

Identifying important outcomes for young people with chronic kidney disease and their caregivers: a nominal group technique study

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Word count (abstract): 332

Word count (body): 3432

Short title: Important outcomes for young people with chronic kidney disease

Abstract

Rationale and Objective: Chronic kidney disease (CKD) has wide-ranging and long-term consequences for young people and their families. The omission of outcomes that are important to young people with CKD and their caregivers limits knowledge to guide shared decision-making. We aimed to identify the outcomes that are important to young people with CKD and their caregivers.

Study Design: We used the nominal group technique whereby participants identified and ranked outcomes and explained their priorities.

Settings and participants: Young people with CKD (stage 1-5, dialysis or transplant) and their caregivers were purposively sampled from six centers across Australia, the United States and Canada.

Analytical Approach: Importance scores were calculated (scale of 0 to 1), and qualitative data were analyzed thematically.

Results: Thirty-four patients (aged 8-21 years) and 62 caregivers participated in 16 groups, and identified 48 outcomes. The five highest ranked outcomes for patients were survival (importance score = 0.25), physical activity (0.24), fatigue (0.20), lifestyle restrictions (0.20) and growth (0.20), and for caregivers, kidney function (0.53), survival (0.28), infection (0.22), anemia (0.20) and growth (0.17). Twelve themes were identified reflecting their immediate and current priorities (wanting to feel normal, strengthening resilience, minimizing intrusion into daily life, imminent threats to life, devastating family burdens, and seeking control over health) and considerations regarding future impacts (protecting health/development, remaining hopeful, concern for limited opportunities, prognostic uncertainty, dreading painful and invasive procedures and managing expectations).

Limitations: Only English-speaking participants were recruited.

Conclusions: Kidney function, infection, survival and growth were the highest priorities for patients with CKD and their caregivers. Young people with CKD also prioritized highly the outcomes that directly affected their lifestyle and sense of normality, while caregiver's highest priorities concerned the long-term health of their child, current health problems, and the financial and family burdens of caring for a child with CKD.

Index words: pediatrics, chronic kidney disease, nominal group technique, outcomes, qualitative research, priorities

Non-technical summary: This study aimed to determine what outcomes are important to young people with CKD and their caregivers. We found that the highest ranked outcomes for patients were survival, physical activity/sports participation, fatigue, lifestyle restrictions and growth, and for caregivers were kidney function, survival, infection, anemia and growth. Young people with CKD prioritized highly the outcomes that directly affected their lifestyle, sense of normality or reflected immediate health concerns, while caregiver's highest priorities concerned the long-term health of their child, as well as their current health problems, and the financial and family burdens of caring for a child with CKD. Research that reports outcomes that are important to young people with CKD and their caregivers can better inform shared decision-making.

Introduction

Chronic kidney disease (CKD) has devastating, long-term and wide-ranging consequences for children and their families. The mortality rate in children with CKD is 30 times higher than that of their aged-matched peers,¹ and their quality of life is constrained by debilitating symptoms, comorbidities, treatment burdens, side-effects and complications.²⁻⁵ Impaired cognitive and psychosocial development and growth contributes to poor outcomes through to adulthood including lower attainment of educational, vocational and social goals.^{2-4,6-8} Caregivers of a child with CKD also experience psychological distress and financial burden, which can impact their child's care and outcomes.⁹⁻¹²

Interventions in CKD can have profound consequences on patients and their families, yet we don't know the impact of interventions on outcomes of importance to patients and families as these outcomes are often omitted from studies.¹³ A systematic review of trials in children with CKD showed that the most frequently reported outcomes were biochemical end-points, whereas mortality was reported in only 14% of studies. Quality of life, fatigue, depression and school performance were reported in less than 1% of studies.¹⁴ Self-esteem, anxiety, social and sports participation, fatigue, diet restrictions, cognitive function, school attendance, and family and financial impact are important to children and families;^{9-12,15-20} but are largely absent from trials.¹⁴

Prior studies have systematically identified outcomes that are important to adults with CKD,^{21,22} but the outcomes that are highly prioritized by children with CKD and caregivers are unknown.^{23,24} This study aims to identify outcomes that are important to children across all stages of CKD, and their caregivers, and the reasons for their prioritization. This may

inform the choice of research outcomes to inform patient-centered decision-making in CKD care.

Methods

Study population

Young people aged 8-21 years with CKD (stage 1-5 pre-dialysis, receiving dialysis, or who have a functioning transplant) and caregivers of patients aged 0-21 years with CKD were eligible to participate. All participants were required to speak English as resources for translation were unavailable. We recruited participants from three centers in Australia (Sydney, Brisbane and Melbourne), two centers in Canada (Vancouver and Calgary), and one center in the United States (Houston). Participants were purposively sampled by the recruiting clinicians to ensure that we included a broad range of demographic (age, gender) and clinical (CKD stage i.e. stage 1-5 CKD and not on renal replacement therapy, hemodialysis, peritoneal dialysis, kidney transplantation ;) diagnosis or cause of CKD (e.g. congenital abnormalities, polycystic kidney disease) characteristics. We obtained informed consent from participants aged over 18 years; and parental consent for participants aged under 18 years. Participants received \$50 (in their local currency) to reimburse travel-related costs. The ethics boards that approved this study are listed in Item S1.

Data Collection

We ran face-to-face focus groups using the nominal group technique (NGT) (Figure S1). NGT involves structured 'brainstorming' to develop a list of outcomes important for research in children with CKD. Participants then individually prioritize the outcomes²⁵ and discuss

their preferences as a group^{22,26,27}. We conducted separate groups for children and caregivers, held simultaneously for two hours. The groups were held in meeting rooms outside of clinical settings. One researcher (CSH, AT, TG) facilitated the groups, while a second facilitator (AFR, AJ, LJJ, AV) recorded field-notes. Each session was audio-recorded and transcribed. The groups were held from June 2016 to August 2017, and were convened until we reached data saturation (i.e. additional groups' no longer elicited new concepts). The question guides are provided in Tables S1-2.

Data analysis

Quantitative analysis: An importance score was used to prioritize the outcomes, based on the participant's rank assigned to each outcome. The importance score for each outcome is computed as the average of the reciprocal rankings. The reciprocal ranking is defined as 1 over the ranking assigned by each participant to each outcome. For example, if mortality is ranked number 1 by one participant and 3rd by another, the reciprocal rankings will be 1 and 1/3, respectively. Each group developed and ranked a slightly different list of outcomes. If the outcome was not ranked by the participant, it was given a 0 as the reciprocal ranking. A higher reciprocal ranking indicates higher priority of the outcome. This score takes into account the importance given to the outcome by the ranking and the consistency of being nominated by participants. This measure is similar to the Expected Reciprocal Rank Evaluation Metric²⁸. The analysis was conducted using R version 3.2.3 (*R Foundation for Statistical Computing, Vienna, Austria*).

Qualitative analysis: We used HyperRESEARCH (ResearchWare Inc.

www.researchware.com, Version 3.5.2) to conduct a thematic analysis to inductively identify

themes that captured the reasons why outcomes were important to participants. CSH performed line-by-line coding and assigned codes to meaningful segments of text. Comparisons were made within and across groups to identify similar and divergent concepts. The preliminary themes were discussed among the research team, and were revised to ensure that they captured the range and breadth of data.

Results

Participant characteristics

In total, 62 caregivers (8 groups) and 34 patients (8 groups) participated. Twenty-nine patients had at least one parent who also participated in the study. Caregivers consisted of ten pairs of participants who were related or spouses. Participant characteristics are shown in Tables 1 and 2. The age of the patients ranged from 8 to 21 years, 19 (56%) were male, and 17 (50%) had CKD (pre-dialysis), 5 (15%) were on dialysis, and 12 (35%) had a transplant. Caregivers were aged from 25 – 60 years old (with children aged from 1 – 22 years old), and most were mothers (76%). Twenty-five (40%) caregivers had children who were pre-dialysis, 14 (23%) had children on dialysis, 22 (35%) had children with a transplant. One parent did not report their child's CKD stage. Nonparticipation was due to inability to attend due to other commitments and illness.

Nominal group ranking

Thirty-four outcomes were ranked by patients and 33 outcomes by caregivers (Tables S9-14 in Supplement). Patients and caregivers ranked a total of 48 unique outcomes (Figure 1). The five highest ranked outcomes for patients were: survival (importance score = 0.25), physical

activity/sport (0.24), fatigue (0.20), lifestyle restrictions (0.20) and growth (0.20); and for caregivers were: kidney function (0.53), survival (0.28), infection (0.22), anemia (0.20) and growth (0.17). Survival, growth, kidney function and infection appeared in the top ten outcomes for both patients and caregivers (Figure 2).

The importance scores for the top ten outcomes by treatment, age, and country are provided in Tables S3-5 for patients and Tables S6-8 for caregivers. For patients, physical activity/sports participation was important across all treatment types. Lifestyle restriction was ranked higher by patients on dialysis, compared to CKD 1-5 and transplantation. Survival, fatigue and lifestyle restrictions were among the top ten outcomes for patients in all age groups. For caregivers, growth, kidney function and survival were important across all treatment stages. Growth was more important to caregivers of younger children, while school was more important to caregivers of young adults. The importance scores for all outcomes by age and treatment are included in Tables S7-10. There were differences by country, however growth, fatigue and survival were in the top ten for all patients, and kidney function and growth were in the top ten for all caregivers.

Qualitative findings

We identified twelve themes that explained the prioritization of outcomes, which we classified into current/immediate impacts and future/long-term outcomes (Figure 2; Table 3). A diverse range of outcomes were important to children and their caregivers, because they had a profound impact on the child's wellbeing, future health and development. Children appeared to give high priority to the outcomes that were relevant to their current or recent experience, particularly outcomes that impacted their self-esteem and daily function (e.g. fatigue, sports and lifestyle restrictions, treatment burdens). While caregivers recognized the

significant burdens placed on their child, their child's long-term health, graft survival and life expectancy was their ultimate priority. They also prioritized immediate and current outcomes including family and financial burdens, frightening complications their child had experienced (e.g. infection) and ongoing problems that they struggled to control (e.g. anemia, kidney function, blood pressure, growth). While some adolescents were concerned about prognostic uncertainty (e.g. graft survival, survival) and limited future opportunities (e.g. career, education, and pregnancy), most children and adolescents expressed optimism regarding these outcomes, and therefore ranked them relatively lower than their caregivers. Caregivers wanted their children to develop greater resilience to cope with their disease. However, they felt their concerns for their child's long-term health and development had to take precedence over short-term issues and impacts.

Caregivers felt that the immediate health problems that they frequently battled with were often the greatest consideration when making decisions about treatments, compared to survival (e.g. kidney function, infection, growth, blood pressure). The themes are described below, with the term 'young people' used for patients with CKD aged 8-21 years. Where data were specific to a patient age group, the terms 'young children' (aged 8-12), 'adolescents' (aged 13-17) and 'young adults' (aged 18-21) were used.

Immediate and current focus

Wanting to feel normal: Young people ranked highly the outcomes that caused them to feel "different" and inferior to their peers including growth, weight, fatigue, and restrictions on their diet, fluid intake and lifestyle and medication burden – "you can't do this you might get sick...we have so much we can't [do]". Physical activity/sports participation was ranked high across all treatments because it provided a sense of belonging to their peers. Some outcomes that impacted normality changed with age, such that young adults were more focused on hospitalization, the ability to travel, sexual function and diet and fluid restrictions than

younger patients, as these reduced their independence and normality. Young adults perceived sex to be “very dangerous” to their health but also desirable and normal at their age, and challenging to discuss openly with their doctor - “you wouldn’t like to tell your doctor”. Caregivers grieved their child’s lack of a normal childhood - “all he’s ever wanted is to be normal.” The child’s quality of life and treatment burden were important considerations in making treatment decisions - “the medication can make your kidney last longer. But is that a good longer? ... You’ve grown, you’ve played, and you have enjoyed your life?” Bladder problems were very important to caregivers, as this had led to social isolation and bullying.

Strengthening resilience for daily challenges: In contrast to their children, caregivers were aware that normality might not be feasible for their child and were therefore focused on improving their resilience to cope with daily struggles such as the burdens of treatment and self-esteem. Some caregivers strived to “keep [their child] positive...and feeling like things are going to get better”. However, many felt unable to help their adolescent with anxiety, low mood or poor self-esteem, and some caregivers of adolescents described their child’s mental health as “the toughest side”. They observed that their child’s emotional difficulties led to reluctance to attend school, socialize, and adhere to treatment.

Imminent threats to life: Patients and caregivers ranked highly the serious complications they experienced, particularly if they occurred suddenly, unexpectedly, and were potentially life-threatening (e.g. severe infections and cardiovascular events).

Devastating family burdens: Adolescents expressed guilt about the stress and burdens that their treatment caused for their family. For caregivers, the inability to work, travel, and care for their other children, due to caregiver responsibilities, was such that they felt CKD had “consumed [their] life, completely” and were desperate for financial/emotional support.

Seeking control over current health: Kidney function was a high priority for young people overall as it was viewed as the cause of their health problems. For patients with CKD stages 1-5, their kidney function indicated their potential need for dialysis or transplant – “when I get bad results I get really bad anxiety”. Infection was important for transplant recipients, because they were frustrated about “getting [the] cold or flu sickness quicker than normal people”. Caregivers of a child with a transplant ranked infection highly because it “pushes [them] back” on their growth, weight and kidney function. For caregivers, particularly those with children nearing renal replacement therapy (RRT), the uncertainty of their child’s prognosis was a “constant battle”. Knowing the indicators of their child’s health (e.g. blood pressure, weight, growth, kidney function, anemia and blood test results) provided a sense of control, even though some caregivers “never really know what it means, [the doctor will] just say it’s good, or it’s bad”.

Future and long-term focus

Parental responsibility to protect health and development: Caregivers felt they had to prioritize their child’s long-term health over the child’s psychosocial well-being because it was their role to protect their child’s future. They felt this was often at odds with their child’s focus on their current problems. Survival was “the most important thing to know”, and drove their treatment decisions. Even if there was no impact on mortality, this was still considered essential information - “I need to know that I can discount that in my decision-making process”. The impact of CKD on their child’s development had become a major concern for some caregivers of adolescents as impaired psychosocial development became apparent– “whether she’s going to be able to live independently, or function efficiently. That worries me a lot”. In hindsight, some reflected that treatment decisions should have considered these

outcomes more strongly and been discussed by their health care providers, for example the impact of the timing of transplant on cognition.

Remaining hopeful: Some patients expressed a positive outlook about their future, and were not overly concerned about graft loss or relapse (e.g. nephrotic syndrome) because their caregivers and clinicians had told them “not to worry about it because it will be fine”.

Concern for limited opportunities: Some adolescents/young adults were worried that they would be unable to achieve their goals in terms of their career, relationships and having a family. They felt that CKD would make them less desirable to others. For caregivers, school performance ranked highly, as they believed their child was disadvantaged due to absences.

Prognostic uncertainty: Survival was ranked highly by young people overall, because it was considered an “obvious” priority, as “no one wants to pass away”. This was discussed in relation to transplant surgery, rather than their overall life expectancy. The risk of graft loss was a constant worry for some adolescent transplant recipients – “it’s a never-ending horror story”. However, graft survival was of higher concern for patients currently on dialysis, as they feared it might fail immediately and they would therefore have to return to dialysis. For caregivers, graft failure was a high priority because they feared their child might have difficulty accessing transplant as an adult patient.

Dreading painful and invasive procedures: Young people with CKD stage 1-5 dreaded the need for dialysis, changing their catheters, or transplant surgery, because they expected these procedures to be painful, invasive and restrictive. Therefore pain, catheter problems and lifestyle restrictions were ranked highly.

Managing expectations: Caregivers of children with a transplant emphasized the importance of being prepared for possible complications and side effects of immunosuppression (e.g. infection) – “you don’t want the bad story all the time but it is good to know so you are prepared”). Caregivers ranked these outcomes highly if they occurred unexpectedly. Some caregivers felt ill-informed about comorbidities associated with CKD, and ranked outcomes like cardiovascular disease high because they wanted to “know more about the disease”.

Discussion

Young people with CKD prioritized most highly the outcomes that directly affected their lifestyle, sense of normality, or reflected immediate health concerns. These included physical activity/sports participation, fatigue, lifestyle restrictions, height, social functioning, hospitalization, infection, medication burden, and kidney function. Outcomes that were highly prioritized by young people generally differed from those of their caregivers. For caregivers, their highest priority was the long-term health of their child, compounded by living in a constant state of uncertainty about their child’s prognosis. Caregivers were also concerned about their child’s current health problems, and the financial and family burdens of caring for a child with CKD, therefore outcomes including kidney function, survival, infection, anemia, growth, financial impact, cardiovascular disease, graft survival, impact on family and blood pressure were of highest priority. Psychosocial outcomes such as anxiety were ranked higher among caregivers of adolescent patients, as at this age, anxiety was particularly acute and the parent-child relationship became more difficult to manage.

The differences in priorities for outcomes between young people and caregivers may be largely explained based on a difference in the timeframe through which they are viewing outcomes. Young people tended to prioritize outcomes that were their current and imminent

concerns, more so than their caregivers. Young people with CKD gave high priority to outcomes that restricted their lifestyle and were markers of normalcy and inclusion at their stage of adolescence. Caregivers felt they had a responsibility to protect their child across their life trajectory but at the same time felt uncertain and unable to control their child's prognosis and outcomes, due to the unpredictability of their child's health and their decreasing parental control and influence as their child reached adolescence.²⁹ Outcomes such as survival and infection were important to both patients and caregivers; but were conceptualized differently. For example, survival was ranked highly by young patients because they were concerned about the mortality risk associated with transplant; whereas caregivers considered their child's overall life expectancy when making treatment decisions.

Variability in the prioritization of outcomes by age and treatment was apparent among young people with CKD. Therefore, we should not consider the priority outcomes among young people with CKD to be fixed and homogenous, as they change with age and as their condition and treatment alters. Fear of transplant surgery was ranked highly by patients with CKD (1-5) and patients who were younger children as they were uncertain about the pain and risk of mortality. Graft survival was a major concern for patients on dialysis as they dreaded the possibility of returning to dialysis after transplant. These outcomes may not be explicitly addressed with young people¹⁷. Young people with a transplant ranked graft survival lower overall, as they felt optimistic about graft survival, which was reinforced by reassurance from their family and clinicians. In contrast, some young people have described feeling cheated by unmet expectations and hopes of improved health after transplantation^{17,18,20}. We found that transplant recipients ranked fatigue, hospitalization, infection, lifestyle restrictions, reduced sports and social participation highly, highlighting these as major challenges after transplantation. Therefore, these outcomes may not only be unexpected, but also highly important as they are the outcomes young people are most keen to avoid. These immediate

priorities deserve discussion and empathy to ensure the young person is comfortable and prepared for transplantation and better equipped to deal with these implications.

Our multinational study used a mixed-method design to identify the priorities for outcomes for patients with CKD and their caregivers, and the reasons for their choices. We used purposive sampling to ensure participants were included with varying demographic and treatment characteristics; and were able to compare the prioritization of outcomes across groups. However, there are some potential limitations. We did not include participants, who were non-English speaking, or from low and middle income countries and participants were highly education. Also, only one child on in-center hemodialysis participated, although, patients with a transplant did reflect on their prior experiences of dialysis. We also had limited data regarding the comorbidities of participants. Some differences were noted in the rankings by country; however the reasons for these differences are uncertain. We speculate this may reflect confounders for example differences in age, stage and treatment modality by country. As the number of caregivers and patients (young people) varied across the different stages of CKD, the observed differences in rankings between caregivers and young people may to some extent reflect differences by stage of CKD. However, the outcomes of physical, lifestyle restrictions and social functioning were in the top ten for all children across all CKD stages, and were not in the top ten for caregivers. This suggests that the differences in priorities for outcomes between patients and caregivers may be irrespective of CKD stage. The qualitative data also support that young people and caregivers have some different priorities, regardless of CKD stage. Further analyses in larger quantitative studies could compare differences between caregivers and patients among subgroups, for example by gender and CKD stage.

Patient- and family-centered care necessitates the recognition and evaluation of outcomes that are important to patients and caregivers and their values and goals attached to these outcomes. There is still a need to address the mismatch between the outcomes reported in trials and those that are most important to patients with CKD and their caregivers to inform clinical decision-making. Consensus-based core outcome sets are uncommon among pediatric health conditions.³⁰⁻³² Core outcomes reflect those that are critically important to patients, caregivers, and clinicians, and they are to be reported as a minimum to strengthen consistency and relevance of trial reports. These studies should be sufficiently powered to evaluate patient centered outcomes. In order to incorporate patient centered outcomes into research there is a need for further research to develop validated assessment tools for example to assess life participation and fatigue. The outcomes identified in this study will directly inform the development of a core outcome set through the Standardized Outcomes in Nephrology – Children and Adolescents (SONG-Kids) Initiative²⁴ This will involve an international Delphi survey to develop a consensus on core outcomes important and relevant to all stakeholders, and the development of validated measures that are also feasible for use in all trials involving children with CKD.

The American Academy of Pediatrics and the United Nations advocate for involvement of children in decisions about their health and treatment.³³⁻³⁶ The priorities of the child, parent(s) and clinician may often be seen as conflicting, therefore shared decision-making can be challenging.³³ Caregivers and clinicians may avoid discussing mortality, graft failure and future concerns such as fertility with young people.³⁶⁻⁴² The outcomes important to children with CKD and their families may go unspoken in time-limited clinical consultations or because they may believe that their concerns are not as important as medical outcomes that are the focus of their consultations. Limited discussion of patient-important outcomes can cause young patients to feel disempowered, harbor unresolved fears, and cause them to

disengage from health care, leading to an ineffective partnership and potentially compromised care and outcomes for children.^{2-5, 10-13}

Kidney function, infection, survival and growth are shared priorities for young people and their caregivers across all stages of CKD. Young people focus on current impacts of CKD including physical activity, fatigue, lifestyle restrictions, hospitalization, social functioning and medication burdens as these impaired their ability to feel normal. Caregivers were focused on gaining control over their child's current health, believed the family and the financial impact to be important considerations, and placed emphasis on their child's long-term health, development and survival. Research that reports outcomes that are important to children with CKD and their caregivers can better inform shared decision-making. The outcomes identified in this study will inform the development of a core outcome set through the SONG-Kids Initiative.²⁴

Supplementary Material

Item S1. Research ethics boards for participating sites

Table S1. Child question guide/runsheet

Table S2. Parent question guide/runsheet

Table S3. Top ten outcomes for children with chronic kidney disease by treatment stage

Table S4. Top ten outcomes for children with chronic kidney disease by age

Table S5. Top ten outcomes for caregivers by child's treatment stage

Table S6. Top ten outcomes for caregivers by child's age

Table S7: Individual ranking of all outcomes– children and adolescents by treatment

Table S8: Individual ranking of all outcomes–caregivers by child's treatment

Table S9: Individual ranking of outcomes–children and adolescents by age

Table S10: Individual ranking of outcomes–caregivers by child’s age

Figure S1. Flow chart of focus group/nominal group technique. *The facilitator suggested other outcomes be added to the list that are frequently reported in trials in children with CKD¹⁴ **The rating exercise was used to allow participants to identify which outcomes were the most important to them

Acknowledgements: We are grateful to the participants that gave their time to participate in these groups and shared their valuable experience.

Supporting and financial disclosure declaration: The authors have no financial relationships relevant to this article to disclose. C.S.H is supported by the NHMRC Program Grant (ID1092957). AT is supported by a NHMRC Fellowship (ID1106716). AV receives grant support from the NHMRC Medical Postgraduate Scholarship (1114539) and the Royal Australasian College of Physicians (Jacquot NHMRC Award for Excellence). The study was funded by The University of Sydney Research Accelerator Grant and the NHMRC Program Grant Better Evidence and Translation in Chronic Kidney Disease (BEAT-CKD) (ID1092957). The funders of this study had no role in the study design, data collection, data analysis, interpretation of data, writing of the manuscript and the decision to submit the report for publication.

Potential Conflicts of Interest: The authors have no conflicts of interest relevant to this article to disclose.

Research idea and study design: All authors; data acquisition: CSH, TG, TG, LJJ, AFR, AJ, KEM, AKV, AT; data analysis/interpretation: CSH, TG, JCC, SB, GR, TZ, LJJ, AFR, AJ, KEM, AT-P, AKV, SIA, TDB-H, JD, SM, MM, AW, SC, SEW, WCW, DB, AD, AAE, SF, DSG, SLG, JG, SS, AS, NJW, H-KY, MZ, HC, AT; supervision or mentorship: JCC, SB, AT-P, AT. Each author contributed important intellectual content during manuscript drafting

or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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Table 1. Characteristics of the children with chronic kidney disease (N=34)

Characteristics	n (%)
Gender	
Male	19 (56)
Female	15 (44)
Country of birth	
Australia	13 (38)
Canada	5 (15)
USA	14 (41)
Other ^a	2 (6)
Age (years)	
8-12	10 (29)
13-17	20 (59)
18-21	4 (12)
Stage of treatment	
Chronic kidney disease 1-5 (no kidney replacement therapy)	17 (50)
Peritoneal dialysis	4 (12)
In-center hemodialysis	1(3)
Transplant	12 (35)
Primary kidney disease	
Congenital abnormalities of kidneys/urinary tract	12 (35)
Nephrotic syndrome	4 (12)
Focal segmental glomerulosclerosis	3 (9)
Polycystic kidney disease	2 (6)
Cystinosis	1 (3)
IgA nephropathy	1 (3)
Not reported or not known	11 (32)

^aOther includes: Mexico and New Zealand;

Table 2. Characteristics of the caregivers of children with chronic kidney disease (N=62)

Characteristics	n (%)
Gender	
Male	13 (21)
Female	49 (79)
Relationship to child with CKD	
Mother	47 (76)
Father	13 (21)
Other (grandmother, aunt)	2 (4)
Country of birth	
Australia	11 (18)
USA	9 (15)
Canada	8 (13)
Other ^a	25 (40)
Not reported	9 (15)
Age (years)	
21-30	4 (6)
31-40	10 (16)
41-50	26 (42)
51-60	10 (16)
Not reported	12 (19)
Highest level of education	
Bachelor degree or higher	19 (31)
Diploma/certificate/trade	18 (29)
Secondary school	11 (18)
Primary school	2 (3)
Not reported	12 (19)
Child's chronic kidney disease treatment stage	
1-5 (no renal replacement therapy)	25 (40)
Peritoneal dialysis	8 (13)
In-center hemodialysis	5 (8)
Dialysis (not specified)	1 (2)
Transplant	22 (35)
Not reported	1 (2)
Child's primary kidney disease	
Congenital abnormalities of kidneys/urinary tract	15 (25)
Nephrotic syndrome	9 (15)
Focal segmental glomerulosclerosis	4 (6)
Polycystic kidney disease	4 (6)
Posterior Urethral Valves	4 (6)
Other ^b	9 (15)
No reported or not known	17 (28)

^aOther includes: England, Ethiopia, Fiji, India, Kenya, Mexico, New Zealand, Pakistan, Poland, Somalia, Vietnam; Other^b includes: Cystinosis, Eagle-Barrett syndrome, IgA nephropathy, Scleroderma, Neurogenic bladder, bladder obstruction, reflux

Table 3: Selected illustrative quotations

Current and immediate focus	
Theme	Illustrative quotations
Wanting to feel normal	<i>Young people^a</i>
	Physical activity, feeling normal, school. Because sometimes I don't feel like other people, and I feel left out sometimes... Like you'll feel different to other people. Other people who don't have problems. (Female, child, CKD, Australia)
	It can affect your relationship with like a boyfriend or a girlfriend. Because people want like a perfect person. And some people can't deal with people who have to take medication and they judge them for having to do it. So, even if they did like you and then they find out you have a medical reason. (Female, adolescent, dialysis, Australia)
	Sometimes we want to hang out with friends, go out, have fun, be normal kids. We really can't with medications, we have restrictions. Like, 'You can't do this, you might get sick. You can't do this, you might get sick'. We have so much we can't. (Female, adolescent, transplant, USA)
	Yeah. Just for me, like I'm playing sports all the time, and I get tired all the time, puffed and wear out quicker than all the others. (Male, adolescent, transplant, Australia)
	Each meal is a well thought out process. You can't just grab something and go. It gets stressful. (Male, adolescent, dialysis, Australia)
	<i>Caregivers</i>
	Just the normality. I find when it comes to sports I'm always saying to my son, you can't do football, better not do basketball, can't do this. It's only in the last 3 months I thought well, hang on... he's still got to be a child. I think research needs to be changed on the approach with that as well, what they can safely do and can't do. (Mother, CKD, Australia)
	She's playing volleyball, so that actually helped her spirits... it helped her depression level, and helped her get back on the social level, and school. (Mother, CKD, Canada)
	All he's ever wanted to be is normal, he's never wanted to be that different kid...the sick kid, so we tell him 'you're not'. (Mother, transplant, Australia)
He would be the first to tell you that not being able to play sports... do things that other kids do, without the exhaustion that goes with kidney disease... (Father, CKD, Canada)	
None of us put "physical activity" and it's important, but they can't move... They're like invalids. My son is, anyway. (Mother, CKD, Canada)	
Strengthening resilience for daily challenges	<i>Caregivers</i>
	But for us at the moment the toughest side is the mental side of him that we haven't had to worry about before. (Father, transplant, Australia)
	Anxiety is very big [for my son]...it got to the point where he wouldn't actually get out of the car to go to school. (Mother, transplant, Australia)
	You know when he looked at himself in the mirror he hated himself. And he felt really embarrassed, and I mean I had to work...like you have got to go to school mate. I said I'm sorry that you're going through this but we just have got to tough it out... He'd come home and just go to his room. Really closed off. (Mother, CKD, Australia)
Imminent threats to life	<i>Young people</i>
	I get concerned with blood pressure because I almost died because of high blood pressure. (Girl, adolescent, dialysis, Australia)
	Because if I like land or fall on my kidneys or something, one of the cysts will pop and I might die or go into ICU or something. (Girl, adolescent, CKD, Australia)
	<i>Caregivers</i>
	I was told prepare to say goodbye to him a few weeks ago, for like the third time in the last twelve months, so you can imagine how very sick he gets. (Mother, dialysis, Australia)
He had cardiac arrest in the nurse's arms... He was literally blue, and I don't ever want to see that again in my entire life (Mother, dialysis, Canada)	
There's actual health concerns like cancer, blood pressure, or cardiovascular, and then there's more social wellbeing and, whilst for me social wellbeing is important, medical is more important". (Mother, dialysis, Australia)	

Devastating family burden	<i>Young people</i>
	[My sister] didn't get her birthday cake because I was in hospital on her birthday. (Female, adolescent, dialysis, Australia)
	I think it makes it a bit difficult...If I feel sick my mum stresses so much. She's got to drop everything just to take me to the hospital. (Female, adolescent, CKD, Australia)
	<i>Caregivers</i>
	I guess, in those years, spending a lot of time, at least 50% of my time in hospital. And then still having to work too, to pay mortgages and cope, and when asking about opportunities for respite, just being told there are none, suck it up. Basically. (Mother, child with CKD, Australia)
	When my son went on hemodialysis, I lost my job. So that was a challenge. You can't really find a job that's going to allow you to leave 3 days a week...(Mother, dialysis, USA)
	We prefer to have [my daughter] at home for her [dialysis]...It's a lot easier for my family. (Mother, CKD, Australia)

Seeking control over current health	<i>Young people</i>
	When I get bad results I get really bad anxiety...I guess it's all the same worry. If that makes sense. I worry about all of it. (Female, adolescent, CKD, Australia)
	I look into the details of each test, because I know that there's going to be specific ranges which I have to be within. (Male, adolescent, transplant, Australia)
	<i>Caregivers</i>
	Well kidney function is important because that is where the disease is stemming from, ultimately. (Mother, CKD, Australia)
	Infections. You are constantly worrying about other children even having the flu, gastro... they have to go to school with 1500 students everyday (Mother, transplant, Australia)
	The biggest challenge for myself is not being able to help, not being able to do something myself...she went from stage 3 to stage 5 in zero months. (Mother, dialysis, USA)
Well see, he's at 16% at the moment, which – might sound stupid – I'm actually happy about, because at least it's still above dialysis. (Mother, CKD, Australia)	
It's actually with his eating and his growth and with him just keeping well...But with [Mycophenolate mofetil] which they say is better for his kidney, he'll get the flu first and gastro and he'll have it like for a month which drains him and pushes him back on the growth.... (Parent, transplant, Australia)	
When we were looking at dialysis, and having a fistula, versus in-home dialysis through the stomach...I never really thought of survival as a pull to either one of those treatments, but I was looking at the impact on health, on family, on time, on all those other things. (Mother, transplant, USA)	
Sometimes you want to know, is this going to succeed? Is this going to make the kid healthy again, or is it not? Ultimately, it's all about survival, but depending on what you're doing at that moment, if you're looking at a medication or treatment, you are looking at, Is this going to get our kidney back to where it needs to be, is this going to get us off certain medications, or is this going to improve quality of life? That might be a primary focus, and survival, you're not thinking about that, you're not thinking about whether they're going to live or die, you're thinking about whether they're going to get healthy from this treatment. (Mother, transplant, USA)	

Focused on future and long-term impacts	
Theme	Illustrative quotations
Parental responsibility to protect health and development	<i>Caregivers</i>
	I think the biggest challenge and the biggest impact to [my daughter's] life is her delayed development, and her delayed milestones, and her learning disabilities, and the things that (I'm now told) go hand-in-hand with transplantation and kidney failure, and I continually now wonder whether it wouldn't have been wiser to transplant her much earlier...It's her cognitive abilities that I think were impacted and it really worries me how she's going to carry on as she gets older and graduates from high school. What she's going to be able to do, and whether she's going to be able to live independently, or function efficiently. That's what worries me a lot. (Mother, transplant, Canada)
	You wonder about things like will they be able to have children themselves, as adults. Or is this medication going to make them sterile. (Mother, transplant, Australia)
	When you have to take them to get blood. "Why do I have to go take blood now? Why do I have to do it if I'm OK?" We need to make sure you're staying OK. (Mother, CKD, Canada)

It's in the background for me because it hasn't been a prominent issue yet, I'm just aware that it will become an issue [cardiovascular disease]. (Mother, child on dialysis, Australia)
Survivability. I think ultimately, that should be the priority. Because that's my priority. So I need to know that I can discount that in my decision-making process. Okay, right, no difference, let's go down the list, what's next important? What do I need to know? If you don't tell me that information, when that's my most important information. (Mother, transplant, Australia)

Remaining hopeful

Young people

They tell me not to worry about it because it will be fine when you grow up. (Female, child, CKD, Australia)
I think this has helped me be more successful, and to focus on what's really needed, and not just take life for granted, and the things that I have. (Male, young adult, transplant, USA)
If it comes back again [nephrotic syndrome]...But they said that there was a high chance that when you're our age it can go away. You never know. (Male, adolescent, CKD, Australia)
It's just recently, my last doctor appointment... my doctor told me that my kidney, my only kidney, could fail in like 4 or 5 years, 'cause the percentage is declining right now... and if it keeps continuing at this rate, I'm going to need a new kidney when I'm 20.... and I don't really know, right? Anything could happen. (Male, adolescent, CKD, Canada)

Concern for limited opportunities

Young people

Being able to get the job you want. Because I want to be HPE teacher. Like a coach or something. And you have to be very fit to do it. (Female, adolescent, dialysis, Australia)
I want to live a life where you can hope that you'll have a family, get married, and you never know... (Female, adolescent, transplant, USA)

Caregivers

It's more living with the experience that they've grown up with and as adults how that's going to affect them and their decision-making process of having relationships with people, or you know, or genetically, if they were to become parents you know, is that gonna be a worry for them. (Mother, CKD, Australia)
His friends are now starting to work, and there's just no way. He's exhausted, a day off school...Employment is going to be huge. (Mother, transplant, Canada)
I'm thinking broader, I'm thinking more about the ability to live independently, be an adult. (Mother, CKD, Canada)

Prognostic uncertainty

Young people

I have another one. Longer lifespan of the transplant. That's my most important...Frankly, this thing could stop working tomorrow. It could be 10 years from now. That's a fear of mine. I try not to think about it too much, but the uncertainty... I plan things out. I like to know what I'm getting into. So the fact that this could, it's a 50/50 chance that it could just stop working, I'll be constantly not wanting to do things. If I want to go outside but I know that I could get bumped in my stomach, I might not go. (Male, young adult, transplant, USA)
I feel like when I get a transplant, I might not have my kidneys as long because I'll get a transplant from someone who is already dead. And they're not going to have as much energy as someone living. (Female, child, CKD, Canada)
First thing is going to be the length of the lifespan of the transplant, because I want it to last longer. I don't want to have to go back on dialysis, or take more medications and the restriction to that. (Male, young adult, transplant, USA)

Caregivers

What if something goes wrong? Is the biggest question you have as a parent? What do we do if Plan A doesn't work? (Mother, CKD, Canada)
I mean the graft survival is huge for me, because he's so young. I was told they're only allowed three transplants in their lifetime... (Mother, dialysis, Canada)
So when it comes to thinking about transplants and all that, at our doctor visits, he just reached stage 3. So anytime you try to ask the doctor about it, you know, they don't want to talk about it. But they don't want to give you an estimate of when he's going to have it, I don't know if it's to not keep our hopes up, or..." (Mother, CKD, USA)

**Dreading
painful and
invasive
interventions**

Young people

Girl 1: I wish that dialysis was better. Girl 2: Because some dialysis really hurts. (Female, child, CKD, Canada)

I was sitting there, hearing, like, 'You're going to need a new one'. I was pretty nervous, because I know you can't just get a new kidney right away. It takes time, and you'll have to go on dialysis in the meantime. And dialysis is a pretty scary thought. I knew this one guy who went on dialysis, and he couldn't really do much physical activity, because you physically couldn't, right? And just... the whole point of being attached to a machine. (Male, adolescent, CKD, Canada)

Having to get a new button. I call it a button but it's a G-tube. I have to get it changed every year, and that hurts. And they always freak me out with the needles. (Girl, CKD, Canada)

And like getting worried and scared about when you're getting ready to have dialysis or surgery. (Female, adolescent, CKD, Australia)

Umm there's the fear of surgery because you get a fear of dying. Because transplant is a risk. (Girl, adolescent, dialysis, Australia)

Caregivers

I think doing the Eprex needle has been the hardest thing... but giving that needle to your child, to your baby, is the hardest thing to do. (Mother, CKD, Canada)

**Managing
expectations**

Caregivers

When they do the studies and stuff if the doctors could get back to us on a variety of things, the survival rates of transplants, the issues with medication that they are having, the side effects. You don't want the bad story all the time, but it is good to know so you are prepared. It's not like omg that's happened now. Sometimes I used to be taken aback by that. If you had just told me that was a side effect I'd be prepared and I'd watch for it. Your just kind of like 'Oh can that happen?'. (Mother, transplant, Australia)

I think parents should be given more education...so that we know what's going on with the kid. And we know more about the disease ...because of kidney there's many other organs in the body that can be affected and having to know that. So we lack a lot of outcomes of the studies you do, we should be informed about that. (Father, CKD, Australia)

The first thing I look for is survival rate. Ultimately, that's the most important thing. (Mother, CKD, USA)

^aLabeled as child (8-12), adolescent (13-17) and young adult (18-21)

Figure legends.

Figure 1. Importance scores for outcomes by children with chronic kidney disease and their caregivers

Importance scores were based on ranks of participants in separate focus groups of children (N=34, yellow bars) and caregivers (N=62, blue bars). Shown are median scores, with standard error represented by error bars. Combined scores (gray bars) were based on rankings of all participants.

Figure 2. Schema depicting themes underpinning the prioritization of outcomes by children with chronic kidney disease and their caregivers.