal Dietitian.
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Legend: CKD: Chronic Kidney Disease any stage; DDFQ: Dialysis Diet and Fluid Non Adherence Questionnaire [37]; DNAQ: Dietary Non Adherence Questionnaire [91]; ESKD: End Stage Kidney Disease; FFQ: food frequency questionnaire; HD: Haemodialysis; IDWG: Interdialytic weight gain; KT: Kidney transplant; ND-CKD: Non dialysing end stage chronic kidney disease; PAPM: Precaution Adoption Process Model [84]; PD: Peritoneal dialysis; RCT: Randomised Control Trial; RABQ: Renal Adherence Behaviour Questionnaire [106].a:France, Germany, Italy, Spain, UK
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yusop et al, 2013, Malaysia [81]</td>
<td>90 / 48.9</td>
<td>HD</td>
<td>31.1</td>
<td>20.0</td>
<td>24.4</td>
<td>82.2</td>
<td>100.0</td>
<td>86.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total number participants</strong></td>
<td><strong>23 177</strong></td>
<td><strong>Weighted mean adherence rate</strong></td>
<td><strong>31.5</strong></td>
<td><strong>68.5</strong></td>
<td><strong>23.1</strong></td>
<td><strong>45.5</strong></td>
<td><strong>79.8</strong></td>
<td><strong>85.6</strong></td>
<td><strong>61.4</strong></td>
<td><strong>TF: 41.4</strong></td>
<td><strong>SF: 72.5</strong></td>
<td><strong>83.1</strong></td>
<td><strong>2.9</strong></td>
</tr>
</tbody>
</table>

Legend: a: gender for total PD group; b: gender proportion for total HD group; CKD: Chronic Kidney Disease; CHO: adherence to recommendations for carbohydrate intake; DDFQ: Dialysis Diet and Fluid Non Adherence Questionnaire; enPCR: equilibrated normalized protein catabolic rate; FFQ: food frequency questionnaire; HD: haemodialysis; IDWG: interdialytic weight gain; K: adherence to low potassium diet; KT: kidney transplant; Na: adherence to recommendations for sodium intake; NDCKD: non-dialysing adults with ESKD; PAPM: Precaution Adoption Process Model tool; PO4: adherence to low phosphate diet; PD: peritoneal dialysis; Renal diet: refers to adherence to all components of the renal diet prescription; RRT: renal replacement therapy type; TF: adherence to recommendations for total fat intake; SF: adherence to recommendations for saturated fat intake; serum bloods: combination of serum potassium, phosphate and/or others (e.g. albumin or urea).
Table 1.3.4. Summary of weighted mean adherence rates for components of the dietary prescription for ESKD2

<table>
<thead>
<tr>
<th>ESKD dietary adherence component</th>
<th>Weighted mean adherence rate (%)</th>
<th>Evidence base</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adherence to fluid recommendations</td>
<td>68.5</td>
<td>28 studies of 20 244 adults with ESKD</td>
</tr>
<tr>
<td>Adherence to energy intake recommendations</td>
<td>23.1</td>
<td>7 studies of 1871 adults with ESKD</td>
</tr>
<tr>
<td>Adherence to protein intake recommendations</td>
<td>45.5</td>
<td>15 studies of 3701 adults with ESKD</td>
</tr>
<tr>
<td>Adherence to the low phosphate diet</td>
<td>79.8</td>
<td>15 studies of 12 571 adults with ESKD</td>
</tr>
<tr>
<td>Adherence to the low potassium diet</td>
<td>85.6</td>
<td>12 studies of 12 284 adults with ESKD</td>
</tr>
<tr>
<td>Adherence to the reduced sodium diet</td>
<td>61.4</td>
<td>3 studies of 207 adults with ESKD</td>
</tr>
<tr>
<td>Adherence to total fat intake recommendations</td>
<td>41.4</td>
<td>2 studies of 319 adults with ESKD</td>
</tr>
<tr>
<td>Adherence to saturated fat intake recommendations</td>
<td>72.5</td>
<td>2 studies of 319 adults with ESKD</td>
</tr>
<tr>
<td>Adherence to carbohydrate intake recommendations</td>
<td>83.1</td>
<td>2 studies of 319 adults with ESKD</td>
</tr>
<tr>
<td>Adherence to fibre recommendations</td>
<td>2.9</td>
<td>1 study of 70 adults with ESKD</td>
</tr>
<tr>
<td>Adherence to the renal diet</td>
<td>31.5</td>
<td>13 studies of 3832 adults with ESKD</td>
</tr>
</tbody>
</table>
Table 1.3.5. Factors associated with dietary adherence in adults with ESKD categorised according to WHO criteria

<table>
<thead>
<tr>
<th>Authors</th>
<th>Patient numbers</th>
<th>ESKD group</th>
<th>Socioeconomic factors</th>
<th>Condition related factors</th>
<th>Therapy related factors</th>
<th>Health care team and system related factors</th>
<th>Patient related factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agondi et al, 2011[51]</td>
<td>117</td>
<td>HD</td>
<td>Higher education level</td>
<td>Older age</td>
<td>Shorter dialysis vintage</td>
<td>Dietary knowledge</td>
<td>Positive beliefs regarding the benefits of the diet</td>
</tr>
<tr>
<td>Ahrari et al, 2014 [38]</td>
<td>237</td>
<td>HD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Social and family support</td>
</tr>
<tr>
<td>Baraz et al, 2010 [59]</td>
<td>63</td>
<td>HD</td>
<td>Higher education level</td>
<td>Being employed</td>
<td>Younger age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chan et al, 2012 [88]</td>
<td>188</td>
<td>HD</td>
<td>Retired or not working</td>
<td>Female gender</td>
<td>Older age</td>
<td>Dietary knowledge</td>
<td>Shorter dialysis vintage</td>
</tr>
<tr>
<td>Chan et al, 2010 [39]</td>
<td>173</td>
<td>PD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Nurse support for home dialysis patients</td>
</tr>
<tr>
<td>Chen et al, 2006 [48]</td>
<td>70</td>
<td>PD</td>
<td></td>
<td></td>
<td></td>
<td>Recipe modification knowledge</td>
<td></td>
</tr>
<tr>
<td>Clark - Cutaa et al, 2014[44]</td>
<td>122</td>
<td>HD</td>
<td>Male gender, Older age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DelBrito-Ashurst et al, 2011 [34]</td>
<td>20</td>
<td>CKD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Taste preferences &amp; palatability</td>
</tr>
<tr>
<td>DelBrito-Ashurst et al, 2013 [61]</td>
<td>56</td>
<td>CKD</td>
<td></td>
<td></td>
<td>Recipe modification knowledge</td>
<td></td>
<td>Strategies to manage the diet at social events</td>
</tr>
<tr>
<td>Dunse et al, 2004 [72]</td>
<td>71</td>
<td>HD</td>
<td>Knowledge of medical complications of dietary non-adherence</td>
<td></td>
<td>Dietary knowledge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elliot et al, 2015 [84]</td>
<td>95</td>
<td>HD</td>
<td>Minimum of high school education White ethnicity</td>
<td>Better quality of life</td>
<td>Shorter dialysis vintage</td>
<td></td>
<td>Perceived benefits of dietary adherence Self-efficacy</td>
</tr>
<tr>
<td>Ford et al 2004 [73]</td>
<td>70</td>
<td>HD</td>
<td></td>
<td></td>
<td></td>
<td>Intensive patient education</td>
<td></td>
</tr>
<tr>
<td>Gordon et al, 2009 [35]</td>
<td>5</td>
<td>KT</td>
<td></td>
<td></td>
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<td></td>
<td>Strategies to manage the diet at social events</td>
</tr>
<tr>
<td>Gordon et al, 2009 [35]</td>
<td>82</td>
<td>KT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Positive beliefs &amp; attitudes about the diet</td>
</tr>
<tr>
<td>Reference</td>
<td>Sample Size</td>
<td>Setting</td>
<td>Demographic Factors</td>
<td>Health/Quality of Life Factors</td>
<td>Other Factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>-------------</td>
<td>---------</td>
<td>---------------------</td>
<td>--------------------------------</td>
<td>---------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kara et al, 2007 [40]</td>
<td>160</td>
<td>HD</td>
<td>Older age</td>
<td>Being married</td>
<td>Presence of family support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Karavetian et al, 2014 [91]</td>
<td>570</td>
<td>HD</td>
<td>Dietary knowledge</td>
<td>Adequate dietitian staffing</td>
<td>Experienced renal dietitian</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Khalil et al, 2011 [76]</td>
<td>100</td>
<td>HD</td>
<td>Absence of depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kugler et al, 2011 [41]</td>
<td>456</td>
<td>HD</td>
<td>Lower education level</td>
<td>Female gender</td>
<td>Being married</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kugler et al, 2005 [33]</td>
<td>916</td>
<td>HD</td>
<td>Female Gender</td>
<td>Older Age</td>
<td>Short dialysis vintage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lam et al, 2010 [42]</td>
<td>173</td>
<td>PD</td>
<td>Retired occupational status</td>
<td>Lower education level</td>
<td>Female gender</td>
<td>Older age</td>
<td>Dialysis vintage &gt;3 years</td>
</tr>
<tr>
<td>Lee et al, 2002 [56]</td>
<td>62</td>
<td>HD</td>
<td>Unemployment or non-working status</td>
<td>Shorter dialysis hours per week</td>
<td>Positive attitudes to diet</td>
<td></td>
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</tr>
<tr>
<td>Lindberg et al, 2009 [64]</td>
<td>4498</td>
<td>HD</td>
<td>Older age</td>
<td>Short dialysis vintage</td>
<td>Higher BMI</td>
<td></td>
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<tr>
<td>Mellon et al, 2013 [19]</td>
<td>50</td>
<td>HD</td>
<td>Older age</td>
<td></td>
<td>Perception that diet fits into lifestyle</td>
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<tr>
<td>Molaison et al 2003 [65]</td>
<td>316</td>
<td>HD</td>
<td>Older age, Female gender</td>
<td>Self-monitoring</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mok et al 2001 [55]</td>
<td>50</td>
<td>HD</td>
<td>Long dialysis vintage</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morales Lopez et al, 2007 [58]</td>
<td>34</td>
<td>HD</td>
<td>Adequate finances</td>
<td>Culturally appropriate format of patient education</td>
<td>Presence of a dietitian on staff</td>
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</tr>
<tr>
<td>O’Connor et al, 2008 [66]</td>
<td>73</td>
<td>HD</td>
<td>Female gender</td>
<td>Older Age</td>
<td>Presence of family support</td>
<td></td>
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</table>

72
<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Sample Size</th>
<th>Dialysis Modality</th>
<th>Factors</th>
<th>Additional Factors</th>
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<tbody>
<tr>
<td>Pang et al, 2001 [67]</td>
<td>92</td>
<td>HD</td>
<td>Lower family income</td>
<td>Lower comorbid disease burden</td>
</tr>
<tr>
<td>Park et al, 2008 [80]</td>
<td>160</td>
<td>HD</td>
<td>Older age</td>
<td>Presence of social support</td>
</tr>
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<td>Poduval et al, 2003 [74]</td>
<td>117</td>
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<td>College education</td>
<td>Malnutrition</td>
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<tr>
<td>Quan et al, 2006 [50]</td>
<td>30</td>
<td>PD</td>
<td></td>
<td>Nurse support for home dialysis patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Education about food composition</td>
<td>Intensive patient education</td>
</tr>
<tr>
<td>Sagawa et al, 2001 [93]</td>
<td>10</td>
<td>HD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Saran et al, 2003 [27]</td>
<td>7676</td>
<td>HD</td>
<td>Unemployed, Male gender, Older age, Married</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Long dialysis vintage</td>
<td>Presence of a dietitian on staff</td>
</tr>
<tr>
<td>Sharp et al 2005 [68]</td>
<td>56</td>
<td>HD</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Intensive patient education</td>
<td>Family support Non-smoking status</td>
</tr>
<tr>
<td>Thomas et al 2001 [92]</td>
<td>276</td>
<td>HD</td>
<td>White ethnicity Female gender</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Dietary knowledge practical shopping skills</td>
<td>Family support Positive beliefs &amp; attitudes about the impact of the diet</td>
</tr>
<tr>
<td>Tsay et al, 2003 [69]</td>
<td>62</td>
<td>HD</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Self-monitoring</td>
<td>High self-efficacy</td>
</tr>
<tr>
<td>Wang et al, 2003 [53]</td>
<td>266</td>
<td>PD</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>No history of fluid overload</td>
</tr>
<tr>
<td>Welch et al 2001 [70]</td>
<td>148</td>
<td>HD</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Positive beliefs &amp; attitudes about the impact of the diet</td>
</tr>
<tr>
<td>Yokoyama et al 2009 [71]</td>
<td>72</td>
<td>HD</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Dialysis staff encouragement</td>
<td>Lower perceived burden of the diet High self-efficacy Good mental health</td>
</tr>
<tr>
<td>Zrinyi et al 2003 [102]</td>
<td>107</td>
<td>HD</td>
<td>Female gender</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>High self-efficacy</td>
</tr>
</tbody>
</table>

Legend: HD: haemodialysis; KT: kidney transplant; NDCKD: non-dialysing adults with ESKD; PD: peritoneal dialysis
SECTION 4: Theoretical Framework and Methodology

1.4.1. Introduction

Chapter 1, Section 3 provides the reader with a comprehensive overview of the evidence regarding the rate of adherence, and factors associated with dietary self-management adherence in ESKD. This synthesis of the evidence fills an important knowledge gap. Using the methodology of an integrative review, 60 papers were selected to summarise the body of evidence. Based on the inclusion criteria, factors such as older age and the presence of social support were consistently associated with improved dietary adherence. This review also identified that there are several determinants of adherence whose relationship to dietary self-management adherence have not been explored in detail. One example of these other determinants is the impact of an individual’s health literacy.

An individual’s health literacy skills are known to influence how an individual manages other self-management tasks in ESKD, such as medications and self-monitoring. It would be reasonable to assume therefore, that inadequate health literacy could also contribute to the suboptimal rates of adherence to dietary self-management in ESKD described in Chapter 1, Section 3. A poor understanding of CKD, or instructions relating to dietary self-management of the disease provided in patient education materials could lead to errors in the dietary self-management process and contribute to worse health outcomes. Understanding more about whether inadequate health literacy may impact on adherence to ESKD dietary self-management is critical for developing strategies that may improve adherence and potentially prevent disease complications and/or progression.

1.4.2. Theoretical Framework

The theoretical framework used to guide the design and interpretation of the studies contained within this thesis is the Health Literacy Skills Framework (HLSF). This framework was chosen because it illustrates the full pathway from development and moderators of health literacy skills, to their application, and the resultant health related behaviours and outcomes. The Health Literacy Skills Framework (conceptualised in Figure 1.4., and adapted from Squiers et al, 2012, page 47),
specifically examines factors known to moderate the development of health literacy skills (such as demographic characteristics and cognitive capabilities), as well as factors that mediate the effects of health literacy on health outcomes (such as the health literacy demand of health related stimuli).

The HLSF describes the relationship between health literacy, comprehension of health information, health behaviours and outcomes \(^6\). The HLSF also employs a socioecological perspective and incorporates investigation of the broader factors (known as ecological influences) that can impact on the health behaviour of interest. These factors may include the family, community resources and the health care system, many of which are similar to those identified in the literature review (Chapter 1, Section 3) as being associated with adherence to the renal diet.

Figure 1.4. Conceptual diagram of the Health Literacy Skills Framework

Legend: Conceptual framework adapted from Squiers et al \(^6\).
1.4.3. Thesis Aims and Objectives:

The overarching aim of this thesis was to explore the issues associated with adherence to dietary self-management in adults with End Stage Kidney Disease (ESKD) using the lens of health literacy.

The specific objectives of this research were to:

1. Synthesise knowledge regarding adherence to dietary self-management in ESKD by:
   a. Describing common methods to measure dietary adherence
   b. Estimating the rate of dietary adherence in ESKD
   c. Describing the factors associated with dietary adherence in ESKD

   The findings from this study are presented in Chapter 1, Section 3.

2. Explore factors that may influence adherence to dietary self-management in adults with ESKD including:
   a. Cognitive capabilities using the Montreal Cognitive Assessment Tool 7 to screen for cognitive impairment in adults with ESKD.

   The findings from this study are presented in Chapter 2.
   b. Health literacy skills using the Health Literacy Management Scale 8 to evaluate health literacy skills in adults with ESKD.

   The findings from this study are presented in Chapter 3.
   c. The health literacy demand of online renal diet education materials.

   The findings from these studies are presented in Chapter 4 and Chapter 5.

3. Explore and describe factors that may impact on the comprehension of dietary self-management advice:
   a. from the perspective of the patient and carer by using Sensemaking methodology 9 to construct the semi structured interview questions.

   The findings from this study are presented in Chapter 6.
   b. from the perspective of the dietitian by using Sensemaking methodology 9 to construct the semi structured interview questions.

   The findings from this study are presented in Chapter 7.
1.4.4. Significance of the research

This thesis contributes to the evidence base of knowledge regarding dietary self-management in adults with ESKD, with a view to informing clinical practice and directing future research endeavours to improve patient care. The increasing demand for renal dietetic services for patients with ESKD, and the suboptimal adherence rates reported in the literature to the renal diet reinforce the need to explore potential strategies to improve dietary adherence. As a result of this research, clinicians will be more informed about factors influencing dietary adherence in ESKD. Dietitians providing care to adults with ESKD will benefit from improved knowledge about barriers and potential strategies they could incorporate into their clinical practice to improve dietary adherence. Patients may also benefit from the findings of this thesis in the longer term by receiving clinical care that addresses the barriers to adherence they may have in order to improve health outcomes. For researchers, the findings of this thesis will provide new directions for research relating to dietary adherence and clinical practice. In summary, an improved understanding of dietary adherence in ESKD may lead to better clinical care and improved patient outcomes.

1.4.5. Methodological Approach

This thesis utilises a ‘sequential explanatory mixed methods approach’. This approach involves collection and analysis of quantitative data, followed by qualitative data collection.

This approach to the thesis was selected because it is considered to be an ideal approach for investigating research questions involving clinical care to patients (especially those involving complex social and behavioural issues) and ensures that the findings are more meaningful and relevant to clinical practice. Other advantages of the sequential explanatory mixed methods approach, include that the qualitative findings can be used to help with the interpretation of the quantitative results, and that data triangulation can be used to determine the convergence and divergence of the quantitative findings.

Further reasoning for incorporating a qualitative component into the study design of this thesis relate to the limitations of previously published qualitative studies on dietary self-management in ESKD. To date, most of the previous qualitative research...
on dietary self-management in people with ESKD has been conducted with predominantly female haemodialysis patients from the USA or UK, or with minority cultural groups in Australia (such as African Americans or Hispanics). In addition, there are a limited number of qualitative studies in the Australasian ESKD setting (n=7); and an overall paucity of qualitative studies utilising patients receiving other types of renal replacement therapy. There are also minimal qualitative studies investigating the determinants of dietary self-management in ESKD from a health care system or therapy related perspective. This is of particular interest in this thesis because whilst renal dietitians are identified by patients with ESKD as trusted health professionals, there are only three qualitative research studies on the utility of the therapeutic approach used by renal dietitians and its impact on dietary self-management.

1.4.6. Methods used in this research

The quantitative methods used in this thesis included cross sectional studies, while both content analysis and semi structured interviews were used as qualitative data collection methods.

Cross sectional studies

Cross sectional studies are the simplest individual level observational study design, which are relatively quick and easy to conduct. Data collection typically involves surveys or questionnaires to determine the prevalence of a behaviour or characteristic in a population. In this thesis the Montreal Cognitive Assessment (MoCA, Chapter 2) and the Health Literacy Management Scale (HeLMS, Chapter 3) were used to describe the cognitive capabilities and health literacy skills of adults with end stage kidney disease. Another important reason for utilising cross sectional studies in this thesis, is that this method has been described as being particularly useful for health care planning purposes. This enables the findings of the research in this thesis to be translated more readily into clinical practice.

Content analysis

Content analysis was used in to analyse renal diet information available online (Chapters 4 and 5) because this research method uses a systematic approach to
analysing large volumes of (usually text) data. This method is increasingly used in health and nutrition education research to examine online and publicly available education materials. The major advantage of using content analysis is that it can be used to make inferences from the data in order to quantify a phenomenon. In this thesis, a deductive approach to the content analysis was applied, which meant that the analysis commenced with a predetermined series of renal diet related key words.

**Semi structured interviews**

The semi structured interviews used to collect qualitative data from both renal dietitians and patients with ESKD patients (Chapters 6 and 7), were chosen because they allow for a small number of predetermined questions to structure a conversation with another person, assist with gaining a deep understanding of the phenomenon from the participant’s perspective of the participant and allow for the exploration of themes. These semi-structured interviews were conducted in person, and/or over the phone. This approach to obtaining data was particularly relevant to achieving the aims of this thesis because important contextual information about food and nutrition related behaviours were able to be obtained.
References:

CHAPTER 2: Factors influencing the development of health literacy skills.

Title: A comparison of the extent and pattern of cognitive impairment among predialysis, dialysis and transplant patients: a cross sectional study from Australia.

Authors:

Kelly Lambert, Department of Clinical Nutrition, Wollongong Hospital, Illawarra Shoalhaven Local Health District, New South Wales, Australia

Judy Mullan, School of Medicine, Faculty of Science, Medicine and Health, University of Wollongong, New South Wales, Australia

Kylie Mansfield, School of Medicine, Faculty of Science, Medicine and Health, University of Wollongong, New South Wales, Australia

Maureen Lonergan, Department of Renal Medicine, Illawarra Shoalhaven Local Health District, New South Wales, Australia
2.1 Executive Summary

Based on the review of the literature presented in Chapter 1, Section 3 of this thesis, adherence to dietary self-management recommendations in ESKD is poor. As we move through the components of the Health Literacy Skills Framework from left to right (shown below), there are several factors (shaded in blue), that influence the development of an individual’s health literacy skills.

Chapter 2 describes a study which used the Montreal Cognitive Assessment Tool to explore the cognitive capabilities of adults with ESKD. In order to ensure representative results, validated alternative language versions in Italian, Macedonian and Arabic for non-native English speakers were used when required. The results indicate that cognitive impairment was present in at least one third (36.1%) of adults with ESKD, and that more than half (53.2%) of dialysis patients were cognitively impaired.
Chapter 2 was published as:


**References:**


A comparison of the extent and pattern of cognitive impairment among predialysis, dialysis and transplant patients: a cross sectional study from Australia.

2.2 Abstract

Aim: The aim of this study was to compare the extent of cognitive impairment and the types of cognitive deficits in an Australian cohort of four patient groups with end stage kidney disease. Characteristics predicting the presence of cognitive impairment were also evaluated.

Methods: Observational cross-sectional study of one hundred and fifty five patients with end stage kidney disease recruited from a regional Australian renal unit. Eligible participants included those whose estimated Glomerular Filtration Rate was < 30ml/min/1.73m²; were undertaking peritoneal or haemodialysis or had received a kidney transplant. The Montreal Cognitive Assessment tool was used to screen the study participants for cognitive impairment and evaluate cognitive deficits. Cognitive impairment was defined as a total Montreal Cognitive Assessment tool score ≤24/30.

Results: The extent of cognitive impairment varied between the four groups with end stage kidney disease. Factors predicting the presence of cognitive impairment included undertaking dialysis, age ≥65, male gender, and the presence of diabetes or cerebrovascular disease. Deficits in executive function, attention, language, visuospatial skills, memory and orientation were common amongst the study participants, and these deficits varied according to which end stage kidney disease group the participants were in. Limitations to the study included the cross-sectional design and that the presence of confounders like depression were not recorded.

Conclusion: The impact of disparities in the cognitive capabilities identified in this study are likely to be far reaching. Tailoring of education and self-management programs to the cognitive deficits of individuals is required.

Keywords: cognitive impairment, dialysis, kidney transplant, predialysis, self-management.
2.3 Introduction

Self-management of End Stage Kidney Disease (ESKD) requires patients to evaluate and respond to changes in clinical symptoms (such as blood glucose levels); to manage and adhere to multifaceted medication regimens (such as phosphate binders), and to implement a complex and often contradictory dietary prescription. Unfortunately, self-management can be compromised by cognitive impairment (CI) 2,3.

The evidence suggests that CI is common in people undertaking dialysis (especially haemodialysis), and that dialysis patients differ significantly from normal controls with respect to the prevalence of CI 4-7. For example, it has been estimated that 8.6-19% of the general population have CI 8-12, whereas 28.9% 13 to 80% 14-16 of dialysis patients may have CI. However, the literature is unclear regarding the extent of CI in those with ESKD not undertaking dialysis, and the evidence regarding transplant patients is conflicting 17-18.

While evidence is consistent that cognitive deficits in orientation, attention and executive function are common in haemodialysis patients 4; the evidence is much less clear about the cognitive deficits in other groups with ESKD 4,19. This is an important knowledge gap because CI is well recognised as an independent predictor of mortality in people with ESKD 20,21, and because it can adversely impact on decision making ability and judgement 22. Correctly identifying those with CI and understanding the types of cognitive deficits has significant implications for the design and delivery of health information (such as dietary education materials), and self-management programs for people with ESKD.

The Montreal Cognitive Assessment Tool (MoCA) 1 has been recommended as an ideal screening tool for CI in people with ESKD 14. This is due to the higher sensitivity and specificity of the MoCA when compared to the Mini Mental State Exam 23. The MoCA assesses a number of cognitive capabilities including executive function, visuospatial skills, attention, language, memory and orientation 1. However, no studies have compared the differences in CI or the types of deficits that may exist between the four common groupings of patients with ESKD: those considered
predialysis; and those undertaking a renal replacement therapy such as haemodialysis, peritoneal dialysis or a kidney transplant. Similarly, there have not been any studies published utilising this tool in people with ESKD in the Australian setting.

Therefore, the aims of this study were to explore whether CI was present among four common groups of patients with ESKD, and to compare and contrast the nature of any cognitive deficits exhibited by these different groups. In addition, factors potentially predictive of CI, such as age, gender and comorbid disease were also explored.

### 2.4 Subjects and Methods

Invitations to participate in this cross-sectional study were sent by mail to all adult patients (≥18 years of age) with ESKD (n=227) attending the renal unit of a large regional Australian hospital. This included patients with ESKD not undertaking dialysis (i.e. those with an estimated GFR<30ml/min/1.73m²) (PRE-group); those undertaking peritoneal dialysis (PD group) or haemodialysis (in centre or at home) (HD group); and those who had received a kidney transplant (KT group). Patients with dementia or known CI, as determined by their treating renal physician, were excluded from the study, as were patients with an acute illness in hospital.

The MoCA tool was administered by one of three research dietitians after receiving written informed consent from the participant. Training regarding the administration and scoring of the MoCA was conducted according to the instructions provided by the author of the MoCA and freely available on the website www.mocatest.org. For those with poor vision, the ‘blind’ version of the MoCA was used. For those undertaking haemodialysis in centre, the MoCA was administered during the second hour of the patient’s haemodialysis session within the renal unit. This was intentional and was designed to assess cognitive capabilities at a time when health professionals often provide education to patients receiving haemodialysis. Professional interpreter services were used with the relevant translated version of the MoCA to complete the assessment with patients who could not communicate in English. Scores on the
MoCA range from 0 to 30 with a higher score being indicative of better cognition. A cut off value of ≤ 24/30 was used to indicate the presence of CI. Calculation of the scores for the domains of executive function, visuospatial skills, attention, language, working memory and orientation utilised the method described by the authors of the MoCA.

Demographic and clinical information such as age, gender, educational level, comorbid chronic disease burden, dialysis adequacy and duration of renal replacement therapy were obtained from the patient records. Details regarding the presence of chronic disease were limited to the presence of lung disease, coronary artery disease, peripheral vascular disease, diabetes, cerebrovascular disease and cancer. These chronic diseases were chosen because this information is routinely collected for all patients receiving a renal replacement therapy in Australia (i.e. dialysis or a transplant). The definition of comorbidity used in this study was three chronic conditions, because this is considered the norm for people with chronic kidney disease. Approval for the study was received from the University of Wollongong Human Research Ethics Committee and all participants provided written and verbal consent.

Statistical analysis was performed using SPSS (version 21; SPSS, Chicago, IL, USA). The Shapiro-Wilk Test was used to assess normality. Scores for the MoCA and its subcomponent scores was negatively skewed and were therefore transformed via reflection and log10 prior to analysis. Differences between groups were analysed using the independent samples t-test or one-way analysis of variance with post hoc analysis using the Bonferroni post hoc test for multiple comparisons. Data is reported as mean and 95% confidence interval, and proportions scoring below normative values for normal controls. Categorical variables are expressed as counts and percentages (%) and were evaluated using Pearson’s Chi Square test. Spearman’s correlation coefficient (rho) was used to determine the relationship between age, dialysis adequacy and duration of renal replacement therapy (RRT) with total MoCA score and sub scores. Logistic regression was used to determine predictors of CI. The dependent variable of CI was dichotomised using a cut off score of ≤ 24/30. All independent variables with a p<0.10 in univariate analyses or variables known to be
associated with CI in the four groups with ESKD (e.g. PVD) were included in the final model. Statistical significance was set at a p value of 0.05.

2.5 Results
A total of 155 individuals agreed to participate in the study (giving an overall response rate of 68.3%). Study participants did not differ from those who declined to participate for age, gender or English speaking status. However, there were significantly more predialysis patients in the group who declined to participate (p<0.001). The median age of the participants was 66 years (Interquartile range, IQR: 55-75), with patients in the transplant group being significantly younger (58.5 (IQR: 49-66) years) than the other three groups (p<0.001, Table 2.1). The majority of study participants were males (n= 92, 59.4%), had less than 12 years of schooling (n=88, 56.8 %) and were undertaking either haemodialysis (n=54, 35%) or had received a transplant (n= 52, 34%) (Table 2.1). The transplant group had a significantly longer duration of renal replacement therapy compared to the dialysis groups (median duration 8.1 years (IQR: 4.1-14.3), p<0.001). Both the peritoneal and haemodialysis groups were achieving dialysis adequacy as evidenced by their Kt/v values. The mean estimated GFR of the predialysis group was 11.9ml/min (sd 4.7) indicating stage 5 chronic kidney disease.

Information regarding comorbid disease burden was not available for 25% (n=41) of the participants including all of the predialysis patients. Half of the participants had more than three comorbidities (Table 2.2), with almost three quarters of the haemodialysis group (n=32, 71.1%) having more than 3 comorbidities. Moreover, the haemodialysis group had significantly greater proportions of patients with coronary artery disease and peripheral vascular disease than the kidney transplant group. Furthermore, more than one third (n=17, 34.7%) of the kidney transplant group had cancer, and this was significantly higher than all other groups.

Binary logistic regression was undertaken to identify independent predictors of the presence of CI. Independent predictors were found to be: undertaking dialysis (OR 3.09, 95% confidence interval: 1.07-8.94, p=0.04); age ≥ 65 (Odds Ratio [OR] 3.31, 95% confidence interval: 1.14-9.65, p=0.03); male gender (OR 3.09, 95% confidence
interval: 1.07-8.89, p=0.04); and the presence of cerebrovascular disease (OR 4.98, 95% confidence interval: 1.27-19.45, p=0.02) or diabetes (OR 3.76, 95% confidence interval: 1.10-12.93, p=0.04) (Table 2.3).

As dialysis was found to be an independent predictor of the presence of CI, the total MoCA scores of the dialysis and non-dialysed patients (predialysis and transplant) were compared (Table 2.4). Results indicate that dialysis patients had significantly lower total MoCA scores (p<0.001) and CI was more commonly present in this patient group than the non-dialysed group (53.2% vs 18.4%, p<0.001). Further analysis of the differences between the four groups indicate that CI was present in all four groups with ESKD (Table 2.5). However, disparities were apparent in the extent and severity of CI between these groups. The proportion of participants with a MOCA score ≤ 24 (indicating CI was present) did not differ between the peritoneal and haemodialysis groups (48.0% versus 55.6%, respectively). The haemodialysis group (55.6%) however, had a significantly higher proportion of patients with CI, compared to the predialysis (16.7%) and kidney transplant groups (19.2%). These results are further reflected in the total MoCA scores (Table 2.5) highlighting that the haemodialysis group had significantly lower mean MoCA scores than the predialysis and kidney transplant groups.

Analysis of the correlation between age, RRT duration and dialysis adequacy with total MoCA scores and scores for the individual domains within the MoCA are summarised in Table 2.6. There was a statistically significant negative association between increasing age and total MoCA score, which was also the case for the following MoCA domains; executive function, visuospatial skills, memory and language (Table 2.6). In addition, RRT duration was weakly associated with attention scores (Spearman’s rho =-0.20; p=0.01). Dialysis adequacy (as assessed by Kt/V) was not associated with any domain or total MoCA score in either the haemodialysis or peritoneal dialysis groups. Further analysis of the relationship between eGFR in the predialysis group and total MoCA score was undertaken. This indicated there was a non-significant relationship between the two variables of eGFR and total MoCA score (n=24; Spearman’s rho 0.06, p=0.80).
An examination of the extent and types of cognitive deficits present in the four groups with ESKD is shown in Figure 2.1. This figure illustrates the proportion of participants achieving MoCA scores below normative values (norms) for normal controls. The norms were derived from 90 healthy older community dwelling Canadians with a normal neuropsychological profile and mean age of 72.8 years. In this study, deficits in executive function were present in all four groups. More than half of the dialysis patients scored below norms compared to 29.2% of the predialysis and 38.5% of the kidney transplant groups. Deficits in visuospatial skills were apparent in half of the predialysis and 44.4% of the haemodialysis groups and this was significantly greater than in the transplant group (15.4%, p<0.05). Deficits in attention were apparent in more than one quarter of the dialysis and transplant groups. Language skills were impaired in all four groups, and to the greatest extent in the peritoneal (60%) and haemodialysis (57.4%) groups. The cognitive domain that was most impaired in all four groups was memory, which affected at least 50% of participants in each of the four groups. Eighty five percent of the haemodialysis group exhibited impairment in this cognitive domain, and this was significantly higher than the predialysis (54.2%) and transplant groups (51.9%, p<0.05). Deficits in orientation were uncommon in most groups, except the haemodialysis group where 46.3% of the haemodialysis group scored below norms, and this was significantly more than in all other groups (p<0.001).

2.6 Discussion
In this cross sectional observational study of four groups of Australian patients with ESKD, we have shown that CI was present in all four groups with ESKD, although disparities were apparent in the types and extent of cognitive deficits. Identified predictors of CI included undertaking dialysis, age ≥ 65, male gender, and the presence of diabetes or cerebrovascular disease. These predictors were common among the study participants indicating that the findings of this study have important implications for the design and delivery of health information and self-management programs for people with ESKD.

Our results regarding the extent of CI are similar to previous studies showing that CI is more common in those undertaking haemodialysis; in those who are
older 13, 15, 20, 34, and that CI was equally common in adequately dialysed peritoneal and haemodialysis patient groups 35. However, our results regarding the extent of CI in those undertaking peritoneal dialysis is higher than almost all previous studies published 13, 15, 36-38. We speculate that the variations from previous studies on the prevalence of CI in peritoneal dialysis are the result of using different assessment tools or applying different study methods when using the MoCA. For example, previous work by Shea et al 13 using the MoCA to screen for CI in those receiving peritoneal dialysis in Hong Kong, utilised a cut off of 21 or 22/30 based on previous validation studies in their setting, compared to a cut off ≤ 24/30 in this study.

There is scarce literature available describing and comparing the cognitive capabilities of predialysis and transplant groups. Our finding, that CI was present in around one in every six predialysis patients (16.7%), and one in every five kidney transplant patients (19.2%), suggests that the prevalence of CI in these groups are not different to that in the general population 8-12 or previous research in these groups 39-41. However, it remains important to note that a substantial number of predialysis and kidney transplant patients still demonstrated impairments (i.e. scores below normative values 1) in the cognitive domains of executive function, visuospatial skills, language and memory, which may in part be related to comorbid disease burden. Further research with larger sample sizes is required in these patient groups to evaluate this hypothesis, as well as to examine the potential impact of impairments in these domains on self-management of ESKD.

Successful self-management requires a range of skills. These skills include: problem solving; making decisions; finding and using relevant resources; developing a partnership between the patient and health professional; making, taking and sustaining self-management actions; and applying and tailoring information obtained to suit the needs of the individual 42. However, all of these components of self-management require adequate cognition to be successful 43. In the heart failure context for example, it has been shown that self-management programs conducted without consideration given to the self-management capacity and cognitive capabilities of participants are likely to be ineffective 44, 45. It is therefore surprising, that there is very little research that directly addresses, or even acknowledges, the
potential impact of CI on self-management in ESKD. Future efforts should therefore be directed to exploring this aspect in more detail in patients with ESKD.

The most common CI related deficit in this study for each of the four patient groups was memory, and similar to the findings of O’Lone et al, where no difference was seen in the extent of memory deficits between the peritoneal and haemodialysis groups. These findings are important because deficits in memory can directly impact on our patient’s ability to learn and recall information provided, subsequently affecting their self-management skills of problem solving, decision making, finding appropriate resources, and sustaining self-management actions. It is also worth noting that MoCA specifically tests working (or short term) memory; and some have suggested that individuals with diminished working memory are probably incapable of adhering to treatment recommendations (even if motivated) due to an inability to retain and retrieve new information. Further research into the use of memory aids or cognitive stimulation training and how these impact on self-management in ESKD is required.

Deficits in executive function were apparent in all four groups of ESKD participants included in the current study. This is a key finding because diminished executive function could impact on the ability of an individual to successfully self-monitor, and to make and sustain appropriate behaviour change in relation to their self-management goals. Research on the impact of deficits in executive function in ESKD are lacking. However, research in other chronic disease cohorts has demonstrated that deficits in executive function are strongly associated with medication non adherence in older adults; poor self-management in individuals with diabetes and higher mortality rates in individuals with heart failure. Strategies often used to improve adherence, such as motivational interviewing or health coaching are likely to be ineffective in individuals with diminished executive function, because normal cognitive function and ability to control impulsive behaviour is assumed.

Finally, deficits in language and attention, like those reported in this study, would also be expected to compromise the ability to learn and perform self-management successfully. Diminished language skills are believed to be a good indicator of the
likelihood that an individual is not able to adequately comprehend and follow advice. In this study, impairments in language were experienced by more than 25% of participants in all four groups. Poor scores on MoCA items relating to language are believed to represent poor retention of auditory information, and in the self-management context, may lead to mishearing instructions or hearing only part of the message. Individuals with diminished language skills may also have difficulties reading, writing and recalling self-management tasks and goals; as well as undertaking multistep instructions for the same reason. Adequate skills in attention are also an important component of learning how to self-manage. Some authors have stated that attention is considered to be the foundation of learning. Deficits in attention therefore reduce the ability of the individual to selectively focus on a given task long enough to accomplish a goal. This skill was especially problematic for those in the haemodialysis group, and in around one in every three patients in the peritoneal dialysis and kidney transplant groups. Studies investigating the utility of specific strategies to improve language and attention deficits in individuals with ESKD are warranted.

The clinical implications of our findings are that self-management support and patient education, that are specifically tailored to the cognitive capabilities, coexisting comorbid disease burden and health literacy skills of the patient with ESKD, are necessary. We believe that the results of our study also support the proposition that health professionals should routinely screen all people with ESKD for CI, which would help to identify patients at risk of poor treatment adherence. In this study, older males undertaking dialysis, with diabetes and cerebrovascular disease would be a high-risk group for CI and we suggest they would be likely to struggle with self-management of their ESKD. Further research is required into the timing and feasibility of innovative tailored approaches to patient education and self-management in people with ESKD. This is an integral part of providing high quality personalised, patient centred health care. This is especially important in nephrology where patients are complex and exhibit multimorbidity, frailty, CI and other geriatric syndromes.

There are several important limitations to this research. Firstly, the cross-sectional nature of this study with relatively small patient numbers prevents inferences.
regarding the potential changes in cognition that may occur when changing between modalities. Unequal numbers between patient groups may have also impacted on our findings. Longitudinal studies with larger sample sizes investigating how cognitive capabilities change over time were not possible in this study but are currently underway by other research groups. Secondly, confounders such as the presence of depression was not recorded in this study, and yet it is well known that depression is strongly associated with CI. Similarly, the comorbid disease status was not recorded for approximately 25% of participants in this study (including all predialysis patients). The fact that those with known cognitive impairment were excluded from the study may underestimate the prevalence of CI. The lack of normative values for patients with kidney disease may also be a potential limitation. The normative values used in this study have also been used in several previous studies with younger CKD populations and found that the MoCA still showed high sensitivity and specificity in these CKD populations. Further, the MoCA has been shown to be age and gender independent. We therefore believe that the use of these norms and the results obtained in this study are appropriate. Additional limitations may include failing to account for several other potential confounders such as cardiovascular disease, stroke, anaemia and uremic toxins. Further investigation of these potential confounders on cognitive impairment is required.

Future work exploring the unexplained, but statistically significant negative relationship between attention and RRT duration is also warranted. The strengths of this study include the nature of the study design and high participant response rate. Finally, even though the results of this study are from a single centre in one local health district, our participants were similar to ANZDATA Registry 2014 figures for age, gender and number of comorbidities. We also believe this to be the first study that has described the extent of CI and the types of cognitive deficits in those with ESKD in an Australian setting.

In summary, the extent of CI and deficits in executive function, attention, language, visuospatial skills, memory and orientation varied between the four ESKD groups investigated as part of this study. Predictors of CI included older age (≥65 years), male gender, undertaking dialysis and diagnosed with diabetes and/or cerebrovascular disease. These findings provide valuable information which can be
used to tailor education and self-management interventions to better suit the needs of these different patient groups.

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The authors declare that the results presented in this paper have not been published previously in whole or part, except in abstract format.

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**Financial disclosure:** The authors declare that they have no other relevant financial interests.

**Contributions:** Research idea and study design: KL, ML; Data acquisition: KL; Data analysis/interpretation: KL, ML, JM, KM; Statistical analysis: KL. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved. KL takes responsibility that this study has been reported honestly, accurately, and transparently and that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant) have been explained.
References


Table 2.1. Demographic characteristics of study participants (n=155).

<table>
<thead>
<tr>
<th></th>
<th>PRE n=24</th>
<th>PD n=25</th>
<th>HD n=54</th>
<th>KT n=52</th>
<th>Total n=155</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years; median (IQR)</td>
<td>70 (63-76)</td>
<td>70 (63-81)</td>
<td>72.0 (58-77)</td>
<td>58.5 (49-66) *</td>
<td>66 (55-75)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Male, n (%)</td>
<td>11 (45.8)</td>
<td>13 (52.0)</td>
<td>36 (66.7)</td>
<td>32 (61.5)</td>
<td>92 (59.4)</td>
<td>0.30</td>
</tr>
<tr>
<td>&lt;12 years of education, n (%)</td>
<td>13 (54.2)</td>
<td>18 (72.0)</td>
<td>54 (63.0)</td>
<td>23 (44.2)</td>
<td>88 (56.8)</td>
<td>0.09</td>
</tr>
<tr>
<td>Renal replacement therapy (years), median (IQR)</td>
<td>N/A</td>
<td>2.5 (1.5-4)</td>
<td>4.25 (2-9)</td>
<td>8.1 (4.1-14.3) *</td>
<td>5.00 (2-9.73)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Dialysis adequacy (Kt/v) median (IQR)</td>
<td>N/A</td>
<td>2.30 (1.95-2.74) a</td>
<td>1.50 (1.3-1.7) b</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Estimated Glomerular Filtration Rate (ml/min), mean (SD)</td>
<td>11.9 (4.7)</td>
<td>N/A</td>
<td>N/A</td>
<td>58.3 (18.3)</td>
<td>43.1 (26.7)</td>
<td>N/A</td>
</tr>
</tbody>
</table>

PRE: Predialysis group; PD: Peritoneal Dialysis group; HD: Haemodialysis group; KT: Kidney Transplant recipient group
IQR: Interquartile range; N/A: not applicable
# Values with this superscript are significantly different from all other groups.

a: Peritoneal dialysis adequacy indicated by Kt/V>1.7 (Reference: 27)
b: Haemodialysis adequacy indicated by Kt/V>1.2 (Reference: 28)
Table 2.2. Disease burden of study participants (n=114).

<table>
<thead>
<tr>
<th>Condition</th>
<th>PRE N=24</th>
<th>PD n=20</th>
<th>HD n=45</th>
<th>KT n=49</th>
<th>Total n=114</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung disease, n (%)</td>
<td>N/A</td>
<td>3 (15.0)</td>
<td>12 (26.7)</td>
<td>8 (16.3)</td>
<td>23 (20.2)</td>
<td>0.38</td>
</tr>
<tr>
<td>Coronary Artery Disease, n (%)</td>
<td>N/A</td>
<td>8 (40.0)</td>
<td>27 (60)</td>
<td>13 (26.5)</td>
<td>48 (42.1)</td>
<td>0.004*</td>
</tr>
<tr>
<td>Peripheral Vascular Disease, n (%)</td>
<td>N/A</td>
<td>4 (20.0)</td>
<td>26 (57.8)</td>
<td>16 (32.7)</td>
<td>46 (40.4)</td>
<td>0.01*</td>
</tr>
<tr>
<td>Diabetes, n (%)</td>
<td>N/A</td>
<td>7 (35.0)</td>
<td>23 (51.1)</td>
<td>14 (28.6)</td>
<td>44 (38.6)</td>
<td>0.08</td>
</tr>
<tr>
<td>Cerebrovascular Disease, n (%)</td>
<td>N/A</td>
<td>2 (10.0)</td>
<td>14 (31.1)</td>
<td>8 (16.3)</td>
<td>24 (21.1)</td>
<td>0.09</td>
</tr>
<tr>
<td>Cancer, n (%)</td>
<td>N/A</td>
<td>1 (5.0)</td>
<td>9 (20.0)</td>
<td>17 (34.7)</td>
<td>27 (23.7)</td>
<td>0.02*</td>
</tr>
<tr>
<td>More than 3 comorbidities, n (%)</td>
<td>N/A</td>
<td>9 (45.0)</td>
<td>32 (71.1)</td>
<td>16 (32.6)</td>
<td>57 (50.0)</td>
<td>&lt;0.0001*</td>
</tr>
</tbody>
</table>

PRE: Predialysis group; PD: Peritoneal Dialysis group; HD: Haemodialysis group; KT: Kidney Transplant recipient group; N/A: not available

# Values with this superscript are significantly different from all other groups.

a: values with this superscript are significantly different from each other.

*P value <0.05 indicates statistically significant
Table 2.3. Logistic regression analyses of factors associated with the presence of cognitive impairment

<table>
<thead>
<tr>
<th>Factor</th>
<th>Odds Ratio</th>
<th>95% CI</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dialysis</td>
<td>3.09</td>
<td>1.07-8.94</td>
<td>0.04*</td>
</tr>
<tr>
<td>Age ≥ 65</td>
<td>3.31</td>
<td>1.14-9.65</td>
<td>0.03*</td>
</tr>
<tr>
<td>Male gender</td>
<td>3.09</td>
<td>1.07-8.89</td>
<td>0.04*</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>4.98</td>
<td>1.27-19.45</td>
<td>0.02*</td>
</tr>
<tr>
<td>Diabetes</td>
<td>3.76</td>
<td>1.10-9.65</td>
<td>0.04*</td>
</tr>
<tr>
<td>≥ 3 comorbidities</td>
<td>0.28</td>
<td>0.03-2.48</td>
<td>0.26</td>
</tr>
<tr>
<td>&lt; 12 years of education</td>
<td>1.57</td>
<td>0.60-4.13</td>
<td>0.36</td>
</tr>
<tr>
<td>Peripheral Vascular Disease</td>
<td>0.36</td>
<td>0.09-1.49</td>
<td>0.16</td>
</tr>
<tr>
<td>Coronary Artery Disease</td>
<td>2.73</td>
<td>0.54-13.79</td>
<td>0.22</td>
</tr>
</tbody>
</table>

*indicates statistically significant (p<0.05)
Table 2.4. MoCA results of study participants according to those undertaking dialysis vs no dialysis.

<table>
<thead>
<tr>
<th></th>
<th>Dialysis (PD and HD group) n=79</th>
<th>Non dialysis (PRE and KT group) n=76</th>
<th>D vs ND P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitively impaired, Proportion, n, (%)</td>
<td>42 (53.2)</td>
<td>14 (18.4)</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>Total MoCA score Mean (95% CI)</td>
<td>23.65 (22.67-24.64)</td>
<td>26.86 (26.18-27.55)</td>
<td>&lt;0.001*</td>
</tr>
</tbody>
</table>

Table 2.5. MoCA results of study participants according to ESKD group (n=155).

<table>
<thead>
<tr>
<th></th>
<th>PRE n=24</th>
<th>PD n=25</th>
<th>HD n=54</th>
<th>KT n=52</th>
<th>Total n=155</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitively impaired, Proportion, n, (%)</td>
<td>4 (16.7) a</td>
<td>12 (48.0)</td>
<td>30 (55.6) ab</td>
<td>10 (19.2) b</td>
<td>56 (36.1)</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>Total MoCA score Mean (95% CI)</td>
<td>27.07 (25.55-28.58) a</td>
<td>24.80 (23.32-26.28)</td>
<td>23.12 (22.11-24.13) ab</td>
<td>26.77 (25.74-27.80) b</td>
<td>25.23 (24.58-25.88)</td>
<td>&lt;0.001*</td>
</tr>
</tbody>
</table>

PRE: Predialysis group; PD: Peritoneal Dialysis group; HD: Haemodialysis group; KT: Kidney Transplant recipient group
*P value <0.05 denotes statistical significance
a,b: values with this superscript are significantly different from each other.
Table 2. 6. Analysis of the correlation between age, RRT duration and dialysis adequacy with MoCA total and domain scores.

<table>
<thead>
<tr>
<th></th>
<th>Age (n=155)</th>
<th>RRT duration (n=154)</th>
<th>Dialysis adequacy (n=69)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Spearman’s rho (p value)</td>
<td>Spearman’s rho (p value)</td>
<td>HD patients (n=52) Spearman’s rho (p value)</td>
</tr>
<tr>
<td>Total MoCA score</td>
<td>-0.30 (&lt;0.001) *</td>
<td>-0.07 (0.38)</td>
<td>0.11 (0.44)</td>
</tr>
<tr>
<td>Executive function score</td>
<td>-0.25 (0.002) *</td>
<td>0.07 (0.41)</td>
<td>0.07 (0.64)</td>
</tr>
<tr>
<td>Visuospatial score</td>
<td>-0.18 (0.03) *</td>
<td>0.05 (0.52)</td>
<td>0.23 (0.11)</td>
</tr>
<tr>
<td>Memory score</td>
<td>-0.32 (&lt;0.001) *</td>
<td>0.04 (0.66)</td>
<td>0.07 (0.62)</td>
</tr>
<tr>
<td>Attention score</td>
<td>-0.08 (0.34)</td>
<td>-0.20 (0.01) *</td>
<td>-0.05 (0.72)</td>
</tr>
<tr>
<td>Language score</td>
<td>-0.24 (0.003) *</td>
<td>-0.06 (0.44)</td>
<td>0.006 (0.97)</td>
</tr>
<tr>
<td>Orientation score</td>
<td>-0.12 (0.13)</td>
<td>-0.04 (0.96)</td>
<td>0.007 (0.96)</td>
</tr>
</tbody>
</table>

Indicates statistically significant (p <0.05). HD: Haemodialysis; PD: Peritoneal Dialysis. Dialysis adequacy assessed using Kt/V and represents 96% of all HD patients, 68% of all PD patients, and overall 87% of all dialysis patients in the study N/A: not applicable as all participants scored maximum points and unable to calculate correlation.
Figure 2.1. Proportion of study participants (n=155) with MoCA domain scores below normative values for normal controls.

PRE: Predialysis group; PD: Peritoneal Dialysis group; HD: Haemodialysis group; KT: Kidney Transplant recipient group.

Values with this superscript (#) are significantly different from all other groups (p<0.001) and (* or ^) significantly different from each other (p<0.05).
CHAPTER 3: Health literacy skills.

Title: A cross sectional comparison of health literacy deficits amongst patients with end stage kidney disease.

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3.1 Executive Summary

In Chapter 1, Section 3 we confirmed that dietary adherence in ESKD is suboptimal. The evidence provided in Chapter 2 indicates that cognitive impairment among adults with ESKD was common, and that deficits in memory, executive function, attention, and language were apparent. According to the Health Literacy Skills Framework (HLSF) \(^1\) (shown below), an individual’s cognitive capabilities and demographic characteristics affect the degree to which people can acquire and exercise their health literacy skills (shaded in green below). These factors then influence their ability to comprehend, in this case, the dietary advice received.

Chapter 3 reports on a study that explored the health literacy skills of adults with ESKD using the multidimensional Health Literacy Management Scale (HeLMS). In order to ensure representative results, the HeLMS was administered using professional Italian, Macedonian and Arabic interpreters for non-native English speakers.
Chapter 3 was published as
A cross sectional comparison of health literacy deficits amongst patients with end stage kidney disease.

3.2 Abstract

Inadequate health literacy in people with chronic kidney disease (CKD) is associated with poorer disease management and greater complications. There is limited data on the health literacy deficits of people with CKD. The aim of this study was to investigate the types and extent of health literacy deficits in patients with CKD using the multidimensional Health Literacy Management Scale (HeLMS) and to identify associations between patient characteristics and the domains of health literacy measured by the HeLMS. Invitations to participate were sent to patients with CKD attending the renal unit of a regional Australian hospital. These patients included pre-dialysis, dialysis (peritoneal and haemodialysis) and kidney transplant patients. This study identified that inadequate health literacy; especially in the domains relating to attending to one’s health needs, understanding health information, social support and socioeconomic factors, was common. Male gender and education level were significantly associated with inadequate health literacy. The type and extent of health literacy deficits varied between CKD groups and transplant patients had more deficits than other CKD patient groups. This study provides useful information for health professionals treating patients with CKD, especially with regards to the design of self-management interventions and health information.

Keywords: health literacy, chronic kidney disease, end stage kidney disease, self-management, patient education, HeLMS
3.3 Introduction

Chronic Kidney Disease (CKD) is becoming increasingly common globally due to the growing prevalence of diabetes mellitus, hypertension, obesity and ageing. CKD progresses to end stage kidney disease (ESKD) in around 2% of cases, and requires treatment such as dialysis, kidney transplant or symptom management only. In Australia, it is predicted that current health services will be unable to meet the increasing demand to care for the growing number of CKD patients who will progress to ESKD. In addition, treatments for those with ESKD who require dialysis or a kidney transplant are expensive. In 2010, the cost to the Australian Government of providing dialysis and transplantation services was estimated to be almost $1 billion AUD.

Strategies to reduce the progression of CKD to ESKD have centred on modifying lifestyle related behaviours. These lifestyle related behaviour changes include: improving medication adherence (e.g. to antihypertensive and/or diabetic medications); avoiding nephrotoxic agents (e.g. non-steroidal anti-inflammatory medications); and adopting positive self-management behaviours (e.g. smoking cessation, weight reduction, a reduction in salt and protein intake, and increasing physical activity levels). Unfortunately, the recommendations for lifestyle related behaviour changes are complex and have not translated into meaningful reductions in the progress from CKD to ESKD.

Health literacy is defined as ‘the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health’. Adequate health literacy (HL) is considered a critical but often overlooked skill set required by individuals with CKD. This skill set is considered essential for compliance with the lifestyle related behaviour changes required for effective self-management and prevention of the progression of CKD. Unfortunately, inadequate health literacy is common in individuals with CKD. A recent systematic review involving six studies with a total of 1,405 patients (mostly of patients receiving haemodialysis from the USA) estimated the overall prevalence of inadequate health literacy in these patients as approximately 23%.
Inadequate health literacy in individuals with CKD is associated with worse health outcomes. These negative outcomes include poorer control of biochemical parameters, worse cardiovascular disease risk profiles, greater numbers of missed haemodialysis treatments and higher rates of hospitalisation; reduced rates of referral for kidney transplantation; poorer peritoneal dialysis performance and higher rates of infection, as well as overall higher rates of mortality.

Measurement of health literacy levels in individuals with CKD have mostly relied on using one-dimensional tools to measure one aspect of health literacy, such as numeracy or reading comprehension. There is little health literacy data available for individuals with CKD measured using multidimensional health literacy tools. There are also only limited studies investigating whether patients with CKD have barriers to finding, understanding and using health information. The Health Literacy Measurement Scale (HeLMS) is a multidimensional health literacy assessment tool that was developed and validated in the Australian setting that captures these health literacy elements.

The aims of this research were to (i) utilise the HeLMS to explore the type and extent of health literacy deficits that people with CKD exhibit and (ii) to explore any associations between inadequate health literacy and patient characteristics, such as age, gender, duration of dialysis or transplant and years of education.

3.4 Methods
This study was approved by the University of Wollongong Health and Medical Human Research Ethics Committee.

Participants and recruitment
Invitations to participate in the study were sent to adult patients (≥18 years of age) with CKD (n=366) attending the renal unit of a large regional Australian hospital. This was restricted to four groups of CKD patients, which included the pre-dialysis patients, those receiving peritoneal dialysis, those receiving haemodialysis and those who had undergone a kidney transplant. Patients with dementia or known cognitive impairment, as determined by their treating renal physician, were excluded from the study.
Demographic details
Information regarding patient characteristics such as age, gender, educational level, and comorbid chronic disease burden were obtained from the patient records where available. Details regarding the presence of other chronic disease were limited to the presence of lung disease, coronary artery disease, peripheral vascular disease, diabetes, cardiovascular disease and cancer. These chronic diseases were chosen because this information is routinely collected for all patients receiving renal replacement therapy in Australia (i.e. dialysis or transplant) 30.

Assessment of Health Literacy
The Health Literacy Management Scale (HeLMS) was used to assess the health literacy of study participants. The HeLMS consists of 29 subjectively rated questions to assess health literacy that are divided into eight health literacy domains (Table 3.1). Five of the HeLMS domains focus on the individual’s abilities (domains 2,5-8), and three of the HeLMS domains (domains 1, 3 and 4) focus on broader factors, such as attitudes, social support and socio-economic factors, all of which could impact on health literacy 29.

The HeLMS tool was administered in the renal unit after receiving informed consent from the patient. For those receiving haemodialysis, the HeLMS was administered during the patient’s haemodialysis session within the renal unit. Professional interpreter services were used to complete the assessment with patients who could not communicate in English.

Statistical analyses
Statistical analysis was performed using SPSS Statistics for Windows version 19, (SPSS, Chicago, IL, USA). The Shapiro-Wilk Test was used to assess normality. Independent samples t-tests or ANOVA were used and data is reported as means and standard deviations (SD). Categorical variables, expressed as counts and percentages (%), were also evaluated using Pearson’s Chi Square with Bonferroni’s post hoc test for multiple comparisons.
Analysis of the HeLMS data was undertaken according to the methods suggested by Briggs et al, 2011 31 and Jordan, 2009 29. Responses to the 29 items within the eight
domains of the HeLMS (Table 3.1) were scored on a five-point Likert scale. To calculate the proportion of individuals with inadequate health literacy, responses were dichotomised as either ‘no difficulty’ (i.e. a score of 5 on the Likert scale) or ‘any difficulty’ (i.e. a score of 1-4 on the Likert scale). If a statistically significant difference was identified for a particular domain within the HeLMS, then further analyses of the responses to the individual items within that domain were undertaken.

Logistic regression was conducted to determine the relationship between relevant statistically significant HeLMS domains or individual items within relevant HeLMS domains using covariates of age, gender, years of education, duration and type of renal replacement therapy. These covariates have been identified previously as predictors of low health literacy in patients with ESKD ¹⁵.

3.5 Results

Participant characteristics

In total, 153 individuals (59.5% male) with CKD volunteered to participate in the study (overall response rate of 42%) with the majority of them having less than 12 years of schooling (56.2 %) and being in either the haemodialysis (34%) or transplant group (34%) (Table 3.2). The mean age of the participants was 64.1 years with patients in the transplant group being significantly younger (56.4 years) than the others. The dialysis (peritoneal and haemodialysis) and renal transplant patients had received their renal replacement therapy for a mean duration of 6.12 years, with the transplant patients having received their treatment for a significantly longer period of time (10.44 years), as compared to the dialysis patients. It is also important to note that the pre-dialysis group had very advanced kidney disease as highlighted by their low mean estimated Glomerular Filtration Rate (eGFR) of 11.9 ml/min (Table 3.2).

Information regarding comorbid disease burden was not available for 39 participants including all of the pre-dialysis participants. The available data regarding selected comorbid disease(s) burden (Table 3.3) indicates that half of the participants had more than three chronic diseases. There were significant differences between the groups regarding the number of chronic diseases (p< 0.05) with the haemodialysis group having a greater proportion of patients with Coronary Artery Disease, Peripheral Vascular Disease and a greater number of individuals with more than three chronic conditions, as compared to the transplant patients. The transplant
patients were significantly more likely to have cancer compared to the peritoneal dialysis patients.

**HeLMS domain scores of health literacy**

The participants’ mean scores for the eight HeLMS domains are displayed in Table 3.4. Results were also included in the table for individual items within domains 1 and 2 which had mean scores of four or less or were found to be statistically significant. The only items with a mean score of 4 or less for each of the groups, included domain 1 [item 7- change your lifestyle to improve your health] and domain 1 [item 23- find the energy to manage your health]. The scores for these items were not statistically significantly different between the groups. Further, analysis of the data indicated a significant difference between the patient groups for domain 2 [Understanding health information], especially between the pre-dialysis and the transplant groups (p<0.05). Statistically significant differences were also apparent between the groups for domain 2 [item 14- filling in forms], domain 2 [item 20- reading written information] and domain 2 [item 27- finding health information]. Transplant patients and haemodialysis patients had significantly lower scores, compared to pre-dialysis patients, for domain 2 [14- filling in forms]. However, haemodialysis patients scored significantly better than transplant patients for domain 2 [27- finding health information]. In addition, pre-dialysis patients scored significantly higher for domain 2 [20- reading written information], as compared to transplant patients.

**Proportion of participants with CKD and inadequate health literacy**

Results in Figures 3.1 and 3.2 are reported as the proportion of participants with scores indicative of inadequate health literacy. This was calculated by dichotomising the data, ‘no difficulty’ (score =5) or with ‘any difficulty’ (scores ≤4). Figure 3.1 indicates that there were statistically significant differences between the groups for domain 2 (Understanding health information). For this domain, pre-dialysis patients had the lowest proportion with inadequate health literacy. For domain 1 (Patient attitudes towards their health) well over 40% of the patients in all groups had inadequate health literacy in this domain, and about one third of all patients demonstrated inadequate health literacy for domain 4 (socio-economic factors for accessing healthcare services). Patients in all groups had the lowest proportions of
inadequate health literacy for domain 5 (accessing GP, health care services) and domain 8 (using health information). Furthermore, pre-dialysis patients in particular had the highest proportion of inadequate health literacy for domain 3 (social support).

Further analysis of the individual HeLMS items within these domains was undertaken (Figure 3.2). This analysis indicated that there were statistically significant differences in proportions with inadequate health literacy between the four groups for the following: domain 1 [item 7 - changing lifestyle to improve health]; domain 2 [item 14 - filling in forms], domain 2 [item 20 - reading written information], and domain 2 [item 27 - finding health information] (Figure 2). Pre-dialysis patients were statistically less likely to have inadequate health literacy deficits for each of these items, except for domain 2 [item 27 - finding health information]. However, transplant patients were significantly more likely to have inadequate health literacy for domain 2 [item 27 - finding health information]. In addition to these statistically significant results, items of potential clinical importance include domain 1 [item 23 - finding the energy to manage their health] and 2 [9 - read health information]. For domain 1 [item 23 - finding the energy to manage their health] over 60% of the dialysis (peritoneal and haemodialysis) and transplant patients had inadequate health literacy. Whereas, for domain 2 [item 9 - read health information] over 20% of the dialysis (peritoneal and haemodialysis) and transplant patients had inadequate health literacy. For each of these items the pre-dialysis patients had the lowest proportion with inadequate health literacy.

*Predictors of Inadequate Health Literacy*

Logistic regression analyses indicated that male gender and less than 12 years of education were statistically significant predictors of inadequate health literacy for HeLMS domain items 2 [14 - filling in forms] and 2 [20 - reading written health information] (Table 3.5). Less than 12 years of education was also a statistically significant predictor of inadequate health literacy for domain 2 [item 27 – finding health information]. Age and the patient’s duration of renal replacement therapy did not appear to be significant predictors of inadequate health literacy for these items.
3.6 Discussion

The findings in this study provide evidence on several aspects of health literacy in an Australian cohort of individuals with chronic kidney disease. Firstly, a high proportion of individuals with CKD had scores suggestive of inadequate health literacy for (domain 1) attitudes towards their health and (domain 4) socioeconomic factors. This study highlighted that transplant patients, even though significantly younger than the other participants, exhibited the greatest number of health literacy deficits, and that male gender and less than 12 years of education were predictors of inadequate health literacy for understanding health information.

Findings from the current study indicate that over 40% of participants in all four groups reported difficulty with their attitudes towards health (domain 1). This is of concern because unless they are able to effectively self-manage their lifestyle behaviours it is highly likely that they will experience progression of their CKD and/or poor health outcomes. It is also important to note that many CKD patients will have multiple chronic diseases that they need to also self-manage (such as those seen in our study). It is suggested therefore, that patient attitudes towards their health be addressed in the design of self-management programs and CKD patient education. There is also a need for further research to investigate the efficacy of nosogological approaches to improve the ability of patients with CKD to attend to their health needs.

In the present study, approximately one in every four participants in the dialysis and transplant groups exhibited difficulties understanding health information (domain 2). This is consistent with qualitative research conducted by Sakraida and Robinson who identified that self-management was limited by the participants’ difficulties finding and utilising health information. This was reportedly due to message confusion or discrepancies between the information content provided and information that was desired by patients with CKD. Other research in a larger group of patients with CKD had reported that difficulties understanding health information may also be the result of the resources focusing too heavily on clinical outcomes rather than practical support. The potential impact of the difficulties dialysis and especially transplant patient’s face in understanding health information and the
impact of this on their treatment choices is unknown and remains an area for future research.

Another important finding in this study was that participants in the pre-dialysis group appear to have less difficulties finding and understanding health information as compared to those participants receiving renal replacement therapy (e.g. dialysis or a transplant). Even though reasons for this finding are unknown, one could speculate that this may be an example of a previously cited suspicion that pre-dialysis patients ‘don’t know what they don’t know’ \(^35\). Alternatively, it may be that these participants are predominantly ‘information receivers’ and only acquire knowledge in a passive manner as a way of coping with their kidney disease \(^36\). Further research is required to clarify these differences between the pre-dialysis patients and those receiving renal replacement therapy.

Education level is commonly associated with inadequate health literacy in CKD \(^15\). In the present study more than 50% of the patients with CKD had less than 12 years of education and more than three additional chronic diseases. This may partly explain our results that many of the participants reported difficulties finding and understanding health information. A recent systematic review was conducted on the comprehensibility of patient education material targeted at individuals with CKD \(^37\). The results indicated that most publicly available resources for people with CKD were written at a level exceeding the ‘average’ patient and were beyond the readability level appropriate for individuals with low literacy. Achieving a degree of understanding about CKD as well as the other chronic diseases a person may have is likely to be challenging in individuals with low literacy. Further research on how people with CKD (especially those with multiple chronic diseases) find health information, as well as research evaluating the sources and quality of health information for patients with CKD could better inform future interventions.

The current study has identified that social support (domain 3) and socioeconomic factors (domain 4) are important issues for pre-dialysis patients and all patients with CKD, respectively. This is consistent with previous research in the CKD context where social support and socioeconomic resources are considered paramount to the success of self-management (especially for transplant patients) \(^15,38\). Health
professionals need to also consider these health literacy elements when providing services and information to patients with CKD.

The authors acknowledge there are several limitations to this study that may impact on the generalisability of results. These include the cross-sectional nature of the research; using relatively small patient numbers from a single local health district; and unequal numbers between patient groups. There was also incomplete data on the comorbid disease burden for approximately 25% of participants in this study, which according to the literature may impact on health literacy in CKD. Another limitation of this study was the use of the HeLMS, which has been recently superseded by the Health Literacy Questionnaire.

Despite these limitations, it is evident that inadequate health literacy, measured using a multidimensional tool, was common amongst this cohort of patients with CKD and should be of concern to health professionals. Importantly, evidence from this preliminary study has highlighted that there are a number of gaps in the current evidence about the impact that inadequate health literacy can have on a CKD patient’s progression to ESKD.

3.7 Conclusion
This study identified that inadequate health literacy, especially in the domains relating to attending to one’s health needs, understanding health information, social support and socioeconomic factors were common for CKD patients. The type and extent of health literacy deficits varied between CKD groups, with transplant patients having the largest proportion of health literacy deficits. This study provides useful considerations for health professionals when providing care for CKD patients, especially with regards to self-management strategies, support and access to reliable and easy to understand health information. Future efforts should be directed to address these potential barriers to effective self-management and optimal health outcomes.
References:

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Perspectives of Living With CKD. American Journal of Kidney Diseases.
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38. Browne, T, Merighi, JR. Barriers to Adult Hemodialysis Patients' Self-
Sep;56(3):547-57.
psychometric development and initial validation of the Health Literacy Questionnaire
Table 3.1. Description of the domains of the HeLMS (adapted from Briggs et al, 2011\(^1\) and Jordan, 2009\(^2\)).

<table>
<thead>
<tr>
<th>Domain</th>
<th>Domain title</th>
<th>Domain description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Patient attitudes towards their health</td>
<td>This domain assesses an individual’s ability to attend to their health needs, willingness to change their lifestyle or adapt their behaviour to maintain their health [Items 2, 7, 13, 23].</td>
</tr>
<tr>
<td>2</td>
<td>Understanding health information</td>
<td>This domain focuses on an individual’s ability to access and understand different formats of health information [Items 9, 14, 20, 27].</td>
</tr>
<tr>
<td>3</td>
<td>Social support</td>
<td>This domain assesses an individual’s ability to seek social support to manage their health. Social support refers to family, friends and broader community networks [Items 11, 15, 21, 28].</td>
</tr>
<tr>
<td>4</td>
<td>Socioeconomic factors for accessing healthcare services</td>
<td>This domain covers broader socioeconomic circumstances of an individual (i.e. financial resources) to be able to access health information and services [Items 16, 18, 24].</td>
</tr>
<tr>
<td>5</td>
<td>Accessing General Practitioner (GP) healthcare services</td>
<td>This domain is concerned with an individual’s ability to access healthcare services and knowing where to seek health information [Items 10, 12, 22, 29].</td>
</tr>
<tr>
<td>6</td>
<td>Communication with health professionals</td>
<td>This domain assesses an individual’s ability to communicate with health professionals to get the information they want about their health [Items 4, 17, 19].</td>
</tr>
<tr>
<td>7</td>
<td>Being proactive</td>
<td>This domain focuses on an individual’s ability to proactively seek and understand information about their health [Items 3, 6, 25].</td>
</tr>
<tr>
<td>8</td>
<td>Using health information</td>
<td>This domain refers to an individual’s ability to understand and use information to make informed health decisions to maintain their health [Items 1, 5, 8, 26].</td>
</tr>
</tbody>
</table>
Table 3.2. Characteristics of study participants (n=153).

<table>
<thead>
<tr>
<th>Patient characteristics</th>
<th>Pre-dialysis group n=24</th>
<th>Peritoneal Dialysis group n=25</th>
<th>Haemodialysis group n=52</th>
<th>Transplant group n=52</th>
<th>Total n=153</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years), mean (SD)</td>
<td>68.0 (10.9)</td>
<td>69.5 (13.2)</td>
<td>67.3 (14.6)</td>
<td>56.4 (12.9) *</td>
<td>64.1 (14.3) #</td>
</tr>
<tr>
<td>Estimated Glomerular Filtration Rate (ml/min), mean (SD)</td>
<td>11.9 (4.7)</td>
<td>N/A</td>
<td>N/A</td>
<td>58.3 (18.3)</td>
<td>43.1 (26.7)</td>
</tr>
<tr>
<td>Duration of renal replacement therapy, years mean (SD)</td>
<td>N/A</td>
<td>2.94 (1.8)</td>
<td>6.1 (5.4)</td>
<td>10.44 (9.0) *</td>
<td>6.12 (7.2) #</td>
</tr>
<tr>
<td>Less than 12 years of education, n (%)</td>
<td>13 (54.2)</td>
<td>18 (72.0)</td>
<td>32 (61.5)</td>
<td>23 (44.2)</td>
<td>86 (56.2)</td>
</tr>
<tr>
<td>Male, n (%)</td>
<td>11 (45.8)</td>
<td>16 (64.0)</td>
<td>28 (53.9)</td>
<td>36 (69.2)</td>
<td>91 (59.5)</td>
</tr>
</tbody>
</table>

# p<0.05, ANOVA
* indicates significantly different from all other groups.
Renal replacement therapy indicates receipt of dialysis or transplantation
N/A not applicable
Table 3.3. Comorbid disease burden of study participants (n=114).

<table>
<thead>
<tr>
<th>Disease</th>
<th>Pre-dialysis group n=0</th>
<th>Peritoneal Dialysis group n=20</th>
<th>Haemodialysis group n=45</th>
<th>Transplant group n=49</th>
<th>Total n=114</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung disease, n (%)</td>
<td>n/a</td>
<td>3 (15.0)</td>
<td>12 (26.7)</td>
<td>8 (16.3)</td>
<td>23 (20.2)</td>
</tr>
<tr>
<td>Coronary Artery Disease, n (%)</td>
<td>n/a</td>
<td>8 (40.0)</td>
<td>27 (60.0) a</td>
<td>13 (26.5) a</td>
<td>48 (42.1) #</td>
</tr>
<tr>
<td>Peripheral Vascular Disease n (%)</td>
<td>n/a</td>
<td>4 (20.0)</td>
<td>26 (57.8) b</td>
<td>16 (32.7) b</td>
<td>46 (40.4) #</td>
</tr>
<tr>
<td>Diabetes, n (%)</td>
<td>n/a</td>
<td>7 (35.0)</td>
<td>23 (51.1)</td>
<td>14 (28.6)</td>
<td>44 (38.6)</td>
</tr>
<tr>
<td>Cardiovascular Disease, n (%)</td>
<td>n/a</td>
<td>2 (10.0)</td>
<td>14 (31.1)</td>
<td>8 (16.3)</td>
<td>24 (21.1)</td>
</tr>
<tr>
<td>Cancer, n (%)</td>
<td>n/a</td>
<td>1 (5.0) c</td>
<td>9 (20.0)</td>
<td>17 (34.7) c</td>
<td>27 (23.7) #</td>
</tr>
<tr>
<td>More than 3 chronic diseases, n (%)</td>
<td>n/a</td>
<td>9 (45.0)</td>
<td>32 (71.1) d</td>
<td>16 (32.6) d</td>
<td>57 (50.0) #</td>
</tr>
</tbody>
</table>

# p<0.05; Values with same superscript (a, b, c, d) are significantly different.
Table 3.4. Mean HeLMS scores for each domain and relevant items for study participants.

<table>
<thead>
<tr>
<th>Domain [item]</th>
<th>Domain descriptor</th>
<th>Pre-dialysis group</th>
<th>Peritoneal Dialysis group</th>
<th>Haemodialysis group</th>
<th>Transplant group</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Patient attitudes towards their health</td>
<td>3.92 (0.77)</td>
<td>4.11 (0.72)</td>
<td>3.99 (0.79)</td>
<td>4.06 (0.86)</td>
<td>4.02 (0.79)</td>
</tr>
<tr>
<td>1 [Item 7]</td>
<td>Change your lifestyle to improve your health</td>
<td>3.62 (0.92)</td>
<td>4 (1.19)</td>
<td>3.69 (1.17)</td>
<td>3.94 (1.12)</td>
<td>3.81 (1.12)</td>
</tr>
<tr>
<td>1 [Item 23]</td>
<td>Find the energy to manage your health</td>
<td>3.67 (1.05)</td>
<td>3.68 (1.25)</td>
<td>3.73 (1.03)</td>
<td>3.94 (1.04)</td>
<td>3.78 (1.06)</td>
</tr>
<tr>
<td>2</td>
<td>Understanding health information</td>
<td>4.88 (0.30)</td>
<td>4.37 (1.12)</td>
<td>4.53 (0.76)</td>
<td>4.36 (0.92)</td>
<td>4.5 (0.85)</td>
</tr>
<tr>
<td>2 [Item 9]</td>
<td>Read health information brochures found in hospitals e.g. at a Dr clinic</td>
<td>4.91 (0.28)</td>
<td>4.28 (1.2)</td>
<td>4.51 (1.08)</td>
<td>4.48 (0.91)</td>
<td>4.53 (0.97)</td>
</tr>
<tr>
<td>2 [Item 14]</td>
<td>Fill in forms e.g. Medicare</td>
<td>4.96 (0.20)</td>
<td>4.36 (1.29)</td>
<td>4.21 (1.18)</td>
<td>4.17 (1.28)</td>
<td>4.34 (1.16)</td>
</tr>
<tr>
<td>2 [Item 20]</td>
<td>Read written information given to you e.g. by a Doctor</td>
<td>4.95 (0.20)</td>
<td>4.32 (1.22)</td>
<td>4.56 (1.06)</td>
<td>4.35 (1.05)</td>
<td>4.51 (1.01)</td>
</tr>
<tr>
<td>2 [Item 27]</td>
<td>Find health information in a language you can understand</td>
<td>4.67 (0.87)</td>
<td>4.52 (1.09)</td>
<td>4.84 (0.36)</td>
<td>4.42 (0.87)</td>
<td>4.62 (0.79)</td>
</tr>
<tr>
<td>3</td>
<td>Social support</td>
<td>4.23 (0.85)</td>
<td>4.61 (0.61)</td>
<td>4.51 (0.74)</td>
<td>4.61 (0.62)</td>
<td>4.52 (0.71)</td>
</tr>
<tr>
<td>4</td>
<td>Socioeconomic factors</td>
<td>4.38 (0.70)</td>
<td>4.49 (0.71)</td>
<td>4.47 (0.73)</td>
<td>4.31 (0.90)</td>
<td>4.40 (0.78)</td>
</tr>
<tr>
<td>5</td>
<td>Accessing GP services</td>
<td>5 (0.0)</td>
<td>4.91 (0.31)</td>
<td>4.96 (0.15)</td>
<td>4.88 (0.37)</td>
<td>4.93 (0.27)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</tr>
<tr>
<td>6</td>
<td>Communication with health professionals</td>
<td>4.76 (0.66)</td>
<td>4.33 (1.08)</td>
<td>4.71 (0.65)</td>
<td>4.66 (0.56)</td>
<td>4.64 (0.71)</td>
</tr>
<tr>
<td>7</td>
<td>Being proactive</td>
<td>4.62 (0.73)</td>
<td>4.53 (0.89)</td>
<td>4.37 (0.97)</td>
<td>4.47 (0.78)</td>
<td>4.47 (0.86)</td>
</tr>
<tr>
<td>8</td>
<td>Using health information</td>
<td>4.75 (0.59)</td>
<td>4.65 (0.78)</td>
<td>4.81 (0.45)</td>
<td>4.74 (0.58)</td>
<td>4.75 (0.58)</td>
</tr>
</tbody>
</table>

# p<0.05; Values with same superscript (a, b, c, d, e) are significantly different (one-way ANOVA).
Scores ≤ 4 suggest inadequate health literacy.
Table 3.5. Results from logistic regression for factors associated with inadequate health literacy for selected HeLMS items.

<table>
<thead>
<tr>
<th>HeLMS domain [item]</th>
<th>Age</th>
<th>Male gender</th>
<th>Duration RRT</th>
<th>Less than 12 years of education</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 [Item 7] Change your lifestyle to improve your health</td>
<td>0.98 (0.96-1.02)</td>
<td>1.4 (0.67-2.901)</td>
<td>0.96 (0.90-1.01)</td>
<td>1.4 (0.67-2.91)</td>
</tr>
<tr>
<td>1 [Item 23] Find the energy to manage your health</td>
<td>0.99 (0.97-1.02)</td>
<td>1.17 (0.57-2.43)</td>
<td>0.94 (0.89-0.99)</td>
<td>1.82 (0.86-3.84)</td>
</tr>
<tr>
<td>2 [Item 14] Fill in forms e.g. Medicare</td>
<td>0.98 (0.95-10.2)</td>
<td>3.19 (1.09-9.34) *</td>
<td>0.96 (0.89-1.04)</td>
<td>6.77 (2.17-21.08)*</td>
</tr>
<tr>
<td>2 [Item 20] Read written information given to you e.g. by a Doctor</td>
<td>1.01 (0.97-1.06)</td>
<td>2.76 (8.82-9.3) *</td>
<td>0.977 (0.9-1.06)</td>
<td>4.58 (1.32-15.82)*</td>
</tr>
<tr>
<td>2 [Item 27] Find health information in a language you can understand</td>
<td>0.99 (0.03-1.04)</td>
<td>2.08 (0.51-8.55)</td>
<td>0.95 (0.86-1.06)</td>
<td>4.93 (1.15-21.08) *</td>
</tr>
</tbody>
</table>

Abbreviations: RRT: renal replacement therapy (i.e. dialysis or transplantation); * p<0.01
Figure 3.1. Comparison of proportions of inadequate health literacy (expressed as a percentage) for the eight HeLMS domains
Notes: PRE, pre-dialysis; PD, peritoneal dialysis; HD, haemodialysis; TP, transplant.
Domain 1: Patient attitudes towards their health; Domain 2: Understanding health information; Domain 3: Social support; Domain 4: Socioeconomic factors; Domain 5: Accessing GP services; Domain 6: Communication with health professionals; Domain 7: Being proactive; Domain 8: Using health information.

*p < 0.05, Pearson’s Chi Square Analysis.

To calculate the proportion of individuals with inadequate health literacy, mean scores for the domain were dichotomised as either ‘no difficulty’ (i.e. a score of 5) or ‘any difficulty’ (i.e. a score of four or less).
Figure 3.2. Comparison of proportions of inadequate health literacy (expressed as a percentage) for selected HeLMS items showing statistical and clinically important items.
Notes: PRE, pre-dialysis; PD, peritoneal dialysis; HD, haemodialysis; TP, transplant.

Domain 1 [item 7] Change your lifestyle to improve your health; Domain 1 [item 23] Find the energy to manage your health; Domain 2 [item 9] Read health information brochures found in hospitals e.g. at a Dr clinic; Domain 2 [item 14] Fill in forms e.g. Medicare; Domain 2 [item 20] Read written information given to you e.g. by a Doctor; Domain 2 [item 27] Find health information in a language you can understand.

*p< 0.05, Pearson’s Chi Square Analysis.

To calculate the proportion of individuals with inadequate health literacy, mean scores for the domain were dichotomised as either ‘no difficulty’ (i.e. a score of 5 on the Likert scale) or ‘any difficulty’ (i.e. a score of 1-4 on the Likert scale).
CHAPTER 4: Health literacy demand of online renal diet information

Title: Evaluation of the quality and health literacy demand of online renal diet information.

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4.1 Executive Summary

Chapter 3 described the health literacy skills of adults with ESKD. Understanding health information and attending to one’s health needs were identified as being particularly problematic for adults with ESKD. Based on the Health Literacy Skills Framework (HLSF), the health literacy demand of health-related stimuli (shaded in purple below and include renal diet information found online) interacts with an individual’s health literacy skills, and subsequently impacts on the ability of individuals to comprehend and use the information to make appropriate renal diet related decisions.

Chapter 4 reports on an evaluation of the health literacy demand of renal diet information found online, that is: on websites and YouTube. Another aim of this study was to categorise the major topics of renal diet information found online, such as generic dietary advice for CKD.
Chapter 4 was published as

4.2 Abstract

**Background:** Dietary modification is critical in the self-management of chronic kidney disease. This study describes the accuracy, quality and health literacy demand of renal diet information for adults with kidney disease obtained from the Internet and YouTube.

**Methods:** A comprehensive content analysis was undertaken in April and July 2015 of n=254 eligible websites and n=161 YouTube videos. The accuracy of the renal diet information was evaluated by comparing the key messages to relevant evidence-based guidelines for the dietary management of people with kidney disease. The DISCERN tool was used to evaluate the quality of the material. Health literacy demand was evaluated using the Patient Education Material Assessment Tool (www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/index.html) and seven validated readability calculators.

**Results:** The most frequent renal diet topic found online was generic dietary information for people with CKD. The proportion of renal diet information obtained from websites that was accurate was 73%. However, this information was mostly of poor quality with extensive shortcomings, difficult to action and written with a high health literacy demand. In contrast, renal diet information available from YouTube was highly understandable and actionable, but only 18% of the videos were accurate, and a large proportion were of poor quality with extensive shortcomings. The most frequent authors of accurate, good quality, understandable, material were government bodies, dietitians, academic institutions and medical organisations.

**Conclusions:** Renal diet information found online that is written by government bodies, dietitians, academic institutions and medical organisations are recommended. Further work is required to improve the quality and most importantly, the actionability of renal diet information found online.
4.3 Introduction

Chronic Kidney Disease affects more than 10% of adults globally. A key component of the self-management of chronic kidney disease (CKD) is adherence to the appropriate dietary prescription. However, the dietary prescription for the management of CKD is considered complex and challenging for many patients. Patients report feeling ‘bewildered’ about the renal diet and often find it difficult to follow. This is further compounded by the nature of the diet prescription, which becomes more complex and changes as CKD progresses.

Adherence to the diet prescription is not only compromised by its complexity but also by other factors which include inadequate health literacy and cognitive impairment. These factors are common in patients with advanced CKD, and they can negatively impact upon their ability to understand, apply and adhere to their diet prescription. Adherence to the renal diet may be compromised further if patients receive conflicting messages about the renal diet from different members of the nephrology team; or if the advice is in contrast to their own beliefs about healthy food choices.

Patients (and their carers) often seek further information or clarification about information provided by their health professional from readily accessible online information sources such as the internet, or the most popular online video sharing website, YouTube. Evidence from the small number of studies investigating technology use by people with CKD indicate that 60% of adults with end stage kidney disease have conducted online searches for health information. Furthermore, information on foods to avoid is a major focus of online searches by people with CKD.

Surprisingly though, there are few studies that have formally evaluated online information for people with CKD. A study by Garg et al evaluated 115 dialysis related YouTube videos. The accuracy of these videos was assessed using a range of relevant evidence-based guidelines for the management of patients undertaking dialysis. The authors found that 16.5% of these videos were misleading and 41.7% were inaccurate. A large proportion (68.4%) of these videos also promoted unproven
therapies. Other content analysis studies of written health information for people with CKD available online have found that information is frequently written at a literacy level that exceeds the health literacy skills of patients with CKD. However, these previous studies did not specifically evaluate the content or quality of renal diet information. An important knowledge gap therefore remains. Thus, the aims of this study were (i) to describe the main categories of online renal diet information (that is, information available on websites and YouTube) (ii) to determine the proportion of online renal diet information that was accurate (evidence based) and (iii) to describe the quality and health literacy demand of online renal diet information.

4.4 Methods

This research was an exploratory study using a combination of desk-based methods used in previous content analysis or health literacy demand studies. As a result, ethics approval was not required.

A list of renal diet related search terms were constructed to search the internet and YouTube (Table 4.1). These search terms were constructed using professional clinical judgement by three members of the research team (KL, AK, LM) about potential search terms that could be used when searching for information about the renal diet. These terms were then discussed with, and informal feedback obtained from individuals with chronic kidney disease (n=3). Search terms were entered into the three most popular search engines used in Australia: Google, Yahoo and Bing. Potential websites for analysis were restricted to the first seven pages of results for each search term in accordance with recent content analyses. An initial pilot search of YouTube using the first two search term combinations yielded more than 97,000 potential videos for evaluation. Therefore, potential videos for analysis were restricted to the first seven pages of results on YouTube, and the search was confined to the first two search terms as shown in Table 4.1.

Exclusion criteria included those websites and YouTube videos: (i) that were not in English; (ii) were not related to kidney disease in humans; (iii) did not provide dietary information for people with kidney disease; (iv) access was prohibited due to
password protection; (v) information retrieved from websites was limited to less than 150 words or (vi) the video was not audible.

Information about the renal diet retrieved from websites or YouTube was categorised into one of nine renal diet topic categories (Table 4.1). Similarly, the authors of the renal diet information were categorised into one of ten categories, with two additional unique author categories of ‘unclear sources’ and ‘patient testimonials’ (Table 4.1) required for categorisation of YouTube videos based on previous research 19.

The accuracy of renal diet information retrieved from the internet and YouTube was evaluated by an experienced renal dietitian, Advanced Accredited Practising Dietitian and first author (KL). Information was considered accurate and therefore ‘evidence based’ if the nutrient prescription and / or the dietary recommendations were consistent with the relevant evidence-based guidelines for the dietary management of kidney diseases 2, 4, 28-31. These evidence-based guidelines were used because they represented the most up to date recommendations for renal dietetic practice at the time of the study. Using an approach that is consistent with previous content analysis work 19, if the online information evaluated contained partially accurate and partially inaccurate information, then the information was classified as inaccurate.

Evaluation of the quality renal diet information

The quality of the renal diet information obtained was evaluated by two members of the research team (AK, LM) using the DISCERN appraisal process and related tool (www.discern.org.uk) 32. The DISCERN tool was originally developed to enable consumers of health information to evaluate the quality of written health information 32. The tool allows users to evaluate the quality of the information by reviewing whether the sources of evidence within the health information are explicit; the material is current, unbiased and reliable. Using this tool, the overall quality of the information is scored using a 5-point Likert scale. An overall DISCERN quality rating score of (2) or below indicates the material is of poor quality and has serious or extensive shortcomings; a rating of (3) indicates the material is of fair quality with potentially important but not serious shortcomings; and a rating of (4) or above
indicates the material has minimal shortcomings and is of good quality. In this study, the proportion of materials considered poor, fair, and good quality are reported.

**Evaluation of the health literacy demand of renal diet information**

The Patient Education Materials Assessment Tool (PEMAT) (www.ahrq.gov/professionals/prevention-chroniccare/improve/self-mgmt/pemat/index.html) was used to evaluate the understandability and actionability of the renal diet information obtained, which is referred to as the ‘health literacy’ demand. According to the authors of the tool, ‘understandability’ refers to health information that is written in a manner that can be understood by health consumers from diverse backgrounds and with varying levels of health literacy. ‘Actionability’ refers to health information that is written in a manner that enables health consumers to easily identify what they need to do, based on the information presented. The PEMAT scores materials on a scale of 0-100, with a score of 100% indicating higher ‘understandability’ and ‘actionability’, respectively. A score of greater than 70% has been set by the authors of the tool as indicative of material that is understandable and actionable. There are two versions of the PEMAT: a version for written information which includes 17 criteria for assessing ‘understandability’ and seven criteria for assessing the ‘actionability’; and an audio-visual version of the PEMAT which includes 13 criteria for assessing ‘understandability’ and four criteria assessing ‘actionability’. Each criteria in both versions of the PEMAT is evaluated in a binary fashion as either agree or disagree.

The literacy demand (readability) of the written diet information retrieved from the websites in this study, was assessed by cutting and pasting written material into an online readability calculator (http://www.readabilityformulas.com/free-readability-formula-tests.php). This calculator provides an average of the estimated reading age and grade level required to read the written material. The average values are obtained by utilising seven previously validated reading formulas: the Flesch Reading Ease formula; the Flesch Kincaid Grade Level, the Gunning FOG formula; the SMOG Index; the Coleman-Liau Index; the Automated Readability Index and the Linsear Write Formula.
**Statistical analysis**

All data was analysed using SPSS Version 21 software (SPSS Inc., Chicago, Illinois, USA). Normality was assessed using the Shapiro Wilk Test, with the data reported as median and interquartile range (IQR). Wilcoxon Rank Sum or Kruskal Wallis tests were used to compare scores between groups (such as understandability and actionability between author types or between websites and YouTube). A p value of p< 0.05 was considered statistically significant.

### 4.5 Results

Internet searches were conducted on the 20\textsuperscript{th} April 2015 and YouTube searches on 2\textsuperscript{nd} July 2015. A total of 1125 websites and 280 YouTube videos were identified using the keyword searches. After exclusion of duplicates and ineligible sites or videos, a total of 254 websites (Figure 4.1) and 161 YouTube videos (Figure 4.2) were eligible for analysis.

The most common categories of renal diet information found on websites and YouTube are shown in Table 4.2. Diet for CKD was the most common type of renal diet information found on both websites and YouTube (39.8% and 82.0% respectively). The next most frequent renal diet topic categories on websites were generic diet information for dialysis (18.1%), followed by diet information for kidney transplant (10.6%). In contrast, miscellaneous renal information (9.9%), and diet for Poly Cystic Kidney Disease (PCKD) (3.7%) were the second and third most frequent renal diet topics on YouTube. Information on the diet for patients considered predialysis was virtually non-existent on YouTube (0.6%) and made up only a small proportion of information from websites (6.3%).

Table 4.2 also indicates that 73.2% of the total number of web pages evaluated (n=254) contained accurate (i.e. evidence based) information. This was significantly higher than the proportion of accurate renal diet information found on YouTube (18.0%, p<0.0001). For the most common renal diet category (‘Diet for CKD’), the majority of the information available from websites was accurate (69.3%). In contrast, the majority of information for this same category on YouTube was
inaccurate (84.8%). A high proportion of information on diet for PCKD was inaccurate (87.5% websites and 66.7% YouTube).

Author categories with a high proportion of accurate renal diet information online included academic, dietetic, government, media outlets and medical organisations (Table 4.3). Notably however, YouTube did not contain any videos from academic or government authors. While commercial organisations were the most frequent authors of online renal diet information, they were also a common source of inaccurate information. The proportion of inaccurate renal diet information produced by commercial sources was significantly higher on YouTube (94.1%) than from websites (43.4%, p<0.0001). Other common author sources of inaccurate material were naturopaths or medical doctors, or material in the form of patient testimonials. Further analysis of the commercial authors on YouTube indicated that n=89 (74.7%) of all videos were produced by just two individuals (data not shown).

Poor quality information with extensive or serious shortcomings constituted approximately half of the renal diet information evaluated on websites (49.6%) and YouTube (58.4%; Table 4.4). The proportion of material from websites considered to be of good quality was 26% and almost all of this material was accurate (n=65/66). In contrast, the proportion of good quality material obtained from YouTube was very small (11.8 %) and 68.4% (n=13/19) was accurate.

Analysis of the health literacy demand of renal diet information is also shown in Table 4.4. Information obtained from websites was written at a median readability level of Grade 10 (IQR: 9-12), and for a median reader age of 14 year old (IQR: 14-17) (Table 4). Readability levels of information from websites did not differ according to accuracy.

Web based information had significantly lower levels of understandability (p<0.0001) and actionability (p<0.0001) when compared to YouTube information. Material considered to be accurate and found on the internet was significantly less understandable than accurate information found on YouTube (p<0.0001). The only category of renal diet information that scored above the PEMAT cut off of 70% for actionability was inaccurate information found on YouTube.
Further examination of the health literacy demand scores of renal diet information according to selected author types are shown in Table 4.5. All authors with a high proportion of accurate information had understandability scores > 70% (Table 4.5). Information on YouTube produced by commercial organisations and medical doctors was significantly more understandable than information produced by the same author types but available on websites (p<0.0001). The only author type from websites that scored >70% for actionability was material authored by government bodies. YouTube based renal diet information that scored highly for actionability was material authored by dietitians or commercial organisations.

4.6 Discussion
High quality, evidence based health information is an essential tool to educate patients about how to take a proactive role in the self-management of their health \textsuperscript{15, 41}. In this study, we found that renal diet information from websites and YouTube was dominated by generic information about the diet for CKD. In addition, we found that the proportion of renal diet information obtained from websites and YouTube that was considered to be accurate, of good quality, and with a low health literacy demand was very low. The results of this study suggest that health professionals should only refer patients to websites or YouTube for renal diet information, if it is accompanied with explicit guidance on how to locate the relatively small number of appropriate high quality, evidence-based materials.

The findings of this study regarding the quality of online renal diet information provide a useful contribution to the small body of content analysis literature in the area of Nephrology. Our findings on readability are consistent with previous work on the readability levels of online CKD related material \textsuperscript{21, 22, 42}. However, our research extends previous work in the CKD context by evaluating the consistency of renal diet information with evidence based guidelines, and by analysing this material with respect to the important and emerging area of health information understandability and actionability \textsuperscript{43}. One of the key points from this study is that evidence based renal diet information from websites is written at a readability level of approximately Grade 10 or a 14-15 year-old high school student. This is more than three levels above the readability levels for health materials recommended by bodies such as the
National Institute of Health and the Australian Clinical Excellence Commission. Exceeding the minimum requirements for plain language health information means that patients (especially those with low health literacy), may not be able to comprehend or use the renal diet information found online to meet their needs.

Patients with CKD are actively engaged and looking for CKD related information online. Indeed, health professionals are often asked to contextualise or clarify online information found by patients or carers of patients with CKD. Consequently, we believe health professionals need to be proactive and help patients navigate the often unruly structure of the internet. However, health professionals often report that they lack confidence on how to instruct their patients to search for appropriate information online. We have therefore constructed a summary of the characteristics of good quality, accurate renal diet information (Table 4.6). This table has been developed using the results of the present study, as well as frequently cited guidance on how to assess the quality of medical information on the internet.

One of the key results in this study is the scarcity of good quality online renal diet information that is both understandable and actionable. This has important implications for adherence by patients to the renal diet. In this study, only academic institutions, government bodies, dietitians and medical organisations scored strongly in terms of understandability and only government bodies, scored well for actionability. However actionable information is highly valued and preferred by patients with CKD. This suggests that more attention is required to the inclusion of simple, practical, actionable instructions (for example, including details on how to incorporate the renal diet into family and social occasions). This would theoretically enable all patients, not just those with inadequate health literacy or impaired cognition to adopt healthy renal diet behaviours. Designing renal diet information that is actionable may also prevent patients from searching for alternative (and possibly inaccurate) information, because the renal diet information they have obtained contains clear instructions on what to change. Designing more

Links to the websites and videos evaluated in this study that meet these criteria are contained here: https://smah.uow.edu.au/medicine/contacts/UOW055691. Table 4.6 could also be used by health professionals with patients in their discussions regarding searching for appropriate renal diet information on the internet or YouTube.
effective renal diet information that is both understandable and actionable could therefore increase patient knowledge and address the key concerns of patients. This may well be an important part of improving renal diet adherence.58

A second key message from this study is that not all online information about the renal diet is accurate. Therefore, renal diet information found online by patients (particularly those obtained from YouTube) may be contradictory to advice they have received from their health care team. This is problematic because it has been observed that when people encounter conflicting health information, substantial cognitive effort is required to process the contradictory information, and this is believed to lead to errors in judgement.60 As a result, we therefore suggest that patients look for renal diet information authored by dietitians, medical organisations, academic institutions or government bodies, as they were the most common sources of accurate information. Material from these organisations is preferred than material authored by commercial organisations, naturopaths, medical doctors or via patient testimonials, because in this study, they were frequently found to be inaccurate. The consequences of following renal diet advice that is inaccurate could be consumption of inappropriate foods, or avoidance of potentially suitable foods. This may result in reduced dietary variety and quality in an already limited diet.

One of the strengths of this study is the use of validated tools to examine the quality and health literacy demand of renal diet information found online. The DISCERN tool was initially developed to enable patients to rate the quality of written information materials about treatment choices.32 However, it has since been shown to distinguish reliably between low and high-quality health publications, websites and patient education materials.61,62 Similarly, the PEMAT has been shown to have strong internal consistency, reliability, and construct validity.33 The DISCERN and PEMAT tools also allow evaluation of how relevant the content is, as well as the complexity and organisation of ideas - key features that readability formulas do not take into account.63 Future research into the development of tools to evaluate the increasingly complex range of multimedia materials available online is required.

The limitations of this study include the cross-sectional nature. Information was also limited to information in the English language only, and non-English material may
be of a different quality. YouTube search terms were also limited to only two combinations for pragmatic reasons. It is also possible that the key word combinations used for searching may not reflect the internet searching practices of all people with kidney disease. Despite this, we believe the nature of the searches we conducted were comprehensive. We did not specifically exclude commercial organisations or other patient support organisations like previous content analysis studies \(^64, 65\). This is because information from these sites may be used to inform the decisions and change the dietary or health behaviours of people with kidney disease \(^66\); and as shown in this study, information from these sources makes up a substantial portion of the information to be found.

Future work should be directed to increasing the number of accurate, high quality renal diet information resources online. One topic area for immediate action would be renal diet information that clearly describes the type of dietary changes required for predialysis patients. Similarly, there is a paucity of accurate evidence-based information online for people with Poly Cystic Kidney Disease. Research that utilises the perspectives of patients with kidney disease regarding the preferred content and format of renal diet related information is also desirable. Further work investigating how patients with chronic kidney disease make sense of, and implement complex renal diet related self-management advice is also required and could be used to inform the design of future dietary self-management programs and health information.

This comprehensive study of online renal diet information has shown that renal diet information available online is often of poor quality, with variable levels of health literacy demand and is dominated by generic information for people with CKD. Web based searches that are directed to renal diet information authored by dietitians, medical organisations, academic institutions or government bodies are recommended because these are likely to be accurate. Future work is required to improve the quality and reduce the health literacy demand of renal diet information online. Engaging with patients and carers about the preferred format and content is also suggested.
**Transparency declaration**

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

**Acknowledgements**

Sincere thanks to Paris Owen for assistance with this project.
References


Table 4.1. List of search terms, renal diet categorisation and author types

<table>
<thead>
<tr>
<th>Search terms</th>
<th>Renal diet topic categories</th>
<th>Author categories</th>
<th>Internet based search</th>
<th>YouTube search</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney Disease Diet</td>
<td>Miscellaneous (such as Acute Kidney Injury, IgA nephropathy, hypertension, fluid restriction, low phosphate diet)</td>
<td>Academic e.g. university or academic body (e.g. ‘.edu’)</td>
<td>Academic e.g. university or academic body</td>
<td></td>
</tr>
<tr>
<td>Renal Disease Diet</td>
<td>Diet information specifically for people with Kidney Stones</td>
<td>Commercial enterprises</td>
<td>Commercial enterprises</td>
<td></td>
</tr>
<tr>
<td>Kidney Foods</td>
<td>Diet information specifically for people with Polycystic Kidney Disease (PCKD)</td>
<td>Dietitians</td>
<td>Dietitians</td>
<td></td>
</tr>
<tr>
<td>Special Renal Foods</td>
<td>Diet information specifically for people with Chronic Kidney Disease (no stage of CKD specified)</td>
<td>Government bodies e.g. National Institute of Health (US) (e.g. ‘.gov’)</td>
<td>Government bodies e.g. National Institute of Health (US) (e.g. ‘.gov’)</td>
<td></td>
</tr>
<tr>
<td>Chronic Kidney Disease and Diet</td>
<td>Diet information specifically for people considered ‘Predialysis’ i.e. CKD stage 4 or 5</td>
<td>Media outlets e.g. radio, TV, newspaper</td>
<td>Media outlets e.g. radio, TV, newspaper</td>
<td></td>
</tr>
<tr>
<td>Polycystic Kidney Disease and diet</td>
<td>Generic diet information for people undertaking any type of dialysis</td>
<td>Medical Doctors</td>
<td>Medical Doctors</td>
<td></td>
</tr>
<tr>
<td>Dialysis and Diet</td>
<td>Diet information specifically for people undertaking peritoneal dialysis</td>
<td>Medical organisations e.g. the National Kidney Foundation or Kidney Health Australia (e.g. ‘.org’)</td>
<td>Medical organisations e.g. the National Kidney Foundation or Kidney Health Australia (e.g. ‘.org’)</td>
<td></td>
</tr>
<tr>
<td>Dialysis and Food</td>
<td>Diet information specifically for people undertaking haemodialysis</td>
<td>Naturopaths</td>
<td>Naturopaths</td>
<td></td>
</tr>
<tr>
<td>Kidney Transplant and Diet</td>
<td>Diet information specifically for people post kidney transplant</td>
<td>Patient support organisations e.g. ‘kidneybuzz.com’</td>
<td>Patient support organisations e.g. ‘kidneybuzz.com’</td>
<td></td>
</tr>
<tr>
<td>---------------------------</td>
<td>---------------------------------------------------------------</td>
<td>--------------------------------------------------</td>
<td>--------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Kidney Disease and food</td>
<td>‘Other’ e.g. wikis</td>
<td>‘Other’ e.g. wikis</td>
<td>‘Other’ e.g. wikis</td>
<td></td>
</tr>
<tr>
<td>Kidney Transplant and food</td>
<td></td>
<td>Unclear source</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kidney Failure and Diet</td>
<td></td>
<td></td>
<td>Patient Testimonial</td>
<td></td>
</tr>
<tr>
<td>Kidney Disease Treatment and Diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4.2. Comparison of the categories and proportion of accurate renal diet information obtained from internet websites and YouTube

<table>
<thead>
<tr>
<th>Categories of renal diet information</th>
<th>Internet websites (n=254)</th>
<th></th>
<th></th>
<th>YouTube videos (n=161)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Accurate n (%)</td>
<td>Inaccurate n (%)</td>
<td>Total n (%)</td>
<td>Accurate n (%)</td>
<td>Inaccurate n (%)</td>
<td>Total n (%)</td>
</tr>
<tr>
<td>Diet for CKD</td>
<td>70 (69.3)</td>
<td>31 (30.7)</td>
<td>101 (39.8)</td>
<td>20 (15.2)</td>
<td>112 (84.8)</td>
<td>132 (82.0)</td>
</tr>
<tr>
<td>Diet for Predialysis CKD</td>
<td>12 (75.0)</td>
<td>4 (25.0)</td>
<td>16 (6.3)</td>
<td>1 (100)</td>
<td>0 (0)</td>
<td>1 (0.6)</td>
</tr>
<tr>
<td>Generic diet information for dialysis</td>
<td>43 (93.5)</td>
<td>3 (6.5)</td>
<td>46 (18.1)</td>
<td>0 (0)</td>
<td>3 (100)</td>
<td>3 (1.9)</td>
</tr>
<tr>
<td>Diet information for peritoneal dialysis</td>
<td>5 (100)</td>
<td>0 (0)</td>
<td>5 (2.0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Diet information for haemodialysis</td>
<td>13 (100)</td>
<td>0 (0)</td>
<td>13 (5.1)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Diet information for kidney transplant</td>
<td>23 (85.2)</td>
<td>4 (14.8)</td>
<td>27 (10.6)</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>2 (1.2)</td>
</tr>
<tr>
<td>Diet for Kidney Stones</td>
<td>11 (84.6)</td>
<td>2 (15.3)</td>
<td>13 (5.1)</td>
<td>1 (100)</td>
<td>0 (0)</td>
<td>1 (0.6)</td>
</tr>
<tr>
<td>Diet for PCKD</td>
<td>2 (12.5)</td>
<td>14 (87.5)</td>
<td>16 (6.3)</td>
<td>2 (33.3)</td>
<td>4 (66.7)</td>
<td>6 (3.7)</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>7 (41.1)</td>
<td>10 (58.8)</td>
<td>17 (6.7)</td>
<td>4 (25.0)</td>
<td>12 (75.0)</td>
<td>16 (9.9)</td>
</tr>
<tr>
<td>Total</td>
<td>186 (73.2)</td>
<td>68 (26.8)</td>
<td>254 (100)</td>
<td>29 (18.0)</td>
<td>132 (82.0)</td>
<td>161(100)</td>
</tr>
</tbody>
</table>
Diet for CKD: diet information for Chronic Kidney Disease (but with no stage of CKD specified); Diet for Predialysis refers to diet for people with CKD stage 4 or 5; Generic diet information for people undertaking any type of dialysis; Generic diet information for people undertaking peritoneal dialysis; Diet information specifically for people undertaking haemodialysis; Diet for people with Polycystic Kidney Disease (PCKD); Miscellaneous: includes topics such as Acute Kidney Injury, IgA nephropathy, hypertension, fluid restriction, low phosphate diet.
Table 4.3. Analysis of the accuracy of renal diet information obtained from internet websites and YouTube according to author type

<table>
<thead>
<tr>
<th></th>
<th>Internet websites (n=254)</th>
<th></th>
<th>YouTube videos (n=161)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Accurate n (%)</td>
<td>Inaccurate n (%)</td>
<td>Total n (%)</td>
<td>Accurate n (%)</td>
</tr>
<tr>
<td>Academic</td>
<td>8 (100)</td>
<td>0</td>
<td>8 (3.1)</td>
<td>0</td>
</tr>
<tr>
<td>Dietitians</td>
<td>17 (100)</td>
<td>0</td>
<td>17 (6.7)</td>
<td>8 (100)</td>
</tr>
<tr>
<td>Government bodies</td>
<td>11 (100)</td>
<td>0</td>
<td>11 (4.3)</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>2 (100)</td>
<td>0</td>
<td>2 (0.8)</td>
<td>0</td>
</tr>
<tr>
<td>Medical organisations</td>
<td>77 (89.5)</td>
<td>9 (10.5)</td>
<td>86 (33.9)</td>
<td>0</td>
</tr>
<tr>
<td>Media outlets</td>
<td>19 (86.4)</td>
<td>3 (13.6)</td>
<td>22 (8.7)</td>
<td>0</td>
</tr>
<tr>
<td>Commercial</td>
<td>39 (56.5)</td>
<td>30 (43.4)</td>
<td>69 (27.2)</td>
<td>8 (6.7)</td>
</tr>
<tr>
<td>Patient support organisation</td>
<td>4 (44.4)</td>
<td>5 (55.5)</td>
<td>9 (3.5)</td>
<td>5 (100)</td>
</tr>
<tr>
<td>Medical Doctors</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
<td>5 (2.0)</td>
<td>5 (62.5)</td>
</tr>
<tr>
<td>Naturopaths</td>
<td>7 (28.0)</td>
<td>18 (72.0)</td>
<td>25 (9.8)</td>
<td>1 (100)</td>
</tr>
<tr>
<td>Unclear source</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Patient Testimonials</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2 (22.2)</td>
</tr>
<tr>
<td>Total</td>
<td>186 (73.2)</td>
<td>68 (26.8)</td>
<td>254 (100)</td>
<td>29 (18.0)</td>
</tr>
</tbody>
</table>
Table 4.4. Analysis of the quality and health literacy demand of renal diet information obtained from internet websites and YouTube

<table>
<thead>
<tr>
<th>Quality of information (evaluated using the DISCERN tool)</th>
<th>Internet websites (n=254)</th>
<th>YouTube videos (n=161)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Accurate n</td>
<td>Inaccurate n</td>
</tr>
<tr>
<td>Poor quality with extensive or serious shortcomings</td>
<td>60</td>
<td>66</td>
</tr>
<tr>
<td>Fair quality with potentially important but not serious shortcomings</td>
<td>61</td>
<td>1</td>
</tr>
<tr>
<td>Good quality with minimal shortcomings</td>
<td>65</td>
<td>1</td>
</tr>
</tbody>
</table>

Health literacy demand (evaluated using online readability calculators and the PEMAT)

<table>
<thead>
<tr>
<th>Readability, median grade level (IQR)</th>
<th>Internet websites (n=254)</th>
<th>YouTube videos (n=161)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Accurate n</td>
<td>Inaccurate n</td>
</tr>
<tr>
<td>Readability, median grade level (IQR)</td>
<td>10 (9-11.3)</td>
<td>10 (9-12)</td>
</tr>
<tr>
<td>Readability, median reader age (IQR)</td>
<td>14 (14-16)</td>
<td>14 (14-17)</td>
</tr>
<tr>
<td>Understandability, median score, % (IQR)</td>
<td>77 (60-92)</td>
<td>56 (42-75)</td>
</tr>
<tr>
<td>Actionability, median score % (IQR)</td>
<td>50 (33-86)</td>
<td>33 (17-40)</td>
</tr>
</tbody>
</table>

IQR: Interquartile range. Values with the same superscript (a,b,c) are significantly different from each other at p<0.0001
A score of <70% indicates poor understandability or actionability.
Table 4.5. Analysis of health literacy demand of renal diet information obtained from internet websites and YouTube according to selected author types.

<table>
<thead>
<tr>
<th>Author</th>
<th>Understandability median score % (IQR)</th>
<th>Actionability median score % (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Internet websites (n=254)</td>
<td>YouTube videos (n=161)</td>
</tr>
<tr>
<td>Authors with a high proportion of accurate information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Academic institutions</td>
<td>76 (55-87)</td>
<td>-</td>
</tr>
<tr>
<td>Government bodies</td>
<td>88 (83-99)</td>
<td>-</td>
</tr>
<tr>
<td>Dietitians</td>
<td>88 (80-100)</td>
<td>100 (95-100)</td>
</tr>
<tr>
<td>Medical Organisations</td>
<td>81 (60-92)</td>
<td>-</td>
</tr>
<tr>
<td>Other authors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commercial</td>
<td>58 (43-77)</td>
<td>91 (89-100)</td>
</tr>
<tr>
<td>Patient Support Organisations</td>
<td>50 (39-88)</td>
<td>88 (76-100)</td>
</tr>
<tr>
<td>Patient Testimonials</td>
<td>-</td>
<td>94 (85-100)</td>
</tr>
<tr>
<td>Medical Doctors</td>
<td>31 (5-62)</td>
<td>89 (69-97)</td>
</tr>
<tr>
<td>Naturopaths</td>
<td>58 (44-78)</td>
<td>89 (89-89)</td>
</tr>
</tbody>
</table>

A score of <70% indicates poor understandability or actionability. Values with the same superscript (a,b,c) are significantly different from each other at p<0.0001
Table 4.6. Characteristics of good quality renal diet information obtained from the internet or YouTube.

- The information is *evidence based* i.e. it is written or created by:
  - a. Dietitians
  - b. Medical organisations (e.g. ‘.org’)
  - c. Academic institutions (e.g. ‘.edu’) or
  - d. Government bodies (e.g. ‘.gov’)

- The information clearly:
  - a. Explains *why* the dietary changes are required
  - b. Does not refer to, or use anecdotal evidence to justify the suggested changes
  - c. Supports advice with references to scientific research results or evidence-based guidelines
  - d. Explains why particular foods may need to be avoided or restricted
  - e. Provides practical food or menu-based substitutes for foods to be avoided

- The information provides specific details in layman’s terms about how to incorporate the dietary changes suggested into existing eating habits or into social eating occasions i.e. it is *understandable and actionable*:
  - a. The information contains clear instructions on *what* actions the person needs to take, in layman’s terms, with specific food or menu examples
  - b. The information contains clear instructions on *when* dietary changes are required, in layman’s terms, with specific food or menu examples
Figure 4.1. Flowchart of website selection

Identification

Number of websites identified through Google search (n=649) → Number of websites identified through Yahoo search (n=602) → Number of websites identified through Bing search (n=643)

Screening

Number of websites from the first 7 pages of search on Google (n=373) → Number of websites from the first 7 pages of search on Yahoo (n=327) → Number of websites from the first 7 pages of search on Bing (n=425)

Eligibility

Number of websites for evaluation (n=1125) → Duplicates excluded (n=800)

Number of websites eligible for evaluation (n=325) → Websites excluded (animals, not in English or not renal diet related) (n=71)

Included

Websites included for evaluation (n=254)
Figure 4.2. Flowchart of YouTube video selection
CHAPTER 5: Health literacy demand of online renal diet information

Title: Should we recommend renal diet related apps to our patients? An evaluation of the quality and health literacy demand of renal diet related mobile applications

Authors:

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5.1. *Executive Summary*

Chapter 4 identified that the quality and accuracy of online renal diet information was highly variable, and that the health literacy demand of the information found on websites and YouTube was high. The complexity of online renal diet information found in apps also interacts with an individual’s health literacy skills and affects their ability to comprehend and use the information to make appropriate renal diet related decisions.

Chapter 5 reports the results of an analysis of the health literacy demand renal diet information available in mobile phone applications (apps) (shaded in purple on the Health Literacy Skills Framework included below).

Chapter 5 was published as

An evaluation of the quality and health literacy demand of renal diet related mobile applications

5.2. Abstract

Objective: Mobile phone applications (apps) are increasingly being used by patients with CKD. We sought to describe the main purpose of commonly available renal diet apps; and to quantify the accuracy of information, technical quality and health literacy demand of renal diet apps.

Design: Content analysis

Setting: All eligible renal diet apps in the Australian Apple App Store, Google Play, Windows Phone and Blackberry App World were evaluated.

Subjects: Eligible apps were in English and were related to kidney disease in humans (of any type or stage). Exclusion criteria included apps which were prohibited due to password protection.

Main outcome measure: Renal diet information in the apps was compared to evidence-based guidelines for the management of kidney disease to quantify information accuracy. App information was evaluated using the Silberg Scale. Technical quality and health literacy demand were evaluated using the Mobile Application Rating Scale (MARS).

Results: A total of 21 apps were eligible for evaluation. The main purpose of these apps were to provide food and nutrition information (57.1%) or for educative purposes for CKD patients (38.1%). Only 47.6% (10/21) of apps contained accurate evidence-based information. Overall, app technical quality was considered acceptable (mean MARS score 3.19 ± 0.35 out of 5), with 80.9% of apps scoring acceptable or greater for app technical quality. Scores for health literacy demand also indicated that most apps (15/21, 71.4%) were acceptable.

Conclusion: A range of apps currently exist that may provide individuals with CKD with useful food and nutrition information or increase their knowledge of the renal diet. These apps are also mainly of acceptable technical quality and health literacy demand. However, caution is required when using renal diet apps, because more than half of the apps evaluated were not accurate and evidence based.

Keywords: Mobile applications, apps, health literacy, quality, renal diet
5.3. Introduction

More than three quarters of the global population own a mobile phone \(^1\), and the proportion of individuals with a smartphone now exceeds 70% in most developed nations \(^2\). This enthusiasm for using digital devices in everyday life has also been accompanied by a proliferation of health-related mobile applications (apps). For example, one recent audit indicated that there were more than 165 000 health related apps available to download \(^3\). Importantly, up to one third of health apps are designed to assist individuals with their chronic disease self-management \(^4\).

Self-management of a chronic disease such as chronic kidney disease (CKD) is complex, and requires an individual to balance complex dietary, lifestyle and medication regimens, as well as monitoring of clinical signs and symptoms \(^5-7\). The types of functionalities embedded into many health-related apps could assist individuals with CKD in their complex self-management tasks \(^8,9\). These functionalities include (but are not limited to) food and exercise diaries, recording and tracking of biochemical and anthropometric data, messaging and alerts, the transfer of clinical data to health professionals, social networking features and the provision of disease related information.

An emerging area of research interest for health professionals is on the potential integration of health apps into their clinical CKD care. For example, a number of studies have confirmed that apps can be used to assist patients with their advanced CKD self-management \(^10,11\); and for remote home dialysis monitoring \(^12,13\). Renal dietitians have also been early to adopt and trial the use of this type of technology. Renal diet related apps have been used to record and track the diet and fluid intake of renal patients in small pilot studies \(^14-16\).

However, the evidence regarding the impact of health apps on health outcomes is less clear \(^17\) and is hampered by the small number of studies with small patient numbers and short follow up periods \(^9,18\). A systematic review of the impact of apps to improve nutrition outcomes found that apps can positively assist individuals with their diet monitoring adherence \(^19\). However, a more recent systematic review that specifically evaluated the impact of apps on dietary and clinical outcomes in CKD \(^20\),
found that none of the five studies using apps resulted in any significant changes to dietary intake, biochemical markers or intradialytic weight gain.

While disappointing, it is possible that these results may also reflect imperfect design features and barriers related to user characteristics. Few studies have specifically tested the use of apps in clinical care with people from diverse backgrounds. This is an important consideration given that individuals with CKD are often older, of lower socioeconomic status, with inadequate health literacy and with varying degrees of cognitive impairment. The applicability, useability and relevance of apps to a large portion of the CKD population are therefore unclear.

Given the paucity of research on the use of apps in CKD, and a willingness for health professionals and patients to use apps, a better understanding of commercially available renal diet apps is warranted. Thus, the aims of this research were (i) to describe and categorise the proposed functions of commonly available renal diet apps (ii) to determine the proportion of renal diet apps containing information that is accurate (evidence based) and (iii) to describe the technical quality and health literacy demand of renal diet apps.

5.4. Methods

This research used a combination of desk based methods as per previous renal diet content analyses and health literacy demand studies. As a result, ethics approval was not required.

A list of renal diet related search terms was constructed by two dietitians and co-authors. These terms were then piloted with CKD patients to ensure that they were representative of typical terms patients would use to search for renal diet related apps. The final search terms used for this study were: ‘kidney diet’, ‘kidney disease’, ‘chronic kidney disease’, ‘renal failure’ and ‘dialysis’. These search terms were then entered into four popular Australasian online mobile application stores: Apple App Store, Google Play, Windows Phone and Blackberry App World, as suggested in the literature during April 2015. Apps were included as part of the study if they (i) were available in English, (ii) related to
kidney disease in humans, and (iii) were designed to provide nutrition or dietary information for people with kidney disease (of any type or stage). Apps were excluded from the study if access was prohibited due to password protection. Apps were evaluated by two dietitians and co-authors (KL and PO), one of whom is an experienced renal dietitian (KL).

**Evaluation of the apps**

Based on the study aims, the apps were evaluated in terms of their specific purpose, accuracy of the renal diet information, technical quality; and health literacy demand.

*Evaluation of the purpose of the app*

The purpose of the app was categorised into one of three categories based on the content of the app. These categories were (i) for educative purposes (e.g. provides information about the renal diet, or advice on how to self-monitor fluid or dietary intake) (ii) to provide food composition or recipe information (e.g. phosphorus content of a food or low electrolyte recipes), or (iii) to provide information to health professionals (e.g. dietary clinical practice guidelines, dietary clinical practice calculators or renal diet related journal apps). In addition to evaluating the purpose of the app content, other information such as a description of the app developer, platform and country of origin were also included in the evaluation.

*Evaluation of the accuracy of information within the app*

Information was considered accurate (evidence based), if the nutrient prescription and/or the dietary recommendations were consistent with the relevant national or international evidence-based guidelines for the dietary management of kidney disease. These evidence-based guidelines were used because they represented the most up to date recommendations for renal dietetic practice at the time of the study. Using an approach that was consistent with previous content analysis work, if the online information evaluated contained partially accurate and partially inaccurate information, then the information was classified as inaccurate.
Evaluation of app quality

App quality was evaluated using two tools. Firstly, the Silberg scale was used to assess the quality of the information contained within the app. Quality in the Silberg scale refers to the credibility (trustworthiness), transparency and currency of the health related information within the app. The Silberg scale contains nine items (see Figure 5.1) and allocates one point for each item. Each item on the Silberg scale is scored on a scale of 0 (present) or 1 (absent). A maximum score of 9 indicates the highest levels of credibility, transparency and currency.

The technical quality of the app was also evaluated using the Mobile Application Rating Scale (MARS), a multidimensional tool specifically designed to classify and assess the technical quality of health related apps. The tool evaluates the following four dimensions of (i) ‘app engagement’, (ii) ‘functionality’, (iii) ‘aesthetics’ and (iv) ‘quality of health information’. Each question is scored on a scale of 1 (inadequate) to 5 (excellent). Online training on the use of the tool was undertaken prior to app assessment.

Evaluation of the health literacy demand of renal diet information

In this study, ‘health literacy demand’ refers to the complexity or difficulty of the app, and evaluates the ability of the app user to understand the information within the app; and to easily navigate within the app to identify what they need to do, based on the information presented. In the absence of available validated tools that can be used to assess the health literacy demand of mobile apps, the engagement, aesthetics and functionality domains of the MARS tool were used to quantify the health literacy demand. These domains were chosen because they evaluate features such as the ability of the app user to understand the information within the app; and their ability to navigate the app, which are considered to best represent health literate apps. Scores for these domains were calculated as per the MARS method.

Statistical analysis

All data was analysed using SPSS Version 21 software (SPSS Inc., Chicago, Illinois, USA). Normality was assessed using the Shapiro Wilk Test. Independent t tests were used to compare Silberg scale and MARS scores between groups (such as mean engagement score between food and nutrition information and for educative purpose...
Fisher’s Exact test was used to determine the difference in proportion of accurate information between groups. A p value of p< 0.05 was considered statistically significant.

5.5. Results

A total of 1066 apps were identified using the keyword searches. After exclusion of duplicates and ineligible apps, a total of 21 apps were included for analysis (Figure 5.2).

Evaluation of the purpose of the app
Details regarding the final 21 apps evaluated are shown in Table 5.1 (A supplementary figure in the published version). The most common purpose of the renal diet apps evaluated was to provide food composition or recipe information (e.g. phosphorus content of a food or low electrolyte recipes; 12/21, 57.1%). This was followed by apps for educative purposes (e.g. provides information about the renal diet, or advice on how to self-monitor fluid or dietary intake; 8/21, 38.1%). Only one app, (Journal of Renal Nutrition), was designed to provide information to health professionals. When country of origin could be determined, all the apps (13/13) originated from the USA. The majority of apps were produced by commercial entities (19/21, 90.5%) at a median cost of $AUD 1.29 (interquartile range: $0-$2.49). Seven apps (33.3%) disclosed the source of their information and all sources were considered trustworthy and reliable (sources included nutrition textbooks, US government sources, reliable non-government organisations or journals).

Approximately half (11/21, 52.4%) of the apps were available on the Apple platform; and one third (7/21, 33.3%) were available on both Apple and Android platforms.

Evaluation of the accuracy of information within the app
Of the 21 apps evaluated only ten (47.6%, Table 5.2) were considered accurate and evidence based. There were no significant differences in the proportions of accurate evidence-based apps between apps that provided food composition or recipe information and those apps designed for educative purposes.
The quality scores for each of the apps are also shown in Table 5.2 (Silberg scale score, maximum score of 9). The mean Silberg scale score was 5.86 ± 1.1. The apps evaluated in this study scored well for: the provision of authorship details (mean score 2.38 ± 0.5, out of 3); and disclosure of ownership and sponsorship (mean score 1.9 ± 0.3, out of 2). In contrast, apps scored poorly for the criteria of attribution (i.e. disclosing the source of their information and providing references) (Table 5.2); with 15/21 (71.4%) apps scoring zero for this criteria. There were no significant differences in app quality scores between the apps that were designed for the provision of food composition or recipe information and those designed for educative purposes for either the total Silberg scale score or each of the sub scores.

Evaluation of the technical quality and health literacy demand of the app
Table 5.3 provides details of the scores for technical quality and health literacy demand. The mean MARS score was 3.19 ± 0.35 out of a possible score of 5. This score indicates that the technical quality of apps was considered acceptable. The scores for technical quality ranged from 2.6 (poor technical quality, Kidney Stone Remedies) to 3.8 (acceptable to good technical quality, My Food Coach). Seventeen of the 21 apps (80.9%) had a MARS score of 3 or more, indicating app technical quality that was considered acceptable as a minimum. There were no significant differences between these same groups for the total MARS score or each of the MARS sub scores. Overall the renal diet apps evaluated in this study scored in the good to excellent range for functionality (mean score 4.09 ± 0.61); and in the poor to fair range for engagement (mean score 2.47 ± 0.42); and aesthetics (mean score 2.89 ± 0.61).

The health literacy demand of renal diet apps is also shown in Table 5.3. The overall mean score of 3.15 ± 0.3 indicates that the apps evaluated have an acceptable health literacy demand. Fifteen of the 21 apps (71.4%) had a MARS score of 3 or more, indicating acceptable app complexity and reasonable ease of navigation. There were also no significant differences in the health literacy demand scores between apps designed for educative purposes and apps designed to provide food and nutrition information.
5.6. Discussion

Mobile health applications show great potential for engaging patients in their own self-management. Prior research has examined the impact of apps on renal dietary and clinical outcomes, as well as renal patient attitudes toward technology. However, unlike previous research, the current study focused on the purpose, accuracy, technical quality; trustworthiness and health literacy demand of renal diet apps. We found that renal diet apps were designed to provide information about food composition or recipe information or were for educative purposes. Overall the technical quality and health literacy demand of the apps were acceptable. However, more than half of the apps did not contain accurate, evidence based renal diet information.

Accurate and well-designed health information is essential for empowering and informing motivated patients about how to take a proactive role in the self-management of their health. The relatively small number of apps in this study that provided accurate renal diet information is similar to the findings of previous work, which examined the renal diet content of YouTube and websites. Analysis of 161 YouTube videos and 254 renal diet websites found that only 18% of YouTube videos and 73% of web based renal diet information was considered accurate (i.e. evidence based). To help overcome this, we agree with suggestions by previous authors, that health professionals (such as renal dietitians) should take a more proactive role in the development of renal diet apps. This will increase the likelihood that they are of good technical quality and accurate. The My Food Coach and H2O Overload apps in this study are examples of this and scored well for app quality.

Individuals with CKD have expressed a desire to use apps to manage their health, and are actively looking for health related information online. Attempts by individuals with CKD to use the apps they may find online, like those evaluated in this study, are potentially problematic. Since individuals with kidney disease are known to struggle with accessing and understanding different formats of health information, we suggest that health professionals should advise individuals with CKD that renal diet apps should be used with caution, since as described above many
are not evidence-based and can be regarded as unreliable sources of renal diet information.

Another confounding factor for patients using renal diet apps is the country of origin for the apps. All of the apps evaluated in this study were produced by U.S based entities and most used U.S food composition datasets. This is an important and serious limitation for users from non U.S. nations because it is well known that using non local data sources can produce significant errors in the assessment of nutrient composition. For example, there are important differences in the phosphate composition of packaged foods available in Australia as compared to the US. In addition, the differences in terminology and availability of common grocery items between different nations (e.g. Australia, the US and the UK), as described in renal diet apps, may also be problematic. The end result is that patients using renal diet apps may be left confused or even misled regarding appropriate renal diet food choices.

Inadequate health literacy is common in those with CKD and poorly designed health apps can serve as an additional barrier to individuals understanding or actioning health information. It is encouraging that the technical quality and health literacy demand of most renal diet apps in this study were considered acceptable, that is the apps were engaging, aesthetically pleasing and functional as determined by the MARS tool. However, this may not always be the case because app developers are not required to design ‘health literate’ apps. It would also be useful to incorporate health literacy principles, including gaining user feedback from people with CKD, and including patient feedback in the design of future renal diet apps. This is an important area for consideration because apps that are trustworthy and accurate, with information transparency, which are easy to adopt and use, are more likely to be ‘prescribed’ or recommended by renal dietitians and other health care professionals. Future research is required to fully elicit how people with CKD use technology, such as apps and the functionalities desired by users to assist them in their self-management tasks. Further research is also required on the utility of apps which contain features of interactivity, such as features that allow health professionals to view the dietary data entered by their patients in real time.
There are some limitations in the current study which need to be acknowledged. Some of the apps have been withdrawn (Lose Kidney Fat, Caution Calculator, Renal Touch) or have changed platforms since the evaluation (Renal Trakkr, KidneyDiet). It is also possible that since the time that the apps were evaluated, modifications or further changes to apps have occurred. Furthermore, the apps were restricted to those in the English language only, which may have limited the number of apps included in the analysis. Despite this however, we believe the searches were comprehensive because all apps stores allow developers to list multiple keywords when describing their app. Finally, although the search terms used to access the apps were piloted with a small number of CKD patients, they may not be representative of all people with kidney disease, especially those with inadequate health literacy.

Online information is unable and unlikely to ever replace personalised face to face, education. However, three quarters of Americans go online on a daily basis. We have constructed a summary table (Table 5.4) that outlines the characteristics of trustworthy, good quality, evidence based, renal diet apps that are of an acceptable technical quality. This is intended to assist those health professionals who have expressed a lack of confidence on how to instruct their patients to search for appropriate information online (including searches for renal diet apps). The recommendations in Table 5.4 utilise the results of the present study, as well as recently cited guidance on how to develop health literate apps. We believe this type of guidance may prevent the development of misconceptions that could occur if individuals with CKD use renal diet apps without appropriate instruction or advice.

**Practical Application**

A range of mobile health applications currently exist that may provide individuals with CKD with useful food and nutrition information or increase their knowledge of the renal diet. However, caution is required when recommending to patients that they use renal diet apps, because more than half of the apps reviewed were not accurate or evidence based.
Acknowledgements

Sincere thanks to Alex Koukomous and Lisa Mesiti for assistance with this project.

Support and financial disclosure:

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References


47. Stoyanov SR. MARS training video. 2015; [https://www.youtube.com/watch?v=25vBwJQIOcE](https://www.youtube.com/watch?v=25vBwJQIOcE), April 28, 2015.


Table 5.1. Description of renal diet apps evaluated (n=21).

<table>
<thead>
<tr>
<th>App title</th>
<th>Description according to manufacturer of app</th>
<th>Additional features or functions</th>
<th>Cost AUD</th>
<th>Country of origin</th>
<th>Developer</th>
<th>Organisation affiliation</th>
<th>Source of app information</th>
<th>Platform</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Apps for educative purposes (n=8)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absolute Healthy Diet Potassium Counter</td>
<td>Allows users to count and track daily intake of potassium from 'heart healthy' and 'not heart healthy' foods.</td>
<td>Dietary analysis, graphical display, 'heart healthy' scores for food items</td>
<td>$1.29</td>
<td>USA</td>
<td>First Line Medical Communications</td>
<td>Commercial</td>
<td>Not specified</td>
<td>Apple</td>
</tr>
<tr>
<td>Alkaline Diet Foods</td>
<td>Created for people with polycystic kidney disease or liver disease. Provides a searchable list of foods, chemicals, herbs and supplements that are 'harmful'.</td>
<td>Searchable listing of foods and ability to create ‘favourite foods’ list.</td>
<td>$1.29</td>
<td>Not stated</td>
<td>Danevas, LLC.</td>
<td>Commercial</td>
<td>Not specified</td>
<td>Apple</td>
</tr>
<tr>
<td>Choose this not that: for kidney stones (oxalate)</td>
<td>Nutrition guidelines for how to prevent and combat calcium oxalate kidney stones.</td>
<td>“My Profile” section enables user to input other comorbidities and the app then ‘tails’ nutrition suggestions</td>
<td>$4.88</td>
<td>USA</td>
<td>Personal Remedies, LLC.</td>
<td>Commercial</td>
<td>US government sources, including US Department of Agriculture and National</td>
<td>Apple/Android</td>
</tr>
</tbody>
</table>
 accordingly. Providers user with answers to questions such as ‘is this food good for me‘; has a graphical display of foods and voice recognition.

<table>
<thead>
<tr>
<th>Dealing With Kidney Stones</th>
<th>Provides info in ebook form on kidney stones and how to prevent or treat kidney stones through diet and herbal remedies.</th>
<th>Nil</th>
<th>Free</th>
<th>Not stated</th>
<th>Bigo</th>
<th>Commercial</th>
<th>Not specified</th>
<th>Blackberry</th>
</tr>
</thead>
<tbody>
<tr>
<td>H20 Overload</td>
<td>Designed for people with kidney disease, heart disease or hyponatraemia who are required to limit fluid intake.</td>
<td>“My Profile” enables the user to track fluid, weight, blood pressure; has a graphical display for weight and blood pressure; can also input and keep track of appointments</td>
<td>Free</td>
<td>USA</td>
<td>National Kidney Foundation (NKF)</td>
<td>Non-profit</td>
<td>Not specified</td>
<td>Android</td>
</tr>
</tbody>
</table>

Institute of Health
<table>
<thead>
<tr>
<th>App Name</th>
<th>Description</th>
<th>Cost</th>
<th>License</th>
<th>Source Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney Stone Natural Remedies</td>
<td>Contains list of natural remedies for kidney stones, describes mechanism of treatment and includes amounts to be taken per day.</td>
<td>Nil</td>
<td>Free</td>
<td>Not stated</td>
</tr>
<tr>
<td>Kidney Stone Remedies</td>
<td>Provides information on kidney stones and remedies.</td>
<td>Nil</td>
<td>Free</td>
<td>Not stated</td>
</tr>
<tr>
<td>Renal Touch</td>
<td>Intended for those on dialysis or soon to be on dialysis. Educates individuals through a Q&amp;A format in 8 areas of kidney health.</td>
<td>Nil</td>
<td>$2.49</td>
<td>Not stated</td>
</tr>
</tbody>
</table>

*To provide food composition or recipe information (n=12)*

<p>| Alkaline Diet Recipes        | Created for people with polycystic kidney disease or liver disease. Provides recipes to help maintain alkalinity, kidney and liver health.                                | $3.79    | Not stated | Danevas, LLC                                                                                                                                | Commercial | Not specified | Apple       |</p>
<table>
<thead>
<tr>
<th>Application</th>
<th>Description</th>
<th>Cost</th>
<th>Provider</th>
<th>App Store</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caution Calculator</strong></td>
<td>Created for users with chronic kidney disease (CKD). Allows user to track total daily calcium and phosphorus intake coming from food and medication. Also includes alternate food suggestions, foods to avoid and provides info on 'bad phosphorus'.</td>
<td>Free</td>
<td>USA Sanofi-Aventis Groupe</td>
<td>Commercial</td>
</tr>
<tr>
<td><strong>Choose this not that: Gout v2</strong></td>
<td>Provides nutrition info and recommendations on a number of foods to help prevent and manage gout, whilst taking into consideration other comorbidities.</td>
<td>$4.88</td>
<td>USA Personal Remedies, LLC.</td>
<td>Commercial</td>
</tr>
</tbody>
</table>

"My Profile" section enables user to input other comorbidities and the app then 'tailors' nutrition suggestions accordingly. Provides user with answers to questions such as 'is this food good for me'; has a graphical display of daily intake, notifications.
<table>
<thead>
<tr>
<th>Healthy Kidneys Grocery List</th>
<th>Provides users with a shopping list of foods to eat on a renal diet.</th>
<th>Shopping list; share lists via email</th>
<th>$2.49</th>
<th>Not stated</th>
<th>Bhavini Patel</th>
<th>Commercial</th>
<th>Not specified</th>
<th>Apple</th>
</tr>
</thead>
<tbody>
<tr>
<td>KidneyDiet®</td>
<td>Designed for individuals with CKD and end-stage renal disease (ESRD) (pre/post dialysis). Provides nutritional information for a range of foods, such as intake of phosphorus, potassium, protein, sodium and fluid, calories, carbs, cholesterol and fat. Allows users to track daily intake of Nutrients against recommended intake.</td>
<td>Dietary analysis, track fluid intake, share though email</td>
<td>Free</td>
<td>USA</td>
<td>Pain Free Living, Inc.</td>
<td>Commercial</td>
<td>Based on USDA database and ESRD guidelines</td>
<td>Apple</td>
</tr>
<tr>
<td>Kidney Diet Foods Checker</td>
<td>Database of over 6000 foods/meals with listing of relevant Nutrients (carbs, fat, protein, phosphorus, protein, sodium, potassium, water)</td>
<td>Favourite foods list</td>
<td>$2.49</td>
<td>USA</td>
<td>Mark Patrick Media, LLC.</td>
<td>Commercial</td>
<td>Not specified</td>
<td>Apple</td>
</tr>
<tr>
<td>App Name</td>
<td>Description</td>
<td>Price</td>
<td>App Store</td>
<td>Developer</td>
<td>License</td>
<td>Access</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Kidney Diet Recipes 100 Easy Meals</td>
<td>Provides recipes and nutritional information of foods suitable for a 'kidney diet'.</td>
<td>$2.49</td>
<td>USA</td>
<td>Mark Patrick Media, LLC.</td>
<td>Commercial</td>
<td>Apple</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lose Kidney Fat App</td>
<td>Provides 'How to' videos for kidney health. Also provides information on the kidney diet, healthy kidneys, drinking water, medicines for kidneys, 'do's and don'ts', water and weight loss.</td>
<td>$1.29</td>
<td>USA</td>
<td>Juan Catanach</td>
<td>Commercial</td>
<td>Apple</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My Food Coach</td>
<td>Provides recipes and food options for people with hypertension, diabetes, osteoporosis, CKD and those on dialysis.</td>
<td>Free</td>
<td>USA</td>
<td>NKF</td>
<td>Non-profit</td>
<td>Apple/ Android</td>
<td></td>
<td></td>
</tr>
<tr>
<td>App</td>
<td>Description</td>
<td>Features</td>
<td>Price</td>
<td>Country</td>
<td>Developer</td>
<td>Type</td>
<td>Origin</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Renal Trkrr</td>
<td>Allows people with CKD to track and share renal health information.</td>
<td>Dietary analysis; a graphical display of daily intake; and can share information from within the app via email</td>
<td>$9.99</td>
<td>USA</td>
<td>Mercy Nzeakor</td>
<td>Commercial</td>
<td>Not specified</td>
<td></td>
</tr>
<tr>
<td>Special Diet Recipes</td>
<td>Provides specialised recipes for people with kidney, diabetes and heart problems.</td>
<td>Ability to share recipes via social media</td>
<td>$1.07</td>
<td>USA</td>
<td>IE Imaging</td>
<td>Commercial</td>
<td>Recipes originate from the American Diabetes Association, Davita Dialysis and the American Heart Association</td>
<td></td>
</tr>
<tr>
<td>The Pocket Dietitian</td>
<td>Offers a personalised dietary prescription for people with diabetes, CKD, ESRD, hypertension, high cholesterol and obesity.</td>
<td>Dietary analysis; meal planner; alerts when daily limit is exceeded; graphical</td>
<td>Free</td>
<td>USA</td>
<td>Pocket Dietitian, Inc.</td>
<td>Commercial</td>
<td>Based on ADA, NKF, AHA and ADA guidelines</td>
<td></td>
</tr>
</tbody>
</table>
### Display of weekly and monthly nutrient intake; share analysis via email

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**For health professional purposes (n=1)**

| Journal of Renal Nutrition | Provides the latest professional research on renal nutrition science and renal dietetics. Appropriate for nutritionists, physicians and researchers working in Nephrology. | Enables the user to download the journal and read on your mobile device. Also contains supplementary content; in-app notifications; a personalised reading list function; add notes to articles function; and share articles via social media and email | Free | Not stated | Elsevier, Inc. | Commercial | Journal of Renal Nutrition | Apple |
---|---|---|---|---|---|---|---|---|
---

Abbreviations: AUD: Australian Dollar; ADA: American Diabetes Association; AHA: American Heart Association; CKD: chronic kidney disease; ESRD: end stage renal disease; info: information; N/A: not available; NKF: National Kidney Foundation; Q&A: question and answer
Table 5.2. Results of evaluation of app accuracy and Silberg scale scores

<table>
<thead>
<tr>
<th></th>
<th>Accurate # (evidence based)</th>
<th>Silberg scale Authorship (3)</th>
<th>Silberg scale Attribution (2)</th>
<th>Silberg scale Disclosure (2)</th>
<th>Silberg scale Currency (2)</th>
<th>Silberg scale score (0-9)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>For educative purposes (n=8)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absolute Healthy Diet Potassium Counter</td>
<td>No</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Alkaline Diet Foods</td>
<td>No</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Choose this not that: kidney stones (oxalate)</td>
<td>Yes</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Dealing with kidney stones</td>
<td>No</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>H20 Overload</td>
<td>Yes</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Kidney Stone Natural Remedies</td>
<td>No</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Kidney Stone Remedies</td>
<td>No</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Renal Touch</td>
<td>Yes</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td><strong>mean (SD) score</strong></td>
<td>-</td>
<td>2.25 ± 0.46</td>
<td>0.38 ± 0.74</td>
<td>1.88 ± 0.35</td>
<td>1.13 ± 0.35</td>
<td>5.53 ± 1.06</td>
</tr>
<tr>
<td>Application</td>
<td>Accurate # (evidence based)</td>
<td>Silberg scale Authorship (3)</td>
<td>Silberg scale Attribution (2)</td>
<td>Silberg scale Disclosure (2)</td>
<td>Silberg scale Currency (2)</td>
<td>Silberg scale score (0-9)</td>
</tr>
<tr>
<td>-------------------------------------------------</td>
<td>-----------------------------</td>
<td>-------------------------------</td>
<td>-------------------------------</td>
<td>-------------------------------</td>
<td>-------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Alkaline Diet Recipes</td>
<td>No</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Caution Calculator</td>
<td>Yes</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Choose this no that: Gout v2</td>
<td>Yes</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Healthy Kidneys Grocery List</td>
<td>No</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>KidneyDiet®</td>
<td>Yes</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Kidney Diet Foods Checker</td>
<td>No</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Kidney Diet Recipes 100 Easy Meals</td>
<td>No</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Lose Kidney Fat App</td>
<td>No</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>My Food Coach</td>
<td>Yes</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Renal Trkrr</td>
<td>No</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Application</td>
<td>Accuracy</td>
<td>Silberg scale Authorship</td>
<td>Silberg scale Attribution</td>
<td>Silberg scale Disclosure</td>
<td>Silberg scale Currency</td>
<td>Silberg scale score</td>
</tr>
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<td>-------------------------------------</td>
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<td>--------------------------</td>
<td>---------------------------</td>
<td>--------------------------</td>
<td>------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Special Diet Recipes</td>
<td>Yes</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>The Pocket Dietitian</td>
<td>Yes</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>1</td>
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<td>1.92 ± 0.29</td>
<td>1 ±0</td>
<td>5.83 ± 0.94</td>
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<td></td>
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<td>2</td>
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<td>0.52 ± 0.87</td>
<td>1.9 ± 0.3</td>
<td>1.05 ± 0.2</td>
<td>5.86 ±1.1</td>
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Accuracy refers to consistency of information and messages with evidence-based guidelines for the management of kidney disease.

Authorship: refers to naming of authors with their affiliations and credentials provided; Attribution refers to information sources named and references given or hyperlinked; Disclosure refers to whether details regarding the ownership of the app is specified and any sponsorship is disclosed; Currency refers to the presence of details naming the date of last modification and whether it has been modified in the month prior to assessment.
Table 5.3. Technical quality and health literacy demand of renal diet apps (n=21).

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<th>MARS aesthetics score (5)</th>
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<td>3</td>
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<td>4</td>
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For health professional purposes (n=1)

| Journal of Renal Nutrition                      | 2.4                       | 4.5                           | 3.3                       | 4.5                        | 3.7                              | 3.4                              |
| Total mean (SD) score                           | **2.47 ± 0.42**            | **4.09 ± 0.61**               | **2.89 ± 0.61**           | **3.34 ± 0.90**             | **3.19 ± 0.35**                  | **3.15 ± 0.3**                   |
MARS: Mobile Application Rating Scale; SD: standard deviation

Health literacy demand scores are the sum of the engagement, aesthetics and functionality domains of the MARS tool converted to score out of 5 according to the MARS method (46).
Table 5.4. Characteristics of good quality renal diet apps.

- The information is accurate and evidence based:
  a. It is written or created by Dietitians, credible non-government medical organisations (e.g. the National Kidney Foundation), Academic institutions (e.g. universities) or Government bodies (e.g. Department or Ministry of Health)
  b. Provides advice or information with references to scientific research results, reliable and reputable food and nutrition databases or evidence-based guidelines

- The app contains information that is of high quality:
  a. The information is current e.g. the date of creation or release and the most recent update is disclosed
  b. The intended target audience and the purpose of the app is described
  c. The app discloses the authors of the information with their credentials and affiliations
  d. The app does not refer to, or use anecdotal evidence to justify any suggested changes
  e. The app should be written in plain language using common everyday words where relevant and in short paragraphs
  f. The app does not contain within app pop ups, distracting visuals, poor resolution images, varying fonts or has a cluttered layout
  g. The app should not contain an overwhelming amount of information and the app is easy to use and navigate

- If the app is designed for educative purposes, the information provides specific details in layman’s terms about how to incorporate the dietary changes suggested into existing eating habits or into social eating occasions i.e. it is understandable and actionable:
  a. Explains why particular foods may need to be avoided or restricted
  b. The information contains clear instructions on what actions the person needs to take, in layman’s terms, with specific food or menu examples
  c. The information contains clear instructions on when dietary changes are required, in layman’s terms, with specific food or menu examples
Figure 5.1. Items contained within the Silberg scale (and adapted to the evaluation of apps)

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Figure 5.2. Flowchart of renal diet app selection.
CHAPTER 6: Comprehension of renal diet information

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

Authors:

Kelly Lambert, Department of Clinical Nutrition, Wollongong Hospital, Illawarra Shoalhaven Local Health District, New South Wales, Australia and School of Medicine, Faculty of Science, Medicine and Health, University of Wollongong, New South Wales, Australia

Kylie Mansfield, Graduate Medicine, Faculty of Science, Medicine and Health, University of Wollongong, New South Wales, Australia

Judy Mullan, Graduate Medicine, Faculty of Science, Medicine and Health, University of Wollongong and Director Centre for Health Research, Australian Health Services Research Institute, University of Wollongong, New South Wales, Australia
6.1 Executive Summary

The studies described in the previous chapters have identified that (i) adherence to the dietary self-management recommendations are suboptimal (ii) cognitive impairment and inadequate health literacy are common in adults with ESKD and (iii) the health literacy demand of online renal diet information is generally high.

The Health Literacy Skills Framework suggests that the comprehension of information, which for this thesis is renal diet information, involves learning two important elements: what the diet consists of, as well as how to apply the renal diet information/advice received. Comprehension of information is shaded in yellow on the HLSF theoretical framework included below.

Chapter 6 reports on a qualitative study which explored factors that impact on the comprehension of dietary self-management advice from the perspective of the patient and/or carer. To achieve this semi structured interviews were conducted using a Sensemaking methodology \(^1\).

The recruitment strategy of purposive sampling was chosen to ensure that a diverse range of patient experiences were represented (based on the demographic
characteristics of individuals), and more specifically, that the perspectives of patients from metropolitan, regional, and rural areas in the health district were included. The aim of the sampling strategy was to achieve data saturation across the entire participant sample and not according to the stage of CKD. The results were derived using the Framework Approach. This approach enables the researcher to explore the data in depth while simultaneously maintaining a transparent audit trail, which enhances the rigour of the analytical processes and the credibility of the findings.

The citation for the accepted version is:


References:


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

6.2 Abstract

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

Methods: The aims of this study were to (i) describe the experiences of CKD patients 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 CKD patients and 10 carers were conducted, using interview questions guided by Sensemaking theory.

Results: Six themes emerged from the data which did not differ according to CKD stage, geographic location or 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.

Keywords: carer, chronic kidney disease, patient, qualitative exploration, renal diet
6.3 Introduction

A key part of the management of Chronic Kidney Disease (CKD) is dietary modification because changes in diet can delay CKD progression and ameliorate the complications of CKD. Other consequences of non-adherence to the dietary self-management recommendations include potentially life threatening hyperkalemia; pulmonary oedema; bone demineralisation; neuromuscular complications; malnutrition and an overall increase in hospitalisations and mortality. Successful dietary self-management and adherence to the appropriate evidence based practice dietary recommendations help to reduce complications and improve patient outcomes.

The dietary prescription for CKD is multifaceted, and the dietary prescription differs between the different stages of CKD. When End Stage Kidney Disease (ESKD) is reached, the dietary prescription also varies between the different renal replacement therapy options. Unfortunately, because of the multifaceted changes to the renal diet, patients with renal disease are often faced with complex decisions about which foods they can or can’t eat on a regular basis. The complexity of the dietary prescription is further exacerbated, if the patient has diabetes or takes warfarin, both of which require further dietary modifications. Because of these challenges, the diet for people with CKD, inclusive of ESKD, is considered to be one of the most complex, restrictive and challenging therapeutic diets.

LITERATURE REVIEW

There is limited information about how patients learn and then apply the advice provided to them about the renal diet. The research available is mostly qualitative in nature and dominated by haemodialysis patients. In these studies, patients have reported that the renal diet is difficult to understand and implement, yet few studies have explored why this is the case. In one of the largest studies to date, 100 patients with CKD reported that they preferred to learn about the renal diet from dietitians and valued receiving a range of patient education resources. However, this study did not explore their experiences of learning, nor how they make sense of and apply renal diet information. Similarly, research on how carers of CKD patients support learning and implementation of the renal diet is also scarce. This is
surprising given that in several quantitative studies, carer and family support has been associated with higher dietary adherence, better diet quality, lower interdialytic weight gains, and improved potassium and phosphate levels.

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

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

Data collection: This qualitative study assumed a relativist ontological position and utilised the ‘Sensemaking’ theoretical framework to construct the semi-structured interview guide (shown in Table 6.1). The focus of ‘Sensemaking’ theory is the exploration of how individuals fill the ‘gaps’ in their understanding when they
encounter situations or information that they do not understand (that is situations or information that does not ‘make sense’). The emotions associated with the ‘Sensemaking’ process, and the nature of the ‘help’ that is provided to the individual to facilitate ‘Sensemaking’ are of particular interest. ‘Sensemaking’ theory can therefore help to obtain useful information about how patients and their carers experience, learn and use the dietary education provided to them about the renal diet.

The individual semi-structured interviews were conducted by the first author, either in person at the renal unit of the patient’s choice or via the telephone. Interviews with patient – carer dyads were conducted at the same time. The semi-structured interview questions were not pilot tested prior to data collection. However, prompt questions (shown in Table 6.1) were used in all interviews to ensure that all participants were prompted in a similar manner. Participant checking of the transcripts was invited but no participant wished to do so. Information regarding patient demographics, stage of kidney disease and duration of renal replacement therapy role were obtained directly from patients and carers during the interviews. Participant recruitment ceased when no new concepts or themes were described by study participants in subsequent interviews (i.e. data saturation was reached). This is in keeping with the literature relating to data saturation in qualitative research that indicates data saturation is reached when interviews contain abundant and repeated accounts of the same phenomenon of interest. This study was approved by the joint University of Wollongong Human Resource Ethics Committee (Application number HE2016/314).

**Data analysis:** Interviews were audiotaped and transcribed verbatim for analysis. Dedoose software was used to manage, store the coding index and code the data. In keeping with the Framework approach used to guide the thematic analysis, line by line coding of the transcripts was conducted by each of the authors, who formed their own initial codes. All authors then met to compare and refine these codes (core concepts) and to organise them into the initial categories. These categories were then further refined via an iterative discussion between the authors to produce the final analytical framework. This analytical framework was then applied to the transcripts and facilitated the identification of the main themes. This process was used to enhance study rigor and to ensure that the analysis reflected the full range and
breadth of data. Illustrative quotes that best captured the essence of the main themes were identified by the main author and the final quotations included in the final manuscript were agreed upon by all authors.

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

The majority of patients (n=21, 81%) reported that the dietitian was the first source of renal diet information. Other details regarding the characteristics of the patient participants are shown in Table 6.2. In brief, over half of the patient participants were undertaking a renal replacement therapy (n=15, 58%) and were male (n=15, 58%). Their median age was 66 years (IQR: 62.75-76 years), with a wide age range (30-86 years). The geographic location of patients was spread evenly across metropolitan (n=8), regional (n=10) and rural (n=8) areas. For those patient participants undertaking a RRT, the majority (n=19, 73%) had more than 6 years’ experience of the RRT; and five of them (19%) had undertaken more than one type of RRT. Interview times ranged from 13 minutes to more than 1.5 hours, with a mean interview length of 30 minutes.

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

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

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

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

> “Diabetes I can understand. Heart I can understand. Kidneys I got no clue”  
> (P11, CKD3b)

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

> “I went out (of the appointment) and my head was just …spinning …I was unprepared and had no idea what to expect” (P10, CKD5)

> “You had to be aware of so many different things…I was very overwhelmed”  
> (Carer P2, HD)

Frustrations regarding the renal diet were attributed to: not receiving helpful advice; perceiving that they had a limited range of foods to consume; receiving didactic advice with no explanation or rationale; and/or receiving dietary advice that included foods or ingredients unfamiliar to them.

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

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

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

Participants also described feeling frustrated about receiving conflicting renal diet advice, from many sources which included patient education sheets, other health practitioners (e.g. doctors and nurses); family and friends; other CKD patients, and the internet. Participants suggested that this conflicting advice contributed to their confusion and/or anxiety, and often left them with more questions than answers.
In addition to feeling overwhelmed and frustrated, patients and carers described feeling fearful about the renal diet. Patients feared that they would consume the ‘wrong’ food, and carers feared that they would serve the ‘wrong’ food.

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

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

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

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

Others perceived that their dietary restrictions contributed to social isolation.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Some participants also felt that the dietetic advice and meal plans lacked individualisation, and that this too hindered sense making.
“I just feel like …the advice is not personalised …so more individualisation is needed” (P19, KT)

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

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

**Theme 4: Carer support is important**

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

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

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

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

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

**Theme 5: Developing problem solving strategies**

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

“We have had to become foodies...because you have got to know what is in it”
Some participants created their own informal peer networks, and used these interactions to discuss the challenges of the diet, and to obtain and share information, such as recipes, food lists and menu ideas. They shared their menu ideas or food lists with family, friends or colleagues to facilitate social eating occasions.

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

Searching for renal diet information on the internet was a strategy described by almost all participants, regardless of their age, gender and/or stage of CKD. They searched online to obtain additional practical information (such as recipes, food lists and meal ideas) and to fill their renal diet knowledge gaps. The internet was described by many participants as the first place they looked for information when told they needed to follow a special diet.

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

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

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

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

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

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

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

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

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

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

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

“It is a matter of experimenting over a long time and testing what you can eat”

(P16, CKD4)

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

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

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

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

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

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

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

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

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

One of the key findings from this study was that there is a long lasting emotional impact that results from receiving renal diet advice, and an ongoing emotional burden associated with applying this advice. Similar to previous research \(^{40-43}\), patients felt poorly equipped to deal with the challenges and complexity of dietary changes required. Interestingly, the emotional experience of carers was similar to that of patients. This finding appears to be novel in the context of dietetic advice, but is similar to previous work by others investigating psychological adaptation to self-management in CKD or other chronic illness contexts \(^{44-49}\). However, participants in this study also described moving on from feeling overwhelmed and frustrated, to accepting that the diet was important to maintain their health and developed strategies enabling them to apply the renal diet to their everyday lives. These are important findings for clinicians because being attentive to the how a patient and their carer may be feeling has been associated with positive clinical benefits \(^{50}\). Being attentive to the emotional state of patients and carers will also influence the timing, content and teaching techniques used by clinicians in their renal diet education \(^{51}\).

Three factors were identified in this study as important facilitators of renal diet sensemaking. The first was input from the dietitian, which is consistent with previous work where dietitians were identified as a preferred and trustworthy source of renal diet information \(^{19,24}\). However, this study extends the evidence base by highlighting that it is not only the dietary information that facilitates sensemaking about the renal diet, but also the reassurance and empowerment that is provided. The importance of carer support was the second facilitator to renal diet sensemaking identified in this study. Carers facilitated and supported health decisions relating to the renal diet, and assisted with learning when memory loss or information overload was experienced.
by the patient. Furthermore, carers also assisted with shopping and meal planning decisions. These findings suggest that to facilitate sensemaking for patients, it is important for dietetic services to be attentive to meeting the renal diet information needs of carers\textsuperscript{52,53}, by routinely inviting and involving them in education sessions\textsuperscript{19}. Specific carer training about the renal diet (such as cooking or meal preparation classes) may also be of use, because it may help to reduce carer burden and improve psychosocial outcomes for both patients and carers\textsuperscript{54,55}. The third facilitator of renal diet sensemaking, identified in the current study, involved the use of strategies to solve renal diet related problems. Some of these problem solving strategies, concur with evidence in the literature, such as feedback from blood tests\textsuperscript{56}, and experimentation\textsuperscript{57}. However, using peers to assist with sensemaking and as a source of practical renal diet advice; developing their own individualised resources; and the use of online resources and technology to assist with sensemaking are new findings. These findings also highlight the need for dietitians (or other clinicians who may be responsible for providing dietary advice to patients with CKD) to be vigilant about what their patients have learned from their peers, how they have individualised their resources and which online resources/technologies they are using. Furthermore, since the quality and accuracy of online renal diet information is highly variable\textsuperscript{58,59} we suggest that clinicians provide guidance about where to locate accurate, reliable and good quality renal diet information, as well as useful and appropriate forums or blogs for interested patients and carers.

The advantage of using Sensemaking theory to guide the semi-structured interview questions is that it helped to identify complexity of the renal diet as a key barrier to sensemaking. This is consistent with previous research which described patients’ difficulties with understanding the health information provided\textsuperscript{60-62}. In addition to the complexity of the diet, patients and carers in the current study described receiving renal diet information that was confusing and contradictory. Some of the difficulties experienced by patients when interpreting messages on diet sheets, could be attributed to the high level of cognitive impairment in patients with CKD\textsuperscript{63}; as well as low health literacy experienced among this patient population\textsuperscript{60,64}. To address potential barriers to sensemaking and difficulties with the interpretation and application of the renal diet that may be due to inadequate health literacy, we recommend incorporating several rounds of teachback\textsuperscript{65} during education sessions to...
evaluate recall, and to ascertain understanding of important or complex concepts 66-70. Other strategies to address health literacy related barriers, include using plain language for all verbal and written communications, which will assist with patient empowerment 71, and adherence to recommendation 72, 73.

Other barriers identified by participants in this study, included perceptions that they had not received adequate individualised practical dietary advice, and that they had difficulties prioritising various components of the renal diet. These findings are similar to those described by previous researchers 23, 24, 43, 56, 61. However, what is novel about the present study findings is that the use of ‘signposting’ could help to overcome these barriers. Signposting could be used to structure dialogue enabling patients and carers to follow where the conversation is going and why 74, 75.

Participants wanted clinicians to explicitly describe or ‘signpost’ elements of the diet or dietary prescription that were considered important for them. Other information that could be signposted included advice about how to eat out, how to include favourite foods, how to combine and manage multiple diet prescriptions (for example the renal and diabetic diet prescriptions), and when and where to go for further information. Further studies evaluating the impact and efficacy of using signposting during patient education encounters are required.

**IMPLICATIONS FOR PRACTICE**

Several recommendations were suggested by participants in the present study to facilitate renal diet sensemaking. For instance, they suggested reassurance from the dietitian to confirm and verify their understanding of important renal diet related concepts was important. Participants also suggested that patient education resources be available in formats which were easy to read and understand with illustrations to facilitate sensemaking. The evidence substantiates that utilising these formats for patient education resources are particularly effective, and have been shown to be superior to traditional methods of instruction 52, 53, 76-78.

Access to peers for support and to facilitate learning about the renal diet were suggested by participants in the present study. Clinicians should therefore consider how to utilise the expertise of peers, not only because it is important to patients 23, 79, but also because they are considered integral components of effective educational
interventions in patients with CKD \textsuperscript{80}. Other suggestions included a desire for clinicians to provide a clear explanation and rationale for the dietary changes, as well as providing guidance about how to manage multiple therapeutic diets (when appropriate).

Another recommendation borne out of the present study findings is to ensure that renal dietary advice is understandable and actionable. Clinicians, such as dietitians, could therefore better support patients to translate information about the renal diet by utilising additional strategies to promote sensemaking and to increase patient and carer knowledge and understanding \textsuperscript{71}. This could be facilitated by using question prompt sheets prior to and during the appointment \textsuperscript{81, 82}; and by discussing appropriate information seeking practices with patients and carers \textsuperscript{83}. Reviewing the need for additional advice and education at an important renal diet transition point, such as when commencing a new RRT, is also recommended. Moreover, multifaceted methods of interaction, such as using both verbal and written communication when delivering the information, in conjunction with phone follow up, and practical group work or workshops should also be considered because these are effective methods for empowering CKD patients and delivering educational interventions \textsuperscript{80}.

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

**CONCLUSION**
Dietary modification is fundamental to the management of CKD. The findings from this study highlight that the experience of learning to interpret and apply renal diet advice is complex, challenging and accompanied by an ongoing emotional burden for patients and carers. Patients and carers value the expertise of the dietitian, but also needed to develop a range of their own problem-solving strategies, over time, to make sense of the renal dietary advice. It is suggested that additional strategies be incorporated into the patient education and counselling process to help future patients and carers to make sense of the renal diet.

**ACKNOWLEDGEMENTS**
Thank you to the patients and carers in this study, some of whom travelled a great distance to share their experiences and expertise. Their commitment to improve services for others is greatly appreciated.

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

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

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35. Godbold NJ. Patterns in sense making interactions: how people make sense of kidney failure in online renal discussion groups.: University of Technology, Sydney Australia. ; 2013.
Table 6.1. Semi structured interview guide based on Sensemaking methodology (34)

<table>
<thead>
<tr>
<th>Describing an experience related to learning about the renal diet</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would like you to think back to a time that really stands out</td>
</tr>
<tr>
<td><strong>Prompts:</strong></td>
</tr>
<tr>
<td>a. What was the reason you were given renal diet advice?</td>
</tr>
<tr>
<td>b. Who gave you the advice?</td>
</tr>
<tr>
<td>c. Where did you go to get the advice?</td>
</tr>
<tr>
<td>d. Was there anyone else there with you?</td>
</tr>
<tr>
<td>e. Were you given anything at the time to help you understand? pamphlet? diet sheet?</td>
</tr>
<tr>
<td>f. How did the experience make you feel?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Describing aspects that facilitated or were barriers to sensemaking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was there any part of the experience of receiving the dietary advice that you found reassuring or helpful to you or your carer?</td>
</tr>
<tr>
<td><strong>Prompts:</strong></td>
</tr>
<tr>
<td>a) What information were you given? In what format?</td>
</tr>
<tr>
<td>b) What were the consequences of being give this?</td>
</tr>
<tr>
<td>c) Did this (name the part) affect the way you followed your diet?</td>
</tr>
<tr>
<td>d) How did (name part or person giving that advice) help / facilitate (and how did that help?)</td>
</tr>
<tr>
<td>e) Was there anything that (name part or person giving that advice) did that hindered following the advice? (and how did it do this?)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Verbalizing the gaps and struggles regarding the sensemaking process</th>
</tr>
</thead>
<tbody>
<tr>
<td>What were the big questions that you were left with as a result of the dietary advice?</td>
</tr>
<tr>
<td><strong>Prompts</strong></td>
</tr>
<tr>
<td>a. What were you trying to figure out?</td>
</tr>
<tr>
<td>b. What did you struggle with?</td>
</tr>
<tr>
<td>c. Was there anything you were left trying to understand?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tapping into emotions associated with sense making</th>
</tr>
</thead>
<tbody>
<tr>
<td>How did this experience (of receiving the dietary information) make you feel?</td>
</tr>
</tbody>
</table>
**Prompts:**

a. What emotions did you have at the time?
b. Was it related to the experience?
c. What conclusions do you come to from this situation?
d. How did you come to those conclusions?

**Recommendations and suggested solutions to improve sensemaking**

What feedback can you offer us so we can improve things? If you could wave a magic wand what would have helped you?

**Prompts:**

a) What was missing from the renal diet advice experience that you had?
b) How did that stop you from following the advice?
c) Was there anything else that was limited, incomplete or not effective or not helpful?
d) What could make a difference?
e) Was there anywhere else that you looked or talked to for renal diet advice?
f) Was there anyone else you talked to, to help you make sense of the advice?
g) How did that help? What did they do that helped you understand?
Table 6.2. Characteristics of patient participants in the study

<table>
<thead>
<tr>
<th></th>
<th>Number of participant n=26</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (male, %)</td>
<td>15 (58%)</td>
</tr>
<tr>
<td>Median (interquartile range) age in years</td>
<td>66.0 (62.75-76.0)</td>
</tr>
<tr>
<td>Age range of participants in years</td>
<td>30-86</td>
</tr>
<tr>
<td>Age category of participants</td>
<td></td>
</tr>
<tr>
<td>30-39 years</td>
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</tr>
<tr>
<td>40-49 years</td>
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</tr>
<tr>
<td>50-59 years</td>
<td>3</td>
</tr>
<tr>
<td>60-69 years</td>
<td>9</td>
</tr>
<tr>
<td>70-79 years</td>
<td>9</td>
</tr>
<tr>
<td>80+ years</td>
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</tr>
<tr>
<td>Marital status of participants</td>
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<tr>
<td>Married / Defacto</td>
<td>21</td>
</tr>
<tr>
<td>Single</td>
<td>2</td>
</tr>
<tr>
<td>Widow</td>
<td>0</td>
</tr>
<tr>
<td>Divorced</td>
<td>3</td>
</tr>
<tr>
<td>Geographic location of participants</td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>8</td>
</tr>
<tr>
<td>Regional</td>
<td>10</td>
</tr>
<tr>
<td>Rural</td>
<td>8</td>
</tr>
<tr>
<td>Stage of CKD / RRT modality</td>
<td></td>
</tr>
<tr>
<td>Predialysis (CKD stage 4 or 5)</td>
<td>9</td>
</tr>
<tr>
<td>Hospital centre based haemodialysis</td>
<td>6</td>
</tr>
<tr>
<td>Home haemodialysis</td>
<td>2</td>
</tr>
<tr>
<td>Peritoneal dialysis</td>
<td>4</td>
</tr>
<tr>
<td>Kidney Transplant</td>
<td>3</td>
</tr>
<tr>
<td>Early CKD (CKD stage 1 or 2)</td>
<td>2</td>
</tr>
<tr>
<td>Have undertaken more than 1 type of RRT</td>
<td>5</td>
</tr>
<tr>
<td>Number of participants receiving diet advice in prior 6 months</td>
<td>8 (31%)</td>
</tr>
<tr>
<td>Median duration of RRT (years, interquartile range)</td>
<td>7 (5-11)</td>
</tr>
<tr>
<td>Years of RRT</td>
<td></td>
</tr>
<tr>
<td>0-1 year</td>
<td>1</td>
</tr>
<tr>
<td>1-5</td>
<td>3</td>
</tr>
<tr>
<td>6-10</td>
<td>6</td>
</tr>
<tr>
<td>&gt;10</td>
<td>5</td>
</tr>
</tbody>
</table>
CHAPTER 7: Ecological influences on health literacy and health outcomes

Title: A qualitative exploration of the experiences of renal dietitians and how they help patients with kidney disease to understand the renal diet

Authors:

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7.1. Executive Summary

Chapter 6 provided evidence that adults with ESKD and their carers found renal dietary advice they received to be overwhelming, frustrating and emotionally challenging. They also described a range of problem-solving strategies they utilised to help them make sense of their renal diet advice.

The Health Literacy Skills Framework (shown below), suggests that comprehension of renal diet advice may be impacted by ecological factors such as the health care system or the health professionals they interact with (shaded in orange below).

Chapter 7 explores the experiences of dietitians, as well as the strategies they use, to provide dietary self-management advice to adults with ESKD. This was achieved by using semi structured interviews with dietitians based on a Sensemaking methodology. Results were again derived using the Framework Approach. This approach enables the researcher to explore the data in depth while simultaneously maintaining a transparent audit trail, which enhances the rigour of the analytical processes and the credibility of the findings.
Chapter 7 was submitted to Nutrition and Dietetics on February 8, 2018 as:

**Lambert K**, Mansfield K, Mullan J. A qualitative exploration of the experiences of renal dietitians and how they help patients with kidney disease to understand the renal diet, submitted to the *Nutrition and Dietetics*,

The citation for the accepted version is:

**Lambert K**, Mansfield K, Mullan J. A qualitative exploration of the experiences of renal dietitians and how they help patients with kidney disease to understand the renal diet, *Nutrition and Dietetics*, Accepted for publication May 24, 2018, DOI: 10.1111/1747-0080.12443

**References:**


A qualitative exploration of the experiences of renal dietitians and how they help patients with kidney disease to understand the renal diet

7.2. Abstract

Aim: Dietary modification is integral to the management of end stage kidney disease. However, adherence to the renal diet is poor. Few studies have explored the perspectives of renal dietitians and how they work with patients to facilitate dietary change. The objectives of this study were to explore the experiences of renal dietitians about educating patients with end stage kidney disease; and to describe the strategies perceived to help patients understand the renal diet.

Methods: Semi structured interviews based on Sensemaking theory were conducted with renal dietitians (n=27) working in Australia and New Zealand from a range of metropolitan, regional and remote areas.

Results: Five major themes across two categories were derived from the data. The renal dietitians in this study experienced feelings of frustration, frequently worked in practice environments with limited or inadequate resources and perceived that establishing trust and demonstrating empathy were important to sense making. Renal dietitians helped patients make sense of and understand the diet by clarifying ambiguities and conflicting information; and simplifying complexity by using simple explanations, individualised advice, and practical support. These strategies were considered critical to the renal diet sense making process.

Conclusions: The experience of providing renal diet advice to adults with end stage kidney disease was emotionally and professionally challenging. Alternative approaches to patient education may help dietitians to empower patients to better understand the renal diet. Further research exploring the experiences of learning about the renal diet from the patient and carer perspective would also help inform future alternative approaches.

Keywords: end stage kidney disease, qualitative research, renal diet, renal dietitian, treatment adherence.
7.3. Introduction

At least one in ten adults globally has Chronic Kidney Disease (CKD).\(^3\) Approximately 2\% of patients with CKD will progress to end stage kidney disease (ESKD).\(^4\) Dietitians play a key role in educating patients with ESKD about adherence to their renal diet,\(^5\) which can help to slow disease progression,\(^6\) mitigate against complications and increase survival.\(^7\),\(^8\) However, the process of educating ESKD patients about their renal diet is complicated by the need to modify many nutrients simultaneously, as well as ongoing changes to the diet prescription over time. Other factors likely to negatively impact on a patient’s ability to comprehend and self-manage their diet include; the presence of cognitive impairment,\(^9\),\(^10\) inadequate health literacy,\(^11\) fatigue,\(^12\) and depression.\(^13\)

A recent review of 60 studies in adults with ESKD found that adherence to the renal diet was as low as 31.5\%.\(^14\) Multiple factors contribute to non-adherence, and as identified by a systematic review of 46 qualitative studies, these may include that patients find the renal diet to be burdensome, challenging and overwhelming.\(^15\) This evidence primarily focuses on the patient and carer perspective, however and little is known from the perspective of the dietitians. The aims of this qualitative study therefore, were to (i) explore the experiences of renal dietitians regarding the process of educating patients with ESKD and (ii) to describe the strategies they perceived to help patients understand the renal diet to support adherence.

7.4. Methods

Renal dietitians, working in all states and territories of Australia and New Zealand, were invited to participate in the study via professional dietetic and nephrology networks. This recruitment strategy was chosen to help ensure a diverse range of professional experiences among study participants from metropolitan, regional and remote areas. A purposive sample of renal dietitians (defined as individuals working predominantly with adults with kidney disease) who worked in these different geographical locations were approached via email by the main author (an experienced renal dietitian).
This study assumed a relativist ontological position, and utilised the ‘Sensemaking’ theoretical framework and methodology to construct the semi-structured interview guide (Table 7.1). The questions used in the interview guide are considered core questions in Sensemaking theory and the only adaptations to these questions were the insertion of reference to the renal diet. The Sensemaking theoretical framework uses dialogue to explore the expertise that individuals develop over time when they encounter situations or information that does not ‘make sense’. Thus, Sensemaking theory was used to explore both the experiences of dietitians, and the strategies they use to help patients comprehend and apply renal diet advice.

The semi-structured interviews lasted 30-60 minutes and were conducted in person or via the phone by the main author. Interviews were audiotaped and transcribed verbatim for analysis. No repeat interviews were undertaken. Participant checking of the transcripts was invited but no participant wished to do so. Field notes describing participant demographics, practice location, staffing ratios, level of dietetic experience, and the general context of the renal dietitian role were obtained from all participants and recorded during the interviews. Participant recruitment ceased when no new themes or concepts were described by dietitians in subsequent interviews. This is in keeping with the literature relating to qualitative research that indicates theoretical data saturation is reached when interviews contain abundant and repeated accounts of the same phenomenon of interest. The distribution of themes across characteristics such as level of dietetic experience and geographic location were achieved using discussion and a consensus approach.

This study was approved by the joint University of Wollongong / Illawarra Shoalhaven Local Health District Human Research Ethics Committee. All data was treated confidentially and to preserve anonymity, direct quotes are accompanied by limited demographic information, such as Dietitian participant number, and the geographic location of their practice (e.g. Metropolitan, Regional or Remote). Details of the study design and analysis are reported according to the COREQ guidelines for the reporting of qualitative research.

Analysis of the transcripts was conducted using the Framework method, The initial step involved line by line coding of the transcripts by all authors, who formed
their own initial codes. These codes were then compared and synthesized by all authors and refined to produce the final analytical framework. This framework was then applied to the transcripts and facilitated the identification of the main themes via an iterative discussion by all authors. This process was used to enhance study rigor and to ensure that the analysis reflected the full range and breadth of data. Illustrative quotes that best captured the essence of the main themes were identified by the main author and the final quotations included were agreed by all authors.

7.5. Results

Descriptive characteristics of the 27 renal dietitians interviewed in the study are shown in Table 7.2. Participants were predominantly female (92.5%), with a mean age of 43.1 years (range 27-59), and most had extensive dietetic and renal dietetic experience. Participants worked in a variety of geographic locations, and approximately half worked full time in nephrology and practiced in a metropolitan area. The case mix of patients seen by the study participants was dominated by those at the predialysis stage or individuals undertaking haemodialysis.

Analysis of the data yielded five themes across two categories: experiences of providing dietary advice and strategies perceived by dietitians to help patients understand the renal diet. These themes did not differ according to the geographical location of the dietitian.

Dietitian experiences of providing dietary advice

Frustration was the first of three major themes that emerged from the interviews about the experience of providing dietary advice to patients with ESKD. These frustrations were often related to the presence of cognitive impairment in patients with ESKD. For example, the scenario below was reiterated by many renal dietitians:

“I was asked to go back again and see the patient... he thought my explanation was absolutely wonderful but he just couldn’t remember any of it” (Dietitian 7, Metropolitan)

Other sources of frustration were the varying levels of patient motivation and engagement. Depression and dialysis related fatigue were perceived to be common and to negatively impact on adherence to the renal diet.
“I think he could take on the advice... but he just did not have the mental resilience or capacity to put anything into action...” (Dietitian 13, Metropolitan)

Participants were also frustrated with the structure of the health system and the types of dietary advice provided by other staff to their patients.

“I feel frustrated at the system and ... at other staff for the messages they have conveyed and you know that you may not see them (the patient) for months or years to correct that” (Dietitian 3, Metropolitan)

The second theme to emerge was that many dietitians work in clinical settings with limited or inadequate resources. Participants described resource constraints, such as inadequate funding to obtain interpreter services (when required), inadequate hours to service the number of patients referred, inadequate staff and a lack of appropriate resources/educational materials. Renal dietitians from all geographical locations described a lack of time as a key factor which negatively impacted on helping patients understand the renal diet.

“Lack of staffing interferes with the ability to review them regularly ...and see how they are going... so instead we are more reactive” (Dietitian 17, Regional)

“We don't have the staff. ...and we are not able to meet the referrals” (Dietitian 27, Remote).

“There's never enough hours for the dietitians to do everything they need to... and how do you triage everyone when everyone is equally important or as needy” (Dietitian 6, Metropolitan)

The consequences of working with limited staff, time and resources were that renal dietitians described utilising social or chance encounters, in hospital waiting rooms or hallways, as informal opportunities for patient education and/or review. Follow up telehealth or phone reviews were perceived by several participants to be ‘cutting corners’, and detrimental to maintaining patient rapport.

Some participants reported that pictorial resources did not assist with renal diet sense making unless accompanied with education sessions. They also believed that there was a need to develop resources better suited to the patient’s health literacy levels. Some suggested that development of low literacy diet sheets were inhibited by public
health system policy directives which prohibited the use of brand names or actual images of packaged foods.

“We wanted to steer the patients in the direction of appropriate low salt packaged foods but we couldn’t create a sheet that would be useful to them because of the policy” (Dietitian 27, Remote)

Other participants highlighted the need for the provision of culturally sensitive practical dietary advice. They expressed a desire for additional cultural awareness training, to better understand how food is used in different cultures, especially during illness.

“Ethnic issues are important… some populations starve an illness and some feed an illness… so it would be nice… to try and understand” (Dietitian 7, Metropolitan)

Many of the participants believed that the diet sheets were primarily ‘Anglocentric’ and often contained meal plans not suited to their ethnically diverse patients.

The final theme about the renal dietitian’s experiences which emerged from the data included the need to establish trust and demonstrate empathy with their patients. Dietitians expressed a strong sense of empathy for the challenges faced by their patients, and felt guilty about the dietary restrictions required.

“I feel like I am often taking away a lot… it made me feel sad” (Dietitian 13, Metropolitan)

To help facilitate a sense of trust, renal dietitians believed that it was important to genuinely acknowledge and understand the challenges imposed by the renal diet.

“If you know their circumstances and what their goals are… you build that relationship with them… you feel there is a trust there… they are more likely to take your advice” (Dietitian 18, Metropolitan)

A collaborative relationship with patients was strongly desired, because it contributed to feelings of pride and professional satisfaction.

“I get… satisfaction when I am able to help them put things (renal diet) in place… that assist them rather than just giving them a piece of paper” (Dietitian 13, Metropolitan)

Several renal dietitians specifically commented that positive descriptions by medical staff about the expertise or input of the renal dietitian generated a greater sense of trust and facilitated ‘sense making’ for patients.
“If... doctors believe in you and they talk to the patient and say ‘I want you to sit down and talk with the dietitian and it is really important’... that makes a big difference” (Dietitian 1, Metropolitan)

Renal dietitians also felt that dietary advice from other health professionals was a potential barrier to patient empowerment, especially if the advice was inaccurate or incongruous with the education received from the dietitian.

**Strategies perceived by dietitians to help patients understand the renal diet**

Two major themes emerged regarding the strategies renal dietitians perceived useful when providing information about the renal diet and to empower patients with their dietary self-management. Firstly, renal dietitians believed that one of their main roles was to clarify ambiguous or contradictory diet information for patients, especially for common questions:

“I think the single biggest question is what can I eat?” (Dietitian 14, Metropolitan)

Renal dietitians believed that the confusing and unfamiliar language used to describe the renal diet (such as ‘low potassium” or “low electrolyte diet”) contributed to this ambiguity.

“People... don't even know about potassium or phosphorus... it's completely foreign to them.” (Dietitian 3, Metropolitan)

They also believed there were many sources of contradictory renal diet information, and this included commonly used renal diet education resources (diet sheets).

“I try and link potassium with plant based foods and phosphate with animal based foods and products” (D26, regional area)

Dietitians felt these resources contributed to patient’s confusion about what to eat. Dietitians also reported that patients often highlighted contradictions and inaccuracies within their own dietary education resources.

“Our diet sheets ...aren’t even consistent... so even we (dietitians) can’t agree... no wonder patients, doctors and nurses are confused” (Dietitian 18, Metropolitan)

“There is a lot of confusion... probably brought about by... our resources... we have... one for salt ...one for phosphate, one for diabetes. But if you go to
“the lower salt options... they are mostly high in phosphate” (Dietitian 23, Remote)

Participants also suggested that patients may receive conflicting advice from different health professionals.

“Inconsistency with different health professionals is a real issue... (contradictory) messages can undermine their (the patient) faith in your advice” (Dietitian 26, Regional)

Study participants believed that their patients, especially those with comorbidities, become even more confused when trying to balance competing dietary priorities.

“A common one is ‘I am a diabetic and I've always been told to eat whole grain and healthy food and now you tell me I can’t eat any of that because of my phosphate’” (Dietitian 22, Metropolitan)

Dietitians were of the opinion that patients (and/or their families) often turned to the internet to obtain renal diet information.

“It seems everybody, even the little 80-year-old ladies get information from the internet... and if they don’t ‘Google’ it... someone in their life will have! ...it is frustrating and I would love to just get rid of that source of misinformation” (Dietitian 15, Regional)

They expressed strong reservations about the renal diet information available on the internet. They also felt strongly that information found online by patients was often contradictory to evidence-based advice, and believed that this contributed to unnecessary diet restrictions, patient confusion and anxiety.

“I actually encourage them not to Google stuff because that can overwhelm them” (Dietitian 15, Regional)

The second major theme to emerge regarding the strategies perceived by renal dietitians to be useful to patients was the need to simplify complexity. Renal dietitians strongly believed that their patients struggled to understand the complexity of the renal diet, possibly due to the sheer number of dietary restrictions required.

“It is just a complicated diet full stop. Particularly when you get to the end where you juggle protein, salt, potassium, phosphorous, fluid...” (Dietitian 3, Metropolitan)

Participants perceived that the experience level of the dietitian influenced how likely they were to simplify their dietary advice. Inexperienced renal dietitians often described feeling like they needed to be “an oracle and fountain” (Dietitian 8,
Metropolitan) of all renal diet knowledge and would provide patients with large amounts of information ‘just in case’ (Dietitian 15, Regional). This was in contrast to more experienced renal dietitians who used a more simplified approach, preferring to give less information to avoid overwhelming patients.

“You want to give them enough to get by and then if something is an issue then at least they have ...heard the name of whatever it is in advance”

(Dietitian 7, Metropolitan)

In an attempt to reduce the complexity of the renal diet, the study participants indicated that they used simple explanations during the education process. They considered these essential for teaching their patients about dietary self-management because they believed patients struggled to understand why a special diet was required, and why it needed to change.

“Depending on who’s sitting in front of me...I try and simplify it ...I pick out of the diet history (food) that is important for them to change to make a difference (Dietitian 3, Metropolitan)

Many participants used the strategy of ‘teachback’ (the process of asking a patient to ‘teachback’ important concepts to the dietitian in an effort to evaluate recall, and to ascertain their understanding of important concepts) to help gauge whether further explanations were required.

“I try and do one thing at a time so they can get their head around one thing and then I try and get them to paraphrase that back” (D10, regional area)

To further simplify the complexity of the renal diet, participants prioritised issues for the patient, and this was often specifically requested by patients.

“Which bit do I concentrate on? That is their question... do I worry about the potassium or ...the phosphate or... the fluid or ... the salt or ...the protein? They struggle to understand what is the most important” (Dietitian 15, Regional)

“I know they (patients) have to learn to put it together themselves ...but sometimes all they can take in is ‘eat this’ and ‘don’t eat that!’” (Dietitian 8, Metropolitan)

Some participants were uncomfortable with this approach because they felt it was inconsistent with their internal beliefs about what constituted patient centred counselling and education.
“A lot of people just want to know what they can and what they can’t have and that is not my style of dietetics …that is a struggle for me” (Dietitian 12, Remote)

Individualisation and layering of dietary advice was another strategy used by participants to reduce the complexity of the renal diet. Many believed that this approach helped to empower their patients to improve adherence to their diet. Individualisation, i.e. tailoring the dietary advice to the needs of the patient was also described as an essential skill that was learned over time with more experience in clinical practice.

“I think my practice has changed over recent years… I spent a lot of time giving out diet charts …whereas I spend a lot more time now giving individualised meal plans and often not giving a whole pile of information” (Dietitian 14, Metropolitan)

Staggering or layering dietary advice over several sessions was described as one of the most important strategies to assist patients with making sense of the renal diet. Participants believed that this strategy, motivated by a perceived need to avoid information overload, reduced the potential for further confusion amongst patients. They also believed that layering advice helped to preserve rapport and empower patients, which in turn facilitated long term professional relationships between themselves and the patient.

“It is a lot about just doing it in bite size pieces and … picking your battles” (Dietitian 17, Regional)

Finally, renal dietitians repeatedly expressed a desire to provide more practical support to their patients but felt that they lacked the time and resources to do so. Cooking classes, supermarket tours, cooking videos, podcasts, lengthy and detailed meal plans, involvement in patient support groups, and conducting home visits were suggested as desirable methods of providing practical support which would help patients understand and make sense of the renal diet.

“They struggle with applying that information to the real world… I would rather spend a couple of hours going out to teach them how to go to the supermarket, rather than just giving them lists …. Giving them actual skills
rather than just talking at them. It all comes back to practical skills”

(Dietitian 13, Metropolitan)

Other strategies perceived by renal dietitians to be useful mechanisms for simplifying the complexity of the renal diet included: plotting biochemistry results with patients on charts; linking dietary changes to symptom control; using anecdotes and stories about how other patients had managed the challenges of the renal diet; talking about the dietary changes in terms of food and not nutrients; and providing food composition lists, such as tables of foods high and low in potassium or phosphate.

7.6. Discussion

The renal diet is an area of self-management that is closely related to clinical outcomes, and is of great importance and interest to patients with ESKD. However, the provision of dietetic education to patients with ESKD is not simple and necessitates specialised knowledge and skills. The purpose of this research was to explore the experience of renal diet education from the perspective of renal dietitians, and to examine the strategies perceived by these dietitians to help their patients make sense of the renal diet. Although education is only one factor influencing adherence to the diet, the renal dietitians in this study emphasised the importance of providing individualised information and practical support to their patients; and recognised that one of their main roles were to clarify ambiguities and to help simplify confusing and complex diet information. The renal dietitians believed that a trusting relationship between themselves and their patients was important to help optimise a patients’ ability to effectively self-manage their renal diets. They also believed that empathy was an important enabler of these relationships. However, renal dietitians indicated that working in health care environments with limited or inadequate resources strongly influenced their ability to effectively provide education to patients to make sense of their renal diet. As a result, the overwhelming emotion described by renal dietitians in this study was one of frustration.

The findings of this study are consistent with previous research that has explored the antecedents to effective dietetic care. This includes studies confirming the importance of providing patient centred nutrition care; and research confirming the critical role of developing rapport with a patient. Also similar to other
previous research, is the finding that renal dietitians in this study, regardless of geographic location reported a distinct discrepancy between ‘ideal’ practice and actual clinical practice. The discrepancy in this study appears to be closely related to renal dietitians not being able to spend adequate time to develop individualised dietary educational resources for their patients and the time to effectively develop the dietitian-patient relationship. Similar to this scenario, nephrologists have also reported that inadequate time is a barrier to facilitating discussions with their patients. Solutions to address this challenge are required from a health system perspective because having adequate time with health professionals helps to facilitate more effective education, self-management, and trust.

In the current study, renal dietitians emphasised that it was equally important for patients to gain knowledge about what to do and why, as well as to be empowered about how to self-manage their renal diets. This suggests that both health literacy (the degree to which individuals can obtain, process, and understand information to make informed health decisions) and patient empowerment (the psychological sense of control and efficacy that an individual can manage their own health behaviours) are considered essential for patients to make sense of, and adhere to the renal diet. This is not unexpected as both health literacy and empowerment are closely related concepts. The study participants described using ‘health literacy sensitive’ techniques, such as teachback; or endeavouring to simplify diet sheets using health literacy principles. The findings of the present study highlight that inadequate time, conflicting input from other multidisciplinary team members and local health service policies can negatively impact patient empowerment and understanding. Increasing patient empowerment is an important global health priority, with the potential to decrease health costs, improve patient outcomes, and is a good predictor of dietary adherence.

Another important finding from this study was that other members of the multidisciplinary team were perceived to be important moderators of how patients make sense of the renal diet. Receiving dietary advice from other members of the team was considered desirable, if it reinforced or supported the key messages delivered by the renal dietitian. This is consistent with previous work on successful lifestyle change in the paediatric context, where all of the multidisciplinary
health care team are ‘singing off the same song sheet’\textsuperscript{46} However, little is known about the knowledge base or impact of non-dietetic nephrology staff providing dietary advice to patients. Only two small surveys have been published and these indicate that the nutrition knowledge of renal health professionals (such as nurses and doctors) was suboptimal\textsuperscript{48,49} This is of concern because many health professionals believe they have a significant role in the provision of dietary advice to patients with chronic disease\textsuperscript{50} Furthermore, findings from a study of patients receiving dietary advice for cardiac rehabilitation indicated that patients stopped following dietary recommendations after receiving contradictory advice from other health professionals\textsuperscript{51} Further research into the relationship between trust in the health professional and patient empowerment is warranted \textsuperscript{52-54}.

The implications of these study findings are both theoretical and practical. Given the high levels of professional frustration reported by renal dietitians in this study, it is important to ensure that they have regular professional supervision. From a theoretical perspective, the pedagogical approaches to renal diet education should be revisited. It is suggested that the educational strategies used by dietitians take into consideration the concurrent high rates of cognitive impairment\textsuperscript{10} and low health literacy\textsuperscript{55} in patients with ESKD. For example, motivational interviewing, a popular behaviour change technique used by dietitians, may not be appropriate or effective for patients who have cognitive impairment or inadequate executive function, attention and memory, as is common among many patients with ESKD\textsuperscript{56}.

Alternative educational approaches should therefore be considered when educating patients with ESKD\textsuperscript{57} From a practical perspective, the educational approaches used by renal dietitians must be effective, as well as pragmatic because of the resource and time constraints experienced by renal dietitians\textsuperscript{58-61} Alternative educational approaches could include the use of question prompt lists\textsuperscript{62,63} reducing the cognitive burden\textsuperscript{64} using dialogue boards\textsuperscript{65} or conversation maps\textsuperscript{66} and increasing the actionability of renal diet patient education resources\textsuperscript{67} Further studies on the usefulness of improved printed patient education materials (such as diet sheets) and supermarket tours should also be undertaken\textsuperscript{68,69}.
There are several limitations to this research. Firstly, it is possible that renal dietitians not included in this study may offer differing perspectives to those described. Secondly, ecological barriers identified in this study, such as the constraints of the health system and local health department policies that dictate staffing and dietetic resource development may also be different in other geographic locations or health jurisdictions. Another limitation is that even though Aboriginal and Torres Strait Islander patients are over represented in the population of Australian adults with CKD, specific issues pertaining to educating this patient group were not specifically explored. Further research in this area would be useful. Despite these limitations, one of the strengths of this study was the wide cross section of renal dietitian perspectives captured during the semi-structured interviews, in terms of level of clinical experience and geographical settings. The researcher who conducted the interviews is also an experienced renal dietitian, and their clinical knowledge and experience of the issues described may have facilitated a richer exploration of the topic.

In conclusion, renal dietitians in the current study found the experience of providing renal diet advice to adults with ESKD, both emotionally and professionally challenging. They employed a range of strategies that assist patients to make sense of the renal diet advice. However, it appears, based on the experiences and perceptions of the renal dietitians who participated in the current study, that alternative approaches to patient education are warranted to help overcome the factors which negatively impact on patient empowerment.

**Authorship Declaration**

Kelly Lambert: Conceptualisation of study design, data collection, data analysis, primary responsibility for writing the article.
Kylie Mansfield: Refinements to study design, data analysis, writing the article.
Judy Mullan: Refinements to study design, data analysis, writing the article.

All authors are in agreement with the manuscript and declare that the content has not been published elsewhere.
Disclosures:

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None of the other authors have any conflict of interest to declare.
References

14. Lambert K, Mullan J, Mansfield K. An integrative review of the methodology and findings regarding dietary adherence in end stage kidney disease BMC Nephrology. 2017;Published online: 23 October 2017 [Epub ahead of print].
I would like you to think back to a time that really stands out in your mind, when you were teaching a patient about the renal diet. It might be the first time or might be another time. I want it to be a time that is memorable – good or bad.

Can you describe that experience of providing the dietary advice?

*Prompts:*

a) What was the reason you were asked to provide the advice?

b) Who was present?

c) Where was the advice provided?

d) What were the issues that stand out for you about this time?

e) How did the experience make you feel?

f) Did you use any particular resources at the time? why or why not

Was there any part of the experience that the patient found reassuring or helpful?

*Prompts:*

f) What information did you provide? In what format?

g) What do you think were the consequences of being given this information?

h) How did you help / facilitate this patient?

Was there any part of the experience that you believe the patient or carer found difficult or unhelpful?

i) What were they? Why?

j) Was there anything that you did that hindered the patient’s ability to follow the advice? (And if so how do you know?)

What do you think are the big questions that patients struggle with as a result of renal dietary advice?

*Prompts:*

a. What do you think they are trying to figure out?

b. Why do you think they struggle with this?

c. Is there anything you try and do to help them understand?

How does providing renal dietary information make you feel?

*Prompts:*

e. What emotions do you have at these times?

f. Are they related to the experience?
g. What conclusions do you come to from this situation?

If you could wave a magic wand what do you think would help patients to understand the renal diet?

Prompts:

h) What do you think is missing from the renal diet advice you provide?

i) How does that stop the patient from understanding or following your advice?

j) Is there anything else that is limited, incomplete, not effective or not helpful?

k) What do you think could make a difference?

l) Is there anywhere else that you suggest people look or talk to for renal diet advice?

m) Why do you think this will help?
Table 7.2. Characteristics of renal dietitians in the study

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number of dietitians</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender (female)</strong></td>
<td>25 (92.3%)</td>
</tr>
<tr>
<td><strong>Mean (sd) age in years</strong></td>
<td>43.1 (11.0)</td>
</tr>
<tr>
<td><strong>Mean (sd) years of experience as a dietitian</strong></td>
<td>18.7 (10.74)</td>
</tr>
<tr>
<td><strong>Median (IQR) years of experience as a renal dietitian</strong></td>
<td>8.0 (4-15)</td>
</tr>
<tr>
<td><strong>Staffing</strong></td>
<td></td>
</tr>
<tr>
<td>- Working full time in nephrology</td>
<td>14 (51.9%)</td>
</tr>
<tr>
<td>- Working between 0.5-&lt;1.0 full time equivalents in nephrology</td>
<td>7 (25.9%)</td>
</tr>
<tr>
<td>- Working &lt; 0.5 full time equivalents in nephrology</td>
<td>6 (22.2%)</td>
</tr>
<tr>
<td><strong>Characteristics of patients usually seen by renal dietitians</strong></td>
<td></td>
</tr>
<tr>
<td>- Predialysis and conservatively managed</td>
<td>26 (96.3%)</td>
</tr>
<tr>
<td>- Hemodialysis</td>
<td>26 (96.3%)</td>
</tr>
<tr>
<td>- Peritoneal dialysis</td>
<td>23 (85.2%)</td>
</tr>
<tr>
<td>- Kidney Transplant</td>
<td>23 (85.2%)</td>
</tr>
<tr>
<td>- All of the above</td>
<td>20 (74.1%)</td>
</tr>
<tr>
<td><strong>Geographic location of renal dietitian services</strong></td>
<td></td>
</tr>
<tr>
<td>- Metropolitan area</td>
<td>16 (59.3%)</td>
</tr>
<tr>
<td>- Regional centre</td>
<td>6 (22.2%)</td>
</tr>
<tr>
<td>- Remote area</td>
<td>5 (18.5%)</td>
</tr>
</tbody>
</table>
CHAPTER 8: Discussion

8.1. Overview of main findings

The overarching aim of this thesis was to explore the issues that could impact upon adherence to dietary self-management in adults with ESKD. Using the Health Literacy Skills Framework (HLSF) to guide the research in this thesis has significantly expanded the existing knowledge base pertaining to dietary self-management adherence in ESKD. The main findings arising from this thesis include:

i. Evidence confirming that adherence to the renal diet in adults with ESKD is suboptimal, especially in terms of adherence to the individual components of the diet, such as energy, protein, and fibre. Notably, only about one third of patients have poor adherence to fluid intake recommendations. Factors such as socioeconomic status, age, social support and self-efficacy were found to be associated with adherence to dietary self-management recommendations. However, other factors relating to food and eating, such as taste and social acceptability of the diet, were also found to impact on adherence to dietary self-management.

ii. Cognitive impairment was found to be common in adults with ESKD, with deficits apparent in memory, attention, language, visuospatial skills and executive function. Whilst the study in this thesis, regarding the cognitive capabilities of adults with EKSD, is the first of its type in an Australian context, the findings are consistent with a recent meta-analysis on the topic.

iii. Inadequate health literacy was also found to be common in adults with ESKD, especially in terms of finding and understanding health information, and attending to self-management needs. Again, whilst this study was the first exploration of health literacy skills of Australian adults with ESKD using a multidimensional tool, the findings were consistent with previous meta-analyses.

iv. The health literacy demand of online renal diet information targeted at adults with ESKD was found to be highly variable with respect to accuracy, understandability and actionability. The methods used to evaluate the health literacy demand of renal diet information were the first of their type from a
dietetic perspective. Given that online searching for health information and technology use is common amongst patients and carers\textsuperscript{5,6}, these methods could be used by dietitians to undertake further health literacy demand research.

v. The thesis findings confirm that patients and carers find renal dietary advice overwhelming and emotionally challenging. Therefore, in an attempt to better comprehend and make sense of the renal dietary advice, patients and carers independently develop their own problem-solving strategies, even though advice from dietitians is highly valued.

vi. The structure of the health care system and resource constraints within this environment were found to impact heavily on the manner in which renal dietitians provide dietary self-management advice to adults with ESKD. To enhance comprehension of the renal diet, renal dietitians proactively try to establish a trusting relationship with their patients, and use strategies, such as providing individualised advice to help patients make sense of the renal diet.

vii. The themes that emerged from interviews with patients and carers were complimentary in nature to the themes expressed by dietitians. These are depicted in Table 8.1

Table 8.1. Comparison of themes from interviews with patients and carers and dietitians.

<table>
<thead>
<tr>
<th>Patient and Carer Themes</th>
<th>Dietitian themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>An overwhelming, frustrating and emotional journey</td>
<td>Frustration</td>
</tr>
<tr>
<td>The renal diet is complex and challenging</td>
<td>Clarifying ambiguities and conflicting information</td>
</tr>
<tr>
<td>Develop problem solving strategies to use and apply the renal diet advice provided</td>
<td>Simplifying complexity</td>
</tr>
<tr>
<td>A desire for additional resources and/or support.</td>
<td>Limited or inadequate resources</td>
</tr>
<tr>
<td>Dietitian input is highly valued Carer support is important</td>
<td>Establishing trust and demonstrating empathy</td>
</tr>
</tbody>
</table>

According to the HLSF\textsuperscript{1}, the cognitive capabilities and health literacy skills of individuals, as well as the health literacy demand of health information have a direct impact on health outcomes. The findings from this thesis contribute to the body of
knowledge regarding these factors and offer additional evidence that could partly explain why dietary self-management adherence in adults with ESKD is so poor. To enhance the cohesion of this thesis, the intent of the remaining discussion is to outline the broader implications of the thesis findings for the clinical practice of renal dietitians, and to suggest areas for future research.

8.2. Implications for clinical practice

Dietitians who work with adults with ESKD need to be aware that inadequate health literacy is present in more than one quarter of their patient population. They also need to be aware that this inadequate health literacy means that these patients may have problems finding and understanding health information. Unfortunately, the current model of care used by dietitians working with patients with ESKD provides no guidance about how to adapt their clinical practice to accommodate the presence of inadequate health literacy, even though a plethora of tools exist to screen for inadequate health literacy. However, as described in this thesis and in the literature, many renal dietitians work in resource poor settings, with little time to administer health literacy assessment tools. Therefore, it is suggested instead that dietitians recognise that inadequate health literacy is a problem amongst many patients and that available resources, such as the ‘universal precautions’ approach to health literacy, could help to address this issue. ‘Universal precautions’ is used as an umbrella term for the steps involved in restructuring models of care in a way that assumes all patients may have inadequate health literacy, and that all patients are at risk of not understanding health information. Not only does this approach benefit the individuals with inadequate health literacy, but there is also convincing evidence from other areas of medicine that this approach improves comprehension and information retention in all patients. The steps involved in the ‘universal precautions’ approach include (i) simplifying communication; (ii) linking patients with supportive systems and (iii) supporting self-management and patient empowerment.

1. SIMPLIFYING COMMUNICATION

The HLSF suggests that the quality and effectiveness of the communication between the patient and dietitian is critical to comprehension of renal dietary self-management advice. If dietitians were to adopt the ‘universal precautions’ approach
to simplify communication then several adaptations would be required to oral and written communication\textsuperscript{15}. These are outlined in more detail in the following paragraphs.

**Improving oral communication**

There are three recommendations for improving oral communication that arise from this thesis and from the broader literature\textsuperscript{15, 21, 22} that could assist dietitians in clinical practice to adopt a ‘universal precautions’ approach to health literacy. These include: using teachback; providing signposting during patient education; and clarifying conflicting information.

Teachback is a communication strategy used to rapidly evaluate patient comprehension of important concepts\textsuperscript{23}. For teachback to work effectively, dietitians are required to actively take responsibility for the quality of the communication. Fortunately, teachback is already naturally embedded into the patient education process used by dietitians\textsuperscript{24}. However, based on the results in this thesis where patients expressed a strong desire for actionable renal diet information, and on the broader literature regarding teachback\textsuperscript{20, 22, 23, 25-27} dietitians would be well advised to ensure that they ask the patient to teachback (or in some cases ‘show back’\textsuperscript{22}) their comprehension of the concept or self-management task in an action oriented manner\textsuperscript{20, 27}, which will help to facilitate sense making. Examples of actionable practical oriented teachback phrasing include: “I want to make sure that I did a good job teaching you today. Can you tell me about some of the strategies you will use to help you stick to your fluid restriction?”; “Show me which part of the food label is important to look at”; “What cooking methods can you use now to help reduce the potassium in foods?” or “Can you tell me how you could change what you had for lunch today to make it more suitable for your diet?”. Empowerment can also be facilitated by asking the patient to take notes during their appointment to help them recap or teachback important points. Dietitians should also be aware that teachback may not be suitable for every patient education encounter or every patient\textsuperscript{28, 29}. For instance, teachback may not be appropriate for patients with cognitive impairment\textsuperscript{28, 30}, which is common in adults with ESKD. In these circumstances, a better alternative would be inviting carers to participate in the dietetic teaching session and utilising them as part of the teachback process.
Another strategy to support improved oral communication between the patient and dietitian about dietary self-management in ESKD is signposting, as highlighted in the patient and carer qualitative interviews. Signposting gives structure to a patient education encounter, and can be used to ‘signpost’ to the patient the direction of the conversation and why that component of the conversation is important. Signposting can be used by the dietitian in different stages of the patient education process, such as:

- At the start of the consultation: “Today we will talk about the sort of diet you need to follow now that you have kidney disease. First, I will get some background information about your kidney disease, then we will talk more about the sorts of foods we recommend you eat” or
- To explain a line of questioning: “To help me give you the right advice about what to eat, I need to ask you questions about what you normally have to eat”.

Other types of signposting that dietitians could utilise include providing explicit guidance about what constitutes successful dietary self-management adherence (e.g. are small deviations from the eating plan allowed?). This type of signposting has been shown to alleviate anxiety associated with food choices and improve adherence. Based on the findings in this thesis, other signposting topics that are important to highlight include simple statements about when and why the renal diet may change; and clear simple statements about what information is considered most important or essential, especially when presenting numerous dietary concepts to the patient.

The renal diet is complex and changes as the patient progresses through the different stages of ESKD or undergoes different treatments. The literature has shown that patients and carers often feel frustration regarding the renal diet, and this was echoed by the patients and carers, as well as the dietitians interviewed in this thesis. One source of frustration is the conflicting information about the renal diet provided by the healthcare professionals involved in the patients care. To reduce this frustration and to simplify communication between the patient and dietitian, it is recommended that the dietitian explore the source types of renal dietary self-management advice that patients and carers may have received. Furthermore, it is suggested that dietitians be proactive and work with other health professionals to
improve understanding of the renal diet and reduce conflicting messages \(^{37}\). In doing so, they would assist with fostering the concept of using ‘distributed expertise’ \(^{38}\) which could include providing other health professional staff with:

- Guidance about when dietetic input is required
- Dietary information dietitians perceive as appropriate for them to provide to patients
- Information regarding where and how to find good quality, accurate online renal diet information that they can direct patient and carers toward

These suggestions may reduce the likelihood of health professionals providing conflicting (and potentially incorrect advice) and may help to improve dietary self-management adherence.

**Improving written communication**

It is not just oral communication that is important to patient education about the renal diet. The patients and carers interviewed in this thesis expressed a preference for written information about the renal diet, and this format of communication was used frequently by dietitians to support patient education. As part of adopting a ‘universal precaution’ approach to health literacy, dietitians should endeavour to assess, create and select easy to understand patient education materials \(^{20}\). They should also be encouraged to regularly evaluate the written materials they use with patients, including commercially sponsored materials \(^{21}\). It is also recommended that dietitians explicitly encourage the patient to bring any prior dietary self-management information they have obtained to the appointment. Recommendations to improve the quality of written information about renal dietary self-management include the following:

- Include essential information only; include numerical information in tables rather than the text; add icons or pictorials to numerical information; and ensure all renal diet resources contain actionable information that emphasises skill building. \(^{39}\).
- Ensure that written information includes practical, culturally appropriate advice about how to adapt the renal diet during social eating occasions (for example, eating out at restaurants or family meal events). Advice about how to adapt
common family recipes to the renal diet is also highly desired by patients and carers.

- Utilise patients and carers to evaluate the patient education materials that are routinely used by dietitians to ascertain their suitability, cultural appropriateness, and actionability 14.

An additional recommendation for dietitians to consider is the need to produce and publish renal diet self-management information in alternative formats, such as videos, infographics or podcasts. Feedback from patients and carers, and evidence from studies on the health literacy demand of online information suggests that the written information, currently available online about renal dietary self-management is not practical, too complex, or not actionable. There was a distinct lack of good quality publicly available renal diet information produced by reputable sources on topics, such as renal diet advice for CKD, predialysis or polycystic kidney disease.

The quality of a patient education resource can be assessed by using validated measures, such as the DISCERN tool. However, this tool is three decades old and rates the quality of the resource/information according to the volume of information, rather than the accuracy of the information. This may be problematic in an era of freely available online information, which is why dietitians should familiarise themselves with more recent guidelines, toolkits and/or design principles for the development of good quality and health literacy sensitive education resources.

Examples of these include:


Dietitians might like to consider establishing collaborations with non-government organisations, such as Kidney Health Australia, the Dietitians Association of Australia or Polycystic Kidney Australia to facilitate and ensure that good quality renal diet information is available online. Focusing on content areas that were found to have few accurate and good quality resources (such as Poly Cystic Kidney Disease or Early CKD) may be a good starting point for these collaborations. Dietitians may therefore need to enquire if, and how, patients and carers are accessing and using online renal dietary self-management resources (including the use of generic health apps) and to then provide patients and their carers with guidelines to judge for themselves if the information they are accessing about the renal diet is of good quality. Table 8.2 contains the recommendations for good quality online information based on the results of this thesis.
Table 8.2. Recommendations to dietitians about good quality online information to recommend to patients and carers (Adapted from Lambert et al\textsuperscript{40}).

<table>
<thead>
<tr>
<th>Online information that is written or created by:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Dietitians</td>
</tr>
<tr>
<td>• Medical organisations (e.g. ‘.org’)</td>
</tr>
<tr>
<td>• Academic institutions (e.g. ‘.edu’)</td>
</tr>
<tr>
<td>• Government bodies (e.g. ‘.gov’)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Online information that:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Explains \textit{why} the dietary changes are required</td>
</tr>
<tr>
<td>• Does not refer to, or use anecdotal evidence to justify the suggested changes</td>
</tr>
<tr>
<td>• Supports advice with references to scientific research results or evidence based guidelines</td>
</tr>
<tr>
<td>• Explains why particular foods may need to be avoided or restricted</td>
</tr>
<tr>
<td>• Provides practical food or menu based substitutes for foods to be avoided</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Online information that:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• provides specific details in layman’s terms about how to incorporate the dietary changes suggested into existing eating habits or into social eating occasions</td>
</tr>
<tr>
<td>• contains clear instructions on \textit{what} actions the person needs to take, in layman’s terms, with specific food or menu examples</td>
</tr>
<tr>
<td>• contains clear instructions on \textit{when} dietary changes are required, in layman’s terms, with specific food or menu examples</td>
</tr>
</tbody>
</table>

2. \textbf{LINK PATIENTS TO NON-MEDICAL SUPPORT SYSTEMS}

The emotional burden of ESKD is well documented\textsuperscript{41-46}. In this thesis, patients and carers also reported that the renal diet contributed to their emotional burden and described the process of learning how to make sense of the renal diet as challenging. To reduce emotional burden and the challenges associated with making sense of the diet, dietitians could consider inviting or linking their patients to non-medical support systems that are not mediated or overseen by health professionals, such as online patient forums, and/or peer support groups. Support such as this has been repeatedly shown to lead to improvements in patient self-management capability\textsuperscript{47-49}, and may help minimise social isolation. Cooking classes are also known to have positive psychosocial benefits for patients and carers. Patients and carers may also find it useful for the dietitian to describe common questions other patients have had regarding dietary self-management, and how other patients and carers have solved
their renal diet related issues. However, this infers that dietitians would need to include additional questions in their history taking assessment to specifically explore the type of renal diet problems they may be struggling with, and the problem-solving strategies they have trialled.

In addition to linking with peer support networks, dietitians could outline to patients the type of ongoing support they can provide. Current evidence suggests that dietary adherence has been shown to occur in an episodic pattern. This means that patients and carers will vary in their need for contact with and support from dietitians. The qualitative patient and carer interviews conducted in this thesis described an unmet need for ongoing access to support from the dietitian, particularly at important transition points, such as a commencing new dietary modifications or renal replacement therapy. Dietitians also expressed a desire to have more frequent contact with patients at these time points but were often unable to arrange appointments due to limited resources. In the absence of access to a dietitian, many patients and carers then developed their own strategies to learn how to self-manage. However, based on the thesis findings there appears to be a need for dietitians to provide guidance about how, and where, to obtain ongoing dietetic self-management support. It is suggested that dietitians explicitly state the preferred methods for patients and carers to contact them (e.g. via phone, email, skype, groups); and encourage them to gain regular feedback by initiating contact. In resource poor environments, it may also be worthwhile for dietitians to consider utilising innovative strategies (such as group sessions, conversation maps \(^{50, 51}\) or telehealth \(^{52}\)) to provide ongoing support to enhance dietary self-management adherence.

3. SUPPORT SELF MANAGEMENT AND PATIENT EMPOWERMENT

The aim of teaching patients about self-management is to enable them to take responsibility for their own health \(^{53}\). However, previous research has shown that patient education programs undertaken without a thorough understanding of self-management capacity and cognitive capabilities are likely to be ineffective \(^{54-56}\). Dietitians should be aware that attempts to improve dietary self-management in adults with ESKD are likely to be impacted by the presence of cognitive impairment in this patient group. In addition, deficits in attention and memory, especially among the dialysis patients will be highly likely to impact on the patient’s ability to learn.
Counselling strategies such as goal setting, behavioural contracts, self-monitoring, and motivational interviewing which are frequently used by dietitians during counselling sessions, may also be ineffective in patients with deficits in their executive function, who are incapable of exercising impulse control and planning for future goals. Thus, new styles of group and individual patient education sessions that account for the variations and deficits in the cognitive capabilities of many patients with ESKD should be considered and trialled.

There are several other implications for dietitians, regarding strategies to support self-management that arise from the findings regarding the presence of cognitive impairment in many patients with ESKD. While cognitive impairment is common, health professionals are not able to accurately identify who is impaired based on their clinical judgement alone. There is also no consensus about the value of screening for cognitive impairment. Some have suggested that routine screening for cognitive impairment should be undertaken. However, it is important to recognise that since screening for cognitive impairment may cause emotional distress, dietitians would need adequate training or additional support services to assist with the screening process. Dietetic models of care that include routine assessment of cognitive capabilities at appropriate times, such as changing RRT type may be an alternative. The timing of patient education regarding dietary self-management is also important given the prevalence of cognitive impairment. The literature remains equivocal regarding whether clinically important fluctuations occur in cognition during dialysis. However, conducting dietary self-management education during dialysis is not recommended because the environment contains many distractions that may negatively influence comprehension and attention.

The impact of cognitive impairment also requires consideration when planning patient education sessions. For example, self-management programs commonly attended by adults with ESKD are often presented in a lecture style format over many hours. Not only is this unappealing to many patients and carers, but as shown in this thesis, memory, attention and executive function are likely to be impaired among many of these patients. An alternative approach would be for dietitians to provide structured, short duration multicomponent interventions.
Due to the presence of language deficits, patients may also mishear instructions or only recall part of the message, making recall of dietary self-management advice challenging. Dietitians should therefore repeat self-management messages numerous times during the patient education session, and provide written instructions that reflect the patient's own words. Additional suggestions for dietitians to support dietary self-management include encouraging the support of other people such as carers to facilitate understanding, as well as to support patient dietary self-management adherence. This could be as simple as inviting carers to attend appointments. Similarly, finances and a lack of social support were found to be important barriers to dietary self-management adherence. It is recommended that dietitians sensitively determine if finances are impacting on adherence to the diet or on other parts of the ESKD treatment regimen. Questions to ascertain these details are included in routine dietetic assessment tools such as the Patient Generated Subjective Global Assessment. Self-management and empowerment can also be encouraged by using question prompt lists prior to and during patient education sessions.

To close this section regarding the implications for dietitians, a summary of the pertinent points for clinical practice from this thesis are included in Table 8.3.

Table 8.3. Recommendations for dietitians regarding the provision of dietary self-management advice to patients with ESKD

<table>
<thead>
<tr>
<th>Prior to the appointment</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Encourage the carer or other support person to attend the appointment with the patient</td>
</tr>
<tr>
<td>• Encourage the patient to bring any prior dietary self-management information obtained to the appointment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>During the appointment</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Adopt a ‘universal precautions’ approach to a patient’s health literacy</td>
</tr>
<tr>
<td>• Undertake several rounds of teach-back to evaluate recall and understanding of important concepts</td>
</tr>
<tr>
<td>• Describe common questions other patients have had when learning the renal diet</td>
</tr>
<tr>
<td>• Promote empowerment by asking the patient or carer to take notes and direct their note taking during the session to recap important points</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>During history taking</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Gauge a patient (and carer’s) prior understanding of kidney disease</td>
</tr>
<tr>
<td>Facilitate sense making</td>
</tr>
<tr>
<td>-------------------------</td>
</tr>
</tbody>
</table>
| Provide actionable – add this term to the discussion, practical advice | • Explain and ask the patient to teachback their understanding of what ‘adherence’ means  
• Use simple explanations or metaphors to convey complex concepts  
• Link explanations about the diet disease relationship to a patient’s biochemical results  
| Signpost | • Discuss how to add flavour to meals within renal diet parameters  
• Discuss the importance of, and how to increase dietary variety within renal diet parameters  
• Provide practical strategies for patients to prepare family meals, eat at restaurants or family events and still adhere to the renal diet  
• Provide a culturally appropriate renal diet food list  
| Prior to leaving the appointment | • Use the teach-back strategy to reinforce important take home messages  
• Reinforce that it takes time to learn and adapt to the renal diet  
| Written dietary self-management education resources | • Ensure education resources clearly explain suitable portion sizes not just ‘serves’  
• Ensure pictorial education resources are printed in colour not black and white  
• Ensure education resources include a meal plan that has been individualised  
• Ensure information contained in diet sheets and patient education resources is understandable and actionable  
• Ensure contradictory information in the diet sheet is minimised or an explanation is provided about how to interpret contradictory information  
| After the appointment | ❍  

**Follow up**  
• Describe that the purpose of follow up is to layer advice over several sessions to reduce confusion  
• Encourage regular follow up (including via email or phone) so that patients can obtain feedback  

**Minimise social isolation**  
• Describe how and where patients and carers can connect non-medical support systems and other patients and carers in the same situation
8.3. Strengths and limitations

Each study within this thesis has included a discussion of the methodological strengths and limitations of the research conducted. The intent of the following paragraphs is to describe more broadly the strengths and limitations of the thesis.

The first strength of this thesis is the use of the HLSF to provide a coherent link between the individual studies that have made up this thesis by publication. An important point to raise about a thesis by compilation approach is that there needs to be an obvious link between chapters, and that the thesis should read as a unified and coherent body of work. The use of a health literacy lens to explore the topic of dietary adherence in ESKD unifies the studies in this thesis. This approach is not only useful because health literacy is directly related to self-management outcomes in kidney disease; but it is also timely because all Australian health care facilities must now address health literacy as part of their accreditation requirements, and dietitians must understand and concur with this requirement.

The other strength of the work in this thesis is that the studies included are supported by robust methodology for health services research and contain carefully constructed objectives. In addition, the inclusion of an integrative review is noteworthy as these types of reviews have been stated to be the most comprehensive in terms of methodological approach, allowing for the inclusion of experimental and non-experimental studies to fully understand the phenomenon analysed. Furthermore, unlike systematic reviews, the integrative review does not rely on a second reviewer for evidence synthesis. Instead the clinical experience of the researcher is used to verify validity of the methods and results, and helps to determine their usefulness in practice. Standardised and validated data collection tools such as the MoCA, HeLMS, PEMAT, DISCERN and MARS were used which outlined clearly the criteria of interest prior to analysis, and were uniformly applied to all data to improve reliability and objectivity. Interrater reliability when scoring with the PEMAT, DISCERN and MARS tools was high (range 83.3% - 94.4%) and relatively large sample sizes utilising purposive samples were used in the qualitative and quantitative components of the research. Additional strengths associated with the qualitative interviews, included a clearly stated-relativist ontological philosophical
position (i.e. that reality is socially constructed, and that a person’s thoughts about reality are influenced by social factors, such as culture, history and language). The qualitative interviews were also supported by the well-established Sensemaking theoretical framework to guide question design and analysis. Multiple coders were used to ensure trustworthy and credible results were obtained from interviews as suggested by experts such as Goodell et al. Data triangulation was also undertaken in the semi-structured interviews to increase the validity of the results. Each study that has been published has also undergone the rigorous peer review process. Careful supervisory oversight was also provided by experienced health service researchers and clinicians. Another important strength of this thesis is that adults across the spectrum of ESKD were included in studies exploring health literacy, cognitive capabilities and their experiences. This is unlike most research to date which has been dominated by studies of hemodialysis patients.

There are a number of limitations associated with this thesis. The first is that the research was conducted with patients located in one regional Australian health district, and as such the results about patients may not be generalisable to other health jurisdictions with different methods of health care provision, or with a differing cultural or socioeconomic composition. The articles extracted for the online content analyses were managed using two reviewers and predefined criteria. However, the ability to replicate the findings of these studies are limited by the constantly evolving content available online. For example, at the time of publishing Chapter 4, several apps had been withdrawn from the app market and were no longer available. Limitations also exist relating to the cross-sectional study design of several studies in this thesis, where trends over time in the extent of cognitive impairment or inadequate health literacy were unable to be determined. Another limitation of this study is the nature of the survey tools utilised, such as the HeLMS tool in Chapter 3. The HeLMS tool is a self-reported questionnaire which reflects the participants’ perceived ability, rather than a measured ability, in relation to their health literacy and ability to undertake health-related tasks. Selection bias is also a possible limitation of the cross-sectional design of these studies. To ascertain if this had occurred, the characteristics of the study population in these cross-sectional studies were compared to those of the ESKD population within ISLHD and nationally and were found to be similar. It is also possible that response bias may have occurred.
with participants in the qualitative interviews in Chapters 6 and 7 because of a prior professional relationship. However, in the present study the presence of a pre-existing relationship with some of the participants may have engendered a sense of trust and participants may have been more likely to participate in the study and offer an honest perspective to a trusted source.

8.4. Recommendations for future research

This thesis has identified characteristics of individuals at high risk of non-adherence to the renal diet. High risk groups include males, younger people, those with low education or inadequate family support, those who are depressed, those with low self-efficacy, and those who have been on RRT a long time. Further research in these high risk groups, especially interventions using specially designed flexible, pragmatic diets would be of great interest. To date, these approaches have only been trialled in adults requiring low protein diets\textsuperscript{107-109} or low salt diets\textsuperscript{110}. Similarly, longitudinal studies are required, investigating if, and how adherence to dietary self-management changes over time, and the reasons for this. Further studies on the use of common patient education strategies like printed patient education materials (such as diet sheets) and supermarket tours are also required because they have modest benefits on self-management behaviours\textsuperscript{111,112}.

The types of deficits demonstrated by patients in this thesis with cognitive impairment were wide ranging. These findings have important implications for dietitians working with adults with ESKD, as well as adults with other chronic conditions. This is because cognitive impairment and inadequate health literacy are common in other chronic conditions such as heart failure, chronic obstructive pulmonary disease and oncology\textsuperscript{113,114}, and are known to impact on dietary self-management capabilities in these areas too\textsuperscript{115,116}. Future dietary self-management research should consider implementing techniques taken from educators in the settings of heart failure\textsuperscript{116}, dementia care\textsuperscript{117}, geriatric memory loss clinics\textsuperscript{118}, traumatic brain injury\textsuperscript{119}, or from cognitive training studies\textsuperscript{120}. These techniques commonly include multicomponent skills based interventions with a carer\textsuperscript{119-122}; that utilise a universal precautions to health literacy and provide individualised education. Teaching brain injured patients to successfully self-manage has also been
demonstrated to be possible when skills based tasks are taught to individuals by breaking the task down into more manageable portions. Longitudinal research exploring if and how cognitive impairment changes in adults with ESKD would also be informative.

Patients and carers interviewed in this thesis suggested that they desired increased contact with the dietitian. The results of the literature review also confirmed that intensive education was associated with improved adherence to the renal diet. Recent evidence from a systematic review suggests that telehealth can improve diet quality and reduce dietary sodium intake in adults with chronic disease. Future research should extend initial feasibility studies and explore the impact of using alternative methods of intensive dietetic contact such as telehealth or group sessions to deliver dietary self-management education to adults with ESKD.

Finally, one of the weaknesses of the evidence base relating to adherence to dietary self-management in ESKD is that studies frequently report the mean intake of a nutrient rather than the proportion or characteristics of adults adhering to recommendations for that nutrient. It is recommended that future researchers report both the proportion meeting the target, as well as the diet quality of study participants using either diet quality scores or by comparing to relevant dietary guidelines. Furthermore, it is suggested that researchers also utilise the recently released best practice guidelines for dietary assessment using self-report. Improving the quality of dietary assessment reporting is not only useful for dietitians, but it can also be used to inform the design of pragmatic interventions that are aimed at improving dietary self-management adherence.

The next step for the researcher that arises from the findings of this thesis is to undertake a research program that has been funded to design, implement and evaluate a health literacy focused dietetic model of care for adults with chronic kidney disease. This research program aims to translate some of the findings of this thesis into current clinical practice, and to identify potential barriers that may make knowledge translation problematic.
8.5. Conclusion

The burden of kidney disease is increasing, and dietary modification is of paramount importance. However, adherence to the diet is challenging and strategies to improve dietary self-management are limited. It is amidst this context, that this thesis has achieved four important outcomes: (i) contributed to the body of knowledge about dietary self-management adherence in ESKD (ii) used the lens of health literacy to explore issues associated with adherence (iii) documented the extent of cognitive impairment in Australian adults with ESKD and (iv) provided evidence based recommendations that can be translated into clinical practice to facilitate improved dietary self-management adherence.
References:


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APPENDIX 1: Presentations related to this thesis

Invited speaker


**Lambert K,** (2016) Content analysis of renal diet information obtained from the internet, YouTube and apps, *Oral presentation,* Dietitians Association of Australia Renal Interest Group NSW Annual Update, St George Hospital, Sydney, March 8, 2016.


**Conference presentations**


'Oral presentation, at the Australian New Zealand Society of Nephrology Annual Scientific Meeting, Canberra, Australia, September 9, 2015.


APPENDIX 2: Awards during candidature

2017
- National Health and Medical Research Council – Medical Research Future Fund Next Generation Clinical Researchers Program Translating Research Into Practice Fellowship 2018-2019
- Renal Society of Australasia Graham Burnley Memorial Scholarship
- Illawarra Health and Medical Research Institute Dame Bridget Ogilvie Award for Clinical Excellence

2016
- Winner of the Illawarra Health and Medical Research Institute PhD Candidate Oral Presentation Sessions
- Winner of the University of Wollongong Faculty of Science Medicine and Health, Health Impacts Research Cluster 3 Minute Thesis Competition
- Illawarra Health and Medical Research Institute Collaborative Research Grant: “Food as Medicine. Can nuts improve bowel health in dialysis patients without compromising biochemical parameters?”
- Dietitians Association of Australia Advanced Accredited Practising Dietitian Status valid from 2016-2021
APPENDIX 3: Statement of contribution of others

The purpose of this statement is to summarise the nature and extent of the intellectual input by the candidate and co-authors for all publications included in this thesis.

- **Chapter 1 section 3:** KL designed the review, conducted the analysis, and takes main responsibility for writing the article. JM and KM contributed to study design, analysis and interpretation.

- **Chapter 2:** KL and ML research idea and study design. Data acquisition and statistical analysis: KL. Data analysis and interpretation: KL, JM, KM, ML. KL takes main responsibility for writing the article.

- **Chapter 3:** KL research idea and study design. Data acquisition and statistical analysis: KL. Data analysis and interpretation: KL, JM, KM, ML. KL takes main responsibility for writing the article.

- **Chapter 4:** KL research idea. KL, AK and LM study design. Data acquisition and statistical analysis: KL, AK, LM. Data analysis and interpretation: KL, JM, KM, AK, LM. KL takes main responsibility for writing the article.

- **Chapter 5:** KL and PO research idea. KL, PO study design. Data acquisition and statistical analysis: KL, PO. Data analysis and interpretation: KL, JM, KM, PO. KL takes main responsibility for writing the article.

- **Chapter 6 and 7:** KL research idea and study design. Data acquisition: KL. Thematic analysis and interpretation: KL, JM, KM. KL takes main responsibility for writing the articles.

All details stated above are confirmed by the supervisors:
Associate Professor Judy Mullan, and Associate Professor Kylie Mansfield
APPENDIX 4: Demographic profile of ISLHD dialysis patients 2010-2015

This table contains demographic information on all patients who commenced dialysis in the ISLHD from 2010-2015. Information is based on the last survey on 31st December 2015.

| Table 1: Demographics (n(%)) of all dialysis patients |
|---------------------------------|-----------------|-----------------|-----------------|
|                                | WGNG n=195      | Australia n=13208 | New Zealand n=2778 |
| **Age at First Treatment**     |                 |                 |                 |
| 0-14                           |                 |                 |                 |
| 15-24                          |                 |                 |                 |
| 25-54                          |                 |                 |                 |
| 55-74                          |                 |                 |                 |
| ≥75                            |                 |                 |                 |
| **Gender**                     |                 |                 |                 |
| Female                         |                 |                 |                 |
| Male                           |                 |                 |                 |
| **Racial Origin**              |                 |                 |                 |
| Caucasian                      |                 |                 |                 |
| Aboriginal/Torres Strait Islander |           |                 |                 |
| Asian                          |                 |                 |                 |
| Māori                          |                 |                 |                 |
| Pacific                        |                 |                 |                 |
| Other                          |                 |                 |                 |
| Not reported                   |                 |                 |                 |
| **Primary Renal Disease**      |                 |                 |                 |
| GN                             |                 |                 |                 |
| Analgesic                      |                 |                 |                 |
| Polycystic                     |                 |                 |                 |
| Reflux                         |                 |                 |                 |
| Hypertension                   |                 |                 |                 |
| Diabetes                       |                 |                 |                 |
| Other                          |                 |                 |                 |
| Uncertain                      |                 |                 |                 |
| Not reported                   |                 |                 |                 |

Legend: WGONG: All new ISLHD dialysis patients; GN: Glomerulonephritis
APPENDIX 5: Demographic profile of ISLHD transplant patients 2010-2015

This table contains demographic information on all patients who received a kidney transplant in the ISLHD from 2010-2015. Information is based on the last survey on 31st December 2015.

Table 1: Recipient demographics (n(%)) of all grafts

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<th>WGNG n=49</th>
<th>Australia n=4699</th>
<th>New Zealand n=684</th>
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<tr>
<td><strong>Age at Transplant</strong></td>
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<tr>
<td>16-34</td>
<td>7 (14.3)</td>
<td>692 (14.7)</td>
<td>125 (18.3)</td>
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<tr>
<td>35-44</td>
<td>5 (10.2)</td>
<td>821 (17.5)</td>
<td>100 (14.6)</td>
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<tr>
<td>45-54</td>
<td>17 (34.7)</td>
<td>1174 (25.0)</td>
<td>187 (27.3)</td>
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<tr>
<td>55-64</td>
<td>12 (24.5)</td>
<td>1377 (29.3)</td>
<td>208 (30.4)</td>
</tr>
<tr>
<td>≥65</td>
<td>8 (16.3)</td>
<td>635 (13.5)</td>
<td>64 (9.4)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>17 (34.7)</td>
<td>1746 (37.2)</td>
<td>217 (31.7)</td>
</tr>
<tr>
<td>Male</td>
<td>32 (65.3)</td>
<td>2953 (62.8)</td>
<td>467 (68.3)</td>
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<td><strong>Racial Origin</strong></td>
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<tr>
<td>Caucasian</td>
<td>47 (95.9)</td>
<td>3630 (77.3)</td>
<td>434 (63.5)</td>
</tr>
<tr>
<td>Aboriginal/Torres Strait Islander</td>
<td>2 (0.4)</td>
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<td>Asian</td>
<td>1 (2.0)</td>
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<td>Māori</td>
<td>44 (0.9)</td>
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<tr>
<td>Pacific</td>
<td>1 (2.0)</td>
<td>110 (2.3)</td>
<td>66 (9.6)</td>
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<tr>
<td>Other</td>
<td>118 (2.4)</td>
<td>7 (1.0)</td>
<td></td>
</tr>
<tr>
<td>Not reported</td>
<td>53 (1.1)</td>
<td>1 (0.1)</td>
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<td><strong>Primary Renal Disease</strong></td>
<td></td>
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<tr>
<td>GN</td>
<td>22 (44.9)</td>
<td>1994 (42.4)</td>
<td>322 (47.1)</td>
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<tr>
<td>Analgesic</td>
<td>1 (2.0)</td>
<td>20 (0.4)</td>
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<td>Polycystic</td>
<td>5 (10.2)</td>
<td>665 (14.2)</td>
<td>96 (14.0)</td>
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<td>Reflux</td>
<td>6 (12.2)</td>
<td>378 (8.0)</td>
<td>39 (5.7)</td>
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<td>326 (6.9)</td>
<td>52 (7.6)</td>
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<td>27 (0.6)</td>
<td>2 (0.3)</td>
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<tr>
<td><strong>Time Since ESKD (months)</strong></td>
<td></td>
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<td>Pre-emptive</td>
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<td>469 (10.0)</td>
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<td>&lt;6</td>
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<td>301 (6.4)</td>
<td>43 (6.3)</td>
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<td>6-11</td>
<td>6 (12.2)</td>
<td>415 (8.8)</td>
<td>33 (4.8)</td>
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<td>12-23</td>
<td>8 (16.3)</td>
<td>726 (15.5)</td>
<td>99 (14.5)</td>
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<td>≥24</td>
<td>33 (67.3)</td>
<td>2788 (59.3)</td>
<td>404 (59.1)</td>
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APPENDIX 11: Geographic location of renal dietitians

To preserve participant anonymity, no specific locations are identified.

Source: Map created using Google images and Scribble Maps
(https://www.scribblemaps.com/create/#lat=-25.39246897569877&lng=137.4815958738327&z=3&t=hybrid)
APPENDIX 12: Disclosures

During the PhD candidature, the PhD candidate (Kelly Lambert) was involved in a professional collaboration between Xyris Software, and Professor Grahame Elder (University of Notre Dame, Sydney and Nephrologist at Westmead Hospital, Sydney and the Garvan Institute). The aim of this collaboration was to design, develop, test and release a prototype of a renal diet app for use by patients and health professionals.

The outcome of this collaboration resulted in the design, development and release of the *Easy Diet Diary – Renal™* mobile phone application into the Australian, New Zealand and Singaporean Apple app stores. This free app is designed to help people with kidney disease to look up and track their daily food intake of renal related *Nutrients* using Australian food databases and bar code scanning technology. Promotional material regarding this app is shown below.
APPENDIX 13: Debriefing questions used with interview participants in Chapter 6 and Chapter 7

The intent of the following debriefing questions was to enable participants to express their perspective on topics outside of the theoretical framework used in the study.

- While you have been interviewed today, did you have any questions about any of it in your mind?

- Did the interview help you in any way?

- What makes you say this?

- Is there anything else you would like to say?

- Do you have any questions for us?

Reference: