

Patients' Experiences after CKD Diagnosis: A Meta-ethnographic Study and Systematic Review

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ABSTRACT

Background

Chronic kidney disease (CKD) is often asymptomatic at first diagnosis and awareness of CKD is low among the general population. Thus, individuals who are unexpectedly identified to have CKD may struggle to adjust to living with this diagnosis. This study aims to synthesize qualitative research exploring patients' views/experiences of the diagnosis of CKD and how they adjust to it.

Study design

Systematic review and meta-ethnography

Setting and Population

Adult patients with CKD stage 1-5

Search Strategy & Sources

MEDLINE, PsycINFO, CINAHL, EMBASE and Web of Science were searched from the earliest date available to November 2015. Qualitative studies were selected that explored patients' views and experiences of a CKD diagnosis and how they adjust to it.

Analytical Approach

Meta-ethnography was adopted to synthesize the findings.

Results

Ten studies involving 596 patients with CKD from secondary care settings were included. Seven key themes were identified: 1) *a challenging diagnosis* 2) *diverse beliefs about causation* 3) *anticipated concerns about progression* 4) *delaying disease progression* 5) *unmet informational needs* 6) *psychosocial impact of CKD* 7) *adjustment to life with CKD*.

Limitations

The review is limited to the views and experiences of participants in the included studies which were mostly conducted in high income countries. Papers not written in English were excluded. The transferability of the findings to other populations may be limited.

Conclusions

This synthesis highlighted variation in patients' understanding of CKD, an overall lack of information on the trajectory of CKD and a need for psychosocial support especially in later stages to help patients adjust to living with CKD. Future research that acknowledges CKD as a condition with diverse complicating morbidities and that explores how patients' information and psychosocial needs vary according to severity and co-morbid conditions would be beneficial. This will support delivery of comprehensible, timely and targeted information about CKD and practical advice about recommended lifestyles changes to manage symptoms and reduce risk of future complicating illness.

INTRODUCTION

Being diagnosed with what is often an asymptomatic condition at onset, coupled with an oftentimes low awareness of kidney disease in the general population ¹, can make it difficult for people to comprehend a diagnosis of chronic kidney disease (CKD). This can pose a barrier to patients making recommended lifestyle changes, and engaging in treatment decisions aimed at reducing disease progression and associated risks such as cardiovascular disease. ² Improved understanding of patients' perceptions and experiences of being diagnosed with, and adjusting to, CKD could inform clinical practice in primary and secondary care by identifying improved ways to broach discussions with patients regarding CKD diagnosis and ongoing management.

Much of the qualitative research conducted with patients with CKD to date has focused on patients' experiences of advanced CKD including end-stage renal disease (ESRD) and renal replacement therapy (RRT). ³⁻⁹ Recent meta-syntheses in CKD have explored patients' perspectives on making decisions about treatment, children's and adults' experiences of living with dialysis and experiences of pregnant women with CKD ¹⁰⁻¹⁴ but none have focused on how people respond to receiving a diagnosis of CKD.

Meta-synthesis is a method which enables a secondary analysis of qualitative data from multiple studies. ¹⁵ Synthesising qualitative research aims to draw together the findings of individual qualitative studies and generate new insights through further interpretation. ^{16 17} This study aimed to synthesise existing qualitative research on patient perceptions and experiences of being diagnosed with, and adjusting to, CKD in order to enhance current understanding of how patients with CKD comprehend and learn to live with their condition.

METHODS

Study Selection Criteria

Studies that explored views and experiences of adult patients in all stages of CKD about being diagnosed with, and adjusting to, CKD were sought for this review. Studies that explored the experiences of receiving RRT in patients with CKD were excluded. Studies involving patients on dialysis that did not ask about receiving dialysis but rather about having and adjusting to life with CKD were included. To be eligible, studies had to use both qualitative methods of data collection and qualitative methods of data analysis. Studies were also excluded if they were not published in English and if they focused on populations other than adults with CKD (e.g. children with CKD, family members, health professionals).

Data Sources and Search Strategy

Five online databases (MEDLINE, PsycINFO, CINAHL, EMBASE and Web of Science) were systematically searched from the earliest date available to November 2015. (See supplementary materials S1). One author (EJT) screened titles and abstracts of all identified papers. Duplicates and those that did not meet the inclusion criteria were excluded. A large number of qualitative studies on CKD were identified. Two authors (EJT & STC) reviewed the titles and abstracts of these studies to determine eligibility for full text review. Reference lists of these papers were reviewed to identify other potential papers not found by the initial search.

Quality Appraisal and Data Extraction

Prior to the synthesis, two authors (EJT & STC) independently extracted data and appraised the comprehensiveness of reporting of each paper. The COREQ checklist was used to appraise the quality of reporting of the identified studies.¹⁸ To avoid missing new data-driven

insights, papers were not excluded from the synthesis due to methodological flaws or lack of reporting. The COREQ checklist was used to systematically examine the strengths and weaknesses of reporting and summarise the comprehensiveness of reporting to enable the reader to assess the trustworthiness and transferability of the studies. Discrepancies were discussed and resolved by consensus within the research team.

Data Analysis

A meta-ethnographic approach was followed to synthesise the findings.¹⁹ Meta-ethnography is a commonly used method of synthesising qualitative research, which aims to interpret and extend the findings of the individual studies whilst ensuring the original context from which data were collected is preserved. It uses the notion of first, second and third order constructs to synthesise qualitative papers, where first order constructs reflect data on participant views, second-order constructs are the original researchers' interpretations of themes arising from data, and third-order constructs are the new, common themes or interpretations derived by the synthesis of second-order constructs from multiple papers. To ensure familiarity with the data each paper was read repeatedly and the findings from each paper (participants' quotations and authors' interpretations of findings) extracted verbatim and imported into NVivo 10. One author (EJT) conducted line-by-line data coding for each paper according to meaning and content. Inductive coding (i.e. grounded in the data, reflecting the language present in original studies) generated a list of codes for each paper and as subsequent papers were coded they were systematically compared and developed (i.e. codes translated into one another or new codes added to the list). A coding manual ensured transparent coding of the data. Initial themes and sub-themes were developed and refined through discussion with the research team. The ENTREQ reporting strategy was followed to ensure clear reporting of our

synthesis.²⁰ Ethics committee approval was waived for this study as it involved a secondary analysis of previously collected data.

RESULTS

Literature search

The database searches yielded 983 citations. After screening for eligibility and duplicates, 216 qualitative studies relating to CKD were identified, of which 146 focused on the views and experiences of adults with CKD (Figure 1). Two authors (EJT & STC) independently categorised these studies according to CKD stage and primary focus of the study (Figure 2). A list of the 146 qualitative papers identified is presented in supplementary materials (Item S2). The vast majority of these papers focused on the experiences of patients diagnosed with CKD stages 5, who had started RRT and/or who were towards end of life. Following eligibility screening, 36 citations were selected for full-text review and 10 papers were included in the synthesis.

Characteristics of identified papers

The ten included studies were published between 2000 and 2015 and represented the views of 596 people with chronic kidney disease from 7 countries, predominantly high income countries (n=6). Data were collected through qualitative interviews (n=7 studies) or focus groups (n=3 studies). All studies had been conducted in secondary care settings and typically had between 20 and 40 participants, though one study had 240 participants (Table 1). Studies explored the views of people across all five CKD stages from both general populations and ethnic minority groups.

Comprehensiveness of Reporting

The comprehensiveness of reporting was variable. All ten studies reported between 12 and 20 of the 32 COREQ categories. Relationship with participants and methodological orientation and theory was generally poorly reported. Participant selection and data collection were relatively well reported and reporting of setting, analysis and findings was good (Table 2).

Results of synthesis

Seven key themes were identified, which represent second order interpretations of the original authors. Example quotes are presented below for each theme. These represent the first order constructs in the analysis. Figure 3 presents the aforementioned themes and their subthemes detailing the relationship between themes and stage of CKD. It seeks to illustrate the authors' interpretation of how patients move through stages of understanding their CKD (third order constructs). Varying demographic information was available in papers. Where available, quotes are labelled with age and gender.

1. A challenging diagnosis

Diagnosis of CKD appeared to be challenging for participants in a number of ways.

Participants often described feeling well and asymptomatic when first diagnosed, which led to feelings of shock and incomprehension about their diagnosis.

“If I had a kidney problem, I should have signs telling me things aren’t right.” (CKD 3-5D, USA) ²¹

Uncertainty about the permanence of CKD was evident, particularly amongst patients with early stage CKD. Whilst some participants understood that CKD is a chronic condition,

others were unsure about the life-long nature of CKD, which suggests differences in understandings of CKD at early and later stages.

“CKD is a long-term disease. My doctor told me clearly that CKD would not go away. There is no medicine that will cure it. I will never get better. I can only maintain my present condition.” (CKD 5, Brazil) ²²

“When you go home you think about it [kidney disease]. Yes, there were questions but the biggest question was ‘is this ever gonna go away?’ ” (CKD 1-3, Canada) ²³

2. Diverse beliefs about causation

Personal and cultural beliefs about the potential causes of CKD were frequently reported. Some participants believed their CKD diagnosis was a result of their own actions such as leading an unhealthy lifestyle (stress, poor eating habits, and alcohol) or long-term medication use. Other participants attributed their CKD to external factors such as heredity or as the result of having other conditions such as diabetes. Two studies involving indigenous Australian and Taiwanese populations highlighted beliefs in supernatural causal factors. In these studies, participants believed that external factors such as karma and black magic had led to the reduction in their kidney function.

“I have been under so much stress my entire life. I think I got CKD because I have high blood pressure, am too tired, and am overstressed. I know that stress affects kidney function.” (CKD 1-3, Taiwan) ²⁴

“My mom got CKD because of her diabetes. I got CKD from my mom.” (CKD 1-3, Taiwan) ²⁴

“A lot of the young Indigenous ones from out there [a remote community], they still regard it as being “caught”. Like if someone has a kidney problem, that’s when he was “caught” or what do you call it? Like black magic.” (Aboriginal woman, CKD 5D, Australia) ²⁵

3. Anticipated concerns about CKD progression

Participants in studies reported concerns about disease progression and future treatment, and the anticipated social and financial burden. Some participants expressed concern about being unable to continue working and about the impact of future treatment on their ability to care for significant others.

‘When you’ve gotten married and you’ve got kids, it starts to affect you and you think oh crikey, in three or four years I won’t be able to work, won’t be any money to pay for this and that. Who’s going to drive me?’ (Man, 51 years CKD stage 4, Australia) ²⁶

4. Delaying disease progression

Experiences of managing CKD were commonly expressed in terms of how participants had made adjustments to their daily life in order to try to delay disease progression. Early stage participants described making recommended lifestyle changes such as increasing physical activity and making dietary changes, and seeking alternative treatments.

“I changed from kind of a lounge lizard sitting in bars, smoking and stuff like that, yeah, to, you know, more healthy life.” (CKD 1-3, Canada) ²³

“After getting CKD, I went to the steam spa at least twice a month. The purpose is to sweat out Western medicine I took in order to reduce the burden on my kidneys.

Chinese medicine suggests eating black foods such as Judas’ ear fungus. I try to eat lots of them.” (CKD 1-3, Taiwan) ²⁴

Although some participants reflected on their positive experiences of managing CKD, other participants viewed strategies to delay disease progression as problematic. Participants reported that age, co-morbidities and contradictory treatments made it difficult for them to make lifestyle changes.

‘I’m a person 75 years old now, going on 76 in a few months, changing my lifestyle now?’ (Man, 75 years, CKD 3, Australia) ²⁶

“I think the really hard part was the liquid, so I can have 250 in total. And a 250 milliliter bottle of coke that was all I could afford in terms of pleasurable liquid. It sounds so silly, but it was like my whole days were preoccupied with where I was going to spend my liquid [allowance].” (CKD 1-3, Canada) ²³

5. Unmet information needs

A common viewpoint was that participants felt they had received insufficient information about CKD and its progression from health professionals. Some participants perceived this lack of information as a deliberate attempt to withhold information. Participants expressed a desire for accessible, disease-specific information (i.e. a full explanation of the disease and its impacts), to be available in clinics and the wider community, and practical advice on managing CKD such as advice on making recommended lifestyle changes and seeking peer

support. These viewpoints were especially evident in studies involving people with early stage CKD.

“I think information should be offered in the beginning, it shouldn’t be withheld, and it’s much harsher to find it out in the end. Hey okay, you’re looking at being on these blood pressure meds the rest of your life, it’s not going to go away. You need to have that realistic expectation from the beginning.” (CKD 1-3, Canada) ²³

“I had to go onto the internet to read really what this [kidney disease] is about...I still didn’t understand what was really happening. I think too the medical terminology was very hard to understand. What we need is someone to break it down in plain English.” (CKD 1-3, Canada) ²³

‘I want to get some mind and body help. How do you get in touch with people with similar conditions and those sorts of things? Some of this stuff [in brochures] for me, it’s a bit more ideas as opposed to practical advice.’ (Woman, 27 years, CKD 3, Australia) ²⁶

In one study involving people with CKD stage 5, participants felt they were inadequately informed about future treatments and expressed a desire for more information on RRT in order to feel better prepared.

6. Psychosocial impact of CKD

A dominant perception amongst participants with stage 5 CKD was that having CKD results in a loss of freedom, a deprivation of normal life and changes to social identity. In particular, participants with stage 5 CKD described how they felt life had become

restricted as they were unable to do their usual social activities due to treatment regimens, fatigue and dietary restrictions. Others expressed this sense of loss of freedom in terms of feeling dependent on others and having to keep up appearances and conceal their true feelings about having CKD.

"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 retraining and going back into the workforce, plus trying to work out how I'm going to pay my bills, my rent. " (Woman, 30s, CKD 5, Australia) ²⁵

"I felt trapped, I can't go out anymore, I used to like going out, travelling, fishing, but I can't do that anymore, I just don't feel like it." (CKD 5, Brazil) ²²

"The biggest problem is that you are so dammed dependent on others all the time when you don't have the strength. You want to, but you can't do anything. That's the worst" (CKD 5, Sweden) ²⁷

7. Adjustment to life with CKD

In learning to live with a diagnosis of CKD, participants described their coping mechanisms for dealing with change. Some participants described how they had got more involved in decision making and with research on CKD. A sense of community and social support was also highlighted as an important factor in improving quality of life and helping people to learn to live with CKD. Participants also described how they tried to 'live life to the fullest' by continuing to enjoy social activities and trying to carry on as usual. Being able to emotionally adjust and accept life with CKD appeared to allow later stage participants to gain a sense of control over their condition.

“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 center, otherwise you find the rest of your life passes you by and you don’t get it back”
(Woman, 60s, CKD 3T, Australia) ²⁵

“I try to live as before. I never say ‘no’ if I’m invited to a party or something like that, because I eat like everybody else...If there is something I can’t manage, for example, if my husband is away, I struggle to make it anyway, because I want to manage it on my own” **(NR, CKD 5D/T, Sweden, 2000) ²⁷**

DISCUSSION

The synthesis highlighted wide-ranging beliefs about CKD causation, uncertainty and concern about CKD progression as well as the need for detailed, accessible information about the condition and its impact, practical advice on making recommended lifestyle changes to reduce future risk, and psychological support to help adjustment to management plans in later stage CKD. Our findings suggest that earlier experiences of CKD involve interpreting a challenging diagnosis, making sense of what has caused the CKD and concerns about the future. People then move on to seeking information about their condition and actively try to delay CKD progression.

The majority of themes were relevant to patients at all stages of CKD, which was surprising given the heterogeneity of the primary studies, however the depth of data reported in the included papers meant that a detailed comparison of views between patients at different stages of CKD was not possible. The psychosocial impact of having CKD was particularly evident amongst people with stage 5 CKD as participants described how they struggled with ‘normal’ life changing and feeling more restricted in what they could do. This suggests that in later stages, experiences appear to be focused on the psychological and social impacts of being diagnosed with CKD and adjusting to a CKD diagnosis by learning to live with the condition.

Willingness to engage in self-management activities and seeking peer or social support were identified by participants as ways of helping to emotionally adjust to, and accept, life with CKD. This finding is similar to other research which suggests that patients with CKD require

comprehensive patient-centered education, and psychosocial and peer support especially when transitioning from earlier stage CKD to ESRD.²⁸ Previous meta-syntheses involving patients with CKD have also highlighted psychosocial impacts such as feeling that life is restricted and the importance of engaging in self-management, peer and social support and positive determination in managing CKD.^{11 12 29} In other disease areas such as cancer, the importance of psycho-social support and information sharing to support patients has been acknowledged.³⁰⁻³² Supportive, clear, high quality communication about CKD and its trajectory is likely to empower people and ensure they are better equipped to engage in self-management and improve their health and psychological well-being.

This synthesis is the first to provide a summary and higher order interpretation of the existing qualitative work on patients' experiences of being diagnosed with, and adjusting to, CKD. The review is limited to the perceptions of participants in the included studies, which were typically conducted in high income countries and findings may be limited in their transferability. We did not search the grey literature or include studies not reported in English, which may have excluded some relevant studies. However, the synthesis did incorporate people's perceptions of all stages of CKD in various geographical locations and as such can offer a higher level of conceptual thinking about how people understand and learn to manage CKD in different contexts. It is acknowledged that the process of synthesising qualitative studies is inherently interpretive and this synthesis is just one possible interpretation of the data.

Further qualitative research in primary care settings and longitudinal qualitative studies exploring adjustment to CKD could enhance understanding about the patient's journey from initial diagnosis to illness progression and RRT. Patients with CKD are likely to be trying to

manage several conditions. Qualitative research to date has focused on CKD as a single condition and so limits our understanding of patients who experience CKD as a multi-morbid condition. Whilst CKD may be the dominant problem for patients who have advanced CKD, in early to moderate CKD it may not be the issue of most concern for patients. In addition, patients with CKD may or may not progress to ESRD and the needs of someone with mild CKD are likely to be different from someone with advanced CKD. Previous research has suggested that doctor's anxiety about disclosing early-stage CKD in primary care can lead to missed opportunities to impart information and practical advice on managing CKD and multi morbidity.³³ It is important to recognise the tension for clinicians regarding improved information sharing and concerns about giving 'too much' information to patients who may not progress to end-stage.

Further qualitative research is required that acknowledges CKD as a multi-morbid condition and explore how patients' information and psychosocial needs vary according to stage, severity, and other morbidities.^{34 35} Greater understanding will support clinicians to deliver comprehensible, timely and targeted information about CKD and its trajectory and practical advice/support to help people to make recommended lifestyles changes and adhere to treatments to reduce future risk.

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TABLES

Table 1: Characteristics of the included studies

Study	Country	CKD stage	No. of participants (recruitment location)	Age (mean)	Data collection method (date)	Data analysis method	Primary focus/aim
Al-Arabi (2006) ³⁶	USA	5D	80 (1 outpatient HD centre)	NS	Semi-structured interviews (NS)	Thematic analysis	To describe how persons with end stage renal disease (ESRD) experience and manage the quality of their daily lives.
Anderson (2008) ³⁷	Australia	5D	241* (9 renal units, 17 dialysis centres)	NS	Interviews (2005-2006)	Thematic content analysis	To explore the understanding of both Indigenous and non-Indigenous Australians with end-stage kidney disease (ESKD) about the cause of their disease, and how this understanding could affect patients' engagement with their treatment.
Campos (2015) ²²	Brazil	5D	23 (1 nephrology unit)	18-60 (40)	Interviews (2012)	Category content analysis	To describe the social representations of illness among people with chronic kidney disease undergoing haemodialysis.
Costantini (2008) ²³	Canada	1-3	14 (1 nephrology clinic)	19-69 (41)	Interviews (NS)	Qualitative content analysis	To elicit participants' perceptions of health, kidney disease, and supports needed for self-management.
Dekkers (2005) ³⁸	The Netherlands	5D	7 (1 dialysis centre)	55-82 (NS)	Semi-structured in-depth interviews (NS)	Interpretative Phenomenological Analysis	Focuses on the moral dimension of experiences of patients with an End Stage Renal Disease (ESRD).
Lin (2008) ²⁴	Taiwan	1-3	15 (1 nephrology unit)	25-77	Semi-structured interviews (2008)	Qualitative content analysis	To describe the illness representation and coping process experience of patients with early-stage CKD in Taiwan.
Lindqvist (2000) ²⁷	Sweden	5D/T	86 (3 renal units)	28-86 (NS)	Unstructured interviews (NS)	Thematic content analysis	To describe the perceived consequences of illness and treatment among end stage renal disease (ESRD) patients.
Lopez-Vargas (2014) ²⁶	Australia	1-4	38 (1 nephrology unit)	20-79 (54)	Focus groups (2011)	Thematic analysis	To elicit the perspectives of patients with stage 1-4 CKD about their disease, with a specific focus on their information needs in managing and living with CKD and its sequelae.
Schell (2012) ²¹	USA	3-5D	29 (1 academic setting, 1 nephrology unit)	65-92 (68)	Focus groups (NS)	Thematic analysis	To describe how nephrologists and older patients discuss and understand the prognosis and course of kidney disease leading to renal replacement therapy.
Tong (2009) ²⁵	Australia	1-5 D/T	63 (4 renal units)	20-78 (52)	Focus groups (NS)	Thematic analysis	To describe the range and depth of experiences and perceptions from patients with CKD stages 1-5 about the meaning of CKD and its treatment

*comprising 146 indigenous, 95 non-indigenous Australians

Key: 5D – stage 5 patients receiving dialysis, 5D/T – stage 5 patients receiving treatment (dialysis and/or transplantation), NS -Not stated.

Table 2: Comprehensiveness of reporting

Item	Studies reporting each item	No. of studies
Personal Characteristics		
Interviewer/facilitator identified	26 36 37	3
Interviewer/facilitator credentials	21-25 27 36 37	8
Occupation of interviewer/facilitator	22 23 27 36 24 37	6
Gender of interviewer/facilitator	/	0
Experience and training in qualitative research	24	1
Relationship with participants		
Relationship established prior to start of study	26 36	2
Participant knowledge of the interviewer	25	1
Interviewer characteristics	/	0
Theoretical framework		
Methodological orientation and theory	22 36 38	3
Participant selection		
Sampling strategy	22 23 25 26 37	5
Method of approach	21 25 26 36	4
Sample size	21-27 36-38	10
No. and/or reasons for non-participation	21 22 26	3
Setting		
Setting of data collection	21 22 24-27 36 38	8
Presence of non-participants (e.g. clinical staff)	38	1
Description of sample	21-26 38	7
Data collection		
Interview guide	21 24-27 38	6
Repeat interviews	/	0
Audio/visual recording	21-27 36-38	10
Field notes	23 25 26	3
Duration of data collection (interview/focus group)	22 24-26 38	5
Data saturation	21 26	2
Returning transcripts for comment	25	1
Data analysis		
Researcher triangulation (no. of data coders)	21 23-27 36 37	8
Description of the coding tree	21 38	2
Derivation of themes	21 23-27 36-38	9
Use of Software	21 25 26 37	4
Participant feedback on the findings	36	1
Reporting		
Participant quotations provided	21-27 36 37	9
Data and findings consistent	21-27 36-38	10
Clarity of major themes	21-27 36-38	10
Clarity of minor themes	21-27 36-38	10

FIGURES

Figure 1: Study Flowchart

Figure 2: Qualitative CKD paper categories mapped out according to CKD trajectory

Figure 3: Key themes and subthemes

SUPPLEMENTARY MATERIALS

Item S1: Search strategies for each database

Item S2: A list of the 146 qualitative studies related to CKD identified by the search that were screened and categorised.