

**Child and caregivers perspectives on access to psychosocial and educational support in
pediatric chronic kidney disease: focus group study**

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Abstract

Background: Children with chronic kidney disease (CKD) generally have worse educational and psychosocial outcomes compared with their healthy peers. This can impair their ability to manage their treatment, which in turn can have long-term health consequences through to adulthood. We attempted to capture the experiences of children with CKD and to describe the perspectives of their parents and caregivers on access to educational and psychosocial support.

Methods: Children with CKD (n=34) and their caregivers (n=62) were sampled via focus groups from pediatric hospitals in Australia, Canada, and the United States. Sixteen focus groups were convened and the transcripts were analyzed thematically.

Results: We identified four themes: disruption to self-esteem and identity (emotional turmoil of adolescence, wrestling with the sick self, powerlessness to alleviate child's suffering, balancing normality and protection); disadvantaged by lack of empathy and acceptance (alienated by ignorance, bearing the burden alone); a hidden and inaccessible support system (excluded from formal psychological support, falling behind due to being denied special considerations); and building resilience (finding partners in the journey, moving towards acceptance of the illness, re-establishing childhood).

Conclusions: Children with CKD and their caregivers encountered many barriers in accessing psychosocial and educational support, and felt extremely disempowered and isolated as a consequence. Improved availability and access to psychosocial and educational interventions are needed to improve the wellbeing and educational advancement of children with CKD.

Introduction

Children with chronic kidney disease (CKD) experience an increased risk of mortality and serious comorbidities, and a subsequently reduced quality of life [1-3]. They must follow a complex medication regimen and may require kidney replacement therapy (KRT) in the form of dialysis or transplantation, all of which contribute to substantial treatment burden [4, 5]. Compared to their well peers, children with CKD are at higher risks of depression and anxiety, and worse educational and social outcomes [5-9].

Anxiety and depression are highly prevalent in children with CKD, with reported incidences of up to 30% among children with CKD stages 3-5 [10-12]. Compared to their age-matched peers, children with CKD have a low-average Full Scale Intelligence Quotient (FSIQ) and experience higher frequencies of school absenteeism [13, 14]. This has an impact through to adulthood. Young adults with CKD also report lower educational attainment and capacity to work and fulfill career goals [15]; in one cross-sectional survey, it was found that young adults on KRT were nine times more likely to report receiving no income, and 15 times more likely to be excluded from paid work due to physical illness [9]. Young adults with childhood CKD are also less likely to be in a relationship, have children, live independently, and be employed, compared to the general population [9].

Despite this, psychosocial and educational issues remain under recognized and challenging to address in children with CKD. This study aimed to explore the child and parental perspectives on access to psychosocial and educational support, to inform strategies and interventions to address potential unmet needs for better care and outcomes.

Methods

This focus group study was conducted as part of the Standardized Outcomes in Nephrology – Children and Adolescents (SONG-Kids) Initiative [16]. In this study, we analyze and report data on access to psychosocial and educational support. We used the Consolidated Criteria for Reporting Qualitative Studies (COREQ) to report this study [17].

Participant selection

Children aged 8-21 years with CKD stages 1-5 were eligible to participate. Parents of children with CKD were also eligible to participate, provided their children were aged between 0-21. Participants were required to be English speakers, due to limited resources to employ trained multilingual facilitators. Participants were recruited from one center in the United States (n=36), two centers in Canada (n=16) and three centers in Australia (n=44). All centers involved in our study were tertiary children's hospitals, with specialist pediatric kidney services. We sampled participants from a variety of demographic (age, gender, socioeconomic status) and clinical backgrounds (CKD stage, diagnosis). We obtained informed consent from participants who were aged over 18 years, and obtained parental written consent for those who were aged under 18 years. Our participants were reimbursed \$50 (in their local currency) to cover the travel costs incurred in attending the focus groups. Ethical approval was provided by the Institutional Review Board of all participating centers (Appendix A).

Data Collection

We conducted 16 focus groups (8 child, 8 adult) of two-hour durations between June 2016 and August 2017, until we reached data saturation. We developed question guides that were informed by literature, following discussions between the investigators (Appendix B). All groups were recorded

and transcribed word-for word. One investigator (CSH, AT, TG) facilitated the group while a second investigator (CSH, AT, AR, AJ, LJ, TG) took field notes.

Analysis

Qualitative data analysis was conducted via HyperRESEARCH software. HyperRESEARCH software ensures that all coding decisions are auditable and explicit. The transcripts are imported into HyperRESEARCH. Sections of relevant transcripts were read through and, line-by-line, manually coded to the themes based on the concepts we identified. We employed investigator triangulation, which is the involvement of more than one investigator in the analysis, to ensure that the themes reflect the full range and depth of the data collected. YZ read through the transcripts and coded the contents using thematic analysis to identify participants' perspectives on psychosocial and educational support [18]. Preliminary themes were discussed with AT, TG and CH, who independently read the transcripts. A schema illustrating the themes and their relationships was later developed (Figure 1).

Results

Participant characteristics are shown in Tables 1 and 2. Overall, 62 caregivers and 34 children participated across the 16 focus groups. The ages of caregivers ranged from 24 to 58 years. Of the caregivers, thirteen (21%) had children who were on dialysis and twenty-two (35%) had children with a kidney transplant. Seven (11%) caregivers had a child with CKD aged younger than 8 years. Children who participated were 8 to 21 years old (we have defined younger children as those aged 8-12 years, adolescents as those between 13 and 17 years and young adults as those aged over 18 years). Of the children, nineteen (56%) were male, five (15%) were on dialysis, and twelve (35%) had received a kidney transplant. Twenty-nine (85%) children had at least one parent who also participated in a focus group.

We identified four themes: disruption to self-esteem and identity, disadvantaged by a lack of empathy and acceptance, a hidden and inaccessible support system, and building resilience. The respective subthemes are described in the following section. The themes are separated to distinguish issues accessing psychosocial and educational support services from related psychosocial/educational difficulties. Selected quotations to support each theme are available in Table 3 with reference to the relevant participant group (parent, child), treatment group and country. Figure 1 portrays the relationships among themes and subthemes.

Psychosocial/educational difficulties

Disruption to self-esteem and identity

Emotional turmoil during adolescence: As they reached adolescence, participants became increasingly aware of the limitations caused by their kidney disease, and spoke of feeling “odd, left out and different” such that they felt anxious, experienced low mood, and isolated themselves socially. The side effects of medication, such as weight gain, “stretch marks” and “puffy cheeks”, made some children reluctant to “leave the house”. Caregivers noted that these physical changes undermined their child’s self-esteem and functioning – “when he looked at himself in the mirror, he hated himself” – and were concerned about the severity and long-term effects of their child’s emotional distress.

Wrestling with the sick self: Children found it difficult to accept that CKD would be part of “the rest of their life”. Adolescents and young adults were uncertain of their ability to achieve future goals – “I want to live a life where you can hope that you’ll have a family, get married, and you never know”. Some caregivers were concerned that their child had developed “a profound sense of [their]

own mortality”. Adolescents imagined they could not be the “perfect person” for a partner, and believed it was “dangerous” for transplant recipients to engage in sexual activity.

Powerlessness to alleviate child’s suffering: Caregivers felt challenged in their own identities as parents, being unable to protect their children from the constant social, educational, developmental, and health problems. In particular, they felt “railroaded” by medical staff, finding their appointments with doctors to be overly focused on medical outcomes rather than addressing their daily concerns. Other caregivers found it heartbreaking having to talk to their children about death when asked, “am I going to die?” and did not know how to help their child with emotional problems and challenging behaviors– “He’s actually having meltdowns. I don’t know how to handle that”.

Balancing normality and protection: Caregivers empathized with their child’s frustrations, stating that CKD had denied their children of normal activities, which then impaired mental health and social development. Some caregivers felt they had balance protecting their child from risks and encouraging them to “experience life”. Some caregivers said that they had previously stopped their child from participating in risky activities that they loved, only to “cause depression”, and therefore decided to prioritize emotional and social wellbeing by allowing them to either participate or find more suitable activities. Some caregivers were also more assertive in their attempts to install a semblance of normality-“I’m not going to let him sit there and ponder or worry about what is wrong with him”- and tried to engage their children in activities to shift or distract them from viewing themselves as a “sick kid”.

Disadvantaged by lack of empathy and acceptance

Alienated by ignorance: Some children felt ignored and misunderstood by their teachers and peers. Those that did disclose their disease were told, “there’s nothing really wrong with you”, and “you look fine”. Children felt threatened at school and this caused a rift between themselves and their

teachers, who they became less likely to approach for help, saying that they "don't get it" and "don't provide [any support]". Caregivers commented on their child's "excruciatingly painful" experiences of being told by their peers, "you're faking it", and "you're a wuss".

Bearing the burden alone: Some children pre-empted that their peers and teachers would neither help nor understand them, and thus kept their thoughts and emotional struggles to themselves – "I really just stayed very distanced from people. I didn't like talking about it". Caregivers commented that their child became "closed off", and could not provide support due to difficulties "teasing [issues] out of them".

Access to psychosocial and education support services

A hidden and inaccessible support system

Excluded from formal psychological support: Some caregivers found the process of accessing psychological support to be bureaucratic and expensive. They stated that psychologists were rarely part of the treating team and psychological services were often not available through the child's hospital. While some caregivers received a referral to see a psychologist (either for themselves or for their children), residing outside of the "catchment area" for eligibility hindered access. Having to discontinue services due to limitations on government-subsidized appointments was disappointing for caregivers, particularly when the child had become "confident" and comfortable with their psychologist. Being unable to access psychological support, "not just for the patients, but for the carers" meant that families were struggling to manage their own anxiety and stress.

Falling behind due to being denied special considerations: Some children believed that their teachers made the schooling experience more difficult for them and felt less motivated to engage with their education. Both children and their caregivers were frustrated with teaching staff for being unwilling

to make small concessions, such as regular bathroom access, that would alleviate their daily struggles. Some caregivers noted that their child was always “trying to play catch up”, and adolescents in particular voiced their anger at not being given any extra provisions to help them catch up and complete assessments. Children and adolescents felt they had no choice but to fall behind or, in some cases, drop out of school because of their frequent absences. They perceived a lack of understanding on the part of the school, and faced unrealistic demands and expectations with regards to catching up on missed work.

Building resilience

Finding partners in the journey: In the absence of formal psychological support, children and their parents turned to communities and friends, who were valuable sources of both encouragement and practical assistance. “Support” came either in the form of acceptance (i.e. friends who didn’t really “think about [the CKD]”), solidarity (peers who would sit out on activities that the child with CKD couldn’t partake in), practical assistance (catching them up on school work) or encouraging their adherence to dietary/lifestyle restrictions - “if they see me with something I’m not supposed to have, they’re like, ‘I’ll take that [from you]’”). Some children and caregivers were reassured that their teachers accommodated their needs and understood necessary restrictions; “they really enforce the ‘no tackling’ rule at school”. Caregivers were also grateful for community members such as their neighbors, who would “cook meals” and alleviate the burden of daily tasks. Some caregivers believed that their child had developed a strong rapport with their medical doctor or psychologist, and considered these relationships to be critical in providing effective emotional support.

Moving towards acceptance of the illness: Adolescents sometimes spoke of CKD as being “just a part of life”, and some said that it has “helped [them] become a better person” by not “taking life for granted”. Some participants, particularly those who had received a kidney transplant, strived to maintain a “positive outlook”, regarding themselves as being “really lucky... really fortunate” in

comparison to others with more serious illnesses. Others acknowledged the impact of CKD on their personal development, saying, “It helped me become a better person.

Re-establishing childhood: Caregivers believed their children were being robbed of their childhood, and spoke of trying to return a sense of normality to their child’s life. Caregivers recognized they had to learn to “speak to [their child] as a kid again”, as they believed that the focus on their disease, treatment and restrictions contributed to their child’s sick identity. Some caregivers recognized the need to keep their children engaged; for example, one parent commented that “playing volleyball”, “actually helped her spirits...and the depression level”.

Discussion

Managing the mental, emotional and educational impacts of CKD can be stressful for both children and their caregivers, yet it was difficult to access psychological services and educational support. There were some differences between patients and caregivers, and by the age of child participants. There were no significant differences in the themes discussed between each of the focus groups themselves, with an equal representation of participants from each age group and country of origin. Caregivers were, however, often better placed to discuss certain topics (for example, the changes they witnessed as their children progressed through adolescence) and there is subsequently a prevalence of caregiver quotes in that domain.

While children and their parents from all three countries shared similar struggles with regards to the impact of CKD on mental health, it was mainly parents in Australia who voiced their disappointment with the limited psychological support available, predominantly in the context of publicly funded services. Though the groups differed in the depth to which they discussed each topic, there were otherwise no significant differences in opinion across groups; this can be evidenced by the geographical spread of quotes under each subtheme. With regards to educational support, children

from all three countries appeared to face the same barriers; namely, they met with resistance from teachers and were not able to access special considerations to keep pace with their peers.

Our results support previous findings that psychosocial wellbeing is particularly thwarted by threats to a child's sense of normality in terms of their identity, acceptance by others, participation with their peers, and limitations on future opportunities [15, 19, 20]. We found that parents of younger children were able to help restore normality through active engagement in sports and other social activities such as camps and scouts. Bailey et al [15] has previously reported that young people with CKD have substantial concerns over their future job prospects. While these concerns were identified in our focus groups, many children appeared to focus more on social outcomes, such as starting a family. Difficulties keeping up in schoolwork due to absenteeism, difficulty concentrating, fatigue and treatment requirements have been well described [21, 22]. Our findings also highlighted that the perceived ignorance and lack of support and flexibility in the school setting, in addition to peer rejection, exacerbated low self-esteem and reinforced the sense of being different to others.

Future Directions

There is a need to improve access to psychosocial and educational support in children with CKD. Specifically, we advocate for the need to 1) improve access to psychotherapy, 2) adopt a family-based model of mental health, 3) help families become advocates for their children and navigate their needs in the school setting and 4) provide training for school staff in ways to accommodate the needs of children with CKD who are challenged at school.

Multiple systematic reviews demonstrate the potential effectiveness of face-to-face psychological interventions (particularly Cognitive Behavioral Therapy (CBT)) in managing anxiety and depression associated with chronic pain [23], irritable bowel syndrome [24], and migraines [25] in pediatric populations. Though CBT has been found to be effective in improving quality of life for

adults with CKD and their carers [26], there is limited research evaluating these interventions in children. This paucity of quality studies presents a challenge to forming a cohesive, evidence-based approach to improving mental health in children with CKD and we strongly advocate for further research, particularly into the efficacy of different psychological therapies in children. In some healthcare jurisdictions, psychological services may be fully or partially subsidized, and only for a limited period; given the importance of continuity in establishing therapeutic relationships with pediatric patients, and the long-term and variable mental health impacts, we would advocate for the provision of ongoing services for children with CKD. Telehealth interventions may also be an effective option for overcoming a number of barriers to accessing therapy.

Family-based psychological interventions that involve the parents and siblings of children with chronic disease can have a positive impact on psychological outcomes for the entire family unit by improving coping and communication, reducing conflict and sharing responsibility for treatment.[5, 27] A systematic review of RCTs has found that involving caregivers in Problem-Solving Therapy (PST), which teaches effective problem-solving skills, is particularly useful in reducing distress in parents caring for an ill child [28], There is substantial evidence that better psychological adjustment in parents translates to better adjustment in their children [29-32].

Children with CKD need additional educational support because of difficulties in functioning academically and socially at school and frequent school absenteeism. Teacher training may be required to understand and support the additional needs of children with CKD [33]. Flexible learning programs would allow children with CKD to access additional assistance in catching up with missed schoolwork. Many pediatric hospitals worldwide have a "hospital school" that aims to minimize disruption to a child's life by connecting them with educational support, particularly during long-term and recurring inpatient admissions. In one study, children were provided with laptops in the hospital, which improved access to educational resources for children who were hospitalized [34].

Individualized education plans are now implemented in many countries such as Australia, the United

Kingdom and United States [35, 36]. These plans were not mentioned by families included in our study and their utilization and effectiveness in this population needs further study.

The impacts of CKD on personal and professional development must also be addressed. In the United Kingdom, a multidisciplinary clinic for youth with CKD facilitated the development of practical professional skills, such as resume writing, as well as skills directed at emotional resilience [37]. Though its specific impact on job-readiness has yet to be reported, preliminary results show a remarkable improvement in engagement with medical services, suggesting that participants develop a greater sense of ownership over their health and wellbeing. The inclusion of skills-based interventions for young adults may help to address concerns about future financial and social independence and, in doing so, can improve outcomes while smoothing the transition from pediatric to adult care [20].

Limitations

This study offers in-depth insights into the unique experiences of children with CKD and their parents/caregivers about access to psychosocial and educational support. We employed investigator triangulation throughout the analytical process to ensure that the pertinent data points would be fully captured in the list of themes. While we successfully captured a range of perspectives, all our participants were from high-income, English-speaking countries, and had received care at specialty pediatric hospitals located in large cities. Furthermore, most of our participant caregivers had incomes above the median for their respective countries. Another potential limitation is that data was not obtained regarding participant engagement with, or evaluation of, existing support services, such as learning plans or psychosocial programs. The applicability of our findings to other populations, from countries with different cultural norms and healthcare systems, cannot be ascertained.

Conclusion

CKD has a profound impact on young people's psychosocial wellbeing and their educational performance, and can limit their ability to engage with both the social, experimental and vocational opportunities of adulthood. Children with CKD and their caregivers encountered many barriers in accessing psychosocial and educational support, and felt helpless, disempowered, and isolated. Schools need a formal framework for delivering individualized educational support to children with chronic kidney disease (e.g. a 504 plan or Individualized Education Plan), as these services may be underutilized and may not address the unique challenges and requirements of children with CKD. A systems-based model of care is needed that integrates the roles of health professionals and the child's family, teachers, and support network, and mobilizes them to create a more comprehensive approach to supporting young people with CKD. Addressing the impact of CKD on a child's psychological wellbeing and educational outcomes may help to mitigate some of the long-term challenges these young people face as they transition to adulthood.

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Table 1. Characteristics of the child participants (N=34)

Characteristics	n (%)
Gender	
Male	19 (56)
Female	15 (44)
Country of birth	
Australia	13 (38)
Canada	5 (15)
USA	14 (41)
Other*	2 (6)
Age (years)	
8-12	10 (29)
13-15	12 (35)
16-18	11 (32)
19-21	1 (3)
Current CKD** treatment stage	
CKD prior to the need for kidney replacement therapy	17 (50)
Home 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 (cause not specified)***	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)

*Others include: Mexico, New Zealand; **CKD: chronic kidney disease; *** including idiopathic nephrotic syndrome

Table 2. Characteristics of the parent participants (N=62)

Characteristics	n (%)
Gender	
Male	13 (21)
Female	49 (79)
Caregiver relationship	
Mother†	47 (76)
Father†	13 (21)
Other (grandmother, aunt)	2 (4)
Country of birth	
Australia	11 (18)
USA	9 (15)
Canada	8 (13)
Other*	25 (40)
Not reported	9 (15)
Age (years)	
21-30	4 (6)
31-40	10 (16)
41-50	28 (45)
51-60	8 (13)
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)
Household annual income (before tax, local currency)	
\$0-39,999	7 (11)
\$40,000 - \$59,999	10 (16)
\$60,000- \$84,999	12 (19)
\$85,000-\$124,999	11 (18)
>\$125,000	8 (13)
Not reported	14 (23)
Child's CKD** treatment stage	
CKD prior to the need for renal replacement therapy	25 (40)
Home peritoneal dialysis	8 (13)
In-center hemodialysis	5 (8)
Dialysis, non-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 (cause not specified)	9 (15)
Focal segmental glomerulosclerosis	4 (6)
Polycystic kidney disease	4 (6)
PUV	4 (6)
Other^	9 (15)
No reported or not known	17 (28)

† Twenty (32%) caregivers were 10 couples with one child with CKD *Other includes: England, Ethiopia, Fiji, India, Kenya, Mexico, New Zealand, Pakistan, Poland, Somalia, Vietnam; **CKD: chronic kidney disease; ^Other includes: Cystinosis, Eagle Barret Syndrome, IGA Nephropathy, Scleroderma, Neurogenic bladder, bladder obstruction, reflux

Table 3. Selective Illustrative Quotations

Theme	Illustrative Quotations
Disruption to self-esteem and identity	<p data-bbox="94 289 305 348">Emotional turmoil during adolescence</p> <p data-bbox="354 289 1498 348">We're too young to have so much stress on medications, we have school, we have activities that we want to do. (Girl, 16+, Transplant, USA)</p> <p data-bbox="354 369 1498 428">Especially in the later years, it's really bad. My daughter is 16 so she's really going through that at the moment where she's very up and down. (Mother of 16+ year old girl, Transplant, Australia)</p> <p data-bbox="354 449 1498 541">I think for [my son], when he was going through it all at school, and explaining to his peers why he looked so physically different... it was all kinds of messed up awkward for him, and you know when he looked at himself in the mirror, he hated himself. (Mother of 12-15 year old boy, CKD, Australia)</p> <p data-bbox="354 562 1498 680">[My son] put on 18 kilos since he had his transplant. He is embarrassed about that, he was a good-looking beautiful blonde boy before and now he is a big balloon. He doesn't want to leave the house. He just goes to school every day and that's about all he does. He just is not the boy he was. (Mother of 12-15 year old boy, Transplant, Australia)</p> <p data-bbox="354 701 1498 760">We also get the teenage rebellious I don't want to take my pills today. I don't want to do it anymore. (Mother of 12-15 year old girl, Transplant, Australia)</p>
Wrestling with the sick self	<p data-bbox="354 779 1498 871">And it can affect your relationship with like a boyfriend or a girlfriend. Because people want like a perfect person. And whenever someone uses the word 'disease', it makes them think that I am contagious. (Girl, 12-15, Dialysis, Australia)</p> <p data-bbox="354 892 1498 984">I feel like us kids are very restricted, being in relationships. Being loved, or having a partner... because they might not like you because you've had a kidney transplant. I would say sex is very, very dangerous for us...so we have a lot of pressure put on us. (Girl, 16+, Transplant, USA)</p> <p data-bbox="354 1005 1498 1098">I want to live a life where you can hope that you'll have a family, get married, and you never know. Because you have a certain time, with a kidney transplant, you have 'this' many years. And then you have to go through the process again. It's a never-ending horror story. (Girl, 16+, Transplant, USA)</p> <p data-bbox="354 1119 1498 1236">One of the things that he has expressed in the last year or so, that is very interesting to me, is that he has a profound sense of his own mortality... [My son's] deep concern... he will turn to me and go 'Am I gonna die?' And you know he's thinking about that. And that's a really incredible burden to have when you are a teenager or a younger child. (Mother of 16+ year old boy, CKD, Canada)</p> <p data-bbox="354 1257 1498 1316">My son worries, he thinks about it all the time. He doesn't think he'll live past 40, he'll tell us that. (Mother of 16+ year old boy, CKD, USA)</p> <p data-bbox="354 1337 1498 1396">Self-esteem, who I am in the world. Sometimes I think he sees himself as a sick person, and that's all that he will be. (Mother of 16+ year old boy, Transplant, Australia)</p> <p data-bbox="354 1417 1498 1476">She needs a goal, she needs a vision, she needs to know she can achieve. (Mother of 8-11 year old girl, Transplant, Australia)</p> <p data-bbox="354 1497 1498 1589">My son retreats a lot into virtual reality. Plays tons of video games. And of course, the guys in the video games... They jump, and they run, and they are invincible, they can push back, and fight back, all the things he can't do. (Mother of 16+ year old boy, CKD, Canada)</p> <p data-bbox="354 1610 1498 1669">She's frustrated because there is no cure. She's not going to get better. (Mother of 8-11 year old girl, CKD, Australia)</p>
Powerlessness to alleviate child's suffering	<p data-bbox="354 1682 1498 1799">'Oh my God, what does this mean for my family, what does this mean for my kid? Is he going to live? Is he going to die? What's going to happen, here?' So many things run through your head... And you have doctors talking to you, tons of things that you don't even know about, and it's overwhelming. It really is. (Mother of 8-11 year old boy, Dialysis, USA)</p> <p data-bbox="354 1820 1498 1913">[My son] went down on a low about six months ago, so I mentioned it to [the pediatrician], I said 'look, you know, he's actually having meltdowns, I don't know how to handle that'. (Mother of 8-11 year old boy, CKD, Australia)</p> <p data-bbox="354 1934 1498 1955">[My daughter] has said, 'Why did this have to happen to me? Why do I have to have this?' And she is</p>

	<p>anxious about the transplant too. (Mother of 8-11 year old girl, CKD, Canada)</p> <p>Whether she's going to be able to live independently, or function efficiently. That's what worries me a lot. (Mother of 16+ year old girl, Transplant, Canada)</p> <p>I suppose as a parent it's the mental impact it has on the caregivers, because I used to do all the treatment.</p> <p>I used to shield [my daughter] from coming to the hospital. I'd stay there and do it all. (Father of 16+ year old girl, CKD, Australia)</p>
Balancing normality and protection	<p>Medication will make your kidney last longer. But is that a good longer? How are you surviving that longer? ... In terms of have you been social. Have you experienced life? Not just experienced hospital life. (Mother of 8-11 year old boy, Transplant, Australia)</p> <p>It's the patient's overall emotional being, while they're sick, after they're sick, the rest of their life... the impact their disease emotionally has for, well, yeah, ever. (Mother of 12-15 year old boy, Dialysis, Australia)</p> <p>I'm not going to let him sit there and ponder or worry about what's wrong with him. (Mother of 8-11 year old boy, CKD, Australia)</p> <p>All he's ever wanted to be is normal, he's never wanted to be that different kid, he's never wanted to be the sick kid, so we tell him 'you're not'. (Father of 12-15 year old boy, Transplant, Australia)</p>
Disadvantaged by lack of empathy and acceptance	
Alienated by ignorance	<p>Your self-esteem gets low, cause if you have a certain thing like a scar and people like see it and judge you. (Girl, 12-15, Dialysis, Australia)</p> <p>It's another way to be bullied. You tell someone and they tell another person and it goes everywhere and they pick on you. (Boy, 12-15, CKD, Australia)</p> <p>Or they shout it out to the whole school and then the whole school knows that you have a disability. And an easy target. (Girl, 12-15, Dialysis, Australia)</p> <p>My friends always want me to play basketball all the time, and I say I can't, 'cause I'm too tired. And they'll say, 'come on!' (Girl, 8-11, CKD, Canada)</p> <p>I wonder of bullying. Where the kids are like 'You're faking it', 'There's nothing really wrong with you', 'You're a wuss, blah, blah, blah'. And he finds it excruciatingly painful, probably so much more than a regular kid being bullied, because he is in a lot of pain, and he <i>is</i> suffering. Just to have the kids talk behind his back that way. (Mother of 16+ year old boy, CKD, Canada)</p> <p>And so some of his friends would go 'Oh, there's nothing wrong with you. You look fine'. (Mother of 16+ year old boy, CKD, Canada)</p> <p>We had major issues with bullying. (Mother of 16+ year old boy, Transplant, Australia, Group 9)</p> <p>And we had one teacher get right up in [child's] face - 'You're not even <i>trying</i>'. And it was just deadly. He was so upset. (Mother of 16+ year old boy, CKD, Canada)</p>
Bearing the burden alone	<p>Mood is a hard one for me. Because whenever I got home from school I always just go straight to my room shut the door and never come out. This was when I was self-conscious with myself, when I was taking the medication. I really just stayed very distanced from people. I didn't like talking about it. Keep to myself a lot. (Boy, 12-15, CKD, Australia)</p> <p>I doubt they [my classmates] would understand or listen. (Boy, 12-15, Transplant, Australia)</p> <p>[My daughter] used to have so many friends, and now she's down to just a few that she trusts. (Mother of 16+ year old girl, Dialysis, USA)</p> <p>He's going out to play during a break in school, and all of a sudden he realizes he's wet, so he's shying away from the group, he's sort of secluding himself. So that ability to be outgoing, to make friends, he's sort of closed that up. (Father of 12-15 year old boy, CKD, Canada)</p> <p>And he's very closed when it comes to anything emotional, until he gets overloaded and breaks down. (Mother of 12-15 year old boy, Dialysis, Canada)</p> <p>As I said, [child] didn't tell anyone about her kidney disease, she was embarrassed about it. (Mother of 16+</p>

	<p>year old girl, CKD, Australia)</p> <p>And adults articulate it. Adults will tell you right off the bat, 'Hey, I need this, I need that'. And kids don't have a narrative to be able to express what's really going on. You have to tease it out of them. (Mother of 16+ year old boy, CKD, Canada)</p>
A hidden and inaccessible system	
Excluded from formal psychological support	<p>She has not had a psychologist. We ask every visit we have, and we're at the Children's Hospital at least twice a month, if not more, we ask every visit and our latest answer was 'Well, the Children's [hospital] doesn't really have a psychological support team'. (Mother of 16+ year old girl, CKD, Australia)</p> <p>She became quite confident with the [psychologist] she was seeing, and then it was finished. (Mother of 8-11 year old girl, Transplant, Australia)</p> <p>I don't think an adult psychologist is the answer for a thirteen year old kid. (Father of 12-15 year old boy, Transplant, Australia)</p> <p>This was at a point where [child] was saying 'I just want to die'. 'Your daughter doesn't fall into our catchment area'. (Mother of 16+ year old girl, CKD, Australia)</p> <p>That's one thing that's really lacking, the psychological support. Not just for the patients but for the carers. Carers Victoria will give you ten sessions, I took them up on that and the psychologist said 'you know what you need to do, you need to stop worrying about everyone'. Well I wish I could, you know? (Mother of 16+ year old girl, CKD, Australia)</p> <p>I'm going to be honest, I have really high anxiety. So me dealing with that ... it's very draining. (Mother of 8-11 year old boy, Dialysis, USA)</p>
Falling behind due to being denied special considerations	<p>For me, it depends which teacher it is. Some don't believe me, but some do. (Girl, 12-15, CKD, Australia)</p> <p>When I started dialysis, I had to drop out of school to do home school, because I couldn't actually do dialysis and school at the same time. (Boy, 16+, Dialysis, USA)</p> <p>It was like 6 months. And when I come back to school, they told me, "You need to do this work in 3 days". So I had 8 classes and I had to do the work in 3 days. (Girl, 16+, Transplant, USA)</p> <p>I went from making A's and B's to barely making C's. It would have been easier if I had some help from the hospital originally. I do now. Some schools don't have that in place. (Boy, 16+, Dialysis, USA)</p> <p>They don't provide anything [at school]. (Mother of 12-15 year old girl, CKD, Australia)</p> <p>[My daughter] was having problems at school because she'd need to go to the toilet. They'd sit down and tell her, 'wait you've got 10 minutes 'til break, you can't go'. She'd just get up and go and get a report against her. (Mother of 12-15 year old girl, CKD, Australia)</p> <p>Again, the educational piece around children with chronic illness... it should be something that they talk about in school. You have no idea what it's like to be in this body, and how- not even trying? Are you kidding me? It is so hard to get up to go to school, to study, to learn, to interact and function when you have this massive compromise you're dealing with, day in and day out. (Mother of 16+ year old boy, CKD, Canada)</p> <p>You're fighting the school now, because they want her up where she's supposed to be, and she may not be there. (Mother of 8-11 year old girl, CKD, Canada)</p> <p>My daughter has had a significant amount of time off school in the earlier years. Now she's sort of trying to play catch up, and she's receiving some extra support, because the school she is at is providing it. But not everybody is going to necessarily get that extra education or support that the child really needs. (Mother of 8-11 year old girl, Transplant, Australia)</p>
Building resilience	
Finding partners in the journey	<p>My friends are like supportive about it. Well only a couple of them are supportive. So if they want to go out that weekend and go to parties and they are like I'm not going to do it because [you] can't do it. (Girl, 12-15, CKD, Australia)</p> <p>I play with my friends who actually play with me. (Girl, 8-11, CKD, Australia)</p>

And when I wasn't there, I had friends and they'd help me catch up on the work so that I wouldn't be behind. I probably wouldn't have graduated if it wasn't for them. (Boy, 16+, Transplant, USA)

My positives – I think I have many friends, and there's always help there. (Girl, 16+, Transplant, USA)

They get it, but they just don't get it... it's really nice when we meet other families in the renal treatment center while she was on dialysis, and just even having 5 minutes with them, would be worth far more than 5 days with some of my normal friends. (Mother of 8-11 year old girl, Transplant, Australia)

[The school] is tremendously supportive, so she's very well-known and also she wears her protective kidney belt all the time so she's kind of very easily seen in the playground. (Mother of 12-15 year old girl, Transplant, Australia)

He does play football at school. I can't stop him all the time either, but the school is well aware of it and they actually enforce really strictly the 'no tackling' rule and all that at school, so I know he's safe there. (Mother of 8-11 year old boy, CKD, Australia)

And I think [therapy] helps. I mean, my daughter really seemed to look forward to it, and she'd have herself ready and say 'Mum, I'm going to talk about this today'. She'd go in and she'd come out and she'd get through the next few weeks, to get herself to the next (Mother of 8-11 year old girl, CKD, Australia)

Moving towards acceptance of the illness

My little brother saw that, and he was constantly crying, saying, 'How come it happened to you, and none of my other brothers?' And I said, 'Well don't think like that, just be glad that you guys are healthy'. And even though I wasn't feeling super positive or happy, I would put on the cheeriest face possible, just so that he could see that I was happy, functioning. So even though I wasn't feeling the best, I always did it for him. (Boy, 16+, Dialysis, USA)

It's made me more accepting. More like optimistic, sort of. Like, looking at things a different way, right? I consider myself to be really fortunate. I haven't had to do any operations, my problem is not really that life threatening. So I think I'm really lucky. (Boy, 16+, CKD, Canada)

I'm really small, but I'm a leader. Front of the pack. And the transplant really changed my life in a positive way, so I kind of want to share that with everybody, that there's hope. You just really got to stick to it, and it'll be OK. Anything is possible. (Girl, 16+, Transplant, USA)

And then when I had the kidney transplant, it made me realize that life is... you have to really appreciate it, because it's short, and you never know what could go wrong. (Girl, 16+, Transplant, USA)

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. (Boy, 16+, Transplant, USA)

Re-establishing childhood

I stopped him from football, I stopped him from soccer, I stopped him from surfing, I stopped him from playing rough at the beach, all that sort of stuff. And all I did was cause depression in him. I had to find a way to be able to speak to him as a kid again, if that makes sense. (Mother of 8-11 year old boy, CKD, Australia)

She's playing volleyball, so that actually helped her spirits. And I think it helped her depression level, and it actually helped her get back on the social level, and school, because she's back to where she needs to be. (Mother of 12-15 year old girl, CKD, USA)

I think we've got to always remind ourselves our kids still have to be kids and we can't hold them back from being kids. (Mother of 8-11 year old boy, CKD, Australia)

I think it's confidence. It's feeling good about themselves. It's going off to the movies. Or to a mates, to a party, or whatever. That I'd expect [my son] to be doing. (Mother of 12-15 year old boy, Transplant, Australia)

Figure 1: Thematic Schema

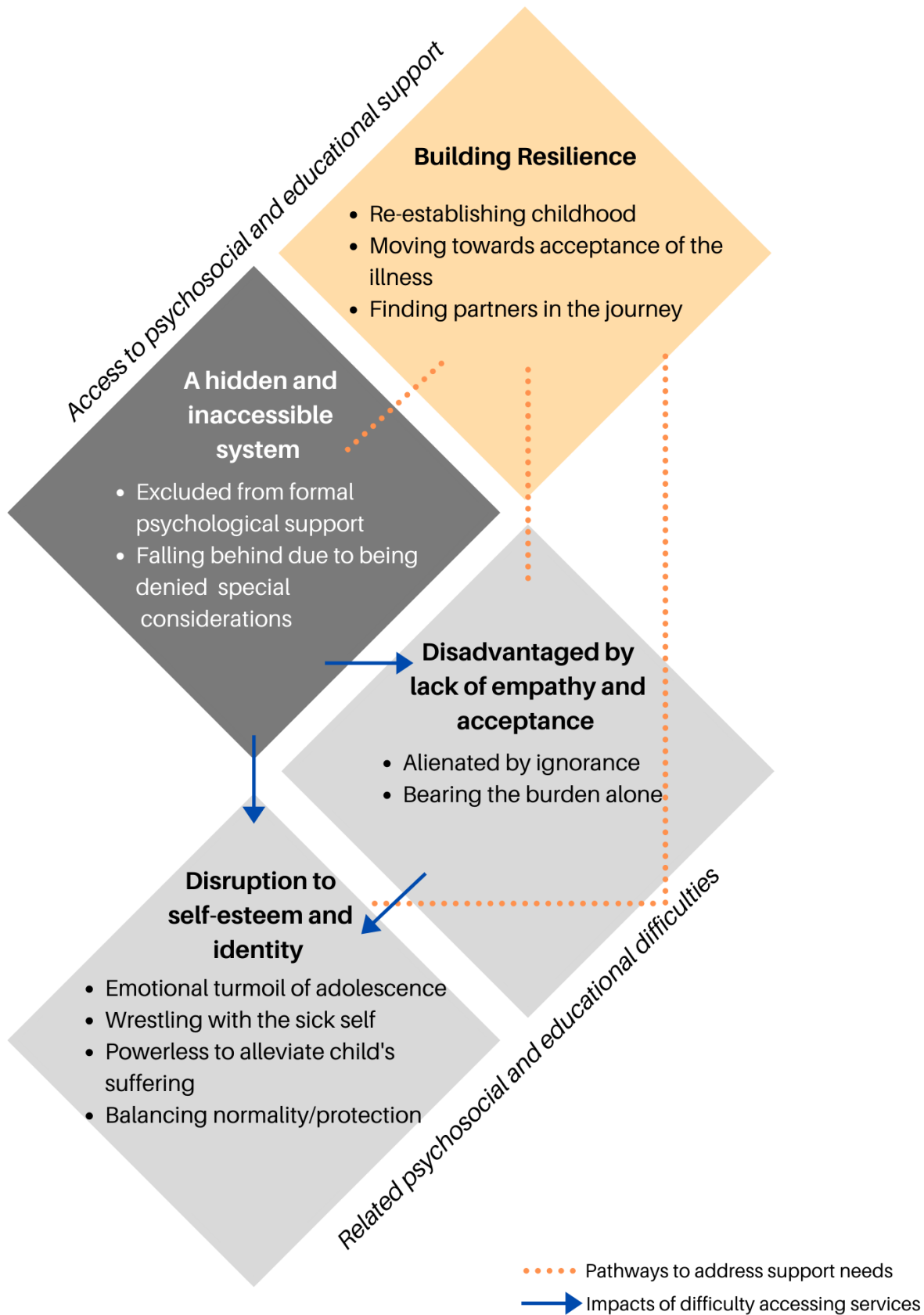


Figure Legends

Figure 1. Thematic Schema

Children with CKD and their caregivers struggled with the increasing severity of emotional problems during adolescence, powerlessness in their ability to alleviate their child's suffering, difficulty achieving their perceived parental role of shielding their children from distress, and navigating a tenuous balance between protecting their child from risk and prioritizing their child's ability to live a normal life. At school, children felt isolated by a lack of empathy and acceptance, reporting feeling alienated by the ignorance of others, and were subsequently forced to bear their burdens alone. Contributing to an overwhelming sense of powerless and disadvantage, caregivers and children found that psychological support was both hidden and inaccessible; children who were unable to access special considerations or educational support felt as though they were falling behind their peers. Building resilience was a central goal for caregivers of children with CKD, in view of the challenges they face with a life of chronic disease. Finding partners and allies in their journey, self-acceptance, and a shift towards acceptance of their illness, and efforts to re-establish a semblance of normal childhood were highlighted as important strategies for managing psychosocial and educational challenges.

Appendix A. Participating Sites and Institutional Review Boards

British Columbia Children's Hospital, The University of British Columbia Research Ethics Board, Vancouver, Canada.

Alberta Children's Hospital, The University of Calgary Research Ethics Board, Calgary, Canada.

Texas Children's Hospital, The Institutional Review Board for Baylor College of Medicine and Affiliated Hospital, Houston, United States.

The Children's Hospital at Westmead, The Sydney Children's Hospital Network Human Research Ethics Committee, Sydney, Australia.

The Royal Children's Hospital, The Melbourne Children's Campus Research Ethics and Governance, Melbourne, Australia.

Queensland Children's Hospital, The Children's Health Queensland Hospital and Health Service Research Governance, Brisbane, Australia.

Appendix B: Question guide

Children

We want to know what it's like for you to have kidney problems

- Can you tell us a little bit about your kidney problems (how long, what treatment you have?)
- What is it like to have kidney problems?
- What are the hardest things about having kidney disease?
 - How has it impacted on your mental health/education? How important are these outcomes to you?
 - How do you deal with these challenges? What types of support have you needed/do you need?

Parents/Caregivers

We would like to hear about your experience caring for a child with CKD

- How did you first find out that your child had kidney disease? How did you react/feel?
- How has the kidney disease/dialysis/kidney transplant changed your life and your child's life?
- What is the most challenging thing about caring for a child with kidney disease?
 - How has it impacted on your child's mental health/education? How important are these outcomes for your child?
 - How could these outcomes be better addressed? What types of support has your child needed/does your child need?
 - How do you deal with these challenges? What types of support has your child needed/does your child need?
 - How could these outcomes be better addressed?