Towards consumer-centred health care and health research in nephrology: understanding patient and family caregiver experiences and perspectives in chronic kidney disease

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

Doctor of Philosophy

School of Public Health

Faculty of Medicine

University of Sydney

July 2008
Declaration

This thesis is submitted to the University of Sydney in fulfilment of the requirement for the Doctor of Philosophy. The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

Signature:............................................................

Date:.............................................
Author’s Contribution

The work presented in this thesis has been carried out by the author under the supervision of Associate Professor Peter Sainsbury, School of Public Health, and Professor Jonathan Craig, School of Public Health, University of Sydney.

The author planned the research, designed the studies, obtained ethics approval, collected, managed and analysed the data, interpreted results, drafted and revised the manuscripts for submission to peer-reviewed journals, and wrote and compiled this thesis.
Ethical Clearance

The study presented in Chapters 3 was approved by The Children’s Hospital at Westmead Ethics Committee, the Sydney Children’s Hospital Ethics Committee and the Human Research Ethics Committee at the University of Sydney.

The studies presented in Chapters 5 and 6 were approved by The Children’s Hospital at Westmead Ethics Committee, the Royal Prince Alfred Hospital Ethics Committee, the Royal Melbourne Hospital Ethics Committee, the Princess Alexandra Hospital Ethics Committee and the Human Research Ethics Committee at the University of Sydney.

All study participants gave written informed consent for participation in the study.
Abstract

Healthcare services and health research aim to improve the physical and psychosocial well-being of consumers, and to offer responsive services needed and valued by them. Research in chronic kidney disease (CKD) has predominantly focused on investigating biomedical aspects and evaluating technological or pharmacological treatment interventions to improve medical management. While research into assessing patients’ and caregivers’ quality of life, and symptom burden, is growing minimal attention has been given to gaining a broad and in-depth understanding about the experiences, psychosocial issues and needs of patients and their caregivers. These need to be considered when planning and delivering patient-centred care and health research across the whole trajectory of CKD.

The studies that form the major part of this thesis explore the perspectives, needs and experiences of CKD patients and their caregivers, within a broad and multidimensional framework encompassing aspects of the nature of the health and illness experiences and consumer perspectives.

In Chapter 2, to understand what is known about parental experiences of caring for a child with CKD, the relevant qualitative literature was systematically reviewed and synthesized. Three inter-related clusters were identified: intrapersonal, interpersonal and external experiences. In Chapter 3, to gain a more detailed and broader understanding of this topic, in-depth interviews were conducted with parents of 20 children with CKD and 4 major themes were identified: absorbing the clinical environment, medicalising parenting, disrupting family norms, and coping strategies.
and support structures. In Chapter 4, to assess the effectiveness of support interventions for caregivers of patients with CKD, a systematic review was conducted which identified only three eligible studies that assessed only the effect of educational material on caregiver knowledge, not other domains.

In Chapter 5, to describe and compare the broad range and depth of experiences and perspectives from predialysis, dialysis and transplantation patients, data from patient focus groups were analysed. The 5 themes that emerged from this data were: personal meaning of CKD, managing and monitoring health, lifestyle consequences, family impact, and informal structures. In Chapter 6, the focus groups were also used to elicit research priorities and identify reasons that patients used to develop their research priorities. A patient focused research agenda was elicited for CKD and 5 reasons that patients used to develop their research priorities were identified: normalisation of life, altruism, economic efficiency, personal concerns and clinical outcomes. During the focus groups, participants repeatedly expressed frustration about the poor public profile, and lack of community-based information on CKD prevention. So in Chapter 7, to assess how Australian news media covered prevention and early detection of CKD, I analysed television and newspaper stories that referred to CKD prevention or early detection. Kidney disease in general, and particularly the prevention and early detection of CKD, received virtually no media attention. When mentioned, it was mainly in the context of transplantation and donor stories, and seldom prevention or early detection, which appears largely unnewsworthy in its current form. At best, CKD received peripheral mention as a secondary concern in diabetes and obesity news stories which focused on lifestyle solutions.
In Chapter 8, to develop a checklist for explicit and comprehensive reporting of qualitative studies (in-depth interviews and focus groups), I performed a comprehensive search in relevant publications for existing checklists used to assess qualitative studies. Seventy-six items from 22 checklists were compiled into a comprehensive list. All items were grouped into three domains: 1) research team and reflexivity, 2) study design, and 3) data analysis and reporting.

The overarching purpose of these studies was to gain a better understanding about the needs, experiences and perspectives of CKD patients and their caregivers. The findings describe the permanent, profound and pervasive impact of CKD on the lives of patients and caregivers across the whole illness trajectory. A more detailed and broader understanding about patient and caregiver perspectives, as presented in this thesis, can support a move towards advancing patient-centred healthcare and research in CKD.
Acknowledgements

I would like to thank Associate Professor Peter Sainsbury and Professor Jonathan Craig, who have made the past 3 years a rich and rewarding experience. It has been a privilege to learn from such supportive, encouraging and committed PhD supervisors. Peter Sainsbury provided guidance, methodological expertise, and constructive and thoughtful feedback. His humour, friendliness and honesty are much appreciated. Jonathan Craig provided direction, challenge, and many research opportunities. I truly respect his leadership, integrity and attitude of excellence.

I wish to thank my colleagues at the Centre for Kidney Research for their friendship, understanding, humour, generosity and support. I wish to thank all the co-authors and contributors for providing support and valuable feedback. Also, I would especially like to thank all the participants who kindly gave their time and energy.

I was supported by the National Health and Medical Research Council Postgraduate PhD Scholarship and the Centre for Clinical Research Excellence in Renal Medicine PhD Scholarship. The Centre for Kidney Research at The Children’s Hospital at Westmead and Kidney Health Australia contributed to the funding of this research.

My deepest heartfelt thanks go to my family. My Dad and Mum, for their constant love, encouragement, and prayers; and my sister Karen, for her support and patience, who never complained whenever I “hassled” her with my barrage of papers and questions. I also thank all my friends who have encouraged me in their own unique ways.
Above all, I thank my Lord Jesus Christ. This incredible journey was only possible because of His love, wisdom, strength, favour and blessings.
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Publications Arising from this Thesis

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The PDF of each article are provided on the CD-ROM enclosed in this thesis.
# List of Abbreviations

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<td>CINAHL</td>
<td>Cumulative Index to Nursing and Allied Health Literature</td>
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<td>CONSORT</td>
<td>Consolidated Standard of Reporting Trials</td>
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<td>CKD</td>
<td>Chronic Kidney Disease</td>
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<tr>
<td>ESKD</td>
<td>End-stage Kidney Disease</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>IAPO</td>
<td>The International Alliance of Patients’ Organizations</td>
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<tr>
<td>MeSH</td>
<td>Medical Subject Heading</td>
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<tr>
<td>NICE</td>
<td>National Institute for Clinical Excellence</td>
</tr>
<tr>
<td>QUOROM</td>
<td>Quality of Reporting of Meta-analyses</td>
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<tr>
<td>RDQoL</td>
<td>Renal-dependent quality of life</td>
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<td>STARD</td>
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1. Introduction

1.1 Background

Healthcare services and health research aim to improve the physical and psychosocial well-being of consumers, and to promote the availability of responsive services that are needed and valued by them. During the last few decades, healthcare providers have increasingly recognised the value of “consumer-centred care” (or “patient-centred care”). In 2001, a report by the Institute of Medicine established patient centredness as one of the 6 essential aims for the 21st-century health care system. In contrast to a “clinician-centred,” “disease-centred” or “treatment-centred” approach, consumer-centredness focuses on the consumers’ needs, perspectives and preferences.

A core principle underlying consumer-centredness is to understand and engage with consumers’ experiences, perspectives, values, preferences and expressed needs. In addition to the availability and technical standard of care, the experiences and perspectives of consumers will influence how people use and benefit from healthcare services and research. Consumer experiences and perspectives can complement those of health professionals and offer a sophisticated, sometimes idiosyncratic, framework of knowledge about their health and other aspects of their lives.

Consumer-centred care can enhance quality of life for consumers, improve adherence to treatment regimens, and reduce morbidity. In research, consumer involvement may make practice and policy more relevant to consumers’ needs, leading to outcomes that
include greater patient satisfaction, improvement in treatment adherence, better acceptance of research findings and reduced risk of litigation.\(^7, 8\)

Consumer-centredness is particularly important in the management of chronic disease.\(^9\) The continuous and complex management of chronic kidney disease (CKD), for example, requires patients and their informal caregivers to adhere to strict medical regimens, deliver technically demanding home-based interventions, and modify their nutritional intake. If the rhetoric of consumer-centredness is to become a reality, a better understanding of consumers’ perspectives on health care and research is needed.

The overarching purpose of this thesis is to better understand the needs, experiences and perspectives of CKD patients, their family and informal caregivers, thereby supporting a move towards greater patient-centredness in care and research in CKD.

1.2 Definition of terms

Many of the terms I have used in this thesis do not have a single, universally accepted definition. The following illustrates the diversity of definitions for significant terms and indicates the definition used in this thesis.

**Consumer**

The term consumer is widely used in healthcare but alternative terms including service-user, patient, citizen, carer, caregiver, or lay person,\(^10\) may be preferred in other circumstances. Broadly, a consumer includes “patients and potential patients, carers,
organisations representing consumers’ interests, and members of the public who are the targets of health promotion programs,”(11) who directly or indirectly use health services. In this thesis, the term consumer includes only individual patients and caregivers.

**Consumer-centred care**

No universally accepted definition of consumer-centred care exists.(2) Various definitions have been proposed that share the same notion of considering the consumers’ needs, perspectives and preferences.(1, 4, 5) In the literature, the terms “consumer-centred,” “user-centred,” “patient-focused,” “consumer-directed” and “patient-centred” have been used with little clear distinction between them. The term “patient-centred” is most frequently used in the literature. I will use the terms consumer-centred and patient-centred interchangeably.

**Consumer-centred health research**

The term “consumer-centred health research” is uncommon. In this thesis, I extend the concept of consumer-centredness from clinical practice to research. I define consumer-centred health research as any research program that considers and incorporates the needs, preferences and experiences of consumers. This is possible at any stage of the research process: deciding the research topic, developing research methods, conducting the research, disseminating results to the participants and stakeholders, and suggesting areas for future research. The principles underpinning consumer-centred care and consumer-centred health research are discussed more fully in the next section.

**Chronic Kidney Disease**
Chronic Kidney Disease (CKD) is a term used to describe kidney damage or reduced kidney function that persists for more than 3 months. In technical terms, CKD includes patients with a glomerular filtration rate of less than 60 ml/min/1.73m$^2$ for 3 months or more. CKD most commonly results from diabetes, nephritis (inflammation of the kidney) and hypertension, and can present at any stage in a person’s lifespan.\(^\text{(12)}\)

Patients with CKD either die from cardiovascular events (for examples, myocardial infarction or stroke) or progress to End Stage Kidney Disease (ESKD). In ESKD, the patient has little or no kidney function and renal replacement therapy in the form of dialysis or transplantation is required to sustain life.\(^\text{(13)}\) In Australia, 1 in 7 Australians over 25 years have at least one clinical sign of existing CKD.\(^\text{(14)}\) In 2006, 2,378 patients commenced renal replacement therapy, a 4% increase from 2005, and 641 transplant operations were performed, a 3% increase from 2005.\(^\text{(12)}\)

In this thesis, the term “CKD” includes those who have not yet received dialysis or a kidney transplant, and patients on renal replacement therapy, which includes dialysis and transplantation.\(^\text{(15)}\)

**Informal caregiver**

Informal caregivers include spouses, siblings, children, relatives and friends, however in this thesis I predominantly focus on parent caregivers. Informal caregivers provide “extraordinary, uncompensated care, predominantly in the home setting, involving significant amounts of time and energy for months or years, requiring the performance of tasks that may be physically, emotionally, socially, or financially demanding.”\(^\text{(16)}\)
Patient

A patient can be defined in many ways and the Merriam-Webster Medical Dictionary defines patient as a “sick individual especially when awaiting or under the care and treatment of a physician or surgeon” or a “client for medical service.” (17) In this thesis, a patient is any person who receives or is waiting for health care.

1.3 Principles underpinning consumer-centred care and health research

As stated, “consumer-centred care” is a widely adopted term but there is no universally accepted definition or theoretical framework. Various definitions have been proposed since it was introduced during the 1950s when Balint proposed that doctors needed to listen to their patients. (3, 18)

For instance, according to The International Alliance of Patients’ Organizations (IAPO), an international organisation for advancing patient-centred care (4), “patient-centred healthcare” is “healthcare that is designed and practiced with the patient at the centre.” This definition is also reflected in the Picker Institute values statement, “All patients deserve high-quality healthcare, and patients’ views and experiences are integral to successful improvement efforts.” (5) The Institute of Medicine defines patient-centredness as “providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical
decisions.” (1) Patient-centredness ensures that the healthcare services and health research are “closely congruent with and responsive to the patients’ wants, needs, and preferences.” (2, 18) These and many other definitions share similar underlying principles.

**Core principles of consumer-centredness**

Consumer-centredness is a holistic concept in which the underlying principles are inextricably linked. However, for the purpose of clarifying the underlying principles of consumer-centredness, I will discuss them as discrete, individual components, drawing on the conceptual framework developed by the Picker Institute (5), which is comprehensive and broadly subsumes the principles proposed by others. The principles have applicability to and implications for both healthcare and research.

1. **Respect for patients’ values, preferences and expressed needs:** to understand the patient’s quality of life and experience of the disease (for instance, the problems, feelings, and personal meaning and implications of the illness for each individual patient, which may be influenced by their values, culture and traditions). (19, 20) This includes the patient’s cognition, such as what they expect and believe, and their confidence about their disease management. (6, 21)

2. **Coordination and integration of care:** to integrate the clinical management, ancillary care, and support services for the benefit of the patient.

3. **Information, communication and education:** to facilitate health promotion, self-management and autonomy consumers should have access to current, relevant and comprehensive information (4) on their clinical status, prognosis, progress,
the process of care, and the support services and educational programs available to them; to be sensitive to patients’ preferences for information and shared decision making; and to provide an appropriate response. (19)

4. Enhance physical comfort: to offer pain management, a comfortable environment, and practical support for daily living.

5. Emotional support: to alleviate stress, fear and anxiety relating to the illness and treatment, including physical disability or disfigurement, social isolation, its impact on the family, and financial burdens.

6. Involvement of family and friends: to recognise the needs and contributions of the patient’s family, friends and informal caregivers (6, 21), and to involve them in decision-making relating to care planning and delivery when the patient agrees; to promote an awareness of the disease, symptoms and treatment among family and friends and to accommodate the needs of informal caregivers.

7. Smooth transition and continuity across service boundaries: to coordinate, plan and support transition of care, offer continuity of care and provide support for self-management and care which is delivered away from the clinical setting.

8. Access to care: to minimise waiting times for appointments and admission, and to provide convenient service hours; to equip patients with skills and resources (including transportation) to access and navigate the health care system.

**Operationalising the principles of patient-centredness**
Efforts to operationalise the principles of patient-centredness can occur on 5 levels that link with and support each other. Patient-centredness can occur at the 1) health care system and public policy level (e.g. emphasis on prevention, promoting public policies and government funding that supports patient-centred care), 2) system or organisational level (e.g. funding, policy, regional governance, service provision models), 3) patient level (e.g. provision of information, needs assessment, satisfaction surveys), 4) provider level (e.g. training and education, multi-disciplinary teams) and 5) community level (e.g. partnerships, service access, transport, environment).

Recently, patient-centredness has been advocated in the care of patients with CKD and attempts have been made to operationalise some of the principles, which are demonstrated in the following examples.

The National Institute for Clinical Excellence (NICE) recommendations for anaemia management in CKD are prefaced by a statement addressing patient-centredness, “Treatment and care should take into account patients’ individual needs and preferences. Good communication between healthcare providers and patients is essential, and should be supported by the provision of evidence-based information offered in a form that is tailored to the needs of the individual patients. Carers and relatives (including parents where appropriate) should have the opportunity to be involved in decisions about the patients’ care and treatment.”(22) Asking open ended, culturally sensitive questions about how the illness impacts on patients, providing patient-friendly information, and considering emotional and social environments, have been recommended(23), as well as a “patient-centred, guideline-supported” approach to communicating prognosis in the dialysis consent process.(24) A new approach to advanced care planning for patients with
end-stage kidney disease (ESKD) has been proposed that emphasizes patient-centredness rather than a document-driven, decision-focused protocol. The model states that the outcomes of advanced care planning should include improved satisfaction, and those which are congruent with patient preferences.(25)

In the Kidney Disease Modernisation Initiative in the UK, professionals and service users are collaborating to develop and evaluate a range of innovative programs to improve the quality of life of patients with kidney disease. Activities include the development of a positive lifestyle program for dialysis patients, conducting a psychological needs analysis and testing cognitive behavioural interventions, and offering peer support services.(26)

A renal-dependent quality of life questionnaire (RDQoL) was developed to measure the impact of kidney disease and its treatment on quality of life. In-depth interviews, were conducted with peritoneal dialysis, haemodialysis and transplant patients to identify items that are relevant and important for patients.(27) Similarly, patient perspectives and preferences were used to develop the patient-centred Choices for Health Outcomes in Caring for End-stage renal disease (CHOICE) Health Experience Questionnaire.(28) However, the questionnaires are not widely and systematically used to assess patient perspectives or experiences. As yet, no formal system for assessing patient perspectives and needs exists in nephrology.

1.4 Consumer perspectives
A comprehensive understanding of patients’ experiences, needs and perspectives can guide professionals towards consumer-centredness in care and health research. (29) Patient centred care should underpin both clinic-based and home-based care, particularly as active self-care is required and encouraged for the optimal and cost-effective management of chronic illness. Therefore taking into account the patients views can lead to increased satisfaction, improved compliance and greater continuity of care. (30)

Healthcare and research are usually professionally driven. There is concern that the knowledge and experience held by consumers are untapped as a healthcare resource. (31) Although the insights and knowledge offered by patients and caregivers, and the values they attached to health outcomes, can be different to those of professionals they need to be given equal status and considered in the development of healthcare and research. (32) The hierarchical distinction between the professional and lay perspectives has been criticized. (33) Rather than being conceptualised as two separate or contradictory perspectives, they should be regarded as complimentary and co dependant. (18)

Substantial work has contributed to understanding the nature of people’s experiences in health and illness. Fundamentally, the lay person’s understanding and perception of illness is a complex social phenomenon, experienced in the context of daily life as a member of the community and a family. (33) The patients’ experiential knowledge and ‘expertise’ of illness are grounded in living with the illness, accepting the diagnosis, managing the disease and symptoms, and monitoring their health status. (34) Without direct experience of the illness, health professionals have limited perspectives on the impact of the illness in its social context and the experience of the illness at the personal level. (35)
Previously, medical perspectives and definitions dominated the understanding of the illness experience, but over the past few decades, knowledge about the illness experience has been significantly broadened. In earlier work by Bury(36), chronic illness was conceptualised as a “biographical disruption.” He described three aspects, which each involved two components, the first component related to what was happening objectively regarding the disease and the second described the affects or changes in the individual. Specifically, the three aspects and its two components are 1) insidious onset and the problem of recognition, 2) emerging disability and the uncertainty about the illness and its management and the rethinking of the person’s biography and self-concept, and 3) an altered situation and the mobilization of resources. Chronic illness disrupted the patients’ relationships and the practical tasks of living. Williams(37) extended Bury’s model by developing a framework for understanding the strategies people used to cope with chronic illness and re-establish a sense of stability, coherence and order. He used the term “narrative construction” to describe the routine way in which people made sense of their lives and explained that people endeavored to locate a logical and meaningful place for the illness in their lives, and were not concerned only with disease aetiology. Charmaz(38) brought focus to patients’ perspectives in the day-to-day contexts within which they live, the ‘loss of self,’ and highlighted the complex interactions between different aspects of the illness experience. For example, the stigma attached to an illness can intensify feelings of social isolation and poor self-esteem.

Later, Frank identified three types of illness narratives: “restitution,” “quest,” and “chaos.”(39) The restitution narrative described how the person finds out about their illness, and then seeks treatment to improve their health. This narrative is usually unsuited to people with chronic illness, in which they can only be treated not cured. The quest narrative is “defined by the ill person’s belief that something is to be gained
through the experience.” The patient gains self-awareness and the ability to help others. This has been exemplified in recent research on assessing the Internet use of people with chronic illness. People used the internet to explain their illness, advise on treatment, offer solutions and interact with each other to give and receive support.(40, 41) In contrast, the chaos narrative is “the anti-narrative of time without sequence, telling without mediation and speaking about oneself without being fully able to reflect on oneself.”(39) When people are in a state of despair and overwhelmed by the intensity and severity of their illness, they become unable to speak coherently. For example, patients attending a neurology clinic with unexplained symptoms gave accounts characterized by uncertainty and confusion, as there was no precise solution to the problem.(42) Hearing other people’s stories can help to reduce their sense of isolation.

It has been acknowledged that awareness and exploration of chronic illness experiences should not only encompass meanings but also include other points of focus such as interpersonal relationships and employment.(43)

1.5 Using qualitative methods

Qualitative methods enable in-depth examination of consumer experiences and perspectives, as encountered in their personal, real-life circumstances.(44) While quantitative survey instruments may be easily accessible, assess psychosocial domains, and are time and resource efficient, they cannot illuminate the participants’ underlying reasons, meanings and thought processes about their health state, the illness, care and health research. Findings from qualitative studies can illuminate the reasons underlying survey results, inform the development of quantitative survey instruments, and guide
further hypothesizing. Qualitative research can capture the individual, family, environmental, social, cultural and organisational factors that shape participants’ opinions.

In this thesis, I used qualitative research methods including meta-ethnography (Chapter 2), in-depth interviews (Chapter 3), focus groups (Chapters 5 and 6), and document analysis (Chapter 6). I used thematic analysis to analyse the data of the qualitative studies (Chapters 3, 5 to 7).

Meta-ethnography was developed by Noblit and Hare (46) and is used to synthesis findings from multiple qualitative studies to derive new insights. This systematic process translates key ideas, metaphors and concepts across different studies to develop a set of overarching concepts or overlapping areas. This can provide more comprehensive knowledge than that derived from single studies, help to inform the development of further studies, and identify gaps in existing research on the topic. In Chapter 2, I report a study where I adopted this method to systematically summarise and synthesis multiple published qualitative studies that examined parental perspectives on CKD among children.

In-depth interviews attempt “to understand the world from the subject’s’ points of views, to unfold the meaning of peoples’ experiences, to uncover their lived world,” through conversation. This technique aims to elicit the participants’ experiences and perspectives on a topic in their own words and is useful in gaining insight into the depth and range of individuals’ experiences and understandings. Questions are open-ended to encourage participants to talk about the topic or issue in their own terms. The types of questions asked can relate to behaviour or experience, opinion or belief, feelings,
knowledge, sensory, and background or demographic. During the interview, probes can be used to ask participants for more detail, encourage participants to continue talking, resolve ambiguities, encourage the participant to finish a line of thought, and reassure participants that the interviewer is paying attention to what is being said.

Face to face in-depth interviews were used in the study of parents of children with CKD reported in Chapter 3, as I wanted to explore emotional and sensitive matters that the participants may not have wished to discuss in the presence of other people.

Focus groups are a “carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment. Each group is conducted with six to eight people by a skilled interviewer.” This method “capitalises on communication between research participants in order to generate data,” allows them to ask each other questions, exchange anecdotes and comment on each other’s experiences and perspectives. The group process can help people to explore and clarify their views in ways that cannot be achieved in a one-to-one interview. Participants can introduce their own ideas and avoid aspects of the topic they do not consider relevant or do not want to discuss. This provides insights into a wide range and form of understanding, and how opinions are constructed. Focus groups are not only useful for finding out about what people think, but also how and why they think the way they do. Focus groups can help people discuss issues they feel too uncomfortable to talk about in an individual interview (for example, issues relating to accepting a kidney transplant from a donor). Additionally, stimulus materials (for example the ranking exercises described in Chapter 6), can encourage participants to engage with one another, explain differing perspectives, and focus discussion around the research topic. For these reasons, focus groups and ranking exercises were used to elicit the data reported in Chapters 5 and 6.
Qualitative document analysis is the systematic examination of documents. It refers to "an integrated and conceptually informed method, procedure, and technique for locating, identifying, retrieving, and analyzing documents for their relevance, significance and meaning."(55) Documents are "constructed in particular contexts, by particular people, with particular purposes, and with consequences – intended or unintended,"(56) and are useful for understanding culture. Examples of documents include media reports, website content, meeting minutes, and personal diaries.(57) The researcher can assess the content, style and language of the documents to gain insight into the phenomenon under study.(58) This approach was used to assess how Australian television news programs and newspapers cover prevention and early detection of CKD (Chapter 7).

The process of qualitative analysis is, "fluid and, crucially, non-linear; the researcher develops the analysis by moving backwards and forwards between the original data and the emerging interpretations."(59) Thematic analysis is commonly used in health care research. The themes and concepts are broadly derived inductively from the data through a process of analysis and constant comparison.(60) The data is not coded into a pre-existing coding framework, or according to the researchers’ preconceptions. I adopted this method to develop descriptive thematic groupings and models that express connections between themes, generate new insights and to elicit a more rich description of the data overall.

While reading the literature during the early part of my doctoral work, I realised that there was a great deal of variation in the standard of reporting qualitative studies in peer reviewed journals. I also discovered that there were several published checklists that provided guidance on judging the quality of qualitative research methods and/or the
quality of reporting qualitative studies. However, there was no widely accepted standard for reporting qualitative studies. In Chapter 8, I report the results of a systematic review of existing checklists for reporting interview and focus group studies and the development of a consolidated checklist. There is currently no consensus among qualitative researchers on the role of quality assessment or reporting criteria, and how they should be applied, and remains a somewhat contentious issue among qualitative researchers.

1.6 The need for the study

Research in CKD has predominantly focused on investigating biomedical aspects and evaluating technological or pharmacological treatment interventions to improve medical management. In healthcare management decisions, explicit acknowledgement of patients’ values and preferences is important, yet there is little data on this.(61) While research into assessing CKD patients’ quality of life and symptom burden and caregiver burden is growing, minimal attention has been given to gaining an in-depth understanding about the experiences, psychosocial issues and needs of patients and their caregivers. These need to be considered when planning and delivering patient-centred care and health research across the whole trajectory of CKD.

CKD is an incurable condition and presents a variety of challenges for those living with it. Patients with CKD face a lifetime of physical, practical, psychological and emotional issues as a result of their diagnosis, co morbidities and treatment-related side effects. Some of these will be experienced during all stages of CKD, while other challenges and issues will be relevant during a specific stage of CKD.
The International Alliance of Patient Organisations proposes that “it would be useful to promote the essence of patient-centred healthcare – that the healthcare system should be designed around the patient with respect for a person’s preferences, values and/or needs.” More rapid and widespread implementation of patient-centredness in care and health research in CKD can be achieved through a better understanding of the needs, experiences and preferences of patients and their families.

This thesis tackles the problem of helping CKD service providers and researchers become more consumer-centred by exploring the perspectives of patients and caregivers across the whole trajectory of CKD including predialysis, dialysis, and kidney transplantation.

1.7 Objectives

The overall purpose of this thesis is to explore a wide range of perspectives, needs and experiences of patients with CKD and their caregivers, in order to assist the development of more consumer-centred care. By examining patients’ and caregivers’ experiences of CKD, CKD patients’ research priorities, support interventions for informal caregivers of people with CKD, and the presentation of CKD prevention and early intervention in the media, my intention is to present wide ranging, though obviously not all-encompassing, consumer perspectives on CKD.

The following research objectives address the overall purpose:

A. Caregiver perspectives on caring for a CKD patient
1. To systematically summarise and synthesise findings from published qualitative studies examining parent experiences about caring for a child with CKD.

2. To gain a more detailed understanding of the experiences of parents of children with CKD by conducting in-depth interviews to explore how CKD affects parental caregivers psychologically, socially and physically.

3. To systematically review and summarise findings from studies on support interventions for informal caregivers of people with CKD.

B. Patient perspectives on CKD, health care and research

4. To describe and compare the range and depth of experiences and perspectives of predialysis, dialysis and transplantation patients about the meaning of CKD and its treatment, impact on lifestyle and relationships, and coping strategies.

5. To elicit priorities for research topics from patients who have CKD and to explore the reasons underlying their selection of research topics.

6. To assess how Australian television news programs and newspapers cover CKD, focusing particularly on the extent and manner in which news covers prevention and early detection of CKD. This aim was developed during the study because participants frequently expressed concerned about the poor public profile of CKD, and lack of information on prevention and early detection.
C. Criteria for reporting qualitative research

7. To develop a checklist for explicit and comprehensive reporting of qualitative studies (in-depth interviews and focus groups). This aim was developed as during the course of reading many papers and texts on qualitative methodology, it became clear there were no generally accepted standards about reporting qualitative research.

The study objectives in this thesis converge to the overall aim, to advance patient-centred healthcare and research in CKD, and hence improve the health and quality of life of patients with CKD and their caregivers.

1.8 Structure of the thesis

In this chapter, I have examined the theoretical and disciplinary frameworks relating to consumer-centredness in care and health research, and health and illness experiences. The contents of chapters 2 to 8 are exact duplicates of the published (Chapter 2, 6, 7, 8), accepted (Chapter 4) or submitted (Chapter 3, 5) manuscripts for journal publication.

In Chapters 2 and 3, the experiences of parents who have children with CKD are described through a systematic review of the literature and in-depth interviews with parents. Chapter 4 systematically reviews studies on support interventions for caregivers of CKD patients.
Chapters 5 describes patients’ experiences and perspective of living with CKD using focus groups, and Chapter 6 elicits patients’ priorities for health research and identifies the reasons underlying their decisions on research topics using focus groups. In Chapter 7, an analysis of news media coverage on the prevention and early detection of CKD in Australia is presented.

In Chapter 8, a framework for reporting qualitative research, developed from existing checklists, is proposed.

The final chapter concludes the thesis with an outline of the main findings of the studies, a discussion of the feasibility, weaknesses and challenges of using qualitative methods to achieve the study objectives, a comparison with existing literature, and consideration of the implications of the results for advancing patient-centred healthcare and research in CKD.
1.9 References


2. The experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies

2.1 Abstract

Objective: The objective of this study was to describe the experiences of parents who have children with chronic kidney disease.

Methods: We conducted a systematic review and meta-ethnography of studies that had used in-depth interviews or focus groups to explore experiences of parents with children who have chronic kidney disease (predialysis, haemodialysis, peritoneal dialysis or after kidney transplantation). We searched 5 electronic databases (through to August 2005) including Medline, EMBASE, PsycINFO, Cumulative Index to Nursing and Allied Health Literature, Sociofile/Sociological Abstract and reference lists of relevant articles.

Results: Sixteen papers that reported the experiences of parents of 358 children with chronic kidney disease were included. Ten themes emerged, which we grouped into 3 interrelated clusters: intrapersonal (living with constant uncertainty, stress and maintaining vigilance despite experiencing fatigue), interpersonal (medicalisation of the parental role, dependency and conflict with staff, and disrupted peer relationships) and external issues (management of the medical regimen, pursuit of information, organising transport, accommodation and finances, adhering to the child’s liquid and diet restrictions and balancing medical care with domestic responsibilities).
Conclusions: In addition to “normal” parental roles, being a parent of a child with chronic kidney disease demands high-level healthcare provider, problem solving, information seeking, and financial and practical skills, at a time when the capacity to cope is threatened by physical tiredness, uncertainty, and disruption to peer support within and outside the family structure. Parents of children with chronic kidney disease need multidisciplinary care, which may lead to improved outcomes for their children.

2.2 Background

Children with chronic kidney disease (CKD) have an incurable condition. They and their families face a lifetime of medical treatment and uncertainty. Renal replacement therapy with dialysis and kidney transplantation for end-stage kidney disease, the most severe form of CKD, has meant survival is possible, but mortality remains 30 times higher than for children without kidney disease(1), and hospitalisation, infection, delayed growth and development, short stature and bone disease are frequent complications.(2, 3) Care is complex and multidisciplinary and often requires multiple medications (some delivered subcutaneously or intravenously), invasive procedures, thrice-weekly haemodialysis for 4-5 hours, or continuous peritoneal dialysis, and nutritional supplementation via enteral tubes and pump devices.

Given the complexity of care required, parents and guardians adopt a health care provider role, in addition to their usual parental responsibilities, and the quality of care they provide is an important determinant of the outcome for their children.(4-7) Parents become nurses, pharmacists and physicians for their children. Parents deliver home-
based interventions, including dialysis and nutritional supplementation, which are
technically demanding and in hospital are provided by highly trained nursing staff. They
monitor their child’s health and recognise symptoms warranting more specialised
assessment and intervention. Many of these are requirements for all parents of children
with chronic disease but the demands on parents of children with kidney disease are
greater because of the complexity of the care, especially for children on home dialysis.

Because of the central role of parents in the care of children with CKD, their own health
and well-being are important. Parents of children with CKD have reported a lower
quality of life, difficulties in managing the child’s care and higher levels of anxiety and
maladaptive behaviour.(8, 9) This in turn can have a detrimental impact on the child’s
personal development and medical treatment. Sufficient support for parents may prevent
or ameliorate these problems and indirectly achieve better outcomes for children.

This systematic review summarises published qualitative studies examining the parents’
experiences about caring for a child with CKD. Although the review focuses on CKD,
the experiences of parenting a child with CKD are likely to share much with parenting a
child who is technologically dependent or chronically ill.(10-12) For this reason, the
results can inform the development, implementation and evaluation of support strategies
offered by general practitioners and speciality multidisciplinary teams for parents who
have children with CKD.

2.3 Methods

Selection Criteria
Studies using interviews or focus groups to explore the experiences of parents of children and adolescents with CKD were included. A child was defined as ≤21 years of age, and any stage of kidney disease was included (predialysis, dialysis or transplant). Non-English articles were excluded to prevent cultural and linguistic bias in translations. Articles were excluded when they used structured questionnaires as the primary method for data collection or included >30% of data from parents of children without CKD. Observational epidemiologic studies, editorials, reviews, nonresearch articles and studies that did not elicit data from parents were also excluded.

**Literature search**

Medical Subject Headings (MeSH) terms and text words for CKD (predialysis, dialysis, transplant) were combined with terms relating to parents (marriage, divorce, marital satisfaction) or children and then combined with MeSH terms and text words for psychological (adaptation, stress, depression, mental fatigue, and mental health) and sociological (support, adjustment, socioeconomic factors, behaviour, group processes, and interpersonal relations) concepts, communication, life change events and quality of life. The searches were carried out in Medline (1966 through August 2005), PsycINFO (1806 through August 2005), Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1982 through August 2005), EMBASE (1980 through August 2005), and sociofile/sociological abstracts (1960 through August 2005) using a detailed search strategy. (See Appendix A.1) The journals ‘Qualitative Health Research’ and ‘Qualitative Research’ were searched using key words relating to kidney disease. We also searched reference lists of relevant studies and reviews.

Two reviewers (AT, AL) screened the abstracts, and studies were discarded when they did not fit the inclusion criteria. Studies that appeared to include relevant data or
information were retrieved and their full-text versions were analysed and examined for study eligibility. Any uncertainties and disagreements were resolved in consultation among the reviewers.

**Quality of reporting**

Unlike for randomized, controlled trials; diagnostic test studies; and observational studies, no uniform guidelines for reporting qualitative studies are available(13). Therefore we searched for tools that are used to appraise qualitative studies(14-20) and for quality assessment checklists in systematic reviews of qualitative studies.(21-26) We distilled existing tools and checklists into a composite checklist of items that covered the characteristics of the research team, study design and analysis and reporting of findings. We did not aim to assess the quality of each study; rather, our intention was to assess the explicitness and comprehensiveness of reporting. The criteria for each domain are found in Table 2.2.

**Synthesis of findings**

We performed a synthesis of the studies that met the inclusion criteria, drawing on the technique of meta-ethnography developed by Noblit and Hare(27) and on modifications to this approach proposed by Campbell et al.(25) We followed the meta-ethnographic approach by recording the key concepts of each study, and systematically identifying common and disparate concepts and themes within and across the studies. To begin the synthesis, we used a recent paper by Baines et al(28) then analysed subsequent papers in comparison with the other studies. Each paper was read repeatedly to ensure all concepts were integrated and the relationships between the key concepts of each study were explored. We used the notion of first-order, second-order and third-order constructs to analyse and reinterpret the studies. First-order constructs are insights offered by the
respondents of each original study. All participant quotations and parent responses paraphrased by the original researchers were extracted as first-order constructs, and grouped for each stage of CKD (predialysis, dialysis and transplant). Second-order constructs are the interpretive themes that were developed by the original researchers from their first-order constructs. We described and listed the themes described by the authors of each original study and counted the number of studies that identified each theme. Third-order constructs are derived from the synthesis of multiple studies. We developed third-order constructs by analysing the second-order constructs to identify new, common themes.

2.4 Results

**Literature search and study descriptions**

Our search yielded 338 articles. Of these, 242 were excluded after title and abstract review because they were ineligible. Of the remaining 96 potentially eligible studies, 80 were excluded because they were nonqualitative research, had no parent participants, did not include children with CKD, were duplicate articles, or only included adult patients. Except for interviews and focus groups, the search did not yield other qualitative study types. Sixteen studies could be included in the review. (Figure 2.1) The characteristics of the study populations of all 16 studies are presented in Table 2.1. (28-43) In 14 studies, data were collected by in-depth or semi-structured interviews, and 2 studies used focus groups. The 16 studies included parents of 358 children with CKD. Of the 15 studies that reported the child’s stage of CKD at the time of data collection, 34 children were in the predialysis stage, 41 children were on peritoneal dialysis, 112 were undergoing haemodialysis and 106 children had received a kidney transplant. Often, parents
described their experiences from previous disease stages in addition to the current stage. Eight studies included parent experiences during the predialysis stage, 14 while their child was on dialysis and 9 during the transplant stage. Of the 10 studies that stated the number of participating fathers and mothers separately, mothers represented 86% (168) of interviewees. All studies were conducted in North America, continental Europe or the United Kingdom.

**Quality of reporting of included studies**

Study details were not provided in almost all studies. (Table 2.2) Interview questions and prompts were not provided in any article, so we were unable to determine whether unreported themes were attributable to: parents’ not being prompted by the researchers, parents’ being prompted but choosing not to discuss the theme or authors’ deciding not to report the themes that parents discussed. Studies generally provided insight into the experiences, perceptions and views of parents but we were unable to assess how data analysis was conducted, because details on data analysis were often not reported.

Studies were not excluded or weighted on the basis of the quality of reporting assessment, because methodological details with which we could assess study quality were limited. Empiric data on the relationship between the quality of reporting qualitative research and the quality of methods are not available; therefore, we have no solid basis on which to judge the quality of the original findings. However, we include the appraisals here as it may indirectly lead to improvements in the quality of reporting qualitative research.

*Synthesis*

First-order constructs
An illustrative selection of first-order constructs is presented in Table 2.3 (the full list is available from the authors).

Second-order constructs
The explanations and theories offered by the authors of the original studies (second-order constructs) were classified by stage of CKD. The quotations provided belong to the authors of each original study.

Predialysis stage: Self-accusation and blame were reported in 6 of 8 studies, with 4 reporting depression, generalised anger, and uncertainty surrounding misdiagnosis and the child’s future. (Table 2.4a)

“The endless questions which are poured on the doctors – when families feel free to do so – indicate overall anxiety and the need to unload guilt feelings which are most important when parents actually feel ambivalent towards this particular child. Depression, self-accusation or aggression towards others are outward signs of the search for someone …(who) can be held responsible for the wrong from which they feel they suffer.”(39)

“The immediate responses [are] characterized by pessimism, a felt lack of understanding, and a fear that the child might die.”(33)

Dialysis stage: The 3 most common themes were emotional turmoil, uncertainty about the child’s prognosis and surrendering control of the child to the clinical staff. Studies reported that parents were satisfied with the provision of care for their child but also identified poor communication between parents and staff. Authors of 6 studies identified
a restriction on the social life of parents. Lengthy and frequent hospital visits were commonly reported and most authors described that parents experienced difficulties with providing medical care and ensuring adherence to liquid and diet restrictions. (Table 2.4b)

“Seeing the child in distress at a time when her own role was unclear seemed, to the mother to symbolize her loss of control over the child’s life, a need to share, if not to surrender, parenting.”(30)

“A mother who has a child of 4.5 years of age, with crying, tells the child’s reaction for this process: ‘Whenever a person drinks water in front of him, he is always gulping as if he were drinking. And this situation makes me miserable.”(29)

“The mothers knew that fear of the ill child kept many people away — particularly, a fear of not knowing what to say. ‘It was like people we chummed around with were scared.”(35)

“When their children were hospitalised they usually felt a need to remain and to maintain the watchful eye. They often met criticism from staff who felt the mothers were being mistrustful or difficult. The mothers often experienced hurt and anger when they themselves were judged. It was important for them to watch over their children, but they also wanted to be recognized as having expertise in their child’s care, to be trusted, and to join the health care team. The mothers wanted to be involved and consulted, rather than remaining on the periphery of the decision-making process. They felt threatened by discussions about their child
that occurred within hearing range, but of which they were not a part. This activity as well as the withholding of reports by health professionals heightened their uncertainty and provoked fear.”(35)

“Ongoing discussions between doctors and the parents hoping to achieve compliance with the dietary restrictions did not really succeed. In response to non-compliance, frequent hospitalisations of the child, decided on by the head doctor, were seen by the parents as disorganising their family life.”(43)

Transplant stage: Parents reported similar emotions to those reported during the dialysis stage but expressed added uncertainty about rejection of the kidney graft. Also, authors identified an increased social freedom and improved interaction within the family. Themes related to the parent kidney donor were repeatedly identified, including the development of a special bond between the child and parent donor, and spousal concern over the donor’s well-being. Six studies reported struggles relating to diet and medication adherence. (Table 2.4c)

“The ‘special’ relationship between the patient and the donor often placed husband and wife at odds over such family matters as discipline of the patient and other siblings, and how much freedom to allow the patient.”(41)

“Transplant complications, like those of dialysis, threw child and family back into the depression and protest of early treatment stages, with feelings of bitterness added as the result of lost hopes.”(30)
“After the turmoil of the first 6 to 12 months, patterns of daily life are apparently restored fairly readily in most families if the child with the transplant is thriving physically.” (34)

Third-order constructs

From the second-order constructs, we identified 10 inter-related third-order constructs which we grouped into 3 themes: 1) intrapersonal issues, which described the personal experiences of the parent (i.e. the psychological, emotional and physical impact of having a child with CKD); 2) interpersonal issues, which were the experiences concerning the parents’ relationships with other people, specifically family members, staff, and friends and acquaintances; and 3) external issues, which included the practical needs, responsibilities and logistical concerns expressed by the parents i.e. household care, diet and nutrition, transport, relocation and employment, medical regimen and hospitalisation and information (Figure 2.2).

Common intrapersonal experiences include the shock faced by parents during the initial diagnosis, followed by constant uncertainty about their child’s prognosis. The lack of confidence in delivering care for the child, the pressure of having to exercise unwavering vigilance and fatigue were also common themes.

The main interpersonal experiences of parents varied. Some parents reported that their marital relationship strengthened, while others described partner neglect and abandonment. Family life was disrupted and some parents faced sibling jealousy and resentment. Generally, the illness constrained the social life of parents but this improved after transplantation. Friends and extended family provided practical support but a lack of understanding was commonly reported. The control of clinical staff over the ill child
and the lack of open communication created tension and frustration in parent-staff relationships. Continuity of care providers reduced parental anxiety.

The main external issue was managing the multiple responsibilities including: adhering to the medical regimen, observing the ill child’s symptoms, integrating medical care and fulfilling domestic duties. Liquid and diet restrictions were particularly difficult to adhere to. Parents were often concerned about their child’s appearance, development and future prospects. Parents were required to arrange transport and accommodation, and some experienced financial hardship. Not all parents received adequate information on the illness and treatment.

2.5 Discussion

We identified 10 themes in the experiences of parents of children with CKD and we grouped these into three clusters: 1) intrapersonal issues (involving the psychological, emotional and physical impact of the child’s illness); 2) interpersonal issues (involving the parents’ interaction within the family and relationships with staff and friends); and 3) external issues (involving the practical needs, responsibilities and logistic concerns of parents). Parents lived with constant uncertainty about their child’s medical prognosis and future prospects. Despite experiencing physical fatigue, parents exercised vigilance in monitoring their child for symptoms and in managing complex healthcare responsibilities. Medical intervention meant that parents had to adapt to a redefined parenting role; parents became dependent on staff members, and some experienced conflict with healthcare providers. The need to deliver difficult and long-term medical interventions directly, and to facilitate many others indirectly by being the conduit
between child and health care provider interfered with the social life and support networks of parents. Parents were required to cope with the intense medical regimen; comprehend information about the disease and treatment; arrange transport, accommodation and finances; adhere to the child’s liquid and diet restrictions; and endeavour to maintain home duties at a time when their own networks for support and resilience were threatened.

A major strength of our study was that we used systematic review methods. We conducted a comprehensive search and an independent assessment of studies with predetermined inclusion and exclusion criteria. Study reporting was appraised and presented according to explicit assessment criteria. Findings were synthesized using an established and reproducible method. To assist health professionals to understand and use the themes, we developed a simple, pragmatic, clinically relevant diagrammatic representation of the findings (Figure 2.2). Both the analytic process and the framework could be applied to other aspects of pediatric clinical care.

No attempt was made to contact the authors of the 16 papers and original interview and focus group transcripts were not obtained. We depended on what was reported by the authors of the primary studies. In qualitative research, empiric data on the relationship between the quality of the reporting and the quality of the methods is not available. For this reason, we did not assess the association between the quality of the reporting and the findings in the 16 studies.

Checklists including CONSORT (Consolidated Standards of Reporting Trials)(44), QUOROM (Quality of Reporting of Meta-analyses),(45) and STARD (Standards for Reporting of Diagnostic Accuracy)(46) for assessing quantitative studies are underpinned
by empiric work, but there is no empiric work available as yet to support the validity of
group quality assessment items for qualitative studies. There is no universally accepted list of
quality assessment criteria for qualitative studies and no evidence about the validity of the
quality of reporting as a proxy for actual study quality; therefore, we chose not to
prioritise or assign weighting to the findings of each study since this would have been
based on unverifiable judgments. Instead, we adopted a pragmatic approach and gave
equal consideration to the findings of the 16 studies.

While this review described parents’ experience of coping with CKD, our synthesis
showed some broad commonalities with findings offered by the wider and more recent
literature on parenting children with chronic illness or disability. (10-12, 47-49) For
example, 1 study described sustained parental uncertainty as ‘living with a time bomb,’
which was intensified by waiting for clinical test outcomes, enduring prolonged intervals
between appointments, and observing abnormal changes in their child’s physical
appearance and behaviour. (10) A recent literature review on the needs of parents with
chronically sick children found that a lack of control caused parental stress, and parents
faced issues relating to the management of time, management of illness, reorganisation of
family life and management of illness. (11) Another review on the experiences of mothers
with disabled children highlighted psychological and somatic distress, fatigue, social
suffering, financial instability, and combative interactions with health professionals. (12)
The themes that emerged from these 2 reviews were similar to those identified in our
study.

Future qualitative studies on parental experiences in CKD, particularly using in-depth
interviews, could expand and assess the constructs developed in our review. Additional
research could identify parental issues that are specific to particular geographic,
demographic and institutional contexts. We also suggest research with support organisations and health care providers involved in the care of children with CKD to assess concordance and dissimilarities between their perspectives and parent perspectives on parental experiences and needs. Their perceptions about parental experiences and needs, based on their encounters with multiple parents, could supplement data obtained from parents and provide healthcare providers and parents a more complete and accurate understanding of parental experiences.

In paediatric clinical care, efforts are often focused on providing medical treatment and tests, performing technical procedures, and monitoring the affected child’s well being, rather than explicitly considering the parents as a target of intervention both to benefit the child indirectly and to make explicit that parents deserve care in their own right. With a better understanding of parent experiences, health care providers could provide more supportive and empathetic care. This systematic review of qualitative studies highlights the need for the clinical team to encompass strategies to provide more support to parents as an important component of pediatric clinical care.

A framework for improving the quality of support services provided to parents who have children with chronic kidney disease can be developed by extrapolating data from the third order constructs presented in Figure 2.2. The development, implementation and evaluation of support interventions would require collaboration with parents and relevant stakeholders including clinical services, and professional and consumer organisations.

Our principal recommendation to health care providers is to develop, implement and evaluate programs that aim to improve the intrapersonal, interpersonal and external experiences of parents; however, the reporting of the original studies’ methods was
always incomplete and therefore our specific recommendations should be given careful, but cautious, consideration. On the basis of this review, strategies to improve intrapersonal well-being should aim to reduce parental anxiety and increase the confidence of parents to manage care for the ill child. The health care team should provide continued attention and be ready to consult, give guidance and provide opportunities for parents to express their concerns and feelings. Parents should be equipped and trained to deliver home-based care and be made aware of and prepared for the role adjustment and emotions that they may experience. For interpersonal issues, we recommend programs that aim to strengthen the family relationship and reduce neglect of other family members, such as family counseling and sibling programs. Parent support groups allow parents to learn and support other parents facing a similar situation.

Professional training for health care personnel can reduce the disparity between professional and parent perceptions of each other, and the professionals’ awareness of the value of caregiver ‘expertise’ can improve the interaction between parents and staff.

When feasible, continuity of care by preferred staff could be offered to parents. To improve support for parents in managing their external issues, we suggest initiatives that aim to improve parent management of the medical regimen by providing parents with comprehensive information and training. Home visits can promote easier transitions between hospital and home care. Information that parents require and perceive to be relevant (e.g. illness, treatment, lifestyle changes, support services, dietary advice) should be provided and readily accessible. Respite care programs could be offered to provide some relief to parents who need recuperation from managing medical and household care.

To improve parental quality of life, which could be expected to improve child outcomes, a comprehensive understanding of parent experiences and perspectives is required.
Despite the current limitations of systematic review methods of qualitative studies, we have demonstrated that they can collate, analyse and render comprehensible a wide scope of relevant information that can be useful for improving the quality of clinical care that is provided to patients and their families.
Figure 2.1 Literature Search

**MEDLINE**
158 citations

**EMBASE**
49 citations

**PsychINFO**
43 citations

**CINAHL**
85 citations

**Other Sources**
3 citations

---

**Title and abstract review**
Excluded (n=242)

- No parent responses or parent assessment 77
- Non-CKD 63
- Non (primary) research articles 32
- Adult CKD patients 32
- Duplicate articles 20
- Questionnaire / No qualitative analysis 10
- Non-English articles 4
- Laboratory research 4

---

**Full-text analysis**
Excluded (n=80)

- Questionnaire / No qualitative analysis 28
- No parent responses or parent assessment 18
- Non (primary) research articles 14
- Non-CKD 11
- Adult CKD patients 7
- Duplicate articles 1
- Unable to determine if CKD patients were children 1

---

**Included in systematic review**

**16 Studies**
(pARENTS of 358 children)
<table>
<thead>
<tr>
<th>Author (Year of Publication)</th>
<th>Country</th>
<th>Fathers (n)</th>
<th>Mothers (n)</th>
<th>Patient age (y)</th>
<th>Pre-dialysis (n)</th>
<th>PD (n)</th>
<th>HD (n)</th>
<th>Tx (n)</th>
<th>Total no. patients</th>
<th>Interview / Focus group</th>
<th>Methodological Orientation Stated</th>
<th>Principal Parent Experiences Explored</th>
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</thead>
<tbody>
<tr>
<td>Baines et al (2001)</td>
<td>United Kingdom</td>
<td>6</td>
<td>1</td>
<td>-</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>7</td>
<td>Semistructured</td>
<td>Social and psychoanalytical theory</td>
<td>Parent donor and child recipient relationship</td>
</tr>
<tr>
<td>Crittenden et al (1977)</td>
<td>United States</td>
<td>0</td>
<td>17</td>
<td>5-10</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>17</td>
<td>17</td>
<td>Interview</td>
<td>-</td>
<td>Coping with stress of treatments</td>
</tr>
<tr>
<td>Hislop and Lansing (1983)</td>
<td>United States</td>
<td>1</td>
<td>3</td>
<td>1-13</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>Semistructured</td>
<td>-</td>
<td>Comparing home PD modalities</td>
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<tr>
<td>Karrfelt et al (2000)</td>
<td>Sweden</td>
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<td>12</td>
<td>0-14</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>18</td>
<td>18</td>
<td>Semistructured</td>
<td>Grounded theory</td>
<td>Decision-making about donation; consequences of and reflections on donation</td>
</tr>
<tr>
<td>Klein and Simmons (1979)</td>
<td>United States</td>
<td>0</td>
<td>65</td>
<td>8-20</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>65</td>
<td>Semistructured*</td>
<td>-</td>
<td>Impact of kidney disease and transplant</td>
</tr>
<tr>
<td>Korsch et al (1973)</td>
<td>United States</td>
<td>-</td>
<td>-</td>
<td>1-20</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>35</td>
<td>35</td>
<td>Semistructured</td>
<td>-</td>
<td>Psychosocial attributes and impact on long-term rehabilitation; family functioning</td>
</tr>
<tr>
<td>MacDonald (1995)</td>
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<td>0</td>
<td>4</td>
<td>-</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>0</td>
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<td>In-depth</td>
<td>Ethnography</td>
<td>Meaning assigned to child’s illness by mothers</td>
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<td>Nicholas (1999)</td>
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<td>0</td>
<td>32</td>
<td>1-18</td>
<td>0</td>
<td>14</td>
<td>10</td>
<td>8</td>
<td>32</td>
<td>In-depth</td>
<td>Ethnography</td>
<td>Experiences and meanings attributed to maternal caregiving</td>
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<tr>
<td>Obrecht et al (1992)</td>
<td>United States</td>
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<td>12</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>In-depth</td>
<td>Thematic analysis</td>
<td>Managing child’s care</td>
</tr>
<tr>
<td>Rainbult (1973)</td>
<td>France</td>
<td>-</td>
<td>-</td>
<td>3-20</td>
<td>30</td>
<td>0</td>
<td>39</td>
<td>0</td>
<td>69</td>
<td>In-depth</td>
<td>-</td>
<td>Psychological issues</td>
</tr>
<tr>
<td>Reichwald-Kluger et al (1984)</td>
<td>Germany</td>
<td>-</td>
<td>-</td>
<td>7-19</td>
<td>0</td>
<td>0</td>
<td>20</td>
<td>0</td>
<td>20</td>
<td>In-depth / Semi-structured*</td>
<td>-</td>
<td>Psychosocial adaptation</td>
</tr>
<tr>
<td>Sampson (1975)</td>
<td>United States</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0</td>
<td>0</td>
<td>8</td>
<td>14</td>
<td>22</td>
<td>Interview</td>
<td>-</td>
<td>Social and emotional adaptation</td>
</tr>
<tr>
<td>Schultz and Farrell (1998)</td>
<td>Canada</td>
<td>3</td>
<td>7</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>10</td>
<td>10</td>
<td>In-depth</td>
<td>Phenomenology</td>
<td>Every day experience and events and meanings attributed to them</td>
</tr>
<tr>
<td>Waisman (1990)</td>
<td>France</td>
<td>-</td>
<td>-</td>
<td>6-20</td>
<td>0</td>
<td>11</td>
<td>4</td>
<td>0</td>
<td>15</td>
<td>Semi-structured</td>
<td>-</td>
<td>Doctor-parent interactions; family relationships and social life</td>
</tr>
<tr>
<td>Cimele (2002)</td>
<td>Turkey</td>
<td>6</td>
<td>25</td>
<td>4-20</td>
<td>0</td>
<td>0</td>
<td>31</td>
<td>0</td>
<td>31</td>
<td>Focus group</td>
<td>Content analysis</td>
<td>Stress factors; coping strategies</td>
</tr>
<tr>
<td>Middleton (1996)</td>
<td>United Kingdom</td>
<td>5</td>
<td>8</td>
<td>-</td>
<td>0</td>
<td>8</td>
<td>0</td>
<td>0</td>
<td>8</td>
<td>Focus group</td>
<td>Discourse analysis</td>
<td>Psychosocial issues</td>
</tr>
</tbody>
</table>

Abbreviations: PD, peritoneal dialysis; HD, hemodialysis; Tx, transplant; (-), not stated by authors; *Data from questionnaires not included; †Study included 1 family with 2 CKD children
Table 2.2 Assessment of reporting of study methods

<table>
<thead>
<tr>
<th>Item</th>
<th>No. of Studies Reporting Each Item (N=16 studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personal Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Interviewer / facilitator characteristics (<em>which author/s conducted the research?</em>)</td>
<td>6</td>
</tr>
<tr>
<td>Credentials</td>
<td>11</td>
</tr>
<tr>
<td>Occupation</td>
<td>7</td>
</tr>
<tr>
<td>Gender</td>
<td>14</td>
</tr>
<tr>
<td>Experience and Training</td>
<td>0</td>
</tr>
<tr>
<td><strong>Relationship with participants</strong></td>
<td></td>
</tr>
<tr>
<td>Relationship established prior to study commencement</td>
<td>3</td>
</tr>
<tr>
<td>Participant knowledge of the interviewer (<em>e.g. personal goals, reasons for doing the research</em>)</td>
<td>1</td>
</tr>
<tr>
<td><strong>Participant Selection</strong></td>
<td></td>
</tr>
<tr>
<td>Sampling (<em>How were participant selected? e.g. purposive, convenience, consecutive, snowball</em>)</td>
<td>16</td>
</tr>
<tr>
<td>Method of approach (<em>e.g. face-to-face, telephone, mail, email</em>)</td>
<td>5</td>
</tr>
<tr>
<td>Sample size (<em>How many participants were in the study?</em>)</td>
<td>16</td>
</tr>
<tr>
<td>Non participation (<em>How many people refused to participate or dropped out? Reasons?</em>)</td>
<td>9</td>
</tr>
<tr>
<td><strong>Setting</strong></td>
<td></td>
</tr>
<tr>
<td>Setting of data collection (<em>Where was the data collected?</em>)</td>
<td>12</td>
</tr>
<tr>
<td>Presence of non-participants (<em>Was anyone else present besides the participants and researchers?</em>)</td>
<td>6</td>
</tr>
<tr>
<td><strong>Data Collection</strong></td>
<td></td>
</tr>
<tr>
<td>Interview guide (<em>Were questions, prompts, guides provided by the authors? Was it pilot tested?</em>)</td>
<td>13</td>
</tr>
<tr>
<td>Repeat interviews (<em>Were repeat interviews carried out? If yes, how many?</em>)</td>
<td>15</td>
</tr>
<tr>
<td>Audio / visual recording (<em>Were audio or visual recording used to collect the data?</em>)</td>
<td>8</td>
</tr>
<tr>
<td>Field notes (<em>Were filed notes made during and/or after the interview?</em>)</td>
<td>5</td>
</tr>
<tr>
<td>Duration (<em>What was the duration of the interviews or focus group?</em>)</td>
<td>8</td>
</tr>
<tr>
<td>Data (or theoretical) saturation (<em>was data saturation discussed?</em>)</td>
<td>3</td>
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<tr>
<td>Transcripts returned to participants</td>
<td>1</td>
</tr>
<tr>
<td><strong>Data Analysis</strong></td>
<td></td>
</tr>
<tr>
<td>Number of data coders</td>
<td>1</td>
</tr>
<tr>
<td>Description of the coding tree</td>
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</tr>
<tr>
<td>Protocol for data preparation and transcription</td>
<td>3</td>
</tr>
<tr>
<td>Use of software</td>
<td>2</td>
</tr>
<tr>
<td><strong>Reporting</strong></td>
<td></td>
</tr>
<tr>
<td>Parent quotations provided</td>
<td>12</td>
</tr>
<tr>
<td>Clear insight into the meaning and perception of parents</td>
<td>13</td>
</tr>
<tr>
<td>Description and explanation of diverse cases</td>
<td>15†</td>
</tr>
</tbody>
</table>

*9/15 conducted repeat interviews; †excluding single family interview
### Table 2.3 Selected first order constructs

<table>
<thead>
<tr>
<th>CKD Stage</th>
<th>First order constructs</th>
</tr>
</thead>
</table>
| Predialysis | I never knew what to ask... I didn't think of questions until later... we were all mixed up, just signed the papers and went.\(^{(30)}\)  
It was hanging over our head that one day the kidneys might fail\(^{(39)}\)  
They really listened. The doctor was so good, took time with us. Nurses were kind -- even kidded with us.\(^{(30)}\) |
| Dialysis | I have heart palpitations and faint whenever I get worried. I cannot make myself comfortable.\(^{(29)}\)  
Having someone depend on you is smothering... it's like somebody's trying to take your life... and I've got to get out of the situation I'm in... I'm fighting for air here and you don't know how to get out.\(^{(37)}\)  
A lot of times we're sleeping and the machine will beep. Then he'll vomit. It's like you don't have a full night's sleep.\(^{(37)}\)  
I wish you had named my brother Ozel (meaning special) instead of Ozer because he is your special child.\(^{(29)}\)  
I've been living with this for three years; I know what I'm talking about. It sort of reached a point with me that I thought, we're losing control over our own child... I made the decision that I'm calling the shots... we really had to sort of push our way to the front.\(^{(35)}\)  
(Health professionals) take away all of my control.\(^{(37)}\)  
I'll go crazy in that closed, depressing place. It was like death, the children were so sick and the parents so down.\(^{(30)}\)  
I hate this hospital. I wish that somebody would just blow it off the face of the earth.\(^{(37)}\)  
And then in the morning when he gets up, I take him off the cycler, he has a bath every morning and then a dressing change and the meds, seven in the morning and three in the afternoon, right now four because he's having another antibiotic...\(^{(35)}\)  
However at home I compare with his healthy peers and understand his regression.\(^{(32)}\)  
Whenever a person drinks water in front of him, he is gulping as if he were drinking. And this situation makes me miserable.\(^{(29)}\) |
| Transplant | We have not had anything serious yet. I keep watching for the next disaster. Someday it might fail, we always know... it finally dawned on me that the kidney is a success but infections and blood pressure -- that's the turmoil we live with, I think it gets harder to accept than easier...\(^{(30)}\)  
We never feel safe, it is as if we were living on a quagmire.\(^{(38)}\)  
It tears him (father) up to think his kidney wasn't perfect.\(^{(39)}\)  
You want to baby him all the time... and you just can't.\(^{(38)}\)  
My husband is both over-protective and over-anxious.\(^{(32)}\)  
We felt isolated before transplant but now we are free to do what we like, just like with an ordinary child.\(^{(32)}\)  
It was an amazing change -- all gung ho since! Doctors, teachers -- no one could believe it was the same child.\(^{(30)}\) |
Table 2.4a. Second-order constructs: pre-dialysis patients

<table>
<thead>
<tr>
<th>CONSTRUCT</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intrapersonal Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Shock of finding out</td>
<td>●</td>
</tr>
<tr>
<td>Conflicting physicians’ opinion about the condition</td>
<td>●</td>
</tr>
<tr>
<td>Uncertainty about the child’s diagnosis and potential kidney failure</td>
<td>●</td>
</tr>
<tr>
<td>Denial about the disease</td>
<td>●</td>
</tr>
<tr>
<td>Self-accusation and blame</td>
<td>●</td>
</tr>
<tr>
<td>Depression and anger</td>
<td>●</td>
</tr>
<tr>
<td>Pursue information about disease and treatment</td>
<td>●</td>
</tr>
<tr>
<td>Hope for recovery</td>
<td>●</td>
</tr>
<tr>
<td>Anxiety about mortality</td>
<td>●</td>
</tr>
<tr>
<td><strong>Interpersonal Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Neglect other family members</td>
<td>●</td>
</tr>
<tr>
<td>Satisfaction with provision of care by staff</td>
<td>●</td>
</tr>
<tr>
<td><strong>External Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Mothers the primary care giver</td>
<td>●</td>
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●, particular theme identified in the study
Table 2.4b. Second-order constructs: dialysis patients

<table>
<thead>
<tr>
<th>CONSTRUCT</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intrapersonal Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Anger, depression, stress, frustration</td>
<td>(28)</td>
</tr>
<tr>
<td>Uncertain of child’s prognosis</td>
<td>(30)</td>
</tr>
<tr>
<td>Denial and suppression of emotions</td>
<td>(31)</td>
</tr>
<tr>
<td>Lack confidence in providing adequate care and meeting staff expectations</td>
<td>(32)</td>
</tr>
<tr>
<td>Relinquish control of the ill-child to clinical staff</td>
<td>(33)</td>
</tr>
<tr>
<td>Constant vigilance over child</td>
<td>(34)</td>
</tr>
<tr>
<td>Subjugation of personal freedom</td>
<td>(35)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>(36)</td>
</tr>
<tr>
<td>Hope for recovery and transplant</td>
<td>(37)</td>
</tr>
<tr>
<td>Mother’s role became unclear</td>
<td>(38)</td>
</tr>
<tr>
<td><strong>Interpersonal Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Over protectiveness of the ill-child</td>
<td>(39)</td>
</tr>
<tr>
<td>Sibling jealousy and neglect</td>
<td>(40)</td>
</tr>
<tr>
<td>Support from siblings</td>
<td>(41)</td>
</tr>
<tr>
<td>Disruptive effect on relationship with spouse</td>
<td>(42)</td>
</tr>
<tr>
<td>Poor communication with staff</td>
<td>(43)</td>
</tr>
<tr>
<td>Satisfaction with provision of care by staff</td>
<td>(29)</td>
</tr>
<tr>
<td>Dependence on staff for parental support</td>
<td>(30)</td>
</tr>
<tr>
<td>Restrictions on social life</td>
<td>(31)</td>
</tr>
<tr>
<td>Weary of explaining to others about the disease, treatment and coping</td>
<td>(32)</td>
</tr>
<tr>
<td>Lack of understanding and support from family and friends</td>
<td>(33)</td>
</tr>
<tr>
<td>Support from other parents who have children with CKD</td>
<td>(34)</td>
</tr>
<tr>
<td><strong>External Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Burden of meeting demands of medical care</td>
<td>(35)</td>
</tr>
<tr>
<td>Difficulties providing adequate nutrition while adhering to liquid and diet restrictions</td>
<td>(36)</td>
</tr>
<tr>
<td>Difficulties organising transport and relocation</td>
<td>(37)</td>
</tr>
<tr>
<td>Extended periods of time spent at the hospital for treatment and tests</td>
<td>(38)</td>
</tr>
<tr>
<td>Unpleasant hospital environment</td>
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</tr>
<tr>
<td>Lack of information about the disease and available support</td>
<td>(40)</td>
</tr>
<tr>
<td>Unhealthy appearance of ill-child</td>
<td>(41)</td>
</tr>
<tr>
<td>Interruption to child’s education and reduced learning capacity</td>
<td>(42)</td>
</tr>
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</table>
Chapter 2: The experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies

<table>
<thead>
<tr>
<th>Financial hardship</th>
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</table>

*, particular theme identified in the study*
### Table 2.4c. Second-order constructs: transplant patients

<table>
<thead>
<tr>
<th>CONSTRUCT</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anger, depression, frustration, stress</td>
<td>● ● ● ● ● ● ● ● ● ● ● ●</td>
</tr>
<tr>
<td>Uncertain of child’s prognosis (including rejection of kidney)</td>
<td>● ● ● ● ● ● ● ● ● ● ● ●</td>
</tr>
<tr>
<td>Suppression of feelings</td>
<td>● ● ● ● ● ● ● ● ● ● ● ●</td>
</tr>
<tr>
<td>Making decisions about donation</td>
<td>● ● ● ● ● ● ● ● ● ● ● ●</td>
</tr>
<tr>
<td>No long-term regret about donation</td>
<td>● ● ● ● ● ● ● ● ● ● ● ●</td>
</tr>
<tr>
<td><strong>Interpersonal Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Unsure how to discuss process and meaning of transplant with child recipient</td>
<td>● ● ● ● ● ● ● ● ● ● ● ●</td>
</tr>
<tr>
<td>Development of a special bond between the child and parent donor</td>
<td>● ● ● ● ● ● ● ● ● ● ● ●</td>
</tr>
<tr>
<td>Over protectiveness</td>
<td>● ● ● ● ● ● ● ● ● ● ● ●</td>
</tr>
<tr>
<td>Sibling jealousy and neglect</td>
<td>● ● ● ● ● ● ● ● ● ● ● ●</td>
</tr>
<tr>
<td>Support from spouse and family members</td>
<td>● ● ● ● ● ● ● ● ● ● ● ●</td>
</tr>
<tr>
<td>Improved interaction within the family</td>
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<td>Donor feelings ignored by staff</td>
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<td>Restrictions on social life</td>
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<td>Increased social freedom</td>
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<td>Impose demands on extended family and friends</td>
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<td>Lack of understanding demonstrated by family and friends</td>
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<td><strong>External Issues</strong></td>
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<td>Liberation from dialysis responsibilities</td>
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<tr>
<td>Improvement of child’s health and physical appearance</td>
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<td>Resumption of the child’s education</td>
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<td>Desire for psychosocial support</td>
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<td>Difficulties organising transport and relocation</td>
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●, particular theme identified in the study
EXTERNAL

Parents experience shock about the diagnosis and live in a state of uncertainty surrounding the child’s prognosis. Parents report constant fatigue and the need to exercise vigilance and describe the loss of personal freedom. Parents receive comfort and support from staff, and appreciate continuity of care. Some parents report dissatisfaction and tense relationships with staff and being forced to relinquish control of the ill-child to the clinical team.

INTERPERSONAL

Parents report either support or lack of understanding from their partner. Siblings provide support, some become jealous and resentful. Overprotectiveness over the ill child, neglect of other family members and disruption to family life are common. Parents face uncertainty about how to discuss transplantation with the child recipient.

INTRAPERSONAL

Parents are responsible for adhering to the medical regimen and observing symptoms and are concerned about their child’s appearance, education and development. Parents struggle to adhere with liquid and diet restrictions and provide adequate nutrition.

Diet and nutrition

Parents struggle to balance and integrate medical care with completing domestic duties.

Household care

Psychological and emotional

Parents experience shock about the diagnosis and live in a state of uncertainty surrounding the child’s prognosis. Depression and anger are common. Lack of confidence in providing adequate care and being forced to re-adjust to new roles and responsibilities also reported.

Physical

Parents report constant fatigue and the need to exercise vigilance and describe the loss of personal freedom.

Staff

Parents receive comfort and support from staff, and appreciate continuity of care. Some parents report dissatisfaction and tense relationships with staff and being forced to relinquish control of the ill-child to the clinical team.

Family

Friends (social life)

Parents report lack of understanding. Some receive support from friends, especially from other parents of CKD children. Restriction on social life improved after transplant.

Siblings provide support, some become jealous and resentful. Overprotectiveness over the ill child, neglect of other family members and disruption to family life are common. Parents face uncertainty about how to discuss transplantation with the child recipient.

Transport, Relocation and Employment

Parents face financial hardship, and difficulties in arranging transport and accommodation.

Medical regimen, hospitalisation and child well-being

Parents are responsible for adhering to the medical regimen and observing symptoms and are concerned about their child’s appearance, education and development.

Information

Parents pursue information about disease and treatment. Some perceive they have inadequate information.
2.6 References


47. Atkin K, Ahmad WIU. Family care-giving and chronic illness: how parents cope with a child with a sickle cell disorder or thalassaemia. Health and Social Care in the Community 2000; 8: 57-69.


3. Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study

3.1 Abstract

Objective: Children diagnosed with chronic kidney disease (CKD) depend on their parents for complex, continuous and intensive support. The study aimed to explore the experiences of parents who have children with CKD.

Patients and Methods: Parents of 20 children with CKD, recruited from two paediatric hospitals in Australia participated in an in-depth interview, qualitative study.

Results: Four major themes were identified, 1) Absorbing the clinical environment: parents struggled to accept the diagnosis and permanence of CKD, felt traumatised watching their child undergo invasive clinical procedures, battled to meet appointments, negotiated with staff for their child’s needs and felt disempowered; 2) Medicalising parenting: parents became caregivers, a role which was stressful, exhausting and overwhelming. Dialysis was unrelenting and consumed the time, thoughts and energy of parents who felt at fault if their child developed infections and other complications. Parents struggled with their child’s psychological problems and episodic aggressive behaviour; 3) Disrupting family norms: CKD caused spousal tension, sibling neglect and influenced family planning; and 4) Coping strategies and support structures: Parents depended on support from their healthcare providers and valued meeting and learning
from other parents of CKD children. Parents also expressed information needs and suggested methods of communicating information.

**Conclusions:** Despite facing profound and pervasive difficulties, parents strived to fulfil their dual parental and healthcare provider responsibilities. Parents appear to need better support structures to help them cope with the difficulties encountered during all stages of their child's illness.

### 3.2 Background

Children diagnosed with chronic kidney disease (CKD) depend on their parents for complex, continuous and intensive support. The psychosocial, physical and financial stresses on parents can affect their ability to cope and influence the quality of care they provide for their child.\(^1\)\(^,\)\(^2\) The healthcare offered by professionals is often centred on the technical and medical interventions focused on the child, while strategies explicitly targeting parental support are often not considered.\(^2\)

Parents of children with CKD are often required to deliver home-based interventions including dialysis and enteral feeding. They must continuously monitor their child’s health, advocate for appropriate health care, be prepared for episodes of infection and other life threatening complications, attend frequent hospital appointments and convey information to health care professionals, family, relatives and teachers.\(^3\) The ability of parents to manage care can impact on the child’s personal development and medical management.
In our recent systematic review of qualitative studies of the experiences of parents who have children with CKD, we found most studies provided few methodological details, did not include all stages of CKD, and had a limited focus (donor-recipient relationship, stress factors, family functioning and maternal care giving).(4)

For a more detailed understanding of the experiences of parents of children with CKD we conducted this in-depth interview study to explore how CKD affects parental caregivers psychologically, socially and physically. We included all CKD stages and also explored parental needs. Indirectly we sought to increase the awareness of parental needs among specialists and multidisciplinary teams, and to guide current and future services for families, leading to improved clinical care and health outcomes of children with CKD.

3.2 Methods

We conducted 20 in-depth interviews with parents of children with CKD from March 2006 to October 2006. On average, each interview lasted 1 hour and was facilitated by (AT) who had had no previous contact with the participants.

Participant selection and setting: Participants were eligible to participate if they were English-speaking adults over 18 years of age, able to give consent, and were a parent of a child who 1) was diagnosed with CKD (pre-dialysis), or 2) undergoing haemodialysis or peritoneal dialysis, or 3) had received a kidney transplant. We used purposive sampling to ensure that we captured the experiences of parents of children in all stages of CKD. We
aimed to include families from minority ethnic groups, a minimum of 8 fathers and 8 mothers, and parents of children ranging from 0-18 years of age. Participants were recruited through The Children’s Hospital at Westmead and the Sydney Children’s Hospital after ethics approvals from both institutions were obtained. Both hospitals provide specialist services to all children with CKD in New South Wales, the most populous state in Australia. The first author (AT) contacted participants by telephone, explained the study and invited them to participate. The interview was arranged in the participant’s home or in the hospital. Interviews were conducted with one parent if their partner had work commitments or if the parent contacted said that their partner would not want to participate.

Data collection: We developed a preliminary question guide from the results of our systematic literature review and discussion among the research team. The questions were sent to a multidisciplinary team involved in the care of children with CKD (including nephrologists, nurses, a psychologist, a social worker and a renal dietician) for their comments. We piloted the questions with a group of 6 parents. The final question schedule included three domains: intrapersonal, interpersonal and external experiences. Intrapersonal issues included psychological, emotional and physical experiences; interpersonal issues included the parents’ relationship with family, medical staff, friends and community; and external issues concerned employment, finances, transport, relocation, responsibilities of the medical regimen, household care, diet, nutrition and information needs. All interviews were digitally audio-recorded and transcribed in full. We collected data until data saturation was observed in the concurrent data analyses. Field notes on participant characteristics, body language and the context around the interview were recorded after each interview.
Analysis and Findings: The transcripts were independently analysed by AT, AL and PS to
develop an appropriate and replicable coding structure. The computer software ‘NVivo7’
was used to assist with storage, coding and searching of data. Through the process of
careful analysis and comparisons between the interviews, we derived descriptive themes
inductively from the data. A summary of our preliminary findings was mailed to the
study participants in June 2007, to inquire whether their priorities were faithfully
interpreted, to enhance the developing analytic framework and to ascertain whether the
account made sense to participants with different perspectives. We received feedback
from parents on 10 out of 20 interviews. All participants appreciated receiving our
preliminary findings and commented the summary was informative, reflected their
experiences and gave them reassurance that they were not alone.

3.4 Results

The participant characteristics are provided in Table 3.1. The sample included one single-
parent and two families residing outside the Sydney metropolitan area. In 19 of the 20
families, the mother was the primary caregiver. Three families refused to be interviewed.

Four themes emerged from the interviews: absorbing the clinical environment,
medicalising parenting, disrupting family norms, and coping strategies and support
structures. Summaries of the themes are provided in Figure 3.1.

Absorbing the clinical environment
Diagnostic procedures, regular check-ups, and lengthy dialysis treatment and transplant procedures forced parents to assimilate into a new environment which parents sometimes described as hostile. Parents experienced heightened uncertainty and emotional stress in hospital, which was often related to receiving the diagnosis, surgical procedures, uncertainty of the child’s outcomes, care perceived as incompetent and insensitive, frequent medical appointments, and observing their child in physical pain.

**Confronting the diagnosis:** Parents experienced shock, disbelief, devastation, confusion and fear of losing their child while they tried to comprehend their child’s diagnosis and the permanent nature of CKD. Communicating the diagnosis sensitively in privacy was important to parents; two parents harboured anger over receiving the diagnosis in public view.

**Invasive procedures:** During their child’s hospitalisation, the needles and tubes protruding from their child’s body was visually traumatic and parents felt distressed and helpless.

“We watch as she’s constantly tortured by the medical process. It hurts to watch.”

**Conflict and trust:** In the hospital, parents felt they became advocates for their child, battling to meet seemingly endless clinical appointments including pathology tests, X-rays, biopsies, waiting for prescriptions and collecting equipment from the appliance departments. Some parents recounted having to deal with hospital staff who they perceived were stubborn and insensitive.
'You go to the hospital and you’re a soldier for your child, you’re there mainly for him, you’re there for him, not for yourself…Sometimes they make it so difficult for you and it’s like I feel like you’re in a battle, and you’re battling for your child.’

Parents appreciated specialists who were attentive and honest. This gave parents the reassurance and ability to entrust their child into the specialist’s care.

‘…they were honest with us, I think that’s what counts the most.’

**Varying quality of care:** Parents valued attentive and caring nurses who had a good relationship with the ill child. Home visits, education and support were appreciated.

‘The renal unit would actually come to my house to give him the needle and I thought that was fantastic.’

‘The dialysis nurse she’s the most beautiful woman I’ve ever met. If I didn’t have her I think I would have lost it.’

Parents became upset, angry and frustrated if they perceived nursing staff to behave in an aggressive, impatient, and inattentive manner towards them. Parents were particularly upset if they felt poor quality care was being delivered by nurses who, in their view, demonstrated no understanding about caring for children, particularly those on dialysis machines. This perspective was mostly directed towards temporary nursing staff employed during staff shortages.
‘There’s a difference between looking after a machine and looking after a machine on a child.

For parents, provision of care extended beyond responding to medical needs. Parents would negotiate with staff members to accommodate their child’s intellectual needs and comfort.

Losing ownership: In hospital, parents relinquished control of their child to clinical staff. They felt excluded from decision making regarding their child’s development and care.

‘Once we went to hospital, he was no longer my child.’

Jeopardising relationship with staff: While most sought information about the illness and treatment from specialists, some parents avoided asking questions for fear of being labeled as troublesome and of jeopardising their relationship with staff.

‘If you ask them more than two questions, you’re a problem parent.’

During extended stays in the hospital, parents felt disconnected from the real world. Repeated and extended hospitalisation was an infringement on normality, disrupting the family lifestyle and routine. Parents who had a thriving child with a kidney transplant felt relieved that hospital visits became less frequent.

‘I can’t walk into that (dialysis) room, my wife and I would rather die. That’s how strongly we feel about it.’
‘I’d like to just cut it (hospitals) right out of my life.’

**Medicalising parenting**

The dual role of parenting and medical caregiving gave rise to fatigue, stress and emotional pain. Parents were required to deliver technological interventions including dialysis, feeding pumps and injections while constantly monitoring their child. The responsibilities involved in caring for a technology-dependent child was burdensome and constrained the parents’ lifestyle.

**A consuming routine:** With children on dialysis, the lives of the carer (usually the mother) would revolve around the dialysis machine, consuming their time, thoughts and energy causing fatigue.

‘Everything needs concentration; you have to be careful in everything.’

‘The alarms would go off every night and you’d have to get up every night and move her and check lines and everything else so it’s a bit of sleep deprivation as well.’

**Pressure and isolation:** Parents would feel responsible if their child acquired an infection so they took extreme hygiene precautions to protect their child. For some, the pressure and isolation of doing peritoneal dialysis at home was overwhelming.
‘It’s always the parents that get the blame you know…it’s a lot of pressure they put onto the parents.’

**Struggle with feeding:** Prior to transplantation, the child’s poor appetite caused great concern for parents. Instead of thriving, the child would appear weak and undernourished. Parents sought the dietician for advice and desperately tried to encourage their child to eat.

‘The hardest thing to deal with was getting your child to eat. I said chronic renal failure - you can cope with that…but the feeding issue really was a big thing.’

Liquid restrictions were imposed on children undergoing dialysis. Withholding water from their children was described as one of the worst things parents had to do.

‘He was vomiting and retching, it just breaks your heart. You really thought they were going to die. He ended up wanting to have showers all the time, morning, noon and night. He was putting his tongue out to get the water.’

For children who were unable to receive adequate nutrition and medication orally, parents were required to insert a feeding tube. This was physically and emotionally difficult. One mother recounted how she detached emotionally from her child while inserting the nasogastric tube:

‘I actually figured out a technique which was basically to lay on the floor, pin the head between my knees, tighten my thighs around his head to hold his head still, and lie my legs across his body, hold them, wrap around them so I could hold his
body down, have his arms under my legs and then shove, shove, shove, shove, shove the tube down his throat.’

**Medical management:** Parents had the responsibility of ensuring their child adhered to the medication regimen. Although they struggled because the medication was unpleasant for the child, it eventually became routine. In one family, the father found it difficult to cope with giving the child injections.

‘He doesn’t want to see our daughter in pain, crying… he does not have to be in the room when I do the injections.’

Some parents used complementary medicine or alternative therapies even if their specialist advised against it.

‘Without the doctors knowing, I was giving her herbs. I was giving her things to improve her circulation. I don’t know if it helped or not but she seemed to be going well.’

**Psychological trauma:** Parents found it difficult to manage their child’s psychological issues and felt they lacked support and information regarding depression and aggression in children with CKD. The psychological and behavioural problems were more difficult to cope with than the medical problem of CKD. Several parents blamed the medication.
“I think you have to be desperate and your child has to be harming themselves before they look at you…sometimes the psychological trauma is far worse than the physical…”

‘No one’s really talked to me but…I worry about how she can have little episodes…I can’t even describe it you know, she’d be just unreasonable, nasty…that’s happened quite a lot so I think that’s what I’d mainly look at, the psychological effects.’

**Disrupting family norms**

The diagnosis of CKD disrupted the dynamics within the nuclear family, the home environment, employment and finances, and recreation. Faced with multiple losses as a family including: reduced time spent with spouses and children, social restrictions, inability to travel, depleting financial reserves; parents tried to cope as leaders of the family unit.

**Spousal tension and dependency:** In spousal relationships, tension and conflict were often instigated and fuelled by guilt and blame. For most families, this was resolved over time and spouses became supportive of each other and felt their relationship had strengthened.

‘We used to fight a lot because my husband was frustrated that our child wasn’t getting better, we were spending all this money, time and energy on getting him well, and nothing was working. We used to fight and he often blamed me for
things and I used to fight and say, how can you blame me for it, it’s out of my control.’

‘It made our relationship, made it stronger if anything. The odds are like 86% of people with (CKD) children separate.’

**Sibling neglect:** In many cases, parents would arrange alternative care for siblings, for instance with relatives. Parents had to restore relationships with siblings who would feel abandoned and neglected.

‘I had to abandon my youngest daughter and really in hindsight, that was hard for me, to abandon my other girls, my other children, but you have to. I had to explain that I needed to focus on (my son), he needs me, he needs to get well.’

‘I had this child who was sick so basically my three year old daughter ended up being put aside. She thought she had this duty of being this perfect child for me. It’s made her life pretty much a nightmare.’

**Household and financial stress:** In the home, parents rearranged their living environment spatially to accommodate medical equipment used for dialysis and feeding. Hospital visits and performing medical care at home meant that parents could not maintain domestic responsibilities including cooking and cleaning. The cost of travel, accommodation and food affected some families financially. They faced temporary financial uncertainty, as parents were unable work at times due to medical care or recovery from kidney donation.
‘You have to take time off work on a constant regular basis, you lose money, you lose energy and everything else with raising an ill child.’

**Decision to donate:** Some parents were faced with the decision to donate their kidney. Although many willingly donated, some felt the pressure of obligation, uncertainty about their decision and resentment over the trauma of the donation process. One worried mother desperately searched for an altruistic donor.

**Social restriction:** The illness also restricted parents’ social life and heavily constrained their recreation and holiday plans. They had some resentment about other families being able to go on holidays.

‘You felt like a prisoner, you sort of felt trapped. You couldn’t really go anywhere or do anything like a normal family.’

**Avoiding the risk of recurrence:** The illness had a major impact on family planning. Some parents decided against having more children and in some cases terminated a pregnancy, as they felt they could not cope with the possibility of having another heavily dependent child and repeat the emotional stress of their experiences.

‘I just wish I had enough guts to do it again but I wouldn’t ‘cause I would never cope with another sick child.’

**Coping strategies and support structures**
We identified internal and external coping strategies parents used to mediate the stresses of care giving. Internal coping strategies were the parents’ intrapersonal psychological and emotional responses or adjustments including: grieving, reframing the problem and focusing on the ill child. External coping sources included family, friends and the community who provided practical and emotional support. Parents expressed the need for more information.

**Internal coping strategies:** Over time, some parents became more assertive and self-confident. Crying and grieving also helped parents to release emotional stress.

‘I just broke down in tears, it just all came out. It was just a build up of 4 years of sadness, and stress and everything.’

Although acceptance was difficult, most parents learned to cope with their circumstances and reframed illness management as their ‘normal.’ Some parents mentally prepared themselves for future problems while others lived one day at a time. Also, parents tried to maintain their physical and emotional resilience by directing their focus on their ill child.

‘You have to be strong for him (son). It’s easy to break down and crumble but you had to do what you had to do.’

‘You’re sort of saving your strength just to help your child through it whereas if you start trying to face it, you just sort of fall apart and you’re not strong enough for the child.’
During several interviews, parents found relief in minimalising the severity of their own problem by comparing themselves with other families who they perceived were in a more desperate situation.

‘There’s always someone worse off and to be honest that’s what keeps you going.’

**External coping strategies:** External sources of emotional support were primarily the immediate family and other parents of CKD children. Parents usually met each other in wards, waiting rooms, support groups or online. Most parents found reassurance in talking with their child’s specialist. Some chose to depend on social workers or counselors for emotional support.

‘You need somebody else who knows exactly how you feel.’

While most parents received practical assistance from family and friends, parents frequently reported a lack of understanding about the illness and its impact on the family. Parents felt they were perceived as overreacting and some relatives did not support the parents’ decision to donate and refused to accept the diagnosis.

‘My family didn’t believe that (my son) had kidney failure. They thought that was just us being over dramatic.’

**Information needs:** Social workers provided information regarding financial support, carer allowance, car parking and accommodation, and parents were grateful for their assistance.
‘They (social workers) were quite good with the practical things, and to me that’s their calling card. Often the best thing is, like they offer free parking or some accommodation or where you can get meals.’

Some parents identified information needs they felt were unmet. They wanted information about: the illness, treatment procedures, other parents’ experiences, dietary advice, warning about complications, how to access financial and practical assistance, and managing psychological and behavioural problems. Parents suggested that information should be made available online and communicated through clinicians, parent networks, health care professionals, pamphlets and videos.

‘When you say something to someone while they’re upset, they don’t hear it properly. I think the information needs to be reinforced (repeated) with parents.

‘Parents should be given enough information to make choices, to make decisions about what’s going on and so they understand what’s going on…the not knowing is a big problem.

3.5 Discussion

Being a parent of a child with CKD was consistently reported as being a pervasive and profoundly negative experience. Parents faced uncertainty about their ability to cope, to deliver complex medical interventions, and about their child’s outcome. They felt burdened with technical procedures and continuous clinic visits, and experienced
relationship stresses and emotional turmoil. Transplantation did not necessarily alleviate the caregiving burden, rather, the nature of their concerns and difficulties varied. Despite facing difficulties, parents strived to consistently deliver their parental and medical responsibilities. Additional support structures and information appear necessary to help parents cope with difficulties encountered during all stages of their child's illness.

Our findings were consistent with our systematic review of the experiences of parents who have children with CKD, which we used to inform our question guide, but in this study we restructured the themes to capture additional issues which arose in this study. Our findings are similar to other studies which have shown that parents with disabled or chronically ill children felt disempowered. In another study, parents were labeled as irrational and dangerous when they expressed anger at what they perceived to be unsatisfactory care. Our findings also reflect previous work on parenting technologically dependent children; parents suffered fatigue, isolation and felt blamed if their child became sick. The parental role was described as extending beyond the ‘normal’ role to include sustaining life and quality of life. The caregiving role dominated the parenting experience; instead of giving comfort and protection, parents were forced to be agents of pain. The assumption of healthcare provider roles by mothers (nurse, psychologist) has also been recognised. Finally, our study complements an existing model for exploring coping strategies in which we categorised parental coping as either internal (cognitive) or external (social coping and networks). Mothers coped by centering their priorities and energy on the ill child which overruled the stress, fatigue and needs of mothers.

Our study has several limitations. The transferability of our findings beyond the two centres is uncertain, but the consistency of our results with the findings of similar studies...
from other countries, albeit in other disciplines, suggests our findings are widely applicable. Second, we did not conduct serial interviews with each family whose perspectives may have changed over time. Third, non-English speaking parents were not included to avoid cultural and linguistic misinterpretation and so we are unable to comment on the transferability of the findings to these families. Finally, we acknowledge that the experiences of parents with a child with CKD are extremely complex, with a study of this type, some simplification of these experiences to aid communication is inevitable. As for any qualitative study, sampling to ensure representativeness of responses was not undertaken. Rather we sought to elicit the broad range of experiences of parents. By 20 interviews no new themes were emerging so additional interviews were not sought.

We have developed a framework that highlights four domains (clinical environment, parental identity, family, and support structures) in which health professionals can help to improve service delivery and sustain parent caregivers. In hospital, parents want to be perceived as joint advocates with clinicians for the child’s care, comfort and improved health. Health professionals could demonstrate an understanding of the plight of parents who feel disempowered, guilty, ill informed, fatigued, hectic and strained by inadequate resources. Strategies to circumvent unnecessary clinical tests, visits or procedures could be addressed. Particular care should be given to the parent-professional interaction in which the diagnosis is discussed.

Parents could benefit from support groups to reduce their sense of isolation and to learn coping skills from other parents relating to nutrition and medical management. Attention needs to be given to managing the child’s psychological and behavioural problems. While there is lack of quality studies in this areas, psycho-educational interventions for parents
and children have been suggested to demonstrate benefit.(12, 13) We also suggest more resources are needed for respite services including kidney camps and access to trained carers to give parents relief.

Services should aim to improve family functioning. Little evidence supporting specific interventions for parents and siblings is available but long term family-based therapies and programs can enhance coping.(14-16) Families facing acute disruption, particularly during frequent or prolonged hospitalisations, could benefit from domestic support, and we suggest that financial assistance be offered to families who require it. Regarding family planning, much debate surrounds prenatal diagnosis and selective abortion but there is little data on what motivates parental decision making.(17) Despite the complex ethical issues surrounding this, it is suggested that professionals should not undermine the mother’s autonomy and avoid medical paternalism.(18)

Providing interventions to parents to enhance their internal and external coping strategies can relieve the burden of care, improve their quality of life and facilitate the task of caring for the ill child. To our knowledge, there are no studies on parental caregiver interventions in CKD. Parents appreciate being asked how they are coping and having their concerns and needs addressed. Information relating to nutrition, financial support, psychological management, coping strategies and parent support groups should be provided.

Healthcare providers caring for children in this study, and healthcare providers in general, may feel that our findings are unduly critical of their conduct and care. While our study highlights parent perspectives of service delivery, we recognise that these can differ from professional perspectives and from what actually happened during a clinical
encounter. Clinicians who aim to achieve the best medical outcomes for the ill child may inadvertently appear to parents as being strict and critical. Inadequate resources can hinder clinicians’ efforts in providing support services. For example, kidney camps and trained carers require substantial resources, which health care funders often do not regard as core services. Existing support services may not always meet all the parents’ needs or may not be delivered when and how parents perceive is appropriate for their needs. Even when offered, some parents may choose to decline services and programs.

Although the family-centred care model, ‘the philosophies, principles and practices that put the family at the heart or centre of services,’ (19) is widely adopted, we identified several areas in need of improvement. These include professional-parent communication, caring for the child’s overall well being, and services addressing the physical, social, emotional and information needs of parents. An in-depth understanding of parental experiences can increase sensitisation to the needs of parents among specialists and multidisciplinary teams, and guide current and future services for families to improve clinical care in pediatric nephrology. Our hope is that this leads to better outcomes for children.
Table 3.1 Participant characteristics

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<td><strong>Child’s CKD stage</strong></td>
<td></td>
</tr>
<tr>
<td>CKD (predialysis)</td>
<td>5</td>
</tr>
<tr>
<td>Haemodialysis</td>
<td>2</td>
</tr>
<tr>
<td>Peritoneal Dialysis</td>
<td>1</td>
</tr>
<tr>
<td>Transplantation</td>
<td>12</td>
</tr>
<tr>
<td><strong>Cultural Background</strong></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>14</td>
</tr>
<tr>
<td>Non-Caucasian / Mixed</td>
<td>6</td>
</tr>
<tr>
<td><strong>Interview participants</strong></td>
<td></td>
</tr>
<tr>
<td>Father only</td>
<td>1</td>
</tr>
<tr>
<td>Mother only</td>
<td>11</td>
</tr>
<tr>
<td>Both parents</td>
<td>8</td>
</tr>
<tr>
<td><strong>Interview Setting</strong></td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>6</td>
</tr>
<tr>
<td>Home</td>
<td>14</td>
</tr>
</tbody>
</table>
Figure 3.1. Thematic schema representing parent perspectives on caring for a child with CKD

- Confronting the diagnosis
- Invasive procedures
- Conflict and trust
- Varying quality of care
- Losing ownership
- Jeopardising relationship with staff

- Absorbing the clinical environment
  - Medicalising parenting
  - A consuming routine
  - Pressure and isolation
  - Struggle with feeding
  - Medical management
  - Psychological trauma

- Disrupting family norms
  - Spousal tension and dependency
  - Sibling neglect
  - Household and financial stress
  - Decision to donate
  - Social restriction
  - Avoiding the risk of recurrence

- Coping strategies and support structures
  - Internal coping strategies (grieving, acceptance, asserting, reframing, focussing on the ill child and comparing)
  - External coping strategies (family, friends, community)
  - Information needs
3.6 References


4. Support interventions for informal caregivers of people with chronic kidney disease: a systematic review

4.1 Abstract

**Background:** A growing number of patients with chronic kidney disease (CKD) rely on non-professional healthcare providers, such as family and friends to manage their long-term condition throughout the trajectory of CKD. These informal caregivers can experience stress, depression, lack of confidence and poor quality of life. Yet, the needs of caregivers are often neglected and under-prioritised. The objective of this review is to evaluate the effectiveness of interventions aimed at providing support to caregivers of people with CKD.

**Methods:** We conducted a systematic review of studies that evaluated any intervention for informal caregivers of CKD patients. We searched five electronic databases (up to January Week 5, 2008) including Medline, EMBASE, PsycINFO, CINAHL, Cochrane Central Register and reference lists of relevant articles.

**Results:** Three studies were identified that evaluated an intervention for caregivers of CKD patients. All three only assessed the effect of educational material on caregiver knowledge. Two evaluated information provided to caregivers of dialysis patients using a pre- and post-test study design. The other study used participatory action research methods to develop and evaluate an information handbook for transplant patients and
their caregivers. Studies consistently found that the provision of information improved caregivers’ knowledge. No other outcomes were reported.

**Conclusions:** Despite the growing recognition of the burden and adverse effects of CKD on caregivers, no high quality evidence is available about the effect of information or support interventions on the physical or psychosocial well-being of informal caregivers and the patients. More attention towards the development and evaluation of services that respond to the support and informational needs of caregivers is needed, and this may also lead to improved outcomes for patients.

### 4.2 Background

A growing number of patients with chronic kidney disease (CKD) are receiving home-based care and require support from non-professional healthcare providers, often family members, to manage CKD. There is concern that caregiving demands, especially in managing dialysis which has a profound and pervasive effect on family and friends, exact a toll on the physical, social and emotional well-being of caregivers. Yet, caregivers’ needs are often neglected and under-prioritised in the medical management of CKD.

Informal caregivers can experience stress from the added responsibilities of managing the patients’ medical treatments, dietary requirements, clinic appointments and psychosocial issues. Increasingly, caregivers are required to provide complex technical care in the home due to the improved clinical outcomes, lower costs and staffing, and convenience associated with home based-dialysis regimens. Research has
consistently shown that caregivers experience depression, anxiety, fatigue, social isolation, relationship strains and financial strains. (7-11)

Support interventions are likely to improve caregivers’ quality of life, satisfaction and ability to cope, which can indirectly improve medical and psychosocial outcomes for the care recipient. Findings from randomised controlled trials (RCTs) in stroke (12, 13), dementia (14-16), asthma (17) and cancer (18, 19) suggest that support and information for informal caregivers can reduce caregiver burden and anxiety and improve the quality of life and psychosocial outcomes for patients and carers.

The effectiveness of support interventions targeting informal caregivers of patients with CKD has not been systematically assessed. The objective of this review is to evaluate the effectiveness of interventions aimed at providing support to informal caregivers of people with CKD, including predialysis, dialysis and transplantation.

4.3 Methods

Inclusion criteria

Studies were included if they met the criteria specified in Table 4.1. Non-English articles were included. Anecdotal reports, case studies, editorials, letters, paid or professional caregiver assessments and studies that included over 50% of illnesses other than CKD were excluded.

Search strategy
Electronic searches were performed in Medline (1950 to January Week 5, 2008),
EMBASE (1980 to January Week 5, 2008), CINAHL (1982 to January Week 5, 2008),
PsychINFO (1806 to January Week 5, 2008) and the Cochrane Central Register of
Controlled Trials by using optimally sensitive search strategies for the identification of
randomised trials developed by the Cochrane Collaboration. (Appendix C.1) Medical
subject headings and text words used were relevant to the population (informal
caregivers) and the condition (CKD). Abstracts and studies were screened and discarded
if they did not fit the inclusion criteria. Studies that appeared to include relevant
information were retrieved and their full-text versions were examined for study eligibility.
Reference lists from the identified articles were searched.

Data extraction and trial quality assessment

From the included studies, we extracted information on study design [RCTs, quasi-RCTs
(allocating participants to different forms of care that is not truly random), non-RCTs,
controlled before-and-after study, prospective cohort study, retrospective cohort study,
historically controlled trial, nested case-control study, case-control study, before-and-
after comparison, case report/case series, interrupted time series and qualitative
research), setting, participant characteristics, intervention, and outcomes assessed.
Standard criteria developed by the Cochrane Collaboration(20) and the Cochrane
Effective Practice and Organisation of Care Group (EPOC)(21) were used to assess the
methodological quality of studies if relevant. These questions included:

1. How was the comparison made? (Between two or more groups receiving
different interventions, or with the same group over time?)
2. Were participants allocated to groups? (e.g. concealed randomisation, quasi-randomisation, action of researchers, time differences, location differences, treatment decisions, patient preference, basis of outcome)

3. Which parts of the study were prospective? (Identification of participants, assessment of baseline and intervention allocation, assessment of outcomes, hypothesis generation)

4. On what variables was comparability between groups assessed? (Potential confounders, baseline assessment of outcome variables)

5. Who were blinded? (participants, investigators, outcome assessors)

6. What was the rate of follow up?

We extracted the data on the sample size, variances, and mean differences from baseline in outcome variables. If summary statistics for change from baseline were not available, the mean, standard deviation and number of people in each group were extracted. We anticipated a wide heterogeneity of interventions and outcomes measure and therefore reported the data separately for each study. If applicable, the summary estimate of effects was calculated with 95% confidence intervals, which is a weighted average of the summative intervention effect across all studies.

### 4.4 Results

*Literature search (Figure 4.1)*
Our search yielded 1178 articles. Of these, 1086 were excluded after title and abstract review because they were ineligible. Of the remaining 92 potentially eligible studies, 89 were excluded after full text review for reasons including: no caregiver intervention assessed, non-research articles, no caregiver assessments, non-CKD, or duplicate articles. Of the 92 full-text articles we reviewed, 56 (61%) explored the physical and psychosocial well-being (quality of life, burden, depression, fatigue, marital stress, loneliness), adjustment, needs and concerns of informal caregivers, but were excluded because no caregiver intervention was assessed. Of these, 24 had focused only on caregivers of dialysis patients. We identified three studies that could be included in the review, which assessed the effectiveness of an intervention for informal caregivers of patients with CKD.(22-24)

**Characteristics of the studies**

The three eligible studies examined the effect of informational material on caregivers’ knowledge and were not RCTs. The characteristics of these studies are provided in Table 4.2. None of these study designs could be assessed according to EPOC criteria for validity or risk of bias.

Two studies used a pre- and post-test study design. One of these studies assessed the effect of an information booklet provided to caregivers of patients on haemodialysis on their knowledge of home care management.(22) The content of the booklet and structure questionnaire was developed from a literature review and input from experts. The caregiver’s physiological function, self-concept, role function and interdependence were evaluated. The post-test evaluation was conducted 1 week after the pre-test and the study found that overall knowledge score was significantly improved after the information
booklet was provided. The overall pre-test knowledge score was 50.35 and 86.25 in the post-test. The overall improvement in the mean score was 35-89 (t=13.4, P<0.001) An analysis of variance demonstrated no correlation between selected demographic variables and post-test knowledge scores.

A similar study evaluated the impact of an educational intervention, delivered by nurses, on the knowledge of caregivers of patients on haemodialysis and peritoneal dialysis.(23) The post-test assessment was conducted 5 months after the pre-test assessment. Four domains of knowledge were assessed which included general knowledge, diet, treatment, and pharmacological treatment. In caregivers of haemodialysis patients, there was an increase in all domains of knowledge assessed, general (P=0.018), diet (P=0.016) and treatment (P=0.040) domains. In the peritoneal dialysis group, caregiver knowledge was significantly increased in the general knowledge (P=0.066), diet (P=0.039) and pharmacological treatment (P=0.046) domains.

The third study used participatory action research methods in which paediatric kidney transplant recipients and caregivers were given a proactive role in developing, evaluating and modifying an information handbook on self-care over an 8-year period.(24) Their opinion and suggestions were obtained by semi-structured interviews. The handbook intervention focused on prevention of immunosuppression-related illnesses, management of side effects and adapting to the illness, and facilitating social support. The participants helped to structure the content and language to the appropriate cognitive level for patients and caregivers. The topics considered important to the participants included diet, immunosuppressive medication, secondary effects, protecting the graft, monitoring side effects and importance of self-care. The participants’ suggestions and opinions were incorporated into the development of the handbook. The
handbook was evaluated after being redistributed to paediatric post-transplant patients and caregivers.

4.5 Discussion

Despite the growing recognition of the burden and adverse effects of CKD on informal caregivers, very little evidence is available about the effect of information or support interventions on their physical or psychosocial well-being. The lack of evidence may be due to inadequate advocacy, funding and support resources available to develop, implement and evaluate support and information interventions for informal caregivers. Core clinical services usually involve responding to the medical needs of the individual patient but often do not include meeting the support and informational needs of their informal caregivers.

Although RCTs are considered to be the gold standard in evaluating the effects of interventions, non-RCT studies can yield clues regarding the effects of interventions. The current, very small evidence base is characterised by a participatory action research study and pre- and post-test studies in which the outcomes before the intervention are compared with the outcomes measured after the intervention. They only assessed an educational intervention and focused on a single outcome of caregivers’ knowledge, and two were short-term. The other interventions and outcomes provided in Table 4.1 have not been assessed. Collectively, caregiver intervention studies in CKD have a very narrow focus.
In comparison, studies in other disciplines have assessed a more comprehensive range of caregiver interventions and outcomes. Several RCTs on caregiver support and information interventions have been conducted in other disciplines, particularly in stroke, dementia and cancer. In one study, 300 caregivers of patients with stroke were randomised to either conventional caregiver instruction or structured caregiver training. Caregiver training reduced costs and caregiver burden while improving psychosocial outcomes in caregivers and patients at 1 year. (12) Another RCT for stroke concluded that family support improved the quality of life for carers. (13) Similarly, caregiving burden was reduced in caregivers of patients with dementia who received occupational therapy, that included cognitive and behavioural interventions, compared with those who did not receive occupational therapy. (14) A three-group RCT conducted with family caregivers of cancer patients found that the coping skills intervention improved caregiver quality of life significantly more than standard hospice care and supportive visits. (18)

As there is insufficient evidence to confirm the benefit of interventions that aim to provide support for caregivers of patients with CKD, we are unable to make recommendations for practice. However, studies exploring CKD caregiver experiences, including caregiving burden, depression and quality of life, suggest that effective support interventions are needed. (25, 26)

To extend beyond understanding the needs and perspectives of informal caregivers, we suggest the use participatory action research methods. Recognised as an “empowering methodology”, it allows participants to be involved in decision-making, planning implementing and evaluating interventions. (27, 28) Participatory action research, used in one of the included studies (24), is a method by which research and action are coupled together to plan, implement and monitor change. The participants become ‘co-
researchers’ and the researcher’s role is to participate in the initiatives and use their research knowledge and expertise to support and facilitate the participants in the research program. This enables the development of programs that considers and incorporates the specific situation and conditions that will influence the outcome of the programs. Because of these reasons, we would contend that these methods are appropriate at this stage, for developing effective support interventions and programs for caregivers of patients with CKD.

Future research can assess a broader range of caregiver interventions including internet-based information, online support groups, psychological therapy, practical support, and elicit suggestions for improving caregiver support from patients and caregivers. In addition to caregivers’ knowledge, other outcomes should be measured including physical, psychological and emotional status, social outcomes, caregiver burden, and patient outcomes, as detailed in Table 4.1.

Given the nature and treatment of CKD, support for caregivers is critical. This is particularly important for caregivers of dialysis patients, especially home-based therapies. These therapies are time consuming, technologically complex and have a profound effect on the patient and caregivers physical and psychosocial well-being, relationships and lifestyle. (5, 8, 25)

The underlying premise of patient-centred care includes responding to the unique needs of individual patients and supporting their informal caregivers in their healthcare provider roles. Our review highlights the current lack of evidence to guide support and well-designed studies are needed to develop effective support interventions for caregivers of CKD patients. Until this is achieved, CKD services may be helping their patients
while contributing to health and social problems for the carers. We hope these findings will draw more attention from the professional renal community, towards the development and evaluation of services to respond to the support and informational needs of informal caregivers.
Table 4.1. Inclusion criteria

| Study design | Any study reporting the development or evaluation of an intervention for informal caregivers of CKD patients, including predialysis, dialysis and transplant. |
| Population | Informal caregivers of adult and paediatric patients with CKD. Informal caregivers are unpaid carers who include spouses, siblings, relatives, friends |
| Intervention | • Information and educational interventions - skills training, written materials, web-based resources, lectures  
• Psychological support – counselling, specialised psychological support, psychotherapy  
• Social support - support groups, meetings, telecommunication or internet based support  
• Practical support - financial, domestic, transport, respite |
| Outcomes | • Physical status – e.g. fatigue, specific health problems  
• Psychological and emotional status – e.g. depression, anxiety, stress, self-esteem, coping  
• Caregiver knowledge and skills  
• Social outcomes – e.g. isolation, family dynamics  
• Caregiver burden – e.g. strain, perceived burden, adjustment  
• Patient outcomes – e.g. psychosocial outcomes (anxiety, coping, stress, attitudes towards caregivers), physical health, knowledge, satisfaction, attitudes, relationship with caregiver |
### Table 4.2. Characteristics and results of evaluation studies

<table>
<thead>
<tr>
<th>Study ID</th>
<th>Design</th>
<th>Setting</th>
<th>Population</th>
<th>Intervention</th>
<th>Outcomes assessed / Endpoint</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fathima 1996 (22)</td>
<td>Pre- and post-test</td>
<td>Single centre, India</td>
<td>30 caregivers of adult HD patients</td>
<td>Information booklet</td>
<td>Post-test difference in knowledge score</td>
<td>Overall knowledge score improved.</td>
</tr>
<tr>
<td>Gonzales* 2005 (23)</td>
<td>Pre- and post-test</td>
<td>Single centre, Spain</td>
<td>95 caregivers of adult (53 HD, 42PD) patients</td>
<td>Oral and written Information delivered by nurses</td>
<td>Post-test difference in 4 domains of knowledge, caregiving load</td>
<td>Knowledge increased in all four domains</td>
</tr>
<tr>
<td>Tornay 2007 (24)</td>
<td>Participatory action research: patient and caregiver opinions and suggestions were obtained to evaluate and modify an information handbook</td>
<td>Single centre, Spain</td>
<td>135 caregivers paediatric Tx patients</td>
<td>Information booklet</td>
<td>Knowledge, self-confidence</td>
<td>Clarified doubts, diminished stress and fear, facilitated adaptation</td>
</tr>
</tbody>
</table>

* Original language in Spanish and translated into English for the purpose of the review; HD, haemodialysis; PD, peritoneal dialysis; Tx, transplantation
Chapter 4. Support interventions for informal caregivers of people with chronic kidney disease: a systematic review

Figure 4.1. Literature Search

- Medline: 408 citations
- Embase: 327 citations
- PsychINFO: 152 citations
- CINAHL: 120 citations
- Cochrane Library: 171 citations

1178 citations

Title and abstract review
- Excluded (n=1086)
  - No caregiver intervention or assessment: 627
  - Non chronic kidney disease: 291
  - Duplicate articles: 168

92 citations

Full text analysis
- Excluded (n=89)
  - No intervention (assessed QoL, perceived burden): 55
  - Non research (anecdotal reports, case studies, editorials): 17
  - No caregiver assessment: 11
  - Non chronic kidney disease: 4
  - Duplicate articles: 2

Included in systematic review (3 studies)
4.6 References


5. Patients’ experiences and perspectives of living with chronic kidney disease

5.1 Abstract

**Background:** While advances in medical interventions are improving survival rates in chronic kidney disease (CKD), patients still face physical and emotional challenges. Explicit incorporation of patients’ values and preferences is important in healthcare management decisions, yet there are few data on this topic in patients with CKD.

**Study design:** Focus group study (three each for pre-dialysis, dialysis and transplant patients), to elicit the range of experiences and perspectives from patients about the meaning of CKD and its treatment, impact on lifestyle and relationships, and coping strategies. Themes were identified and compared across all 3 phases of the CKD spectrum.

**Setting and participants:** Patients enrolled in 4 dialysis and kidney transplant centres in Australia.

**Results:** Five major themes were identified, 1) personal meaning of CKD, 2) managing and monitoring health, 3) lifestyle consequences, 4) family impact, and 5) informal support structures. Patients had to adjust to the disruptive and permanent implications of the illness on their physical health, identity, emotions, family, lifestyle, relationships and employment. The overwhelming fatigue, complex treatment regimens, side effects, and
liquid and diet restrictions imposed major constraints on patients. Patients appreciated specialist medical care, but described the health-care system as non-integrated and felt they received insufficient information and psychosocial support. Choice of treatments was based upon lifestyle, family impact and physical comfort, seldom on clinical outcomes. Time was needed to comprehend the diagnosis, cope with uncertainty, integrate their treatment regimen into their daily routine, and to re-establish a sense of normality in their lives and their family.

Conclusions: Patients with CKD face long-term, pervasive psychosocial effects. Rather than focusing on clinical targets, greater attention may need to be given to providing information, psychosocial, and practical support at a patient, not organ-specific level, and to maximise patient and family quality of life.

5.2 Introduction

While advances in technological and pharmacological interventions are improving survival rates in chronic kidney disease (CKD), patients still face many physical and emotional challenges as a result of their diagnosis, co morbidities and treatment-related side effects.(1, 2) Yet, little attention has been given to gaining a broad and detailed understanding about the experiences, perspectives and needs of patients.(3, 4)

There are a growing number of studies assessing the quality of life of dialysis, transplant, and to a lesser degree, predialysis patients.(2) However, the patients’ subjective experiences and perspectives are usually assessed with questionnaires and quantified. Quantitative instruments may not capture the diverse aspects of patients’ experiences, life
situations, and the practical issues they consider important, and currently no instrument is universally accepted. Studies assessing patients’ perspectives and lived experiences in-depth are scant, specifically focussed on dialysis (3, 5, 8, 9) or transplant patients (6, 10, 11), and not across all phases of the CKD spectrum. In healthcare management decisions, explicit acknowledgement of patients’ values and preferences is important, yet there are few data on this, particularly in the setting of CKD.

This study aimed to describe the range and depth of experiences and perspectives from predialysis, dialysis and transplantation patients about the meaning of CKD and its treatment, its impact on lifestyle and relationships, and the coping strategies adopted by patients. More rapid and widespread implementation of patient-centred care in CKD may be achieved through a better understanding of the needs, experiences and preferences of patients.

### 5.3 Methods

This study was undertaken to elicit research priorities from CKD patients, but the focus group method used had two components. The first component focussed on eliciting priorities for research topics from patients who had CKD and explored the reasons underlying their selection of research topic. This component has been published elsewhere and methods described in detail. (Chapter 6) Here we report the second component, which focused on understanding patients’ perspectives and experiences of CKD during the nine focus groups.
Focus groups are widely used and particularly well suited to examine people’s experiences of diseases and of health services.\(^{(14)}\) The method capitalises on group interaction and allows participants to ask each other questions, exchange anecdotes and comment on each other’s experiences and perspectives.\(^{(15)}\) Participants can introduce their own ideas and avoid aspects of the topic they do not consider relevant or do not want to discuss. This provides insights into a wide range and form of understanding, and how opinions are constructed.

Participants and setting: Patients were eligible to participate if they were English-speaking, 18 to 80 years of age, able to give informed consent, and were in one of three CKD phases (diagnosed with CKD, but not currently needing dialysis (predialysis patients), undergoing haemodialysis or peritoneal dialysis, and kidney transplant recipients). We conducted three focus groups with each of the three patient types.

Participants were purposively selected to provide a mix of age, ethnic background and gender. For each focus group, eight participants were approached either face-to-face or by telephone and invited to participate by their nephrologist or by the primary investigator (AT). Participants were offered reimbursement for their time and transport expenses; three (4.8%) declined reimbursement. The focus groups were convened in non-clinical settings and in the absence of their doctor to encourage openness during discussion.

Data collection: Participants were asked about their experiences of CKD using the following 4 questions: 1) I have no direct experience of CKD, how would you explain to someone like me what it’s like to live with CKD? 2) What helps you to live with CKD? 3) What makes it harder to live with CKD? 4) What solutions have you found to deal
with these problems, is there anything else you can think of that would make life better for people with CKD? The facilitator was careful to ensure maximum opportunity for participants to interact with each other. All sessions were digitally audio-recorded and transcribed in full. The facilitator and note taker debriefed after each focus group to record important insights and observations.

Analysis: The transcripts were entered into QSR NVivo 7, a software program used to assist with storage, coding and searching of data. The transcripts were reviewed line-by-line by the first author, who searched for concepts, themes and ideas, and developed a preliminary coding scheme. Transcripts were read and coded by three authors independently, who compared and discussed their individual coding choices, and resolved any disagreements by discussion. The coding scheme was revised to develop a final coding structure that captured all data on the patients’ experiences of CKD. Through a process of careful analysis and comparisons, we inductively developed categories of descriptive themes and sub-themes from the data, which examined patient experiences and perspectives across all stages of CKD. For each theme, we compared the data between predialysis, dialysis and transplant groups and identified differences in the content and nature of the participants’ responses.

Ethics approval was obtained from the four institutions involved in the study (Princess Alexandra Hospital, Brisbane; Royal Prince Alfred Hospital, Sydney; Westmead Hospital, Sydney; and Royal Melbourne Hospital).

5.4 Results
The 9 focus groups involved 63 participants (88% attendance rate), aged from 20 – 78 years (mean 52.3 years); 30 (48%) were male. Of the 63 participants, 50 (79%) were Caucasian and 13 were from nine different national backgrounds. Reasons for non-attendance included work commitments, illness-related problems and difficulty in arranging transport.

Participants in all 9 groups talked extensively about their experiences, attitudes, concerns and coping processes, including where relevant previous phases of CKD. Group dynamics, interactions and contextual details are provided in Table 5.1. (Please refer to Appendix D1. for detailed focus group field notes and observations). We identified 5 main themes from the analysis of field notes and transcripts: personal meaning of CKD, managing and monitoring health, lifestyle consequences, family impact, and informal support structures. (Table 5.2) Definitions and illustrative quotes for each theme are provided below. A detailed comparison of the themes identified in the predialysis, dialysis and transplant participant groups is provided in Table 5.3.

**Personal meaning of CKD**

**An incomprehensible diagnosis:** Initially, it was difficult for participants to understand and accept the diagnosis, which caused them to feel vulnerable and confused. Many expressed feeling shock and described the experience as traumatic and overwhelming.

**Crisis and confusion:** Frequently, participants felt trapped in a paradox of appearance versus reality. Internally, participants felt very ill and fatigued, but externally they appeared well and healthy.
“It’s a feeling, not something obvious. With chronic kidney disease, you don’t look different. They tell you, you look good, but they don’t see what’s inside.”

(Female, 40s, predialysis)

However, some transplant patients with a functioning kidney felt well and refused to be labeled as having CKD.

“I don’t consider that I have chronic kidney disease now,” (Female, 50s, transplant)

“But you have end-stage kidney failure.” (Female, 40s, transplant)

“No, my kidney’s working just fine.” (Female, 50s, transplant)

Living with CKD was explained in terms of losing normality and having a pervasive and permanent impact on the participants’ identity and life. Participants felt they were living in limbo.

“I don’t know what it’s like to be normal anymore, to feel normal.” (Female, 30s, predialysis)

“You’re never off the hook. Even if you get a transplant, you’re still not off the hook.” (Female, 60s, dialysis)

**Emotional struggle and coping:** Participants were fearful and anxious about their treatment and uncertain prognosis. Some expressed feeling depressed, particularly during the early stage of their illness. However, most participants developed mental coping by thinking positively and engaging in activities to preoccupy their minds.
“If I’m going to feel this bad for the rest of my life, do I just want to end it now?” (Female, 40s, predialysis)

“Be positive, look at the big picture and make it a part of your life. Live your life as much as you can within your limitations, but don’t allow it to become the centre otherwise you find the rest of your life passes you by and you don’t get it back.” (Female, 60s, transplant)

**Physical constraints:** Overwhelming fatigue affected work life and limited social participation. Many participants felt that their need for copious amounts of sleep was “wasting” time and this often caused a strong sense of guilt, regret and helplessness.

“you just sleep your life away.” (Female, 40s, transplant)

“and I feel guilty knowing that I have to sleep.” (Female, 30s, predialysis)

The physical symptoms and side-effects mentioned by participants included cramping, restless leg syndrome, nausea and vomiting.

**Managing and monitoring health**

**Navigating the health system:** Participants recurrently commented on having to traverse a non-integrated, disease-centered healthcare system. They felt splintered, treated as separate disease entities and not as whole people.
“We go there as renal patients but we go there with baggage from all the other departments as well…they should encompass all parts of our body.” (Female, 40s, transplant)

“Everyone likes to keep their own departments very distinct…you’re not being looked at holistically.” (Female, 40s, predialysis)

“He should take a little more interest rather than just fob me off and say, go see another doctor, because it may be related or not related to the kidney problem.” (Male, 60s, predialysis)

Participants highly valued the attentive, non-judgmental medical care from specialists and nursing staff. They discussed their need to be involved and respected in decision making about their treatment. Some felt emotional and psychological support was lacking. The participants across all focus groups talked at length about their encounters with GPs who they perceived had little knowledge about diagnosing and treating kidney disease. Participants found this exasperating, and some described the need to educate their GP about CKD.

**Managing medicines:** Although taking multiple medications was confusing, and often caused unpleasant side effects, the participants adhered to the regimen out of a sense of duty to the hospital and doctors, to avoid guilt and blame, and ultimately to survive. Some participants mentioned that over time, their confidence in medication protocols waned as they realised dosages were often “hit and miss.”
Managing dialysis: Participants often explained their underlying reasons for choosing a particular dialysis modality and advised each other about the different lifestyle impacts and restrictions imposed. They made decisions regarding their preferred dialysis modality based on family and lifestyle impact, environment, pain and physical comfort.

“I couldn’t see why we had to go to hemo, I said we’ll choose PD, it still gives us the flexibility of travel.” (Male, 60s, dialysis)

“We chose to do it at home for freedom, I don’t like hospitals, they’re normally very cold.” (Male, 50s, transplant)

“I tried the evening one, I didn’t like it, I found it too restrictive. I had to go to bed at certain time; I had to spend so many hours in bed. At 1 o’clock in the morning, sometimes I wake and it’s wrapped around me, and it’s alarming.” (Female, 30s, dialysis)

“I’ve got 2 kids I’ve got to get to school in the morning, do the lunches, I have to do that when I wake up and its like I’m screaming from the dialysis room, have you got your shirt on? And it was doing my head in because I can’t break myself into so many pieces and wear all different hats. I was beginning to resent it and thinking I chose the wrong form. I’m better off doing hemo and disappearing three times a week and coming back. You have to choose exactly which one works into your lifestyle.” (Female, 30s dialysis)

“To be honest, if I had the room for it, I’d have nocturnal dialysis.” (Male, 30s, dialysis)
Although necessary for survival, dialysis was an unrelenting mental, emotional and time imposition. Predialysis patients dreaded dialysis, and transplant patients worried about the possibility of having to dialyse again. Participants hated and feared the process, particularly when trying to come to terms with it initially. Most routinized dialysis by working with time constraints and occupying themselves with an activity during dialysis time (e.g. work, exercise, entertainment). In dialysis and transplant groups, participants advocated and shared strategies for avoiding despair.

“If you made that machine the centre of your life, and you made love to the machine three times a week, and it was the centre of your life, everything else went blurgh. You have to make it part of your life, so you live life as much as your energy levels and limitations allow, that’s part of your life, you don’t allow it to become your centre.” (Female, 60s, transplant)

“Treat it like the friend you don’t like, you could certainly attempt to try and appreciate it for what it really is, rather than this inconvenient mess that gives you pain or whatever.” (Male, 30s, dialysis)

In one focus group, some participants argued that the reliability of the dialysis routine was better than the uncertainty of graft failure and immunosuppression side effects in transplantation.

**Managing transplantation:** Participants acknowledged that transplantation restored freedom and energy, and allowed them to eat, drink and travel with less restraint. However, the decision to accept a kidney from a live donor was complex. Participants
described feeling excessive pressure from donors and clinicians, family expectations, self-reproach for putting another person at risk, fear of graft failure and side effects.

“For me to take a transplant from either of my two daughters is anathema to me because I don’t want to violate their bodies.” (Female, 40s, predialysis)

“I’d never take a kidney from a living person; I worry that they’ll be having one kidney and something going wrong with it.” (Male, 50s, dialysis)

“Initially I was completely resistant to it. I said there’s no way I’m having someone else go through any kind of pain on my behalf…they said, your mother would do anything for you and by saying no, you’re actually hurting her. So I suddenly realised, hang on, I’m almost selfish for saying no to such a gift, and it’s for that reason I will accept. I didn’t come to that ultimate decision easily. It’s taken me a year and a half.” (Male, 30s, dialysis)

Differing perspectives on accepting a living donor kidney were offered within groups, but rather than debating the issues, the participants supported, respected and justified each other’s opinions.

“My wife is wanting to give me a kidney, I’m sort of having second thoughts about whether I really want to accept it, what’s the point of putting her through all that trauma if in 5 or 6 years time …” (Male, 50s, dialysis)

“If you were in her situation, would you want her to accept your kidney? Would you be happy?” (Female, 20s, dialysis)
“Ask her also, would you prefer to be a donor or a carer? Because her life may improve without you on dialysis, you can go on those holidays that you wanted to go on.” (Male, 30s, dialysis)

Some transplant recipients felt immense pressure to maintain their kidney for their donor, and blame and guilt if they lost the kidney.

“What hit the most, is dealing with losing (the kidney). That was harder for me than going on dialysis, because I thought I did something wrong, and she gave me a gift.” (Female, 20s, dialysis)

“It’s like you broke her present.” (Female, 40s, dialysis)

The physical, psychological and behavioural side effects of transplantation were discussed mainly among transplant recipients. Some had anticipated that the transplant would offer dramatic health improvement but were disappointed when they experienced side effects, particularly cancer.

“I’d gone from managing dialysis to all of a sudden, supposedly feeling much better but I felt rotten. I had skin cancers, I had all sorts of complications from the medication.” (Female, 60s, transplant)

Some patients were perplexed about the “high” and the aggression they experienced, which they believed were caused by corticosteroids. The transplant patients questioned each other about memory loss and lack of concentration that they suspected were related to transplant medications.
Lifestyle consequences

**Interrupted education and employment:** Significant stressors for participants across all focus groups were the loss of career, financial problems, difficulty in re-entering the workforce, and facing illness stigma at work. The illness absorbed their time, energy, vitality and finances.

“There’s no way I can go back to working where I used to, there’s no way I can stand on my feet for 8 hours doing the heavy work I used to do, there’s all the re-training and going back into the workforce, doing all that, plus trying to work out how I’m going to pay my bills, my rent.” (Female, 30s, predialysis)

“A lot of things I grappled with, huge financial stress, and the potential loss of the career that I’ve spent 12 years building.” (Female, 40s, predialysis)

**Diet restrictions:** Again, across all focus groups, participants repeatedly spoke of their struggle to understand and maintain vigilance in adhering to dietary restrictions. They tried to make sense of paradoxical nutritional advice. For example, they were advised to lower protein intake but would become sick because of lowered immunity. Participants also felt they received mixed messages about salt intake. Participants were aware of the minerals they needed to restrict, but agreed they needed more comprehensive guidance on food purchasing and preparation. Also, participants had two competing priorities: liquid and dietary restrictions set by healthcare providers and the need to participate fully in social gatherings.
“Well for the sake of a function, I’ll get into it, and I’ll apologise tomorrow, and feel crook for a couple of days… You can really beat yourself about that, and diets and everything else, to me they’re just following the rule most of the time, the occasional thing won’t hurt you too much.” (Male, 60s, dialysis)

**Social isolation:** Many participants were resentful about being unable to travel and go on holidays during the period they required dialysis. Because of fatigue and side effects, patients felt forced to give up social activities (e.g. sport). Some participants felt they lost self-esteem or felt alone. Repeatedly, they vented their frustration about the poor public profile of CKD, and felt their disease was receiving inadequate attention and public support. Groups consistently agreed that they had to contend with a general ignorance from employers, friends and the community. Some patients said friends and colleagues found dialysis too confronting. Transplant patients were exasperated about the general misconception that transplant was a cure.

“I think it’s a lonely kind of existence. My friends backed off while I was on dialysis, the general public doesn’t have a good understanding with that, so you lose a lot of self esteem and you find you do withdraw from things.” (Female, 50s, transplant)

“That’s what people don’t understand, because I’ve had friends say go to the doctor, get your tablet, and get yourself fixed up! And just get a transplant! This is why I get cranky with some of my girlfriends, “just go get a transplant, you’ll be right.” But they don’t realise there’s problems with just having transplant. It’s not perfect.” (Female, 40s, transplant)
“I just feel really uncomfortable around people, and more so since I got the PD catheter put in.” (Female, 30s, dialysis)

“No one quite understood what you were going through. I mean everyone found the (dialysis) machine amazing. Some could see the machine and others couldn’t. They could walk into the room, others couldn’t do it. And when they saw you well, see you walking around, they’re like, ‘he’s ok,’ and there was no appreciation of just how bad you did feel, so there wasn’t that understanding, it was never there, everyone was like sympathetic but they could never relate to how bad you feel. It’s certainly something that’s hard to explain and even today, even today, people think there’s nothing wrong with you.” (Male, 50s, transplant)

**Home relocation and responsibilities:** A few participants relocated for access to better health services. Some needed domestic support, as they were physically unable to maintain their home.

**Family impact**

**Emotional burden:** The discussion often extended beyond the patients’ individual experiences and coping strategies, to acknowledge the burden of CKD on their partners, parents and children. The participants survived and most tried to be strong for their families. Dialysis participants, in particular, felt guilty for being unable to participate in family activities, depriving their family of freedom, and depending on them for medical interventions.
“But you know he looked so much better, he felt, after my transplant, he couldn’t bear looking at me on the machine, you know, I never forced him to look, that’s why I didn’t dialyse at home, but he just, sort of all the stress, the, to go from my husband as well, having to you know, it’s very hard on families I think, very hard.” (Female, 50s, transplant)

“Your partner’s got to be prepared to accept that you know your get up and go is gone in every aspect of your life for that period in time.” (Female, 40s, transplant)

“If there’s anything I feel guilty about, is that I’ve loaded my family with something that they shouldn’t have to deal with, but because of me they’ve got to deal with this. Because of me, my eight year old has got to be efficiently handling, the blood going around in the lines and all that. Like it’s a big deal for a little kid.” (Female, 30s, dialysis)

**Genetic risk:** For some participants, CKD was genetic and they had relatives who were also diagnosed with CKD.

**Informal support structures**

**Community support:** Participants appreciated financial and practical support from employers, friends, relatives, and community organisations like churches. Transplant participants considered initiatives like the Transplant Games to be important for helping to take the focus off the illness and worry. For some participants however, financial and time constraints impeded access to this event.
Peer support: Participants reiterated the value of support from other CKD patients, which they received at dialysis units, and in online support groups and many commented that they benefited from talking with other patients during the focus group. The mutual understanding reduced their sense of isolation and anxiety.

“I’ve found the PD unit was like a real community support, you know you could go in and make a cup of tea, and people know you by your first name and that really helped to kind of get away from the earlier experience of the whole focus on figures.” (Female, 40s, predialysis)

“The most important thing for me is to hear about how other patients are getting on with their treatment and so forth, and you know people that have been able to go on outback trips and so forth even though they’re doing dialysis. People point out that you can actually go overseas and plug into other units, and all sorts of things, so you know I think that sort of personal sort of anecdotal evidence is very important when you’re looking down the track at the machine. In terms of information, it’s always a bit of a balance… the doctor doesn’t always know how you’re feeling, or how things are affecting you.” (Male, 50s, predialysis)

“Something like this (focus group) where we can talk to other people who are in our situation, who maybe not in our age group, but we know they’ve gone through exactly what we’re going through… cause the problem is you think you’re on your own.” (Female, 30s, predialysis)
5.5 Discussion

Patients with CKD have had to adjust to the disruptive and permanent implications of a pervasive illness on their physical health, identity, emotions, family, lifestyle, relationships and employment. The overwhelming fatigue, complex treatment regimens, side effects, and liquid and/or diet restrictions imposed physical and social constraints on patients. Time was needed to comprehend the diagnosis, cope with uncertainty, integrate their treatment regimen into their daily routine, and to re-establish a sense of normality in their lives and their family.

Patients appreciated specialist medical care, but felt they had to negotiate and navigate a non-integrated system. They were required to visit multiple clinical disciplinary and diagnostic departments, which disrupted their lifestyle, consumed time, finances and energy, impacted on their family and gave them a sense of a fragmented self. Healthcare systems need to be more integrated, and patient-centred rather than provider-centred. Strategies to improve coordination of care between settings are needed. Also, at an organisational level, health delivery and support systems should ideally ensure easy access to and continuity of care. Implementing accessible and integrated services with continuity of care is a substantial challenge, but it has been demonstrated to improve patient and clinician satisfaction and increase service delivery efficiency.(16)

Patients chose treatments based on lifestyle, family impact and physical comfort, not on clinical outcomes. Rather than narrowly focusing on medical outcomes such as quantitative biochemical targets, consultations and clinical decision-making need to encompass the patients’ psychological state, sense of self, perceived needs, personal preferences, family, social, financial, environmental and cultural situations, and support
structures. Given the complexities, multiplicity and variability of consumer concerns, clinicians need to encourage patients and caregivers to express their concerns and share in decision-making, rather than assume what patients prefer. For example, in addition to clinical outcomes, clinicians should assist patients to consider the potential impact and risks their decisions will have on their family, lifestyle, home, employment, energy and physical comfort.

Patients felt they received insufficient information and psychosocial support. Patients perceived that if their biochemical and other targets were achieved that the clinicians felt their treatment was effective. Patients wanted more from their clinicians. Rather than focussing on achieving clinical targets, greater focus is needed on what patients’ value and need: informational, psychosocial, and practical support. While patients’ appreciated efforts by clinicians to improve clinical outcomes, many unmet information and psychosocial support needs were identified. A comprehensive understanding of patients’ experiences, needs and perspectives can guide healthcare providers towards patient-centred care.(17) Taking patients’ views into account can lead to increased satisfaction, improved compliance and greater continuity of care.(7, 18)

Our findings also highlight the different experiences, needs and perceptions of patients that are unique to the predialysis, dialysis and transplant phases of CKD. During the predialysis phase, patients felt vulnerable and overwhelmed by the diagnosis and clinical environment. Being an invisible disease, patients felt poorly understood by others. They also felt fatigued, unable to cope with work, and ill-equipped to follow dietary guidelines. Dialysis was an unrelenting imposition on patients’ lives and exacted a physical and emotional toll on their family. Patients struggled to adhere to the strict liquid and/or diet restrictions and felt socially isolated. However, they demonstrated the ability to
incorporate dialysis into their daily routine, adopt a positive attitude, and preoccupy themselves with work and activities. After transplant, patients strived for normality. They felt more energetic, free, and less of a burden on the family. However, they still faced the complex moral choices surrounding their transplant, the potential devastation of kidney rejection and the physical and psychological side effects of immunosuppression.

The focus groups facilitated participant interaction and the findings were derived inductively from the data, not within an a priori analytic framework. This enabled an in-depth examination of a range and depth of patient experiences and perspectives, as encountered in the participants’ personal, real-life circumstances. While quantitative survey instruments may be easily accessible, assess psychosocial domains, and are time and resource efficient, they impose categories important to researchers onto participants’ experience, rather than allowing participants to define what is important in their own terms. This study has a number of limitations. Non-English speaking participants were not included to avoid cultural and linguistic misinterpretation and we are unable to comment on the transferability of the findings to these groups. The groups were formed for each CKD phase, and were heterogenous in gender, age and ethnicity. Therefore, participants may have been reluctant to raise some sensitive topics, for instance gender-specific issues. Finally, as for any qualitative study, sampling to ensure representativeness of responses was not undertaken. Rather we sought to elicit the broad range of patient experiences.

Our findings are broadly consistent with those offered by other in-depth studies examining the experiences of patients with CKD, which have focussed on either the dialysis or transplant phase only. Studies during dialysis have also found that patients survived, searched for a state of satisfaction and adjusted to new identities by learning to
cope with the uncertainty, constraints and intrusiveness of dialysis. They depended on family and caregivers’ support to maintain their complex treatment regimen, which often incurred demands and sacrifices on family caregivers. One focus group study identified a range of patients’ concerns about dialysis, which included freedom and control, social relationships, anxiety, role function, energy and body image. Similarly, our findings demonstrate that patients consider the impact of dialysis on a range of aspects of quality of life.

In kidney transplantation, studies have also found that despite having some improvement in their quality of life, patients faced long-term, pervasive psychosocial effects. These included the pressure not to disappoint, constant vigilance, preoccupation with self-care, intrusiveness of medical care, struggle to regain a sense of normality, coping with medication and side effects and facing the constant threat of graft failure. Patients did not always readily accept offers of living donor kidneys; they were concerned about risking the donor’s well-being, compromising relationships, and disappointing the donor if the kidney failed. One study found that recipients were unaware that donors could personally benefit but our findings showed that some patients also felt they could not refuse the right of the donor to want to give their kidney, and they also considered whether their potential donor wanted to be a donor or a caregiver. Our study extends previous findings by comparing the perspectives and experiences of patients across the whole spectrum of CKD including predialysis, dialysis and transplantation. (Table 5.3)

Patients in all phases of CKD face long-term, pervasive psychosocial effects. A comprehensive understanding of their experiences and perspectives provides insight on ways to help patients face the physical and emotional challenges, and improve patient-
centred care in nephrology. Strategies to integrate health care services are needed to improve patient satisfaction. Patients need more information about the potential impact of treatment on lifestyle, family, and physical impact, so they can be more confident in their decision-making with regards to treatment options. Also, rather than focusing on achieving clinical targets, greater attention on providing adequate information, psychosocial, and practical support is needed. Responding to patients’ perspectives, values and needs might facilitate better patient-centred care in nephrology.
### Table 5.1. Characteristics of each focus group

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Location</th>
<th>CKD Stage</th>
<th>Emotional disposition of the group</th>
<th>Group Dynamics</th>
<th>Dominant focus of discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>8</td>
<td>Brisbane</td>
<td>Predialysis</td>
<td>Anxiety, depression</td>
<td>Open, cohesive, jovial</td>
<td>Psychological impact, financial stress, comorbidities (CKD not overriding other health issues), healthcare not holistic</td>
</tr>
<tr>
<td>2</td>
<td>6</td>
<td>Brisbane</td>
<td>Dialysis</td>
<td>Confusion, anger, frustration</td>
<td>Listless, venting, subdued</td>
<td>Impact on work, community acceptance, technical and practical aspects of dialysis</td>
</tr>
<tr>
<td>3</td>
<td>8</td>
<td>Brisbane</td>
<td>Transplant</td>
<td>Gratitude</td>
<td>Reflective, articulate</td>
<td>CKD transplant is the dominant health issue, appreciate the healthcare system, compliance</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>Sydney</td>
<td>Predialysis</td>
<td>Fearfulness, depression, confusion, isolation</td>
<td>Jovial</td>
<td>Financial stress and employment, fear and uncertainty of the future, diet, stigma</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
<td>Sydney</td>
<td>Dialysis</td>
<td>Anger, guilt, depression to positive outlook</td>
<td>Supportive, shared practical tips</td>
<td>Fatigue, determination to be normal</td>
</tr>
<tr>
<td>6</td>
<td>8</td>
<td>Sydney</td>
<td>Transplant</td>
<td>Gratitude</td>
<td>Talkative</td>
<td>Emotional impact on carers, family, donors, professional and patient communication</td>
</tr>
<tr>
<td>7</td>
<td>8</td>
<td>Melbourne</td>
<td>Predialysis</td>
<td>Fear, denial, uncertainty</td>
<td>Formal, competitive, tense, intellectual</td>
<td>Uncertainty of the future, prevention, informational support</td>
</tr>
<tr>
<td>8</td>
<td>7</td>
<td>Melbourne</td>
<td>Dialysis</td>
<td>Positive</td>
<td>United, supportive, energetic, warm, open</td>
<td>Coping strategies, family impact, kidney donation, impede travel, control (dialysis vs. transplant)</td>
</tr>
<tr>
<td>9</td>
<td>8</td>
<td>Melbourne</td>
<td>Transplant</td>
<td>Lonely</td>
<td>Reserved, serious, formal</td>
<td>Determination to be normal, lack of understanding, CKD is not visible</td>
</tr>
</tbody>
</table>
Table 5.2. Themes representing patient perspectives and experiences of CKD

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
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</thead>
<tbody>
<tr>
<td>Personal meaning of CKD</td>
<td>• An incomprehensible diagnosis</td>
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<tr>
<td></td>
<td>• Crisis and confusion</td>
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<tr>
<td></td>
<td>• Emotional struggle and coping</td>
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<tr>
<td></td>
<td>• Physical constraints</td>
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<tr>
<td>Managing and monitoring</td>
<td>• Navigating the health system</td>
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<tr>
<td>health</td>
<td>• Managing medicines</td>
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<tr>
<td></td>
<td>• Managing dialysis</td>
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<tr>
<td></td>
<td>• Managing transplantation</td>
</tr>
<tr>
<td>Lifestyle consequences</td>
<td>• Interrupted education and employment</td>
</tr>
<tr>
<td></td>
<td>• Diet restrictions</td>
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<tr>
<td></td>
<td>• Social isolation</td>
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<td></td>
<td>• Home relocation and responsibilities</td>
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<tr>
<td>Family impact</td>
<td>• Emotional burden</td>
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<tr>
<td></td>
<td>• Genetic risk</td>
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<tr>
<td>Informal support structures</td>
<td>• Community support</td>
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<td></td>
<td>• Peer support</td>
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</table>
### Table 5.3. Comparison matrix of themes across 3 phases of CKD

<table>
<thead>
<tr>
<th>Theme</th>
<th>CKD (pre-dialysis)</th>
<th>Dialysis</th>
<th>Transplantation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personal meaning of CKD</strong></td>
<td>The initial feeling after receiving the diagnosis was despair and disbelief. CKD patients felt vulnerable, helpless, overwhelmed and confused while trying to grasp the clinical language and environment. Some were looking to blame somebody for their illness. Others who had known about their diagnosis for a longer period of time were learning to accept and deal with the illness.</td>
<td>Time was needed to accept the diagnosis. Dialysis patients were still confronting the permanence and long-term implications of the diagnosis of CKD. They realised CKD could only be treated, not cured.</td>
<td>Transplant patients had come to terms with the diagnosis and were focussed on adapting to their treatment regimens, although they still remembered the initial shock when they received the diagnosis.</td>
</tr>
<tr>
<td>Crisis and confusion</td>
<td>The external appearance of CKD patients did not reflect how sick they felt inside. This caused them to feel perplexed and upset particularly when people around them appeared to be inconsiderate and unsympathetic. Often they felt they were living in a limbo, had lost a sense of normality and needed to adjust to their new CKD identity. Some patients with other co morbidities felt kidney disease had equal prominence with their other health issues.</td>
<td>Patients frequently described dialysis as an unrelenting routine that dominated their lives physically, emotionally and mentally. It diminished their self-esteem and constrained their daily activities. Patients on dialysis lost their independence and had to rearrange many aspects of their life.</td>
<td>Transplant patients felt being labelled as being sick or disabled was incongruous to how well and normal they felt inwardly. They wanted to be normal and disliked going to hospital for periodic clinical follow up because it made them appear ‘different.’</td>
</tr>
<tr>
<td>Emotional struggle and coping</td>
<td>CKD patients expressed feelings of fear, depression, constant anxiety, and uncertainty. A few expressed that having a positive mental attitude and engaging in other activities enabled them to cope.</td>
<td>Many dialysis patients adopted a positive attitude as they realised that remaining resentful was of no benefit to themselves or others. They occupied themselves with other activities. Some parents mentioned they had to remain strong for their children.</td>
<td>Transplant patients also discussed adopting a positive mindset and some said they reoriented CKD as a peripheral part of life rather than the centre of life.</td>
</tr>
<tr>
<td>Physical constraints</td>
<td>CKD patients frequently suffered unpredictable periods of tiredness and listlessness. They were unable to participate in physical activities and felt they had slowed down considerably. They found it difficult to get out of bed and manage their daily tasks, which often caused them to feel guilty and inept.</td>
<td>Dialysis patients felt immobilised by the constant, intense and overwhelming fatigue and exhaustion. They felt drained, and physically and mentally incapacitated.</td>
<td>Transplant patients did not feel exhausted but remembered feeling fatigued during the CKD and dialysis stages.</td>
</tr>
<tr>
<td>Managing and monitoring health</td>
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</tbody>
</table>
### Navigating the health system

| CKD patients described the healthcare system as being non-integrated. They felt they did not receive holistic care, and were being tossed between different healthcare providers. Having to attend multiple appointments was time consuming and tiring. | Dialysis patients desired involvement in decision-making and wanted to be recognised as having expertise in their treatment. They felt medical care was too focused on clinical targets, and that more psychological and emotional support was needed. Also, individualised care and unhurried consultations were important to dialysis patients. | Almost all transplant patients expressed gratitude for the medical care delivered by the transplant team. |

### Managing medicines

| CKD patients followed their medication regimen although they admitted to forgetting to take their medicine on the rare occasion. However, they felt they did not suffer any serious consequences for forgetting. | Oral medications in the form of large tablets were unpleasant. However, most patients established a medicine-taking routine. | Initially, patients found it difficult to develop and adhere to a complicated medicine regimen but knew they had to be responsible. They complied with their medical regimen out of an obligation to the hospital and specialists, to avoid the risk of graft failure and dialysis, and did not want to be blamed if something went wrong. Some patients negotiated with their specialists to adjust their dosages to counteract the side effects. |

### Managing dialysis

| CKD patients were fearful about the impending possibility of commencing dialysis. They were aware and concerned about the impact dialysis would have on their lifestyle, physical comfort, and work, and were worried they might not be able to manage the dialysis themselves. | Dialysis patients often talked about preferences of dialysis modalities, which were based on comfort, lifestyle impact, travel, family impact, environment and pain tolerance. They also advised each other on how to incorporate dialysis into their daily routine. In one dialysis group, patients preferred the reliable routine of dialysis than the risk of potential side effects and graft failure in transplantation, which they believed would disrupt and devastate their lives. Some patients despised the dialysis machine and the unyielding pressure it imposed on them. A few hid the dialysis machine in a closed room, refusing to integrate it into their family living environment. | Transplant patients feared the possibility of having to dialyse again if their graft failed. They also chose their dialysis modality based on lifestyle and comfort. A few remembered feeling alone in making their decisions and thought patients needed a better explanation of the impact each dialysis modality would have on lifestyle. |

### Managing transplantation

| Some CKD patients hoped for a transplant to improve their quality of life. However, a few worried about the potential unpleasant side effects of immunosuppression. Also, patients who faced | Dialysis patients felt guilty about risking the donor’s well being and putting donors through surgery-related trauma, and worried about the consequences of living with one kidney. At the | Transplant patients had found it difficult to accept a kidney from a living donor, but some also felt they would have deprived the donor the right to donate if they had |
Chapter 5. Patients’ experiences and perspectives of living with chronic kidney disease

the possibility of accepting a kidney from a live donor felt guilty about violating their donor’s body, worried about the potential health consequences to the donor and did not want to feel responsible for transplant-related detrimental outcomes in the donor. same time, some felt it was wrong to refuse the offer of a kidney if their family member wanted to donate. The decision to accept a kidney was predominantly based on the nature of the relationship patients had with their potential donor. Some dialysis patients recalled the trauma and guilt they felt when their transplanted kidney had failed. Despite knowing the unpleasant side effects of immunosuppression and devastation of losing the donated kidney, patients also appreciated the prospects of freedom and “normality” if the transplant was successful.

refused. Transplant patients were very concerned about the donor’s well being post-transplant, and felt the medical, emotional and financial needs of donors were often neglected. Patients who were not experiencing side effects felt increased freedom and regained a sense of normality after transplant. For others, kidney rejection and the side effects of immunosuppression, including cancers, bone disease and emotional, mental and behavioural abnormalities, shattered their expectations of regaining their vitality, health and freedom after a transplant.

| Lifestyle consequences | Being physically and mentally unable to cope, CKD patients faced the loss of career and employment and some had to relinquish their jobs. They suffered accumulating financial stress and some were forced to continue working. | Dialysis patients struggled to keep their jobs and some forced themselves to keep working despite feeling fatigued and sick. Some employers were not comfortable about patients dialysing at work, while other patients felt their employers were supportive. | Transplant patients discussed how dialysis had affected their work and advocated the need to establish support system to facilitate re-entering the workforce. The younger patients recalled taking long absences from school. |
| Interrupted education and employment | CKD patients were aware of their dietary restrictions and disciplined themselves to follow the advice but were bewildered as they struggled to identify what types of foods they could purchase and prepare. Also, if they reduced their protein intake, they would become frequently sick. CKD patients wanted more comprehensive dietary guidance on how to prevent progression of CKD. | Dialysis patients found it difficult to adhere to food and liquid restrictions, particularly during social gatherings. Occasionally, they compromised and chose to endure the consequences and to make up for it later. While the restrictions aimed to prevent detrimental outcomes, patients believed it was not a nutritious diet and speculated this caused other problems. | Transplant patients were free from diet and liquid restrictions but mentioned that the liquid and diet restrictions had an impact on the family and their social life. |
| Diet restrictions | CKD patients became unable to participate in physical activities including running and tennis. | Some dialysis patients lost self-esteem and confidence. They perceived their friends felt uncomfortable around them because of the dialysis. While some family and friends were sympathetic, patients still experienced a profound sense of isolation and loneliness, as others could not fully relate and understand what they were | Patients with a functioning kidney transplant appreciated the ability to travel. However, they were often exasperated about the general misconception that transplant was a cure. |
| Social isolation | | | |
Chapter 5. Patients’ experiences and perspectives of living with chronic kidney disease

| Home relocation and responsibilities | Not discussed. | A few dialysis patients had to relocate from rural or remote areas for better access to healthcare services. Some struggled to maintain their domestic responsibilities and practical support was needed. | Not discussed. |

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<th>Family impact</th>
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<td>Emotional burden</td>
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| Genetic risk | A few parents mentioned their children worried about their risk of getting CKD. | Some parents had children with CKD, and felt they had to demonstrate positive coping and strength for the sake of their children. | Some patients mentioned they had other family members who were diagnosed with CKD, and also worried about possibility of other family members being diagnosed with the disease. A few were uncertain about having children because of the risk. One mother recalled feeling upset at having to fight against her doctor’s advice to terminate her pregnancy because of hypertension and kidney disease. |

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<tr>
<th>Informal support structures</th>
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<tbody>
<tr>
<td>Community</td>
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<tr>
<td>support</td>
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<td>--------------</td>
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<tr>
<td>Peer support</td>
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6. Patients’ priorities for health research: focus group study of patients with chronic kidney disease

6.1 Abstract

Background: The inclusion of consumer preferences in prioritising research topics is widely advocated, but prioritisation is driven largely by professional agendas.

Methods: Patients with chronic kidney disease (CKD) were purposively sampled from four kidney dialysis and transplant centres in Australia to participate in nine focus groups (three each for pre-dialysis, dialysis and transplant patients), which were conducted from July 2006 to September 2006. Each involved 6-8 participants. Transcripts were coded and thematically analysed to identify recurrent research topics and the participants’ reasons for their choices.

Results: Participants suggested eight research priorities: prevention of kidney disease, better access to and improvement in kidney transplantation, reduction of symptoms of CKD and complications associated with treatment, new technological therapies, psychosocial aspects of living with CKD, whole body not organ-specialised care, and improvement in dialysis and caregiver support. Five major reasons for selection were identified: normalisation of life (developing therapies and regimens that fit into daily living), altruism (considering the welfare of others before personal needs), economic efficiency (channeling resources for maximum economic gain), personal needs
preferences based on feelings, values, personal needs), and clinical outcomes (improving health states and the physiological condition of patients with CKD).

**Conclusions**: A patient-focused research agenda is possible to elicit for CKD, and by inference for other healthcare issues. Unlike researchers who focus on specific interventions and questions, consumers think in terms of broad themes, and quality of life outcomes. Effective methods for translating a patient-focused agenda into research priority setting and resource allocation are now needed.

### 6.2 Background

Health research is largely community funded and ostensibly aims to improve outcomes for consumers. The inclusion of consumer perspectives in research priorities is widely advocated, yet research priorities are largely driven by professional agendas.\(^{1-3}\) Consumers are rarely given a role in this decision making process and the preferred mechanisms for consumer involvement remain unclear.\(^{4, 5}\) Consequently, the limited resources for health research may be directed towards research which consumers do not value as highly as researchers.\(^2\)

The experiences and knowledge of patients can complement those of clinicians, health professionals and researchers.\(^6\) Patient involvement in identifying and prioritising research topics may make practice and policy more relevant to consumers’ needs, leading to outcomes that include greater patient satisfaction, improvement in treatment adherence, better acceptance of research findings and reduced risk of litigation.\(^3, 7\)
Research to identify patient priorities for health research is scarce. According to a recent systematic review most studies have not reported explicit and comprehensive details on how patient priorities were obtained. Only three studies, involving osteoarthritis, asthma and spinal cord injury have identified treatment-related research priorities of patients. To our knowledge, no studies have explored the underlying rationales for patients’ decisions on research priorities and no studies on research priorities of chronic kidney disease (CKD) patients are available.

This study was conducted to elicit priorities for research topics from patients who have CKD and to explore the reasons underlying their selection of research topics.

### 6.3 Methods

We conducted nine focus groups from July to September 2006. Each focus group lasted 2 hours and was facilitated by one of the authors (S.C. or A.T.) who had had no contact with the participants before the study. One observer (B.H.) recorded field notes on group dynamics and interactions, participant characteristics, body language and the context surrounding the discussion. Ethics approval was obtained from the four institutions involved in the study (Princess Alexandra Hospital, Brisbane; Royal Prince Alfred Hospital, Sydney; Westmead Hospital, Sydney; and Royal Melbourne Hospital).

**Participant selection:** Patients were eligible to participate if they were English-speaking, 18-80 years of age, able to give informed consent, and were in one of three CKD stages (diagnosed with CKD, but not currently needing dialysis (predialysis patients),
undergoing haemodialysis or peritoneal dialysis, and kidney transplant recipients). We conducted three focus groups for each of the three patient types.

Participants were purposively sampled for each focus group to achieve equal numbers of male and female participants from a wide age range and various cultural backgrounds. For each focus group, eight participants were approached either face-to-face or by telephone and invited to participate by the recruiting nephrologist or by the primary investigator (A.T.). Participants were offered reimbursement for their time and transport expenses; three declined reimbursement.

**Setting:** The focus groups were convened in neutral locations external to the hospitals to encourage openness during discussion.(11)

**Data collection:** We developed a list of preliminary questions, to pose to the focus groups, from a literature review and discussion among the research team. After input from 11 multi-disciplinary collaborators (nephrology, public health, health economics, qualitative research, social work, and consumer representative), the schedule was finalised, and is provided in Appendix E.2. Each focus group had three phases, preliminary questions about the participants’ experiences of CKD, specific questions about the participants’ research priorities and an exercise for the participants to rank priorities for research.

To maximise participant engagement an activity was developed(12) for the third phase of the focus group that enabled participants to allocate ‘money’ between competing research priorities. For each of five ranking exercises, participants were given a sheet of paper on which was listed several research topics (see Appendix E.1). Ten counters (each
representing one million dollars) were provided to each participant. The facilitator explained, ‘There is a limited amount of money and resources for research and decisions have to be made. Please distribute your money to the different research topics written on the sheet of paper, and think about how you are making those decisions. Also, please add topics that you think should be included but are not listed on the paper.’ We were not seeking consensus or a quantitative score for each list. Rather, we were aiming to understand how participants came to allocate resources, and to record their interactions around their allocations. For this reason, we encouraged debate and allowed participants to change their distribution of money during the discussion. All sessions were digitally audio-recorded and transcribed in full.

**Analysis:** The transcripts were entered into QSR Nvivo 7, a software program used to assist with storage, coding and searching of data. The transcripts were reviewed line-by-line by a single author (A.T.) who searched for concepts, themes and ideas, and developed a preliminary coding scheme. Transcripts were read and coded by three authors independently (A.T., B.H., P.S.) who compared and discussed their individual coding choices. Any disagreements were resolved by discussion. The coding scheme was revised based on these discussions to develop a final coding structure that adequately captured desired and relevant information. Through a process of careful analysis and comparisons (between individuals and groups), we inductively developed two categories of descriptive themes from the data. The first category of themes examined the research priorities expressed by the participants. The second category differentiated the ways in which participants explained their research prioritisations, i.e. the reasons for their choices.
A summary of our preliminary findings was mailed to the study participants in June 2007, to enhance the developing analytic framework and to ascertain whether the account made sense to participants with different perspectives. We received feedback from 18 out of 63 participants. Participants appreciated the summary and some commented further on their individual priorities, suggested that the summaries should be sent earlier, and requested information on how the study would make an impact on the research agenda.

6.4 Results

The nine focus groups involved 63 participants (88% attendance rate), aged from 20 to 78 years (mean 52.3 years); 30 (48%) were male. Of the 63 participants, 50 (79%) were Caucasian and 13 were from nine different national backgrounds. Reasons for non-attendance included work commitments, illness-related problems and difficulty in arranging transport.

The participants valued the opportunity to engage with one another. Participants shared their experiences of coping with their illness, and the facilitators were careful to ensure they were able to achieve this goal in the group. However participants also engaged enthusiastically with the issue of research priorities. Participants suggested a wide range of topics and desired research outcomes based on their experiences, what was important to them and what they thought could be improved.
From the analysis of transcripts and field notes, we identified eight main research areas that participants nominated as priorities (Table 6.1). Additional quotes for each research topic are provided in Table 6.2.

**Prevention:** Primary and secondary prevention of CKD were nominated frequently as the highest priority in all focus groups. The participants were averse to undergoing dialysis and transplantation and frequently stated that prevention was of higher priority than treatment or a cure. For prevention of CKD, participants suggested that research should focus on raising the public profile of CKD in the community, health promotion, and discovering the causes of CKD.

“I would like them to try and stop the renal disease becoming so prevalent.”

(Female, 50s, transplant)

Research on screening for detecting CKD and non-medical treatments of early CKD such as lifestyle factors, including dietary control and complementary medicines, and devising ways of putting the disease into remission were all identified as priority areas.

**Complications and symptoms:** Research to reduce complications and symptoms relating to CKD and the side effects of dialysis and transplant treatment were very important to the participants. They described a range of symptoms, complications and side effects that they experienced personally including cancer, heart disease, bone disease, fatigue, cramping and vomiting. All groups discussed the importance of research focused on eliminating the need for immunosuppressants and developing better treatments to reduce symptoms and complications.
Transplantation: While most participants perceived quality of life to be better after transplantation compared with dialysis treatment, some expressed a preference for dialysis. Rather than face the uncertainty and trauma of kidney rejection and immunosuppression, the minority favoured the predictability of the dialysis routine once they learned to integrate the regimen into their lifestyle. All participants recognised the current limitations and problems in transplantation (e.g. graft rejection, immunosuppression, lack of donors) and felt that research should aim to increase the availability of organs and donor numbers, reduce the time spent on the kidney transplant waiting list, improve matching between patients and donors, prolong graft survival and reduce post-transplantation drugs. Although xenotransplantation was discussed, it was considered of low priority due to the high risk of infection.

Technological solutions: Participants wanted current treatment to be revolutionised; they did not want to undergo dialysis, take immunosuppressants and depend on a donor for a kidney. Stem cell research, cloning and developing mechanical kidneys were considered important topics to include in the research agenda. Some participants wanted research to deliver an alternative to needles and the pain of dialysis.

Psychosocial needs and support: The need for more research on psychological and social support was discussed frequently. The participants felt that health professionals often overlooked the range of mental health and social problems prevalent in the CKD population. More specifically, the key issues they believed could be improved related to: depression and poor coping, employment (how to re enter the workforce, seek employment and improve employers’ understanding towards CKD patients), information needs, and strengthening the family relationship.
Some patients who had received or were going to receive a transplant from a living donor faced tension within the donor-recipient relationship. For example, some felt obliged to accept a living donor kidney from their relative, at the same time feeling apprehensive about the health risks they felt they were imposing on that donor and about taking on the significant burden of being responsible for maintaining the donor’s kidney. The following interaction highlights the anguish that occurs with the loss of a donated kidney.

“But we were both incredibly sad (after the kidney was rejected), that was what hit the most, it’s that dealing with losing that was harder for me than going on dialysis, cause then I thought I did something wrong, and she gave me a gift.”

(Female, 40s, dialysis)

“It’s like you broke her present.” (Female, 20s, dialysis)

Whole body care: Some participants felt that clinicians tended to narrow their focus to individual health issues, rather than broadly examining and managing the problem as a whole. They believed that health professionals needed to approach health research holistically and recognise the interdependence of health problems including heart disease, diabetes, obesity and lupus.

“I think that’s sometimes partly the problem, that they’re not actually looking at the whole picture…I don’t think it’s easy to separate research on blood pressure, diabetes and heart disease etcetera because they’re so inextricably linked.”

(Female, 40s, predialysis)
**Dialysis:** Dialysis was reported to be a time-consuming and sometimes painful process that interfered with lifestyle and reduced quality of life. The participants identified many areas for improvement in both haemodialysis and peritoneal dialysis treatment. They wanted machines to be less cumbersome and easier to operate and treatment to consume less time. Participants who had experienced dialysis believed it was important to improve vascular access into the bloodstream and the medication required while on dialysis.

“There are lots of problems and lots of ways that (dialysis) could be improved like the big drama of getting access to the bloodstream.” (Female, 60s, dialysis)

**Caregiver support:** As CKD patients, the participants experienced the personal effects of the disease but they were also aware that CKD had a devastating impact on caregivers. Some described the trauma, emotional stress, feelings of neglect and poor coping of their partners or other family members who had to take on care giving responsibilities. The participants suggested that it was important for research to focus on addressing caregiver needs and support.

**Reasons underpinning participants’ research priorities**

We identified five reasons that participants used to explain their choice for research topics: normalisation of life, altruism, economic efficiency, personal concerns and clinical outcomes. The five reasons were not mutually exclusive; some choices for research topics were supported by more than one reason.

**Normalisation of life:** Developing therapies and treatment regimens that fit in with other aspects of daily living was important for participants. The diagnosis of CKD and
the intensive, technically demanding regimen of dialysis disrupted participants’ lifestyles.
The need for normality was more apparent in pre-dialysis and dialysis participants than transplant participants; transplantation allowed most participants a higher degree of normality and independence. A desire to reclaim a sense of normality frequently underpinned participants’ choices for research into better and more compact dialysis machines.

“I think if they can sink money into improving the dialysis and making it so that it works better and frees you up then that’s good enough for me.” (Male, 50s, dialysis)

Altruism: We coded as ‘altruism’ any talk in which participants identified research topics based on the consideration of the welfare of others over and above the participants’ individual needs as a patient. In making decisions on which research topic was of higher importance, the tension of wanting both personal and population benefit posed difficulties for the participants. However altruism was consistently observed across all three types of participant groups. The participants agreed that the reason research on prevention should be highest priority was because it would benefit the community and future generations.

“Even though I’m in the dialysis stage, I think it’s more important to focus on the others.” (Female, 20s, dialysis)

Also, participants considered the well-being of living donors and insisted that research focus on developing a cure or improving treatment so there would be no requirement for potential donors to jeopardise their own health by donating their kidney.

“It isn’t worth someone going through what they have to go through to give a kidney.” (Female, 30s, predialysis)
Participants thought that research to understand the psychosocial issues faced by patients was important because it would benefit patients undergoing, or about to undergo, similar experiences.

“I think we need to learn more about the experiences of people like ourselves who’ve gone through, it needs to be passed on and gathered, and put to better advantage so that we can help others.” (Male, 50s, transplant)

**Economic efficiency:** We coded as ‘economic efficiency’ any talk about channelling the available resources for maximum effectiveness or getting the best value for money.

Participants considered the long-term economic benefits and cost of conducting research when prioritising their choices for research. For example, they agreed that resources would be better channelled towards research on prevention and transplantation than dialysis, which was perceived to be a less cost-effective treatment.

“I think the main aim is to keep people off dialysis so if you’ve got a transplant, the aim is to keep it operating for as long as you can … dialysis is just so expensive.” (Male, 60s, transplant)

**Personal concerns:** We coded as ‘personal concerns’ any talk in which preferences, feelings and values were given as reasons for participants’ decisions on research topics.

The participants themselves recognised that their own individual experiences and emotions often influenced their choices in a range of research areas. Personal concerns were linked to a range of research topics including complications, transplantation, psychosocial needs and support, technological solutions and whole body research.
“I wish there’s a better alternative to what’s currently available. In terms of research in the dialysis area, something that doesn’t take a lot more time but something that is not as cumbersome as I expect it to be and probably a lot more comforting. I think comforting is the key issue I’m looking for right now.” (Male, 50s, predialysis)

Participants diagnosed with CKD and who had not received dialysis treatment or transplantation felt that they were not being looked at holistically and emphasised the importance of the need for collaborative research across medical disciplines. During this earlier stage in the illness trajectory, the personal importance of other illnesses and problems (e.g. heart disease, diabetes, blood pressure, lupus) was comparable in magnitude to kidney disease. However, in the later stages, kidney disease became the dominant illness in the participants’ lives.

**Clinical outcomes:** We coded as ‘clinical outcomes’ any talk in which participants suggested research topics to improve clinical outcomes and the physiological condition of the people diagnosed with CKD. Participants’ knowledge of the clinical outcomes (e.g. risk of mortality, morbidity and adverse effects) influenced their choice of topics particularly within the area of complications and transplantation.

“I think heart disease in chronic kidney disease is quite important because of the calcifications, cause through the prednisolone (immunosuppressant) we were taking all those years ago, I think it’s terribly important because it can cause the calcification in your valve, in your arteries etcetera and I do find that quite important.” (Female, 60s, transplant)
6.5 Discussion

Patients with CKD had eight priority areas for research: preventing CKD, reducing complications and symptoms, improving access to and outcomes of kidney transplantation, developing better technological solutions, developing better understanding of psychosocial needs, improving whole body care, improving dialysis treatment and developing caregiver support. Some of these priorities were not unexpected, and perhaps overlap with professionally driven priorities, but we were able to demonstrate that elicitation of patients’ research priorities was feasible, and a coherent and comprehensive list of research priorities could be obtained. Many differences between a clinician-researcher and patient-generated list of topics are apparent. Patients think more broadly, are more thematic, and focus on outcomes. Clinician-researchers think more mechanistically, and focus on specific questions and interventions. How healthcare should be delivered, both to the patient, and the caregivers, in a holistic way matters to patients, but appears not to be a priority of research funders who promote discovery-type and pharmacological research preferentially. Specifically participants did not identify understanding disease processes as a priority topic, which underpins much basic science research. Only basic science, which has a reasonable chance of contributing to better clinical outcomes, is implicitly valued. In contrast, the disciplines of health services research, and qualitative research are implicitly needed if these priorities are to be realised.

A significant and novel contribution of this work is the identification of five reasons that patients used to develop their research priorities (normalisation of life, altruism, economic efficiency, personal concerns and clinical outcomes). This aspect of patient’s
research prioritisation has not been reported previously. It provides a framework for understanding the factors that influence patients’ decisions about research priorities, and is transferable to all healthcare topics and not limited to kidney disease. By generating these five reasons, participants in our study have explicitly demonstrated they understand the inevitable tensions in research, such as between the good of the individual and the good of society. They have shown that they understand the values attached to good clinical outcomes may vary across individuals. The recognition of economic efficiency in research is an important observation. Usually limited to allocation of competing interventions into clinical practice, our participants recognised that opportunity cost applied equally to research funding. Criteria for research funding, such as those specified in grant assessment criteria of major funding bodies (13-15), are typically weighted to the research productivity of the individual, which can and is quantified. Our participants have advocated for a similarly quantitative approach to the potential benefit of a study by trading off the cost of the study with the potential health gain. Usually this is captured under the domain of “significance” but this is not explicitly quantitative nor does it have an economic perspective. Given the scarce resources of healthcare research, it should be.

Despite the policy of all major international research funding agencies to include consumers in the process of setting priorities for research (16-20), there are very sparse data on how this can be achieved. A recent bibliography identified 96 reports relating to patients’ priorities for research or health outcomes (21). Almost all studies have focused on patient preferences for treatment, but we identified three that specifically explored patients’ research priorities. Similar to these studies, patient priorities were expressed by patients in terms of general research areas, including better medication to reduce side effects, prevention and psychosocial interventions. However these studies did not provide insights into patient’s reasoning about research priorities.

The agenda for health research is influenced by factors beyond the patient-reasons we identified. Researcher and reviewer interests, study feasibility, innovation, quality of the methods and ethical considerations influence both government and non-government
funding for research. Commercial interests also affect decisions about what research
should be funded; a significant amount of health research is sponsored by industry who
often have an investment strategy embedded in studies designed to maximised
profits.(22, 23) These considerations are not necessarily inappropriate, simply
incomplete. Including patient perspectives can broaden the research agenda and help to
ensure that the limited resources are channelled towards research that optimises the mix
of benefits.

Our study demonstrates that if the right research methods are employed, patients’
priorities for research can be elicited. These participants provided a set of research
priorities and ways of reasoning which run parallel to, complement, and may be quite
different from the research priorities and means of reasoning used by other stakeholders,
including governments, industry, health professionals and researchers. Health
professionals and researchers draw on their own unique cultural norms and expertise
when they construct research questions. They are informed by medical knowledge and
the conventions of scientific inquiry, including the need to specify, in technical language,
particular problems regarding aetiology, disease progression or intervention and
management to investigate.(24-26) In contrast, these participants spoke in general terms
and related research to hoped-for improvement to their own and others’ quality of life.
This is unsurprising as it resonates with other findings concerning lay knowledge of
health issues. We all use personal experiences, views about ourselves and others, and an
in-depth understanding of the circumstances and social context in which we live to
produce sophisticated and idiosyncratic frameworks of knowledge about our health and
other aspects of our lives.(27-29) What has been missing, and what this study aims to
provide, is a conduit through which these different ways of setting research priorities can
influence one another.
Innovative methods are needed to better engage patients in agenda setting, rather than involving them in the same way as health professionals. We have demonstrated that focus groups and mock funding allocation exercises are feasible and productive and we encourage others to use similar methods for identifying priorities across different health conditions. Citizen juries provide a more deliberative approach, which, despite their added cost, may produce more sophisticated results. More detailed exploration of patients’ reasons for choosing particular research priorities may, however, require in-depth face-to-face interviews, perhaps following involvement in a focus group or citizens’ jury. To be provocative, however, we would also contend that the inclusion of consumers in grant review panels for health research is a tokenistic approach. This study has demonstrated the richness and range of understanding that can come from engagement with patients’ personal experiences of a particular illness. It is unlikely that a single ‘consumer’ on a panel could ever be adequately equipped to offer this depth and breadth of insight. Well-designed and reported qualitative research about priorities across a range of research areas would provide a more methodologically sound route for incorporation of lay knowledge into funding allocation decisions. The principles of reasoning generated in this study – normalisation of life, altruism, economic efficiency, personal concerns and clinical outcomes – have particular potential: secondary analytic work across a large number of qualitative studies such as this one may, in future, produce principles of reasoning which could be applied across research areas.

Although this study was conducted with CKD patients from 4 centres, the findings are applicable and transferable across settings and health disciplines. A patient-focused research agenda was possible to develop, was thematic and outcomes focused and could be used to refine and prioritise specific topics proposed by health-related researchers.
The five reasons underlying patients’ research priorities demonstrate that they understand the tensions in prioritising research, the variation in disease course and clinical outcomes between patients and recognise that opportunity cost applies to research funding. Decision-making processes for selecting research topics should be made explicit. This study presents a model by which these decisions can incorporate consumer values and perspectives, facilitate active and effective consumer participation and avoid tokenism.
Table 6.1. Research priorities elicited from patients with chronic kidney disease

<table>
<thead>
<tr>
<th>Research Areas</th>
<th>Definition</th>
<th>Subtopics</th>
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<tbody>
<tr>
<td>1 Prevention</td>
<td>Primary prevention (reduce prevalence of CKD)</td>
<td>• Raise the public profile of CKD</td>
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<td>• Health promotion</td>
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<td>• Aetiology (Discover the genetic, lifestyle and environmental</td>
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<td>causes of CKD)</td>
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<td></td>
<td></td>
<td>• Reduce prevalence of CKD in Indigenous populations</td>
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<td>2 Complications and symptoms</td>
<td>Secondary prevention (prevent progression of CKD in patients)</td>
<td>• Screening - detection of CKD</td>
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<td></td>
<td></td>
<td>• Improve dietary control to prevent progression of CKD</td>
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<tr>
<td></td>
<td></td>
<td>• Complementary medicines</td>
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<tr>
<td>3 Kidney Transplantation</td>
<td>Increase access to organs and improve graft survival.</td>
<td>• Increase access to organs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Improve graft survival</td>
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<tr>
<td>4 Technological solutions</td>
<td>Advance biotechnological research and improve technological interventions</td>
<td>• Stem cell and cloning</td>
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<td>• Develop mechanical kidneys</td>
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<td>• Alternative to needles</td>
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<td>5 Psychosocial research</td>
<td>Understand the psychological and social impact of having CKD</td>
<td>• Depression</td>
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<td>• Coping mechanisms</td>
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<td>• Donor-recipient relationship</td>
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<td>• Employment</td>
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<td>• Information needs</td>
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<td>6 Whole body</td>
<td>Conduct collaborative research with other researchers.</td>
<td>• Diabetes</td>
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<td>• Heart Disease</td>
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<td>• Lupus</td>
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<td>• Obesity</td>
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<td>7 Dialysis</td>
<td>Improve dialysis treatment</td>
<td>• Vascular Access</td>
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<tr>
<td>8 Caregiver support</td>
<td>Improve support for caregivers</td>
<td>• Assess caregiver burden</td>
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<td></td>
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<td>• Implement caregiver support</td>
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Table 6.2. Quotations to illustrate the nine research topics identified

<table>
<thead>
<tr>
<th>Research Areas</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Prevention (primary)</td>
<td>‘What I’d like research to be able to do eventually is to prevent people from getting chronic kidney disease, to be able to track it early enough so they don’t have this chronic disease.’ (Female, 60s, transplant)</td>
</tr>
<tr>
<td>Prevention (secondary)</td>
<td>‘If someone has got chronic renal troubles, if research could come up with some way that you can delay the destruction of the kidney, slowing down the rate of decay, that gives people so much more time’ (Male, 40s, transplant)</td>
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<tr>
<td>2 Complications and symptoms</td>
<td>‘I suppose I’d like to see more research on some of the side effects that come with dialysis. Restless leg syndrome is one of my favourites that will get me out of bed a couple of times a week, I don’t sleep very well.’ (Male, 60s, dialysis)</td>
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<td></td>
<td>‘You know the regime with regards to the tablets is quite important because transplant is not a cure, it’s still an ongoing thing. People don’t realise it’s the side effects that can be very, very ugly.’ (Male, 60s, transplant)</td>
</tr>
<tr>
<td>3 Kidney transplantation</td>
<td>‘I think the big deal is the transplant because I think the more people that you can get transplanted successfully, it’s better all round, it gets people off dialysis, and it gets people having the best quality of life they can have even if it is a treatment.’ (Female, 30s, dialysis)</td>
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<td></td>
<td>‘I want my transplant to last for the rest of my life so I want them to do research into what can happen down the track. How can we prevent that (rejection) happening?’ (Female, 40s, transplant)</td>
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<tr>
<td>4 Technological solutions</td>
<td>‘An artificial kidney and then I don’t need to ask anyone for a transplant, and I don’t need to worry about someone’s body being violated after (the transplant). We should be making an artificial kidney.’ (Female, 40s, predialysis)</td>
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<td></td>
<td>‘I’d like to see a lot more stem cell research so you can grow your own kidneys.’ (Male, 50s, transplant)</td>
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<tr>
<td>5 Psychosocial research</td>
<td>‘I think there’s work to be done on the quality of life side of it, more information and being informed about lifestyle and so forth.’ (Male, 50s, predialysis)</td>
</tr>
<tr>
<td>6 Whole body</td>
<td>‘Yeah I think, do you guys talk to each other? You know, do you do collaborative research?’ (Female, 40s, predialysis)</td>
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<td></td>
<td>‘I had the same problem; they’ve got different units for different things. It’s like they don’t talk to each other. They don’t look at you holistically. The kidney looks at that part, someone else looks at that part and someone else looks at that part.’ (Female, 50s, predialysis in the same focus group)</td>
</tr>
<tr>
<td>7 Dialysis</td>
<td>‘If they get their peritoneal thing infected, they’re in big trouble because they have to suddenly get access to the blood stream too but if anything happens to my access, to the blood stream, they’ve got to find another access and that causes a lot of heartache. It really does, and it’s not something they’ve got down to a fine art, that’s the difficult thing.’ (Female, 60s, dialysis)</td>
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<tr>
<td>8 Caregiver support</td>
<td>‘It’d be interesting to bring your partners along too to something like this (focus group). It’s all right us saying how we feel, but sort of sometimes they don’t tell us how they feel.’ (Male, 50s, predialysis)</td>
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### Table 6.3. Reasons underpinning research theme prioritisation with supporting quotations

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Illustrative Quotes</th>
</tr>
</thead>
</table>
| Normalisation of life    | ‘I’ve also put some money into the treatment because if people have gone beyond that level (dialysis), they do need better treatment, to make it easier. I have family who have been on all sorts of dialysis, peritoneal and overnight, and all of them have their down and upsides and they all take time and they all interfere with lifestyle.’ (Female, 50s, predialysis)  
  ‘Can they create a small machine that’s portable, that can travel with us so that we can manage as an individual, that we don’t lose our independence, or we lose a bit of independence but not completely? I think to me that would be really important. (Male, 50s, predialysis)’ |
| Altruism                 | ‘Well I’d like, not for me, I’d like to see them help prevent the occurrence of chronic kidney disease in future generations. That’s what I look forward to. I think I’m beyond, there’s no way I can look forward to a cure but I’d like to, along the lines of future generations, whether it’s through stem cell research or preventative measures, I’d like to see work in those areas because I think preventing it, or curing it, for future people. I think it’s too late for me.’ (Male, 60s, predialysis)  
  ‘But when you actually think about millions of dollars in research, that benefits everybody, common sense kind of tells you that you want to prevent something before it gets to that and my individual case kind of pales in significance to that, in comparison.’ (Female, 40s, predialysis) |
| Economic efficiency      | ‘I’d spend more money on prevention because it’s certainly better than the cure and the cure costs a lot more than prevention.’ (Male, 60s, predialysis)                                                                                                                                                                                  |
| Personal concerns        | ‘Interestingly, it was hard to do because, although we just sat here before talking about understanding the kind of complex factors about our lives, when I actually came to devoting money to it, I thought, gee that’s really selfish you know because we need to put it into prevention. But then I was selfish anyway.’ (Female, 40s, predialysis)  
  ‘I suppose in the predialysis stage, I found the thing that was the hardest to cope with was the lack of energy and something like Aranesp (iron supplement) was a great improvement to me but not really enough.’ (Male, 60s, dialysis)  
  ‘I mean I’m doing what I think for me because heart disease hasn’t been a problem for me so I’m not going to do any research there.’ (Female, 30s, dialysis)  
  ‘I looked at this and I feel only one way you can approach it and that’s looking at it through the way it’s affecting you. So if it’s affecting me, I’d like to see more money put into that area, purely selfish sort of perspective, but that’s how I basically made (my decisions).’ (Male, 50s, dialysis) |
| Clinical outcomes        | ‘I’d put diabetes at the top of the list because I think diabetes leads to a lot of the kidney problems cause diabetes ends up being a problem with the small blood vessels, and kidneys are just loaded with small blood vessels. (Male, 60s, transplant)’ |
6.6 References


7. An analysis of media coverage on the prevention and early detection of chronic kidney disease in Australia

7.1 Abstract

News media raise public awareness about health and can influence public policy agenda. Recently, nephrologists have sought to make prevention and early detection of chronic kidney disease (CKD) a healthcare priority. We assessed the extent and manner in which Australian television news and newspapers cover CKD prevention or early detection. Electronic news databases for print media and television programs were searched (May 2005 to March 2007) for items referring to CKD prevention or early detection. We analysed all relevant items for spokespeople, main news frame, focus of responsibility, proposed solutions and trigger/reason for publication. Of the 2,439 newspaper articles and 10,430 television broadcasts retrieved, only 214 (8.77%) articles and 7 (0.06%) broadcasts were eligible. Kidney transplantation dominated CKD-related news. Lay person or high-profile advocates were virtually absent. Risks of cardiovascular disease and mortality conferred by CKD were not emphasized by news reports; instead, CKD received peripheral mention as a secondary consequence of diabetes or obesity. Few reports cited the economic consequences of CKD. The media focused on lifestyle causes and solutions, whereas nonlifestyle causes and screening and prevention strategies were rarely mentioned. Kidney health professionals need to actively engage with the media in efforts to amplify desired messages on CKD prevention or early detection. Medical journals, research institutions, universities, hospitals and advocacy groups should issue
press releases that highlight newsworthy aspects of this topic. Extending news media coverage can help to exert an influence on health policies and agenda setting and increase public awareness to improve prevention and early detection of CKD.

7.2 Introduction

News media are a major and influential source of health information for the public. (1, 2) Chronic kidney disease (CKD) is a worldwide public health problem (3), and recently nephrologists have sought to raise the public health profile of the importance of prevention and early detection of kidney disease. (4-6) Raising public awareness of CKD through the media could help accomplish this goal.

For instance, evidence about the impact of mass media coverage on behaviour change in relation to screening, medicine-taking, and treatment preferences (7-11) suggests that media coverage might prompt individuals, particularly those at risk of CKD, to seek health care for early diagnosis and management, both important for preventing disease progression. Also, media coverage could influence public policy agendas for improving kidney health, for instance by influencing the allocation of resources for research and education and providing leverage for legislative and policy change. (12)

Studies have examined how other chronic diseases, including cancer (13-17), diabetes (18-21) and heart disease (20-22) are portrayed in the media. The only study considering media coverage of CKD was limited to a simple content analysis describing the proportion of television coverage of CKD compared with other health topics including breast cancer, heart disease and influenza vaccine, and concluded that CKD receives
relatively poor coverage. (23) No studies have examined CKD prevention and early
detection in television or print news media.

We assessed how Australian television news programs and newspapers cover CKD,
focusing particularly on the extent and manner in which news covers prevention and
early detection of CKD. This information can inform health professionals, kidney health
advocates and researchers about ways to improve advocacy through the media to
promote the prevention and early detection of CKD.

7.3 Methods

Search strategy and data extraction

We searched newspaper and television news databases for articles which referred to
prevention or early detection of CKD from May 2005 to March 2007. (See Appendix F.1
and F.2 for data on media sources)

Television: Television broadcasts were obtained from a media-monitoring project (24)
which archives all health-related stories in news, current affairs and infotainment
programs broadcast on all five free-to-air channels in Sydney. The database indexes all
broadcasts according to health related categories. All video files of television broadcasts
related to kidney disease were provided on DVD.

Newspapers: For print media, we used the online database, Factiva, to search the twenty
major metropolitan and national Australian newspapers for the same period. The
keywords kidney, dialysis, renal and nephrology were entered in Factiva’s free text search field, with all irrelevant items retrieved then excluded (eg: “kidney bean”). All newspaper articles were entered into QSR Nvivo 7, a software program used to assist with storage, coding and searching of data.

Two reviewers viewed all the television broadcasts and newspaper articles, and removed items that made no reference to prevention or early detection of CKD.

**Analysis**

We coded each included news item and analysed themes for each of the following questions adapted from previous work (25):

1. **Who were the spokespeople?** (Persons quoted directly or indirectly, who referred to prevention and/or early detection of kidney disease)

2. **How was CKD prevention or early detection framed?** (Words, phrases and passages that defined CKD prevention or early detection, proposing to readers and viewers how the issue should be understood)

3. **Who was being proposed as responsible for the problem?**

4. **Who was being suggested should solve the problem and what solutions were proposed?**

5. **Why was the story in the news at this time?**

The framework we used to analyze the data can inform how desired messages can be framed so that they might be more useful and relevant to the public audience.
7.4 Results

Of 10,430 television news items on all health issues available in the media database broadcast between May 2005 and March 2007, CKD or kidney transplantation was classified as the principal or secondary story in only 43 (0.004%) items. Of these, 36 items were excluded from further analysis as prevention or early detection of CKD were not discussed. Our search of newspaper coverage yielded 5,624 articles. Of these, 3,185 were not related to kidney disease and excluded as entirely irrelevant, leaving 2,439 which referred to any aspect of kidney disease. A further 2,225 of these were excluded because they did not refer to early detection and management, most commonly because they focused on kidney transplantation (Figure 7.1). Overall, during the 23 month study period we identified 214 newspapers articles and 7 television broadcasts which referred explicitly to the detection or prevention of CKD (Figure 7.1). For items included in the study, excerpts from television news and newspaper articles for the following themes are provided in Table 7.1.

Who were spokespeople?

In 158 media items that referenced spokespeople or sources, five principal groups were identified: medical experts, health advisory groups, government officials, researchers featured in journal reports and laypersons.

*Medical experts:* Renal physicians and professors were the most frequently quoted or referenced sources. (Figure 7.2) They provided biomedical information, described signs and symptoms of CKD, emphasized its economic and life costs, and advocated the need
Chapter 7. An analysis of media coverage on the prevention and early detection of chronic kidney disease in Australia

for lifestyle changes to prevent CKD. Research findings on the magnitude of the problem were sometimes used as a ‘news hook’ to preface expert statements.

*Health advocacy groups:* Kidney Health Australia, the peak consumer organisation in Australia promoting kidney and urinary tract health, were repeatedly quoted on advocating government action for kidney disease and the importance of prevention and early detection.

*Government:* Statements about the social and economic impact of CKD from the Federal Health Minister and other politicians were cited in newspaper articles. Government voices underlined the administrative and managerial problems of CKD, for example, in anticipating the unsustainable costs threatening the health care system and identifying the need for a national strategy to address the problem.

*Research findings:* New research findings, often based on Australian studies, were used to highlight the important of CKD prevention and early detection. The media frequently reported research that revealed a high prevalence of CKD among diabetics, which was previously unknown.

*Lay people:* Views of lay people about CKD prevention or early detection were infrequent. Patients and individuals at high-risk of CKD believed that lack of awareness and fear of diagnostic testing hampered the fight against kidney disease. They invoked serious, emotive appeals against ignorance and urged people to be vigilant in managing and checking their health status.

**How was CKD prevention and early detection framed?**
Stories referring to CKD prevention and early detection, and its medical and economic implications were rare. Little attention was given to the importance of CKD early detection or prevention in reducing cardiovascular morbidity and mortality. Potentially newsworthy issues in CKD that were absent in news media coverage are summarised in Table 7.2.

**CKD embedded as a secondary problem in coverage of topical health conditions:** CKD was embedded as a secondary problem in 52% of included articles. These articles focussed on health issues that are regarded as more topical, such as diabetes and obesity, with CKD often receiving peripheral mention as one of the consequences of Type 2 diabetes, obesity, and less often, hypertension, therefore suggesting that early diagnosis and management of these conditions could prevent CKD. CKD was discussed as the primary problem in the remaining 48% of included articles.

**Startling statistics:** Epidemiological data were used to emphasize the threat, risk and severity of CKD. Prevalence, incidence, mortality and morbidity data were expressed as proportions, absolute figures and ratios, and were often linked to descriptive terms that communicated the escalating magnitude of the problem.

**An overwhelming economic burden:** In 11% of the media items, CKD was presented as a major financial burden that could potentially overwhelm the healthcare system. Expressions including ‘balloon to,’ ‘threatening to overwhelm’ and ‘growing fast’ described the rapidly increasing costs incurred by expensive dialysis and transplantation procedures.
Silent and sinister: CKD was described as an insidious illness in eight articles, with three personifying the disease as a “silent killer.” CKD was said to be undiagnosed because symptoms only appeared when the patient reached end-stage kidney disease. Reports warned that CKD patients were required to undergo dialysis or transplantation and were at an increased risk of cardiovascular disease.

Threatening the vulnerable: In stories about the Indigenous health crisis, attention was given to the high rate of CKD in Indigenous communities compared with the general population. Few articles (4%) warned that children were at risk of CKD.

Who is responsible for the problem?

The apparent inaction and ignorance of individuals, government and doctors, and socio-cultural factors were blamed for the increasing problem of CKD. The greatest responsibility was apportioned to individuals, with 74% of references in this category blaming poor lifestyle choices and refusal to recognise the seriousness of the disease. Some articles also blamed socio-cultural factors (societal affluence, increased work pressure and having to ‘drive the kids to school for fear of accidents”) as contributing to unhealthy lifestyles, which in turn exacerbated the problem of CKD.

"People are now less active and we have higher rates of obesity contributing to an epidemic of type 2 diabetes and that's causing an epidemic of kidney failure."

(The Courier Mail, metropolitan newspaper, 3 March 2007, page 73)

The government was also criticised for its inaction in developing and implementing a coordinated, national strategy to counter the ‘epidemic.’ In one article, doctors who failed
to test and diagnose CKD were labelled as incompetent. No emphasis was given to genetic or familial predisposition, type 1 diabetes and other non-lifestyle causes of CKD.

Who should solve the problem and what solutions were proposed?

Individuals were advised to make better lifestyle choices and monitor their health, general practitioners were urged to identify and manage patients at high risk of kidney disease, and community efforts were encouraged to prevent kidney disease. Kidney health advocates urged the government to develop and implement early detection and prevention strategies. (Table 7.1)

People were advised to “stop thinking it won’t happen to them” and to heed warnings about changing their lifestyle, as illustrated by the following headings:

LOSE FAT FOR YOUR KIDNEYS. (The Advertiser, metropolitan newspaper, 4 January 2006, page 29)

GOOD HEALTH IN PEOPLE’S OWN HANDS...Measures to prevent renal and cardiovascular disease included a balanced diet, regular exercise, not smoking, and not drinking alcohol excessively… (Mercury, metropolitan newspaper, 6 November 2006, page 11)

In media reports, general practitioners were urged to be accountable for identifying and testing high-risk patients. However, the media placed more emphasis on achieving behavioural change. Strong directives were aimed particularly at individuals in high-risk
categories for CKD, advising them to monitor their health status and to access diagnostic services through general practice and home test kits.

In mid-2005, government efforts in kidney disease prevention were briefly recognised in newspaper articles, one titled ‘Minister looks at free kidney test.’ The Federal Health Minister participated in the launch of ‘Wee Week,’ a national kidney disease awareness campaign, and announced that a proposal for a free national screening test was being considered. After this period, the media reported that no government strategy was in place and repeatedly publicised Kidney Health Australia’s persistent efforts in lobbying the federal government for funding commitment and national strategies (including screening programs) to address the kidney disease ‘crisis’.

Modifying lifestyle factors for primary prevention of CKD in the general population were the focus of news media reports. Increasing efforts to improve understanding about screening, genetic susceptibility factors, understanding non-lifestyle causes of CKD, secondary prevention and planning public health policy were seldom suggested.

Why was the story in the news?

We were unable to infer the reasons for publication in 135 (61.1%) articles. For the remaining articles, five major reasons for publication could be inferred. Stories were published with the release of new research findings, health awareness campaigns, government meetings, health summits and medical breakthroughs. (Table 7.1)

Release of new research findings: Of the 86 media items in which the reason for publication could be inferred, 30% announced the release of new research findings. Stories often
reported findings based on the Australian population, increasing its relevance and proximity to the core audience.

Coinciding with health awareness campaign: CKD prevention and early detection stories were often published during national and international awareness campaigns for kidney disease, diabetes and hypertension. Kidney Health Australia’s ‘Wee Week,’ in 2005, received more media attention than in other years because the Federal Health Minister was involved in the launch.

Government meetings: Stories containing pleas for government action to prevent CKD usually appeared around the time of government meetings and elections.

Health summits: Newspaper articles announced that international and local medical experts were attending health summits located in Australia. In these articles, expert quotes were often provided to demonstrate the importance of addressing kidney disease.

Medical breakthroughs: In 2005, a few reports announced a new, “more accurate” test for detecting kidney disease. Although the formula was devised in the United States, its potential use in Australian pathology laboratories was emphasized in a tone of hopeful anticipation. The test was sensationalised as the ‘biggest breakthrough,’ a ‘landmark formula’ and a ‘frontline weapon.’

7.5 Discussion
In the present study, we observed that kidney disease in general, and particularly the prevention and early detection of CKD received virtually no media attention, either in print or television media. When kidney disease was mentioned, it was in the context of transplantation and donor stories, and not prevention or early detection, which appears largely unnewsworthy in its current form. At best, CKD received peripheral mention as a secondary concern in diabetes and obesity news stories which focussed on lifestyle solutions. The rising rates of CKD were reported but the news media did not highlight CKD as a known independent predictor of cardiovascular disease or death, report on non-lifestyle causes of CKD such as genetic or idiopathic disease, or use public advocates as a source of information.

Two-thirds of all spokespeople referring to CKD prevention and early detection represented in the media were medical experts and kidney health advocates. Testimonials offered by laypersons or high profile personalities were not prominent, but were frequently featured in stories on kidney transplantation and organ donation. The media made no mention of prevention or early detection when Australia’s wealthiest man, Kerry Packer, had chronic kidney disease. Instead, stories focussed on his survival on a transplanted kidney from his helicopter pilot.

In the media, excessive focus on CKD as a consequence of ‘diabesity’ possibly stigmatised CKD as a lifestyle disease. For example, ‘ alarm ing’ findings from an Australian study generated media interest which reported that experts were unaware that 50 percent of patients with Type 2 diabetes had CKD and general practitioners failed to routinely assess kidney function. Emphasising CKD as a lifestyle disease may create a misleading impression that CKD is less serious and detract attention from efforts in to
prevent CKD not caused by lifestyle factors. Data from Australian, US and UK renal registries show that glomerulonephritis (due to infections, immune diseases and vasculitis), and hereditary and congenital factors cause over half of CKD but these received no media attention. (26-28)

Progression to end-stage kidney disease requiring dialysis or transplant was mentioned in the media as a potential consequence of CKD. However, premature death and comorbidities associated with CKD were rarely reported. Concordant findings in the medical literature demonstrate that premature death due to CKD is more likely than progression to end-stage kidney disease, and CKD is an independent predictor of cardiovascular disease, (29-32) infections and cancer. (3) Although evidence demonstrates these causal associations, they received negligible coverage in the news media.

The media primarily focused on solutions that could be controlled, for example through lifestyle changes, targeted screening and government action. Reporters strongly urged people to improve their lifestyle by exercising and developing healthy eating habits. An emphasis on blood pressure control was notably absent in the media. Controlling hypertension can prevent progression of CKD and reduce the risk of cardiovascular events resulting in premature death. (33, 34)

High-risk groups for CKD screening, as identified in the media, included diabetics, smokers, Indigenous Australians and hypertensive individuals. This is largely consistent with national and international recommendations. (3, 35) No evidence exists to support whole population screening for CKD but studies demonstrate that targeted community screening encourages at-risk individuals to seek health assessments and management from their physicians. (36, 37) There were examples of both the journalist and health
professionals advocating for the government to actively engage in screening, surveillance and public awareness programs.

Of note, an estimated 16% of Australian adults have at least one indicator of kidney damage (38) while in comparison, the prevalence rate of Australians receiving renal replacement therapy in 2004 was 718 per million population. Of these patients, 44.4% had a functioning transplant. (39) With the renal community advocating for greater public awareness about the prevention and early detection of CKD (34), our findings highlight the currently very low profile of CKD in the media and the need for increased news coverage and provide insight on how to amplify desired messages to promote prevention and early detection of kidney disease in the media. Although no empiric data exists on public reception of news media coverage of CKD, findings from our study and other studies on mass communication in health offer some guidance on extending coverage. In particular, we will refer to three factors influencing the visibility of health information in the media: 1) credibility of sources, 2) issuing of press releases and 3) newsworthiness. (40)

In our study, less than ten percent of news items sourced medical journals. Research suggests medical journals are trusted as credible sources and frequently cited by journalists. (41, 42) Promoting the latest research findings to journalists can help to gain media interest. For example, experts anticipate that early detection of CKD will facilitate interventions to postpone death, improve quality of life and reduce numbers requiring renal replacement therapy. (5, 43) Press releases and interviews could emphasise findings from recent studies which have consistently demonstrated that late referral of CKD patients is frequent and associated with increased mortality and cardiovascular co-morbidity. (44-46)
Issuing press releases increases the likelihood of attracting media attention. Journalists rely on press releases from medical journals, research institutions, universities and hospitals. (47) Advocates should enlist press release writers to distil health information from these sources to clearly and succinctly highlight the significance of CKD prevention and early detection. Press releases must also encapsulate newsworthy aspects of CKD early detection or prevention. (48)

The characteristics of ‘newsworthiness’ include prominence, human interest, drama, timeliness, relevance, unusual phenomena and proximity. (49) These help to determine the propensity for a story to be published in mainstream news media. (40) Health stories that garner media attention usually include health professionals, patients and celebrities as spokespeople. Renal specialists have been urged to initiate contact with local news media and to make themselves available for interviews and commentary to publicise the message that ‘CKD is common, harmful, and treatable.’(34) Also, given the media’s propensity for human interest and celebrity stories (7, 25), we suggest enlisting patients, caregivers and high profile persons to serve as spokespersons for promoting prevention and early detection of CKD. The “authenticity” added to news coverage by having affected persons relating their stories can greatly enhance news interest.

More media attention is given to illnesses with visible disabling effects, diseases that appear to strike indiscriminately and unfairly, such as breast cancer, and those with higher death rates (including heart disease and cancer).(20) CKD is largely invisible to the person in the street and in its very limited media coverage is frequently portrayed as a lifestyle disease. Consequently, advocates and professionals need to think about how to
make CKD and its associated risks more perceptible to the public. For example, greater visibility of CKD in the media could be achieved by highlighting the higher rates of mortality and heart disease in this population.

Figures about the life and health care costs of CKD routinely appeared in the stories. While statistics and figures convey a sense of reliability, stories need to incorporate a new and interesting angle to become newsworthy. (50, 51) Given that the impact of kidney failure on lifestyle and mental health were rarely mentioned, emphasising lifestyle implications could help to increase reportage of CKD prevention and early detection. (40) Also, in view of the growing public enchantment with natural medicine, (52, 53) health experts could offer current information about the potential role of complementary and alternative therapy in early detection and prevention of CKD.

Future research should explore barriers and opportunities for delivering CKD prevention messages by conducting interviews with journalists and news media organisations. Also, interviewing members of the public, policy makers and professionals about their perceptions of current and unreleased media reports can help to distil information into a message that is well-supported, complete and interesting to the audience. Research on audience reception of mass media news coverage about early detection and prevention of CKD is required.

As for any complex intervention, evaluating the precise impact of news media coverage on chronic disease is problematic, being confounded by a multitude of measurement and attributional problems. (54) However, much evidence suggests that news media influences health knowledge, health related behaviour and policy agenda setting. For example, news media coverage of risks of hormone replacement therapy was associated with sustained
falls in HRT use. (9) Promoting public awareness through the news media can encourage healthy behaviour and impact both directly and indirectly on disease outcomes. Also, we are aware that access by minority communities to news media may be limited and it is difficult to assess the extent of its relevance and effectiveness in minority communities. For example, Australian Aboriginal people are culturally and linguistically diverse and live in a broad range of social settings. Few data exists on the outcomes population-based interventions, including mass media, on ethnic minority communities. (55) While the cultural hegemony of mass media is recognized, health messages can be targeted to minority groups through local or cultural broadcasting. It is worth noting, that the media themselves have a very detailed understanding of how to reach minority groups. In Australia, Indigenous broadcasting services are licensed by the Australian Communications and Media Authority as a community broadcasting services dedicated to Indigenous programming. (56)

The news media are often criticised for presenting unsubstantiated and alarmist health-related claims and the nature of coverage depends largely on the journalists’ intuition, and organisational and external socio-economic pressures. (51, 57) Also, media coverage of health news stories can be influenced by business interests, for instance pharmaceutical companies. (58) While there is concern that journalists might be unable to recognise or overlook the commercial pressure from companies, the onus is on health professionals and the scientific community to disseminate impartial health information that assists patients and the community to make informed decisions. (42) Health professionals should endeavour to engage effectively with the press. The renal community share partial responsibility for conveying medical information to the community, and they can help to strengthen the quality of information delivered though the media. (34, 57) Media messages can target the general population, healthcare
professions and policy makers. Indirectly, this will exert an influence on health policies, agenda setting and increase public awareness to improve prevention and early detection of CKD.
Figure 7.1 Process of searching and identifying Sydney television and Australian newspaper source. Articles included in the analysis focus on CKD prevention and early detection.
Figure 7.2. Spokespersons quoted or referenced in 158 media items

*HCP, Healthcare professional
**Table 7.1. Excerpts from newspaper articles and television broadcasts to illustrate news themes**

<table>
<thead>
<tr>
<th>Themes</th>
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<tr>
<td><strong>Who were the spokespeople?</strong></td>
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<tr>
<td>Medical experts</td>
<td>Prof Thomas said the signs of kidney disease were difficult to set apart from diabetes itself, so doctors needed to be sure to regularly test their diabetic patients. (Herald Sun, metropolitan newspaper, 7 August 2006, page 12)</td>
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<tr>
<td>Health advocacy groups</td>
<td>Kidney Health Australia CEO Anne Wilson says: “Research shows over 25 per cent of all patients coming to dialysis and transplantation do not see a kidney specialist until less than 90 days before dialysis starts, which is a clear indication of the need for a national awareness campaign.” (The Age, metropolitan newspaper, 17 February 2001, page 51)</td>
</tr>
<tr>
<td>Government</td>
<td>Health Minister Tony Abbot has asked his department for proposals for a testing system. That would allow people worried about their kidneys to ask their doctors for a free test… “there are screening measures that may well be cost-effective.” (The Sunday Mail, state newspaper, 5 June 2005, page 52)</td>
</tr>
<tr>
<td>Medical Journal</td>
<td>Half of all diabetics also have chronic kidney disease, a landmark national study has revealed. (Daily Telegraph, metropolitan newspaper, 7 August 2006, page 12)</td>
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<td>Lay people</td>
<td>“Kidney disease can happen to you, so don’t assume it won’t…there are more and more Australians turning up with this disease and you could be one of them. So go to the doctor regularly…” (The Sunday Herald Sun, metropolitan newspaper magazine insert, 4 December 2005, page 4)</td>
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| **How was CKD prevention and early detection defined?** |                                                                                                                                                                                                 |
| CKD embedded as a secondary problem in topic health conditions | The obesity epidemic is posing a new threat, with experts of rapidly escalating kidney disease in developed countries, including Australia. (The West Australian, state newspaper, 13 March 2006, page 14) |
| Startling statistics | The number of people with end-stage kidney disease, their only hope of being a transplant, leapt to 13 625 by the end of 2003, a tripling over 20 years. The problem is difficult to detect in its early stages. (The Advertiser, metropolitan newspaper, 23 November 2006, page 13) |
| An overwhelming economic burden | The warning comes a new figures show the national cost of end-stage kidney disease is forecast to rise from $559 million in 2004 to 899 million by 2010, with no sign of growth plateauing…we need to work to prevent this disease…(The Sunday Mail, state newspaper, 25 March 2007, page 26) |
| Silent and sinister | ’(Medical expert during a press conference) Below the surface, chronic kidney disease is lurking in at least half of all individuals with Type 2 diabetes.’ (Seven News Evening, TV, 6 August 2006) |
| ’We call disease the silent killer because you can lost up to 90 per cent of kidney function before you are even feeling sick.’ (The West Australian, state newspaper, 31 May 2004, page 27) |
| Threatening the vulnerable | Renal failure in remote communities is devastatingly high, up to 30 times the rate of non-indigenous communities. Governments spend millions on dialysis machines but where are the programs to make them unnecessary? (Sunday Age, metropolitan newspaper, 5 June 2005, page 16) |
One-quarter of NSW school students are overweight or obese, and a significant proportion of those are already showing early signs of kidney, heart or liver damage. (The Sunday Telegraph, metropolitan newspaper, 6 August 2006, page 17)

### Who should solve the problem and what solutions are proposed?

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<th>Who should solve the problem</th>
<th>What solutions are proposed</th>
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| **Individuals:** make better lifestyle choices and monitor their health | ‘Lifestyles are a big issue at the moment because the leading cause of kidney failure requiring dialysis or transplantation is type 2 diabetes.’ Exercising more and eating less to maintain a health weight is the best way of avoiding type 2 diabetes. (The Courier Mail, metropolitan newspaper, 3 March 2007, page 73)  
If you’re at high risk then you need to go to your GP and get some checks on a regular basis. ‘Get your blood pressure and your cholesterol checked. Have your doctor check for diabetes and for a kidney check….That’s hugely important because the reality is if you can identify kidney disease early you can halt the disease or slow the progression by up to 50 per cent.’ (Sunday Herald Sun, metropolitan newspaper, magazine insert, 4 December 2005, page 4) |
| **General practitioners:** identify and test ‘high risk’ patients | He said early diagnosis was partly up to GPs knowing which patients were at risk, then testing kidney function with blood tests and doing tests to detect protein in urine. (The Courier Mail, metropolitan newspaper, 3 March 2007, page 73) |
| **Community** | ‘It will take the whole community including families, schools, industry, business and the non-government sector to effectively tackle this epidemic,’ (The Courier Mail, metropolitan newspaper, 20 September 2005, page 1) |
| **Government** | Kidney Health Australia has been lobbying for a national government strategy for early detection and better treatment of kidney disease. ‘We are keen to get government to put money into the earlier end (of kidney disease).’ (The West Australian, state newspaper, 27 September 2006, page 9) |

### What was the story in the news?

| What was the story in the news? | What were the details?
<table>
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<tr>
<td><strong>Release of new research findings</strong></td>
<td>An Australian study of 3900 people with Type 2 diabetes found 50 per cent had impaired kidney function. (The Australian, national newspaper, 7 August 2006, page 3)</td>
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<tr>
<td><strong>Coincides with health awareness campaign</strong></td>
<td>Health Minister Tony Abbot yesterday launched Wee Week. The slogan ‘Are you one in three? Check your wee’ is based on the fact that one in three Australians is at risk of developing kidney disease and the urine test helps detect the disease. (The NT news, state newspaper, 31 May 2005, page 2)</td>
</tr>
<tr>
<td><strong>Government meeting</strong></td>
<td>As the population ages, the number of Australians needing dialysis is forecast to double in the next decade, a federal parliamentary standing committee will be told by Kidney Health Australia…To ensure chronic kidney disease is detected early, KHA wants high risk groups contacted yearly about screening. (The Daily Telegraph, metropolitan newspaper, 18 August 2005, page 26)</td>
</tr>
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<td><strong>Health summits</strong></td>
<td>Wenck, a GP for 30 years, is one of three doctors on a discussion panel tomorrow at the Brisbane Obesity Summit…’What we need is, at various stages, preventative health checks so that we can pick up potential problems and encourage patients to make changes at an early stage…’ (The Courier Mail, metropolitan newspaper, 20 September 2005, page 1)</td>
</tr>
<tr>
<td>Medical breakthrough</td>
<td>Kidney disease can now be diagnosed much earlier because of a breakthrough in testing procedures, experts say. Kidney Health Australia’s medical director Tim Mathew said US researchers had developed a more accurate way of assessing kidney damage. (The Daily Telegraph, metropolitan newspaper, 29 July 2005, page 15)</td>
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Table 7.2. Potentially newsworthy issues in CKD

- Lay people’s views on the importance of CKD early detection or prevention
- Celebrity advocates for kidney health
- Transplant recipients advocating better prevention
- Other causes of CKD: genetic and familial predisposition, infection, immune diseases, vasculitis, Type 1 diabetes
- More resources for research on screening and prevention programs
- Developing policy to promote kidney health
- Death is more likely than progression to end-stage kidney disease
- CKD is an independent cause of cardiovascular disease
- Control of hypertension
- Early referral can reduce mortality and cardiovascular events
7.6 References


8. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

8.1 Abstract

Background: Qualitative research explores complex phenomena encountered by clinicians, health care providers, policy makers and consumers. Although partial checklists are available, no consolidated reporting framework exists for any type of qualitative design.

Objective: To develop a checklist for explicit and comprehensive reporting of qualitative studies (indepth interviews and focus groups).

Methods: We performed a comprehensive search in Cochrane and Campbell Protocols, Medline, CINAHL, systematic reviews of qualitative studies, author or reviewer guidelines of major medical journals, and reference lists of relevant publications for existing checklists used to assess qualitative studies. Seventy-six items from 22 checklists were compiled into a comprehensive list. All items were grouped into three domains: i) research team and reflexivity, ii) study design and iii) data analysis and reporting. Duplicate items and those that were ambiguous, too broadly defined and impractical to assess were removed.
Findings: Items most frequently included in the checklists related to sampling method, setting for data collection, method of data collection, respondent validation of findings, method of recording data, description of the derivation of themes, and inclusion of supporting quotations. We grouped all items into three domains: i) research team and reflexivity, ii) study design, and iii) data analysis and reporting.

Conclusions: The criteria included in COREQ, a 32-item checklist, can help researchers to report important aspects of the research team, study methods, context of the study, findings, analysis and interpretations.

8.2 Background

Qualitative research explores complex phenomena encountered by clinicians, health care providers, policy makers and consumers in health care. Poorly designed studies and inadequate reporting can lead to inappropriate application of qualitative research in decision making, health care, health policy and future research.

Formal reporting guidelines have been developed for randomised controlled trials (CONSORT)(1), diagnostic test studies (STARD), meta-analysis of RCTs (QUOROM)(2), observational studies (STROBE)(3) and meta-analyses of observational studies (MOOSE)(4). These aim to improve the quality of reporting these study types and allow readers to better understand the design, conduct, analysis, and findings of published studies. This process allows users of published research to be more fuller informed when they critically appraise studies relevant to each checklist and decide upon applicability of research findings to their local settings. Empiric studies have shown that
the use of the CONSORT statement is associated with improvements in the quality of reports of randomised controlled trials.(5) Systematic reviews of qualitative research almost always show that key aspects of study design are not reported, and so there is a clear need for a CONSORT-equivalent for qualitative research.(6)

The Uniform Requirements for Manuscripts Submitted to Biomedical Journals published by the International Committee of Medical Journal Editors (ICMJE) do not provide reporting guidelines for qualitative studies. Of all the mainstream biomedical journals (Figure 8.1), only the British Medical Journal (BMJ) has criteria for reviewing qualitative research. However the guidelines for authors specifically record that the checklist is not routinely used. In addition, the checklist is not comprehensive and does not provide specific guidance to assess some of the criteria. Although checklists for critical appraisal are available for qualitative research, there is no widely endorsed reporting framework for any type of qualitative research.(7)

We have developed a formal reporting checklist for in-depth interviews and focus groups, the most common methods for data collection in qualitative health research. These two methods are particularly useful for eliciting patient and consumer priorities and needs, to improve the quality of health care.(8) The checklist aims to promote complete and transparent reporting among researchers and indirectly improve the rigour, comprehensiveness and credibility of interview and focus group studies.

**Basic definitions**

Qualitative studies use non-quantitative methods to contribute new knowledge and to provide new perspectives in health care. While qualitative research encompasses a broad
range of study methods, most qualitative research publications in health care describe the use of interviews and focus groups.(8)

**Interviews**

In-depth and semi-structured interviews explore the experiences of participants and the meanings they attribute to them. Researchers encourage participants to talk about issues pertinent to the research question by asking open-ended questions, usually in one-to-one interviews. The interviewer might re-word, re-order or clarify the questions to further investigate topics introduced by the respondent. In qualitative health research, in-depth interviews are often used to study the experiences and meanings of disease, and to explore personal and sensitive themes. They can also help to identify potentially modifiable factors for improving health care.(9)

**Focus groups**

Focus groups are semi-structured discussions with groups of 4 to 12 people that aim to explore a specific set of issues.(10) Moderators often commence the focus group by asking broad questions about the topic of interest, before asking the focal questions. Although participants individually answer the facilitator’s questions, they are encouraged to talk and interact with each other.(11) This technique is built on the notion that group interaction encourages respondents to explore and clarify individual and shared perspectives.(12) Focus groups are used to explore views on health issues, programs, interventions and research.

**8.3 Methods**

*Development of a Checklist*
Search Strategy

We performed a comprehensive search for published checklists used to assess or review qualitative studies, and guidelines for reporting qualitative studies in: Medline (1966 – Week 1 April 2006), CINAHL (1982 – Week 3 April 2006), Cochrane and Campbell protocols, systematic reviews of qualitative studies, author or reviewer guidelines of major medical journals, and reference lists of relevant publications. We identified the terms used to index the relevant articles already in our possession and performed a broad search using those search terms. The electronic databases were searched using terms and text words for research [standards], health services research [standards] and qualitative studies [evaluation]. Duplicate checklists and detailed instructions for conducting and analysing qualitative studies were excluded.

Data Extraction

From each of the included publications, we extracted all criteria for assessing or reporting qualitative studies. Seventy six items from 22 checklists were compiled into a comprehensive list. We recorded the frequency of each item across all the publications. Items most frequently included in the checklists related to sampling method, setting for data collection, method of data collection, respondent validation of findings, method of recording data, description of the derivation of themes, and inclusion of supporting quotations. We grouped all items into three domains: 1) research team and reflexivity, 2) study design, and 3) data analysis and reporting. (Tables 8.2-8.4)

Within each domain we simplified all relevant items by removing duplicates and those that were ambiguous, too broadly defined, not specific to qualitative research, or impractical to assess. Where necessary, the remaining items were rephrased for clarity.
Based upon consensus among the authors, two new items that were considered relevant for reporting qualitative research were added. The two new items were identifying the authors who conducted the interview or focus group and reporting the presence of non-participants during the interview or focus group. The COREQ checklist for explicit and comprehensive reporting of qualitative studies consists of 32 criteria, with a descriptor to supplement each item. (Table 8.1)

8.4 COREQ: Content and rationale (See Table 8.1)

Domain 1: Research Team and Reflexivity
A) Personal Characteristics: Qualitative researchers closely engage with the research process and participants and are therefore unable to completely avoid personal bias. Instead researchers should recognise and clarify for readers their identity, credentials, occupation, gender, experience and training. Subsequently this improves the credibility of the findings by giving readers the ability to assess how these factors might have influenced the researchers’ observations and interpretations. (13-15)

B) Relationship with participants: The relationship and extent of interaction between the researcher and their participants should be described as it can have an effect on the participants’ responses and also on the researchers’ understanding of the phenomena. (16) For example, a clinician-researcher may have a deep understanding of patients’ issues but their involvement in patient care may inhibit frank discussion with patient-participants when patients believe that their responses will affect their treatment. For transparency, the investigator should identify and state their assumptions and personal interests in the research topic.
Domain 2: Study Design

A) Theoretical Framework: Researchers should clarify the theoretical frameworks underpinning their study so readers can understand how the researchers explored their research questions and aims. Theoretical frameworks in qualitative research include: grounded theory, to build theories from the data; ethnography, to understand the culture of groups with shared characteristics; phenomenology, to describe the meaning and significance of experiences; discourse analysis, to analyse linguistic expression; and content analysis, to systematically organise data into a structured format. (10)

B) Participant Selection: Researchers should report how participants were selected. Usually purposive sampling is used which involves selecting participants who share particular characteristics and have the potential to provide rich, relevant and diverse data pertinent to the research question. (13, 17) Convenience sampling is less optimal because it may fail to capture important perspectives from difficult-to-reach people. (16) Rigorous attempts to recruit participants and reasons for non participation should be stated to reduce the likelihood of making unsupported statements. (18) Researchers should report the sample size of their study to enable readers to assess the diversity of perspectives included.

C) Setting: Researchers should describe the context in which the data was collected because it illuminates why participants responded in a particular way. For instance, participants might be more reserved and feel disempowered talking in a hospital setting. The presence of non-participants during interviews or focus groups should be reported as this can also affect the opinions expressed by participants. For example, parent interviewees might be reluctant to talk on sensitive topics if their children are present. Participant characteristics, such as basic demographic data, should be reported so readers
can consider the relevance of the findings and interpretations to their own situation. This also allows readers to assess whether perspectives from different groups were explored and compared, such as patients and health care providers. (13, 19)

D) Data collection: The questions and prompts used in data collection should be provided to enhance the readers’ understanding of the researcher’s focus and to give readers the ability to assess whether participants were encouraged to openly convey their viewpoints. Researchers should also report whether repeat interviews were conducted as this can influence the rapport developed between the researcher and participants and affect the richness of data obtained. The method of recording the participants’ words should be reported. Generally, audio recording and transcription more accurately reflect the participants’ views than contemporaneous researcher notes, more so if participants checked their own transcript for accuracy. (19-21) Reasons for not audio recording should be provided. In addition, field notes maintain contextual details and non-verbal expressions for data analysis and interpretation. (19, 22) Duration of the interview or focus group should be reported as this affects the amount of data obtained. Researchers should also clarify whether participants were recruited until no new relevant knowledge was being obtained from new participants (data saturation). (23, 24)

Domain 3: Analysis and Findings

A) Data Analysis: Specifying the use of multiple coders or other methods of researcher triangulation can indicate a broader and more complex understanding of the phenomenon. The credibility of the findings can be assessed if the process of coding (selecting significant sections from participant statements), and the derivation and identification of themes are made explicit. Descriptions of coding and memoing demonstrate how the researchers perceived, examined and developed their understanding.
of the data. (17, 19) Researchers sometimes use software packages to assist with storage, searching and coding of qualitative data. In addition, obtaining feedback from participants on the research findings adds validity to the researcher’s interpretations by ensuring that the participants’ own meanings and perspectives are represented and not curtailed by the researchers’ own agenda and knowledge.(23)

B) Reporting: If supporting quotations are provided, researchers should include quotations from different participants to add transparency and trustworthiness to their findings and interpretations of the data.(17) Readers should be able to assess the consistency between the data presented and the study findings, including the both major and minor themes. Summary findings, interpretations and theories generated should be clearly presented in qualitative research publications.

8.5 Discussion

The COREQ checklist was developed to promote explicit and comprehensive reporting of qualitative studies (interviews and focus groups). The checklist consists of items specific to reporting qualitative studies and precludes generic criteria that are applicable to all types of research reports. COREQ is a comprehensive checklist that covers the necessary components of study design that should be reported. The criteria included in the checklist can help researchers to report important aspects of the research team, study methods, context of the study, findings, analysis and interpretations.

At present, we acknowledge there is no empiric basis which shows that the introduction of COREQ will improve the quality of reporting of qualitative research. However this is no different than when CONSORT, QUOROM and other reporting checklists were
introduced. Subsequent research has shown that these checklists have improved the quality of reporting of study types relevant to each checklist (5, 25), and we believe that the effect of COREQ is likely to be similar. Despite differences in the objectives and methods of quantitative and qualitative methods, the underlying aim of transparency in research methods and, at the least, the theoretical possibility of the reader being able to duplicate the study methods should be the aims of both methodological approaches.

There is a perception among research funding agencies, clinicians and policy makers, that qualitative research is “second class” research. Initiatives like COREQ are designed to encourage improvement in the quality of reporting of qualitative studies, which will indirectly lead to improved conduct, and greater recognition of qualitative research as inherently equal scientific endeavour compared with quantitative research that is used to assess the quality and safety of health care. We invite readers to comment on COREQ to improve the checklist.
Figure 8.1 Development of the COREQ Checklist

Title and abstract review
Excluded (n=445)
- No appraisal checklist 218
- Qualitative methods 127
- Primary fieldwork 58
- Mixed methods 31
- Comment or debate 6
- Duplicate article or checklist

Full text analysis
Excluded (n=77)
- No appraisal checklist 33
- Comment or debate 25
- Duplicate article or checklist
- Qualitative methods 8

538 citations
13 sources
Excluded n=7
- No author reviewer guidelines for qualitative studies
- Duplicate appraisal checklist

93 citations
6 sources
22 Tools or guidelines included

16 citations

Items identified from the 22 tools/checklists
N=76 items
- Research team and reflexivity 24
- Study design 25
- Data analysis and reporting 27

Items excluded n=46
Reasons for exclusion
- Duplicate item or overlapping definition
- Not specific to qualitative studies
- Impractical to assess
- Ambiguous, obscure definition

Items not found in existing checklists n=2
Reasons for inclusion
- Suitable for assessment
- Clear definition
- Key characteristic for qualitative research

COREQ 32-item checklist
- Research team and reflexivity 8
- Study design 15
- Data analysis and reporting 9

*Reference (26, 27)
†Reference(6, 28-32)
‡Author and Reviewer Guidelines provided by BMJ, JAMA, Lancet, Annals of Internal Medicine, NEJM
# Table 8.1. Consolidated Criteria for Reporting Qualitative studies (COREQ): 32-item Checklist

<table>
<thead>
<tr>
<th>No</th>
<th>Item</th>
<th>Guide Questions / Description</th>
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<tbody>
<tr>
<td></td>
<td><strong>Domain 1: Research Team and Reflexivity</strong></td>
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<tr>
<td></td>
<td><strong>Personal Characteristics</strong></td>
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</tr>
<tr>
<td>1.</td>
<td>Interviewer / facilitator</td>
<td>Which author/s conducted the interview or focus group?</td>
</tr>
<tr>
<td>2.</td>
<td>Credentials</td>
<td>What were the researcher’s credentials? e.g. PhD, MD</td>
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<tr>
<td>3.</td>
<td>Occupation</td>
<td>What was their occupation at the time of the study?</td>
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<tr>
<td>4.</td>
<td>Gender</td>
<td>Was the researcher male or female?</td>
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<tr>
<td>5.</td>
<td>Experience and Training</td>
<td>What experience or training did the researcher have?</td>
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<tr>
<td></td>
<td><strong>Relation with participants</strong></td>
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<tr>
<td>6.</td>
<td>Relationship established</td>
<td>Was a relationship established prior to study commencement?</td>
</tr>
<tr>
<td>7.</td>
<td>Participant knowledge of the interviewer</td>
<td>What did the participants know about the researcher? e.g. personal goals, reasons for doing the research</td>
</tr>
<tr>
<td>8.</td>
<td>Interviewer characteristics</td>
<td>What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic</td>
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<tr>
<td></td>
<td><strong>Domain 2: Study Design</strong></td>
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<tr>
<td></td>
<td><strong>Theoretical Framework</strong></td>
<td>What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</td>
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<td>9.</td>
<td>Methodological orientation and Theory</td>
<td></td>
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<tr>
<td>10.</td>
<td>Sampling</td>
<td>How were participants selected? e.g. purposive, convenience, consecutive, snowball</td>
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<tr>
<td>11.</td>
<td>Method of approach</td>
<td>How were participants approached? e.g. face-to-face, telephone, mail, email</td>
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<tr>
<td>12.</td>
<td>Sample size</td>
<td>How many participants were in the study?</td>
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<td>13.</td>
<td>Non participation</td>
<td>How many people refused to participate or dropped out? Reasons?</td>
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<td></td>
<td><strong>Setting</strong></td>
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<tr>
<td>14.</td>
<td>Setting of data collection</td>
<td>Where was the data collected? e.g. home, clinic, workplace</td>
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<td>15.</td>
<td>Presence of non-participants</td>
<td>Was anyone else present besides the participants and researchers?</td>
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<tr>
<td>16.</td>
<td>Description of sample</td>
<td>What are the important characteristics of the sample? e.g. demographic data, date</td>
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<td></td>
<td><strong>Data Collection</strong></td>
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<tr>
<td>17.</td>
<td>Interview guide</td>
<td>Were questions, prompts, guides provided by the authors? Was it pilot tested?</td>
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<tr>
<td>18.</td>
<td>Repeat interviews</td>
<td>Were repeat interviews carried out? If yes, how many?</td>
</tr>
<tr>
<td>19.</td>
<td>Audio / visual recording</td>
<td>Did the research use audio or visual recording to collect the data?</td>
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<tr>
<td>20.</td>
<td>Field notes</td>
<td>Were field notes made during and/or after the interview or focus group?</td>
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<tr>
<td>21.</td>
<td>Duration</td>
<td>What was the duration of the interviews or focus group?</td>
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<td>22.</td>
<td>Data saturation</td>
<td>Was data saturation discussed?</td>
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<tr>
<td>23.</td>
<td>Transcripts returned</td>
<td>Were transcripts returned to participants for comment and/or correction?</td>
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<td></td>
<td><strong>Domain 3: Analysis and Findings</strong></td>
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<td></td>
<td><strong>Data Analysis</strong></td>
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<td>24.</td>
<td>Number of data coders</td>
<td>How many data coders coded the data?</td>
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<td>25.</td>
<td>Description of the coding tree</td>
<td>Did authors provide a description of the coding tree?</td>
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<td>26.</td>
<td>Derivation of themes</td>
<td>Were themes identified in advance or derived from the data?</td>
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<td>27.</td>
<td>Software</td>
<td>What software, if applicable, was used to manage the data?</td>
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<td>28.</td>
<td>Participant checking</td>
<td>Did participants provide feedback on the findings?</td>
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<td><strong>Reporting</strong></td>
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<td>29.</td>
<td>Quotations presented</td>
<td>Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number</td>
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<td>30.</td>
<td>Data and findings consistent</td>
<td>Was there consistency between the data presented and the findings?</td>
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<tr>
<td>31.</td>
<td>Clarity of major themes</td>
<td>Were major themes clearly presented in the findings?</td>
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<tr>
<td>32.</td>
<td>Clarity of minor themes</td>
<td>Is there a description of diverse cases or discussion of minor themes?</td>
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Table 8.2. Items included in 22 published checklists

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<td>Examination of role, bias, influence</td>
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*Other publications; †Systematic review of qualitative studies; BMJ, British Medical Journal - editor’s checklist for appraising qualitative research); (●) item included in the checklist
Table 8.3. Items included in 22 published checklists

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### Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

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*Other publications; †Systematic review of qualitative studies; BMJ, British Medical Journal - editor’s checklist for appraising qualitative research); (●) item included in the checklist
### Table 8.4. Items included in 22 published checklists

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*Other publications; †Systematic review of qualitative studies; BMJ, British Medical Journal - editor’s checklist for appraising qualitative research); (●) item included in the checklist
8.6 References


23. Popay J, Rogers A, Williams G. Rationale and standards for the systematic review of qualitative literature in health services research. Qualitative Health Research 1998; 8: 341-351.


26. Critical Skills Appraisal Programme (CASP) 10 Questions to help you make sense of qualitative research: Milton Keynes Primary Care Trust; 2002.


9. Discussion and conclusions

9.1 Summary of findings

In this thesis, I have explored the multifaceted, contextual and complex nature of consumer experiences, needs and perspectives of illness, care and health research in CKD. I have concentrated on exploring the experiences of parent caregivers who have children with CKD, support for caregivers of CKD patients, and the experiences of adult CKD patients and their priorities for health research. The findings unravel the consumer-centred principle, to understand the patient’s quality of life and experience of the disease (problems, feelings, and personal meaning and implications of the illness for each individual patient) which may be influenced by their values, culture and traditions. (1, 2) This includes the patient’s cognition, such as what they expect, and believe, and their confidence about their disease management. (3, 4) While the domains in each study are often intricately interconnected, I have conceptualised and described the themes separately for clarification.

Caregiver perspectives on caring for a CKD patient

In the systematic review and meta-ethnography of qualitative studies on the experiences of parents who have children with CKD (Chapter 3), ten themes emerged grouped into 3 inter-related clusters: intrapersonal (living with constant uncertainty, stress, and maintaining vigilance despite experiencing fatigue), interpersonal (medicalisation of the parental role, dependency on and conflict with staff, and disrupted peer relationships) and external issues (management of the medical regimen, pursuit of information,
organising transport, accommodation and finances, adhering to the child’s liquid and diet restrictions, and balancing medical care with domestic responsibilities).

Findings from the in-depth interview study of parents (Chapter 4) were consistent with the systematic review, which we used to inform our question guide, but in this study we restructured the themes to capture additional issues that arose. Four major themes were identified: 1) Absorbing the clinical environment: parents struggled to accept the diagnosis and permanence of CKD, felt traumatised watching their child undergo invasive clinical procedures, battled to meet appointments, negotiated with staff for their child’s needs and felt disempowered; 2) Medicalising parenting: parents became caregivers, a role which was stressful, exhausting and overwhelming. Dialysis was unrelenting and consumed the time, thoughts and energy of parents who felt at fault if their child developed infections and other complications. Parents struggled with their child’s psychological problems and episodic aggressive behaviour; 3) Disrupting family norms: CKD caused spousal tension, sibling neglect and influenced family planning; and 4) Coping strategies and support structures: Parents depended on support from their healthcare providers and valued meeting and learning from other parents of CKD children. Parents also expressed information needs and suggested methods of communicating information. CKD had a profound and pervasive effect on informal caregivers, yet their needs are often neglected and under-prioritised in the medical management of CKD. Despite this, no high quality evidence is available about the effect of information or support interventions on the physical or psychosocial well-being of informal caregivers and the patients. In the systematic review of support interventions for caregivers of CKD patients (Chapter 5), only three studies assessed the effect of a support intervention on caregivers. The three studies evaluated the effect of educational material on caregiver knowledge only.
Patient perspectives on CKD, health care and research

Patients with CKD had to adjust to the disruptive and permanent implications of the illness on their physical health, identity, emotions, family, lifestyle, relationships and employment. (Chapter 5) The overwhelming fatigue, complex treatment regimens, side effects, and liquid and diet restrictions imposed physical and social constraints on patients. Patients appreciated specialist medical care, but described the health-care system as non-integrated and felt they received insufficient information and psychosocial support. Regarding treatment options, patients based their decision-making on lifestyle, family impact and physical comfort, seldom on clinical outcomes. Time was needed to comprehend the diagnosis, cope with uncertainty, integrate their treatment regimen into their daily routine, and to re-establish a sense of normality in their lives and their family.

A patient-centred research agenda was possible to elicit for CKD (Chapter 6). Patients suggested eight research priorities: prevention of kidney disease, better access to and improvement in kidney transplantation, reduction of symptoms of CKD and complications associated with treatment, new technological therapies, psychosocial aspects of living with CKD, whole body not organ-specialised care, and improvement in dialysis and caregiver support. Five major reasons for selection were identified: normalisation of life (developing therapies and regimens that fit into daily living), altruism (considering the welfare of others before personal needs), economic efficiency (channeling resources for maximum economic gain), personal needs (preferences based on feelings, values, and personal needs), and clinical outcomes (improving health states and the physiological condition of patients with CKD).
During the focus groups, participants repeatedly expressed frustration about the poor public or media profile of CKD, and the lack of community-based information on prevention and early detection. This prompted the media analysis of CKD prevention and early detection in Australian news media, in Chapter 8, which confirmed the patients’ perceptions. Kidney disease in general, and particularly the prevention and early detection of CKD, received virtually no media attention, either in print or television media. When kidney disease was mentioned, it was mostly in the context of transplantation and donor stories, and seldom prevention or early detection, which appears largely unnewsworthy in its current form. At best, CKD received peripheral mention as a secondary concern in diabetes and obesity news stories which focused on lifestyle solutions. The rising rates of CKD were reported but the news media did not highlight CKD as a known independent predictor of cardiovascular disease or death, report on non-lifestyle causes of CKD such as genetic or idiopathic disease, or use public advocates as a source of information.

In the course of reading many qualitative papers and texts on qualitative methodology, it became clear there were no generally accepted standards about reporting qualitative research. In the course of this research, I have developed a checklist as a first attempt to establish a standard for reporting qualitative research. (Chapter 8)

In summary, CKD had a profound and pervasive impact on patients and caregivers. Patients and caregivers appreciated the medical care, which aimed to prolong life and improve clinical outcomes, but they experienced a range of practical, emotional, social and informational challenges. They had to confront and learn to comprehend the shocking long-term and disruptive implications of CKD, cope with fatigue, uncertainty, social isolation, financial costs, lifestyle constraints, family burden, liquid and diet
restrictions, and manage the technical, time-consuming and demanding treatment regimen. CKD, sometimes a genetic disease, meant that difficult decisions had to be made regarding family planning. Some of these challenges became more prominent during a specific CKD stage, or they affected caregivers or patients differently. Having to contend with the poor understanding and awareness about CKD in the community, and among family and friends, also added to their stress. Support structures, both formal and informal, were needed to help them adjust and re-establish a sense of routine. The CKD patients’ and caregivers’ illness experience and meanings, preferences and support needs, offer insight on ways to improve health care policy and practice, decision-making and health research.

9.2 Strengths and limitations

The work presented here encompasses qualitative research including a systematic review of qualitative studies (meta-ethnography), in-depth face-to-face interviews, focus groups and document analysis. I used the constant comparative method to analyse the data of each study. I derived descriptive themes from the data and revised the coding scheme until all relevant and desired information were explored and captured. Data collection ceased when few or no new themes were emerging. The findings demonstrate that these methods were appropriate for: eliciting a range and depth of consumer perspectives, producing relevant, novel and sensible findings, and fulfilling the study objectives.

I encountered several challenges in conducting the studies. Establishing rapport was relatively unproblematic but it was initially difficult to establish complete trust with some participants. Frequent and prolonged contact with clinicians meant that some parents of
children with CKD and adult patients were initially distrustful and anxious that what they said might jeopardise their care and relationships with staff. I had to emphasize that what they said during the interview was confidential, de-identified in reports, and stored in a secure location. I also encountered sensitivity among staff about findings which related to the care they provided. They felt the findings were unduly critical of their conduct and care, and I had to acknowledge that parent perspectives of service delivery can differ from professional perspectives, and from what actually happened during a clinical encounter. Clinicians who aim to achieve the best medical outcomes for the ill child may inadvertently appear to parents as being strict and critical. Inadequate resources can hinder clinicians’ efforts in providing support services. Reflexivity often concentrates on the relationship between the researchers and the participants, particularly the influence that being involved in the research may have on the participants and the phenomenon being studied, and the effect that the participants have on the researchers. What is less often considered are the potential effects of the research findings on third parties, in this case the professionals involved in the care of the children of the parents interviewed. As researchers we have an obligation to report our findings fully and honestly, particularly if we are hoping that service improvements may follow. We also have an obligation not to represent third parties unfairly or to be insensitive to the potentially demoralising effects the findings may have on them.

In-depth interviews and focus groups can also be mentally and emotionally taxing, which perhaps was intensified in some instances by the sensitive and potentially distressing nature of the topic. I also observed that patients and caregivers derived emotional benefit during the interview and focus group process, which has been reported in other studies.(7-9) Many expressed that they felt less isolated when they learned of other caregiver and patient experiences. Of note, the focus groups became a form of peer
support in which the participants, all in the same stage of CKD, provided and exchanged emotional support. On a few occasions, participants became momentarily emotional as they recalled a distressing moment or realised the interview or focus group allowed them to express their feelings for the first time. However, I did not observe any severe or long lasting distress.

For the focus group study, 8 to 10 participants were recruited for each group; however, some dialysis patients felt too sick and fatigued to participate. The difficulties in recruiting dialysis patients for research have been reported. As patients talked about feeling fatigued, the facilitators assured them that they could take a break or lie down, and they were not obliged to remain in the focus group. However, all continued to participate in the focus groups. A higher number of dialysis patients may need to be invited to participate in a focus group study to ensure adequate attendance. Strategies to ensure that the voices of very ill patients are also heard should be developed. For example, researchers may need to be more flexible with the time, duration and location of data collection.

The studies are not without limitations. The systematic review and in-depth interview study examined the perspectives of parent who have children receiving paediatric care. Given the selection of participants, not all relevant aspects could be addressed, for example transitional care. The interviews and focus groups were conducted once, not serially over a period of time, and the participant perspectives may have changed over time. Also, I was unable to examine systematically any possible “therapeutic” effects of conducting qualitative interviews or the effects of building stronger rapport and trust during a series of interviews. Non-English speaking participants were not included to avoid cultural and
linguistic misinterpretation so I am unable to comment on the transferability of the findings to these groups. As for any qualitative study, sampling to ensure representativeness of responses was not undertaken. Rather we sought to elicit the broad range of experiences of patients and caregivers.

9.3 Comparison with other studies

Prominent theories on the nature of people’s experiences in health and illness provided an initial framework for understanding CKD patient and caregiver experiences and perspectives. Chronic illness disrupts the patients’ identity, relationships and practical tasks,(11) and can exacerbate a sense of isolation and lowered self-esteem in patients.(12, 13) At the same time, patients adopt coping strategies and attempt to re-establish a sense of stability.(14) The findings presented in this thesis support and demonstrate that these theories are relevant and applicable, even to caregivers. CKD disrupted the patients’ and caregivers’ sense of self, relationships and lifestyle, and they needed to mobilise coping strategies to re-establish a sense of stability and routine. Also, participants reported intensified feelings of social isolation, poor self-esteem, financial stress and interrupted employment and education.

I have built on and extended these theories by describing additional aspects of patients’ and caregivers’ experiences and perspectives on health, care, and research, some CKD-specific. These include decision making with regards to dialysis and kidney transplantation, navigating the non-integrated health care system, CKD information needs, fluid restrictions, physical and emotional impact of fatigue, and genetic uncertainties. Finally, the reasons underlying CKD patients’ research priorities were a
novel finding since no empirically based theories have explored the underlying rationales for patients’ decisions on research priorities.

In CKD, studies that explore a range and depth of patients’ and caregivers’ perspectives and experiences are scant. As discussed in previous chapters, my findings were broadly consistent with findings from other studies. However, the studies in the thesis highlighted a wider scope of patient and caregiver issues, compared across the trajectory of CKD, and identified important patient and caregiver issues that had not been reported in previous studies. These included detailed perspectives of caregivers and patients about the impact of CKD on family planning, work, patient-professional communication, coping with liquid and diet restrictions, non-integrated healthcare, and decision-making processes on dialysis and transplantation.

9.4 Implications for practice

Despite the intent and attempts to improve patient centredness, there is concern that few significant improvements have been made in terms of patient access and continuity of care, and that clinicians do not consistently or formally assess patients’ needs, beliefs, and understanding of the illness, and do not include them in decision-making. In CKD, there is no standard or formal mechanism to achieve the desired policy imperatives of consumer-centredness.

Health professionals need to value and demonstrate a solid understanding of consumer perspectives, needs and experiences, in order to provide patient-centred care. CKD exerts a rippling effect on patients and caregivers, impinging on many aspects of their
lives, not only on the patients’ medical state. Rather than narrowly focusing on medical outcomes such as quantitative biochemical targets, consultations and clinical decision-making need to encompass the patients’ psychological state and sense of self, perceived needs, personal preferences, family, social, financial, environmental and cultural situations, and support structures. For example, the results from the studies demonstrate that patient and caregiver decision-making regarding medical management was largely not based on clinical considerations. Instead, patients carefully considered the potential impact and risks their decisions would have on their family, lifestyle, home, employment, energy and physical comfort.

Even in accounting for consumer perspectives, clinicians should avoid making decisions based only on their own opinion of what consumers in general prefer. Given the complexities, multiplicity and variability of consumer concerns, clinicians need to encourage each patient and caregiver to express their concerns and share in decision-making, rather than assume what they prefer. This can lead to better patient satisfaction and improved outcomes.

To reduce patients’ and caregivers’ sense of isolation, healthcare providers can also communicate the experiences and perspectives of patients and caregivers in a written or verbal manner. Recently, Kidney Health Australia have published a booklet containing personal accounts of people living with kidney failure. The booklet, and other similar resources, should be provided to patients and caregivers, and evaluated to assess its effect on patients and caregivers and how the content or mode of delivery can be improved.(16) While these resources are usually developed for patients, strategies to improve professional knowledge about patient and caregiver issues are also needed.
To facilitate a better understanding of consumer perspectives, needs and experiences, the range and depth of patient and caregiver issues should not be a peripheral addendum in professional education, but integrated as a core component. A strong rhetoric on teaching patient-oriented care is emerging, supporting the expansion of the disease-orientated model by incorporating domains including the patient’s illness experience, psychosocial context, values, perceived needs, function, and emotional support. (3, 17-19) My findings can inform the development of professional curricula aimed at health professionals who provide care for CKD patients, to enhance their interpersonal skills and understanding of patient experiences, needs and perspectives.

Publishing patients’ perspectives, experiences and priorities in prominent nephrology journals, widely read by the professional renal community, can broaden healthcare providers’ knowledge on consumer perspectives. However, studies of patient perspectives in scientific nephrology journals were relatively few and generally use quantitative survey techniques. The parent in-depth interview paper was the most difficult to publish. While reviewers felt the topic was interesting and important, they provided critical appraisal based on criteria established for quantitative research, for example representativeness and generalisability. I had to explain that qualitative research usually aims to reflect the commonality and diversity within a given population, rather than generalisability or representativeness. (20)

Efforts are needed to increase knowledge about the value of qualitative approaches. For instance, top ranking biomedical journals including the British Medical Journal, Lancet and the Journal of the American Medical Association have educated readers on the value of qualitative research and suggested approaches to appraise the studies. (21-23) Qualitative research needs to be better recognised and accepted among editors and
reviewers of prominent nephrology journals. I hope that the reporting checklist will assist in this regard.

At an organisational level, health delivery and support systems should ideally ensure easy access to and continuity of care. Also, healthcare systems need to be more integrated. Patients and caregivers felt they had to negotiate and navigate a non-integrated system. They were required to visit multiple clinical disciplinary and diagnostic departments, which disrupted their lifestyle, consumed time, finances and energy, impacted on their family and gave them a sense of a fragmented self. Strategies to improve coordination of care between settings are needed. Implementing accessible and integrated services with continuity of care is a substantial challenge, but it has been demonstrated to improve patient and clinician satisfaction and increase service delivery efficiency.(15)

In health research, the inclusion of consumer perspectives in research priorities is widely advocated, yet research priorities are largely driven by professional agendas.(24-26) Consumers are rarely given a role in this decision making process and the preferred mechanisms for consumer involvement remain unclear.(27, 28) There is a richness and range of understanding that can come from engagement with patients’ personal experiences of a particular illness, so it is unlikely that a single ‘consumer’ on a panel could ever be adequately equipped to offer this depth and breadth of insight. Rather than including consumers in grant review panels for health research, an arguably tokenistic approach, innovative methods are needed to better engage patients in agenda setting, rather than involving them in the same way as health professionals.

9.5 Implications for research
This thesis highlights two major directions: 1) broadening our understanding of consumers’ experiences in CKD, and 2) discovering how best to help professionals respond to this new knowledge. This research sets important groundwork by offering insights into a range and depth of patient and caregiver experiences and perspectives in CKD, drawing attention to an extensive scope of issues requiring further investigation.

The findings in this thesis will be extended with post-doctoral research. This section outlines general areas for future research and details a preliminary research agenda for the postdoctoral research program.

This thesis focused on caregivers of children with CKD and adult patients diagnosed with CKD. Qualitative research should also be used to examine the experiences, needs and perspectives of other patient groups including paediatric and adolescent CKD patients, and caregivers of adults with CKD. For example, transition is often a very delicate episode in the continuum of care to young adult patients. Therefore, research with patients who have transitioned from paediatric care to adult care is needed to better understand this important aspect of nephrological care.

The work in this thesis could also be extended to other settings, for instance to further investigate the impact of the structural, financial and organisational characteristics of different healthcare systems (i.e. in other countries) or the different circumstances of patient’s own lives on the experiences and perspectives of patients and caregivers.

To examine divergent viewpoints between consumers and professionals, research should also be conducted with health professionals and policy makers in the professional renal community. Often the perspectives, preferences and values can be different which can
affect the consumer-health professional relationship. Comparing the different views can provide useful insights into communication between the consumers and professionals, identify and resolve misconceptions, and help health professionals consider the full range of issues important to consumers.

In regards to the checklist for reporting qualitative research (Chapter 8), it would be useful to know the degree to which the individual criteria influence the usefulness of qualitative research reports to readers. Ways to empirically assess the “usefulness” of each item in the checklist are needed so that the checklist can be refined, with a stronger argument able to be mounted for the items that remain in the checklist.

Postdoctoral research program

The needs of caregivers are often neglected, and additional support structures are needed. A broader review of support interventions for caregivers in other areas of medicine would inform the development of support programs for patients with CKD. Specifically, we aim to conduct a research study with parents who have children with CKD to develop an information handbook and an online support system for parents. The study will use participatory action research methods. As described in the systematic review of caregiver interventions (Chapter 4), this method is recognised as an “empowering methodology”, it allows participants to be involved in decision-making, planning, implementing and evaluating interventions.(29, 30) Research and action are coupled together to plan, implement and monitor change. The participants become ‘co-researchers’ and the researcher’s role is to participate in the initiatives and use their research knowledge and expertise to support and facilitate the participants in the research
program. This enables the development of programs that consider and incorporate the specific situations and conditions that will influence the outcome of the programs.

Towards the end of completing this thesis, I was awarded The Mark Cocks Transplant Research Scholarship to conduct a study that focuses on quality of life issues post-transplant in adolescents. This study aims to: 1) explore adolescents’ perceptions of the major determinants of post-transplantation quality of life, 2) elicit strategies from them on ways to improve their quality of life, and 3) evaluate utilities-based quality of life instruments in adolescent transplantation. This measures their preference for a specific level of health status or specific health outcome, and is useful in the context of economic evaluations to examine the efficiency and usefulness of health programs. For aims 1 and 2, a qualitative study design will be used. In-depth, face-to-face interviews will be conducted initially with 25 – 30 adolescent kidney transplant recipients (aged 11-21 years) from Australia and New Zealand. Participants will be purposively sampled to reflect demographic characteristics in the national registry. The final number of interviews will depend on when new information ceases to arise. After demographic details are obtained, the participants will be asked for their perspectives on: a) their experiences and perspectives relating to the psychosocial impact of the illness, b) transplantation processes and treatment, c) post transplantation needs and concerns, and d) how clinical, ancillary support services can effectively respond to their needs and concerns. All interviews will be audio recorded and transcribed. Coding and analysis will accord to thematic analysis. For the third aim, utility assessment will be performed using standard utility measurement tools (e.g. time trade-off techniques), to assess the participants’ current health state against perfect health with no kidney disease.
In kidney disease, the clinical outcomes for patients are poor irrespective of treatment, but have different implications for patients and families. The next step is to further clarify differences in outcomes preferences for clinical practice and research, and to implement sustainable change in both settings, towards a more patient-focussed agenda. This can help to ensure that the insights gained from consumers can influence clinical services, care and health research. Based on the findings presented in this thesis, I also intend to elicit also experiences and perspectives from caregivers of adult CKD patients and identify strategies to improve caregiver support.

**9.6 Conclusions**

In conclusion, this thesis offers a comprehensive, detailed and deeper understanding about the preferences, needs and values of consumers across all stages of CKD. CKD has a pervasive and profound impact on patients’ and caregivers’ physical, mental and emotional well-being, personal identity, relationships with family and friends, lifestyle, and roles and responsibilities. Despite facing the continuous and devastating challenges, patients and caregivers used an array of mental coping strategies, and formal and informal support structures. Patients had clear priorities for health research and identified the underlying reasons for their choices. The coalescence of consumer and professional experiences and perspectives can make practice and research more relevant and responsive to the needs of consumers, thereby supporting a move towards greater consumer-centredness in care and health research in CKD, better health and social outcomes for patients and their caregivers, and better job satisfaction for healthcare professionals and researchers.
9.7 References


17. Wellbery C. Medical education must be more patient centred to be relevant. British Medical Journal 2006; 333: 813.


A.1 Search Terms

kidney diseases/
kidney failure/
kidney failure, chronic/
chronic kidney.tw.
chronic renal.tw.
(kidney adj3 (insuff$ or diseas$ or failure)).tw.
(renal adj3 (insuff$ or diseas$ or failure)).tw.
pre-dialysis.tw.
predialysis.tw.
kidney transplantation/
graft survival/
graft rejection/
exp renal replacement therapy/
renal replacement therap$.tw.
(hemodia$ or haemodia$).tw.
(hemofilt$ or haemofilt$).tw.
(biofil$ or ultrafilt$).tw.
peritoneal dialysis/
dialysis.tw.
exp child/
exp child, preschool/
pediatric$ or paediatric$
adolescent
parents/
parenting/
father$ or father-child
paternal.mp
mother$ or mother-child
maternal.mp
family/
child rearing/
Psychology, social/
quality of life/
adaptation, psychological/
stress, psychological
social support/
Social adjustment/
socioeconomic factors/
affective symptoms/
depression/
mental fatigue/
communication/
social behavior/
emotions/
group processes/
interpersonal relations/
mental health/
life change events/
mariage/
divorce/
marital satisfaction.mp.
Appendix B

B.1 Parent Interview Guide

Introduction / briefing

Thank you very much for your willingness to participate and be interviewed. I have been involved in research in chronic kidney disease and now I am doing a research project on the experiences of parents who have children with chronic kidney disease.

As part of my research project, I will also be talking to other families who have children with chronic kidney disease because I want to understand and hear about the experiences, needs and concerns of parents who care for children with chronic kidney disease.

I hope that by talking with parents, we can provide information to health providers and help improve the care and support given to families.

Basically, we will just sit and talk about what it is like to look after a child with chronic kidney disease.

I am going to leave this (digital recorder) here, to record our conversation. This is to help me keep and analyse the data later on. Please let me know if you want me to stop recording at anytime. Otherwise, just try not to pay any attention to it.
Before we begin, do you have any questions you would like to ask me?

**Interview questions / prompts**

**Introduction Question**

Now if I can just take you back to when your child was first diagnosed with chronic kidney disease, can you please tell me about that? And then, what happened later on during your child’s treatment?

**Intrapersonal Issues:**

*Physical, psychological, emotional*

- Could you tell me, how has this affected you personally?
- How did you react?
- Can you describe how your daily life has been affected or changed?
- How has your health been? Are you feeling tired?
- How did you cope, or how are you coping now?
- Are you able to express your feelings openly?

**Interpersonal Issues:**

*Relationship with family, medical staff, friends, community*

- How is your husband/wife/partner coping? Do they have any concerns?
- How about your other children? How have they responded to your child’s illness?
- Have you been given help from relatives, friends?
• Do you know of other parents who have children with chronic kidney disease?

• About the medical care you receive, how has that been for you? How do you feel about that?

**External Issues:**

*Employment, finances, transport, relocation, responsibilities of the medical regimen, household care, diet and nutrition, information, health services*

• Can you take me through a typical day, by describing the things you have to do?

• What are the more difficult things you have to manage? Why?

• How has your child been coping at school?

• Can you tell me about giving your child medications?

• How much information do you have about kidney disease?

• Are there any needs you have that have not been met?

• Can you please describe your hospital visits?

**Support and Research:**

• Now, I would be interested to hear how you think the experiences of parents could be improved? What can you suggest?

• What sort of things, programs, circumstances might lead to better experiences for parents who have children with chronic kidney disease?
Close

Your thoughts and perspectives have been extremely valuable. Is there anything else you would like to say or is there anything you would like to ask about? Again, thank you very much for taking the time to talk to me about your experiences. Can I arrange a time to meet with you again?
Appendix C

C1. Search Strategies

<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers/ (caregiver* or carer*).tw (informal adj5 (caregiver* or carer*).tw exp parents/ spouses/ Renal insufficiency/ Exp renal insufficiency, chronic/ (chronic kidney failure* or chronic renal failure*).tw (chronic kidney disease* or chronic renal disease*).tw (end stage kidney disease* or end stage renal disease*).tw (esrd or eskd).tw (chronic renal insufficiency or chronic kidney insufficiency).tw kidney transplantation/ renal dialysis/</td>
<td>Caregiver/ (caregiver* or carer*).tw (informal adj5 (caregiver* or carer*).tw exp parents/ spouse/ caregiver burden/ caregiver support/ chronic kidney failure/ (chronic kidney failure* or chronic renal failure*).tw (chronic kidney disease* or chronic renal disease*).tw (end stage kidney disease* or end stage renal disease*).tw (esrd or eskd).tw kidney transplantation/ dialysis/</td>
<td>Caregivers/ Caregiver burden/ Caregiver support/ (caregiver* or carer*).tw (informal adj5 (caregiver* or carer*).tw exp parents/ spouses/ caregiver burden/ exp kidney diseases/ (chronic kidney failure* or chronic renal failure*).tw (chronic kidney disease* or chronic renal disease*).tw (end stage kidney disease* or end stage renal disease*).tw (esrd or eskd).tw kidney transplantation/ dialysis/</td>
<td>Caregivers/ Caregiver burden/ Caregiver support/ (caregiver* or carer*).tw (informal adj5 (caregiver* or carer*).tw exp parents/ spouses/ (chronic kidney failure* or chronic renal failure*) (chronic renal disease* or chronic kidney disease*) (end stage kidney disease* or end stage renal disease*) (eskd or esrd) (chronic renal insufficiency or chronic kidney insufficiency) renal insufficiency renal insufficiency, chronic</td>
<td></td>
</tr>
</tbody>
</table>
Appendix D.

D1. Focus group field notes and observation

Anthropologist: Bronwyn Hall

Observations: Field note observations of nine focus groups on patients’ perspectives on CKD research priorities

Location: Brisbane, Sydney, Melbourne

Overall themes: Humor, financial stress, work, positive, outlook, diet, psycho-social, patient as expert, CKD language, don’t look sick so lack of understanding from others, internal debate with being “normal”, CKD not homogenous, CKD impact on family, carers and donor, issue of planning life, health system not integrated, media representation, prevention, stem cell research, transplant issues with donor, group as support.

This Document Includes:
1. Brisbane
   - Table of Issues
   - Mapping the Dominant Lines of Communication and Group Layout
   - Field Notes
2. Sydney
   - Table of Issues
   - Mapping the Dominant Lines of Communication and Group Layout
   - Field Notes
3. Melbourne
   - Table of Issues
   - Mapping the Dominant Lines of Communication and Group Layout
   - Field Notes

Social Mapping Legend: Lines of Communication

←→ Dominant conversations between participants (shared)

--- Dominant conversations from one person (one way)
### Table Summary of Issues by Groups Brisbane

<table>
<thead>
<tr>
<th>ISSUE</th>
<th>PRE-DIALYSIS RESPONSE</th>
<th>DIALYSIS RESPONSE</th>
<th>TRANSPLANT RESPONSE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EMOTION</strong></td>
<td>Anxiety, Depression</td>
<td>Confusion, Anger</td>
<td>Gratitude</td>
</tr>
<tr>
<td><strong>DISEASE FOCUS</strong></td>
<td>Not primarily about CKD. More about range of other illnesses.</td>
<td>Identity Crisis, Sick, Issue of work.</td>
<td>All about CKD. Defining feature of life.</td>
</tr>
<tr>
<td><strong>HEALTH SYSTEM</strong></td>
<td>Confusion, No straight answers, Not holistic</td>
<td>Self Medicate, Resistance</td>
<td>Compliance, Appreciation</td>
</tr>
<tr>
<td><strong>RESEARCH PRIORITIES</strong></td>
<td>Psycho-social, mental health, prevention and cure, Links to other diseases.</td>
<td>Community Information and Education</td>
<td>Prevention and better treatments</td>
</tr>
<tr>
<td><strong>RESPONSE TO REIMBURSEMENT</strong></td>
<td>Disappointment at having to wait for cheque. Thought being paid cash on the day.</td>
<td>No problems. Even saw humor in it, Saw it as part of the system they always deal with.</td>
<td>Did not want money. Some did not know they were being paid. Others asked to put it towards research.</td>
</tr>
<tr>
<td><strong>COPING STRATEGIES</strong></td>
<td>Humor, Positive outlook</td>
<td>Self-management, Practical</td>
<td>Thankful, Belief in medical system</td>
</tr>
<tr>
<td><strong>GROUP DYNAMIC</strong></td>
<td>Open, Cohesive</td>
<td>Not able to focus on task, Sick. Needed to vent</td>
<td>Reflective</td>
</tr>
</tbody>
</table>
**Group One Brisbane: Pre Dialysis Group. Eight (8) members. 19th July 2006. Brisbane Convention Centre 9.30am.**

**Layout**

![Layout Diagram]

**Overall Observations and Comments Group 1**

- The group started at 9.30 and most people arrived 10-15 minutes early. Tea and coffee was served outside the room and participants gathered and talked freely among each other. There was a lot of laughing and joking and the group was well bonded by the time they came into the room for the group to begin.
- People sat wherever they liked and the spread of male: female was even around the table.
- Participants all contributed, but P6 was quietest. Perhaps 10 minutes into the group, P6 talked about how lucky she is and how she felt like others in the room were much worse off than she was. The group discussed this and P5 told her it doesn’t matter what your problems are “we are all part of the CKD family”, but she appeared more distant from the group after making her comment and could see that she felt like she had little to contribute because everyone else had so much going on. She listened attentively, but didn’t speak, which suggested she didn’t feel like she had the right to comment. When directly addressed by facilitator P6 had things to say, which also suggests she was following what was going on and does have contributions to make, but felt unsure about talking based on the fact that she has few issues and has been lucky to have a good experience.
• The group was high energy. They focused on staying positive and joked a lot. The conversation was lively and moved freely.

• The group as a whole focused on feelings of having CKD and the psycho-social issues tied in such as anxiety and depression. The whole group enthusiastically agreed that they have problems with things like anxiety, stress, depression etc, but P2 was the person who brought up the idea. P2 was very articulate and a health professional herself and in many ways lead this dimension of the conversation. Interestingly, during the exercise about 4 participants added psycho-social to the list of research priority areas. Often when P2 spoke, there were a lot of nods around the table and people tended to keenly support what she said about her experiences of CKD as though she were articulating for everyone what they have always wanted to put into words.

• P2 also raised the issue of financial strain and how much CKD draws on your resources especially because so many people have to leave work because they are so tired. The group again all agreed with this and financial stress was a theme raised a number of times during the course of the group.

• P7 was German and had a softly spoken voice. She was quite hard to hear because of the volume of her voice and her accent.

• As a whole the group had a plethora of health issues from heart attacks, lupas, diabetes, cancer, and CKD was just one health issue of many. At this stage patients didn’t identify CKD as their overriding or main health issue. They talked about how they all got CKD from so many different/other health issues and there was a commonality in the CKD mainly through the feelings they shared (NOTE: in later groups, CKD was the definitive health issue of the group).

• Focus was on how you are not looked at holistically in a hospital setting. Participants told stories of how they are the ones who need to remind doctors of their other health issues and potential issues with taking various types of medication, because specialists focus so narrowly on one aspect of their health.

• As a whole, the group stuck to the tasks and was able to articulate the areas they wanted research to focus on. The main theme of their research allocations and general comments was a need for an increase in the connection between CKD and other illnesses and also better connection between the health systems and different departments in hospitals. They felt ignored and that their own opinion on what was happening for them was not taken on board by hospital staff.

• At the end of the group, participants were asked to fill out a form to receive the reimbursement for their time. Participants reacted to this as most seemed to be under the impression that they were going to get money on the day. Some people seemed quite put out. P5 asked for reimbursement for petrol he put in his car the day before, but said he didn’t have a receipt. Others had public transport tickets with them, but needed them to get back home. This was a difficult situation to manage because all participants were looking to get money on the spot and in light of the discussions on financial pressures, this was a difficult end to a successful group. The group were productive and happy until this point and it did change the group dynamic.

Layout

Overall Observations and Comments Group 2

- Overall, group two were sick. P3 was vision impaired and walked with a cane. She struggled to stay awake at times during the group.
- P4 was an older man who wanted to tell his story. He talked openly to the group, but towards the end of the group, P1 and P6 were talking a lot and he broke off (twice) into a separate conversation with P5. P5 seemed conscious of not having separate conversations going within the group and both times managed to redirect P4’s comments to the larger group.
- P1 and P5 had a lot of direct conversation, inclusive of the group, but focused on one another.
- Equally P1 and P6 had a lot of conversation directed at each other, rather than the group.
- P6 was fairly quiet at first, she was passionate, but not overbearing in the amount she contributed. Towards the end, P6 talked over the top of people on a number of
occasions and worked herself up as she spoke escalating from a normal speaking voice to loudly expressing her anger.

- P1 took on the role of ‘expert’ of the group. He had a huge level of knowledge on all dimensions of the illness and spoke to the group in an educational tone.
- The overall focus of this group was on story telling and sharing resources. The group all had a lot to say in terms of their own experiences. They wanted to share their experiences and an opportunity when everyone in the room understood what they are going through was an opportunity too good to miss. The conversation centered around identity.
- The group was not able to focus on the tasks. They would answer the first question the facilitator asked, but then move back onto sharing their own experiences.
- It was clear than this group are so involved in the illness, they were so sick, that they were unable to focus on the broader research questions
- Further, it also became clear that these people don’t have many opportunities to network and share their experiences with each other.
- P1 and P5 knew each other, but most others had not met each other, even if they had seen each other around the hospital.
- The level of jargon used was much more developed than Group 1. This group were comfortable taking in CKD jargon.
- There was a medical focus in terms of their medical experiences
- There was also a focus on community acceptance, and many shared their experience of having to do dialysis and change bags in public or work places.
- P3 was a younger woman who still works and initially the group were congratulating her on keeping her job, despite the challenges. At the end of the group, it seemed that her father was making her go to work. Then the group became very protective of her and P1 asked for her number so he could call her father, and put him in contact with other carers. Most people in the group swapped numbers, accept P2.
- P2 was fairly quiet during group, however she spoke when directly addressed. She seemed nervous. People wanted to stay at end of group and when group officially ended, no-one moved. P2 picked up her bag and had it over her shoulder, but stayed, on the edge of her seat for a few minutes before leaving.
- Focused on the technical or practical aspects of what they are going through. Less on emotional like first group.
- Two members of the group P1 and P5 stayed behind for ½ hr after group and had another coffee. Partner of P1 waited for him while the group was on because she could not come into the room and participate. After the group the facilitator had a lengthy discussion with the partner and she was close to tears, as she explained how she is always left out, but she is his carer so she has a lot to say, too. This is an important issues and more focus groups could be conducted with carers, as they are also experts in CKD.
- This group were asked to fill out the forms to receive reimbursement, but their reaction was quite different. When facilitator explained that we would like to give cash, but because of hospital policy we would have to send cheque, and that may take a few weeks, the group laughed sympathetically and suggested they were use to hospital time. They had no issue with not being paid.
Group Three Brisbane: Transplant Group. Eight (8) members. Friday 20th July 2006. 3rd Floor Buranda Plaza Cnr Cornwall St and Ipswich Rd, Buranda, QLD 9.30am.

Layout

Overall Observations and Comments Group 3

- This group was very articulate and reflective on their illness and their lives
- P1 was the ‘expert’ in the group and was outspoken about his views. He regularly disagreed with P5 and P4; and a powerful triangle formed between the three where they agreed and disagreed but were essentially having a private debate.
- P2 contributed to the group regularly and always spoke to the whole group. He focused on how simple things are if you just do what you are told with medications, just eat the right food etc. he was very black and white.
- P3 and P8 were very quiet and did not contribute to group after initial introductions.
- P8 was late and group had started by the time she arrived. This seemed to create a distance for her than she never quite bridged. Soon after she arrived she told her story and cried as she spoke. At the end she told me she feels lucky and has no health problems and didn’t have much to contribute because she is fine now. She
won’t let bad thoughts enter her mind. She is very religious and prayed her faith plays a huge role in her understanding, interpretation and management of her condition.

- P7 was a young man who had many issues. He was articulate about research priorities and addressed the group.
- P6 was an older woman who had been told about P7, but much like Group 2, these people didn’t know each other. (Apart from P5 and P6)
- P5 was a challenger and often challenged or disagreed with the group
- P4 talked more about her son with CKD than her own experience.
- This group defined themselves as CKD patients. By this stage all other illnesses and issues paled in comparison to living with CKD.
- This group also displayed a compliance with the medical world and a deep appreciation for what the doctors have done. They were grateful and happy that the health system is there, they take each day as a blessing.
- When the group was asked to fill out the forms to receive reimbursement, a number of them said they didn’t want to be paid and they would prefer the money go to research.
- This group was articulate about research priorities.
## Table Summary of Issues Sydney

<table>
<thead>
<tr>
<th>ISSUE</th>
<th>PRE-DIALYSIS RESPONSE</th>
<th>DIALYSIS RESPONSE</th>
<th>TRANSPLANT RESPONSE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EMOTION</strong></td>
<td>Fear</td>
<td>Move on from anger, guilt, shock to positive outlook</td>
<td>Grateful</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Confusion</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Isolation</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>DISEASE FOCUS</strong></td>
<td>Look the same on outside. Role of diet Questioning “what is it?” Support groups</td>
<td>Fatigue. Determination to be ‘normal’ Diet</td>
<td>Others. Family, carers, donor. Much wider than medical definition of CKD</td>
</tr>
<tr>
<td><strong>HEALTH SYSTEM</strong></td>
<td>Not holistic</td>
<td>Doesn’t help carers or family</td>
<td>No communication. Patient as expert</td>
</tr>
<tr>
<td><strong>RESEARCH PRIORITIES</strong></td>
<td>Psychological Aspects</td>
<td>Aboriginal Stem Cell Better dialysis machines Side effects of drugs</td>
<td>Psycho-social not just with patients, but also with carers and donors and family.</td>
</tr>
<tr>
<td><strong>RESPONSE TO REIMBURSEMENT</strong></td>
<td>Paid on day. Very grateful.</td>
<td>Paid on day</td>
<td>Paid on day</td>
</tr>
<tr>
<td><strong>COPING STRATEGIES</strong></td>
<td>Other interests Humor</td>
<td>Feel Lucky Plan your time</td>
<td>Exercise</td>
</tr>
<tr>
<td><strong>GROUP</strong></td>
<td>Jovial</td>
<td>Used as support group. Share ideas and tricks Focused on task</td>
<td>Talkative</td>
</tr>
</tbody>
</table>
Group One Sydney: Pre-dialysis Five (5) members. Thursday 31st August 2006.
Lorraine Crapp Room Sydney Aquatic Centre, Olympic Park. 9.30am.

NOTE: There were three empty chairs at the table. One between P4 and P5 and two between facilitator and P1.

Overall Observations group 1

- P1: Female focus on weight issue, had walking stick
- P2: Male outspoken, political, entertainer
- P3: Male older (70’s) quiet
- P4: Male research focus
- P5: Female laughed a lot
- The first group members arrived at Aquatic Centre about ½ hour early. There were issues with people finding the room, so the note taker waiting in foyer to walk people to the room. The venue was not ideal for the Sydney groups. There were a lot of noises and distractions with the room next door being a child care centre and voice over on PA and drilling in room next door.
- Male:female split equal with facilitator included. Women on one side and men on the other side of the table.
- Group used a lot of humor
- P1 and P5 had most direct dialogue
- P3 did not contribute unless addressed and he didn’t express many issues.
- Financial stress, having to leave work and “putting your life on hold”
- Fear of the unknown - there was confusion about what will happen to them and what caused CKD
- Depression featured as a unifying experience because of feeling tired, shocked, sick, disappointed, confused
- Overwhelming having to learn a new CKD language
• You look the same, but you aren’t. Hard to get acceptance from others and yourself the CKD is real
• No just CKD. All sorts of other health issues
• Medical experience is not holistic. Doctors don’t know about CKD. Lack of understanding from other medical staff
• Patients have to become their own experts. Forced to because of segregated medical system.
• The group focused on the role of the government in making CKD a priority or not. This was lead by P2.
• Also focus on media interpretation “it’s your fault”
• Focus also on practical assistance. Wanting support groups, ad campaigns, employment packs for employers.
• Diet was a big issue and the types of food you can eat.
• Having other interests as a way of coping.
• Patients were reimbursed cash on the day.

Overall Observations group 2

- Two participants arrived almost an hour early. Other were also early
- P1: Calm talkative and addressed group when spoke
- P2: Very positive and talkative. Concentration of dialogue between P2 and P3. P2 son has CKD so wanted to see what she can do to help his life. Father died of CKD. Brought a list written down of her research priorities.
- P3: Outspoken
- P4: Knowledgeable, but troubled with issues. Talkative.
- P5: Aboriginal. Expert. Began talking a lot but withdrew in the end.
- All participants contributed fairly equally although P2 and P3 spoke to each other and P5 didn’t speak for the second part of the group when task was underway.
- This group wanted to share their experiences and talked about dialysis before the group started. It was an information exchange. A comment was made that a person wanted to “bench mark” themselves against others. This shows the lack of interaction between CKD patients normally.
- Issues about forced early retirement and changes to life, but had moved on from self blame and depression to reframing it as positive and creating coping strategies
- Major coping strategy was keeping busy.
- Talked about being up and down
- CKD patients are not a homogenous group
- Praise for medical staff and support they receive
- Group stayed and chatted for a while after and did not move away fast. They showed each other shunts and scars.

Overall Observations Group 3

- Males on one side and females on the other
- P5 and P4 addressed the whole group when they spoke.
- Conversation was led by P6, 3, 7, 2 darting across the table back and forth
- P8 was a softly spoken Indian woman, she was quiet for most of the group and had her arms crossed for most of the group. She shared a personal story and there was a lot of noise interruption from outside.
- P3 was a ‘yarner’ and told stories about his life and philosophies
- P4 was fidgety
- P6 spoke to P8 about his philosophies
- All men didn’t speak for first 15 minutes
- P7 was ‘expert’ and knowledgeable and had a strong presence (not overbearing)
- Focus was on the interaction between the health system, the patient, doctors, family, donors.
- Emotional impact of CKD on patients, family/carers and donors was a strong focus. It’s not just about the patient
- CKD is “non-specific”
- Doctors are great, but social workers not helpful for this group
- Very wide picture of CKD including education, medical, psycho-social, geographic, cultural, indigenous, donor, isolated people, financial.
- Lack of communication between medical staff
- Issues for the donor as well as the recipient
• Issues of choice was collectively acknowledged. They needed to know they still had choices with CKD.
• Strong focus on need for family support and emotional family support and support groups for patients
• Effects of drugs
• Patient as expert was the main focus of discussion. They all agreed that in the medical system there is a lack of communication and you have to be the one who is on top of your own situation and know drugs given by each doctor because often they react and have a negative impact. Between the GP, specialists, nurses, social workers, dietitian, eye doctor etc no-one asks what the other doctors are prescribing or considers the impact of the drugs they prescribe on other illnesses the patient might be experiencing e.g. diabetes, blood pressure.
## Table Summary of Issues Melbourne

<table>
<thead>
<tr>
<th>ISSUE</th>
<th>PRE-DIALYSIS RESPONSE</th>
<th>DIALYSIS RESPONSE</th>
<th>TRANSPLANT RESPONSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>EMOTION</td>
<td>Denial&lt;br&gt;Fear&lt;br&gt;Uncertainty</td>
<td>Positive&lt;br&gt;Up and down&lt;br&gt;Resentment&lt;br&gt;Control</td>
<td>Lonely</td>
</tr>
<tr>
<td>DISEASE FOCUS</td>
<td>No CKD - it’s not real. Asymptomatic</td>
<td>Debate on transplant v dialysis&lt;br&gt;Choice</td>
<td>Relationship to diet and obesity and diabetes&lt;br&gt;Non-visibility of disease</td>
</tr>
<tr>
<td>HEALTH SYSTEM</td>
<td>Too focused on prescribing drugs. Need alternatives</td>
<td>Satisfied</td>
<td>Disconnected. Patients are people not parts</td>
</tr>
<tr>
<td>RESEARCH PRIORITIES</td>
<td>Prevention&lt;br&gt;Information&lt;br&gt;Stem cell</td>
<td>Information&lt;br&gt;Stem cell</td>
<td>Young v old, diabetes, stem cell</td>
</tr>
<tr>
<td>RESPONSE TO REIMBURSEMENT</td>
<td>Thanks</td>
<td>One person didn’t want money</td>
<td>One person didn’t want money</td>
</tr>
<tr>
<td>COPING STRATEGIES</td>
<td>Ignore problem&lt;br&gt;Diet&lt;br&gt;Exercise</td>
<td>Exercise&lt;br&gt;Stay busy&lt;br&gt;Part of life, not defining feature ‘normal’</td>
<td>‘Try to be ‘normal’&lt;br&gt;Keep working</td>
</tr>
<tr>
<td>GROUP</td>
<td>Stiff, competitive, tense</td>
<td>United, supportive</td>
<td>Reserved, serious.</td>
</tr>
</tbody>
</table>

Layout

P6(f)          P7(m)          P8(f)

P5 (m)          Facilitator (f)

P4 (m)          P1 (m)

Note taker     P3 (f)          P2(m)

Overall Observations and Comments Group 1 Melbourne

- Before group started, participants said they thought there was going to be a lot of people at the group and didn’t realise it was so small. They said they wanted to see people on dialysis to see what they look like. P6 said she wanted to see others, but didn’t want to at the same time because she didn’t want to know how sick she could become.
- Very stiff group. Very intellectual approach and formal in language and ‘discussion’ of CKD. Felt stuffy and professional. People kept referring to their “background” and it was competitive in terms of who had what knowledge. In the end, this became an obvious tension which came from so much uncertainty and unknowing, confusion and resistance about the future.
- Very unsure about the future.
- P8 was younger and has had CKD since a child. Until 18 years old, medical staff spoke to parent, rather than to her.
- Focus on prevention - how can we prevent it progressing
- P1 set himself up as the expert and there was some tension between P1 and P2.
- P2 was in denial about having a chronic disease. She was seeking information about diet, exercise, anything she could do to ‘get better’. P1 was trying to get her to see that things don’t get better.
- Lots of technical and sophisticated language was used like “asymptomatic”. P6 initially said she was asymptomatic and that caught on. It took a while for people to relax and dig a bit deeper into their emotions. In light of all the discussion of others
not knowing about CKD, it seems that people have their spiel about how positive their life is, and it took a bit to break through this.

- P1 was very definite in his opinions and spent a lot of time trying to pass his views onto others.
- Strong focus on diet.
- Issues of looking okay so no-one understands
- There was a tension, a struggle between acceptance v uncertainty about the future
- Interesting attention was given to alternative therapies.
- Focus on CKD as a complex condition with no straight answers, no formula to follow. Everyone is different.
- A comment was made that dialysis seems old fashioned.
- There was an ‘information block’ the issue of accessing information, being able to take it on, or ignore it, craving information but not wanting to really hear about the future.
Carlton Crest Hotel 12.30pm

Layout

P6(m)      P7(m)

P5 (f)      Older side

P4 (f)      Younger side

Facilitator (f)

P1 (m)

Table

Note taker  P3 (f)  P2(f)

Overall Observations and Comments Group 2 Melbourne

• P2 was late but she knew P1 and they hugged when she arrived
• P7 was quietest but not uncomfortable
• P5 was bubbly and loud
• P4 was older woman who was very honest, even when others were collectively agreeing. P4, 6 and 7 kept a balance between positivity of ‘young’ side of table.
• Use of metaphors in this group that haven’t seen strongly before. “I just treat it like a part-time job” “It’s like having a new born baby” “It’s the friend you don’t like” “My machine is my best friend. I love my best friend” “Imagine you live outside your body”
• There was a warmth and honesty and acceptance in this group that was very powerful. There was a underlying positivity, but people were open about the things that were difficult. It was a balanced and endearing discussion.
• P3 and P2 exchanged numbers and want to make a documentary together.
• A couple of participants had transplants and were back on dialysis. This provided a really interesting discussion about the pros and cons of dialysis and transplant.
• Coping by not holding onto resentment and keeping busy.
• Have to remember they are sick and slow down
• Guilt from impact on family
• Trying to be ‘normal’ v giving CKD the recognition it deserves.
• Travel was a huge issue for this group of people and this was symbolic of feeling chained down, trapped and attached to a machine. Cabin fever. Envy of others who can just go wherever they want.
Lucky

Exercise. Even talked about exercising while dialyzing. It’s all about using your time and turning it into something positive. Maintaining choice in life.

Planning and issue of control in your life. Transplant doesn’t guarantee control because you still get sick. Dialysis is easier to plan around.

Impact on stage of life. P2 wants to move out of home, but she is dependent on mother for dialysis.

P6 didn’t want money. He said he got more out of it than he put in and he didn’t want to take the money.

The group talked for ½ over time. They all stayed in their chairs and continued on with their discussion. After they left the room, they kept their discussions alive in the hallway and compared their needle scars.

Layout

<table>
<thead>
<tr>
<th>P6(f)</th>
<th>P7(f)</th>
<th>P8 (f)</th>
</tr>
</thead>
<tbody>
<tr>
<td>P5 (m)</td>
<td></td>
<td></td>
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<tr>
<td>(f)</td>
<td>Female side</td>
<td>Facilitator</td>
</tr>
<tr>
<td>P4 (m)</td>
<td></td>
<td>Male side</td>
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<tr>
<td></td>
<td></td>
<td>P1 (f)</td>
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</tbody>
</table>

Table

| Note taker | P3 (m) | P2(m) |

Overall Observations and Comments Group 3 Melbourne

- People arrived from 9.10am. Men arrived first
- More formal group in dress and approach to discussion
- P1 was a younger woman. She became the spokes person for young peoples CKD experienced in the group.
- Participants collectively focused on change and how things are different ‘now’ compared to when they were diagnosed. Treatment, dialysis, information access is all better now
- Issue of being lonely. You’re a lone soldier with CKD
- Talked about family, but focus was on how little others understand what they are going through.
- Creation of ‘dialysis room’ or hiding it in the house. Like a family secret
- Again, non-visibility of disease featured as a massive issue
- Issue of work. For P4 it was very much about keeping job to feel ‘normal’ even when very, very sick. P4 quite traumatized
- Diet issue again, but this time focus on looking anorexic
- P7 made a lot of contributions. “It’s a sinister disease” but focused on “our path” in life. It seems when people have a framework for understanding CKD they manage to function better.
- Issue of stem cell came up again. This is currently in the media, so could be having an impact of people’s interest in it.
- There was a general talk about childhood obesity and the issue of diabetes in CKD.
- Doctors need to understand the human side of CKD. Patients are people, not parts.
• P4 was most talkative in the beginning and initiated the conversation, but withdrew in the end
• P4 and P5 were restless in the end.
• It’s almost like they were well behaved and reserved to talk about their feelings.
## E1. Ranking Exercises

### Research about the:
- predialysis stage of chronic kidney disease
- dialysis stage of chronic kidney disease
- transplant stage of chronic kidney disease

### Research that aims to:
- discover the causes of chronic kidney disease
- help to prevent chronic kidney disease
- lead to better diagnosis of chronic kidney disease
- improve treatment for people with chronic kidney disease
- understand the experiences and needs of people with chronic kidney disease

### Research that aims to:
- understand how chronic kidney disease works in the body
- discover more effective treatments for chronic kidney disease
- prevent chronic kidney disease in the community
- help clinicians and hospitals to provide better services to people who have chronic kidney disease

### Research about:
- Bone disease in chronic kidney disease
- Cancer in chronic kidney disease
- Blood pressure in chronic kidney disease
- Anaemia in chronic kidney disease
- Heart disease in chronic kidney disease
- Nutrition in chronic kidney disease
Research that aims to help:

- children with chronic kidney disease
- adolescents with chronic kidney disease
- young adults with chronic kidney disease
- middle-aged adults with chronic kidney disease
- older adults with chronic kidney disease
E2. Focus group question guide

FOCUS GROUP

Welcome each individual

Invite each individual to have refreshments

We will be talking to 9 groups all together – 3 in Sydney, Melbourne and Brisbane.

We would like to get an idea of what you think is important for research in chronic kidney disease.

We want money and expertise to be channelled into studies that are relevant to you.

We hope to use this as an opportunity to hear from you, hear about your concerns and thoughts. Hopefully, your perspectives will be included in the research agenda.

Give opportunity to ask questions. We will be recording the session so I can transcribe and analyse the data later on.

Begin questions

<table>
<thead>
<tr>
<th><strong>Topic</strong></th>
<th><strong>Question Guides</strong></th>
</tr>
</thead>
</table>
| 1 Introduction | 1. Introduction and name cards  
2. Not experts in CKD: expert researchers employed by CKD experts  
3. CKD experts want to hear your experiences and opinions on CKD  
4. All of you:  
   - have chronic kidney disease but not yet receiving dialysis or Tx  
   - are receiving either haemodialysis or peritoneal dialysis  
   - have had a kidney transplant  
5. Is it OK for me to use the term CKD?  
6. This will be kept confidential, including from clinicians  
7. ANY QUESTIONS ABOUT THE PROJECT  
8. Might agree, might disagree: please feel free to disagree |
<p>| 2 Introduction | 1. Say your name for the transcriber and what made you decide to come along |
| 3 Icebreaker | 1. This group is about CKD: when I say CKD, what is the first thing that comes to mind? |
| 4 Experiences | 1. As I said I have no direct experience of CKD, how would you explain to someone like me what its like to live with CKD? |</p>
<table>
<thead>
<tr>
<th></th>
<th>Helpful / difficult</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td></td>
<td>1. What <strong>helps</strong> you to live with CKD?</td>
<td>2. What makes it <strong>harder</strong> to live with CKD?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. [list some of the issues that they said make it harder]: What <strong>solutions</strong> have you found to deal with these problems?</td>
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<td>4. Is there <strong>anything else</strong> that you think would make life better for people with CKD?</td>
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</table>

<table>
<thead>
<tr>
<th></th>
<th>Research</th>
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</thead>
<tbody>
<tr>
<td>6</td>
<td></td>
<td>1. You have CKD and we've talked a bit about what helps and what makes it harder. Researchers are working on CKD. What would you like their <strong>research</strong> to do for you?</td>
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<td></td>
<td></td>
<td>2. Making decisions about research money:</td>
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<tr>
<td></td>
<td></td>
<td>a. Distribute 10 foam beads to each participant</td>
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<td></td>
<td></td>
<td>b. Explain that there’s limited money for research and decisions have to be made about where it should go: they are going to distribute their sweets between some research projects as though they are money</td>
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<td></td>
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<td>c. Distribute first forced choice handout.</td>
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<td></td>
<td></td>
<td>d. Ask participants to <strong>DISTRIBUTE</strong> 10 ‘counters’ while thinking about <strong>HOW</strong> they are making their decisions.</td>
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<td></td>
<td>e. When all finished, talk about the <strong>process</strong> of distributing: <strong>how</strong> they decided, what made it <strong>easier</strong> to decide, what made it <strong>harder</strong>. Give opportunity to <strong>change</strong> distribution during the conversation.</td>
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<td>f. Repeat for each handout.</td>
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<td>3. <strong>CAN YOU THINK OF ANY OTHER ISSUES THAT RESEARCH FUNDERS SHOULD TAKE INTO ACCOUNT?</strong></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Close</th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td></td>
<td>The aim of this research is to find out what you think research in CKD should focus on and what it should deliver for you. Is there anything that we haven’t talked about that you think is important?</td>
<td>Thank participants.</td>
</tr>
</tbody>
</table>
APPENDIX F

F1. Data Sources

<table>
<thead>
<tr>
<th>Television sources (Channel, program)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nine, 60 minutes</td>
</tr>
<tr>
<td>Nine, Sunday</td>
</tr>
<tr>
<td>Nine, A Current Affair</td>
</tr>
<tr>
<td>Nine, Today</td>
</tr>
<tr>
<td>Nine, National Nine Evening News</td>
</tr>
<tr>
<td>Nine, Nightline</td>
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<tr>
<td>Nine, Amazing Medical Stories</td>
</tr>
<tr>
<td>Ten, News</td>
</tr>
<tr>
<td>Ten, Late News</td>
</tr>
<tr>
<td>Seven, Sunrise</td>
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<tr>
<td>Seven, Evening News</td>
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<tr>
<td>Seven, Today Tonight</td>
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<tr>
<td>Seven, Weekend Sunrise</td>
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<tr>
<td>SBS, Insight</td>
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<td>SBS, Dateline</td>
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<tr>
<td>SBS, World News Australia</td>
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<tr>
<td>SBS, Living Black</td>
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<tr>
<td>SBS, Cutting Edge</td>
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<tr>
<td>ABC, Stateline</td>
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<td>ABC, 7:30 Report</td>
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<td>ABC, ABC News</td>
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<tr>
<td>ABC, Four Corners</td>
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<tr>
<td>ABC, Australian Story</td>
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<tr>
<td>ABC, Foreign Correspondence</td>
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<tr>
<td>ABC, National Press Club Address</td>
</tr>
<tr>
<td>ABC, Catalyst</td>
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<tr>
<td>ABC, Media Watch</td>
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</table>
## F2. Newspaper sources

<table>
<thead>
<tr>
<th>Newspaper sources</th>
<th>Circulation*</th>
<th>Total No. articles indexed Jan 2005 – March 2007</th>
<th>No. of articles retrieved</th>
<th>No. of articles included</th>
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<tbody>
<tr>
<td>The Australian</td>
<td>13 538</td>
<td>106 801</td>
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<td>The Australian Financial Review</td>
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<td>8622</td>
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<td>The Advertiser (Adelaide)</td>
<td>195 903</td>
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<tr>
<td>The Age (Melbourne)</td>
<td>201 000</td>
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<td>The Canberra Times</td>
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<tr>
<td>The Courier Mail (Brisbane)</td>
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<td>91 493</td>
<td>576</td>
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<td>The Daily Telegraph (Sydney)</td>
<td>396 497</td>
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<td>432</td>
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<tr>
<td>The Herald Sun (Melbourne)</td>
<td>554 700</td>
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<td>The Mercury (Hobart, TAS)</td>
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<td>The NT News</td>
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<td>The Sun Herald (Sydney)</td>
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<td>The Sydney Morning Herald</td>
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<tr>
<td>The Western Australian</td>
<td>205 610</td>
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<td>434</td>
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<tr>
<td>TOTALS</td>
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</table>

*State of the Newsprint Media Australian Press Council (Available online at http://www.presscouncil.org.au/snpma/ch03.html)