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Patient and caregiver perspectives on terms used to describe kidney health

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ABSTRACT

Background and objectives: The language used to communicate important aspects of kidney health is inconsistent and may be conceptualized differently by patients and health professionals. These problems may impair the quality of communication, care, and patient outcomes. We aimed to describe the perspectives of patients on terms used to describe kidney health.

Design, setting and participants: Patients with chronic kidney disease (CKD, (n=54)) and caregivers (n=13) from the United States, United Kingdom, and Australia participated in 10 focus groups to discuss terms for kidney health (including kidney, renal, CKD, end-stage kidney disease, kidney failure, and descriptors for kidney function). We analysed the data using thematic analysis.

Results: We identified four themes: *provoking and exacerbating undue trauma* (fear of the unknown, denoting impending death, despair in having incurable or untreatable disease, premature labeling and assumptions, judgment, stigma and failure of self); *frustrated by ambiguity* (confused by medicalized language, lacking personal relevance, baffled by imprecision in meaning, opposed to obsolete terms); *making sense of the prognostic enigma* (conceptualizing level of kidney function, correlating with symptoms and life impact, predicting progression and need for intervention); and *mobilizing self-management* (confronting reality, enabling planning and preparation, taking ownership for change, learning medical terms for self-advocacy, educating others).

Conclusions: The obscurity and imprecision of terms in CKD can be unduly distressing and traumatizing for patients, which can impair decision-making and self-management. Consistent and meaningful patient-centered terminology may improve patient autonomy, satisfaction and outcomes.

Key words: chronic kidney disease, communication, education, nomenclature, patient-centered care,

INTRODUCTION

Patients with chronic kidney disease (CKD) have an increased risk of mortality, life-threatening adverse events such as cardiovascular disease, and treatment complications.(1-5) The unpredictability and uncertainty of the disease course and complexities in management necessitates patient-centered communication and education to support shared decision-making.(4, 6-9) However, inconsistencies in the use of medical terms used in CKD, which may also be inaccessible and confusing, makes this challenging and could harm patients.(8, 10-18) Across medical specialties, there are concerns that "inappropriate use of medical terms in healthcare professional-patient communication"(19) can impair patient awareness, empowerment, autonomy, mental health, satisfaction and adherence.(8, 17-21)

The terms used for kidney health may be imprecise, misleading and difficult to understand.(18, 22-24) Some terms are conceptualized differently by patients and health professionals.(15, 22, 25) For example, "renal" and "kidney" are used to described kidney health, but "renal" may be unfamiliar to patients and the public, preventing awareness and advocacy. Some patients are unsure about the meaning of "chronic" in CKD,(15, 22) and the term "end-stage kidney disease" could provoke panic and despair, and disengagement from health services. Problems with communication may also contribute to barriers to accessing kidney replacement therapies including home dialysis or transplantation. Another challenge is that patients may be asymptomatic until they reach kidney failure. Difficulties in understanding terms have been found to cause fear and intimidation, preventing patients from communicating with their nephrologist and accessing information.(18, 21)

There is little evidence on how patients and caregivers define and interpret the terms used for kidney health, and its impact. This study aimed to describe the broad range and depth of patient and caregiver beliefs and perspectives on terms commonly used to describe aspects related to kidney health. Such insights may help to ensure that the terms used for kidney health can better support communication, decision-making, self-management and outcomes in patients with kidney disease.

METHODS

Context

This focus group study was commissioned by Kidney Disease Improving Global Outcomes (KDIGO) in preparation for a Consensus Conference on Nomenclature for Kidney Function and Disease to inform the revision of nomenclature for kidney disease, and to establish a patient-centered and precise glossary of terms related to kidney disease. We used the Consolidated Criteria for Reporting Qualitative Studies (COREQ)(26) to report this study.

Participant selection

Patients aged 18 years and over, English-speaking, and with stage 1-5 CKD, receiving dialysis, or who had received a kidney transplant, and their caregivers (family members involved in the care of the patient) were eligible to participate. Participants were identified and recruited from hospitals and the KDIGO Patient Network. Ethics approval was provided by The University of Sydney (2015-288), Baylor College of Medicine (H-43848), Imperial College Healthcare NHS Trust, and Sheffield Teaching Hospitals NHS Foundation Trust (18/WS/0084). To obtain a wide diversity of perspectives, we used a purposive sampling strategy to include a broad range of demographics (age, gender, educational attainment), and clinical (stage of CKD, diagnosis) characteristics. Invitations were sent by email and by post. Informed consent was obtained from all participants.

Data Collection

The two-hour focus groups were conducted from March to May 2019 in meeting rooms external to clinical settings. Focus groups are used to encourage participants to discuss and clarify their views to elicit a breadth and depth of data rather than to assess frequency of different opinions.(27, 28) The question guide was developed from the literature.(3, 10, 11, 15, 18-21, 29, 30) and discussion with the investigator team, which included patients (Supplementary Material). We asked questions about terms used to describe kidney health that participants perceived to be challenging, the meaning and impact of these terms, and suggestions for alternative terms.We asked about specific terms: kidney *vs.* renal, chronic kidney disease, end-stage kidney disease, kidney failure, kidney function (including descriptors and measures for kidney function e.g. CKD stages, estimated Glomerular Filtration Rate (eGFR)). A researcher (AT or TG both women with experience in qualitative research and not known to the participants prior to the study) facilitated the group, and a co-facilitator (JS, LD, NSR, AB) took field notes. We convened focus until we reached data saturation. All groups were audio-recorded and transcribed verbatim.

Analysis

We used thematic analysis to analyze the data. All transcripts were imported into HyperRESEARCH software to facilitate data analysis. AT reviewed the transcripts line-by-line to inductively identify concepts related to patient and caregiver perspectives on terminology for kidney health. The preliminary themes were discussed with the co-facilitators JS, TG, NSR, AB, LD who also read the transcripts (investigator triangulation), and sent to participants for comment (member-checking), and the feedback was integrated into the final analysis to ensure it reflected the breadth and depth of the data. A thematic schema was developed to summarize and depict relationships among the themes (Figure 1).

RESULTS

In total, 54 patients with CKD and 13 caregivers participated in 10 focus groups in the United States (3 groups, n=21), United Kingdom (3 groups, n=18), and Australia (4 groups, n=28). Participant characteristics are shown in Table 1. Forty-three (64%) were aged over 50 years and 43 (64%) were female. Five were diagnosed with CKD during childhood (under 18 years). Patients were on a variety of treatment modalities, on hemodialysis (n=14), used peritoneal dialysis (n=4), or had a kidney transplant (n=20), or not on kidney replacement therapy (n=16). Most (n=51) had high educational attainment (professional certificate, undergraduate or post-graduate degree).

We identified four themes: provoking and exacerbating undue trauma, frustrated by ambiguity, making sense of the prognostic enigma, and mobilizing self-management. The respective subthemes are described in the following section. Selected quotations to support each theme are available in Table 2. The focus groups contributing to each theme are indicated in Supplementary Table 1. The thematic schema is provided in Figure 1.

Provoking and exacerbating undue trauma

Fear of the unknown: Terms that were unfamiliar, obscure and with a negative connotation (e.g. chronic, end-stage) caused shock and fear in patients and families, which remained unresolved for some – "you always remember the day you're told you've got chronic kidney disease, it stays with you, the language they use, it's critical." Being uncertain of the meaning and implications, the words were "doom-laden," "scary," and sounded "extreme and severe."

Denoting impending death: The term "end-stage kidney disease" indicated to participants that death was imminent – "I literally thought I had months to live – I had accepted the fact I was going to die and needed to take care of business so that my daughter was going to be taken care of.” It caused participants to perceive themselves to be “on a cliff, about to fall off.” The term was “daunting,” “demoralizing,” and compounded feelings of isolation. Participants noted that “end-stage” in other conditions such as cardiovascular disease, cancer, cystic fibrosis, referred to “those last few months of life, when you're at the end,” or meant palliative care. For some patients, it took time to realize that it meant “end stage for the kidney, it’s not end stage for our life.” They suggested to use “milder” terms such as referring to the stages of CKD, or to explain that “kidneys are not functioning very well” so patients would know that “it is serious but also understand how it’s not the end of the road, there’s a life beyond.” Some patients in the United States considered that “end-stage renal disease” may be necessarily severe to access Medicare reimbursement for dialysis.

Despair in having incurable and untreatable disease: For some patients, the word “disease” had given them “false hope” because the term “disease” implied there was a cure. Some perceived the term “end-stage” to mean the “end of a healthy life, the end of a positive mindset,” and initially thought there was “nothing you can do about it.” The term “chronic” was understood by some to mean that things would not improve – “if they're chronic, I don't know that they get better.” They felt helpless, unable to control what was happening, and lost hope – “if you have cancer you can fight it and win it or lose it. If you have kidney failure, it’s for life. You don’t fight, you don’t win, you don’t lose, you just live with it.” Seeing the decline in their own kidney function was described as “watching this guillotine.” Some suggested that “failure” may be preferred as a term compared with “end-stage kidney disease” because “you know that you can come back from that, there are options where you can continue.”

Premature labelling and assumptions: Some despised the term “pre-dialysis” because it was unnecessarily precipitating the need for dialysis – “it assumes you know what the future holds.” This was due to fear and reluctance to commence dialysis. They voiced that some patients could not get access to dialysis, may choose not to commence dialysis, or had stable kidney function and may not be ready to consider kidney replacement therapy – “that alludes to something that might not happen for that person, if you’re called a pre-dialysis patient, is time ticking before I start that?” “Pre-dialysis” was deemed a “derogatory” term because it implied passivity in patients – “I don't want someone telling me I'm pre-dialysis because I could change my lifestyle.” Some suggested it would be “better to talk about the function that they do have, than what might happen in the future.”

Judgment, stigma, and failure of self: Terms such as “disease” and “failure” impaired self-esteem and sense of personhood. Some experienced “depression” because they were “labelled with the disease,” or had interpreted “failure” to mean that their “physical existence is failing,” or they had “done something wrong.” They emphasized that these concepts had to be “separated from the person.” In comparing with diabetes, some noted, “no one says, ‘you’ve got diabetes, your pancreas has failed’,” and that clinicians did not use “end-stage pancreas failure.”

Frustrated by ambiguity

Confused by medicalized language: Participants emphasized that the word “kidney” should be used instead of “renal” to improve awareness and understanding among patients and the general community, to support education and advocacy – “What's renal failure? It's totally Greek to me.” Some defined “renal” as “the whole system, the bladder,” whereas kidney was the organ. They noted that the term “renal” exacerbated confusion in patients with CKD who had cognitive impairment, including difficulty in concentrating. Some argued that “doctors don’t have to speak a different language to patients” so patients could relate to them – “It’s about making things simple for everybody, so that language isn’t a weapon.” “Chronic” and “acute” were considered very “medicalized with no immediate translation into common usage,” and other terms such as “low clearance,” “GFR,” and “nephrology” were confusing.

Lacking personal relevance: Participants identified terms that were not applicable at an individual level or to specific populations and recognized that establishing terms was challenging with “so many different trajectories, it’s really difficult to lump together and talk about them the same.” “CKD stages” were not useful if patients were already at “end-stage” at diagnosis – “when I first got diagnosed, I was in stage 5 so that meant nothing to me.” “Pre-kidney replacement therapy/pre-dialysis” would not apply to all patients as “it is not a luxury that everybody has.” Also, patients in the United States recognized there were differences in estimating eGFR African American patients, which led to confusions about this term, ““they have in parenthesis that if you're African American it's a different number [for eGFR], but they didn't explain why it's a different”.

Baffled by imprecision in meaning: Some felt that certain terms did not convey kidney function and disease with adequate accuracy. Some thought “CKD stages” were “vague”. The word “disease” was perceived to be inappropriate for patients who had a congenital “abnormality,” or had “declining kidney function due to cardiac issues.” “Chronic” was regarded as too “severe” for patients in the earlier stages of kidney disease. “Kidney failure/impairment” were suggested as terms that were “honest” – “Is it just kidney failure? Can we just ditch the end stage rubbish? Because that's the period when your kidneys actually fail, when they're no longer able to do the job filtering out the fluids and the toxins.”

Opposed to obsolete terms: Some regarded the term “end-stage” to be outdated because kidney replacement therapy was available to prolong life – “the more technology develops, the less appropriate that word ‘end’ becomes. For the majority of people, there are life sustaining treatments out there, dialysis and transplant.” They asserted that classifying patients living long-term with dialysis or transplant as “end-stage” was “misplaced,”– as one caregiver stated, “my husband was on dialysis for 20 years, that’s hardly end-stage.”

Making sense of the prognostic enigma

Conceptualizing level of kidney function: Participants believed that terms should enable understanding of their level of kidney function, how this compared with normal function, and progression of disease. Some suggested that stages of CKD had to be more clearly defined, similar to stages of cancer, and that numerical values (e.g. GFR) be qualified (e.g. early, moderate, advanced; or lower, middle, high) to facilitate comprehension about severity – “what is this level, is that good or bad? I didn’t really understand.” Some were confused with the use of percentages in describing kidney function – “so if it has to be [an eGFR] over 60 do you consider 60 a hundred percent? What is the hundred percent. I've heard up to [a GFR of] 115 so when you do a percentage it might be information that's not accurate.”

Correlating with symptoms and life impact: Terms such as GFR and CKD stages sometimes lacked meaning as they did not appear to correlate consistently with the presence or severity of symptoms – “I was in Stage 5 and I still didn’t have any symptoms.” One caregiver stated, “I could see vomiting and all the symptoms, but I didn't understand how that was connected [with the GFR].”

Predicting progression and need for intervention: Participants felt that terms should give an indication of their disease trajectory and when they may need interventions including medications, dialysis, or a kidney transplant. In reference to CKD stages, some realized that “there was really no set amount of time that each stage went through,” and would only be useful if the stages corresponded with “different stages of treatment.” Some were aware that GFR was used in decisions about commencing dialysis – “you know your GFR is five, you need to get on dialysis.”

Mobilizing self-management

Confronting reality: Some accepted that terms such as “end-stage kidney disease” were necessarily “damaging and painful to the patient” so they would reflect its seriousness. For some, it forced them to understand the severity, irreversibility, and incurability of kidney disease, and to have realistic expectations about their prognosis.

Enabling planning and preparation: Terms such as “stage” of CKD, “kidney failure,” and “GFR” were perceived by some participants to provide opportunities for preparing for the future. Despite “causing anxiety,” such terms were regarded as “beneficial in that they give you a sense of planning” and to make decision about dialysis or kidney transplant.

Taking ownership for change: Terms that caused alarm were believed by some participants to encourage patients to “get their act together” and take responsibility for their health, prompting them to modify behaviors to slow progression of kidney disease. For example, “pre-dialysis” instigated lifestyle changes to delay commencement of dialysis – “if you're saying pre dialysis in my mind that says I'm about to go on dialysis but then I'm going to wonder is there something I can do to keep me from going on dialysis.” They compared this with diabetes – “when you are told you're pre-diabetic, you go crazy, change your diet!” The CKD stages were also regarded as useful for those who were “goal-oriented,” as they would be motivated to “do things to keep me moving to Stage 2.” Terms such as “renal” meant that kidney disease “becomes something that's not your own … it's a text book.”

Learning medical terms for self-advocacy: Some acknowledged that medical terminology could be “intimidating” but urged that patients had a responsibility to learn the language as “this is your life.” It was unavoidable and some commented that patients were “much more capable of shaping ourselves to their [doctors’] language.” They suggested that patients needed to be proactive in seeking explanations of the terms with their doctor.

Educating others: Simple terms such as “kidney” rather than “renal” were considered important for communicating with family members and the community about their disease and treatment, including living donor kidney transplantation – “my brother, he gave me my kidney, he's not medical either. We are having a kidney transplant, not a renal. It's a kidney.” Participants stated that words such as “end-stage” could inadvertently frighten others, cause them to assume “you’re probably really sick so they associate you in a way like you must be dying or something and it gets taken out of proportion,” and diminish access to support.

DISCUSSION

Terms for kidney health that were confusing, ambiguous, and obsolete led to frustration and caused distress in patients and caregivers. The shock and trauma in patients were compounded by terms that triggered fear of the unknown, signalled imminent death or need for dialysis, undermined their sense of hope for treatment, and connoted failure and end-stage of personhood. Patients emphasized the need for consistent terms to enable them to understand their level of kidney function and prognosis, particularly in terms of symptomology and predicting the need for interventions, including medications and kidney replacement therapy. Others believed that the use of direct and serious terms compelled patients to confront the risks and reality of kidney disease, plan and prepare for managing kidney disease, and take ownership for enacting lifestyle changes. Some felt they needed to learn and understand medical terms so they could advocate for themselves. They urged for the use of simple and accessible terms to educate family and those in their social networks, and to promote awareness and knowledge among patients and the general community.

There were no clear differences in attitudes or beliefs about terms based on demographics (including educational attainment) and clinical characteristics, except by country. Patients in the United States noted that the term “end-stage renal disease” was used as a billing code to qualify for Medicare reimbursement for dialysis and speculated that this was the reason for the use of a serious or severe term. The term “low clearance” was specifically mentioned by patients in the United Kingdom, which was thought to be a confusing term. There were polarized opinions on negative-sounding terms such as “end-stage kidney disease” or “pre-dialysis.” Some believed this caused depression that prevented acceptance of the disease, or instigated a paralyzing fear that inhibited coping, self-management and decision-making. Some patients feared and wanted to avoid dialysis because it signified they were in final stage of the disease, and expected that dialysis would constrain and limit their lives; and thus expressed an aversion to being labelled as “pre-dialysis.” In contrast, others felt these terms urged and prompted lifestyle changes, and enabled them to prepare for treatment. However, these opinions did not appear to link with specific participant characteristics.

The use of confusing and inappropriate terms and its detrimental impacts, from the patient perspective, have also been demonstrated in other medical disciplines including oncology(31), cardiology(12), infectious disease(10), psychiatry(16), pediatrics(11, 30), dermatology(16), urology(13, 14), and anaesthesiology(32). For example, in tuberculosis, there have been calls to remove “judgmental and criminalizing,” terms such as “suspect” and “defaulter” because they placed blame for the disease and adverse outcomes on the patient (10). Similarly, in psychocutaneous medicine, terms such as “trichotillomania, delusions of parasitosis, neurotic excoriation” were identified to be offensive and insensitive to patients, potentially becoming barriers to accessing treatment(16). The few studies in kidney disease have shown that terminology can be difficult to understand and cause confusion(15, 21). Our findings reveal how common terms used for kidney health are perceived by some patients to be ambiguous and may impact upon the patients’ identity, emotional and psychosocial wellbeing, and undermine their ability to monitor and manage their health. Also, it has been recognized among nephrologists that terms such as pre-dialysis are ambiguous and ill-defined(33).

Studies suggest that patients want to be informed about their diagnosis early, despite the fear and distress of receiving the diagnosis. However, some clinicians may be reluctant to emotionally overwhelm patients with information about their diagnosis and prognosis (24, 34). Patient-provider communication requires careful consideration of terms and how these may be interpreted by patients and caregivers, as well as education and counseling to manage the potential consequences. Also, effective shared decision making is based on a common understanding of the language used.

Our study was conducted across three countries and generated in-depth and nuanced insights about patient and caregiver perspectives on terms used to describe kidney health. We achieved reasonable diversity in demographic and clinical characteristics. However, there are some potential limitations. We did not include non-English speaking participants given our focus on terms used in the English language; and 63% were White. We acknowledge that 30% of the participants had received a kidney transplant, however there were no notable differences in perspectives on nomenclature compared with patients without a kidney transplant. There were relatively few older adults (seven per cent were aged over 70 years) who participated, therefore the transferability of the findings to the older population is uncertain. Of note, 89% of the participants had a high level of education (i.e. completed 12th grade), and recognize that we may not have captured how patients with lower educational attainment and health literacy comprehend and react to terms for kidney health. We acknowledge that there is an association of ethnicity and educational status on health literacy. Despite this, confusion and misinterpretation of terms were apparent in our study, which highlights the critical role of terminology in health literacy.

The Institute of Medicine defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”(35) It refers to communication among patients, health professionals, social networks, and research, to promote patient understanding and engagement in care.(29) Patients with chronic kidney disease have limited health literacy(36-38), which has been found to be associated with increased mortality and hospitalization, reduced access to treatment (including transplantation), and worsened quality of life.(29, 38-40) Another challenge is that patients may be asymptomatic until they have kidney failure. The use of terms that are not easily understood, imprecise in meaning, and cause catastrophizing whereby patients perceive the term (e.g. end-stage kidney disease) to mean they were near-death or without treatment options, can prevent patients from seeking and comprehending relevant health information, and from making decisions. It can be difficult to disentangle terminology and communication, as both contribute to the lack of awareness and understanding. Given the link between poor understanding of terminology and low functional health literacy(41), there is potential for appropriate and consistent terminology to increase patient participation and engagement in care(42). Thus, ensuring that terminology is patient-centered provides an opportunity to improve health literacy in this population. Also, the findings highlight the complexity of hope(43), and the opportunities to cultivate hope and realistic expectations with prognostic information(44).Based on our findings, we outline suggestions for terminology in Table 3.

With increased availability and access to health information (e.g. electronic health records, research publications) facilitated by the Internet and technology, we suggest that key terms to describe and characterize kidney health should be clear, patient-centered, and consistent to improve communication and satisfaction with care. There is a need for more research in patient-clinician communication in the context of CKD(45). The Kidney Disease Improving Global Outcomes (KDIGO) Consensus Conference on Nomenclature for Kidney Function and Disease was recently convened to refine and revise nomenclature used to describe various aspects pertaining to kidney health.(46) The findings from this study informed the discussion at the conference. Efforts are underway to work with researchers, clinicians, journal editors and managers, and patients and caregivers to develop a patient-centered glossary of terms to improve consistency of use in research, practice and policy.(46)

Some common terms to describe kidney health are obscure and imprecise. This can lead to extreme and unresolved trauma and guilt that impairs capacities for information-seeking, decision-making, managing treatment, and coping. There is a need for consistent and meaningful terms, education and counselling regarding the use of terms that mitigate against psychosocial harms, and communication strategies that support coping, decision-making about treatment, and self-management. The development and use of patient-centered terminology for kidney health may improve patient autonomy, satisfaction and outcomes.

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Table 1. Characteristics of the participants (N=67)

Characteristics	N (%)
Role	
Patient	54 (81)
Caregiver	13 (19)
Sex	
Male	24 (36)
Female	43 (64)
Country	
United States (3 groups)	21 (31)
Australia (4 groups)	28 (42)
United Kingdom (3 groups)	18 (27)
Ethnicity[a]	
White	42 (63)
African American	11 (16)
African British	4 (6)
Asian	4 (6)
Other[a]	6 (9)
Age (years)	
18-30	4 (6)
31-50	20 (30)
51-70	38 (57)
>70	5 (7)
Marital status	
Single	16 (24)
Married/Partnered	39 (58)
Divorced/separated	10 (15)
Widowed	2 (3)
Number of children	
0	18 (27)
1-2	32 (48(
3 or more	17 25)
Employment	
Full time	24 (36)
Part time/casual	11 (16)
Student	3 (4)
Not employed/disability	13 (19)
Retired	16 (24)
Education	
Before 10th grade (before age 16 years)	4 (6)
Completed 10th grade (age 16 years)	5 (7)
Completed 12th grade (ages 17-18 years)	7 (10)
Professional certificate	11 (16)
Undergraduate degree	22 (33)
Postgraduate degree	18 (27)
Age at time of diagnosis*	
<18	5 (7)
18-30	11 (16)
31-50	23 (34)
51-70	14 (21)
Cause of kidney disease*	
Diabetes	9 (13)
Hypertension	19 (28)
PKD	7 (10)
Glomerulonephritis	19 (28)
Infection	2 (3)

Immune/autoimmune	7 (10)
Reflux nephropathy	1 (1)
Unknown/don’t know	3 (4)
Other	6 (9)
Type of kidney replacement therapy (current)*	
None	16 (24)
Hemodialysis	14 (21)
Peritoneal dialysis	4 (6)
Kidney transplant	20 (30)
Duration of KRT (Current)*	
Less than 6 months	1 (1)
6 to 12 months	3 (4)
1-3 years	13 (19)
4-6 years	7 (10)
More than 6 years	15 (22)

*not applicable to caregivers; [a]Included Hispanic Latino (n=1), Aboriginal Australian (n=1), Pakistani (n=2), Middle Eastern (n=1), Indian (n=1); PKD, polycystic kidney disease; numbers may not total 67 if not reported, or participants could select multiple options. Approximately N=37 refused to participate or did not attend the focus groups due to other commitments, illness, or did not want to participate.

Table 2: Selected illustrative quotations

Theme	Quotations
Provoking and exacerbating undue trauma	
Fear of the unknown	Chronic actually sounds terrible right, really bad. (Woman, 30s, P, undergraduate degree, US, G1)
	The fear factor – chronic or end-stage – something you've not heard before, there's also this fear in the back of your mind. If I go and try and look for that, what am I going to uncover? Do I really want to know? If we just changed the terminology a little bit, it might not be as scary…because you've just not heard that term or it sounds quite extreme or severe. (Woman, 20s, P, undergraduate degree, UK, G9)
Denoting impending death	End means there is no middle ground. Dialysis is buying me time, even today, after two years of being on dialysis means the end. (Woman, 40s, P, undergraduate degree, US, G3)
	When you're still trying to deal with having a fistula made, having to go to surgery, having to spend time in hospital, having to be away from your family. Trying to deal with that, and you have that 'end stage' in the back of your head. It really does compound the feelings of desperation and isolation, especially when you are in hospital for a week plus by yourself. (Woman, 50s, P, undergraduate degree, Aus, G5)
	Start digging the hole… it basically says you've hit the end. You're on the cliff, about to fall off. End stage sounds like you're pushing up daisies next week. (Man, 50s, P, professional certificate, Aus, G6)
	I thought it meant terminal, first time I heard it [end-stage kidney disease]. (Woman, 60s, P, postgraduate degree, UK, G8)
Despair in having incurable or untreatable disease	To me that means your kidneys are gone forever. No hope. (Woman, 50s, P, completed 10th grade, US, G1)
	The word disease for me implies that there's a cure, to me. For those three years it was giving me a sense of false hope. We will forever be on immune suppressant drugs with a transplant or we will be on dialysis. There is no cure for us (Woman, 18-30, P, completed 12th grade, US, G2)
	Once they say 'end-stage,' it's kind of like, why not let nature run its course? (Man, 40s, P, undergraduate degree, US, G2)
	It was quite upsetting the first time [end-stage kidney disease] was mentioned. It's just basically denial, what does it actually mean? It just feels quite depressing like there's nothing you can do about it. I never thought I would have dialysis. When it was told to me I had kidney issues I was quite young, it gives no hope to your life. What are you going to do next? (Man, 30s, P, postgraduate degree, UK, G9)
Premature labeling and assumptions	Pre dialysis is derogatory. I'm in Stage three I don't want someone telling me I'm pre dialysis because I could change my lifestyle. Right. I mean I could stay in Stage three for the rest of my life. (Woman, 60s, P, postgraduate degree, US, G1)
	'Kidney disease without kidney therapy' is not the best. That's putting these people who are still somewhat okay for a period of time in a situation where you're in a chronic situation. (Woman, 30s, P, professional certificate, US, G2)
	It's probably better to talk about the function that they do have, than what might happen in the future. (Man, 50s, P, postgraduate degree, US, G2)
	[Pre-dialysis] alludes to something that might not happen for that person. It goes back to the whole fear thing. If you're called a pre-dialysis patient, it's like oh, is time ticking before I start that? (Woman, 18-30, P, undergraduate degree, UK, G9)
	I would love to think that everybody would not have to go on dialysis, because I can deal with taking tablets. I just can't deal with being stuck to a machine. (Woman, 30s, P, professional certificate, UK, G10)
Judgment, stigma, and failure of self	I had a two or three year span of a really bad depression after all of those diagnoses, and on top of the depression being labeled with a disease. (Woman, 18-30, P, completed 12th grade, US, G2)
	So the connotation of that word, isn't helpful. Your kidneys fail and so will you. By association, your physical existence is failing, so kidney's aren't working possibly, kidney's are reducing function might be better because that's a little more succinct. Separate it from the person. If you've got chronic, or I've got chronic kidney failure, it's a little bit pointed. And psychologically, that doesn't help, because we're probably all troubled with depression at some point. (Man, 50s, P, professional certificate, Aus, G4)
	I sometimes struggled with different medical professionals who said to me 'oh, you've got kidney failure' and it was a bit like, I had done something wrong. I had a bacterial infection and autoimmune disease and I couldn't control all those factors but I felt like sometimes when kidney failure was used at me by other people. I just felt criticized. (Women, 50s, P, undergraduate degree, Aus, G5)

Frustrated by ambiguity	
Confused by medicalized language	Doctors don't have to speak a different language to the patients and their families, they can just spell it out and just say exactly what it is, don't use doctor jargon, just use words that every day people can understand. There's been times when I'm in the hospital with her [my mum] and I'm hearing things, I'm like, "Why is he just not saying it straight out? Like you're using all these big words and stuff." (Woman, 18-30, C, postgraduate degree, US, G3) Kidney is talking about kidney specifically whereas renal is talking about the overall renal function. (Man, 50s, P, professional certificate, Aus, G6) Low clearance is one of them, so confusing.(Woman, 50s, P, postgraduate degree, UK, G8) All the discussions the doctors were having around me, GFR, GFR. I just couldn’t understand one bit of it. It scared me because no one was telling me anything. I felt like a cattle being led into slaughter. I couldn’t understand. I was told, you’ve got to have a fistula. I said, excuse me. GFR, fistula, what are we talking of here? (Man, 60s, P, postgraduate degree, UK, G8) It’s about making things simple for everybody, so that language isn’t a weapon. (Woman, 50s, P, postgraduate degree, UK, G8)
Lacking personal relevance	Also, there's a misunderstanding, his kidney function is perfect. There's nothing wrong with his kidney function, but his kidney has to be removed, and it's because of a cancer. The labeling for him as the end stage, of a kidney function, was not really appropriate. (Woman, 50s, C, postgraduate degree, US, G2) Even when they're putting the GFR out there for you to read and understand they have in parenthesis that if you're African American it's a different number, but they didn't explain why it's a different number, that my muscle mass is different. So if I understood that, then I would have, I could have possibly understood GFR a lot earlier in my journey than it took me all these years to understand. (Woman, 40s, P, undergraduate degree, US, G3) Pre-kidney replacement, it is not luxury that everybody has. (Woman, 18-30, P, completed 12th grade, US, G3)
Baffled by imprecision in meaning	As long as there's like clear definitions to the stages, then that would work. (Woman, 30s, P, professional certificate, US, G2) Is it just kidney failure? Can we just ditch the end stage rubbish? Because that's the period when your kidneys actually fail. You know, when they're, when, they're no longer able to do the job filtering out the fluids and the toxins. (Woman, 60s, P, postgraduate degree, Aus, G5) I’d rather them say your kidney function, because you know that they’re still working, but you don’t know how bad it is. If they say your kidney function is getting worse, then you can deal with that. But when they say now you’re at stage three, now you’re at stage four kidney disease, you think, what is that? What is stage three, what is stage four? (Woman, 50s, P, completed 10th grade, UK, G10)
Opposed to obsolete terms	The more technology develops, the less appropriate that word end becomes. I know that there are people out there for whom it is almost the end. But for the majority of people ... Well I think the majority of people, there are life sustaining treatments out there. Dialysis and transplant. (Woman, 40s, P, undergraduate degree, Aus, G7) So I've been end stage for 14 years. (Woman, 60s, P, professional certificate, Aus, G7)
Making sense of the prognostic enigma	
Conceptualizing level of kidney function	I'm still having trouble understanding what GFR is, I still don't have that. So you all are saying numbers and percentages. (Woman, 50s, P, before 10th grade, US, G1) I used to get confused about kidney failure and my nephrologist would say 'your not in kidney failure yet, you've got kidney disease.' So [my nephrologist] was using it as the end point kidney failure but I was thinking my kidneys are failing. (Woman, 50s, P, undergraduate degree, Aus, G5) They utilize GFR to put you into whatever the stage is that your in. (Woman, 40s, P, undergraduate degree, Aus, G7)… I like that better than the whole end stage. (Woman, 60s, P, professional certificate, Aus, G7) So what is this level, is that good or bad? Because I didn’t really understand. If it’s at this level, because they take your bloods, if it’s at this level does it mean it’s good? Does it mean that I have to start preparing for my funeral plans? (Woman, 50s, P, undergraduate degree, UK, G8)
Correlating with symptoms and life impact	The symptoms are not matched up at all. I was in stage five and I still didn't have any symptoms. (Woman, 30s, P, undergraduate degree, US, G1) And in the stages say this part is going to increase or this symptom may increase in severity in this stage. That way it won't be click like a surprise when it happens. (Woman, 40s, P, undergraduate degree, US, G1) My doctor said, well you can have dialysis anytime now. It's a matter of how you're feeling. And I was going back and saying I'm feeling really good. But the strange thing I found was, earlier on, I was feeling much more sick and that wasn't coinciding with my bloods? I've got a few major diseases so it was really difficult

	to work out where the fatigue's coming from or where the nausea's coming from. (Woman, 50s, P, undergraduate degree, Aus, G5) I could see vomiting and all the symptoms but I didn't understand how that was connected.(Woman, 18-30, C, completed 12th grade, Aus, G5)
Predicting progression and need for intervention	There was really no set amount of time that each stage went through. We were initially told okay, stage 2, you've got at least about two years, then you'll go into stage 3, and you'll have about six months to a year. No, that didn't happen, it just went off the cliff. (Woman, 50s, P, postgraduate degree, US, G2) Is it one of those things that you put a time onto though? Because that's the difficulty. Because if you're at stage one, how long are you going to be stage one for, how long before stage two? (Man, 50s, P, professional certificate, Aus, G7) Staging could be useful if there are different stages of treatment, depending on where you're at. But if the treatment doesn't change, then GFR effectively is you measure where you sit on a spectrum, which is effectively what staging is right? (Woman, 40s, P, undergraduate degree, Aus, G7) Stage one is your kidneys are not working, full stop. Stage two is getting bad, stage three is getting to the fistula stage, stage four, dialysis, stage five is not working. (Woman, 50s, P, postgraduate degree, UK, G8)
Mobilizing self-management	
Confronting reality	The words are kind of damaging and painful to the patient, but they're a necessary damage, because you have to understand. End-stage is a really harsh term, but I feel like it's a good term, because you have to really drill it home that that really is the last stage of whatever you're going through. You can't in your head be like, if you hadn't been told end stage. If you'd been told that you're a stage 5, in my head at 14, I would have been like, oh, it's just stage 5. I can still reverse it. But when they told me it was end stage and that I had a disease, like, a chronic condition that would go on forever, that really helped me understand, however much it hurt. However much it pained me to understand that I was going to be like this for the rest of my life. (Woman, 18-30, P, completed 12th grade, US, G2) What patients want is honesty. They don't want any BS. They want to know what the situation is. The term chronic explains that your kidneys have given up the ghost, and you need mechanical assistance to help you. (Mans, 60s, P, professional certificate, Aus, G6) Heart conditions are much more prevalent than renal disease, it’s better known through the public, everybody’s known somebody who’s had a heart attack or their family. They use things like congestive heart failure, they say heart failure, they talk about angina. These are all quite serious terms, but we do it – then heart attack. They have connotations to scare the heck out of people as well. How do you impart bad news and serious news which can impact on someone’s life? You can make them devastated, but on the other hand there are people resistant to getting the message. (Man, 60s, P, postgraduate degree, UK, G9)
Enabling planning and preparation	It makes you prepare cause this is the end of the stage. I'm like okay well I have some time to figure things out. (Woman, 30s, P, undergraduate degree, US, G1) But I think the stages are beneficial in that they give you a sense of planning. If you allow them to cause anxiety, or give you something to start researching online, then it could not be very good, but I think the planning aspect of the stages is beneficial. (Woman, 30s, P, professional certificate, US, G2)
Taking ownership for change	Pre dialysis in my mind that says I'm about to go on dialysis but then I'm going to wonder is there something I can do to keep me from going on dialysis if you put it that way. (Woman, 50s, P, completed 12th grade, US, G1) It explains the disease but it lets you know if you have to change. You could say pre-dialysis and if you change you're not going to go to chronic. You got chronic and you change. You won't go to full blown kidney disease. (Man, 50s, P, undergraduate degree, US, G1) CKD stages works more people because as human beings, we're goal oriented. I'm in Stage one or however it's classified, and if I do these things, it'll keep me from moving to stage two. A step down. You're working to keep from being in if going down the scale. Right. It's closer to the machine then. (Woman, 50s, P, completed 12th grade, US, G1) And they have to categorize it for me as a patient to know so that I can get my act together, maybe. (Woman, 40s, P, undergraduate degree, US, G3)
Learning medical terms for self-advocacy	I'm actually very grateful for the big words and understanding the terminology, exactly what they mean. Because I can actually have a full interactive conversation with my doctor, or any doctor, and they cannot really tell me anything that I don't understand. Understanding the big words, although it can be intimidating, this is your life. It's not going to change. For me, I'm appreciative of the words.(Woman, 30s, P, professional certificate, US, G2) We are much more capable of shaping ourselves to their language. (Woman, 50s, P, undergraduate degree, Aus, G5) This is a different language. Languages do different things, like engineers have languages, nurses have languages, and I thought I’m going to learn the language. I deliberately wrote down all the terms that I didn’t understand, and then I started reading the relevant clinical journals, but only the clinical ones, so I could try and teach myself, a self-taught one on it. The most useful things that people explained to me were GFR and creatinine, and the idea that one is high and one is low. So I’ve come to terms with the beast. (Woman, 50s, P, postgraduate degree, UK, G8)

Educating others	Its also hard for the families. You've got to think about how that terminology is used in the general population. It has a very final ring to it. You don't want your family frightened to death because you really need them. (Woman, 50s, P, undergraduate degree, Aus, G5) I would say kidney so I can help educate someone else. (Woman, 30s, P, professional certificate, Aus, G5) You think there would be more support and less stigma if your family and friends understood more about it? Rather than just being told, "Oh, end stage kidney disease”. (Woman, 60s, P, undergraduate degree, Aus, G5) But then if you have to explain to parents, siblings, child, I have end-stage kidney failure, they’re probably going to understand even less than we do. Potentially it could be detrimental. (Woman, 18-30, P, undergraduate degree, UK, G9)

P, patient; C, caregiver; AUS, Australia; UK, United Kingdom; US, United States; G, group ID

Table 3. Suggestions and implications for terminology for kidney health for use in patient-facing contexts

Suggestions in use of terms
• Avoid the term “end-stage kidney disease” as appropriate to minimize undue confusion and distress.
• Use the term “kidney” instead of “renal” where possible.
• Avoid terms such as “pre-dialysis” where possible.
• The use of terms to describe kidney level of function “e.g. GFR, low clearance, creatinine, CKD stages” may need to be supported by education; and discussion about possible symptoms and need for interventions.
• The use of the term “disease” may need to be clarified and supported with education and counseling.
• “Kidney failure” may be acceptable, however this may be supported with counseling to clarify that this refers to the kidney, and treatment options are available.
• Provide information in a comprehensible, compassion manner that takes into account the patient’s individual context, circumstances and concerns.

Figure legends.

Figure 1. Thematic schema

Frustration with the ambiguity of terms used to describe kidney health could provoke and exacerbate undue distress and trauma. Patients indicated a preference for terms that conveyed meaningful information about their prognosis, life impact and need for intervention. Some terms were perceived to mobilize and motivate self-management for preventing the progression of CKD. Of note, multiple themes could be applicable to the same terms.

Supplementary Files

1. Questions Guide
2. Table S1. Focus groups contributing to each theme